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Parenting and Psychosocial Functioning in Youth with Spina Bifida: Making Connections with Other CNS-Related Chronic Health Conditions

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LOYOLA UNIVERSITY CHICAGO

PARENTING AND PSYCHOSOCIAL FUNCTIONING IN YOUTH WITH SPINA BIFIDA: MAKING CONNECTIONS WITH OTHER CNS-RELATED CHRONIC HEALTH CONDITIONS

A DISSERTATION SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL
IN CANDIDACY FOR THE DEGREE OF
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PROGRAM IN CLINICAL PSYCHOLOGY

BY
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ABSTRACT

Parenting practices have been linked to psychosocial outcomes in children who have chronic health conditions that affect the central nervous system (CNS), such as spina bifida (SB). However, there remains a need for (1) more evidence-based assessments that capture parenting in SB, (2) additional research focused on parenting in early childhood in SB, as this is a critical developmental period that has been understudied, and (3) systematic reviews that synthesize parenting research across CNS-related conditions to guide future work. This dissertation includes three papers that aim to address each of these gaps in the current literature. Specifically, the first study developed and validated a novel measure of parental scaffolding for children with SB. The second study examined the parenting experiences and needs of families who have a young child with SB through dissemination of a national survey. The third study synthesized the parenting literature for children with five CNS-related chronic health conditions (i.e., SB, traumatic brain injury, cerebral palsy, epilepsy, and brain tumors). Results are discussed within the context of the Bio-Neuropsychosocial Model of Adjustment in Individuals with SB. These findings can guide the development of family-based interventions to improve the wellbeing of children with SB and their families.

CHAPTER ONE

INTRODUCTION

Overview of Spina Bifida

Spina bifida (SB) is the most common congenital birth defect affecting the central nervous system. This complex condition develops during the first trimester of fetal development, when the neural tube fails to fully close and leaves a portion of the spinal cord exposed to the amniotic fluid environment (Copp et al., 2015). This prolonged exposure results in neurodegeneration in utero (i.e., nerve death and disrupted axonal connections), as well as a constellation of physical challenges, including motor and sensory neurological problems (e.g., lower limb weakness, paralysis), bladder and bowel dysfunction (e.g., incontinence), and orthopedic complications (e.g., club foot, scoliosis; Copp et al., 2015; Fletcher & Brei, 2010).

In addition to physical disabilities, SB can also cause neurocognitive difficulties. As a group, youth with SB demonstrate a distinct cognitive profile that is characterized by intact associative processing (e.g., ability to access or categorize information, such as vocabulary and number facts) and impaired assembled processing (e.g., ability to integrate information, such as reading comprehension and math algorithms; Dennis et al., 2006). These underlying processing deficits cut across content domains, resulting in youth with SB experiencing difficulties within multiple academic areas (Dennis & Barnes, 2010; Dennis et al., 2006). Two additional cognitive domains in which youth with SB can struggle are executive functioning, the higher order cognitive skills necessary to self-regulate and guide behavior, and attention (Burmeister et al., 2005; Gioia et al., 2000; Rose & Holmbeck, 2007). Specifically, youth with SB have demonstrated impairments in cognitive flexibility and shifting, working memory, planning/organization, self-monitoring, task initiation, emotional control, and focused and selective attention (Burmeister et al., 2005; Rose & Holmbeck, 2007; Tazari et al., 2008; Tuminello et al., 2012).

Notably, SB is often referred to as a "snowflake condition," as no two people with the condition are affected in the exact same way (Copp et al., 2015; Stiles-Shields et al., 2019). For instance, one child with SB may have pervasive challenges in the previously described domains, whereas another child may not. Despite this considerable variability in the clinical presentation of SB, a higher lesion level and the presence of more abnormalities in the brain and spine (e.g., hydrocephalus, Chiari II malformation) have generally been linked to worse motor and cognitive outcomes (Copp et al., 2015; Rose & Holmbeck, 2007). Additionally, of the four types of SB (i.e., myelomeningocele, meningocele, lipomyelomeningocele, and occulta), myelomeningocele is the most common (about 76% of cases) and severe (CDC, 2022; Sandler, 2010).

Common Psychosocial Challenges

Youth with SB possess numerous strengths and areas of resilience. Specifically, findings suggest that youth with SB demonstrate normative levels of externalizing problems (Holmbeck et al., 2003). Youth also have social strengths, including fundamental social skills (e.g., asking a friend to get together, choosing an activity) and close friendships across development (Devine et al., 2012; Stiles-Shields et al., 2019). Such qualities can enrich daily living and help individuals to cope with the challenges posed by SB. Indeed, a recent study found that social skills, in particular, may aid with the acquisition of medical responsibility during childhood (Stiles-Shields et al., 2021).

Despite this, youth with SB are also at increased risk for psychosocial difficulties, including anxiety, depression, and social isolation (e.g., fewer friendships, less likely to have social interactions outside of school), as compared to children without a chronic health condition or those who are typically developing (Holmbeck & Devine, 2010; Holmbeck et al., 2003; Holmbeck et al., 2010). Prior work has shown that many of these psychosocial difficulties begin to appear as youth approach adolescence and emerging adulthood (Holmbeck et al., 2003). However, psychosocial difficulties may emerge prior to this developmental period, particularly with regard to autonomy development (Davis et al., 2006; Winning et al., 2021). For instance, a recent study found that although youth with SB gain skills necessary to navigate daily life (i.e., *adaptive functioning* skills) across development, youth seem to consistently experience difficulties with self-care (e.g., eating, dressing, grooming) and home living skills (e.g., cleaning, food preparation) from ages 8 to 18 relative to normative samples (Winning et al., 2021). Other studies with even younger children have documented challenges with daily living skills (e.g., ability to feed independently) in early childhood (Lomax-Bream et al., 2007).

Multiple indicators of condition severity, such as the presence of hydrocephalus, higher spinal lesion, physical challenges, and executive functioning and attention problems, have all been linked to poorer psychosocial adaptation in youth with SB (Holbein et al., 2017; Holmbeck et al., 2003; Stern et al., 2018; Verhoef et al., 2006; Winning et al., 2021). For example, cognitive challenges may make it more difficult for youth to problem-solve and utilize helpful coping strategies when managing stressors, or to complete the complex medical regimen that often accompanies SB, in turn, leading to adjustment challenges (e.g., depression) and less medical autonomy (Lee et al., 2012; Stern et al., 2018). Moreover, past work suggests that physical challenges may preclude social engagement due to accessibility issues within the environment (Barf et al., 2009). In line with this finding, it is vital to acknowledge that difficulties with psychosocial functioning and autonomy development experienced by those with SB likely stem from person-environmental interactions (Dunn et al., 2016). Indeed, the social and physical environments in which individuals with SB exist often do not adequately accommodate and support those with disabilities and/or chronic health conditions. Thus, all long-term adjustment difficulties should not be distilled down to purely personal factors, but rather considered within the context of external or situational stressors (e.g., accessibility barriers that can contribute to isolation, inadequate support within the healthcare system that can contribute to difficulties with self-care and transitioning to adult medical providers; Dunn et al., 2016).

The Influence of Parent Behaviors

Given these findings, there is a need to isolate environmental factors that can be modified to best support individuals with SB. Family factors are one promising mechanism for intervention, particularly during childhood and adolescence. As highlighted by the bio-neuropsychosocial model of adjustment in individuals with SB, the family system exerts influence on youth with SB and plays a role in shaping their psychosocial adjustment over time (Holmbeck & Devine, 2010). Moreover, relationships with family members are particularly important and salient for youth with SB, as youth can tend to be socially isolated from peers (Holmbeck et al., 2003).

Past work in the context of SB has linked various aspects of family functioning, including specific parenting behaviors (e.g., warmth/acceptance, enforcement of age-appropriate rules), to better adjustment across multiple domains in youth with SB (e.g., academic outcomes, emotional adjustment, autonomy development; Holmbeck & Devine, 2010; Holmbeck et al., 2002). Parenting that is supportive and provides structure may help youth to gain vital skills to help manage SB and its sequelae, with one study documenting positive associations between parental responsiveness and use of adaptive coping strategies (e.g., problem-focused coping) among youth with SB (McKernon et al., 2001). However, it is important to note that parents of youth with SB may be prone to utilizing less adaptive parenting strategies, such as authoritarian parenting, psychological control, and intrusiveness (Holmbeck & Devine, 2010; Sawin et al., 2003; Vermaes et al., 2007). These parenting strategies are associated with worse child outcomes and may partially explain the higher levels of adjustment difficulties found among those with SB (Holmbeck & Devine, 2010; Holmbeck et al., 2002).

Associations have also been found between other parent factors, including parent psychological adjustment and stress levels, and outcomes among youth with SB. Notably, a subset of parents of youth with SB appear to experience considerable stress, anxiety, depressive symptoms, and somatic complaints (Holmbeck & Devine, 2010; Holmbeck et al., 1997; Vermaes et al., 2005). Studies have also found that parents of children with SB experience social isolation, and often feel less competent and satisfied as parents (Grosse et al., 2009; Sawin et al., 2003). Such difficulties with psychological adjustment and managing stress are associated with worse quality of life, medical responsibility, internalizing and externalizing symptoms, and adaptive functioning among youth with SB (Driscoll et al., 2018; Driscoll et al., 2020; Friedman et al., 2004). One explanation for these findings is that that parental distress precludes parents’ ability to engage in effective parenting behaviors and, in turn, negatively affects children with SB (Driscoll et al., 2020).

Gaps in the Literature

Despite these initial findings highlighting the potential influence of parent distress and parenting on children with SB, several fundamental gaps remain in the existing literature that must be addressed to inform the development of family-based interventions. First, there is a need to create and validate measures of parenting within this population, as evidence-based assessments are currently limited and may not fully capture these families' unique, dyadic interactions. Indeed, validated assessments of parent-child relationships more broadly remain insufficient in pediatric psychology (Alderfer et al., 2008). Some measures that are used within the larger child population have psychometric properties (e.g., reliability, validity) that are not ideal and/or have not been examined in the specific pediatric chronic health samples in which they are used (Alderfer et al., 2008). That being said, a few questionnaire measures have demonstrated acceptable internal consistency in previous SB research (e.g., Revised Children's Report of Parental Behavior Inventory [CRPBI], Parent Protection Scale [PPS]; Driscoll et al., 2020; McKernon et al., 2001). Additionally, one observational measure has been developed to assess family interactions in the context of SB: The Family Interaction Macro-coding System (FIMS; Holmbeck et al., 2007). However, there remains a need to grow the evidence base in this area to ensure that research studies are accurately capturing the salient parent-child interactions occurring in families who have a child with SB.

Second, there is a need to better understand the parenting experiences of families with *young* children with SB, as most prior research has focused on children who are school-aged (ages 8 and older) rather than children in early childhood. Early childhood is a crucial developmental period, as this is a time in which children are rapidly acquiring foundational skills (e.g., cognitive, motor, socio-emotional) that will be built upon as they progress into middle childhood and adolescence (Black et al., 2017). Previous work has highlighted challenges across multiple developmental areas in young children with SB (Danzer et al., 2011; Landry et al., 2013; Lomax-Bream et al., 2007). Given that the brain is especially malleable to environmental influences during early childhood (Arranz et al., 2010; Black et al., 2017), high quality parent-child interactions and access to appropriate environmental supports (e.g., educational, community, medical) during this time to may be able to prevent the emergence or lessen the severity of the psychosocial problems that have been documented among older children with SB (Holmbeck & Devine, 2010; Holmbeck et al., 2003; Holmbeck et al., 2010). Thus, there is a need to shift the research focus to earlier in the developmental continuum to characterize the parenting experiences and resource needs of families of young children with SB, as this can ultimately inform the development of targeted, early intervention efforts.

It is important to note that some studies have included children under the age of 8 with SB in their sample when assessing parent stress (Macias et al., 2001; Macias et al., 2003; Grosse et al., 2009; Lemanek et al., 2000; Ong, 2011) or parenting (Landry et al., 2013; Lomax-Bream et al., 2007; Malm-Buatsi et al., 2015). However, multiple studies were limited by their use of samples with a large age range (e.g., 1-23 years), restricting our understanding of the potentially unique experiences associated with parenting a young child with SB. Moreover, no studies have systematically examined how multiple aspects of the family environment (e.g., parental adjustment, parenting behaviors) relate to child outcomes in this younger age group or the needs of parents as they navigate larger social systems (e.g., educational, community, and medical settings) while caring for their young child with SB.

Finally, there is a need to review and synthesize existing literature on parenting in children with other central nervous system (CNS)-related chronic health conditions. CNS-related chronic health conditions can be characterized as those defined by their CNS involvement, such as SB, epilepsy, and cerebral palsy. Notably, research in pediatric psychology often occurs in silos, such that it is conducted with each chronic health condition in isolation. This hinders advancements in the identification and understanding of maladaptive family processes, as well as the effective delivery of clinical care. Given that research on parenting in SB is still in the earlier stages, it is important to draw upon the lessons learned in populations with similar cognitive challenges to guide future work in this area.

The Current Studies

To address these gaps in the literature, the current set of studies sought to (1) create a novel parenting measure specifically for children with SB, (2) characterize relations between parenting stress, parenting behaviors, and emotional and behavioral functioning in young children with SB, and (3) review lessons learned from other CNS-related chronic health conditions to guide future work in this area. Specifically, in the ***first study***, "Development of an Observational Parental Scaffolding Measure for Youth with Spina Bifida," accepted for publication in the *Journal of Pediatric Psychology*, a novel observational measure of parental scaffolding specifically for youth with SB was developed and validated (Winning et al., 2020). Parental scaffolding can be defined as a process whereby parents provide support and structure to help a child master a task that is currently beyond their ability level (Hammond & Carpendale, 2015; Wood et al., 1976). Because of its positive influence on child development (Baker et al., 2007; Bibok et al., 2009), this process may be able to help children with SB gain skills and compensatory strategies to manage SB and its sequelae. Indeed, findings from this paper revealed positive associations between parental scaffolding and children's academic competence, academic independence, and social skills (i.e., cooperation, self-control). This was the first study to examine parental scaffolding in the context of SB and provides a novel measure that can be used to capture this important facet of parenting in future research.

The ***second study***, "Parenting and Psychosocial Adjustment in Families of Young Children with Spina Bifida," extended past research with school-aged children with SB to encompass those who are in early childhood. Specifically, this study examined predictors of child adjustment, as well as parenting stress and behaviors, in families of young children (ages 3-7) with SB. This study filled a significant gap in the literature, given the importance of early childhood for cognitive, socio-emotional, and motor development (Black et al., 2017) and the influential nature of the family environment during this developmental period (Arranz et al., 2010; Black et al., 2017). One of the primary strengths of this study was its recruitment of a diverse, national sample of children with SB. An additional aim of this study was to characterize the educational-, community-, and medical-related needs of families who have a young child with SB. If families' needs were not being met during early childhood, this was expected to add to parenting stress and reduce parents' ability to engage in positive parenting behaviors with their child.

The ***third study***, "Parenting in Children with CNS-Related Chronic Health Conditions: A Systematic Review," sought to synthesize existing research on parenting among children with CNS-related chronic health conditions (i.e., SB, epilepsy, cerebral palsy, traumatic brain injury, brain tumor). Specific goals included reviewing (1) types of parenting assessed and methods of measurement, (2) associations between parenting and child psychosocial, health-related, and cognitive functioning, (3) potential interaction effects between parenting and cognitive functioning, and (4) the quality of existing research. This review also provided recommendations for future research and intervention efforts. Therefore, this study advanced understanding of the nature and influence of parenting for children with a range of conditions that affect the CNS, serving as a resource for all clinicians and researchers working with families of these children.

CHAPTER TWO

DEVELOPMENT OF AN OBSERVATIONAL PARENTAL SCAFFOLDING MEASURE FOR YOUTH WITH SPINA BIFIDA

Introduction

Spina bifida (SB), a congenital birth defect affecting the central nervous system, occurs in approximately 3 of every 10,000 live births in the United States (Boulet et al., 2008). While advancements in medical care have improved newborn survival rates (McLaughlin et al., 1985), SB continues to have a widespread impact on the well-being of youth. In particular, youth with SB contend with notable physical disabilities, neurocognitive deficits, and problems with psychosocial adjustment (Copp et al., 2015; Holmbeck et al., 2003). Such difficulties can negatively affect adult educational and employment outcomes, as well as overall quality of life (Bier et al., 2005; Holmbeck & Devine, 2010). This pervasive impact of SB on youth and their families underscores the importance of isolating modifiable factors that help children with SB overcome these challenges.

Family factors have gained increasing attention in the pediatric psychology literature as being one potential protective factor (e.g., Holmbeck & Devine, 2010; Kazak, Alderfer, & Reader, 2017). Indeed, research in the context of SB has linked the family environment and specific parenting behaviors (e.g., warmth/acceptance, enforcement of age-appropriate rules) to academic outcomes, psychosocial adjustment, and autonomy development in youth (Holmbeck & Devine, 2010; Holmbeck, Shapera, & Hommeyer, 2002; Loomis, Javornisky, Monahan, Burke, & Lindsay, 2008; O'Hara & Holmbeck, 2013). Despite this evidence, as well as theories highlighting the influential nature of parenting on child skill and behavioral development (Baumrind, 1989; Vygotsky, 1978), research examining parenting in SB remains limited.

Parental scaffolding, a process through which adults support children's learning and ultimately enhance task performance, may be one important parenting process that fosters skill development in this population (Wood, Bruner, & Ross, 1976). The concept of scaffolding originated from the tutoring literature, but has since been applied across diverse settings and populations. Today, scaffolding can broadly be defined as a behavior, whereby adults, "facilitate or otherwise shape children's learning by transforming tasks that are beyond the child's current abilities into activities that the child can understand and master" (p. 369; Hammond & Carpendale, 2015). During the scaffolding process, parents support children's mastery of regulatory strategies by engaging and maintaining the child's interest, helping them to manage their frustration, and structuring the task to match the child's ability/developmental level (Bibok, Carpendale, & Muller, 2009; Wood et al., 1976). Notably, research in the field of developmental psychology has linked greater parental scaffolding to better executive functioning and attention, problem-solving, behavioral functioning, and academic outcomes among typically developing children (Bibok et al., 2009; Hammond, Muller, Carpendale, Bibok, & Liebermann-Finestone, 2012; Mattanah, Pratt, Cowan, & Cowan, 2005; Neitzel & Stright, 2003).

Though most existing work in this area focuses on typically developing children, researchers have begun extending the scaffolding literature to include children with disabilities (e.g., intellectual, language; Baker, Fenning, Crnic, Baker, & Blacker, 2007; Guralnick, Neville, Hammond, & Conner, 2008), as well as a traumatic brain injury (TBI; Gerrard-Morris et al., 2010; Treble-Barna et al., 2016). Preliminary work indicates that scaffolding provided by adults may promote the development of social skills, cognition, and emotion regulation in children with disabilities or cognitive impairment (Baker et al., 2007; Norona & Baker, 2014; Gerrard-Morris et al., 2010). Thus, parental scaffolding may be especially important for neurologically vulnerable populations, such as individuals with SB, as it may help children compensate for cognitive challenges.

Since its creation, the concept of scaffolding has been operationalized in many ways. When Wood and colleagues (1976) first coined the term in the context of tutoring, they theorized that scaffolding consists of six specific processes, including: (1) recruitment (e.g., engaging child's interest in the task), (2) direction maintenance (e.g., ensuring that child's actions are geared toward task objectives), (3) frustration control (e.g., regulating child's negative emotions), (4) reduction in degrees of freedom (e.g., simplifying task), (5) marking critical features (e.g., highlighting aspects of the task critical for completion), and (6) demonstration (e.g., modeling how to complete the task). As a result, a number of studies have employed methodologies that encompass some or all of these basic tenets when applying the concept of scaffolding specifically to parent-child interactions. Yet, there is variability in the types of scaffolding assessed (e.g., verbal versus nonverbal scaffolding), the tasks developed to elicit scaffolding behaviors from parents, and the coding systems employed to quantify these behaviors (e.g., Bernier, Carlson, & Whipple, 2010; Landry et al., 2002).

With regard to the differences in methodologies used to assess scaffolding, past research has examined observed parent-child interactions across completing a variety of tasks, including solving puzzles (Bibok et al., 2009), cleaning up after a tea party (Hammond & Carpendale, 2015), completing typical daily activities and toy play (Gerrard-Morris et al., 2010; Landry et al., 2002), problem-solving paper-and-pencil tasks (e.g., maze; Baker et al., 2007), and conversing about event-type memories (e.g., an important and sad memory; McLean & Mansfield, 2012). When it comes to coding these observational data, studies focusing only on verbal scaffolding have often coded the content of adults' verbalizations, such that hints, prompting, elaborations, and conceptual linkages that facilitated problem-solving were coded as scaffolding (Bibok et al., 2009; Landry et al., 2002). In contrast, studies focusing on both verbal and nonverbal scaffolding have used principles from Wood et al. (1976) to create coding guides (e.g., parents rated on five-point scale based on how often they meet scaffolding criteria; Hammond & Carpendale, 2015; Hammond et al., 2012) or used codes from existing rating systems as a proxy for scaffolding (e.g., autonomy-support; Bernier et al., 2010).

While the majority of the aforementioned studies examined parental scaffolding in the context of younger, typically developing children, scaffolding research with older children and adolescents (Abbeduto, Weissman, & Short-Meyerson, 1999; Mattanah et al., 2005; McLean & Mansfield, 2012) and those with disabilities/health conditions does exist (Baker et al., 2007; Gerrard-Morris et al., 2010; Guralnick et al., 2008). Research with these populations has generally utilized methods similar to those just described. However, given differences in cognitive functioning across these groups, some studies have tailored tasks to match the developmental level of these participants (Baker et al., 2007; Mattanah et al., 2005; McLean & Mansfield, 2012).

Given the variability in the scaffolding literature and the fact that this construct has yet to be explored in the context of SB, the current study sought to validate a measure of parental scaffolding by utilizing a new methodological approach. First, similar to past research, scaffolding was conceptualized as a verbal and nonverbal process in accordance with the framework provided by Wood and colleagues (1976). Second, observational tasks that were (1) developmentally appropriate, and (2) specific to the experiences of those with SB were utilized to elicit parent-child interactions that likely naturally exist within the home. Third, to assess each component of the scaffolding process, this study used a validated observational coding system that has been employed with a variety of chronic health conditions to quantify aspects of parent-child interactions (i.e., Family Interaction Macro-coding System [FIMS]; Holmbeck, Zebracki, Johnson, Belvedere, & Hommeyer, 2007). Although this coding system has not yet been used to assess parental scaffolding, six codes from the FIMS that aligned with the scaffolding framework proposed by Wood and colleagues (1976) and were thought to capture key elements of the scaffolding process were used to create a scaffolding composite.

Collectively, this new approach was chosen due to the lack of consensus in the literature regarding the best method of assessment and because SB is distinct from and more complex than the other child populations in which scaffolding has previously been assessed (i.e., the condition is akin to having a physical/intellectual disability and chronic medical condition combined; Stiles-Shields et al., 2018). As such, family interaction tasks requiring motor movement (e.g., cleaning up materials, problem-solving paper-and-pencil tasks) and/or higher order cognitive skills (e.g., discussing an event-type memory) were not appropriate due to the limitations common in this population (Copp et al., 2015; Holmbeck et al., 2003). Instead, interaction tasks were tailored to the specific needs and challenges faced by individuals with SB, such as accessibility barriers to socialization. Additionally, as previously discussed, the FIMS coding system was designed for and has been validated with this unique population (Kaugars et al., 2010).

Convergent validity for the scaffolding composite was examined by assessing correlations with questionnaires assessing similar parenting constructs, including acceptance (i.e., warmth, nurturance, emotional support), behavioral control (i.e., demanding appropriate behavior, enforcement of behavioral compliance), and psychological control (i.e., intrusive, attempting to control behavior using manipulation; Steinberg & Silk, 2002). It was expected that scaffolding would be positively associated with parent ratings of acceptance and behavioral control, but negatively associated with parent ratings of psychological control. Although these correlations were expected to be of moderate magnitude, scaffolding was hypothesized to be its own distinct parenting construct and correlations were therefore expected to be significant but modest. Concurrent validity for the scaffolding composite was evaluated by assessing correlations with questionnaires measuring youth's academic functioning and social skills (Holmbeck & Devine, 2009). Based on previous scaffolding research (e.g., Baker et al., 2007; Mattanah et al., 2005), it was expected that scaffolding would be positively associated with youth's academic and social outcomes. In particular, greater scaffolding was hypothesized to be associated with greater academic competence, performance, and independence, as well as greater social cooperation, assertion, and self-control in youth with SB.

Methods

Participants

Participants were recruited as part of a larger, ongoing longitudinal study examining family adjustment among youth with SB (e.g., O'Hara & Holmbeck, 2013). Data for the current analyses were from the baseline assessment and focused exclusively on parenting, as well as academic- and social-related outcomes in youth with SB. Families of youth with SB were recruited from four hospitals and a statewide association in the Midwest. Trained graduate and undergraduate research assistants approached families during hospital clinic visits and sent recruitment letters. At enrollment, eligible children: (a) were diagnosed with SB (types included myelomeningocele, lipomeningocele, and myelocystocele); (b) were ages 8-15; (c) were proficient in English or Spanish; (d) had the involvement of at least one primary caregiver; and (e) were living within 300 miles of the laboratory (to allow for data collection at participants' homes).

One hundred and sixty three of the 246 families approached for recruitment initially agreed to participate in the study. Of those 163 families, 21 families could not be contacted or later declined, and two families did not meet the inclusion criteria. Therefore, the final sample of participants included 140 families of children with SB (53.6% female; 53.5% Caucasian; *M* age = 11.40). Those who declined participation did not differ from participants with regard to type of SB (i.e., myelomeningocele vs. other), χ^2 (1) = 0.0002, shunt status, χ^2 (1) = 0.003, or occurrence of shunt infections, χ^2 (1) = 1.08 (all *p*'s > .05).

Given our interest in parent-child interactions, only families who completed the family interaction task at the baseline assessment were included in the current analyses, yielding a final subsample of 137 families (98% of the larger sample). Youth included in this subsample did not differ from the larger sample with regard to age, gender, type of SB, lesion level, shunt status, or SES. Children with SB ranged from 8 to 15 years of age (*M* = 11.41 years, *SD* = 2.45), and 53.3% were female. Approximately half of the children were Caucasian (52.6%). With regard to family structure, most parents were married to the child’s biological mother/father (67.9%). Some biological parents had separated (2.2%) or were divorced and never remarried (5.8%), whereas others were remarried (2.9%) or living with a significant other after the divorce (0.7%). The remaining families had a variety of family structures (e.g., widowed, separated/divorced from step-parents, never married; 20.5%). For most children, both their mother and father participated in the family interaction task (75.2%). However, a number of children participated with only their mother (22.6%) or father (2.2%). Additional demographic information is presented in Table 1.

Table 1. Child Demographic and Condition-Related Characteristics.

	n (%) or *M* (*SD*)
Gender: female	73 (53.3)
Age	11.41 (2.45)
Race	
Caucasian	72 (52.6)
African-American/Black	18 (13.1)
Hispanic/Latino	39 (28.5)
Other	8 (5.9)
Family SES	39.46 (16.00)
IQ	85.70 (19.68)
Spina bifida type	
Myelomeningocele	116 (84.7)
Lipomeningocele	13 (9.5)
Myelocystocele	2 (1.5)
Unknown/Not reported	6 (4.4)
Lesion level	
Lumbar	68 (49.6)
Sacral	41 (29.9)
Thoracic	21 (15.3)
Unknown/Not reported	7 (5.1)
Shunt present	104 (75.9)

Note. Demographic information is based on a sample of 137 youth with spina bifida (SB) who participated in family interaction tasks at T1 with at least one parent. SES = socioeconomic status; IQ = intelligence quotient.

Procedure

The current study was approved by university and hospital institutional review boards. Trained research assistants (i.e., undergraduate and graduate students) collected data in families' homes during two separate 3-hour home visits at the baseline assessment. Prior to data collection, parents provided informed consent and children provided assent. Parents also completed releases of information allowing the research team to obtain data from medical charts, health professionals, and teachers. During the home visit, parents and youth independently completed questionnaires and participated in videotaped structured family interaction tasks. Families received gifts (e.g., t-shirts, pens) and monetary compensation ($150) for their participation.

Observational Assessment of Parent-Child Interactions

Following a warm-up game (i.e., family builds a tower based on a set of rules), parents and youth with SB completed three interaction tasks that were counterbalanced. Tasks included: (1) two age-appropriate vignettes, (2) transferring of condition-related responsibilities task, and (3) a conflict task. During the two vignettes, families were presented with two age-appropriate, socially relevant situations that youth may encounter and they were asked to discuss potential resolutions. One of these situations was specific to individuals with SB (e.g., whether or not a child with SB will be able to go on a weekend trip organized by their school), whereas the other was broader (e.g. child is feeling left out by a friend). During the transferring of responsibilities task, families identified and discussed one or two SB-related responsibilities that could eventually be transferred from the parent(s) to the child (e.g., independent catheterization). Given the variability in the presentation of SB (Copp et al., 2015; Holmbeck et al., 2003), families were free to self-identify responsibilities that they deemed appropriate for transfer. Prior to conducting the conflict task, families completed the Parent-Adolescent Conflict Scale (PAC; Prinz, Foster, Kent, & O'Leary, 1979) where they indicated the presence, frequency, and intensity of potentially conflictive issues. In addition to the standard 15-items included in the scale (e.g., "Whether s/he does chores around the house"), 10 items were added for the current study to assess conflict specific to SB (e.g., "How s/he does his/her skin checks" or "How s/he talks about spina bifida with others"; Psihogios & Holmbeck, 2013). For the conflict task, families were presented with the five issues that they rated on the PAC as the most common and intense across family members; they were then asked to discuss and problem-solve potential resolutions to at least three of the issues. Families were given 10 minutes to complete each of the four interaction tasks. All tasks were coded and included in the scaffolding composite to obtain a comprehensive assessment of scaffolding across different contexts.

Coding of Observational Data

Family interactions were coded using the Family Interaction Macro-coding System (FIMS), which is a macro-coding method that has been used with families of youth with a variety of chronic health conditions (Holmbeck et al., 2007; Kaugars et al., 2010). After viewing an entire family interaction task, trained undergraduate and graduate students rated the family on codes assessing interaction style, conflict, affect, control, problem-solving, and family systems using five-point Likert type ratings. All interactions were coded by two trained undergraduate and/or graduate students to increase interrater reliability. Coders completed comprehensive training and were required to achieve 90% reliability prior to coding the videotapes. Overall, the FIMS consists of 113 separate codes, 36 code types, and an additional seven family systems code types (e.g., ‘‘Family is overly close, stuck, over concerned with each other’’). Each of the code types includes ratings for each individual family member (i.e., mother, father, child), only the parents (i.e., mother, father), or for the family as a whole (Kaugars et al., 2010). Behavioral descriptions for each code are outlined in the manual (Holmbeck et al., 2007).

In the current study, six codes from the FIMS were used to capture and create a composite measure of parental scaffolding (see Table 2 for specific codes). Higher scores on the composite indicate that more scaffolding behaviors by parents were observed, whereas lower scores indicate the absence of scaffolding (i.e., less of these scaffolding-type behaviors were observed). The selection of these six codes was guided by both a review of the existing literature and theoretical formulations. As previously discussed, the literature review indicated that parental scaffolding is a process through which caregivers enhance children’s learning and skill-mastery by adapting tasks to meet the child’s ability level (Bibok et al., 2009; Wood et al., 1976). After this review of the literature, a rational approach to measure development was employed whereby maternal and paternal scaffolding were assessed using codes that mapped onto four theoretical domains: recruitment, direction maintenance, frustration control, and reduction in degrees of freedom (Wood et al., 1976). While the scaffolding framework proposed by Wood and colleagues (1976) includes six theoretical domains (i.e., recruitment, direction maintenance, frustration control, reduction in degrees of freedom, marking critical features, and demonstration), these four domains were selected as being the most appropriate, given the nature of the family interaction tasks. More specifically, the tasks used in the current study focused on discussions between parents and children (i.e., problem-solving areas of conflict within the family and potentially difficult SB-related situations), rather than being more hands-on in nature (e.g., solving a puzzle or mathematical equations). In other words, parents were generally scaffolding youth's problem-solving of various situations that are relevant to this complex medical population. Thus, the scaffolding domains of marking critical features and demonstration were not relevant, given the types of tasks employed in this study. Other nonverbal elements of the scaffolding process (e.g., gesturing, facial expressions) were assessed and included in the coding process.

Table 2. FIMS Items Included in the Scaffolding Composite.

Scaffolding Theoretical Domain	FIMS Items
Recruitment	Requests input from child* Promotes dialogue and collaboration
Reduction in degrees of freedom	Structuring of task
Direction maintenance	Requests input from child*
Frustration control	Attempted resolution of issues Supportiveness Humor and laughter

Note. FIMS = Family Interaction Macro-coding System. *FIMS item fulfills two theoretical domains, but was only included once in the scaffolding composite.

Questionnaire Measures

Demographics. Mothers and fathers reported on demographic information, such as youth age, gender, and race/ethnicity. The Hollingshead Index of Socioeconomic Status (SES) was used to assess family SES, with higher scores indicating higher SES (Hollingshead, 1975). Additionally, SB-related medical information, including SB type (i.e., myelomeningocele,

meningocele, or lipomeningocele), lesion level (i.e., sacral, lumbar, or thoracic), and shunt status, was collected via parent-report on the Medical History Questionnaire (MHQ; Holmbeck et al., 2003) and medical chart reviews.

Parenting behaviors. Maternal and paternal parenting behaviors were assessed via parent report on the Child's Report of Parent Behavior Inventory (CRPBI-P; Schludermann & Schludermann, 1970). On this 52-item measure, parents rate items (e.g., "I am very patient with my child") on a three-point scale ranging from 1 (*not like me as a parent*) to 3 (*a lot like me as a parent*). The CRPBI-P yields three parenting dimensions, including acceptance/rejection, autonomy/psychological control, and firm/lax control. In the current study, these three dimensions were labeled as acceptance, behavioral control, and psychological control, respectively. Internal consistency was adequate for each of these dimensions (α = 0.63–0.81).

Academic competence. Teachers and parents reported on youth's academic competence using the Parent/Teacher Rating Scale of Child's Actual Behavior (PRSCAB/TRSCAB), based on the Harter Self-Perception Profile for Children (Harter, 1985). This measure consists of 15 items and yields five subscales: scholastic competence, social acceptance, athletic competence, physical appearance, and behavioral conduct. For each item on the PRSCAB/TRSCAB, the respondent is asked to first identify which of two statements best describes the youth (e.g., "My child is really good at his/her school work," or "My child can't do the work assigned"), and then to rate whether the statement is "really true" or "sort of true" for the child. Both the teacher and parent versions have shown adequate psychometric properties (Cole, Gondoli, & Peeke, 1998). The scholastic competence subscale was used in the current study and internal consistency was adequate for the sample (α = .75-.91).

Academic performance. Teachers reported on youth's academic performance using the Teacher Report Form (TRF; Achenbach & Rescorla, 2001), a widely used and validated measure for children ages six to 18 years old. The TRF yields T-scores and percentiles for eight problem subscales, three second-order problem subscales, nine DSM-oriented subscales, and two adaptive functioning subscales. The academic performance subscale consists of six items; for each item, the teacher is asked to list a school subject and then rate the student's performance for that subject on a scale from 1 (*far below grade level*) to 5 (*far above grade level*). The academic performance subscale was used in the current study and internal consistency was adequate (α = .97).

Academic independence. Teachers rated youth's academic independence using the Child Behavior Questionnaire (CBQ) which was developed for the current study, based on work by Egeland, Pianta, and O'Brien (1993). This 67-item measure assesses academic motivation, social competence and peer acceptance, compliance, and disruptive behavior, as well as the child's completion of SB-related tasks. Teachers also rate their relationship with the child's parents and their perception of the parent's overprotectiveness. The academic independence subscale (i.e., behavioral compliance, required assistance from the teacher, and the child's attention level) was used in the current study and demonstrated adequate internal consistency in this sample (α = .80).

Social skills. Teachers and parents reported on youth's social skills using the Social Skills Rating System (SSRS; Gresham & Elliot, 1990). This measure assesses skills essential for social competence, yielding subscales related to social skills and problematic behaviors. Teachers and parents rated how frequently the child engages in various behaviors, from 0

(*Never*) to 2 (*Very Often*). The current study used three social skill subscales: cooperation, assertion, and self-control. The SSRS has demonstrated satisfactory internal consistency (Gresham & Elliot, 1990) and internal consistency was adequate in this sample across all three subscales ($\alpha = .78\text{-}.90$).

Data Analytic Plan

Interrater reliability coefficients were computed for the maternal and paternal scaffolding composites using intraclass correlations (ICCs). ICC values ≤ .40 indicated poor to fair agreement, .41–.60 moderate agreement, .61–.80 good agreement, and .81–1.00 excellent agreement between the two coders (Landis & Koch, 1977). To determine internal consistency of the maternal and paternal scaffolding composites, Cronbach's α's were calculated using item mean scores across the two coders and four tasks for each item. Adequate internal consistency was defined as reliability coefficients of .70 or higher.

Pearson bivariate correlations were used to examine associations between parental scaffolding and the parent questionnaire variables to establish convergent validity. In particular, convergent validity was examined by computing Pearson correlations between the maternal and paternal scaffolding composites and scales selected from questionnaires assessing similar parenting constructs (i.e., acceptance, behavioral control, psychological control). Strong, statistically significant correlations (i.e., $p < .05$) between observational scaffolding scores and similar questionnaire data were considered evidence of convergent validity. Concurrent validity was also evaluated by calculating correlations between the scaffolding composites and youth's academic functioning and social skills (Holmbeck & Devine, 2009). Guided by findings in the broader literature, significant associations between these variables provided further evidence of validity (e.g., Baker et al., 2007; Mattanah et al., 2005). Consistent with guidelines outlined by

Cohen and colleagues (1992), the magnitude of correlation coefficients were interpreted as follows: $r = .10$ denoted a small effect, $r = .30$ denoted a medium effect, and $r \geq .50$ denoted a large effect.

Results

Scaffolding Reliability

Interrater reliability. Prior to computing reliabilities, the six items included in the scaffolding composite were collapsed across all four observational tasks (i.e., warm-up, vignettes, transferring of condition-related responsibilities task, and conflict task) for each coder. Interrater reliabilities were then computed for the scaffolding composite using intraclass correlations (ICCs), in which the maternal and paternal scaffolding composites were examined separately. Both the maternal and paternal scaffolding composite demonstrated adequate interrater reliability. Reliability coefficients were .71 and .76 for mothers and fathers, respectively.

Internal consistency. Each of the six items included in the scaffolding composite were collapsed across coders and the four observational tasks to create mean scores. Next, Cronbach's α reliability coefficients were computed to determine the internal consistency of the maternal and paternal scaffolding composites. Cronbach's α's were adequate for both composites. Alpha coefficients were .83 and .86 for mothers and fathers, respectively.

Scaffolding Descriptives

Mean scores for maternal and paternal scaffolding were 3.31 (*SD* = 0.36) and 2.99 (*SD* = 0.47) on a five-point Likert scale, respectively. Paired samples t-tests revealed significantly higher levels of scaffolding in mothers than in fathers, $t(102) = 6.89$, $p < .001$. When examining links between the demographic variables and parental scaffolding using bivariate Pearson correlations, no significant associations were found between parental scaffolding and child age or gender. While greater maternal scaffolding was associated with a higher IQ in youth with SB, $r = .21$, $p < .05$, associations between paternal scaffolding and youth IQ were nonsignificant. One-way ANOVAs examining differences in maternal and paternal scaffolding based on SB type (i.e., myelomeningocele, meningocele, or lipomeningocele) were also nonsignificant. However, one-way ANOVAs indicated that scaffolding levels differed significantly between Caucasian, African-American, and Hispanic/Latino mothers, $F(2, 123) = 13.52$, $p < .001$, and fathers, $F(2, 97) = 3.18$, $p < .05$. Post hoc comparisons revealed that Caucasian ($M = 3.43$, $SD = 0.30$) and Hispanic/Latino mothers ($M = 3.27$, $SD = 0.35$) engaged in significantly higher levels of scaffolding than African-American mothers ($M = 2.98$, $SD = 0.41$). Similarly, Caucasian fathers ($M = 3.05$, $SD = 0.49$) engaged in significantly higher levels of scaffolding than African-American fathers ($M = 2.62$, $SD = 0.59$). SES was also positively correlated with both maternal ($r = .37$, $p < .001$) and paternal scaffolding ($r = .27$, $p < .01$).

Scaffolding Validity

Parenting measures. Bivariate correlation coefficients and *p* values are presented in Table 3. As expected, the maternal scaffolding composite was positively associated with maternal-report of acceptance and negatively associated with maternal-report of psychological control. Similarly, paternal scaffolding was negatively associated with paternal-report of psychological control and a positive trend emerged for paternal-report of acceptance ($p = .065$). All other correlations between parental scaffolding and parent-report questionnaires were not significant (see Table 3).

Table 3. Correlations Between Observed Parental Scaffolding and Parent Report of Other Parenting Behaviors.

Child Report of Parent Behavior (CRPBI) Scales	Maternal Scaffolding	Paternal Scaffolding
1. Acceptance	.32***	.19
2. Behavioral Control	-.12	-.15
3. Psychological Control	-.26**	-.21*

Note. Ns range from 87 to 122. Correlations for mother report on CRPBI are presented for maternal scaffolding and correlations for father report on CRPBI are presented for paternal scaffolding. **p* < .05. ***p* < .01. ****p* < .001.

Youth academic and social outcomes. Bivariate correlation coefficients and *p* values are presented in Table 4. To minimize the chance of Type 1 error, data reduction techniques were employed (Holmbeck, Li, Schurman, Friedman, & Coakley, 2002). Specifically, for constructs with mother, father, and teacher report on questionnaires (i.e., academic competence, social skills), data from all three informants were aggregated if $\alpha \geq .70$ (i.e., reports were treated as items on a scale). If data from all three informants did not meet this criterion, then data from two informants were aggregated if $r \geq .40$. Reports of academic competence met the initial alpha criterion and therefore mother, father, and teacher report were averaged to create a composite score ($\alpha = .76$). Academic performance and independence were examined using only teacher report. While mother, father, and teacher reports of social skills did not meet the initial alpha criterion, mother and father report were correlated above .40 and were therefore averaged (*rs* = .51-.55, *ps* <.001). Teacher report of social skills was examined separately in all analyses.

Consistent with our hypotheses, bivariate correlations revealed significant associations between maternal scaffolding and youth's academic competence and independence, such that greater maternal scaffolding was associated with better academic competence and independence. A positive trend emerged between maternal scaffolding and academic performance (*p* = .061). Though a positive trend emerged between paternal scaffolding and academic performance (*p* = .099), all other correlations between paternal scaffolding and youth's academic outcomes were nonsignificant (see Table 4).

With regard to youth's social skills, bivariate correlations revealed significant associations between scaffolding and self-control in youth. As expected, higher levels of both maternal and paternal scaffolding were associated with better social self-control (parent-report). Moreover, greater paternal scaffolding was associated with more social cooperation in youth (parent-report). Contrary to our hypothesis, neither maternal nor paternal scaffolding was associated with parent-report of social assertion. All correlations between parental scaffolding and teacher-report of social skills were nonsignificant.

Table 4. Correlations Between Parental Scaffolding and Youth's Academic and Social Outcomes.

Scales/Composites	Maternal Scaffolding	Paternal Scaffolding
Parental Scaffolding		
1. Maternal Scaffolding	-	
2. Paternal Scaffolding	.22*	-
Youth Academic Functioning		
3. Academic Competence (M, F, T)	.19*	.12
4. Academic Performance (T)	.18	.18
5. Academic Independence (T)	.19*	-.05
Youth Social Functioning		
6. Social Cooperation (M, F)	.02	.25*
7. Social Assertion (M, F)	.06	.15
8. Social Self-Control (M, F)	.23*	.23*
9. Social Cooperation (T)	.13	-.11
10. Social Assertion (T)	.05	.15
11. Social Self-Control (T)	.08	.10

Note. Ns range from 87 to 131. Reporters for each scale denoted in parentheses. M = Mother Report, F = Father Report, T = Teacher Report. *$p < .05$.

Discussion

Mounting evidence indicates that parental scaffolding may bolster skill development (e.g., executive functioning, attention), as well as promote better academic and social outcomes among children (Baker et al., 2007; Bibok et al., 2009; Hammond et al., 2012; Mattanah et al., 2005). As such, this parenting behavior may be particularly important and impactful for children with a neurological impairment, such as SB, who frequently struggle across these domains of functioning (Copp et al., 2015; Holmbeck et al., 2003). Despite the potential benefits of scaffolding, this construct has yet to be examined in families of youth with SB. Thus, the current study sought to create and validate a new observational measure of parental scaffolding in this population. Given literature suggesting that mothers' and fathers' parenting behaviors may differentially affect youth outcomes, separate composites were created to assess maternal and paternal scaffolding (Lansford, Laird, Petit, Bates, & Dodge, 2014). Overall, results provide preliminary psychometric support for this scaffolding measure.

Creation of the scaffolding composite was guided by the existing literature, including a widely accepted framework by Wood and colleagues (1976). Consistent with this framework, four distinct elements of the scaffolding process were assessed in the present study and included in the scaffolding composite: recruitment, direction maintenance, frustration control, and reduction in degrees of freedom (Wood et al., 1976). Not only was the scaffolding composite rooted in the literature and theoretically based, but it also demonstrated adequate reliability and internal consistency. Adequate interrater reliability coefficients (i.e., ICCs) indicate that these parenting behaviors were able to be reliably evaluated by coders using the macro-coding system. Additionally, both the maternal and paternal scaffolding composite demonstrated satisfactory internal consistency (i.e., Cronbach's alpha coefficients), suggesting that items chosen during measure development are assessing the same general construct.

In addition to reliability, the maternal and paternal scaffolding composites demonstrated convergent validity. First, multiple significant associations were found between the scaffolding composites and parent-report on the CRPBI-P, which is a valid, psychometrically sound questionnaire (Schludermann & Schludermann, 1970). As expected, maternal and paternal scaffolding were both negatively associated with the psychological control scale on the CRPBI-

P. Moreover, a positive association emerged between maternal scaffolding and the acceptance scale on the CRPBI-P. In the context of the broader parenting literature, acceptance is conceptualized as a parenting behavior that is warm, nurturing, and emotionally supportive, whereas psychological control is considered parenting that is intrusive and attempts to control children via manipulation (Steinberg & Silk, 2002). Therefore, given the supportive nature of scaffolding, findings were in the expected direction and consistent with past work. Notably, the scaffolding composite and the CRPBI-P produced relatively modest, small-to-medium effects, providing support that scaffolding is its own distinct parenting construct.

As evidence of concurrent validity, associations were found between the scaffolding composite and youth's academic and social outcomes in the expected directions. With regard to academics, significant associations emerged between maternal scaffolding and youth's academic competence and independence, whereas no significant associations were found for paternal scaffolding. These findings for maternal scaffolding mirror previous research, suggesting that scaffolding may not only have important implications for typically developing children, but also for those with disabilities/health conditions such as SB (e.g., Baker et al., 2007; Mattanah et al., 2005). Considering the lack of significant associations between paternal scaffolding and youth's academic outcomes, it is possible that mothers are uniquely situated to support academic independence and task success (e.g., improving ability to complete school work and figure out answers) in youth with SB (Lansford et al., 2014). Relatedly, maternal and paternal scaffolding were positively associated with youth's social self-control, and paternal scaffolding was positively associated with youth's social cooperation (i.e., both social skill composites were based on mother- and father-report). These correlations are consistent with a study by Baker and colleagues (2007) linking scaffolding to future social skills among children with developmental delays, further supporting the validity of this measure and highlighting the potential benefits of scaffolding behaviors for youth with SB. However, it is important to note that findings in the social domain were mixed, such that social skills based on teacher report were not significantly associated with the maternal or paternal scaffolding composite. This lack of significant findings for teacher report of social skills may be because other SB-related factors (e.g., condition severity, IQ, school support) are more salient predictors of youth's social skills in the classroom. Additionally, teachers must manage a classroom of many students and, as such, may not be as attuned to each child's specific skills, whereas parents may be more sensitive to or aware of their child's social abilities across a variety of contexts (e.g., home, sports, playdates with friends).

Associations between parental scaffolding and youth outcomes are also particularly notable given the age range of youth in this sample (i.e., ages 8-15 years old). The broader literature primarily focuses on the effects of parental scaffolding in the context of early childhood (i.e., younger than age 8; e.g., Bibook et al., 2009; Hammond et al., 2012), rather than in later childhood and early adolescence. Indeed, research has found that the effects of parental scaffolding may diminish over time (Treble-Barna et al., 2016), which may have reduced the likelihood of finding significant associations with scaffolding in the present study. This may help to explain the lack of significant correlations between parental scaffolding and a number of child outcome variables. That being said, numerous significant correlations between parental scaffolding and youth academic and social outcomes did emerge. One possible explanation for these findings is that the developmental age of youth with SB may be significantly lower than their chronological age, thus increasing parental involvement and influence throughout the lifespan. Additional research delineating the interplay between parental scaffolding and child adjustment across development in the context of SB is needed.

Interestingly, there was variability in parental scaffolding levels based on parent demographic factors and SB-related characteristics. Consistent with the notion that there are distinct differences in parenting behaviors displayed by mothers and fathers (Lansford et al., 2014), mothers demonstrated significantly higher levels of scaffolding than fathers. Moreover, findings indicate that there may be differences in mothering and fathering across racial and ethnic groups, as well as based on SES. Parents of youth with SB who are from lower SES backgrounds may experience greater stress (Holmbeck & Devine, 2010) and have less time to engage in adaptive parenting styles because they are trying to meet the family's basic needs. Additionally, there may be cultural differences in parenting across different racial and ethnic groups (Garcia Coll, Meyer, & Brillon, 1995), which should be considered and further examined in future research. Lastly, maternal scaffolding was positively associated with youth IQ, indicating that parents may adapt their behaviors to meet their child's ability level (Guralnick et al., 2008).

The current study had a number of strengths. First, there is a clear need to create an observational measure of parental scaffolding that can be used with families of youth with SB and other health/neurodevelopmental conditions, given the implications these behaviors could have for youth's long-term adjustment. Notably, observational measures of parent-child interactions, in general, provide researchers with a unique opportunity to directly witness dynamic family interactions and obtain objective data, as well as identify potential areas for intervention. Second, the use of four parent-child interaction tasks provide rich, observational data that captures parental scaffolding across a number of different contexts (e.g., navigating and problem-solving conflict/difficult social situations). Third, the creation of the parental scaffolding composite was grounded in theoretical formulations from the broader literature and the items used are from a validated observational coding system (i.e., FIMS; Holmbeck et al., 2007; Kaugars et al., 2010). Fourth, youth's academic and social functioning were assessed via reports from multiple informants (i.e., parents and teachers), which is important given differences in perspectives and the amount of contact each of these adults may have with youth (La Greca & Lemanek, 1996). Finally, validity and reliability were comprehensively assessed, including interrater reliability, internal consistency, and convergent and concurrent validity. Importantly, the evaluation of validity employed questionnaire methods which differed from the observational assessment strategy used to examine parental scaffolding.

Despite these strengths, results from this study should be interpreted in light of several limitations. Although this scaffolding composite was based on theoretical formulations in the literature, employing a rational approach to measure development can be inherently biased and subjective. Additionally, the sample used in the current study consisted mainly of individuals with SB who are higher functioning (i.e., 74.5% had IQs greater than 70). Indeed, there might be distinct differences in the dynamics of family interactions between higher and lower functioning individuals; differences in psychometric properties for the scaffolding composite between these groups could be evaluated with a larger overall sample. Moreover, generalizability of these findings to other populations may be limited considering the unique presentation of SB, such that individuals can experience a constellation of cognitive and physical deficits that vary in severity (Copp et al., 2015). Finally, it is possible that reciprocal relationships exist between parental scaffolding and youth functioning, such that youth's functioning affects parental scaffolding behaviors and vice versa. These bidirectional relationships were not examined in the present study due to the cross-sectional nature of the data. Thus, additional, longitudinal research examining the reliability and validity of this scaffolding composite, as well as the long-term implications of scaffolding in this population, is needed.

In summary, the current study is the first to apply the scaffolding concept to families of youth with SB. Preliminary evidence of the validity and reliability of the scaffolding composite supports the future use of this measure with individuals with SB. Given the overlap between SB and many other chronic conditions (e.g., physical and intellectual disabilities, medical conditions), this measure may also be applicable to research with other pediatric populations. Results from this study provide researchers with a novel tool for measuring dynamic parenting processes in the context of multimethod research. Future work should further establish the validity of this measure and examine how these scaffolding composites intersect with SB-related characteristics (e.g., condition severity) and impact other outcomes (e.g., functional independence, self-care and medical responsibility). Improving understanding of the impact of scaffolding on outcomes among youth with SB may, in turn, aid clinicians who seek to develop interventions. More specifically, the parenting behaviors implicated in the scaffolding process, including requesting input from children, promoting dialogue and collaboration, structuring of the task, attempted resolution of issues, supportiveness, and humor and laughter, are likely teachable. Indeed, past work suggests that parenting behaviors are often amenable to change via coaching interventions (e.g., Antonini et al., 2014; Schuhmann, Foote, Eyberg, Boggs, & Algina, 1998). Furthermore, future work should examine the clinical utility of this scaffolding measure, such as whether it is sensitive to changes in parenting over time (Alderfer et al., 2008). Improving knowledge about the impact of parental scaffolding has the potential to enhance long-term outcomes for youth with SB.

CHAPTER THREE

PARENTING AND PSYCHOSOCIAL ADJUSTMENT IN FAMILIES OF YOUNG CHILDREN WITH SPINA BIFIDA

Introduction

Spina bifida (SB) is a congenital birth defect that occurs when the neural tube fails to fully close during early pregnancy (Copp et al., 2015). This condition occurs in approximately 3 of every 10,000 live births in the United States (Boulet et al., 2008). Notably, the clinical presentation of SB is highly variable, such that some children demonstrate significant physical and cognitive challenges, whereas others do not (Copp et al., 2015). Youth with SB are also at increased risk for psychosocial difficulties, such as anxiety, depression, social isolation and school challenges, relative to children without a chronic health condition or those who are typically developing (Holmbeck & Devine, 2010; Holmbeck et al., 2003; Holmbeck et al., 2010).

The bio-neuropsychosocial model of adjustment in individuals with SB highlights how psychological functioning in those with SB is influenced by biological (e.g., SB severity), neuropsychological (e.g., executive functioning), and social (e.g., family environment) factors across development (Holmbeck & Devine, 2010). In accordance with this model, prior research demonstrates that SB severity (e.g., lesion level, abnormalities in the brain and spine such as hydrocephalus) is linked to a variety of outcomes. Initial work in this area suggested that greater SB severity was related to proximal functional status variables (e.g., physical/athletic and cognitive outcomes), as opposed to distal psychological adjustment outcomes (Hommeyer et al., 1999; Verhoef et al., 2006). However, emerging research partially contradicts these findings, indicating that SB severity may also be related to some distal outcomes (e.g., psychological quality of life; Bellin et al., 2013a; Bellin et al., 2013b).

The social environment – particularly the family system – has also been shown to account for variance in adjustment outcomes among youth with SB. Parenting that is warm, supportive, and enforces developmentally appropriate limits has been linked to more favorable child outcomes (Holmbeck et al., 2002; Murray et al., 2015; O'Hara et al., 2013). Outside of SB, research has also identified adaptive and maladaptive overarching dimensions of parenting, such as authoritative (i.e., high responsiveness, high demandingness), authoritarian (i.e., low responsiveness, high demandingness), and permissive parenting (i.e., high responsiveness, low demandingness), that are associated with child outcomes in the general population (Baumrind, 1971; Baumrind & Black, 1967; Maccoby & Martin, 1983) and other populations with neurological risk (i.e., traumatic brain injury [TBI]; O'Toole et al., 2021; Schorr et al., 2020). Specifically, authoritarian and permissive parenting are thought to have negative consequences for child adjustment, whereas authoritative parenting is associated with more positive child adjustment outcomes (O'Toole et al., 2021; Schorr et al., 2020). Studies also suggest that parenting moderates the influence of neurological risk on child outcomes. For instance, the effects of TBI severity on child emotional and behavioral problems have been found to vary as a function of parenting, such that the effects are exacerbated by maladaptive parenting and buffered by adaptive parenting (Schorr et al., 2020; Treble-Barna et al., 2016).

Another component of the family system that appears to contribute to child outcomes is parent adjustment. For a subset of parents, having a child with SB may result in parents feeling less competent in their parenting role, being more socially isolated, and experiencing greater levels of stress and psychological maladjustment (Grosse et al., 2009; Holmbeck & Devine, 2010; Sawin et al., 2003; Vermaes et al., 2005). Notably, evidence suggests that parents of children with SB experience elevated levels of stress in relation to their parenting role (i.e., "parenting stress") compared to parents of children without a chronic condition (Pinquart, 2018). Such parenting stress has been shown to have negative downstream effects on child outcomes (Driscoll et al., 2018), which may be due to a reduction in parents' ability to engage in positive parenting behaviors with their child over time (Greenley et al., 2006).

The broader literature suggests that parent-child interactions may have a particularly salient influence during early childhood. Indeed, this is a time in which children are rapidly acquiring new, foundational skills (e.g., motor, speech/language, social emotional) that can have lasting effects on future functioning and well-being (Jones et al., 2015; Masten et al., 2010; Walker & Henderson, 2012). High quality interactions with parents during this time may help children to develop important self-regulatory and cognitive abilities to offset some of the challenges associated with SB and facilitate the attainment of important developmental milestones (Arranz et al., 2010; Black et al., 2017). Despite the developmental importance of early childhood, the majority of research with children who have SB has focused on school-aged children and adolescents (i.e., ages 8 and older). Some studies have examined parent stress (Macias et al., 2001; Macias et al., 2003; Grosse et al., 2009; Lemanek et al., 2000; Ong, 2011) or parenting (Landry et al., 2013; Lomax-Bream et al., 2007; Malm-Buatsi et al., 2015) in samples that include young children with SB. However, these latter studies are limited by a wide age range (e.g., 1-23 years) and/or have yet to examine how the family environment may interact with SB severity to affect child outcomes.

An additional limitation of the existing literature is a lack of understanding of the resources and information needed by families who have a young child with SB. Research with families of older children with SB has revealed needs across educational-, community-, and medical-based settings (Jenkins et al., 2021). However, families who have young children with SB may have unique needs as they are in the earlier stages of navigating these systems. Current guiding principles in rehabilitation psychology highlight how adaptation to disabilities and/or chronic health conditions are the result of interactions between an individual and their environment (Dunn et al., 2016). As such, if families are not receiving adequate environmental supports and resources while trying to care for their child with SB, this may compound parent and child adjustment difficulties. Taken together, there is a need to more comprehensively examine social-environmental factors that contribute to adjustment in early childhood, as this can inform the future development of family-based interventions.

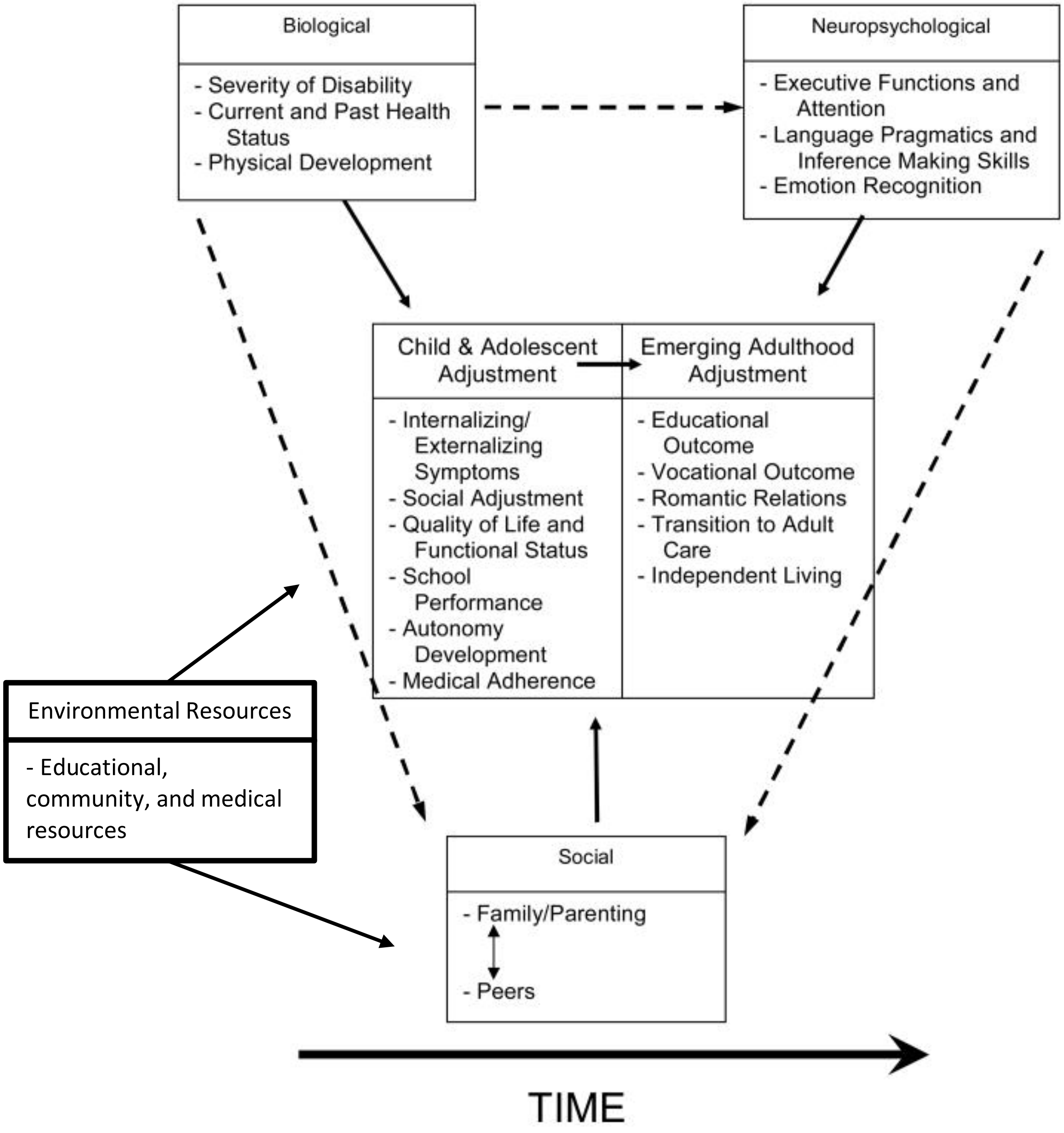
The current study sought to address these critical gaps in the existing literature and shed light on areas of need for families of young children with SB, a population that has been significantly understudied. For our *first aim*, we examined whether parenting stress and parenting behaviors during early childhood moderated associations between SB severity and child emotional and behavioral functioning. Based on past research with older children and young adults who have SB (Bellin et al., 2013a; Hommeyer et al., 1999), we anticipated that young children with SB who had a more severe condition presentation (e.g., presence of a shunt, higher lesion level, greater difficulties with ambulation) would demonstrate worse emotional and behavioral functioning given environmental constraints those face when living with a disability (Dunn et al., 2016). Additionally, we expected parenting stress and parenting behaviors to play a moderating role, such that greater SB severity would be more strongly associated with worse child outcomes in the presence of greater parenting stress and less positive parenting behaviors. Predictions were informed by pediatric-oriented research findings that adaptive parent-child interactions may help to buffer against the negative effects of condition-related risk (Treble-Barna et al., 2016). The documented negative effects of parenting stress (Driscoll et al., 2018) and condition severity (Bellin et al., 2013a; Bellin et al., 2013b) may also be cumulative, resulting in the poorest child outcomes. Of note, these specific parent-level factors have been chosen as they may be more easily targeted via intervention than are broad level family factors, such as family environment.

The *second aim* was to examine demographic and condition-related predictors of parenting stress and parenting behaviors in families of young children with SB. In accordance with the larger literature on school-aged children with SB (Holmbeck & Devine, 2010; Vermaes et al., 2008), it was hypothesized that families from minoritized racial and ethnic groups, who have fewer financial resources, and who have a child with greater SB severity would report higher levels of parenting stress due to such environmental stressors. Indeed, the pervasive impact of systemic racism and ableism may contribute to the stress parents experience when caring for a child with SB (Bixby, 2023; Jones et al., 2020). Additionally, systemic racism has historically limited the inclusion of diverse samples in research, reducing our understanding of the experiences and perspectives of families from different cultural backgrounds (Holmbeck &

Devine, 2010). As such, associations between parental race/ethnicity and parenting behaviors were exploratory in nature to ensure that our understanding of parenting was not biased and could generalize to diverse populations. Finally, given evidence that effective parenting requires internal resources that may be challenging to muster amid financial hardship (Hoff & Laursen, 2019; Winning et al., 2020) or navigating a more severe medical condition (Narad et al., 2019), parents with fewer financial resources and a child with greater SB severity were also expected to demonstrate less of an ability to engage in adaptive parenting behaviors. e

For the *third aim*, we sought to characterize specific family and child educational, community, and medical needs to deepen our understanding of the types of support and services that families of young children with SB need across these settings. We anticipated that more family unmet needs would be associated with higher levels of parenting stress and lower levels of adaptive parenting behaviors. Notably, this study design was broadly informed by an integrated framework that incorporated educational, community, and medical resources into an existing bio-neuropsychosocial model of adjustment in individuals with SB (Holmbeck & Devine, 2010; See Figure 1).

Figure 1. Integrated Bio-Neuropsychosocial Model of Adjustment in Individuals with Spina Bifida.



Note: Model adapted from Holmbeck & Devine (2010) to account for educational, community, and medical resources.

Methods

Participants

Participants were recruited nationally with support from the Spina Bifida Association (SBA), Illinois Spina Bifida Association (ISBA), and Spina Bifida Texas (SBTX). These national and state health organizations are dedicated to improving the lives of individuals with SB through education, advocacy, and research. SBA, ISBA, and SBTX advertised the study on associated list-serves, Facebook pages, and chapter websites. Parents and/or caregivers who expressed an interest in participating in the study via email were screened based on eligibility criteria and then provided the study survey link. One screening question was asked in two different ways to identify potential "bots" (i.e., "what age is your child?" and "what year was your child born?"). Parents and/or caregivers of children with SB were eligible to participate if (1) their child was between three and seven years of age, (2) they were 18 years of age or older, (3) they spoke English or Spanish, (4) they were able to answer the survey questions independently and without the assistance of others (ensuring privacy and honesty in responses), and (5) no other caregivers had participated from their family (certifying that the assumption of data independence was not violated). Participating families were compensated with a $25 Amazon Gift Code.

Procedure

Following IRB approval, parents completed an online survey via Research Electronic Data Capture (REDCap; Harris et al., 2009), a secure, web-based application designed to collect and manage research data. This survey was available in English and Spanish. Similar to previous national online surveys with families of children with SB (Kritikos et al., 2022; Stiles-Shields &

Holmbeck, 2020), parents provided consent prior to completion of the survey via a digital waiver of documented consent. Specifically, parents agreed to participate by selecting a "yes" box after reading about the details of the study. To ensure data quality and limit fraudulent records, participants received personalized survey links that limited one response per person and the survey included time stamps, attention checks/repeated items (e.g., demographic items were randomly repeated throughout the survey), and open-ended questions (Griffin et al., 2022). Additionally, participants completed the survey anonymously to promote honest responses. A rigorous data cleaning process was used following survey completion, such that participants with incomplete or inaccurate data (e.g., demographic inconsistencies) as well as those who completed the survey in 10 minutes or less (as this was substantially lower than the 30 minute estimated survey completion time and would prohibit most of the survey from being accurately completed) and/or demonstrated straightlining (i.e., provided identical answers to questions using the same response scale), were removed. At the end of the survey, participants provided their contact information via an alternative survey link for compensation purposes.

Measures

Demographics and SB Severity. Parents provided demographic information, such as parent and child age, gender, and race/ethnicity. Additionally, parents reported on child SB-related medical information, including SB type, lesion level, shunt status, and ambulation status. Consistent with past research (Hommeyer et al., 1999), a severity composite was created using the following variables: shunt status (no = 1; yes = 2), (2) myelomeningocele (no = 1; yes = 2); (3) lesion level (sacral = 1, lumbar = 2, thoracic = 3); and (4) ambulation status (no assistance/braces = 1, assistive devices [crutches, walker] = 2, wheelchair = 3). Severity scores calculated using this method can range from 4 to 10, with higher scores indicating higher levels of severity. Previous research has demonstrated validity of this composite, such that it was significantly associated with health professionals' rating of SB severity ($r = 0.60$, $p < .001$; Hommeyer et al., 1999).

Parenting Stress. The Parenting Stress Index, Fourth Edition Short Form (PSI-4-SF; Abidin, 2012) was used to capture parenting stress. This 36-item measure includes three subscales: Parental Distress (e.g., how supported and competent parents feel in the parental role), Parent-Child Dysfunctional Interaction (i.e., parents' satisfaction with parent-child interactions) and Difficult Child (i.e., child behavior and temperament that influence the parent-child relationship). These three subscales combine to form a Total Stress scale (i.e., overall level of stress being experienced in role as parent), which was used in this study. Previous versions of the PSI have been used in research with families of children with SB (Driscoll et al., 2020; Friedman et al., 2004) and the measure demonstrated adequate internal consistency in this sample (α = .95).

Parenting. The Parenting Practices Questionnaire (PPQ; Robinson et al., 1995) was used to capture three parenting dimensions that correspond with Baumrind's (1966) authoritarian, authoritative, and permissive styles. For each item on this 62-item measure, parents indicated how frequently they engaged in that parenting practice with their child (1 = Never, 5 = Always). The PPQ has demonstrated reliability and validity and been used in research with other pediatric chronic health populations (Micklewright et al., 2012; Potter et al., 2011). Consistent with previous work (Schorr et al., 2020), total scores for each of the three dimensions were used in this study and internal consistency was adequate (α = .62 – .93).

Child Emotional and Behavioral Adjustment. The Behavior Assessment System for Children, Third Edition (BASC-3) assessed adaptive and problem behaviors, as well as psychosocial functioning (Reynolds & Kamphaus, 2015). Parents completed the preschool version for children ages 2 to 5 and the child version for children ages 6 to 7. These versions have comparable structures, resulting in four composites that were used in the current study: externalizing problems (e.g., hyperactivity, aggression scales), internalizing problems (e.g., anxiety, depression scales), behavior symptoms index (e.g., atypicality, attention problems scales), and adaptive skills (e.g., adaptability, social skills scales). Note that the item asking about suicidal ideation was removed due to the study's online, confidential nature. Additionally, parent responses to the anxiety and depression scales were used to create the composite measure of child internalizing problems (r = .76). The somatization scale was not included in the composite given the potential inflation of this score in individuals with SB (Friedman et al., 2007). Per manual guidelines (Reynolds & Kamphaus, 2015), T scores 60-69 are considered At-Risk and ≥ 70 are considered Clinically Significant for the clinical scales (i.e., externalizing problems, internalizing problems, behavior symptoms index). For adaptive skills, T scores 31-40 are considered At-Risk and ≤ 30 are considered Clinically Significant. The BASC-3 has demonstrated adequate convergent and criterion validity (Reynolds & Kamphaus, 2015).

Family Needs Assessment. Family educational, community, and medical needs were captured using the Social and Community Support Questionnaire (SCSQ), which was derived from the ACCESS Needs Assessment for Parents Scale (Kennedy et al., 1998). Although the original measure includes 75 SB-specific questions, the current study used an abbreviated version that includes 13 modified items from the original survey, as well as 6 new items (i.e., 19 items total). Sample items include, “Adequate equipment that fits my child” and “Opportunities for my child to be in group therapy sessions led by a trained professional.” For each of these items, participants answered if the item is important to them (Yes/No) and then subsequently indicated the extent to which the item is being taken care of for their family (1 = Not taken care of at all to 5 = Well taken care of). Items were examined individually to identify items most commonly endorsed as being both (1) important to the parent *and* (2) not taken care of (i.e., scores of 1 or 2 on the Likert scale). Items that met these two criteria were also summed to create a total score of unmet needs ($\alpha = .77$). Following the SCSQ, parents were given the opportunity to provide write-in responses to the following questions: (1) Please describe any additional resources or supports that you need to help care for your child, and (2) What parenting challenges have you encountered while caring for your child with spina bifida?

Data Analytic Plan

Descriptive statistics were used to summarize demographic information, SB characteristics, and all outcomes of interest. Variables measuring parenting stress, parenting behaviors, and child emotional and behavioral functioning were examined for outliers (i.e., any value that was greater than three standard deviations from the mean and was not part of the normal distribution; Cohen et al., 2003). Consistent with guidelines outlined by West et al. (1995), variables were considered skewed if their skewness value was greater than 2.0. Pearson correlations were used to examine associations between demographic factors (i.e., child age and race, family income) and parenting stress, parenting behaviors, and child emotional and behavioral functioning, revealing that only family income was associated with outcomes of interest. Therefore, this variable was included as a covariate in aim 1.

For the *first aim*, a series of hierarchical multiple regression analyses were conducted to evaluate the degree to which SB severity was associated with child emotional and behavioral functioning (i.e., externalizing problems, internalizing problems, behavior symptoms index, and adaptive skills). Family income was used as a proxy for socioeconomic status and was included as a covariate in all models. Variables were entered in the following order: (step 1) covariate – family income; (step 2) independent variable – SB severity composite. Moderation models tested in PROCESS (Hayes, 2018) were also used to examine whether parenting stress and parenting behaviors during early childhood moderated associations between SB severity and child emotional and behavioral functioning. If a significant two-way moderating effect was revealed, post hoc analyses were used to examine whether simple slopes significantly differed from zero.

Next, for the *second aim*, another series of multiple regression analyses were conducted to evaluate the degree to which demographic (i.e., family income) and condition-related factors (i.e., SB severity) were associated with parenting stress and parenting behaviors (i.e., authoritarian, authoritative, and permissive). Separate regression models were conducted for each independent variable. Independent samples t-tests were used to examine differences in parenting stress and parenting behaviors based on parent race/ethnicity. Specifically, parent-reported race/ethnicity was used to create a dichotomous variable that represented the likelihood that parents had been impacted by systemic racism (i.e., High Likelihood vs. Low Likelihood). Specifically, parents who self-identified as non-Hispanic White were thought to be less likely to be negatively impacted by systemic racism (i.e., comprised the ‘Low Likelihood’ group) than parents from other racial and ethnic backgrounds.

Finally, for the *third aim*, item-level responses were examined to characterize the items that were most commonly endorsed as being both (1) important to the parent *and* (2) not taken care of (i.e., scores of 1 or 2 on the Likert scale). Multiple regression analyses were used to evaluate associations between the number of family unmet needs (i.e., total score on SCSQ) and parenting stress and parenting behaviors. Parent brief, write-in responses regarding additional supports needed and parenting challenges were coded through thematic content analysis (Braun & Clarke, 2006; Hickey & Kipping, 1996). Specifically, for each question, two team members (A.M.W., E.W.) first read through the responses independently to get a sense of the data and then clustered responses that portrayed similar themes and generated codes. The team discussed the rationale for each theme, reviewed direct quotes, and revised codes/themes until consensus was reached.

Post hoc power analyses were conducted using G*Power to ensure that the sample size was sufficient for the planned analyses (Faul et al., 2007; Faul et al., 2009). The sample size of 47 caregivers was adequately powered to detect medium to large effects for regression analyses with one or two independent variables (1 predictor, 1 covariate) and independent samples t-tests. For the moderation models (1 predictor, 1 moderator, 1 interaction, 1 covariate), the sample size was adequately powered to detect large effects.

Results

Participants

Sixty-eight caregivers of young children with SB were consented to participate in the study. Twenty-one participants were removed during the data cleaning process (see Procedure section), resulting in 47 caregivers (29 mothers, 18 fathers) being included in the current analyses. Family demographic and child condition-related characteristics are presented in Table 5. The majority of participating caregivers were White (55.3%) and married to their child's biological father (87.2%), and 42.6% had a household income between \$50,000-\$99,999. Approximately half of the children were female (53.2%) and White (55.3%), which is generally representative of the larger SB population (CDC, 2009). The largest proportion of children had myelomeningocele (the most severe type of SB; 42.6%) compared to any other SB type, a shunt (59.6%), and a lumbar lesion level (61.7%). Children in the sample ranged in age from 3 to 7 years old (*M* Age = 5.15 ± 0.93).

Preliminary Analyses

Descriptive statistics for study variables are summarized in Table 6. None of the variables contained outliers or were skewed based on the criteria previously discussed (see Data Analytic Plan; Cohen et al., 2003; West et al., 1995). Results indicated that, on average, parents' ratings of children's externalizing problems and adaptive skills were in the normative range compared to same aged peers, whereas ratings of internalizing problems and on the behavior symptoms index were in the At-Risk range. Notably, parents reported Clinically Significant difficulties for a number of children with regard to externalizing problems (7, 14.9%), internalizing problems (12, 25.5%), behavior symptoms (13, 27.7%), and adaptive skills (3, 6.4%).

Table 5. Family Demographic and Child Condition-Related Characteristics (*n* = 47).

Child Variables	***n* (%) or *M* (*SD*)**
Sex: female	25 (53.2)
Age	5.15 (0.93)
Race	
White	27 (57.4)
African-American/Black	12 (25.5)
Other[a]	1 (2.1)
Missing	1 (2.1)
Ethnicity	
Hispanic/Latino	7 (12.8)
Non-Hispanic/Latino	40 (85.1)
Spina bifida type	
Myelomeningocele	23 (42.6)
Meningocele	9 (19.1)
Lipomeningocele	6 (12.8)
Occulta	3 (6.4)
Not Sure	9 (19.1)
Lesion level	
Thoracic	14 (29.8)
Lumbar	29 (61.7)
Sacral	3 (6.4)
Not Sure	1 (2.1)
Shunt present	28 (59.6)
Caregiver Variables	***n* (%) or *M* (*SD*)**
Sex: female	29 (61.7)
Age	34.23 (5.08)
Race	
White	27 (57.4)
African-American/Black	12 (25.5)
Other[a]	1 (2.1)
Missing	1 (2.1)
Ethnicity	
Hispanic/Latino	7 (12.8)
Non-Hispanic/Latino	40 (85.1)
Family Income	
Under $10,000	2 (4.3)
$10,000-$49,999	16 (34.0)
$50,000-$99,999	20 (42.6)
$100,000-$149,999	5 (10.6)
Over $150,000	4 (8.5)
Relationship Status: Married to child’s father	41 (87.2)

Note. [a]The “Other” category is comprised of individuals who self-identified with racial groups outside of the NIH-specific categories at the time of assessment, including individuals who self-identified as more than one racial identity.

Table 6. Descriptive Statistics for Study Variables ($n = 47$).

Variable	***M* (*SD*)**	**Range**
SB Severity	7.81 (1.35)	5-10
Child Externalizing Problems	57.79 (12.48)	39-87
Child Internalizing Problems	60.81 (11.87)	33.50-83
Child Behavior Symptoms Index	61.83 (12.86)	34-86
Child Adaptive Skills	43.55 (10.08)	14-70
Parenting Stress	99.66 (26.02)	41-157
Authoritarian Parenting	48.36 (14.86)	21-78
Authoritative Parenting	103.40 (16.02)	70-135
Permissive Parenting	37.00 (10.03)	18-56
Number of Family Unmet Needs	3.47 (3.88)	0-17

Note. Descriptive statistics reported for child externalizing problems, internalizing problems, behavior symptoms index, and adaptive skills are represented as T-scores to aid with interpretation of results. SB = spina bifida.

Aim 1: Parenting Stress and Parenting Behaviors as Moderators of the Association between Spina Bifida Severity and Child Outcomes

Hierarchical regression analyses revealed that SB severity was not significantly associated with child emotional and behavioral functioning (i.e., externalizing problems, internalizing problems, behavior symptoms index, and adaptive skills). However, family income was entered as a covariate in the first block of all regression models and was negatively associated with externalizing problems, internalizing problems, and the behavior symptoms index. Results from these regression analyses are summarized in Table 7.

Next, moderation models were tested with PROCESS to determine whether parenting stress and parenting behaviors moderated the association between SB severity and child emotional and behavioral functioning, while continuing to control for family income. Authoritarian parenting significantly moderated the association between SB severity and child internalizing problems, F(4,42) = 6.07, $\Delta R^2 = .37$, *b* = .25, SE = .09, *p* = .009, and child behavior symptoms index scores, F(4,42) = 8.00, $\Delta R^2 = .43$, *b* = .23, SE = .09, *p* = .017. Post hoc analyses revealed that greater SB severity was associated with more internalizing problems only at high levels of authoritarian parenting, *b* = 5.00, *SE* = 1.97, *p* = .015. SB severity was not associated with internalizing problems at low, *b* = -3.19, *SE* = 1.73, *p* = .072, and moderate, *b* = 1.81, *SE* = 1.19, *p* = .137, levels of authoritarian parenting (Figure 2). Additionally, greater SB severity was associated with higher behavior symptoms index scores at moderate, *b* = 3.71, *SE* = 1.22, *p* = .004, and high, *b* = 6.67, *SE* = 2.02, *p* = .002, levels of authoritarian parenting, but not at low levels of authoritarian parenting, *b* = -.91, *SE* = 1.77, *p* = .611 (Figure 3). All other moderation models were not significant.

Aim 2: Predictors of Parenting Stress and Parenting Behaviors

Results from regression analyses and independent samples t-tests indicated that SB severity and parent race/ethnicity (respectively) were not significantly associated with parenting stress or parenting behaviors (i.e., authoritarian, authoritative, and permissive). However, regression analyses revealed that lower family income was associated with greater parenting stress. These results are summarized in Table 8.

Aim 3: Family Unmet Needs

Quantitative Results. Family unmet needs across educational, community, and medical settings were categorized as items that parents endorsed as being both (1) important *and* (2) not taken care of (i.e., scores of 1 or 2 on the Likert scale) on the SCSQ. Frequencies for parent unmet needs are displayed in Table 9. The two most frequently endorsed unmet needs by parents were opportunities to provide support to other parents of newborn children with SB (28%) and for their child to engage in individual therapy with a trained mental health professional (28%). Additionally, a number of parents endorsed unmet needs regarding opportunities for their child to talk to other children of the same age who have SB (26%) and an older person with SB who can serve as a model or mentor (26%), as well as not having adequate state and federal funds (26%). As shown in Table 10, the total number of family unmet needs was not significantly associated with parenting stress or parenting behaviors.

Qualitative Results. When asked to describe any additional resources or supports that would help parents care for their young child with SB, thirteen (28%) of parents stated that they did not have any other needs that were not already captured on the SCSQ. One parent (2%) described needs related to accessing respite care. The remaining parents (14, 30%) reinforced needs already captured on the SCSQ, including accessible activities, financial assistance, accessible public transportation, support for their child with schoolwork, and opportunities for their child to access mental health support and learn self-care.

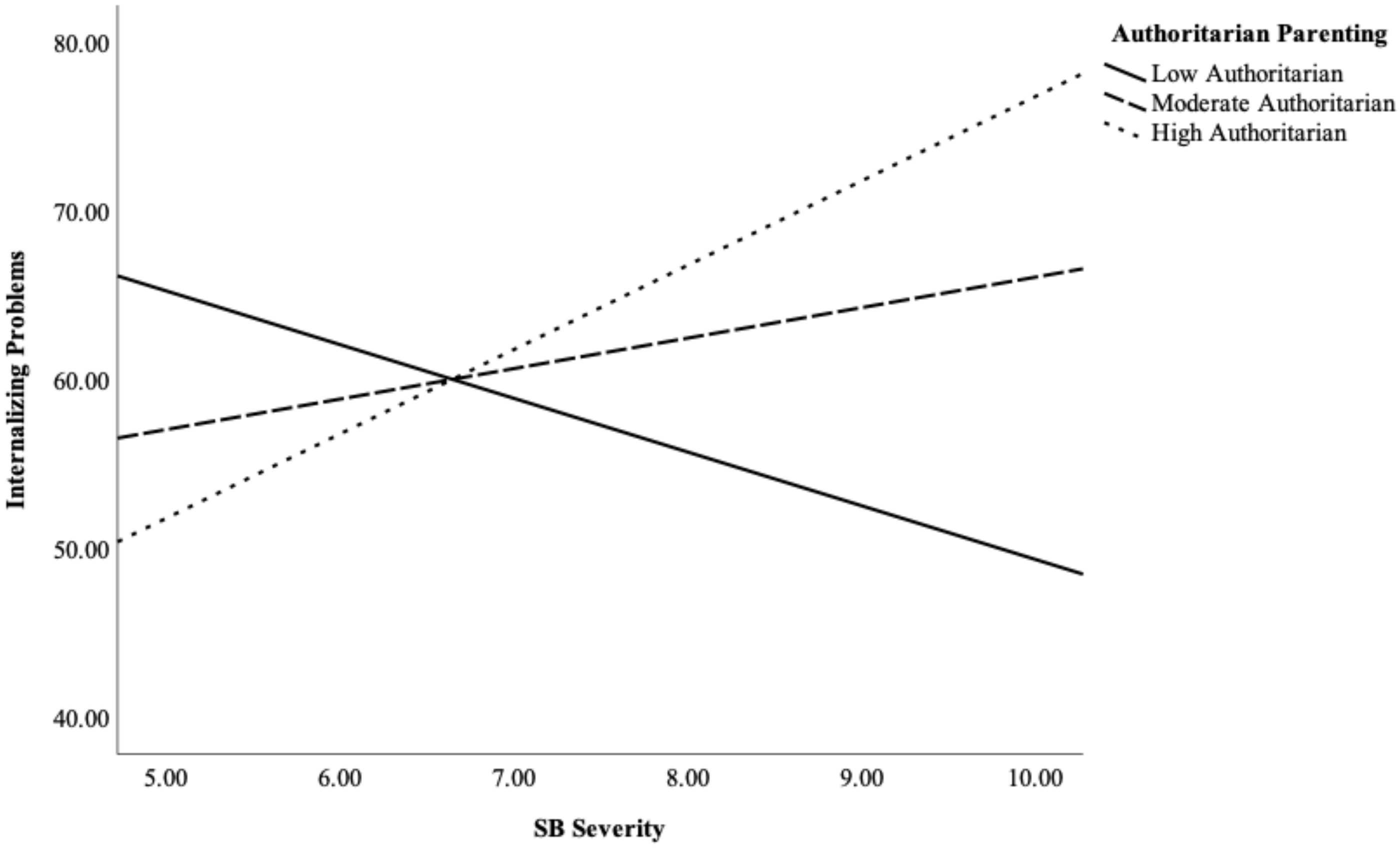
Responses to the second open-ended question regarding parenting challenges when caring for a young child with SB resulted in six themes: time management (9, 19%), discrimination (7, 15%), social isolation (5, 11%), financial stress (4, 9%), parent distress (6, 13%), and knowing effective parenting strategies (5, 11%; see Table 11 for sample quotes). Parent write-in responses were generally brief in nature (i.e., a couple of words or one short sentence), but provided initial insight into the parenting challenges faced by families of young children with SB. First, parents described difficulties with time management, noting that their child requires a high level of care and they are unable to be away from their child for long periods of time. Parents noted that these demands can be tough to balance with work and other responsibilities. Second, parents endorsed personally feeling discriminated against for having a child with SB, as well as described discrimination their child has experienced, based on ethnicity and/or their child's health condition (e.g., physical disability, latex allergy). Third, parents reported challenges related to social isolation, noting that at times their child is excluded by peers and/or unable to participate in activities with friends or siblings due to accessibility barriers (e.g., places advertised as "wheelchair accessible" are not). Fourth, parents highlighted the financial stress that accompanies having a child with SB, with one parent noting how this negatively impacts their ability to care for their child. Fifth, while parents underscored their love and concern for their child, they also described experiencing emotional distress in relation to their parenting role. Finally, parents expressed feeling unsure about how to effectively parent their child with SB, including setting limits, providing instruction, and scaffolding social development.

Table 7. Spina Bifida Severity as a Predictor of Child Emotional and Behavioral Functioning.

		Child Externalizing Problems		**Child Internalizing Problems**		**Child Behavior Symptoms Index**		**Child Adaptive Skills**	
Predictors		***β***	**ΔR^2**	***β***	**ΔR^2**	***β***	**ΔR^2**	***β***	**ΔR^2**
Step 1	Family Income	-.36*	.13*	-.32*	.10*	-.38**	.14**	.13	.02
Step 2	Family Income	-.38**	.17*	-.33	.10	-.40**	.19**	.15	.06
	SB Severity	.19		.02		.22		-.22	

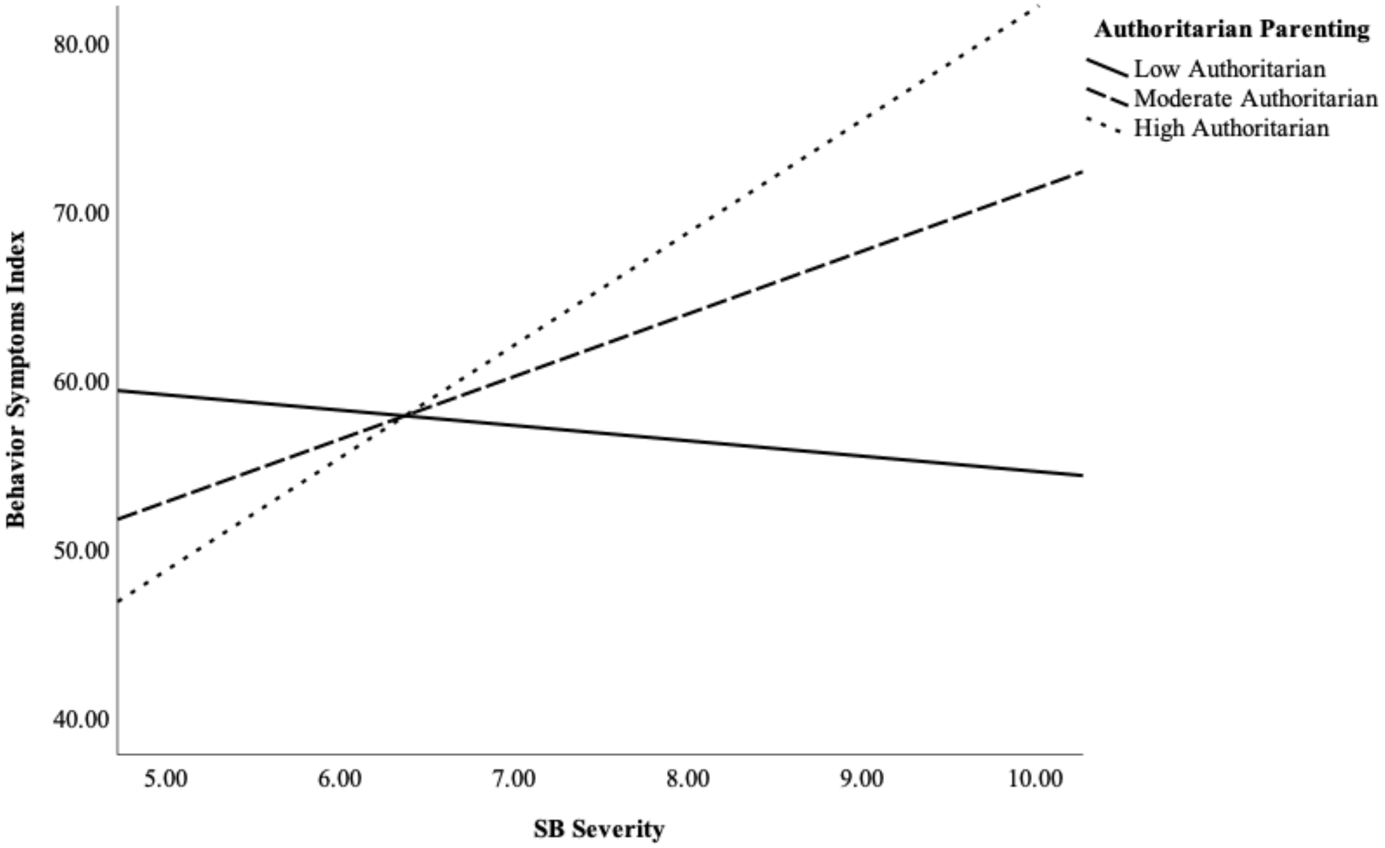
Note. SB = spina bifida. **p* < .05, ***p* < .01, ****p* < .001.

Figure 2. Authoritarian Parenting as a Moderator of the Association Between Spina Bifida Severity and Child Internalizing Problems.



Note. SB = spina bifida.

Figure 3. Authoritarian Parenting as a Moderator of the Association Between Spina Bifida Severity and Child Behavior Symptoms Index.



Note. SB = spina bifida.

Table 8. Relationship of Demographic and Condition-Related Variables to Parenting Stress and Parenting Behaviors.

	Parenting Stress		**Authoritarian Parenting**		**Authoritative Parenting**		**Permissive Parenting**	
Categorical Variables	***M* (*SD*)**	***d***	***M* (*SD*)**	***d***	***M* (*SD*)**	***d***	***M* (*SD*)**	***d***
Parent Experience of Systemic Racism								
Low Likelihood, *n* = 26	99.27 (30.11)	-.07	45.69 (15.15)	-0.43	105.92 (15.80)	0.37	36.12 (10.14)	-0.28
High Likelihood, *n* = 20	101.10 (20.61)		52.10 (14.37)		99.95 (16.47)		38.85 (9.67)	
Continuous Variables	***β***	**ΔR^2**	***β***	**ΔR^2**	***β***	**ΔR^2**	***β***	**ΔR^2**
Family Income	-.29*	.08*	-.28	.08	.25	.06	-.27	.07
SB Severity	.07	.01	-.12	.01	-.09	.01	.13	.02

Note. Separate regression models were conducted for each continuous independent variable (family income, SB severity). Differences in parenting stress and behaviors based on the likelihood of parent experiences of systemic racism were examined using independent samples t-tests. SB = spina bifida. **p* < .05, ***p* < .01, ****p* < .001.

Table 9. Frequencies of Family Unmet Needs.

Item	% Met	% Unmet
1. Wheelchair accessibility	96%	4%
2. Public transportation that is accessible	91%	9%
3. Adequate health insurance for my child	89%	11%
4. Adequate state and federal funds	74%	26%
5. Adequate equipment that fits my child	81%	19%
6. Learning materials about SB for me to read	91%	9%
7. Activities for my child (girl/boy scouts, church, sports, etc.)	79%	21%
8. Opportunities for my child to learn selfcare, and appropriate dressing and grooming	85%	15%
9. Someone for my child to talk to who will help them feel better about themselves	81%	19%
10. Opportunities for my child to talk with other children of the same age who have SB	74%	26%
11. A chance for my child to talk to an older person with SB who can serve as a model or mentor	74%	26%
12. A chance for me to talk to other parents who have children with SB	79%	21%
13. A chance for me to provide support to other parents of newborn children with SB	72%	28%
14. Opportunities for my child to be in group therapy sessions led by a trained mental health professional	81%	19%
15. Opportunities for my child to be in individual therapy sessions with a trained mental health professional	72%	28%
16. Adequate support from extended family (grandparents, brothers, sisters, aunts, uncles, cousins, etc.)	83%	17%
17. Someone to help my child with their schoolwork	87%	13%
18. Access to neuropsychological and/or academic testing for my child	81%	19%
19. Adequate school services and/or accommodations for my child	81%	19%

Table 10. Family Unmet Needs as a Predictor of Parenting Stress and Parenting Behaviors.

	Parenting Stress		**Authoritarian Parenting**		**Authoritative Parenting**		**Permissive Parenting**	
Predictors	β	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2
Number of Family Unmet Needs	.20	.04	-.11	.01	-.23	.05	.07	.00

Note. *$p < .05$, **$p < .01$, ***$p < .001$.

Table 11. Sample Quotes about Parenting Challenges Related to Caring for a Young Child with Spina Bifida.

Themes	Sample Quotes
Time Management	“Combining my job and taking care of my child with Spina Bifida has really been challenging for me.”
Discrimination	“I feel that I am discriminated by others for the way they see my child.”
Social Isolation	“Isolation of my kid. He sometimes faces isolation in social activities. I have to advocate for him to be included countless times and also provide him with the necessary emotional support.”
Financial Strain	“Finance(s), sometimes I run out of cash and I’m not able to take care of him very well.”
Parent Distress	“The emotional distress is really taking a toll.”
Knowing Effective Parenting Strategies	“The biggest challenge is not knowing if I’m doing things right. It is difficult to observe his behavior and not know if it is due to the physical limitations that he has due to the condition with which he was born or for some other reason.”

Discussion

Guided by the bio-neuropsychosocial model of adjustment in individuals with SB (Holmbeck & Devine, 2010), the overarching goal of the current study was to examine adjustment, as well as parenting experiences and resource needs, in families who have a young child (ages 3-7) with SB. Results revealed that, on average, young children with SB experienced At-Risk levels of internalizing problems and behavior symptoms index scores compared to normative samples. Additionally, interactions between both biological (e.g., SB severity) and social (e.g., parenting) factors appeared to contribute to outcomes in this population. Findings from this study can inform the development of targeted, family-based intervention efforts during early childhood.

Internalizing problems were one of the most salient areas of concern, with approximately 25% of young children scoring within the clinically significant range on this scale. These rates are comparable to those found in studies of young children with hydrocephalus (Fletcher et al., 1995) and align with evidence of elevated internalizing problems in the broader SB population (Holmbeck & Devine, 2010). Such difficulties may be due to a multitude of factors, including cognitive functioning (e.g., verbal IQ, executive functioning), stigma, and maladaptive coping (Coakley et al., 2006; Kelly et al., 2012). Of note, a number of children also demonstrated clinically significant scores on the behavior symptoms index, which may again be reflective of underlying mood concerns (e.g., withdrawal), as well as attention problems that are more common among those with SB compared to peers (Wasserman et al., 2016). Collectively, these findings in the context of the larger literature suggest that, for some children, adjustment difficulties emerge when they are young and may persist across development, underscoring the need for early intervention in this population.

When examining predictors of child adjustment, two-way interactions between SB severity and authoritarian parenting were found. Specifically, greater SB severity was associated with more internalizing problems at high levels of authoritarian parenting, and more behavior symptoms at moderate and high levels of authoritarian parenting. At low levels of authoritarian parenting, SB severity was not associated with worse outcomes. The larger parenting literature suggests that authoritarian parenting (i.e., low responsiveness, high demandingness) leads to greater internalizing problems over time (Pinquart, 2017) and can amplify the negative effects of neurological insult (Wade et al., 2006; Yeates et al., 2010). Therefore, limited responsiveness and warmth from parents may compound the impact of SB in early childhood, leading to greater adjustment difficulties. Another possible explanation is that having a child with more significant SB sequelae and emotional/behavioral difficulties elicits a maladaptive parental response (i.e., authoritarian parenting). Due to the cross-sectional nature of our study, we are unable to make assertions about causality; however, reciprocal processes between parenting and child functioning have been documented in younger children (ages 12-18 months) with SB (Lomax-Bream et al., 2007). Future longitudinal work could tease apart the interplay between these variables during this unique developmental period to better understand how parent-child interaction patterns evolve over time.

A noteworthy finding in the current study was that lower family income was associated with greater externalizing problems, internalizing problems, and behavior symptoms in young children with SB. This is consistent with research suggesting that low family income may limit parents' access to resources that can support their child's cognitive, social, emotional, and physical wellbeing (Conger & Donnellan, 2007). These findings, as well as the significant negative associations that emerged between family income and parenting stress, suggest that families of young children with SB who have fewer financial resources may benefit most from increased psychosocial support. Unexpectedly, no other significant findings emerged when examining SB severity, parental race/ethnicity, and family unmet needs as predictors of parenting stress and parenting behaviors. These results build upon work suggesting that, even in the face of chronic illness and sociodemographic risk, families of children with SB are adaptable and demonstrate considerable resilience (Lennon et al., 2015; Papadakis & Holmbeck, 2021).

It is important to note that, in the current analyses, parent race/ethnicity was conceptualized to capture the likelihood of parents experiencing systemic racism. Specifically, parents who self-identified as non-Hispanic White were categorized as having a low likelihood of experiencing systemic racism as compared to those from other racial and ethnic backgrounds. On one hand, the lack of significant differences in parenting stress and behaviors based on experiences of systemic racism in the current study may be promising; highlighting immense resilience and supporting use of the PPQ to capture parenting in families from diverse backgrounds. However, great caution should also be taken when interpreting these findings given the dichotomous nature of this variable, as well as the limited racial and ethnic diversity of the study sample. Future research should use a more accurate and direct measure of systemic racism in lieu of race/ethnicity as a proxy for many reasons – one of which being that this variable blends diverse racial and ethnic experiences into a single category (Galán et al., 2021). Additionally, this variable uses the experience of non-Hispanic White families as a reference group with which to compare other racial and ethnic groups. This is problematic as it can inadvertently position Whiteness as the "norm" or standard for parenting experiences (Daniels & Schulz, 2006).

Consistent with this systems approach, it was hypothesized that the educational, community, and medical settings in which families were embedded would also influence parenting stress and parenting behaviors. While parents endorsed multiple unmet needs across these settings, contrary to hypotheses, the overall number of unmet needs was not significantly associated with parenting stress or parenting behaviors. The two most frequently endorsed unmet needs (identified by 28% of families) pertained to opportunities to provide support to other parents of newborn children with SB, as well as for children to participate in individual therapy with a trained mental health professional. These findings suggest that families may find it meaningful to provide support to other families who have a child with SB and are in the early stages of parenting. SB medical clinics, as well as community advocacy groups, could help facilitate connections between parents as appropriate. Additionally, there is a clear need to increase the level of psychosocial support available to families of children with SB during this developmental period.

Given evidence that parenting plays an influential role in adjustment among young children with SB, parenting skills programs may be one promising way to increase psychosocial support for these families. Past research with typically developing children and those with neurological risk (e.g., TBI) has shown that parenting behaviors are amenable to change (Landry et al., 2008; Landry et al., 2012) and can lead to significant improvements in child emotional and behavioral outcomes (Brown et al., 2013). Additionally, research has found that the effects of web-based parent training programs are particularly salient for families with a lower socioeconomic status (Raj et al., 2015), suggesting that these types of interventions may be a useful tool in reducing disparities among those with SB. It is notable that parents themselves also described a need for increased knowledge of effective parenting strategies in the qualitative portion of this study; as well as challenges related to time management (e.g., balancing a job with child's SB-related care), discrimination based on ethnicity and/or SB (e.g., physical disability), social isolation of children with SB, and parent distress. These responses provide initial insight into potential targets for future psychosocial interventions in this population.

However, stakeholder analyses that capture the rich, lived experiences of these families are needed to ensure that intervention development is centered on the priorities of this population.

Despite filling a notable gap in the existing literature, limitations of the current study should be acknowledged. First, findings from this study are based on cross-sectional data collected from a single informant. Future work focused on this age group should utilize a longitudinal, mixed-methods approach, including performance-based assessments of child functioning and observational measures of parent-child interactions. Second, it is recommended that studies focused on this age group recruit samples with more ethnic diversity, as the number of Hispanic/Latino families in this study was limited despite higher prevalence rates in this population (Copp et al., 2015). Third, only about 50% of families in this study indicated that their child had myelomeningocele, the most severe type of SB that makes up about 76% of cases (CDC, 2022), and about 20% were unsure of their child's specific SB diagnosis. Future research should strive to include more children with myelomeningocele and incorporate medical chart reviews to corroborate SB-related medical information. Fourth, to avoid narrowly characterizing those with SB based on disability, research in this area should incorporate strengths-based approaches as well (Perrin, 2019).

In conclusion, studies within the field of pediatric psychology that focus on early childhood are needed to better understand complex interactions between condition-related factors, child development, and the family system. Findings in the current study provide preliminary evidence that authoritarian parenting, characterized by low warmth and high control, may compound the effects of SB sequelae and negatively affect outcomes during early childhood. Additionally, results suggest that parents face multiple challenges when parenting a young child with SB and there is a need for additional psychosocial support. It is likely especially important to consider the role of intersectionality and how overlapping systems of oppression across multiple identities (e.g., disability, SES, race/ethnicity) contribute to outcomes in children and families. Further research is needed to better understand how to appropriately target and develop family-based interventions in this population. However, these findings point towards potential avenues for intervention to improve the lives of young children with SB and their families.

CHAPTER FOUR

A SYSTEMATIC REVIEW OF PARENTING IN CHILDREN WITH CNS-RELATED CHRONIC HEALTH CONDITIONS

Introduction

Due to advancements in medical care, survival rates for children with chronic health conditions have notably improved in recent years (Halfon & Newacheck, 2010). As a result, children with such conditions are now living well into adolescence and adulthood. While encouraging, these improvements in survival rates also pose new challenges related to promoting long-term health outcomes and positive development. This may be particularly true for children with chronic health conditions that affect the central nervous system (CNS) – as these conditions, as well as the treatments necessary for survival, can have lasting effects on the brain and cognitive development (Compas et al., 2017).

Spina bifida, cerebral palsy, epilepsy, traumatic brain injuries (TBI), and brain tumors are five of the most common CNS-related chronic health conditions (Camfield & Camfield, 2015; Copp et al., 2015; Faul et al., 2010; Graham et al., 2016; Porter et al., 2010). While several other conditions can have implications for the CNS (e.g., sickle cell disease, diabetes; Compas et al., 2017), each of the five forementioned conditions is *defined* by their CNS involvement and dysfunction (e.g., spina bifida results from failed closure of the neural tube, cerebral palsy occurs following nonprogressive injury to the developing brain; Copp et al., 2015; Graham et al., 2016).

Specific cognitive challenges in executive functioning, the higher order skills needed to plan and guide behavior, and attention have been documented within each of these conditions (Bottcher et al., 2010; Konigs et al., 2015; Mangeot et al., 2002; Olsson et al., 2014; Reuner et al., 2016; Rose & Holmbeck, 2007). Moreover, problems in these cognitive domains are thought to negatively impact other areas of functioning, such as school performance (Murphy et al., 2021; Wasserman & Holmbeck, 2016), social dexterity (Holland et al., 2018; Lennon et al., 2015; Whittingham et al., 2014; Wolfe et al., 2013) and/or emotional (e.g., internalizing problems) and behavioral adjustment (e.g., externalizing problems; Kelly et al., 2012; Modi et al., 2019).

Considering the cognitive and psychosocial difficulties that can be experienced by those with CNS-related chronic health conditions, research focused on identifying factors that promote positive long-term outcomes is of the utmost importance. Consistent with a social-ecological framework (Kazak et al., 2017), past research among children with CNS-related conditions indicates that the family environment may be one particularly salient factor, linking less conflict and greater cohesion within the family environment to better child outcomes (e.g., executive functioning, academic achievement, quality of life, adaptive functioning; Ach et al., 2013; Anderson et al., 2012; J'May et al., 1993; Mendes et al., 2017). Indeed, social ecology highlights how the social systems in which children with CNS-related chronic health conditions are embedded – such as the family system – can play a significant role in how children adapt to such conditions and child development more broadly (Kazak et al., 2017). Notably, there is also research to suggest that specific parenting styles and behaviors contribute to the overall family environment (Hill, 1995; Maccoby & Martin, 1983). These specific parenting behaviors may be more easily targeted through intervention, as compared to broad-level family factors.

As noted in a 2013 meta-analysis that examined differences in parenting between children with and without chronic health conditions (Pinquart et al., 2013), past research has generally focused on three dimensions of parenting: (1) parental responsiveness (e.g., warmth and support; Baumrind, 1967), (2) demandingness (e.g., behavioral control, rules, regulation, and structure; Baumrind, 1967), and (3) promotion of autonomy (e.g., vs. overprotection and psychological control, scaffolding; Holmbeck et al., 2002a; Steinberg, 2010; Steinberg & Silk, 2002). Across these three dimensions, the majority of past research in pediatric psychology has focused on parental acceptance (i.e., warmth, emotional support), behavioral control (i.e., demanding appropriate behavior, enforcement of behavioral compliance), and psychological control (i.e., intrusive, attempting to control behavior via manipulation). For instance, researchers have linked higher levels of parental acceptance and behavioral control, and lower levels of parental psychological control, to more favorable child outcomes (e.g., less internalizing/externalizing problems and somatic complaints; Holmbeck et al., 2002b; Murray et al., 2015; Rodenburg et al., 2005). Combinations of parental responsiveness and demandingness have also been used to characterize the influence of various overarching parenting styles, including authoritative (i.e., high responsiveness, high demandingness), authoritarian (i.e., low responsiveness, high demandingness), permissive (i.e., high responsiveness, low demandingness) and neglectful parenting (i.e., low responsiveness, low demandingness; Baumrind, 1971; Baumrind & Black, 1967; Maccoby & Martin, 1983). Specifically, authoritative parenting has been shown to contribute to better executive functioning and social competence, as well as fewer internalizing and externalizing problems, among children with CNS-related conditions (Schorr et al., 2020; Wiley & Renk, 2007).

The promotion of autonomy is likely especially important for children with CNS-related conditions. Indeed, parenting that promotes autonomy by encouraging children's independent choices and problem-solving may help children to develop important self-regulatory behaviors and executive functioning skills (Grolnick & Ryan 1989; Valcan et al., 2018). Parental scaffolding, a process whereby parents provide support and structure to help a child master a task that is currently beyond their ability level (Wood et al., 1976), can also fall under the classification of autonomy promotion. Scaffolding aims to help children ultimately perform tasks independently over time, as the level of parental support lessens in conjunction with increased child skill mastery. Initial work examining parental scaffolding in children with TBI and spina bifida has found that scaffolding is not only positively associated with child social skills and academic outcomes (Winning et al., 2020), but may also lessen the severity of internalizing problems following insult to the CNS (Treble-Barna et al., 2016).

Past research suggests that parenting may be directly linked to child outcomes among those with CNS conditions (Schorr et al., 2020; Treble-Barna et al., 2016; Wiley & Renk, 2007; Winning et al., 2020), as well as moderate the influence of cognitive functioning on such outcomes (O'Hara et al., 2013; Stern et al., 2020). Specifically, the impact of cognitive challenges, characteristic of many of these CNS conditions, may be exacerbated in the presence of less adaptive parenting styles (e.g., psychological control) and ameliorated in the presence of positive parenting styles (e.g., behavioral control; O'Hara et al., 2013). Such cognitive-environmental interactions have served as a guide for family-based interventions in the context of pediatric TBI (Antonini et al., 2014).

Overall, a number of studies have examined parenting in children with CNS-related chronic health conditions (Schorr et al., 2020; Stern et al., 2020; Wiley & Renk, 2007; Winning et al., 2020); however, this literature has not been synthesized through a comprehensive systematic review. While a meta-analysis comparing the parent-child relationship and parenting behaviors in families with and without a child with a chronic health condition has been conducted (Pinquart et al., 2013), this prior review focused primarily on group differences and did not seek to characterize associations with child outcomes or whether parenting can serve a protective role against cognitive challenges commonly associated with CNS-related conditions. Parenting may be particularly important for children with CNS-related conditions, as it may help children to develop important coping and self-regulatory skills, as well as compensatory strategies. Synthesizing this literature is important to help guide researchers and clinicians who work with these children and their families in developing relevant family-based interventions and providing effective clinical care.

To achieve this aim, this study systematically reviewed the parenting literature for children with spina bifida, cerebral palsy, epilepsy, TBI, and brain tumors. In accordance with the Cochrane Collaboration (Higgins & Green, 2011), which recommends developing specific research questions and aims prior to completing a systematic review, our goals were to review: (1) types of parenting assessed and methods of measurement, (2) associations between parenting and child cognitive, psychosocial, and health-related functioning, (3) potential interaction effects between parenting and cognitive functioning in predicting child outcomes, and (4) the quality of existing research. This review also provided recommendations for future research and intervention efforts.

Methods

Search Strategy

The search strategy was developed in collaboration with the lead authors (A.M.W., C.S.S.) and an experienced medical research librarian (J.W.) in September 2021. The following databases were searched: PubMed/MEDLINE, Scopus, CINAHL, PsycINFO, Cochrane Database of Controlled Trials, the Cochrane Database of Systematic Reviews, and Google Scholar. To include as many studies as possible, each database was searched from the date of inception to September 16, 2021 and there were no restrictions on geography, age of participants or language of publication. The search included subject headings and keywords for children with spina bifida, cerebral palsy, epilepsy, TBI, and brain tumors, as well as for parenting dimensions and styles. Controlled vocabularies were also searched (e.g., MeSH terms; see Appendix B for reproducible search string).

Inclusion Criteria

Inclusion criteria for the systematic review was as follows: (1) subjects include youth ages 0-18 years or parents of these youth (i.e., mean age ≤ 18 years), (2) population includes youth with a CNS-related chronic health condition (i.e., spina bifida, cerebral palsy, epilepsy, TBI, brain tumors), (3) article examines parenting (i.e., behaviors, styles, dimensions; articles solely examining parenting confidence, self-efficacy, or communication as “parenting” were not included), (4) written in English, and (5) publication in a peer-reviewed journal (i.e., no conference abstracts, dissertations, or book chapters). Studies with samples < 20 were excluded to minimize pilot data. Articles that combined a sample of children with a CNS-related condition with children who had other medical conditions (e.g., various types of cancer) were not included unless results were presented separately for the CNS-related condition(s).

Study Selection and Data Extraction

Literature searches were uploaded into Covidence, an online software program that allows for reviewer collaboration during the study selection process. The review team included six reviewers (A.M.W., C.S.S., O.C., E.W., E.D., T.H.), who independently screened all article titles and abstracts. Two reviewers independently screened full-text articles. The lead author (A.M.W.) and one other team member (O.C., T.H.) extracted data (e.g., sample size, primary outcomes) independently for each eligible study using an online extraction form (Büchter et al., 2020). Any discrepancies throughout the study selection and extraction process were resolved by a third independent team member.

Quality Assessment

Two members of the review team independently rated the quality of the study by completing a checklist that has been used in another systematic review (Kritikos et al., 2021; see Appendix C for checklist). The 11 questions on this checklist pertained to methodological criteria, such as “Have actual probability values been reported for the main outcomes?” and “Were the main outcome measures used accurate (valid and reliable)?” Each item was scored as “yes,” “no,” and “not applicable.” Kappa scores were calculated to determine agreement between raters across the 11 items. None of the items had a substantially low Kappa score based on criteria used in a previous systematic review (i.e., scores with negative values or values < .20; Kritikos et al., 2021) and were therefore retained in the quality assessment. However, a Kappa score was unable to be calculated for one item (“Is the sample size stated?”) due to 100%

agreement between raters. Percentage agreement between raters is presented in Appendix C. Additionally, for each study included in the review, the number of items scored as "yes" were summed and divided by the total number of applicable items (max = 11), resulting in a possible range of 0.0 – 1.0. The total proportion score for each study is reported in Table 13. Interrater reliability was also calculated for these total proportion scores and was in the acceptable range (Intraclass Correlation Coefficient = .77).

Data Synthesis

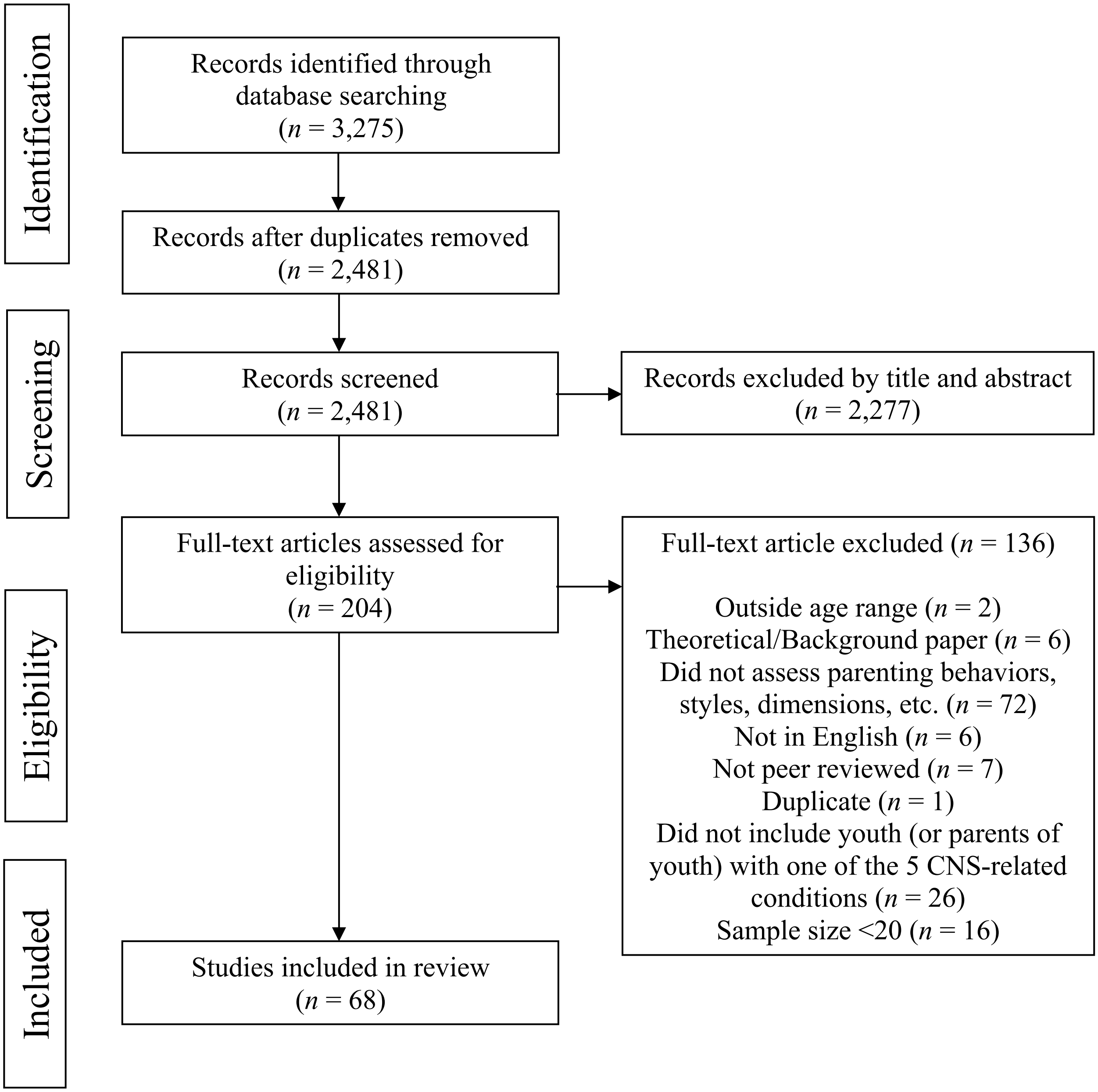
A meta-analytic approach was not appropriate for this review due to variability in outcome measures, methodologies, and age ranges. Therefore, a systematic narrative analysis framework was used. Consistent with this approach, the review summarized results from included studies and made connections across CNS-related chronic health conditions (Siddaway et al., 2019). For articles that included conditions outside of the five designated CNS-related conditions (e.g., autism spectrum disorder), the review only summarized findings for the CNS-related condition group and (if applicable) the typically developing comparison group. Of note, orthopedic injury is the control group typically used to evaluate the consequences of TBI and, as such, was included in the narrative analysis for articles focusing on TBI.

Results

Included Studies

Of the 2,481 article titles that were initially screened (see Figure 4 for the PRISMA flow diagram), 204 full text articles were reviewed for inclusion, and 68 were included in the review for data extraction. TBI was the most common CNS-related condition in the included articles (*n* = 22), followed by cerebral palsy (*n* = 19), spina bifida (*n* = 16), and epilepsy (*n* = 12; note that one study focused on both those with spina bifida and cerebral palsy). While some of the screened articles focused on parenting in families of children with a brain tumor, none of these studies ultimately met inclusion criteria (e.g., combined sample of children with brain tumors with other types of cancer, sample sizes less than 20). Sample sizes of the included articles ranged from 20 to 297 families of children with a CNS-related condition. The age of children included in the studies varied widely, ranging from 3 months to 23 years old. While many of the studies focused on TBI ($n = 15$) and cerebral palsy ($n = 10$) included children ≤ 6 years old in their samples, studies including this age group in the context of spina bifida ($n = 3$) and epilepsy ($n = 3$) were limited. About half of the articles used cross-sectional designs ($n = 35$, 51,5%) and most used quantitative methods ($n = 66$, 97.1%), rather than qualitative ($n = 1$, 1.5%) or mixed methods ($n = 1$, 1.5%). A brief overview of study descriptive characteristics is presented in Table 12. Information regarding study characteristics for all 68 studies included in the review is summarized in Table 13.

Figure 4. PRISMA Flow Diagram for Study Inclusion.



Note. Adapted from "Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement," by Moher et al. (2009).

Table 12. Descriptive Information for Studies Included in the Review (*n* = 68).

Study Characteristics	***n***	***%***
Type of Study		
Quantitative	66	97.1
Qualitative	1	1.5
Both Quantitative and Qualitative	1	1.5
Pediatric Conditions		
Traumatic Brain Injuries	22	32.4
Cerebral Palsy	19	27.9
Spina Bifida	16	23.5
Epilepsy	12	17.6
Brain Tumors	0	0.0
Measure of Parenting*		
Children's Report of Parental Behavior Inventory	15	22.1
Parenting Practices Questionnaire	11	16.2
Perceptions of Parents Scale	5	7.4
Measure developed in study	2	4.4
Other self-report measure(s)	23	33.8
Observational measures	27	39.7
Interview or Open-Ended Questions	1	1.5
	Range	
Sample Size	20 – 297	

Note. For studies that compared children with a CNS-related condition to controls, sample size refers to the CNS-related group only. *Studies can fall within in multiple categories

Measures of Parenting

Most studies used well-validated, paper-and-pencil measures to assess parenting, with the most common including the Children's Report of Parental Behavior Inventory (CRPBI), Parenting Practices Questionnaire (PPQ), and Perceptions of Parents Scale (POPS). Twenty-seven studies used observational measures to assess parenting and one study used a semi-structured interview. Only two articles explicitly examined the psychometric properties of parenting measures as a central aim of the study (Kaugars et al., 2010; Winning et al., 2020). These studies found that observed parenting behaviors (e.g., parental acceptance, behavioral control, psychological control, scaffolding), assessed using an observational coding system (i.e., the Family Interaction Macro-coding System; FIMS) in families of children with spina bifida, demonstrated adequate psychometric properties, including convergent validity with conceptually similar self-report measures (Kaugars et al., 2010; Winning et al., 2020).

Trends in Parenting

When comparing parenting in families of children with a CNS-related condition to norms or comparison groups, a common finding was that parents of children with cerebral palsy, spina bifida, and epilepsy tended to demonstrate more overprotectiveness (Holmbeck et al., 2002a; Jankowska et al., 2015; O'Toole et al., 2016). One study found that mothers were more likely to be overprotective than fathers and that cognitive ability helped to explain (i.e., partially mediated) differences in overprotectiveness between parents of children with spina bifida and typically developing children (Holmbeck et al., 2002a). Qualitative findings provided deeper insight into how this overprotection may be experienced by children, such that children with epilepsy described feeling frustrated by heightened levels of parental supervision and reported often reassuring parents of their wellbeing (O'Toole et al., 2016).

In addition to elevated levels of overprotectiveness, parents of youth with cerebral palsy were also found to have an authoritarian style of parenting (Cook, 1963) and demonstrate less autonomy-supportive parenting behavior (De Clerq et al., 2022a), more demanding attitudes (Jankowska et al., 2015), more parenting structure (Cunningham et al., 2019), more responsiveness (De Clerq et al., 2019), more overreactive parenting (De Clerq et al., 2022a), and less possessiveness (Harper, 1977) than parents of typically developing children. However, findings were also mixed, with other studies documenting less psychologically controlling behavior (De Clerq et al., 2022a) and less intrusiveness (Harper, 1977) among parents of children with cerebral palsy. This latter finding differed from results reported in a study with children who have spina bifida, which found that parents of these children demonstrated more intrusiveness than controls (Zukerman et al., 2011). One study explicitly focused on infants who had both cerebral palsy and a developmental delay, finding that mothers were more verbally and physically directive, as well as engaged in fewer positive initiation and response behaviors, than mothers of typically developing children (Hanzlik, 1990). Notably, parenting behaviors, on average, were found to remain stable over a two-year period for families of children with cerebral palsy (De Clerq et al., 2022b); however, another study using online daily diaries revealed that there is significant *daily* variability in the parenting styles that caregivers employ (Dieleman et al., 2021b).

Findings in the context of TBI revealed less warm responsiveness (Fairbanks et al., 2013; Wade et al., 2008; Wade et al., 2011) and nurturance (Root et al., 2016), as well as more restrictiveness (Root et al., 2016) and directive statements (Wade et al., 2008), among caregivers of children with TBI compared to those with an orthopedic injury. Narad et al. (2019) also found that parents of children with TBI exhibited significant declines in warmth and involvement over time as compared to those with an orthopedic injury.

Predictors of Parenting

Demographic and Condition-Related Factors. One study found differences in parenting between mothers and fathers, with fathers engaging in less scaffolding than mothers (Winning et al., 2020). However, most studies focused only on mothers (*n* = 12) or parents/caregivers more broadly (*n* = 56), with no studies exclusively examining parenting among fathers. There were mixed findings regarding cultural differences in parenting, such that some studies found that there were differences in parenting across racial and ethnic groups (Malm-Buatsi et al., 2015; Winning et al., 2020), whereas others did not (Devine et al., 2011). Notably, this suggests that existing measures of parenting used in CNS populations may not be accurately capturing the strengths of *all* families across diverse cultural backgrounds.

In terms of child sex, one study found that parents of typically developing children demonstrated higher levels of nurturance for females as compared to males, yet this pattern was not present within families of children with a neurodevelopmental condition (i.e., cerebral palsy or spina bifida; Shapiro et al., 2014). However, another study found that parents of females with cerebral palsy demonstrated more responsive and autonomy-supportive parenting than parents of males (Dieleman et al., 2021a). Autonomy-granting by mothers increased with child age among children with cerebral palsy (Cohen et al., 2008), which is akin to findings that protectiveness decreased with child and parent age among children with spina bifida (Malm-Buatsi et al., 2015).

When examining the influence of condition-related factors on parenting, one study found that disability severity among those with cerebral palsy was negatively associated with child-reported maternal intrusiveness (Harper, 1977). Seizure type (Carlton-Ford et al., 1997) and child IQ (Winning et al., 2020) were also linked to parenting among children with epilepsy and spina bifida, respectively; with the latter findings suggesting that parents may adapt their parenting to meet the ability level of their child (Winning et al., 2020).

Parent Factors. Parent wellbeing emerged as one significant predictor of parenting across multiple CNS-related conditions. Among children with cerebral palsy, parental psychological need satisfaction was found to positively relate to autonomy support (Dieleman et al., 2021a; Dieleman et al., 2021b) and responsive parenting (Dieleman et al., 2021b), but negatively relate to psychological control (Dieleman et al., 2021b). Similarly, parental need frustration was found to positively relate to psychological control (Dieleman et al., 2021a). One study documented interactions between parents' own psychological needs and child behavior in predicting daily parenting, such that the combined presence of both parental need frustration and externalizing child behavior predicted elevated levels of psychologically controlling parenting behavior (Dieleman et al., 2021b). For both children with epilepsy and cerebral palsy, parental depression, anxiety, and/or stress was linked to the use of less adaptive parenting styles (Barfoot et al., 2017; Chapieski et al., 2005; Rodenburg et al., 2007). Yet, it is worth noting that studies with young children who sustained a TBI (Wade et al., 2008) and with children who have spina bifida (Schellinger et al., 2012) did not find associations between caregiver depression and parenting.

Findings indicate that the stress parents experience in relation to their parenting role (i.e., "parenting stress") may help to explain the link between parent mental health and parenting. Indeed, Rodenburg et al. (2007) found that greater depression among parents of children with epilepsy was related to less parental behavioral control and more parental psychological control via increased parenting stress. Among families of children with SB, paternal parenting stress (*not* maternal) was found to be positively related to adaptive parenting behaviors cross-sectionally, but negatively related to adaptive changes in parenting behaviors over time (Greenley et al., 2006). One study also documented links between parents' confidence in managing their child's condition (i.e., epilepsy) and behavior and parenting, such that confidence was positively associated with an authoritative parenting style and negatively associated with permissive and authoritarian parenting styles (O'Toole et al., 2021).

Certain parent characteristics and values may also have implications for parenting. For instance, parental autonomous motivation (i.e., internally driven motivation for parenting that aligns with parents' own values and sense of self) was positively associated with responsive and autonomy-supportive parenting, and negatively associated with psychologically controlling parenting (Dieleman et al., 2021a). Moreover, parents who reported being more mindful during interactions with their child demonstrated more responsiveness and less psychologically controlling behaviors (Dieleman et al., 2021b). In contrast, neuroticism was positively linked to overprotective and demanding parenting attitudes (Jankowska et al., 2015).

Finally, studies suggest that parental coping behaviors may have implications for parenting. Among children with epilepsy, parent engagement in problem-focused coping was predictive of greater parental supportiveness and less parental psychological control (Rodenburg et al., 2007). In contrast, parent use of emotion-focused coping was predictive of less parental behavioral control and greater parental psychological control, and these relationships were mediated by parenting stress (Rodenburg et al., 2007). In other words, findings suggested that parent use of emotion-focused coping may be linked to greater parenting stress, thereby negatively impacting parenting behaviors (Rodenburg et al., 2007). Relatedly, among children with cerebral palsy, use of denial as a coping strategy was positively associated with overprotectiveness, whereas use of religion as a coping strategy was positively associated with demandingness (Jankowska et al., 2015).

Child Factors. Child behavior may help to explain differences in parenting among parents of children with CNS-related conditions relative to parents of typically developing children. For instance, Wade et al. (2008) found that less behavior regulation among those with a TBI, as compared to controls, partially explained lower levels of warm responsiveness and higher levels of directiveness from parents. However, child behavior regulation did not *fully* explain group differences in parenting, suggesting that other mechanisms are also likely at play (Wade et al., 2008). Studies in the context of epilepsy have documented similar correlations, finding that child externalizing behavior was negatively associated with autonomy support (Dieleman et al., 2021a; Dieleman et al., 2021b) and responsive parenting (Dieleman et al., 2021b), and positively associated with psychological control (Dieleman et al., 2021b). It may be that difficult child behaviors make it challenging for parents to engage in adaptive parenting strategies due to increased parenting stress, as suggested by Rodenburg et al. (2007). Indeed, Rodenburg et al. (2007) found that more child behavioral problems due to epilepsy and a more difficult child temperament were associated with less parental supportiveness and behavioral control (respectively), and that both relationships were mediated by parenting stress.

On the other hand, findings in the context of cerebral palsy revealed that parents demonstrated higher levels of responsive parenting in the presence of higher levels of child prosocial behavior and lower levels of child internalizing problems (Dieleman et al., 2021b). Yet, there may be some disruptions in the reciprocity between parent and child behavior among those with CNS-related conditions. Wade et al. (2008) found that child cooperation was associated with parental warm responsiveness only for those with an orthopedic injury and not for the TBI groups.

Social-Environmental Factors. Social-environmental factors, such as lower SES and greater life stressors, were linked to the use of less adaptive parenting styles for those with TBI and spina bifida (Narad et al., 2019; Winning et al., 2020). Social relationships within and outside of the home were also linked to parenting behaviors. Specifically, greater family cohesion was predictive of more parental supportiveness, whereas greater social support (from partner, friends, family, etc.) was predictive of more parental behavioral control and less parental psychological control in families of children with epilepsy (Rodenburg et al., 2007). Mediation models indicated that the relationship between social support and parenting was mediated by parenting stress, such that greater social support was linked to less parenting stress, which in turn contributed to higher levels of parental behavioral control and lower levels of parental psychological control (Rodenburg et al., 2007). Interestingly, among families of children with spina bifida, conflict within the home was linked to the use of less adaptive parenting cross-sectionally, but more adaptive parenting trajectories over time (Greenley et al., 2006). While initially counter-intuitive, the authors speculated that conflict within the home in the short-term may prompt parents to adapt their parenting style and restructure the parent-child relationship in adaptive ways over time (Campbell et al., 2022; Greenley et al., 2006).

Associations with Youth Outcomes

Cognitive Development. For children with spina bifida ages 3-36 months, cognitive and language skills were positively correlated with and demonstrated faster growth in the presence of higher quality parenting (i.e., maternal warmth, responsiveness, and maintaining the child's chosen focus of attention; Landry et al., 2013; Lomax-Bream et al., 2007). Notably, these trends were similar when comparing children with spina bifida to typically developing children (Lomax-Bream et al., 2007). While a bidirectional relationship between parent and child behavior emerged during early development (12–18 months), by 26 months, the direction of this relation became one of mother to child (Lomax-Bream et al., 2007).

Almost all articles examining links between parenting and cognitive development in children with CNS-related conditions focused on those who sustained a TBI in early childhood (i.e., ages 3 to 7; *n* = 5). On a broad level, certain adaptive parenting styles (e.g., warm responsiveness, scaffolding) were found to predict higher scores across multiple domains of cognitive development in young children with TBI (e.g., general conceptual ability, verbal fluency, pragmatic judgement; Gerrard-Morris et al., 2010). However, findings regarding attention and executive functioning were a bit more nuanced. For attention, studies revealed that permissive parenting, negativity, and low levels of warm responsiveness were associated with more attention problems (Kurowski et al., 2011; Treble-Barna et al., 2016b; Wade et al., 2011). High levels of warm responsiveness, in particular, were found to exert a protective effect, such that group differences in ADHD symptoms between children who sustained a severe TBI and those with a moderate TBI or orthopedic injury were present at low, but not high, levels of warm responsiveness (Treble-Barna et al., 2016b). However, after one-year, parental warm responsiveness no longer appeared to exert a protective effect (Treble-Barna et al., 2016b).

With regards to executive functioning, permissive and authoritarian parenting styles were linked to worse postinjury executive functioning among young children with TBI (Kurowski et al., 2017; Potter et al., 2011; Schorr et al., 2020), whereas authoritative parenting was associated with better executive functioning (Schorr et al., 2020). Some findings suggested that these associations do not emerge until later in the recovery process (e.g., 12 and 18 months, 6 years; Potter et al., 2011; Schorr et al., 2020). The authors speculated that parenting may not be as closely tied to executive functioning during the initial, rapid rate of organic neural recovery following TBI, but may have greater effects once chronic deficits are identified (Potter et al., 2011). Of note, studies by Kurowski et al. (2017) and Smith-Paine et al. (2018) indicated that the impact of parenting on executive functioning after sustaining a TBI may also vary depending on the presence of certain child genetic factors.

Psychosocial and Behavioral Functioning. On a broad level, studies documented positive associations between adaptive parenting styles (i.e., autonomy supportive, accepting, and/or responsive parenting) and psychosocial strengths (De Clerq et al., 2019; De Clerq et al., 2022b) and psychosocial quality of life among children with cerebral palsy (Aran et al., 2007). Moreover, psychosocial functioning was found to worsen over time in the presence of higher levels of permissive and authoritarian parenting among young children with TBI (Yeates et al., 2010). Across all four CNS-related conditions, less adaptive parenting styles (e.g., rejection, overprotectiveness, lower acceptance, higher psychological control, higher permissive parenting, lower emotional support, lower warm responsiveness, lower authoritative parenting) were associated with greater child internalizing problems (Austin et al., 2004; De Clerq et al., 2022b; Han et al., 2016; Holmbeck et al., 2002a; Wade et al., 2011; Wiley & Renk, 2007), depressive symptoms (Carlton-Ford et al., 1997; Holmbeck et al., 2002a; Schellinger et al., 2012), and/or anxiety (Cohen et al., 2008), as well as worse emotional/behavioral adjustment (Lloyd et al., 2021; Schorr et al., 2020). Parental responsiveness and demandingness were related to an increase in problem-focused coping over time among youth with spina bifida (McKernon et al., 2001). Notably, Treble-Barna et al. (2016b) also found that the negative effects of TBI on internalizing problems were moderated by parental scaffolding; however, these effects lessened over time and eventually inverted, such that greater scaffolding was eventually linked to more internalizing symptoms among those with a severe TBI. The authors speculated that while scaffolding may be effective when children are younger and/or first sustain a TBI, it may eventually become less effective or even bothersome over time as the child ages and recovers (Treble-Barna et al., 2016b).

From a behavioral perspective, less adaptive parenting styles (e.g., controlling, higher negativity, lower warmth/responsiveness, overprotectiveness, rejection, higher permissive parenting, lower authoritative parenting) were linked to greater externalizing/behavior problems (Austin et al., 2004; Carlton-Ford et al., 1997; De Clerq et al., 2019; De Clerq et al., 2022b; Holmbeck et al., 2002a; Moscato et al., 2021; Raj et al., 2014; Schorr et al., 2020; Wade et al., 2011; Wiley & Renk, 2007), more impulsiveness (Carlton-Ford et al., 1997), and/or higher everyday functioning problems (Moscato et al., 2021; Raj et al., 2014) across all CNS-related conditions. In contrast, emotional support, autonomy promotion, sensitivity, and scaffolding from parents was negatively associated with child behavioral difficulties (Barfoot et al., 2017) and externalizing problems (Austin et al., 2004). Interaction effects suggest that the influence of parenting on behavior may differ by child sex(Pianta & Lothman, 1994; i.e., the relationship between maternal support/affect and externalizing problems was only present for male children, not female children) and be more pronounced depending on child personality characteristics, such as extraversion and conscientiousness (De Clerq et al., 2022b). Notably, parenting has been found to moderate the effects of TBI on youth outcomes, with authoritarian parenting initially suppressing behavior problems in young children with TBI (e.g., at 6 months post-injury), but then exacerbating these problems over time (e.g., 18 months post-injury; Yeates et al, 2010). When attempting to explain these links between parenting and child behavior, mediation models have revealed that parental overprotectiveness may contribute to externalizing problems by negatively influencing child autonomy among those with spina bifida (Holmbeck et al., 2002a). Additionally, findings in the context of epilepsy indicated that parenting may mediate associations between the broader family context (e.g., family functioning, conflict over child rearing) and child externalizing problems (Han et al., 2016).

Not only were links found between greater parental overprotectiveness and less child autonomy among those with spina bifida (Holmbeck et al., 2002a), but similar relations were found among those with epilepsy. Specifically, one study found that parents of children with epilepsy who are high in both indulgence and controlling behaviors imposed more activity restrictions on their child in daily life (Rodenburg et al., 2013); with the authors speculating that, in turn, this may have implications for child autonomy. Both studies highlighted the complexity of balancing the need for restrictions and limits when parenting a child with a CNS-related condition, while also granting appropriate autonomy to promote long-term adjustment (Holmbeck et al., 2002a; Rodenburg et al., 2013).

Results indicated that parenting also has implications for school functioning. Higher levels of parental scaffolding were found to be associated with greater academic skills among children with spina bifida (Winning et al., 2020), whereas parental support was linked to greater child confidence/involvement in an independent problem-solving task and scholastic competence among those with epilepsy (Lothman et al., 1990). Qualitative findings from one study with children with cerebral palsy indicated that children were more responsive when asked to complete a worksheet when parents demonstrated emotional availability in their parenting approach (e.g., warmth, were attuned to child cues; Barfoot et al., 2017).

Research regarding social skills and social functioning has centered on families of children with spina bifida, TBI, and cerebral palsy. Specifically, responsive parenting early in development was found to have an indirect effect on social problem-solving through early executive functioning and social language skills among those with spina bifida (Landry et al., 2013). As these children age and transition into middle childhood, scaffolding from parents was also found to be positively associated with social skills (Winning et al., 2020). Among children with TBI, parenting styles (e.g., authoritative, permissive, nurturance) were linked to social competence (Schorr et al., 2020) and peer rejection (Root et al., 2016). Parenting was also found to serve a protective role among children with TBI when testing a moderated mediation model. Specifically, Deighton et al. (2019) found that while theory of mind mediated the relationship between TBI and peer rejection/victimization (i.e., severe TBI predicted lower theory of mind and, in turn, greater peer rejection/victimization), the relationship between theory of mind and peer rejection/victimization was no longer significant at high levels of parental nurturance. For those with cerebral palsy in early and middle childhood, parent sensitivity, structuring, and nonintrusiveness were negatively associated with child peer problems (Barfoot et al., 2017) and parent verbosity (i.e., parental reliance on talking even when it is an ineffective parenting strategy) was associated with less social persistence (e.g., saying or doing things to keep other children interested) when interacting with peers (Miller et al., 2014).

While these studies all focused on children and adolescents with CNS-conditions, parenting during this timeframe may have lasting effects on child outcomes. Indeed, studies in the context of spina bifida found that parenting behaviors during childhood (i.e., when children are ages 8/9 and 14/15) were predictive of adjustment outcomes among emerging adults with spina bifida, particularly social, educational, and emotional functioning (Murray et al., 2014; Zukerman et al., 2011).

Adaptive Functioning. Broadly, the American Association on Intellectual and Developmental Disabilities (AAIDD) characterizes adaptive functioning as a collection of conceptual, social, and practical skills needed to function and meet the demands of daily life (Schalock et al., 2010). Guided by this definition, parenting was found to be associated with adaptive functioning outcomes for those with cerebral palsy, TBI, and epilepsy. For those with cerebral palsy, higher levels of permissive and authoritarian parenting were associated with lower adaptive functioning scores and/or greater functional impairment among children with a TBI (Lloyd et al., 2021; Wade et al., 2016). Additionally, maternal protectiveness was negatively associated with daily living skills and socialization scores (i.e., interpersonal relationships, play and leisure activities, and coping skills in social situations)_on The Vineland Adaptive Behavior Scales for children with epilepsy (Chapieski et al., 2005; Sparrow et al., 1984). One reason parents may be engaging in less helpful parenting practices may be due to distress, with Micklewright et al. (2011) finding that greater parental distress was associated with lower child adaptive functioning in children with TBI via more engagement in authoritarian parenting practices. Gene-environmental interactions may also be present, as Treble-Barna et al. (2016a) found that the impact of parenting on adaptive functioning varied depending on the presence of certain alleles in the child who sustained a TBI.

Health-Related Outcomes. Aran et al. (2007) found that greater autonomy granting predicted greater physical QOL for school-aged children with cerebral palsy, above and beyond the degree of disability. All other studies focused on links between parenting and child medical responsibility or adherence in families of children with spina bifida. Findings indicated that parents may modulate their level of control based on the vulnerability of their child and ability to safely take on responsibility for medical tasks (Driscoll et al., 2020). Indeed, Driscoll et al. (2020) found that overprotective parenting mediated the relationship between maternal perception of child vulnerability and responsibility for medical tasks among youth with spina bifida.

Another study revealed interactions between parenting and child cognitive functioning when predicting adherence, such that *higher* levels of maternal behavioral control and *lower* levels of paternal behavioral control buffered against the association between executive dysfunction and lower levels of adherence (O’Hara et al., 2013). Additionally, the association between executive dysfunction and lower levels of adherence was found to be stronger in the presence of higher paternal psychological control. While the finding regarding paternal behavioral control is somewhat counterintuitive, the authors noted that this finding speaks to the need for more research that is inclusive of fathers to better understand and assess parenting in this group (O’Hara et al., 2013). Stern et al. (2020) extended this study by examining relationships longitudinally, finding that higher levels of maternal acceptance and lower levels of paternal psychological control were related to more youth medical responsibility two years later. Parenting behaviors were also found to moderate the relationship between neuropsychological functioning and future medical responsibility, such that greater planning/organizing skills were associated with medical responsibly in the presence of high paternal acceptance and low paternal psychological control (Stern et al., 2020). A three-way interaction between cognitive shifting skills, maternal acceptance, and child age revealed that acceptance moderated the association between cognitive shifting and medical responsibility for adolescents with spina bifida, but not for younger children. Further, the relation between cognitive shifting and medical responsibility was only significant at low levels of acceptance, with lower cognitive shifting skills associated with less medical responsibility (Stern et al., 2020).

Interventions

Six studies evaluated the effects of an intervention on parenting in the context of TBI (*n* = 2), cerebral palsy (*n* = 3), and epilepsy (*n* = 1). In families of children with a TBI, two studies examined the effectiveness of an online parenting skills training, Internet-based Interacting Together Everyday: Recovery After Childhood TBI (I-InTERACT), in improving parenting skills and child behavior after early TBI (Antonini et al., 2014; Wade et al., 2017). The pilot randomized controlled trial (RCT) compared I-InTERACT to an online resources (internet resources comparison [IRC]) group (Antonini et al., 2014) and the follow-up RCT compared I-InTERACT to an IRC group, as well as an abbreviated parent training (Express) group (Wade et al., 2017). Broadly, both studies found that positive parenting behaviors (e.g., specific praise following compliant child behaviors) improved in groups that received parenting skills training (Antonini et al., 2014; Wade et al., 2017).

Two studies (Whittingham et al., 2014; Whittingham et al., 2019) tested the efficacy of Stepping Stones Triple P (SSTP) with and without Acceptance and Commitment Therapy (ACT) in targeting parenting in families of children with cerebral palsy. Results from this RCT revealed differences in dysfunctional parenting styles across the three treatment groups (SSTP, SSTP + ACT, waitlist control) postintervention, such that SSTP with ACT was associated with decreased parental overreactivity and verbosity (Whittingham et al., 2014). However, mediation models did not reveal significant indirect effects of the intervention on child behavior and adjustment via parenting style, with the authors suggesting that other aspects of parenting that were not captured may have been the key ingredient of change (Whittingham et al., 2019). Another study with infants who have cerebral palsy found that 12 months of neurodevelopmental therapy (i.e., physical therapy) led to greater improvements in parenting (i.e., maternal emotional and verbal responsivity) relative to 6 months of infant stimulation (i.e., cognitive, sensory, language, and motor activities) followed by 6 months of neurodevelopmental therapy (Palmer et al., 1990).

Finally, one study examined the impact of a support group focused on education and psychosocial support for parents of children with epilepsy (Fernandes et al., 2001). Prior to the support group, 76.19% of parents reported feeling the need to constantly protect their child with epilepsy, with this percentage decreasing immediately following the support group (28.57%) and six months later (14.29%).

Quality Assessment

Proportion scores on the 11 items of the quality assessment checklist ranged from 0.23 to 0.95 with a mean score of 0.75 (*SD* = 0.13). The proportion scores for each individual study included in the review are listed in Table 13. Thirty-eight percent (*N* = 26) of studies received a "no" from both reviewers when asked "Were the subjects asked to participate in the study representative of the entire population from which they were recruited?"

Discussion

The current systematic review included 68 articles that examined parenting among children with CNS-related conditions. While we reviewed the literature across five CNS-related conditions (i.e., spina bifida, cerebral palsy, epilepsy, TBI, and brain tumors), none of the included studies focused on children who had brain tumors due to not meeting inclusion criteria (e.g., combined those with brain tumors with other non-CNS cancers). The included studies provide insight into the types of parenting assessed and methods of measurement among those with a CNS-related condition, as well as parent and child correlates, interaction effects with child cognitive functioning, the quality of existing research, and intervention efforts.

Overall, findings from the review highlight the influential role that parenting plays in the development and long-term adjustment of children with CNS-related conditions. There was significant variability in the types of parenting assessed across studies and conditions, but adaptive parenting styles (e.g., warm responsiveness, scaffolding, authoritative approaches) were generally linked to greater cognitive, emotional, and behavioral functioning, whereas the inverse was revealed for maladaptive parenting styles (e.g., overprotectiveness, psychological control, permissive and authoritarian approaches). Personal characteristics of parents and their children (e.g., demographic factors, emotional and behavioral adjustment, coping styles) were found to correlate directly with the parenting styles that were employed within the home. Based on these findings, specific recommendations for future research include: (1) validating parenting measures that are sensitive to the potentially unique dynamics within families of children who sustain an insult to the CNS, (2) prioritizing parenting research during early childhood, (3) increasing diversity within study samples to better understand variability in parenting across social contexts (e.g., SES, ethnicity/culture), (4) seeking greater inclusion of varied family structures within research, and (5) adapting parent-focused interventions across CNS populations to grow the evidence base in pediatric psychology.

First, we recommend *validating parenting measures that are sensitive to the potentially unique dynamics within families of children who sustain an insult to the CNS*, as this is empirically and clinically beneficial. Notably, only two articles included in this review explicitly examined the psychometric properties of parenting measures, both of which focused on coded observations of parenting among children with spina bifida (Kaugars et al., 2010; Winning et al., 2020). These two articles tailored the observed parent-child interaction tasks to meet the specific needs of this population, allowing for greater specificity of the measure. For instance, one task involved discussing one or two spina bifida-related medical responsibilities that could eventually be transferred from the parent(s) to the child, such as independent catheterization. Assessing parenting behaviors within the context of the medical condition families are facing allows researchers to capture patterns of behavior that may not be detected using measures developed for the general population. That said, parenting measures that have been well-established in the general population do have utility and often demonstrated adequate internal consistency when used in studies with families of children with CNS-related conditions. However, investigating other forms of reliability (e.g., test-retest) and validity (e.g., convergent validity) is needed to refine our methods of measurement (Alderfer et al., 2008). Moreover, due to the heterogeneity of measures included in this review, it was difficult to draw conclusions about the levels of certain parenting styles (e.g., structure, rigidity) that may be adaptive or maladaptive. Establishing norms and clinical cutoffs that are predictive of child outcomes may be useful in clinical settings. It may be that children with CNS-related conditions who are at risk of cognitive difficulties (e.g., inattention, executive functioning challenges; Bottcher et al., 2010; Konigs et al., 2015; Mangeot et al., 2002; Olsson et al., 2014; Reuner et al., 2016; Rose & Holmbeck, 2007) benefit from increased supervision, support, and structure during certain periods of development.

Additionally, we recommend *prioritizing parenting research during early childhood*, particularly for children with spina bifida and epilepsy. Limited studies had examined this timeframe in these two populations, as compared to those with TBI and cerebral palsy who had over three times the number of articles that were inclusive of this age group. Early childhood is a time in which children are rapidly acquiring new, foundational skills (e.g., motor, speech/language, social emotional) that can have lasting effects on future functioning and wellbeing (Jones et al., 2015; Masten et al., 2010). Review findings suggest that high quality interactions with parents during this time may promote cognitive development in children with CNS-related conditions (Gerrard-Morris et al., 2010; Landry et al., 2013), as well as buffer the negative effects of neurological risk on adjustment outcomes (Treble-Barna et al., 2016b). The influence of parenting after CNS insult may also change over time in relation to recovery and developmental factors (Treble-Barna et al., 2016b; Yeates et al., 2010). Future research in this area among those with spina bifida and epilepsy could examine how the effects of parenting change across all developmental periods (e.g., early childhood vs. middle childhood vs. adolescence), as well as potential bidirectional effects between parenting and child behavior, to identify *when* intervention efforts may be most impactful for these populations. Moreover, given evidence from this review suggesting that parenting behaviors themselves are not static over time (Greenley et al., 2006), elucidating salient predictors of parenting within these developmental periods may help to better identify families at risk for difficulties as children age and effectively target intervention efforts.

Our third recommendation is to *increase diversity within study samples to better understand variability in parenting across social contexts*. Evidence from the broader literature suggests that the social contexts in which families are embedded (e.g., SES, ethnicity/culture, community) may shape parenting (Luster & Okagaki, 1993). Indeed, not only could parenting vary based on parents' cultural beliefs regarding acceptable child behaviors and disciplinary practices, but also the family's access to resources and social supports (Kotchick & Forehand, 2002). Yet, many studies included in this review used convenience samples (e.g., data collection from clinics) and samples were frequently not deemed representative of the populations from which they were recruited. A few studies documented links between parenting and contextual factors, such as SES, life stressors, and ethnicity (Malm-Buatsi et al., 2015; Narad et al., 2019; Winning et al., 2020). However, given that measures of parenting were typically initially developed and used with middle class, White families, these tools may not fully capture the parenting experiences and strengths of parents from systemically marginalized groups. Greater inclusion of underrepresented families in research and conducting stakeholder analyses that capture the voices of these families may provide greater insight into their parenting experiences and needs.

Relatedly, there is also a need for *greater inclusion of varied family structures within research*. Mothers were the primary caregiver represented in the reviewed studies. However, some studies documented differences in the correlations between parenting and child outcomes across caregivers. For instance, Greenley et al. (2006) found that the impact of parenting stress on parenting behaviors was more pronounced for fathers as compared to mothers (Greenley et al., 2006). There have been multiple calls within the field of psychology to have greater inclusion of fathers and other caregivers (e.g., extended family members in multigenerational homes) in research, as parenting is thought to differ across caregivers and based on child gender (Alderfer et al., 2008; Bornstein, 2012). Additionally, there is a need to capture and better understand how parenting experiences may differ based on family structure (e.g., same-sex parents, divorced parents, single parents). Improving understanding of all individuals who contribute to the caregiving environment and diverse family structures would increase inclusivity within our family systems approach.

Finally, our last recommendation is to *adapt parent-focused interventions across CNS populations to grow the evidence base in pediatric psychology*. There remains a significant need to develop high quality, evidence-based interventions within the field (Palermo, 2014). Within this review, six studies had evaluated the effects of an intervention on parenting across three of the CNS-related conditions: TBI, cerebral palsy, and epilepsy. Interventions focused on teaching parenting skills, as well as providing parents with psychosocial support and education, documenting promising results. While there are clear differences in the needs and challenges experienced among children within each CNS-related condition (e.g., conditions such as spina bifida are present at birth, whereas TBI is an acute event that disrupts typical child development), the primary components of these interventions can likely be adapted for other groups. By partnering together, pediatric psychologists may be able to more effectively develop evidence-based approaches to improve patient care.

While this review utilized sound methodology, a few limitations should be acknowledged. First, as previously noted, a meta-analytic approach was not used due to variability in the measures, methodologies, and age ranges of included studies. Therefore, it is possible that the narrative approach introduced bias into the review process, despite the stringent review protocol. Second, some of the included studies did receive poor quality ratings, which are provided in Appendix C. Third, as previously noted, there is a need for more diverse representation in future studies regarding race, ethnicity, and family structures. Finally, families of children with brain tumors were ultimately not included in the review due to not meeting inclusion criteria (e.g., study samples combined children with brain tumors and other types of cancer). Findings of this review may be able to inform continued research efforts with families of children with brain tumors.

Research in the broader field of pediatric psychology has indicated that parenting that is warm, supportive, structured, and appropriately grants autonomy may promote optimal outcomes for children (Kazak et al., 2017). These processes may be particularly influential for children who have a condition that affects their CNS and interact with neurological factors to affect long-term adjustment. Refining our ability to quantify and understand parenting processes across diverse samples and with all caregivers within the family system can drive the development of targeted, effective interventions. Such interventions have the power to provide crucial psychosocial and parenting support to improve the well-being of children with CNS-related conditions.

Table 13. Characteristics of Studies Included in the Review (*n* = 68).

Lead Author	**Country**	**Type of Study**	**Study Design**	**Specific Condition(s)**	***N***	**Youth Age *M*, *SD* (Range)**	**Parenting Measure**	**Main Parenting Findings**	**Quality Assessment Rating**
Antonini et al., 2014	USA	Quantitative	Longitudinal	TBI	20 children and parents in online parenting skills training group (Internet-based interacting together every day: recovery after childhood TBI [I-InTERACT]); 17 children and parents in internet resource comparison (IRC) group	I-InTERACT: 5.60, 2.09 (3-9) IRC: 5.24, 2.14 (3-9)	Observational	The I-InTERACT group was more likely to demonstrate positive parenting behaviors post-intervention than the IRC group and had a higher percentage of labeled praise following child compliance; parents in both groups were less likely to demonstrate undesirable parenting behaviors post-intervention (e.g., commands, criticism); the number of sessions completed by the I-InTERACT group was positively associated with the number of labeled praises parents provided and negatively associated with questions parents asked during child-directed play	0.82
Aran et al., 2007	Israel	Quantitative	Cross-sectional	Cerebral Palsy	39 youth with cerebral palsy, siblings, and parents	12.0, 3.1 (6-18)	CRPBI	Parenting style positively correlated with physical and psychosocial aspects of QOL; autonomy allowing parenting style predicted physical and psychosocial aspects of QOL, above and beyond the degree of disability;	0.70

Lead Author	**Country**	**Type of Study**	**Study Design**	**Specific Condition(s)**	***N***	**Youth Age *M, SD* (Range)**	**Parenting Measure**	**Main Parenting Findings**	**Quality Assessment Rating**
								accepting parenting style predicted psychosocial QOL, above and beyond degree of disability	
Austin et al., 2004	USA	Quantitative	Longitudinal	Epilepsy	224 children with epilepsy and caregivers	8.4, 3.0 (4-14)	Unnamed scale created for the study	Support of child autonomy was negatively associated with child externalizing problems and total behavior problems; an increase in support of child autonomy was associated with a decrease in child internalizing problems and total behavior problems; an increase in parental provision of emotional support was associated with a decrease in internalizing problems	0.77
Barfoot et al., 2017	Australia	Both	Cross-sectional	Cerebral Palsy	23 children with cerebral palsy and mothers	4.87, 3.27 (2-11)	Observational	Parent depression was negatively associated with sensitivity, structuring, and nonintrusiveness; parent stress was negatively associated with structuring; parent sensitivity, structuring, and nonintrusiveness were negatively associated with child peer problems; parent sensitivity and structuring were negatively associated	0. 89

Lead Author	Country	Type of Study	Study Design	Specific Condition(s)	*N*	Youth Age *M*, *SD* (Range)	Parenting Measure	Main Parenting Findings	Quality Assessment Rating
								with child behavioral difficulties; children appeared to be more responsive to parents who demonstrated emotional availability (e.g., warmth, attuned to child cues) in their parenting	
Driscoll et al., 2020	USA	Quantitative	Longitudinal	Spina Bifida	140 youth with spina bifida, 128 mothers	11.43, 2.46 (8-15)	PPS, Observational	Maternal overprotection significantly mediated the relationship between maternal perception of child vulnerability and youth responsibility for medical tasks	0.77
Carlton-Ford et al., 1997	USA	Quantitative	Cross-sectional	Epilepsy	37 children with epilepsy and caregivers	10.04 (6-13)	CRPBI	Caregiver psychological control was positively associated with child behavioral problems (i.e., home behavior problems, school behavior problems, impulsiveness) and depressed mood; children with simple seizures reported lower levels of psychological control than those with other seizure types	0.68
Chapieski et al., 2005	USA	Quantitative	Longitudinal	Epilepsy	56 children and mothers	8.6 (6-12)	Parental Protectiveness Scale, Parental Problem-Solving Directiveness Questionnaire	Maternal anxiety about epilepsy was associated with increased protectiveness and directiveness; maternal protectiveness was negatively associated with daily living skills and socialization	0.64

Lead Author	**Country**	**Type of Study**	**Study Design**	**Specific Condition(s)**	***N***	**Youth Age *M, SD* (Range)**	**Parenting Measure**	**Main Parenting Findings**	**Quality Assessment Rating**
Cohen et al., 2008	Israel	Quantitative	Cross-sectional	Cerebral Palsy	30 children with cerebral palsy, siblings, and mothers	Cerebral Palsy: 11.66, 3.17 (6-18) Siblings: 12.16, 3.67	CRPBI	For children with cerebral palsy, autonomy-granting by mothers increased with child age and more rejection by mothers was associated with higher anxiety	0.83
Cook, 1963	USA	Quantitative	Cross-sectional	Cerebral Palsy	53 mothers of children with cerebral palsy[d]	6.3 (4-10)	PARI	Mothers of children with cerebral palsy were characterized as having punitive attitudes and a strong authoritarian orientation	0.32
Cunningham et al., 2009	USA	Quantitative	Cross-sectional	Cerebral Palsy	41 children with cerebral palsy and parents; 60 typically developing controls and parents	Cerebral Palsy: 8.76, 1.81 (6-12) Controls: 8.91, 1.73 (6-12)	PDI	Higher levels of parenting structure among parents of children with cerebral palsy compared to controls; when controlling for cognitive ability, parenting did not significantly predict social outcomes for those with cerebral palsy	0.64
De Clerq et al., 2019	Belgium	Quantitative	Cross-sectional	Cerebral Palsy	121 youth with cerebral palsy and parents[a]	10.9, 2.3 (7-15)	CRPBI, POPS, PCS	Highest levels of responsive parenting in parents of children with cerebral palsy; correlations between psychologically controlling parenting and externalizing problems; responsiveness and autonomy support correlated with more psychosocial strengths	0.75

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De Clerq et al., 2022a	Belgium	Quantitative	Cross-sectional	Cerebral Palsy	67 children with cerebral palsy and parents; 167 children without a disability and parents	Cerebral Palsy: 12.44, 2.67 (6.70-17.97)[e] Controls: 13.31, 0.45 (12.35-14.73)	POPS, PCS, CRPBI, PS	Parents of children with cerebral palsy demonstrated less autonomy-supportive parenting behavior, less psychologically controlling behavior, and more overreactive parenting compared to parents of children with autism spectrum disorder and without a known disability	0.84
De Clerq et al., 2022b	Belgium	Quantitative	Longitudinal	Cerebral Palsy	118 children and caregivers (104 mothers, 12 fathers, 2 legal guardians)	10.9, 2.9 (4.6-17.0)	PBS, POPS	On average, externally controlling and autonomy-supportive parenting behavior did not change over time; externally controlling parenting was associated with higher levels of behavioral problems, with these associations being most pronounced among children low scores on Extraversion, Conscientiousness, or Imagination; autonomy-supportive parenting was associated with higher levels of psychosocial strengths, with this association being most pronounced among children high on Emotional Stability	0.82
Deighton et al., 2019	USA, Canada	Quantitative	Cross-sectional	TBI	13 children with severe TBI and	Overall Sample: 10.45, 1.47	CRPR-Q	Moderated-mediation model revealed that the relationship between	0.81

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					parents; 39 children with complicated mild/moderate TBI and parents; 32 orthopedic injury controls and parents	(8-13) Severe TBI: 9.81 Complicated Mild/ Moderate TBI: 10.57 Controls: 10.57		TBI (both severe TBI and complicated mild/ moderate TBI) and peer rejection/victimization was mediated by theory of mind and moderated by parental nurturance; specifically, the mediating effect of theory of mind was only significant at low and average levels of parental nurturance	
Devine et al., 2011	USA	Quantitative	Cross-sectional	Spina Bifida	103 children, 108 mothers, 94 fathers	Hispanic: 11.97, 2.38 (8-15) Non-Hispanic White: 11.38, 2.35 (8-15)	PPS	No significant differences in parental protectiveness between Hispanic and non-Hispanic White parents	0.85
Dieleman et al., 2021a	Belgium	Quantitative	Longitudinal	Cerebral Palsy	117 children and parents (104 mothers, 11 fathers, 2 guardians)	10.98, 2.85 (4.62–17.04)	POPS, PCS, CRPBI	Parents of girls demonstrated more responsive and autonomy-supportive parenting; parents' yearly psychological need satisfaction and frustration was associated with yearly fluctuations in autonomy-supportive and psychologically controlling parenting, respectively; yearly child externalizing behavior was negatively associated with autonomy-supportive	0.82

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								parenting; parents' autonomous motivation was positively associated with responsive and autonomy-supportive parenting, and negatively associated with psychologically controlling parenting	
Dieleman et al., 2021b	Belgium	Quantitative	Longitudinal	Cerebral Palsy	58 parents (52 mothers, 5 fathers, 1 guardian)	12.68, 2.83 (7-19)	BMPS, POPS, PCS, CRPBI	There was daily variability in parents' autonomy-supportive, psychologically controlling, and responsive behaviors, which correlated with fluctuations in both child behavior and parents' psychological needs; mindful parenting was positively associated with responsiveness and negatively associated with psychologically controlling parenting	0.85
Fairbanks et al., 2013	USA	Quantitative	Longitudinal	TBI	21 children with severe TBI and caregivers; 59 children with complicated mild/moderate TBI and caregivers; 116 orthopedic injury controls	Severe TBI: 5.06, 1.00 (36 to 84 months)[a] Complicated Mild/ Moderate TBI: 4.98, 1.21 (36 to 84 months)	Observational	Mothers of children with complicated mild/moderate TBI demonstrated lower levels of maternal warm responsiveness than mothers of controls at baseline and 6 months	0.73

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						Controls: 5.10, 1.08 (36 to 84 months)			
Fernandes et al., 2001	Brazil	Quantitative	Cross-sectional	Epilepsy	21 children with epilepsy, 16 mothers, 10 fathers	(5-15)	Single items about parenting as part of a larger questionnaire	Prior to the support group, 76.19% of parents reported feeling the need to constantly protect their child with epilepsy and 38.10% were afraid of reprimanding their child; parents reported a decrease in the need to constantly protect their child immediately following the support group (28.57%) and six months later (14.29%)	0.23
Gerrard-Morris et al., 2010	USA	Quantitative	Longitudinal	TBI	23 youth with severe TBI youth and caregivers; 21 youth with moderate TBI and caregivers; 43 youth with complicated mild TBI and caregivers; 117 orthopedic injury controls and caregivers	Severe TBI: 5.0, 1.0 (3-6)[a] Moderate TBI: 5.2, 1.2 (3-6) Complicated-Mild TBI: 5.0, 1.2 (3-6) Controls: 5.1, 1.1 (3-6)	Observational	Higher warm responsiveness predicted higher global cognitive ability and pragmatic judgement; higher scaffolding predicted higher pragmatic judgement, verbal fluency, recognition of pictures, recall of digits, sentence repetition, and cognitive switching; a group x scaffolding interaction revealed that global cognitive ability deficits were significant for the severe TBI group at a low level of scaffolding and for the	0.82

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								moderate TBI group at a high level of scaffolding	
Greenley et al., 2006	USA	Quantitative	Longitudinal	Spina Bifida	68 youth with spina bifida, 68 mothers, 55 fathers/step-fathers; 58 youth with diabetes, 58 mothers; 68 healthy controls, 68 mothers, 52 fathers/step-fathers	Spina Bifida: 8.34, 0.48 (8-9) Controls: 8.49, 0.50 (8-9)	CRPBI, Observational	Family conflict was negatively associated with adaptive parenting behavior at Time 1 (T1) and positively associated with adaptive parenting change, with findings being more robust for the spina bifida sample; parenting stress was positively associated with adaptive parenting at T1 and negatively associated with adaptive parenting change for fathers of children with spina bifida	0.82
Hanzlik, 1990	USA	Quantitative	Cross-sectional	Cerebral Palsy	20 infants with cerebral palsy and their mothers; 20 typically developing controls and their mothers	Cerebral Palsy: 17.7 months (8-32 months) Controls: 8.8 months (3-18 months)	Observational	Mothers of infants with cerebral palsy were more verbally and physically directive, as well as engaged in fewer positive initiation and response behaviors	0.61
Han et al., 2016	Korea	Quantitative	Cross-sectional	Epilepsy	297 youth with epilepsy, 240 mothers, and 57 fathers	15.4, 1.9 (11-18)	CRPBI	The autonomy–control and love–rejection axes of the CRPBI were each associated with internalizing and externalizing problems, such that greater control and rejection were related to more problems; family functioning and conflict over child rearing were	0.84

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								both indirectly related to child externalizing problems through the love–rejection axis	
Harper, 1977	USA	Quantitative	Cross-sectional	Cerebral Palsy	70 children with cerebral palsy; 70 typically developing controls	Cerebral Palsy: Males = 14.37, 2.4; Females = 14.41, 2.4 Controls: Males = 14.13, 2.3; Females = 14.19, 2.3	CRPBI	Children with cerebral palsy rated their mothers as less possessive and intrusive than typically developing children; disability severity among those with cerebral palsy was negatively associated with maternal intrusiveness	0.61
Holmbeck et al., 2002a	USA	Quantitative	Cross-sectional	Spina Bifida	68 children with spina bifida and parents; 68 typically developing controls and parents	Spina Bifida: 8.34, 0.48 (8-9) Controls: 8.49, 0.50 (8-9)	CRPBI, PBI, Observational	Parents of children with spina bifida were more overprotective than parents of controls, with cognitive ability partially mediating this relationship; mothers were more likely to be overprotective across samples; parental overprotectiveness was negatively associated with child autonomy and positively associated with behavioral problems; for the spina bifida sample, parental overprotectiveness was associated with less child autonomy which, in turn, was associated with more externalizing symptoms	0. 74

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Jankowska et al., 2015	Poland	Quantitative	Cross-sectional	Cerebral Palsy	27 mothers of children with cerebral palsy; 28 mothers of typically developing controls	Cerebral Palsy: (2-7) Controls: (2-7)	Parenting Attitude Scale	Mothers of children with cerebral palsy demonstrated significantly higher levels of overprotective and demanding attitudes compared to controls; for these mothers, neuroticism was positively associated with overprotective and demanding attitudes; positive correlations were found between denial coping and overprotective parental attitude, as well as between use of religion as a coping strategy and demanding parental attitude	0.67
Kaugars et al., 2010	USA	Quantitative	Longitudinal	Spina Bifida	68 youth with spina bifida, 68 mothers, 55 fathers/step-fathers; 68 healthy controls, 68 mothers, 52 fathers/step-fathers	Spina Bifida: (12-13)[f] Controls: (12-13)	CRPBI, Observational	Observed parental acceptance, behavioral control, and psychological control demonstrated convergent validity with conceptually similar self-report measures	0.59
Kurowski et al., 2011	USA	Quantitative	Longitudinal	TBI	68 children with moderate-to-severe TBI and parents; 75 orthopedic injury controls and parents	59.20 months, 13.36 months (3-7 years)	PPQ	Higher levels of permissive parenting were associated with more attention problems among children with severe TBI	0.75

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Kurowski et al., 2017	USA	Quantitative	Longitudinal	TBI	15 youth with severe TBI youth and caregivers; 40 youth with moderate TBI and caregivers; 70 orthopedic injury controls and caregivers	Severe TBI: 5.12, 0.97[a] (3-7) Moderate TBI: 5.27, 1.15 (3-7) Controls: 5.07, 1.08 (3-7)	PPQ	Among children with moderate TBI, higher levels of authoritarian parenting was associated with increasing executive dysfunction over time; the presence of the COMT AA genotype buffered the adverse effects of authoritarian parenting on post injury development of executive functioning	0.82
Landry et al., 2013	USA, Canada	Quantitative	Longitudinal	Spina Bifida	49 children with spina bifida and mothers; 54 typically developing controls and mothers	Spina Bifida: 12 months Controls: 12 months	Observational	Responsive parenting at 12-18 months of age was correlated with early executive functioning/social language at 3 years of age; responsive parenting had an indirect effect on social problem-solving through early executive functioning/social language skills	0.68
Lloyd et al., 2021	Australia	Quantitative	Cross-sectional	TBI	107 children with TBI and parents	12.66, 2.6 (8-16)	PPQ	Higher levels of permissive parenting style related to lower adaptive functioning, as well as greater emotional and behavioral problems	0.80
Lomax-Bream et al., 2007	USA	Quantitative	Longitudinal	Spina Bifida	91 children with spina bifida and mothers; 74 typically	Spina bifida: (3-36 months) Controls: (3-36 months)	Observadational	Both groups demonstrated higher levels of development and faster growth in cognitive and language	0.77

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					developing controls and mothers			skills in the presence of higher quality parenting	
Lothman et al., 1990	USA	Quantitative	Cross-sectional	Epilepsy	20 children with epilepsy and mothers	118.8 months (97-143 months)	Observational	Significant associations were found between emotionally supportive parenting and child confidence, flexibility, positive affect, scholastic competence, and social acceptance; maternal respect for child autonomy was associated with child confidence, task involvement, flexibility, positive affect, dependence, and behavioral conduct	0.50
Lothman et al., 1993	USA	Quantitative	Cross-sectional	Epilepsy	59 children with epilepsy and mothers	114 months (86-157 months)	Observational	Maternal support was positively associated with child confidence/involvement in an independent problem-solving task and scholastic competence, specifically for boys	0.50
Malm-Buatsi et al., 2015	USA	Quantitative	Cross-sectional	Spina Bifida	51 youth with spina bifida, 84 caregivers	11, 6 (1-23)	PPS	Caregiver protectiveness scores were negatively associated with child and parent age; protectiveness varied across racial/ethnic groups; Protectiveness was highly correlated for married couples	0.85
McKernon et al., 2001	USA	Quantitative	Longitudinal	Spina Bifida	68 youth with spina bifida, 68	Spina Bifida: 8.34, 0.48	CRPBI, Observational	Maternal and paternal responsiveness predicted	0.86

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					mothers, 55 fathers/step-fathers; 68 matched healthy controls, 68 mothers, 52 fathers/step-fathers	(8-9) Controls: 8.49, 0.50 (8-9)		an increase in children's use of problem-focused coping strategies; change in paternal responsiveness and maternal responsiveness and demandingness was related concurrently to change in coping	
Micklewright et al., 2011	USA	Quantitative	Cross-sectional	TBI	21 children with TBI and parents; 23 orthopedic injury controls and parents	TBI: 13.5, 2.6 Controls: 14.1, 2.6	PPQ	Mediation models indicated that higher parental distress was associated with greater engagement in authoritarian parenting practices and, in turn, lower child adaptive functioning across groups	0.73
Miller et al., 2014	Australia	Quantitative	Cross-sectional	Cerebral Palsy	48 youth with cerebral palsy and parents	7.92, 2.33 (5-14)	PS	Greater verbosity associated with less social persistence with peers	0.75
Moscato et al., 2021	USA	Quantitative	Longitudinal	TBI	116 youth with TBI and parents	14.72, 1.72 (12-17)	Observational	Higher parental negativity predicted higher everyday functioning problems and externalizing behaviors; higher parental warmth predicted fewer everyday functioning problems and externalizing behaviors; bidirectional effects between these variables were not significant	0.73

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Murray et al., 2014	USA	Quantitative	Longitudinal	Spina Bifida	50 children with spina bifida and parents; 60 typically developing controls and parents	Spina Bifida: 8.34, 0.48 (8-9) Controls: 8.49, 0.50 (8-9)	Observational	Parenting behaviors, particularly behavioral control, autonomy promotion, and psychological control, were predictive of adjustment outcomes in emerging adults with spina bifida	0.86
Narad et al., 2019	USA	Quantitative	Longitudinal	TBI	23 youth with severe TBI youth and caregivers; 64 youth with moderate TBI and caregivers; 119 orthopedic injury controls and caregivers	Severe TBI: 4.96, 1.00 (3-7)[a] Moderate TBI: 5.06, 1.20 (3-7) Controls: 5.12, 1.07 (3-7)	PPQ	Changes in parenting over time was generally not significantly related to injury group; levels of authoritative parenting remained stable over time, whereas levels of permissive and authoritarian parenting declined for all participants by 3.5 years post-injury; levels of warmth and involvement declined over time for those with TBI; SES and stressors were related to parenting	0.77
O'Hara et al., 2013	USA	Quantitative	Cross-sectional	Spina Bifida	140 youth with spina bifida, 129 mothers, and 106 fathers	11.43, 2.46 (8-15)	Observational	Associations were found between parenting behaviors and youth medical adherence; maternal and paternal behavioral control and paternal psychological control moderated associations between executive functioning and adherence	0.84

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O’Toole et al., 2021	Ireland	Quantitative	Cross-sectional	Epilepsy	47 youth with epilepsy and 72 parents	13.19, 2.82 (8-18)	PSDQ	Authoritative parenting was associated with greater parent and child psychosocial well-being; authoritarian and permissive parenting was associated with worse parent and child psychosocial well-being	0.65
O'Toole et al., 2016	Ireland	Qualitative	Cross-sectional	Epilepsy	29 children with epilepsy	11 years, 8 months (6-16)	Semi-structured interviews	Children with epilepsy described challenges related to parental overprotection as parents had adopted heightened levels of supervision to promote seizure safety; two subthemes emerged for parental overprotection: children reassuring parents and child frustration with the level of parental supervision	0.64
Palmer et al., 1990	USA	Quantitative	Longitudinal	Cerebral Palsy	25 infants and parents in Group A (12 months of neuro-developmental therapy); 23 infants and parents in Group B (6 months of infant stimulation + 6 months of neuro-	Group A: 15.0 months (12-19 months) Group B: 15.5 months (12-19 months)	MCRE, Observational	Greater improvement in maternal emotional and verbal responsivity in Group A compared to Group B	0.64

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					developmental therapy)				
Pianta & Lothman, 1994	USA	Quantitative	Cross-sectional	Epilepsy	51 youth with epilepsy and mothers	114 months (86-157 months)	Observational	Interaction effects were found for child gender and maternal support/affect, such that higher maternal support/affect was associated with lower externalizing problems among boys	0.56
Potter et al., 2011	USA	Quantitative	Longitudinal	TBI	20 youth with severe TBI and caregivers; 55 youth with moderate TBI and caregivers; 97 orthopedic injury controls and caregivers	Severe TBI: 5.03, 1.05 (3-6)[a] Moderate TBI: 5.01, 1.19 (3-6) Controls: 5.04, 1.08 (3-6)	PPQ	Higher levels of authoritarian parenting were associated with greater executive difficulties at 12 and 18 months after injury for children with moderate TBI; authoritative and permissive parenting styles were not associated with postinjury executive skills	0.77
Rodenburg et al., 2007	The Netherlands	Quantitative	Cross-sectional	Epilepsy	91 parents of children with epilepsy (81 mothers, 10 fathers)	8 years and 5 months, 2.42 (4-18)	CR-Q, PCIQ-R, A-PARI	Family stressors, resources, and coping behaviors all predicted parenting; parenting stress mediated the influence of child functional status, child temperament, parental depression, family cohesion, and social support on parental behavioral control; parenting stress mediated the influence of parental depression,	0.91

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								family cohesion, and social support on parental psychological control; parenting stress mediated the influence of emotion-focused coping behaviors on supportive parenting	
Rodenburg et al., 2013	The Netherlands	Quantitative	Cross-sectional	Epilepsy	73 parents of children with epilepsy (65 mothers, 8 fathers)	8.7, 2.5 (4-18)	Limit-Setting Scale, A-PARI	The influence of indulgent parenting on restrictions in daily life/activities on children with epilepsy was moderated by controlling parenting	0.62
Raj et al., 2014	USA	Quantitative	Cross-sectional	TBI	46 children with severe TBI and caregivers; 71 children with complicated mild/moderate TBI and caregivers	14.47, 1.72 (12-17)	Observational	Caregiver negatively and warmth were positively and negatively associated with child externalizing behaviors, respectively	0.84
Root et al., 2016	USA	Quantitative	Longitudinal	TBI	67 youth with TBI and mothers; 93 socially-typical controls and mothers	TBI: 10.36, 1.49 (8-13) Controls: 10.35, 0.52 (9-12)	CRPR-Q	Mothers of children with TBI reported more restrictiveness and less nurturance than the control group; maternal nurturance moderated the relation between injury group and peer rejection, such that children with TBI were more rejected by classmates compared to controls at low levels of maternal nurturance	0.80

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Schellinger et al., 2012	USA	Quantitative	Longitudinal	Spina Bifida	68 youth with spina bifida, 68 mothers; 68 matched healthy controls, 68 mothers	Spina Bifida: 8.34 (8-9) Controls: 8.49 (8-9)	CRPBI	Low maternal acceptance, as well as high behavioral and psychological control, were risk factors for child depressive symptoms at several time points	0.82
Schorr et al., 2020	USA	Quantitative	Longitudinal	TBI	15 youth with severe TBI and caregivers; 40 youth with Complicated mild/moderate TBI; 71 orthopedic injury controls and caregivers	Severe TBI: 5.12, 0.97 (3-6)[a] Complicated Mild/ Moderate TBI: 5.21, 1.21 (3-6) Controls: 5.07, 1.06 (3-6)	PPQ	Late parenting styles (not early) predicted outcomes across all groups, such that more permissive parenting predicted worse behavioral adjustment, executive functioning, and social competence, and more authoritative parenting predicted better social competence and executive functioning; severe TBI interacted with parenting style for several outcomes, with ineffective parenting exacerbating the negative effects of TBI.	0.77
Shapiro et al., 2014	USA	Quantitative	Cross-sectional	Cerebral Palsy, Spina Bifida	49 youth with a neuro-developmental condition (cerebral palsy = 41, spina bifida = 8) and parents; 60 typically developing	Neuro-developmental Condition: Males = 9.41, 1.74; Females = 8.28, 1.20 Controls: Males = 8.80, 1.73; Females = 9.03, 1.75	PDI	Two-way interaction was found between diagnosis and sex when predicting parental nurturance, such that parents of typically developing children reported more nurturing parenting behaviors toward girls than boys, but this pattern was	0.56

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					controls and parents	Total: 8.95, 1.88 (6-12)		absent for parents of children with a neurodevelopmental condition	
Smith-Paine et al., 2018	USA	Quantitative	Longitudinal	TBI	75 youth with TBI and caregivers; 70 orthopedic injury controls and caregivers	TBI: 5.21, 1.09[a] (3-7) Controls: 5.07, 1.08 (3-7)	PPQ	Significant 3-way interaction was found between genotype x permissive parenting x injury, such that children with TBI who were carriers of the risk allele (T-allele) demonstrated poorer executive functioning than non-carrier controls only in the presence of high levels of permissive parenting; significant 2-way interaction was found between genotype x authoritarian parenting, such that carriers of the risk allele demonstrated poorer executive functioning than non-carriers only in the presence of low levels of authoritarian parenting	0.73
Stern et al., 2020	USA	Quantitative	Longitudinal	Spina Bifida	89 youth with spina bifida, 86 mothers, 79 fathers	11.10, 2.44 (8-15)	Observational	Two-way interactions between planning/organizing skills and paternal acceptance, and planning/organizing skills and paternal psychological control, were found when predicting youth	0.95

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								responsibility for medical tasks; a three-way interaction between cognitive shifting skills, maternal acceptance, and child age was found	
Treble-Barna et al., 2016a	USA	Quantitative	Longitudinal	TBI	65 youth with TBI and caregivers; 70 orthopedic injury controls and caregivers	TBI: (3-7) Controls: (3-7)	PPQ	In the context of low authoritarianism, children with TBI who were carriers of the APOE e4 allele showed poorer adaptive functioning relative to non-carriers with TBI and children with OI; at high levels of authoritarianism, non-carriers with TBI showed the poorest adaptive functioning across groups	0.77
Treble-Barna et al., 2016b	USA	Quantitative	Longitudinal	TBI	20 children with severe TBI and caregivers; 52 children with moderate TBI and caregivers; 95 orthopedic injury controls and caregivers	Severe TBI: 4.98, .94 (36 to 84 months) Moderate TBI: 4.97, 1.20 (36 to 84 months) Controls: 5.08, 1.08 (36 to 84 months)	Observational	During the first year postinjury, the effect of TBI on behavior was exacerbated by less adaptive parenting behaviors and buffered by more adaptive parenting behaviors for children with severe TBI; by 18 months postinjury, the moderating effect of parent behaviors diminished, such that children with severe TBI demonstrated more behavior problems than children with moderate	0.82

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								TBI and controls regardless of parent behaviors or in the presence of parent behaviors that were originally protective	
Wade et al., 2008	USA	Quantitative	Cross-sectional	TBI	80 youth with TBI and caregivers; 113 orthopedic injury controls and caregivers	Severe TBI: 4.74, 0.88 Moderate TBI: 5.22, 1.17 Complicated Mild TBI: 4.89, 1.24 Controls: 5.14, 1.07	Observational	Caregivers of children with TBI exhibited less warm responsiveness and more directive statements than controls; child behavior mediated group differences in parental responsiveness and directiveness; child cooperativeness was associated with parental warm responsiveness in the control group, but not the TBI groups	0.81
Wade et al., 2011	USA	Quantitative	Longitudinal	TBI	19 children with severe TBI and caregivers; 51 children with moderate TBI and caregivers; 109 orthopedic injury controls and caregivers	Severe TBI: 5.18, 0.99 (3-7)[a] Moderate TBI: 4.87, 1.23 (3-7) Controls: 5.04, 1.10 (3-7)	Observational	Among children with severe TBI, parental warm responsiveness and negativity were associated with child externalizing behaviors and attention-deficit/ hyperactivity disorder symptoms; warm responsiveness was also associated with internalizing symptoms	0.91
Wade et al., 2016	USA	Quantitative	Cross-sectional	TBI	16 children with severe TBI and caregivers; 14 children with moderate TBI and caregivers;	Severe TBI: 11.72 (11.03 to 12.80)[b] Moderate TBI: 12.21 (11.68 to 12.55)	PPQ	Functional impairments were greater among children with any TBI compared to controls at high levels of authoritarian parenting; functional impairments	0.84

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					28 children with complicated mild TBI; 72 orthopedic injury controls and caregivers	Mild Complicated TBI: 11.97 (10.71 to 12.80) Controls: 11.72 (11.23 to 12.28)		were greater among children with complicated mild and severe TBI compared to controls at high permissive parenting levels, but greater for children with moderate TBI compared to controls at low levels of permissive parenting	
Wade et al., 2017	USA	Quantitative	Longitudinal	TBI	36 children and parents in abbreviated parent training (Express) group; 39 children and parents in Internet-based Interacting Together Everyday: Recovery After Childhood TBI (I-InTERACT) group; 38 children and parents in internet resources comparison (IRC) group	5.4, 2.2 (3-9)	Observational	The two parenting skill groups, Express and I-InTERACT, demonstrated increases in positive parenting behaviors and decreases in negative parenting behaviors over time; moderated mediation models indicated that changes in parenting skills mediated improvements in behavior in children with higher baseline symptoms	0.77
Whittingham et al., 2014	Australia	Quantitative	Longitudinal	Cerebral Palsy	22 parents in waitlist control group; 22 in SSTP group;	Waitlist Control: 4.96, 2.95 (2-12)	PS	The three groups showed differences in dysfunctional parenting styles postintervention, such that SSTP with	0.91

Lead Author	**Country**	**Type of Study**	**Study Design**	**Specific Condition(s)**	***N***	**Youth Age *M*, *SD* (Range)**	**Parenting Measure**	**Main Parenting Findings**	**Quality Assessment Rating**
					23 in SSTP + ACT group	SSTP: 5.45, 3.16 (2-12) SSTP + ACT: 5.52, 3.17 (2-12)		ACT was associated with decreased parental overreactivity and verbosity	
Whittingham et al., 2019	Australia	Quantitative	Cross-sectional	Cerebral Palsy	22 parents in waitlist control group; 22 in SSTP group; 23 in SSTP + ACT group	Waitlist Control: 4.96, 2.95 (2-12) SSTP: 5.45, 3.16 (2-12) SSTP + ACT: 5.52, 3.17 (2-12)	PS	No significant indirect effects of the intervention on child behavior and adjustment via parenting style; Indirect effect of SSTP with ACT on parental overreactivity via psychological flexibility	0.74
Wiley & Renk, 2007	USA	Quantitative	Cross-sectional	Cerebral Palsy	31 caregivers of children with cerebral palsy (24 mothers, 6 fathers, and 1 grandfather)	6.4, 3.7 (1-15)	PAQ, PCRI	Authoritarian and authoritative parenting styles were negatively associated with child internalizing problems; Authoritative parenting style was negatively associated with externalizing problems	0.78
Winning et al., 2020	USA	Quantitative	Cross-sectional	Spina Bifida	137 youth with spina bifida, 134 mothers, and 106 fathers	11.41, 2.45 (8-15)	CRPBI, Observational	Observational scaffolding measure demonstrated acceptable psychometric properties; maternal scaffolding was positively associated with IQ, academic competence, academic independence, and social self-control in	0.89

Lead Author	**Country**	**Type of Study**	**Study Design**	**Specific Condition(s)**	***N***	**Youth Age *M, SD* (Range)**	**Parenting Measure**	**Main Parenting Findings**	**Quality Assessment Rating**
								youth with SB; paternal scaffolding was positively associated with social cooperation and social self-control; differences in scaffolding emerged between mothers and fathers, as well as across demographic variables	
Yeates et al., 2010	USA	Quantitative	Longitudinal	TBI	19 youth with severe TBI youth and caregivers; 56 youth with complicated-mild/moderate TBI and caregivers; 99 orthopedic injury controls and caregivers	Severe TBI: 4.96, 1.00 (3-6) Complicated-Mild/ Moderate TBI: 5.04, 1.20 (3-6) Controls: 5.11, 1.07 (3-6)	PPQ	Group differences in behavioral adjustment became more pronounced over time at high levels of authoritarian and permissive parenting; however, the severe TBI group showed increases in behavioral problems over time even at lower levels of permissive parenting	0.91
Zukerman et al., 2011	USA	Quantitative	Longitudinal	Spina Bifida	68 children with spina bifida and parents; 68 typically developing controls and parents	Spina Bifida: (8-9) Controls: (8-9)	Observational	Higher levels of maternal intrusiveness in the spina bifida sample; Greater maternal intrusiveness decreased the odds of ever experiencing a romantic relationship during emerging adulthood across both groups	0.64

Note. Youth age is provided for the baseline time point (if longitudinal) and in years, unless otherwise indicated. For studies that included children with multiple types of diagnoses (e.g., Down syndrome), only the CNS-related condition and control groups are described in the table, except for TBI (those with an orthopedic injury are the control group often used to evaluate the consequences of

TBI). ACT = Acceptance and Commitment Therapy; A-PARI = Amsterdam version of the Parental Attitude Research Instrument; ASD = Autism Spectrum Disorder; BMPS = Bangor Mindful Parenting Scale; CRPBI = Children's Report of Parental Behavior Inventory; CR-Q = Child-Rearing Questionnaire; CRPR-Q = Child-Rearing Practices Report Questionnaire; IQ = Intelligence Quotient; QOL = Quality of Life; TBI = Traumatic Brain Injury; MCRE = Mother-Child Relationship Evaluation; PAQ = Parental Authority Questionnaire; PARI = Parental Attitude Research Instrument; PBI = Parental Bonding Instrument; PBS = Parental Behavior Scale; PCIQ-R = Parent Child Interaction Questionnaire – Revised; PCRI = Parent–Child Relationship Inventory; PCS = Psychological Control Scale; PDI = Parenting Dimensions Inventory; POPS = Perceptions of Parents Scale; PPQ = Parenting Practices Questionnaire; PPS = Parent Protection Scale; PS = Parenting Scale; PSDQ = Parenting Styles and Dimensions Questionnaire; SSTP = Stepping Stones Triple P.

[a] The ages reported for all groups represent age at injury

[b] The ages reported for all groups represent the median age and interquartile range

[d] The group of mothers with children with cerebral palsy were compared to mothers of children with four other conditions (i.e., blind, deaf, Down syndrome, "organic")

[e] The group of children with cerebral palsy and their parents were compared to families of children in three other groups (ASD, Down syndrome, without known disability)

[f] The group of children with spina bifida and caregivers were also compared to those with diabetes

CHAPTER FIVE

DISCUSSION

As depicted in the bio-neuropsychosocial model of adjustment (Holmbeck & Devine, 2010), evidence suggests that parenting plays an important role in the adjustment of children with SB. Indeed, adaptive parenting practices (e.g., warmth/acceptance, enforcement of age-appropriate rules) have been linked to better emotional and behavioral outcomes in this population (Holmbeck & Devine, 2010; Holmbeck et al., 2002). Yet, several fundamental gaps remain in the parenting literature, including the need for (1) more evidence-based assessments that capture parenting in SB, (2) additional research focused on early childhood in SB, as this is a critical developmental period that has been understudied, and (3) systematic reviews that synthesize findings across CNS-related conditions to provide direction for future research. The current set of studies sought to start addressing these gaps, with the hope that findings will ultimately guide the development of family-based interventions to improve the wellbeing of children with SB and their families.

The ***first study***, “Development of an Observational Parental Scaffolding Measure for Youth with Spina Bifida,” published in the *Journal of Pediatric Psychology*, developed and validated a novel observational measure of parental scaffolding (i.e., a process whereby support and structure is provided to enhance task performance) specifically for youth with SB (Winning et al., 2020). This measure was created using an existing observational coding system that has demonstrated acceptable psychometric properties when used with children who have a variety of chronic health conditions, including SB (i.e., FIMS; Holmbeck et al., 2007; Kaugars et al., 2010). Findings from this first study provided preliminary psychometric support for the scaffolding measure. The measure not only demonstrated adequate reliability and internal consistency, but also convergent validity – such that associations with a psychometrically sound questionnaire (i.e., the CRPBI-P) were in the expected directions and modest, indicating that parental scaffolding is its own distinct parenting construct. Additionally, associations were found between parental scaffolding and child outcomes, with greater parental scaffolding associated with increased academic competence, academic independence, and social skills (i.e., cooperation, self-control). Regarding demographic characteristics, there were differences in scaffolding across racial/ethnic groups; also, SES was positively associated with both maternal and paternal scaffolding, whereas child IQ was positively associated with maternal scaffolding.

The ***second study***, “Parenting and Psychosocial Adjustment in Families of Young Children with Spina Bifida,” extended past research with school-aged children with SB by focusing on the parenting experiences and needs of families in early childhood (i.e., ages 3-7). Parents in this study endorsed a number of unmet needs, with one of the most common unmet needs relating to opportunities for their child to receive individual therapy with a trained mental health professional. Notably, approximately a quarter of young children with SB were found to have clinically significant elevations in internalizing problems and on the behavior symptoms index. Two-way interactions between SB severity and authoritarian parenting were found to contribute to these outcomes, such that greater SB severity was associated with more internalizing problems only at high levels of authoritarian parenting, and more behavior symptoms only at moderate and high levels of authoritarian parenting. Qualitative data provided deeper insights into the challenges associated with parenting a young child with SB, including difficulties with time management, discrimination, social isolation of the child with SB, parent distress, and limited knowledge of effective parenting strategies. Finally, lower income families were found to be at risk for poorer outcomes, such that lower family income was linked to worse child emotional and behavioral problems, as well as greater parenting stress.

Finally, the ***third study***, "Parenting in Children with CNS-Related Chronic Health Conditions: A Systematic Review," synthesized results from 68 articles examining parenting in families of children with four distinct CNS-related chronic health conditions (i.e., SB, epilepsy, cerebral palsy, TBI). Findings of this review revealed that there was significant variability in the measures used to assess parenting across articles. Additionally, only two articles comprehensively examined the psychometric properties of parenting measures used with CNS populations. Both articles focused on families of children with SB, one of which was Winning et al. (2020; i.e., the first study in this series). When examining links between parenting and child outcomes, results indicated that adaptive parenting styles (e.g., warm responsiveness, scaffolding, authoritative approaches) were often linked to greater cognitive, emotional, and behavioral functioning, whereas the opposite was found for maladaptive parenting styles (e.g., overprotectiveness, psychological control, permissive and authoritarian approaches). Personal characteristics of parents and their children, such as demographic factors, emotional and behavioral adjustment, and coping styles, were also found to correlate directly with the parenting styles that were employed within the home. This review revealed several limitations of the current parenting literature, highlighting a need for greater diversity within study samples, as well as more research examining parenting in early childhood (for SB and epilepsy) and developing evidence-based parenting interventions.

Several conclusions can be drawn from this series of studies. First, across studies, there was evidence that parenting may not only be directly associated with child outcomes, but also moderate the effects of neurological risk. For instance, the first study demonstrated links between parental scaffolding and child academic and social outcomes. This aligns with the larger scaffolding literature, which suggests that scaffolding from parents may positively influence cognitive, emotional, behavioral, and academic outcomes in children (Baker et al., 2007; Bibok et al., 2009; Hammond et al., 2012; Mattanah et al., 2005; Neitzel & Stright, 2003; Norona & Baker, 2014; Gerrard-Morris et al., 2010). Given that these are areas in which children with SB often experience difficulties, parental scaffolding may be an important parenting practice to support children with this condition throughout development. In the second study, interactions between SB severity and authoritarian parenting highlighted how maladaptive parenting practices may compound the effects of SB sequelae, thereby negatively affecting child emotional and behavioral functioning. Similar interaction patterns were found in the third study, which revealed that parenting also interacts with injury severity in the context of pediatric TBI when contributing to child outcomes (e.g., Wade et al., 2011). Taken together, these results provide support that children who sustain a more severe insult to the CNS may have increased vulnerability and sensitivity to parenting practices used within the home.

Findings also highlight how the family system does not exist within a vacuum and must be considered within the broader social context. Across studies, results revealed that having access to fewer financial resources was linked to greater parenting stress, less parental scaffolding, and worse child outcomes. This corresponds with research suggesting that lower family income may limit access to important resources that support children's cognitive, social, emotional, and physical wellbeing (Conger & Donnellan, 2007), as well as result in parents feeling more overwhelmed in their parenting role (Holmbeck & Devine, 2010). Financial hardship may also have downstream effects on parents' ability to muster the internal resources needed to engage in effective parenting practices (Hoff & Laursen, 2019).

Notably, there were mixed findings across studies regarding differences in parenting based on ethnic or cultural background. This is consistent with evidence in the broader general child literature suggesting that there are both similarities and differences in the parenting styles employed across development in families from various national, ethnic, and regional groups (Lansford et al., 2021). When interpreting this data, it is crucial to consider that existing parenting measures – including our novel measure of parental scaffolding – may not fully capture the strengths of families from diverse cultural backgrounds. For instance, some have argued that the interaction patterns often considered characteristic of 'scaffolding' may be culturally rooted and typical to Western families (e.g., adults providing explicit instruction; Mermelshtine, 2017). Therefore, scaffolding measures may fail to recognize the ways in which parent-child learning occurs in families from diverse cultural backgrounds. Barbara Rogoff's work (e.g., Rogoff, 2014) highlights how a more fluid definition of scaffolding, such as 'guided participation,' may be a more culturally responsive way to conceptualize these types of parent-child interactions (Mermelshtine, 2017). As researchers, it is crucial that we ensure our tools that assess parenting capture the strengths and perspectives of *all* families, not just those from Western societies.

Moreover, both the first and third study suggest that more research is needed to evaluate the psychometric properties of parenting measures used with CNS populations. While the first study in this series systematically examined the reliability and validity of a parental scaffolding measure (Winning et al., 2020), the third study revealed that only one other article has focused on this area to date (Kaugars et al., 2010). There have been calls within the broader field of pediatric psychology to attend to the psychometric properties of measures that assess the family environment, such as parenting, to ensure that measures are accurate and stable when used with families of children with a medical condition (Alderfer et al., 2008). Additionally, there is a need to develop clinical cutoffs and/or a standardized approach for interpreting scores on these parenting measures (Alderfer et al., 2008). Approaching this process thoughtfully is likely particularly important for families of children with CNS-related conditions given the level of cognitive vulnerability. Indeed, higher levels of certain parenting styles that are considered maladaptive in the general population (e.g., increased rigidity and structure), may be adaptive when supporting a child with cognitive challenges in managing a complex medical condition, such as SB.

Findings from the first study in this series revealed promising psychometric properties for a novel scaffolding measure developed for families of children who have SB (Winning et al., 2020). However, additional research is needed to further establish the reliability, validity, and utility of this measure. Differences in scaffolding and its associations between mothers and fathers highlights the importance of considering how scaffolding may look different – but be just as impactful – across various types of caregivers. Additionally, the parental scaffolding measure was not associated with child age, which was somewhat unexpected and contrasts with research focused on typically developing children (Mermelshtine, 2017). As children grow and develop, their ability to manage more complex tasks autonomously often increases; therefore, we might expect that the scaffolding parents provide evolves and/or lessens over time. In support of this idea, longitudinal scaffolding research in the general population has found that mothers tend to use less explicit instruction and more contingent responding (i.e., appropriately shift their level of intervention following the success or failure of the child) as children age (Conner & Cross, 2003).

That said, examining parental scaffolding in families of children with SB is challenging, given heterogeneity in the clinical presentation of this condition (Copp et al., 2015). Some children with SB demonstrate developmental delays, whereas others do not (Copp et al., 2015). Therefore, parental scaffolding may present differently in families of children with SB compared to those with a typically developing child, with parents tailoring their interactions to meet their child's own personal needs. Indeed, parental scaffolding was found to be positively associated with child IQ in the first study, suggesting that parents may have adjusted their scaffolding to be sensitive to their child's level of understanding. This aligns with research in other conditions in which there is neurological vulnerability, with one study finding that mothers used more complex scaffolding with children who were born full term compared to those born preterm (Lowe et al., 2013). Future research could further tease apart the nature and influence of scaffolding across the developmental continuum in SB, including early childhood. Scaffolding could not only be examined on a broad level, as it was in the first study, but also in a more nuanced manner to capture how often parents are intervening at the appropriate time (e.g., providing appropriate direction following a success or failure; Conner & Cross, 2003). In addition to emotional and behavioral functioning, associations between parental scaffolding and child medical outcomes (e.g., adherence, responsibility) could be examined to determine whether this parenting strategy can be leveraged to support medical autonomy and the transition into adulthood in adolescents and young adults with SB—another area in which youth experience difficulty (Psihogios et al., 2015).

Another conclusion that can be gleaned from this series of studies is the importance of additional parenting research focused on young children with SB. Study two showed that parents of young children with SB (ages 3-7) were already endorsing significant concerns regarding their child's emotional and behavioral functioning, as well as parenting challenges. Moreover, the third study revealed that only three articles had examined parenting in children ≤ 6 years old in the context of SB (out of 16 total articles), whereas there were over three times the number of articles focused on this age group in the cerebral palsy and TBI literature. Findings within TBI indicated that parenting may have unique effects when children are young and these effects may change over time (Treble-Barna et al., 2016). Indeed, Treble-Barna et al. (2016) speculated that, while scaffolding from parents may be effective when children are younger and/or first sustain a TBI, it may become less effective over time as the child ages and recovers. SB is distinct from TBI in that disruption of the CNS is present from birth, rather than following an acute injury, and neurological effects are enduring and may even worsen over time (Bowman et al., 2001). Therefore, the interplay between neurological and environmental factors, as well as how they affect child functioning across development, may be different for the SB population.

Strengths and Limitations

The current series of studies have several strengths, including creation of a new scaffolding measure that can be used in the context of SB (study one), examination of an understudied developmental period in SB (study two), and a comprehensive systematic review of parenting in CNS-related conditions that can serve as a resource for all clinicians and researchers working with families of these children (study three). Additional strengths include the use of well-validated measures (studies one and two), as well as the use of multiple informants (study one) and methods (studies one and two). Although the second study sought to recruit a national sample, which was a strength, participation from Hispanic/Latino families was limited. Given that there is a higher rate of SB in this population (Copp et al., 2015), this may reduce the generalizability of our findings. Future work focused on early childhood could use purposive sampling strategies and offer measures in both English and Spanish to ensure that these families are well-represented in samples. On a broader level, continued research with more diverse samples is needed to increase inclusivity within our family systems approach and better understand how parenting may differ across social contexts (e.g., cultural beliefs), varied family structures (e.g., same-sex parents, divorced parents, single parents), and types of caregivers (e.g., fathers, extended family members). A final limitation was the use of a narrative approach for the systematic review (third study), which was necessary due to variability in the measures, methodologies, and age ranges of included studies, but may have introduced bias into the review process.

Clinical Implications and Conclusions

Findings across studies point to parenting as a promising avenue for intervention. Parenting skill programs in other neurological (e.g., TBI) and at-risk populations have led to improvements in parenting skills (Landry et al., 2008; Landry et al., 2012), parent distress (Raj et al., 2015), and child outcomes (Landry et al., 2017; Landry et al., 2021; Wade et al., 2017). Such interventions could be adapted for families of children with SB to support families in early childhood when parenting may be particularly influential (Arranz et al., 2010; Black et al., 2017). Helping parents to incorporate positive parenting strategies (e.g., warmth, responsiveness, scaffolding) during this period of development may have lasting effects and improve the trajectory of children's psychosocial symptom profile over time. Additionally, results from these studies indicated that families with less financial resources may benefit most from psychosocial interventions. In fact, web-based interventions targeting parenting skills and caregiver stress management have been found to have the most robust effects on lower-income parents (Raj et al., 2015), suggesting that this may be a useful tool to reduce disparities in families of children with SB.

Overall, this research demonstrated the influential role of social-environmental factors in adjustment among children with conditions that affect the CNS. Psychosocial interventions that teach parents effective parenting and stress management skills may help promote the best outcomes for these children and their families, particularly those with limited access to financial resources. However, more research is needed to ensure that parenting measures are valid, reliable, and sensitive to treatment effects when used with CNS populations. In the context of

SB, in particular, interventions created with other CNS populations could be adapted to better meet the needs of these families and promote well-being across the developmental continuum.

APPENDIX A

MEASURES

Questionnaire Measures (Alphabetized):

Behavior Assessment System for Children, Third Edition (BASC-3)

Child Behavior Questionnaire (CBQ)

Child’s Report of Parent Behavior Inventory (CRPBI-P)

Parenting Practices Questionnaire (PPQ)

Parent/Teacher Rating Scale of Child’s Actual Behavior (PRSCAB/TRSCAB)

Parenting Stress Index, Fourth Edition Short Form (PSI-4-SF)

Social and Community Support Questionnaire (SCSQ)

Social Skills Rating System (SSRS)

Teacher Report Form (TRF)

Observational Measures:

Family Interaction Macro-coding System (FIMS)

APPENDIX B

SEARCH STRING

Table with Final Search Terms

"Parenting/psychology"[MeSH] OR "Parent-Child Relations/psychology"[Mesh] OR parent behavior* OR parent behaviour* OR parent bond* OR parent involvement OR parent interaction* OR parent training OR parents behavior* OR parents behaviour* OR parents involvement OR parents interaction* OR parents training OR parenting approach* OR parenting behavior* OR parenting behaviour* OR parenting effectiveness OR parenting interaction* OR parenting involvement OR parenting intervention* OR parenting overprotect* OR parenting practice* OR parenting program* OR parenting respons* OR parenting skill* OR parenting style* OR parenting training OR parental involvement OR parental process* OR parental care OR parental bond* OR parental behavior* OR parental behaviour* OR "Parental demandingness" OR parental effectiveness OR parental interaction* OR parent-child interaction* OR child-parent interaction* OR mother-child interaction*	"Brain Diseases"[Mesh] OR "Central Nervous System Neoplasms"[Mesh] OR "Craniocerebral Trauma"[Mesh] OR "Nervous System Diseases"[Mesh] OR "Neural Tube Defects"[Mesh] OR "Seizures"[Mesh] OR "central nervous system" OR brain cancer* OR brain disease* OR brain metastases OR brain neoplasm* OR brain tumor* OR brain damage OR brain injur* OR head injur* OR cancer of the brain OR cerebral palsy OR craniocerebral trauma OR epilep* OR “neural tube defects” OR seizure* OR Spina bifida

OR child-mother interaction* OR father-child interaction* OR parent-infant interaction* OR infant-parent interaction* OR mother-infant interaction* OR infant-mother interaction* OR father-infant interaction* OR child rearing OR raising children OR effective parenting OR positive parenting OR dysfunctional parenting OR negative parenting OR "parenting children"	

PubMed: 1,689

((Parenting/psychology[MeSH] OR Parent-Child Relations/psychology[Mesh] OR parent behavior*[Title/Abstract] OR parent behaviour*[Title/Abstract] OR parent bond*[Title/Abstract] OR parent involvement[Title/Abstract] OR parent interaction*[Title/Abstract] OR parent training[Title/Abstract] OR parents behavior* [Title/Abstract] OR parents behaviour*[Title/Abstract] OR parents involvement[Title/Abstract] OR parent* interaction*[Title/Abstract] OR parents training [Title/Abstract] OR parenting approach*[Title/Abstract] OR parenting behavior* [Title/Abstract] OR parenting behaviour*[Title/Abstract] OR parenting effectiveness[Title/Abstract] OR parenting interaction*[Title/Abstract] OR parenting involvement[Title/Abstract] OR parenting intervention* [Title/Abstract] OR parenting overprotectedness[Title/Abstract] OR parenting practice*[Title/Abstract] OR parenting program*[Title/Abstract] OR parenting respons*[Title/Abstract] OR parenting skill*[Title/Abstract] OR parenting style*[Title/Abstract] OR parenting training [Title/Abstract] OR parental involvement[Title/Abstract] OR parental process*[Title/Abstract] OR parental care[Title/Abstract] OR parental bond*[Title/Abstract] OR parental behavior*[Title/Abstract] OR parental behaviour*[Title/Abstract] OR Parental demandingness[Title/Abstract] OR parental effectiveness[Title/Abstract] OR parental interaction*[Title/Abstract] OR parental overprotection[Title/Abstract] OR maternal overprotection[Title/Abstract] OR parent-child interaction*[Title/Abstract] OR child-parent interaction*[Title/Abstract] OR mother-child interaction*[Title/Abstract] OR child-mother interaction*[Title/Abstract] OR father-child interaction*[Title/Abstract] OR parent-infant interaction*[Title/Abstract] OR infant-parent interaction*[Title/Abstract] OR mother-infant interaction*[Title/Abstract] OR infant-mother interaction*[Title/Abstract] OR father-infant interaction* OR child rearing[Title/Abstract] OR raising children[Title/Abstract] OR effective parenting[Title/Abstract] OR positive parenting[Title/Abstract] OR dysfunctional parenting[Title/Abstract] OR negative parenting[Title/Abstract] OR parenting children[Title/Abstract]))

AND ((Brain Diseases[Mesh] OR Central Nervous System Neoplasms[Mesh] OR Craniocerebral Trauma[Mesh] OR Nervous System Diseases[Mesh] OR Neural Tube Defects[Mesh] OR Seizures[Mesh]) OR (central nervous system[Title/Abstract] OR brain cancer*[Title/Abstract] OR brain disease*[Title/Abstract] OR brain metastases[Title/Abstract] OR brain neoplasm*[Title/Abstract] OR brain tumor*[Title/Abstract] OR brain damage[Title/Abstract] OR brain injur*[Title/Abstract] OR head injur*[Title/Abstract] OR cancer of the brain[Title/Abstract] OR cerebral palsy[Title/Abstract] OR craniocerebral trauma[Title/Abstract] OR epilep*[Title/Abstract] OR neural tube defects[Title/Abstract] OR seizure*[Title/Abstract] OR Spina bifida[Title/Abstract]))

Scopus: 337

(Title-Abs ({parent behavior} OR {parent behaviors} OR {parent behavioral} OR {parent behaviour} OR {parent behaviours} OR {parent behavioural} OR {parent bond} OR {parent bonds} OR {parent involvement} OR {parent interaction} OR {parent interactions} OR {parent training} OR {parents behavior} OR {parents behaviors} OR {parents behavioral} OR {parents behaviour} OR {parents behaviours} OR {parents behavioural} OR {parents involvement} OR {parents interaction} OR {parents interactions} OR {parents training} OR {parenting approach} OR {parenting approaches} OR {parenting behavior} OR {parenting behaviors} OR {parenting behavioral} OR {parenting behaviour} OR {parenting behaviours} OR {parenting behavioural} OR {parenting effectiveness} OR {parenting interaction} OR {parenting interactions} OR {parenting involvement} OR {parenting intervention} OR {parenting interventions} OR {parenting overprotectiveness} OR {parenting practice} OR {parenting practices}
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AND (TITLE-ABS ({central nervous system} OR {brain cancer} OR {brain cancers} OR {brain disease} OR {brain diseases} OR {brain metastases} OR {brain neoplasm} OR {brain neoplasms} OR {brain tumor} OR {brain tumors} OR {brain damage} OR {brain injury} OR {brain injuries} OR {head injury} OR {head injuries} OR {cancer of the brain} OR {cancers of the brain} OR {cerebral palsy} OR {craniocerebral trauma} OR epilep* OR {neural tube defects} OR seizure* OR {spina bifida}))

CINAHL: 404
Cochrane Central Register of Controlled Trials: 95
Cochrane Database of Systematic Reviews: 3

((((MH "Parenting") OR (MH "Parental Behavior") OR (MH "Parent-Child Relations"))
OR TI (“parent behavior*” OR “parent behaviour*” OR “parent bond*” OR “parent involvement” OR “parent interaction*” OR “parent training” OR “parents behavior*” OR “parents behaviour*” OR “parents involvement” OR “parents interaction*” OR “parents training” OR “parenting approach*” OR “parenting behavior*” OR “parenting behaviour*” OR “parenting effectiveness” OR “parenting interaction*” OR “parenting involvement” OR “parenting intervention*” OR “parenting overprotect*” OR “parenting practice*” OR “parenting program*” OR “parenting respons*” OR “parenting skill*” OR “parenting style*” OR “parenting training” OR “parental involvement” OR “parental process*” OR “parental care” OR “parental bond*” OR “parental behavior*” OR “parental behaviour*” OR “Parental demandingness“ OR “parental effectiveness” OR “parental interaction*” OR “parent-child interaction*” OR “child-parent interaction*” OR “mother-child interaction*” OR “child-mother interaction*” OR “father-child interaction*” OR “parent-infant interaction*” OR “infant-parent interaction*” OR “mother-infant interaction*” OR “infant-mother interaction*” OR “father-infant interaction*” OR “child rearing” OR “raising children” OR “effective parenting” OR “positive parenting” OR “dysfunctional parenting” OR “negative parenting” OR "parenting children")
OR AB (“parent behavior*” OR “parent behaviour*” OR “parent bond*” OR “parent involvement” OR “parent interaction*” OR “parent training” OR “parents behavior*” OR

“parents behaviour*” OR “parents involvement” OR “parents interaction*” OR “parents training” OR “parenting approach*” OR “parenting behavior*” OR “parenting behaviour*” OR “parenting effectiveness” OR “parenting interaction*” OR “parenting involvement” OR “parenting intervention*” OR “parenting overprotect*” OR “parenting practice*” OR “parenting program*” OR “parenting respons*” OR “parenting skill*” OR “parenting style*” OR “parenting training” OR “parental involvement” OR “parental process*” OR “parental care” OR “parental bond*” OR “parental behavior*” OR “parental behaviour*” OR "Parental demandingness" OR “parental effectiveness” OR “parental interaction*” OR “parent-child interaction*” OR “child-parent interaction*” OR “mother-child interaction*” OR “child-mother interaction*” OR “father-child interaction*” OR “parent-infant interaction*” OR “infant-parent interaction*” OR “mother-infant interaction*” OR “infant-mother interaction*” OR “father-infant interaction*” OR “child rearing” OR “raising children” OR “effective parenting” OR “positive parenting” OR “dysfunctional parenting” OR “negative parenting” OR "parenting children"))

AND ((((MH "Brain Diseases")” OR “(MH "Brain Neoplasms")” OR “(MH "Brain Injuries")” OR “(MH "Nervous System Diseases")” OR “(MH "Neural Tube Defects")” OR “(MH "Seizures"))
OR TI ("central nervous system" OR “brain cancer*” OR “brain disease*” OR “brain metastases” OR “brain neoplasm*” OR “brain tumor*” OR “brain damage” OR “brain injur*” OR “head injur*” OR “cancer of the brain” OR “cerebral palsy” OR “craniocerebral trauma” OR “epilep*” OR “neural tube defects” OR “seizure*” OR “Spina bifida”)
OR AB ("central nervous system" OR “brain cancer*” OR “brain disease*” OR “brain metastases” OR “brain neoplasm*” OR “brain tumor*” OR “brain damage” OR “brain injur*” OR “head injur*” OR “cancer of the brain” OR “cerebral palsy” OR “craniocerebral trauma” OR “epilep*” OR “neural tube defects” OR “seizure*” OR “Spina bifida”)))

PsycINFO: 605

((((MA "Parenting") OR (MA "Parental Behavior") OR (MA "Parent-Child Relations"))
OR TI (“parent behavior*” OR “parent behaviour*” OR “parent bond*” OR “parent involvement” OR “parent interaction*” OR “parent training” OR “parents behavior*” OR “parents behaviour*” OR “parents involvement” OR “parents interaction*” OR “parents training” OR “parenting approach*” OR “parenting behavior*” OR “parenting behaviour*” OR “parenting effectiveness” OR “parenting interaction*” OR “parenting involvement” OR “parenting intervention*” OR “parenting overprotect*” OR “parenting practice*” OR “parenting program*” OR “parenting respons*” OR “parenting skill*” OR “parenting style*” OR “parenting training” OR “parental involvement” OR “parental process*” OR “parental care” OR

“parental bond*” OR “parental behavior*” OR “parental behaviour*” OR “Parental demandingness“ OR “parental effectiveness” OR “parental interaction*” OR “parent-child interaction*” OR “child-parent interaction*” OR “mother-child interaction*” OR “child-mother interaction*” OR “father-child interaction*” OR “parent-infant interaction*” OR “infant-parent interaction*” OR “mother-infant interaction*” OR “infant-mother interaction*” OR “father-infant interaction*” OR “child rearing” OR “raising children” OR “effective parenting” OR “positive parenting” OR “dysfunctional parenting” OR “negative parenting” OR "parenting children")
OR AB (“parent behavior*” OR “parent behaviour*” OR “parent bond*” OR “parent involvement” OR “parent interaction*” OR “parent training” OR “parents behavior*” OR “parents behaviour*” OR “parents involvement” OR “parents interaction*” OR “parents training” OR “parenting approach*” OR “parenting behavior*” OR “parenting behaviour*” OR “parenting effectiveness” OR “parenting interaction*” OR “parenting involvement” OR “parenting intervention*” OR “parenting overprotect*” OR “parenting practice*” OR “parenting program*” OR “parenting respons*” OR “parenting skill*” OR “parenting style*” OR “parenting training” OR “parental involvement” OR “parental process*” OR “parental care” OR “parental bond*” OR “parental behavior*” OR “parental behaviour*” OR "Parental demandingness" OR “parental effectiveness” OR “parental interaction*” OR “parent-child interaction*” OR “child-parent interaction*” OR “mother-child interaction*” OR “child-mother interaction*” OR “father-child interaction*” OR “parent-infant interaction*” OR “infant-parent interaction*” OR “mother-infant interaction*” OR “infant-mother interaction*” OR “father-infant interaction*” OR “child rearing” OR “raising children” OR “effective parenting” OR “positive parenting” OR “dysfunctional parenting” OR “negative parenting” OR "parenting children"))

AND ((((MA "Brain Diseases")” OR “(MA "Brain Neoplasms")” OR “(MA "Brain Injuries")” OR “(MA "Nervous System Diseases")” OR “(MA "Neural Tube Defects")” OR “(MA "Seizures"))
OR TI ("central nervous system" OR “brain cancer*” OR “brain disease*” OR “brain metastases” OR “brain neoplasm*” OR “brain tumor*” OR “brain damage” OR “brain injur*” OR “head injur*” OR “cancer of the brain” OR “cerebral palsy” OR “craniocerebral trauma” OR “epilep*” OR “neural tube defects” OR “seizure*” OR “Spina bifida”)
OR AB ("central nervous system" OR “brain cancer*” OR “brain disease*” OR “brain metastases” OR “brain neoplasm*” OR “brain tumor*” OR “brain damage” OR “brain injur*” OR “head injur*” OR “cancer of the brain” OR “cerebral palsy” OR “craniocerebral trauma” OR “epilep*” OR “neural tube defects” OR “seizure*” OR “Spina bifida”)))

Google Scholar: top 100, sorted by relevance, citations and patents removed

(Parenting OR mothers OR fathers) AND (behavior OR interactions OR training OR effective) AND (CNS OR "brain tumor" OR "brain injury" OR "brain damage" OR "head injury" OR "cerebral palsy" OR seizure OR "spina bifida")

APPENDIX C

QUALITY ASSESSMENT TOOL AND NOTES

Quality Assessment Tool and Notes

Item	Description	Percentage Agreement (Both raters agreed yes or no)
1. Are the main outcomes to be measured clearly described in the Introduction or Methods section?	If the main outcome measures are first mentioned in the results section, not the Intro or Methods, the question should be answered NO.	98.5%
2. Is the setting of the study described?	Where did the study take place?	73.5%
3. Is the source of the subjects studied stated?	Where were subjects recruited from?	98.5%
4. Is the distribution of the study population by age described?		63.2%.
5. Is the sample size stated?		100%
6. Are non-participants/subjects lost to follow-up described?	This should be answered N/A if the study is only one timepoint. This should be answered NO if a study does not report the number of participants lost to follow-up. To answer YES, the study should describe characteristics of those participants lost to follow-up, such as differences between those lost to follow-up and those retained.	58.8%
7. Have actual probability values been reported (e.g., 0.035 rather than < 0.05) for the main outcomes except where		85.3%

the probability value is less than 0.001?		
8. Are confidence intervals/standard deviations given?		91.2%
9. Were the subjects asked to participate in the study representative of the entire population from which they were recruited?	The study must identify the source population for patients and describe how the patients were selected. Patients would be representative if they comprised the entire source population, an unselected sample of consecutive patients, or a random sample. In addition, a representative sample should be reflected in the demographic characteristics of the sample. Does the sample's age, gender, race/ethnicity, and socioeconomic status represent the population with this illness?	75.0%
10. Was the participation/follow-up rate > 80%?		48.5%
11. Were the main outcome measures used accurate (valid and reliable)?	For studies where the outcome measures are clearly described, the question should be answered YES. For studies that refer to other work or that demonstrate the outcomes measures are accurate the question should be answered YES.	98.5%

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Chapter Five

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VITA

Dr. Adrien Winning graduated from the Clinical Psychology Ph.D. program at Loyola University Chicago, specializing in children, adolescents, and families. She received her B.S. in Neuroscience and Psychology from The Ohio State University (OSU) in 2015, graduating cum laude. Her interest in pediatric psychology developed while working as a research assistant at Nationwide Children's Hospital studying family adjustment to various pediatric medical conditions (e.g., cancer, neonatal disorders). At Loyola, Dr. Winning has been a member of Dr. Grayson Holmbeck's research lab and has worked on numerous projects examining the interrelationship between neuropsychological, psychosocial, and family functioning in the context of spina bifida. Dr. Winning received her M.A. in Clinical Psychology from Loyola in 2020, with her master's thesis examining the impact of neuropsychological functioning and parental scaffolding on adaptive functioning trajectories in youth with spina bifida. Through these experiences, Dr. Winning has had the immense privilege of sharing her teams' innovative research via the dissemination of multiple presentations and peer-reviewed articles. She has received multiple awards and honors from regional and national organizations including the Society for Pediatric Psychology, Illinois Spina Bifida Association, and Loyola University Chicago. Dr. Winning completed her predoctoral internship in Behavioral Medicine at Cincinnati Children's Hospital Medical Center.