

Mental Health

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Introduction

Multiple studies have shown that children with Spina Bifida have lower Health Related Quality of Life (HRQOL) than both typically developing individuals without Spina Bifida and children with other chronic health conditions.¹⁻⁵ Variables such as resilience (e.g., attitude towards Spina Bifida, hope and future expectations, coping skills) have been strongly related to higher HRQOL and quality of life (QOL). In contrast, depression, a lack of optimism and reduced executive functioning are related to lower QOL/HRQOL.⁵ The interplay between the neuropsychological patterns of development in children, family functioning and quality of life is the context within which the mental health of children with Spina Bifida is best understood.

Children with Spina Bifida tend to score below average on measures of neuropsychological functioning that involve the construction or integration of information.⁶⁻⁷ The ability to shift attention appropriately (sometimes referred to as executive functioning) is important to social development. Impairments in this area are associated with subsequent internalizing of symptoms (i.e., depressive and anxiety symptoms).⁸

Children with Spina Bifida also tend to have social difficulties, including social immaturity and passivity, fewer friends, and fewer social contacts outside of school. They also have fewer romantic relationships during adolescence.⁹⁻¹¹ These social difficulties appear to continue into adulthood.^{9,12} Youth with Spina Bifida may also exhibit lower levels of sexual maturation, knowledge, and experience.¹³⁻¹⁵

Children with Spina Bifida are more dependent on their parents for guidance, show less intrinsic motivation at school and exhibit less behavioral autonomy at home.^{9,12,17} Levels of decision-making autonomy lag behind typically developing peers by about two years.¹⁷ Pain and depressive symptoms interfere with social involvement.¹⁸

Children with Spina Bifida exhibit lower levels of participation in physical activities and activities of daily living.¹⁹⁻²⁰ Higher levels of physical activities are related to adaptive outcomes (i.e., participation and HRQOL). Some evidence exists that weight management interventions that include physical activities are effective in this population.²¹

The transition from pediatric to adult Spina Bifida health care poses significant challenges.²³ For instance, the reported quality of health tends to decline from adolescence to young adulthood, presumably due to difficulties in navigating the transition to health care for adults with Spina Bifida.^{21,23}

Regarding psychosocial adjustment during emerging adulthood, young adults with Spina Bifida, like their younger counterparts, are at-risk for depressive symptoms and anxiety²³⁻²⁴, but they are less likely to engage in at-risk behaviors than their typically developing peers (e.g., using alcohol and having multiple sexual partners).²⁵ With respect to relationship quality, 43 to 77% live with their parents²⁶⁻²⁷ but over half (52-68%) have had a romantic relationship, although this latter rate is lower than in typically developing young adults.²⁷ The lowest level of life satisfaction is in the areas of romantic relationships, employment, and financial

independence.²⁸⁻³¹

Regarding educational and vocational outcomes, emerging adults with Spina Bifida are less likely to go to college than typically developing youth.^{22,24,25,27,31} With respect to employment, recent studies report rates of full- or part-time employment ranging from 36-48%^{1,31}, which are significantly lower than those found in typically developing youth and in those with other chronic conditions. With respect to community participation and social integration, participation in leisure and recreational activities tends to be low, with over 50% participating in no activities.²⁸ Studies that examine the employment and community participation of middle-aged adults with Spina Bifida document a decline in workforce participation over time, particularly among those with high levels of motor impairment and lower educational levels.³²⁻³³ Bowel and bladder incontinence is also associated with unemployment and social isolation among adults with Spina Bifida.³⁴⁻³⁵

Access to mental health services is a critical issue throughout the lifespan for children with Spina Bifida and their parents and other family members. Such services could begin just after birth for parents as they adjust to having a child with Spina Bifida. During the school years counseling for learning and emotional issues can be accessed via the child's IEP or 504 Plan. Camp programs can also provide emotional support and a context where children and youth can learn independence and self-management skills. Individual psychotherapy by skilled pediatric psychologists and social workers may be needed during adolescence and adulthood for emotional, educational, and vocational issues related to the transition to adulthood. Regional Independent Living Centers can offer peer counseling and referral to mental health services for adults with Spina Bifida.

Outcomes

Primary

1. Achieve optimal mental health throughout the lifespan as evidenced by adaptive psychological, social, and participation outcomes.

Secondary

1. Maximize adaptation across all factors that are predictive of mental health outcomes (including neuropsychological, family, peer, academic, biological, and condition-related predictors). Access services and supports across appropriate domains to optimize mental health throughout the lifespan.

Tertiary

1. Maximize self-management, independence, quality of life, and transition-to-adulthood outcomes by addressing mental health challenges.

0-11 months

Clinical Questions

1. What parenting interventions can promote mental health for parents and children?

Guidelines

1. Assess family functioning, stressors and supports. Identify strengths and build on resources and supports that encourage resilience.^{10,24}
2. Provide parents with detailed information about Spina Bifida.¹ (Prenatal Counseling Guidelines)
3. Connect families with contact information of local Spina Bifida Association (SBA) Chapters, community resources, and the SBA's National Resource Center. (clinical consensus) (<http://spinabifidaassociation.org/chapters/>)

- (<http://spinabifidaassociation.org/national-resource-directory/>)
4. Address developmental strengths and concerns through information and support. (clinical consensus)
 5. Refer to early intervention services [INSERT LINK TO EARLY INTERVENTION] and the American Academy of Pediatrics. (clinical consensus) (INSERT LINK TO <https://www.aap.org/en-us/Pages/Default.aspx>)
 6. Assess quality of parent-child attachment.¹⁰
 7. Promote effective parenting skills in stimulation, caregiving, and enjoyment of the child to optimize typical child development.^{1,10} (Neuropsychology Guidelines)
 8. Screen for post-partum depression and post-traumatic stress disorder. (Prenatal Counseling Guidelines)

1-2 years 11 months

Clinical Questions

1. What is the psychosocial impact of having Spina Bifida on mental health and adaptation across the lifespan?
2. Which domains of mental health are most adversely affected in individuals with Spina Bifida and in what areas of mental health are individuals with Spina Bifida most resilient?
3. What are some common maladaptive behaviors that can negatively impact persons with Spina Bifida across the lifespan?
4. What resources or practices are most effective at mitigating mental health issues in this population?

Guidelines

1. Address developmental concerns and optimize typical child development by building on resilience, resources, and supports.¹ (Self-Management and Independence Guidelines)
2. Encourage families to offer developmentally-appropriate choices in daily life activities, including such things as picking up toys, cleaning up, and doing imitative housework.¹⁰
3. Encourage developmentally-appropriate play and social opportunities. (clinical consensus) (Family Functioning Guidelines, Physical Activity Guidelines)
4. Assess parenting skills and provide education on parenting strategies and behavior management techniques as needed.¹⁰
5. Provide additional age-appropriate information about Spina Bifida as the child grows.¹
6. Continue participation in early intervention services, as appropriate. (clinical consensus) (Appendix: Early Intervention Services, Individualized Educational Plans (IEP) and 504 Plans)
7. Consider referrals for parent-to-parent support opportunities. (clinical consensus)
8. Encourage families to participate in SBA and SBA Chapter-related activities and events (e.g., Spina Bifida Education Days, Walk-N-Roll for Spina Bifida, and other activities organized by local Chapters). (clinical consensus) (<http://spinabifidaassociation.org/chapters/>)

3-5 years 11 months

Clinical Questions

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- Spina Bifida and in what areas of mental health are individuals with Spina Bifida most resilient?
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Guidelines

1. Discuss with parents the importance of their child's socialization and developing friendships with their peers and taking advantage of opportunities for activities. (36, 37) (Family Functioning Guidelines, Neuropsychology Guidelines)
2. Encourage participation in preschool educational programs. (clinical consensus)
3. Discuss the importance of making and keeping schedules/routines, doing chores, modeling behaviors, and making age-appropriate choices and decisions. (clinical consensus)
4. Assess social and psychological development and identify resources that build on strengths and encourage resilience.^{9,36}
5. Refer for social skills training as indicated.³⁶
6. Include optimization of mental health when developing an Individualized Education Program (IEP, IFSP or 504 Plan). (clinical consensus) (Appendix: Early Intervention Services, Individualized Educational Plans (IEP) and 504 Plans)
7. Provide additional age-appropriate information about Spina Bifida as the child grows.¹
8. Refer parents to the local school district to begin the process of requesting special education or classroom support (IEP, IFSP, or 504 Plan) needed to optimize their child's participation in school. (clinical consensus) (Appendix: Early Intervention Services, Individualized Educational Plans (IEP) and 504 Plans)

6-12 years 1 month

Clinical Questions

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3. What are some common maladaptive behaviors that can negatively impact persons with Spina Bifida across the lifespan?
4. What resources or practices are most effective at mitigating mental health issues in this population?

Guidelines

1. Encourage participation in community activities for recreation.^{19-20,28,36,37,38} (Physical Activity Guidelines)
2. Promote the development of friendships by helping families to identify social opportunities (e.g., participation in camps, adaptive sports programs/events, Walk-N-Roll for Spina Bifida, Boy and Girl Scouts, church youth groups, YMCA activities, and SBA and SBA Chapter social events).³⁶
3. Assess the child for depression, anxiety, bullying (including cyber bullying), and social participation. Similarly, identify the child's strengths and build on resources that encourage resilience. Initiate individual and family interventions when appropriate.^{9,23}

4. Encourage activities and hobbies that improve face-to-face social contact. (clinical consensus)⁴⁰
5. Promote transfer of age-appropriate medical responsibility from parent to child in those who have the requisite abilities and cognitive capacity.¹⁷ (Family Functioning Guidelines)
6. Discuss the importance of increasing household responsibilities that are appropriately modified to account for mobility and cognitive limitations. (clinical consensus)
7. Refer children with emotional and/or behavioral difficulties for psychological support and counseling. Identify community resources for social and psychological development (e.g., camps, recreation centers and more).^{9,12}
8. Assess the family's relationship with their child's school and encourage parents to be advocates for their children in the school setting. (clinical consensus) (Family Functioning Guidelines)
9. Promote the child's independence and choice in social activities. Promote self-care so that the child is able to be independent in social settings.³⁶ (Self-Management and Independence Guidelines)
10. Promote appropriate after-school sports and club activities.³⁸
11. Provide additional age-appropriate information/knowledge about Spina Bifida as the child grows. Begin to include child in clinical decision-making.³⁹ (Neuropsychology Guidelines)
9. Promote and encourage participation in community and SBA and SBA Chapter-related activities. (clinical consensus) (<http://spinabifidaassociation.org/chapters/>) (<http://spinabifidaassociation.org/national-resource-directory/>)

13-17 years 11 months

Clinical Questions

1. What is the psychosocial impact of having Spina Bifida on mental health and adaptation across the lifespan?
2. Which domains of mental health are most adversely affected in individuals with Spina Bifida and in what areas of mental health are individuals with Spina Bifida most resilient?
3. What are some common maladaptive behaviors that can negatively impact persons with Spina Bifida across the lifespan?
4. What resources or practices are most effective at mitigating mental health issues in this population?

Guidelines

1. Assess peer relationships and friendships.³⁶⁻³⁷
2. Assess for at-risk behaviors (alcohol, drug, or tobacco use and unsafe or unprotected sex), and identify areas of strength and build on resources that encourage resilience.²⁸
3. Screen for depression or anxiety and initiate individual and family interventions when appropriate.^{9,23}
4. Provide counseling and/or behavioral support as needed. (clinical consensus)
5. Promote transfer of medical responsibility from parent to child in those who have the requisite abilities and cognitive capacity.¹⁷ (Self-Management and Independence Guidelines)
6. Refer for social skills training as needed.³⁶
7. Encourage activities and hobbies that improve face-to-face social contact.⁴⁰ (clinical consensus)

8. Provide counseling regarding sexuality, sexual functioning, fertility, and contraception. Focus on sexual safety issues.¹³⁻¹⁵ (Sexual Health and Education Guidelines)
9. Discuss the safe use of and choices around drugs and alcohol and conduct risk assessment in this domain.²⁵
10. Discuss the importance of initiating and organizing opportunities for social activities.³⁶
11. Discuss the relationship between independence and interdependence and mental health. (clinical consensus) (Self-Management and Independence Guidelines)
12. Facilitate the child's involvement with a peer role model, such as a teen with Spina Bifida who is of a similar age). (clinical consensus)
13. Provide or refer to opportunities for formal or informal mentoring. (clinical consensus)
14. Encourage the teen to participate in the school's IEP transition team meeting. (clinical consensus)
15. Develop a plan for the teen's transition to independent living, post-secondary education, vocational training, and career interests. (clinical consensus) (Transition Guidelines)
16. Develop a plan for transition from pediatric to adult health care. (clinical consensus) (Transition Guidelines)

18 + years

Clinical Questions

1. What is the psychosocial impact of having Spina Bifida on mental health and adaptation across the lifespan?
2. Which domains of mental health are most adversely affected in individuals with Spina Bifida and in what areas of mental health are individuals with Spina Bifida most resilient?
3. What are some common maladaptive behaviors that can negatively impact persons with Spina Bifida across the lifespan?
4. What resources or practices are most effective at mitigating mental health issues in this population?

Guidelines

1. Screen for depression or anxiety and initiate interventions when appropriate.^{6-7,11}
2. Continue the transfer of medical responsibilities in young adults with Spina Bifida who have the requisite abilities and cognitive capacity.¹⁶
3. Encourage activities and hobbies that improve face-to-face social contact. (clinical consensus)
4. Encourage ongoing efforts to promote friendship and social intimacy.³⁷
5. Encourage and promote vocational or occupational goals and pursuits. (clinical consensus) (Transition Guidelines)
6. Maintain efforts for good general health promotion and exercise, as well as specialized Spina Bifida care. Optimize health to reduce the risk of obesity and maximize social opportunities and mental health.^{39,41} (Physical Activity Guidelines)
7. Recommend SBA resources (<http://spinabifidaassociation.org/learn-about-sb/adults/>). (clinical consensus)
8. Continue to refine the plan to ease transition from pediatric to adult health care. (Transition Guidelines)

Research Gaps

1. What services and supports can be utilized to mitigate barriers to optimal mental health throughout the lifespan?
2. What are the links between mental health and the following outcomes: self-management, independence, continence, quality of life, and the transition from pediatric to adult health care?
3. What interventions are available to enhance mental health across the lifespan in individuals with Spina Bifida?
4. What methods have been implemented by providers who care for children and adults with Spina Bifida and have an identified mental health diagnosis to guide their transition to adult health care?
5. What resilience factors mediate mental health outcomes in children and adults with Spina Bifida?

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