

Risk and Protective Influences in the Lives of Siblings of Youths with Spina Bifida

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The impact of childhood chronic health conditions like spina bifida (SB) is a shared family experience. However, the lived experience of siblings is not well known. One hundred and fifty-five brothers and sisters of a child with SB responded to an open-ended question included in an anonymous self-administered mail questionnaire designed to enhance awareness of how adolescent siblings experience this chronic condition. Content analysis performed by interdisciplinary authors identified four domains—Rewards and Consequences of Spina Bifida, Journey Toward Acceptance of Spina Bifida, Emotional Climate of Siblings, and Qualities of the Social Environment—that depict emotional complexity in response to the diverse risk and protective influences present in the lives of siblings. By bolstering the siblings' strengths and resources found in their adaptive coping mechanisms, spirituality, cohesive family ties, and supportive peer friendships, social workers and other health care professionals may help them to successfully navigate the intense and confusing emotions that may naturally spring from the challenges and opportunities associated with SB.

KEY WORDS: *chronic health condition; family-centered care; risk and resilience; siblings; spina bifida*

With advances in health care and rehabilitative technology enabling youths with spina bifida to live longer and in the context of their families (Bowman, McLone, Grant, Tomita, & Ito, 2001), potential stressors, such as caregiving demands, financial concerns, and health worries, are truly a shared family experience. *Spina bifida* (SB), a congenital spinal cord injury, results in a range of complications depending on the level of damage to the spinal cord. Almost all children with SB have neurosurgery in the first days of life to close the protrusion of spinal cord contents most often located at the thoracic level of the spine or lower (Hunt, 1999). In addition, the majority will have surgery for hydrocephalus in the early days of life. The ventriculoperitoneal shunt (from the ventricles in the brain to the abdomen) inserted to treat hydrocephalus can function well for years and need few surgical revisions or may have to be changed multiple times because of infection or malfunction (Heinsbergen, Rotteveel, Roeleveld, & Grotenhuis, 2002).

Although the severity of medical problems varies, most youths with SB have altered mobility that results in their use of crutches, braces, or a wheel chair; altered innervations of body organs that result

in lack of control of bladder and bowel or a decrease of gastrointestinal motility that can cause problems such as chronic constipation; changes in the musculoskeletal system, often requiring foot, tendon, scoliosis, or tethered cord surgery; absent or decreased sensation below their SB lesion; latex allergy; and neuropsychological deficits (Bowman et al., 2001; Mitchell et al., 2004). These youths typically have the capacity to be independent in dressing, grooming, and other self-care activities, though they may be slower to develop these skills, especially if they live in homes that are not accessible. Furthermore, although most youths with SB will not be able to control their bladder and bowels voluntarily, they and their families can perform bladder and bowel programs to achieve continence (Borzyskowski, Cox, Edwards, & Owen, 2004; Krogh, Lie, Bilenberg, & Laurberg, 2003).

The complex medical, social, emotional, and financial challenges associated with SB may heighten vulnerability to poor psychosocial functioning in both the affected child (Appleton et al., 1997) and the surrounding family members (Holmbeck et al., 1997). There is a paucity of research on sibling adjustment, though some data support an elevated risk of behavior difficulties (Tew & Laurence, 1973).

The purpose of this study is to raise awareness about the risk and protective influences present in the lives of siblings of youths with SB so that resources may be mobilized to decrease vulnerability and bolster resilience.

LITERATURE REVIEW

Two studies have generated an initial picture of the complex array of stressors and growth opportunities spawned by the experience of living with a brother or sister with SB. In the earliest work, Pinyerd (1983) interviewed 12 siblings, ranging in age from 6 to 12 years, about their daily life experiences. Although their stories generally depicted acceptance of SB in their lives, the siblings acknowledged hardships found in missed or disrupted social life opportunities, worry about hospitalizations or injury to their brothers and sisters, and uneven parental attention. Kiburz (1994) similarly found an overall healthy picture of sibling life in her interviews with 15 school-age siblings, but their stories revealed jealousy around differential attention, health concerns, and sadness related to reduced opportunities to engage in physical activities with their brothers and sisters.

These studies in SB provide a contrast to research on sibling life across other populations that seem to depict a more pronounced, negative influence of the chronic health condition (CHC) in their lives. For example, siblings of youths with diabetes reported "constant feelings of sadness, worry, and emotional distress over their sibling's illness" (Hollidge, 2001, p. 20). Themes of embarrassment, jealousy, guilt, and conflict about pursuing one's own needs have also consistently surfaced (Bendor, 1990; Hollidge, 2001; Lehna, 1998). Awkward responses to the family in public settings (Cate & Loots, 2000), teasing and bullying of their siblings with CHC (Adams, Peveler, Stein, & Dunger, 1991), and restricted opportunities for peer socialization (Bendor, 1990) have presented additional challenges for some.

Offering a balance to these psychosocial difficulties are growth opportunities linked to the experience of having a sibling with a CHC. Specifically, siblings have identified increased empathy for people with chronic conditions (Cate & Loots, 2000), greater patience and sensitivity (Tritt & Esses, 1988), enhanced maturity (Murray, 1998), and the development of leadership skills (Kiburz, 1994) as personal benefits. Positive influences of the CHC on social relationships are also evident in the literature. Some siblings have commented that the shared experience

strengthened family bonds (Adams et al., 1991). In addition, there is evidence that sibling interactions when one member has a CHC are more positive than those relationships between pairs without a CHC (Cuskelly & Gunn, 2003). However, even when siblings described a strong attachment to their brothers and sisters, they acknowledged that the CHC placed challenges on this relationship in terms of communication difficulties (Cate & Loots, 2000) and restricted play activities (Kiburz, 1994).

In summary, the influence of a CHC in the lives of siblings is not uniform. Instead, there is diversity in how siblings perceive its impact on themselves and on their relationships. Although these accounts of sibling life offer an important initial glimpse into the experiences of some, siblings of youths with SB are an understudied population, with the adolescent voice particularly limited. Because the influence of SB on the family and the attitudes and behaviors of the siblings may all change over time, learning about the adolescent sibling's perspective of the risk and protective influences in their lives is essential. Also, the face-to-face interview format used in the previous SB research may have restricted sibling responses in terms of sharing "feelings they deemed negative or socially inappropriate" (Kiburz, 1994, p. 229). An anonymous data collection process might therefore yield a contrasting window into the inner world of sibling life. The present study addresses these apparent gaps in the literature by offering knowledge about the influence of SB in the lives of adolescent siblings.

CONCEPTUAL FRAMEWORK: RISK AND RESILIENCE

Grounded in ecological and developmental theories, the risk and resilience perspective of human behavior acknowledges multilevel forces on the developmental trajectories of youths (Fraser, Kirby, & Smokowski, 2004; Greene, 2002). Both *risk factors* that "increase the probability of onset, digression to a more serious state, or maintenance of a problem condition" and *protective factors* that modify risk are observed at the individual, family, and environmental levels (Fraser et al., 2004, p. 14). It recognizes that these forces exert different kinds of influence over the course of the child's life (Bellin & Kovacs, 2006) and captures how it is possible for children who are exposed to similar adverse circumstances to have divergent psychosocial outcomes (Greene, 2002). This integrated framework guided examination of

the siblings' stories for themes of the salient risk and protective factors operating in their daily lives.

METHOD

The data reported here come from a larger mixed-method investigation that explored correlates of adjustment in adolescent siblings of youths with SB (Bellin, 2006). The quantitative component of the study addressed the relationship of individual (attitude toward illness), family (family satisfaction, sibling warmth and conflict), and environmental factors (peer support) to psychological and behavioral adjustment. The open-ended section was designed to tap the insider's perspective regarding the day-to-day experiences of siblings. We were particularly interested in identifying any additional salient aspects of the sibling experience not included in the quantitative component of the study. Reported here are the findings from responses to one open-ended question about sibling life included in an anonymous self-administered mail questionnaire.

Sample

A convenience sampling strategy was used to recruit 254 families from the Spina Bifida Association (SBA) and three SB clinic sites over a 15-month period. To be eligible to participate, the adolescent had to meet the following criteria: be between ages 11 and 18 years; speak English; have no current major health condition (for example, life-threatening, progressive, or incapacitating condition such as cancer or juvenile diabetes); and resided in the same household as the brother or sister with SB who was at least six months old. Of the 224 eligible adolescents who completed the survey, 155 (69.2 percent) responded to the open-ended question. No significant differences were found between respondents and non-respondents on their psychological and behavioral adjustment or on key demographics such as gender, age, and race.

Procedure

The study was reviewed and approved by the Institutional Review Board of the associated university, the Professional Advisory Board of SBA, and the human subjects protections committees at the SB clinic sites. Interested families responded to flyers or newsletter advertisements circulated through the SBA and clinic sites. Mailed study packets included consent forms, the adolescent survey, a matched parent survey that collected family demographics

and SB clinical data, and a return postcard for the purpose of sending adolescent participants a \$15 gift card and entering participants into a \$100 gift card raffle (Bellin, 2006).

Data Collection and Data Analysis

Data were collected through one open-ended question designed to elicit information about the sibling's experiences of living with SB. Specifically, participants were asked to "describe any additional thoughts, feelings, opportunities, or challenges related to living with a brother or sister who has SB. Topics for consideration might include the benefits as well as the difficulties of having a sibling with SB in terms of friendships, activities, and family relationships."

The typical respondent wrote a half page of comments; however, a minority generated a single sentence or several pages of reflections. Comments were transcribed verbatim. Content analysis was performed on the data (Morse & Field, 1995). The inductive process, in which the analysis process systematically moved from the specific to the general (Padgett, 1998), began with the unitizing of raw data in which the smallest, stand-alone unit of data that held meaning was identified and isolated, whether it was a single word, phrase, sentence, or paragraph (Rodwell, 1998). The process continued with open coding of the data in the development of emerging domains and themes, and subthemes (Morse, 1991). To assess for representation of the thematic results across participants, each excerpt of raw data was tagged with information about developmental stage, gender, and birth order (older or younger than sibling with SB). Participants were grouped into an early adolescence (EA) (10 to 12 years), middle adolescence (MA) (13 to 15 years), or late adolescence period (LA) (16 to 18 years). Though saturation, or repetition and redundancy in the data (Padgett, 1998), was observed, data from all 155 participants who responded in the open-ended section were analyzed.

Our interdisciplinary research team used several techniques to enhance the rigor of the analysis. First, the authors with backgrounds in social work and nursing independently reviewed the transcripts to develop a preliminary coding scheme. Next, the coding scheme, developed through consensus decision, was applied to the set of transcripts, with decisions about the ongoing development and collapsing of domains, themes, and subthemes tracked in a

methodological journal (Sandelowski, 1993). The raw reactions, impressions, and concerns, as well as the identification of biases embedded in the research process, were bracketed in a reflexive journal (Wall, Glenn, Mitchinson, & Poole, 2004). These methodological and reflexive journals provided an "audit trail" for the work to be cross-checked (Lincoln & Guba, 1985). A blind reviewer with expertise in qualitative research and clinical practice in health care independently tracked the process of reaching the final domains, themes, and subthemes from the initial transcripts. The interdisciplinary triangulation further enhanced the rigor and depth of understanding of the results (Janesick, 1998).

RESULTS

Participants reported a mean age of 13.83 years ($SD = 2.26$) and had lived with a brother or sister with SB for an average of 9.96 years. Paralleling the demographics from the larger study (Bellin, 2006), a majority was female ($n = 88$, 56.8 percent), white ($n = 138$, 89 percent), older than the sibling with SB ($n = 110$, 71 percent), and resided in two-parent households ($n = 133$, 85.8 percent) with an annual income of \$46,000 or more ($N = 100$, 64.5 percent). There was a fairly equal distribution of participants across the developmental periods, though more fell in the MA ($n = 68$, 43.9 percent) than in the EA ($n = 50$, 32.3 percent) or LA period ($n = 37$, 23.9 percent). The majority of youths with SB had a shunt ($n = 132$, 85.2 percent), with an average of 2.5 revisions to the shunt ($SD = 6.35$). A lumbar-level lesion ($n = 62$, 42.8 percent) was most often reported. Last, nearly half of the parents considered the SB to be severe in nature ($n = 75$, 48.7 percent).

Analysis of responses in the open-ended section revealed the following four domains capturing the lived experience of siblings of youths with SB: domain 1: the Rewards and Consequences of SB; domain 2: the Journey Toward Acceptance of SB; domain 3: the Emotional Climate of Siblings; and domain 4: the Qualities of the Social Environment of Siblings. Each theme begins with a description emerging from the data, a synthesis of participants' data pertinent to the theme, and select exemplars.

Domain 1: The Rewards and Consequences of SB

The first domain taps into the vast and varied ways SB is present in the lives of the siblings. Four themes illuminating its diverse influences emerged: (1) im-

pact of spina bifida on daily life; (2) the omnipresence of spina bifida; (3) opportunities created by the experience of spina bifida; and (4) the development of unique knowledge and responsibilities.

Theme 1: Impact of SB on Daily Life. This theme reflects the sibling's attitude about the impact of SB on day-to-day life routines. Some considered their lives to be "different but not hard." One male sibling in middle adolescence shared, "living with someone with a physical disability doesn't have many disadvantages, and some decent advantages, so spina bifida probably isn't as bad of a handicap as one might think, if 'handicap' can even be applied, at least from my perspective." A second group of participants, typically those in early adolescence, acknowledged a more pronounced impact of SB but seemed to externalize its impact from their feelings about their sibling. One sibling, for example, acknowledged, "even though her hardships have limited me, I love her unconditionally through embarrassment, tiredness, challenges, and just plain hard moments." In contrast, a small group of siblings shared stories that reflected greater negativity and personal hardships, "Sometimes having a brother with spina bifida does not allow me to do certain things or have specific things...until I move out of the house and graduate from college, I will have trouble experiencing the things a normal child would."

Theme 2: The Omnipresence of SB. Another theme emerging in this domain relates to the pervasive nature of SB. It surfaced in a number of dimensions of sibling life, and especially in health, future, and financial concerns and restrictions on social life. These aspects of the SB experience were felt most by girls in early or middle adolescence. One commented, "Having a sister with spina bifida is hard because you always have to be careful of what she does and where she goes." The uncertainty of illness exacerbation and possibility of death also triggered alarm, "Sometimes I feel I will lose her. That makes me sad." Another shared, "He is sick a lot and that can be pretty scary. Sometimes you don't even know if he'll live." Concerns about the future care needs and capacity for independent living highlighted the chronicity component of SB. One sibling who was a twin raised the following questions, "How will spina bifida affect her adult years? Will she have to live with my parents? Will she be able to drive? These are things I worry about."

The financial cost of "medical stuff" associated with SB was another common indicator of its

pervasive nature. A girl in middle adolescence provided a particularly candid picture of how SB can shift financial priorities, "Another 'down' of having a brother with spina bifida is that he needs to have crutches, braces, a wheelchair, special bikes, surgeries, etc. These all cost extreme amounts of money, which could have been spent on other things... the house, toward the mortgage, or something." Finally, participants recalled how SB at times limited family and individual social life opportunities. One older female sibling in early adolescence lamented, "Sometimes you can't go out to some places that aren't handicap accessible... sometimes I have to stay home and watch her and not go out with my boyfriend or friends."

Theme 3: Opportunities Created by the Experience of SB. Helping to balance out perceived challenges were personal benefits generated by the SB experience. Siblings in the early adolescence period reflected more on the superficial rewards such as coveted parking spots, "one good thing about having a sister with spina bifida is that you get good parking spaces" and amusement park privileges, "we can get on rides quicker in some theme parks." In contrast, participants in the middle or late adolescence period tended to emphasize more intrinsic benefits of their experience found in unique social connections, "I have had the privilege of meeting and getting to know many amazing people" and personal growth, "Having a sister with spina bifida has helped me in a way because I feel I am more respectful of other people. I understand that people are different and I don't judge them." The experience of SB also shaped their worldview in terms of increased appreciation for their own abilities. One sibling, for example, learned to "not take for granted my health and most importantly, my legs." Another commented on her freedom of not having to worry about bowel and bladder problems, of not having "to 'remember' to go to the bathroom... I was blessed with a body that needs little care in comparison."

Theme 4: The Development of Unique Knowledge and Responsibilities. A final theme that emerged in this domain related to sibling knowledge and tasks specific to SB, as well as more general responsibilities in the home that, in their opinion, differentiated them from peers. One male in middle adolescence considered, "having a brother with spina bifida puts many responsibilities on me that my peers and classmates do not have." Other siblings wrote that

the additive responsibilities caused them to "mature faster." Involvement in caregiving also generated specialized knowledge related to SB. Their stories revealed familiarity with physical therapy stretching exercises, shunt protection, and surgeries common to SB, including back closure and shunt revisions. One female sibling shared, "When we're playing with her or holding her, we try to incorporate physical therapy methods, and when she was young, we had to be extra careful of her shunt area, back, and neck."

Domain 2: The Journey toward Acceptance of SB

This domain reflects the process in which siblings were engaged to adjust to and integrate SB into their lives. Five themes emerged: (1) coming to terms with SB; (2) questioning the fairness of SB; (3) more challenging early years; (4) perceiving the sibling as "normal"; and (5) the role of spirituality in the meaning-making process.

Theme 1: Coming to Terms with SB. The development of coping mechanisms to meet the challenges that "are never going to change" emerged as a central part of this journey. The capacity to acknowledge hardships and to embrace the positive aspects of their experiences was an important balance for some siblings. One male participant in early adolescence emphasized the value in "finding the good side of things." Other stories were less positive but similarly stressed the need to develop individual and family strategies to adjust and adapt to the ongoing presence of SB in their lives. A girl in late adolescence advised, "No one is exempt from this burden, and it's something each family must learn to deal with."

Theme 2: Questioning the Fairness of SB. Another component of the journey toward acceptance for some participants was a search for understanding why their sibling had SB and not themselves or others. An older girl asked, "Why this little girl? She didn't do anything to deserve this kind of life." Survivor guilt, or guilt stemming from the status of being the "healthy" sibling, was noted in some stories. One participant wrestled with this experience in the following way, "She's younger than I am and has a lot of health problems. Sometimes I wonder why she has so many and I don't have any."

Theme 3: More Challenging Early Years. Their stories also shed light on the trajectory of adjusting and adapting to SB. Participants acknowledged greater difficulty in the early years, "I used to say

things like I would rather have a normal sister and call her names and say I wish you weren't my sister, but now I love her for who she is." The passage of time has perhaps created room for them to make sense of and accept SB in their lives. For example, one girl, reflecting on her life, said, "When I was younger, I used to be bummed about having a brother with spina bifida, but now that I'm older, I realize it's not his fault or anyone else's."

Theme 4: Perception of Sibling with SB as "Normal." Despite the complex care responsibilities and physical limitations associated with SB, participants wrote about the importance of viewing and treating their siblings no differently than they would if the sibling did not have SB. This "normalizing" piece emerged as another step in the journey of accepting and integrating SB into their lives. One participant shared, "I don't see her as a sick little girl with problems when I look at her. I see a loving, caring, funny girl. I don't judge her at all. I take her for who she is."

Theme 5: The Role of Spirituality in Achieving Acceptance. A final theme emerging in some stories was how their spirituality guided them to a place of understanding. One participant shared the following reflection, "We are all part of God's plan and if it is for my little sister to have spina bifida, then it must be for a reason." Their beliefs and trust in a higher power gave them patience "to let the special plan for the sibling work itself out" as described by an older sibling. It also provided comfort during periods of medical uncertainty; "it pains me when she is in the hospital, yes, but I know God loves her and is going to take care of her."

Domain 3: The Emotional Climate of Siblings

Five themes reflecting the complexity of the siblings' emotional state emerged in the third domain: (1) overall positive perception of self and life experiences; (2) conflicted, ambivalent feelings about having a sibling with SB; (3) protective and empathic concerns for sibling with SB; (4) struggles with public response; and (5) feeling undervalued and overlooked.

Theme 1: Overall Positive Perception of Self and Life Experiences. Though acknowledging "some flaws," participants generally described themselves and their life experiences in favorable terms. Only a minority seemed to be struggling. However, these stories did not point to the experience of living with

a sibling who has SB as the root of their difficulties. For example, a female sibling in middle adolescence summed up her life in the following way, "One bad incident after another. That's my life. It seems that my life will never be happy. I don't think... I am always depressed and whenever (rarely) I'm happy, I get depressed immediately."

Theme 2: Conflicted, Ambivalent Feelings about Having a Sibling with SB. Particularly striking were reflections that shed light on the emotional complexity of their feelings about their brothers and sisters with SB. Their stories suggest that the experience of having a sibling with SB is one that "stirs up many emotions." The "emotional roller coaster" experience of SB came through in the words of a younger participant in early adolescence who disclosed, "I am sad when my sister is in the hospital. I get angry when we have to go to the doctor. I love my sister." Undertones of guilt, deprivation, jealousy, and embarrassment also surfaced in their stories, especially among female participants who were in early or middle adolescence. Some experienced shame in complaining about "small stuff when I should be stronger because my sister has been through so much." Envy was often linked to perceived differences in attention and uneven distribution of family resources, as indicated by an older sibling, "Our family has devoted a lot of time and money on her. It can really make me jealous." Finally, some participants suggested that having a sibling with SB is "hard and embarrassing." Another commented that the embarrassment left her wanting to "curl up in a hole and disappear."

Theme 3: Protective and Empathic Concerns for Sibling with SB. Even when struggling with negative, and at times confusing, emotions about having a brother or sister with SB, participants consistently expressed strong protective concerns and empathy for the adversity encountered by their siblings. Their stories suggest that witnessing teasing and bullying was particularly difficult. One sibling proposed to challenge perpetrators by having them consider, "How would you feel if somebody came up to you and just started pushing you around and you were helpless to do anything about it." Some participants appeared to move beyond empathy and to a place of internalizing their siblings' challenges. For example, a male participant declared,

I think it is wrong that people think differently of her because of her disability. It makes me

very angry when people make fun of her. I mean angry enough that when they make fun of her if they are about my age and a boy I will beat them up."

Another admitted, "It tears me up when he is rejected or made fun of." Others had difficulty accepting their siblings' life-long physical limitations and delayed or missed developmental milestones, "Sometimes it breaks my heart when she asks me questions like 'What's it feel like to walk?' And it just hurts to know that she may never get to walk in her life." Another similarly shared, "The hardest thing about having a sibling with spina bifida is watching her struggle with everything that comes easily to most people."

Theme 4: Struggles with Public Response. We also learn from participants' reflections that a perception of being judged by strangers weighed heavily on their minds. Because many youths with SB use a wheelchair or leg braces to ambulate, these physical differences may set them and their families apart in public settings. The experience of being stared at and "having your every move scrutinized because of your sister" struck an emotional chord, particularly with female siblings who were in middle or late adolescence. One sibling shared, "When we would go to the store, I would often catch people looking at us and them staring. I would give them a look and they would turn away. It made me feel sad."

Theme 5: Feeling Undervalued and Overlooked. An undercurrent of frustration about a general lack of awareness of how SB affects siblings was also evident in their stories. This theme increases our appreciation of the importance in acknowledging and valuing the sibling experience. The raw emotions of one sibling's experience came through in the following story,

My family went on a trip to Disneyland once, all expenses paid, with a group of other families, all of which had a chronically ill child. It was sponsored by a TV station. Their goal was to give us one weekend with "normal" lives. I watched that TV station one morning and someone called in, saying to leave the siblings at home so more sick children can go. I cried. People seem to think that the siblings of special needs kids are void of emotion. That trip was amazing for one reason: People cared about making my life normal—not just hers.

Difficulties in accessing resources for siblings further exacerbated feelings of isolation, "I have looked for a type of support group—anything for siblings of special needs kids. There is nothing. Most people don't understand...something like a support group would really help, but usually I end up keeping most of it to myself."

Domain 4: Qualities of the Social Environment of Siblings

Captured in this final domain are the qualities of siblings' social interactions in the family and peer contexts. Five themes emerged: (1) cohesive family relations, (2) experiences of differential treatment and expectations, (3) warmth and closeness in the sibling relationship, (4) influence of SB on the sibling relationship, and (5) the nature of peer relations.

Theme 1: Cohesive Family Relations. The participants' stories reflected a positive, united family environment. The experience of SB seems to have strengthened family ties, with members drawing closer and rallying to support each other, especially during periods of health crisis and uncertainty. The siblings' stories highlight family resilience in the face of these challenges, "Times have gotten hard in our family with the countless surgeries, but I am proud of my entire family for being so strong and supportive of each other." In fact, some considered the shared SB experience to generate family bonds that seemed "greater than those of others."

Theme 2: Experiences of Differential Treatment and Expectations. Greater diversity was found in the siblings' perception of discipline and distribution of responsibilities in the home environment. A subset of participants denied any "special treatment in our house" and instead depicted the family environment as one in which "everyone, including my sister with spina bifida, is treated the same, disciplined, rewarded, etc. the same." Other participants, often female siblings in early or middle adolescence, described different levels of expectations, chores, and attention in the family environment. However, these discrepancies were generally accepted as a part of their life, "My parents are harder on me, and easier on her. It is often unfair, but I cope."

Theme 3: Warmth and Closeness in the Sibling Relationship. Despite the perceived inequalities in the family environment, the majority of participants used warm, positive terms to describe the sibling relationship. They expressed great admiration for their brothers and sisters, "My sister is an amazing

We learn from participants' stories that risk experiences are also encountered in the broader social spheres of their lives.

person. I don't think I could handle all the doctor appointments and medicines I would have to take," and commonly regarded them as friends. The extent of affection was unmistakable in the following statement from a sibling in early adolescence: "I love my sister more than I like chocolate and I love chocolate. She is the best thing in my life." An older boy considered the experience of SB to have created a particularly strong bond, "Her having spina bifida has somehow given me a special love for her." Though sibling conflict and estrangement surfaced in some stories, the discord appeared to fall along a continuum of typical sibling interactions. For example, one girl in middle adolescence shared the following: "My sister and I don't get along too badly. We share lots of things but not much of thoughts and feelings."

Theme 4: Influence of SB on the Sibling Relationship. Participants' reflections generally minimized the impact of SB on the sibling relationship. In fact, this relationship was commonly depicted as no different from that of peers without a CHC. An older female emphasized, "Spina bifida is not a factor for me when it comes to me and my relationship with my brother. It's just there is nothing special." However, a sense of loss about the inability to share regular childhood activities, especially those that involved a physical component, surfaced in the stories of participants in early or middle adolescence. A younger boy expressed this loss in the following way, "I do not have the freedom to go out and play within our neighborhood with a companion. I look at other children with brothers or sisters who are playing outside, riding bikes, or swimming, and I say to myself, 'What would it be like if my brother could walk?'"

Theme 5: The Nature of Peer Relations. Relationships with peers emerged as a final theme of sibling life in participants' reflections. Here they denied a negative effect of SB on the ability to establish or maintain friendships. One sibling shared, "It's not really difficult for me to make friends or have them over because they always think that he's the cutest thing." They described supportive peer relationships and seemed to develop a social circle

comprised of friends with heightened maturity. An older male sibling considered, "My friends are nice boys and enjoy her company." The inclusive efforts of their friends were acknowledged and appreciated by the siblings, "I have very understanding friends. My brother likes to pretend all my friends are his girlfriends. They go along with it and make pretend dates with him. I am very happy that I have the friends that I do."

DISCUSSION

The siblings' candor and generosity in sharing personal reflections shed light on key risk and protective influences surfacing in several dimensions of their lives. These stories reflect greater risk for psychosocial difficulty in the early years of adjustment to SB, with stories of deprivation, loss, and unmet needs more common. A major contribution of their participation in this study is our enhanced appreciation of the intense and, for some, conflicted feelings siblings hold about having a brother or sister with SB, particularly for those in early adolescence. Mixed feelings, including affection, sadness, anger, embarrassment, and protection, may cause confusion for some. Other stories suggest there may be reluctance to share the full depth of their emotions, that some tend to repress their reactions to hardships in light of the perceived greater difficulties experienced by their brothers and sisters. Findings of a restricted expression of emotions parallel the work of Hollidge (2001), who found that siblings tended to internalize their difficulties. This internalization process may heighten vulnerability to negative psychosocial outcomes for some.

We learn from participants' stories that risk experiences are also encountered in the broader social spheres of their lives. Witnessing the teasing and bullying of their siblings with SB was a particularly devastating experience for some. Though this part of sibling life was absent in the previous studies in SB, these data indicate a deep emotional effect—anger, sadness, and frustration in response to abuse were palpable in their words. Participants' stories reflect a similar emotional pain brought about by the family's experience of being stigmatized in public settings. It is interesting that although participants generally denied a direct negative effect of SB on their own lives, their stories suggest a heightened risk for emotional vulnerability linked to observations of their siblings' experiences with marginalization, discrimination, teasing, and bullying.

Another risk factor found in the social environment of siblings is related to perceived challenges in identifying and linking up with formal and informal resources. Stories shared in this research suggest that resources to address and support sibling needs are limited and difficult to access. The opportunity to participate in this research appeared to be a cathartic exercise for some, as indicated by unsolicited comments about how meaningful it was to have an outlet to communicate their feelings. One sibling wrote, "Thank you for giving me a chance to express my feelings," and another expressed, "thank you for listening to what I have to say." These voices suggest, however, that a more consistent and accessible avenue to share and process feelings is needed. Given the current emphasis on family-centered care across disciplines, the recommendation offered by one sibling for us to learn about "what it is like to be a sibling of someone with special needs" and, ultimately, to address unmet needs, seems paramount.

A range of inherent personal resources and protective influences found in the family and broader social setting might mitigate the effects of the risk experiences that siblings encounter and protect them from emotional distress or negative psychosocial outcomes. For example, we learn from participants' stories that the development of coping strategies that enable them to acknowledge hardships and to embrace unique opportunities related with SB is an important step in their journey of coming to terms with the pervasive presence of the condition in their lives. A protective influence in "finding the good side of things" is supported by research linking a positive attitude about the effect of SB and healthy psychological functioning in siblings (Taylor, Fuggle, & Charman, 2001). The development of specialized knowledge related to SB emerged as another key piece in achieving acceptance. Similar to previous sibling research in SB (Kiburz, 1994), participants reflected on surgical techniques (for example, shunt placement) and bladder management programs. It is possible that learning about SB and taking part in caregiving activities are empowering experiences that, in turn, protect against fear, anxiety, and uncertainty. Indeed, a lack of knowledge about the CHC has been proposed as an underlying cause of sibling maladjustment (Williams et al., 1997).

A particularly intriguing finding was the role spirituality played in helping some siblings successfully integrate SB into their lives. Their belief in a higher power facilitated the meaning-making

process and provided comfort during times of uncertainty or crisis. However, the influence of spirituality has generally been overlooked in studies of sibling adjustment. Further confounding the issue is the apparent lack of prominence of spirituality in the lives of adolescents with SB (Bellin, Sawin, Roux, Buran, & Brei, 2007) and their parents (Sawin et al., 2003). Consequently, more research is indicated to better understand how it may be tapped into as a protective mechanism.

Several resources found in the siblings' social environments may also provide a protective buffer against negative psychosocial outcomes in the face of hardships. Consistent with reports from adolescents with SB (Bellin et al., 2007) and their parents (Sawin et al., 2003), the shared SB experience seems to have strengthened family bonds. From a family systems perspective, we appreciate that the health of the surrounding family environment and sibling adjustment are often interrelated and mutually reinforcing. A protective influence of the family milieu on sibling adjustment is substantiated by our quantitative work that found satisfaction with family interactions to be associated with positive adjustment outcomes (Bellin, 2006). In these data, the sibling relationship seemed to be a particularly special sanctuary. Their stories consistently revealed great affection and admiration for their brothers and sisters with SB. However, whereas this relationship was generally perceived as no different from that of their peers, some participants seemed to mourn the loss of a typically developing sibling to share regular childhood activities. The physical limitations have previously been described as one of the hardest aspects of having a sibling with SB (Pinyerd, 1983).

Strong, supportive peer relations form another layer of protection in the lives of these participants. Participants seemed to have aligned themselves with companions who welcome and embrace opportunities to include the sibling with SB in social activities. Despite the multiple, time-intensive ways SB may be present in the lives of siblings, including daily caregiving responsibilities, frequent health care appointments, surgeries, and hospitalizations, siblings have carved out time to develop and maintain close peer relations.

In summary, these data offer new insights into the range of risk and protective influences present in the lives of siblings of youths with SB, a story shared from the perspective of siblings themselves. A final contribution of this research was to delin-

ate salient concepts of sibling life previously not included in the larger program of research testing a model of sibling adjustment (Bellin, 2006). Specifically, emerging from the data were sibling empathy, effect of teasing and bullying, development of unique SB knowledge, identification of siblings in early adolescence as potentially at risk of difficulties, and the role of spirituality in adjustment.

IMPLICATIONS FOR PRACTICE

A family-centered assessment should, by definition, include questions about the sibling experience. Time spent addressing sibling needs might help prevent the onset of more profound psychosocial difficulties. These data suggest it is important to screen for those siblings who are socially isolated, report a lack of support in their home environment, are confused or uncertain about their sibling's condition, or hold a negative appraisal of the effect of SB on their lives. Also, several themes emerging in this research suggest that the siblings may be at risk of "getting lost" or perhaps being treated differently by parents and others. One practice implication to help minimize this risk is to remind parents of the importance of individual time with each child. Although this is true in all families, it may be especially important in families with a child with a chronic condition like SB who may require additional parental time and attention related to medical appointments, hospitalizations, and daily care activities.

Social work practitioners may address these multi-level risk factors through group work. Interacting with peers who similarly have a sibling with a CHC has yielded positive effects on sibling adjustment (Naylor & Prescott, 2004). A group setting may provide siblings with a safe space to express and process their range of emotions and experiences, it is hoped without fear of judgment. By sharing difficult experiences in a protected group environment, siblings may comfort each other, provide suggestions for change, and perhaps become empowered by the process.

METHODOLOGICAL CONSIDERATIONS AND FUTURE DIRECTIONS

The lack of demographic diversity in this study emerges as an important methodological consideration, as the risk and protective influences surfacing in the lives of these siblings may not reflect those from more diverse ethnic or racial backgrounds and family environments. Other limitations relate to the

nature of data collection. The data were potentially restricted by the cognitive ability of participants to express themselves in writing. In addition, the lack of opportunity for follow-up or probing limits our confidence in the themes that emerged in analysis and the patterns of these themes across developmental stages, gender, and birth order.

The singular lens on sibling life is also noteworthy. To fully appreciate the sibling experience, it would be important to gain a better understanding of the reciprocal relationship between the siblings. Our team is particularly interested in interviewing both members of the sibling dyad to enrich our understanding of interaction in this special relationship. We also hope that future investigations explore in more depth the experience of teasing and bullying with siblings across developmental periods. This aspect of sibling life is understudied but commands attention given the immediate and long-term ramifications for both children with SB and their siblings. Ultimately, the domains and themes emerging in these data provide a foundation on which future exploration of the lived experience of siblings may be based.

CONCLUSION

This analysis may enhance family-centered social work services by delineating key aspects of the adolescent sibling's experience of living with SB. Data reveal generally resilient siblings who, overall, have successfully integrated the challenges and opportunities generated by the experience of SB. The risk experiences described in their stories no doubt present credible threats to their psychosocial health, but by helping siblings draw out and build on their inherent strengths and protective resources found in the broader social environment, we may better support their resilience. **HSW**

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