

The Experience of Adolescent Women Living with Spina Bifida Part I: Self-Concept and Family Relationships

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KEY WORDS

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Adolescent women with spina bifida (SB) face unique and diverse challenges. The purpose of this qualitative component of a larger mixed-method study on adaptation was to heighten rehabilitation nurses' understanding of self-concept and family relationships during adolescence. Interviews were conducted with 31 adolescent women and analyzed for themes. The women described a range of experiences, including challenges of typical adolescence, specific concerns about living with SB, school-based stressors, and incidences of teasing and bullying. The overall self-concept was primarily positive, despite the diverse stressors encountered. A significant source of strength was the close relationships with parents, although an undercurrent of tension related to independence was also expressed. Results from this study support the need for rehabilitation nurses to address not only the functional status but also the well-being and psychosocial challenges of adolescent women with SB.

Advances in healthcare, technology, and rehabilitative services have dramatically increased expectancy and quality of life for youth with chronic health conditions (Meleski, 2002). One population that has especially benefited from progress in health services is youth born with spina bifida (SB; Blum, Resnick, Nelson, & St. Germain, 1991). Described as one of the most complex chronic health conditions (Bowman, McLone, Grant, Tomita, & Ito, 2001), SB is the second most common congenital condition, occurring in 20.09 of every 100,000 live births (Mathews, Honein, & Erickson, 2002). The incomplete neural tube closure in utero typically results in a range of health complications including hydrocephalus, lower extremity weakness or paralysis, neurogenic bladder, neurogenic bowel, and neurocognitive challenges (Kinsman, Levey, Ruffing, Stone, & Warren, 2000). Comprehensive management of SB by rehabilitation nurses entails attention to both the broad range of complex physical needs and developmental, social, economic, rehabilitative, and mental health challenges to help youth adjust and adapt successfully.

The present qualitative component of a larger mixed-method investigation of adaptation in adolescents with SB aims to heighten rehabilitation nurses' awareness of adolescent women's experience of living with SB. Because the majority of prior research in SB typically combined data across genders, the current study uniquely contributes to the literature by focusing on the daily life challenges, rewards, and experiences of risk and protective factors among adolescent women with SB in areas of family life, school, peer relationships, and developmental competencies.

Literature Review

Data are mixed as to whether adolescents with SB are at risk for poorer psychosocial adjustment compared with their peers. One body of research suggests heightened vulnerability to maladjustment among adolescents with SB caused by difficulties in social skills, problem solving, and social isolation (Simeonsson, Huntington, McMillen, Halperin, & Swann, 1997), school-based challenges and experiences of discrimination (Kennedy et al., 1998), and delayed transition toward opportunities for independent activities and responsibilities (Blum et al., 1991). Compared with their peers without chronic conditions, these studies found youth with SB at greater risk for behavioral and social competence problems (Zurmöhle et al., 1998), depressive mood (Appleton et al., 1997), and low self-concept (Kazak & Clark, 1986).

In contrast, other data highlight the possibility for positive self-concept among adolescents with SB (Edwards-Beckett, 1995; Spaulding & Morgan, 1986). Although Holmbeck and colleagues (2003) observed youth with SB to be less socially mature and to have fewer social contacts outside school than youth without chronic conditions, no group differences emerged in feelings of self-worth. Factors contributing to adolescents' positive self-image include family characteristics such as cohesion, satisfaction, and resources (Sawin, Buran, Brei, & Fastenau, 2003) and perceived age-appropriate treatment by parents (Wolman & Basco, 1994). More specifically, research reveals positive relationships between family cohesion and satisfaction and adolescent perception

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of quality of life (Sawin, Brei, Buran, & Fastenau, 2002), with low levels of family conflict protecting against distress and adjustment difficulties (Murch & Cohen, 1989). Parenting styles also appear to influence adjustment outcomes, with data supporting associations between overprotective parenting and behavioral maladjustment (Holmbeck et al., 2002).

Although there is a growing body of literature on factors supporting or hindering adaptation for adolescents with SB, very few studies have examined the unique lived experience among adolescent women. However, some research suggests this population is especially at risk for psychosocial challenges. Appleton et al. (1997) observed that young women with SB demonstrated more difficulties in areas of depressive symptoms and low self-worth than their male counterparts. Other research corroborates findings of lower self-image among these young women (Cartright, Joseph, & Grenier, 1993), with older adolescents particularly at risk for social isolation and loneliness (Hayden, Davenport, & Campbell, 1979).

In summary, although adolescents with SB may successfully transition into adulthood, data indicate that this special population encounters a range of challenges during the adolescent journey. To increase understanding of the complex and diverse experiences of risk factors and adaptation, this study explores family life, relationships, school, and developmental competencies among adolescent women with SB.

Background

The theoretical touchstone for this study integrates the Ecological Model of Adaptation in Spina Bifida (Sawin et al., 2002; Sawin, Buran, et al., 2003) with the Middle-Range Theory of Inner Strength in Women with chronic health conditions (Roux, Dingley, & Bush, 2002). This integrated framework combines the emphasis on adolescent resilience and family resourcefulness of the Ecological Model with the concept of connectedness in the Theory of Inner Strength. Together, these theories describe a process of response and adaptation to a chronic condition through fostering strengths over a long period of time.

The Ecological Model (Sawin et al., 2002; Sawin, Buran, et al., 2003) for adolescents with SB depicts the relationship of risks (i.e., SB severity, including hydrocephalus, level of lesion, neuropsychological status), demographic factors (age, gender, and socioeconomic status), and protective factors (adolescent resilience factors, family resourcefulness, and health-care adequacy) to adaptation. Adaptation includes becoming skilled in managing physical health to reduce the impact of secondary conditions, developing positive mental health, developing age-appropriate

social activities, and achieving academic success and a positive quality of life.

The Theory of Inner Strength in Women adds useful specificity to the broader adolescent resilience and family resourcefulness concepts in the Ecological Model. The Theory of Inner Strength has four major concepts describing the process of learning to live with a chronic health condition: anguish and searching, or finding meaning in the diagnosis; connectedness, or support from self, family, and friends; engagement, or reframing circumstances; and movement, or realistic appraisal of one's limitations (Roux et al., 2002). Using this integrated framework as a touchstone for the study, the participants' stories were examined for strengths and connectedness or challenges that hindered inner strength and adaptation.

Methods

This study was part of a mixed-method investigation that explored adaptation in adolescents with SB (Sawin, Buran, et al., 2003). Reported here are the findings on the experiences of self-concept and family relationships while growing up with SB that emerged from interviews with 31 adolescent women with SB. Data from the larger quantitative study were reported earlier (Buran, Sawin, Brei, & Fastenau, 2004; Sawin et al., 2002; Sawin, Buran, et al., 2003).

The three global domains that described the adaptation of the adolescents with SB and their families were self-concept and family relations, peer relationships, and self-management. This article examines experiences of self-concept and family relationships in women aged 12–21 years living with SB.

Procedure

Before initiating the study, approval was obtained from the university internal review board for human subjects protection. Eligibility for participation in the overall study included the following criteria: 12–21 years of age, English speaking, functioning at grade-appropriate level in school, and no other major progressive health conditions. Potential participants were recruited in an outpatient SB clinic in the Midwest. Eligible adolescents and their parents or legal guardians were informed of the study by staff during clinic visits. Interested families were subsequently contacted by telephone by a research staff member who explained the overall study purpose and scheduled interviews. After informed consent and assent was obtained, data were collected via face-to-face interviews or by telephone. 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.

Data Collection and Data Analysis

Data were collected via a demographic tool and a semistructured interview designed to elicit expression of the adolescent's experiences of living with SB. The global research question was, "What is it like to be a teen with spina bifida?" The interview included other guiding questions to elicit information on their specific life experiences in areas of everyday stresses and coping strategies, family relationships, and perception of self in terms of strengths and limitations.

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

During the initial analysis, the data were classified according to the participant's age and level of lesion to ascertain whether themes clustered by particular age group (e.g., early vs. late adolescence) or level of lesion. The thematic exemplars crosscut all developmental stages and level of lesions. That is, no theme or subtheme was exclusive to a particular age group or level of lesion. Subsequently, the labeling of the developmental stage was changed to reflect only early adolescence (EA; 12–14 years), middle adolescence (MA; 15–17 years), or late adolescence (LA; 18 years or older) to increase confidentiality.

Several techniques of rigor were used in the analysis. First, a blind reviewer, who has expertise in qualitative research, served as a consultant to enhance the trustworthiness of analysis while generating domains, themes, and subthemes. Initially, with this consultant, the first two authors independently reviewed four randomly selected transcripts to generate a beginning coding scheme for the data. The first author and the second author subsequently analyzed 12 additional transcripts to establish common domains, themes, and subthemes. 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 domains and themes. Descriptions of the domains 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 for trustworthiness and consistency with clinical reality.

Findings

A majority of the 31 adolescents with SB in this analysis were non-Hispanic white (97%) and had

Figure 1. Domain: Self-Concept and Family Relationships

<p>Theme 1: Appraisal of Self</p> <ul style="list-style-type: none">• Identification of personal strengths• Areas of self-dislike or perceived difficulties• Perception of self as a typical adolescent
<p>Theme 2: A Continuum of Impact of Spina Bifida on Life Experiences</p> <ul style="list-style-type: none">• Positive appraisal of impact• Mixed impact• Negative appraisal of impact• Growth-enhancing opportunities engendered by SB
<p>Theme 3: Stresses of Everyday Life</p> <ul style="list-style-type: none">• School-related stress• The experience of teasing and bullying• Spina-bifida challenges• Mobility-related stress
<p>Theme 4: Strategies and Skills to Manage Stress</p> <ul style="list-style-type: none">• Use of problem-solving• Patterns of sequential coping• Maladaptive and avoidance strategies• Importance of support from family and friends
<p>Theme 5: Family Relationships</p> <ul style="list-style-type: none">• Close, generally positive connections with parents• Undercurrent of tension in relationships with parents• Sibling relationships: "We have our spats"
<p>Theme 6: Perception of Impact of Spina Bifida on Family</p> <ul style="list-style-type: none">• Minimal impact• Moderate impact• High impact

hydrocephalus (87%). 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%). Ages of the participants ranged from 12 to 21 years, with a mean age of 15.84 years.

Analysis of the interviews yielded two domains capturing the day-to-day experiences of living with SB: the Self-Concept and Family Relationships Domain and the Peer Relationships Domain. This article presents the six themes identified in the Self-Concept and Family Relationships Domain (**Figure 1**). The six major themes were appraisal of self, continuum of impact of spina bifida on life experiences, stresses of everyday life, strategies and skills to manage stress, family relationships, and perception of impact of spina bifida on family.

Theme 1: Appraisal of Self

In the appraisal of self theme, participants shared reflections about their overall self-concept and specific areas of competence. Three subthemes provided greater insight to self-perception among these young women: identification of personal strengths, areas of

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self-dislike, and perception of self as a typical adolescent. Because thematic exemplars were not exclusive to a particular developmental age, the data are labeled only by early (EA), middle (MA), or late (LA) adolescence.

Identification of Personal Strengths: Participants highlighted a range of attributes and qualities they regarded positively about themselves, from valuing autonomy (“I like that I can do stuff for myself.”) and interpersonal skills (“I go out and meet new people.”) to physical attractiveness (“I think I’m pretty.”). The adolescent women considered themselves mature, trustworthy, patient, and easygoing. They also celebrated the uniqueness about self.

- “[I like] that I’m different.” (MA).
- “I like myself, and I’m not something I’m not.” (MA).

Areas of Self-Dislike or Perceived Difficulties: Balancing the personal strengths were the perceived difficulties and negative attributes. Although the majority of adolescent women described a desire for change in some dimension of self, a subset regarded themselves as just right (“I don’t think there’s anything I dislike about myself.”). In this subtheme, participants expressed frustration in areas of physical qualities (“Don’t like my body image.”) and personality style (“If I can get over my shyness. . .”). The younger participants in particular expressed frustrations related to physical appearance. One participant commented, “Don’t like my body image. I don’t like my looks. I’m getting better about it. At times I think I am fat or ugly.”

Limitations related to SB seemed to weigh heavily on participants’ minds, regardless of developmental stage.

- “That I have to use crutches and can’t walk like everybody else and that I can’t fully go to the bathroom like you can.” (EA).
- “I keep wishing that the wheelchair would just leave.” (EA).
- “Probably the spina bifida. If I could go without that, I definitely would.” (MA).
- “Don’t want to be in this chair. I wish I could walk, and I wish I didn’t have spina bifida.” (LA).

Perception of Self as a Typical Adolescent: Though acknowledging differences related to life as an adolescent with SB, some of these young women perceived themselves as regular teens with normal teenage changes.

- “I’d say it’s pretty much like being a regular teen, only I have certain schedules and stuff you have to follow.” (EA).
- “I lead a pretty normal life from any other teenager.” (LA).

They also expressed a desire to not be treated as different or have special privileges and articulated a hope to pursue typical adolescent activities without limitations imposed on them.

- “People know that I don’t want special treatment.” (MA).
- “I’m a normal person—I’m just in a wheelchair. . . . I’m going to do the same things that everybody can do.” (MA).

Theme 2: Continuum of Impact of Spina Bifida on Life Experiences

In this theme participants evaluated the influence of SB on their daily life experiences. Adolescents typically offered a balanced view of the challenges and rewards presented by SB (“Sometimes it overpowers me, but other times it’s okay.”). Although some reported a negative impact, growth-enhancing opportunities were also highlighted. Four subthemes emerged: positive appraisal of impact, mixed impact, negative appraisal of impact, and growth-enhancing opportunities engendered by SB. Because thematic exemplars were noted across the developmental stages, the labeling of data was changed to reflect only early (EA), middle (MA), and late (LA) adolescence.

Positive Appraisal of Impact: A group of participants described the impact of SB on their daily life experiences as primarily positive.

- “Pretty cool [life as teen with SB].” (EA).
- “Probably a pretty positive one [impact of SB].” (LA).

Mixed Impact: Others described a mixed effect of SB on daily life experiences, reporting periods of difficulty alternating with experiences of low impact. More difficult periods seemed to be associated with the early years of adjustment and adaptation and during symptom exacerbation.

- “It’s been more good than bad.” (MA).
- “Sometimes it overpowers me, but other times it’s okay.” (LA).
- “I think when I was little, it had more of an impact because I would be sick a lot. So, I wouldn’t be able to make friends very easily cause I wouldn’t see them that much. But, I mean, as for how I live or anything, it hasn’t affected me much.” (LA).

Negative Appraisal of Impact: A final group of participants depicted a largely negative influence of SB, with impact noted especially in restricted interpersonal relationships and family social activities. Acknowledgment of an adverse effect was noted more often among middle and late adolescents.

- “It’s hard—not being able to do some of the things your friends can do.” (MA).

Some older participants described a pattern of persistent unpleasant interactions with peers.

- “Sometimes people are afraid to come up to me and talk to me because I’m disabled.” (LA).
- “Very hard. There’s things that I’m not able to do . . . like if my family goes to a picnic or something where there’s a lot of rocks, I can’t go because I can’t walk on them and I can’t take my wheelchair.” (LA).

The challenging management responsibilities of SB were also associated with high impact.

- “I think the urologist wants me to start getting to where I’ll get on the toilet and just sit there and push. I don’t have time to do it with school, homework.” (MA).

Experiences of embarrassment likewise weighed heavily on participants’ minds, regardless of developmental stage.

- “It’s hard, really hard. Getting around and . . . certain people, like, looking at you and saying, ‘Well, she’s not, he or she’s not right because she’s in that wheelchair,’ or something like that. Because I’ve had it happen to me, several times.” (EA).
- “I don’t go to friends’ houses because I don’t want them saying, or their little siblings saying, ‘Your friend wears a diaper!’ Or something like that. That scares me.” (EA).
- “I’ll get stared at and stuff like that and that goes right through me.” (LA).

Growth-Enhancing Opportunities Engendered by SB: Despite the perceived negative influence of SB for some participants, a number of the adolescent women reflected on benefits and opportunities created by SB. The adolescent women reflected that living with SB taught them patience and acceptance of others.

- “I have learned to accept everybody, no matter what they look like or what color they are.” (LA).

Participants also described enhanced, close family relationships stemming from the presence of SB in their lives.

- “I’m more family-oriented than usual, than teenagers would be.” (LA).

Theme 3: Stresses of Everyday Life

The adolescent women shared thoughts about sources of daily life challenges. They articulated typical adolescent irritants, such as family relations and school-based stress, as well as additive frustrations and concerns related to life as a teenager with SB. Four subthemes captured the range of stressors: school-related stress, the experience of teasing and bullying, spina bifida challenges, and mobility-related stress.

School-Related Stress: The school environment created a number of challenges, especially in areas of academic achievement.

- “School . . . probably getting work done, cause sometimes I think that there’s just not enough hours in the day.” (LA).
- “Taking tests was kind of stressful. . . . I usually lose concentration sometimes.” (LA).

The Experience of Teasing and Bullying: The experience of teasing and bullying emerged as a powerful negative descriptor of some participants’ lives (“In school, you get made fun of.”). This was especially noted for the younger adolescents. However, some older participants described a pattern of persistent unpleasant interactions with peers.

- “I feel like a lot of people, like, put me down because I have spina bifida and because I do look different than others. I’ve been made fun of all my life. . . . I wish that God would have put it on somebody else, because I don’t, you know, I don’t know why I deserve it and all that and stuff. It’s all kinds of stuff. I beat myself up over it.” (LA).

Spina Bifida Challenges: Stress resulting from daily management of SB, including self-care and health monitoring, and daily living tasks such as dressing and transfers also emerged as a common challenge encountered by the adolescent women across the developmental stages. Participants frequently noted the hassle of incontinence and catheterization.

- “I really am incontinent, so I never know when it’s going to happen.” (EA).
- “Cathing is stressful. It is going better, a lot better, but that was stressful, really stressful.” (MA).

Concerns about future health needs and childbearing abilities were also noted among the women.

- “I’m kind of worried about that [health] cause I don’t know how good it will be. I know I’ve got it [spina bifida] and everything, but I’m not sure if it will get, like, worse, or if it will just stay the same like it is now.” (LA).
- “[I worry that] I’d have a kid and still have it [SB], and still have what I have.” (EA).

Mobility-Related Stress: A final grouping of data highlighted the challenges of mobility for participants. Frustration was articulated by both younger adolescents (“Like knowing my friends are going somewhere or something and like I can’t do it. Then that makes me kind of upset.”) and older adolescents (“Not being able to go anywhere is stressful.”).

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Theme 4: Strategies and Skills to Manage Stress

Although the adolescent women encountered complex and diverse stressors, they also reported rich inner strengths, capabilities, and resources to help circumvent negative impacts. Participants described four subthemes related to stress management: use of problem solving, patterns of sequential coping, maladaptive and avoidance strategies, and importance of support from family and friends. As in other themes, exemplars of strategies and skills for stress management were evident across the developmental stages, and so the labeling of data was reduced to reflect early (EA), middle (MA), and late (LA) adolescence.

Use of Problem Solving: For some participants, use of problem solving was a key skill to manage daily life challenges. They relied on both internal problem-solving strategies and external resources, such as processing the stressor with the school counselor, to “figure it out,” as described by an MA participant. The problem-solving experience involved taking time out for some participants.

- “I’d rather just go in my room and have everybody just leave me alone and let me think about it. And if I think about it, then I’ll come back in and discuss it with you.” (LA).
- “I go to like my learning room. If I’m at home, I go to my room and calm myself down.” (LA).

Patterns of Sequential Coping: In their description of skills and strategies, the adolescent women also reported a stepwise selection of inner coping resources and supports.

- “It all depends on what the problem would be. Sometimes I handle it myself, or if I don’t think I can handle it, I’ll go talk to a really close friend.” (MA).
- “I try to figure it [problem] on my own, and if I can’t, I just talk to my Mom about it.” (MA).

Maladaptive and Avoidance Strategies: Although the majority of participants demonstrated constructive coping skills, a group relied on less adaptive strategies in their efforts to negotiate stress. Some reported experiencing intense anger that, at times, climaxed in yelling at friends or family or even the destruction of property.

- “I get mad, sometimes. Well, I don’t blow up. I just get really mad.” (EA).
- “Sometimes I just like to go in my room and punch the heck out of my door. Yes, that’s a good stress reliever.” (MA).
- “Sometimes I have a tendency to take it out on people at school. And I take it out a lot on my brother.” (MA).

Importance of Support from Family and Friends:

Finally, the positive and centering influence of family and peer social support was also acknowledged by a number of participants.

- “I think of something good and if I don’t think of something, I call my best friend. She makes me feel better.” (EA).
- “I usually talk to my Mom.” (EA).
- “If I can’t talk to my parents, then I’ll call one of my best friends and they’ll try to help me. Or I talk to my grandparents, and I have aunts and uncles that I talk to. I usually talk to either family members or friends.” (LA).

Theme 5: Family Relationships

The significance of family relationships in the lives of the adolescent women consistently emerged in the data. Participants depicted cohesive bonds with parents, connections that served as a major outlet for social interaction. Three subthemes were identified: close, generally positive connections with parents; undercurrent of tension in relationships with parents; and typical, transient conflict in sibling relationships.

Close, Generally Positive Connections with Parents: The absence of high adolescent–parent conflict was notable in participants’ descriptions of their connections with parents. They highlighted the social importance of the relationship (“We do everything together.”) and acknowledged the uniqueness of the close relationship (“I get along with my parents more than I think some of my friends do.”). Some participants considered their parent as their “best friend” or confidant.

- “We’re like best friends. We do everything together.” (EA).
- “We do things together 90% of the time.” (MA).
- “My dad is just, like my best friend. He’s awesome. He’s—I don’t know why, but he’s been like, real close to me, for some reason. Me and my dad are just, like, friends, and that’s rare for, like, daughter and dad.” (LA).

Undercurrent of Tension in Relationships with Parents: Although the parental relationship was portrayed primarily as positive, some adolescents reported conflict, especially around areas of control and power.

- “We have our moments of fighting.” (EA).
- “She’s cool. She gets on my nerves sometimes, obviously. She tries to take control of what I’m doing . . . and I don’t like people to take control of me.” (MA).

- “We have some fights about things because I’m stubborn sometimes, and sometimes so are they.” (LA).

Typical, Transient Conflict in Sibling Relationships: Transient conflict was more common in the description of sibling interactions by the younger adolescents. However, the interactions with brothers and sisters were perceived as no different from those of other sibling pairs; “We have our disagreements, like brother and sister,” commented one EA participant.

A range of sibling relationships was reported. For some adolescent women, the sibling bonds were positive and cohesive (“I love spending time with my brothers and sisters.”). A subset of participants regarded their brothers and sisters as friends and as sources of support during difficult times.

Another group characterized the sibling relationship as one of mutual avoidance. “I try to ignore him, but he does these little things that really push my buttons,” acknowledged an MA participant.

A third group of participants described ongoing conflict in their sibling relationship, manifested in fighting and anger.

- “My brother and I, we don’t really have a good relationship.” (MA).
- “Me and my brother, we don’t get along too well. We try, but there’s sometimes fights. We’re basically getting tired of it. We’ve been doing it for years now.” (MA).

A few participants reflected on the source of conflict underlying their sibling relationship.

- “My eight-year-old little brat sister. She gets into my stuff. . . . When my sister messes with me, I try to chase her, and I can’t go fast enough.” (EA).
- “They [sisters] think she [Mom] treats me different, but I don’t.” (MA).

Theme 6: Perception of Impact of Spina Bifida on Family

The impact of SB on surrounding family members was captured in this sixth and final theme. A continuum of adolescents’ beliefs were presented, although the majority of participants described the influence of SB as one of mixed impact (“It’s kind of hard sometimes.”). Three subthemes were identified: minimal impact, moderate impact, and high impact.

Minimal Impact: A group of adolescent women perceived no significant implications for the lived experience of family members. Younger adolescents more often saw little or no bearing of SB on the surrounding family. One MA participant captured this perspective: “I don’t think it’s affected them at all.”

Moderate Impact: Alternatively, others considered family members to be somewhat affected by their

experience. Older participants more commonly reflected that difficulties were linked largely to the early adjustment and adaptation period.

- “Sometimes I feel like I stop them [family] from doing something that they want to do.” (EA).
- “Probably at first it was kind of hard but now it doesn’t seem hard.” (LA).
- “I know it was hard on them when I was little, but now that I can take care of myself, I don’t think that it fazes them at all. I mean, I was always sick, and I had to go to the doctor a lot. And when I was in the hospital and I had surgeries, my Mom really stayed with me. I know that made it hard on her but now it’s okay.” (LA).

High Impact: A final group of participants described a substantial impact of SB on surrounding family members. In particular, these adolescent women highlighted the complex and uncertain medical course and the financial and social consequences of SB.

- “It’s kind of hard, with all my surgeries—stuff I have to go through.” (MA).
- “It’s probably had a pretty big impact. I mean, like money-wise and dealing with my attitudes about things.” (MA).
- “When my parents got divorced, I felt like it was my fault. . . . It’s had a major impact on our family. They’ve had to do things, like, rearrange the house where, like, I could get through, and um, you know, they had to open up doors for me and things like that that normally, normal kids could do it their selves.” (LA).

Discussion

A major finding of this study is the range of risk factors and experiences of adaptation among adolescent women with SB. Despite the many challenges stemming from life as an adolescent with SB, including stressors of monitoring and management of SB, mobility-related concerns, and experiences of embarrassment, teasing, and bullying, a majority of participants described an overall positive self-concept. Consistent with the Theory of Inner Strength in Women (Roux et al., 2002), most participants were searching to integrate the meaning and implications of SB in their lived experience—some more successfully than others. For example, whereas several adolescent women believed the experience of SB differentiated them from their peers, others did not consider themselves different. This latter perception is captured best, perhaps, by a participant in middle adolescence who described herself as a “normal person . . . going to do the same things that everybody can do.”

Older participants more commonly reflected that difficulties were linked largely to the early adjustment and adaptation period.

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Findings of an overall positive self-concept are consistent with prior studies involving adolescents with SB (Cartright et al., 1993; Murch & Cohen, 1989). Yet participants in this study acknowledged several areas of perceived difficulties, including a desire to change physical qualities such as short stature and mobility problems, personality traits such as shyness or a short temper, and peer social interactions. These findings corroborate prior investigations. For example, although King, Shultz, Steel, Gilpin, and Cathers (1993) noted similar overall self-appraisal in a group of adolescents with chronic physical conditions including SB and normative peers, differences emerged in specific areas of self-concept. Female participants who had a physical condition expressed lower social acceptance, athletic competence, and romantic appeal than their peers.

Data from this study suggest that adolescent women with SB hold realistic perceptions about their personal strengths and challenges, illustrating movement by honest self-appraisal and facilitation of balance and desired change (Roux et al., 2002). In their research with adolescents with a range of physical conditions, including SB, Specht, King, and Francis (1998) surmised that the lower developmental competencies reflect appropriate self-appraisals, that “many are not athletically competent and they may not be as socially accepted as their peers, or have been provided with paid job opportunities” (p. 114). Importantly, several growth opportunities from the experience of SB also emerged in our data, providing a balance to the limitations and challenges associated with SB. In the present research, the adolescent women described enhanced family relationships, development of patience, and acceptance of differences as positive attributes engendered by their daily life experience of SB.

It is also important to note that participants reported a range of coping mechanisms protecting against distress, a concern related to both SB and general adolescent challenges such as family tension and school-based responsibilities. Consistent with the notion of engagement (Roux et al., 2002), the adolescent women drew on rich resources in their efforts to offset a negative impact of stress. The use of problem solving and patterns of sequential coping, in which participants selected coping strategies that countered the type and severity of the encountered stressor, dominated adolescents’ descriptions, as did the importance of support from family and friends. However, less adaptive coping behaviors such as avoidance and displacement were also reported. The adolescents’ use of disengagement coping—strategies that seek to remove the person from working through the stressful experience—is of particular concern given its link to poorer adjustment

to disability (Livneh & Wilson, 2003). Clearly, adolescent women with SB who possess underdeveloped or maladaptive coping skills are especially at risk for psychosocial difficulties, especially in combination with low self-concept.

Of interest in this study, no participant described using spirituality or formal religion in her effort to adjust to or withstand adversity. Contrasting findings come from the work of Treloar (2002), who noted a stabilizing effect of spirituality in the lives of women with disabilities. Other research similarly highlights the importance of the spirituality component of connectedness (Roux et al., 2002) in the daily lives of women with chronic physical conditions (Boswell, Knight, Hamer, & McChesney, 2001). However, methodological distinctions are noteworthy; both studies surveyed adult populations and had the specific intent to explore the role of spirituality.

Another key finding of this study is the generally positive, cohesive family environment surrounding the adolescent women with SB. Close bonds were particularly evident in the adolescent–parent relationship. Not only were parents an influential force in the daily lives of the adolescent women, in part because of the complex monitoring and management of SB, but they also fulfilled an important social outlet role for these young women. The absence of overarching adolescent–parent conflict in the SB population is consistent with prior research (Blum et al., 1991; Sawin, Bellin, et al., 2003). Although the majority of participants regarded their parents and their relationship in a positive light, an undercurrent of tension was present, especially in areas of independence and control.

Transient conflict was more prevalent in the description of sibling relationships. The adolescent women characterized their connections, which ranged on a continuum from high-conflict to close, comforting bonds, primarily as typical. Interestingly, there was no consistent pattern with regard to how the participants perceived the impact of SB on their families. Whereas some found no significant implications for their parents and siblings, others described profound emotional, social, and financial stressors stemming from the intense and lifelong management of SB.

Implications for Practice

Effective individualized interventions that optimize physical and mental health and enhance daily functioning for adolescent women with SB rest on a sophisticated, holistic understanding of the lived experience of these young women. These data support patterns of challenges and experiences of adaptation, but unique journeys also emerged. Rehabilitation nurses and other health professionals assisting

young women with SB therefore must listen for the unfiltered voices to appreciate both individual inner strengths and capabilities and threats to successful psychosocial adjustment.

An important contribution of the present research is our enhanced understanding of the trajectory of adolescent development for young women with SB, illuminating areas for intervention. Because many of the adolescent women with SB encountered bullying and teasing in school, addressing this potential risk experience appears to be an important role for nurses and other health professionals. Considering the profound negative impact teasing or taunting may hold for the self-concept of adolescents with spina bifida (Wolman & Basco, 1994), comprehensive interventions are indicated.

Other evidence supports the importance of individual assessments and interventions complemented by school-based supports. For example, Zacijek-Farber (1998) regards the education of peers about chronic physical conditions (e.g., exposing myths and misunderstandings) as essential to reducing social isolation and experiences of teasing and bullying, thus bolstering healthy psychosocial adjustment for students with such conditions.

Successful interventions need to involve school nurses partnering with teachers, social workers, and rehabilitation nurses in school activities aimed at dispelling myths and raising compassion and understanding in youth without chronic conditions. With the parents' permission, the rehabilitation nurse can serve as a collaborator with the school team to improve social integration and follow-up. In addition, the rehabilitation nurse can serve as a consultant on professional updates or new techniques, teaching plans, and criteria regarding referral to the SB clinic and the need for further rehabilitation. In most schools, although the school nurse has a great depth of practice, collaboration with a rehabilitation nurse integrates a broader and more comprehensive plan of care that should be cultivated. Greatest success for long-term positive effects depends on early and continued intervention between the professional school team and rehabilitation nurses. This collaborative care and education program should begin with the early school-age population (e.g., preschool) and continue consistently throughout the developing years with interventions for adolescents in the high school setting.

Rehabilitation nurses play an important role by helping their colleagues in the school setting remain abreast of healthcare developments, thus enhancing the quality of life of youth with SB. Rehabilitation nurses working with preadolescents and adolescents need to consider both school-based interventions and individual assessment and interventions. A holistic

understanding of the strengths and limitations of youth with SB entails learning about their functioning in a broad range of environments, not just in the rehabilitation setting.

Evidence also supports tailored, individual clinical interventions that enhance the coping skills of adolescents encountering adverse circumstances. Problem-directed coping strategies, with the active use of behavioral and cognitive strategies, are particularly effective in altering stressful situations, whether related to teasing and bullying, family conflicts, or stress of SB management (Livneh & Wilson, 2003). Additional interventions designed to enhance the overall well-being of adolescent women with chronic health conditions include engaging such women in decision making, assertiveness training, and goal setting around academics, treatment, and achievement of developmental milestones (Grey, Boland, Davidson, Li, & Tamborlane, 2000; King et al., 1993).

Another contribution of this study to clinical practice is the heightened awareness of the close, positive family relationships supporting these young women. Family-centered interventions can bolster family protective mechanisms; mobilizing families' internal strengths and resources may help circumvent stress experienced by adolescent women with SB. Because family-level protective factors may directly influence resilience in adolescents with SB (Sawin, Buran, et al., 2003), a central component of a successful transition program is family support, especially during periods of adjustment and adaptation (Blum et al., 1993). Parents need specific suggestions, however, because achieving a balanced parent-adolescent relationship is challenging given the level of parent involvement in managing SB over the course of an adolescent's life (Wolman & Basco, 1994).

Rehabilitation nurses need to be especially attuned to overprotective parenting, which may delay achievement of typical adolescent milestones (Blum et al., 1991). Because data suggest that age-appropriate treatment by parents profoundly influences the self-esteem of adolescents with SB (Wolman & Basco, 1994), shaping family assessment and intervention around promoting independence and autonomy appears important to fostering inner strength and adaptation in these young women and their families. In summary, the interactive dance of individuation and independence that parents and their adolescents with SB are engaged in holds significant implications for whether these young women develop social, self-management, and independence skills (Sawin, Bellin, et al., 2003). This is an important area in need of further examination from the perspective of the adolescent with SB.

Greatest success for long-term positive effects depends on early and continued intervention between the professional school team and rehabilitation nurses.

The Experience of Adolescent Women Living with Spina Bifida Part I: Self-Concept and Family Relationships

Study Limitations

Although our research heightens understanding of the unique lived experience of adolescent women with SB, several methodological limitations must be noted. First, our sample was comprised almost exclusively of Caucasian families. Knowledge of the experience of adolescents from different ethnic and racial backgrounds is greatly needed, especially given the higher incidence of SB in Hispanic families (Mathews et al., 2002). Also, we do not know whether these data reflect the experience of urban and rural populations. Whether and how the range of risk and adaptation or inner strength-building opportunities differs between adolescents from different cultures or geographic regions needs further study. To ensure the development of accurate, effective prevention and intervention programs, developing a knowledge base that reflects the diversity of adolescent populations is essential. A qualitative study on the experience of living with SB from the perspective of adolescent men and women is currently being conducted in a larger, multisite investigation.

Another demographic limitation of this study is the large percentage of adolescents with married parents. It is possible that a two-parent household offers a more readily accessible support network for these young women, influencing their psychosocial development, independence and self-management opportunities, social relationships, and experiences of stress and adaptation.

It is not clear whether the themes identified for adolescents and young women with SB in this study are useful in working with young women who grow up with or experience other physical disabilities. Clinicians can use the themes identified here as possibilities to be confirmed as they work with adolescents and young women. However, additional investigations are needed to determine which experiences are unique to SB and which are more universal to adolescent women with disabilities.

Conclusions

This study offered the opportunity to listen to the unfiltered voices of adolescent women with SB. Although the data reflected a range of experiences, several themes emerged to guide rehabilitation nurses and other health professionals in their work with this population. In particular, finding a balance between enhancing and mobilizing the inherent capabilities and strengths of adolescent women with SB and their families while simultaneously reducing exposure to risk experiences is a central part of facilitating positive psychosocial adjustment and adaptation to living with a chronic health condition.

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burden of care and the potential impact on family members and caregivers over time. King et al. describes a pilot study of an intervention to promote problem solving with stroke caregivers. Previous work identified that these caregivers often had little preparation for their new role as caregiver for a spouse. Caregiver depression was not uncommon. The aim of the study was to test a problem solving intervention that could be implemented by trained nurses. Anticipating and using evidence-based approaches to promote care is an important characteristic of rehabilitation nursing.

Bellin et al. describe how nurturing a “can do” attitude and sense of normalcy within the family

is important to the individual’s sense of self and relationships within family and community. The conversations with adolescent women living with spina bifida remind us that, as rehabilitation nurses, our actions can influence attitudes of the child and parents in a way that will have an impact on their emotional, as well as physical, development.

Our commitment to planning and working with patients and families to create a life that is healthy and rewarding for all is the essence of our profession. There is something for every rehab nurse, from novice to expert, to enjoy and to learn in this issue of *Rehabilitation Nursing*.