Self Management

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The work group used a primary definition of self-management from the literature on spina bifida delineating self-management for youth and emerging adults as:

- An active daily and flexible process in which youth and their parents share responsibility and decision making for achieving control of their condition, health and well-being through a wide range of activities and skills. The goal of this increasing responsibility is to develop self-management behaviors needed for transition to adulthood and independent living. (Sawin, Bellin, Roux, Buran & Brei, 2009 adapted from Schilling Grey & Knafl, 2002).

Guideline users, especially those working primarily with adults, may also find the following definition helpful “Self-management is the interaction of health behaviors and related processes that patients and families engage in to care for a chronic condition (Modi et al, 2012)”
Primary Outcomes

• Children, adolescents, and adults with SB perform self-management behaviors at the highest level of their ability.

Secondary Outcomes

• Interventions that address the foundational skills necessary for self-management and complex self-management behaviors are introduced throughout the life span as appropriate. Self-management goals are evaluated yearly with the family, child, adolescent, and adult.

Tertiary Outcomes

• Adolescents transitioning to adulthood with a guardian responsible for their health care, perform condition self-management behaviors in the areas of medication management, prevention of complications, implementation of bladder and bladder program, skin surveillance, and communicate findings to their guardian and/or health care providers at their highest level of their ability.

• Young adults without a guardian are fully responsible to implement condition and advanced self-management behaviors (e.g., making appointments, ordering medications, arranging for transportation, conducting basic living skills [cooking and laundry], managing money, managing insurance, and communicating with their health care provider).
Prenatal/Infancy (through age 1 year)

Clinical Questions:
• What are the approaches that optimize individual and family self-management?
Prenatal/Infancy (through age 1 year)

Guidelines

1. Provide orientation to families that include the expectation for optimal self-management according to individual’s SB status and age (see prenatal guidelines).
2. Provide instruction and support to families regarding knowledge and skills needed to manage their infant’s SB and related issues.
3. Evaluate and support family function (see family guidelines).
4. Identify and makes referrals to early intervention programs.
Clinical Questions:

• What are the approaches that optimize individual and family self-management?
Toddler (1-3 years)

Guidelines

1. Provide anticipatory guidance regarding developmental needs of children (such as exploration of environment, routines, and age-appropriate choices).

2. Provide instruction and support to families regarding knowledge and skills needed to manage their toddler’s SB and related issues.

3. Teach families to offer daily age-appropriate choices such as choice between two articles of clothes, two cereals for breakfast, and two books to read, etc.

4. Encourage families to expect participation in daily life activities, including such things as picking up toys, cleaning up, and imitating housework.

5. Identify and make referrals to early education programs.
Preschool (3-5 years)

Clinical questions

• What are the approaches that optimize individual and family self-management?
Preschool (3-5 years)

Guidelines

1. Provide instruction and support to families regarding knowledge, skills, and behaviors needed to manage their pre-schooler’s SB and related issues.

2. Discuss the need to expand range of daily life activities and chores and the use of strategies to achieve this expansion that accommodates the child’s learning style and/or mobility.

3. Provide guidance that developing autonomy skills is maximized when there are clear and consistent consequences for inappropriate behavior (see mental health guidelines).

4. Identify and make referrals to community resources which promote self-efficacy such as early education programs.
Clinical Questions

1. What are the approaches that optimize individual and family self-management?

2. What self-management skills, abilities, and behaviors should be targeted at school age?

3. Does specific self-management skill training improve self-management behaviors (e.g., taking medication)?

4. What instruments are available to measure self-management skills, abilities, and behaviors in school age youth?
School Age

Guidelines

1. Provide instruction and support to youth and families regarding knowledge and skills needed to manage SB and related issues. Teach child basic self-management skills, including skills to prevent secondary conditions (CIC, skin care, equipment care, bowel and bladder care, wheelchair maintenance and propulsion) based on individual abilities. Youth with SB may develop foundational skills and SM behaviors at a slightly later age (2-5 years delay) and may need more deliberate practice. However, most SM behaviors are achievable by most young adults with SB.

2. Assist families in knowing how to incrementally involve the child in organizing school work and self-management activities and how to begin to transition to parental supervision.

3. Discuss the need to expand range of daily life activities and chores and the use of strategies to achieve this expansion that accommodates the child's learning style and/or mobility.

4. Serve as a resource to school systems regarding transportation, learning skills, health issues, and development of self-management skills.

5. Emphasize positive attitudes, self-esteem, assertiveness and self-empowerment.
School Age

Guidelines

6. Assess peer relationships and encourage peer involvement.

7. Assess bladder and bowel management programs for eventual independent self-management.

8. Consider using an age-and condition-appropriate assessment instrument (see SM instrument appendix) especially if the child has executive functioning impairments.

9. Discuss with parents the need to help their child develop basic money management skills.

10. Support the development of language with purposeful interactions and activities.

11. Encourage use of technology to enhance self-management.
Clinical Questions:

1. What are the approaches that optimize individual and family self-management?
2. What self-management skills, abilities, and behaviors should be targeted to the adolescent?
3. Does specific self-management skill training improve independence with self-management behaviors (e.g. taking medication, skin checks)?
4. What health care self-management skills are most important for those with SB to master, or most impact health outcomes?
5. How can comprehensive preparation for self-management be integrated into a complex multi-disciplinary clinic?
6. What instruments are available to measure self-management skills, abilities and the actual performance of self-management behaviors in adolescents?
1. Evaluate self-management in appropriate areas (e.g. managing medications, prevention of complications, skin care, equipment care, and bowel and bladder care, ability to make health care appointments. Assuming responsibility for health care encounters and other self-management of Spina Bifida is sequential. Full responsibility for self-management is critical for successful transition.

2. Initiate discussion and develop action plans to address deficits in SM skills, abilities and behaviors as needed.
   a) Use a valid and reliable instrument to assess self-management skills, abilities and actual performance of SM behaviors in adolescents.
   b) Encourage increasing responsibility for behaviors such as adolescent management of medication, bowel and bladder programs, skin-monitoring.
   c) Support development of skills necessary for SM (e.g., decision making, goal setting, self-regulation and communication).
   d) Evaluate and monitor cognitive functions as they underpin decision-making, goal-setting, self-regulation, self-management, socialization, and transition issues (see neuropsychology guideline).
Teenage

Guidelines

2e. Assess ability to use transportation; encourage enrollment in driver’s education, (adaptive) if the teen possesses cognitive/motor abilities. If driving not realistic teach (or have family teach) adolescent how to use alternate transportation (e.g., public transportation, van services for individuals with disabilities, etc.).

2f. Expand self-management interventions to encompass everyday living activities such as laundry, meal preparation, managing finances, making health care appointment and ordering supplies.

2g. Encourage family to expand range of responsibilities for daily life activities, chores, and jobs.
Teenage

Guidelines

3. Encourage participation in IEP planning that addresses self-management in transition (see transition guideline).

4. Support family functioning strengths related to self-management (family satisfaction, family resources –see family guidelines).

5. Discuss sexuality, contraception (including latex allergy precautions), marriage, childbearing issues, genetic counseling, and folic acid supplementation (see sexuality education guidelines).

6. Assess individual and system barriers to self-management (e.g., school services, advocacy, assertiveness, and insufficient adult services).

7. Encourage use of technology to enhance self-management.
Clinical Questions

1. What are the approaches that optimize individual and family self-management?
2. What self-management skills, abilities, and behaviors should be targeted at young adulthood?
3. Does specific self-management skill training improve independence with self-management behaviors (e.g., taking medication, monitoring skin status)?
4. What are the most effective methods for promoting self-management?
5. Is performing more self-management behaviors independently related to improved health or functional outcomes (depression, QOL, secondary conditions such as UTI, pain)?
6. Does increased independence with health care self-management increase community participation?
7. How can comprehensive preparation for self-management be integrated into a complex multi-disciplinary clinic?
8. What instruments measure the individual’s performance of self-management behaviors in adulthood?
Guidelines

1. Evaluate full responsibility for self-management behaviors in appropriate areas as needed (e.g. managing medications, prevention of complications, skin care, equipment care, and bowel and bladder care, ability to make health care appointments).

2. Evaluate if adult has expanded self-management to encompass everyday living activities such as laundry, meal preparation, managing finances, making health care appointment and ordering supplies.

3. Initiate discussion and develop action plans to address deficits in SM skills, abilities and behaviors as needed.
   a) Use a valid and reliable instrument to assess self-management skills, abilities and actual performance of SM behaviors in adults.
   b) Support development of skills necessary for SM (e.g., decision making, goal setting, self-regulation and communication).
   c) Evaluate and monitor cognitive functions as they underpin decision making, self-management.
   d) Assess ability to use transportation; encourage enrollment in driver’s education, (adaptive) if the adult possesses cognitive/motor abilities and has not done so already. If driving not realistic teach (or have family teach) adult how to use alternate transportation (e.g., public transportation, van services for individuals with disabilities, etc.).
Adult Guidelines

4. Encourage use of technology to enhance self-management.

5. Expand discussion of sexuality, contraception (including latex allergy precautions), marriage, childbearing issues, genetic counseling, and folic acid supplementation (see sexuality guidelines).

6. Encourage involvement in empowerment activities (e.g., sports, organizations, mentoring, camp etc.).

7. Support family functioning strengths related to self-management (family satisfaction, family resources—see family guidelines).

8. Assess individual and system barriers to self-management (e.g., advocacy, assertiveness, insufficient adult services).

9. Encourage planning and use of support services (e.g., services for students with disabilities in college setting) for self-management in new environments (see transition guidelines).

10. Evaluate if systematic evaluation of SM behaviors with valid and reliable instruments and subsequent action plans to address SM deficits yield change in health status.
Research Gaps

• What are the foundational skills and abilities that need to be developed in toddlers, pre-school agers, and school agers that facilitate the development of SM behaviors in adolescents and young adults?

• What interventions optimize the development of these foundational skills and abilities early in childhood?

• What interventions are effective in closing the gap between SM behaviors in adolescents/young adults with SB and their typically developing peers?

• How can interventions to enhance SM be integrated into clinical care?

• What interventions need to be targeted to mid and older adolescents and their parents to change their roles in self-management?

• Do additional components need to be delivered outside of clinical care?

• What structure(s) of clinical services are optimal for coordinated, comprehensive transition to adult care?

• Does routine clinical assessment of SM behaviors with the development of action plans with the adolescent and their family enhance yield improved outcomes?
References


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