



**SPINA BIFIDA
ASSOCIATION**

Spina Bifida - Self Concept, Family and Peer Relationships

**International Federation for Spina Bifida
and Hydrocephalus Conference**

Spina Bifida Hydrocephalus Ireland

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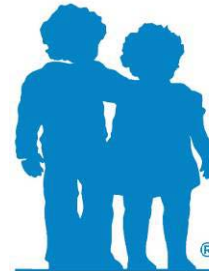


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Young at heart

Parents, Families and AYA are Experts

Health Care Providers (HCP) and research can provide useful information to families and AYA. This information can be considered, examined and evaluated to see how it “helps” in your specific situation.

Purpose

- Share information regarding self concept, family and peer relationships
 - Pilot work with 66 families with an Adolescent/Young Adult (AYA) in one setting
 - Multi-site study of 140 families with an AYA with SB.
 - Follow up study of 50 of these families
 - Work from our colleagues (Holmbeck et al 2010 and Bellin et al 2010, Special issues of Developmental Disabilities Research Reviews, Volume 16, No 1, 2010)
- Generate discussion between parents, families, persons with Spina Bifida and health care provider perspectives

Parents, Adolescents and Young Adults
(AYA) with Spina Bifida:

YOU MAKE A DIFFERENCE!

Although there are challenges in self
concept, peers and family relationships,
some AYAs have shared with us
information you may find helpful as you
encounter these challenges

What Do AYA Tell us About Self-Concept

- Appraisal of Self
 - Identify personal strengths
 - Areas of self-dislike or perceived difficulties
- Many see self, at least in part, as typical adolescent
- Continuum of Impact of Spina Bifida on Life experiences
 - “Sometimes it overpowers me, but other times its okay”
 - Positive appraisal of impact
 - Mixed impact
 - Negative appraisal of impact

Stresses of everyday life

- School-related stress
 - The school environment created a number of challenges especially in the area of academic achievement
 - “Taking tests was kind of stressful....I usually lose concentration sometimes.”
- The experience of teasing or of bullying
 - The experience of teasing and bullying emerged as a powerful negative description of some (“In school you get made fun of”).
 - Many AYA report this gets better with time
 - Others find ongoing issues:
 - “I feel like a lot of people, like, put me down because I have spina bifida and because I do look different than others. I’ve been make fun of all my life.I wish that God would have put it on somebody else, because I don’t, you know, I don’t k now why I deserve it and all that stuff. It’s all kinds of stuff. I beat myself up over it. “

Stresses of everyday life

- Spina-bifida challenges:
 - Stress resulting from daily management of spina bifida, including self-care, health monitoring and daily tasks is common.
 - I really am incontinent, so I never know when it's going to happen
 - Cathing is stressful, really stressful.
 - Concerns about future health needs
 - I'm kind of worried about that [health] cause I don't know how good it will be. ..but I'm not sure if it will get worse, or if it will just stay the same like it is now."
 - [I worry that] I'd have a kid and still have spina bifida.
 - Mobility-related stress
 - Frustration articulated by both younger adolescents ("Like knowing my friends are going somewhere or something and like I can't do it. Then that makes me kind of upset") and older adolescents ("Not being able to go anywhere is stressful ")

Strategies and Skills to Manage Stress

AYA described 4 themes to manage stress

- Use of problem-solving
 - AYA relied on both internal problem solving strategies and external resources such as processing a challenge with a school counselor “to figure it out”. Some participants took time out
 - I’d rather just go to my room and just have everyone leave me alone and let me think about it. And if I think about it and then I will come back and discuss with you
 - I go to my learning room. If I am at home I go to my room and calm myself down
- Patterns of sequential coping
 - Stepwise selection of inner coping resources and supports
 - It all depends on what the problem would be. Sometimes I handle it myself, or if I don’t think I can handle it, I’ll go talk to a really close friend.”
 - I try to figure it [problem] out on my own and if I can’t I just talk to mom about it.”

Strategies and Skills to Manage Stress

- Support from family and friends
 - Was important to most participants in our studies
 - I think of something good and if I don't think of something, I call my best friends. She makes me feel better.” “ I usually talk to my mom.” “If I can't talk to my parents then I'll call one of my best friends and they'll try to help me. Or I talk to my grandparents, and I have aunts and uncles that I talk to.”
- Maladaptive and avoidance strategies
 - While most used constructive coping skills, a group relied on less adaptive strategies. Some reported experiencing intense anger that led to yelling at friends/family and even destruction of property
 - “I get really made sometimes.” “Sometimes I just like to go in my room and punch the heck out of my door.” “Sometimes I have a tendency to take it [stress]out on people at school. I take it out on my brother a lot.”

Factors Related to Self Concept / Competence / Self Esteem

- From our work the factors related to positive mental health (self concept and lack of depression) are:
 - Beliefs
 - Attitude toward SB (those with more positive attitude have more positive outcomes).
 - Hope (those with higher levels of hope have more positive outcomes).
 - Coping—those that have lower use of negative coping (avoiding and venting) and higher use of social support have more positive outcomes).

Factors Related to Self Concept / Competence / Self Esteem

– Beliefs

- Sexuality Beliefs (Those who have more positive beliefs about sexuality for AYA with SB have more positive outcomes).
- Confidence in Communication and problem-solving (AYA with higher confidence, those that are more sure of their communication and problem solving, are more likely to have more positive outcomes).
- Future Expectation (AYA with higher expectations for future also have more positive outcomes).
- Stress (AYA reporting lower stress in everyday life also report more positive outcomes).

– Secondary conditions

- Pain, urinary tract infections, skin breakdown, overweight

Family

A Huge Strength for AYA with SB

- Across multiple studies and investigators, data show that AYAs with SB typically have a strong and close relationships with their family with high
 - Cohesion
 - Satisfaction
 - Activities
- AYA say
 - “We are like best Friends. We do everything together.”
 - “We do things together 90% of the time”

4 Patterns of Parental Impact on AYA with SB

- (a) Restrictive Parenting: “She’s overprotective.”
- (b) Balanced Parenting: Parenting Balances Protection and Promotion of Independence: “Different with certain situations.”
- (c) Ongoing Parental Involvement: “In case I do need help.”
- (d) Balancing Independent Decision-Making with Parental Guidance: “Sometimes it’s very good advice.”

Restrictive Parenting

- “I feel sometimes that , um that she [Mom] thinks she know more than I do about myself, and, um, I feel sometimes that she doesn’t respect me, she doesn’t respect like what I say. One thing that really annoys me about her is she’s always got to get into my catheters...sometimes I’ll come home and they’ll be laying out. I’m a private person; I don’t like my personal stuff laid out.” “Mom just really needs to wake up and realize that I’m not always going to do what she wants me to do, and I’m my own person.”
- “I feel like I don’t have any privacy. It’s like this morning we got into a fight because she just barged right in, and I didn’t have any clothes [on]”

Restrictive Parenting

- “She tries to take control of what I’m doing...and I don’t like people to talk control of me.”
- “When I want to spend the night at a friend’s house or something—my Mom’s always afraid of letting me go over there and stuff”
- “Certain things that she [Mom] tells me that drive me insane...it just drives me nuts. The other day I was helping with supper. We were making deviled eggs, and I ask her if I could do it, just ask her how to do it. “Well, it’s too hard, you can’t.’ I’m 17. I can do it. It makes me so mad”

A Thought to Ponder

Although “protection” is critical to making sure our children survive the dangers of life, especially early in childhood when they cannot protect themselves. And overprotection may be viewed as a “normal response to a difficult situation” in which the child needs to be protected due to some risk like SB.

It should also be considered as potentially undermining the development of AYA with complex chronic conditions like spina bifida.

Families Can Build Autonomy Skills

Parents from our study advise:

- “The other thing is, I let him go places a lot. Like on Tuesday he had a friend come home with us. ...Even though there was snow they wanted to go to [restaurant], which is about five blocks away. And I just gave him some money and they all went to... And he bought his brother a meal too, and then brought back the receipt and the change, and knows how to get the right change.’
- “But I let him get full of mud. I mean some parents wouldn’t let him, you know they’d think, “Oh, poor kid, can’t walk,” and, “Oh, he’s going to get all full of mud.” I’m like, “Go ahead. Get full of mud.”

Balanced Parenting

- “They don’t point out all the differences. They try to point out all the normal things about me that are not different from others. They encourage me to do things that people with spina bifida don’t normally do, like I go ice skating...They try to just get me out in the world so I’m not all enclosed in my own little world.”
- “Well, they got [me] involved in sports, like playing softball when I was little, and then they made sure I got out to do normal things.”

The Process of Shared Decision Making in SB

Ongoing Parental Involvement

- “If I forget about it [cathing], she usually remind me, ‘When was the last time you cathed yourself? Have you cathed yourself yet?’”

Working Together to Get Things Accomplished.

- “My parents decide when, if I need to go to the doctor, and, um, either one will make the appointment.”
- “I usually know when things run out and stuff. So I tell them that I need something. Then they get on the phone and order it, and they usually go pick it up at the drug store or [it] comes in by mail.”

AYA Perception of Impact of SB on Family “It’s hard sometimes”

- “I don’t think it’s affected them at all.”
- “Sometimes I feel like I stop them [family] from doing something that they want to do.”
- “Probably at first it was kind of hard but now it doesn’t seem hard.”

Impact of SB on Family Continued

- “I know it was hard on them when I was little, but now that I can take care of myself, I don’t think it phases them at all. I mean I was always sick, and I had to go to the doctor a lot. And when I was in the hospital and I had surgeries, my Mom really stayed with me. I know that make it hard on her but now its ok.”
- “It probably had a big impact. I mean, like money-wise and dealing with my attitude and things.”
- “They had to do things for me that normally, kids could do for themselves.”

Family Factors Related to Outcomes

- The family is a protective factor for AYA with SB. Family factors (reported by both AYA and parent) are associated with both positive mental health (MH) and quality of life (QOL).
 - The relationship across studies remains strong in both AYA and young adults
 - Families model social competence. AYA who participate in more activities with families also participate in more activities with peers

Family Factors Related to Outcomes

- In our large study we explored “how the family” has an protective influence on outcomes.
 - In our work the family appears to influence outcomes through influencing their AYA’s beliefs
 - Families who have higher cohesion, satisfaction, and spend more time in activities with their AYAs have AYAs who have more positive beliefs (e.g., attitude, hope, coping, future expectations, and confidence in problem solving). These AYA with more positive beliefs report higher mental health and quality of life.

The Challenge of Peer Relationships and Development of Social Skills

- Development of social skills is somewhat altered for many with SB.
- The presence of learning issues and to some extent hydrocephalus can alter the trajectory of developing social skills especially with peers.
- Research has shown AYA with SB tend to have fewer friends, be less likely to have social contact outside of school, and less dating during adolescence.

What do AYA Tell us about Their Experience with Peers?

Some AYA reported:

- Positive relationships with peers with and without a disability
 - “I am no different than other kids my age.”
 - “I have friends I do different things with, but I have several close friends I could tell anything to.”
- Find that their friends “treat me like normal”
 - Most of my friends have learned to look through my SB and like me for who I am.

What do AYA Tell us about Their Experience with Peers?

Others AYAs reported:

- Challenges in peer connections:
 - “I just sit there and watch everybody else play.”
 - “I go to school, ride the bus, don’t like it. Sit by myself, don’t have anyone to talk to.”
 - “I don’t do anything with friends outside of school.”
 - “From the time I get home to the time I go to bed [I watch television].”

What do AYA Tell us about Their Experience with Peers?

- Many reported “peer” connectedness with adults as a primary socialization or friendship.
 - “Everything is cool because I hang out with the bus driver.”
 - “I want to hang out with the adults”
 - “The janitors at our school, I mean I love them to pieces. They are so sweet. They build me ramps for things.”
 - “The thing I like best [about school] there are some great teachers in my school ..I really enjoyed them.”

What do AYA Tell us about Their Experience with Peers?

- Having these friendship relationships with adults was protective.
 - But if they are the only relationships the AYA has it may be problematic as they do not include age-appropriate social skills.
 - In addition the relationships lack the intimate component important for future development.

What do AYA Tell us about Their Experience with Peers?

- Romantic connectedness. The AYAs:
 - Discussed the desire to meet someone and develop a romantic relationship.
 - Voiced fears about not being liked because they were in a wheelchair and they were aware of the need for the romantic partner to see them as a person and not the disability.
 - Related limited or varied dating experience. Potential selection of partners was seen as limited. “High-school guys are just into perfect females and scared, you know, scared to try something new.”
- This resulted in a lack of confidence and experience in decision making with intimate partners.

What do AYA Tell us about Their Experience with Peers?

- Issues of boundary setting and awareness of potential abuse was also evident
 - “When I do feel like I am being taken advantage of, I just say ‘Hey, I don’t want you to do that to me.’ You know, because that has happened.”

What do AYA Tell us about Sexuality ?

- 49% have been given information about fertility/ contraction
 - 46% - information came from their school
 - 24% - information came from parents
 - 25% - information came from an (HCP)
- 24% reported getting information regarding SB and fertility/contraception
 - 46% - information came from a HCP
 - 23% - information came from parents
 - 23% - information came from their school

What do AYA Tell us about Sexuality ?

- 65% report getting information regarding Sexually Transmitted Infections (STI)
 - 70% - information came from school
 - 18% - information came from an HCP
 - 13% - information came from parents
- 42% reported that they wanted additional information on fertility/contraceptives/STIs and SB
 - 60% - would like this information from HCP
 - 29% - would like this information from parents

Peer Factors Related to Outcomes

- To date little research has addressed factors related to socialization
 - Other researchers find this surprising given that this area is problematic for many with SB
(Holmbeck and Devine, 2010)
- The amount of peer activities has been related to mental health and quality of life in our work and in others.
 - More peer activities are related to higher self concept, lower depression and higher quality of life.
 - Information on sexuality issues and skills in social relationships are both needed to enhance age-appropriate socialization

Summary

- AYA with SB as a group have fairly positive sense of self
- Family is a strong protective factor for AYA with SB
 - Though some parenting styles may not promote independence as effectively
- Socialization and peer relationships remain a substantial issue for AYA with SB.
- AYA report missing basic information about relationships, sexuality and sexual health.
- There have been no studies that address critical information on building social skills basic to Romantic relationships.

For Discussion: What Action Steps Address These Findings

- How does the AYA
 - Build a positive self concept ?
 - Build on strong family support to enhance self, concept and social skills?
 - Develop typical peer networks and social skill?
- How does the family and health care provider (HCP) support the child or AYA to:
 - Build a positive self concept
 - Build on strong family support to enhance self, concept and social skills.
 - Develop typical peer networks and social skill

Adolescents and Young Adults

What can you do?

- Pick a priority skill/experience you want to change or learn
 - Engage caring adults and or peers, as needed, in building a plan to address this skill
 - Develop a plan that include goals, strategies you will use, and ways you will know that you have been successful
 - Figure out how you will revise the plan if it does not work at first.
- Having a skill, hobby or interest is a critical protective factor

Take Home Messages

- The skills for social interaction, peer relationships and autonomy, have to be deliberately built from early childhood.
- Some AYA themselves push the boundaries, agitate for more independence and seek ways to step out to new experiences.
- Many others want to, but, from the research, we know they do not take the initiative and wait for others to lead the way. This may be due to executive function/non-verbal learning difficulties.

Take Home Messages

- Families are the critical “teacher” in this process and their skill and knowledge is to be respected.
- Parents tell us they need to plan and be thoughtful about building social skills. They say there is so much to do that sometimes this important area gets lost.
- AYA tell us that they are living in the moment –and do not always think ahead about these important skills—but that they want to be involved with making decisions.

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