Health Care Guidelines for Persons Living with Spina Bifida

Care coordination working group

Definition of Care Coordination:

“Care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care.” International Journal of Care Coordination (Reference #8 Butler, et al)

Overall Outcomes:

**Primary**: Maximize overall health and functioning of individuals living with Spina Bifida throughout the lifespan by improved access to team based, patient centered coordinated care for medical, social, educational, equipment and other developmentally relevant related services.

**Secondary**: Promote comprehensive and coordinated uninterrupted access to medical/subspecialty, and allied health professional services throughout the lifespan with appropriate communication between patients and team members. (14)

**Tertiary**: By maintaining up to date coordinated care for individuals living with spina bifida minimize medical complication rates, control cost of care, and minimize emergency room use and unanticipated hospitalization, morbidity and mortality. (12)

Infancy and Prenatal Clinical Questions

What is the role and responsibility of the care coordinator during pregnancy for expectant mothers carrying children with the prenatal diagnosis of spina bifida and during early infancy?

What is the optimal method to promote effective communication between multiple team members’ patients and their families to best serve patient needs, prevent complications, and improve the overall patient experience of care. (5, 14)

What evidence exists showing the success of care coordination program in improving the overall health of Spina Bifida patients?

How does the care coordinator collaborate with team members, allied health services, and community partners to optimize the opportunities and overall quality of life of their patients?
What are the common barriers (staffing, logistical, community resources etc.) to creating an effective patient centered care coordination program within the multidisciplinary Spina Bifida clinic?

What aspects of a care coordination program do families/patients find most helpful and improve their perception of the care they receive (14)?

**Infant/Pregnancy Guidelines**

1. Spina Bifida Care coordinator when possible should be available to provide support and education for the family throughout the pregnancy after a prenatal diagnosis of SB has been made. These consults may take place as part of a maternal fetal health visit in a high risk pregnancy center. The goals may include assisting the family with coping with the new diagnosis. Providing overall education to the family on what to expect during early infancy and the NICU stay including general information on the condition signs and symptoms related to myelomeningocele. The care coordinator may assist in coordinating prenatal visits for other subspecialties neurosurgery urology orthopedics that will care for the family in early infancy. The primary role of the care coordinator during this stressful time for families is to convey the message that the family is not alone with this diagnosis. There will be a care team well prepared to provide them with the support they need to help care for their child (11).

2. The time period during pregnancy or early infancy the care coordinator can use to introduce the family to the Spina Bifida Center and multidisciplinary team when available and beginning the process of arranging post discharge follow up. The care coordinator through counseling and encouragement assists the family to accept the diagnosis. Develop the medical home for the infant and family with spina bifida, including the identification of the specific lead professional or nurse case manager who will serve as the point of contact for the family providing education, resources, and support.(1,11)

3. Provide broad and appropriate early education across the SB spectrum for families with Neonates/Infants. This may include topics such as educating the family on early urologic work-up and management possibly including CIC teaching. Other topics may include education on latex allergy and precautions, education re early orthopedic interventions, and education to help families recognize potential neurosurgical complications.

4. Care coordination should work closely with NICU staff to ensure that parents have the necessary patient care skills and education for discharge and a smooth transition to home care

5. Communicate and collaborate between family and multidisciplinary and sub specialty Spina Bifida team members to arrange and execute the early infancy follow-up appointments monitoring and care plan.(2,6)

6. Refer families to state Part C early intervention services and title 9 programs

7. Make referrals to local Spina Bifida Association chapters and parent support groups as available

**Toddler Clinical Questions**

How do the roles and responsibilities of the care coordinator evolve over time as the patient with SB ages?

How does the care coordinator collaborate with team members, allied health services, and community partners to optimize the opportunities and overall quality of life of their patients? (5, 10, 11)
What is the optimal method to promote effective communication between multiple team members’ patients and their families to best serve patient needs, prevent complications, and improve the overall patient experience of care.

What are the common barriers (staffing, logistical, community resources etc.) to creating an effective patient centered care coordination program within the multidisciplinary Spina Bifida clinic? (2)

What aspects of a care coordination program do families/patients find most helpful and improve their perception of the care they receive? (14)

**Guidelines**

1. Coordinate with family and multidisciplinary spina bifida care team to ensure the toddler patient with spina bifida is up to date on all sub specialty care visits, imaging and monitoring and equipment needs where appropriate. This includes assistance with insurance authorization or referrals when needed (6).

2. Provide further education across the SB spectrum for Toddlers/families to better empower families to manage their own care and recognize complications and emergencies. Identify gaps in the family knowledge base.

3. Monitor family progress with therapies and treatments encourage continued participation in early intervention services.

4. Collaboration with team members to identify gaps or barriers to achieving the goals of the patient care plan gain assist with additional referrals as appropriate.

5. When applicable care coordination should update the patient’s primary care provider on the current care goals and recommendations of the Spina Bifida Multidisciplinary care team. Use two way communication to obtain updated records from the PMD as well (immunizations, growth charts, developmental screenings etc.).

6. During the toddler years the care coordinator should begin emphasizing with the family early independence for the toddler. Encouraging activities such as learning to help put on shoes and braces etc. will promote greater independence and autonomy, and promote further discussions of independence as the child ages.

**Preschool Clinical Questions**

How do the roles and responsibilities of the care coordinator evolve over time as the patient with SB ages?

What evidence exists showing the success of care coordination program in improving the overall health of Spina Bifida patients? (10)

What is available in the literature to support optimal teaching and education of patients and their caregivers throughout the lifespan to maximize early independence? (18)

What is the optimal method to promote effective communication between multiple team members’ patients and their families to best serve patient needs, prevent complications, and improve the overall patient experience of care.
What are the common barriers (staffing, logistical, community resources etc.) to creating an effective patient centered care coordination program within the multidisciplinary Spina Bifida clinic?

What aspects of a care coordination program do families/patients find most helpful and improve their perception of the care they receive?

**Preschool Guidelines**

1. Provide further developmentally appropriate patient care education across the SB spectrum for Preschoolers/families to better empower families to manage their own care and recognize complications and emergencies. Identify and or improve gaps in the family knowledge base specifically related to the preschool period (mobility progress, toilet training/bowel bladder care speech/cognitive development etc.)
2. Prepare family for early independence, entering preschool school, and completion Individual educational plan (IEP/S04 plan).
3. Coordinate with family and multidisciplinary spina bifida care team to ensure the preschool patient with spina bifida is up to date on all sub specialty care visits imaging and monitoring and equipment needs where appropriate including assistance with insurance authorization when needed(2,6).
4. Assess family dynamics in coping with the diagnosis and evaluate psychosocial stressors for the family. Assist with referrals to mental health and social services when appropriate.
5. Care coordinator to serve family as lead contact person and information provider for the multidisciplinary medical home for the preschooler with spina bifida. Monitor family needs and prescriptions for durable medical equipment, supplies and medications as needed(1)

**School Age Clinical Questions**

How do the roles and responsibilities of the care coordinator evolve over time as the patient with SB ages?

What evidence exists showing the success of care coordination program in improving the overall health of Spina Bifida patients? (10)

How does the care coordinator collaborate with team members, allied health services, and community partners to optimize the opportunities and overall quality of life of their patients?

What is the optimal method to promote effective communication between multiple team members’ patients and their families to best serve patient needs, prevent complications, and improve the overall patient experience of care.

What are the common barriers (staffing, logistical, community resources etc.) to creating an effective patient centered care coordination program within the multidisciplinary Spina Bifida clinic? (2)
What aspects of a care coordination program do patients find most helpful and improve their perception of the care they receive? (2)

School Age Guidelines

1. Provide further developmentally appropriate patient care education across the SB spectrum for School age children/families to better empower families to manage their own care and recognize complications and emergencies. Identify and or improve gaps in the family knowledge base specifically related to the school age period (mobility progress, toilet training/bowel bladder care academic/cognitive development school and social functioning etc.)

2. Monitor primary school functioning, and updated IEP/504 plan. Encourage participation in age appropriate activities with peers with and without spina bifida outside of school. Encourage participation opportunities such as camps or special family weekends that provide safe places to develop peer relationships with children who may have similar medical challenges.

3. Coordinate with family and multidisciplinary spina bifida care team to ensure the school age patient with spina bifida is up to date on all sub specialty care visits imaging and monitoring and equipment needs where appropriate. This may include assistance with insurance authorization when needed (2, 6).

4. Assess family dynamics in coping with the diagnosis, and evaluate psychosocial stressors for the family. Assess for depression and anxiety and assist with referrals to mental health and social services when appropriate.

5. Work with the individual school age child, family and Spina Bifida Team members and therapists to start progress on self-care goals and education. Monitor family progress in self-care at regular intervals and clinic visits. Teach self-advocacy and encourage child to participate as much as possible in their own self-care.(3)

6. Care coordinator to serve family as lead contact person and information provider for the multidisciplinary medical home for the school age child with spina bifida. Monitor family needs and prescriptions for durable medical equipment, supplies and medications as needed.(1,11)

Teenage Clinical Questions

How do the roles and responsibilities of the care coordinator evolve over time as the patient with SB ages?

What evidence exists showing the success of care coordination program in improving the overall health of Spina Bifida patients? (13)
How does the care coordinator collaborate with team members, allied health services, and community partners to optimize the opportunities and overall quality of life of their patients? (17)

What is the optimal method to promote effective communication between multiple team members’ patients and their families to best serve patient needs, prevent complications, and improve the overall patient experience of care.

What are the common barriers (staffing, logistical, community resources etc.) to creating an effective patient centered care coordination program within the multidisciplinary Spina Bifida clinic? (14)

What aspects of a care coordination program do patients find most helpful and improve their perception of the care they receive? (13)

What is the care coordinator’s role in educating and bringing adult providers into the care team to ensure seamless transition of care- and in developing transition goals and processes for patients as they age out of the pediatric system to ensure continuity of care?(13,14)

**Teenage Guidelines**

1. Provide further developmentally appropriate patient care education across the SB spectrum for teenagers/families to better empower families to manage their own care and recognize complications and emergencies. Identify and or improve gaps in the family knowledge base specifically related to the teenage age period (mobility progress, bowel bladder care sexuality, academic/cognitive development school and peer social functioning high risk behaviors etc.)

2. Monitor secondary school functioning, and updated IEP/504 plan including preparation for college. Encourage participation in age appropriate activities with peers outside of school. Provide information where appropriate for driver education and training programs for patient with spina bifida.

3. Coordinate with family and multidisciplinary spina bifida care team to ensure the teenage patient with spina bifida is up to date on all sub specialty care visits imaging and monitoring and equipment needs where appropriate. This may include assistance with insurance authorization when needed.(2,6)

4. Work with the individual teenage child, family and Spina Bifida Team members and therapists to continue progress on self-care goals and education. Monitor family progress in self-care at regular intervals and clinic visits with goal of achieving as much independence as is realistically possible for the patient. Teach self-advocacy and encourage teenager to participate as much as possible in their own self-care. When appropriate discuss what limitations in independence the child may have due to deficits in memory, cognition and executive functioning. Provide parents with additional resources and support services as needed(9,12,13)
5. Begin preparing patient for transition to adult health care including familiarizing patient and family with the Spina Bifida Association transition and independent living health care guidelines. Encourage family to develop and assemble their own health care folder and records for use during travel, outside hospitals etc. Encourage teenager when capable to make their own medical appointments, and to start leading the conversation with specialists and other providers during clinic visits. Assist with family awareness that transition to adult life involves many aspects beyond health care including educational planning or job training, independent living arrangements and financial planning(4,16,18).

6. Assess family dynamics in coping with the diagnosis, and evaluate psychosocial stressors for the family. Assess for depression, anxiety, substance abuse and high risk behaviors; and assist with referrals to mental health and social services when appropriate.

7. Care coordinator to serve family as lead contact person and information provider for the multidisciplinary medical home for the teenager with spina bifida. Monitor family needs and prescriptions for durable medical equipment, supplies and medications as needed.

**Adult Clinical Questions**

How do the roles and responsibilities of the care coordinator evolve over time as the patient with SB ages?

What evidence exists showing the success of care coordination program in improving the overall health of Spina Bifida patients?

How does the care coordinator collaborate with team members, allied health services, and community partners to optimize the opportunities and overall quality of life of their patients?

Does care coordination need to be done in a clinic setting? Are there models for care coordination for adult patients who see doctors independently?

What is the optimal method to promote effective communication between multiple team members’ patients and their families to best serve patient needs, prevent complications, and improve the overall patient experience of care.

What are the common barriers (staffing, logistical, community resources etc.) to creating an effective patient centered care coordination program within the multidisciplinary Spina Bifida clinic? (4)

What aspects of a care coordination program do patients find most helpful and improve their perception of the care they receive?

What evidence exists showing the success of care coordination program in improving the overall health of Spina Bifida patients?
What is the care coordinator’s role in educating adult providers and in developing transition goals and processes for patients as they age out of the pediatric system to ensure continuity of care?(17)

How can the care coordinator provide a two-way education flow where the pediatric team educates adult providers and the adult patient outcomes provide evidence based information on where additional teaching and efforts are needed throughout the pediatric years?(16,17)

When there are gaps in care such as lack of access to adult subspecialty providers how can the care coordination team best intervene to advocate for and assist the patient?(16,17)

Adult Guidelines

1. Coordinate the successful transition of the adult with spina bifida from pediatric to adult providers. Care coordinator to be knowledgeable of the resources for adult spina bifida patients in their geographic area. Educate adult spina bifida patients where appropriate on key differences between the adult and pediatric providers including the possibility of the lack of an adult multidisciplinary spina bifida team (4).

2. Conduct an inventory of the adult patient’s ability to provide self-care, complete activities of daily living, and manage mobility equipment and transportation needs. For patients with significant intellectual disability who may be unable to live independently assist family with conservatorship process, maintaining SSI and insurance coverage

3. Assist with referrals to Vocational and employment training opportunities as needed

4. Assist with referrals to Driver education training opportunities as needed and or referral for appropriate pre driver training evaluations vision, ability to use lower extremities vs hand controls etc.

5. Coordinate with spina bifida providers to ensure the adult patient with spina bifida is up to date on all sub specialty care visits imaging and monitoring and equipment needs where appropriate. This may include assistance with insurance authorization when needed.(2,6,9)

6. Assess individual dynamics in coping with the diagnosis, and evaluate psychosocial stressors for the adult with spina bifida. Assess for depression, anxiety, substance abuse and high risk behaviors; and assist with referrals to mental health and social services when appropriate.

7. Care coordinator to serve adult as lead contact person and information provider for the multidisciplinary medical home for the adult with spina bifida. Monitor individual needs and prescriptions for durable medical equipment, supplies and medications as needed. Special considerations may be needs to apply care coordination principles to assist adult patients who see multiple different providers independently.(4)

8. Assess and monitor for clinical deterioration in the adult patient loss of mobility, chronic pain, obesity, assist with medical referrals as appropriate.(9,16)

Research Gaps
1. There are very few data based studies demonstrating the benefits of Spina Bifida care coordination programs resulting in improved health outcomes, decreased morbidity and mortality, higher quality of life, improved success and independence in adulthood and decreased cost of care in patients with spina bifida. More research needs to be completed to compile scientific evidence of the effectiveness of care coordination programs so that a best practices model of care coordination for the spina bifida patient may be developed.

References


