

Guidelines for the Care of People with Spina Bifida

Family Functioning

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Introduction

Family functioning in the context of Spina Bifida is best explained by a *resilience-disruption* model, whereby some aspects of normative family functioning are disrupted by having a child with Spina Bifida, but where most families are able to adapt and exhibit significant resilience. The impact on the family of having a child with Spina Bifida varies considerably.¹⁻² Overall, there are relatively low rates of family-level dysfunction (10-15%) and high levels of family resilience. Parents of children with Spina Bifida show few differences in marital function compared to families of typically-developing children.^{3,4} The quality of the marital relationship prior to the birth of a child with Spina Bifida is an important predictor of parental adjustment. Findings for siblings suggest both positive and negative effects of having a sibling with Spina Bifida.⁵ Positive family attitudes toward Spina Bifida, overall family satisfaction, and the degree of sibling conflicts are important predictors of sibling adjustment.^{6,7} Family cohesion appears to be somewhat lower in families with children who have more significant cognitive impairment.⁸

Parental stress in families who are raising children with Spina Bifida is higher than in the general population⁹, particularly among mothers, single parents, older parents, and/or economically disadvantaged and culturally-diverse parents. This is an example of cumulative risk, which is an important construct relevant to both family functioning and Spina Bifida care. The complexity of the child's condition and parental personality traits (e.g., extraversion, agreeableness, emotional stability) have also been found to be significant predictors of parental stress.⁹

Studies including fathers and mother-father dyads in the literature on Spina Bifida are scarce. However, discrepancies in adjustment between mothers and fathers exist, with perceptions of high child vulnerability being associated with more mental health difficulties in fathers, and lower parenting alliance within couples.¹⁰ Mothers report higher levels of parenting stress and anxiety than fathers, but factors such as marital and employment statuses also contributed to mothers' distress, while being involved in recreational activities with other families affected by Spina Bifida served as a positive intervention for mothers.¹¹ Interventions for fathers should target parental personal distress and parenting stress.¹²

Although parents of children with Spina Bifida exhibit resiliency across multiple domains, a portion of them are at risk for emotional distress. For example, it is common for parents of children with Spina Bifida to feel less satisfied and competent as parents, to have a lower

Guidelines for the Care of People with Spina Bifida

quality of life, to have smaller social networks, to be less optimistic about the future, and to feel more isolated.^{13,14} Spina Bifida has a significant impact on parental adjustment and outcomes such as sleep duration and anxiety, especially for mothers.^{15,16} Parents may also experience Post Traumatic Stress Disorder (PTSD) and depression.^{13,15,17} Parents of adolescents and young adults with Spina Bifida are at increased risk for experiencing depression and lower family quality of life.^{18,19} Additional factors including family satisfaction, depressive symptoms, and parenting stress also contributed to lower family quality of life.¹⁹ Medical variables, such as presence of ventriculo-peritoneal (VP) shunts are related to increased levels of parental anxiety and depression, while prenatal repair of myelomeningocele resulted in more positive parental functioning.²⁰ The alterations in parent functioning that occur as a result of having a child with Spina Bifida impact the psychosocial adjustment of children.^{21,22}

The prevalence rates of Spina Bifida are highest for Latinos compared to all other racial/ethnic groups, however family functioning research on this population is limited. Ethnicity moderated the relationship between family function and youth psychosocial functioning, such that psychosocial functioning was associated with family conflict in Latino youth, but was associated with family cohesion, conflict, and stress for non-Latino youth.²³

Parents of youth with Spina Bifida exhibit higher levels of parental intrusiveness (i.e., overprotectiveness, perceived child vulnerability) and these behaviors are often linked with less functional child outcomes (e.g., lower levels of independent decision-making). However, these effects are often modified by the child's cognitive level (e.g., children with lower IQs have parents who are more controlling or have lower expectations of milestone achievement.^{24,25}),¹¹ Parents of children with Spina Bifida tend to be less responsive to preparing for pubertal development than is the case in families of typically-developing children (i.e., in typically developing families, family conflict tends to increase normatively during the adolescent developmental period as a function of pubertal change; this tends not to be the case in families of youth with spina bifida).²⁶

Nonetheless, adolescence is a challenging time as parents and teens negotiate the gradual transfer of medical management from parent to child, although parents can positively influence their child's transition to adult care by providing structure, support and developmentally appropriate expectations for participation in self-care.²⁷ Family conflict is associated with diminished medical adherence in this age group.²⁸ Few family intervention studies specific to Spina Bifida have been conducted to better understand this important topic.²⁹ (Self-Management and Independence Guidelines, Transition Guidelines).

Outcomes

Primary

1. Maximize family resilience and adaptation to multiple Spina Bifida-related and normative stressors as appropriate for developmental level.

Secondary

Guidelines for the Care of People with Spina Bifida

1. Maximize parental adaptation, expectations, and responsiveness to the changing developmental level of the child by identifying and reinforcing effective parenting techniques.
2. Maximize independence of the child within the family context, given developmental level and condition-related constraints.

Tertiary

1. Minimize parental and marital stress and maladaptation when raising a child with a serious chronic health condition.
2. Maximize family engagement in social activities, including parental self-care activities.
3. Maximize parental knowledge of Spina Bifida and advocacy.

0-11 months

Clinical Questions

1. What is the impact of having a child with Spina Bifida on family functioning (including parental adjustment, marital functioning, effect on the siblings and extended family, and familial participation in social activities) and how does this impact change as children move through various stages of lifespan development?
2. What resilience and vulnerability factors are predictive of familial adaptation at each level of child development?
3. What parenting behaviors facilitate adaptive child outcomes (including independence-related outcomes such as self-management and the transfer of health care responsibilities from parent to child) and how do these adaptive parenting behaviors vary developmentally?
4. What interventions or approaches can promote family functioning?

Guidelines

1. Refer families who have received a prenatal diagnosis of Spina Bifida for prenatal counseling and consultation with members of a Spina Bifida multidisciplinary clinical team. Assess family dynamics and adjustment in response to diagnosis.¹⁹ (Prenatal Counseling Guidelines)
2. Assess for postpartum depression. Provide information about Spina Bifida, parenting, treatments, support groups, and the Spina Bifida Association. (clinical consensus).
3. Coordinate services during the transition from the hospital stay to subsequent clinic follow-up, stressing the need for ongoing multi-specialty care.¹⁹
4. Teach necessary home care procedures such as post-surgical care, skin care, and clean intermittent catheterization, as needed.¹⁹
5. Assess family dynamics and adjustment (e.g., post-traumatic stress disorder in parents) during infancy.^{5,7,19}
6. Refer the parents or caregivers to infant intervention and appropriate state programs (e.g., Supplemental Security Income) and financial resources as needed. Provide financial counseling if necessary. (clinical consensus)
7. Provide support and ongoing counseling as needed to parents, the child, and siblings.^{16,19}

Guidelines for the Care of People with Spina Bifida

8. Provide anticipatory guidance for parents regarding strengths and possible cognitive and behavioral challenges in children with Spina Bifida and their siblings.^{16,19}
9. Teach parents to advocate for themselves and their child when working with medical, educational, and agency staff. (clinical consensus)
10. Be aware that although interventions should target all families, some families are particularly at-risk for adjustment and adherence difficulties (e.g., those from lower socioeconomic backgrounds and single-parent families).¹⁸
11. Assess the family's ability to carry out medical regimens, and identify possible barriers to adherence, such as need for caregiver support and parental beliefs regarding alternative therapies.¹⁷
12. Assess the family's perspective on the experience of the birth of a new baby. Encourage family to reframe Spina Bifida as one part of their baby's experience and to appreciate the other typical aspects of birth and infancy.

1-2 years 11 months

Clinical Questions

1. What is the impact of having a child with Spina Bifida on family functioning (including parental adjustment, marital functioning, effect on the siblings and extended family, and familial participation in social activities) and how does this impact change as children move through various stages of lifespan development?
2. What resilience and vulnerability factors are predictive of familial adaptation at each level of child development?
3. What parenting behaviors facilitate adaptive child outcomes (including independence-related outcomes such as self-management and the transfer of health care responsibilities from parent to child) and how do these adaptive parenting behaviors vary developmentally?
3. What interventions or approaches can promote family functioning?

Guidelines

1. Provide support and ongoing counseling as needed to parents, the child, and siblings.^{16,19} (Mental Health Guidelines)
2. Be aware that although interventions should target all families, some families are particularly at-risk for adjustment and adherence difficulties (e.g., those from lower socioeconomic backgrounds and single-parent families).¹⁸
3. Promote effective parenting techniques or provide referral for such services.¹¹
4. Provide anticipatory guidance for parents regarding possible behavioral challenges and autonomy needs in children with Spina Bifida and their siblings.^{16,19} (Mental Health Guidelines, Neuropsychology Guidelines)
5. Provide anticipatory guidance on achievement of developmental milestones and refer for therapeutic intervention, if necessary (<https://www.aap.org/en/practice-management/bright-futures/bright-futures-in-clinical-practice/>)
6. Assess family's need for additional counseling, financial resources, or other support services. (clinical consensus)
7. Inform families of advocacy resources and encourage them to contact the appropriate governmental and non-governmental authorities to obtain additional information, referrals, and support. (clinical consensus)

Guidelines for the Care of People with Spina Bifida

8. Encourage the parents or other primary caregivers to teach other family members or close friends how to provide for the child's specialized care needs and how to access other needed services. Alternatively, families can arrange for child care by trained professionals. (clinical consensus)
9. Educate parents about the importance of engaging in personal activities that promote parental well-being.⁵
10. Refer the parents to early intervention services, if these are not already in place. (clinical consensus)
11. Assess the family's ability to carry out medical regimens, and identify possible barriers to adherence, such as need for caregiver support and parental beliefs regarding alternative therapies.¹⁷
12. Assess parents' mental health symptoms (e.g., PTSD, anxiety, depression) to identify whether interventions are needed.

3-5 years 11 months

Clinical Questions

1. What is the impact of having a child with Spina Bifida on family functioning (including parental adjustment, marital functioning, effect on the siblings and extended family, and familial participation in social activities) and how does this impact change as children move through various stages of lifespan development?
2. What resilience and vulnerability factors are predictive of familial adaptation at each level of child development?
3. What parenting behaviors facilitate adaptive child outcomes (including independence-related outcomes such as self-management and the transfer of health care responsibilities from parent to child) and how do these adaptive parenting behaviors vary developmentally?
4. What interventions or approaches can promote family functioning?

Guidelines

1. Provide support and ongoing counseling as needed to parents, the child, and siblings.^{16,19}
2. Provide anticipatory guidance for parents regarding possible behavioral challenges and autonomy needs in children with Spina Bifida and their siblings^{16,19} (Mental Health Guidelines, Neuropsychology Guidelines)
3. Teach parents to advocate for themselves and their child when working with medical, educational, and agency staff. (clinical consensus)
4. Be aware that although interventions should target all families, some families are particularly at-risk for adjustment and adherence difficulties (e.g., those from lower socioeconomic backgrounds and single-parent families).¹⁸
5. Assess parenting skills such as discipline, behavior management, and sibling relationships.¹¹
6. In the context of family functioning, address self-care abilities and refer to therapies (OT, PT). (clinical consensus)
7. Discuss issues that affect children with Spina Bifida when they transition to school. (clinical consensus)

Guidelines for the Care of People with Spina Bifida

8. Advise parents of their child's' right to free and appropriate education in the least restrictive environment through the public schools (i.e., explain services available under the Individuals with Disabilities Education Act). (clinical consensus)
9. Assess the family context for helping the child to develop self-management skills and to carry out medical regimens and identify possible barriers to adherence.¹⁷ (Self-Management and Independence Guidelines, Transition Guidelines)
10. Management and Independence Guidelines, Transition Guidelines)
11. Assess parents' mental health symptoms (e.g., PTSD, anxiety, depression) to identify whether interventions are needed.

6-12 years 11 months

Clinical Questions

1. What is the impact of having a child with Spina Bifida on family functioning (including parental adjustment, marital functioning, effect on the siblings and extended family, and familial participation in social activities) and how does this impact change as children move through various stages of lifespan development?
2. What resilience and vulnerability factors are predictive of familial adaptation at each level of child development?
3. What parenting behaviors facilitate adaptive child outcomes (including independence-related outcomes such as self-management and the transfer of health care responsibilities from parent to child) and how do these adaptive parenting behaviors vary developmentally?
4. What interventions or approaches can promote family functioning?

Guidelines

1. Provide support and ongoing counseling for parents, the child, and siblings, as needed.^{16,19}
2. Provide anticipatory guidance for parents regarding possible behavioral challenges and autonomy needs in children with Spina Bifida and their siblings.^{16,19} (Mental Health Guidelines, Neuropsychology Guidelines)
3. Be aware that although interventions should target all families, some families are particularly at-risk for adjustment and adherence difficulties (e.g., those from lower socioeconomic backgrounds and single-parent families).¹⁸
4. Assess family dynamics and relationships with school staff. (clinical consensus)
5. Educate family on school-based accommodations [e.g., 504 plan or Individual Education Plan (IEP)] to address academic, social, and physical health difficulties. Provide family with information on accessing these services:
<https://www.spinabifidaassociation.org/resource/iep-and-504-plans> (clinical consensus)
6. Reinforce appropriate family leisure activities. (clinical consensus)
7. Reinforce effective parental discipline, behavioral management, and expectations.¹¹
8. Encourage the family to facilitate medical self-management in their children with Spina Bifida, as developmentally appropriate.^{17,20-21} (Self-Management and Independence Guidelines)
9. Facilitate parents' understanding of the importance of fostering their child's independence and participating in chores and other activities of daily living.¹⁹ (Self-Management and Independence Guidelines)

Guidelines for the Care of People with Spina Bifida

10. Encourage social activities such as sleepovers, camp overnights, dating, and social and recreational activities outside the home. Encourage development and maintenance of friendships.²²
11. Emphasize positive attitudes, assertiveness, and self-empowerment of family members. (clinical consensus)
12. Encourage the family to develop strategies that gradually empower their children toward independence such as decision-making and problem-solving.^{11,20-21} (Self-Management and Independence Guidelines)
13. Assess the family context for helping the child to develop self-management skills and to carry out medical regimens and identify possible barriers to adherence.¹⁷ (Self-Management and Independence Guidelines, Transition Guidelines)
14. Assess parents' mental health symptoms and levels of parental stress to identify whether interventions are needed.²²

13-17 years 11 months

Clinical Questions

1. What is the impact of having a child with Spina Bifida on family functioning (including parental adjustment, marital functioning, effect on the siblings and extended family, and familial participation in social activities) and how does this impact change as children move through various stages of lifespan development?
2. What resilience and vulnerability factors are predictive of familial adaptation at each level of child development?
3. What parenting behaviors facilitate adaptive child outcomes (including
4. independence-related outcomes such as self-management and the transfer of health care responsibilities from parent to child) and how do these adaptive parenting
5. behaviors vary developmentally?
6. What interventions or approaches can promote family functioning?

Guidelines

1. Provide support and ongoing counseling for parents, child, and siblings, as needed.^{16,19}
2. Be aware that although interventions should target all families, some families are particularly at-risk for adjustment and adherence difficulties (e.g., those from lower socioeconomic backgrounds and single-parent families).¹⁸
3. Assess parent-child communication and their relationship. Aid parents to encourage the development of autonomy in their child with Spina Bifida.¹¹ (Self-Management and Independence Guidelines)
4. Encourage the family to begin planning for their child's transition to adult health care. (Transition Guidelines)
5. Begin discussions of other important developmental milestones, including educational and vocational achievement, living independently, and community participation. (Transition Guidelines)
6. Give advice to the child and family about the right to free and appropriate education in the least restrictive environment through the public schools (i.e., explain services

Guidelines for the Care of People with Spina Bifida

available under the Individuals with Disabilities Education Act and Section 504 of Vocational Rehabilitation Act of 1973). (clinical consensus)

7. Assist with normative sexual education, as well as specific issues relevant to the teen's condition. Work with the teen to navigate sexual expression in a safe and mature fashion. (Sexual Health and Education Guidelines)
8. Continue to encourage the family to facilitate medical self-management in their child with Spina Bifida.²⁰⁻²¹ (Self-Management and Independence Guidelines)
9. Assess the family context for helping the child to develop self-management skills and to carry out medical regimens and identify possible barriers to adherence.¹⁷ (Self-Management and Independence Guidelines, Transition Guidelines)

18+ years

Clinical Questions

1. What is the impact of having a young adult with Spina Bifida on family functioning (including parental adjustment, marital functioning, effect on the siblings and extended family, and familial participation in social activities) and how does this impact change as children move through various stages of lifespan development?
2. What resilience and vulnerability factors are predictive of familial adaptation at each level of child development?
3. What parenting behaviors facilitate adaptive child and adult outcomes (including independence-related outcomes such as self-management and the transfer of health care responsibilities from parent to child) and how do these adaptive parenting behaviors vary developmentally?
4. What interventions or approaches can promote family functioning?

Guidelines

1. Provide support and ongoing counseling for parents, young adults, and siblings, as well as older adults with Spina Bifida, as needed.^{16,19}
2. Work with families to support the development of maximal vocational and social independence.¹⁹
3. Continue to work with the family to support medical self-management in their young adult.²⁰⁻²¹
4. Continue working with the family to ensure a successful transition to adult health care. (Transition Guidelines)
5. Work with the young and older adults to navigate sexual expression in a safe and mature fashion. (Sexual Health and Education Guidelines)
6. Assess the family context for helping the young adult to develop self-management skills and to carry out medical regimens and identify possible barriers to adherence.¹⁷ (Self-Management and Independence Guidelines, Transition Guidelines)

Research Gaps

Guidelines for the Care of People with Spina Bifida

1. What interventions are available to facilitate adaptive parenting behavior?
2. What interventions are available to enhance familial, marital, and parental adjustment outcomes?
3. What interventions are available to maximize familial resilience and adaptation at each level of the child's development?
4. What interventions are available to support families as they transfer medical management from parent to child, and the transition from pediatric to adult health care?
5. How does the characteristic cognitive profile of children and young adults with Spina Bifida complicate the unfolding of self-management within the family context?

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Guidelines for the Care of People with Spina Bifida

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Guidelines for the Care of People with Spina Bifida

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