Transition
Ellen Fremion, Chair
Kathy Smith
Sue Leibold
Sue Mukherjee
Julianne Lane
Ann Modrcin
Melissa Kaufman
Outcomes

• **Primary**: Maximize and support independence in self-care, daily living responsibilities, education/vocation, and social engagement for individuals with spina bifida throughout life.

• **Secondary**: Promote uninterrupted access to comprehensive healthcare services, educational/vocational opportunities, and community supports to promote health, development, and independence throughout life.

• **Tertiary**: Provide patient-centered and coordinated chronic condition management throughout the process of transitioning from pediatric to adult care, including orientation to adult healthcare services, preventative health strategies, self-management support, and adaptive resources.
Prenatal/Infancy (through age 1 year)

Clinical Questions
1. How can a patient’s probable trajectory regarding future independence be identified?
2. What strategies have been successful in enhancing self-care skills?
Prenatal/Infancy (through age 1 year)

Guidelines

1. Healthcare providers should discuss realistic expectations for optimizing independence during routine infant visits.
2. Families should be connected to parent groups and if possible, adults with spina bifida for encouragement and mentorship.
3. Ensure regular follow up for spina bifida specific and general health and developmental screenings.
Toddler (1-3 years)

Clinical Questions

1. How can a patient’s probable trajectory regarding future independence be identified?
2. What strategies have been successful in enhancing self-care skills?
Toddler (1-3 years)

Guidelines

1. Provide anticipatory guidance regarding developmental needs for toddlers.
2. Promote engagement in age-appropriate activities and refer to appropriate therapies and early intervention.
3. Refer to community resources that promote independence and peer inclusion.
4. Encourage families to expect participation in daily life activities.
5. Teach families to regularly offer age-appropriate choices.
6. Families should be connected to parent groups and adults with spina bifida.
7. Ensure regular follow up for spina bifida specific and general health and developmental screenings.
Preschool (3-5 years)

Clinical Questions

1. How can a patient’s probable trajectory regarding future independence be identified?
2. What strategies have been successful in enhancing self-care skills?
Preschool (3-5 years)

Guidelines
1. Provide anticipatory guidance developmental needs for preschoolers.
2. Refer to community resources that promote independence and peer inclusion.
3. Encourage family educational opportunities.
4. Encourage families to expect participation in daily life activities.
5. Involve the child in daily self-care.
6. Review expectations for appropriate behavior with families.
7. Discuss diagnosis using age-appropriate language and pictures.
Guidelines (cont)

8. Families should be connected to parent groups and if possible, adults with spina bifida for encouragement and mentorship.

9. Ensure regular follow up for spina bifida specific and general health and developmental screenings. Provide referrals to appropriate services as needed to support patient developmental progress.
School Age

Clinical Questions:
1. How can a patient’s probable trajectory regarding future independence be identified?
2. What strategies have been successful in enhancing self-care skills?
School Age
Guidelines:

1. Assess for self-care ability and have individualized, step-wise goals. Parents need to be supported as coaches.
2. Children should be expected to do routine care independently by middle school.
3. Encourage family educational opportunities.
4. Children should participate in age and ability appropriate household chores.
5. Discuss diagnosis with the child using age-appropriate language and pictures.
7. Assess peer relationships and socialization.
8. Emphasize positive attitudes and self-empowerment with realistic goals.
Clinical Questions: Primary Outcomes

1. How can a patient’s probable trajectory regarding future independence be identified?
2. What are barriers and facilitators to participating in emerging adult milestones for individuals with SB?
3. What strategies have been successful in enhancing self-care skills?
Clinical Questions: Secondary Outcomes

1. What are patient centered perceptions of a successful transition experience?

2. What are the systems level barriers to successful transition and strategies that have effectively mitigated them?

3. What are the best strategies to find and engage adult providers?

4. What are the essential elements for transition preparation and hand-off to promote uninterrupted access to care for individuals with SB?
Clinical Questions: Tertiary Outcomes

1. Do individuals with spina bifida prioritize learning self-management skills, becoming independent, and setting their own goals?
2. What are the key readiness parameters for patients with spina bifida that can be measured over time?
3. What are the preventative and chronic condition management considerations in the transition age group?
4. What are examples of successful transition models of SB?
Teenage

Guidelines

1. Assess for self-care ability and have individualized, step-wise goals.
2. Emphasize positive attitudes and self-empowerment while setting realistic goals to increase responsibilities.
3. Teens should be expected to be the primary managers of their self-care routines. Parents/caregivers should still have a supervisory roll.
Teenage

Guidelines (con’t)

4. Encourage involvement in community activities
5. Assess for learning difficulties in school and with self-care
6. Encourage the teen to participate in IEP planning that addresses transition.
7. Assess individual and system barriers to access to care and chronic condition management during the transition.
Teenage

Guidelines (con’t)

8. Use electronic health care records and internet resources to support transition care coordination

9. Assess access and ability in using public and private transportation.

10. Discuss sexual health.

11. Assess mental health and family/peer relationships. Refer for mental health care as needed.
Clinical Questions: Primary Outcomes

1. What are barriers and facilitators to participating in emerging adult milestones for individuals with SB?
2. What strategies have been successful in enhancing self-care skills?

Secondary Outcome

4. What are patient centered perceptions of a successful transition experience?
5. What are the best strategies to find and engage adult providers?
6. What are the essential elements for transition preparation and hand-off to promote uninterrupted access to care for individuals with SB?
Adult

Clinical Questions: Secondary Outcome
1. What are patient centered perceptions of a successful transition experience?
2. What are the best strategies to find and engage adult providers?
3. What are the essential elements for transition preparation and hand-off to promote uninterrupted access to care for individuals with SB?
**Clinical Questions: Tertiary Outcome**

1. Do individuals with spina bifida prioritize learning self-management skills, becoming independent, and setting their own goals?

2. What are the preventative and chronic condition management considerations in the transition age group?

3. What are examples of successful transition models of SB?
Adult

Guidelines:

1. Assess for self-care ability and chronic condition management including ability to detect health problems and take appropriate action.
2. Regularly evaluate and monitor cognitive function.
3. Encourage social and community engagement.
4. Ensure continuity of primary health care and continued access to comprehensive and coordinated specialty care.
5. Assess for independently living needs.
6. Discuss sexual health
7. Assess mental health and family/peer relationships
1. Studies to identify best practices for comprehensive care for adolescents and adults with spina bifida are needed.
   1. preventative health in general and related to spina bifida
   2. assessment of secondary conditions related to spina bifida and aging
   3. access to care
   4. self-management support throughout transition.

2. Educational programs for health care professionals are needed to improve their awareness and knowledge of the medical and social issues of transition and adult life for individuals with spina bifida.

3. Best practice interventions to support self-management development, developmental milestone achievement, and maximal adult independence are needed.
References


References


