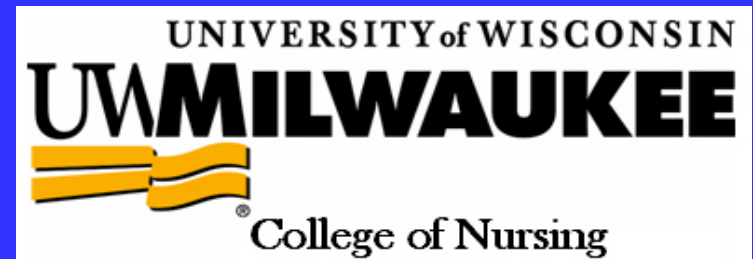


Family-Centered Perspective in Spina Bifida: The Sibling Experience



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What do we know about siblings?

- What are their strengths?
- What are their areas of difficulty?
- If you could ask your child to describe the influence of spina bifida in his/her life, what would he/she say?

Purpose of This Session

- 1) To share findings from a national study of adolescent siblings
- 2) To support a family perspective in spina bifida research
- 3) To learn about how the siblings are doing in several aspects of their adjustment
- 4) To learn about the factors associated with siblings doing well in their adjustment
- 5) To learn about the experience of living with spina bifida from the viewpoint of the sibling

Framework for this Study

- ❖ Family Systems Perspective
- ❖ Family-Centered Care
- ❖ Risk and Resilience Perspective of Child Development

Family Systems Perspective

- ❖ Shows how the whole family experiences the condition
- ❖ Common things we've learned about the influence of childhood chronic conditions on the family:
 - ❖ Redistribution of family resources
 - ❖ Shifting of family timetables
 - ❖ Potential minimizing of individual and family developmental needs
 - ❖ May cause unique difficulties for the siblings

What Does Family-Centered Care Look Like?

- ❖ Families and Health Care Professionals are equal partners in designing the care for children
- ❖ Services focus on the needs and strengths described by families
- ❖ Family diversity is acknowledged and respects
- ❖ Assessment and intervention services target *whole* family

Where are the Siblings in Family-Centered Care?

- ❖ “There is probably no population for whom the concept of family-centered care is more relevant than children with chronic illnesses and disabilities” (Patterson & Hovey, 2000).
- ❖ In a study exploring adjustment of siblings of youth with diabetes, no participant could recall having a conversation about their needs with a healthcare professional or teacher

Prior Research: Assumption of Sibling Difficulties

- ❖ Crisis/stress perspective has dominated research and assumes that living with a child with a chronic health condition will lead to problems for surrounding family members
- ❖ Rethinking the sibling experience: Moving from Pathology To Co-Existing Strengths & Needs

Present Research: Risk and Resilience Perspective of Human Behavior

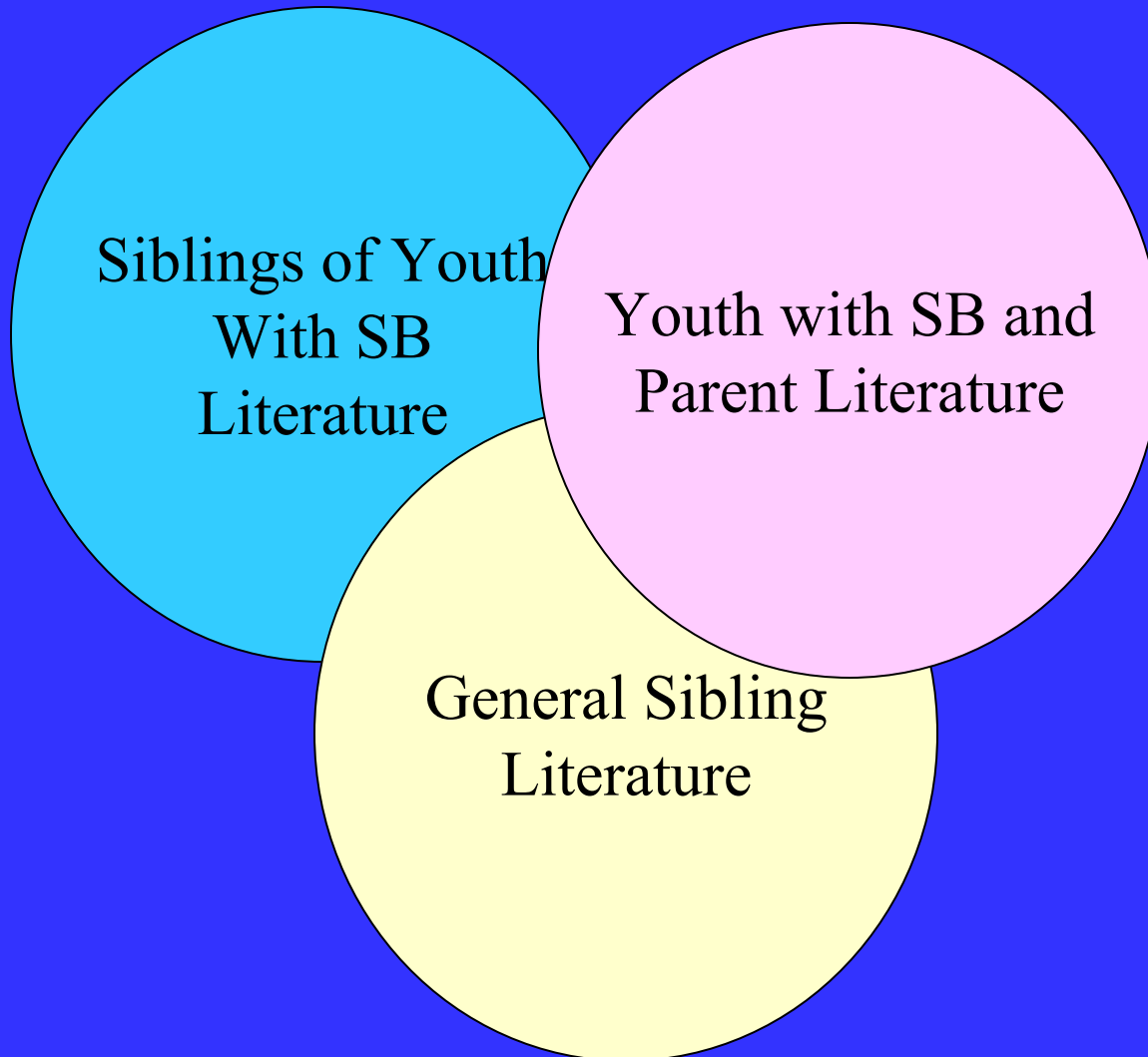
- ❖ There is a large range of findings on how siblings are doing. So...
- ❖ We need to learn why some siblings have problems but others do not

How are Siblings Doing?

We investigated Sibling:

- ❖ Self-Concept (How the siblings think about themselves)
- ❖ Prosocial Behavior (Ability and Interest in Helping Others)
- ❖ Behavior Problems (Acting Out, Peer Problems, Depression)

Reviewed Literature



Potential Factors Influencing Sibling Adjustment

We looked at:

Spina Bifida Factors

- Parent perception of severity
- Parent perception of learning disability?
- Presence or absence of hydrocephalus and number of shunt revisions;
- Location of spina bifida lesion

Potential Factors Influencing Sibling Adjustment

Child and Family Factors

- Attitude Towards Spina Bifida
- Satisfaction with Family
- Conflict in Sibling Relationship
- Warmth in Sibling Relationship
- Classmate Support
- Close friend Support

Other Important Factors

- Sibling Gender
- Sibling Birth Order (Older or Younger)

Major Research Questions

What are the factors related to sibling:

- 1) Self-concept
- 2) Prosocial behavior
- 3) Behavior problems

Qualitative Component of Study

Explored the unique experiences of living with spina bifida from the *perspective of the sibling*

Areas the siblings were encouraged to reflect upon:

- ❖ *What are the challenges?*
- ❖ *What are the rewards?*
- ❖ *What are your family relationships like?*
- ❖ *What are your peer relationships like?*

How We Conducted the Study

- ❖ Recruited families over a 15-month period
- ❖ Used self-report surveys
- ❖ Participants were compensated for their time:
 - Each sibling received: \$15 gift card
 - Sibling Raffle: \$100 gift card
 - Parent Raffle: \$100 gift card

Where We Recruited our Families

- ❖ National SBAA Conferences
- ❖ National SBAA Newsletter and Listserv emails
- ❖ State Chapters of SBAA
 - ❖ Families from 33 States participated (including Alaska!)
- ❖ 3 Military Spina Bifida Clinics

Total # Participating Families = 224

Characteristics of the Participating Adolescents

Average Sibling Age: 13.81 years

Average # Years Living with Sibling who has SB: 9.78 years

| Variable | Category | % |
|--------------------------|------------------|------|
| Sex | Female | 54.5 |
| | Male | 45.5 |
| Ethnicity | Caucasian | 87.1 |
| | Hispanic/Latino | 8.0 |
| | African American | 2.7 |
| | Native American | 1.3 |
| Birth Order ¹ | Younger | 26.8 |
| | Older | 71.4 |

¹Older or younger than sibling with spina bifida

Characteristics of the Family

| <u>Variable</u> | <u>Category</u> | <u>%</u> |
|---|-----------------------|----------|
| Parent Marital Status | Married/partnered | 87.9 |
| | Divorced | 5.8 |
| | Separated | 3.1 |
| | Widowed | 2.2 |
| | Single, never married | 0.9 |
| Family Annual Income | \$25,000 or less | 14.8 |
| | \$26,000-\$35,999 | 9.8 |
| | \$36,000-\$45,999 | 8.0 |
| | \$46,000-\$55,999 | 11.2 |
| | \$56,000 or above | 54.9 |
| Sex of Child with SB | Female | 57.6 |
| | Male | 39.0 |
| Average Age of Child with SB: 10.93 years | | |

Spina Bifida Characteristics

| Variable | Category | % |
|----------------------------|-------------|------|
| Level of lesion | Cervical | 1.3 |
| | Thoracic | 18.8 |
| | Lumbar | 39.7 |
| | Lumbosacral | 28.6 |
| | Sacral | 5.8 |
| Hydrocephalus | Yes | 88.8 |
| | No | 11.2 |
| Shunt | Yes | 86.2 |
| | No | 13.8 |
| Average # Shunt revisions: | | 2.20 |

Spina Bifida Characteristics (Parent Report)

| Variable | Category | % |
|---------------------|-------------------|------|
| SB is severe | Strongly Agree | 11.6 |
| | Agree | 37.1 |
| | Neutral | 7.6 |
| | Disagree | 36.2 |
| | Strongly Disagree | 7.1 |
| Learning Difficulty | Strongly Agree | 17.9 |
| | Agree | 34.4 |
| | Neutral | 8.5 |
| | Disagree | 32.3 |
| | Strongly Disagree | 16.5 |

Questionnaires We Used

Description of Questionnaires

Factors

Definition

Attitude Toward SB¹

Attitudes about spina bifida impact on own life

Satisfaction with
Family Functioning²

Approval of family interaction style in areas
of communication, problem-solving, and
expression of feelings

Sibling Relationship-
Warmth³

Sibling interactions characterized by affection,
companionship, intimacy, and admiration

Sibling Relationship-
Conflict³

Sibling interactions characterized by
competition, antagonism, and quarreling

¹Child Attitude Toward Illness Scale (Austin & Huberty, 1993)

²Family APGAR (Austin & Huberty, 1989)

³Sibling Relationship Questionnaire (Furman & Buhrmester, 1985)

Factors

Definition

Classmate Social
Support⁴

General peer support

Close Friend Social
Support⁴

Peer intimacy

Adjustment Outcomes

Self-Concept⁵

How one feels about oneself

Prosocial Behavior⁶

Ability and interest to help others

Behavior Problems⁶

Acting out, peer problems, and depression

⁴Social Support Scale for Children (Harter, 1985)

⁵Children's Self-Concept Scale (Piers & Herzberg, 2002)

⁶Strengths and Difficulties Questionnaire (Goodman, 1997)

Qualitative Component

The final part of the survey offers you the chance to describe any additional thoughts, feelings, opportunities, or challenges of living with a brother or sister who has spina bifida.

Things you might include: The benefits as well as difficulties of having a sibling with spina bifida in areas of friendships and family activities, relationships, and anything else you want us to know.

Results:

Descriptive Data from
the Questionnaires

How the Siblings Are Doing?

Self-Concept Scores

(How the Siblings Feel About Themselves)

High Self-Concept: 27.7%

Typical Self-Concept: 64.7%

Low Self-Concept: 7.6%

****Average score for siblings was HIGHER than average score from standard data**

Prosocial Behavior Scores (Ability and Interest in Helping Others)

Typical Behavior: 93.3%

Borderline Behavior: 4.0%

Low Behavior: 2.7%

Behavior Problems (BP) Scores (Acting Out, Peer Problems, Depression)

Typical BP: 82.1%

Borderline BP: 11.6%

High BP: 6.3%

Average Score

Scale Range

Attitude Toward SB

3.76

1 - 5

Family Satisfaction

3.62

1 - 5

Sibling Warmth

3.45

1 - 5

Sibling Conflict

2.41

1 - 5

Classmate Support

3.34

1 - 4

Close friend Support

3.43

1 - 4

Results: Factors Supporting a Healthy Self-Concept

- 1) A positive attitude toward SB
- 2) Satisfaction with family
- 3) Support from classmates

Results: Factors Supporting Prosocial Behavior

- 1) Warmth in the sibling relationship
- 2) For siblings who were YOUNGER only:
close friend support

Results: Factors *Protecting Against* Behavior Problems

- 1) Less conflict in the sibling relationship
(really true for YOUNGER siblings)
- 2) For OLDER siblings only: Satisfaction
with family
- 3) Support from classmates

What did the Survey Teach Us?

- ❖ Overall, siblings demonstrate healthy self-concept and behavior
- ❖ Broad range of protective factors associated with doing well
- ❖ Most important factors: the sibling relationship and peer social support

Results: Qualitative Data

Domains

- 1) The Influence of Spina Bifida in the Lives of Siblings
- 2) The Emotional Climate of Siblings
- 3) Making Meaning of the Spina Bifida Experience
- 4) Qualities of the Siblings' Relationships
- 5) Acknowledging the Sibling Experience

Domain 1: The Influence of Spina Bifida in the Lives of Siblings

- a) A Continuum of Impact
- b) The Omnipresence of Spina Bifida
- c) Opportunities Created by the Experience of Spina Bifida
- d) The Development of Unique Knowledge and Responsibilities
- e) The Influence of Spina Bifida on the Sibling's Worldview

Theme 1a:

A Continuum of Influence of SB

“I think having a spina bifida sibling is different, but it is not hard” (older male EA)

“Even though her hardships have limited me, I love her unconditionally through embarrassment, tiredness, challenges and just plain hard moments” (older female MA)

“Sometimes having a brother with spina bifida does not allow me to do certain things...until I move out of the house I will have trouble experiencing the things a normal child would” (younger male MA)

Theme 1b: The Omnipresence of SB

“It’s not always difficult to have a sister with spina bifida, but there are so many appointments, medicines, and money involved” (older female MA)

“Sometimes I feel I will lose her. That makes me sad” (younger female EA)

“How ill 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” (same-age male MA)

Theme 1c: Opportunities Created by the Experience of SB

“Our family can park in the handicap spaces and we can get on rides quicker in some theme parks” (older male EA)

“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” (younger female MA)

Domain 2: The Emotional Climate of Siblings

- a) Overall Positive Self-Perception
- b) Conflicted, Ambivalent Feelings About Having a Sibling with Spina Bifida
- c) Protective and Empathetic Concerns
- d) Awareness and Impact of Public Response

Theme 2a: Overall Self-Perception

“I’m having a great life” (younger male MA)

“I am pretty much ‘normal’ despite some flaws” (older female MA)

“I am always depressed and whenever (rarely) I’m happy, I get depressed immediately” (older female MA)

Theme 2b: Conflicted, Ambivalent Feelings about Having a Sibling with SB

“Sometimes I feel embarrassed to have my little brother as a sibling and other times I love him to death” (older female MA)

“Having a sibling (sister for me) with spina bifida can definitely be challenging, embarrassing, tiring. It’s an emotional roller coaster” (older female MA)

Theme 2c:

Protective and Empathetic Concerns

“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” (younger male MA)

“Sometimes it breaks my heart when she asks me questions like ‘What’s it feel like to walk?’” (older female MA)

Domain 3: Making Meaning of the Spina Bifida Experience

- a) The Journey Toward Acceptance of Spina Bifida
- b) Questioning the Fairness of Spina Bifida
- c) More Challenging Early Years
- d) Perception of Sibling as “Normal”
- e) The Role of Spirituality

Theme 3a: The Journey Toward Acceptance of SB

“There are many bad aspects, but I have learned to deal with them because they are never going to change. I just keep looking at everything good we are able to have” (older female MA)

“Some people are born that way, and you just have to find the good side of things” (older male EA)

“No one is exempt from this burden and it’s something each family must learn to deal with” (older female LA)

Theme 3b: Questioning the Fairness of SB

“I look at her sometimes and think why her? Why this little girl? She didn't do anything to deserve this kind of life” (older female MA)

“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” (older female LA)

Theme 3c: More Challenging Early Years

“When I was younger, I felt held back because I was always watching out for him. Sometimes my friends would play a game that he couldn’t and I would have to stay with him. Now that I am more mature, I can see that I should always be joyful when I’m sticking up for him and not letting him be left behind” (older male MA)

Theme 3d: Perception of Sibling with SB as Typical

“ I don't see her as a sick 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” (older female MA)

Domain 4: Qualities of the Siblings' Relationships

- a) Cohesive Family Relations
- b) Experiences of Differential Treatment and Expectations
- c) Warmth and Closeness in the Sibling Relationship
- d) Perception of the Sibling Relationship as Normal
- e) Supportive Peer Relations

Theme 4a: Cohesive Family Relations

“The relationships in our family seem greater than those of others” (younger male MA)

“I think having a sister with spina bifida makes a closer bond in our family” (older female MA)

“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” (older female LA)

4c: Warmth and Closeness in the Sibling Relationship

“I love my sister more than I like chocolate and I love chocolate. She is the best thing in my life” (older female EA)

“I admire him for his strength and courage concerning his condition” (older female LA)

“We fight a lot and don’t get along much of the time” (older male LA)

4d: Perception of Sibling Relationship as Typical

“Spina bifida is not a factor for me when it comes to me and my relationship with my brother” (older female MA)

“Me and my sister who has spina bifida are just like normal brothers and sisters. We fight but in the end we always love each other” (older male MA)

“He’s just like everybody’s little brother—annoying sometimes but that’s his job” (older female MA)

Domain 5: Acknowledging the Sibling Experience

- a) Appreciation of a Forum to Express Self
- b) Feeling Overlooked and Undervalued

5a: Appreciation of a Forum to Express Self

“Thank you for giving me a chance to express myself” (older male EA)

“Thank you for listening to what I have to say” (older female EA)

5b: Feeling Undervalued and Overlooked

“My family went on a trip to Disney World once, all expenses paid, with a group of other families, all of which had a chronically ill child. It was sponsored by a radio station. Their goal was to give us one weekend with ‘normal’ lives. I listened to that radio 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” (older female LA)

What did the Qualitative Data Teach Us?

- ❖ Overall acceptance for the presence of SB in their lives
- ❖ Journey toward acceptance is marked by intense and sometimes conflicted emotions
- ❖ There are a number of resources to support siblings: close family relationships, especially the sibling relationship, growth opportunities, and spirituality

Take Home Message for Families

- ❖ Support the sibling relationship
 - Explore factors leading to problematic sibling interaction
- ❖ Encourage peer interaction
 - Refer to therapeutic group work (SibShop)
- ❖ Ask sibling about perception of spina bifida

Take Home Message for Families

- ❖ Explore thoughts about family environment
 - What is working well? How might the family change?
- ❖ Create one-on-one time for siblings to share strengths and areas of need

Study Limitations

- ❖ Poor demographic diversity
 - Most were Caucasian and in 2-parent households
 - Protective factors may be different with different groups
- ❖ Possibility of skewed picture of adjustment
 - Some studies have found parents to report a more negative picture of sibling functioning than sibling self-report data

What's Next??

Test an intervention for kids with SB and their siblings that will support:

- 1) sibling relationship

- 2) quality of life for child with SB

- 3) quality of life for sibling

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- ❖ Participation in research helps us identify important issues for the SB community.