The Experience of Parenting an Adolescent with Spina Bifida

Kathleen J. Sawin, DNS RN CPNP FAAN
Melissa Hayden Bellin, MSW PhD candidate
Gayle Roux, PhD RN CNS NP-C
Constance Buran, DNS RN
Timothy J. Brei, MD
Philip S. Fastenau, PhD

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Parents of adolescents with spina bifida (SB) face unique challenges of which they may not be aware. The purpose of this study was to heighten awareness of the challenge of parenting such adolescents. This enhanced understanding can help rehabilitation professionals optimize their interventions with families. In this qualitative study, which was part of a larger mixed-method descriptive investigation exploring adaptation by adolescents with SB, we used content analysis to evaluate 20 parent interviews for common domain, themes, and subthemes. The analysis yielded four major domains: (a) daily life experiences, (b) the dance of individuation, (c) reflections on parenting, and (d) practice suggestions for healthcare professionals. Overall, experiences of the parents were positive. Parents described meeting daily demands and balancing independence-dependence needs with the adolescent as major challenges. Rehabilitation professionals must provide guidance to foster autonomy, decision making, cognitive skill building, and coping skills to help parents and adolescents manage independence-dependence issues and multiple life demands.

Kathleen Sawin is professor and research chair for the Nursing of Children, a position jointly sponsored by the University of Wisconsin–Milwaukee and Children's Hospital of Wisconsin. At the time this research was conducted, she was an associate professor at the School of Nursing, Virginia Commonwealth University and pediatric nurse practitioner in the Spina Bifida Program at Children's Hospital in Richmond, VA. Melissa Hayden Bellin is a research assistant at the Uniformed Services University Department of Pediatrics and a doctoral student at the School of Social Work at Virginia Commonwealth University. Gayle Roux is an assistant professor at the Department of Maternal-Child Nursing at the Virginia Commonwealth University. Constance Buran is the manager of the Rehabilitation Medical Service Area and the clinical director of the Cerebral Palsy and Spina Bifida Programs at Clarian Health Partners and the James Whitcomb Riley Hospital for Children in Indianapolis, IN. Timothy Brei is an associate professor of clinical pediatrics and medical director of spina bifida and cerebral palsy programs, Section of Developmental Pediatrics, IU School of Medicine and the James Whitcomb Riley Hospital for Children. Philip Fastenau is associate professor in the Department of Psychology at Indiana University Purdue University Indianapolis and adjunct assistant professor of clinical psychology in the Department of Psychiatry at Indiana University School of Medicine. Address correspondence to Kathleen Sawin, University of Wisconsin–Milwaukee, College of Nursing, PO Box 413, Milwaukee, WI 53201-0413, or e-mail sawin@uwm.edu.

Advances in health care and technology have dramatically increased the life span of children with chronic health conditions and disabilities (Brown, Kreig, & Belluck, 1995; Meleski, 2002). As these children become adolescents and grow into young adulthood, it is critical that rehabilitation nurses and other professionals understand a family's perspective on parenting an adolescent with a disability. Rehabilitation professionals who have an enhanced understanding of parents' experiences in rearing children with spina bifida (SB) may be more effective in working with such adolescents and their parents. Indeed, Patterson (1995) argued that failure to identify, value, and thus empower these families to discover and build on their own capacities has been a barrier to efficacious intervention with them.

One population that has experienced a significant increase in life expectancy as a result of medical progress is that of children born with SB (Blum, Resnick, Nelson, & St. Germaine, 1991). Specifically, recent data suggest that at least 75% of children born with SB can expect to survive into adulthood (Bowman, McLone, Grant, Tomita, & Ito, 2001). Spina bifida, a spinal cord impairment with related central nervous system changes, is caused by a lack of neural tube closure early in pregnancy. This condition, one of the most common disabilities in children, occurs in 20 in of every 100,000 live births (Centers for Disease Control and Prevention, 2002). Children and adolescents with SB frequently require rehabilitation hospitalizations for orthopedic and neurosurgical operations. Further, they experience skin and urological problems resulting from their condition (Zurmöhle et al., 1998) and are often underachievers in independence, education, and employment (Bowman et al., 2001). Our purpose in this study was to increase awareness about the experiences parents have in rearing adolescents with SB by exploring their perceptions of daily routines, family rewards and challenges, and effect of the condition on a family's social life and well-being.

Theoretical orientation

The notion that change in one part of a family system affects all other parts is particularly relevant to conceptualizing how one member's chronic health condition may influence the well-being of the family as a whole (Bradford, 1997; Cox & Paley, 1997). Indeed, a significant stressor that affects one person's

functioning may likewise affect the psychosocial outcomes of other family members (Williams et al., 1997). One specific family systems model, the resiliency model of family stress, adjustment, and adaptation, describes the relation of stress to family strengths and limitations (McCubbin, Thompson, & McCubbin, 1998). This model and others suggest that the impact of a child's disability is evident as families adjust their timetables to accommodate the situation and reallocate their resources to meet the financial and psychosocial costs associated with the disability. Further, the potential to minimize developmental needs of other family members, and the emerging role conflicts associated with caregiving responsibilities, may increase the strain on the family (Gustafsson, Bjorksten, & Kjellman, 1994; Quittner, DiGirolamo, Michel, & Eigen, 1992; McCubbin, et al., 1998; Quittner, Opipari, Regoli, Jacobsen, & Eigen, 1992; Wambolt & Levin, 1995).

Other family theorists (Bradford, 1997; Minuchin, Colapinto, & Minuchin 1998; Navarre, 1998; Papero, 2000) believe that a person's capacity for differentiation is often a function of the condition of family boundaries. Importantly, highly differentiated people who maintain individuation while pursuing a measure of connectedness with family members are viewed as being more flexible and adaptive to stressful situations (Brown & Christensen, 1999; Papero, 2000). Alternatively, the Bowen theory (Papero, 2000) is one that regards people who have a low differentiation of self as being vulnerable to dysfunction in stressful experiences. Bowen's assertion that extreme enmeshment among family members may impair life stage development has particular importance for families that are balancing a desire to protect with a push toward normalcy and independence for youths with disabilities such as SB (Papero, 2000). An adaptive family response to the demands associated with rearing a child or adolescent with a disability is often predicated on the development of family subsystems that support the cohesion, flexibility, and problem-solving capacities of the larger family unit (Patterson & Garwick, 1994). Thus, the family systems theory highlights the importance of the parents' experiences in understanding the eventual outcomes for their adolescents.

Literature review

Knafl, Breitmayer, Gallo, and Zoeller (1996) suggest that the family unit and the lives of individual family members are often "profoundly touched by the presence of a person with a chronic illness in the family" (p. 315). Although there are substantial data regarding the psychosocial experiences of youths with SB (Appleton et al., 1997; Blum, 1983; Loomis, Javornisky, Monahan, Burke, & Lindsay, 1997; Wallander, Feldman, & Varni, 1989; Zurmohle et al., 1998) and the impact of SB on the family as a whole (Loebig, 1990; McCormick, Charney, & Stemmler, 1986), less is known about parents' experiences in rearing their adolescents with SB. Researchers do, however, observe that parents of children with a disability may be at risk for psychological distress resulting from caregiving demands. These demands may include the physical care of their children; negotiating healthcare, educational, and other service domains; the emotional toil of helping their children cope with their illness; and the balancing of competing family needs (Canning, Harris, & Kelleher, 1996; Ievers, Brown, Lambert, Hsu, & Eckman 1998; Meleski, 2002; Quittner, DiGirolamo et al., 1992; Quittner, Opipari et al., 1992).

While some studies suggest that parents of youths with SB are at risk for poor adaptation, greater levels of psychological distress, and less perceived parenting competence compared with parents of children without a health condition (Holmbeck et al., 1997; Macias, Clifford, Saylor, & Kreh, 2001), there is significant diversity in psychosocial outcome in this population (Kronenberger & Thompson, 1992; Noojin & Wallander, 1996). In contrast to previous data that indicated low levels of parenting satisfaction, Lemanek, Jones, and Lieberman (2000) found that mothers of children with SB felt they were effective in their parenting role. In addition, Spaulding and Morgan (1986) observed that parents did not differ from a matched comparison group in their parenting attitude, marital adjustment, perception of child behavior, child self-concept, stress, or overall family functioning.

Importantly, research suggests that a major predictor of SB's high impact on the family is the number of activities of daily living (ADL) in which the youth is engaged (McCormick et al., 1986). Also, in their study of 164 parents of children with neurodevelopmental disabilities, including SB, King, King, Rosenbaum, and Goffin (1999) found child behavior problems to be the most important predictor of parental well-being. Loebig (1990) found, however, that most families can adequately meet the needs of all family members, despite the high caregiving demands. Moreover, although parents expressed concern about childhood development and future independence, there was a theme of optimism about their children.

In summary, there is conflicting evidence about the nature of a family's experience with parenting a child with SB, and a paucity of material that focuses on such families. Further, little is known about a family's daily experience of living with this chronic health condition. Our study addressed these gaps in our knowledge of parent experiences in rearing adolescents with SB.

Method

This study was part of a larger, mixed-method, descriptive investigation into adaptation by adolescents with SB (Sawin, Brei, Buran, & Fastenau, 2003). The data reported here are from qualitative interviews of the adolescents' parents obtained from a subsample of the larger study. Approval from the University Internal Review Board was obtained before the study was initiated. The 20 participants in this sample were the primary caregiving parents, or step-parents of adolescents who were 12–21 years old, English speaking, functioning at grade-appropriate level in school, and who had no other major progressive medical conditions.

Eligible parents were informed of the study by clinic staff during appointments with their adolescent at an SB clinic. Interested parents were contacted by telephone by a research staff member, who explained the study's purpose and scheduled interviews.

The interviews were done in the participants' homes or via telephone and written consent to be interviewed was obtained. The parents were assured that they could end the interview at any time and no identifying information would be included in the final report.

Data were collected via a demographic tool and a semi-structured interview that included the following open-ended questions: (a) What has been your experience being a parent of a teen with SB? (b) What impact has having a teen with SB had on your family life? (c) What has been most rewarding and most stressful? (d) Are your expectations for your son/daughter different in any way from your other children; if so, how? (e) Some parents feel the need to protect their teen with SB, others feel the need to "keep them normal." What describes your family best? (f) What do you believe is important in raising a child with SB?

Questions intended to elicit elaboration on the parent's experiences and feelings were asked throughout the interview by the interviewer. These included "Tell me more about that," or "Can you give me an example of that?" All interviews were conducted by a trained qualitative researcher with knowledge of family theory and substantial clinical experience with adolescents with SB and their families. The interviews lasted between 45 minutes and 3 hours and 30 minutes, with the average interview lasting 1 hour and 40 minutes. The interviews were audiotaped and transcribed verbatim.

Content analysis was done to examine the qualitative data for common domains, themes, and subthemes (Morse & Field, 1995). Initially, the principal investigator (Sawin) and the second author (Bellin) independently reviewed two selected transcripts to search for preliminary commonalities and to develop a coding scheme. Subsequently, Sawin, Bellin, and Roux independently examined the next 12 transcripts to establish common domains, themes, and subthemes. They then discussed the findings and collaborated on the analysis of the final category structure and descriptions. When no new themes or subthemes were identified and each domain was saturated, data were examined to find relationships between the themes and descriptions were written (Morse & Field, 1995). The final six interviews were examined to ensure that saturation was established. No new data emerged with this analysis. Salient and exemplar statements from the 20 interviews were extracted to describe each category and subcategory. The participants' exact words were used to describe the themes when it was possible to do so.

We used several techniques of rigor in this analysis. First, the third author (Roux), who has expertise in qualitative research, served as a consultant to enhance the trustworthiness of the analysis while generating common themes and subthemes. Second, six additional interviews were examined to confirm saturation. Third, the remaining three authors (Buran, Brei, Fastenau), who have extensive clinical experience with this population, reviewed the domains, themes, subthemes, and exemplars to confirm placement and to ensure consistency with clinical reality. Finally, the first three authors wrote field notes documenting decisions and memos that described feelings and biases (Sandelowski, 1993). This process confirmed the domains and the majority of the themes and it also resulted in a combination of several themes or subthemes.

Results

A majority of the adolescents in this analysis were female (70%), non-Hispanic white (95%), had a shunt (90%), and were most frequently (78%) the second or third child in the family. The level of spinal lesion spanned all levels in a fairly equal distribution: thoracic/high lumbar (35%), lumbar (20%), lumbosacral (20%), or sacral (25%). The mean age of the adolescents was 16.3 years (*SD* = 2.4), and 90% were in school. Interviews were conducted with 18 mothers and 2 fathers. Most of the participants were married (90%) and were fairly well educated. Complete demographic information is reported in **Table 1**.

Analysis of the interviews yielded four major domains that included 12 themes and 7 subthemes (**Table 2**). The four major domains were: (a) daily life experiences, (b) the dance of individuation, (c) reflections on parenting an adolescent with SB, and (d) practice suggestions for healthcare professionals. Each family was assigned a number, and that number appears after the exemplar in this report. Finally, pseudonyms were used for the children and appear in brackets.

Domain 1: Daily life experiences

Parents described typical successes and challenges of everyday life, including their responsibilities related to SB and the tasks that are part of family life. This domain included five themes that reflected parents' daily experiences: (a) ever-present monitoring and managing; (b) sense of feeling overwhelmed with daily family responsibilities; (c) coping strategies; (d) family relationships; and (e) restrictions on the family's social life.

Ever-present monitoring and managing: Participants reported that monitoring and managing was a central theme of their daily experiences. Three subthemes emerged in this domain: (a) the uncertainty of SB; (b) the anxiety of adolescence; and (c) managing SB on a daily basis. The ever-present monitoring had an uncertainty component that weighed heavily on parents' minds. Specifically, they reported the following:

> (The) unknown is the biggest part. (Family 3)
> I'm scared about what is going to happen next. (Family 15)

> The one I worry about the most is the shunt, because that's the one we've been through the most. When she gets a headache, we all get a little nervous because she's had two really bad episodes with the shunt. (Family 2)

In addition, participants expressed worry about typical adolescent behaviors with the added concern related to SB. For example

> Even now, there's times I have to really grab a hold of him and say "We need to talk about this," because he's quick to make snap decisions, which is fairly normal with young people anyway, uh, he can be so detrimental. (Family 1)

> Half and half, worry because she does have spina bifida and worry because she's a teenager. (Family 10)

> The only thing that worries me when he became of age was driving and only because

Table 1. Demographic Characteristics of the Family

	n	%
Participant Variables		
Gender of participant interviewed		
Female (mother/stepmother)	18	90
Male (father)	2	10
Race/ethnicity		
Non-Hispanic White	19	95
African-American/other	1	5
Marital status		
Married	18	90
Separated/divorced	2	10
Educational level (of 20 people interviewed)		
High school	7	35
Attended college or formalized training	11	55
Graduate degree	0	0
Post-graduate training	1	5
Missing data	1	5
Employment status (of 20 people interviewed)		
Female parent	9 (of 18 interviewed)	50
Male parent	2 (of 2 interviewed)	100
Family employment status (All families)		
Female parent	10 (of 20 families)	50
Male parent	17 (of 20 families)	85
Adolescent Variables		
Gender (adolescent)		
Female	14	70
Male	6	30
Level of lesion		
Thoracic/high lumbar	7	35
Lumbar	4	20
Lumbosacral	4	20
Sacral	5	25
Adolescent IQ M = 90, SD = 14.7* (available for 13 participants)		
80 or less	4	20
81–99	4	20
Above 100	5	25
Missing data	7	35
*(*Similar M and SD (M = 90.8; SD 18.4) in 50 adolescents from a larger study whose IQ scores in the three categories had **36%; 32%; 38% [AU: Please cite the study]** respectively)*		
Adolescent age M = 16.3, SD = 2.4		
12–13 years old	4	20
14–15 years old	5	25
16–17 years old	8	40
18–21 years old	3	15

> he's still my baby, I worry about him more than I have any of the kids. (Family 17)

> The responsibilities are there. We've had problems with that [glued to TV when chores are to be done] and that has nothing to do with her limitations or her disabilities. It's just being lazy, and that's being a typical teenager. (Family 12)

Finally, participants described "managing SB on a daily basis," that is, the ongoing management of the adolescent's disability as a predominant activity in family life.

> Keeping doctor appointments and medications. So much to keep straight, things can go wrong and with our everyday life. (Family 6)

> Her cathing [catherization] is the most [stressful], that would be the big one. (Family 10)

> Keeping him clean—diarrhea, cleaning up after that… changed bowel management so he sits on toilet after school until he goes and you have to stay there until you're done. Sometimes he's not done, and that's when I have to clean him up. I want him to have MACE [Malone antegrade continence enema] so he can be independent, get his own place, cath himself. (Family 7)

> We have to have someone with her constantly, we don't leave her alone. (Family 5)

> [He] has more supervision, we never leave him alone, always one of us [is] with him. (Family 6)

Sense of feeling overwhelmed with daily family responsibilities: Participants had strong opinions about their struggles to

Table 2. Domains, Themes and Subthemes Identified from Interviews

Domain 1: Daily Life Experiences

A. Ever-present monitoring and managing, "More supervision"
   1. Uncertainty about spina bifida
   2. Anxiety of adolescence
   3. Managing spina bifida on a daily basis

B. Overwhelmed with daily family responsibilities, "In charge of everything"
C. Coping strategies, "Don't sweat the small stuff"
D. Family relationships, "We've always been so close"
E. Restrictions on family social life "This is just the way our life is"

Domain 2: Dance of Individuation: The challenge of independence

A. Skill building, "Bring him up to speed"
B. Levels of protection "Trying to decide where to cut the umbilical cord and how much"
   1. Overprotective parenting
   2. Blended parenting
   3. Fostering independence
   4. Parent and adolescent tension over push for independence

C. Overriding worry, "I worry about her independence when she's gone from the house"
D. A range of expectations, "Treat them the same" to "Expect less of them."

Domain 3: Reflections on parenting an adolescent with spina bifida

A. Rewarding, "I would not change a thing"
B. Personal growth through parenting experience, "Lessons learned"
C. Cautious optimism for achieving independence goals, "Not far behind but a little bit"

Domain 4: Practice implications for healthcare professionals

keep up with daily family responsibilities, beyond that of the care of their adolescent.

> [I am] overwhelmed, in charge of everything, dishes, house, spend time with [Ann]. (Family 5)

> I think it's all the family responsibilities. (Family 17)

> Normal day-to-day life stresses (Family 11)

> If I get overwhelmed, it's not with the spina bifida—it's being so involved in everything else and frustrated with myself to say "no, I can't do any more." I guess that's it. (Family 20)

Coping strategies: Participants reported the importance of coping and indicated a range of coping skills or strategies they used to successfully manage the challenges of everyday life.

> Cope with stress with a sense of humor. If you don't have one, you better find it. (Family 3)

> Communication is really a big plus and don't sweat the small stuff… just let some stuff go. (Family 5)

> Sometimes you have to have a good cry, say a prayer. Believing in God is a great comfort, a great help. (Family 2)

> My faith in the Lord is what I'd say really gets us through. (Family 8)

> I have a wonderful husband who is very, very supportive and very loving. (Family 20)

> I cope with I have a really good friend that I talk to, you know and I can tell her all my problems. (Family 17)

Family relationships: Many participants reported that the strong, positive relationships between adolescents and their parents and in the entire family were a part of their daily life experiences.

> We've always been so close and, you know, I've always handled a lot of the things when he was growing up. (Family 17)

> Family-wise, it's brought us all closer. (Family 9)

> My mom has always been really great. I went back to work after she was 6 months old and my mother took care of her and taught her a lot of things. (Family 2)

> Anything as a family, we've always done [together]. (Family 20)

> Our kids are very close. (Family 20)

> As the kids grew up they were more sensitive to other people… Sometimes they have to learn, sometimes they have to talk to him and they give him more slack than they'd probably give each other. (Family 1)

Restrictions on family social life: Participants agreed that a major impact of SB on the family was the restriction of their daily social life. For some families, it is an accepted reality of life while others strive to work around the restrictions.

> This is just the way our life is and… certain things we don't do. (Family 20)

> Well, I've been told by the other kids that I won't let them do things because [Carol] can't do it. (Family 15)

> We have to change our schedule [because of] going to doctor a lot. (Family 10)

> Less activities [as a family]. (Family 13)

> You can't let it disrupt the whole family. No big deal, even if she was in a wheelchair, we'd go and do just like we do now, wouldn't make a difference to us. (Family 16)

Domain 2: Dance of individuation

The parents' delicate balancing of their desire to protect the adolescent and yet to push the child toward normalcy and independence is reflected in the dance of individuation domain. A range of parenting approaches, from acknowledging overprotection to encouraging autonomy, was described. Four themes were identified in this domain: (a) skill building; (b) levels of protection; (c) overriding worry; and (d) range of expectations.

Skill building: Central to the dance of individuation was an understanding of the need to equip the adolescent with skills to both manage their disability and to succeed in life. Generally, participants reported the need to "catch the adolescent up" to the demands and life tasks they will face.

> Insurance stuff—gotta learn it. Bring him up to speed. (Family 4)

> For [John] it is learning the skills to take care of himself—survival skills. [He] needs to take care of himself, medication, hygiene, personally, physically, socially. (Family 6)

> I've been thinking about things I need to do to get her to that point so she could do something like that [being a veterinarian]. (Family 3)

> I try to teach, to catch her up to where I feel she should be at this point. (Family 12)

> One of the things I think he should be able to do now—needs to learn to do—a little more things for himself. (Family 17)

Levels of protection: Most participants expressed concern about how much independence was appropriate for their adolescent. Generally, families were "trying to decide where to cut the umbilical cord and how much" (Family 5), but found that "the hardest part [was] kind of untying the apron strings, letting herself get in trouble" (Family 14).

Four subthemes describing the levels of protection issues parents experience emerged from this data: (a) overprotective parenting; (b) blended parenting; (c) fostering independence; and (d) parent-adolescent tension.

A group of participants described themselves as primarily *overprotective parents*. They were more comfortable closely monitoring their adolescent while acknowledging their more protective behaviors.

> We're overprotective. (Family 3)

> I won't let him get married unless I know the woman will take better care of him than I do. Otherwise, [I am] not letting him out of the house. (Family 7)

> We protect her because that is where we're at right now…but we really, really want her to be able to drive, to dress herself, to go when she wants to go, and we want her to be like a regular child. (Family 20)

> I think he can handle things a lot more than I think he can, [but] you know, I still think of him as a little boy. (Family 17)

In contrast, other participants described a *blended parenting* approach of protectiveness and a desire to encourage independent experiences for their adolescent. They often reported conflict between the two objectives. They were working to help the adolescent live a normal life, but they were still protective.

> Sometimes I am overprotective, 'you're not going to do that, you'll get hurt.' But I also want to see her be out on her own and be independent and see how she can do and get a job. (Family 10)

> We are trying so hard to protect our kids that we're not letting them mature at the right age. But then, at 18, we want them to be totally responsible and they're not ready… they've never had the freedom of choices. (Family 1)

> I think I work hard to keep them normal, but I also think that I protect them more. I think in my situation I try I do both. I want them to be as normal as possible, but then I don't let them do something because they're in a wheelchair. (Family 18)

> I usually say, 'Look, I know you want to be Mr. Independent, but I've been taking care of you for years, I've been involved in this for years and I do know a little bit more how to get things done.' Sometimes I let him go off on his own and fall. That sounds terrible, but sometimes they have to have them knocks and bruises to realize. (Family 1)

> As a parent, [I] have to step back and get out of the routine… we don't want him to do everything, not fair to go from 0 to 100… but it's easy to go past time, gotta watch that. (Family 4)

The third subtheme, *fostering independence,* describes the group of participants who emphasized allowing their adolescents to develop autonomy and self-reliance through independent experiences.

> I let her do whatever she feels comfortable doing. I don't hold her back. (Family 16)

> We do want her to be as independent as possible. (Family 2)

> Encourage him to do normal stuff and not miss out on experiences. (Family 6)

> I've kind of learned to take her and help her so far, and let go. (Family 15)

However, participants did report having concerns that their decision to foster independence may put their child at risk.

> I have to think about what's good for her rather than what's good for me, because if I thought about it only in my perspective, you know, you keep your child in a bubble and you'd be perfectly happy and they'd be miserable. So I have to sometimes let her go and the whole time I'm worrying. (Family 2)

> Maybe I have let her do too much… I would feel bad if something happened that I told her go out and try to do anything you want to do; I think that's what really concerns me. (Family 16)

Finally, some participants described *parent and adolescent tension over the push for independence*. They reported challenges in encouraging their adolescent to become more independent, while others expressed concern over the adolescent's drive for greater autonomy.

> I ask him things like, have you had a bowel movement lately, and once in a while I have to make sure that he's not been wet or anything. Yeah, once in a while he gets mad at me. (Family 17)

> She's real independent, she's always argued with me that she can do it herself, that she doesn't need my help. (Family 18)

> I get mad at her. If she's went too long [without cathing], she's taking a vacation from her cathing. That's what we really have an issue with. I get mad at her because I know you're going to make yourself sick. (Family 15)

> I've tried real hard, you know, just like this Medicaid thing, I let him go down and apply for it the first time, he was turned down. Then he gets all upset, that I don't need him. (Family 1)

Overriding worry: Most parents perceived their adolescent as vulnerable, and they were worried about their ability to live independently and to manage their condition.

> I worry about her looking for work and being independent, looking for a place to live, being out on her own and who will take care of her now I won't be there. I think about that a lot now if she will be able to take care of herself. (Family 10)

> I think I always worry about if she is independent enough. Have we taught her all the things we need to teach her. (Family 2)

> She's real good about standing up for herself, but sometimes you worry about how things will be, societywise. How things will be for her once she gets out on her own. (Family 2)

> They think they've become adults and can cope with everything themselves and they're not. (Family 1)

> When it's time for her to be on her own, and just keeping her safe, if she gets her own place, uh, some self-defense type classes. (Family 14)

> I am concerned about his future employment. My concern with getting a job is that they expect them to get it after a while, and I don't know how soon he would get it. It's just going to be a little bit harder, I think. (Family 19)

Some parents were especially apprehensive about the potential social vulnerability of their adolescent.

> Now I guess the hard thing is, just because he's different… I just worry about if he'll have girlfriends. (Family 17)

> She likes boys, but she's with that wheelchair and those braces. (Family 14)

> I thought kids would tease her about having a big tricycle. (Family 3)

Participants also worry about their adolescent's ability to handle the health and financial aspects of SB.

> You can't work at McDonald's and pay these medical bills. I don't want to see him hemmed in Medicaid... such a waste of an individual to sit [at] home. (Family 4)

> I worry more about his health and less about his social life. (Family 6)

> Whether she'll live through it [having a baby] concerns me. (Family 15)

Range of expectations: The fourth theme in the dance of individuation domain addressed the expectations that parents held for the adolescents who have normal intelligence. Parents reported a range of expectations from "treat them the same" to "expect less of them." Parents described an effort to have their adolescents participate in typical activities but were realistic about limitations imposed by their disability.

The majority of participants said their expectations of their SB adolescents are the same as they are for other youths in the family.

> I don't treat them like they have handicap. They're regular kids, they got a handicap. I push them, they need to do things. (Family 6)

> Has same rules as everybody else. (Family 10)

> I've tried to give him the same range [of activities] that the other kids have. (Family 1)

> The girls all have responsibilities in laundry, and we have a rotating shift on dishes. It's the rules of the house. She's no different than the other two. (Family 16)

> We try to be realistic, at same time I don't want her to settle for less. (Family 3)

> We've really tried to treat [her] the same. She's got jobs that are expected of her. Obviously she can't carry out the trash but there's plenty of things to do, so I really feel like we've expected the same out of her. (Family 8)

Some parents, however, expected more from their adolescent with SB.

> I probably do expect more out of [Beth] and I catch myself doing that. I try to push her more than the others. (Family 16)

> As a teen I expect more from her, not to be so dependent on me. (Family 3)

> I don't use her handicap or disabilities as a fallback for her, to let her "oh well, I can't do this because of [my] handicap." I don't want her to be able to use that as an excuse. (Family 12)

Others expressed lesser expectations.

> I expect more from [Sam] and [Joe] than I do from [Sheila] and [Valerie] as far as things they should do around the house. I don't really expect [the girls] to do any particular chores around the house. (Family 18)

> She didn't have as many chores… so probably I treat her a little different because she couldn't do it as easily, or she couldn't do it at all. (Family 11)

Domain 3: Reflections on parenting an adolescent with spina bifida

The third domain describes parents' thoughts, attitudes, and philosophies about rearing an adolescent with SB. Three themes delineating these reflections emerged from the data. Parents found the experience to be rewarding. Families also reported opportunities for personal growth, both in their personal life and in the areas of advocacy and education. Finally, participants report being cautiously optimistic about the future of their child.

Rewarding: The majority of participants described an overall positive view of their parenting.

> It definitely has brought us closer together; I wouldn't know anything else. (Family 16)

> If I had a choice between [Ann] with spina bifida or [a] healthy child... I'd take Ann with spina bifida any day. (Family 5)

> We don't think of it as a problem, it's just our life. She's a blessing. (Family 20)

> We often say we wouldn't be together, she held us together, we wouldn't be together without her. (Family 3)

> If I had to do it all over again, I'd do it. It's not been anything more than what we've been able to handle. (Family 8)

Personal growth through parenting experience: Participants described several benefits realized from their experience of rearing an adolescent with SB. Specifically the experience enhanced their personal growth, facilitated their development of advocacy skills, and extended their education.

> I have learned so much through her. (Family 5)

Taught me a lesson. (Family 3)

It's been a real blessing because it makes you more sensitive to other people who are not perfect. (Family 8)

Sometimes I've found I have to push the law. Get in there and ask questions, getting more involved. (Family 1)

I've had to educate myself more about things. (Family 1)

Medically, I have learned more than I wanted, but it helped me when my grandparent was sick. (Family 5)

Parents' cautious optimism for achieving developmental goals: This third theme reflected parents' hopes that their adolescents would participate in typical developmental activities, hopes tempered by realistic expectations that such participation might be at a slightly later age. Parents characterized this expectation as "not far behind, but a little bit."

With the other kids, before they came out of their teen years, they were pretty much getting more independent and not relying on us as much. He's almost 22, and he reminds [me] of the other boys when they were about 16. Not real far behind, but a little bit. (Family 1)

I see her driving a little car, and you know, working somewhere, and trying to get her first apartment, you know. (Family 15)

She's looking to work this summer. I was waiting until she [turned] 15 to take on responsibilities. (Family 16)

Her limitations [are] slowing her down a little bit. The maturity level is not the same. She's almost 17, and I would let my 14-year-old daughter do more than I would her. (Family 12)

I would like to see her go on to college if she can and be independent on her own. I would like to see her get married one day. (Family 18)

She has always wanted to work in a hospital doing something. A lot of it just depended on what she can physically do, as far as her limitations. (Family 20)

I don't think academically she's going to make it [to college]. I can't see her doing that but I think that if she got into some type of trade school. (Family 15)

Domain 4: Practice implications for healthcare professionals

Although there was no specific research question regarding professionals working with their children, parents were asked at the conclusion of the interviews whether they had anything else to share or that they were worried about. Participants identified concerns that have practice implications for professionals. They expressed a need for increased communication, teamwork, and partnership among healthcare professionals, educators, and the family. Specifically, they voiced a need for more information about resources in the community, and guidance in rearing a youth with SB.

I would like to see the hospitals feed their information to the schools letting them know... the school just doesn't understand and they weren't educated, you know, and I think that they [healthcare professionals] should educate the teachers. (Family 15)

I just wish the schools would work more with the hospitals and with the social workers, you know, to get a better environment all around. (Family 15)

This Individualized Education Plan (IEP) time gets me stressed out. They're just worried about passing her through, and I'm worried about getting her prepared for life. I don't think the school is really worried about that. (Family 8)

If I would have known that there was help out there... no one told me. You know, nobody had told me anything like that any services were available. (Family 15)

I wish somebody would have told me [discussion was about folic acid]. (Family 16)

One good advice that my pediatrician gave me, because I was afraid to bring her home from the hospital and you know how do I treat her, and he said treat her just like you would, you know she is a normal child. That's what I've always tried to do. (Family 18)

Discussion

A major finding of this study was parents' overall positive perception of the experience of rearing an adolescent with SB, and their positive perception of their adolescent. While admitting the stress of everyday monitoring and management of the condition, the families uniformly reported positive perceptions. Findings included an overall positive attitude, enhanced family life, and personal growth opportunities for parents, including opportunities for becoming involved in advocacy and education activities.

These findings are consistent with those of Bier and Liebling (1996), who interviewed 63 parents of children 3–16 years of age with SB. Their data supported an optimistic parent perception of family life with a child with SB. Despite the ongoing demands in managing the condition, the families found effective ways to cope with daily stresses. Moreover, they reported positive contributions to family life. A majority of mothers in Loebig's (1990) study similarly reported positive effects of parenting youths with SB, including learning to slow down, to enjoy the "little things" more, to not take life too seriously, and to learn to prioritize. Further, studies that used comparison groups of families without a youth with a chronic condition found little difference in parenting attitudes and overall family functioning (Spaulding & Morgan, 1986). Even with increased stress, parents retained a positive outlook on raising their youths with SB.

Another important finding was that parents pointed to daily life demands, and not tasks related to managing SB, as their major cause of stress. Indeed, many parents expressed difficultly in keeping up with normal day-to-day life stresses, including feeling overwhelmed with family responsibilities. Previous studies corroborate this finding (McCubbin, 1998; Samuelson, Foltz, & Foxall, 1992).

Members of a clinical research team (Brei, Woodrome, Fastenau, Sawin, & Buran, 2003) examined the impact of the adolescent's neuropsychological (or cognitive) deficits on parental depression in a larger sample set from which the study's qualitative sample was drawn. In both the quantitative and qualitative studies, parents' coping strategies and protective factors helped to alleviate many stresses associated with parenting a child with SB. However, these protective resources did not ameliorate the distress that stemmed from the adolescent's learning deficits in their school and home life. That is, parents of adolescents with SB—even those with good coping strategies and positive protective factors—have great difficulty dealing with neuropsychological deficits and school performance issues that their teen might have. The neuropsychological deficits also have an impact on the adolescent's functioning at home in the areas of self-care, self-management, and household responsibility.

A major contribution of this study is that it provides an increased understanding of the participants' perceptions of the interactive dance toward independence in which parents and their adolescents are engaged. The delicate balancing act needed between a desire to protect and the push for independence clearly dominates the parents' descriptions of their families. Although parents are aware of the importance of success with developmental tasks for their adolescents, they are also concerned with the safety issues involved with managing a complex health condition. Additionally, many parents report the need to monitor activities and limit risk taking. While some parents spoke of instilling in their adolescents decision-making, social, and overall life skills, others perceive their adolescent as being vulnerable and needing protection. Additionally, whereas many parents worry about future independence, some are more aggressive in encouraging their teens to participate in typical adolescent activities. Most parents agonize over when and how to "cut the cord" and "untie the apron string," frequently extending the developmental timeline that is typical for other youths. Importantly, while there is some tension between the adolescent and parent about independent activities, the depiction of the dance is not one of overarching conflict or adolescent demand for autonomy.

These findings are consistent with select earlier studies that reflected a harmonious parent-adolescent relationship with a notable lack of conflict. However, even in these close, positive relationships, adolescents with SB reported overprotectiveness, which may delay adolescent development (Blum et al., 1991; Holmbeck et al., 2002). This study provides insight into the struggle that parents face. Complicating this "dance of individuation" is the parent's perception of the adolescent's relative passivity and acceptance of overprotection and dependence. Importantly, Holmbeck et al. (2002) found that perceived overprotectiveness led to lower levels of parents' willingness to grant their adolescent with SB autonomy and decision-making ability. If these adolescents are to successfully transition to being competent, independent adults, these patterns might be problematic. Indeed, the significance of fostering individuation is supported by findings of a positive relationship between perceived family encouragement of independence in youths with SB and the achievement of favorable outcomes as young adults (Loomis et al., 1997).

An opposing perspective is supported by Murch and Cohen (1989), who found that families that placed a high value on independence caused anxiety in youths with SB. The authors hypothesized that the adolescents may feel that they are being pushed beyond their capabilities. It is important to note, however, the impact on their anxiety over their parents emphasizing independence was very low. In addition, some researchers and clinicians suggest that a measure of anxiety is functional in the achievement of competence and developmental goals. Ultimately, parents are challenged to foster an environment that promotes optimal psychosocial development in their adolescents.

Implications for practice

Of particular importance for rehabilitation professionals who serve children with a disability such as SB and their families is a capacity to help the family by nurturing the youth through stressful periods, and by teaching family members tangible ways to strengthen adaptive functioning (Brown & Lambert, 1999). The rehabilitation team needs to equip parents early on with the skills and resources needed to traverse the critical adolescence developmental stage. Parents in this study, along with others from previous research, expressed a need for greater support on psychosocial aspects of their adolescents' condition, including a desire for more anticipatory guidance in the areas of vocational/educational training, sexuality, and daily living skills (Rinck, Berg, & Hafeman, 1989; Samuelson et al., 1992). Thus, while the rehabilitation team can help with the important outcomes of functional status and medical management of the condition, effective, family-centered care must also attend to the crucial developmental skill building.

Two major focuses are needed in supporting families that are coping with SB: a lifelong focus and an adolescent-specific focus. In the former, rehabilitation team members must discuss autonomy skills and cognitive development early and continuously to encourage experience in decision-making appropriate for the developmental stage. In addition, it is recommended that

rehabilitation professionals assess parents' need for anticipatory guidance and resources on an ongoing basis. For optimal success, it is crucial that these interventions start early in a child's life. For example, a toddler can be given options: which shirt to wear, what breakfast cereal to eat, or where to go for a walk. The focus on making appropriate decisions continues through the school years. Moreover, age-appropriate chores should be assigned for all children. Creativity may be needed to develop an appropriate chore for a child with mobility impairments, but the data suggest that this is critical to developing self-sufficiency (Sawin et al., 1999).

The finding by Brei et al., (2003) that parents were distressed by the teen's neuropsychological or learning deficits and needed skill building mirrors what participants are describing in this qualitative study. Parents were challenged and concerned over the lack of interface between rehabilitation professionals and school staff. The role of a neuropsychologist in collaborating with other rehabilitation team members may not be emphasized enough in many SB settings. After a clinical neuropsychological examination, the neuropsychologist should write recommendations addressed specifically to the school staff and then work with the school and parents to plan appropriate interventions that are tailored to the adolescent's specific cognitive deficiencies. Parents and caregivers should be involved in this intervention plan so as to follow up at home with cognitive skill building, providing motivational support, and guiding homework assignments. Rehabilitation professionals should provide specific suggestions to families for optimizing development of these skills in the home setting (Tanguay, 2001).

Promoting an adolescent-focused approach for parents of youths with SB is also a key role for rehabilitation team members. It is important for families to serve as a safety net for youths who are learning new self-management skills, because it can be overwhelming for young adolescents striving to assume total responsibility for managing their condition. Blum et al. (1991) suggest that the transition process, initiated in childhood, progresses into adolescence with the youth assuming responsibilities commensurate with her or his developmental capacities (also see developmentally based skills checklist, Sawin et al., 1999). Data from studies of other chronic conditions indicate optimal health outcomes are realized when parents turn over the responsibility for care of a condition to the adolescent gradually and in a supported environment. While the sample in this study was one of youths of normal intelligence and functioning at grade level, similar approaches—modified for level of cognitive ability—should yield optimal outcomes in youths with delayed cognition.

To fully and successfully achieve transitioning responsibilities, parents need concrete suggestions. The "drivers-license model" is a useful analogy for helping parents prepare their adolescents for self-care. While driving with a learner's permit, adolescents' new driving skills are closely monitored by parents. Youths need to practice new driving skills in multiple situations. Even when the license is obtained, parents may remain closely involved. They may limit the number of riders, the route, the time spent driving, or discuss how to drive in unfamiliar settings or how to get help in unforeseen occurrences. Parents often reassess the driver's skill, and if needed, arrange for additional training. The adolescent's driving skill continues to grow under supervision until he or she can drive independently, first on familiar roads and later on unfamiliar routes.

A similar approach may be used to foster independence in adolescents with SB through money management lessons, participation in household chores, and assumption of responsibilities, including taking medications, ordering supplies, and making appointments. A new instrument, The Adolescent Self-Management and Independence Scale (AMIS) (Sawin, Buran, Brei, & Fastenau, 2002b; Sawin et al., 2003) can be used by either the parent or the adolescent to assess whether these important skills have been achieved.

Study limitations

Although our study provides useful new insights into the experience of parenting an adolescent with SB, its methodological limitations must be noted. This sample included an unusually large percentage of married participants (90%). If marital status gave families in this study a more stable and more readily available support system, it may have influenced the family story of daily management, family rewards and challenges, the perceived effect on the social life of the family of having a teen with SB, and the experience of raising that teenager with SB. The picture this study painted therefore may not reflect the experience of single parents. For example, in a mixed method descriptive study of 10 mothers of children ages 5–11 years with SB, single mothers reported more negative experiences in both qualitative and quantitative data than did married mothers (Loebig, 1990). There was a significant difference in the quantitative data on the social relations subscale of the Impact on Family Scale, with single mothers reporting a greater effect than married mothers. Further, single mothers indicated that being a single mother was a more significant stressor than was parenting a child with SB.

Seventy-four percent of the 19 mothers with a child with SB in Havermans and Iser's (1991) study were married. Interestingly, four of the five divorced participants indicated that their child was the main reason for the divorce. This may suggest that single-parent families may have experiences different from those of married parents.

Contrasting data were reported by Holmbeck et al. (2002), who conducted a comparison study of preadolescents with SB and matched controls. Even with the large percentage of married parents in their study (81%), they found differences between SB and comparison samples that included more parental overprotection in both the questionnaire and observational measures and a larger effect of overprotectiveness on decision-making autonomy and parental willingness to grant autonomy. Clearly, there was some effect of raising a child with SB regardless of marital status.

It is possible that our study's sample may have been biased by the marital status of the participants. Perhaps single parents are too overwhelmed by daily life to participate in research studies. Future research should make greater efforts to attract single mothers and fathers to ensure that their views are represented. Study incentives such as childcare, transportation, and meals provided during the interviews may be especially useful in gaining access to this population.

Becoming comfortable with one's body and developing a sexual identity are essential developmental tasks for adolescents. Although the questions asked of parents did not directly address sexuality, it is

surprising that sexuality issues and concerns were not prominent in the parent data. Data from adolescents reveal their dissatisfaction with the content and extent of sexuality information available to them, especially about the impact of SB on sexuality. In addition, these adolescents worry about whether they can have a child and if that child will be healthy (Sawin, Buran, Brei, & Fastenau, 2002a). It would be important to address sexuality directly in further studies of parenting an adolescent with SB.

Another demographic limitation of this study is that it was composed largely of Caucasian families. Efforts to obtain a more diversified sample, including use of interpreters, should be made in future studies. Capturing the experiences of diverse populations is particularly important, given the increased incidence of SB in Hispanic families (CDC, 2002).

In conclusion, rehabilitation team members have an important role in families' efforts to maximize existing strengths while minimizing threats to their coping strategies. Understanding the parent's experience is critical in developing and implementing effective interventions. The rehabilitation professional is in a unique position to help family members maintain a viable functioning level during the period of adolescent transitioning (Atkin & Ahmad 2000; Bergman, Lewiston, & West, 1979; Brown et al., 1995), thus facilitating the adolescent's optimal growth. In this study, parents expressed a need for an increased partnership with heathcare providers and greater collaboration among all professionals who provide services to youth with SB and their families. Clearly, rehabilitation team members can provide leadership in meeting both of these needs, thus supporting parents in their efforts to successfully transition adolescents with SB into competent, independent adults.

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Continuing education articles discuss current trends and issues affecting rehabilitation nursing. This continuing education offering (code number RNC-219) will provide 1 contact hour to those who read this article and complete the application form on page 214. This independent study offering is appropriate for all rehabilitation nurses. By reading this article, the learner will achieve the following objectives:

1. Describe the overall experience reported by parents of adolescents with SB in this study.
2. Discuss what impact the parent's approach to the "dance of individuation" has on nursing practice.
3. Identify age-related priorities (toddler/preschool/school/school age) for optimizing independence in children with spina bifida.