

## The Experience of Adolescent Women Living with Spina Bifida Part II: Peer Relationships

Gayle Roux, PhD RN NP-C • Kathleen J. Sawin, DNS CPNP FAAN • Melissa Hayden Bellin, PhD MSW LCSW • Constance F. Buran, DNS RN • Timothy J. Brei, MD

### KEY WORDS

*ecological model of adaptation*  
*peer relationships*  
*spina bifida*

*Relationships are much more complex for those with disabilities than for those without disabilities. This study was part of a larger mixed-method investigation that explored comprehensive aspects of adaptation in adolescents with spina bifida (SB). The purpose of this qualitative component of the study was to explore the experiences of peer relationships in 31 adolescent women with SB. The participants were interviewed, and analysis was conducted for common themes. The five major themes and one subtheme were peers without disabilities (subtheme: peers with disabilities), normalization, challenges in peer connectedness, peer connectedness with adults, and romantic connectedness. Whereas some participants voiced close connections with peers, others described prejudices, stereotyping, and limited dating experiences. Results from this study support the need for comprehensive assessment of social relationships in adolescent women with SB and active interventions to address problems identified. Rehabilitation nurses are in a key position to implement social interventions in adolescents and young women with SB.*

Evidence indicates that compared with those of adolescents without disabilities, social relationships with peers and dating relationships are much more complex for those with disabilities (Holmbeck et al., 2002; Sawin, Brei, Buran, & Fastenau, 2002b; Sawin, Buran, Brei, & Fastenau, 2003; Stevens et al., 1996). Adolescent women with spina bifida (SB) may find themselves in a socially devalued role and experience limited social interactions or activities with peers. Indeed, the social attitudes and response from peers during adolescence may be more challenging to adolescent development than living with SB itself (Davis & Huber, 2004). An early important study on family and peer issues in adolescents with SB or cerebral palsy conducted by Blum, Resnick, Nelson, and St. Germaine (1991) reported that, as with all youth, peers are very important for adolescents with SB. In this study, social contact for study participants was limited, and only 14.7% of youths with SB had been on a date.

The purpose of this qualitative component of a larger research study exploring comprehensive adaptation in adolescents with SB (Sawin, Brei, Buran, & Fastenau, 2002a) was to explore the experience of peer relationships, both social and romantic, in women aged 12–21 years living with SB. Previous research on social relationships for adolescents with SB has not had a gender-specific focus on the needs of women. This study contributes gender-specific evidence on the experiences of social and intimate relationships in adolescent women living with SB. It is critical that rehabilitation nurses and other

professionals understand the social context of these adolescents in order to be more effective in providing optimal health care.

### Literature Review

Few studies have uniquely focused on the experience of peer relationships for adolescents with disabilities such as SB. Available data suggest that this population is at risk for poor social competence and social isolation. For example, Holmbeck et al. (2003) examined psychosocial development in preadolescents with SB and a matched comparison group of preadolescents without disabilities. In comparison to their peers without disabilities, youth with SB tended to be less socially mature, less socially engaged, and more passive in their interactions. Moreover, the preadolescents with SB, particularly those from low socioeconomic homes, were found to have less social contact outside school. The authors speculated that this passivity was linked with lack of social engagement and fewer extracurricular activities. The authors also emphasized that this younger age group, aged 8 and 9 years, was chosen to examine social differences before adolescence, because they hypothesized that social challenges in children with SB begin early in development. Profound differences in social competence and peer relationships likewise emerged in the work of King, Shultz, Steel, Gilpin, and Cathers (1993). In their research with adolescents with physical disabilities, including SB, and those without a chronic condition, the authors found the group with disabilities to report lower social acceptance and

romantic appeal. These data suggest that the challenges of developing and maintaining peer relationships persist beyond the preadolescent period.

A grounded theory study (Skar, 2003) conducted in Sweden examined peer relationships in 12 adolescents, aged 15–19 years, with physical disabilities including SB, cerebral palsy, muscular dystrophy, and rheumatic disease. Results indicated that whereas the adolescent participants saw themselves as being “normal” and regular members of peer groups, the peer groups saw them as different. Participants acknowledged difficulty in developing peer relationships because of both physical and social barriers and reported few experiences of peer contact outside regular school hours. Interestingly, in this study the adolescents with physical disabilities compensated for limited peer relationships by creating anonymous relationships on the Internet. In addition, a pattern of selecting friends who were either younger or older emerged because they found it easier to form and maintain relationships with these groups.

Wagner and colleagues (2003) interviewed parents of adolescents with disabilities aged 13–16 who were in special education classes for diverse conditions from speech and language impairment to multiple disabilities. Findings indicated that youth with autism and multiple disabilities were among the least likely to be involved with individual friends. From 27% to 40% of the adolescents in these categories were reported to never see friends outside school. However, about 50% participated in organized group activities and about one third in community service.

Finally, in a national Canadian survey, Stevens et al. (1996) compared 101 students with physical disabilities, including SB, with adolescents without disabilities. A total of 29% of adolescents with physical disabilities had been on a date, and 21% thought they would be married by 25 years of age, with 12% foreseeing children by the same age. However, when they were compared with peers without disabilities, the broader scope of friendships was more restricted. The authors noted that their findings were consistent with prior work indicating that a lack of transportation and mobility limitations limited leisure activities outside of school. The group with disabilities described less intimate friendships. Also, friendships were more likely to be confined to the school setting, with fewer adolescents with disabilities reporting time spent with friends after school or in the evenings.

In summary, although adolescents with SB can successfully transition into adulthood, previous data indicate that this special population encounters a range of challenges in initiating and maintaining relationships. To increase understanding of the

complex and diverse experiences of relationships, this qualitative component of the larger study explores the context of peer, social, and romantic relationships among adolescent women with SB.

### Background

The theoretical touchstone of this study integrated the Ecological Model of Adaptation in Spina Bifida (Sawin et al., 2002a; Sawin, Buran, et al., 2003) with the Middle-Range Theory of Inner Strength in Women with chronic health conditions (Roux, Dingley, & Bush, 2002). These theories describe a process of response and adaptation to a chronic condition. The Ecological Model (Sawin et al., 2002a; Sawin, Buran, et al., 2003) integrates developmental, systems, and situational perspectives to explain individual adaptation. For adolescents with SB, the holistic Ecological Model depicts the relationship of risks (SB severity, neuropsychological status), demographic factors (age, gender, and socioeconomic status), and protective factors (adolescent resilience factors, family resourcefulness, and healthcare adequacy) influencing adaptation. Adaptation includes becoming skilled in managing physical health to reduce the impact of secondary conditions, developing positive mental health, participating in age-appropriate social activities, and achieving academic success and a positive quality of life.

The Middle-Range Theory of Inner Strength in Women adds useful specificity to the broader adolescent resilience concept in the Ecological Model. The Theory of Inner Strength is based on a premise of identifying and understanding the social context, connectedness, and strength-building capacities of people integrating a challenging life event such as SB into their normal lives. Inner strength is defined as “capacity to build the self through a developmental process that positively moves the individual through challenging life events” (Roux et al., 2002).

The Ecological Model, with special emphasis on age-appropriate social activities, and the Theory of Inner Strength, with special emphasis on the concept of connectedness, were used as a theoretical background of the study in the context of social and intimate relationships. Using this framework as a touchstone for the study, we examined the participants’ stories for strengths that fostered positive relationships and connectedness or challenges that hindered inner strength and adaptation. For this qualitative component of the larger study, the experiences in age-appropriate social activities and adaptation outcomes of adolescent women with SB were specifically examined.

---

*Findings indicated that youth with autism and multiple disabilities were among the least likely to be involved with individual friends.*

---

# The Experience of Adolescent Women Living with Spina Bifida Part II: Peer Relationships

## Methods

This study was part of a larger mixed-method investigation that explored comprehensive aspects of adaptation in adolescents with SB and their families. Integrating qualitative and quantitative methods was selected because this provides completeness and confirmation of data (Risjord, Dunbar, & Moloney, 2002). Data from the larger quantitative study were reported earlier (Buran, Sawin, Brei, & Fastenau, 2004; Sawin, Bellin, et al., 2003; Sawin et al., 2002a; Sawin, Buran, et al., 2003). The three global domains that described the adaptation of the adolescents with SB and their families included two domains that delineated the experience of living with SB—(1) self-concept and family relationships, and (2) peer relationships—and a third domain that addressed the meaning of self-management. The purpose of this qualitative component (Morse & Field, 1995) of the larger study was to examine experiences of peer and romantic relationships in women aged 12–21 years living with SB.

Before initiating the study, approval was obtained from the university internal review board for human subject protection. Eligibility for participation in the overall study included the following criteria: women 12–21 years of age, English speaking, functioning at grade-appropriate level in school, and having no other major progressive health conditions. Potential participants were recruited in an outpatient SB clinic in the Midwest.

After informed consent and assent were obtained, data were collected via face-to-face or telephone interviews by two trained researchers. The adolescents were assured that they could end the interview at any time and that no identifying information would be included in the final report. Findings are reported here as early adolescence (EA, 12–14 years), middle adolescence (MA, 15–17 years), and late adolescence (LA, 18–21 years) rather than by real or false names to increase confidentiality. In addition, the thematic results were examined for representation across participants and were found to include experiences of adolescents from all developmental stages and levels of lesion. That is, no theme or subtheme was exclusive to a particular age group or level of lesion.

Data were collected via a demographic tool and a semistructured interview designed to elicit expression of experiences with peer and social relationships by female adolescents with SB. For this qualitative component of the study, adolescents were initially asked questions on their experiences living with SB, the rewards and challenges they experienced, and how they adapted to them. The global research question was, "What is it like to be a teen with spina bifida?" The research questions were sequenced to initiate with general questions on their experiences with peers and

social activities and advance to the more sensitive questions on dating experiences and future goals.

Trained nurses with knowledge of adolescence and family theory conducted the interviews, which lasted between 30 and 60 minutes, with the average interview lasting 45 minutes. The interviews were audiotaped and transcribed verbatim. Analysis was done to examine the interview responses for common domains and themes (Morse & Field, 1995).

Several techniques of rigor were used in the analysis. One of the authors, who has extensive experience in qualitative research, served as a method expert to enhance the trustworthiness of analysis while generating domains and themes. Initially, the first three authors independently reviewed four randomly selected transcripts to generate a beginning coding scheme for the data. The three authors subsequently analyzed 12 additional transcripts to establish common domains and themes. The authors tracked decisions about the coding of data and development and collapse of domains, themes, and subthemes in methodological journals (Sandelowski, 1993). The first three authors then reviewed the remaining 15 transcripts, collaborated on the analysis of the final structures, and examined the data for relationships between the domain and themes. Descriptions of the domain and themes were written with particular attention to incorporating exemplar statements from the adolescents' interviews. The final two authors, who have extensive clinical experience with this population, reviewed the domains, themes, and exemplars to confirm placement and to ensure consistency with clinical reality.

## Findings

A majority of the 31 adolescents with SB in this analysis were non-Hispanic whites (97%) with ages ranging from 12 to 21 years, with a mean age of 15.84 years. Most of the participants had parents who were married (80.65%). The levels of lesion spanned the spinal cord in a fairly equal distribution: thoracic and high lumbar (25.81%), lumbar (32.26%), lumbosacral (22.58%), and sacral (19.35%). A large number of participants (87%) had hydrocephalus.

Analysis of the 31 interviews yielded three domains capturing the experiences of living with SB: (a) the Self-Concept and Family Relationships Domain, (b) the Peer Relationships Domain, and (c) the Self-Management Domain. The present article presents the themes identified in the Peer Relationships domain. The five major themes and one subtheme describing peer connectedness in the Peer Relationships Domain were peers without disabilities (subtheme: peers with disabilities), normalization, challenges in peer connectedness, peer connectedness with adults, and romantic connectedness (**Figure 1**).

**Figure 1. Domain: Peer Connectedness Relationships**

<p>Theme 1: Peers without Disabilities          “They’ll do basically anything for me and I’ll do anything for them.”</p> <p>Sub-theme: Peers with Disabilities          “Knowing she’s going through what you’re going through.”</p> <p>Theme 2: Normalization          “They treat me like I’m normal.”</p> <p>Theme 3: Challenges in Peer Connectedness          “I just sit there and watch everybody else play.”</p> <p>Theme 4: Peer Connectedness with Adults          “Everything is cool because I hang out with my bus driver.”</p> <p>Theme 5: Romantic Connectedness          “They gotta like me—they gotta look at me instead of my disability.”</p>
--

The female participants described many positive experiences of nurturing relationships with peers. Descriptions of satisfying relationships with peers without disabilities and with disabilities were shared. The theme of being treated as “normal” by peers, and the feeling that the participants with SB considered themselves normal, was a strong thread throughout the stories. However, difficulties were also expressed regarding exclusion from cliques, experiences of isolation such as sitting by themselves on the bus, and lack of inclusion in recreational activities. The thematic description and exemplars evident from the participants are given here with groupings of early (EA), middle (MA), and late (LA) adolescents.

**Theme 1. Peers Without Disabilities:**  
*“They’ll do basically anything for me and I’ll do anything for them.”*

Participants described receiving nurturing from friends. The participants shared experiences in which going to the movies, feeling no different from other kids, and hanging out created a tie to the adolescent peer group and social world. The need to have social relationships and activities outside school was very prominent in the stories. Having friends to share feelings, they did not want to disclose to parents was a need expressed by many participants. However, despite many positive experiences, limitations in attending activities outside school and difficulties in both meeting and keeping friendships with age-appropriate peers were also shared.

- “I am no different than other kids my age, making new friends.” (EA).
- “I have plenty of friends.” “I’d say I have a couple of special friends.” (EA).
- “We like to talk on the phone, hang out with friends, go to movies together. Just go party and have fun.” (EA).

- “Hang out, go bike riding, go to movies... . You can usually tell them stuff that sometimes you can’t tell parents. Like, cause they would probably freak.” (MA).
- “I have friends I do different things with, but I have several close friends that I could tell them anything and they could tell me. I have pretty good relationships with them.” (MA).
- “I have a friend that has been friends with me for, well, almost 20 years, and so we’re really good friends. We’re considered sisters. I have another couple of friends that I think we’ve been friends for about 10 or 11 years and they’re basically sisters to me, because they’ll do basically anything for me and I’ll do anything for them.” (LA).
- “She’s always there when I need her. If I have anything on my mind, I can go talk to her.” (LA).

**Subtheme. Peers with Disabilities**

In Theme 1, participants also described nurturing and grounding experiences in their relationships with peers with disabilities. Although the adolescent women acknowledged special friendships with other adolescents with disabilities, they were not the sole circle of friends. Nevertheless, the importance of peers with a disability offering empathy and knowing what they were going through was a voiced strength of these relationships. Reaching out and connecting to other adolescents with disabilities created a sense of validation, social meaning, and giving to others.

- “[I have] a best friend. . . . She has a disability, too. It’s not a major disability, but I mean just knowing, I mean, she’s going through what you’re going through in a way.” (EA)
- “I’ll sit next to a girl from special ed. and her friend, and we get along. We’ll sit there and do sign language back and forth.” (MA)
- “I have friends that are like me, and I have other friends with other disabilities.” (LA)

**Theme 2. Normalization: “They treat me like I’m normal.”**

Typical teen activities, social outings with peers, and activities centered on body image were described by a majority of the adolescent women. Participation in these social activities emerged as an important parameter of being “like normal teenagers.” The sense of being treated by peers as normal, because they considered themselves normal, was a very distinct need throughout the stories. Attention to body image, hair, makeup, and sharing clothes was a typical experience of the participants communicating a very desired parameter of the peer relationship.

---

*Reaching out and connecting to other adolescents with disabilities created a sense of validation, social meaning, and giving to others.*

---

## The Experience of Adolescent Women Living with Spina Bifida Part II: Peer Relationships

- “Most of my friends have learned to look through my spina bifida and like me for who I am.” (EA)
- “I have the greatest friends ever, really. They’re so supportive of me. Um, they don’t really treat me any differently than they treat anybody else. I mean, they treat me like I’m normal, because I am normal. It’s just the fact that I can’t walk, is really the only thing that’s not normal.” (LA)
- “I’ve had friends for like 19 years so and I’ve made a couple of new friends but they don’t seem to have a problem with it [SB].” (LA)
- “Like normal teenagers basically. We go out and stuff . . . shopping. Sharing each other’s clothes.” (LA)
- “Doing hair and make-up together.” (LA)

### **Theme 3. Challenges in Peer Connectedness: “I just sit there and watch everybody else play.”**

Despite many positive and nurturing peer relationships, experiences of isolation, exclusion, teasing, bullying, and difficulties in forming friendships were also shared. Participants related spending time on isolated activities such as watching television and playing on the computer as compensation for social connections and friendships. Physical and psychological barriers to participation in activities outside the school environment were evident in the stories. Participants often shared experiences that demonstrated they were not openly received by peers as part of the desired clique. Challenges and barriers in connectedness with peers were shared in the following stories:

- “I go to the playground. I just sit there and watch everybody else play.” (EA)
- “I go to school, ride the bus, don’t like it. Sit by myself, don’t have anyone to talk to.” (EA)
- “I try to be in a clique, and I try and I try. I don’t like that ‘cause it’s hard.” (EA)
- “From the time I get home to the time I go to bed [I watch television].” (EA)
- “Invite a bigger group of people, they’re going to group up, and they won’t care about me. I invited people to my house, and they go back to ignoring me real quick.” (MA)
- “I don’t do anything with friends outside of school.” (MA)
- “When I was younger I used to get teased a lot. . . . It was too, it was painful, but it wasn’t that painful but it hurt at the time.” (LA)
- “I usually go [choose friends] with how they treat me and how their personality is and just

how nice they are to me basically. If they can be nice to me and be nice to my other friends, then I will consider them a friend.” (LA).

### **Theme 4. Peer Connectedness with Adults: “Everything is cool because I hang out with my bus driver.”**

The participants shared experiences in which adult teachers, bus drivers, and janitors offered a sense of belonging to the social world. The adult relationships were helpful to offset some difficulties in both meeting and keeping friendships with age-appropriate peers. Encouragement from teachers and caring relationships with adults were used to offset some of the isolation and rejection experienced by peers.

- “I usually use a handicapped bus. It’s the county bus driver. Her name is Mrs. B. . . . Everything’s cool ‘cause I hang out with my bus driver.” (EA).
- “I want to hang out with the adult, not the kids.” (EA).
- “School is not on level ground, so they have a ramp and it’s very, very steep and I have trouble pushing up that. So, my bus driver—I don’t know why—but she was kind enough to ask the other bus driver if she could have one of the other kids walk in with me.” (MA).
- “The janitors at our school, I mean I love them to pieces. They’re so sweet. They built me ramps for things that I couldn’t, you know, get up to.” (MA).
- “The thing I like best [about school], there are some great teachers in my school, and I’ve really enjoyed having some of them. . . . I like being in the classes with them and having lunch with them sometimes.” (LA).
- “If I go anywhere, I usually go with Mom.” (LA).
- “Sometimes if I had PE [physical education], it didn’t feel like I fit in. . . . My teacher would say, ‘Honey, you can do it. Come on,’ and then that would make me feel good.” (LA).

### **Theme 5. Romantic Connectedness: “They gotta like me—they gotta look at me instead of my disability.”**

Participants discussed the desire to meet someone and develop a romantic relationship. However, the participants related limited or varied dating experiences. They voiced fears of not being liked because they were in a wheelchair and were cognizant of the need for a romantic partner to see them as a person,

---

*Social isolation  
fostered by  
insensitivity  
seriously hinders  
social independence.*

---

not a disability. The adolescent women described some ambivalence and searching regarding sexual information and choices. They also shared feelings about decision-making difficulties with selection of partners and sexual boundaries. Very evident throughout the stories were examples that dating experiences and potential selection of partners was limited, resulting in lack of a confidence and experience in decision making with intimate partners.

- "There's this boy that I like. He's in between me and my friend Jane, and her best friend Nancy told me ... I didn't deserve anybody like him because the only person I deserve is somebody handicapped." (EA).
- "I wish [had a boyfriend]." (MA).
- "Not dating right now, but mom and I had the talk. Not so much about sexuality but about dating." (MA).
- "High-school guys are just into perfect females and scared, you know, scared to try something new." (MA).
- "First person I dated. Met him [fiancé] in June." (MA).
- "Now that I've lost 45 lbs and I'm walking, I get more comments from guys. I get more things than touching and you know but that hasn't happened to me before and it's kind of a hard thing to, um, not get too involved in that. Knowing when to say stop, knowing where my boundaries are. When I do feel like I'm being taken advantage of, and I just say 'Hey, I don't want you to do that to me.' You know, because that has happened." (MA).
- "Um, it's hard to find guys that like me, like you know, um, I was so afraid my boyfriend wasn't going to like me because I was in a wheelchair." (LA).
- "And in order to have children I feel that I have to be married. So, I've got to find a man somewhere. I don't know. John keeps saying he's Mr. Right, but I don't know. I've been dating him three days." (LA).
- "If they don't like me, that's their problem. And if they do, well that's fine." (LA).
- "They gotta like me—they gotta look at me instead of my disability." (LA).

## Discussion

Variations existed in the adaptation outcome and level of connectedness experienced by the participants. Whereas some participants voiced close connections with peers and romantic partners, others described prejudices, stereotyping, and very limited dating experiences.

These challenges may prevent adolescent women with SB from being socially and sexually active.

Indeed, data suggest women with disabilities have lower rates of marriage than women without disabilities and lower rates of marriage than men with disabilities (Davis & Huber, 2004). The American values of achievement, beauty, and sexual prowess are challenging for adolescents with SB if they have limited dating experiences or peer and social connectedness. People with disabilities are "rarely portrayed as sexual beings in popular media. This gives us the impression that they should not be a part of our 'everyday lives,' which includes romance, intimacy, sexuality, and parenting" (Neufeld, Klingbeil, Bryen, Silverman, & Thomas, 2002, p. 857). Young women need to believe in their own inner strengths and the value they bring to friendships so that they will not be overwhelmed by discrimination or challenges. Social isolation fostered by insensitivity seriously hinders social independence (Zacijek-Farber, 1998).

The results from this study are consistent with findings from Skar (2003) in which adolescent women often saw themselves as "normal" and doing "all the normal teenage stuff," yet they were sometimes conceptualized by peers in terms of their disability or their status of being in a wheelchair. This indicates that interventions must target both adolescents with disabilities and those without disabilities to effectively generate a change in attitude and social behavior.

At the conclusion of this study, the authors examined the qualitative findings for variations or consistency with the quantitative findings in the larger study of adolescent men and women with SB (Sawin et al., 2002b). Overall, the stories reflected by these adolescent women were very consistent with the previous quantitative findings that both men and women with SB expressed positive experiences in developing individual close friendships but lower overall social competence. These male and female adolescents overwhelmingly reported that they had sexual feelings similar to those of their peers. Nevertheless, in the group 12–18 years of age, 36% had never dated. When asked whether having SB interferes with being close to a boyfriend or girlfriend, 44% agreed, 39% disagreed, and 16% were unsure. In addition, these adolescents reported a lower level of perceived romantic appeal and low dating behavior and expressed worry about sexual issues (Sawin et al., 2002b).

The quantitative results in the larger mixed-method study were also examined for evidence of progress from earlier studies, in which only 14.7% of participants with SB (Blum et al., 1991) and 29% of adolescents with physical disabilities (Stevens et al., 1996) had been on a date. Although the adolescent women in this study were older than those studied by Blum et al., findings of this study indicated some progress in social relationships and dating when participants were examined in a developmental sequence from

## The Experience of Adolescent Women Living with Spina Bifida Part II: Peer Relationships

early to late adolescence. In this study, 25% of the 31 adolescents with SB described themselves in a committed relationship, defined as dating one person for 2 months or more. Of these participants in a committed relationship, all but one were 18 or older. Attending after-school activities, group dates, or chaperoned dates was reported by 38% of the participants ranging in age from 13–20 years. In the total group of participants, 35% had been on an individual date, including those in committed relationships and those who had chaperoned dates. Indeed, some participants in late adolescence demonstrated more age-appropriate activities and psychosocial adaptation in situations such as dating opportunities and experiences and more adaptive statements such as “If people don’t like me, it is their problem.”

The Ecological Model and Theory of Inner Strength in Women support the premise that social development is facilitated by interaction and nurturing connections with friends and family. Data from this study delineate the important function of connectedness with peers for these young women. Data from our previous qualitative analysis support the strong connectedness with family (Bellin et al., 2007). Results from the analysis of quantitative data indicate that family members can role model positive behaviors. Adolescents who spend more time in activities with family are significantly more likely to also participate in more activities with peers (Sawin, Buran et al., 2003).

### Implications for Practice and Research

This study and others substantiate a body of findings on rewards and difficulties in the experiences of social and romantic relationships for adolescent women with SB. Data from this analysis support the inclusion of the Inner Strength concept of connectedness as it reflects the impact of the peer and romantic relationships experienced by the women. Rehabilitation nurses and other members of the healthcare team must assess the social context of the developing adolescent woman to evaluate risk factors for social isolation and delays in psychosocial development. Rehabilitation nurses should assess each individual adolescent with SB and his or her family to provide resources and interventions to improve social confidence and opportunities for connectedness and positive adaptation. The current challenge for rehabilitation nurses and researchers highlights the following practice and research implications.

Social development assessment, including peer and romantic relationship assessment, must be integrated into the comprehensive rehabilitation assessment of preadolescents, adolescents, and young adult women with SB by rehabilitation nurses and other rehabilitation professionals. Whereas some

adolescents are progressing steadily in social development, others are isolated, discriminated against, and limited in peer relationships. The most effective way to identify those at risk is to screen all preadolescents and adolescents during each rehabilitation evaluation.

Although the data suggesting difficulties with social development for adolescents with disabilities are compelling, much of the research has been cross-sectional. Longitudinal assessments and research studies are needed to determine the trajectory of this development over the preadolescent, adolescent, and young adult years in order to effectively target interventions.

The body of knowledge on challenges with social relationships justifies a progression to intervention studies testing strategies to improve social and sexual development. Evidence supports interventions aimed at changing behavior of a targeted population of children and adolescents in schools (Harrell, McMurray, Gansky, Bangdiwala, & Bradley, 1999) are most effective if delivered to all students in a school setting rather than delivered only in “carve-out programs” for those at risk. Collaborative research teams including rehabilitation professionals, experienced researchers, and education professionals need to focus on intervention studies addressing both preadolescents and adolescents with disabilities and those without disabilities. Adolescents with disabilities are connecting with peers without disabilities. Therefore, interventions and outcome measures must examine social change and improved health outcomes from the perspective of both populations. These intervention studies probably would be most effective if initiated in the early preadolescent age groups.

Results of future intervention studies must be readily translated into policy with school and social programs to enhance the connectedness and health of young women with SB and other chronic health conditions.

### Limitations of the Study

The participants were primarily Caucasians living in the Midwest, attending an SB clinic, and from families with two parents. Further study with inclusion of adolescents from varied cultural and geographic backgrounds is needed. In addition, it is not clear whether the themes identified for adolescents and young women with SB in this study are applicable to young women who grow up with or experience other physical disabilities. Additional investigations are needed to determine which experiences are unique to SB and which are more universal to adolescent women with disabilities. However, the

strength of the study is the insider perspective and rich details the adolescent women shared regarding their social world and dating experiences. A rigorous body of knowledge is emerging. Future intervention studies with interdisciplinary research teams made up of rehabilitation nurses and other professionals must address the complex needs of this population to enhance positive adaptation in peer and intimate relationships.

### Acknowledgments

The authors would like to thank Beth Rodgers, PhD RN FAAN, for review of a previous draft of this article. The authors would also like to acknowledge Janet Kain, Susan Modlin, and Vanessa Patrick for their assistance with data collection and database management.

This project was funded in part by the American Association of Spinal Cord Injury Nurses; the Clarian Health Partners; National Institutes of Health Institutional National Research Service Award #5 T32NR07066; Maternal and Child Health Bureau Leadership Education in Adolescent Health, Indiana University; and Alpha Chapter, Sigma Theta Tau.

### About the Authors

Gayle Roux, PhD RN NP-C, is an associate professor and associate dean for faculty at Loyola University Chicago's Marcella Niehoff School of Nursing. Address correspondence to her at [groux@luc.edu](mailto:groux@luc.edu).

Kathleen J. Sawin, DNS CPNP FAAN is a professor at the College of Nursing, University of Wisconsin, Milwaukee and Joint Research Chair in the Nursing of Children at Children's Hospital of Wisconsin and the College of Nursing, University of Wisconsin, Milwaukee.

Melissa Hayden Bellin, PhD MSW LCSW, is an assistant professor at the University of Maryland, Baltimore, School of Social Work, Baltimore, MD.

Constance F. Buran, DNS RN, is a pediatric clinical nurse specialist at the Riley Hospital for Children, Indianapolis, IN.

Timothy J. Brei, MD, is a developmental pediatrician at the Riley Hospital for Children, Indiana University School of Medicine, Indianapolis, IN.

### References

Bellin, M., Kathy, S., Roux, G., Baran, C., & Brei, T. (2007). The experience of adolescent women living with spina bifida part I: Self-concept and family relationships. *Rehabilitation Nursing, 32*(2), 57-67.

Blum, R. W., Resnick, M. D., Nelson, R., & St. Germaine, A. (1991). Family and peer issues among adolescents with spina bifida and cerebral palsy. *Pediatrics, 88*(2), 280-285.

Buran, C. F., Sawin, K. J., Brei, T. J., & Fastenau, P. S. (2004). Adolescents with myelomeningocele: Their activities, beliefs, expectations, and perceptions. *Developmental Medicine & Child Neurology, 46*, 244-252.

Davis, R., & Huber, K. (2004). Class, ethnicity, physical status, and sexual orientation: Implications for health and health-care. In M. Condor (Ed.), *Women's Health* (pp. 29-37). Upper Saddle River, NJ: Prentice Hall.

Harrell, J. S., McMurray, R. G., Gansky, S. A., Bangdiwala, S. I., & Bradley, C. B. (1999). A public health vs. a risk-based intervention to improve cardiovascular health in elementary school children: The Cardiovascular Health in Children Study. *American Journal of Public Health, 89*(10), 1529-1535.

Holmbeck, G. N., Johnson, S. Z., Wills, K. E., McKernon, W., Rose, B., Erklin, S., et al. (2002). Psychosocial adjustment in preadolescents with a physical disability: The mediational role of behavioral autonomy. *Journal of Consulting and Clinical Psychology, 70*(1), 96-110.

Holmbeck, G. N., Westhoven, V. C., Phillips, W. S., Bowers, R., Gruse, C., Nikolopoulos, T., et al. (2003). A multi-method, multiinformant, and multidimensional perspective on psychosocial adjustment in preadolescents with spina bifida. *Journal of Consulting and Clinical Psychology, 71*(4), 782-796.

King, G. A., Shultz, I. Z., Steel, K., Gilpin, M., & Cathers, T. (1993). Self-evaluation and self-concept of adolescents with physical disabilities. *The American Journal of Occupational Therapy, 47*(2), 132-140.

Morse, J., & Field, P. A. (1995). *Qualitative research methods for health professionals*. Thousand Oaks, CA: Sage.

Neufeld, J., Klingbeil, F., Bryen, D., Silverman, B., & Thomas, A. (2002). Adolescent sexuality and disability. *Physical Medicine and Rehabilitation Clinics of North America, 13*, 857-873.

Risjord, M. W., Dunbar, S. B., & Moloney, M. F. (2002). A new foundation for methodological triangulation. *Journal of Nursing Scholarship, 34*(3), 269-275.

Roux, G., Dingley, C., & Bush, H. (2002). Inner strength in women: Metasynthesis of qualitative findings in theory development. *Journal of Theory Construction & Testing, 6*(1), 4-15.

Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *Advances in Nursing Science, 16*, 1-8.

Sawin, K. J., Bellin, M. H., Roux, G., Buran, C. F., Brei, T. J., & Fastenau, P. S. (2003). The experience of parenting an adolescent with spina bifida. *Rehabilitation Nursing, 27*, 173-185.

Sawin, K. J., Brei, T. J., Buran, C. F., & Fastenau, P. S. (2002a). Factors associated with quality of life in adolescents with spina bifida. *Journal of Holistic Nursing, 20*(3), 279-304.

Sawin, K. J., Brei, T. J., Buran, C. F., & Fastenau, P. S. (2002b). Sexuality issues in adolescents with a chronic neurological condition. *Journal of Perinatal Education 11*(1), 22-33.

Sawin, K. J., Buran, C. R., Brei, T. J., & Fastenau, P. S. (2003). Correlates of functional status, self-management, and developmental competence outcomes in adolescents with spina bifida. *Spinal Cord Injury Nursing, 20*(2), 72-85.

Skar, R. N. (2003). Peer and adult relationships of adolescents with disabilities. *Journal of Adolescence, 26*(6), 635-649.

Stevens, S. E., Steele, C., Jutai, J., Kalnins, I., Bortolussi, J., & Biggar, W. D. (1996). Adolescents with physical disabilities: Some psychosocial aspects of health. *Journal of Adolescent Health, 19*, 157-164.

Wagner, M., Cadwallader, T. W., & Marder, C. (with Cameto, R., Cardoso, D., Garza, N., Levine, P., & Newman, L.). (2003). *Life outside the classroom for youth with disabilities*. Menlo Park, CA: SRI International. Available at [www.nlts2.org](http://www.nlts2.org).

Zacijek-Farber, M. L. (1998). Promoting good health in adolescents with disabilities. *Health and Social Work, 23*(3), 203-214.