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# Health Professional Expectations for Self-Care Skill Development in Youth With Spina Bifida

Rachel Neff Greenley

Spina bifida (SB) is one of the most common congenital birth defects, affecting roughly 3.4 per 10,000 live births (Lie, 2006). It is caused by a failed closure of one or more vertebrae during the early weeks of gestation and results in significant neurological impairment at or below the lesion site (Lie, 2006). Although specific functional impairments vary by individual, most youth with the myelomeningocele type of SB must engage in clean intermittent catheterization several times daily, complete daily bowel programs, and perform daily skin checks to identify areas of injury or skin vulnerability. Research suggests that some youth and young adults with SB have lower levels of independent functioning in the domains of independent living, employment, and community functioning (Andren & Grimby, 2004; Benjamin, 1988; Date, Yagyu, Asari, & Ohmoto, 1993; Dillion, Davis, Duguay, Seidel, & Shurleff, 2000; Greenley, Holmbeck, Zukerman, & Buck, 2006; Lonton, Loughlin, & O'Sullivan, 1984; McDonnell & McCann, 2000). For individuals with SB to function autonomously, mastery of bowel and bladder care is critical (Oppenheimer, 2006). In addition,

The author examined expectations for the development of self-care skills for youth with spina bifida (SB) among a multidisciplinary group of health professionals, including physicians, nurse practitioners, nurses, and other professionals. Ninety-seven professionals from U.S. SB clinics completed a Web-based survey of expectations for youth attainment of bowel, bladder, and skin care skills. Professionals rated expectations for two hypothetical vignettes: a child with moderate SB severity and a child with greater severity. Most professionals believed that all skills were attainable by the end of elementary school in the moderate severity condition. Expectations for skill attainment in the severe condition were lower and significantly later (end of high school) than in the moderate condition. Professionals who treated more patients annually expected earlier bowel and bladder skill attainment. Findings highlight the importance of developing different timelines for nursing education of youth with moderate versus more severe condition impairment.

urinary tract infections (UTIs) and serious skin ulcerations or infections can evolve into chronic problems that require ongoing medical intervention and have a negative impact on the health of those with SB. In one study, 47% of admissions for adults with SB were for treatment of potentially preventable secondary conditions (serious urological infections, renal problems, or pressure sores) (Kinsman & Doehring, 1996).

The salience of bowel, bladder, and skin care tasks for individuals with SB makes these critical issues for health professionals treating this population to address. Teaching youth to gradually take on more responsibilities in these areas is of paramount importance, so as youth transition to adulthood, they can achieve their potential with respect to independent functioning. Moreover, mastery of self management skills may have important implications for positive psychosocial functioning in this population.

Pediatric nurses are in an optimal position to provide such education given their ongoing relationship with these patients. However, few published guidelines exist for education in these domains (Liptak, 2006; Shurtleff, Sobkowiak, & Walker, 2006). The current study was designed to assess the expectations of a multidisciplinary group of health

professionals with regard to development of self care skills of youth with SB. This study examined a) health professional opinions about the attainability of various bowel, bladder, and skin care skills for youth with SB; b) if expectations of health professionals varied as a function of patient condition severity or health professional demographic factors; and c) what age health professionals believed youth with SB with varying levels of condition severity should be able to accomplish these tasks.

Such information is helpful in designing intervention efforts to maximize youth self-care skills. To the extent that health professionals believe the majority of youth with SB should be able to perform key self-care skills, teaching these skills can be the focus of clinical intervention efforts. Conversely, for domains in which independent functioning is not expected, efforts can focus on identifying long-term supportive services. Finally, with respect to the provision of clinical services for youth with SB, no published guidelines exist that provide specific suggestions to nurses or other professionals about appropriate times to introduce discussions of the development of self-care skills for youth with varying degrees of condition-related impairments. Findings of the current investigation have poten-

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**Rachel Neff Greenley, PhD**, is an Assistant Professor of Psychology, Department of Psychology, Rosalind Franklin University of Medicine and Science, North Chicago, IL.

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tial generalizability clinically in that they provide information to those treating children with SB about typical ages at which other practitioners would expect youth with varying degrees of impairment to accomplish self-care tasks in the bowel, bladder, and skin care domains, thereby offering a "timeline" for nursing education and intervention.

## Method

### Procedure

This study was reviewed and deemed exempt by the investigator's Institutional Review Board. Participants were identified using the Spina Bifida Association of America (SBA) online listing of SB clinics in the United States. Administrators of clinics listed were contacted via telephone by a research assistant and were asked to distribute an email describing the online survey to all health professionals within their clinic. Administrators provided information about the number of staff to whom the email was forwarded to determine response rate. If clinic administrators preferred not to provide their email addresses, a letter was mailed to clinics with instructions on accessing the survey.

The email distributed by clinic administrators included an overview of the purpose of the study, as well as a URL link to the survey. Participants who clicked on the link were first directed to an information page about the study. Those who clicked "yes" provided their consent to participate and were directed to the survey. Participants who clicked "no" were directed to a Web page thanking them for considering participation and instructing them to close their browser window. Participants were able to close their browser window at any time and were informed that doing so would end their participation and would result in no data being recorded or sent. Completed surveys were emailed to the study investigator via an encrypted script void of identifying information.

### Participants

Valid contact information was available for 131 sites listed on the SBA registry. Seventy-two of the 131 sites contacted agreed to participate (55%), three sites declined to distribute emails (2%), and 56 sites (43%) were unresponsive after repeated attempts to contact the site (up to

three calls, including two messages left for each site). Participating sites varied with respect to the number of health care professionals working at that site ( $M = 7.6$ ,  $SD = 4.9$ , range = 2-30).

Participants included 97 U.S. health professionals, including physicians ( $n = 19$ , 20%), nurses ( $n = 31$ , 32%), nurse practitioners ( $n = 23$ , 24%), occupational or physical therapists ( $n = 20$ , 21%), social workers ( $n = 3$ , 3%), and a liaison for parents ( $n = 1$ , 1%). Participants ranged in age from 26 to 67 years ( $M = 47.5$ ,  $SD = 8.4$ ), were predominantly female ( $n = 80$ ; 82%), and most worked in an urban locale ( $n = 70$ ; 72.2%). Experience treating youth with SB ranged from 1 to 35 years ( $M = 12.46$ ,  $SD = 10$ ), and participants reported treating a median of 120 patients annually ( $SD = 168.9$ , range = 3-800).

### Measures

Health professionals completed a 6-item demographics questionnaire in which they provided their age, gender, professional affiliation, years of experience treating youth with SB, number of patients with SB treated annually, and practice location.

The Health Professional Expectations in Spina Bifida Survey is a 25-item measure of expectations for youth self-care skills created for the present study. Health professionals provided ratings of the age at which they would expect a child with 1) moderate impairment and 2) severe impairment to achieve independence in various tasks. Ratings were made as follows: 1 = preschool years (ages 3 to 5), 2 = elementary school years (ages 6 to 11), 3 = middle school/junior high years (ages 12 to 13), 4 = high school years (ages 14 to 18), and 5 = post-high school (ages 18 and up). For each item, health professionals could also endorse that a task was "not attainable." To reduce variability in perceptions of moderate or severe impairment, brief descriptions of patients were provided. These descriptions were formulated based on typical presentations of youth with SB, and accuracy was confirmed by a team of multidisciplinary health professionals with expertise in SB management.

The moderate impairment condition was described as follows: "Patient A has a low lumbar level lesion, ambulates with ankle-foot braces, and has shunted hydrocephalus. Patient A has some bowel and bladder sensation but must be catheterized every four hours and must use a bowel management program. Patient A's IQ

is in the average range." The severe impairment condition was described as follows: "Patient B has a thoracic level lesion, ambulates using a wheelchair, and has shunted hydrocephalus. Patient B has very limited bowel and bladder control, and wears Pull-ups<sup>®</sup> because of incontinence. Patient B's IQ is in the borderline range." The survey assessed health professional expectations in five domains: general self care, bladder and bowel management, skin care, knowledge of condition, and general condition management skills. This investigation used items from the bowel and bladder (7 items;  $\alpha$  moderate = 0.88,  $\alpha$  severe = 0.90) and skin care (4 items;  $\alpha$  moderate = 0.88,  $\alpha$  severe = 0.87) domains.

## Results

### Perceptions of Attainability Of Self Care Skills

In the moderate impairment condition, nearly all professionals surveyed believed all bowel, bladder, and skin care tasks were attainable (see Table 1). For the severe impairment condition, health professional ratings of attainability were lower. In the bowel and bladder domain, nearly all respondents rated assisting with catheterization or bowel program as attainable tasks, while recognizing signs of a UTI or of bowel problems were rated as attainable by roughly three-quarters of those surveyed. Catheterizing independently, completing the bowel program independently, and cleaning oneself following a bowel or bladder accident were rated as attainable by one-half to two-thirds of respondents. Regarding skin care, over two-thirds of respondents reported skills as attainable in this domain.

### Differences in Expectations As a Function of Condition Severity

To examine if health professional expectations for mastery of bowel, bladder, and skin care tasks differed as a function of condition severity, paired *t*-tests were conducted. In these analyses, ratings of "not attainable" were excluded. To control for multiple comparisons, a Bonferroni correction was employed, with the *p* value set at  $p < 0.0045$ . For all items, mean age of attainment was significantly younger for the moderate impairment condition (see Table 2).

**Table 1.**  
**Median and Modal Health Professional Ratings of Skill Development for Bowel, Bladder, and Skin Care Tasks**

Task	Moderate				Severe			
	Percentage (n) of Health Professionals who Rated Task as Attainable	Median Age of Attainability <sup>1</sup>	Modal Age of Attainability <sup>1</sup>	SD	Percentage (n) of Health Professionals who Rated Task as Attainable	Median Age of Attainability <sup>1</sup>	Modal Age of Attainability <sup>1</sup>	SD
Assist parent in catheterization	100% (96)	1	1	0.65	91% (87)	2	2	1.01
Assist parent in completing bowel program	100% (94)	2	2	0.69	84% (78)	3	2	1.06
Perform pressure relief exercises/ weight shifts correctly	100% (92)	2	2	0.91	82% (76)	3	2	1.07
Identify objects that may contain latex	100% (93)	2	2	0.90	76% (70)	4	2	1.15
Perform self-catheterization independently	99% (95)	2	2	0.74	64% (61)	3	3	0.87
Recognize signs of bowel problems and report to parent	99% (94)	2	2	0.78	73% (69)	3	3	1.04
Recognize signs of a urinary tract infection and report to parent	99% (95)	2	2	0.73	75% (71)	3	4	0.99
Clean up after self following bowel or bladder accident	100% (96)	2	2	0.71	53% (50)	4	4	0.86
Take safety precautions to protect insensate skin	100% (94)	2	2	0.92	72% (67)	4	4	1.03
Complete daily skin inspections and report areas of concern to parent	100% (94)	2.5	2	0.87	69% (65)	4	4	1.06
Perform bowel program independently	100% (94)	3	3	0.84	54% (51)	4	5	0.98

<sup>1</sup>Note: 1 = preschool years, 2 = elementary school years, 3 = middle school/junior high years, 4 = high school years, 5 = post-high school.

### Differences in Expectations As a Function of Health Professional Characteristics

Analyses were conducted to examine if health professionals' expectations for age of attainment of self-care skills varied as a function of key health professional characteristics, including type of profession (coded as physician, nurse, nurse practitioner, or occupational/physical therapist), years of experience, and number of patients seen annually. In these analyses, ratings of "not attainable" were excluded. No differences in mean bowel and bladder subscale age of attainment rat-

ings were documented as a function of profession type for either the moderate ( $F[3, 88] = 0.856, p = 0.467$ ) or severe conditions ( $F[3, 81] = 1.166, p = 0.328$ ). Further, no differences in health professionals' skin care subscale age of attainment ratings as a function of profession were found for either the moderate ( $F[3, 86] = 0.338, p = 0.798$ ) or severe conditions ( $F[3, 77] = 1.483, p = 0.226$ ).

Regarding health professional experience, no significant associations were documented with mean age of attainment ratings for the bowel and bladder subscale in either the moder-

ate ( $r = -0.129, p = 0.209$ ) or severe ( $r = -0.050, p = 0.641$ ) conditions. Similarly, no relationships between years of experience and mean age of attainment ratings for the skin care subscale were documented in either the moderate ( $r = -0.029, p = 0.782$ ) or severe ( $r = 0.034, p = 0.756$ ) conditions.

Number of patients with SB treated annually was significantly associated with health professional mean ratings of age of attainment for bowel and bladder tasks in the moderate ( $r = -0.228, p = 0.032$ ) and severe ( $r = -0.252, p = 0.022$ ) conditions. In both cases, treating more youth with SB on an

**Table 2.**  
**Paired Samples *t*-Tests Comparing Mean Age of Task Attainment for Moderate and Severe Conditions**

Task	<i>t</i>	<i>df</i>	<i>p</i>
Assist parent in catheterization	-10.737	86	0.000
Perform self-catheterization independently	-12.301	60	0.000
Recognize signs of a urinary tract infection and report these to the parent	-9.246	70	0.000
Assist parent in completing bowel program	-11.406	77	0.000
Perform each step of bowel program independently	-11.012	50	0.000
Recognize signs of bowel problem and report these to parent	-10.022	68	0.000
Clean up after self following bowel or bladder accident	-11.508	49	0.000
Complete daily skin inspections and report areas of concern to parents	-10.346	64	0.000
Perform pressure relief exercises/weight shifts correctly	-9.028	73	0.000
Take safety precautions to protect insensate skin	-11.717	66	0.000
Identify objects that may contain latex	-10.546	69	0.000

annual basis was associated with expectations for younger age of skill attainment. No significant associations between number of patients treated annually and mean ratings of age of attainment of skin care tasks were found for the moderate ( $r = -0.186, p = 0.087$ ) or severe ( $r = -0.186, p = 0.102$ ) conditions.

### Health Professional Modal Ratings of Age of Task Mastery

Table 1 displays modal and median ages of expected attainment for bowel, bladder, and skin-care tasks in the moderate and severe conditions. The standard deviation is included as an index of variability in health professional ratings. In general, there was less variability in attainment ratings for the moderate than for the severe condition.

For the moderate condition, bowel and bladder tasks with modal attainable ratings during the preschool years included assisting the parent with catheterization, while the following tasks had modal ratings of attainability during the elementary school years: assisting the parent in completing bowel program, performing self-catheterization independently, cleaning up after self following a bowel or bladder accident, and recognizing warning signs of bowel problems. Finally, independently completing one's bowel program had a modal attainability rating during the middle school years. Regarding skin care, all tasks had modal ratings of attainability during the elementary school years.

For the severe condition, no tasks had modal ratings of attainability

during the preschool years, while assisting the parent in catheterization and with bowel program had modal ratings of attainability during the elementary school years. Tasks with modal attainable ratings during the middle school years included performing independent self-catheterization and recognizing signs of bowel problems. Cleaning up after oneself following a bowel or bladder accident and recognizing signs of a UTI were tasks with modal attainment ratings during the high school years, while performing the bowel program independently had a modal attainment rating of post-high school. In the skin care domain, performing pressure relief exercises and identifying objects containing latex had modal ratings of attainability during the elementary school years, while taking safety precautions to protect skin and completing daily skin inspections had modal attainability ratings during the high school years.

### Discussion

This study examined expectations of health professionals who treat youth with SB concerning the age of attainment of self-care skills in bowel, bladder, and skin care domains. Findings revealed several key points. First, the vast majority of health professionals surveyed believed that in the moderate severity condition, all bowel, bladder, and skin care skills are attainable for youth with SB. Moreover, for all but two tasks (completing daily skin inspections and reporting areas of concern to parents, independently completing one's

bowel program), health professionals expected these tasks to be accomplished before the end of the elementary school years. Health professionals' expectations for attainment of key self-care skills in the severe condition group were lower. Although most believed that youth could successfully assist with bowel and bladder tasks, nearly 25% of respondents rated the tasks of recognizing signs of UTIs or warning signs of bowel problems as unattainable. Furthermore, bowel and bladder tasks that were the most complex (such as independently self-catheterizing, independently completing bowel program, and cleaning up after self following an accident) were viewed as unattainable by at least one-third of those surveyed. Even when tasks rated as unattainable were excluded, statistical analyses confirmed that the mean age of skill attainment was significantly later in the severe condition as compared to the moderate condition. Although type of profession and years of experience did not significantly relate to health professional ratings of expected age of skill attainment, the number of patients treated on an annual basis was associated with health professional ratings of bowel and bladder skill attainment for both the moderate and severe impairment condition.

The current findings should be interpreted within the context of several limitations. First, the response rate for the online survey was relatively low, and the survey was developed specifically for use in the present study. Moreover, comparisons of urban versus rural locales could not be performed given the very small

number of practitioners from rural areas who participated. However, the lower number of participants from rural areas may reflect the fact that many SB centers are affiliated with academic medical centers located in urban or suburban locales. In addition, this study assumed that the opinions of health professionals are valid indicators of which children with SB can learn self-care skills and when they can learn them. However, health professionals may not necessarily hold accurate opinions/expectations in this domain, and significant variability across individuals and families exists with respect to self-management skill attainment. In the absence of a cohesive body of research that provides information on what

and what to teach children with SB. In addition, research describing the age at which children with SB are taught self-care skills and factors that inhibit or facilitate this learning are also critically needed. Finally, exploration of health professional expectations for the development of self-care skills in other domains is also imperative because independent functioning of individuals with SB includes managing numerous other tasks (both condition-related and general daily life tasks) (Liptak, 2006).

These findings elucidate the importance of developing different timelines of education for youth with moderate versus more severe impairments. Moreover, they suggest that different foci for education may be warranted in certain domains. Educational efforts with youth with moderate-condition severity should begin in the pre-school years and should emphasize independent attainment of bladder, bowel, and skin-care skills. However, efforts directed to youth with more severe presentations may be better started during the elementary school years and may need to focus on development of supportive strategies to aid the child in maximizing his or her own involvement while ensuring adequate supports to successfully complete the task. In the severe impairment condition, tasks that had greater cognitive demands (for example, recognizing warning signs of UTIs or bowel problems) because they require the patient to monitor for presence of symptoms and recognize these symptoms as associated with an underlying issue requiring medical attention were viewed as less attainable.

Similarly, bowel and bladder tasks that were the most complex in terms of cognitive and manual dexterity demands (for example, independently catheterizing, independently performing bowel program, and cleaning up after oneself following an accident) were viewed as the most unattainable. These findings are similar to those documented by Davis, Shurtleff, Walker, Seidel, and Duguay (2006), which indicated that adolescents with SB who had higher verbal IQs had earlier autonomy skill acquisition. Thus, intervention efforts to improve youth problem-solving skills

as well as introduce assistive devices to reduce manual dexterity demands may be of benefit for those youth with more severe presentations. ■

**Intervention efforts to improve youth problem-solving skills as well as introduce assistive devices to reduce manual dexterity demands may be of benefit for those youth with more severe presentations.**

age children with SB learn self-care skills, the results of this study can be viewed as a first step in better understanding this important issue.

Finally, the use of hypothetical cases only partially addresses the complexity of the condition, so any generalizations to individual patients must be made with caution. However, given that these vignettes were developed with the help of professionals with expertise treating youth with SB, it is believed they provide an important starting point for educational timeline development.

Future research is warranted in several areas. First, a more comprehensive understanding of the mechanisms by which greater patient contact may lead to more positive beliefs about skill development could inform future intervention efforts. Additionally, future studies that incorporate a more detailed examination of the real-life practices of health professionals in introducing and teaching self-management skills (at what ages are different classes of skills introduced, what factors influence when and if health professionals focus on teaching independent skill acquisition) would also be of benefit, as would research on the rationales that health professionals provide for their professional judgments about when

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