Family Functioning

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Outcomes

• **Primary**: Maximization of family resilience and adaptation to multiple SB-related and normative stressors as appropriate for developmental level.

• **Secondary**: Maximization of developmentally-appropriate parental adaptation, expectations, and responsiveness to the changing developmental level of the child, while maintaining effective parenting techniques. Maximize independence of the child within the family context, given developmental level and condition-related constraints.

• **Tertiary**: Minimization of parental and marital stress and maladaptation when raising a child with a serious chronic health condition. Maximization of family engagement in social activities, including parental self-care activities. Maximization of parental knowledge of spina bifida and advocacy.
Prenatal/Infancy (through age 1 year)

Clinical Questions

1. What is the impact of having a child with SB on family functioning (including parental adjustment, marital functioning, siblings, 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?
Prenatal/Infancy (through age 1 year)

Guidelines

1. Refer families who have received a prenatal diagnosis of spina bifida for consultation to members of a spina bifida multidisciplinary clinical team. Assess family dynamics and adjustment in response to diagnosis.

2. Provide information about spina bifida, parenting, treatment modalities, support groups, and the SBA.

3. Coordinate services during the transition from hospital stay and subsequent clinic follow-up, stressing the need for ongoing multi-specialty care.
Prenatal/Infancy (through age 1 year)

Guidelines

4. Teach necessary home care procedures related to needs of child with spina bifida such as post surgical care, skin care, and clean intermittent catheterization.

5. Assess family dynamics and adjustment during infancy.

6. Refer to infant intervention, appropriate state programs (SSI), financial resources as needed. Provide financial counseling as needed.

7. Provide support and ongoing counseling.
Prenatal/Infancy (through age 1 year)

Guidelines

8. Provide anticipatory guidance regarding child development behavior.

9. Teach parent advocacy.

10. Interventions should target at-risk families, such as those from lower SES backgrounds and single-parent families.

11. Assess adherence to medical regimen
Clinical Questions

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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?
Toddler (1-3 years)

Guidelines

1. Interventions should target at-risk families, such as those from lower SES backgrounds and single-parent families.

2. Promote effective parenting techniques.

3. Provide anticipatory guidance regarding behavior and autonomy needs.

4. Advise parents of their child’s’ right to free and appropriate education in the least restrictive environment through the public schools.
Toddler (1-3 years)

Guidelines

5. Inform families of advocacy resources and encourage them to contact appropriate authorities.

6. Assess family need for additional counseling, financial resources, or other support services.

7. Encourage family to teach other family members or close friends how to provide for the child’s specialized care needs or how to access other services. Alternatively, families can arrange for trained childcare.
Guidelines

8. Educate parents about the importance of personal activities that promote parental well-being.

9. Refer to Early Intervention Services, if not already in place

10. Interventions should target at-risk families, such as those from lower SES backgrounds and single-parent families.

11. Assess adherence to medical regimen
Preschool (3-5 years)

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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?
Preschool (3-5 years)

Guidelines
1. Provide support and ongoing counseling.

2. Provide anticipatory guidance regarding child development behavior.

3. Teach parent advocacy.

4. Interventions should target at-risk families, such as those from lower SES backgrounds and single-parent families.
Guidelines

5. Re-assess parenting skills (discipline, behavior management, sibling relationships).

5. Address self-care abilities and refer to therapies (OT, PT).

6. Discuss issues of transition to school.

7. Assess adherence to medical regimen
School Age

Clinical Questions

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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?
School Age

Guidelines
1. Provide support and ongoing counseling.

2. Provide anticipatory guidance regarding child development behavior.

3. Interventions should target at-risk families, such as those from lower SES backgrounds and single-parent families.

4. Assess family dynamics and relationships with school.
School Age

Guidelines

5. Expand information on appropriate interventions for academic and social difficulties. Parents should be provided with current and accurate information about home schooling, and the impact that such a strategy has on family members and the family system.

6. Encourage advocacy activities and resources.

7. Serve as a resource to school systems regarding health issues, IEP planning, and socialization.

8. Reinforce appropriate family leisure activities.
School Age

Guidelines

9. Reinforce effective parental discipline, behavioral management, and expectations.

10. Encourage family to facilitate medical self-management in their children with spina bifida

11. Facilitate parents understanding independence and activities of daily living (ADL) including chores.

12. Encourage social activities such as sleep-overs, camp overnights, dating, and social and recreational activities outside the home.
School Age

Guidelines

13. Emphasize positive attitudes, assertiveness, and self-empowerment of family members.

14. Encourage family to develop strategies that gradually empower their children toward independence such as decision-making and problem-solving.

15. Assess adherence to medical regimen
Teenage

Clinical Questions

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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?
Teenage

Guidelines

1. Provide support and ongoing counseling.

2. Interventions should target at-risk families, such as those from lower SES backgrounds and single-parent families.

3. Assess parent-adolescent communication and relationship. Aid parents in encouraging autonomy development in youth with SB.
Teenage

Guidelines

1. Provide support and ongoing counseling.

2. Interventions should target at-risk families, such as those from lower SES backgrounds and single-parent families.

3. Assess parent-adolescent communication and relationship. Aid parents in encouraging autonomy development in youth with SB.
Teenage

Guidelines

4. Encourage family to begin planning for the transition to adult health care. Related to this, begin discussions of other important developmental milestones, including educational and vocational achievement, living independently, and community participation.

5. Assist with sexual education specific to the teen’s’ condition.

6. Refer for vocational assessment.
Teenage

Guidelines

7. Continue to encourage family to facilitate medical self-management in their children with spina bifida

8. Assess adherence to medical regimen
Clinical Questions

1. What is the impact of having a child with SB on family functioning (including parental adjustment, marital functioning, siblings, 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?
Adult

Guidelines

1. Provide support and ongoing counseling

2. Work with families to support the development of maximal vocational and social independence.

3. Continue to work with family to support medical self-management in their young adults
Adult

Guidelines

4. Continue working with family to ensure a successful transition to adult health care

5. Work with young adult to navigate sexual expression in safe and mature fashion.

6. Assess adherence to medical regimen
1. What interventions are available that maximize familial resilience and adaptation at each level of the child’s development?
2. What interventions are available that facilitate adaptive parenting behavior?
3. What interventions are available that enhance familial, marital, and parental adjustment outcomes?
4. What interventions are available to support self-management, the transfer of medical management from parent to child, and the transition from pediatric to adult health care?
5. How does the characteristic cognitive profile of youth with SB complicate the unfolding of self-management within the family context?
References


References


References
