





## RESEARCH ARTICLE

# Parents' school-related concerns and perceived strengths in youth with spina bifida

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## Abstract

**Background:** Although the academic difficulties of children with spina bifida (SB) are well-documented, there is limited literature on parents' views of their children's school experiences and school-related supportive services. Thus, the current study examined parents' school-related concerns, as well as perceived areas of strength, among children with SB.

**Methods:** Using a mixed-methods approach, 30 families (29 mothers and 19 fathers) of children with SB (ages 8–15 years) completed questionnaires and interviews. Content analysis was used to generate themes from interview data about parents' school-related concerns and perceptions of their child's strengths.

**Results:** Overall, six themes emerged when assessing both parents' concerns and perceived strengths. Some parents did not endorse school concerns or strengths for their child. However, other parents described concerns related to academic performance, cognitive abilities, lack of school support, missed school and/or class time and disengagement, as well as strengths such as academic skills, cognitive abilities, persistence, self-advocacy and agreeableness. Despite parents' concerns about their children's academic performance, quantitative data revealed that less than 50% of children had received a neuropsychological evaluation and/or academic accommodations; additional quantitative data supported the qualitative findings.

**Conclusions:** The mixed-methods approach used in this study provides a richer understanding of parents' experiences in the school setting when they have a child with SB. Results can inform clinical practice, identifying a need to improve academic support for children with SB and help parents manage education-related stressors.

## KEYWORDS

children, parent concerns, school, spina bifida, strengths

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## 1 | INTRODUCTION

Spina bifida (SB) is a congenital birth defect that occurs during the first month of pregnancy when the neural tube fails to fully close (Copp et al., 2015). Children with SB are at risk for multiple cognitive and physical challenges, such as hydrocephalus, orthopaedic problems, paralysis of the lower extremities and bladder and bowel dysfunction (Copp et al., 2015). In turn, these difficulties can have a cascading impact and negatively affect other domains of functioning, such as academic performance (Dennis et al., 2006; Holmbeck et al., 2003; Holmbeck & Devine, 2010). Indeed, past research has shown that children with SB demonstrate poorer academic outcomes compared to typically developing peers (Holmbeck et al., 2003), as well as experience specific learning problems (e.g., learning disability in reading, writing and math; Mayes & Calhoun, 2006).

Numerous condition-related factors may negatively impact school functioning in children with SB. First, children often present with a specific cognitive profile, such that they have a relative strength in 'associative processing' (i.e., less complex data-driven tasks) and weakness in 'assembled processing' (i.e., more complex tasks requiring the integration of multiple content domains; Dennis et al., 2006). Therefore, while children may demonstrate intact abilities in some academic domains (e.g., word recognition), they may struggle in others (e.g., reading comprehension; Dennis et al., 2006). More specific cognitive difficulties, including executive dysfunction and inattention, are also common and can negatively impact academic success (Burmeister et al., 2005; Wasserman & Holmbeck, 2016). In addition to cognitive vulnerabilities, children with SB must also manage the physical complications that frequently accompany this condition and a complex medical regimen (e.g., bladder and bowel programme; Copp et al., 2015). This may lead to school absences and/or reduce the amount of time that children with SB are receiving academic instruction in the classroom (Lindsay et al., 2017), both of which could have implications for performance.

Although it is well-established that children with SB are vulnerable to academic difficulties, little is known about (1) the explicit concerns of parents in the school setting when a child has SB and (2) potential areas of strength (e.g., personality factors; Guay et al., 2010; Poropat, 2009). On a broad level, parents of children with SB report that school is one of their most salient areas of concern and that their needs for services are not being met (Buran et al., 2002). Thus, additional research in this area is needed to characterize the specific academic needs of children with SB and better understand how to support the parents of these children. Additionally, evidence suggests that children with SB want healthcare professionals to take a strengths-based approach to treatment, as these children are often already acutely aware of what they are unable to do (McPherson et al., 2017). As such, it is important to elucidate specific strengths among those with SB that could be capitalized on to support academic functioning, especially as strengths-based approaches have been shown to be effective (Grant, 2012).

### Key Messages

- This study improves understanding of the school-related concerns experienced by parents of children with SB and elucidates skills that may bolster academic success in this population.
- Findings indicate that parents experience a number of concerns related to their individual child (e.g., cognitive and/or academic skills) and the larger school-system (e.g., lack of school support). Moreover, a significant percentage of children had not received supportive services (e.g., neuropsychological assessment, academic accommodations), despite parents voicing concerns during interviews.
- These results serve as a call to action, highlighting the need to better support those with SB and their families within the educational system. Clinicians can play an important role by maintaining open communication with families about academic concerns, making appropriate referrals and helping parents to harness their child's strengths and advocate effectively for their child's needs.

Using a mixed-methods approach, the current study sought to describe the experiences of parents who have a child with SB in the school setting (Wu et al., 2019). First, a brief interview assessed parents' specific school-related concerns for their child with SB and perceptions of academic strengths. Second, children with SB were administered a performance-based neuropsychological assessment to capture general intellectual functioning (IQ). Third, parents and teachers completed questionnaires assessing children's academic support (e.g., neuropsychological testing, accommodations) and outcomes (e.g., performance and independence). Through integration of these qualitative and quantitative data, this study aimed to isolate the unique challenges faced by parents of children with SB in the educational system and link them to important contextual factors. Indeed, variability in parent concerns may exist based on a child's condition-severity, academic performance and/or whether appropriate supports have been implemented within the school setting.

## 2 | METHODS

### 2.1 | Participants

Participants were recruited from four hospitals and a statewide SB association in the Midwest as part of a larger, ongoing longitudinal study examining family and psychosocial adjustment in children with SB (e.g., Devine et al., 2012; Driscoll et al., 2020; Winning

et al., 2020). Families were approached during regularly scheduled clinic visits and/or sent recruitment letters. Eligible children: (a) were diagnosed with SB (myelomeningocele, lipomeningocele, myelocystocele); (b) were ages 8–15; (c) were proficient in English or Spanish; (d) had the involvement of at least one primary caregiver; and (e) were living within 300 miles of the laboratory to allow for data collection at participants' homes.

Two hundred and forty-six families were approached for recruitment and 163 initially agreed to participate in the study. Twenty-one families were ultimately excluded as they were unable to be contacted or later declined participation, and two did not meet inclusion criteria. Thus, the final sample of participants included 140 families of children with SB (53.6% female, 53.5% White,  $M_{age} = 11.40$  years old at Time 1). Those who declined participation did not significantly differ from those who agreed to participate based on SB type (myelomeningocele versus other),  $\chi^2(1) = 0.0002$ , shunt status,  $\chi^2(1) = 0.003$ , or occurrence of shunt infections  $\chi^2(1) = 1.08$  (all  $p$ 's > .05). Families were contacted for follow-up every 2 years.

A subset of 30 families (29 mothers, 19 fathers) who completed a qualitative interview related to youth's academic functioning at the baseline assessment were included in the current study. This sample of 48 total parent interviews was selected in accordance with qualitative research guidelines suggesting that nine to 24 interviews are generally needed to achieve saturation (i.e., the point in data collection or analyses when no new themes [code saturation] or insights into these themes [meaning saturation] emerge; Hennink et al., 2017). This subsample was randomly selected using a number generator and is representative of the larger sample. There were no significant differences in children's IQ, age, gender, race, lesion level, or family socio-economic status between the larger sample and this subsample. Children were on average 11.33 years old ( $SD = 2.44$ ), most had a diagnosis of myelomeningocele (73.3%), and a little over half were female (53.3%) and White (53.3%; see Table 1 for additional information).

## 2.2 | Procedure

University and hospital institutional review boards approved the current study. Parents provided informed consent and children provided informed consent (>18 years) or assent (<18 years). Parents also completed releases of information permitting the research team to obtain data from medical charts, health professionals and teachers. Next, trained research assistants collected data in families' homes during two separate three-hour home visits. During home visits, family members independently completed questionnaires, interviews and videotaped interaction tasks. Children also completed a neuropsychological test battery. Data from the questionnaires, the neuropsychological battery and interviews are included in the present study. While families who primarily spoke Spanish were included in the larger study, they were not included in this subsample due to barriers transcribing/coding the interviews. Families were compensated for their time.

**TABLE 1** Child demographic and condition-related characteristics

	<i>n</i> (%) or <i>M</i> ( <i>SD</i> )
Gender: Female	16 (53.3)
Age	11.33 (2.44)
Race/ethnicity	
White	16 (53.3)
African-American/Black	6 (20.0)
Hispanic/Latino	7 (23.3)
Asian	1 (3.3)
Family SES	42.18 (15.56)
IQ	86.28 (20.72)
Spina bifida type	
Myelomeningocele	22 (73.3)
Lipomeningocele	7 (23.4)
Myelocystocele	1 (3.3)
Lesion level	
Thoracic	2 (6.7)
Lumbar	16 (53.3)
Sacral	9 (30.0)
Unknown/not reported	3 (10.0)
Shunt present	15 (50.0)

Note: Demographic information is based on a sample of 30 youth with spina bifida (SB). SES = socio-economic status; IQ = intelligence quotient.

## 2.3 | Measures

### 2.3.1 | Interview

#### *Academic concerns and skills*

Parents reported on their concerns regarding their child's academics, as well as their perceptions of their child's skills/strengths that help them to succeed in school, using the Parental Audiotape Questionnaire (PAQ). The PAQ is a 10-item questionnaire interview that parents answer privately using an audio recorder. Although this measure has been used to assess Expressed Emotion (EE) in past work (Kelly et al., 2010), responses were evaluated using content analysis in the current study. The following two questions from the school functioning domain of the PAQ were used:

1. What skills does your child have that help him/her to succeed in school?
2. Do you have any other concerns about your child's performance at school?

### 2.3.2 | Questionnaires

#### *Demographic and spina bifida characteristics*

Parents reported on demographic and academic information (e.g., past neuropsychological evaluations, diagnosis of Attention-Deficit/

Hyperactivity Disorder [ADHD], current academic accommodations). The Hollingshead Index of Socio-economic Status (SES) assessed SES, with higher scores indicating higher SES (Hollingshead, 1975). Additionally, parent-report on the Medical History Questionnaire (MHQ; Holmbeck et al., 2003) and medical chart reviews were used to assess SB type, lesion level and shunt status.

#### *Child IQ*

Children were administered the Vocabulary and Matrix Reasoning subtests from the Wechsler Abbreviated Scale of Intelligence (WASI). These subtests were used to compute an estimated Full-Scale IQ (Wechsler, 1999). The WASI is a reliable, well-validated measure, with a normative mean of 100 and standard deviation of 15 (Vocabulary  $\alpha = 0.89$ , Matrix Reasoning  $\alpha = 0.92$ ; Wechsler, 1999).

#### *Child academic competence, performance and independence*

To assess academic competence among children with SB, parents and teachers completed the 15-item Parent/Teacher Rating Scale of Child's Actual Behavior (PRSCAB/TRSCAB) which is based on the Harter Self-Perception Profile for Children (Harter, 1985). The scholastic competence subscale was used in the current study, and scores on this subscale can range from 1 to 4. A clinical cut-off of 2.5 was utilized (i.e., mean scores lower than 2.5 were considered indicative of clinically significant difficulties) to integrate quantitative and qualitative data. Internal consistency for this subscale was adequate ( $\alpha = 0.70\text{--}0.89$ ).

Additionally, teachers reported on the child's academic performance using the Teacher Report Form (TRF; Achenbach & Rescorla, 2001). The TRF assesses behavioral and emotional problems over the past 2 months. Per manual guidelines, academic performance scores  $\leq 4$  (i.e., borderline range) were considered indicative of clinically significant difficulties (Achenbach & Rescorla, 2001). Internal consistency for the academic performance subscale was excellent ( $\alpha = 0.99$ ).

Finally, teachers reported on the child's academic independence using the Child Behavior Questionnaire, which was developed for the current study based on work by Egeland et al. (1993). On this 67-item measure, teachers rate the child's academic and social independence, and their relationship with the child's parents. The academic independence subscale (e.g., behavioural compliance, required assistance from the teacher) was used in the current study and scores could range from 1 to 5. A clinical cut-off of 3 was used in the current study, such that mean scores lower than 3 were considered indicative of clinically significant difficulties. Internal consistency for the subscale was adequate ( $\alpha = 0.91$ ).

#### *Parent stress*

Parents completed the Family Stress Scale (Quittner et al., 1990). This 19-item questionnaire contains common stressors among families with a child with SB, which parents rated using a five-point scale ranging from 1 (*not at all stressful*) to 5 (*extremely stressful*). The 'educational concerns' item was used in the current study.

## 2.4 | Data analyses

Descriptive statistics were calculated for all quantitative data. Data reduction techniques were employed to reduce the number of analyses and chance of Type 1 error (Holmbeck et al., 2002). Specifically, an alpha coefficient was calculated for mother, father and teacher report of academic competence (i.e., each report was treated as an item in a scale). Because  $\alpha = 0.84$ , all three responses were aggregated into a composite score.

For qualitative data, audio recordings of interviews with parents were transcribed verbatim by trained research assistants (authors C.F., M.S., A.C.). Content analysis was used to capture key quotes and generate themes about parents' school concerns for their child with SB, as well as perceived areas of strength (Hickey & Kipping, 1996; LoBiondo-Wood & Haber, 2006). Each question from the PAQ was coded separately through the same, iterative process. Three researchers (authors A.W., M.R., E.W.) independently read the transcripts in batches of 10, first reading the transcripts to get a sense of the data and then clustering similar responses together to create preliminary thematic categories. After processing each batch of 10 transcripts, the researchers discussed emerging themes, identified relevant quotes and reviewed the coding system. As changes were made to the coding system (e.g., creating new thematic categories or renaming categories), the researchers recoded the transcripts through consensus. Data that did not fit into an existing category was revisited as each batch of transcripts was analysed and as data were recoded.

To ensure credibility of the data, the first author developed a comprehensive data management system, which included a list of all themes and extracted quotes. Additionally, data was reviewed until saturation was reached (i.e., no new themes or nuances/insights into these themes emerged while reviewing the final batch of 10 transcripts; Hennink et al., 2017). All researchers reached consensus on the final themes and reviewed the data based on the final coding scheme to ensure that the coding process was comprehensive.

In general, this study adhered to recommendations from Wu et al. (2019) regarding mixed-methods research. Qualitative and quantitative data were examined separately and integrated via multiple methods to provide deeper understanding and insight into the educational experiences of families whose child has SB. First, mothers and fathers were dichotomized into two groups based on whether or not they endorsed school concerns during the interview (i.e., discrete yes/no groups for mothers and fathers). Using independent samples *t*-tests and chi-square analyses, this variable was then used to examine group differences in quantitative data across a number of academic domains (e.g., IQ, academic performance). This 'quantitizing' (Wu et al., 2019) of the qualitative data provided greater understanding of the context in which parent concerns occur. Because sample sizes were relatively small, effect sizes are presented for dichotomous (Cramer's *V*) and continuous (Cohen's *d*) outcomes to aid with the interpretation of group differences. For Cohen's *d*, 0.20 denotes a small effect, 0.50 denotes a medium effect and 0.80 denotes a large effect (Lakens, 2013). For Cramer's *V*, 0.10 denotes a small effect,

0.30 denotes a medium effect and 0.50 denotes a large effect (Cohen, 1988). Additionally, for each theme that emerged regarding parent school concerns, relevant quantitative data were included for those families that endorsed that particular theme (e.g., number of children who had received a neuropsychological evaluation).

### 3 | RESULTS

Six major themes emerged from the data regarding school concerns and skills (see Table 2 for quotes). The six themes that emerged for school concerns were (1) No Concerns, (2) Academic Performance, (3) Cognitive Abilities, (4) Lack of School Support, (5) Missed School and/or Class Time and (6) Disengagement. For school skills, the six themes that emerged were (1) No Skills, (2) Academic Skills, (3) Cognitive Abilities, (4) Persistence, (5) Self-Advocacy and (6) Agreeableness.

### 3.1 | School concerns question

#### 3.1.1 | No concerns

Of the 30 families (mothers = 29, fathers = 19) who participated in the study, a number of mothers ( $n = 11$ , 38%) and fathers ( $n = 7$ , 37%) denied having any concerns related to school. For some parents, this lack of concern stemmed from their child doing well academically, whereas others noted that they were not concerned due to the high levels of support that their child was receiving at school and/or at home. Two mothers (18%) endorsed homeschooling their child, indicating that they were able to monitor their child's academic progress. One mother (9%) stated that she was more focused on the 'medical' aspects of SB rather than the 'intellectual'. Notably, there were four discrepancies between mothers and fathers, such that one parent endorsed school concerns for their child and the other did not.

**TABLE 2** Sample quotes for parents' school concerns and perceived strengths

Themes: School concerns	Sample quotes
No concerns	'No, none whatsoever. She has a good support team at home and great support team at school'. (Mother)
Academic performance	'I do have certain concerns of certain subjects that require time based, like math...my biggest concern in school would be math'. (Father)
Cognitive abilities	'There are some concerns here lately. He kind of does present with some attention issues like ADHD...poor organization and inattentiveness that's probably gotten worse in the last couple years'. (Mother)
Lack of school support	'She does struggle with a lot of things. She has to master something before she can move on to something else, and we have been going over this with the school system for I do not know how long. She has her own aid, but they do not understand that she has to have one-on-one all the time, and a lot of times her aid is helping other children and it's taking away from her'. (Mother)
Missed school and/or class time	'I think she misses more school than other children do. And so that concerns me sometimes, that she's gonna fall behind'. (Mother)
Disengagement	'Well it's just the fact that you know he's okay with D's you know. D's are passing to him and right now I'm not sure if it's a stage he's going through or what it is, but he does not realize that turning in incomplete homework papers does not prepare him for the tests at the end ...'. (Father)
Themes: School strengths	Sample quotes
No skills	'[child's name] does not really show a lot of interest in school...so I'm not really sure he has any extra skills in that department'. (Mother)
Academic skills	'[child's name] is a really good reader...she has a really good vocabulary. And even in math when it comes to like just basic skills, she's actually better at sort of just adding, subtracting, memorizing multiplication than her older two siblings are. So, in terms of fundamentals, she's got some strengths there that help her succeed in school'. (Father)
Cognitive abilities	'One of [child's name]'s great skills is her organizational ability. She's one of the most organized people I've ever known...another skill she has is simply the ability to focus and to stay focused'. (Father)
Persistence	'I think the best part is that he wants to learn. Even when he gets frustrated, he wants to know about everything. Math, and science, and social studies are not the biggest things he likes, but he really tries to understand and take an interest'. (Mother)
Self-advocacy	'She's also found someone at study hall who's not her math teacher but...she's found him to explain things even better than her own teacher. So, she is never afraid to go up to him during study hall and pick his brain about "can you explain this from a different perspective"'. (Mother)
Agreeableness	'She wants to succeed as far as pleasing her teacher...she will not want to fail or get a bad score and have her teacher think poorly of her'. (Mother)

*Concerns versus no concerns*

Table 3 displays quantitative data for mothers and fathers who did and did not endorse school concerns. Although sample sizes were small, independent samples *t*-tests and chi-square analyses were used to examine differences between groups (i.e., concerns versus no concerns) for both mothers and fathers. Overall, analyses revealed that there were no significant differences between groups across any of the academic variables. However, large effects were observed, such that children's academic independence scores were lower among mothers who endorsed academic concerns compared to those who did not. Children's academic independence scores were also lower among fathers who endorsed academic concerns, representing moderate to large effects. Similar moderate to large effects were found for academic competence, such that children's scores were lower among fathers who endorsed academic concerns. Children's academic competence scores were also lower among mothers who endorsed concerns, representing small to moderate effects. Mean scores for academic performance were not significantly different and fell in the subclinical/normative range for both groups.

On average, children's IQs fell in the low average range for both groups; however, there were children with an IQ lower than 70 (i.e., extremely low range) in the group of families who endorsed school concerns (Mothers = 3 children, 17%; Fathers = 1 child, 8%), as well as in the group who did not endorse concerns (Mothers = 3 children, 27%; Fathers = 2 children, 29%). Mothers and fathers who endorsed academic concerns also reported somewhat higher levels of stress related to educational concerns on the Family Stress Scale, representing small to moderate and large effects, respectively.

### 3.2 | Academic performance

Challenges in academic content domains was a particularly salient theme that emerged, especially for mothers (Mothers = 10, 34%;

Fathers = 3, 16%). Four mothers (40%) noted that they were broadly concerned about their child's grades and that their child with SB may not be able to 'keep up' with peers academically, especially as demands increase. One father (33%) explicitly noted that his child struggled with 'time-based' tasks.

However, the majority of parents reported more specific concerns regarding their child's performance in math. Parents identified concerns about their child performing below grade-level or having difficulties 'getting [a response] onto the paper' despite knowing the answer. In addition to math, one mother (10%) and one father (33%) endorsed concerns related to language arts (i.e., reading and writing skills).

Of the 13 parents ( $n = 10$  children) who had concerns about their child's academic performance, only three of these children (30%) had received a neuropsychological evaluation and only four (40%) were receiving academic accommodations (i.e., academic 'help', pull-out services, or self-contained classroom). Moreover, six of these children (60%) demonstrated clinically significant difficulties on quantitative measures of academic performance, competence and independence (i.e., across these three subscales, the six children were not always the same children).

### 3.3 | Cognitive abilities

Three mothers (10%) and five fathers (26%) endorsed a variety of concerns regarding the impact of cognitive challenges (i.e., executive functioning and attention) on their child's academic performance. Parents worried about their child's difficulties with organization, comprehension of lessons and homework, ability to understand abstract concepts, and the significant amount of time that it took their child to complete assignments. One father (20%) expressed concern that his child would present with a non-verbal learning disorder in the future as a result of hydrocephalus. Additionally, multiple parents reported concerns related to attention, indicating that their child struggled with

**TABLE 3** Differences in academic outcomes based on parent concerns versus no concerns

Variable	Mothers			Fathers		
	Concerns ( $n = 18$ )	No concerns ( $n = 11$ )	<i>d/V</i>	Concerns ( $n = 12$ )	No concerns ( $n = 7$ )	<i>d/V</i>
Child age	11.17 (2.36)	11.27 (2.53)	0.041	11.75 (2.83)	10.86 (3.02)	0.304
Child IQ	89.00 (21.16)	82.91 (21.25)	0.287	90.67 (18.46)	87.86 (24.41)	0.130
Neuropsychological evaluation	7 (38.9)	3 (27.3)	0.610	3 (25.0)	1 (14.3)	0.622
Academic accommodations	7 (38.9)	2 (18.2)	0.242	1 (8.3)	2 (28.6)	0.243
Academic performance	46.94 (10.76)	45.38 (11.59)	0.140	46.30 (8.92)	50.50 (14.14)	0.355
Academic competence	2.73 (0.78)	3.04 (0.59)	0.448	2.78 (0.70)	3.19 (0.67)	0.598
Academic independence	3.34 (0.87)	3.93 (0.51)	0.827	3.40 (0.77)	3.83 (0.75)	0.566
Educational concerns	2.31 (1.08)	1.91 (1.14)	0.360	2.50 (1.08)	1.57 (0.79)	0.983

Note: IQ = intelligence quotient. Outcomes are presented as  $n$  (%) or  $M$  ( $SD$ ) depending on whether variable is dichotomous or continuous, respectively. All statistical comparisons were nonsignificant. Effect size calculations are presented for all dichotomous (Cramer's  $V$ ) and continuous (Cohen's  $d$ ) outcomes. Analyses for academic performance were conducted using raw scores, but group means are reported as  $T$ -scores to aid with interpretation.

attention to detail, ‘focusing’, or that their mind had ‘a tendency of wandering’.

Of the eight parents ( $n = 7$  children) who had concerns about their child's cognitive abilities, only one of these children (14%) had received a neuropsychological evaluation and only one (14%) was receiving academic accommodations. None of the children had been diagnosed with ADHD. Of these seven children, a number demonstrated clinically significant difficulties in academic performance ( $n = 2$ , 29%), competence ( $n = 4$ , 57%) and independence ( $n = 3$ , 43%).

### 3.4 | Lack of school support

Given their child's unique set of challenges, three mothers (10%) and one father (5%) described difficulties advocating for the support that their child needed in the school system. As noted by parents, some youth with SB require intensive, one-on-one time with aids in the classroom or have learning problems that interfere with their ability to fully engage with school material. These needs are not always addressed, leaving parents with the responsibility to ‘take it up’ with the school. In bigger classes, parents indicated that their child sometimes got ‘lost in the shuffle’. Parents also expressed concerns about the future, noting that although their child was well-supported, they were worried that this would not always be the case.

Of the four parents ( $n = 4$  children) who had concerns about their child's lack of school support, only two of these children (50%) had received a neuropsychological evaluation and only two (50%) were receiving academic accommodations. Moreover, two children (50%) demonstrated clinically significant difficulties across all academic outcomes (i.e., performance, competence and independence).

### 3.5 | Missed school and/or class time

Concerns about missing school or class time due to medical sequelae associated with SB was another theme that emerged (Mothers = 3, 10%; Fathers = 2, 11%). Parents highlighted that their child often had to miss class time because of sickness or being in the hospital and, as a result, they worried that s/he would fall behind in their coursework. When children were able to attend school, parents reported that their child still experienced ‘disruptions’ in class time due to demanding bathroom schedules.

Of the five parents ( $n = 4$  children) who had concerns about their child's missed school and/or class time, none of these children had received a neuropsychological evaluation and only one (25%) was receiving academic accommodations. All four children had lower spinal lesions (i.e., two had lumbar and two had sacral), which are associated with less cognitive and medical challenges (Copp et al., 2015). One child (25%) demonstrated clinically significant difficulties in academic performance and independence, but was not receiving accommodations.

### 3.6 | Disengagement

A final theme regarding school concerns that arose during this study was disengagement (Mothers = 5, 17%; Fathers = 2, 11%). Parents expressed worries that their child tended to disengage from school, such that they disliked school and/or homework and struggled to stay motivated (e.g., demonstrated lack of effort, ‘lazy’) or finish assignments. One mother (20%) noted that her child tended to ‘give up’ when school material was more challenging, whereas another expressed concerns that her child was more interested in social interactions (e.g., texting peers) than schoolwork.

Of the seven parents ( $n = 7$  children) who had concerns about their child's disengagement from school, only four of these children (57%) had received a neuropsychological evaluation and only two (29%) were receiving academic accommodations. Some of these 7 children demonstrated clinically significant difficulties in academic performance ( $n = 2$ , 29%), independence ( $n = 2$ , 29%) and competence ( $n = 5$ , 71%).

### 3.7 | School skills question

#### 3.7.1 | No skills

While most parents identified skills or strengths that their child had to succeed in school, a subset of mothers ( $n = 5$ , 17%) and fathers ( $n = 2$ , 11%) did not. Some of these parents explicitly stated that their child did not have any school-related strengths, whereas others simply transitioned into highlighting concerns. One mother (20%) and one father (50%) noted that their child was receiving academic accommodations and therefore did not have any skills.

#### 3.7.2 | Academic skills

A core theme that emerged was that 11 mothers (38%) and six fathers (32%) felt that their child had specific academic skills to help them succeed. Ten parents (59%) indicated that their child was an ‘avid’ and strong reader. Others endorsed good study skills, computer skills, or being a strong test-taker, as well as mastery of basic academic material (e.g., math facts). One mother (9%) felt that her child's ‘love’ of school and learning more broadly was her biggest strength.

#### 3.7.3 | Cognitive abilities

While cognitive abilities were a concern for multiple parents, nine mothers (31%) and nine fathers (47%) also identified areas of cognitive strength. Some children were higher functioning, with parents indicating that their child was intelligent and learned material quickly. Other parents described more specific strengths, such as their child's ability to stay organized or pay attention.

### 3.7.4 | Persistence

Six mothers (21%) and five fathers (26%) described their child's persistence and tendency to stick with challenging tasks as their biggest academic strength. In particular, parents indicated that their child was 'motivated' or was 'determined' to understand course material, even if it was frustrating or difficult. One mother (17%) felt that her child was too persistent, placing too much 'pressure' on herself to be a straight A student.

### 3.7.5 | Self-advocacy

Another theme that emerged was the concept of self-advocacy. While this theme primarily emerged during interviews with mothers ( $n = 5$ , 17%), it was endorsed by one father (5%). Mothers noted that their child was not afraid to advocate for themselves at school, such that they asked for help and/or asked questions as needed. One mother (20%) indicated that her child was comfortable seeking support not only from her classroom teacher but also from other teachers and adults (e.g., parents).

### 3.7.6 | Agreeableness

A consistent theme that emerged from mothers ( $n = 7$ , 24%), as well as one father (5%), was the tendency of children with SB to want to please those around them. Not only did parents note that their child was a good listener and followed directions at school, but they also explicitly stated that their child wanted to 'please' others. One mother (14%) indicated that her child helped other students in class as needed.

## 4 | DISCUSSION

Using a mixed-methods approach, the current study provides insight into the school-related concerns of parents who have a child with SB and strengths that children with SB possess to help them succeed academically. With regard to concerns, parents described worries related to their child's academic performance, cognitive abilities, lack of school support, missed school and/or class time and tendency to disengage from school. Concerns regarding academic performance in particular were generally either broad (e.g., ability to keep up with peers) or centred around math, aligning with past research indicating that children with SB demonstrate a relative weakness in math (Dennis & Barnes, 2010). Also consistent with past work (Burmeister et al., 2005), parents endorsed concerns about their child's cognitive abilities, namely executive functioning and attention. On the one hand, it is encouraging that parents identified challenges that are known to be prevalent in this population, as parents may be attuned to the specific needs of their child. However, these concerns, coupled with quantitative data indicating that

children with SB were not receiving sufficient academic support, are alarming.

Specifically, quantitative data revealed that well below 50% of the children whose parents endorsed academic/cognitive concerns had received a neuropsychological evaluation and/or were receiving academic accommodations. None had received a formal diagnosis of ADHD, despite research suggesting a prevalence rate of approximately 30% in this population (Burmeister et al., 2005) and parents' explicit concerns about attention. Additionally, about half of children were experiencing clinically significant difficulties across multiple indicators of academic functioning (e.g., performance and independence). Not only does this integration of qualitative and quantitative data highlight a need for greater academic support for children with SB, but this sentiment was also stated directly by some parents in this study. One potential explanation for these findings is that teachers and school officials do not completely understand SB or appreciate the severity of its sequelae (Nabors et al., 2008), highlighting a need for greater education about the condition within schools. From a medical perspective, it may also be that the physical complications associated with SB often take precedence over psychosocial concerns (Copp et al., 2015). To improve communication with families about their educational needs, clinicians could create structured checklists on which parents are able to endorse any academic and cognitive concerns during routine clinic visits. Once concerns are identified, clinicians should facilitate appropriate referrals (e.g., formal testing), educate parents about their rights and help parents to advocate for their child, as can be seen in Figure 1 (Ng et al., 2015).

Similar interventions could be helpful for parents who endorsed concerns regarding their child's missed school and/or class time and tendency to disengage from school (see Figure 1 for possible interventions). Individuals with SB must contend with multiple physical complications (Copp et al., 2015) and as such, should receive accommodations that help them catch up to peers after missing class time (e.g., access to notes). Furthermore, families concerned about their child's disengagement from school often described difficulties with motivation and task completion. Given that these are also common concerns for children with ADHD (Volkow et al., 2011), it is possible that some of these children had undiagnosed learning problems and would have benefitted from formal testing.

It is worth noting that a subset of parents did not express school-related concerns for their child with SB, which is not surprising given variability in the presentation of SB (Copp et al., 2015). However, discrepancies between mothers and fathers were found, such that one parent endorsed concerns and the other did not. Therefore, it is important to capture multiple perspectives, both in clinical and research settings, when determining the academic needs of those with SB (La Greca & Lemanek, 1996). Indeed, given that there were no statistically significant differences in IQ or academic outcomes between parents who did and did not endorse concerns, it is possible that some parents without concerns were missing signs that their child was struggling academically. Educating parents about the potential for cognitive and academic challenges as their child with SB progresses through school is essential (Dennis et al., 2006; see Figure 1).



Theme	Description and Examples	Possible Clinical Implications and Interventions
No Concerns	Child is receiving adequate support at school; family is primarily focused on medical needs associated with SB; multiple discrepancies between mothers and fathers (i.e., one parent had concerns whereas the other did not)	Conduct psychosocial assessments that include multiple perspectives (i.e., mother, father, teacher); provide education about potential for cognitive/academic challenges in the future and “signs” parents should monitor <sup>2</sup>
Academic Performance	Broad concerns about child’s grades, especially as they progress through school; specific concerns primarily about math	Refer for formal testing; educate parents about their rights within the school system and provide resources (e.g., sample letters requesting an evaluation from the school); have parents sign releases so clinician can contact the school and advocate for the child; administer assessments in which clinician (e.g., psychologist) is proficient; ensure any accommodations through IEP or 504 plan are appropriate and monitor progress over time; capitalize on the child’s areas of strength; deliver appropriate psychosocial interventions (e.g., organizational skills training for children with ADHD <sup>3</sup> )
Cognitive Abilities	Executive functioning (e.g., organization) and attention difficulties (e.g., trouble focusing, poor attention to detail); slower processing speed	
Lack of School Support	Child’s academic needs are not currently being fully addressed (e.g., lack of one-on-one support or evaluation of learning problems) or family is concerned that they will not be addressed in the future	
Missed School and/or Class Time	Falling behind in coursework due hospitalizations and sickness; receiving less instruction in the classroom and/or less interaction with peers; disruptions due to frequent bathroom breaks	Ensure accommodations are in place to support child through absences, such as providing access to notes/note taking services or ensuring that school staff are available to review missed material
Disengagement	Lack of motivation; dislikes school and/or homework; tends to disengage when school material is challenging	Refer for formal testing if learning difficulties suspected; ensure child is receiving adequate academic support and/or accommodations; assess psychosocial functioning (e.g., mood, confidence) and address symptoms that could be interfering with school; utilize additional strategies to promote success (e.g., skills coaching, reward system) <sup>4</sup>

**FIGURE 1** Possible interventions to address Parents' School concerns in the context of spina bifida. IEP = individualized education program. ADHD = attention-deficit/hyperactivity disorder. <sup>1</sup>La Greca, A. M., & Lemanek, K. L. (1996). Editorial: Assessment as a process in pediatric psychology. *Journal of Pediatric Psychology, 21*(2), 137–151. <sup>2</sup>Copp, A. J., Adzick, N. S., Chitty, L. S., Fletcher, J. M., Holmbeck, G. N., & Shaw, G. M. (2015). Spina bifida. *Nature Reviews Disease Primers, 1*, 15007. <sup>3</sup>Evans, S. W., Owens, J. S., & Bunford, N. (2014). Evidence-based psychosocial treatments for children and adolescents with attention-deficit/hyperactivity disorder. *Journal of Clinical Child & Adolescent Psychology, 43*(4), 527–551. <sup>4</sup>Ahmann, E., Saviet, M., & Joy Tuttle, L. (2017). Interventions for ADHD in children and teens: A focus on adhd coaching. *Pediatric Nursing, 43*(3), 121–131

One of the significant contributions of this study is its focus on skills that children with SB possess to succeed in school. Parents described five main skill areas, including academic skills, cognitive abilities, persistence, self-advocacy and agreeableness. The academic skills and cognitive abilities reported by parents mirror existing literature (Dennis et al., 2006), whereas the themes of persistence, self-advocacy and agreeableness expand our understanding of the strengths of those with SB. Children with SB and related conditions are often viewed through a deficit lens and characterized by what they cannot do (e.g., Climie & Mastoras, 2015; McPherson et al., 2017). Shifting some of the focus to nurturing strengths may feel more balanced and hopeful for children with SB and their families and make interventions more personalized (Rosenbaum & Gorter, 2012).

Strengths of the present study include the mixed-methods approach, inclusion of both mothers and fathers and use of teacher-report data when assessing academic outcomes. However, there are limitations that should be considered. Specifically, only families who spoke English were included in this sample, despite the inclusion of Spanish-speaking families in the larger study due to barriers with coding interview data. Future work should incorporate more diverse perspectives. On the other hand, we chose to be inclusive of different

types of SB and levels of condition severity, resulting in greater heterogeneity in our sample which hopefully increased the generalizability of the results.

Current guidelines recommend monitoring the development of children with SB from an early age (Spina Bifida Association, 2018). Yet, despite this recommendation, results from this study suggest that a number of children are underserved by the educational system. Healthcare providers can play an important role in supporting, educating and advocating for families of children with SB. Considering more than 60% of mothers and fathers in this study endorsed at least one school-related concern, increasing support for parents of these youth is also crucial to help alleviate parenting stress. Future research should seek to characterize barriers to receiving formal testing for children with SB and appropriate accommodations, as this could further support intervention development.

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## DATA AVAILABILITY STATEMENT

Research data are not shared.

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