

Guidelines for the Care of People with Spina Bifida

Mental Health

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Introduction

Mental health, defined as our emotional, psychological, and social well-being, impacts how we think, feel, and behave. It influences how people deal with stress, interact with others, and make choices. Positive mental health allows individuals to pursue their goals and realize their potential, while poor mental health can interfere with achievement of life goals. Mental health problems can impact children and adults with Spina Bifida in various ways, and may include symptoms of anxiety, depression, and attention deficit hyperactivity disorder.¹ Mental health attributes such as resilience (e.g., attitude towards Spina Bifida, hope and future expectations, and coping skills) have been strongly related to higher health-related quality of life (HRQOL) and quality of life (QOL). In contrast, depression, a lack of optimism, post-traumatic stress symptoms, and reduced executive functioning are related to lower QOL/HRQOL.^{1,2} Early identification and treatment of mental health challenges aid in promoting optimal development and growth throughout the lifespan.

The mental health of children with Spina Bifida is best understood within the overarching context of the interplay between neuropsychological functioning, patterns of child development, family functioning, social functioning, culture, and quality of life.³ For example, children with Spina Bifida tend to score below average on measures of neuropsychological functioning that involve the construction or integration of information.^{4,5} The ability to shift attention appropriately (one aspect of executive functioning) is important to social development, and impairments in social development may be associated with subsequent internalizing symptoms (i.e., depressive and anxiety symptoms).⁶ Family functioning factors, such as family cohesion, conflict, and stress can also play important roles in children's mental health.

Social difficulties, including social immaturity and passivity, fewer friends, and fewer social contacts outside of school are important issues for many children with Spina Bifida, and tend to continue into adulthood.^{7,8} These youth have fewer romantic relationships during adolescence^{7,9,10} and may also exhibit lower levels of sexual maturation, knowledge, and experience than their unaffected peers.¹¹⁻¹³ Young adults with Spina Bifida identify the areas of romantic relationships, employment, and financial independence as the lowest levels of life satisfaction.¹⁴⁻¹⁷ And, although more than half (52% to 68%) of them have had a romantic relationship, this rate is lower than in typically developing young adults.¹⁴ Additional variables, such as pain and depressive symptoms can also interfere with social involvement.¹⁸

In terms of independence, youth with Spina Bifida are more dependent on their parents for guidance, show less intrinsic motivation at school, exhibit less behavioral autonomy at home and their levels of decision-making autonomy lag behind typically developing peers by about two years.^{7,8,19} As a group, 43% to 77% of adults with Spina Bifida live with their parents^{14,20} and between 25% and 45% demonstrate clinical levels of depressive symptomatology.²¹ Research

suggests that improving self-management in adults has been associated with decreased depression.²²

Children with Spina Bifida exhibit lower levels of participation in physical activities and activities of daily living.^{4,23} Certain health characteristics, such as a foot deformity and/or severe constipation, may contribute to lower levels of participation, poorer perceived mental health, and social difficulties.⁸ Some evidence exists that weight management interventions that include physical activities are effective in this population.²⁴ Importantly, participation in activities of daily living and physical activity can help to improve mental health for this population.

The transition from pediatric to adult Spina Bifida health care poses significant challenges.²⁵ 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.^{24,25} Young adults with Spina Bifida, like their younger counterparts, are at-risk for depressive symptoms and anxiety,^{21,25-28} but they are less likely to engage in some at-risk behaviors than their typically developing peers (e.g., using alcohol and having multiple sexual partners).^{22,27,29}

Access to mental health services is a critical issue throughout the lifespan for children with Spina Bifida, their parents and other family members. Such services may begin for parents after prenatal diagnosis and/or as soon as the baby is born, as parents adjust to living with Spina Bifida. During the school years, counseling for learning and emotional issues can be accessed through mental health programs and services and special education. Camp programs can also provide emotional support and a context where children and youth can learn independence and self-management skills.³⁰ Centers for Independent Living, consumer-controlled, community-based, cross-disability, nonresidential private non-profit agencies found in every state, can offer peer counseling and referral to mental health services for adults with Spina Bifida. Finally, individual psychotherapy by skilled pediatric and adult psychologists and social workers may be needed during adolescence and adulthood for emotional, educational, and vocational issues related to the transition to adulthood.

Outcomes

Primary

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

Secondary

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

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.^{7,26}
2. Provide parents with detailed information about Spina Bifida.³¹ (Prenatal Counseling Guidelines)
3. Connect families with contact information of local Spina Bifida Association (SBA) [Chapters](#), the [SBA's National Resource Center](#), and community resources. (clinical consensus)
4. Address developmental strengths and concerns through information and support. (clinical consensus)
5. Refer to early intervention services.
6. Assess quality of parent-child attachment.⁹
7. Promote effective parenting skills in stimulation, caregiving, and enjoyment of the child to optimize typical child development.^{9,31} (Neuropsychology Guidelines)
8. Screen for postpartum depression and post-traumatic stress disorder. (Prenatal Counseling Guidelines).

1-2 years 11 months

Clinical Questions

1. Assess family functioning, stressors and supports. Identify strengths and build on resources and supports that encourage resilience.^{9,26}
2. What is the psychosocial impact of having Spina Bifida on mental health and adaptation across the lifespan?
3. 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?
4. What are some common maladaptive behaviors that can negatively impact persons with Spina Bifida across the lifespan?
5. 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.³¹ (Self-Management and Independence Guidelines)
2. Encourage families to offer developmentally appropriate expectations in daily life activities, including such things as picking up toys, cleaning up, and doing imitative housework.⁹
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.⁹
5. Provide additional age-appropriate information about Spina Bifida as the child grows.³¹
6. Continue participation in early intervention services, as appropriate. (clinical consensus) (Appendix: Early Intervention Services)
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 SBA Chapters](#)). (clinical consensus)

- Promote and encourage participation in community and [SBA](#) and [SBA Chapter-related activities](#) such as Spina Bifida Education Days and Walk-N-Roll for Spina Bifida. Recommend [SBA resources](#) found in spinabifidaassociation.org. (clinical consensus)

3-5 years 11 months

Clinical Questions

- Assess family functioning, stressors and supports. Identify strengths and build on resources and supports that encourage resilience.^{2,9}
- What is the psychosocial impact of having Spina Bifida on mental health and adaptation across the lifespan?
- 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?
- What are some common maladaptive behaviors that can negatively impact persons with Spina Bifida across the lifespan?
- What resources or practices are most effective at mitigating mental health issues in this population?

Guidelines

- Discuss with parents the importance of their child's socialization and developing friendships with their peers and taking advantage of opportunities for activities.^{32,33} (Family Functioning Guidelines, Neuropsychology Guidelines)
- Encourage participation in preschool educational programs. (clinical consensus)
- Discuss the importance of making and keeping schedules/routines, doing chores, modeling behaviors, and making age-appropriate choices and decisions. (clinical consensus)
- Assess social and psychological development and identify resources that build on strengths and encourage resilience.^{7,32}
- Refer for social skills training as indicated.³²
- 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) Include optimization of mental health when developing an Individualized Education Program (IEP, IFSP or 504 Plan). (clinical consensus) (Appendix: Individualized Educational Plans (IEP) and 504 Plans)
- Provide additional age-appropriate information about Spina Bifida as the child grows.³¹
- Promote and encourage participation in community and [SBA](#) and [SBA Chapter-related activities](#) such as Spina Bifida Education Days and Walk-N-Roll for Spina Bifida. Recommend [SBA resources](#) found in spinabifidaassociation.org. (clinical consensus)

6-12 years 11 months

Clinical Questions

- Assess family functioning, stressors and supports. Identify strengths and build on resources and supports that encourage resilience.^{9,26}
- What is the psychosocial impact of having Spina Bifida on mental health and adaptation across the lifespan?
- 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?
- What are some common maladaptive behaviors that can negatively impact persons with Spina Bifida across the lifespan?
- What resources or practices are most effective at mitigating mental health issues in this population?

Guidelines

1. Continue to assess family function, especially family conflict and stress.³
2. Encourage participation in community activities for recreation.^{4,15,23,32-34} (Physical Activity Guidelines). Encourage activities and hobbies that improve face-to-face social contact.³⁵ (clinical consensus) Promote appropriate after-school sports and club activities.³⁴
3. 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).³²
4. 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.^{7,25} 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).^{7,8}
5. Assess the child for chronic pain symptoms, which may be related to internalizing symptoms and refer for multidisciplinary intervention.³⁶
6. Promote transfer of age-appropriate medical responsibility from parent to child in those who have the requisite abilities and cognitive capacity.¹⁹ (Family Functioning Guidelines)
7. Discuss the importance of increasing household responsibilities that are appropriately modified to account for mobility and cognitive limitations. (clinical consensus)
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.³² (Self-Management and Independence Guidelines)
10. Provide additional age-appropriate information/knowledge about Spina Bifida as the child grows. Begin to include child in clinical decision-making.³⁷ (Neuropsychology Guidelines)
11. Promote and encourage participation in community and [SBA](#) and [SBA Chapter-related activities](#) such as Spina Bifida Education Days and Walk-N-Roll for Spina Bifida. Recommend [SBA resources](#) found in spinabifidaassociation.org. (clinical consensus)

13-17 years 11 months

Clinical Questions

1. Assess family functioning, stressors and supports. Identify strengths and build on resources and supports that encourage resilience.^{9,26}
2. What is the psychosocial impact of having Spina Bifida on mental health and adaptation across the lifespan?
3. 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?
4. What are some common maladaptive behaviors that can negatively impact persons with Spina Bifida across the lifespan?
5. What resources or practices are most effective at mitigating mental health issues in this population?

Guidelines

1. Assess peer relationships and friendships.^{32,33}
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.^{15,38}

3. Screen for depression or anxiety and initiate individual and family interventions when appropriate.^{2,7,25} Certain health characteristics, such as a foot deformity and/or severe constipation, may contribute to poorer perceived mental health and social functioning.⁸
4. Assess the child for chronic pain symptoms, which may be related to internalizing symptoms and refer for multidisciplinary intervention.³⁶
5. Provide counseling and/or behavioral health support as needed. (clinical consensus)
6. Promote transfer of medical responsibility from parent to child in those who have the requisite abilities and cognitive capacity.¹⁹ (Self-Management and Independence Guidelines)
7. Refer for social skills training as needed.³⁹
8. Encourage activities and hobbies that improve face-to-face social contact.³⁵ (clinical consensus)
9. Provide counseling regarding sexuality, sexual functioning, fertility, and contraception. Focus on sexual safety issues.^{11–13} (Sexual Health and Education Guidelines)
10. Discuss the safe use of and choices around drugs and alcohol and conduct risk assessment in this domain.²⁶
11. Discuss the importance of initiating and organizing opportunities for social activities.³²
12. Discuss the relationship between independence and interdependence and mental health. (clinical consensus) (Self-Management and Independence Guidelines)
13. 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)
14. Provide or refer to opportunities for formal or informal mentoring. (clinical consensus)
15. Encourage the teen to participate in the school's IEP transition team meeting. (clinical consensus)
16. Develop a plan for the teen's transition to independent living, post-secondary education, vocational training, and career interests. (clinical consensus) (Transition Guidelines)
17. Develop a plan for transition from pediatric to adult health care. (clinical consensus) (Transition Guidelines)
18. Promote and encourage participation in community and [SBA](#) and [SBA Chapter-related activities](#) such as Spina Bifida Education Days and Walk-N-Roll for Spina Bifida. Recommend [SBA resources](#) found in spinabifidaassociation.org. (clinical consensus)

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.^{4,5,10,27} Certain health characteristics, such as a foot deformity and/or severe constipation, may contribute to poorer perceived mental health and social functioning.⁸
2. Screen for health risk behaviors, including substance use, exercise status and eating habits, which may be more likely in patients reporting depression.³⁸

3. Continue the transfer of medical responsibilities and encourage self-management behaviors in young adults with Spina Bifida who have the requisite abilities and cognitive capacity.⁴⁰
4. Encourage activities and hobbies that improve face-to-face social contact. (clinical consensus)
5. Encourage ongoing efforts to promote friendship and social intimacy.³³
6. Encourage and promote vocational or occupational goals and pursuits. (clinical consensus) (Transition Guidelines)
7. 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.^{37,41} (Physical Activity Guidelines)
8. Promote and encourage participation in community and [SBA](#) and [SBA Chapter-related activities](#) such as Spina Bifida Education Days and Walk-N-Roll for Spina Bifida. Recommend [SBA resources](#) found in spinabifidaassociation.org. (clinical consensus)
9. Continue to refine the plan to ease transition from pediatric to adult health care. (Transition Guidelines)
10. Develop efficient referral resources for coordinated Spina Bifida and mental health care.²⁷

Research Gaps

1. What services and supports can be utilized to mitigate barriers to optimal mental health throughout the lifespan?
2. What interventions are available to enhance mental health across the lifespan in individuals with Spina Bifida?
3. 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?
4. What resilience factors mediate mental health outcomes in children and adults with Spina Bifida?

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