OVERALL OUTCOMES

Primary: Achieve optimal developmentally-appropriate mental health throughout the lifespan (across psychological, social, and participation outcomes)

Secondary: Maximize adaptation across all factors that are predictive of mental health outcomes (including neuropsychological, family, peer, academic, biological and condition-related predictors). Access services and supports across appropriate domains to optimize developmentally-appropriate mental health throughout the lifespan.

Tertiary: Maximize self-management, independence, quality of life, and “transition” outcomes by addressing mental health challenges.

OUTCOMES

• Infancy

  • Clinical Questions
    o What is the psychosocial impact of having SB on mental health and adaptation across the lifespan?
    o Which domains of mental health are most adversely affected in individuals with SB and in what areas of mental health are individuals with SB most resilient?
    o What are some common maladaptive behaviors that can negatively impact persons with spina bifida across the lifespan?

  • Guidelines
    • Assess family functioning, stressors, and supports.
    • Provide parents detailed information about spina bifida.
    • Connect families with local SBA chapters and community resources.
    • Address developmental concerns through information and support.
    • Refer to Early Intervention Services.
    • Assess quality of parent-child attachment.
• Promote effective parenting skills in stimulation, care giving, and enjoyment of infant to optimize typical child development.

• Evidence

Children with SB have a lower health-related quality of life (HRQOL) than both typically developing individuals without spina bifida and children with other chronic health conditions (Copp et al., 2015; Murray et al., 2015; Padua et al., 2002; Rofail et al., 2014; Sawin & Bellin, 2010). These differences are stable across age and gender. Shunted hydrocephalus and lack of mobility are associated with HRQOL. Other predictors include SES, pain, parenting stress, and other family factors (Sawin & Bellin, 2010).

Beginning in late childhood and across different ethnic groups, youth with SB tend to have higher levels of depressive symptoms and lower self-esteem (Holmbeck et al., 2003; Bellin et al., 2010; Nichols et al., 2015).

Youth with SB tend to have social difficulties, including social immaturity and passivity, fewer friends, and fewer social contacts outside of school. They also have fewer romantic relationships during adolescence (Holmbeck & Devine, 2010; Holmbeck, Westhoven et al, 2003; Wallander et al., 1989). These social difficulties appear to continue into adulthood (Holmbeck, Westhoven et al, 2003; Holmbeck, DeLucia et al., 2010). Youth with SB rate their close friendships as closer and are more likely to see their peers as best friends rather than the reverse. They also report less companionship, security, and closeness in their friendships than their typically developing peers (Devine et al., 2011).

Youth with SB are more dependent on their parents for guidance, show less intrinsic motivation at school, and exhibit less behavioral autonomy at home (Friedman et al., 2009; Holmbeck, Westhoven et al., 2003; Holmbeck, DeLucia et al., 2010). Intrinsic motivation is a robust predictor of psychosocial adaptation during the school years (Coakley et al., 2006). Levels of decision-making autonomy lag behind typically developing peers by about 2 years (Devine et al., 2011). Pain and depressive symptoms interfere with social activity involvement (Essner et al., 2014).

Youth with spina bifida tend to exhibit lower levels of sexual maturation, knowledge, and experience—especially those with higher lesion levels (Gatti et al. 2009; Linstow et al., 2014; Visconti et al., 2012). Parents are less likely to discuss sexuality with their children with SB than is the case with typically developing youth (Blum et al., 1991). Bowel and urinary incontinence have been associated with worse sexual satisfaction.

Youth with spina bifida tend to score below average on most measures of neuropsychological functioning, including executive functioning (Iddon et al., 2004; Rose & Holmbeck, 2007). Such functioning tends to be associated with social functioning which is, in turn, associated with subsequent internalizing
symptoms (i.e., depressive and anxiety symptoms; Lennon et al., 2014)

A large proportion of youth with SB have a significantly high number of risk factors for cardiovascular disease (CVD; Buffart et al., 2008; Oliviera et al, 2014; Soe et al., 2012), and they exhibit lower levels of participation in physical activities and activities of daily living (Buffart et al., 2009; Marques et al., 2015). Higher levels of physical activities are related to adaptive outcomes (i.e., participation and HRQOL). Some evidence exists that weight management interventions are effective in this population (Rimmer et al., 2013).

• **Toddler**

• **Clinical Questions**
  - What is the psychosocial impact of having SB on mental health and adaptation across the lifespan?
  - Which domains of mental health are most adversely affected in individuals with SB and in what areas of mental health are individuals with SB most resilient?
  - What are some common maladaptive behaviors that can negatively impact persons with spina bifida across the lifespan?

• **Guidelines**
  - Address developmental concerns and optimize typical child development.
  - Encourage families to offer developmentally appropriate choices in daily life activities, including such things as picking up toys, cleaning up, and imitative housework.
  - Encourage developmentally appropriate play and social opportunities.
  - Assess parenting skills and provide education on parenting strategies and behavior management techniques as needed.
  - Provide additional age appropriate information about SB as the child grows.

• **Evidence**
  
  See evidence under “Infancy”
• **Preschool**

• **Clinical Questions**
  o What is the psychosocial impact of having SB on mental health and adaptation across the lifespan?
  o Which domains of mental health are most adversely affected in individuals with SB and in what areas of mental health are individuals with SB most resilient?
  o What are some common maladaptive behaviors that can negatively impact persons with spina bifida across the lifespan?

• **Guidelines**
  
  • Discuss with parents the importance of socialization/friendships with peers and potential opportunities for activities.
  
  • Encourage participation in preschool educational programs.
  
  • Discuss the importance of schedules/routines, modeling behavior, age appropriate choices and decision-making and chores.
  
  • Assess social and psychological development.
  
  • Refer for social skills training as indicated.
  
  • Include optimization of mental health when developing an Individualized Education Program (IEP) Provide additional age appropriate information about SB as the child grows.

• **Evidence**

  See evidence under “Infancy”

• **School Age**

• **Clinical Questions**
What is the psychosocial impact of having SB on mental health and adaptation across the lifespan?
Which domains of mental health are most adversely affected in individuals with SB and in what areas of mental health are individuals with SB most resilient?
What are some common maladaptive behaviors that can negatively impact persons with spina bifida across the lifespan?

- **Guidelines**
  - Encourage participation in community activities for recreation.
  - Promote friendship development by assisting families to identify friendship opportunities (i.e. participation in Camps, Adaptive sports programs/events, Walk-and-Rollathon for SB)
  - Assess for depression, anxiety, bullying, and social participation.
  - Promote transfer of age appropriate medical responsibility from parent to child in those who have the requisite abilities/cognitive capacity.
  - Discuss importance of increasing household responsibilities appropriately modified for mobility and cognitive limitations.
  - Refer children with emotional and/or behavioral difficulties for psychological support and counseling. Identify community resources for social and psychological development (camps, recreation centers, etc).
  - Assess family relationships with school. Encourage parents to be advocates for their children in the school setting
  - Promote independence and choice in social activities. Promote self-care so that the child is able to be independent in social settings.
  - Promote appropriate after school sports and club activities.
  - Provide additional age appropriate information about SB as the child grows.
  - Promote and encourage participation in SBA related activities

- **Evidence**
See evidence under “Infancy”

- **Teenage**

- **Clinical Questions**

  - What is the psychosocial impact of having SB on mental health and adaptation across the lifespan?
  - Which domains of mental health are most adversely affected in individuals with SB and in what areas of mental health are individuals with SB most resilient?
  - What are some common maladaptive behaviors that can negatively impact persons with spina bifida across the lifespan?

- **Guidelines**

  - Assess peer relationships and friendships.
  - Assess for at risk behaviors (alcohol, drug, tobacco use; unsafe sex)
  - Screen for depression or anxiety and initiate individual and family interventions when appropriate.
  - Provide counseling and/or behavioral support as needed.
  - Promote transfer of medical responsibility from parent to child in those who have the requisite abilities/cognitive capacity
  - Refer for social skills training as needed.
  - Provide counseling regarding sexuality, sexual functioning, fertility and contraception.
  - Discuss avoidance of drugs/alcohol.
  - Discuss importance of initiating and organizing opportunities for social activities.
  - Discuss the relationship between independence and mental health.
  - Facilitate involvement with role model.
  - Provide opportunities for formal or informal mentoring.
- Participate in IEP school transition team.
- Plan for transition to independent living, post secondary education, vocational training, and career interests.
- Plan for transition from pediatric to adult health care

- Evidence
  
  See evidence under “Infancy”

- Adult

- Clinical Questions
  
  - What is the psychosocial impact of having SB on mental health and adaptation across the lifespan?
  - Which domains of mental health are most adversely affected in individuals with SB and in what areas of mental health are individuals with SB most resilient?
  - What are some common maladaptive behaviors that can negatively impact persons with spina bifida across the lifespan?

- Guidelines
  
  - Screen for depression or anxiety and initiate interventions when appropriate.
  
  - Continue transfer of medical responsibility from parent to child in those who have the requisite abilities/cognitive capacity
  
  - Encourage activities and hobbies that improve face-to-face social contact.
  
  - Encourage ongoing efforts to promote friendship and intimacy.
  
  - Facilitate vocational or occupational pursuits.
• Maintain efforts for good general health promotion and exercise as well as specialized spina bifida care. Optimize health to reduce obesity risk and maximize social opportunities and mental health.

• Recommend SBA resources

• Continue transition from pediatric to adult health care

• Evidence

The transition to adult health care (from pediatric care) poses significant challenges (Cox et al., 2011). Barriers to a successful transition must be addressed.

The mortality rate among youth with spina bifida is roughly 1% per year from ages 5 to 30 (Bowman & McLone, 2001; Oakeshott, Hunt, Poulton, & Reid, 2010), with the rate being highest among those with the highest lesion levels (Oakeshott, Hunt, Poulton, & Reid, 2010).

Among survivors, the quality of individuals’ health tends to decline from adolescence to young adulthood, presumably due to difficulties in navigating the transition to adult health care.

Regarding psychosocial adjustment, emerging adults with SB, like their younger counterparts, are at-risk for depressive symptoms and anxiety (Bellin et al., 2010), but they are less likely to engage in at-risk behaviors (e.g., alcohol use, multiple sexual partners), possibly due to their lower rates of social integration (Murray et al., 2014).

Regarding educational and vocational outcomes, emerging adults with SB are less likely to go to college (41-56% of individuals with SB go to college vs. 66% of typically developing youth; Bowman & McLone, 2001; Zukerman, Devine, & Holmbeck, 2011).

With respect to employment, recent studies report rates of full- or part-time employment ranging from 36-48% (Copp et al., 2015; Zukerman et al., 2011), which are significantly lower than those found in typically developing youth and in those with other chronic conditions.

With respect to relationship quality, between 43 to 77% live with their parents (Bowman & McLone, 2001; Cope et al., 2013) but over half (52-68%) have had a romantic relationship (Cope et al., 2013), although this latter rate is lower than in typically developing young adults (Zukerman et al., 2011). The lowest level of life satisfaction is in the areas of romantic relationships, employment, and financial independence (Cope et al., 2013). The high rate of obesity in this population (i.e., rates tend to be over 40%),
coupled with their continence issues, likely undermine young adults’ efforts to have romantic relationships.

With respect to community participation and social integration, participation in leisure and recreational activities tends to be low, with over 50% participating in no activities (Boudos & Mukherjee, 2008). The most common barriers to community participation are: lack of motivation, lack of information, and time constraints (Boudos & Mukherjee, 2008). Moreover, younger individuals and those without shunts tend to participate more than older and more impaired individuals.

The best predictors of successful navigation of young adult milestones appear to be condition-related (i.e., hydrocephalus and mobility status; Cope et al., 2013), neuropsychological (e.g., executive functioning, Zukerman et al., 2011), personality-based (e.g., intrinsic motivation; Zukerman et al., 2011), familial (e.g., SES, parental intrusiveness; Zukerman et al., 2011), and logistical (e.g., transportation, accessibility; Barf et al., 2009). Other factors may include: financial concerns (including lack of health insurance), lack of job training and vocational rehabilitation services, employment discrimination, stigmas related to physical appearance, and a lack of autonomy-related socialization during early childhood (Dicianno et al. 2008).

- **RESEARCH GAPS**

The following questions have not been answered with well-designed studies and/or RCTs:

What services and supports can be utilized to mitigate barriers to optimal mental health throughout the lifespan?

What are the links between mental health and the following outcomes: self-management, independence, quality of life, and the transition from pediatric to adult health care?

What interventions are available that enhance mental health across the lifespan in individuals with SB?

What methods have been implemented by SB providers to guide transition to adult health care in individuals with SB who have an identified mental health diagnosis?

References


