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RESEARCH PAPER



# South African adolescents living with spina bifida: contributors and hindrances to well-being

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## ABSTRACT

**Background:** Spina bifida myelomeningocele is a major cause of disability among adolescents. However, little research is available in low-income nations such as South Africa. Investigating the contributors and hindrances to well-being in adolescents with spina bifida myelomeningocele may yield novel insights. In this study we included both adolescents and their primary caregivers to examine their perspectives on caring for and facilitating improvements in the life of the adolescents living with spina bifida myelomeningocele.

**Objectives:** To identify and document the perceptions of adolescents with spina bifida myelomeningocele and their primary caregivers on the factors that contribute to and hinder the well-being of adolescents living with spina bifida myelomeningocele in South Africa.

**Method:** An explorative qualitative research design was utilized, guided by a positive psychology theoretical framework. Fourteen participants, consisting of seven adolescent-primary caregiver dyads, were interviewed. Data were analyzed using thematic analysis and coded inductively using ATLAS.ti software.

**Results:** We identified eight themes describing participants' perceptions on contributors and hindrances to the well-being of adolescents with spina bifida myelomeningocele. Contributing factors included: family support, social groups, special needs education, sport participation, striving for independence, and finding meaning in life. Hindrances included: structural (lack of resources, medical care and mobility challenges) and social (bullying and harmful friendships, secrecy about the condition, social isolation and unhappiness) hindrances to well-being.

**Conclusion:** Acknowledging the contributors and hindrances to the well-being of adolescents with spina bifida myelomeningocele is crucial for guiding informed positive interventions and preventing blind spots. Given the limited number of positive contexts, concentrated effort is required to facilitate opportunities for growth in a range of environments. Primary caregivers lack insight into the positive and negative aspects of the adolescents' lives. We suggest families prioritize bonding time and open communication.

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## KEYWORDS

Adolescent; disability; positive psychology; primary caregiver; South Africa; spina bifida myelomeningocele

## ► IMPLICATIONS FOR REHABILITATION

- Exploring the perspectives of adolescents living with spina bifida and their parents regarding well-being is important to develop appropriate interventions.
- Adolescents living with spina bifida value social support and social interaction as ways to maintain well-being.
- Special needs education institutions with curriculums tailored to adolescents with spina bifida promote comfort, acceptance, and personal excellence.
- Sport contributes to the mental, social and physical well-being of adolescents with spina bifida. Sport inspires and offers opportunities for success, it improves school attendance, increases positive affect, and provides opportunities for close relationships with friends and family.
- Finding ways to mitigate the stigma around spina bifida is necessary to improve adolescents' well-being within South Africa.

## Introduction

Spina bifida (SB), a congenital birth defect caused by incomplete fusion of the neural tube, is a major cause of disability among children and adolescents globally [1–4]. In South Africa (SA), prevalence rates range between 0.77 and 6.1 per 1000 live births [5] with more females born with SB compared to males [6,7]. In sub-Saharan Africa, prevalence rates are between 9.95 and 15.27

per 10 000 live births [8], with global rates predicted to rise [9]. Globally neural tube defects occur more often in women, however some studies report SB is more prevalent among men [10,11].

SB myelomeningocele (SBM), the most common and severe form of SB, is a complex chronic disorder associated with physical and cognitive impairments requiring life-long medical management [1,3,12–14]. Despite the magnitude of the disorder, there is

little to no literature on the experiences of adolescents in low and middle-income countries, such as SA [4,5,11,15,16]. SA communities often stigmatize and discriminate against people with a disability and their families, resulting in shame and social isolation [17,18].

The challenges adolescents with SB face include achieving independence, life satisfaction and well-being [11,19–21]. During adolescence, physical and intellectual disabilities manifest more noticeably as social dynamics become increasingly complex, resulting in impaired social competence and limited social contacts or quality friendships [12,19,22]. The available literature predominantly focuses on the risk factors, challenges and inhibitory aspects of living with SB [21,23,24]. As a result, little is known about the positive contexts and experiences of living with SB globally and in the SA context, especially from the perspectives of both adolescents and their primary caregivers [12,21]. Exploring these experiences provides insight into how individuals assign meaning to their disability, often adopting self-understanding from their socio-political context [24,25]. Conceptualizing and ordering these experiences into a particular psychological framework [11,22,25] enables researchers to investigate target areas and optimize the limited available positive contexts to facilitate improved social function and well-being [22,23,26,27].

Participants tend towards bias, inaccurately reporting on the adolescents' friendships and social functioning [28,29]. We subsequently interviewed both adolescents and their primary caregivers as multiple informants who contribute their perspectives holds some benefit [29,30]. For this study the researchers used a positive psychology framework developed by Ryff and Singer [31] to investigate the adolescent-primary caregiver dyads' perceptions of the contributors and hindrances in the lives of adolescents with SBM [31–34]. Ryff and Singer's [31] model serves as a comprehensive conceptualization of the three tenets of well-being (emotional-, psychological- and social well-being), which were incorporated into the interview schedules questions [35].

## Methodology

### Research design

We used an explorative qualitative research design and semi-structured interviews, asking 13 open-ended questions with follow-up probes. The interview schedule included four different types of questions (contrast, descriptive, evaluative and structural) [36] to develop rich narrative reports of individuals' personal experiences of well-being. Interviewees were encouraged to voice their beliefs, feelings and assumptions in response to the questions asked [32,36]. Interview questions were designed to incorporate three measures of well-being (emotional-, psychological- and social well-being) [31].

### Setting

Participants were recruited from the Cape Flats, an expansive low-lying area southeast of central Cape Town, South Africa. During apartheid, many non-white population groups were forcefully relocated to the Cape Flats area. Grassy Park, the municipality where the non-governmental organization (NGO) resides, is home to population groups that are predominantly Afrikaans – (37.8%) and English-speaking (57.9%), are ethnically Colored (an official term used in SA for population classification and census data) (87.4%), have low levels of higher education (10.1%), and are of a low socioeconomic status, with no income recorded for (9.8%) of households [37].

### Research participants and sampling

Purposive sampling was used to invite adolescents aged 13–16 years with a primary diagnosis of SBM and one primary caregiver, either a parent (biological or non-biological) or a legal guardian, to both participate in the study.

Exclusion criteria for adolescent participants of the study were as follows: a) Adolescents of moderate to severe mental handicap, due to the nature and complexity of the interview questions; b) Adolescents with SB other than myelomeningocele, due to the nature of symptoms being less pronounced.

### Recruitment strategy

Participants were recruited with the help of an NGO in Cape Town that provides support services to children with disabilities and special needs. Participants were invited via informational flyers with accompanying contact permission forms. Willing adolescent-primary caregiver dyads were telephonically contacted to arrange the interviews. One adolescent participant did not meet the inclusion criteria and was excluded from data analysis.

### Data collection

The research was conducted during the period July–October 2017. Interviews were conducted in English using a semi-structured interview schedule. The interviews were designed to be approximately 45 min in length. An English–Afrikaans interpreter was used for assistance during one interview. Participants completed a demographic form (gender, age, ethnicity, socioeconomic status, education level and living situation) at the time of the interview. Interviews were conducted at a time and location convenient for the participants. The interviews were conducted individually in a private room, in an office at the NGO, or in the participants' homes. All information was kept confidential and coded numbers were used to de-link participants from the data.

### Data analysis

To enable comprehensive data analysis, the interviews were audio-recorded and transcribed verbatim. Two transcriptionists were employed to produce verbatim transcripts of all of the interviews. ATLAS.ti version 7 was utilized for coding the transcripts. Thematic analysis was used to generate themes that capture the codes in categories so that the data could be interpreted [33]. The themes that resulted from the interviews were pooled into two groups (adolescents and primary caregivers), and the contributing factors to well-being were noted and compared to relevant literature.

### Ethical considerations

Ethics approval was obtained from the Stellenbosch University Research Ethics Committee, project number SU-HSD-004628. Permission was obtained from the NGO to conduct research on their premises. The English–Afrikaans interpreter signed a confidentiality agreement. Due to transportation challenges and for convenience, participants could opt to have the interviews at their homes. We certify that we adhered to all applicable institutional and governmental regulations concerning the ethical use of human volunteers during the course of this research.

**Table 1.** Socio-demographics of the sample.

Variables	Demographic factor	n (%)
Gender –Adolescents	Male	5 (71.4)
	Female	2 (28.6)
Gender–Primary caregiver	Male	2 (28.6)
	Female	5 (71.4)
Primary language	Afrikaans	3 (21.4)
	English	3 (21.4)
	Bilingual (Afrikaans/English)	2 (14.3)
	IsiXhosa	6 (42.9)
Primary caregiver status	Single mother	2 (28.6)
	Both parents	4 (57.1)
	Other	1 (14.3)
Primary caregiver interviewed	Mother	5 (71.4)
	Father	1 (14.3)
	Grandparent	1 (14.3)
Primary caregiver education	Incomplete high school	3 (42.86)
	Graduated high school	3 (42.86)
	Incomplete college/university	1 (14.29)
Combined family income monthly (US Dollar)	181–362\$	5 (71.4)
	725–1087\$	1 (14.3)
	Excess of 1087\$	1 (14.3)
Religious affiliation	Christian	10 (71.4)
	Islamic	4 (28.6)
Age (years)	Mean	14.5
Age (years)	Adolescents	49.5
	Caregiver	Range
	Adolescents	39–75
	Caregiver	

## Results

### Participant characteristics

A total of 14 interviews were conducted. Seven adolescent participants were interviewed (5 male and 2 female) all living with spina bifida myelomeningocele. The adolescent participants had varying degrees of ambulation. We excluded one adolescent participant from data analysis given the co-occurrence of SMB and hydrocephaly. Sociodemographic data of the population are shown in Table 1. During data analysis we identified six contributor and two hindrance themes and their corresponding subthemes, shown in Table 2. The themes highlight the positive and negative factors affecting the well-being of adolescents with SBM.

### Contributors to well-being themes

#### Family support

**Role of primary caregiver.** Adolescent participants highlighted their need for an attentive, consistent and loving caregiver. Adolescent participants spoke about their desire for quality family time in the form of activities, outings and holidays, especially with their primary caregivers. All the single-parent households that formed part of the sample are headed by biological mothers who are often the sole pillar of emotional support and comfort. Adolescent participants desired greater attention and involvement from their fathers. Primary caregivers spoke of their attempts at

**Table 2.** The main contributors and hindrances to adolescents SBM well-being.

Contributors
Family
Role of primary caregiver
Additional support
Friends
Peer support
Technology
School
Special needs school
School facilities
Sport
Independence
Finding meaning in life
Faith
Community
Hindrances
Structural challenges
Lack of resources
Medical care
Mobility challenges
Social challenges
Bullying and harmful friendships
Secrecy about the condition
Social isolation
Unhappiness

Abbreviation: SBM: spina bifida myelomeningocele.

fostering a relationship where the fathers could provide the adolescents with support:

“I told him I’m not alone here your dad is also there you must go to him, but he doesn’t want to” (P7, 53-year-old female).

**Additional support.** Primary caregivers believed sibling relationships to be an important source of support. However, the adolescent participants felt that sibling relationships varied in their quality and nature, and that they desired closer sibling relationships. Extended family (e.g. aunts, uncles, cousins) received praise for the support they provided:

“And I can only speak of my experience, and say that I was blessed in many ways, with a big family support” (P5, 42-year-old female).

Participants also spoke of the importance of disclosure of the adolescent’s medical condition to friends and family as a means to obtain additional support. Families that disclosed their child’s condition to their social circles emphasized the benefits of acceptance and openness:

“Yes just they mustn’t be shy for their child... The people must adjust around them, and the families must try to adapt to how they are man. They mustn’t feel out because of their disability” (P11, 45-year-old female).

#### Social groups

Adolescents reported two distinct and separate social groups: school friends and neighborhood friends. These two groups of friends had multiple intertwining benefits; normalizing SBM, promoting self-acceptance, disrupting negative self-perceptions and challenging perceived limitations. Participants emphasized the importance of building strong healthy friendships in both groups, and primary caregivers acknowledged their desire to facilitate this process.

**Peer support.** Adolescent participants highlighted their need for emotional support, acceptance and understanding from their peers, and emphasized these as important contributors to their

well-being. Primary caregivers pointed out that the two social groups differ:

"I think the only good influences that she has are the ones that are in the neighbourhood, because... I don't know they not negative..." (P2, 43-year-old male).

**Technology.** All participants were aware of the benefits of engaging in recreational and prosocial afterschool activities and of technology for well-being in the form of communication, education and entertainment. Primary caregivers believed that the benefits of mobile phones for the adolescents' social well-being outweigh the potential risk factors.

### **Special needs education**

**Special needs school.** The adolescent participants all attend academic institutions for students with disabilities or special needs education. All participants felt that the adapted curriculums at these institutions were more appropriate than mainstream schooling. Primary caregivers emphasized the importance of finding the right institution for their adolescent and an educational program tailored to the adolescent's specific needs. Primary caregivers praised the school's attempts to promote comfort and acceptance:

"And what I really admire at school, is that the children, I mean they help each other, they care for each other, which at mainstream schools they don't do that!" (P11, 45-year-old female).

Primary caregivers and the academic institutions make attempts to encourage personal excellence:

"I find it to be one of the best schools. So, at school they are also motivated because they see a lot of them around and also they see some of the ex-students who come and motivate..." (P2, 43-year-old male).

**School facilities.** Facilities (academic, cultural and sporting) and training programs teach trades and skills essential for well-being and the empowerment of the adolescents. Adolescent participants enjoyed school and the educators and the opportunities available to them. Their vocational and academic aspirations varied, although all participants had ambitions of completing their secondary education.

### **Sport participation**

Sport was a ubiquitous theme that emerged in relation to all spheres of the adolescents' lives. Regardless of the functional challenges (particularly ambulation), all adolescents enjoyed participating in activities with their able-bodied and disabled peers. Traditional games are typically adapted for disabled youths to participate:

"...And you know, they would like, know he can't kick the ball, so they'll throw the ball to each other, and then they play hide and seek or you know, those type of things..." (P5, 42-year-old female).

Primary caregivers endorsed sport activities and acknowledged their numerous benefits, recognizing how spectating at sporting events provides greater involvement in their adolescents' lives:

"[adolescent participant] at school was involved in the wheelchair dance competitions and then there's... volleyball... That she played at school. They put them in a lot of stuff at school. She's participating in all stuff that we go watch" (P3, age unknown female).

Sport promoted feelings of acceptance, confidence, happiness and improved school attendance. Participants draw inspiration from athletes and former pupils who have improved their lives through sport. Adolescent participants find meaning in life

through sport, friendship and athletic success. One participant offered advice to others with SBM:

"Tell them to join sports, that's all I can tell. I think, first I didn't want to do athletics, now I can beat everyone." (P13, 15-year-old male).

### **Striving for independence**

The medical (self-care) and functional assistance adolescents require vary in nature and extent. Across households, mothers provide the majority of the care needed. Adolescent participants highlighted the need for structure, support, life guidance and goal setting. All participants emphasized the benefits of discipline and consistency of self-care:

"We have done so many things, trying to inculcate in her she needs to do what she's supposed to be doing all the time. She needs to be consistent" (P2, 43-year-old male).

Primary caregivers discussed parenting styles, suggesting progressively giving more responsibility while instilling perseverance:

"I always encourage him and I always tell him that things are gonna get better. Things will get better and he has big dreams, you know, he always say he wants to drive..." (P11, 45-year-old female).

### **Finding meaning in life**

All the participants highlighted family, friends, school and sport as giving life meaning. Adolescent participants emphasized their altruistic inclinations:

"What gives my life meaning is also helping and being there for elderly people and helping those that need my help..." (P4, 13-year-old female).

The participants also addressed the topic of character. Adolescent participants emphasized respect, good manners, self-confidence, perseverance, mindfulness and hard work. Primary caregivers emphasized positivity, strength and unity.

**Faith.** Faith and religious ideology were important to many participants attempting to make sense of the disability, believing it gave their lives direction and hope. Primary caregivers reconciled the adolescent's frustrations with being disabled by explaining it as God's will: "God had chosen them as a special child" (P3, age unknown female).

Participants' respective places of worship provide support, community and the opportunity for families to congregate:

"I'm grateful that I've got family, great friends... I'm grateful because God created me, I'm unique. Thankful for the love of my family, what they gave..." (P1, 13-year-old female).

**Community.** Participants reported that local hospitals offer them support, education and guidance in a comfortable and enjoyable setting. Participants reported that these support groups provide a sense of empowerment, belonging and hope, as well as the opportunity to learn from one another:

"There's no support... So we're trying to do that, like maybe on one occasion we have like maybe the, the session for the boys, where they'll do shaving, or you know, self-care" (P5, 42-year-old female).

Participants offered functional suggestions of how to improve the lives of people living with SB, such as expanding wheelchair accessibility in public spaces and raising awareness and acceptance of SB:

"Yes, I do think that if it's put out there and the media is aware of it that it would change things. Because I find that people tend to hide their kids" (P5, 42-year-old female).

## Hindrances to well-being themes

### Structural challenges

**Lack of resources.** Participants revealed aspects of their lives that are constrained due to limited financial resources. Transportation costs, housing, school fees, access to technology, sanitary and medical equipment and medical care were among the essentials that constantly cause tension and reduce quality of life.

**Medical care.** Participants spoke of the medical issues they have had to endure, including the numerous operations associated with SB care, such as replacing shunts as the adolescents grow, managing kidney problems, serious infections and other known SB-related events such as motor vehicle accidents. Primary caregivers emphasized the importance of consistent effort and foresight in planning for necessary treatment. All participants had fears concerning the health of the adolescents:

"I'm just worried about her health because ... she's don't know, looks like [adolescent participant] don't see the importance of her stuff that she must do" (P3, age unknown female).

**Mobility challenges.** Mobility and ambulation often leave adolescents feeling hopeless about future independence, self-worth and quality of life:

"Cause I don't wanna be like in a wheelchair. It's not fun to be in. Then I can do nothing, like say my now I wanna go play soccer then I can't cause I'm here in. And then I can't do what other children can do" (P8, 13-year-old male).

Primary caregivers spoke of the emotional and physical strain of caring for the adolescents. Primary caregivers attempted to separate the wheelchair from the adolescents' identities.

"You know ... And that is why I always tell him, the wheelchair doesn't define you. You are your own person, that is just your means to get around ... But it doesn't define you as a person because you are your own person. Whatever choices you make, then that's the choices you're gonna live with" (P5, 42-year-old female).

### Social challenges

**Bullying and harmful friendships.** Adolescents reported that bullying occurred on a regular basis, both at school and in their neighborhoods. Name calling, social exclusion and physical assault were among the accounts given by the adolescents and primary caregivers. Parents were largely aware of the incidents of bullying. The adolescent participants spoke of the anger and frustration they felt at times, and one participant admitted to fighting back, while other participants were unable to. As one primary caregiver recalled:

"I don't know, [adolescent participant] ... if she gets um supported by her friends at school because she was she was usually the child that was bullied at school. Because I think it was two years ago, not last year, but she came home with her eye with a blue eye that one of the children did hit her. So I'm not sure" (P3, age unknown female).

The adolescent participants often have few friends and at times struggle to differentiate good role models and supportive friends from negative ones. A few of the adolescents reported harmful friendships and relationships. Peer pressure was a powerful vehicle for maladaptive behaviors such as underage drinking and smoking of tobacco products. Adolescent participants reported their caregivers being largely unaware of their maladaptive behaviors:

"I ... my mommy don't know so ... I smoke, but my mommy knows I drink a little" (P4, 13-year-old female).

**Secrecy about the condition.** There was inclination towards privacy and secrecy regarding the nature of the disability. The

primary caregivers spoke of how very few people in their social circles, including family, were fully aware of the diagnosis. Even fewer people had been informed in cases where the participants could walk and pass as "normal", despite the adolescents attending special needs schools. There was a lack of congruence between accepting the diagnosis and promoting the well-being of the adolescent:

"You know, so a lot of people know nothing about spina bifida. A lot of people even our families they have no idea. And even when they see children who look like ... they have no idea and yet there are so many people even in our country living with spina bifida" (P2, 43-year-old male).

**Social isolation.** Structural challenges limit afterschool social activities and as a result participants were often confined to socializing with neighborhood friends. Safety came up several times as a great concern shared by all participants. An adolescent participant spoke of her fears:

"Of those killing, killing kids, girls, taking girls and grabbing them and killing taking the body parts. I don't go outside anymore. I never go outside" (P1, 13-year-old female).

Primary caregivers often isolate the adolescent at home out of fear for their safety. As a result the adolescent participants would play and socialize in the street directly in front of their homes:

"We don't go out like to the mall, we just see each other at school and on the streets" (P1, 13-year-old female).

The adolescents' isolation inhibited prosocial opportunities or extracurricular activities. The adolescent participants were afraid to visit friends in the neighborhood, to visit local public areas such as play grounds or even to frequent their nearby corner shops. A primary caregiver spoke of her inability to take her adolescent to the local library:

"No, I didn't take him yet, must walk there and all the skollies [criminals], gangsters is that side" (P7, 53-year-old female).

**Unhappiness.** The adolescent participants feel powerless in their lives and were uncertain as to what brought them happiness. They also frequently experience periods of boredom, unhappiness and sadness:

"When asked "when do you feel most happy": That would be only like half the time, or like at school. Like ja" (P12, 16-year-old male).

The adolescents struggle to come to terms with their disability, as one primary caregiver describes:

"He's not happy at the moment. I don't know when he will accept it. But he is not happy at all" (P14, 75-year-old male).

All the participants struggled with abstract questions on happiness and meaning of life, responding with confusion or lack of insight. The adolescent participants occasionally stated that they had no positives in specific areas of their lives. Primary caregivers admitted to often having no inkling as to their adolescents' thoughts.

## Discussion

This research aimed to identify adolescent-primary caregiver dyads' perceptions of contributing factors and hindrances to the well-being of adolescents with SBM. A set of six contributors and two hindrances to well-being was derived from the data. We and other researchers are convinced that optimizing the contributing factors and minimizing hindrances will culminate in increased well-being and life satisfaction and reduced levels of mental illness [2,23,35,38].

In accordance with previous research [39,40], we found that mothers were the primary pillars of support (emotional and functional) and were instrumental in fostering and implementing improvements that could benefit the whole family [27]. All of the participants emphasized the importance of stable caregiving, quality family time and open communication [24,41]. All participants felt that increased involvement by fathers and the extended family would provide support for both primary caregivers and adolescents, in turn reducing stress and improving the families' ability to cope and their overall well-being [2,12,23,42]. We found that adolescent-sibling relationships varied in their nature and quality. There is some evidence to suggest that stronger sibling relationships may provide an additional and meaningful emotional support base [23,39].

Participants who had disclosed their adolescents' medical condition to family and close friends felt that disclosure promoted acceptance, understanding and provided additional social support [43,44]. Families that were more secretive and selective about whom they told, had fewer resources to draw from. Prior research illustrates how adolescents are fearful of disclosing their condition to others out of fear of bullying [11]. Friendships are highly valued, especially for their contributions to feelings of acceptance and happiness, while disrupting negative self-perceptions and challenging perceived limitations [23,41].

Harmful friendships, peer pressure and bullying were problems the adolescents had to deal with on a regular basis [11,20,21,24,45]. These negative influences and a lack of positive social interactions can lead to poor mental and physical health and an array of harmful and maladaptive coping mechanisms [22,26]. Our findings suggest that primary caregivers should endorse close beneficial friendships in both friendship groups (school and neighborhood) given their mutual and separate benefits [21,23,24,26]. Social isolation can be caused by a variety of factors, such as lack of resources or safety concerns. The participants' fears and safety concerns are warranted given that the Cape Flats region in which the families reside has a high crime rate [46]. The detrimental effect of living in such a hostile environment on their emotional and mental health is incalculable [24]. As a result, the adolescents have fewer social interactions and less opportunities for prosocial and extracurricular activities. Participants consider prosocial hobbies an effective means to stimulate the adolescents mentally and socially, potentially deterring them from engaging in maladaptive behaviors. The adolescents' development is hindered by their social isolation and a lack of resources in the communities, such as safe spaces for learning, opportunities to develop skills, and recreational facilities for sport and culture.

The participants experience periods of boredom, sadness and depression, as seen in prior research [26]. The participants' depressed affect, powerlessness and inability to see positive influences in particular areas of their lives could be due to the dire circumstances in which they live. The apparent and perceived lack of resources and the internalized powerlessness are compounded by their identity of being disabled [24,25]. Participants should draw on the resources they have available, as the number of positive social contexts that an adolescent has is not important, but rather the quality [26]. We suggest that access to technological resources such as mobile phones could enable the shy and socially impeded adolescents to communicate with their friends [41,47] so that they feel like "regular" teenagers [48].

Participants maintain that special needs academic institutions designed to suit the functional and cognitive abilities of the adolescents are paramount for optimal scholastic and social development [49]. Optimized education is crucial given that adolescents

with SB struggle with decision-making and concentration, culminating in reduced scholastic competence and greater dependence on parental guidance relative to their typically developing peers [21,50,51]. In our study, participants reported that these special needs schools promote feelings of comfort, community and acceptance while promoting personal achievement. Further, our findings demonstrate that open and honest communication between primary caregivers and adolescents regarding academic and vocational interest is important [11] given that the lives of youths with disabilities can be transformed through educational and skills-based training programs [52,53].

Participants experienced sporting activities both at school and in the neighborhood as an effective means to build self-confidence, self-acceptance, promote friendships, embolden perseverance and encourage school attendance. These activities are particularly pertinent as prior research shows that individuals living with SBM generally have poor health-related physical fitness [54,55]. Regular physical activity promotes physical health and psychosocial well-being for able-bodied and disabled adolescents [56,57]. Sport participation in impoverished SA communities was reported to improve health and fitness, provide an opportunity for socialization, increase social cohesion, create a sense of belonging and achievement, prevent maladaptive behaviors, and reduce criminal activity [56,58]. The reality is that over one-third (37.5%) of public high school students from across SA engage in insufficient physical activity [59]. SA adolescent girls habitually perform more moderate-to-vigorous intensity physical activity (MVPA) compared with their male counterparts [60] however, boys participate in more MVPA at school and in club sport [61]. Physical activity programs and interventions could provide a learning opportunity and increase physical activity and well-being, especially for people with disabilities and people from under resourced communities [57,62]. Our finding suggests that providing adequate facilities for academic and sporting activities in these resource-lacking communities may empower adolescents and promote well-being. Primary caregivers' involvement and support of sporting activities emphasize their active involvement in their children's lives and well-being, crucial given that sport participation is associated with social support, not disease-related characteristics [54].

Adolescents are in the process of developing independence and self-agency [11,22,38,63]. The primary caregivers generally struggle to help the adolescents with the physical and emotional aspects of relying on a wheelchair for mobility. The adolescents' negativity was often linked to their reliance on the wheelchair, as their identity and sense of worth have become interwoven with the use of the wheelchair [23-25,45]. Our findings suggest that families should consider the capabilities and functional limitations of the adolescents, focusing on attainable goals. Participants suggested a gradual transfer of responsibility from primary caregivers to adolescents. These suggestions are in line with prior research, emphasizing the need to identify strengths to encourage during this process [20,27,64]. Appropriate parenting styles are imperative for inculcating decision-making skills, self-confidence, discipline and respect for self and others, all values deemed important by the adolescents [65]. It is crucial to instill an internal locus of control, as quality of life and independence are largely affected by functional ability [12,21,24].

The adolescents' self-understanding was largely influenced by their economic, cultural and social-political context [25,66]. Most participants draw meaning in life from subjective interpretations, with an emphasis on accepting one's disability, finding one's life purpose and persevering in the face of adversity [24,25], these

views were largely related to altruism and faith-based ideology [24,67]. Participants felt that faith-based organizations and communities play a minor role in promoting self-acceptance and improved well-being, contrary to other researchers' findings [67].

The adolescent participants have had numerous medical complications, requiring constant medical care [3,13]. All participants were concerned about the health of the adolescents. They felt the best way to deal with this was to be proactive by attending regular checkups, being consistent with self-care and performing the required operations timeously. Participants spoke of ways in which their lives may be improved, such as drawing on the available resources (support groups and hospitals) that provide professional care, education and a sense of community [23,42,68].

Limited financial resources inhibited participants' access to free medical care provided at government hospitals and clinics as public transport does not typically accommodate people with disabilities [69,70]. Impracticality, time restraints and indirect costs often meant that participants received care when it was feasible not when it was needed. Physical access to health care affects an array of health outcomes, and closer proximity to health services increases usage, however many South Africans especially in rural communities must travel far to reach the nearest clinic [71,72]. The majority of South Africans (90%) live within 7 km of a public health facility, and about two-thirds live within 2 km, however few of the facilities provide adolescent- and youth-friendly services [70,73]. Despite the SA commitment to improve health care there continues to be structural and systemic factors that hamper effective provision of youth- and disability-friendly services [69].

Prevalence rates of SB are higher among SA females, however the adolescent sample in this study contained a greater number of males [5,6]. Participants were recruited from an NGO which provides care for children with a disability. The skewed gender ratio could be a result of greater numbers of male children requiring the special care services provided by the NGO.

All participants enjoyed the interview process and left feeling that they had more insight and motivation to be proactive and take ownership of their lives. Primary caregivers became aware of how little they know about particular areas of their adolescents' lives. The adolescents struggled to answer the positively framed questions, which highlights their circumstance and the day-to-day hardships, both structural and social in nature. Despite these challenges, the adolescents were optimistic about the future, had ambitions and dreams of success and were looking forward to communicating more with their primary caregivers about how to facilitate improvements in their lives.

### Recommendations

Expanding on this research could produce further insight into what improvements can be made to the lives of South Africans living with SB. Contributing to the growing body of positive psychology literature for people with disability in Southern Africa could in time lead to improved interventions and informed policy changes. Involving the adolescents and primary caregivers as active participants in research has led to better outcomes in the process of innovation and transformation. Special needs educators could be included in future research into the lives of adolescents with SB.

### Limitations

We found a number of limitations to this study. Firstly, the majority of the participants spoke in their second or third language,

potentially reducing comprehension of questions and richness of responses. Secondly, there was a lack of privacy during the home-based interviews, which may have influenced participant responses. Thirdly, we adhered to principles of qualitative research and data saturation, but it is possible that additional interviews may have provided contradictory views. As such, while our findings may be transferable to other similar contexts, they should not be generalized.

### Conclusion

In this study, we identified six contributors and two hindrances to the well-being of adolescents with SBM. Understanding and highlighting the perceptions of both adolescents with SBM and their primary caregivers enabled us to pinpoint positive contexts that are crucial to well-being. Acknowledging the contributors and hindrances to well-being is essential for guiding informed positive interventions and preventing blind spots. Given the primary caregivers' lack of insight into the positive and negative aspects of the adolescents' lives, we suggest that families prioritize bonding time and open communication. The adolescents with SBM have access to a limited number of positive contexts, necessitating a concerted effort to improve the existing contexts while facilitating opportunities for growth and improved well-being in a range of environments. Fostering strong and healthy relationships within the family and peer groups is imperative. Attending a school that caters to the adolescents' specific educational needs is ideal, especially when coupled with a sport program that bolsters school attendance while improving physical, social and emotional well-being. Adolescents are in the process of becoming independent, especially with regard to self-care. Primary caregivers must therefore gradually transfer responsibility while encouraging and supporting their adolescents. Primary caregivers must support their adolescents as they begin to tussle with existential questions such as the meaning of their lives and their identities. The structural and social hindrances to well-being could in part be reduced or mitigated by the family working together to address the issues.

### Disclosure statement

The authors declare no conflict of interest. The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

### Disclaimer

The views expressed in the submitted article are that of the authors, and not that of any institution or funder.

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