


‘I Wish the School Had a Better Understanding of the Diagnosis’: parent perspectives on educational needs of students with sex chromosome aneuploidies

Talia Thompson^{1,2} , Nicole Stinnett³, Nicole Tartaglia^{1,2}, Shanlee Davis^{1,2} and Jennifer Janusz^{1,2}

¹University of Colorado School of Medicine, USA; ²Children’s Hospital Colorado, USA; ³University of Colorado Denver, USA

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Students with sex chromosome aneuploidies (SCAs) are at increased risk for learning disabilities and often require individualized supports in the school setting. Parents of students with rare disorders such as SCAs possess a unique understanding of their child’s educational experiences and play a crucial role in the development of successful school support plans. This international survey study aimed to inductively capture parent perspectives on educational needs and supports for students with SCAs. Parents of youth with SCAs ages 5-21 years (n = 305) provided free-text responses to open-ended questions about their child’s education. Qualitative content analysis using a bioecological systems framework resulted in three overarching themes. Overall, parents identified multiple factors related to the SCA diagnosis that act as barriers to learning, a strong need for school-based social and emotional supports, and elusive or incomplete educational support plans. Based on these findings, we recommend developing robust family-school partnerships, increased collaboration between the school and the child’s medical team, and acknowledgement of the significant role the genetic condition plays in the educational experiences of students with SCAs. Specific suggestions for school support plans for students with SCAs are explored, such as providing school-based behavioral health supports and explicit teaching of executive function strategies.

Introduction

Students with sex chromosome aneuploidies (SCAs) are at increased risk for learning disabilities and often require individualized supports in the school setting. Parents play a major role in the development of successful school

support plans for students with disabilities (Barger et al., 2019; El Nokali, Bachman and Votruba-Drzal, 2010; Goldrich Eskow et al., 2018) and are required by special education law to be active participants in the special education process (Fish, 2008). However, prior research has shown parents of children with neurodevelopmental disorders and rare conditions often report educators lack knowledge of their child’s condition, and that their opinions and expertise are ignored as they are left out of the educational decision-making process (Elbaum, Blatz and Rodriguez, 2016; Paz-Lourido et al., 2020; Starr and Foy, 2012; Tucker and Schwartz, 2013). Parent–school collaboration is particularly important for students with SCAs, as the genetic diagnosis is associated with a host of potential medical and neurodevelopmental features that can impact a student’s success in school. Children with SCAs often require a range of services within multiple systems of support, including but not limited to, special education, speech and occupational therapies, behavioural health supports and medical interventions. Parents of children with SCAs are not only experts on the unique patterns of strengths and needs in their own children but they also often possess a more nuanced understanding of the SCA diagnosis than professionals (Richardson, Riggan and Allyse, 2021). Therefore, it is critical to understand parent perspectives and priorities regarding the educational needs of students with SCA conditions.

Sex chromosome aneuploidies

SCAs are the most common chromosomal abnormalities, accounting for an estimated 1 in 500 live births (Jacobs, 1979). SCAs are characterized by the presence of an abnormal number of sex (X and Y) chromosomes. Typical males have one X and one Y chromosome (XY), whereas females typically possess two X chromosomes (XX). Trisomy conditions are the most commonly occurring SCAs, in which affected males are born with either

an extra X or Y chromosome (XXY/Klinefelter syndrome; XYY/Jacob syndrome) and affected females are born with an extra X chromosome (XXX/trisomy X syndrome). While less prevalent, there are cases where children may possess two or three additional sex chromosomes (e.g., tetra and pentasomy SCAs: XXYY, YYYY, XXXX, XXXYY, etc.).

Though SCAs lack a distinct, recognizable physical phenotype, a variety of cognitive and behavioural traits are prevalent in children with SCAs. General cognitive ability for this population is highly variable; however, the majority of individuals with the most common SCA trisomy conditions (XXY, XYY and Trisomy X) have full scale IQs that fall at the low end of the average range, often with relatively higher nonverbal reasoning skills than verbal processing abilities (Leggett et al., 2010; Urbanus, van Rijn and Swaab, 2020). Those with tetrasomy and pentasomy conditions have higher rates of borderline IQ or mild intellectual disability. Studies have documented high rates of attention-deficit hyperactivity disorder (ADHD) (Tartaglia et al., 2012), as well as other executive function (EF) deficits that can interfere with learning (Boada et al., 2009; Janusz et al., 2020; van Rijn and Swaab, 2015). Learning disabilities are common for children with SCAs, with rates of dyslexia and disorders of written expression as high as 75% in some study samples (Bender, Linden and Harmon, 2001; Ratcliffe, 1982). Increased rates of language disorders, autism spectrum disorder (ASD), mood disorders and anxiety are found across all SCA conditions (van Rijn, 2019). Many children with SCAs require early intervention, special education, speech language therapy, and behavioural health supports for behaviours related to anxiety, low frustration tolerance or challenges with emotional regulation (Bender, Linden and Robinson, 1993; Linden and Bender, 2002; Robinson, Bender and Linden, 1990; Rovet et al., 1996; Thompson et al., 2020).

Parent perspectives

Although previous quantitative studies have documented profiles of learning deficits and increased rates of educational supports (Bender et al., 1993; Berglund, Stochholm and Gravholt, 2020; Linden and Bender, 2002; Skakkebaek et al., 2014), detailed descriptions of the educational experiences of students with SCAs are missing from the literature. A thorough understanding of how students with SCAs experience school, why they require supports and which supports parents perceive as particularly promising might prove useful for the educational teams working with this unique student population. An inductive, qualitative approach encourages parents to share their child's educational experiences in an open-ended manner and allows for emergent themes, highlighting priorities for children and their families that can be used to guide future research and inform interventions (Brantlinger et al., 2005). Predetermined topics that researchers and clinicians believe to be important may not actually be a

priority for those living with SCAs, and using qualitative methods supports the alignment of research goals with the needs of the community (Pugach, 2001; Resch et al., 2010). Qualitative research also expands upon quantitative results by providing rich, descriptive context and delving deeper into the lives and experiences of affected individuals (Fetters, Curry and Creswell, 2013). Finally, qualitative research methods give voice to parent communities who are often overlooked and undervalued, despite the critically important role they play in their children's lives (Worcester et al., 2008).

Prior qualitative research with parents of children with SCAs has mostly focused on the diagnostic experience and medical care, where parents have reported a desire for more supportive delivery of the diagnosis as well as more holistic and optimistic presentation of SCAs from medical professionals (Jaramillo et al., 2019; Riggan et al., 2021). Richardson et al. (2021) found parents of children with SCAs are often forced to assume the roles of 'expert' and 'advocate' as they navigate the multiple systems in which their children interact, including the educational, medical and social support systems. To date, there are no studies specifically exploring parent perspectives on the educational experiences of students with SCAs. This study aimed to inductively capture parent perspectives on the challenges that occur in students with SCAs leading to the need for educational supports, how schools serve children with SCAs and the types of educational supports that are most helpful. A bioecological systems perspective (Bronfenbrenner, 1994) considering the microsystem (interpersonal relationships, direct influences), mesosystem (interaction between those in the child's microsystem), exosystem (indirect systemic influences) and macrosystem (broad socio-cultural beliefs) guided the study design and interpretation of findings.

Methods

Study design and recruitment

This international survey study includes findings from the qualitative portion of a larger survey study on the educational needs of students with SCA conditions. Quantitative results are published elsewhere (Thompson et al., 2021). Participants were recruited from May through June 2019 to complete an electronic survey via email listservs and social media for the eXtraordinary Kids Clinic, an interdisciplinary clinic serving children with SCAs at Children's Hospital Colorado (Tartaglia et al., 2015) and the Association for X & Y Variations (AXYS), an advocacy group for individuals with SCA. Participants were included in the study if they were the parents or caregivers of a child ages 0–21 with a diagnosis of SCA. Results included in this study are limited to children ages 5–21 to best represent the school-age experience. All participants consented to participate in the electronic survey study, results were anonymous and the study was approved by the Colorado Multiple Institutional Review Board (COMIRB # 19-055).

Response rates were not calculated, as the internet-based survey was sent with an open URL and it was not possible to determine a denominator.

Instrument

The broader survey included both closed and open-ended questions about school support plans and educational outcomes. The survey was developed with a multidisciplinary team of experts in SCA conditions (developmental behavioural paediatrician, endocrinologist, genetic counsellor, special educator, school psychologist, clinical psychologist and neuropsychologists) and tested with parents of children with SCAs. This study focuses on free-text responses to two open-ended questions: ‘What is most challenging for your child as a student?’ and ‘Please provide any additional information or opinions regarding therapies, education, or supports that you think are important or you would like to share with us, positive or negative, to help us better understand current needs and supports for individuals with X&Y chromosome variations.’

Data analysis

A qualitative content analysis approach was used to interpret parent responses. All data were uploaded into ATLAS.ti analytic software. Two members of the research team (school psychologist with expertise in SCAs and qualitative methods and a school psychology graduate student with training in qualitative analysis) conducted an initial round of coding to develop the coding structure for the study (Saldaña, 2015). Coders applied a bioecological systems theory of development framework to deductively code each response for content related to the individual child and systems of support (Bronfenbrenner, 1994). Additionally, open coding (Saldaña, 2015) was used to inductively capture novel and emergent themes in the data. Coders worked independently to code 20% of the data, and then met to collectively define codes, compare and discuss any coding differences, and consensus code an additional subset of data until thematic saturation was met. Codes were analysed for patterns, frequencies and co-occurrences. Networks were established to demonstrate connections between open codes and pre-determined codes for bioecological systems levels and to aggregate the data into broader categories (subthemes). Thematic findings were triangulated with results from the quantitative strand of the survey to verify credibility of interpretation. Finally, the team collaboratively reduced the data into three overarching themes to describe parent perspectives and priorities on educational experiences for their children with SCAs.

Results

Demographics

A total of 379 survey respondents met inclusion criteria for the current study, and 305 participants provided at least one codable free-text response used in these analyses

Table 1: Sample demographics

	M ± SD or N (%)
Total N	305
Age (years)	
Child	13.1 ± 4.5
Parent	47.4 ± 7.8
Grade levels	
Elementary-primary	49 (16.1)
Elementary-intermediate	54 (17.7)
Middle school	75 (24.6)
High school	78 (25.6)
Post-secondary	49 (16.1)
Condition	
XXY	152 (49.7)
XYY	47 (15.4)
XXX	39 (12.7)
XXYY	44 (14.4)
XXXYY	17 (5.6)
Other (tetra and pentasomy SCAs)	6 (2)
Respondent	
Mother	277 (90.8)
Father	28 (9.2)
Child sex	
Male	261 (85.3)
Female	44 (14.4)
Highest education completed: respondent	
College degree or higher	210 (68.9)
Less than college degree	90 (29.5)
Choose not to respond	5 (1.6)
Timing of SCA diagnosis	
Prenatal	117 (38.4)
Postnatal	188 (61.6)
Country of residence	
USA	248 (81.3)
Canada	13 (4.3)
European Nations (e.g., UK, Italy and Sweden)	29 (9.5)
Australia/New Zealand	9 (3)
Other/unreported (e.g. South Africa, Mexico and Brazil)	6 (2)

(see Table 1). The sample was international and diverse in terms of child age, grade level, SCA condition and timing of SCA diagnosis. The majority of respondents were college educated (68%) and mothers (91%) from the USA (81%), and XXY was the most common SCA diagnosis (50%). Codable free-text responses included single words, short phrases and lists and brief paragraphs describing the child and issues related to education and systems of support.

Qualitative themes

Qualitative analysis resulted in three overarching themes describing parent perspectives on the educational needs of their children with SCAs: ‘SCA factors as barriers to learning’, ‘need for social and emotional supports’ and ‘elusive and incomplete educational support plans’. Table 2 shows themes, subthemes, associated bioecological systems level (Bronfenbrenner, 1994) and open codes with frequencies for each code. Each theme is comprised of subthemes which are supported by several illustrative parent quotes.

SCA factors as barriers to learning. Parents reported several learning challenges related to the SCA phenotype, such as problems with reading, executive dysfunction and limited strength and vitality. Respondents described

educators with limited understanding of SCAs and who were unaware of how to best support their children.

Reading is hard—Reading, spelling and writing problems were reported frequently by parent respondents. One mother of a 1st grader with XXY wrote:

‘Reading and writing are both proving to be challenges. He has made huge progress in reading this year, but still isn’t reading with the speed and ease his teachers are hoping for. Spelling is also a challenge. He tends to overcomplicate words when he sets out to spell them and often thinks they have more letters/sounds than they actually do.’

Several parents described problems with speech and language related to their child’s reading problems:

Table 2: Themes, subthemes, systems levels and open codes with code frequencies

Theme	Subthemes	Systems level ¹	Open codes (frequency)	
SCA factors as barriers to learning	Reading is hard	Individual	Language arts challenges (102) Learning (13)	
	Executive dysfunction	Individual	Executive function (35) Focus/attention (28) Cognitive shifting (6) Organization (14) Processing speed (12)	
	Limited strength and vitality	Individual	Stamina (12) Fatigue (7)	
	Educators unfamiliar with SCAs	Microsystem	Lack of awareness (29)	
		Macrosystem	Lack of recommendations (16)	
Need for social and emotional supports	Trouble making	Individual	Social skills (37)	
	Friends	Microsystem	Communication (26) Peer problems (16) Immaturity (10)	
		Individual	Self-regulation (34)	
		Microsystem	Behaviour therapy (21) Anxiety (18) Behaviour problems (7)	
	Elusive and incomplete educational support plans	Borderline scores don’t qualify	Exosystem	Missed cutoff/borderline scores (15) Testing/assessments (14)
Started too late, ended too early		Exosystem	Early intervention (40) Academic therapies/interventions (48) Academic support plans (17) Timing of genetic diagnosis (14)	
		Parents as advocates	Mesosystem	Lack of support (18)
			Macrosystem	Parent as advocate (11) Schools lack resources (5)
Alternative settings		Microsystem	Alternative school (17)	
	Exosystem	Classroom setting (11)		

¹ Bronfenbrenner (1994).

‘She mispronounces words often, I am not sure if this is a phonetics reading disconnect or a processing problem, but it makes taking tests challenging if a teacher says a word one way and she pronounces a completely different word when she reads it or talks about it,’
(mother of 8th grader with XXX)

The mother of a 9th grader with XXY described her son’s greatest challenge in the classroom as:

‘Reading. He absolutely hates to read.’

Executive dysfunction—Parents described tremendous EF challenges as a barrier to learning, including poor organization, inattention and trouble with cognitive shifting. These challenges were evident across all grade levels; younger children reportedly struggled to manage frequent transitions throughout the school day and focus in busy classrooms. The mother of a kindergartner with XXY wrote:

‘He’s easily distracted by things most kids wouldn’t notice.’

Similarly, one respondent described her fourth grade son with XYY as:

‘Easily distracted by the hub-bub going on in the general classroom.’

For older students, deficits in EF had a more global impact:

‘Organizing his time and just about everything else in his life. His room, schedule, school locker etc. are all a complete mess. Homework is constantly late. He is also having a hard time deciding what he wants to do with his life,’
(mother of 11th grader with XXY)

Deficits in planning, not turning in assignments even if they’ve been completed, challenges initiating tasks and poor time management interfered with success in grades and on high stakes exams. Many parents reported they carried the heavy burden of helping their child manage, such as the mother of an 11th grader with XYY who stressed her son’s greatest struggle:

‘Organization! He does not write any assignments down. Just won’t/can’t do it. We’ve tried every strategy to get him to be more organized and accountable but nothing works.’

Further, the need for supports did not end after high school graduation; the mother of a college student with XXX described:

‘[She] gets anxious when deadlines are approaching and is a little immature for her age but is getting better as college progresses. She’s learning to juggle school/work and setting priorities better also, but still needs our help.’

Limited strength and vitality—Several parents reported that their children were sluggish, lacked energy and stamina and struggled to keep pace with their peers. One mother of a 3rd grader with XYY wrote:

‘Teachers don’t realize how hard it is for him to simply get through the day because he gets tired so easily. Classroom conversations move quickly and he often can’t formulate his thoughts into words fast enough.’

Frequent breaks were required for some students to persist through the daily agenda:

‘He tires easily and has to take a lot of ‘brain breaks’’
(Mother of 4th grader with XYYY)

One mother of a 9th grader with XXY summarized her sons greatest challenge in the classroom as simply:

‘Staying awake.’

Educators unfamiliar with SCAs—Parents described challenges with teachers and school staff who had little understanding of SCAs:

‘I wish the school had a better understanding of the diagnosis,’
(mother of 2nd grader with XXY)

One mother of a 5th grader with XXY shared a story of an unaware school administrator’s dismissal of her son’s medical needs:

‘My son is going into middle school. I contacted the principal to request that gym class be put into his schedule (it’s an elective that not everyone takes). I gave a brief and reasonable explanation of how XXY is tied up with the endocrine system, and how he needs exercise more than the average kid but doesn’t necessarily seek it out. I also said it would actually help him pay attention and help him academically if gym were woven into his daily schedule. The principal sort of blew me off and said ‘We’ll see what we can do, but we don’t generally make special scheduling requests.’ . . . This situation really got under my skin: it’s a reasonable and easy request. I felt like the principal, who had never heard of XXY, just thought I was another meddling parent’
(mother of a 6th grader with XXY)

Another mother reported the school's lack of awareness led to an inappropriate special education classroom placement throughout her son's educational career:

'K-12 was awful, stuck him in a class with disabled kids, had never heard of KS [XXY], it was like dropping him off at kindergarten every day. Really regret telling the school district he had KS [XXY]'
(mother of 21-year-old with XXY who received GED)

Although some parents felt an increased understanding of SCAs might improve their child's educational experience, others lamented the lack of evidence-based school recommendations specific to children with SCAs.

'[We need] more knowledge given to teachers... More detailed ways of dealing with this. It's like the parent is on a rollercoaster and we never know what to expect or how to fix it. The special needs teacher and myself are at a loss because what works today doesn't work tomorrow'
(mother of 1st grader with XXY)

Need for social and emotional supports—A clear need for social and emotional supports for students with SCAs in the school setting was evidenced by reports of trouble making friends and challenges with self-regulation.

Trouble making friends—Parents cited a number of social skills difficulties. Many described immaturity and trouble connecting with others, such as a mother of a 9th grader with XXYY who emphatically described her child's biggest problem at school:

'SOCIAL SKILLS!!!! He still just doesn't 'get it'. He has no friends and it's always a struggle. Social media is a huge problem but he tries so hard to make connections. He's approximately 2 years behind in maturation compared to his peers.'

Social problems seemed to increase with age, as students with SCAs matured more slowly than their peers:

'The social scene of 5th grade has gotten a lot more complicated, and he has a hard time keeping up with the other kids, and he often feels lonely and left out,'
(Mother of 5th grader with XXY)

For some students, school was their primary opportunity to socialize:

'He knows he is different and is not fully accepted socially by his peers because of his differences. He socializes in school, but does not have friends outside of school day and extra-curricular activities,'
(Mother of high school senior with XYY)

Self-regulation—Respondents made frequent reports of internalizing behaviours; students becoming anxious and

overwhelmed and then shutting down in the school setting. A father of a 9th grader with XXX wrote:

'When her anxiety level rises, doing anything else becomes nearly impossible.'

Parents described narrow windows of tolerance, in which their children struggled to remain engaged in learning while regulating their emotions:

'He breaks down easily when he is pushed too much. He needs the challenge but at the same time it's a struggle,'
(mother of 4th grader with XXXY)

Reports of impulsivity and emotional outbursts suggested externalizing behaviours were also a problem for a subset of students with SCAs.

'His behavior is always a challenge. He has meltdowns and tantrums but his teacher this year knows how to deal with it. He gets easily frustrated with new things but gets bored with things he already knows. He has meltdowns at home but can be the sweetest boy,'
(mother of 6th grader with XYY)

Many parents reported their child benefitted from behavioural health supports in the school and/or with private therapists:

'He has low self-esteem and is critical of his school work although he is a good student. He is afraid to turn in art work and projects in fear it won't be as good as his peers. He sees a psychologist minimum of 1 [time per] month for 5 years now and enjoys having someone that's not his parents to discuss any issues with'
(mother of 12th grader with XXY)

Elusive and incomplete educational support plans. Parents described educational support plans as elusive or incomplete due to borderline scores that made it difficult to qualify for special education, starting too late or ending too early. Respondents also reported that they needed to strongly advocate for their children to receive adequate support services. A subset of parents described positive alternative school placements that reduced barriers to learning.

Borderline scores don't qualify—Respondents frequently mentioned children who just barely missed the cutoff to qualify for special education:

'Always has been 'behind' in school, but not enough for the school to provide supports,'
(mother of 5th grader with XXX)

Many children were denied special education services despite their diagnosis of a genetic condition associated

with risks for educational problems coupled with current skill deficits:

‘I think there is not enough weight given to the [XXX] diagnosis in the schools. My daughter struggles more as the work gets harder, but she needs to fall behind before they offer any support. She was tested and is just right above the cut off for anything other than the 504 [individualized accommodation plan] which I feel doesn’t help at all,’
(mother of 6th grader with XXX)

Parents described a sense that their children would inevitably require supports but that the schools were waiting for their children to fail before stepping in:

‘My son is borderline in every way right now. Based on research, we know that won’t always be the case. The schools will only provide services when he starts to fall behind,’
(mother of kindergartener with XYYY)

Started too late, ended too early—In general, many parents emphasized ‘the earlier, the better’ for educational supports. The mother of a recent high school graduate with XXY attributed her son’s success to proactive early interventions:

‘Don’t wait! If there’s even the slightest delay, address it. Early intervention was key for our son.’
(speech therapy, OT)

Some parents believed educators’ lack of awareness of SCA conditions led them to dismiss early warning signs and miss opportunities for prevention early in their child’s educational career. The mother of a 1st grade student with XXY expressed her frustration with the idea of waiting to start services until his academic difficulties were more pronounced:

‘I do not think our school understands that our child is at risk for learning difficulties due to his diagnosis. I think they have a more ‘wait and see’ philosophy which is not acceptable to us.’

On the other hand, some parents described services being dropped too quickly and the mistaken assumption that progress would continue after the school discontinued services. One mother of a 3rd grader with XXX described her daughter losing physical therapy services despite continued challenges:

‘On a recent [physical therapy] exam, she is now testing in the 16th percentile (low average) compared to the 5th percentile from a few years ago, so she no longer qualifies for assistance. Difficulties with language and anxiety compound her difficulties, but that

may not show up in 1:1 testing. I feel if her physical therapist understood trisomy X better, they might take a more holistic approach to thinking about their evaluation, her eligibility, and her treatment.’

Parents as advocates—Parents frequently described themselves as educational advocates for their children. Some described contentious relationships with the schools, such as the mother of a recent high school graduate with XXX who recalled:

‘The public school was difficult and they didn’t provided services until forced.’

Several parents described a need to fight hard for their children, while others reported a need to research all of their options rather than merely accepting what the schools offered:

‘Schools really don’t want you asking for things, and as such, are very tight lipped about various options for learning environments, so as a parent you REALLY are forced to do tons of research to try and find anything out that might be available to you and could help your child,’
(Mother of 8th grader with XYY)

Other families advocated outside the schools to raise awareness in their community and to find supplemental supports.

Alternative settings—Some parents noted they had opted out of traditional public schools after watching their child struggle. Respondents described private schools with unique pedagogy (e.g., Montessori, Waldorf) or schools specifically designed to support students with learning disabilities:

‘For [traditional] middle school, there was no curriculum, teachers were young and worked hard but each class had a different set of expectations. It was disastrous for my son. Now that he attends a school with very strong built in supports, teachers and staff with lots of experience working with students who learn differently and a structured environment, he’s thriving,’ (Mother of 9th grader with XXY)

Smaller class sizes, classroom accommodations, a focus on the whole child and teachers with strong classroom management skills were noted as critical for many children with SCAs. One mother of an 11th grader with XXX described her daughter’s success with an arts-based education:

‘She earned a space in an arts high school and this environment is well suited to her. Lots of creativity, only 4 classes each semester so she could focus and not be overwhelmed switching classes 7 times a day.’

While these specialized learning environments appeared helpful, they were not accessible to all survey respondents:

‘Having more schools/options specifically designed to educate children who need smaller class sizes, additional time to learn, and allow the children to learn at the pace they can would be wonderful. I know there are schools that exist, but they are private, expensive, and not available in all areas,’ (mother of 2nd grader with XYY).

Discussion

This was the first study to explore parent perspectives and priorities on the educational experiences of children with SCAs. Using a qualitative content analysis approach expanded upon our quantitative results, which indicate high rates of school supports for students with SCAs (Thompson et al., under review). Qualitative themes amplified parent voices and provided rich and nuanced details with specific examples of *how* children with SCAs experience school and *why* they may struggle or require extra supports. Parents reported a variety of perspectives on barriers to learning, such as trouble reading, lagging EF skills and a lack of vitality and stamina required to successfully make it through a long school day in a busy and chaotic classroom. Additionally, parents reported educators lacked awareness of SCAs and knowledge of evidence-based educational interventions specific for students with SCAs. Social and emotional concerns were also listed as barriers to learning, requiring significant supports both in and outside of the school setting. Finally, parents frequently reported challenges with accessing special education due to borderline assessment results; schools missing key opportunities for early interventions or removing services prematurely when children made even a small amount of academic progress. Many respondents described a need to advocate strongly to receive what they perceived as adequate educational support services. Alternative school placements, with smaller class sizes, focused curriculum, individualized accommodation plans and highly supportive teachers were helpful for a subset of the sample.

Our findings support prior literature documenting high rates of reading disabilities for students with SCAs (Pennington et al., 1982; Skakkebaek et al., 2014), as well as EF issues known to impact learning such as attention, working memory and cognitive shifting (Janusz et al., 2020; Tartaglia et al., 2012; Urbanus et al., 2020). Furthermore, our findings expand upon prior literature documenting poor social skills related to language disorders (Ratcliffe, 1982) and reduced social cognition (Cordeiro et al., 2012; van Rijn et al., 2014), internalizing conditions such as anxiety and depression (van Rijn, 2019; Skakkebaek et al., 2018) and general fatigue and a lack of strength and stamina (Nielsen, Pelsen and Sørensen, 1988) by illustrating how these related conditions might impact a student’s educational experience. Using a qualitative analytic approach to the topic breathed life into these well-

documented aspects of the SCA phenotype in the literature. By allowing parents to freely express their child’s greatest challenges and asking them to extrapolate on issues they think are most important for researchers to know, we gained a richer understanding of how the psychoeducational profile in SCAs interacts within educational environments. This systems approach highlights areas where systemic change might most benefit students with SCAs.

Special education services are often underfunded, leaving many local schools with unfunded mandates to support students with disabilities (Dhuey and Lipscomb, 2011; Kolbe, 2021). Stringent qualification criteria (e.g., cut-off scores of two standard deviations below the mean on standardized assessments) help schools objectively determine which students will receive individualized support plans (Yell, Shriner and Katsiyannis, 2006). Our findings suggest parents of students with SCAs often feel these qualification criteria unfairly exclude their children from interventions they could benefit from based on their genetic diagnosis. Competing interests between schools and families can result in adversarial relationships rife with conflict. Prior qualitative research has documented parents, especially mothers, of children with SCAs often assume the exhausting role of expert and advocate in healthcare settings (Richardson et al., 2021). Our findings confirm that parents of children with SCAs play the role of advocate in the schools, in a large part, due to a lack of knowledge surrounding the SCA diagnosis. Additionally, we found that subclinical and borderline scores often associated with the phenotype are particularly challenging when trying to secure school support services, and that social–emotional supports are viewed as a very important and lacking for many children with SCA.

Practical implications

Our results support a systems approach to educating students with SCAs (Table 3). Building strong family–school partnerships (Barger et al., 2019; El Nokali et al., 2010) and acknowledging parent expertise is critical for students with SCAs, as they often possess complicated developmental profiles and require parents to coordinate supports from a multitude of systems. External educational advocates may be useful partners for parents as they negotiate the special education process (Phillips, 2007). Advocates are most helpful when they act as allies, and work to enhance communication with the schools, mediate conflicts and provide emotional supports to parents (Gershwin and Vick, 2019; Nespor and Hicks, 2010).

Results suggest that students will benefit from schools that possess a better understanding and greater respect for the educational impact of SCAs. Whenever possible, educators should partner and collaborate with medical providers as part of the educational assessment process, as each party has valuable information that could help inform a child’s programming. Teachers have daily exposure to their students and can inform physicians

Table 3: Recommendations for a systems approach to supporting students with SCAs

Systems level for supports	Recommendations for educators
Individual	<p>Increased frequency of psychoeducational evaluations using standardized norm-referenced assessments, as academic demands change over time and students with SCAs may fail to keep pace with peers</p> <p>Evidence-based academic (esp. reading and writing) interventions as needed</p> <p>Direct instruction in executive function strategies</p> <p>School-based behavioural health supports and direct social-skills instruction</p>
Microsystem	<p>In middle and high school, assign dedicated case manager to support management of multiple classes, differing teacher expectations and planning and initiation of class projects</p> <p>Classroom accommodations to remove barriers related to executive function and fatigue (e.g., frequent breaks, preferential seating and extended time)</p> <p>Appoint teachers with strong classroom management skills, high degree of empathy, knowledge of SCA conditions</p> <p>Implement friendship groups, intentional group placement and class partners to facilitate peer relationships</p> <p>Calm classes and smaller class size whenever possible</p> <p>Utilize a SCA-informed approach to behavioural challenges that includes recognition of the role of EF, reduced endurance, anxiety, sensory sensitivities and other behavioural features of the genetic condition</p>
Mesosystem	<p>Develop robust family-school partnerships</p> <p>Choose harmonious and compatible peer groups for student when possible</p> <p>Collaboration between school, medical team and behavioural health providers</p>
Exosystem	<p>Consider disability categories for special education qualification that acknowledge the genetic condition (e.g., Other Health Impaired in the USA)</p> <p>Utilize multi-tiered systems of support, including targeted preventative interventions to reduce risk for academic or social problems</p> <p>Monitor student progress closely and initiate support services as early as possible</p> <p>Continue monitoring and provide accommodations and consultation services if student no longer meets criteria for special education</p> <p>Consider external educational advocates to enhance communication and mediate conflict</p> <p>Add study skills classes or study hall with adult supervision to student's schedule</p>
Macrosystem	<p>Educate school staff on SCA conditions and how SCA affects a specific student, with examples of previous supports that were effective</p> <p>Support families in their advocacy efforts and partner with SCA advocacy organizations</p>

about behavioural changes after medication changes or partner with providers to support therapeutic goals. Medical providers, including private behavioural health therapists, can consult with schools on specifics of a child's condition and prognosis, as well as evidence-based interventions that may be most useful for children with SCAs. Further, as prior research shows, parents carry an undue burden of service coordination in SCAs (Richardson et al., 2021). Medical and education teams can offer families a release of information document allowing open communication as needed and to the level of parent comfort. School nurses and school psychologists may be able to act as liaisons, bridging the educational and medical systems to enhance quality of care (Sheridan et al., 2009).

Schools may also benefit from qualifying a child for special education with an educational diagnosis that reflects

the SCA diagnosis. In the USA, the special education category Other Health Impaired (OHI) honours the fact that the student's educational challenges are a result of their underlying genetic diagnosis and that this is a lifelong condition that will likely require ongoing supports (Hodge & Asola, 2019). Highlighting the medical diagnosis on a child's educational support plan could potentially help qualify younger students for support services as early signs of school problems arise and dissuade educational teams from discontinuing special education when the student makes progress. Furthermore, research has shown children with learning disabilities commonly associated with SCAs (e.g., dyslexia, ADHD) are often labelled by teachers and parents as 'lazy' or 'unintelligent', especially prior to a diagnosis (Glazzard, 2010; Lundin, 2020; Thompson, Bacon and Auburn, 2015). Specifying the student's SCA diagnosis in the special education plan might encourage a team to consider a student's inattention,

cognitive rigidity, fatigue or trouble learning as part of a medical problem that warrants interventions and accommodations, rather than disobedience or a lack of motivation.

Classroom accommodations and interventions targeting EF concerns and fatigue may be useful for students with SCAs. While not specifically trialled in students with SCA, research has determined explicit teaching of EF strategies (e.g., planning, goal setting, self-instruction), biofeedback enhanced relaxation and mindfulness meditation can improve EF in the classroom (Takacs and Kaszai, 2019). Classroom accommodations such as extended time, frequent breaks, preferential seating, chunking of assignments and testing in a separate may be particularly useful for this student population. Behavioural health supports in the school setting may also benefit students with SCAs, including social skills groups (e.g., lunch bunch) and mental health supports (e.g., pressure pass to leave the classroom as needed to manage emotions; individual and small group interventions to teach self-regulation). Noticing student assets and providing students with opportunities to utilize and share their strengths in the school setting may contribute to overall student well-being. Prior studies have shown children with SCAs are prone to exceptional kindness, an eagerness to please, creative thinking and perseverance (Thompson et al., 2022). Finally, many students with SCAs will not have the option to attend the specialized schools with small class sizes and modified curriculum that some of our participants reported as beneficial. However, educators and parents can make intentional classroom placement decisions within a child's current school to best meet a student's needs (e.g., choosing experienced teachers with strong classroom management skills and high degrees of empathy).

Limitations

This study was limited by the survey design, in that parents were required to type responses and may have edited their thoughts or left out important details due to space limitations or fatigue with survey completion. Qualitative themes were triangulated between investigators and with prior research, including statistical results from quantitative survey questions, however, we were unable to confirm family reports of school services or hear the perspectives from school personnel or the students themselves. Regardless, the survey design was a good fit for a purely exploratory study such as this initial probe into the educational experiences of students with SCAs. The relatively large and diverse sample provided an overview of the topic and generated multiple hypotheses to be tested in future studies, such as the potential for interventions targeting EF and social-emotional skills to improve educational outcomes for students with SCAs. Ample research opportunities exist for more in-depth, and novel methods such as interviewing, case studies, classroom observations, photo elicitation and review of educational

records to better understand the educational experiences of students with SCAs.

Conclusion

Students with SCAs have a unique educational profile that may be challenging to support within the schools. Challenges with reading and writing, EF, fatigue/endurance, social skills and emotion management may act as barriers to learning, and are frequently triggered in busy classroom environments. Skills hovering in the borderline range are common to the SCA phenotype and are not often well served by special education systems with limited resources and strict cut-offs for qualification. As a result, families may feel they need to advocate strongly for their child to receive adequate support services. To improve the educational experience of children with SCAs, we recommend increased collaboration between the school and the child's medical team, strong parent partnerships and acknowledgement of the significant role the genetic condition plays in the educational experiences of students with SCAs.

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Conflict of interest

We have no known conflicts of interest to disclose.

Address for correspondence

Talia Thompson,
Children's Hospital Colorado,
13123 East 16th Avenue, Box B140,
Aurora, CO 80045
USA.
Email: talia.thompson@childrenscolorado.org

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