2017

Spina Bifida

Grayson N. Holmbeck
Loyola University Chicago, gholmbe@luc.edu

Kathy Zebracki

Jaclyn Lennon Papadakis

Colleen F. Bechtel Driscoll

HANDBOOK OF PEDIATRIC PSYCHOLOGY

FIFTH EDITION

edited by

MICHAEL C. ROBERTS
RIC G. STEELE

Handbook of PEDIATRIC PSYCHOLOGY

FIFTH EDITION

edited by

MICHAEL C. ROBERTS
RIC G. STEELE

THE GUILFORD PRESS
New York London

A Division of Guilford Publications, Inc.
370 Seventh Avenue, Suite 1200, New York, NY 10001
www.guilford.com

Paperback edition 2018

Printed in the United States of America

This book is printed on acid-free paper.

Last digit is print number: 9 8 7 6 5 4 3 2

Library of Congress Cataloging-in-Publication Data

Names: Roberts, Michael C., editor. | Steele, Ric G., editor.
Title: Handbook of pediatric psychology / [edited by] Michael C. Roberts, Ric G. Steele.
Description: Fifth edition. | New York : The Guilford Press, [2017] | Includes bibliographical references and indexes.
Identifiers: LCCN 2016057548 | ISBN 9781462529780 (hardback) | ISBN 9781462536085 (paperback)
Subjects: LCSH: Pediatrics—Psychological aspects. | Sick children—Psychology. | BISAC: PSYCHOLOGY / Psychotherapy / Child & Adolescent. | MEDICAL / Psychiatry / Child & Adolescent. | SOCIAL SCIENCE / Social Work. | MEDICAL / Nursing / Psychiatric.
Classification: LCC RJ47.5 .H38 2017 | DDC 618.920001/9—dc23
LC record available at *https://lccn.loc.gov/2016057548*

CHAPTER 24

Spina Bifida

Grayson N. Holmbeck, Kathy Zebracki,
Jaclyn Lennon Papadakis, and Colleen F. Bechtel Driscoll

Spina bifida (SB) is a relatively common congenital birth defect that has a pervasive impact on the physical, neurocognitive, psychological, and social functioning of affected individuals and their families. Given the characteristics of this condition as well as the complexities of medical adherence in this population, pediatric psychologists are uniquely qualified to provide assessment and intervention services to these individuals.

SYMPTOMS, DIAGNOSIS, AND SCOPE

During the early stages of normative embryonic development, the neural tube closes and ultimately forms the brain and spinal cord. When this closure fails, a neural tube defect (such as SB) can develop, with the majority of abnormalities involving the lower portions of the spinal cord (sacral and lumbar areas).

Diagnosis

SB can be diagnosed with advanced prenatal ultrasound or maternal serum alpha-fetoprotein (Copp et al., 2015). Postnatally, a diagnosis can be made by using X-ray, magnetic resonance imaging, or computed tomography. There are four types of SB, varying in severity (Copp et al., 2015):

1. Occulta, the mildest form, is often referred to as "hidden" SB; there is no open lesion, and generally there are no symptoms or associated disabilities.
2. Closed neural tube defects (e.g., lipomeningocele) occur when the spinal cord has a malformation of fat, bone, or meninges; in most cases there are no symp-

toms, although some individuals may experience loss of motor function and bladder and bowel dysfunction.

3. In meningocele, the spinal fluid and meninges protrude through the abnormal vertebral opening; however, the spinal cord remains intact.
4. Myelomeningocele is the most severe form of SB. The spinal cord is exposed and causes moderate to severe disability, including partial to complete paralysis as well as bladder, bowel, and sexual dysfunction.

Most studies of SB have been conducted with samples that are largely or exclusively made up of individuals with myelomeningocele. Thus, unless stated otherwise, this subpopulation is the focus of this chapter.

Epidemiology

Across all types, SB occurs in approximately 3 of every 10,000 live births. Incidence, however, differs among ethnic/racial groups and geographically. Hispanics have the highest rate (4.2 per 10,000 live births), followed by non-Hispanic European Americans (3.2 per 10,000), and African Americans (2.6 per 10,000; Boulet et al., 2008). The mortality rate among youth with SB is roughly 1% per year from ages 5 to 30, with the rate being highest among those with the highest lesion levels (Bowman, McLone, Grant, Tomita, & Ito, 2001; Oakeshott, Hunt, Poulton, & Reid, 2010). Lifetime direct costs for a child with SB are estimated at $600,000, with slightly over one-third for medical costs and the remainder for indirect costs, including special education, assistive technology, caregiver support, and loss of future earnings (Copp et al., 2015).

Causation and Prevention

Despite advances in the medical management of SB, knowledge of the underlying mechanisms causing this neural tube defect remains incomplete. Genetic factors are believed to be primary components of causation; however, few genes involved in SB have been identified (Copp et al., 2015). There are also several nongenetic factors linked with SB; of these, inadequate maternal folic acid consumption is the most well-established risk factor.

Clinical Presentation

The severity of disability in SB is linked with the level of lesion on the spinal cord, with higher levels causing more impairment. In some cases, there is a tethering of the spinal cord (i.e., tissue attachments that stretch the spinal cord and limit its movement) during growth. Common manifestations of myelomeningocele include motor and sensory neurological deficits below the level of the lesion (e.g., paralysis); neurogenic bladder (e.g., incontinence, urinary tract infections) and bowel (e.g., incontinence, constipation); spasticity; orthopedic conditions (e.g., contractures, hip dislocation, and scoliosis); and pressure ulcers. SB is also often associated with hydrocephalus (excessive accumulation of cerebrospinal fluid in the ventricles of the brain, which is treated with a shunt—a drainage tube surgically placed in the brain) and with the Chiari II malformation (struc-

tural defects in the cerebellum, accompanied by symptoms such as apnea or swallowing difficulties in infants and by headache, scoliosis, and balance/coordination issues in children and adults).

Individuals with SB also frequently exhibit hearing and visual impairments; coordination disorder; difficulties with visual–spatial processing; reductions in finger dexterity and hand function; and seizures. They experience cognitive and academic difficulties as well, including executive dysfunction; attention problems (focusing and shifting); and difficulties with reading, pragmatic language, language comprehension, and math (Copp et al., 2015).

PSYCHOLOGICAL ASPECTS OF SPINA BIFIDA: INDIVIDUAL AND FAMILY FUNCTIONING

The psychological adjustment of individuals with SB is likely to be determined by the interacting influences of multiple biological, neuropsychological, social, and contextual factors (see Figure 24.1).

Psychosocial Adjustment

Youth with SB are at risk for exhibiting higher levels of depressive symptoms and lower levels of self-concept than comparison children (Holmbeck et al., 2003). Children with SB also exhibit social difficulties (i.e., they tend to be socially immature and passive, have fewer friends, and date less during adolescence; e.g., Holmbeck et al., 2003), and these difficulties are maintained over time (Holmbeck, DeLucia, et al., 2010). Youth with SB tend to be more dependent on adults for guidance and are less likely to express their own viewpoints during observed family interactions (Holmbeck et al., 2003).

Youth with SB have reduced health-related quality of life (HRQOL) as compared to both healthy samples and samples of youth with other chronic health conditions; these differences tend to be stable across age groups, gender, geographical location, and time (Murray et al., 2015; Sawin & Bellin, 2010). Some measures of condition severity are associated with HRQOL, including presence of hydrocephalus and lack of mobility (Cope et al., 2013; Dicianno, Gaines, Collins, & Lee, 2009). Other robust predictors of HRQOL include socioeconomic status (SES), pain levels, and parenting stress (Bellin et al., 2013).

Family Functioning

Research on families of youth with SB (Holmbeck, Greenley, Coakley, Greco, & Hagstrom, 2006) supports a resilience–disruption view of family functioning (Costigan, Floyd, Harter, & McClintock, 1997), whereby the presence of a child with SB disrupts normative family functioning, but many families exhibit considerable resilience. Families of youth with SB from lower-SES backgrounds are particularly at risk for lower levels of family cohesion, supporting a cumulative-risk view of such families (Holmbeck, Coakley, Hommeyer, Shapera, & Westhoven, 2002).

With respect to the functioning of parents, a meta-analysis of 15 studies (Vermaes, Janssens, Bosman, & Gerris, 2005) found medium to large negative effects for the

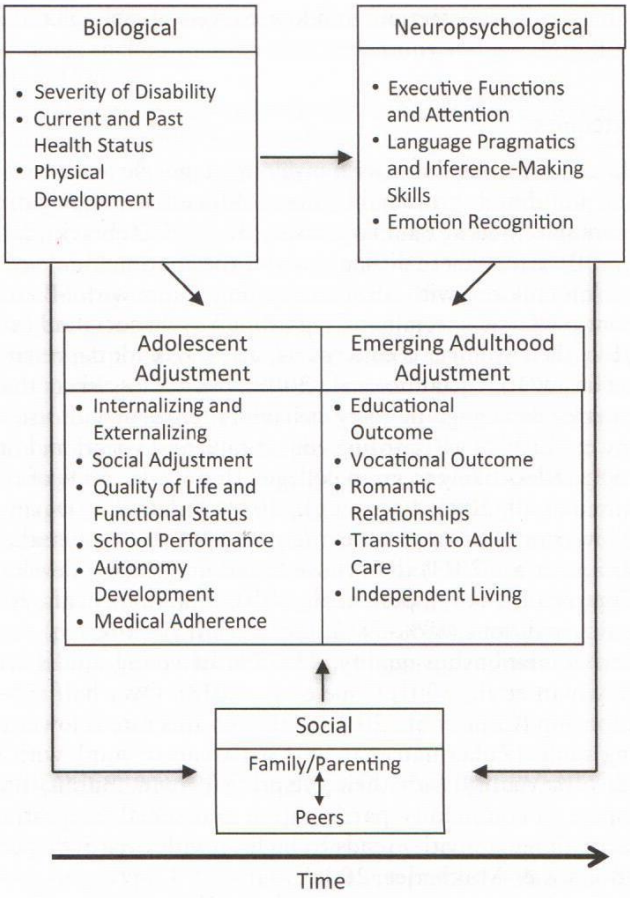

FIGURE 24.1. Bioneuropsychosocial model of psychological adjustment in adolescents and emerging adults with spina bifida. From "Psychosocial and family functioning in spina bifida" by G. N. Holmbeck and K. A. Devine, 2010, *Developmental Disabilities Research Reviews, 16*(1), 40–46. Copyright © 2010 by John Wiley and Sons. Reprinted with permission.

impact of SB on mothers' and fathers' psychological adjustment, with somewhat larger effect sizes for mothers (d = 0.73) than for fathers (d = 0.54), as well as negative effects on parental stress and quality of parenting (Holmbeck, Johnson, et al., 2002; Vermaes, Gerris, & Janssens, 2007). Such parents feel less satisfied and competent as parents, feel more isolated, are less adaptable to change, and hold less optimistic views about the future than comparison parents (Holmbeck et al., 1997). Parents who are single, older, socially isolated, and/or from an ethnic minority group or a low-SES background are particularly at risk for such outcomes (Holmbeck, Coakley, et al., 2002). Siblings of children with SB are better adjusted when their families have more positive attitudes

toward SB, greater family satisfaction, and lower levels of sibling conflict (Bellin, Bentley, & Sawin, 2009).

Young Adult Outcomes

The quality of health for individuals with myelomeningocele tends to decline from adolescence to young adulthood, presumably due to difficulties in navigating the transition to adult health care (Holmbeck, Bauman, Essner, Kelly, & Zebracki, 2010; Liptak, Kennedy, & Dosa, 2010). Given these difficulties and the continued role of parents as caregivers for their adult children with SB, many young adults with SB continue to receive medical care from pediatric specialists. Regarding psychosocial adjustment, emerging adults with SB, like their younger counterparts, are at risk for depressive symptoms and anxiety (Bellin et al., 2010; Dicianno et al., 2009), but are less likely than their typically developing age-mates to engage in risky behaviors (e.g., alcohol use, multiple sexual partners; Murray et al., 2014). Regarding educational and vocational outcomes, emerging adults with SB are less likely to go to college (41–56% vs. 66% of typically developing youth; Bowman et al., 2001; Cope et al., 2013; Zukerman, Devine, & Holmbeck, 2011) and have lower rates of employment (e.g., 36–48%; Cope et al., 2013; Liptak et al., 2010; Zukerman et al., 2011) than those found in typically developing youth (e.g., roughly 75%; Cope et al., 2013; Liptak et al., 2010; Zukerman et al., 2011) and in youth with other chronic conditions (68%–78%; Liptak et al., 2010).

With respect to relationship quality, 43–77% of young adults with SB live with their parents (Bowman et al., 2001; Cope et al., 2013). Over half (52–68%) have had a romantic relationship (Cope et al., 2013), although this rate is lower than in typically developing young adults (Zukerman et al., 2011). Parents of youth with SB are less likely to discuss issues of sexuality with their offspring (Sawin, Buran, Brei, & Fastenau, 2002). With respect to community participation and social integration, participation in leisure and recreational activities tends to be low, with over 50% participating in no such activities (Boudos & Mukherjee, 2008).

More generally, the best predictors of successful navigation of young adult milestones appear to be condition-related (i.e., hydrocephalus, lesion level, 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); logistical (e.g., transportation, accessibility; Barf et al., 2009); and financial (e.g., lack of health insurance). Other predictors include lack of job training and vocational rehabilitation services, employment discrimination, and stigmas related to physical appearance (Dicianno et al., 2008, 2009).

MANAGEMENT OF SB AND THE ROLE OF THE PEDIATRIC PSYCHOLOGIST

Individuals with SB require lifelong, extensive, and active treatment from an interdisciplinary team that focuses on the following: bladder and bowel management, mobility, skin care and other self-care activities, health care maintenance, psychological well-being, educational and vocational counseling, social services, recreation and leisure activities, and prevention and management of complications. Interestingly, research on

adults with SB has indicated that up to one-half of hospitalizations are due to potentially preventable conditions, such as urinary tract infections and pressure ulcers (Mahmood, Dicianno, & Bellin, 2011).

The ultimate goal in treating youth with SB is for them to experience satisfying and productive lives as independently functioning and healthy adults in society (Zebracki, Zaccariello, Zelko, & Holmbeck, 2010). Providing anticipatory guidance to parents and caregivers, such as long-term implications of living with a disability, is crucial as these youth move through various developmental stages. SB clinics often include teams of specialized physicians, nurses, pediatric neurosurgeons, urologists, orthopedic surgeons, physical therapists, occupational and recreational therapists, nutritionists, pediatric psychologists, and social workers. Pediatric psychologists can take on a variety of roles within such an interdisciplinary team. Along with social workers, pediatric psychologists can provide support to family members, as well as psychosocial services addressing mental health problems (e.g., depressive symptoms, medical adherence difficulties). Given the array of cognitive, emotional, psychosocial, and learning impairments seen in SB, regular comprehensive neuropsychological, psychosocial, psychoeducational, and speech–language evaluations are strongly recommended to monitor declines and to provide recommendations for intervention and treatment (Deaton & Castaldi, 2011). Psychologists can also engage in interventions aimed at improving HRQOL, coping, and participation, and can employ behavioral strategies with the goals of improving medical adherence (particularly for catheterization, bowel programs, and skin checks), enhancing general living skills, and/or encouraging independence in the management of medical care.

EVIDENCE-BASED ASSESSMENTS AND INTERVENTIONS

In contrast to the extensive literature on evidence-based interventions for other chronic physical conditions (e.g. Type 1 diabetes), there is a lack of such interventions for families of young people with SB (Holmbeck et al., 2006). More generally, with only two exceptions (Betz, Smith, & Macias, 2010; Stubberud, Langenbahn, Levine, Stanghelle, & Schanke, 2015), no randomized clinical trials (RCTs) have been reported for this population across all of the psychosocial domains listed in Figure 24.1.

For example, in one of the two RCTs conducted with individuals with SB, goal management training was employed to address executive functioning impairments in this population (Stubberud et al., 2015). Findings revealed that the intervention produced significant improvements in executive functioning, self-reported depressive and anxiety symptoms, HRQOL, and coping skills. Other preliminary work points to the need for more RCTs. A manualized summer camp-based intervention was developed to target independence and social skills among children, adolescents, and young adults with SB (Holbein et al., 2013; O'Mahar, Holmbeck, Jandasek, & Zukerman, 2010). Preliminary research on this intervention found that statistically significant gains occurred in individualized goals and in the independent management of SB-related responsibilities.

In the area of assessment, most investigators have relied on generic measures or have adapted illness-specific measures developed for other populations. For example, O'Hara and Holmbeck (2013) assessed medical adherence with the Spina Bifida Self-Management Profile, an adaptation of the Self-Management Profile that was originally

developed for youth with Type 1 diabetes (Wysocki & Gavin, 2006). Also, Kaugars et al. (2011) and Holbein, Zebracki, and Holmbeck (2014) provided validation data for an observational coding system to be applied to observed family and peer interactions, respectively; this system was an adaptation of a coding system developed by Smetana, Yau, Restrepo, and Braeges (1991). On the other hand, some measures have been developed specifically for this population (e.g., the Kennedy Krieger Independence Scales—Spina Bifida Version; Jacobson et al., 2013).

ISSUES OF DIVERSITY

As is the case for other pediatric health conditions, research is needed on how the presence of SB may affect individuals and families differently, depending on the presence of various diversity characteristics (e.g., race, ethnicity, language, age, gender, sexual orientation, religion, geographic location, SES, education, family structure, disability status, physical appearance). The few studies that have examined racial/ethnic differences among individuals with SB have found differences in health-related and psychosocial outcomes (Chowanadisai et al., 2013; Devine, Holbein, Psihogios, Amaro, & Holmbeck, 2012; Swartwout, Garnaat, Myszka, Fletcher, & Dennis, 2009). Other diversity characteristics that are important to consider include cultural and religious/spiritual beliefs. Because a family's culture—the beliefs, values, meanings, and actions that shape the lives of an identified group of people—has an impact on all aspects of family life, it is important to understand how the meaning of and response to SB may vary, depending on culture-based normative beliefs (Ripat & Woodgate, 2011).

EMERGING AREAS AND RECOMMENDATIONS FOR FUTURE CLINICAL WORK AND RESEARCH

Clinical Recommendations

Clinics can enhance comprehensive care by adopting a model for identifying families in need of treatment for psychosocial difficulties. For example, Kazak (2006) has presented a pediatric psychosocial preventative health model (PPPHM), based on a social-ecological framework. (See also Carter et al., Chapter 9, this volume.) According to this model, all families receive a brief assessment to determine what level of services they need—universal, targeted, or clinical/treatment. Importantly, risk factors can change, and families can move among these three risk status groups over time.

Recommendations for Future Research

The literature on family and psychosocial functioning in individuals with SB will benefit from theory-driven advances that include the following features: (1) a developmental emphasis; (2) a focus on both illness-specific and general family processes; (3) models examining mediational processes; and (4) models taking into account family-related variables (e.g., autonomy-promoting parenting) that serve as potential buffers for associations between risk factors (e.g., neurological status) and negative outcomes (e.g., academic failure). It is also recommended that research be programmatic and longitudinal.

Predictor and outcome variables all need to be assessed over time, particularly during key developmental periods or transition points (e.g., early childhood, transition to elementary school, early adolescent transition, transition to early adulthood).

In conclusion, using theoretical models such as the bioneuropsychosocial model (see Figure 24.1) to inform future research studies will help move the field toward a better understanding of the various factors that influence child psychosocial adjustment and family functioning in youth with SB. Moreover, the field would do well to identify areas of resilience, and factors associated with resilience, in youth with SB and their families.

ACKNOWLEDGMENTS

Completion of this chapter was supported in part by research grants from the National Institute of Child Health and Human Development (No. RO1 HD048629) and the March of Dimes Birth Defects Foundation (No. 12-FY13-271).

REFERENCES

Barf, H. A., Post, M. W., Verhoef, M., Jennekens-Schinkel, A., Gooskens, R. H., & Prevo, A. J. (2009). Restrictions in social participation of young adults with spina bifida. *Disability and Rehabilitation, 31*(11), 921–927.

Bellin, M. H., Bentley, K. J., & Sawin, K. J. (2009). Factors associated with the psychological and behavioral adjustment of siblings of youths with spina bifida. *Families, Systems, and Health, 27*(1), 1–15.

Bellin, M. H., Dicianno, B. E., Osteen, P., Dosa, N., Aparicio, E., Braun, P., & Zabel, T. A. (2013). Family satisfaction, pain, and quality-of-life in emerging adults with spina bifida: A longitudinal analysis. *American Journal of Physical Medicine and Rehabilitation, 92*(8), 641–655.

Bellin, M. H., Zabel, T. A., Dicianno, B. E., Levey, E., Garver, K., Linroth, R., & Braun, P. (2010). Correlates of depressive and anxiety symptoms in young adults with spina bifida. *Journal of Pediatric Psychology, 35*(7), 778–789.

Betz, C. L., Smith, K., & Macias, K. (2010). Testing the Transition Preparation Training Program: A randomized controlled trial. *International Journal of Child and Adolescent Health, 3, 595–607.*

Boudos, R. M., & Mukherjee, S. (2008). Barriers to community participation: Teens and young adults with spina bifida. *Journal of Pediatric Rehabilitation Medicine, 1*(4), 303–310.

Boulet, S. L., Yang, Q., Mai, C., Kirby, R., Collins, J. S., Robbins, J. M., . . . National Birth Defects Prevention Network. (2008). Trends in the postfortification prevalence of spina bifida and anencephaly in the United States. *Birth Defects Research: Part A. Clinical and Molecular Teratology, 82*(7), 527–532.

Bowman, R. M., McLone, D. G., Grant, J. A., Tomita, T., & Ito, J. A. (2001). Spina bifida outcome: A 25-year prospective. *Pediatric Neurosurgery, 34*(3), 114–120.

Chowanadisai, M., de la Rosa Perez, D. L., Weitzenkamp, D. A., Wilcox, D. T., Clayton, G. H., & Wilson, P. E. (2013). The role of ethnicity and culture on functional status in children with spina bifida. *Journal of Pediatric Rehabilitation Medicine, 6*(4), 203–213.

Cope, H., McMahon, K., Heise, E., Eubanks, S., Garrett, M., Gregory, S., & Ashley-Koch, A. (2013). Outcome and life satisfaction of adults with myelomeningocele. *Disability and Health Journal, 6*(3), 236–243.

Copp, A. J., Adzick, N. S., Chitty, L. S., Fletcher, J. M., Holmbeck, G. N., & Shaw, G. M. (2015). Spina bifida. *Nature Reviews Disease Primers, 1,* 15007.

Costigan, C. L., Floyd, F. J., Harter, K. S. M., & McClintock, J. C. (1997). Family process and adaptation to children with mental retardation: Disruption and resilience in family problem-solving interactions. *Journal of Family Psychology, 11*(4), 515–529.

Deaton, A. V., & Castaldi J. (2011). The role of the child clinical psychologist in life care planning. In S. Riddick-Grisham & L. Deming (Eds.), *Pediatric life care planning and case management* (2nd ed., pp. 133–145). Boca Raton, FL: CRC Press.

Devine, K. A., Holbein, C. E., Psihogios, A. M., Amaro, C. M., & Holmbeck, G. N. (2012). Individual adjustment, parental functioning, and perceived social support in Hispanic and non-Hispanic white mothers and fathers of children with spina bifida. *Journal of Pediatric Psychology, 37*(7), 769–778.

Dicianno, B. E., Gaines, A., Collins, D. M., & Lee, S. (2009). Mobility, assistive technology use, and social integration among adults with spina bifida. *American Journal of Physical Medicine and Rehabilitation, 88*(7), 533–541.

Dicianno, B. E., Kurowski, B. G., Yang, J. M., Chancellor, M. B., Beijani, G. K., Fairman, A. D., . . . Sotirake, J. (2008). Rehabilitation and medical management of the adult with spina bifida. *American Journal of Physical Medicine and Rehabilitation, 87*(12), 1027–1049.

Holbein, C. E., Murray, C. B., Psihogios, A. M., Wasserman, R. M., Essner, B. S., O'Hara, L. K., & Holmbeck, G. N. (2013). A camp-based psychosocial intervention to promote independence and social function in individuals with spina bifida: Moderators of treatment effectiveness. *Journal of Pediatric Psychology, 38*(4), 412–424.

Holbein, C. E., Zebracki, K., & Holmbeck, G. N. (2014). Development and validation of the Peer Interaction Macro-Coding System Scales (PIMS): A new tool for observational measurement of social competence in youth with spina bifida. *Psychological Assessment, 26*(4), 1235–1246.

Holmbeck, G. N., Bauman, L., Essner, B., Kelly, L., & Zebracki, K. (2010). Developmental context: The transition from adolescence to emerging adulthood in youth with disabilities and chronic health conditions. In D. Lollar (Ed.), *Launching into adulthood: An integrated response to support transition of youth with chronic health conditions and disabilities* (pp. 21–47). Baltimore, MD: Brookes.

Holmbeck, G. N., Coakley, R. M., Hommeyer, J., Shapera, W. E., & Westhoven, V. (2002). Observed and perceived dyadic and systemic functioning in families of preadolescents with spina bifida. *Journal of Pediatric Psychology, 27*(2), 177–189.

Holmbeck, G. N., DeLucia, C., Essner, B., Kelly, L., Zebracki, K., Friedman, D., & Jandasek, B. (2010). Trajectories of psychosocial adjustment in adolescents with spina bifida: A 6-year, four-wave longitudinal follow-up. *Journal of Consulting and Clinical Psychology, 78*(4), 511–525.

Holmbeck, G. N., & Devine, K. A. (2010). Psychosocial and family functioning in spina bifida. *Developmental Disabilities Research Reviews, 16*(1), 40–46.

Holmbeck, G. N., Gorey-Ferguson, L., Hudson, T., Seefeldt, T., Shapera, W., Turner, T., & Uhler, J. (1997). Maternal, paternal, and marital functioning in families of preadolescents with spina bifida. *Journal of Pediatric Psychology, 22*(2), 167–181.

Holmbeck, G. N., Greenley, R. N., Coakley, R. M., Greco, J., & Hagstrom, J. (2006). Family functioning in children and adolescents with spina bifida: An evidence-based review of research and interventions. *Journal of Developmental and Behavioral Pediatrics, 27*(3), 249–277.

Holmbeck, G. N., Johnson, S. Z., Wills, K. E., McKernon, W., Rose, B., Erklin, S., & Kemper, T. (2002). Observed and perceived parental overprotection in relation to psychosocial adjustment in preadolescents with a physical disability: The mediational role of behavioral autonomy. *Journal of Consulting and Clinical Psychology, 70*(1), 96–110.

Holmbeck, G. N., Westhoven, V. C., Phillips, W. A., Bowers, R., Gruse, C., Nikopoulos, T., . . . Davison, K. (2003). A multimethod, multi-informant, and multidimensional perspective on psychosocial adjustment in preadolescents with spina bifida. *Journal of Consulting and Clinical Psychology, 71*(4), 782–796.

Jacobson, L. A., Tarazi, R. A., McCurdy, M. D., Schultz, S., Levey, E., Mahone, E. M., & Zabel, T. A. (2013). The Kennedy Krieger Independence Scales—Spina Bifida Version: A measure of executive components of self-management. *Rehabilitation Psychology, 58*(1), 98–105.

Kaugars, A. S., Zebracki, K., Kichler, J. C., Fitzgerald, C. J., Greenley, R. N., Alemzadeh, R., & Holmbeck, G. N. (2011). Use of the Family Interaction Macro-coding System with families of adolescents: Psychometric properties among pediatric and healthy populations. *Journal of Pediatric Psychology, 36*(5), 539–551.

Kazak, A. E. (2006). Pediatric psychosocial preventative health model (PPPHM): Research, practice, and collaboration in pediatric family systems medicine. *Families, Systems, and Health, 24*(4), 381–395.

Liptak, G. S., Kennedy, J. A., & Dosa, N. P. (2010). Youth with spina bifida and transitions: Health and social participation in a nationally represented sample. *Journal of Pediatrics, 157*(4), 584–588.

Mahmood, D., Dicianno, B., & Bellin, M. (2011). Self-management, preventable conditions and assessment of care among young adults with myelomeningocele. *Child: Care, Health and Development, 37*(6), 861–865.

Murray, C., Holmbeck, G., Ros, A., Flores, D., Mir, S., & Varni, J. (2015). A longitudinal examination of health-related quality of life in children and adolescents with spina bifida. *Journal of Pediatric Psychology, 40,* 419–430.

Murray, C., Lennon, J. Devine, K., Holmbeck, G. N., Klages, K., & Potthoff, L. (2014). The influence of social adjustment on normative and risky health behaviors in emerging adults with spina bifida. *Health Psychology, 33,* 1153–1163.

Oakeshott, P., Hunt, G. M., Poulton, A., & Reid, F. (2010). Expectation of life and unexpected death in open spina bifida: A 40-year complete, non-selective, longitudinal cohort study. *Developmental Medicine and Child Neurology, 52*(8), 749–753.

O'Hara, L. K., & Holmbeck, G. N. (2013). Executive functions and parenting behaviors in association with medical adherence and autonomy among youth with spina bifida. *Journal of Pediatric Psychology, 38*(6), 675–687.

O'Mahar, K., Holmbeck, G. N., Jandasek, B., & Zukerman, J. (2010). A camp-based intervention targeting independence among individuals with spina bifida. *Journal of Pediatric Psychology, 35*(8), 848–856.

Ripat, J., & Woodgate, R. (2011). The intersection of culture, disability and assistive technology. *Disability and Rehabilitation: Assistive Technology, 6*(2), 87–96.

Sawin, K. J., & Bellin, M. H. (2010). Quality of life in individuals with spina bifida: A research update. *Developmental Disabilities Research Reviews, 16*(1), 47–59.

Sawin, K. J., Buran, C. F., Brei, T. J., & Fastenau, P. S. (2002). Sexuality issues in adolescents with a chronic neurological condition. *Journal of Perinatal Education, 11*(1), 22–34.

Smetana, J. G., Yau, J., Restrepo, A., & Braeges, J. L. (1991). Adolescent–parent conflict in married and divorced families. *Developmental Psychology, 27,* 1000–1010.

Stubberud, J., Langenbahn, D., Levine, B., Stanghelle, J., & Schanke, A. K. (2015). Emotional health and coping in spina bifida after goal management training: A randomized controlled trial. *Rehabilitation Psychology, 60,* 1–16.

Swartwout, M. D., Garnaat, S. L., Myszka, K. A., Fletcher, J. M., & Dennis, M. (2009). Associations of ethnicity and SES with IQ and achievement in spina bifida meningomyelocele. *Journal of Pediatric Psychology, 35*(9), 927–936.

Vermaes, I. P., Gerris, J. R., & Janssens, J. M. (2007). Parents' social adjustment in families of

children with spina bifida: A theory-driven review. *Journal of Pediatric Psychology, 32*(10), 1214–1226.

Vermaes, I. P., Janssens, J. M., Bosman, A. M., & Gerris, J. R. (2005). Parents' psychological adjustment in families of children with spina bifida: A meta-analysis. *BMC Pediatrics, 5*, 32–44.

Wysocki, T., & Gavin, L. (2006). Paternal involvement in the management of pediatric chronic diseases: Associations with adherence, quality of life, and health status. *Journal of Pediatric Psychology, 31*(5), 501–511.

Zebracki, K., Zaccariello, M., Zelko, F., & Holmbeck, G. (2010). Adolescence and emerging adulthood in individuals with spina bifida: A developmental neuropsychological perspective. In J. Donders & S. Hunter (Eds.), *Principles and practice of lifespan developmental neuropsychology* (pp. 183–193). Cambridge, UK: Cambridge University Press.

Zukerman, J. M., Devine, K. A., & Holmbeck, G. N. (2011). Adolescent predictors of emerging adulthood milestones in youth with spina bifida. *Journal of Pediatric Psychology, 36*(3), 265–276.

PSYCHOLOGY

HANDBOOK OF PEDIATRIC PSYCHOLOGY

FIFTH EDITION

edited by MICHAEL C. ROBERTS AND RIC G. STEELE

"The fifth edition of this handbook substantially updates a highly valued classic, with contributions from the top scholars in the field. In addition to management of common pediatric conditions, the volume covers professional and public policy issues relevant to practitioners and researchers alike." —Gerald P. Koocher, PhD, ABPP, Professor of Psychology and Dean, College of Science and Health, DePaul University

"The quintessential resource for pediatric psychology. The editors have captured not only the vitality of the field, but also the depth and breadth of the science underlying effective interventions." —Sharon Berry, PhD, ABPP, Director of Training and Associate Clinical Director, Children's Hospitals and Clinics of Minnesota

"There is exciting new content on training and competencies in pediatric psychology, eHealth applications, and epigenetics, to name just a few topics. In the fifth edition, science and practice are engaged in a meaningful collaboration….A 'must have' for every reference shelf and for graduate courses in pediatric psychology." —Barry S. Anton, PhD, ABPP, past president, American Psychological Association; Distinguished Professor Emeritus, University of Puget Sound

THOUSANDS OF PRACTITIONERS AND STUDENTS HAVE RELIED ON THIS HANDBOOK, NOW THOROUGHLY REVISED, FOR authoritative information on the links between psychological and medical issues from infancy through adolescence. Sponsored by the Society of Pediatric Psychology, the volume explores psychosocial aspects of specific medical problems, as well as issues in managing developmental and behavioral concerns that are frequently seen in pediatric settings. The book describes best practices in training and service delivery and presents evidence-based approaches to intervention with children and families. All chapters have been rigorously peer reviewed by experts in the field.

New to This Edition • Chapters on rural health, the transition to adult medical care, prevention, and disorders of sex development • Expanded coverage of epigenetics, eHealth applications, cultural and ethnic diversity, spina bifida, and epilepsy. • Many new authors; extensively revised with the latest information on clinical populations, research methods, and interventions. • Chapters on training and professional competencies, quality improvement and cost-effectiveness, and international collaborations.

Michael C. Roberts, PhD, ABPP, is Dean of Graduate Studies and Professor and former Director of the Clinical Child Psychology Program at the University of Kansas.

Ric G. Steele, PhD, ABPP, is Professor and Director of the Clinical Child Psychology Program at the University of Kansas.

Cover design by Paul Gordon

Sign up for exclusive offers! www.guilford.com/e-alerts

The Guilford Press
370 Seventh Avenue
New York, NY 10001
www.guilford.com

ISBN 978-1-4625-3608-5