Care Coordination Plenary Panel and Spina Bifida Association Care Coordination Guidelines for Persons Living With Spina Bifida
June 29, 2019

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Guidelines for the Care of People with Spina Bifida

• An Initiative of the Spina Bifida Association
  The Guidelines were developed to provide every healthcare professional—from generalists to specialists—a road map of the best evidenced-based and expert treatment available from birth through adulthood.

• One hundred Spina Bifida experts from around the world spent three years developing these Guidelines that cover 25 topics ranging from bowel management to sexuality to physical activity and more.

• www.spinabifidaassociation.org
Guidelines for the Care of People with Spina Bifida 25
Topics available at www.spinabifidaassociation.org

• **System of Care** • Care Coordination  Health Promotion and Preventive Health Care Services • Prenatal Counseling  • Transition

• **Psychosocial Context for Self-Management** • Family Functioning  • Mental Health • Self-Management and Independence  • Quality of Life

• **Neuropsychology and Neurosurgery** • Neuropsychology  • Neurosurgery

• **Mobility, Orthopedics, and Physical Activity** • Mobility  • Orthopedics
  • Physical Activity
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• **Urology and Sexual Health** • Men's Health • Sexual Health and Education
  • Urology • Women's Health

• **Specific Health Issues** • Bowel Function and Care • Endocrine: Puberty and Precocious Puberty
  • Endocrine and the Use of Human Growth Hormone • Integument (Skin)
  • Latex and Latex Allergy in Spina Bifida • Nutrition, Metabolic Syndrome, and Obesity
  • Sleep-Related Breathing Disorders

• **Appendix** • Early Intervention Services, Individualized Educational Plans (IEP) and 504 Plans
• Care coordination is an essential component of health care delivery.
• Patient- and family-centered care within a medical home is a foundational component.
• Outcomes are optimized when there collaboration among the multiple medical systems and providers, community services, and support agencies with whom families and people with Spina Bifida interact.
• Effective care coordination typically requires dedicated paid personnel.
• Care coordination activities are not the sole responsibility of a single individual or provider. Rather, all people who interact with patients and families have a role to play in care coordination.
• The second concept, team-based care.
• Co-management with defined roles, data sharing, and collaborative care protocols among primary care, community-based services, and subspecialty care.
• Full implementation of these Guidelines to optimize outcomes for people with Spina Bifida cannot rest with the Spina Bifida clinic alone.
• While the Spina Bifida clinic may direct the overall health care planning in many cases, optimal care is best achieved as a partnership between families and people with Spina Bifida, primary and subspecialty care providers, health systems, and community services.
Care coordination from SB Healthcare Guidelines Definition

• “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
Care coordination (also described as case management services), in the case of patients with Spina Bifida and their families, is a process that links them to services and resources in a coordinated effort to maximize their potential by providing optimal health care. However, care coordination for patients with Spina Bifida and their families can be complicated due to the medical complexities of the condition and the need for multidisciplinary care, as well as economic and sociocultural barriers to coordination of care. Care coordination is often a shared responsibility by the multidisciplinary Spina Bifida team. For this reason, the care coordinator, or spina bifida team, has the primary responsibility for overseeing the overall treatment plan for the individual with Spina Bifida. The care coordination includes communication with the primary care provider in a patient’s medical home.
Goals of Care Coordination

• Generally, the goals of care coordination are the following:
  • gain access to and integrate services and resources,
  • link service systems with the family,
  • avoid duplication and unnecessary cost, and
  • advocate for improved individual outcomes.
Outcomes organization

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

• Secondary: Promote comprehensive, coordinated and uninterrupted access to medical, subspecialty, and allied health professional services throughout the lifespan with appropriate communication between the person with Spina Bifida and members of their care team. Promote routine screenings and testing congruent with Spina Bifida guidelines for specific secondary conditions.

• Tertiary: Maintain up-to-date coordinated care for individuals living with Spina Bifida to minimize medical complication rates, help control cost of care, and minimize emergency room use and unanticipated hospitalization, morbidity, and mortality.
• Pregnancy to 11 months
• 1-2 years
• 3-5 years
• 6-12 years
• 13-17 years
• 18+ years

• Clinical Questions
• Followed by Care Coordination Guidelines Related to a specific age range and developmental stage
• Research Gaps and Future Directions
Clinical Questions Similar Between Age Groups

• 1. How do the roles and responsibilities of the Spina Bifida Care Coordinator evolve over time as people with Spina Bifida age?

• 2. What evidence exists to show the success of the care coordination program in improving the overall health of children with Spina Bifida?

• 3. What literature is available to support optimal teaching and education of children and their caregivers throughout the lifespan to maximize early independence?

• 4. What is the best way to effectively communicate between multiple Spina Bifida care team members, people with Spina Bifida and their families to best serve their needs, prevent complications, and improve their overall experience of care?

• 5. What are the common barriers to creating an effective patient-centered care coordination program within the multidisciplinary Spina Bifida clinic? Examples of barriers could include insufficient training, logistical difficulties, and unavailability of personnel and community resources.

• 6. What aspects of a care coordination program do families and their children find most helpful and improve their perception of the care they receive?
Older Age Group Questions

• Older age group Clinical Questions
• What is the Spina Bifida Care Coordinator’s role in
• 1) educating and bringing adult providers into the care team to ensure seamless transition of care
• 2) developing transition goals and processes for people as they age out of the pediatric system to ensure continuity of care?
Examples of some Age Specific Guidelines Birth to 1

• Pregnancy Through Age 11 months Spina Bifida Coordinator May

• Provide support and education throughout the pregnancy. These consults may take place as part of a maternal fetal health visit in a high-risk pregnancy center.

• Assist family with coping with diagnosis

• Assist NICU Staff with discharge planning and multidisciplinary appointments

• Introduce concept of multidisciplinary team to family and provide broad general education on Spina Bifida topics to the family
Examples of some Specific Guidelines Ages 1-3

• Spina Bifida Care Coordinator work with the family and the multidisciplinary care team to ensure that the child with Spina Bifida is up-to-date on all sub-specialty care visits, imaging, monitoring, and equipment needs where appropriate. This may include assistance with insurance authorization or referrals.

• Educate family on recognizing common complications and emergencies

• Assess Family coping Skills: Mental Health Referrals if Needed

• Monitor and document enrollment in therapies and early intervention programs
Examples of some Specific Guidelines Ages 3-5

• The coordinator should improve the family knowledge base specifically related to the preschool period mobility progress, skin inspection, bowel and bladder care, speech/cognitive development.

• Coordination with PMDs (all ages)

• Prepare the family for early independence, entering preschool, and planning special education and health related services in the school.
• Monitor primary school functioning IEPs and school health plans.
• Encourage participation in age-appropriate activities outside of school with peers, with and without Spina Bifida. Encourage participation in activities such as camps or special family weekends that provide safe places to develop peer relationships with children who may have similar medical challenges.
• Engage the school nurse to help facilitate self management and independence.
• Teach self-advocacy and encourage the child to participate as much as possible in his or her own self-management.
Examples of some Specific Guidelines Ages 13-17

• Identify and or improve gaps in the family knowledge base specifically related to the teenage age period sexuality, academic/cognitive development, social functioning at school and with peers, high risk behaviors.

• Monitor secondary school functioning including preparation for college or other higher education opportunities.

• Where appropriate, provide information for driver education and training programs for the teenager with Spina Bifida.

• Self Management Assessment

• Transition to Adult Care

• Conservatorship if appropriate
Examples of some Specific Guidelines Ages 18+

• Knowledge of resources for adults with Spina Bifida in their geographic area

• Coordinate the successful transition from pediatric to adult providers for adults with Spina Bifida. Educate adults with Spina Bifida about the key differences between adult and pediatric providers, including the possibility that there may not be an adult multidisciplinary Spina Bifida team nearby.

• Conduct an inventory of the adult’s ability to provide self-management, complete activities of daily living, and manage mobility equipment and transportation needs

• Employment or Vocational Training if needed
Research Gaps

• 1. What database studies demonstrate the benefits of Spina Bifida care coordination programs, specifically regarding improved health outcomes, decreased morbidity and mortality, higher quality of life, improved success and independence in adulthood and decreased cost of care?

• 2. What research exists regarding the effectiveness of care coordination programs to develop a best-practices model of care coordination for the person with Spina Bifida?

• 3. How do the roles and responsibilities of the Spina Bifida Care Coordinator evolve over time as the person with Spina Bifida ages?
Research Gaps

4. What are the common barriers to creating an effective patient-centered care coordination program within the multidisciplinary Spina Bifida clinic?

5. What aspects of a care coordination program do families and individuals with Spina Bifida find most helpful and improve their perception of the care they receive?

6. What is the Spina Bifida Care Coordinator’s role in 1) educating and bringing adult providers into the care team to ensure seamless transition of care and in 2) developing transition goals and processes for people as they age out of the pediatric system to ensure continuity of care?
Thus Care Coordination is a very big job

• How Can We Measure the Care Coordination Services we provide?
• How can we ascertain how our patient/family consumers experience these benefits and their perceptions of the quality of the care coordination programs within their Spina Bifida Center

• CCMT Care Coordination Measurement Tool
  • A care coordination Value Capture Tool
• PICS Pediatric Integrated Care Survey
  • A family experience of care integration
Learning collaborative clinics will implement the Pediatric Integrated Care Survey (PICS) and/or the Care Coordination Measurement Tool (CCMT).

Both tools are intended to collect data that moves the care team closer to triple aim outcomes: improved patient experience, improved health outcomes, reduced cost (and improved provider experience!)

Generally, anonymized data collection and rapid cycle QI methodology allow for IRB exemption but would be decision of home institution.
• Best way to improve coordination is to measure it

• Intended to be adapted to reflect activities and outcomes of teams in diverse settings

• Tool can be implemented in different ways depending on goal of collecting data

• Paper version or web-based versions have been used in past

• Access CCMT
Thank you for your attention. Save Questions for the End of all presentations please.