

# Parents' Perception of Self-Management Behaviors for Their Children With Spina Bifida in South Korea: A Qualitative Study

Hyun Jung Yun<sup>1</sup>, PhD, RN, Eun Kyoung Choi<sup>2</sup>, PhD, RN, CPNP & Sang Won Han<sup>3</sup>, PhD, MD

## Abstract

**Purpose:** This study aimed to explore parents' perceptions of self-management behaviors for their children with spina bifida (SB).  
**Design:** Qualitative method.

**Methods:** In-depth interviews were conducted with nine Korean parents of children with SB. The data were analyzed using the content analysis method.

**Findings:** Parental perceptions of the experiences of self-management behaviors in children with SB were classified into risk factors that hinder self-management behaviors and protective factors that accelerate them. Each category of factors was then further classified into child-, parent-, and school-related factors.

**Conclusions:** To promote self-management behaviors in children with SB, reducing risk factors and promoting protective factors considering child, family, and school dimensions based on cultural differences are necessary.

**Clinical Relevance:** Rehabilitation nurses should be considered essential healthcare providers who can offer stepwise guidance to achieve self-management behaviors in children with SB according to their stage of development.

**Keywords:** Behavior; child; self-management; spina dysraphism.

Spina bifida (SB) is the most common neural tube defect and is the incomplete formation of the closure of the embryonic neural tube (Copp et al., 2015). Its prevalence at birth in the United States is approximately 3.0 per 10,000 (Lloyd et al., 2013). In Korea, the incidence is similar to that of England and Canada, with approximately 2.62 newborns with SB per 10,000 live births (Choi et al., 2009; International Clearinghouse for Birth Defects Surveillance and Research, 2008).

Although advances have been made in medical care and treatment, many adults continue to live with SB

(Szymanski, Cain, Hardacker, & Misseri, 2017). Moreover, individuals with SB continue to struggle to manage their various medical conditions such as clean intermittent catheterization (CIC), urinary and fecal incontinence, complex bowel management, daily skin checks, monitoring of shunt functioning, and use of orthopedic devices (Kapoor, De Carlo, Raman, Thibadeau, & Kancharla, 2019; Yun & Kim, 2017). With a goal of adulthood independence, achieving self-management—an individual's ability to manage the symptoms; treatment, physical, and psychological consequences; and lifestyle changes inherent to living with a chronic illness—is critical (Allen, Vessey, & Schapiro, 2010; Lindsay, Kingsnorth, McDougall, & Keating, 2014; Sohmaran & Shorey, 2019). To achieve this goal, it is necessary to develop self-management skills systematically.

According to the life course model for individuals with SB (Swanson, 2010), during school years, children begin to learn self-management skills. If they effectively master these skills during this period, their health condition and quality of life will improve as they transition into adolescence and adulthood. Thus, helping children with SB gain accurate knowledge of their condition and self-management techniques and teaching them how to manage their condition independently are important for them to grow up healthy and enjoy a higher quality of life (Yun

**Correspondence:** Eun Kyoung Choi, Yonsei University College of Nursing, Yonsei-ro 50-1, Seodaemun-gu, Seoul, South Korea, 03722. E-mail: ekchoi@yuhs.ac

<sup>1</sup> Department of Nursing, Cheongju University, Cheongju, South Korea.

<sup>2</sup> Mo-Im Kim Nursing Research Institute, College of Nursing, Yonsei University, Seoul, South Korea.

<sup>3</sup> Department of Urology and Urological Science Institute, Yonsei University College of Medicine, Seoul, South Korea.

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& Kim, 2017). Although parents mostly manage the condition for their infant or preschool children, school-aged children must begin self-management, because they spend most of their time at school. Thus, the average age to begin learning to execute CIC independently is 8 years, about the time children in South Korea enter school (Campbell, Moore, Voaklander, & Mix, 2004). Despite this recommendation, medical adherence in many medical domains (e.g., bowel, diet, exercise, and skin checks) appears to dip to below the expected 50% rate during late childhood in the United States (Psihogios, Kolbuck, & Holmbeck, 2015). Therefore, healthcare providers should support increased attention to self-management behaviors in school-aged children.

Parents are important in increasing self-management skills for children with SB. Parental expectations and encouragement could foster children's independent skill development, sharing health management responsibility. Conversely, parental overprotection could hinder developmental potential (Fremion & Dosa, 2019; Swanson, 2010). Therefore, to understand self-management of children with SB, the parents' perception of their child's self-management should be understood. Parental involvement in SB medical care appears to be essential for optimally achieving self-management (Fremion & Dosa, 2019).

Children with SB face several common difficulties in self-management, but the type and severity can vary depending on cultural characteristics, which should not be overlooked. For example, Confucianism could be a barrier to achieving self-management, because it is associated with disease-related stigma; being different or having a child who is different implies inferiority (Choi & Yoo, 2015). Furthermore, because the Korean society is relatively homogenous, negative attitudes toward differences might be strong (Choi, Ji, Bae, & Jang, 2019). For this reason, Korean children with SB often hide their condition (unless they have a walking disorder), which could also be a barrier to self-management (Lim, Lee, Davis, & Park, 2016). Furthermore, Korean parents typically take full responsibility for their child's care, because they tend to not disclose their child's condition to others (Choi et al., 2015), and the support systems for children with chronic conditions in Korea are still limited (Choi & Yoo, 2015). Thus, Korean parents tend to be more overprotective of their children, which in turn delays children's acquisition of self-management skills. As a result, only 58% of Korean children with SB (aged 7–12 years) conduct self-CIC (Lim et al., 2016); however, the rate in the United States is 78% (Atchley et al., 2018). This could provide practitioners clues for achieving a higher rate.

Previous studies on self-management of SB mostly focused on adolescents (Greenley, 2010; Sawin, Buran, Brei,

& Fastenau, 2003) or adults (Mahmood, Dicianno, & Bellin, 2011) in Western cultures. Studies on SB in Korea have covered prenatal diagnosis, surgery, or treatment, with limited psychosocial difficulties experienced by children with SB (Choi et al., 2015; Choi, Im, & Han, 2017; Choi, Shin, Im, Kim, & Han, 2013). Gaps in current research exist regarding issues of self-management in children with SB and in the cultural differences related to self-management in East Asia. Hence, this study aimed to explore the parents' perceptions of self-management behaviors for their children with SB in South Korea, which may provide basic data for developing self-management programs to help children with SB grow into independent and healthy adults.

## Design and Methods

### Design

This qualitative descriptive study used an in-depth analysis of Korean parents' perceptions of their children's experiences of self-management behaviors in SB. Content analysis with an inductive approach was used to enhance knowledge, understand phenomena (Elo & Kyngäs, 2007; Schreier, 2012), and verify the experiences of self-management behaviors in children with SB by parental perspective.

The questions used in this study were based on the Individual and Family Self-Management Theory, which defines self-management as a complex and dynamic phenomenon consisting of contextual, process, and outcome dimensions (Ryan & Sawin, 2009). The contextual dimension includes condition-specific factors, physical and social environments, and individual and family characteristics. Such contextual dimensions could affect self-management. Therefore, key questions included contextual dimensions consisting of condition-specific, individual, family, and physical and social environment factors.

### Participants

Nine parents of children with SB were selected using purposive sampling. Twenty-four parents were approached about participating when their children with SB visited an outpatient clinic; however, only nine chose to participate. Participants were parents of school-aged children with SB registered with an SB clinic at a children's hospital in Seoul. Inclusion criteria ensured that the participants (i) were parents of elementary school children (aged 7–12 years) with SB, (ii) were without cognitive disorders, and (iii) had the ability to communicate. Data were collected until data saturation was reached (i.e., new categories, themes, or explanations stopped emerging from the data) based on consensus among the researchers (Morse, Barrett, Mayan, Olson, & Spiers, 2002).

Ethical Considerations

This study was conducted after receiving approval by the institutional review board of Yonsei University Health System (No. 4-2012-0567). Prior to data collection, the researcher explained the purpose and method of research to parents who visited the SB clinic and provided subject information formulated for parents. Signed consent forms were obtained from parents who agreed to participate. Participants were notified that the choice of whether to participate would not influence their forthcoming care at the SB clinic. Anonymity and confidentiality were guaranteed, and the researcher included only minimal information about each child’s demographics and disease characteristics to avoid unintended disclosure. Numbers were assigned to distinguish participants from recordings and results, and all personal identification information was deleted. Participants were given the opportunity to take a break during the interviews, and the interviewer was sensitive to their emotions. All participants completed the interviews. Participants were all provided with contact information of the pediatric nurse practitioner at the SB clinic in case the interview caused distress or if they wished for further conversation.

Data Collection

Individual interviews were conducted using a semistructured interview schedule designed by the first author (Table 1).

Each interview lasted about an hour, and the interviews were conducted in a private, comfortable location. Participants were given breaks of up to 30 minutes, and if they needed emotional or psychological support, the pediatric nurse practitioner at the SB clinic could support them at any time. All interviews were recorded with the participants’ consent, and the recorded data were transcribed verbatim immediately. Data collection was carried out from January 3 to March 14, 2013.

Data Analysis

The interview transcripts were analyzed using content analysis, which is a process of systematically analyzing documents (Downe-Wamboldt, 1992; Miles, Huberman, & Saldana, 2019). The categories and their contents were derived inductively from the data during the analysis process. Qualitative data were organized using open coding, creating categories and abstraction (Elo & Kyngäs, 2007; Schreier, 2012; Table 2). The interview transcripts were read repeatedly, and phrases and sentences judged to be related to self-management behaviors of children with SB were classified as units of analysis. Significant phrases and sentences were underlined and carefully redrafted (open coding process), with great care taken to preserve the original meaning. The redrafted sentences underwent a thorough second reading for final extraction of phrases and sentences. Meaning units were inductively derived

Table 1 Semistructured Interview Schedule for Qualitative Research

Phase	Interview Contents/Questions
Introduction	<div>1. Introduce the researcher</div> <div>2. Explain the process, time, confidentiality, and recording of the responses</div> <div>3. Sign consent forms</div>
Interview key questions	<div>1. Condition-specific factors</div> <div><div>• What are the tasks that children with spina bifida usually do by themselves or with their parents’ help to cope with their condition?</div><div>• Why does the child practice self-management under parental supervision?</div><div>• What was the most difficult aspect of your child’s self-care?</div><div>• What is the most worrying aspect about your child’s condition?</div></div> <div>2. Individual and family factors</div> <div><div>• What do you think about the characteristics of your child? (probe: personality, habits, etc.)</div><div>• Which individual characteristics of your child influence self-management?</div><div>• If your child is not able to self-manage by themselves, which of your child’s characteristics do you think affect this ability?</div></div> <div>3. Family factors</div> <div><div>• What roles does the family play to help your child self-manage their conditions?</div><div>• What do you think is the most important aspect of raising your child?</div><div>• As a parent, how are you helping your child to self-manage their condition?</div></div> <div>4. Physical and social environments</div> <div><div>• How have your child’s friends/teacher helped in self-management?</div><div>• Has your child faced difficulties in self-management because of a friend/teacher? Has your child faced any difficulties in school? If yes, how did you resolve the problem?</div></div>
Finishing	<div>• Is there anything else that you would like to add?</div>

**Table 2** Example of Data Analysis Process

Meaning Units	Coding Units	Subcategories	Categories	(Sub)theme
"I tell my child, 'One of the good ways to make yourself comfortable is to just accept it if you cannot do anything about it anyway.'"	Parental help	Parents helping to accept condition	Parents help their child to accept the condition positively	(Parent-related) protective factors
"I always tell my children, 'your condition only gives a little discomfort in your daily life.'"	Parental help	Parents helping to acknowledge condition positively		
"I do not do those things for him. If he says he has wet the bed, I make him get up early in the morning to clean it up himself."	Parenting attitude	Independent parenting methods	Raising an independent child	
"I let my child do it early, since he has to do it anyway in the future."	Parenting attitude	Fostering independence		

from phrases and sentences. Phrases and sentences were coded using meaning units on coding trees. Coding units were grouped in consideration of the similarities and differences. The categorization was drawn up and defined by repeatedly reading coding units selected from these participants' statements (creating categories process). In this process, researchers coded and decided the categories through discussion and reaching consensus, regarding which items belong in one category. Finally, each category was titled using content characteristic words, and abstraction was conducted by formulating a general description of the factor affecting self-management of children with SB by parental perspective (abstraction process). Based on the similarities, subcategories were grouped as categories, and categories were grouped as themes. Content analysis was continued until all themes were saturated systematically (Downe-Wamboldt, 1992; Miles et al., 2019).

### Rigor

The researcher transcribed the recorded contents of the interviews verbatim immediately after each interview to ensure the credibility of data. The same interviewer (the first author) conducted all of the interviews, ensuring their authenticity through prolonged engagement and to ensure data saturation (Malterud, Siersma, & Guassora, 2016). The researcher has 8 years of clinical experience working at a children's hospital, helping with the understanding of children's experiences with chronic conditions. The researcher also studied qualitative research methodology in graduate school, has participated in several international qualitative conferences, and has experience conducting qualitative research using content analysis methods. To minimize researcher's bias through reformulation and categorization, the final themes were deduced only after consultation with an expert team including three nursing professors and one doctoral student with experience in qualitative research who discussed plausibility by

analyzing the data and reached consensus. In addition, a pediatric nurse practitioner at the SB clinic verified the validity of the final themes, categories, and meaning units to ensure that the findings were consistent with the provided data for confirmability. Furthermore, Tong, Sainsbury, and Craig's (2007) 32-item Checklist of Consolidated Criteria for Reporting Qualitative Research was used to ensure rigor when providing information about the study, such as the methods, context of the study, findings, analysis, and interpretations (see Supplemental Digital Content, <http://links.lww.com/RNJ/A17>).

## Results

### Participant Demographics

Eight mothers and one father were interviewed. Table 3 presents the characteristics of each participant and their children, such as children's self-management related to elimination hygiene. The mean age of the parents was  $39.8 \pm 2.68$  years. Among the children, 44.4% were boys, and the mean age of the children was  $10.7 \pm 2.0$  years. All of the children needed CIC, and 33.3% had urinary incontinence. Many (88.9%) of the children needed active bowel management, and 33.3% needed aids for mobility.

### Self-Management Behavior Themes in Children With SB

According to parental perception, self-management behaviors in children with SB were classified into risk factors that hinder self-management behaviors and protective factors that accelerate such behaviors. Each category was then further classified into child-, parent-, or school-related factors (Table 4).

### Theme 1: Risk Factors of Self-Management Behaviors in Children With SB

#### Child-Related Factors

Categories of the child-related risk factors of self-management behaviors in children with SB were "forgetting time

**Table 3** Participant Characteristics (n = 9)

	Child's Gender	Child's Age (years)	Type of Spina Bifida	Voiding Status	Defecation Status	Ambulatory Status	Participating Parent	Parent's Age (years)	Parent's Education Level	Parent's Perceived Economic Status
A	Boy	10	LMMC	CIC	Enema	Ankle-foot orthoses	Mother	37	College	Low
B	Boy	12	LMMC	CIC and wearing pad	Enema	No assistance	Mother	45	High school	Middle
C	Girl	11	MMC	CIC and wearing pad	Enema and laxatives	No assistance	Mother	39	High school	Low
D	Girl	9	MMC	CIC	Enema	Ankle-foot orthoses	Father	40	College	Middle
E	Boy	13	LMMC	Wearing pad	Enema	No assistance	Mother	39	High school	Middle
F	Boy	12	MMC	CIC	Enema	No assistance	Mother	41	High school	Middle
G	Girl	8	MMC	CIC	Enema	Ankle-foot orthoses	Mother	39	High school	Middle
H	Girl	13	LMMC	Spontaneous voiding and CIC	Spontaneous defecation	No assistance	Mother	36	College	Middle
I	Girl	8	Unspecific spina bifida	CIC	Spontaneous defecation and laxatives	No assistance	Mother	42	High school	High

Note. CIC = clean intermittent catheterization; LMMC = lipomeningomyelocele; MMC = meningocele.

for his/her self-management” and “fear of exposure of his/her condition.”

The parents reported that their children had difficulties managing urination because they forgot when to change pads or perform catheterization. They hoped their children would complete their self-management activities in a timely manner. On the other hand, children with SB tended to fear that their friends might find out about their condition. Some thought that their friends would tease or bully them. Moreover, some children with SB were reluctant to inform even teachers about their condition, even though they could provide great help at school.

*Forgetting time for his/her self-management.*

*“The only thing I want for my child is to have some sense of time. He is so preoccupied playing that he forgets it, even though the teachers at school set the time for him” (Mother A).*

*Fear of exposure of his/her condition.*

*“My child tries to hide it (the disease) from his teachers and friends. It worsens as he moves on to higher grades. He even asks me not to tell his homeroom teacher. He thinks there’s no need for others to know since he always goes to the restroom during the break” (Mother E).*

### Parent-Related Factors

The parents of children with SB thought self-management could not be done in a clean and hygienic manner in the school without their assistance. They also worried their children could not perform difficult self-management tasks, such as completing transanal irrigation or CIC, by themselves. Therefore, the parents were anxious about exposing their children to new environments and did not allow the children to participate in school trips.

**Table 4** Parental Perceptions of the Experiences of Self-management Behaviors in Children with Spina Bifida

Subtheme	Categories of Risk Factors (Theme 1)	Categories of Protective Factors (Theme 2)
Child-related factors	<ul style="list-style-type: none"> <li>• Forgetting his/her self-management time</li> <li>• Fear of exposure of his/her condition</li> </ul>	<ul style="list-style-type: none"> <li>• Knowing his/her health status</li> <li>• Disclosing his/her condition</li> <li>• Understanding his/her own method of self-management</li> </ul>
Parent-related factors	<ul style="list-style-type: none"> <li>• Parents worry over their child’s self-management ability</li> <li>• Parents are worried when their child is exposed to new environments</li> <li>• Parents do not know the proper time for the child’s initiation of self-management</li> </ul>	<ul style="list-style-type: none"> <li>• Parents help their child to positively accept the condition</li> <li>• Parents encourage their child to engage in successful self-management</li> <li>• Parents raise their child to be independent</li> </ul>
School-related factors	<ul style="list-style-type: none"> <li>• Changing a private room to facilitate children’s self-management in school</li> </ul>	<ul style="list-style-type: none"> <li>• Teacher support for their child’s self-management</li> <li>• School environment that supports children with disabilities</li> </ul>



The parents who hesitated to allow their children to attempt self-management tasks stated that they did not know the best time to initiate self-management to facilitate their children's independence.

*Parents worry over their child's self-management ability.*

*"Even if my child says he can manage the leakage of urine or feces by himself at school, I'm not sure if that could be done properly. He's a boy, so he doesn't clean himself thoroughly, and he might also smell. I'm so anxious about that, I can't even take any employment. I'm constantly sitting by the phone because his teacher might call anytime when he's at school" (Mother B).*

*Parents are worried when their child is exposed to new environments.*

*"I'm always uneasy about sending my child to a new environment. My biggest worry is fecal leakage. This anxiety keeps me from letting my child go to a new place" (Mother C).*

*Parents do not know the proper timing for the child's initiation of self-management.*

*"Actually, I'm not really sure how long I must help him. It cannot continue forever, but I'm not sure when I should let him start doing it on his own" (Mother G).*

## School-Related Factors

Children with SB could not use the restroom near their classroom for self-management tasks, such as catheterization or changing pads, for fear of catching their friends' attention. Instead, they used restrooms far from their classrooms or faculty restrooms. Their parents suggested the need for an independent space for catheterization at school.

*Changing a private room to facilitate children's self-management in school.*

*"It makes my child uneasy even in the restroom, because other kids peek through a crack in the door or look down from the space above. He's so uneasy that he just wets his pants. That's more comfortable for him, you know. The school health room has no curtains around each bed. If only there were curtains, it would be so much simpler since he can easily manage catheterization without any spill-over issues" (Mother B).*

## Theme 2: Protective Factors of Self-Management Behaviors in Children With SB

### Child-Related Factors

As they progress to higher grades, children with SB can understand their health status depending on whether they can control their own urine and bowel movements and conduct self-management behaviors. Children with SB

uniquely perform self-management behaviors by avoiding other people's attention or preparing in advance.

*Knowing my health status.*

*"When the child was younger, he had no urine and bowel control to know when he had to go to the toilet. Now that he's older, it seems that he has that control. If I ask, 'OO, don't you have to go to the toilet?' He replies, 'Mom, I know when I have to. I'm fine for now.' Now it seems that he is aware of his condition and manages it accordingly" (Mother H).*

*Understanding my own way of self-management.*

*"My child is quite active and has a knack for working it out well. He is quite skillful in covering with his clothes and not letting others know. It's good that he's not the type to just sit curled up at home" (Mother B).*

### Parent-Related Factors

The participants showed support for their children by helping them acknowledge and positively accept their condition. They rewarded their children with compliments and encouragement whenever they successfully engaged in self-management behaviors, inspiring the children to be more successful in self-management. The parents' child-rearing methods also fostered independence in their children to perform self-management behaviors and other daily life activities.

*Helping their child to positively accept the condition.*

*"I tell my child, 'One of the good ways to make yourself comfortable is to just accept it if you cannot do anything about it anyway.' I had a talk with my husband that if we cannot change anything, we should just accept it and help our child feel more comfortable with it" (Mother H).*

*Encouraging their child to engage in successful self-management.*

*"I always compliment my child. If he accomplishes catheterization and asks, 'Mom, do you hear that? You hear that, right?' I always clap and say, 'Yeah, I can hear that. You're doing great.' This encourages him" (Mother I).*

*Raising an independent child.*

*"Independence and self-reliance are extremely important. I make my child do everything on his own, such as waking up in the morning, going to bed, and other daily routine activities. I don't do those things for him. If he says he has wet the bed, I make him get up early in the morning to clean it up himself" (Mother E).*

### School-Related Factors

The participants said that the schoolteachers cared for the children and did not feel uncomfortable with self-management

tasks. They supported the children in maintaining a positive relationship with their peers. The parents said that children with a gait disturbance were assigned to classrooms on the first floor or to a special class where teachers always remained with the children for assistance. Such school environments helped the children achieve successful self-management.

*Support of teachers for self-management.*

*“The special class teacher checks how much water the child drinks and makes a mental note of the catheterization time. The child does the catheterization himself, but the teacher checks the time for him” (Mother A).*

*School environment that considers children with disabilities.*

*“When assigning the classes every semester, the school always makes a first-floor classroom available for the class my child is assigned to. If other children ask about it, the teacher explains the reason” (Father D).*

## Discussion

This study explores parents' perceptions of experiences of self-management behaviors in their school-aged children with SB. The researchers identified five child-, six parent-, and three school-related factors as experiences of self-management behaviors in children with SB.

Choosing whether to disclose their SB to people around them was an important child-related factor in self-management behavior according to parental perspectives. This factor is very closely related to SB type. Unlike in Western countries, in South Korea, lipomeningomyelocele is considerably more common than meningomyelocele, which is a more severe type than lipomeningomyelocele due to intensive prenatal care. Thus, most in utero cases of myelomeningocele are terminated (although this is not legal, it is often practiced clinically) because of prenatal intensive screening (Choi, Ji, & Han, 2017). As a result, only 18.7% of South Korean individuals with SB need a mobility aid (Choi, Ji, & Han, 2017; Choi, Kim, Ji, Lim, & Han, 2018), whereas about 50% of their Western counterparts require such aid (Szymanski et al., 2015). Thus, in South Korea, less than 20% of people with SB have visible disabilities. At the same time, Korean individuals with SB experience similar rates of bladder (71%) and bowel problems (42%) as Western individuals with SB (75% and 53%, respectively; Choi, Ji, & Han, 2017; Choi, Kim, Ji, Lim, & Han, 2018; Szymanski et al., 2015). Therefore, Koreans with SB may suffer more psychological and mental difficulties because they must administer concealed self-management behaviors.

Disclosing their condition is very difficult for South Korean children with SB due to the negative perception of disability and lack of opportunity to understand people with SB (Choi et al., 2019). Children with SB and their parents fear exposure, because people with better-recognized diseases (e.g., pediatric cancer, diabetes) still experience stigma in South Korea (Seo & Song, 2019; Son, 2011). In particular, the bladder and bowel problems faced by children with SB more substantially affect body image and self-esteem than do problems of other chronic conditions (Luther & Christian, 2017). Thus, these children fear social isolation and prejudice if exposed.

Research comparing peer relationships of children with SB in the United States (Devine, Holmbeck, Gayes, & Purnell, 2012) showed that children with SB spent less time with their friends and received low levels of emotional support from them. Moreover, children with SB demonstrated less adaptive social behaviors in peer interactions, and there were differences in language and attentional abilities between children with SB and their peers (Holbein et al., 2015); this may also be true for school-aged children. Qualitative research on incontinence and social participation in children with SB and their parents in Canada showed that incontinence reduced their independence. Most of the children were able to explain to their peers about SB; however, they left out any information about bowel and bladder control problems (Fischer, Church, Lyons, & McPherson, 2015). The invisibility of SB and cultural factors may pressure children with SB to keep it hidden.

However, disclosing their condition was a protective child-related factor. Interest and support from parents or teachers are necessary to facilitate positive peer relationships for children with SB. To achieve this goal, improved bladder/bowel dysfunction awareness programs for the public, school teachers, and children's peers should be developed and implemented. Such interventions could be effective in reducing stigmatization of SB or other disabilities, because schools play a central role in teaching youth ethical behaviors, social skills, and positive attitudes toward chronic conditions (Weisman, Kia-Keating, Lippincott, Taylor, & Zheng, 2016).

In terms of family-related experiences, from a parental perspective, parental readiness and attitude toward children's self-management are critical. In this study, the risk factors of self-management behaviors in children with SB as perceived by the parents included “parents worry over their child's self-management ability” and “parents are worried when their child is exposed to new environments.” In these cases, parental risk factors lowered children's opportunities to practice self-management. Similarly, if parents perceive their children as vulnerable, they

can only focus on the complex care management rather than their children's self-management (Luther & Christian, 2017).

Protective factors for self-management were also perceived by parents in this study, including "encouraging their child to engage in successful self-management" and "raising an independent child." Self-management is affected by parents' child-rearing attitudes. A proper balance between protection, autonomy, and shared decision-making with children is needed to achieve optimal self-management (Sawin & Thompson, 2009). According to the Life Course Model for SB (Swanson, 2010), children's self-management programs should be started during preschool, allowing for an efficient application to school-aged children, and achievement of independence by adolescence. Health monitoring needs must be shared responsibly during childhood (Gall, Kingsnorth, & Healy, 2006). During this period, rehabilitation nurses are in an optimal position to provide stepwise goals and guidelines (Greenley, 2010). Thus, rehabilitation nurses should systematically support children at various stages of development with parents providing ongoing support.

Several factors indicate that the school environment could be a risk factor as well as a protective factor according to parental perspectives. In previous studies, the lack of a dedicated place to perform CIC was identified as the most common barrier to self-management in school-aged children (Lim et al., 2016), who had to use restrooms far from their classroom to avoid their friends' negative attention (Katrancha, 2008), indicating the need for an independent space at school to perform such activities without disturbance from other students. It was also noted during the interviews that a constant information exchange between parents and healthcare providers regarding the children's condition was required so that children could dependently accomplish catheterization at school.

### **Limitations**

This study has a few limitations. First, this study focused on parental perspectives regarding the experience of self-management behaviors in children with SB instead of verifying the children's subjective experiences. Future study should include interviews with school-aged children to understand their voices. As in all qualitative research, these parents' descriptions may not reflect other developmental stages or other chronic conditions of school-aged children with SB. Second, compared to Western countries, South Korea has different cultural characteristics, such as stigma against chronic conditions, as well as different parental perceptions of such experiences. Therefore, these findings may not be universally generalizable. However, as there are

many Asian families living in Western countries, it could be helpful to understand their perspectives and experiences regarding children with SB. In addition, future research could benefit from comparisons with this study. Third, the generalizability of these results to fathers of children with SB might be limited as most study participants were mothers. Lastly, the period of data collection might also be a limitation. It is recommended that, in the future, similar studies be conducted, although no studies on this topic have been conducted in the last 7 years.

### **Implications for Practice**

These findings provide an understanding and awareness of parents' perspectives of factors related to self-management in school-aged children with SB, especially in Asian countries, including South Korea. To improve self-management in children with SB, we should consider the child, family, and school factors. Furthermore, reducing risk factors and improving protective factors is essential. From this perspective, rehabilitation nurses are essential healthcare providers who can offer stepwise guidance to achieve self-management behaviors in children with SB according to their stage of development. For example, for school-aged children, self-management is viewed within the context of play, because children often forget to incorporate self-management practices into their daily lives. In addition, rehabilitation nurses can work alongside children with SB and their parents to achieve self-management and evaluate their achievement levels. Furthermore, in this process, rehabilitation nurses need to consider cultural differences in disclosing the child's condition and communicate effectively with the children and their parents to achieve their common goals. Simultaneously, rehabilitation nurses should assist children with SB to disclose their condition to others and to adapt to the process of improving the quality of their lives.

### **Conclusion**

Parents' perceptions of the experience of self-management behaviors in children with SB were classified into protective factors that accelerated self-management behaviors and risk factors that hindered them. Each category included child-, parent-, and school-related factors. Therefore, to promote self-management behaviors in children with SB, reducing risk factors and promoting protective factors are necessary while considering child, family, and school dimensions based on cultural differences. Further studies are needed to develop an integrated self-management program that can help children with SB grow into independent and healthy adults.



## Key Practice Points

- Protective and risk factors exist in self-management behaviors in children with spina bifida (SB).
- Child-, family-, and school-related factors help improve self-management of SB.
- Rehabilitation nurses can provide guidance for stepwise self-management in children with SB.

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## Conflict of Interest

None.

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## References

- Allen, P. J., Vessey, J., & Schapiro, N. A. (2010). *Primary care of the child with a chronic condition* (5th ed.). St. Louis, MO: Mosby Elsevier.
- Atchley, T. J., Dangle, P. P., Hopson, B. D., Graham, A., Arynchyna, A. A., Rocque, B. G., ... Wilson, T. S. (2018). Age and factors associated with self-clean intermittent catheterization in patients with spina bifida. *Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach*, 11, 283–291. doi:10.3233/PRM-170518
- Campbell, J. B., Moore, K. N., Voaklander, D. C., & Mix, L. W. (2004). Complications associated with clean intermittent catheterization in children with spina bifida. *The Journal of Urology*, 171(6 Pt 1), 2420–2422. doi:10.1097/01.ju.0000125200.13430.8a
- Choi, E. K., Han, S. W., Shin, S. H., Ji, Y., Chon, J. H., & Im, Y. J. (2015). Long-term outcome of transanal irrigation for children with spina bifida. *Spinal Cord*, 53(3), 216–220. doi:10.1038/sc.2014.234
- Choi, E. K., Im, Y. J., & Han, S. W. (2017). Bowel management and quality of life in children with spina bifida in South Korea. *Gastroenterology Nursing*, 40(3), 208–215. doi:10.1097/SGA.0000000000000135
- Choi, E. K., Ji, Y., Bae, E., & Jang, M. (2019). Parents' needs concerning their children with spina bifida in South Korea: A mixed method study. *Journal of Pediatric Nursing*, 47, e36–e44. doi:10.1016/j.pedn.2019.04.018
- Choi, E. K., Ji, Y. J., & Han, S. W. (2017). Sexual function and quality of life in young men with spina bifida: Could it be neglected aspects in clinical practice? *Urology*, 108(10), 225–232. http://dx.doi.org/10.1016/j.urology.2016.11.054
- Choi, E. K., Kim, S. W., Ji, Y. J., Lim, S., & Han, S. W. (2018). Sexual function and quality of life in women with spina bifida: Are the women with spina bifida satisfied with their sexual activity? *Neurourology and Urodynamics*, 37(5), 1786–1793. doi:10.1002/nau.23525
- Choi, E. K., Shin, S. H., Im, Y. J., Kim, M. J., & Han, S. W. (2013). The effects of transanal irrigation as a stepwise bowel management program on the quality of life of children with spina bifida and their caregivers. *Spinal Cord*, 51(5), 384–388. doi:10.1038/sc.2013.8
- Choi, E. K., & Yoo, I. Y. (2015). Resilience in families of children with Down syndrome in Korea. *International Journal of Nursing Practice*, 21(5), 532–541. doi:10.1111/ijn.12321
- Choi, J., Seo, K., Han, Y., Lee, S., Bu, Y., Lee, S., ... Yee, N. (2009). *Congenital anomaly survey and statistics* (Vol. 306). Seoul, South Korea: Ministry of Health & Welfare.
- Copp, A. J., Adzick, N. S., Chitty, L. S., Fletcher, J. M., Holmbeck, G. N., & Shaw, G. M. (2015). Spina bifida. *Nature Reviews: Disease Primers*, 1, 15007. doi:10.1038/nrdp.2015.7
- Devine, K. A., Holmbeck, G. N., Gayes, L., & Purnell, J. Q. (2012). Friendships of children and adolescents with spina bifida: Social adjustment, social performance, and social skills. *Journal of Pediatric Psychology*, 37(2), 220–231. doi:10.1093/jpepsy/jsr075
- Downe-Wamboldt, B. (1992). Content analysis: Method, applications, and issues. *Health Care for Women International*, 13(3), 313–321. doi:10.1080/07399339209516006
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107–115. doi:10.1111/j.1365-2648.2007.04569.x
- Fischer, N., Church, P., Lyons, J., & McPherson, A. C. (2015). A qualitative exploration of the experiences of children with spina bifida and their parents around incontinence and social participation. *Child: Care, Health and Development*, 41(6), 954–962. doi:10.1111/cch.12257
- Fremion, E. J., & Dosa, N. P. (2019). Spina bifida transition to adult healthcare guidelines. *Journal of Pediatric Rehabilitation Medicine*, 12(4), 423–429. doi:10.3233/PRM-190633
- Gall, C., Kingsnorth, S., & Healy, H. (2006). Growing up ready: A shared management approach. *Physical & Occupational Therapy in Pediatrics*, 26(4), 47–62.
- Greenley, R. N. (2010). Health professional expectations for self-care skill development in youth with spina bifida. *Pediatric Nursing*, 36(2), 98–102.
- Holbein, C. E., Lennon, J. M., Kolbuck, V. D., Zebracki, K., Roache, C. R., & Holmbeck, G. N. (2015). Observed differences in social behaviors exhibited in peer interactions between youth with spina bifida and their peers: Neuropsychological correlates. *Journal of Pediatric Psychology*, 40(3), 320–335. doi:10.1093/jpepsy/jsu101
- International Clearinghouse for Birth Defects Surveillance and Research. (2008). *Annual report*. Retrieved from <http://www.icbdsr.org/resources/annual-report/>
- Kapoor, R., De Carlo, K., Raman, L., Thibadeau, J., & Kancherla, V. (2019). Needs assessment survey for children and adults with spina bifida in Georgia. *Journal of Pediatric Rehabilitation Medicine*, 12(4), 383–392. doi:10.3233/PRM-190567
- Katrancha, E. D. (2008). Clean intermittent catheterization in the school setting. *The Journal of School Nursing*, 24(4), 197–204. doi:10.1177/1059840508319865
- Lim, S. W., Lee, H. E., Davis, M., & Park, K. (2016). Perceived barriers and difficulties of intermittent catheterization: In Korean patients with spinal dysraphism and their parents. *Neurourology and Urodynamics*, 35(3), 395–399. doi:10.1002/nau.22716
- Lindsay, S., Kingsnorth, S., McDougall, C., & Keating, H. (2014). A systematic review of self-management interventions for children and youth with physical disabilities. *Disability and Rehabilitation*, 36(4), 276–288. doi:10.3109/09638288.2013.785605
- Lloyd, J. C., Wiener, J. S., Gargollo, P. C., Inman, B. A., Ross, S. S., & Routh, J. C. (2013). Contemporary epidemiological trends in complex congenital genitourinary anomalies. *The Journal of Urology*, 190(4 Suppl), 1590–1595. doi:10.1016/j.juro.2013.04.034
- Luther, B. L., & Christian, B. J. (2017). Parent perceptions of health promotion for school-age children with spina bifida. *Journal for Specialists in Pediatric Nursing*, 22(1), e12168. doi:10.1111/jspn.12168
- Mahmood, D., Dicianno, B., & Bellin, M. (2011). Self-management, preventable conditions and assessment of care among young adults with myelomeningocele. *Child: Care, Health and Development*, 37(6), 861–865.

- Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, 26(13), 1753–1760. doi:10.1177/1049732315617444
- Miles, M. B., Huberman, M. A., & Saldana, J. (2019). *Qualitative data analysis: A methods sourcebook* (4th ed.). Thousand Oaks, CA: Sage Publication.
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2), 13–22. doi:10.1177/160940690200100202
- Psihogios, A. M., Kolbuck, V., & Holmbeck, G. N. (2015). Condition self-management in pediatric spina bifida: A longitudinal investigation of medical adherence, responsibility-sharing, and independence skills. *Journal of Pediatric Psychology*, 40(8), 790–803. doi:10.1093/jpepsy/jsv044
- Ryan, P., & Sawin, K. J. (2009). The individual and family self-management theory: Background and perspectives on context, process, and outcomes. *Nursing Outlook*, 57(4), 217–225. doi:10.1016/j.outlook.2008.10.004
- Sawin, K. J., Buran, C. F., Brei, T. J., & Fastenau, P. S. (2003). Correlates of functional status, self-management, and developmental competence outcomes in adolescents with spina bifida. *SCI Nursing*, 20(2), 72–85.
- Sawin, K. J., & Thompson, N. M. (2009). The experience of finding an effective bowel management program for children with spina bifida: The parent's perspective. *Journal of Pediatric Nursing*, 24(4), 280–291. doi:10.1016/j.pedn.2008.03.008
- Schreier, M. (2012). *Qualitative content analysis in practice*. Thousand Oaks, CA: Sage Publications.
- Seo, K., & Song, Y. (2019). Self-stigma among Korean patients with diabetes: A concept analysis. *Journal of Clinical Nursing*, 28(9–10), 1794–1807. doi:10.1111/jocn.14789
- Sohmaran, C., & Shorey, S. (2019). Psychological interventions in reducing stress, depression and anxiety among parents of children and adolescents with developmental disabilities: A systematic review and meta-analysis. *Journal of Advanced Nursing*, 75, 3316–3330. doi:10.1111/jan.14166
- Son, S. Y. (2011). Illness experience of adolescents with hematologic malignancies. *Journal of Korean Academy of Nursing*, 41(5), 603–612. doi:10.4040/jkan.2011.41.5.603
- Swanson, M. E. (2010). Need for the life course model for spina bifida. *Pediatric Clinics of North America*, 57(4), 893–901. doi:10.1016/j.pcl.2010.08.001
- Szymanski, K. M., Cain, M. P., Hardacker, T. J., & Misseri, R. (2017). How successful is the transition to adult urology care in spina bifida? A single center 7-year experience. *Journal of Pediatric Urology*, 13(1), 40.e41–40.e46. doi:10.1016/j.jpuro.2016.09.020
- Szymanski, K. M., Misseri, R., Whittam, B., Raposo, S. M., King, S. J., Kaefer, M., ... Cain, M. P. (2015). Quality of Life Assessment in Spina Bifida for Adults (QUALAS-A): Development and international validation of a novel health-related quality of life instrument. *Quality of Life Research*, 24(10), 2355–2364. doi:10.1007/s11136-015-0988-5
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated Criteria for Reporting Qualitative Research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. doi:10.1093/intqhc/mzm042
- Weisman, H., Kia-Keating, M., Lippincott, A., Taylor, Z., & Zheng, J. (2016). Mental health stigma prevention: Pilot testing a novel, language arts curriculum-based approach for youth. *Journal of School Health*, 86(10), 709–716. doi:10.1111/josh.12427
- Yun, H. J., & Kim, H. S. (2017). Self-management behaviors of children with spina bifida. *Journal of Neuroscience Nursing*, 49(1), 15–21. doi:10.1097/JNN.0000000000000223

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