



# Spina Bifida - Adolescent Activities, Beliefs, Expectations and Perceptions

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# Outline

- Review of Spina Bifida (SB)
- Developmental and psychosocial issues in SB
- Research Conceptual Framework
- What adolescents and young adults (AYA) tell us about their beliefs, expectations and perceptions
- What AYA tell us about their activities
- Moving from “I think I can” to “I can” – What professionals can do to help

# Review of Spina Bifida

- One of a group of disorders called Neural Tube Defects (NTD) related to abnormal in utero formation of the nervous system (spinal cord and brain)
- Defect occurs by the end of the 4<sup>th</sup> week of gestation
- Multi-factorial cause – both genetic and environmental factors
  - Folic acid
  - Obesity
- Causes a number of other medical problems and has significant effects on learning and psychosocial status

# Medical Issues in Spina Bifida

- Nervous System
  - Hydrocephalus in 80-90% leading to ventriculoperitoneal (VP) shunt
- Musculoskeletal System
  - Varying degrees of paralysis and sensory impairment
  - Ambulation ranging walking (usually with braces) to full wheel chair use
- Genitourinary System
  - Bladder incontinence (Neurogenic bladder)
    - Managed by intermittent catheterization and medicines
    - Urinary tract infections
- Gastrointestinal System
  - Bowel incontinence

# Medical Issues in Spina Bifida

- Growth and Nutrition
  - Obesity
  - Osteoporosis / Osteopenia (at least in non-walkers)
- Skin
  - Pressure ulcers / skin breakdown
- Pain
  - Occurs frequently in adults but also appears to occur more frequently in adolescents than previously recognized
- Latex sensitivity / allergy
- Eye problems
  - Strabismus (eyes crossing)
- Seizure disorders
  - 10-20%

# Developmental and Psychosocial Issues in Spina Bifida

- Development is an ongoing process
- All development takes place in the context of meeting and responding to challenges
- Accomplishing early developmental tasks lays the foundation for what happens later
- The fundamental accomplishments of child and adolescent development are social and development of overall competence

# Promoting Self-Competence and Independence in Persons with Spina Bifida

- Promoting self-efficacy, effective coping strategies, social activities with peers, and skill-building in academics / jobs and daily living skills
- Challenges in persons with SB
  - Mobility challenges
  - Different social experiences may alter social development
  - Learning issues in SB may impact the acquisition of living skills and school/vocation skills
  - Temperament may be different – more content to let others do than to try themselves

# Promoting Self-Competence and Independence in Persons with Spina Bifida

- Challenges for families
  - Life with a child with (SB) may be more complex
  - Altered family relationships – parents and siblings
  - May experience more social isolation themselves
  - May have increased risk of depression
  - Additional financial stresses
- Challenges in societal participation
  - Schools responsive to the different learning needs in SB
  - Adequate job supports / training
  - Accessibility of public spaces
  - Activities that include people with SB

# Learning Issues in Spina Bifida

- Approximately 80% of persons with SB have normal cognition
  - Mean IQ slightly lower than general population
- Estimated 30-40% of children with SB have attention problems
- Majority of children with SB appear to have learning challenges
- Concept of Non-verbal Learning Disabilities (NLD)
  - Distinct patterns of strengths and weaknesses in how the brain processes, manages, learns and remembers information

# Non-Verbal Learning Disabilities

- Processing Strengths
  - Verbal-auditory learning
  - Verbal memory
  - Rote (memorization) learning
- Processing Weaknesses
  - Visual-spatial learning and attention
  - Comprehension
    - Bringing together parts to make meaning out of a whole
    - Underlying meaning as opposed to rote memory
    - Includes reading comprehension
  - Executive functions

# Executive Functions Definition

- “The cognitive process that regulates an individual’s ability to organize thoughts and activities, prioritize tasks, manage time efficiently, and make decisions.”

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- Executive function skills components
  - Attention
  - Mental flexibility
  - Organization
  - Novel problem solving

Information presented here is part of a larger study:

## Secondary Conditions and Adaptation in Spina Bifida

Interdisciplinary descriptive cross-sectional model testing study of adolescents with Spina Bifida and their families, and a comparison peer group, looking at factors associated with the occurrence of various secondary conditions and adaptation outcomes in SB

Funded by:

1. Association of University Centers on Disability (AUCD) through a cooperative agreement with Centers for Disease Control (CDC)
2. American Association of Spinal Cord Injury Nurses
3. Alpha Chapter, Sigma Theta Tau

# Secondary Conditions and Adaptation in Spina Bifida

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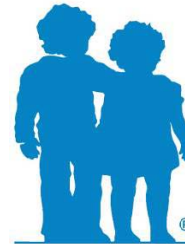


INDIANA UNIVERSITY  
SCHOOL OF MEDICINE

Riley Hospital *for* Children



UNIVERSITY of WISCONSIN  
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College of Nursing



Children's  
Research Institute

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UNIVERSITY OF  
Cincinnati

Cincinnati  
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Children's  Hospital  
PEDIATRIC SPECIALTY CARE OF RICHMOND, VA.

*Young at heart*



# Study Framework

## Ecological Model

Biologic and situational perspectives combine to reflect the risks and protective processes that influence adolescent secondary conditions and adaptation in Spina Bifida.

# Study Framework

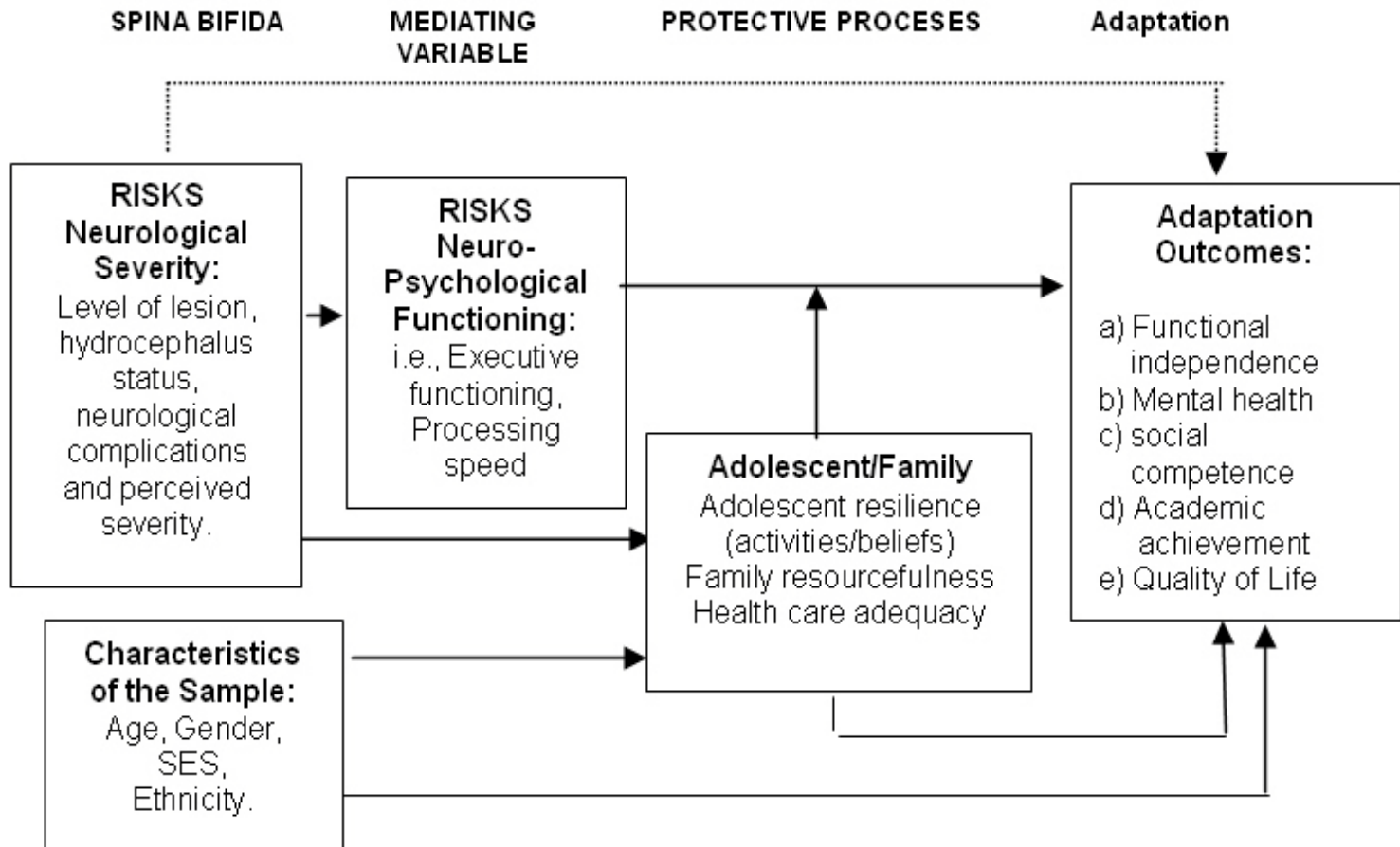
- Risk factors
  - Neurologic severity
  - Neuropsychological processes
  - Demographic characteristics
- Protective Processes
  - Adolescent beliefs and activities
  - Family resourcefulness
  - Perceived health care adequacy

# Study Framework

- Outcomes (Dependent Variables)
  - Functional independence
  - Mental health
  - Social competence
  - Academic achievement / job status
  - Quality of life

# Figure of Study Model

## Secondary Conditions and Adaptation in Spina Bifida



# Family Resourcefulness Measures

- Family Adaptation, Cohesion, Evaluation Scales (FACES II)
  - Measure of family cohesion
- Family Adaptation Partnership, Growth, Affection and Resolve (APGAR) Scale
  - Measure of family satisfaction
- Family Inventory of Resources Management and Mastery Subscale (FIRM)
  - Family mastery
- Resnick's Over-Protectiveness Scale
  - Measure of parenting relationships / style

# Outcomes Measures

- Physical
  - WeeFIM®
  - Adolescent Self-Management and Independence Scale (AMIS II)
- Mental Health
  - Child Depression Inventory or Beck Depression Inventory
  - Child Behavior Checklist or Young Adult Behavior Checklist
  - Harter Self-Perception Profile for Adolescents (SPPA)
    - Self-worth Scale
- Social Competence
  - Harter Self-Perception Profile for Adolescents (SPPA)
  - Child Behavior Checklist
    - Social Competence
- Quality of Life
  - Spina Bifida Health Related Quality of Life Scale
  - Single Item Global Quality of Life question

# Study Inclusion and Exclusion Factors

- Adolescents/young adults
  - Between 12-25 years of age
  - English speaking
  - No previous documentation of mental retardation and functioning within 2 grade levels appropriate for age
  - Could be in a learning disabilities resource program

# Description of Sample Population

- 139 families participated; 98 with full data
  - Neuropsychological assessment, parent and adolescent interviews data
- 48% male; 52% female
- 81% Caucasian
- 34% thoracic/high lumbar; 40% lumbar or lumbosacral; 21% sacral
- Mean age 15.55 years (SD 3.248)
- 88% shunt [shunt status score 3.24] (SD 2.85)
  - Shunt score 0=if no shunt; (1+ number of revisions if shunt)
- 75% living in 2 parent home

# What (AYA) tell us About their Beliefs, Expectations and Perceptions

## Concept and Measure

Mean (SD)

### 1. Hope

Snyder's Hope Scale

3.04 (0.38)

8 items

Scored: 1=definitely false; 4 definitely true

### 2. Attitude

Child Attitude Toward Illness Scale (CATIS)

3.60 (0.64)

16 items

Scored: 1=very negative; 5=very positive

### 3. Future

Future Expectations Scale

4.36 (0.75)

14 items

1=sure I cannot accomplish; 3=uncertain

5=sure I can accomplish; 6=already accomplished

# What (AYA) tell us About Their Beliefs, Expectations and Perceptions

## Concept and Measure

Mean (SD)

### 4. Adolescent Coping

#### Adolescent Coping For Problem Experiences

(ACOPE) 12 items 1=never; 5=most of the time

Scores are additive with max score in each subscale of 20

Social Support

14.81 (3.11)

Avoiding

5.45 (1.92)

Venting

8.42 (3.03)

### 5. Communication Efficacy

#### General Communication Efficacy Scale

71.3 (17.7)

#### Difficult Communication Efficacy Scale

64.3 (18.1)

0-100 visual analogue scoring

0=not confident at all; 100=very confident

# What AYA tell us About Their Activities

## Concept and Measure

Mean (SD)

### 1. Adolescent Decision Maturity

#### Adolescent Decision-Making Inventory (ADI)

0=immature decision-making;1=transitional decision-making

2= mature decision-making

Total	0.87 (0.47)
Condition DM	0.91 (0.56)
Coping DM	0.75 (0.65)
Identity DM	0.80 (0.68)
Peers DM	0.85 (0.65)
Family DM	0.98 (0.71)
Egocentric Thinking	0.93 (0.70)
Goals DM	0.89 (0.60)

# What AYA tell us About Their Activities

<u>Concept and Measure</u>	<u>Mean (SD)</u>
<b>2. Decision Making Participation</b> <u>Adolescent Activities Inventory (AAI)</u> <u>AAI Decision Making Total Score</u> 20 items 1=parent always decides; 3=50/50; 5=teen always decides	3.59 (0.8)
<b>3. Household Responsibility</b> <u>AAI Chores Scale Total Score</u> 1=never; 3=do routinely	1.75 (0.30)
<b>4. Friendship Activities</b> <u>AAI Friendship Activities Scale Total Score</u> 1=never; 3=sometimes; 5=a lot	2.80 (0.78)
<b>5. Family Activities</b> <u>AAI Family Activities Scale Total Score</u> 1=never; 3=sometimes; 5=a lot	3.46 (0.58)

# Additional Findings

- Decision-making maturity
  - Only those over 18 years old achieved any score indicative of mature decision-making
  - Many individuals over 18 still only scored from 0.29 – 1.4 on various subscales
- Participation in household chores
  - 18% cleaning their room routinely; 73 % only occasionally
  - 36% wash dishes; 48% occasionally; 37% never
  - 43% made snacks routinely; 40% occasionally; 11% never
- Activities
  - Tend to center around family rather than peers
  - Usually involve TV or “home activities” rather than activities out in the community
    - Averaged more than 3 hours TV a day

# Additional Findings

- AYA are:
  - Generally are hopeful, both about the expectation of achieving positive outcomes and the ability to achieve them
  - Somewhat positive in their attitude about their condition
  - Generally reported using more adaptive coping methods

But

- Most are not actively engaged in many decision-making activities
- Generally are not mature in their decision-making, even as older AYA
- Don't participate in family chores frequently or consistently
- Relatively low levels of activities with peers / friends

# Additional Finding - Outcomes

- While AYA are generally independent with most daily functional tasks (usually requiring only supervision), they require significant assistance with more complex self-management / independence tasks
- Mean depression scores were in the non-depression range
  - 13% of AYA sample were above the cut-off and identified as depressed
    - A recent study of adults with SB 18-25 years of age [Mean age 21.05 (SD 2.11)] indicated depression in 41% and anxiety in 31%.  
M.H. Bellin, et al, 2009
- Scores overall reflected a mildly positive self-esteem, though AYA reported an overall lower social competence
- AYA generally reported a positive health related quality of life

# Correlations of Activities and Beliefs to Outcomes

- Adolescent activities correlate primarily with physical outcomes, particularly self-management.
  - Chores and use of coping
  - Age was significant in self-management portion
  - measure of daily executive functioning [Behavior Rating Inventory of Executive Functions (BRIEF)] also correlated with self-management
  - Shunt status correlated with self-management; level of lesion correlated with functional status

# Correlations of Activities and Beliefs to Outcomes

- Adolescent attitudes, beliefs and expectations correlate most strongly with mental health outcomes
  - Hope, decision-making and attitude toward illness and communication efficacy
  - Family activities and family cohesion
  - Over-protectiveness correlated with both self-esteem and depressions
    - The more overprotective the lower the self-esteem and the higher the depression
  - Age correlated with depression
    - The higher the age the more likely to have depression
  - Measures of executive function also correlated with both depression and self-esteem

# Correlations of Activities and Beliefs to Outcomes

- Both adolescent beliefs and activities correlate to social competence outcomes
  - Future expectations and communication self-efficacy
  - Family activities were significant
  - No measures of neurologic severity (Level of lesion, shunt status) were significant
- Adolescent beliefs correlate strongly to quality of life
  - Attitude toward illness, communication efficacy and future expectations, and teen's perception of family satisfaction
  - Measures of secondary conditions were significant
  - No measure of neurologic severity was significant
  - No measure of adolescent activities was significant
  - No measure of neuropsychological function was significant

# What Professionals can do to Help

## Moving from “I Think I Can” to “I Can”:

- While a focus on the medical is necessary, it is not sufficient
  - Recognition of the intersection of medical issues, social environment, family styles and learning issues as important influences that affect progress toward independence / autonomy
  - Know the resources you have available
    - SBHI / IF / SBA – family support organizations / workers
    - Psychologists, counselors
    - Government agencies, schools, adaptive sports organizations
- Take a developmental perspective
  - Each stage of development builds upon the next

# Moving from “I Think I Can” to “I Can”: What Professionals can do to Help

- Support the family
  - Status of the family important for many adaptation outcomes
  - Be watchful for family isolation and parental depression
  - Single parents and those of lower socioeconomic status are particularly vulnerable and may need more support
- Understand the learning challenges that may be present in SB
  - Especially the higher order cognitive and executive functions
  - Help parents understand how these may influence how skills toward independence are taught and learned

# Moving from “I Think I Can” to “I Can”: What Professionals can do to Help

- Help families take the long view and the developmental view
  - “Transition begins in infancy”
  - Parents need to ask themselves “Is what I am doing today helping my child to be independent as an adult?”
  - Help parents understand the “tasks” at different stages of development in the child
  - Help parents address “overprotective” parenting styles and individuals with SB the condition of “learned helplessness”

# Moving from “I Think I Can” to “I Can”: What Professionals can do to Help

- Support meaningful roles for the child / adolescent with SB within the family, school and community
  - Chores, chores, chores – and consequences!
  - Support positive expectations and forward momentum
  - Encourage developmentally appropriate opportunities for independence
  - “Creative parenting”
    - Adapting developmentally appropriate tasks
  - “Anticipatory parenting”
    - What’s happening in people two years older than my child?”
- Families may need help to develop the home “Individual Educational Plan” (IEP)

# Moving from “I Think I Can” to “I Can”: What Professionals can do to Help

- Encourage and support interactions with peers
  - Families may need assistance with ideas for encouraging appropriate play activities
  - Adaptive sports
  - Various clubs / organizations
- Encourage activities that build upon skills / interests
  - Hobbies
  - Music / art
- Encourage families to advocacy

# Summary

- We can capitalize on the hopeful, expectant beliefs of children, adolescents and young adults with Spina Bifida.
- We can work together to foster the activities and experiences in all ages that move persons further down the road toward independence / autonomy to achieve to their best capability.

# Additional Findings - Outcomes

<u>Concept and Measure</u>	<u>Mean (SD)</u>
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## 1. Physical Outcomes

<u>WeeFIM®</u>	5.57 (1.28)
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1=totally dependent; 7=totally independent

Adolescent Self-Management and Independence Scale

(AMIS II) 1=totally dependent; 7=totally independent

<u>Total Score</u>	3.62 (1.25)
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<u>Self -Management:Condition</u>	4.58 (1.52)
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<u>Self-Management: Independence</u>	2.91 (1.28)
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- Mean score of the WeeFIM was at supervision level
- Total score of AMIS indicated AYA able to do only 50-75% without assistance; Scores significantly lower for more complex self-management tasks

# Additional Findings – Outcomes

<u>Concept and Measure</u>	<u>Mean (SD)</u>
<b>2. Mental Health</b>	
<u>Child Depression Inventory</u>	47.54 (10.28)
<u>Beck Depression Inventory</u>	10.04 ( 7.82)

- Mean depression scores are in the non-depression range
- 13% of AYA sample were above the cut-off and identified as depressed.

## Harter Self-Perception Profile for Adolescents (SPPA)

1==low; 4=high

<u>Self-esteem</u>	3.17 (0.74)
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- Score reflects a mildly positive self-esteem

# Additional Findings – Outcomes

Concept and Measure

Mean (SD)

## 3. Social Competence

Harter Self Perception Profile for Adolescents (SPPA)

1=low; 4=high

Social Competence

2.96 (0.74)

- Child Behavior Checklist (CBCL) could not be calculated for 35% of sample as there were insufficient social activities to be able to calculate a score.

## 4. Health Related Quality of Life

Spina Bifida Health Related Quality of Life Scale

1=low; 5=high

Total Score

4.20 (0.5)

Single Item Total Quality of Life

84.47 (22.97)

visual analogue score from 0-100