Self-Management in Spina Bifida: A Synthesis of the Literature

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Disclosures

• Dr. Sawin is a co-author of the Individual and Family Self-Management Theory and co-creator of the AMIS II but has no financial conflicts to disclose for this presentation.

• Dr. Bellin has nothing to disclose.

• Dr. Woodward has nothing to disclose.

• Dr. Brei, the medical director of SBA, is a co-creator of the AMIS II but has no financial conflicts to disclose for this presentation.
Background

• Developing the skills for Spina Bifida (SB) self-management is a central task for children, adolescents and young adults transitioning into adulthood.

• Three self-management (SM) research priorities were delineated in the 2003 SB Research Agenda:
  • Assessment of ways to measure self-management
  • Factors that affect the teaching and learning of self-management
  • Optimizing use of assistive devices.
Purpose

• Conduct structured review of research articles published in peer-reviewed journals (2003-2017) that address SM in individuals with SB and critically appraise fit with 2003 priorities.
Background

• Definition of SM in adolescents and emerging adults with spina bifida:
  • 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).

• Broader definition potentially useful across ages/conditions:
  • The interaction of health behaviors and related processes that patients and families engage in to care for a chronic condition (Modi et al., 2012)
Methods

• A literature search was conducted using PRISMA guidelines.
• The PubMed, CINAHL and PsychINFO data bases were searched using the terms spina bifida (or myelomeningocele) and self-management or self-care. No age limitation were set.
• Research articles were included if they addressed self-management or self-care and were written in English.
• Studies were omitted if they used a combined disability sample where the sample of individuals with SB was not specifically reported.
Results

• Of the 22 studies identified:
  • Three were systematic reviews of the literature.
  • Three were RCT or Quasi Experimental Intervention studies. An additional four studies evaluated the feasibility, usability, or acceptability or piloted a mobile interventions in adults.
  • Nine were descriptive; of these two were longitudinal and the rest were cross-sectional. One was qualitative.
  • Three were psychometric studies that addressed the development of a self-management instrument.
Results - Interventions

• Self-management interventions for adolescents with SB and other CHC generally show at least one significant improvement (Lindsay et al., 2014).
  • The one exception was a short workshop-based intervention for adolescents which yielded no significant differences in groups (Betz, Smith, & Macias, 2010).

• Camp-based psychosocial interventions promoting skill-building have shown promise in developmentally diverse samples of youths SB (Holbein et al., 2013).

• Family oriented interventions may be most effective in younger adolescents (Greenley et al., 2006; Lindsay et al., 2014).
Results – Technology Interventions

• Although tested mostly in adults, technology holds promise for expanding SM in children, adolescents and adults.

• Technology-based interventions conducted by the Pittsburg team have found a number of eMobile interventions feasible, have piloted these approaches, and have implemented several small RCT to evaluate outcomes (Dicianno et al, 2009; Dicianno et al., 2016; 2015, Farman, 2013; Parmanto et., al, 2015).

• A mobile health intervention did improve self-management, especially for those who were high users of the technology (Dicianno et al., 2016).
Results

• Self-management behaviors have been reported as low in youth with SB (Buran et al., 2004; Davis et al., 2006; Psihogios et al., 2015).
  • Davis et al detailing behaviors achieved in those 12-18 years old with IQ of 80 or better as 2-5 years later than typically developing peers (TYP).
  • It is not clear if this lag is developmentally appropriate for those with SB or due to lack of expectations and support.
  • Basic behaviors were achieved by age 12 included dresses appropriately, making shopping choices, cleans room, knows phone number, and shops with assistance.
  • Other behaviors such as saves money, cooks pre-packed means, plans activities with peers and arranges own transportation were generally achieved during adolescents but 2-5 years later than TDP.
Results

• Advanced behaviors achieved by typically developing peers and generally not achieved by youth with SB by age 18 included: does own laundry, cooks independently, manages bank account without assistance, manages allowance, makes own appointments.

• Participants did not generally enter adolescence with high levels of SB knowledge but developed them during adolescence (knowing signs of skin ulcer, bowel problems, shunt failure and UTI).

• Adolescents report “ever-present” catherization and bowel management. These issues were seen as part of the journey of skill-building to achieve independence. Further they describe a “dance of individuation” where they need their parents involvement –but not too much (Sawin, Bellin, Roux, Buran, & Brei, 2009).
Results

- Data support some difference in report of SM behaviors between parent and adolescent although the relationship of parent and adolescent SM scores is fairly high in later adolescents/young adults and higher than in earlier adolescents (Psihogios & Holmbeck, 2013; Sawin et al., 2006; Sawin et al., in press).

- Generally there is more agreement on SM behaviors when compared to other less concrete beliefs (Sawin et al., 2006).
Results

• Factors associated with self improved self-management included:
  • Older age (Buran et al., 2004; Jacobson et al., 2013)
  • Decreased severity of SB (Sawin et al., 2003)
  • Increased self-efficacy (Sawin et al., 2003)
  • Responsibility for chores (Buran et al., 2004)
  • Experience with decision making (Sawin et al., 2006)
Instruments Assessing Self-Management in Individuals with Spina Bifida
Four self-management measures have been used in published studies of self-management and spina bifida:

- Adolescent Self-Management and Independence Scale II (Sawin et al., 2006)
- Kennedy Krieger Independence Scales (Jacobson et al., 2013)
- Sharing of SB Management Responsibilities Scale (Psihogios, Kolbuck, Holmbeck 2015).

Each with a specific focus and preliminary psychometrics.
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<td>Psychometric study to evaluate the KKIS-SB, a caregiver-reported measure of self-care skills based on adequate executive functioning. 18 skill based items and 4 parent expectation items. Tested with parents of 100 youth and YA with SB. 4 factors and two primary subscales:</td>
<td>Exploratory factor analysis, reliability and construct validity. BRIEF (Behavior Report Inventory of Executive Function)</td>
<td>Correlations between KISS-SB and BRIEF BRI and MI summary scales $r = -0.031$ to $0.56$) and 5 subscales (inhibit, shift, working memory and monitor) ($-0.29$ to $-0.62$) support validity. Age related changes support both subscales. KISS-SB also related to scales of the ABAS II.</td>
<td>Parent scales with reliability and validity. Child scales also have psychometric support data (not published). KISS-SB supplies a highly-specialized assessment of SM abilities and behaviors based on a known area of challenge in individuals with SB (executive functioning).</td>
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Development of the Adolescent/Young Adult Self-Management and Independence Scale - AMIS II: Psychometric Data (Sawin, Hefelfinger, Brei, & Cashin, 2017)

Goal: to evaluate the reliability and validity of the 17-item Adolescent/Young Adult Self-Management and Independence Scale II which measures self-management behaviors. 201 AYA and 129 of their parents from 3 studies of AYA with SB.

Age range for instrument 12-adult (only tested in ages 12-25)

The exploratory factor analysis was conducted with parent data and Confirmatory factor analysis with AYA data. Chronbach alpha was used for reliability, Intra-Class Correlation (ICC) for stability and Pearson’s correlations for evaluation of concurrent validity with other variables.

All analyses support the 2 factor AMIS II; Condition Self-Management and Independent Living Self-Management CFA=GFI and CFI=86-.95; RMSEA=.057 and α=.72-.89. ICC=0.82).

Used in 5 published peer-reviewed studies and 3 others in process/

Has established R and V and has been used in adolescent and adult populations. Recommended for use.
**Condition**

self-management in pediatric spina bifida: A longitudinal investigation of medical adherence, responsibility-sharing, and independence skills

(Psihogios et al., 2015)

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<th>SB Self-Management Profile (SBSMP)</th>
<th>No reliability computed due to large number of NA) Adherence scoring system (1,0) created for all domains</th>
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<tr>
<td>based on Diabetes measure, parent reported adherence to treatments (diet, catherization, bowel program, skin checks and exercise subscales) (indicates that task is being completed but not who did it)</td>
<td>Has promise for future use especially if one wishes to compare to diabetes. Several scales needed may have item burden in clinical practice.</td>
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<td>Sharing of SB responsibilities Scale (SOSBMR) 34 items –who primarily responsible for each task (parent child equal or NA)</td>
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<td>Medial Independence Skills –Parent evaluation of child’s knowledge and ability to do SB skills (yes no not sure or NA) but does not measure if the child does them on a consistent basis.</td>
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## Authors and Journals

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<th>Disciplines</th>
<th>Journals Where Studies Were Published</th>
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<tr>
<td>• Psychology</td>
<td><strong>Interdisciplinary</strong> (International Journal of Child and Adolescent Health, Neural Tube Defects, Child Care Health and Development), <strong>Disability/Rehabilitation</strong> (Archives of Physical Medicine and Rehabilitation; Journal of Rehabilitation Medicine, Disability and Rehabilitation, Research in Developmental Disabilities)</td>
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<td>• Nursing</td>
<td><strong>Nursing</strong> (Pediatric Nursing, SCI Nursing, Rehabilitation Nursing)</td>
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<td>• Medicine</td>
<td><strong>Pediatric</strong> (Developmental Medicine and Child Neurology, Pediatrics)</td>
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<td>• Social Work</td>
<td><strong>Psychology</strong> (Journal of Pediatric Psychology; Rehabilitation Psychology, Journal of the International Neuropsychological Society)</td>
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<td>• Physical Therapy</td>
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<td>• Rehabilitation Psychologist/counselors/professionals</td>
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Implications

• Foundational skills for SM (choices, chores, decision making, autonomy skills and problem solving) need to be enhanced starting when the child is a toddler.

• Families should be encouraged to expand range of every day living skills and responsibilities. Community experiences such as school activities, camps, rehabilitation approaches or sports can be used to empower children, adolescents and adults to increase SM behaviors.

• Providers need to assess SM and initiate action plans to address any self-management deficits as soon as they are identified.

• Technology-based wellness programs show promise for improving SM behaviors in adults.
Limitations

- Only three databases were included (Medline, CINAHL and PsychINFO). Sample limited.

- ROL did not capture the foundational skills needed to develop self-management
  - Autonomy
  - Problem Solving
  - Self-efficacy
Conclusion

• Progress in advancing self-management in SB has been made since 2003:
  • There is preliminary information on the factors that affect the teaching and learning of self-management
  • Progress has been made on the assessment of self-management with several instruments available.
  • Research has begun on the use of technology especially mHealth

• However, self-management evidence is still limited.
• Gaps remain in multiple areas, especially in ways to enhance SM in the clinical setting, the effective use of mHealth, the effectiveness of family/community based interventions, and in strategies that address executive functioning limitations in SM.
References


References


References


• Khan, F., Amatya, B., Ng, L., & Galea, M. (2015). Rehabilitation Outcomes in Persons with Spina Bifida: A Randomized Controlled Trial. *Journal of Rehabilitation Medicine, 47*(8), 734-740.
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