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Spina bifida (SB) is a congenital birth defect causing a wide variance of physical and intellectual disabilities. The first objective of this study was to examine SES and parental perceived support as predictors of HRQoL among youth with SB. It was hypothesized that lower SES would predict lower youth HRQoL, and higher parental perceived support would predict higher youth HRQOL. The second objective of this study was to examine parental perceived support as a moderator of the association between SES and youth HRQoL. Parental perceived support was hypothesized to serve as a buffer of the negative impact that low SES has on HRQoL. Results indicated significant effects of SES on school, physical, and total HRQoL subscales when covariates were not included. In addition, parental perceptions of social support from family members were significantly associated with Emotional HRQoL in youth with SB. There was a significant interaction between SES and parental perceived support from friends predicting youth Social HRQoL. However, post-hoc simple slope analyses were not significant. This study works to expand the understanding of the roles of SES and parental perceived social support on the HRQoL in children with SB, a population susceptible to poor quality of life due to the physical and cognitive challenges commonly associated with this condition.

Spina bifida (SB) is a congenital birth defect believed to have both genetic and non-genetic causes, including gene mutations and inadequate maternal folic acid consumption, respectively (Copp et al., 2015). Data from a 12-state study from 1997-2007 by the Centers for Disease Control and Prevention (CDC) estimated SB to occur for 3 out of every 10,000 live births (CDC, 2016b). During the early stages of normative embryonic development, the neural tube closes to ultimately form the brain and spinal cord. When that closure fails, it can produce a variety of neural tube defects, such as SB. In SB, the failed closure typically occurs in the thoracic, lumbar, or sacral regions of the spine, which often results in impaired functioning of the legs, bladder, and bowel (Holmbeck, Zebracki, Papadakis, & Driscoll, 2017). In addition, hydrocephalus, a condition in which cerebrospinal fluid is obstructed from properly flowing within and away from the brain, commonly occurs in those with SB and often requires the placement of shunt to aid the drainage of this excess fluid (Copp et al., 2015). Individuals with SB are susceptible to secondary complications, such as bowel and bladder incontinence, urinary tract infections (UTIs), and pressure sores and skin

breakdowns from lack of mobility (Holmbeck et al., 2017).

The effects of SB vary widely across both physical and cognitive domains. The type of SB is identified by the location of the spinal lesion. Types include meningocele, which the CDC attributes to causing "minor disabilities", and spina bifida occulta, which typically produces few disabilities (CDC, 2016a). Myelomeningocele (MM) is the most common and most severe form of SB, causing a moderate to severe physical disability (CDC, 2016a). In addition, MM is associated with brain abnormalities and cognitive impairments (Murray, 2013).

Health-Related Quality of Life

The World Health Organization (WHO) defines quality of life as the perception an individual has regarding their "position in life in the context of the culture and value systems in which they live in relation to their goals, expectations, standards, and concerns" that can be affected by physical and mental health, independence level, and interpersonal relations (WHO, 1997). More specifically, health-related quality of life (HRQoL) is a subjective measurement of an individual's perception of well-being and encompasses the "lived experience" of a health condition (Levi & Drotar, 1998). This construct is an important variable in research that seeks to evaluate a health condition's impact on a child's lifestyle (Sawin, Brei, Buran, & Fastenau, 2002). However, prior research on HRQoL in children with SB is relatively limited and has typically focused on HRQoL around times of medical procedures related to secondary complications of SB (Murray et al., 2014). Past research has indicated that youth with SB have clinically and statistically lower HRQoL when compared to both a non-clinical sample of youth and youth with other chronic health conditions (Murray et al., 2014). Among a sample of youth with hydrocephalus from various medical conditions, participants with MM reported the lowest HRQoL (Kulkarni, Cochrane, McNeely, & Shams, 2008). These studies suggest that youth with SB are at risk for reduced HRQoL; thus, further research is needed to investigate predictors of HRQoL in this population.

Socioeconomic Status and Health-Related Quality of Life

Park, Turnball, and Turnball (2002) report that, among U.S. children and adolescents from ages 3 to 21, 28% of children with disabilities are living below the poverty line, compared to only 16% of typically developing children (Park, Turnball, & Turnball, 2002). The finding that children with disabilities are more likely to live in lower income households provides impetus for exploring the intersection of SES and well being in this population. SES has been found to be inversely correlated with the status of numerous health conditions, including cardiovascular disease, diabetes, gastrointestinal disease, and adverse birth outcomes (Adler & Ostrove, 1999). However, there is a lack of research on the association between SES and outcomes, such as HRQoL, among youth with SB.

A study by Kulkarni and colleagues (2008) in Canada examined social and economic factors associated with HRQoL among children with hydrocephalus, with approximately one third of their sample consisting of youth with SB. Examined factors included family structure, parent education, parent employment status, and annual household income. They found that lower household income and lower parental education attainment were significantly associated with worse HRQoL (Kulkarni et al., 2008). The results of this study illustrate that several SES factors can have a negative effect on HRQoL among youth with SB. In addition, if the

effects of SES can be seen in Canada, a country with a public health care system that is intended to eliminate health disparities by economic class, then one might expect the effect of SES to be greater in the U.S., where no such system exists. More research is needed regarding how SES may put youth with SB at risk for low HRQoL and what protective factors may buffer against the negative effects of low SES.

Parental Perceived Social Support and Youth Health-related Quality of Life

Having a child with a disability demands time and economic resources, and can adversely affect familial relationships, autonomy, and psychological well-being (Seligman & Darling, 1989). Parents of children with disabilities are susceptible to high levels of stress given the demands of a chronic illness and disability (Cousino & Hazen, 2013). In adults, the accumulation of stressors has been linked to higher rates of psychological disorders (Cronin, Becher, Christians, Maher, & Dibb, 2015). Ong and colleagues (2011) conducted a study comparing parenting stress between mothers of children with SB and mothers of typically developing youth (Ong, Norshireen, & Chandran, 2011); their results revealed that mothers of children with SB had significantly higher parenting stress, greater dysfunction in parent-child interactions, and lower general health compared to their control parent counterparts (Ong et al., 2011).

While both being of low SES and having a child with a disability or chronic illness may put parents at risk for increased dysfunction, social support may protect against both sources of stress. The American Psychological Association (APA) identifies "making connections" as one of the ten main ways to build resilience, or adapt well in the face of adversity and stress (APA, 2016). Seligman and Darling (1989) cite a common classification system for social support, which includes three "ecological" levels of support: intimate relationships, friendships, and neighborhood or community support.

One study found that perceived social support significantly predicted well-being in parents of children with physical disabilities (Hung, Wu, Chiang, Wu, & Yeh, 2009). Similar results have been reported in studies of parents of children with intellectual disabilities. Hassall, Rose, and McDonald (2005) found that mothers who perceived higher social support experienced less parenting stress (Hassall et al., 2005). Thus, parental social support has been found to be an important factor for the well-being of parents with children with disabilities. Parental social support is a valuable area of study not only for the potential benefits for that individual, but for the entire family, as relationships external and internal to the immediate family can directly and indirectly affect all members (Dunst, Trivelle, & Deal, 1994).

However, access to social support has been found to be lowest among the most economically needy families (Henly, Danzinger, & Offer, 2005), and lower parental education has been found to be associated with smaller social networks (Ajrouch, Alysia, Blandon, & Antonucci, 2005). Interestingly, social support from peer role models has been shown to have positive medical benefits for youth of low SES, but the benefits were not found for youth of higher SES (Chen, Lee, Cavey, & Ho, 2013). Thus, it may be that social support has a greater impact on those of lower SES when such support is present. There is no research on how social support experienced by parents moderates associations between SES and child outcomes, but research in other related domains suggests that parental social support may benefit youth from low SES to a greater degree than youth from high SES due to the higher level of stress found among low SES families.

Indeed, improving parental well-being through social support systems has a documented association with positive child psychological outcomes (El-Dardiry, Dimitrakaki, Tzavara, Ravens- Sieberer, & Tountas, 2012), including all domains of HRQoL (Kulkarni et al., 2008). A meta-analysis that examined the psychological adjustment of parents of children with SB found that parental adjustment enhanced their ability to complete tasks related to SB care, including coping with stress associated with the condition (Vernaes, Janssens, Bosman, & Gerris, 2005). Conversely, Ong and colleagues report that unresolved stress in parents with chronic stress can have negative implications for their child's future adjustment (Ong et al., 2011; Friedman, Holmbeck, Jandasek, Zukerman, & Abad, 2004). Finally, the SB literature lacks a close examination of parental social support and the potential benefits it may have for children living with SB.

The Current Study

Youth with SB appear to be at a high risk for poor HRQoL. However, literature on contributing factors of poor HRQoL is lacking. As previously stated, SB can cause a wide variety of cognitive and physical impairments. This study used child intelligence (IQ) and Gross Motor Function (GMF) scores to measure cognitive functioning and level of physical impairment in the participants, respectively. Subsequently, these constructs were controlled for in order to draw conclusions about the SB population as a whole. In doing so, this study aimed to understand the relationships among HRQoL, SES, and parent support separate from the cognitive and physical impairments of an individual participant. Current research suggests that SES may be a predictor of HRQoL; specifically, lower SES may put youth at risk for poor HRQoL (Kulkarni et al., 2008). However, there may be factors that serve to protect against the negative effects of low SES. Parents of low SES face added stressors that may impact them and their child. In families of youth with SB, the combination of added stress from raising a child with a disability and the financial strain and lack of resources that are present in lower SES families may impact youth outcomes, such as lowering a child's HRQoL. However, SES as it specifically relates to HRQoL in youth with SB remains largely unexplored. The importance of parental social support for families of youth with disabilities makes this a likely positive predictor of child HRQoL (Kulkarni et al., 2008). In line with previous research, it may also be that parental perceived social support moderates the association between SES and HRQoL in youth with SB.

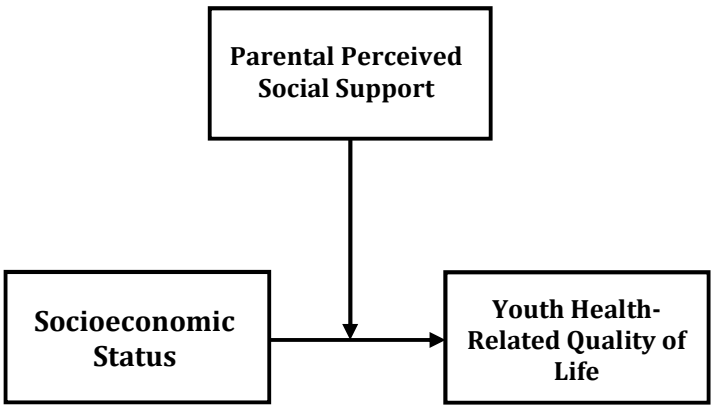

Figure 1. *Proposed Model of Parental Perceived Social Support as a Moderator of the Association Between Socioeconomic Status and Youth Health-Related Quality of Life*

The current study seeks to expand the understanding of HRQoL in children with SB, and the potential roles of SES and parental perceived support. Specifically, the first objective of this study is to examine SES (Objective 1A) and parental perceived support (Objective 1B) as predictors of HRQoL among youth with SB. It is hypothesized that lower SES will predict lower youth HRQoL, and

higher parental perceived support will predict higher youth HRQOL. The second objective (Objective 2) of this study is to examine parental perceived support as a moderator of the association between SES and youth HRQoL (Figure 1). It is hypothesized that parental perceived support will serve as a buffer of the negative impact that low SES has on HRQoL, in that higher levels of parental perceived support will be more beneficial for those of low SES compared to those of high SES. Though expected to have a greater impact in families of lower SES, the positive effects of high parental social support on child reported HRQoL is expected to occur at all levels of SES.

Method

Participants

This study's sample was part of a larger longitudinal study investigating psychosocial, family, and social functioning among youth with SB from childhood to young adulthood (Devine et al., 2012). Participants were youth with SB and their families who were recruited from four Midwestern hospitals and a statewide SB association. Families were approached about participating during regularly scheduled clinic visits and/or were sent recruitment letters. After completing a screening from a research assistant, interested families were asked to participate if they met the following criteria: (1) the child was between the ages 8 and 15, (2) the child had a diagnosis of SB, (3) the child was able to speak and read English or Spanish, (4) at least one caregiver was involved, and (5) the family lived within 300 miles of the research lab.

Of the 246 families approached for participation, 163 agreed to participate. However, 21 families were unable to be contacted later, and 2 families were discovered not to meet eligibility criteria, leading to a final sample of 140 families. In comparison to all other racial/ethnic groups, the prevalence of SB is highest in Hispanic groups (Boulet et al., 2008). Thus, Hispanic families were oversampled in the larger study to better understand SB in this population. Of the families who declined to participate, youth did not differ from participants with respect to SB type, presence of shunt, or occurrences of shunt infections (*p's* > .05). Of participating youth with SB, 53.6% were female and the mean age was 11.43 years. See Table 1 for more demographic and condition-related information on the sample.

Table 1.
Demographic and Condition Related Information

Characteristic	*n*(%) or *M*(SD)
Age	*11.43*(2.46)
Gender	
Male	*65*(46.4%)
Female	*75*(53.6%)
Race/Ethnicity	
Caucasian	*74*(52.9%)
African-American/Black	*19*(13.6%)
Hispanic	*39*(27.9%)
Asian	*2*(1.4%)
Multi-racial	*6*(4.3%)
SB Type	
Myelomeningocele	*122*(87.1%)
Lipomeningocele	*10*(7.1%)
Other	*8*(5.7%)
Shunt Status	
Yes	*110*(76.8%)
No	*30*(21.4%)
GMF	
1 (few impairments)	*18*(12.9%)
2	*34*(24.3%)
3	*30*(21.4%)
4 (severe impairments)	*53*(37.9%)
Missing	*5*(3.6%)
WASI (IQ)	*85.68*(19.68)

Procedure

Institutional Review Board (IRB) approval was obtained from participating hospitals and the home university of the larger longitudinal study. For data

collection, two trained members from the research team visited participating families in their homes every two years for the completion of questionnaires, neuropsychological testing, interviews, and video recordings of family and peer interactions. Releases of information forms were also obtained to collect data from medical charts, health care professionals, and teachers. Questionnaires were available in Spanish. All families were compensated $150 upon completion of home visits and questionnaires. The present study utilized child and mother questionnaire data from the first time point.

Measures

Demographic Information and SES. SES was measured using the Hollingshead Four Factor Index (Hollingshead, 1975). Both parents' occupations and education levels were assigned scores and combined to create a total SES score for each family. In cases of a one-parent household, that individual's occupation and education were used. A higher score on the Hollingshead Four Factor Index indicates higher SES.

Child Intelligence. Child intelligence (IQ) was measured using the vocabulary and matrix reasoning subtests of the Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999). The vocabulary subtest measures expressive vocabulary, verbal knowledge, and fund of information. The matrix reasoning subtest measures nonverbal fluid reasoning. The WASI has been found to be highly reliable for children ages 6-16 years (Wechsler, 1999).

Medical Information. SB type (i.e., myelomeningocele, lipomeningocele, or other), SB lesion level (i.e., thoracic, lumbar, or sacral), and shunt status (yes/no) were collected from medical records after obtaining parental release of information. If no medical records were available, medical data were gathered from the parent questionnaires.

Gross motor functioning (GMF) was coded using the Gross Motor Function Classification System for SB (Wilson, Washington, Engel, Ciol, & Jensen, 2006). This system was designed to capture clinical distinctions in GMF with scores ranging from Level I to Level V, indicating minimal limitations in gross motor functioning to the highest degree of motor dysfunction, respectively. Coders were trained using actual study cases and all achieved pre-determined standards for inter-rater reliability (> 90% agreement rate). Following training, a single coder provided motor classifications for each participant. The original GMFCS scale demonstrated good inter-rater agreement (Kappa = .75 for children 2 years and older; Palisano et al., 1997).

Child Health-Related Quality of Life. Child HRQoL was assessed using self-report data on the Pediatric Quality of Life Inventory Version 4.0 Generic Core Scales (PedsQL; Varni, Seid, & Kurtin, 2001). The PedQL consists of 23 questions across four domains: physical, emotional, social, and school functioning. With the prompt "In the past one month, how much of a problem has this been for you…", an example item from the physical functioning scale is "It is hard for me to run." An example from the emotional functioning scale is "I feel sad or blue" and an example from the social functioning subscale is "It is hard to keep up when I play with other kids." Finally, a sample question from the school functioning scale is "It is hard to pay attention in class." Questions were answered on a 5-point scale from 0 "never a problem" to 4 "always a problem." The PedQL demonstrates good overall internal consistency (α = .80). While standard scores are used when comparing HRQoL to typically-developing or control samples (e.g., Murray et al., 2014), mean scores were used in the current study. In addition to each subscale being analyzed individually (i.e., physical, emotional, social, and school), a total HRQoL scale included all four subscales, and a

psychosocial HRQoL scale included all but the physical domain.

Parental Perceived Social Support. The measures chosen to examine this construct mirror the theoretical framework of Seligman and Darling's (1989) "ecological" levels of social support. Parental perceived social support was assessed using two versions of Perceived Social Support (PSS) scale: one measuring perceived social support from friends (PSS-FR) and the other measuring perceived social support from family members (PSS-FA). Both measures contain 20 items that reflect emotional, informational, feedback, and reciprocal supports and are answered with "Yes", "No", or "Don't Know". A sample item from the PSS-FR is "My friends enjoy hearing about what I think." A sample item from the PSS-FA is "My family is sensitive to my personal needs." Tested among college-aged populations, both PSS scales have been found to have high internal consistency (α = .90 for PSS-FA and α = .88 for PSS-FR; Procidano & Heller, 1983).

Parental perceived social support from the community was assessed using the Social and Community Support Questionnaire (SCSQ), derived from the ACCESS Needs Assessment for Parents Scale (Kennedy et al., 1998). While the original measure includes 75 SB-specific questions, the current measure was reduced to 13 items to reduce overall participant burden and 3 new items were developed specifically for the larger longitudinal study to capture developmental changes. A sample item includes "Adequate state and federal funds." Respondents answer if the item is important to them ("Yes"/"No") and subsequently rate on a 5-point scale the extent to which this item is being taken care of for their family (1= "Not taken care of at all" to 5= "Well taken care of").

Statistical Analyses

Objective 1. Cross-sectional hierarchical regression analyses were conducted to determine whether SES predicted youth HRQoL, while controlling for IQ and GMF (Objective 1A). Cross-sectional hierarchical regression analyses were also conducted to determine whether the three types of parental perceived social support (i.e., from family, friends, and the community), predicted youth HRQoL, while controlling for IQ and GMF (Objective 1B). Assuming a power of .80, and an alpha of .05, a sample of 34 is required to detect large effect sizes (R^2 = .35) and a sample of 76 is required to detect medium effect sizes (R^2 = .15) for analyses with three predictors (Cohen, 1992). Thus, the current study had enough power to detect medium to large effect sizes.

Objective 2. Hierarchical regression analyses testing moderation effects were conducted to determine if the effects of SES on youth HRQoL varied significantly as a function of parental perceived support (family support, friend support, community support). Such analyses were based on methods outlined by Aiken and West (1991), and Holmbeck (1997). Specifically, a separate regression analysis was conducted for each perceived parental support moderator. Variables were entered simultaneously within the following steps: (1) IQ, GMF, (2) SES, parental perceived social support, and (3) SES X parental perceived support interaction. Assuming a power of .80, and an alpha of .05, a sample of 38 is required to detect large effect sizes (R^2 = .35) and a sample size of 84 is required to detect medium effect sizes (R^2 = .15) for analyses with 5 predictors (Cohen, 1992). Thus, the current study had enough power to detect medium to large effect sizes.

Results

Descriptive information on study variables can be found in Table 2. Preliminary analyses tested correlations among study variables (see Table 3). Results revealed SES to be significantly positively correlated with IQ, physical HRQoL, school HRQoL, and total HRQoL, and significantly

negatively correlated with community support. Parental perceived social support from family was significantly positively correlated with parents' social support from friends and with the emotional HRQoL of youth.

Table 2.
Descriptive Statistics for Study Variables

Variable	*M*(SD)	Range
Hollingshead SES	*39.44*(15.90)	8.0-66.0
HRQoL		
Physical	*2.35*(0.86)	0.0-4.0
Emotional	*2.59*(0.81)	0.6-4.0
Social	*2.66*(0.90)	0.0-4.0
School	*2.30*(0.88)	0.0-4.0
Total Psychosocial	*2.51*(0.67)	0.93-4.0
Total	*2.50*(0.61)	0.91-3.96
Parental Social Support		
Family (PSS-FA)	*20.93*(4.11)	11.0-36.0
Friends (PSS-FR)	*20.76*(4.33)	10.0-35.0
Community (SCSQ)	*3.37*(0.85)	1.0-5.0

Note. SES = socioeconomic status. HRQoL = health-related quality of life. The Total score includes all four HRQoL subscales, while the Total-Psychosocial score excludes the Physical subscale.

Objective 1. Objective 1A of this study was to examine SES as a predictor of child HRQoL, while controlling for IQ and GMF. Results revealed that SES did not significantly predict any type of child HRQoL when controlling for IQ and GMF. However, when covariates were not included, greater SES predicted greater school HRQoL (p < .05),greater physical HRQoL (p < .01), and greater total HRQoL (p < .05).

Objective 1B was to examine perceived parental support from family, friends, and the community as predictors of child HRQoL, while controlling for IQ and GMF. Results revealed that greater perceived parental support from family was predictive of greater emotional HRQoL (p < .05). This finding was also significant when IQ and GMF were not controlled for (p < .05). All results for Objective 1A and 1B can be found in Table 4.

Objective 2. The second objective of this study was to examine parental perceived support as a moderator of the association between SES and youth HRQoL, when controlling for IQ and GMF. It was hypothesized that parental perceived support would buffer the negative impact of low SES on HRQoL, such that higher levels of parental perceived support would be more beneficial for those of low SES compared to those of high SES. This hypothesis was partially supported as results revealed a significant interaction between SES and parental friend support when predicting youth social HRQoL (p < .05; Table 5). table However, post-hoc simple slope regression analyses revealed no significant moderation effects for either youth with *high* parental friend support (p = .12) or those with *low* parental friend support (p = .21). This suggests that while the associations between SES and youth Social HRQoL significantly differs between those with *high* parental friend support and those with *low* parental friend support (i.e., as evidenced by the significant interaction), changes in SES within each group are not significantly associated with youth Social HRQoL (i.e., as evidenced by the non-significant post-hoc simple slopes; Figure 2).

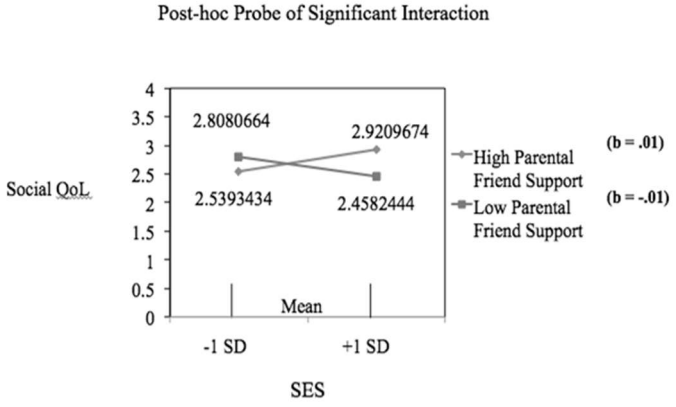

Figure 2. *Post-hoc Probe of Significant Interaction Between Parental Friend Support Moderating Socioeconomic Status Effects on Youth Social Health-Related Quality of Life*
Note. SES = socioeconomic status. HRQoL = health-related quality of life.
Note. Bars within figure indicate standard error

Table 4.

Significant Results of SES and Parental Perceived Social Support as Predictors of Youth HRQoL

	Youth HRQoL									
Independent Variable	Social		Emotional		School		Physical		Total	
	β	*t*	β	*t*	β	*t*	β	*t*	β	*t*
SES	.07^{ns}	.62	.07	.66	.19*	2.03	.26*	2.88	.23*	2.53
Social Support										
Friends	-.04^{ns}	-.45	.02^{ns}	.15	-.13^{ns}	-1.45	.05^{ns}	.51	-.03^{ns}	-.34
Family	-.04^{ns}	-.44	.21*	2.24	.08^{ns}	.88	-.01^{ns}	-.18	.06^{ns}	.64
Community	-.06^{ns}	-.61	.15^{ns}	1.48	.003^{ns}	.03	.03^{ns}	.29	.04^{ns}	.43

Note. SES = socioeconomic status. HRQoL = health-related quality of life. Analyses controlled for both for IQ (as measured by WASI estimated full-scale) and GMF (gross motor function). Bolded results did not include covariates. *p < .05, ** p < .01, ***p <.001, ^{ns} not significant.

Table 5.

Interactions Between SES and Parental Perceived Social Support as Predictors of Youth HRQoL

	Youth HRQOL									
Independent Variable	Social		Emotional		School		Physical		Total	
	β	*t*	β	*t*	β	*t*	β	*t*	β	*t*
SES X Friend Support	.23*	2.07	-.19^{ns}	-1.67	-.07^{ns}	-.61	-.08^{ns}	-.78	-.04^{ns}	-.38
SES X Family Support	.05^{ns}	.48	-.003^{ns}	-.03	.01^{ns}	.06	.02^{ns}	.22	.03^{ns}	.29
SES X Community Support	.21^{ns}	1.97	.08^{ns}	.78	.17^{ns}	1.67	-.03^{ns}	-.28	.13^{ns}	1.27

Note. Parental perceived social support is conceptualized as the moderator between the association of SES and HRQoL. Interactions were only tested for main effects that were found in Objective 1 (see Table 3). SES = socioeconomic status. HRQoL = health-related quality of life. Analyses controlled for both for IQ (as measured by WASI estimated full-scale) and GMF (gross motor function). *p < .05, ** p < .01, ***p <.001, ^{ns} not significant

Discussion

The purpose of this study was to examine the effect of SES and parental perceived social support on HRQoL in youth with SB, a population susceptible to poor quality of life due to the physical and cognitive challenges that may be associated with this condition. In addition, parental perceived social support was evaluated as a potential protective factor to determine if the association between SES on

HRQoL was moderated by parental perceived social support.

As previously stated, SES did not predict youth HRQoL when controlling for IQ and GMF. However, when those controls were not included, lower SES predicted lower school, physical, and total HRQoL. These findings are consistent with past literature that found lower SES to be associated with lower HRQoL (Kulkarni et al., 2008), and suggest that youth from families of low SES may have lower HRQoL in these domains, possibly due to fewer resources in the home, community, and at school (Aikens & Barbarin, 2008). Low SES may also be correlated to lower HRQoL in these domains because of neighborhood factors, such as unsafe recreation areas, or less access to items needed for daily living with this condition. However, controlling for IQ and GMF is an important addition to the analyses due to the variation of these two constructs among people with SB, including participants in our sample. Importantly, SES and IQ are significantly positively correlated in our sample (see Table 3), meaning that those with higher SES tend have higher IQs. Since SES does not predict youth HRQoL when controlling for IQ and GMF, this suggests that these two variables may play a greater role in determining a child's HRQoL than does his/her family's SES. The implication of this finding is that the severity of physical and cognitive impairments from the condition can be expected to have a high impact on HRQoL, regardless of SES. This finding is important because it highlights the variance of cognitive and physical impairments in this population and can direct focus of medical providers toward improving the daily lives of youth with higher levels of condition severity. For example, this finding may provide impetus for more research on and greater access to high quality products for ambulation or devices to assist with daily living for youth whose GMF and IQ are lowest.

Table 3.

Correlations among Study Variables

Variable	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.
1. SES	--	.476**	-.157	.258**	.056	.089	.185*	.142	.229*	-.061	-.004	-.209*
2. IQ		--	-.204*	.242**	.023	.108	.279**	.179	.238**	.016	.036	-.117
3. GMF			--	-.347**	-.003	-.023	-.094	-.051	-.196*	.134	-.025	.026
Youth HRQoL												
4. Physical				--	.162	.339**	.360**	.374**	.743**	-.061	.058	-.010
5. Emotional					--	.427**	.387**	.758**	.623**	.207*	.018	.133
6. Social						--	.424**	.802**	.744**	-.049	-.039	-.062
7. School							--	.779**	.726**	.077	-.126	-.024
8. Psychosocial Total								--	.897**	.094	-.063	.020
9. Total									--	.034	-.022	.012
Parental Perceived Social Support												
10. Family Support										--	.447**	.120
11. Friend Support											--	-.015
12. Community Support												--

Note. SES = socioeconomic status. IQ = intelligence quotient (as measured by WASI estimated full-scale). GMF = gross motor function. HRQoL = health related quality of life. For Youth HRQoL, "Total" includes all four subscales, while "Psychosocial Total" does not include the Physical subscale. *p<0.05, **p<0.01

Parental social support from family was found to be predictive of youth emotional HRQoL, when controlling for IQ and GMF. These results partially supported the hypothesis that higher parental support would predict higher HRQoL, and highlight the impact of parental socialization on youth emotional development. This finding suggests that parents who have greater support from their family may have children who are better emotionally adjusted. Previously cited literature corroborates this result, as social support used to improve parental well-being is associated with more positive child psychological outcomes (El-Dardiry et al., 2012). Though not all aspects of youth HRQoL are impacted by parental support, this finding implies that relationships inside the home can impact the emotional development of their children. This finding provides grounds for more publically funded support groups for parents of youth with SB to improve parental relations. Subsequently, higher emotional HRQoL of youth with spina bifida could be important for improving the family's attitude towards spina bifida as well as the youth's acceptance of his or her health condition and tolerance of tasks necessary for care.

In addition, a significant interaction was found between SES and parental perceived support from friends. However, the post-hoc simple slope analyses were not significant, meaning that within the group of parents with high levels of support and within the group of parents with low levels of support, changes in SES were not significantly associated with changes in youth HRQoL. These findings were surprising given past literature suggesting that social support has a positive impact on economically disadvantaged parents and families (Cronin, 2015). Regardless of parents experiencing high friend support or low friend support, SES was not significantly related to HRQoL within each group. It could be that the present study is underpowered to detect these effects. Further research with larger samples may find more evidence of this association.

The strengths of this study include a relatively large sample size of 140 participating youth and their parents, allowing for the detection of medium to large effects. In addition, the participants varied in age (i.e., 8 to 15 years), allowing us to understand relation between study variables among school-aged children and early adolescents. Finally, given the range of cognitive and physical functioning found in youth with SB, this study controlled for IQ and GMF, which ensure a purer understanding of the effects among the variables of interest.

While the larger study from which these data were collected has a longitudinal design; the current study only utilized data from the first time point of data collection. Therefore, the current study is limited by its cross-sectional design, as effects are not shown throughout development for individual participants. In addition, most information for this study was extracted from self-report questionnaires. Self-report data are subject to confounds such as demand characteristics or evaluation apprehension (Pelham & Blanton, 2013). Among the self-report data available for the study, only mother data was used for measuring parental perceived social support. Finally, the SES variable presents unique challenges. While this study utilized a composite of occupational prestige and educational attainment to determine SES, other pediatric researchers argue broader sociodemographic factors should be considered (e.g., income, family structure, insurance status, wealth, assets, neighborhood characteristics; Cheng, Goodman, & The Committee on Pediatric Research, 2015).

Based on the results of this study, health care providers might assess the social support systems that

parents have within the home as a way of improving the emotional HRQoL of youth with SB. In addition, future research can continue to build upon these findings. For example, a more comprehensive measure of SES may be utilized to more accurately determine if it has an effect on HRQoL in this population of youth and their families. Utilizing data from both parents, rather than only maternal reports, may also be a valuable avenue for future research for a more holistic overview of a family's social supports. Gender may be another variable to consider, as female adolescents have been shown to report worse psychological health compared to males (Geckova et al., 2003). Finally, a longitudinal, rather than cross-sectional, examination of SES, HRQoL, and the moderating protective factors may provide valuable insight into how associations among these variables unfold over the course of adolescence in youth with SB.

About the Author

Hailing from Cleveland, OH, Natalie graduated from Loyola University Chicago ('17) with a Bachelor of Science degree in Psychology. She minored in Dance and Business Administration and also completed Loyola's Interdisciplinary Honors program. Her research article was completed as an undergraduate honors thesis while working as a research assistant in the Chicago Healthy Adolescent Transition Study (CHATS) Lab under the direction of Grayson N. Holmbeck, PhD, with additional mentorship from Jaclyn L. Papadakis, PhD. As Natalie moves beyond undergraduate studies, she plans to pursue Masters degrees in Social Work and Public Health and may some day continue to a PhD in Social Work, with the goal to utilizing academic pursuits to improve the lives of society's vulnerable populations. Outside of school and work, Natalie enjoys nothing more than a sipping a cup of coffee with a friend, reading a book, doing yoga, or attending a dance class.

Originally from Freeport, IL, Jaclyn recently earned her doctoral degree from Loyola University Chicago's ('18) Clinical Psychology graduate program, where she completed her predoctoral clinical internship at Lurie Children's Hospital of Chicago. Jaclyn completed her undergraduate studies in Psychology and Human Services in 2010, as well as her Master of Arts in Clinical Psychology in 2015. Her research interests center around the psychosocial functioning and family functioning in families of children with chronic illnesses and the impact of socioeconomic and cultural factors on child health. Jaclyn aims to be a pediatric psychologist in an academic medical center, doing both clinical and research work. In Jaclyn's free time, she enjoys running, playing sports, watching movies, going to dog parks, and spending time with family and friends.

Grayson Holmbeck, PhD, is a professor of Psychology at Loyola University Chicago, where he also serves as the Director of Clinical Training for graduate studies. He completed undergraduate coursework at Brown University ('80) and earned his doctoral degree in Clinical Psychology from Virginia Commonwealth University ('87). Grayson is the Principal Investigator (PI) for the Chicago Healthy Adolescent Transition Study (CHATS), a longitudinal study examining the psychosocial effects of spina bifida on adolescent development and family functioning. He is also PI of a study examining the effectiveness of a camp-based independence program for children, adolescents, and young adults with spina bifida. Additionally, Grayson has served as the editor of the Journal of Pediatric Psychology since 2013. The father of two, Grayson enjoys playing tennis, listening to music, and traveling in his free time.

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