

Adolescents with Spina Bifida and Parents' Perceptions of Engaging in Social Activities

BY

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THESIS

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This thesis is dedicated to my mother, husband, and sons.

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LIST OF ABBREVIATIONS

SB	Spina Bifida
SBA	Spina Bifida Association
IRB	Institutional Review Board
UIC	University of Illinois at Chicago
CNS	Central Nervous System
PI	Primary Investigator
ISBA	Illinois Spina Bifida Association
SBW	Spina Bifida Wisconsin

SUMMARY

The purpose of this study was to better understand adolescents with spina bifida (SB) and their parents' perceptions and expectations of their social functioning. The specific aims were to (a) describe adolescents' and parents' perceptions of facilitators and challenges to social functioning, (b) describe parents' perceptions and expectations of social functioning for their adolescent, and (c) describe adolescents' perceptions of parents' expectations. Holmbeck and Devine's bio-neuropsychosocial model guided this study.

This dissertation includes two manuscripts, an integrative review and report of a qualitative study. The first manuscript is an integrative review about parental expectations and social functioning in children and adolescents with SB. In the second manuscript, adolescents' and parents' perceptions and expectations about social functioning are reported. Moreover, the manuscript focused on adolescent's and parent's perceptions of facilitators and challenges to social functioning. The appendices include the interview guide and sociodemographic questionnaires, for adolescents and parents, and the approval of human subject research from the Institutional Review Board of the University of Illinois at Chicago were obtained.

I. PARENTAL EXPECTATIONS AND SOCIAL FUNCTIONING IN CHILDREN WITH SPINA BIFIDA: AN INTEGRATIVE REVIEW

Background

Spina bifida (SB) is a congenital neural tube defect that affects the spine and can occur anywhere throughout the spinal column (Centers for Disease Control and Prevention [CDC], 2015). The degree of severity of SB and the intensity of the associated physical challenges are determined by the size and location of the opening in the spine and the damage to underlying nerves (CDC, 2015). A range of physical symptoms can be observed in children with SB, including loss of mobility, incontinence, and hydrocephalus (CDC, 2015). Any physical impairments invariably affect other dimensions of the lives of children with SB, such as their psychological, social, and intellectual capacities. In addition, the challenges that children with SB face have long-term implications that contribute to ongoing and increasing impairment of their social functioning in adolescence and beyond (Fischer et al., 2015).

Spina bifida can profoundly affect individuals with the condition and their families and communities. In terms of healthcare costs, a 2013 study of a national inpatient sample in the United States of all ages showed that hospitalizations related to birth defects of the brain and spine, including SB, cost more than \$1.6 billion (Arth et al., 2017). According to Grosse et al. (2016), the estimated lifetime cost of care for a person with SB in the United States was \$791,900, comprising \$513,500 in medical costs, \$63,500 in developmental services and special education costs, and \$214,900 in caregiver time costs.

Social functioning is defined as individuals' interactions with their environment along with their ability to fulfill their roles within that environment (Kelly et al., 2011). For children with SB, social functioning can take the forms of participation in activities at home or at school; engagement in recreational activities; and formation of close relationships with friends, partners,

and family members (Kelly et al., 2011). Social participation is an important determinant of health outcomes and has been associated with quality of life, morbidity, and mortality (Levasseur et al., 2010). Among children with SB, those who experience continence issues (estimates range from 48% to 76% of such children) are at risk of decreased participation in social activities, fewer peer relationships, and reduced self-esteem (Fischer et al., 2015). The severity of incontinence depends on SB severity; more severe cases may lead to more serious neurogenic bladder conditions (Verhoef et al., 2005). Due to their health-related symptoms, children with SB are at risk of having poor social participation (Barf et al., 2009), and SB's effects on the social aspects of their lives may adversely impact their ego and confidence in adolescence (Kelly et al., 2011). In addition, researchers have found that bowel incontinence was associated with lower health-related quality of life in children with SB (Sawin et al., 2007).

In general, research has shown that parents' perceptions and expectations play a critical role in their children's academic success (Yamamoto & Holloway, 2010). When parents held high expectations for the academic performance of their school-age children, those children tended to earn higher grades, achieve higher scores on standardized tests, and persist longer in school compared to those with parents having relatively low expectations (Davis-Kean, 2005; Pearce, 2006; Vartanian et al., 2007). Furthermore, in a study focusing on the relationship between parents' expectations and post-high school outcomes of adolescents with disabilities (graduating with a standard diploma, post-school employment, and enrollment in and completion of postsecondary education), high parental expectations were significantly and positively associated with the adolescents' level of autonomy (Doren et al., 2012).

Parental expectations are defined as parents' "beliefs or judgments...about their children's future achievement" (Yamamoto & Holloway, 2010). In other words, parents expect

their children to behave in certain ways and to assume social responsibilities, therefore children's social functioning, especially that of children with conditions such as SB, matters a great deal to their parents (Yamamoto & Holloway, 2010). In most studies involving children with SB, researchers have concentrated on parents' expectations of their children's academic performance (Sanchez-Sandoval et al., 2019). To the best of our knowledge, no studies have focused on evaluating the social functioning of children and adolescents with SB considering their parents' expectations.

Aim

This integrative review aimed to determine the extent to which children with SB engaged in social activities and to evaluate the possible influence of parental expectations on their ability to participate in such activities. Therefore, a strategic search for published articles addressing these matters was performed, and relevant data were extracted from those articles for synthesis and evaluation.

Methods

Data Sources

Whittemore and Knafl's (2005) framework provided the basic conceptual structure for this integrative review. An integrative review was conducted because it allowed more diverse articles in the literature to be included than a systematic review would permit. The databases searched for relevant articles included the Cumulative Index of Nursing and Allied Health Literature (CINAHL), MEDLINE, PubMed, the Excerpta Medica Database (EMBASE), and PsycINFO, with a focus on both nursing and sociological abstracts. The search terms used were *spina bifida*, *parental expectations*, *family functioning*, *social participation*, *social adjustment*, and *social functioning*. In consideration of the PRISMA (2020) guidelines, initial screening of titles and

abstracts took place from October 2020 through September 2022, 216 potentially useful articles were identified; of these, 95 were duplicates, and 105 did not meet the inclusion criteria, resulting in exclusion of 200 articles (see Figure 1). Therefore, 16 articles that met the inclusion criteria were reviewed, and their data were analyzed and synthesized. Figure 1 summarizes the article selection process (Page et al., 2021).

Inclusion and Exclusion Criteria

As inclusion criteria, studies had to (1) involve children with SB aged ≤ 18 years; (2) be published in English between 2000 and 2021; and (3) address the participation of children with SB in social activities at home, at school, with family, or with friends. Studies were excluded if they failed to report relevant information regarding the social functioning of children with SB, focused exclusively on adults with SB, or were pilot studies. The review focused on children with SB ≤ 18 years old because the foundations for social functioning are generally developed during childhood and because adolescents tend to struggle with their social skills as they transition to adulthood. Social functioning is particularly important for social skill development in children with SB. In addition, the initial cutoff year of 2000 was selected because the review was intended to focus on more up-to-date study findings regarding children's social functioning and skills.

Study Synthesis

The 16 selected articles were categorized based on their methodology, use of foundational theories, data analysis techniques, and conclusions. A literature review matrix table (Table 1) was then developed and used to organize and analyze information from the articles (Garrard, 2020). Relevant data were extracted from each study, organized in ascending chronological order, and synthesized using the review matrix.

Quality Appraisal

The methodological quality of each selected study was evaluated using the quality appraisal tool developed by Olsen and Baisch (2014), which includes four components: type of study, sampling method, data collection method, and type of analysis. The scores assigned for study types range from 1 = best practice report to 6 = quantitative experimental design. The sampling method scores are assigned as follows: 0 = not explained or NA, 1 = convenience, 2 = purposive or case matching (CM), and 3 = random or 100%. For the data collection method used, a score of 1 or 0 is assigned depending on whether data collection methods and tools are explained (1) or not (0). Finally, based on the highest level of analysis reported, analysis type is scored as follows: 1 = narrative, 2 = descriptive statistics, and 3 = inferential statistics. Consequently, total tool scores range from 5 to 13; the higher the total, the better the quality of the study (Olsen & Baisch, 2014). For each study reviewed, the total quality appraisal score was included in the matrix table (Table 1).

Results

Participant Characteristics

Withing the sample, the total number of children with SB was 1,124, and the total number of parents was 405. Specifically, study participants included children aged 7 to 12 years and adolescents aged 13 to 18 years; seven studies included parent participants as well. Participants with SB or spinal cord injuries (SCI) were included in one of the studies, but study findings for children with SCI were not included in this review because they are not part of this review purpose.

Research Design

The studies included both quantitative and qualitative research designs. Five of the studies were qualitative in nature (Antle et al., 2009; Bakaniene & Prasauskiene, 2019; Fischer et al., 2015; Kristén et al., 2003; Papadakis & Holmbeck, 2021). These studies employed phenomenological, grounded, descriptive, cross-sectional designs. The remaining 11 studies employed quantitative designs (Barf et al., 2009; Devine et al., 2012; Essner et al., 2014; Field & Oates, 2001; Flanagan et al., 2013; Holbein et al., 2016; Kelly et al., 2010; Liptak et al., 2010; Marques et al., 2015; Peny-Dahlstrand et al., 2013; Winning et al., 2020). Among the quantitative studies, cross-sectional, prospective, longitudinal, and experimental designs were employed.

Study Quality

Overall quality appraisal scores for the 18 studies ranged from 7 to 9 out of 13 on the quality appraisal tool of Olsen and Baisch (2014) (see Table 1). Five articles that did not provide details about the sampling method or data collection method were scored as low as 7 (Barf et al., 2009; Field & Oates, 2001; Kristén et al., 2003; Liptak et al., 2010; Peny-Dahlstrand et al., 2013).

Themes Identified

The detailed synthesis of study results resulted in identification of three social functioning themes: (1) social participation of children with SB, (2) parents' relationships with children with SB, and (3) peer relationships with children with SB. Each of the themes is described in detail below.

Theme 1: Social Participation of Children with SB

Social participation of children with SB was reported in nine articles. For example, Field and Oates (2001a) concluded that children with SB tended to have lower social functionality than children without chronic health conditions or than children with other chronic diseases such as SCI and cystic fibrosis (CF). Although these researchers found that levels of social participation of children with SCI and SB were similar, children with SB participated in fewer activities than those with paraplegic SCI. In another study, Field and Oates (2001a) found statistically significant differences between parents of children with CF and parents of children with SB regarding their views of their children's social participation or functionality.

Various factors contributing to restricted social participation among children with SB were identified in the review. Barf et al. (2009) affirmed participation restrictions among youth with SB, as only 16% lived independently at age 21 and 53% did not have a job after finishing high school. However, Fischer et al. (2015) revealed that children with SB who achieved bladder continence were more independent and participated in more social activities than those who did not. On the other hand, children with SB who used wheelchairs tended to have more limitations in social activities due to difficulties with building accessibility and long-distance transportation. In addition, children's intellectual disabilities played a major role in their level of participation in social and physical activities. In Field and Oates' (2001a) study, the main participation limitations of children with SB were due to bowel/bladder incontinence, hydrocephalus, shunt, and a high level of lesions. Several other studies found that children's participation restrictions were attributable to continence issues, impaired motor functions, limited access and transportation, and emotional distress (Barf et al., 2009; Fischer et al., 2015; Peny-Dahlstrand et al., 2013). Furthermore, Barf et al. (2009) found that children with SB reported difficulties

related to long-distance transportation (19% to 36%), accessibility (10% to 42%), emotional barriers (20% to 32%), physical impairments (22% to 40%), and financial constraints (3% to 17%) that they perceived as barriers to their participation. In addition, among children having SB and hydrocephalus, a high level of lesion was associated with more participation restrictions (Barf et al., 2009).

In addition, children with SB can have learning and intellectual disabilities that may increase the risk of their not participating in social activities (Barf et al., 2009; Liptak et al., 2010a). It is evident from the literature that children with SB experience issues with communication and learning disabilities that have adverse effects on their community participation (Liptak et al., 2010a). For example, some children with SB, especially those with hydrocephalus and shunt, tend to have difficulty paying attention, work slowly, and have trouble making decisions (CDC, 2015).

Theme 2: Parents' Relationships with Children with SB

Parents' perspectives regarding support for their children with SB were reported in two articles. According to Antle et al. (2009), parents expressed ongoing concern about bathroom routines and the challenges and stressors these routines may present. These researchers also found mothers to be the most important source of support for children with SB across LaGreca's four domains of tangible, information, companionship/belonging/ mutuality, and emotional support. In addition, mothers provided a great deal of care by imparting health-related information and by providing support for their children's emotional well-being and sense of self in order to ensure their quality of life.

Children with SB who achieved bladder continence were more independent and participated in more social activities than children who had not (Fischer et al., 2015). However,

despite parents' strong level of support, the researchers reported that most parents believed their children with SB differed in aspects of their social participation from children with no ailments, including siblings. In another qualitative study addressing parents' conception of how their children with physical disabilities were influenced by outdoor sporting activities, three thematic categories emerged from interviews: achieving good health, being part of a social group, and learning a sporting activity. These categories reflected the importance that parents placed on sporting activities for children and adolescents with physical disabilities (Kristén et al., 2003).

Theme 3: Peer Relationships with Children with SB

Children and adolescents with SB were more likely to identify a healthy peer than another child with SB as their best friend, but the reverse was not always true (Devine et al., 2012a). While peers are a potential source of support for children and adolescents with SB, researchers have reported the level of peer support to be low (Antle et al., 2009; Devine et al., 2012a). Even though most children with SB try to explain their condition to their friends, they rarely discuss the difficulties surrounding bowel and bladder issues, which are precisely the challenges that most interfere with their social participation (Peny-Dahlstrand et al., 2013). In addition, peer acceptance of friends with SB varied considerably among studies, with some children reporting many close friends and others saying that they had no friends (Devine et al., 2012a; Fischer et al., 2015). In one study, Peny-Dahlstrand et al. (2013) found that 89% of children with SB had low levels of active participation and involvement in activities at schools, especially structured activities in recess and playground settings.

Discussion

This integrative review aimed to determine the extent to which children with SB engaged in social activities and to evaluate the possible influence of parental expectations on their ability

to participate in such activities. We found that many children and adolescents with SB appeared to have limited engagement in social activities with friends or family members. Researchers have observed lower social functionality in children and adolescents with SB compared to children with other chronic diseases. In addition, although some studies reported that mothers served as the primary source of support for children with SB, researchers have given little attention to how parents' expectations influence the social functioning of children and adolescents with SB. In fact, very few studies have focused on (a) parental views about their children's engagement in social activities and (b) the influence of parental views on the social success of children with SB.

Some studies focused on the challenges that children with SB faced when engaging in social activities. For example, continence issues and problems with motor function were major restrictions for most participants (Barf et al., 2009; Fischer et al., 2015). Among the studies reporting incontinence problems, difficulties varied from minimal to significant based the severity of the children's condition. Children with SB considered incontinence to be a significant issue because of the physical problems they had experienced and because of their embarrassment and need to hide their condition from their peers.

Based on the literature, children born with disabilities are viewed as vulnerable by their parents, especially when compared to healthy peers or siblings. This viewpoint may lead to overprotective behavior on the part of parents, which can in turn results in less functioning in a child. According to Holmbeck et al. (2003), parents of children with SB showed greater overprotective behavior than parents of children without the disease, and children of overprotective parents may have less autonomy, less social maturity, and limited ability to interact with other children.

There are limitations to this review. First, the review focused only on studies published in English, and thus relevant studies published in other languages may have been omitted. Second, the studies generally included children ≤ 18 years old but reported findings for children of various ages, making comparison of their findings more difficult. Third, in the quality appraisal performed for this review, scores were lower for nine articles because they did not address their sampling and data collection methods; this limitation of these articles reduced the usefulness of their findings and conclusions. On the other hand, the nine studies that detailed their research methods received overall quality appraisal scores of 8 and 9, suggesting that their findings can be considered more reliable and meaningful. Despite these limitations, to our knowledge, this is the first integrative review to examine the ability of children with SB to engage in social activities and to evaluate how their parents' views may affect the children's participation in such activities.

Practice and Research Implications

This integrative review focused on participation of children with SB in social activities and the impacts of parental expectations on children's ability to participate. The review synthesizes findings of 18 studies to produce a better understanding of circumstances that facilitate children's participation in social activities with family members and friends. With this understanding, nurses can help parents develop proactive ways to encourage their children to become more socially engaged, thus improving their quality of life. For example, nurses can collaborate with parents to develop a realistic plan for their child's socialization based on the child's developmental age and the severity of the condition. In addition, nurses can assist children with SB in increasing their social participation by asking them about their goals and expectations for social functioning.

Furthermore, this review's findings underscore the importance of developing nursing interventions to maximize the social functioning of adolescents with SB, regardless of their physical limitations. Future research should further examine the impact of parents on their children's ability to engage in social activities and to become more socially involved with family and friends. Such research could reveal avenues for parents and other caregivers to empower children and adolescents with SB, helping them better understand and accept their bodies and take pride in their identity rather than viewing themselves as broken or shameful (Fischer et al., 2015). In addition, the limited body of research on the association between incontinence and social participation should be expanded, and nurses should familiarize themselves with such research so that they can better help children with SB to avoid social isolation.

Conclusion

Many children and adolescents with SB have limited ability to engage in social activities with friends or family members. These limitations are mainly due to continence issues and problems with motor functions. Nurses and other healthcare professionals need to strive to maximize the social participation of children with SB regardless of their physical limitations. In particular, nurses need to take advantage of their interactions with parents and children to discuss opportunities for the children's social involvement. From a research perspective, no articles were found that specifically addressed how parents could improve the ability of children with SB to participate in social activities. Thus, future nursing research should focus on addressing this gap with the ultimate goal of maximizing the social functioning of children and adolescents with SB.

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Table 1*Matrix Table of Parental Expectations and Social Functionality in Children with Spina Bifida*

Study	Purpose of Study	Design & Sample	Results	Quality Appraisal
Boudos et al. (2008) USA	Examine baseline participation of people with spina bifida (SB) in several domains (e.g., school, employment, community activities, physical activity, and peer social relationships) and identify barriers to community participation	Quantitative, cross-sectional study 101 (10-32 years old) 31 (10-17 years old)	<ul style="list-style-type: none"> Only 30% of children with SB took part in an organized social activity at least once per week. The most frequent participation barriers were low motivation (38%), lack of information (25%), and time constraints (21%). 	Type of study = 4 Sampling = 1 Method = 2 Analysis = 1 Total score = 8
Field & Oates (2001) Australia	Assess parents' perspectives about the participation of children with SB compared to children with cystic fibrosis (CF)	Quantitative, cross-sectional study 166 total parents 69 children with CF 97 children with SB	<ul style="list-style-type: none"> Statistically significant differences were found between the views of parents of children with CF and parents of children with SB ($p < 0.025$). Parents reported challenges in finding activities that included the entire family because of the limited number of activities that both adults and children with SB could participate in. 	Type of study = 4 Sampling = 0 Method = 1 Analysis = 2 Total score = 7

Table 1 (Continued)

Study	Purpose of Study	Design & Sample	Results	Quality Appraisal
Kristén et al. (2003) Sweden	Describe parents' perceptions about the influences of participation in a sports program on children and adolescents with physical disabilities	Qualitative, phenomenological study 20 parents	<ul style="list-style-type: none"> Descriptive analysis revealed that parents viewed sports as health education and as a way for their children to increase their participation in society. 	Type of study = 3 Sampling = 2 Method = 0 Analysis = 2 Total score = 7
Antle et al. (2009) USA	Gain perspectives on the nature of social support based on four main domains of LaGreca's model for youth with SB and their parents	Qualitative study 29 parents 21 youth with SB	<ul style="list-style-type: none"> Mothers were found to be the most important source of support for youth with SB across LaGreca's four domains (tangible, information, companionship/belonging/mutuality, and emotional support). 	Type of study = 3 Sampling = 2 Method = 1 Analysis = 1 Total score = 7
Barf et al. (2009) USA	Determine participation restrictions among young adults with SB in relation to their health conditions and activity limitations	Quantitative, cross-sectional study 179 youth with SB	<ul style="list-style-type: none"> Among youth with SB, 16% lived independently at the age of 21, 53% did not have a job after finishing their education, and 71% did not have a partner, all indicating the limitations of their participation in society. 	Type of study = 4 Sampling = 1 Method = 0 Analysis = 2 Total score = 7
Liptak et al. (2010) USA	Describe <u>social participation</u> outcomes and identify factors affecting <u>participation</u> in youth and young adults with SB	Quantitative, population-based, prospective study 130 youth and young adults with SB	<ul style="list-style-type: none"> Social participation of youth with SB was found to be influenced by many factors. Compared to youth without SB, they were less likely to be competitively employed, have a driver's license, or spend time with friends. Specifically, 76% were competitively employed or attended school, 30% had a driver's license or learner's permit, and 15% spent time with friends and were going on dates. 	Type of study = 4 Sampling = 1 Method = 1 Analysis = 2 Total score = 8

Table 1 (Continued)

Study	Purpose of Study	Design & Sample	Results	Quality Appraisal
Devine et al. (2012) USA	Characterize general friendships of youth with SB	Quantitative, longitudinal study 106 youth with SB	<ul style="list-style-type: none"> Many similarities were observed between youth with SB and their peers. More youth with SB considered peers to be their best friends than peers considered youth with SB to be their best friends. Compared with peers, youth with SB spent fewer days with friends and showed lower levels of security, companionship, and emotional support from friends and families. 	Type of study = 4 Sampling = 2 Method = 1 Analysis = 2 Total score = 9
Kelly et al. (2011) USA	Examine how social participation of youth with SB varies by age and related factors (gender, family characteristics, and SB-related factors)	Quantitative, cross-sectional study 63 youth with SB including 19 (2-5 years old), 21 (6-12 years old), and 23 (13-18 years old) youth	<ul style="list-style-type: none"> Older youth with SB participated less in recreational, physical, and skill-based activities than younger youth with SB. Social participation was positively associated with caregiver employment. Youth's physical and skill-based activities were negatively related to the presence of a shunt and recent major medical issues. Bladder and bowel incontinence was a barrier to social participation for children aged 6–12 years. 	Type of study = 4 Sampling = 1 Method = 1 Analysis = 2 Total score = 8
Flanagan et al. (2013) USA	Describe psychosocial outcomes of children and adolescents with early-onset spinal cord injury (SCI) or SB	Quantitative, cross-sectional study 137 youth including 54 youth with SB and 83 youth with SCI	<ul style="list-style-type: none"> Children with SCI and SB showed similar levels of participation intensity, with scores of 2.1 (of a possible 7) for children with SB and 2.2 for children with SCI. Children with SB participated in fewer activities than those with paraplegic SCI. 	Type of study = 4 Sampling = 1 Method = 1 Analysis = 2 Total score = 8

Table 1 (Continued)

Study	Purpose of Study	Design & Sample	Results	Quality Appraisal
Peny-Dahlstand et al. (2013) Sweden	Evaluate how children with SB participate in school-related activities and explore whether their motor and process skills for task performance were related to their level of active school participation	Quantitative, cross-sectional study 50 children with SB	<ul style="list-style-type: none"> • Among children with SB, 89.6% had a low level of active participation and involvement in school activities even though their frequency of participation was high. • Motor and process skills were found to be the most significant determinants of participation. 	Type of study = 4 Sampling = 0 Method = 1 Analysis = 2 Total score = 7
Essner et al. (2014) USA	Evaluate a model of social competence in youth with SB	Quantitative, longitudinal study 108 youth with SB	<ul style="list-style-type: none"> • Among youth with SB, the association between social competence and pain decreased with greater social activity involvement. • Decreased social activity showed a significant negative effect on social competence. 	Type of study = 4 Sampling = 2 Method = 1 Analysis = 2 Total score = 9
Bloeman et al. (2015) Netherlands	Describe both personal and environmental factors essential for participation in physical activity as experienced by children with SB and their parents, with the goal of developing better intervention strategies for improving participation in physical activity among youth with SB	Qualitative, grounded study 33 children with SB 42 parents	<ul style="list-style-type: none"> • Personal factors related to physical activity participation in children with SB included bowel and bladder care, competence in skills, sufficient fitness, medical events, and self-efficacy. • Environmental factors related to children's physical activity participation included support from others, use of assistive devices for mobility and care, having information related to possibilities for adapted sports, and access to sports facilities. 	Type of study = 4 Sampling = 2 Method = 1 Analysis = 2 Total score = 9

Table 1 (Continued)

Study	Purpose of Study	Design & Sample	Results	Quality Appraisal
Fischer et al. (2015) Canada	Explore the experiences of children with SB and their parents with regard to the children's social participation, continence issues, and peer relationships	Qualitative, phenomenological study 11 children with SB 10 parents	<ul style="list-style-type: none"> Children with SB who achieved bladder continence were more independent and participated in more social activities. SB adversely impacted children's social lives and led to rejection and social isolation, which in turn led to stigma and poor social functionality. 	Type of study = 3 Sampling = 2 Method = 1 Analysis = 1 Total score = 7
Marques et al. (2015) USA	Identify relationships between psychosocial variables and physical activity in children and adolescents with SB	Quantitative, cross-sectional study 31 children with SB	<ul style="list-style-type: none"> About 38.7% of the children with SB participated in physical activity. No relationship was found between participation in physical activities and psychosocial variables. A statistically significant positive correlation was found between perception of competence and participation in non-organized physical activity (odds ratio = 9.55, $p < 0.05$). 	Type of study = 4 Sampling = 0 Method = 1 Analysis = 2 Total score = 7
Holbein et al. (2016) USA	Evaluate changes in academic performance that occurred over time among children with SB and the influence of parental expectations	Quantitative, experimental study 68 families of children with SB	<ul style="list-style-type: none"> For children with SB, parents lowered their expectations for academic and social performance over time due to the condition; however, optimistic parents showed increased expectations. Family expectations that parents and siblings held for children with SB were significantly affected by healthcare providers. 	Type of study = 4 Sampling = 2 Method = 1 Analysis = 1 Total score = 8

Table 1 (Continued)

Study	Purpose of Study	Design & Sample	Results	Quality Appraisal
Bakaniene et al. (2019) Lithuania	Analyze patterns and predictors of social participation in Lithuanian children and adolescents with SB	Qualitative, cross-sectional study 99 parents of children with SB	<ul style="list-style-type: none"> • Children with SB showed limited participation in school/preschool and in community settings. • Children's mental abilities played a role in their participation level at home or in school/preschool. 	Type of study = 3 Sampling = 1 Method = 1 Analysis = 2 Total score = 7
Winning et al. (2020) USA	Examine the reliability of observed measurement of parental scaffolding and its impact on social and academic performance among youth with SB	Quantitative, experimental study 137 families of youth with SB	<ul style="list-style-type: none"> • Scale validity and reliability were found to be acceptable to evaluate parental scaffolding, which was directly associated with academic performance and social functionality in youth with SB. • Positive parental scaffolding was linked to independence, self-control, and social cooperation in youth. 	Type of study = 3 Sampling = 2 Method = 1 Analysis = 2 Total score = 8
Papadakis and Holmbeck (2021) USA	Investigate the relationship between sociodemographic factors and various characteristics of youth with SB, including their health and their psychosocial, and neuropsychosocial functioning	Quantitative, longitudinal study 140 youth with SB	<ul style="list-style-type: none"> • Youth with SB having sociodemographic risks experienced greater pain but fewer urinary tract infections. • Academic performance and age difference did not affect these relationships. For some youth with SB, academic performance and social functionality were significantly negatively affected by sociodemographic factors such as race and ethnicity, health insurance status, education level, and employment status. 	Type of study = 3 Sampling = 2 Method = 1 Analysis = 1 Total score = 7

Note: CF, Cystic Fibrosis; SB, Spina Bifida; SCI, Spinal Cord Injury.

Note. Quality appraisal scores were assigned using the Olsen & Baisch (2014) Appraisal Tool.

Note. Parental scaffolding refers to how a parent guides a child's learning during a goal-focused activity by providing or eliminating support at different stages depending on the developmental level and learning needs of the child.

Table 2*Description of Social Function Measures for Children with Spina Bifida*

Study	Measure	Purpose	Participant Age Range	Measure Description	Reliability ^a	Validity ^b
Liptak et al. (2010)	Children's Assessment of Participation and Enjoyment (CAPE)	Participation	6-21 years	<ul style="list-style-type: none"> • Two domains: Informal (40 items) and Formal (15 items) • Five dimensions assessed for each domain: diversity, intensity, with whom, where, and enjoyment 	**	**
Fischer et al. (2015)	Assessment of Preschool Children's Participation (APCP)	Participation	2-5 years, 11 months	<ul style="list-style-type: none"> • Diversity and intensity scores in five areas: play, skill development, active physical recreation, social activities, and total 	*	**
Flanagan et al. (2010)	Availability and Participation Scale (APS)	Participation, Environment	5-18 years	<ul style="list-style-type: none"> • Two scales: availability (27 items) and participation (29 items) 	*	*
Flanagan et al. (2010)	School Function Assessment (SFA)	Participation, activity	5-12 years	<ul style="list-style-type: none"> • Three parts: participation, task support, and activity performance 	**	***
Essner et al. (2014)	The Activities Competence Scale of the Child Behavior Checklist	Emotional/behavioral problems and social competencies	6-18 years	<ul style="list-style-type: none"> • Three parts: activities, social competence, and school competence 	**	**

^a(*) One type of reliability (internal consistency or test-retest) was tested with acceptable results; (**) Reliability was acceptable in terms of both internal consistency and test-retest stability (Cronbach's alpha >0.70 in 70%).

^b(*) One type of validity (e.g., structural, construct, or criterion) was tested with acceptable results; (**) Two types of validity were tested with acceptable results; (***) Three types of validity were tested with acceptable result.

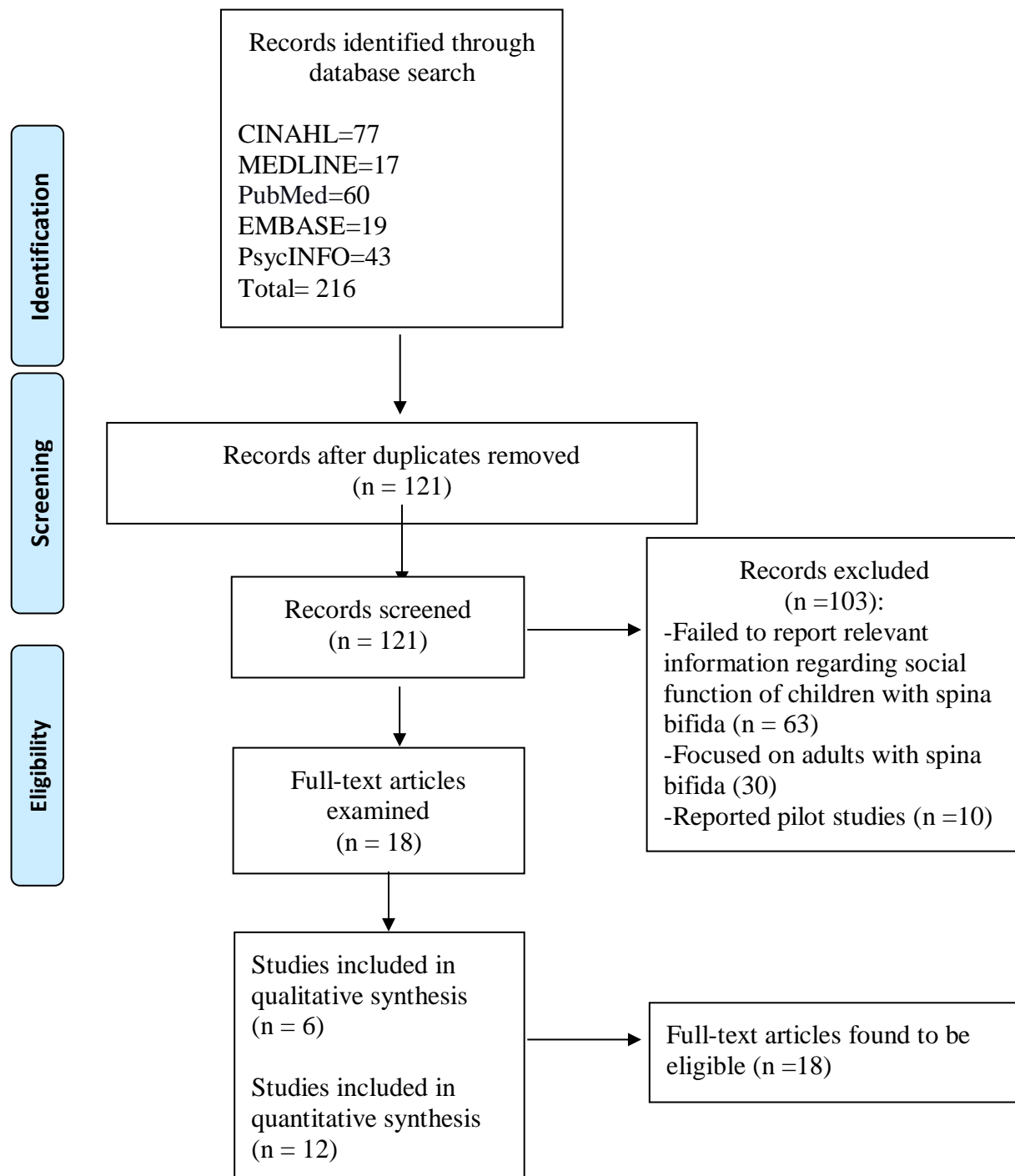


Figure 1. *PRISMA Diagram*

II. ADOLESCENTS WITH SPINA BIFIDA AND PARENTS' PERCEPTIONS OF ENGAGING IN SOCIAL ACTIVITIES

Introduction

Spina bifida (SB) is a congenital birth defect that affects the spine and impacts approximately 3 of every 10,000 live births in the United States (Centers for Disease Control and Prevention [CDC], 2011). This condition can occur throughout the spine because of the neural tube's incomplete closure. When this condition occurs, the spinal column does not form and develop as it should, potentially leading to damage to the spinal cord and nerves (CDC, 2011). The degree of severity of an individual's SB and the extent to which physical challenges manifest are determined by the size and location of the spinal opening and the damage to the underlying nerves (CDC, 2015). Any such physical impairments invariably affect other dimensions of the lives of individuals with SB, such as their psychological, social, and intellectual competencies. The specific aims of this study were to (a) describe adolescents' and parents' perceptions of facilitators and challenges to social functioning, (b) describe parents' perceptions and expectations of social functioning for their adolescent, and (c) describe adolescents' perceptions and expectations of their social functioning and perceptions of their parents' expectations

Background

Spina bifida (SB) profoundly affects not only the individuals having the condition, but also entire families and communities. In 2016, the estimated lifetime cost of care for a person with SB in the United States, including caregiver costs, was \$791,900 (Grosse et al., 2016). Another study of a national inpatient sample conducted in the US in 2013 showed that hospitalizations related to birth defects of the brain and spine (including SB) cost more than \$1.6 billion for people of all ages (Arth et al., 2017). Due to the complexities of their condition, adolescents with SB tend to exhibit poor social engagement (Barf et al., 2009; Kelly et al., 2011).

The challenges faced by adolescents with SB have long-term implications that contribute to ongoing and increasing impairment of their social functioning (Fischer et al., 2015).

Social functioning poses a significant challenge for adolescents with SB. Researchers have reported that unlike adolescents with cystic fibrosis, who do engage in recreational activities outside the family, adolescents with SB tend to limit their participation in leisure activities to those performed with family members (Field & Oates, 2001). This limited participation was attributable to their physical disabilities such as bowel/bladder incontinence, hydrocephalus, shunting, and level of lesions (Barf et al., 2009; Fischer et al., 2015). Furthermore, in one study that investigated the experiences of adolescents with SB and their parents related to social participation and peer relationships, most parents who participated in interviews did not view their children as “typical” (Bakaniene et al., 2018). Although previous studies have shown that adolescent and children with SB have lower ability or desire to be involved in social functions, the reasoning and attitudes behind parents’ expectations of social functioning in their adolescents with SB remain elusive.

Social participation is an important determinant of health and has been associated with quality of life (Levasseur et al., 2010) which is a person’s “perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (World Health Organization Quality of Life (WHOQOL), 1998, p.1). Furthermore, social functioning promotes increased self-esteem, which facilitates good health and functional independence (Levasseur et al., 2010). Among adolescents with SB, 48% to 76% experience continence issues, and these adolescents are at risk of decreased participation in social activities, fewer peer relationships, and diminished self-esteem (Fischer et

al., 2015). Researchers found that bowel incontinence was associated with lower health related quality of life (Sawin et al., 2007).

Children and adolescents with chronic diseases tend to have limited social functioning compared to healthy children and adolescents (Pinquart & Teubert, 2012). This limitation can be due to a variety of factors, as some chronic diseases limit the type and extent of physical activities, contact with peers, and school attendance. Pinquart and Teubert (2012) explained that this limitation may be attributable to physical restrictions (e.g., for cerebral palsy and SB), reduced motivation and persistence (e.g., for chronic fatigue syndrome), prolonged or repeated hospitalizations or frequent doctor's appointments (e.g., during cancer treatment), and special transportation requirements. Furthermore, cognitive impairment related to diseases of the central nervous system (CNS) such as SB can impair academic functioning as well as social understanding, which is an aspect of social functioning (Pinquart & Teubert, 2012). Moreover, associations between physical disability and adolescent social functioning may be related to limitations of the members of the social network, such as parents, teachers, and peers. Finally, behavior problems associated with chronic illness, such as aggression or depressive mood, may affect social and academic functioning (Pinquart & Shen, 2011).

Many children and adolescents with SB have poor social adjustment throughout development stages (Landry et al., 2013). Some previous research in this area has focused on the limitations and challenges that children with SB faced when engaged in social activities. For example, continence issues were a major limitation for most participants in studies by Fischer et al. (2015) and Kelly et al. (2011). Among the studies that have reported on incontinence problems in children with SB, difficulties ranged from minimal to significant depending on the type of SB present. Children with SB considered their incontinence to be a significant issue,

notonly because of the physical discomfort they experienced, but also because they tended to feel embarrassment and a need to hide it from their peers. In fact, incontinence issues have been identified as a major barrier to social participation in most studies (Fischer et al., 2015; Kelly et al., 2011).

In another study, the researchers emphasized the importance of overcoming incontinence issues by encouraging caretakers to offer increased support. They also stressed the importance of encouraging children and adolescents with SB to feel more empowered by helping them to better accept their bodies as they are and not to see themselves as defective (Fischer et al., 2015). One study of social functioning and physical activity in children with SB was sponsored by the Portuguese Association of Spina Bifida and Hydrocephalus in 2013. That study involved 31 students with SB aged 10 to 17 years (Marques et al., 2015), and explored the relationships among adolescents with SB; physical activity involvement; and psychosocial factors such as attitudes, sports interests, and perceptions of competence. The researchers found no significant relationships among having SB, physical activity involvement, and psychosocial characteristics except for perceptions in competence, as most of the participants did not engage in regular physical activity. Among the study variables, only participants' positive perceptions were significantly associated with greater participation in non-organized physical activity (Marques et al., 2015). These researchers' direct probing of students' propensity to engage in physical activities provided evidence of these individuals' low interest in social and physical interactions with others, especially organized activities that were typically school directed. Another reason cited for students' reluctance to engage in school-directed organized activities was that they involved required fees. Predictors of physical activity involvement among individuals with SB included barriers such as lower levels of musculoskeletal development and aerobic fitness. With

respect to students' perceptions, a perceived ability to engage in leisure and social activities was deemed an important motivator for participating in physical activities (Marques et al., 2015).

Adolescents and their parents experience facilitators as well as challenges to social functioning. In one study, adolescents with myelomeningocele had significant difficulties due to the involvement of multiple systems dysfunction (Buran et al., 2004). Myelomeningocele is the most severe form of SB and has been associated with negative consequences throughout life. In addition, researchers have found that bowel and bladder problems limit physical activities and social life (specifically for those who cannot catheterize themselves) (Boudos & Mukherjee, 2008; Flanagan et al., 2013). Furthermore, children with SB who used a wheelchair tended to have more limitations in social activities due to difficulties related with building accessibility and long-distance transportation (Barf et al., 2009). Finally, adolescents' intellectual disabilities played a major role in their level of participation in social and physical activities.

Parents' perceptions and expectations have been found to play a critical role in adolescents' academic success (Yamamoto & Holloway, 2010). Students whose parents held high expectations tended to earn higher grades, achieve higher scores on standardized tests, and persist longer in school than those whose parents had relatively low expectations (Davis-Kean, 2005; Pearce, 2006; Vartanian et al., 2007). Furthermore, in a study that focused on the relationship between parents' expectations and post-school outcomes of adolescents with disabilities, parents' expectations that their adolescent would achieve each of the study outcomes (graduating from high school with a standard diploma, post-school employment, and enrollment in and completion of postsecondary education) were significantly and positively associated with adolescents' level of autonomy (Doren et al., 2012).

Parents' expectations and children's outcomes were investigated in a study called the National Longitudinal Transition Study NLTS-2 which examined the main effects of parents' school and post-school outcome expectations on the actual outcomes achieved by typical children (Doren et al., 2012). That study considered parents' intentional alignment of their children's future endeavors with their own expectations. In the NLTS-2 parents' expectations were found to significantly predict the level of autonomy, and autonomy predicted a several postschool outcomes. In other studies of families, a direct pathway was established between parents' expectations and their children's academic prowess, college education or degree, and professional achievements (Blustein et al., 2002; Chen & Gregory, 2009). In fact, many studies have shown that parents' expectations for adolescents' abilities, skills, and education have a strong influence on the outcomes experienced by adolescents and young adults (Agliata & Renk, 2008; Yazedjian et al., 2009). For instance, positive parents' expectations have been associated with better academic skills and college outcomes among students with disabilities (Yazedjian et al., 2009).

Given the fact that little research attention has been devoted to the social functioning of children with SB, this study was performed to explore the perceptions and expectations of adolescents with SB and their parents regarding the adolescents' social functioning. The goal was to identify facilitators and challenges for adolescents' social functioning that could be used to inform interventions for adolescents with SB.

Methods

Design and Sample

In this study, a qualitative, descriptive design was used to explore adolescents' and parents' perceptions and expectations of the social functioning of adolescents with SB, with

particular attention to facilitators and challenges for social functioning. Because limited research is available on this phenomenon, a qualitative, descriptive design was chosen to provide a rich, detailed description of participants' perceptions and expectations in this regard. Furthermore, the qualitative, descriptive design was selected due to the subjective nature of the social functioning phenomenon and the varying experiences of this phenomenon among the participants (Bradshaw et al., 2017).

A total of 20 individuals, including 10 adolescents with SB and 10 of their parents (one mother or father of each adolescent) participated in the study. The inclusion criteria for adolescent participants were as follows: (1) diagnosed with the most common and severe type of SB, myelomeningocele; (2) aged 12 to 17 years; (3) able to speak English; and (4) had the cognitive ability to participate in an interview. Each parent participant had to be (1) the mother or father of one of the adolescent participants and (2) able to speak English. Adolescents with severe cognitive impairment, cerebral palsy, or neuromuscular impairments were excluded because their ability to engage in social activities could be very limited.

Recruitment and Data Collection

Once study approval was obtained from the Institutional Review Board (IRB) of the University of Illinois at Chicago (UIC), the principal investigator (PI) gained study approval from the Spina Bifida Association (SBA), Illinois Spina Bifida Association (ISBA), and Spina Bifida Wisconsin (SBW). In supporting participant recruitment, SBA, ISBA, and SBW posted a study flyer on their online social media accounts. Individuals who were interested in participating in the study and who thought they were eligible clicked a link in the flyer to access and complete an eligibility screening questionnaire situated on UIC REDCap, a secure web application for managing online surveys. Based on their questionnaire responses, individuals

meeting the eligibility criteria were sent an email from the PI through UIC REDCap to schedule individual adolescent and parent interviews. Through this convenience sampling approach, the PI recruited 20 participants (10 adolescent-parent dyads) who met the inclusion criteria and were willing to participate in the study. The PI planned to recruit approximately equal numbers of male and female adolescents, but the final adolescent sample consisted of nine males and one female.

Prior to and at the time of each interview, the PI responded to any adolescent or parent questions or concerns about providing informed consent. Once all questions and concerns were resolved, participants provided written electronic consent on UIC REDCap; among the participants, parents provided consent/permission for themselves and for their adolescent children, and adolescents also provided consent for themselves. After this process was completed, parents completed a demographic characteristic questionnaire (Appendix A) for both themselves and their adolescents on UIC REDCap. The PI then exported all participant data directly from UIC REDCap to a password-protected computer.

All interviews were conducted via a video conferencing platform (Zoom). To ensure participant confidentiality, each participant was assigned a study code, and the list matching participant names to their codes was kept in a secure location separate from the study data. Following the interview guide (Appendix B), the PI interviewed adolescents and parents separately, and the interviews lasted 45 to 60 minutes. After obtaining the permission of the participants, the interviews were audio-recorded via Zoom to facilitate accurate, verbatim transcription. The PI also recorded relevant observations in field notes. After the interviews were completed, a \$20 Amazon gift card was sent to each participant via email as a token of appreciation.

Theoretical Framework

Holmbeck and Devine's (2010) bio-neuropsychosocial model was used to guide exploration of adolescents' perceptions and expectations of their social functioning and their parents' perceptions and expectations regarding the social functioning of their adolescents with SB (see Figure 2). According to Holmbeck and Devine (2010), the bio-neuropsychosocial model focuses on the adjustments of individuals with SB, which are likely determined by the interacting influences of multiple biological, neuropsychological, and social factors. For the purposes of this study, the PI focused on two theoretical concepts of the model: adolescent adjustment and social factors. Each theoretical concept and subconcept is defined and described in Table 4.

Interview Guide

A semi-structured interview guide based on Holmbeck and Devine's (2010) bio-neuropsychosocial model (Figure 2) was used to explore adolescents' and parents' perceptions of facilitators and challenges to social functioning, adolescents' perceptions and expectations of their own social functioning, and parents' perceptions and expectations of their adolescent children's social functioning. The interview guide contained open-ended questions and accompanying probes based on two components of the bio-neuropsychosocial model: adolescent adjustment (functional status, quality of life, social adjustment) and social factors (family/parenting and peers) (Holmbeck & Devine, 2010).

Rigor and Trustworthiness

Demonstration of the quality of the research process and the data collected is essential in qualitative research (Creswell & Creswell, 2017; Morse et al., 2002). The PI established trustworthiness and credibility by developing a rapport with each participant prior to the interview. To achieve this rapport, the PI introduced herself and her study to the participant,

described the exact role and intentions of the PI, and showed personal interest in the participant's well-being (Creswell & Creswell, 2017; Morse et al., 2002). To ensure credibility, the PI wrote thick description of the data collected. In addition, the PI carefully documented the data collection, analysis, and interpretation processes; for example, the PI noted unique topics of interest during the interviews, recorded her thought process during coding, wrote a rationale for each merging of codes, and ultimately wrote a detailed explanation of the meaning and significance of each theme identified (Creswell & Creswell, 2017; Morse et al., 2002).

Transferability was attained by means of purposive sampling in terms of adolescents with SB and their parent who met the inclusion criteria and were interested. Also, dependability was maintained by employing two coders and by performing an inter-coder agreement process.

Data Management and Analysis

Data analysis was based on Hsieh and Shannon's (2005) techniques and occurred concurrently with data collection. Using the Zoom audio-recording feature, the PI transcribed each interview electronically. Each transcript was then checked against the recording to confirm transcription accuracy, and any errors were corrected. The PI employed Atlas.ti Visual Qualitative Data Analysis (QDA) software (version 8.0.43) to organize the data, manage the coding effort, and assign data to selected codes.

The bio-neuropsychosocial model, including the components of adolescent adjustment (social adjustment, quality of life, and functional status) and social factors (family/parenting and peers), and the interview guide were used to guide the data analysis (Holmbeck & Devine, 2010). The PI identified definitions for each theoretical concept and subconcept from the bio-neuropsychosocial model and the literature. During initial coding, the analysis was guided by the research questions and involved identifying and categorizing all instances of social functioning

in adolescents with SB; subsequently, the PI developed new codes that arose from the data and assigned new codes. Any participant's text that could not be categorized using the initial coding scheme was assigned a new code (Hsieh & Shannon, 2005). Finally, descriptive data compiled for each thematic category and subcategory were described in detail.

Using a codebook developed for adolescents with SB and for their parents, the PI coded all the interview transcripts, and a second coder independently coded four of the transcripts. The PI and second coder met twice to compare their coding. Based on the PI and second coder's discussions and clarifications, the codebook was revised several times until a consensus was reached. Subsequently, one expert on qualitative research and SB reviewed the transcripts and revised codebook, and they provided feedback that the PI then incorporated.

Results

Sample Characteristics

A total of 10 adolescent-parent dyads participated in the study interviews. The adolescents' ages ranged from 12 to 17 years, and their mean age was 13 years; they included one adolescent girl and nine adolescent boys. The adolescents varied in their mobility level and cognitive ability. Three mothers and seven fathers were interviewed. Among both the adolescent and parent participants, 9 of 10 were African-American, and 1 was an Indian-American. The participants' characteristics are summarized in Table 3.

Analysis of transcripts of the interviews with the 10 adolescents (Table 5) and their parents (Table 6) yielded the themes and subthemes presented in Tables 5 and 6. These themes and subthemes are described below, first for the adolescent interviews and then for the parent interviews.

Adolescent Themes and Subthemes

Functional Status

Functional status refers to an adolescent's ability to perform routine daily activities required to meet basic needs, fulfill usual roles, and maintain health and well-being (Leidy, 1994). The themes identified within functional status included facilitators of performing social/daily activities and challenges of performing social/daily activities due to SB.

Facilitators of Performing Social/Daily Activities. Facilitators of performing social/daily activities were factors that made social life better or easier for adolescents with SB. Adolescents noted that receiving ongoing treatment for their condition, such as taking medication and consulting healthcare providers, was a key facilitator for their functional status and being able to perform activities. For example, a 14-year-old explained that “[seeing] a doctor and [having] medication...improve my condition a lot.” The subthemes identified were social activities with family and friends, sharing the condition with friends, treatment of the condition, and family role.

Social Activities with Family and Friends. Social activities with family and friends were a crucial component of social functioning. Adolescents spent a great deal of time with family members and friends while performing different types of activities, such as playing video games, swimming, reading books, and dog walking. One 14-year-old stated that, “[I] spend a lot of time with my family; I spend so much time with my father. We do play video games [and] go swimming on the weekends. Sometimes we go for checkups in the hospitals.”

Adolescents described the time spent with family and friends as fun, enjoyable, and valuable. Most adolescents performed activities outdoors, but one preferred indoor activity.

Many of the adolescent males enjoyed spending time with their fathers more than with other family members. For instance, a 14-year-old explained, “I enjoy my dad’s company. He is like a mentor to me. Sometimes we go spend time with my family together; sometimes we swim all of us.” Another, a 13-year-old, stated, “I do like to play with my dad...When he is around me, I feel happy and when I need assistance to make me busy...I can even laugh and make my moments so pretty incredible and [an] amazing time.”

Sharing the Condition with Friends. Adolescents highlighted their willingness to share their SB condition with friends. They talked about sharing complaints regarding their SB, such as pain, skin sores, and walking difficulties, that were obvious to others and that they could not hide. For example, a 14-year-old explained, “They actually know three of them...They see me when I am in pain sometimes with crutches. They know that spina bifida is [a] condition I was born with...There is no way I can avoid it--they know I [was] born with this disease.”

Family Role. The central role of family as providing great help, courage, and motivation was acknowledged by many adolescents. For instance, a 14-year-old stated, “My assistan[ce] mostly come[s] from my mom. We go and sit for medication, and she calls our personal doctor to come to my home.” Another 13-year-old said, “What has worked for me is motivation from my father and my mother and my sibling and also...activities.” Moreover, a 14-year-old explained, “I need to hold their hands. They do assist me because I use crutches and braces.”

Challenges of Performing Social/Daily Activities. With respect to SB-related challenges of performing social/daily activities, three subthemes were identified. They consisted of condition-related challenges (mobility limitations and assistance needed, cognitive and communication impairments, pain and skin problems, and being unable to be active for very long), stigma and bullying, and parental protection/restrictions.

Condition-Related Challenges. Most of the adolescents required assistance to perform social and daily activities, and this assistance varied from minimal to extensive. The level of assistance adolescents needed varied depending on their mobility limitations. For instance, wheelchair-dependent adolescents required much more help than those who could walk independently or used braces or walkers. In this regard, a 12-year-old explained, “Sometimes...when I’m going to school...it’s like I cannot travel alone. I need to lean on...my parents...When...my father is going for a walk, I do go with him so that I can hold hands when I need [to].” A 13-year-old stated, “It is a nice time because [my parents] always accompany me when I go out, and in the school, I need to hold their hands [for] assistance because I use crutches and braces.”

Most adolescents recognized the challenges of being unable to walk independently and its effect on performing activities on their own. For instance, a 12-year-old said, “Because you know...I cannot walk properly....I can bend and even at some point, I can have back pain, and they can see me.... I can cry or need assistance from someone else.”

When adolescents were asked about their ability to build relationships with other children, they expressed difficulties related to cognitive and communication impairments. For example, a 14-year-old said about “the challenges I face when developing friendships...I see that someone is not ready to be my friend. I see that I am not their type because I am not walking well...Yeah some stigmatize me...Yeah, those are some of the challenges, and...I have a speech deficit.” Another, 13-year-old also stated, “There’s a lot of difficulty because of some problem with [my] expression or maybe to understand [me].” Furthermore, some adolescents saw themselves as different from peers because of the cognitive and communication impairments

they experienced. For example, a 14-year-old stated, “I am different from them [due to]...my cognitive ability.”

When discussing engaging in activities, adolescents frequently reported pain in their back or legs and painful skin sores. For example, one 13-year-old said, “the challenge I face in having the social life I want is because of the pain I experience in my back.” Most of the adolescents were able to express their pain to their peers in general terms without giving details. For instance, a 13-year-old stated, “Sometimes I am in pain, and I cannot...handle it in the activities. They [friends] know I have this condition--they understand, but they do not know details about...SB.”

Most adolescents talked about their mobility challenges and inability to be active for an extended time as well as the great impact these had on their activities. For instance, a 14-year-old stated, “I think using crutches and braces affects my engagement in social activities.” Another 14-year-old explained, “I use the wheelchair to do [that] stuff. I say [that the] wheelchair affects me. It reduces playing; like when we are playing football, it really affects me.” A 13-year-old stated, “The biggest challenges are time. I cannot do [activities] for [a] long time, just a short time, and then I get to sit down and relax.”

Stigma and Bullying. Most adolescents expressed experiences with stigma (i.e., unfair disapproval) or bullying (i.e., intimidation, coercion, or harm) due to their SB, mainly in school settings. For example, a 13-year-old claimed people “cannot understand that you have this condition. They...just laugh at you.” Additionally, a 14-year-old stated, “You see that I cannot talk straight, I talk...a bit weird.... And also, I do...things due to my condition, so they teased me a lot.” Most adolescents thought they were being stigmatized due to their SB and consequently tended to have negative feelings about themselves, especially in school. One 13-year-old believed that stigma and bullying occurred because other children did not have enough

understanding of SB. For instance, another 13-year-old explained, “I have been teased and bullied because some other kids...do not understand my condition. They think that it is the worst condition...a bad condition that someone cannot live with.” It was evident that stigma and bullying took a variety of forms, such as laughing at adolescents with SB, pushing them, and interfering with their activities. For example, a 14-year-old described undergoing physical torment and stated, “the schoolboys, they always like bullying us when we are playing together. They like to interfere with the play.” Most of the adolescents indicated that stigmatization by peers was the largest challenge that prevented them from engaging in social activities.

Parental Protection/Restrictions. Adolescents highlighted parents’ placing restrictions on aspects of their social life to protect them. Some parents preferred that their adolescents have a small circle of friends to protect them from stigma and bullying. For example, a 14-year-old explained, “My parents...do not want me to have many friends. They do not want me to make new friends due to bullying and stigmatization.”

Quality of Life

In this study, quality of life refers to adolescents’ perceptions of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, and concerns (Skevington et al., 2004). The themes identified within quality of life included meaning of quality of life, facilitators for quality of life, and challenges to quality of life.

Meaning of Quality of Life. The adolescents described their quality of life positively regardless of their condition. For most of the adolescents, quality of life meant being in a good mood and being able to enjoy life. This involved engaging in activities that made them happy and feeling that they were enjoying life as others did. Most adolescents believed that they experienced life best by engaging in social activities. Additionally, they believed that

participation in social life promoted their healthy development and happiness. For example, a 14-year-old said, “I can say that quality of life is the extent to which I can do something or...actually...gain happiness in life.” Also, a 12-year-old adolescent defined quality of life as follows: “I think life [is] about being happy and being loved. And I’m happy and have [a] good family. I can live normal[ly] despite my condition.”

Facilitators for Quality of Life. The facilitators for quality of life included factors that made quality of life better or made life easier. The facilitator subthemes included school, family, and peer facilitators. In general, schools, family members, and friends played a major role in providing adolescents with SB with support and courage, thus contributing to their quality of life.

School Facilitators. Most of the adolescents believed that their schools’ well-laid out systems played a major role in developing their social life and maintaining their quality of life. For instance, a 14-year-old said that when faced with stigma, “I do...have [a] support system, including my friends, my father, my mother, [and] the school administration.” Another, 12-year-old experienced support from “a close friend because they don’t judge my condition, they are supportive, [and] they can come over...every weekend.”

Family Facilitators. Adolescents considered family members to constitute their primary social network in life. For example, a 14-year-old stated, “I don’t think I have a lot of challenges because my family has done a lot [for] me, so I feel like I’m comfortable the way I am.” Another 14-year-old considered their mother to be their primary support system, explaining that “My mom take[s] care of me most of the time. She likes to tell a lot of stories. She knows the mysteries, and she tells stories, gives me advice [for] how to deal with [a] situation, and mentors [me]. She tells the steps to take...to deal with the situation.” Thus, family members made a major contribution to adolescents’ quality of life.

Peer Facilitators. Adolescents acknowledged the importance of supportive peers who provided assistance, encouragement, and support that contributed to their quality of life. The adolescents shared their experiences of stigma and bullying with these peers and tended to stay with them to form a comfort zone. For example, a 14-year-old explained, “Sometimes I stay with friends who are kind to me, always staying with me, because others tease me. So, I don’t want to stay with [those who tease me] most of the time.”

Challenges for Quality of Life. Another theme that emerged was challenges for quality of life, which consisted of the subthemes of stigma and bullying, struggling with physical activities, and financial challenges.

Stigma and Bullying. Adolescents with SB experienced stigma and bullying when attempting to build rapport and relationships with others their age. For instance, one 13-year-old explained, “when I tried to get some close friends, I was stigmatized. I was isolated by others. Yeah, it is hard.” In addition, a few adolescents experienced stigma and bullying because of their limited cognitive abilities. For example, a 14-year-old stated, “at first, they stigmatize because [my] cognitive skills are a bit low, not like other friends of mine, so they stigmatize me about that....They told me that you are not able to make it....I feel sometimes I am angry.”

Struggling with Physical Activities. Most of the adolescents stated that they experienced challenges in engaging in physical activities. For example, most said that they experienced pain when they engaged in activities such as playing football. Others said that they could not do physical activities as well as other children, including swimming, jumping, or even moving around. One 14-year-old explained,

The challenge is like I cannot...play or swim for a bit more time...Maybe I can do some activities...slightly [but] not [for] a lot of time. I cannot maximize our time, and I can be only active for [a] small time. I cannot do the activities like other people.

In addition, another 14-year-old stated, “I...like playing football, like rolling like other kids. Maybe I’m jumping high. I am not comfortable with that.”

When adolescents were asked about what helped them with their physical activities, most stated that camps and programs, such as guidance and counseling programs in school, were the best approach. For instance, a 14-year-old said, “Can you tell me about any programs or camps? It is very helpful to me. They are...able to support me well [in] my journey [with] this condition.”

Social Adjustment

Social adjustment can be defined as “the degree to which people engage in competent social behavior and adapt to their immediate social context” (Romera et al., 2016, p. 2). The themes of social adjustment were the importance of social life to quality of life, similarities to versus differences from other adolescents, adolescents’ perceptions about themselves/protective factors, and benefits of social/daily activities.

Importance of Social Life to Quality of Life. When adolescents engaged in social life through playing, they tended to boost their mood, enjoy themselves, and perceive improved physical and mental health. A 14-year-old described social life as fun and enjoyable, explaining that “what fun mean[s] to me...is hang[ing] out with my best friends and parents.” Another, 12-year-old adolescent expressed that social life “can prevent me from [becoming constipated and] can help me to achieve and maintain [a] healthy weight.” Also, a 13-year-old said that my “social

life is important for me because [it promotes my] mental development [and] improves my mental health.”

Similarities and Differences with Other Adolescents. When adolescents were asked about their similarities to their peers, most saw themselves like other adolescents without chronic health conditions. Adolescents believed that participation in social activities was an important factor to be similar to peers without SB. For instance, a 14-year-old adolescent claimed, “I consider myself similar to other kids. I do not consider myself as different because...the activities that they are doing, like table tennis [and] doing puzzles,” were the same as what the adolescent did.

Adolescents’ Perceptions about Themselves/Protective Factors. Adolescents’ perceptions about themselves were generally positive. Individuals described themselves as having positive personality traits such as humility, high self-esteem, honesty, trustworthiness, loyalty, self-control, a good work ethic, and respect for others. As one 13-year-old said, “For me, I can say that I am a child with...good moral values. I always listen to what my parents say, and I am humble.” Another 13-year-old also stated that they were “humble” and yet “a person with high esteem.” This adolescent added that “despite the fact that I [was] born with that condition, I have high esteem with my friends.” Also, a 14-year-old said, “I am respectful...I’m humble and always kind to other students in school.”

Benefits of Social/Daily Activities. Adolescents emphasized the benefits that resulted from engagement in social and daily activities, such as a boost in their mood, enjoyment, and perceived improvements in their physical and mental health. A 14-year-old described social life in terms of fun and enjoyment, explaining “what fun mean[s] to me...is hang[ing] out with my best friends and parents.” Also, 12-year-old expressed social life “can prevent me from [becoming constipated and] can help me to achieve and maintain [a] healthy weight.”

Furthermore, a 13-year-old said my “social life is important for me because [it promotes my] mental development [and] improves my mental health.”

Family/Parenting

Adolescents commented on family and parenting in terms of their perception of family’s ability to promote their physical, emotional, social and cognitive development (Brook, 2012).

The related themes that emerged included good family relationship/family engagement and adolescents’ expectations/perceptions about parents.

Good Family Relationship/Family Engagement. Good family relationships and togetherness helped to reduce the overall impacts of SB on adolescents. Most adolescents described their relationships with family members as good, close, and supportive. They also indicated that their family members, particularly their mothers and fathers, were their primary supporters. Moreover, some adolescents stated that their parents treated them like other children regardless of their SB. For instance, a 13-year-old stated, “My family, I can say that they are a very nice loving family. Yeah, we are four. My family has been very close with me in this condition; they supported me in this journey with my condition.” Similarly, a 12-year-old commented, “My mom and dad are generous people, and they love me as their son, and regardless of my disorder they do treat me like other kids, and likewise, they want me to display things in the house like other kids.”

Although both mothers and fathers were considered the primary supporters, two adolescents described their mothers as the primary supporters due to their intense devotion. A 12-year-old stated, “My mom is loving and caring. I think she is my closest person. My dad only brings me the presents just like the rest of my siblings, and I do not feel neglected; they are always there for me.” Additionally, a 14-year-old said, “My family is good, they are okay. Perhaps it’s

fun...when my dad is not always around. We [my mother and I] always go to enjoy ourselves. Maybe we go swimming, playing, dancing, and play with my older brother.” On the other hand, various adolescents said that they spent a great deal of time with their fathers. For example, “I enjoy my dad’s company. He is like a mentor to me. Sometimes we go spend time with my family together; sometimes we swim all of us.”

Adolescents’ Expectations/Perceptions about Parents. Adolescents’ expectations and perceptions about their parents encompassed their social activities, friends, and social life as well as their parents’ strength.

Social Activities. When adolescents were asked about their parents’ expectations concerning their social activities, they indicated that their parents encouraged them to engage more, with some parents encouraging more social activities regardless of adolescents’ limitations. In addition, parents’ encouragement was manifested in actions such as taking their adolescents to social activities, teaching them how to make more friends, and facilitating friendships. A 13-year-old stated, “My parents have high expectations of me. They want me to be active in the social activities. Yeah, I think...that my parents want me to make more friends and do more social activities.” Also, a 14-year-old said, “My parents expect me to engage in activities that make me happy [with a] few friends.”

Friends. On the other hand, some adolescents said their parents insisted that they have few friends in order to protect them from friends’ inappropriate behavior, such as stigmatizing behavior and bullying. In addition, they emphasized that their parents wanted them to have friends who were supportive and helpful in meeting their individual needs. One 13-year-old stated that their parents “don’t expect much from my social life. They just expect me to moderate my social life with a few friends who can help me out in difficult times.” Also, another 13-year-

old said, “Sometimes my mom feels...low expectations because she is very strict about [my] having more friends. Sometimes I...feel that I can have more friends, but... more friends are trouble, so I have not [made them].” This adolescent added, “My mom has low expectations because she doesn’t want me to have many friends. Yes, they are inviting trouble. [She says that] just the five you have is enough friends to support [you].”

Social Life. Most of the adolescents highlighted the importance of social life because it fostered emotional and physical health. Due to SB-related limitations, adolescents’ social life relied on their friends and family members. For example, a 13-year-old adolescent explained, “Generally, my social life [involves] my friends. They are able to assist me with my condition, and even my siblings and my mother...socially supported me a lot, and I appreciate that.”

Parents’ Strengths. Positive traits of parents were acknowledged by adolescents, and these traits impacted their perceptions of their parents as a whole. Adolescents viewed parents as loving and caring and as treating them fairly. For example, a 12-year-old stated,

“My mama and dad, they are generous people, and they love me as [their] son.... I have [a] disorder, [but] they do treat me like other kids, and they want me to display things in the house like other kids [do].... My parents [are] always hard working, [and] they want to make sure that the time I get is valuable. They do want to keep me around, and they get [help from] my neighborhood when [needed]. It is very important.”

Peers

Adolescents discussed their peers, meaning members of their societal group in terms of age, grade, or status (Merriam-Webster, 2003). The peer-related themes identified were the benefits of friendship, the challenges of making friends, and the number of friends (with most adolescents mentioning three to four friends or close peers).

Benefits of Friendship. Despite their difficulties forming friendships, most adolescents expressed the importance of having friends for various reasons. For instance, one 14-year-old said that a friend was someone “who can support me in difficulties [and] who comes and helps me when I’m in pain. Yeah, [a] friend is always with me despite what I am facing.” Also, some adolescents felt that having friends increased their self-esteem. For example, a 13-year-old stated that friends improved their self-esteem by engaging in activities with them, making them laugh, and supporting them during difficulties. In addition, a 12-year-old adolescent said, “Social life for me is critically important because it can promote my self-esteem.”

Some adolescents even reported that their friends were as important to them as their family members. For example, a 14-year-old said, “My friends...I may see if they are like part of my family. You have a lot of time for them. Yeah, I mean it’s so important to me.” Adolescents described friends as being supportive and encouraging when they faced issues related to their disability. For instance, a 13-year-old commented, “Generally, my social life is my friends--they can assist me with my condition.”

Challenges of Making Friends. Challenges of making friends constituted another theme. Its subthemes included difficulties in making friends and drug use among adolescents’ acquaintances.

Difficulties in Making Friends. When asked about their ability to make friends, most adolescents said that their difficulty making friends was a major challenge to their social life. Adolescents explicitly stated that their inability to make friends was due to their limited ability to engage in the activities that their healthy peers performed. For example, when asked about their ability to form friendships, a 13-year-old said, “I cannot create many friends. I cannot engage in more social activities like my friends who are normal.” Also, a 12-year-old said, “I do not like

[the fact that] I cannot make many friends with the disease. Some of the friends...cannot be okay with you. At some point, they just go away.” In addition, a 13-year-old stated, “the challenge I always face when developing friendships is that of isolation.”

Drug Use. Two adolescents addressed difficulties with making friends due to others’ drug use. For instance, a 14-year-old stated, “Sometimes you have friends who [are] engaged in drugs...They may end up sometimes introducing you to the drugs. I often always [stay] away from those friends. I try to go away from those friends.”

Number of Friends (three to four). Adolescents repeatedly stated that they had three to four friends. For example, a 13-year-old noted “I have actually three friends. They are really close friends. I go to my friends’ house, and they always come over.”

Parent Themes and Subthemes

Functional Status

Functional status refers to parents’ perceptions of adolescents’ ability to perform normal daily activities required to meet basic needs, fulfill usual roles, and maintain their health and well-being (Leidy, 1994). The themes identified within functional status for parents were facilitators of performing social/daily activities and SB-related challenges of performing social/daily activities.

Facilitators of Performing Social/Daily Activities. Parent-perceived facilitators of performing social and daily activities were factors that made social life better or easier for adolescents with SB. The subthemes identified were social activities with family and friends, wheelchair users, parents’ role, and school programs.

Social Activities with Family and Friends. Parents spent most of their time in a variety of activities with the adolescents and their friends. Also, family members, including mothers,

fathers, and siblings, were the primary individuals who interacted and engaged with the adolescents. For example, one parent stated, “I can say I usually engage with him mostly. And actually, he has two brothers and one sister, [and] they sometimes also engage with him.” Another parent stated, “He usually engages with me and his mother and some of his friends around our house.”

Parents felt that their adolescents enjoyed activities, especially with friends of their age. For instance, one parent stated “I can say that [among] the activities he usually does...he has been going out with his friends to play basketball. Sometimes he tells me that [he is] crawling with [his] friends, yeah, and even playing some cards with his friends.”

Wheelchair Users. Some of the adolescents with SB who used a wheelchair had more freedom to move around, engage in activities, and feel like part of the community. Wheelchairs helped adolescents to live full and active lives, regardless of their SB limitations. For instance, one parent of an adolescent using a wheelchair stated that, “My son likes swimming, crawling [in] the tunnels, rolling over the mat or pillow, [and] sometimes likes pushing.” While, others considered using wheelchair as challenge, as one parent said that, “the challenge [is] that he is in a wheelchair where he needs assistance and [experiences] pain.”

Parents’ Role. Parents played a central role in adolescents’ lives, and this role included helping with activities, initiating friendship for their adolescents, giving the right medication, and supporting and motivating them during difficult times. For example, a parent explained that, “Sometimes I do assist him, but I mostly encourage him to participate independently in some of the activities. But the activities he cannot do alone, I do help him.” Another parent said that, “I help him through...talking with him and then through finding some friends who can help [him] and [provide] understanding. He came through it.”

School Programs. Parents emphasized the importance of school programs, particularly those providing guidance and counseling. Teachers played a primary role, as one of the parents explained “The teacher talks with them [and] tells them about the importance of being together and tries to talk with them every day, [encouraging them] to be together and...also to engage and make more friends.” Another parent stated, “I am always taking him to programs in school so that some of the other kids can realize about his condition as a person [who] likes camping and [guidance] and counseling.”

Challenges of Performing Social/Daily Activities. SB-related challenges of performing social/daily activities included three subthemes: condition-related challenges, stigma and bullying, and parental protection.

Condition-Related Challenges. Most parents reported that their adolescents with SB had various difficulties with engaging in activities. Condition-related challenges were described as needing assistance, stigma and bullying, pain and skin problems, cognitive-communication disorders, time constraints on activities, and using a wheelchair.

Adolescents with SB tended to depend on others, particularly their parents, while engaging in social and daily activities, and thus the presence of parents was essential for adolescents’ engagement in social life. For example, one parent said “I have to engage with him sometimes and with friends and with siblings sometimes. He needs help, like pushing [his] wheelchair, [because] he cannot do it alone. Also, [he needs help with] washing his clothes.” Another parent explained “At some point, things like serving the food and even rinsing and washing his clothes, he cannot do it for himself. The things my son needs help with [include] hanging the clothes. He only washes them. He has problems with [his] back, [and] at some point he feels pain, so I can assist him by, like, [hanging] clothes outside.”

In addition, adolescents suffered from pain and skin sores due to SB. One parent reported “He has a lot of skin sores and a lot of pain, so there are a lot of difficulties he is facing...in adolescence, and he cannot engage in all those activities.”

Parents talked about cognitive-communication disorders in adolescents with SB, particularly myelomeningocele. For instance, one parent said, “He has less attention, I can say [a] short attention span, and maybe difficulty in solving problems when he is annoyed with little things.”

Another challenge related to SB was time constraints on activities, as some adolescents had difficulties with playing for a long time because they tired easily. For instance, a parent stated, “He is not able to spend a lot of time with his friends or go [to] other friends’ houses, yeah, things like that.”

Stigma and Bullying. Parents maintained that adolescents experienced stigma and bullying due to their SB, mainly in school. The stigma and bullying took a variety of forms, such as despising adolescents, isolating them, laughing at them, pushing them, and others. For example, one parent stated that, “he has been despised [by] friends, and he has been isolated because he has not been able to maintain his stability for a long period of time.” Another parent said that, “My son, he hasn’t developed many friends...Because my son suffers from spina bifida...they always at some point laugh at him.” In addition, the stigma and bullying that adolescents experienced in the school setting negatively impacted their relationships with others. For instance, one parent explained that, “He does not engage with many friends. You know, the friends from school, at some point they can laugh at him [because] he’s very weak [and] he’s not even able to control the ball well like the other kids.”

Parental Protection. Parents highlighted a range of protective roles and attitudes they held with respect to their adolescents with SB. A few parents were concerned about the possibility of their adolescents' using drugs and wanted to protect them. For example, in talking about their son's social activities and making more friends, one parent said that "he cannot most of the time go and make friends [because] for example, many times friends try to engage him in drugs."

Quality of Life

In the context of the parent interviews, quality of life referred to parents' perceptions of their adolescents' position in life within their culture and value system and in relation to their goals, expectations, and concerns (Skevington et al., 2004). The themes that emerged were the meaning of, facilitators of, and challenges to quality of life.

Meaning of Quality of Life. The definition of quality of life expressed by parents involved the degree to which adolescents could enjoy life and be happy. For example, one parent defined quality of life as "the degree of enjoying life [and] living happily." Another parent said that, "Quality of life actually means a lot. I can say that [it is] the degree or the extent [to] which [one] is able to see life [and] to enjoy life [when one] comes upon challenges [in] life."

Facilitators of Quality of Life. This theme involved facilitators of quality of life, which were viewed as factors that made quality of life better. The subthemes included school, family, and peer facilitators.

School Facilitators. In school, teachers played a vital role in addressing stigma and bullying issues that detracted from adolescents' quality of life. School teachers actively prevented stigma and bullying by enforcing applicable rules and stating that students had to be

treated equally. For example, a parent said that, “I visit schools, and...I can tell the teachers, and then they can solve conflicts and [provide] counseling.”

Family Facilitators. Parents supported and initiated actions to improve their adolescents’ health and well-being. Additionally, parents took action to help their adolescents build friendships with others. One of the parents explained that, “I took him to people in the church. Then he [could] talk. We had dinner together, and then we [could] share a number of activities that other people [were] doing.”

Peer Facilitators. Parents stated that the peers and friends of adolescents with SB were important facilitators of their quality of life. For instance, one parent said that, “The friends that he has helped him a lot to have some confidence and to remove [his] fear of participating in social activities.”

Challenges to Quality of Life. The fifth theme arising from the parent interviews was challenges to adolescents’ quality of life. The subthemes that emerged were stigma and bullying, struggling with physical activities, and financial challenges.

Stigma and Bullying. Parents noted that their adolescents complained about experiencing stigma in school and that this in turn impacted their relationships with others. For example, a parent said that stigma “Does reduce the relationship with...friends...because of bullying and teasing in school.”

Struggling with Physical Activities. Parents said that most adolescents with SB struggled with some activities such as football, jumping, swimming, and traveling. One parent explained about a daughter, “She cannot engage in activities like football.” Another parent explicitly stated that their adolescent was unable to fully participate in activities due to her condition. For instance, the parent said that, “Obviously, there’s some things she can’t even do, like the

swimming. Yeah, those are some of the...social activities that she cannot engage in, that the condition [affects].”

Financial Challenges. One parent acknowledged that financial concerns presented a challenge to their adolescent’s quality of life. This parent stated that, “The challenge [is] like financial...If I want to take him to vocational activities, which are very expensive, at some point, maybe I don’t have the money and it’s becoming a big challenge to take him. I cannot at some point. I can see that I have to do more hard work so I can make everything right for him.”

Social Adjustment

Social adjustment can be defined as “parents’ perceptions about the degree to which adolescents engage in competent social behavior and adapt to the immediate social context (Romera et al., 2016). The themes of social adjustment were the importance of social life to quality of life, benefits of social/daily activities, similarities and differences with other adolescents.

Importance of Social Life to Quality of Life. As a sixth theme, parents emphasized the importance of their adolescents’ engagement in social life to their quality of life. Parents said that through playing, adolescents tended to boost their mood, enjoy themselves, improve their physical and mental health, and feel like children without chronic health conditions. Speaking of their daughter, one parent noted that social life was “very important to her. It [keeps] her happy [and] busy, and she is hanging out with friends. She is being normal, I mean [living] a normal life, just like the rest of [her] friends, it is very important to her to have that part in life and experience it.” Another parent had similar views, stating that social life was “very important, since you know these social activities...promote the healthy growth and development [of] my

son. It makes strong bones...and again, they do balance, and also it maintains and develop the flexibility of the joints.”

Benefits of Social/Daily Activities. The seventh theme was the benefits of social/daily activities. Parents felt that these activities improved the physical and mental health of their adolescents. For example, speaking about their son, one parent said that, “I want him to develop mental health and even to grow and develop and to be happier [at] all times. I don’t want him to be sad.” In addition, this parent said that activities “[pushed] his mentality and knowledge. He gets a lot of knowledge he shares between people. You know, my son gets to know the things that he doesn’t know at some point...And my son promotes even [his] health. [He needs] strong bones [to] maintain and develop flexibility.”

Similarities and Differences with Other Adolescent. In this eighth theme, most parents saw their adolescents as being similar to othered adolescents regardless of the challenges relate to SB. For instance, one parent stated about their son, “It’s not different since he is doing [things] like other kids.” And another parent said that, “They are similar. I do not think they are different because when I check the activity of other kids, [it] is close to [the activity of] my son.”

Family/Parenting

Parents commented on family and parenting in terms of their “perception of family’s ability to promote their physical, emotional, social and cognitive development” (Brook, 2012). The related themes that emerged included good family relationship/family engagement, and parents’ expectations/perceptions about their adolescents.

Good Family Relationships/Family Engagement. For the ninth theme, most of the parents said that they had strong and supportive relationships with their adolescents with SB. For instance, one parent stated, “I say about me and my son that we have strong relationships. We are

being together. I spend good time together with my son. I have been supporting him for a long time, since he [was] born with this condition. I have been with him all along, and...we are good together.” Parents also expressed loving and caring attitudes toward their adolescents. For example, a parent said that, “My relationship with my son is...good. In fact..., I love him so much...I do love him [and] I care a lot for him, and I want him to get all what he decides.”

Parents’ Expectations/Perceptions about their Adolescents. The tenth theme was parents’ expectations/perceptions toward their adolescents. The subthemes identified were social activities, relationships with friends, having a normal life, adolescents’ strength/protective factors, physical challenges, experience of nurturing a child with SB, being born with SB, and social life.

Social Activities. Parents varied significantly in their attitudes toward adolescents’ social activities, as some parents preferred that their children engage in more and different activities, while others preferred involvement in simple activities where the children felt confident. For example, one parent stated, “I just expect him to...come along with doing the social activities well to participate.” On the other hand, a few parents expressed distinct perceptions regarding the realities of having SB. For instance, in speaking about their son, one such parent explained that, “I don’t really expect him to participate that much....because [with] the condition, now...he needs to be assisted, so I don't expect much participation.”

Relationships with Friends. Some parents encouraged their adolescents to have more friends, but some parents insisted on keeping the circle of friends small. For example, in talking about their son, one parent stated that, “I tell him to keep the circle [of] friends small [and] not [to engage...with bad...friends.” Another parent said that, “I don’t expect [him] to live with a lot of ...friends, yes, because I feel not everyone really understands him because of the condition.”

Having a Normal Life. Many parents said that their adolescents with SB engaged in normal activities like others regardless of their limitations. For example, one parent explained that, “My son, he was born with spina bifida, and then I took him to the hospital, and he has...recovered very well, and he is doing all the things that normal people do.” Most of the parents also expressed positive perceptions about their adolescents’ living a normal life. Also, adolescents’ participation in social activities was viewed as an important predictor of their being children without chronic health conditions. For instance, one parent said that in “my relationship with [my] daughter..., we usually talk like a mom [and] daughter....Therefore, whenever she needs me...to help her with standing, she only [wants to] have fun when she’s playing....I always make her feel normal like the other children.”

Adolescents’ Strengths/Protective Factors. Positive adolescent attributes described by parents included the children’s being honest, kind, hard-working, and generous. For instance, one parent said about their son, “He is honest, yeah, so generous [and] obedient, so he’s [a] good boy.” Another parent said that, “My son is confident. He loves playing. He loves to interact with...four friends, and at some point, he is also easy-going.”

Physical Challenges. Parents expressed low expectations of their adolescents engaging in activities due to physical challenges related to their SB. Speaking of their son, one parent said that, “[My] expectation is low. I do not expect him to do much because he is straining most of the time. Like pain, there is pain [bouncing off his] skin.”

Experience of Nurturing a Child with SB. Based on their experience of nurturing their children, parents felt that their adolescents’ handling of their SB was improving as they got older. This improvement resulted in adolescents’ development of social and communication skills. For example, a parent said that, “He has been improving...When he was a kid, at some

point he [had no] friends. So it's like [as] he is growing up, he is engaging...with friends, he can ...socialize with friends and things like that.' This parent added, "You [wouldn't have known] when he was young, [but] he can now [help] in the house. Yes, he can manage...to understand everything, [including] that this is something [he has been] born with... so he has to cope with it."

Being born with SB. Parents acknowledged that their adolescents were born with SB due to a genetic condition. As one parent explained, "[My] son [got] the genetic problem when he was born. He developed that genetic disorder in the hospital...We have been told that this is a disease, but it is about [a] genetic disorder."

Social Life. The importance of adolescents' social life was acknowledged by many parents, as it helped their children to learn skills, interact with others, and grow. For instance, a parent explained that, "It's very important..., you know, interacting with other people. You get to learn some new skills and even develop open minds and even make [them] stronger and have...feelings about the world."

Peers

Parents defined their adolescents' peers as members of their societal group in terms of age, grade, or status (Merriam-Webster, 2003). The peer-related themes identified were the benefits of friendship, and the challenges of making friends.

Benefits of Friendship. As an eleventh theme, parents said that friends played a vital role in their adolescents' lives. This role took a variety of forms, such as providing assistance, encouragement, and support. For instance, one parent said about friendship, "It is important because he needs assistance...He cannot make it alone, so I think the relationship is important for him." Also, this parent said that, "[Friends] do help him as much as they can."

Challenges of Making Friends. The twelfth theme involved challenges of making friends. The subthemes identified were stigma and bullying and SB related conditions.

Stigma and Bullying. Parents noted that their adolescents experienced stigma and bullying, mostly in school. For example, discussing their son, one of the parents stated that, “The friends from school, at some point, they can laugh at him [because] he’s very...weak [and] he’s not even able to control the ball...like the other kids in school.”

SB-Related Conditions. Adolescents suffered from limited relationships with others due to SB-related conditions. Speaking of their son, one parent said that, “He cannot stand or maintain stability so [he cannot have a] relationship with the other kids that...are normal.” Another parent explained that, “It is hard to find a friend who can understand him that easy and also friends that [are] willing to help him around.”

Similarities and Differences between Adolescent and Parent Perceptions

In this study, both the adolescents’ and parents’ interview responses reflected the theoretical concepts of adolescent adjustment and social factors. For example, all the participants discussed adolescents’ adjustment to new environments and their engagement in social activities. Adolescents with SB and parents showed similarities in their responses regarding adolescents’ limited ability to perform normally in various contexts and to meet their own basic needs. Both groups acknowledged that the adolescents faced several SB-related challenges in attempting to engage in normal activities. These included feeling pain while walking, experiencing cognitive-communication disorders and skin problems, needing physical assistance, and taking more time to get things done. In addition, both groups recognized that the adolescents faced stigma and bullying due to their condition and had to function within parental restrictions.

Adolescents' and parents' perceptions also showed various similarities with respect to quality of life, societal values, goals, and expectations among the adolescents. Both groups indicated that the primary facilitators for improving the adolescents' quality of life originated with school, family, and peers. Adolescents and parents shared similar insights as to facilitators that would take the initiative to help the adolescents, these included teachers at school and the family at home. In addition, the adolescents and parents both indicated that the children faced challenges from stigma and bullying and from struggling with physical activities.

Several similarities also emerged in terms of how the adolescents and parents perceived engagement in competent social behavior and adaptation to social contexts among the children with SB. Both adolescents and parents acknowledged the importance of social life in improving the adolescents' quality of life.

Adolescents and parents also agreed that good family relationships and engagement in social activities were essential in promoting the physical, emotional, and cognitive development of children with SB as they moved toward adulthood. Adolescents and parents also shared similar perceptions about the factors negatively affecting the adolescents' ability to make friends, including stigma, bullying, and having to gain acceptance from peers.

Interview responses also revealed various differences in adolescents' and parents' perceptions about the adolescents' social functioning and the expectations of the parents. For example, some parents felt that their adolescents' social activities should extend beyond the school and family context and to the community, but no adolescents expressed this view. Regarding adolescents' functional status, some parents perceived that their children with SB benefited from wheelchair use as a facilitator for performing their daily activities. Among the adolescents, depending on their mobility status, some recognized the need for their use of a

wheelchair, and others felt that they could instead depend on support from their friends and families for facilitation.

In addition, parents perceived that their children with SB would have a normal life, be like children without health conditions, develop relationships with others, possess self-protection characteristics, and be nurtured by other children with SB, all while experiencing physical challenges. However, adolescents perceived that they needed the support of their friends and parents to promote their physical, emotional, and cognitive development.

With regard to their peers, two adolescents with SB were concerned about becoming involved in drug abuse within their social group. In addition, two parents of other adolescents expressed this concern regarding their children. However, most parents expressed concern about stigma and bullying, hoping that their adolescents would make friends with others having similar conditions and with peers in their social group. Stigma and bullying were considered a significant challenge for social life by both adolescents and parents.

Finally, parents' perceptions about their adolescents' social activities and friends also differed somewhat. For example, some parents encouraged their adolescents to engage in more activities and have more friends regardless of their SB challenges. In contrast, other parents preferred that their children with SB confine themselves to simple activities that they were confident in performing and that they limit themselves to a small circle of friends in order to protect themselves from stigma and bullying.

Parents played a central role in encouraging adolescents with SB to meet their basic needs and to engage in activities both within and outside the home. Adolescents described family members, particularly their mother and father, as highly supportive and as contributing to their motivation to live their life fully.

Discussion

This study was conducted to explore the perceptions and expectations of adolescents with SB and their parents regarding the adolescents' social functioning. The specific aims of this study were to (a) describe adolescents' and parents' perceptions of facilitators of and challenges to social functioning, (b) describe parents' perceptions and expectations of social functioning for their adolescents, and (c) describe adolescents' perceptions of parents' expectations. The significance of the study findings with respect to each of these aims is discussed below.

Aim 1: Describe adolescents' and parents' perceptions of facilitators of and challenges to social functioning

The themes that emerged under the Aim 1 were facilitators of performing social/daily activities and SB-related challenges of performing social/daily activities. A major finding of this study is that despite their various SB-related challenges, including mobility limitations and need for assistance, cognitive and communication impairments, pain and skin problems, being unable to be active for very long, and stigma and bullying, adolescents with SB maintain supportive relationships with their families. The challenges observed are consistent with Bellin et al.'s (2007) results, in which stress resulting from daily SB management, including self-care and health monitoring as well as daily living tasks such as dressing and physical transfers, also emerged as a common challenge encountered by adolescent females across developmental stages. In this study, although participants were mostly male, adolescents and parents said that they had a supportive and cohesive family similar to adolescent females and in the present study, the nine male adolescents as well as the single female all viewed their family lives in much the same positive way (Bellin et al., 2007). On the whole, additional research is needed to better

understand the different challenges that adolescents with SB face in daily life as well as the importance of having a support system across their developmental stages.

Aim 2: Describe parents' perceptions and expectations of social functioning for their adolescents

Once again, multiple themes emerged under study Aim 2. These themes included meaning of quality of life, facilitators of quality of life, challenges to quality of life, the importance of social life to quality of life, benefits of social/daily activities, similarities and differences with other adolescents, good family relationship/family engagement, parents' expectations/perceptions about their adolescents, benefits of friendship, challenges of making friends, and having “three to four” friends.

Based on the study findings, parents tended to perceive that the rate at which their adolescents showed progress in behaving competently corresponded with the adequacy of their social adjustment. However, the rate of social adjustment does not necessarily translate into improved quality of life (Lawson et al., 2018). In fact, their condition often results in adolescents with SB feeling lonely and requiring a change of environment to reduce their sense of isolation. Ideally, their social adjustment results in better relationships with others and in making friends outside school, which in turn helps adolescents with SB to avoid social difficulties in adulthood (Kritikos et al., 2020). Moreover, social adjustment reduces the adolescents' risk of depression and thus may improve their quality of life. Furthermore, social adjustment can help adolescents with SB to achieve sexual maturity and gain diverse social experience like their peers without chronic health conditions (Kritikos et al., 2020).

It is evident from the study that parents generally believed that their adolescents could engage in social activities and have a normal social life regardless of related difficulties. Thus,

from a psychosocial perspective, the study findings indicate that the resilience demonstrated by a family plays an important role in improving the social behavior and outcomes of an adolescent with SB. Family resilience was found to promote positive parenting, and children appeared to emulate their parents' resilience and develop self-esteem rather than aggressive or depressive characteristics. These findings are consistent with those of Bellin et al. (2007), who evaluated the experiences of adolescent females with SB and found that a close relationship with parents was a significant source of strength for them.

Findings from the present study suggest that parents considered school, family, and peers to be facilitators for improving adolescents' quality of life in ideal circumstances. In addition, study results indicate that parents viewed their adolescents' engagement in sports as improving their muscle function and enhancing their quality of life. However, parents recognized that challenges such as stigma and bullying, financial constraints, and adolescents' struggles with physical activities often detracted from their quality of life. Similarly, Thong et al. (2019) found that given the nature of SB, adolescents and their parents encountered various emotional, environmental, and physical challenges that limited the children's desired quality of life.

Aim 3: Describe adolescents' perceptions of parents' expectations

Multiple themes emerged under study Aim 3. These included facilitators of quality of life, challenges to quality of life, the importance of social life to quality of life, similarities and differences with other adolescents, adolescents' perceptions about themselves/protective factors, benefits of social/daily activities, good family relationship/family engagement, adolescents' expectations/perceptions regarding their parents, benefits of friendship, challenges of making friends, and having "three to four" friends.

Study findings showed that the benefits of engaging in social activities were fully recognized by adolescents. Similarly, Verschuren et al. (2012) found that adolescents with physical impairments recognized the psychosocial and physical benefits of sports engagement. Moreover, social functioning has been shown to promote self-esteem, in turn facilitating good health and functional independence (Levasseur et al., 2010). Both Verschuren et al. (2012) and the present study revealed that adolescents understood the benefits of being engaged in activities to their social, physical, and emotional well-being.

Adolescents' perceptions regarding their parents' expectation varied significantly. According to the adolescents, some of their parents encouraged them to have more friends and to engage in different activities, while other parents preferred to keep their circle of friends small to protect them from stigma and bullying. As for adolescents' perceptions of parental expectations regarding their school performance, the study participants did not directly comment on this matter, and previous research in this area is absent from the SB literature. However, studies have shown that healthy students whose parents held high expectations tended to earn higher grades, achieve higher scores on standardized tests, and persist longer in school than those whose parents had relatively low expectations (Davis-Kean, 2005; Pearce, 2006; Vartanian et al., 2007). Clearly, parents' expectations for the academic achievement of adolescents with SB and adolescents' perceptions of those expectations require future research.

An important study finding is that parent participants in the study viewed their adolescents with SB as being similar to other children from a social perspective. However, in a previous study that investigated the experiences of adolescents with SB and their parents with respect to social participation and peer relationships, most parents interviewed did not view their children as "typical" (Bakaniene et al., 2018). This inconsistency in research results highlights

the need for additional research to more comprehensively understand parents' views of their adolescent children with SB and the factors affecting their perspectives. The sample in this study was unusual. Adolescent participants were mostly African American males (9 of 10) and participating parents mostly dads (7 of 10); 7 of 9 pairs were dads/sons. This study gave voice to an often "unheard" population.

Study Limitations

This study applied content analysis to interview data supplied by 10 adolescent-parent dyads to achieve the study aims. First, because all interviews were conducted and recorded using a video conferencing platform (Zoom), accurate transcription of the interview content was sometimes problematic as it was sometimes difficult to determine specific words from the recording. In addition, although thematic analysis has been shown to be effective in evaluating qualitative data, it is subjective in nature and is susceptible to research bias. Furthermore, this study probably involved social desirability bias, as interview participants were likely motivated to provide socially acceptable responses. Also, the qualitative nature of the study, the small sample size, and the fact that males comprised 90% of the adolescents interviewed all preclude generalization of the findings to the entire population of adolescents with SB and their parents. Finally, although the bio-neuropsychosocial model provided theoretical direction for this study, the PI found that this model was not entirely suitable to support the specific aims of the study. For example, the PI found that while the model includes various interrelated concepts and subconcepts relevant to the study, they were not explicitly explained by the model developers. Based on this study's findings, the family/parenting construct of the bio-neuropsychosocial model should be extended to explicitly include family relationships and family function, as they

appear to have a strong influence on both development of social skills and overall quality of life among adolescents with SB.

Despite these limitations, this study contributes to scientific understanding of the perceptions of adolescents with SB and their parents with regard to adolescent social functioning. Moreover, unlike previous studies, the present study employed a sample predominantly consisting of African American parents and male adolescent children. Thus, the findings provide a novel perspective on SB-related experiences and perceptions in this population.

Implications for Research and Practice

Based on this study's findings, the content analysis approach was found to be a practical means of interpreting qualitative data collected from parents dealing with adolescents having SB. The parent participants understood concepts that could boost their adolescents' development, particularly adolescent's engagement in social activities and family members' various contributions to adolescent's overall well-being. With this understanding, parents were able to support their adolescents more effectively, spending considerable time with them and learning about methods of behavioral modification to improve their quality of life. However, additional research is essential to direct and boost the efforts of parents in applying helpful socialization and support strategies, thereby reducing their children's stressors and improving their quality of life.

In practice settings, nurses can also contribute to the social functioning and well-being of adolescents with SB by screening them for issues such as experience of stigma and bullying. In addition, nurses can participate in development of interventions to aid parents in supporting their adolescent's social functioning. Such interventions should be tailored to the adolescent's age, their stage of development, and the severity of their SB. With effective nursing intervention,

parents can be guided to give their adolescent with SB more assistance in becoming socially active while pursuing their personal goals.

This study was performed to explore the perceptions and expectations of adolescents with SB and their parents with regard to social functioning. Supportive family cohesion and relationships were evident, and adolescents appeared to have moderate to high quality of life despite their disease. In addition, findings indicated that facilitators of adolescents' social functioning most importantly included family, friends, and school support. Principal challenges to adolescents' social functioning were stigma and bullying, pain, skin problems, and limitations in their cognitive-communication skills and ability to participate in longer physical activities.

Conclusion

Study findings showed that the benefits of adolescent engagement in social activities were fully recognized by the adolescents themselves and their parents. In addition, the adolescents and parents reported strong family ties, relationships, and support. Despite their various SB-related challenges, adolescents engaged in a variety of social activities with family members, schoolmates, and other peers that were identified as facilitators for improving adolescents' quality of life. However, the adolescents and parents both recognized that stigma and bullying from other children and the adolescents' struggles with physical activities often detracted from their quality of life. A particularly important study finding was that parents viewed their adolescents with SB as being similar to other children, their condition notwithstanding. Given the study findings, nurses and other healthcare professionals should strive to maximize the social participation of adolescents with SB regardless of their physical limitations. In particular, nurses can take advantage of their interactions with adolescents with SB and their parents and to discuss opportunities for the children's social involvement.

Additional nursing research is needed to determine how adolescents' engagement in social activities can be maximized by the adolescents and their parents.

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Table 3*Description of Study Participants*

Gender	Parent Interviewed	Age (years)	Grade	Ambulation	Race
Male	Dad	14	8	Walk independently	African American
Male	Dad	13	5	Walk with braces and walker	African American
Male	Dad	14	6	Walk with braces and walker/ Wheelchair dependent	African American
Male	Dad	14	8	Walk independently/Walk with braces	African American
Male	Mom	13	7	Powerful wheelchair	African American
Male	Dad	14	8	Walk with braces and walker/ wheelchair	African American
Male	Dad	12	6	Walk with braces and walker	African American
Male	Mom	13	8	Walk with braces	African American
Male	Dad	13	8	Walk with braces and walker	African American
Female	Mom	12	5	Wheelchair	American Indian/Indian Alaskan

Table 4

Definition/Description of Bio-Neuropsychosocial Model Concepts and Subconcepts as Applied to Adolescent-Parent Dyads

Theoretical Concepts	Theoretical Sub-concepts	Definition/Description
Social Adjustment: Parents/adolescents perceptions about the degree to which adolescents engage in competent social behavior and adapt to the immediate social context	Adolescent adjustment	<ul style="list-style-type: none"> ● Adjustments that adolescents with spinal bifida have made to adapt to their environment and participate in social activities ● These adjustments are determined by their engagement in social activities, communication, and interaction with family and friends.
	Functional status	<ul style="list-style-type: none"> ● Parents'/adolescents' perceptions about adolescents' ability to perform normal daily activities required to meet basic needs, fulfill usual roles, and maintain health and well-being
	Quality of Life	<ul style="list-style-type: none"> ● Parents'/adolescents' perception about what they think their adolescents' quality-of-life perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, and concerns
Social Factors: Social conditions that affect human behavior. Examples include socioeconomic and educational levels, environmental circumstances (e.g., crowding), and the customs and mores of the social group	Family/Parenting	<ul style="list-style-type: none"> ● The process of raising a child and promoting and supporting the child's physical, emotional, social, and cognitive development to adulthood and across the lifespan
	Peers	<ul style="list-style-type: none"> ● Parents/adolescents' perception of adolescents' belonging to the same societal group in terms of age, grade, or status

Table 5*Adolescent Interview Themes and Subthemes*

Theme	Subthemes
1. Facilitators of performing social/daily activities	<ul style="list-style-type: none"> • Social activities with family and friends • Sharing the condition with friends Family Role
2. Challenges of performing social/daily activities	<ul style="list-style-type: none"> • Condition related challenges • Stigma and bullying Parental protection/restrictions
3. Meaning of quality of life	
4. Facilitators for quality of life	<ul style="list-style-type: none"> • School facilitators • Family facilitators Peer facilitators
5. Challenges for quality of life	<ul style="list-style-type: none"> • Stigma and bullying • Struggling with physical activities
6. Importance of social life to quality of life	
7. Similarities and differences with other adolescents	
8. Adolescents' perception about themselves/protective factors	
9. Benefits of social/daily activities	
10. Good family relationship/family engagement	
11. Adolescents' expectations/perceptions about parents	<ul style="list-style-type: none"> • Social activities • Friends • Social life • Parents strengths
12. Benefits of friendship	
13. Challenges of making friends.	<ul style="list-style-type: none"> • Difficulties in making friends • Drug use
14. Number of friends (three to four)	

Abbreviation: SB, Spina Bifida.

Table 6*Parent Interview Themes and Subthemes*

Theme	Subthemes
1. Facilitators of performing social/daily activities	<ul style="list-style-type: none"> • Social activities with family and friends • Wheelchair users • Parents role • School programs
2. Challenges of performing social/daily activities	<ul style="list-style-type: none"> • Condition related challenges • Stigma and bullying • Parental protection
3. Meaning of quality of life	
4. Facilitators of quality of life	<ul style="list-style-type: none"> • School facilitators • Family facilitators • Peer facilitators
5. Challenges to quality of life	<ul style="list-style-type: none"> • Stigma and bullying • Struggling with physical activities • Financial challenges
6. The importance of social life to quality of life	
7. Benefits of social/daily activities	
8. Similarities and differences with other adolescents	
9. Good family relationship/family engagement	
10. Parents' expectations/perceptions toward their adolescents	<ul style="list-style-type: none"> • Social activities • Relationships with friends • Having a normal life • Adolescents' strength/protective factors • Physical challenges • The experience of nurturing a child with SB • Being born with SB • Social life
11. Benefits of friendship	
12. The challenges of making friends	<ul style="list-style-type: none"> • Stigma and bullying • SB-related conditions

Abbreviation: SB, Spina Bifida.

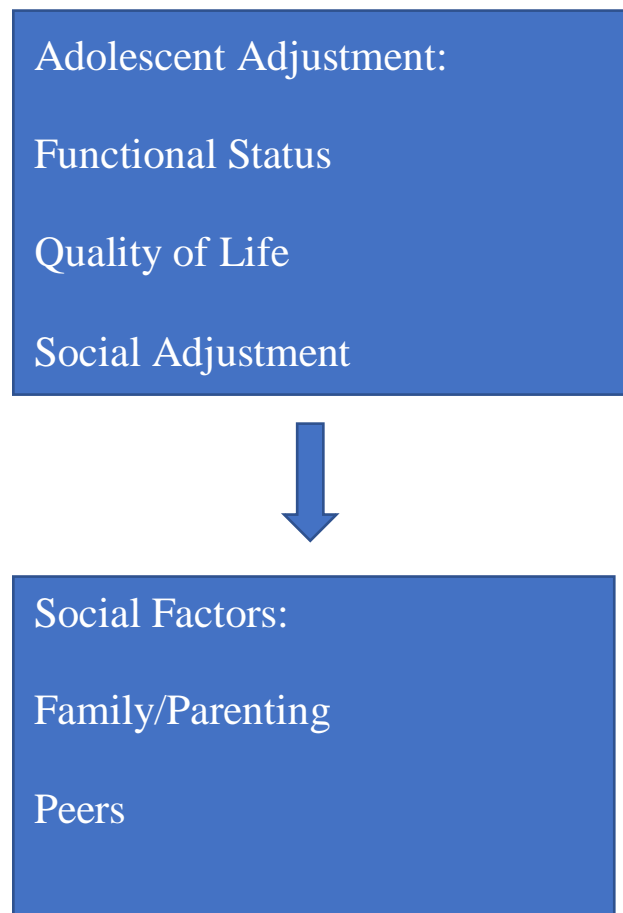


Figure 2

*Modified Theoretical Framework of Bio-Neuropsychosocial Model by Holmbeck, G. N., Westhoven, V. C., Phillips, W. S., Bowers, R., Gruse, C., Nikolopoulos, T., ... & Davison, K. (2003). Note. From "A multimethod, multi-informant, and multidimensional perspective on psychosocial adjustment in preadolescents with spina bifida. *Journal of Consulting and Clinical Psychology*, 71(4), 782. Copyright by Elsevier Ireland Ltd. Adapted with permission.*

APPENDICES

Appendix A

Demographic Questionnaire

For Parents:

1-Age:

2- Gender:

- a. Female
- b. Male

3-Ethnic category:

- a. Hispanic or Latino
- b. Not Hispanic or Latino

4-Race:

- a. American Indian/Alaskan Native
- b. Asian
- c. Black or African American
- d. Native Hawaiian or other Pacific Islander
- e. White
- f. Others, please specify

5-Highest level of education completed:

- a. Elementary/primary education
- b. Secondary education
- c. Postsecondary/higher education
- e. College

6-Marital Status:

- Married
- Widowed
- Others

For adolescents:

1-Age:

2- Gender:

- a. Female
- b. Male

3-Ethnic category:

- a. Hispanic or Latino
- b. Not Hispanic or Latino

4-Race:

- a. American Indian/Alaskan Native
- b. Asian
- c. Black or African American
- d. Native Hawaiian or other Pacific Islander
- e. White
- f. Others, please specify

5-Highest level of education completed:

- a. Elementary/primary education
- b. Secondary education
- c. Postsecondary/higher education
- e. College

6-Ambulation Levels:

- Walks independently
- Walks with braces
- Walk with braces and walker
- Uses a manual wheelchair
- Uses a power wheelchair

Appendix B

Interview Guide for Adolescents

Social functioning means an individuals' engagement in any type of activities within the community.

1. Can you tell me a bit about your family?
2. Can you tell me a bit about yourself?
3. What are your favorite activities?
4. Describe what fun mean to you?
5. What kind of things do you do with your friends?
6. Tell me more about your time with friends outside of school?
7. What does being a close friend mean to you?
8. What kind of challenges do you face when developing friendship?
9. Do you ever get teased or bullied? Why? What do you do when you are teased/bullied?
10. How important is a social life for you? What challenges do you face in having the social life you want? What has worked for you in getting the social life you want?
11. What does quality of life mean to you?
12. What role does your social life play in quality of life?
13. Do you ever feel stigma from others? How does it feel to experience stigma? What do you do when this happens? Where does the stigma come from (peers, school, parents, etc.)?

"If adolescent does not know what stigma is, the PI will provide them with this definition: negative feelings that people have about particular circumstances or characteristics that somebody may have"

14. Do you feel your expectations for social life (activities and relationships) are the same or different than your father/mother? If different, how so?
15. What do you think your parents expect about your social life?

Interview Guide for Parents

Social functioning means an individuals' engagement in any type of activities within the community.

1. Could you tell me a bit about your adolescent?
2. Describe your adolescent's social activities. What kind of things does he/she like to do?
3. Describe what fun looks like for your adolescent with SB?
4. How important do you think social activities and relationships are for your adolescent?
5. Describe your expectations of your adolescent social activities and relationships.
6. Describe how spina bifida has affected your adolescent's social activities, relationships and quality of life?
7. Tell me about the experiences you have had to get your child and now adolescent involved in social activities.
8. What kind of challenges have you experienced in supporting your adolescent to create close friendship?
9. What do you see as the biggest benefits and challenges for your adolescent engaging in social activities?
10. How important is your adolescent's social life?
11. Do you think your adolescent, or your family has experienced stigma? If so, has that influenced your adolescent's social life?
12. What does quality of life for your adolescent mean to you? For your adolescent? What influence does your adolescent's social life have on their quality of life?
13. Describe how do you consider your adolescent (e.g., typical or different)?

APPENDIX C

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice Initial Review – Expedited Review

September 2, 2021
Ranya Bafail
Population Health Nursing Science

RE: **Protocol # 2021-0734**
“Adolescents’ with Spina Bifida and Parents’ Perceptions of Engaging in Social Activities”

Dear Mx. Bafail:

Members of Institutional Review Board (IRB) #2 reviewed and approved your research protocol under expedited review procedures [45 CFR 46.110(b)(1)] on September 2, 2021. You may now begin your research.

Principal Investigators must complete a [COVID-19 Human Subjects Research Review Worksheet](#) for a protocol COVID safety assessment prior to initiating or re-starting any research activities that require in-person contact between research subjects and staff during the COVID-19 pandemic.

For additional information about this process, please refer to the [Human Subjects Research Review page on the OVCR website](#). If you need assistance, questions may be directed to research@uic.edu.

Your research meets the criteria for review under expedited review procedures [45 CFR 46.110] Categories: 6, 7

Please note the following information about your approved research protocol:

Please remember to submit a letter of support from the Spina Bifida Association (SBA) that indicates they agree to support passive recruitment of potential participants and, if applicable, any other research-related activities. The letter should be on letterhead, be signed by an authorized executive at the site, and be accompanied by an Amendment form when submitted to the UIC IRB.

Please note that minor administrative edits have been made to the Parent Consent and Permission document. If the edits are not acceptable, kindly contact the IRB/OPRS.

Protocol Approval Date: September 2, 2021
Approved Subject Enrollment #: 20
Performance Site: UIC
Sponsor: None

Research Protocol:

- a) Adolescents' with Spina Bifida and Parents' Perceptions of Engaging in Social Activities; 09/01/2021

Documents that require an approval stamp or separate signature can be accessed via [OPRS Live](#). The documents will be located in the specific protocol workspace. You must access and use only the approved documents to recruit and enroll subjects into this research project.

Recruitment Materials:

- a) Eligibility Screening; Version 3; 09/01/2021
- b) Recruitment Flyer; Version 3; 09/01/2021
- c) Interview Script; Version 3; 09/01/2021

Assents:

- a) Assent; Version 3; 09/01/2021
- b) A waiver of documentation (written signature) on the assent document has been granted for this minimal risk research for adolescent participants who opt to provided verbal assent, which will be documented by the investigators on the assent document, under 45 CFR 46.117(c) (participants will be provided with an assent document containing all of the elements of consent and parent/guardian permission will also be obtained)
- c) Exceptions to informed consent for identifying, recruiting, and eligibility screening of potential participants has been acknowledged under 45 CFR 46.116(g)

Parental Permission:

- a) Parent Consent and Permission; Version 4; 09/02/2021

[Additional Determinations for Research Involving Minors:](#) The Board determined that the research satisfies 45 CFR 46.404 (no greater than minimal risk to children is presented and the IRB finds that adequate provisions are made for soliciting the assent of the children and the permission of their parents or guardians). The Board further determined that, according to 45 CFR 46.408, one parent must sign the permission document, as one parent's signature is sufficient, and age appropriate assent will be obtained from each child.

Please remember to:

→ Use only the IRB-approved and stamped consent documents when enrolling new subjects.

→ Use your **research protocol number** (2021-0734) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with the [policies](#) of the UIC Human Subjects Protection Program (HSPP) and the guidance [Investigator Responsibilities](#).

Please note that the UIC IRB has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.

Please be aware that if the [scope of work](#) in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS office at (312) 996-1711 or me at (312) 996-2014. Please send any correspondence about this protocol to OPRS via [OPRS Live](#).

Sincerely,

Sandra Costello
Assistant Director, IRB # 2
Office for the Protection of Research
Subjects

cc: Catherine Vincent (faculty advisor), Human Development Nursing Science
Kathy Sparbel, Population Health Nursing Science

**Approval Notice
Amendment – Expedited Review
UIC Amendment # 1**

October 13, 2021

Ranya Bafail
Population Health Nursing Science

RE: **Protocol # 2021-0734**
“Adolescents’ with Spina Bifida and Parents’ Perceptions of Engaging in Social Activities”

Dear Dr. Bafail:

PIs must complete a [COVID-19 Human Subjects Research Review Worksheet](#) for a protocol COVID safety assessment prior to initiating or re-starting any research activities that require in-person contact between research subjects and staff during the COVID-19 pandemic.

For additional information about this process, please refer to the [Human Subjects Research Review page on the OVCR website](#). If you need assistance, questions may be directed to research@uic.edu.

Your application was reviewed and approved on October 13, 2021. The amendment to your research may now be implemented.

Please note the following information about your approved amendment:

Amendment Approval Date: October 13, 2021

Amendment:

Summary: UIC Amendment #1 dated and received via OPRS Live on October 12, 2021 is an investigator-initiated amendment submitting a letter of support from the Spina Bifida

Association (SBA) indicating they agree to support passive recruitment of potential participants (letter dated 10/12/21).

Approved Subject Enrollment #: 20

Performance Sites: UIC, Spina Bifida Association (SBA)

Sponsor: None

Institutional Proposal (IP) #: Not applicable

Please be sure to:

- Use your research protocol number (2021-0734) on any documents or correspondence with the IRB concerning your research protocol.
- Review and comply with the [policies](#) of the UIC Human Subjects Protection Program (HSPP) and the guidance [Investigator Responsibilities](#).

Please note that the IRB has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.

Please be aware that if the [scope of work](#) in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS at (312) 996-1711 or me at (312) 355-0816. Please send any correspondence about this protocol to OPRS via [OPRS Live](#).

Sincerely,

Alison Santiago, MSW, MJ
Assistant Director, IRB # 2
Office for the Protection of Research Subjects

cc: Catherine Vincent (Faculty Advisor)
Kathy Sparbel, Population Health Nursing Science, M/C 802

**Approval Notice
Amendment – Expedited Review
UIC Amendment # 2**

November 9, 2021

Ranya Bafail
Human Development Nursing Science

RE: **Protocol # 2021-0734**
“Adolescents’ with Spina Bifida and Parents’ Perceptions of Engaging in Social Activities”

Dear Mx. Bafail:

PIs must complete a [COVID-19 Human Subjects Research Review Worksheet](#) for a protocol COVID safety assessment prior to initiating or re-starting any research activities that require in-person contact between research subjects and staff during the COVID-19 pandemic.
For additional information about this process, please refer to the [Human Subjects Research Review page on the OVCR website](#). If you need assistance, questions may be directed to research@uic.edu.

Your application was reviewed and approved on November 9, 2021. The amendment to your research may now be implemented.

Please note the following information about your approved amendment:

Amendment Approval Date: November 9, 2021

Amendment:

Summary: Amendment Summary: UIC Amendment #2, dated 11/05/2021 and accepted via OPRSLive 11/07/2021, is an investigator-initiated amendment to add Illinois Spina Bifida Association as passive research performance site. Illinois Spina Bifida Association will post the recruitment flyer on the social media/website (Letter of Support from Illinois Spina Bifida Association dated 11-4-21 submitted; Appendix K submitted).

Approved Subject Enrollment #:

20

Performance Sites:

UIC, Spina Bifida Association (SBA), Illinois Spina Bifida Association

Sponsor:

None

Institutional Proposal (IP) #:

None

Grant/Contract No:

None

Grant/Contract Title:

None

Documents that require an approval stamp or separate signature can be accessed via [OPRS Live](#). The documents will be located in the specific protocol workspace. You must access and use only the approved documents to recruit and enroll subjects into this research project.

Please be sure to:

- Use your research protocol number (2021-0734) on any documents or correspondence with the IRB concerning your research protocol.
- Review and comply with the [policies](#) of the UIC Human Subjects Protection Program (HSPP) and the guidance [Investigator Responsibilities](#).

Please note that the IRB has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.

Please be aware that if the [scope of work](#) in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS at (312) 996-1711 or me at (312) 413-1518. Please send any correspondence about this protocol to OPRS via [OPRS Live](#).

Sincerely,

Alma Milat, BS
IRB Coordinator, IRB # 2
Office for the Protection of Research Subjects

cc: Catherine Vincent, Human Development Nursing Science, M/C 802

Crystal Patil, Human Development Nursing Science, M/C 802

**Approval Notice
Amendment – Expedited Review
UIC Amendment # 3**

November 12, 2021

Ranya Bafail
Human Development Nursing Science

RE: **Protocol # 2021-0734**
“Adolescents’ with Spina Bifida and Parents’ Perceptions of Engaging in Social Activities”

Dear Dr. Bafail:

PIs must complete a [COVID-19 Human Subjects Research Review Worksheet](#) for a protocol COVID safety assessment prior to initiating or re-starting any research activities that require in-person contact between research subjects and staff during the COVID-19 pandemic. For additional information about this process, please refer to the [Human Subjects Research Review page on the OVCR website](#). If you need assistance, questions may be directed to research@uic.edu.

Your application was reviewed and approved on November 12, 2021. The amendment to your research may now be implemented.

Please note the following information about your approved amendment:

Amendment Approval Date: November 12, 2021

Amendment:

Summary: Amendment Summary: UIC Amendment #3, dated and accepted via OPRSLive 11/10/2021, is an investigator-initiated amendment to add Spina Bifida Wisconsin as passive research performance site. The site will post the recruitment flyer on the social media and/or website (Letter of Support dated 11-8-21 submitted; Appendix K submitted).

Approved Subject Enrollment #:

20

Performance Sites:

UIC, Spina Bifida Association (SBA), Illinois Spina Bifida Association, Spina Bifida Wisconsin

Sponsor:

None

Institutional Proposal (IP) #:

None

Grant/Contract No:

None

Grant/Contract Title:

None

Please be sure to:

- Use your research protocol number (2021-0734) on any documents or correspondence with the IRB concerning your research protocol.
- Review and comply with the [policies](#) of the UIC Human Subjects Protection Program (HSPP) and the guidance [Investigator Responsibilities](#).

Please note that the IRB has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.

Please be aware that if the [scope of work](#) in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS at (312) 996-1711 or me at (312) 413-1518. Please send any correspondence about this protocol to OPRS via [OPRS Live](#).

Sincerely,

Alma Milat, BS
IRB Coordinator, IRB # 2
Office for the Protection of Research Subjects

cc: Catherine Vincent, Faculty Sponsor, Human Development Nursing Science, M/C 802
Crystal Patil, Human Development Nursing Science, M/C 802

CURRICULUM VITA

Ranya Bafail MSN, RN

1212 S Michigan Ave

Chicago, IL 60605 U.S.

US Mobile: +3122825782, KSA Mobile: +966 556366020

Email: rbafai2@uic.edu

Education:

2018 to present

PhD, University of Illinois at Chicago\School of Nursing

2015 to 2018

MSN, University of Michigan\ School of Nursing

Master degree in Acute Care Pediatric Nurse Practitioner Program

GPA 3.40 out of 4.00

2006 to 2011

BSN, King Saud bin Abdulaziz University for Health Sciences (KSAU-HS \CON-J)

Bachelor degree in Nursing Science GPA: 4.58 out of 5.00

LICENSURE AND CERTIFICATES:

2016 to Present.

State of Michigan Nursing License

License No.:4704323492. Specialty: Registered Nurse

2015 to Present.

American Heart Association PALS Provider

2015 to Present.

American Heart Association BLS Provider

2012 to Present.

Saudi Commission for Health Specialties

License No.: 12-J-N-0031632. Specialty: Nursing B.S.C

PROFESSIONAL EMPLOYMENT

Teaching Experience:

2012 to 2014 Teaching Assistant in KSAU-HS College of Nursing

Position Title: Clinical Teaching Assistant in Pediatric Nursing Course.

Guide, assess and evaluate them in pediatric medical unit in the National Guard hospital for the rest of the semester.

Assess and evaluate the students in the fundamental course regarding nursing competency and procedures skills within the simulation sessions.

Served as a board member of a clinical teaching assistant committee that evaluates all pediatric

nursing competencies and procedures for the undergraduate pediatric nursing course according to the updated evidence-based committee.

Clinical Experience:

2016 to 2018. Pediatric Acute Care Nurse Practitioner Student at the University of Michigan:

58 Clinical Hours in a Pediatric Primary Care Private Clinic

657 Clinical Hours in a Pediatric Acute Care setting at C.S. Mott Children's Hospital:

168 Clinical Hours in Pediatric Gastroenterology Outpatient Clinic

100 Clinical Hours in Hematology/Oncology Outpatient Clinic

2012 to 2014. Registered Nurse in NICU in NGHHA-Jeddah

2011to 2012 Nursing Internship in NGHHA- Jeddah

2006 to 2011 Nursing Student Training in NGHHA – Jeddah

PROFESSIONAL MEMBERSHIP:

2020 to Present. Midwest Nursing Research Society

2017 to Present. The Alumni Association of the University of Michigan

2016 to present. National Association of Pediatric Nurse Practitioners

2008 to Present. Saudi Nursing Society

Research:

Elarousy, W., Abdulshakoor, E., Bafail, R., & Shebaili, M. (2014). The effectiveness of E-learning in enhancing neonatal resuscitation skills, knowledge and confidence of undergraduate nursing students. *International Journal of Nursing & Clinical Practices*, 1, 102-109.

doi:10.15344/2394-4978/2014/102

HONOR:

2017 Sigma Theta Tau International Honor society of Nursing in MSN

2012 Graduate Bachelor Degree with Second Honor

2010-2011 Certificate of Appreciation: Outstanding Academic Performance

PROFESSIONAL ORAL PRESENTATIONS:

Peer Reviewed:

Elarousy, W., Abdulshakoor, E., Bafail, R., & Shebaili, M. (2014). The effectiveness of E-learning in enhancing neonatal resuscitation skills, knowledge and confidence of undergraduate nursing students. *International Journal of Nursing & Clinical Practices*, 1, 102-109.

doi:10.15344/2394-4978/2014/102

PROFESSIONAL CERTIFICATIONS:

UMHS Courses:

April 1-4, 2020. Midwest Nursing Research Society

2016 to 2017 Online courses and tests

Blood Borne Pathogens Course

HIPAA Course

OSHA's Law and Regulations Course

Critical Incident Course

Fire Safety Course

POC Glucose Course
Patient Safety Course
Stroke Basics Course

March 19th, 2017. Practical Approaches to the Comprehensive Care of Patients with MS:
Interactive Cases
March 19th, 2017. Early Diagnosis and Individualized Management of IPF: Strategies for Shared
Decision-Making to Improve Outcomes
March 18th, 2017. T-Cell Epitope Biology: Informing a New Generation of Immunotherapy for
Grass Pollen-Induced Allergic Rhinitis
March 18th, 2017. Action Item: Improving Return on Awareness of Emerging Multiple Sclerosis
Treatment Options
March 18th, 2017. Influenza Vaccination in Children—Costs and Benefits
March 18th, 2017. Current Issues in Diabetes: Managing Diabetes Distress; Is There an App for
It? Gestational DM Prevention; New Insulin Outcomes Trials
March 11th, 2017. Identification and Management of Patients Born Small for Gestational Age
March 11th, 2017. Building Healthy Foundations: Emerging Data and Evolving Concepts in
Early Childhood Nutrition
March 13th, 2017. Nutritional Insights: Highlights from Advances in Neonatal and Pediatric
Nutrition 2015
April 20th, 2013 National Guard Resuscitation hospital
May 14th, 2013. Scientific Research Paper Writing Course
May 7th to 8th, 2013. Pediatric Critical Care Course
November 25th, 2012. Neonatal resuscitation program(NRP) provider course
May 18th, 2011. Pain management workshop
Apr 27th, 2011. Basic Medication Safety Course
Jun 19th, 2011. I.V. Therapy Course

PROFESSIONAL DEVELOPMENT:

Attendee:

Apr 30 to May 1st, 2013. How to Interpret Laboratory Results?
Mar 24th, 2013. Qualitative Research
Mar 28th to 31st, 2011. Second Scientific Conference for Higher Education

Volunteer:

2010. As a member of the Students Government I participate in organizing:
Gulf Nursing Day
International Nurses Day
World Diabetes Day
Oct. 28th, 2010. Participate in set a new Guinness world record for " The Largest Human
Awareness Pink Ribbon" with 4000 Saudi women
2009. Participate in World Diabetes Day Campaign in the National Guard Hospital
2009, from 11 JULY 2009 To 19 AUG. Dr. Bakhsh Hospital, Al Sharafiyah – Jeddah 2008 and
2009. Participate in Breast Cancer Day
Kuehne + Negel LTD. Secretary:
■ From 1ST of JULY 2008 To 29TH of SEP. 2008.
■ From 1ST of JULY 2010 To 29TH of SEP. 2010.

2007, from 16 JUNE 2007 To 21 AUG 2007 in Al-Thgher Hospital, Jeddah
2007. Participate in World Diabetes Day Campaign in Al- Serafi Mega Mall