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Assessment of health status in adolescents with spina bifida in the West Bank, Palestine: sense of coherence and self-perceived health

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ABSTRACT

Purpose: To assess self-perceived health and sense of coherence (SOC) in adolescents with spina bifida (SB) in the West Bank, Palestine, compared to a healthy reference group. Further, to assess the association between impairment levels in the adolescents with SB and their self-perceived health and SOC.

Methods: Fifty adolescents with SB and 150 healthy adolescents completed measures of self-perceived health – the Pediatric Quality of Life Inventory (PedsQL™ 4.0) – and SOC. The rehabilitation center nurses identified the physical impairments of the adolescents with SB from their medical records, and classified them by impairment severity.

Results: Adolescents with SB reported lower self-perceived health (PedsQL median 55, IQR 42–67), than the reference group (median 85, IQR 74–90), $p < 0.001$, and lower SOC (median 47, IQR 44–50) than the reference group (median 55, IQR 44–61), $p < 0.001$. Impairment level was inversely associated with both self-perceived health and SOC.

Conclusions: The low self-perceived health and SOC among adolescents with SB in Palestine indicate the need for collaboration between policy makers and providers to improve these adolescents' physical and social environment and to promote the rehabilitation services provided for them.

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Adolescents; disability; perceived health; rehabilitation; sense of coherence; spina bifida

► IMPLICATIONS FOR REHABILITATION

- The low self-perceived health and SOC among adolescents with SB in Palestine highlight the need to develop appropriate interventions to promote their health, independency, and self-care management.
- Collaboration of the caregivers and health care providers is required to develop, implement, and evaluate intervention programs that might promote coping abilities of the adolescents with SB.
- A multidisciplinary approach is needed to set goals that have a meaningful impact on social, emotional, behavioral, and educational conditions of the adolescents with SB and in different settings, for example, home, school, and community.
- The environment in Palestine presents barriers to the social engagement of adolescents with SB, and new ways are needed to enhance their participation in the society to promote their self-concept and wellbeing.

Background

Spina bifida (SB) is a serious congenital neural tube defect affecting multiple organ systems and leading to complex physical impairments. The primary functional deficits experienced often include lower limb paralysis and sensory loss, bladder and bowel dysfunction, hydrocephalus and consequent learning difficulties at varying levels [1]. The worldwide incidence of neural tube defects including SB ranges between 1 and 10 per 1000 live births [2]. Data from Palestine have reported an incidence of 2.3 per 1000 fetuses [3].

In recent years, survival beyond childhood in patients with SB has increased due to the advanced medical, surgical, and rehabilitation measures for these children [4]. The longer survival rate, together with the long-term complications of SB and its

psychosocial consequences, can lead to stressful and challenging experiences that might impact these individuals' health and quality of life (QoL) [5].

Adolescents with SB often face the stigma of disability, social exclusion, body image concerns, and low self-concept [6,7]. These problems interfere with their normative developmental tasks, including independency and identity formation [8]. In this context, there has been an increased focus on health, daily life experiences and QoL as important health outcomes among children with SB [7,9]. Despite the clear evidence of psychosocial distress and impaired QoL for children with SB in western countries (i.e., Europe and North America) [10,11], little is known about the effect on children with SB in countries of the Middle East (e.g., Palestine). For this vulnerable group, whose lives are shaped by

protracted political conflict, low socioeconomic status, and challenging sociocultural norms [12], these factors can be supposed to have an even stronger impact.

It is likely that the protracted political conflict in Palestine and the consequent impact on various social determinants of health, entail an important threat on people's life, and violate children's rights to health, wellbeing and education [13]. The fragmented health care system in Palestine, and the barriers to accessing health care facilities, might cause enduring health problems among children with disabilities [14]. Moreover, the stigma toward persons with disabilities in Palestine that is still embedded in the Arab culture, is one of the most common reasons for the negative consequences and undue suffering [15]. For example, children with SB in Palestine are caught in a state of stress and vulnerability due to social exclusion and stigma [7]. Mothers of children with SB in Palestine face negative attitudes from a society that perceive having a child with disability as shameful and embarrassing for the family [16]. These mothers experienced a high emotional impact ranging from a sense of guilt to constant anxiety and psychosocial burden [16]. To protect themselves and escape the social stigma, some families in Palestine tend to lock away the disabled child from society and avoid health or social services [17]. Fear of the social stigma might create serious problems in social adjustment for these children and their families [15].

A possible protective factor to maintain health and well-being in this challenging context is sense of coherence (SOC), which is a key concept of the salutogenic model developed by Antonovsky [18]. The SOC concept, with its three components, comprehensibility, manageability, and meaningfulness, refers to the way of viewing the world which might facilitates successful coping with trauma and adversity [19]. It reflects the individual's resources and capabilities to maintain health and well-being, and is considered to explain how individuals, regardless of distressing circumstances can remain well [18]. SOC may therefore be considered an important factor in stress-related resilience due to its role in mediating the impact of social, cultural, and political stressors on the individuals' well-being and adjustments [19]. Thus, can be assumed to affect how adolescents with SB cope with their disease and perceive their health and well-being.

Therefore, assessing SOC as well as self-perceived health in adolescents with SB might determine how their wellbeing is affected by growing up with the disease in the specific context of the West Bank, Palestine. The aim of this study was (i) to assess self-perceived health and SOC in adolescents with SB in the West Bank, Palestine, in comparison to a healthy reference group and (ii) to assess the potential association between impairment levels in the adolescents with SB and their self-perceived health and SOC.

Methods

Study design

A cross-sectional study design was used, with data collection from December 2016 to February 2018 in the West Bank, Palestine.

Sample and setting

Adolescents with SB

A convenience sample of 50 adolescents with SB participated in the study at the time of their regular visit to the three largest rehabilitation centers of the West Bank Palestine. The inclusion criteria were (1) being born with SB, (2) being 13–18 years of age, (3) having attended school, and (4) being able to understand the

questions. The exclusion criteria were (1) inability to participate related to reduced intellectual ability and (2) moderate to severe memory and concentration difficulties. The inclusion and exclusion criteria were applied by experienced nurses who screened the adolescents' medical records before inviting the adolescent to participate. These nurses also received a training on how to check for these criteria. Twenty-six of the participating adolescents came from the south (Hebron), 11 from the middle (Ramallah) and 13 from the north (Nablus) of the West Bank.

Adolescents in the reference group

A reference group consisting of 150 healthy adolescents in the age range 13–18 years was recruited from eight regular schools located in the north, south, and center of the West Bank. Sixty-five participants in the reference group came from the south (Hebron), 45 from the middle (Ramallah), and 40 from the north (Nablus) of the West Bank. Adolescents with any known chronic disease or cognitive deficit were excluded.

Data collection

As part of the recruitment method and prior to data collection, the researchers conducted two pre-study visits to the study settings to meet the health managers and school administrators. This was to explain the purpose of the study and to ask for their agreement to recruit adolescents to take part.

For adolescents with SB, after the agreement of the health managers in the rehabilitation centers where the adolescents were registered, the nurses who worked there were informed about the purpose of the study and provided with instructions about the questionnaire. The nurses identified eligible adolescents with SB from their medical records and recruited them when they attended their regular clinic appointments for rehabilitation and check-ups. The nurses informed the adolescents and their guardians about the study and asked if they were willing to participate, whereupon they obtained the adolescents' assent and a signed consent from their parents. The nurses identified 55 eligible adolescents, of whom two declined without giving any reason, and three did not participate due to hospital admission on the day of their agreement to participate. This brought the total number to 50 participants, who filled out self-report questionnaires independently at the rehabilitation centers, under the supervision of the nurses.

For the healthy reference group, the administrators of the selected schools identified eligible participants, informed them and their parents about the purpose of the study and obtained the adolescents' assent and their guardians' signed consent. Adolescents in the reference group completed the questionnaire in the classroom under the supervision of the first author. The adolescents were told that they were free to withdraw at any time. The response rate of the reference group was 100%, with no missing data except for reported gender.

Measurements

Sociodemographic characteristics were recorded using questions about age, sex, and place of residence.

Clinical characteristics of the adolescents with SB were classified by the nurses in charge and were verified by referring to the patients' files. The nurses classified the participants' clinical characteristics into three levels according to the severity of their impairment in terms of mobility, bowel and bladder functions, and the level of the lesion on the spine (sacral lesion, mid-to-low

Table 1. Demographic and clinical characteristics of the study participants (N = 200).

	Adolescents with spina bifida n = 50	Adolescents in reference group n = 150	p Value
Age in years, mean (SD)	14.6 (1.6)	14.5 (1.4)	0.753
Gender, n (%)			0.874
Male	23 (46%)	72 (48%)	
Female	27 (54%)	78 (52%)	
Residency, n (%)			0.072
City	16 (32%)	63 (42%)	
Village	22 (44%)	40 (27%)	
Refugee camp	12 (24%)	47 (31%)	
Lesion level, n (%)			
Sacral	11 (22%)		
Mid-to-low lumbar	33 (66%)		
High lumbar	6 (12%)		
Impairment in mobility, n (%)			
Walks with no assistive device	6 (12%)		
Walks with an assistive device	23 (46%)		
Full-time wheelchair use	21 (42%)		
Impairment in bladder function, n (%)			
Independent control of bladder	2 (4%)		
Uses CIC without help	21 (42%)		
Uses CIC with help	27 (54%)		
Impairment in bowel function, n (%)			
Independent bowel control	12 (24%)		
Uses enema without help	21 (42%)		
Uses enema with help	17 (34%)		
Hydrocephalus, n (%)			
No hydrocephalus	28 (56%)		
Hydrocephalus with shunt	22 (44%)		

CIC: clean intermittent catheterization.

Statistical between-group comparisons were conducted using the Mann–Whitney *U* test for age and the chi-square test for gender and area of residency. $p \leq 0.05$ was considered significant.

lumbar, or high lumbar). The presence or absence of hydrocephalus was also recorded.

Self-perceived health was measured using the Arabic version of the Pediatric Quality of Life Inventory, version 4 (PedsQL™ 4.0) Generic Core Scales for adolescents aged 13–18 years. This instrument is often used to investigate health-related quality of life (HRQoL) in pediatric populations with acute and chronic health conditions. It consists of 23 items on a five-point Likert scale [20]. The PedsQL 4.0 was originally designed by Varni et al. [21], with four subscales: *physical functioning* (eight items), *emotional functioning* (five items), *social functioning* (five items), and *school functioning* (five items). To obtain a total score, the items are reverse scored and transformed into a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0). Scale scores are computed as the sum of the items divided by the number of items answered; the higher the score, the better the respondent's self-perceived health. The individual scales can be combined to yield summary scores in two domains: a *physical health summary score* (the same as the physical functioning subscale) and a *psychosocial health summary score* (derived from the emotional, social, and school functioning subscales). The Arabic version of the PedsQL 4.0 has shown sufficient reliability and validity in public health settings for children and adolescents aged 18 years or younger in Arab countries [20].

Despite the importance of HRQoL in health and medicine, there is a considerable debate about the appropriate and clear use of this concept [22]. Some researchers have defined HRQoL as a subjective, multidimensional and dynamic concept that is dependent upon the stage of development and the severity of the illness [23]. HRQoL has also been defined as the patient's perception of the impact that illness and treatment have on his or her life [24]. According to Varni et al. [21], HRQoL was identified as a complex construct which encompasses physical, psychosocial, and emotional functioning. The literature reveals a debate about the concept of HRQoL and the frequent use of the term by

researchers when they are actually evaluating the individual's self-perceived health [22,25]. It is claimed that HRQoL instruments often give insights into self-perceived health or functional abilities rather than HRQoL [22,25]. Accordingly, in this study, the PedsQL 4.0 was used to represent self-perceived health.

Sense of coherence was measured using the Arabic version of the Sense of Coherence Questionnaire SOC-13. The SOC scale has proven reliable and valid in several cultural contexts and through approximately 500 published studies in 33 languages over the past few decades [26]. We used the short version of the questionnaire (SOC-13), which encompasses three domains: *meaningfulness* (four items) *comprehensibility* (five items), and *manageability* (four items). Each of the 13 items was scored on a seven-point Likert scale representing a total scoring range from 13 to 91. The higher the score, the stronger the SOC. Scores of 13–60 indicate weak SOC, 61–75 indicates moderate SOC, and 76–91 indicates strong SOC [27].

Data analysis

The data were analyzed using SPSS statistics software (IBM SPSS Statistics 24, 2016, Armonk, NY). Frequencies, percentages, mean, and standard deviation were used to describe the demographic and clinical characteristics of the participants. Unpaired two-group analysis for nominal data such as gender and place of residency was conducted using chi-square tests. The non-parametric Mann–Whitney *U* test was used to compare age, self-perceived health status, and SOC between children with SB and the reference group of healthy adolescents. Results are presented as median and IQR, and a *p* value of less than 0.05 was considered statistically significant. The associations between demographic characteristics, clinical characteristics, self-perceived health, and SOC among the participants were analyzed using Spearman's rank correlation (r_s) test.

Table 2. Comparison of self-perceived health and sense of coherence between adolescents with spina bifida and healthy adolescents ($N = 200$).

	Adolescents with spina bifida ($n = 50$)		Adolescents in reference group ($n = 150$)		p Value
	Median	IQR (Q1–Q3)	Median	IQR (Q1–Q3)	
PedsQL™ 4.0					
Total scale score	55	(42–67)	85	(74–90)	<0.001
Physical health summary score	42	(28–59)	89	(78–93)	<0.001
Psychosocial health summary score ^a	59	(44–76)	83	(70–90)	<0.001
Emotion functioning scale	60	(40–85)	70	(60–85)	0.1
Social functioning scale	48	(25–66)	95	(85–100)	<0.001
School functioning scale	65	(55–90)	85	(75–95)	0.09
SOC					
Total scale score ^b	47	(44–50)	55	(44–61)	<0.001
Meaningfulness	15	(13–16)	20	(14–23)	<0.001
Manageability	15	(14–16)	16	(12–20)	0.68
Comprehensibility	18	(16–19)	19	(16–23)	0.009

PedsQL™ 4.0: Pediatric Quality of Life Inventory, version 4; SOC: Sense of Coherence-13 scale; IQR: interquartile range.

Statistical comparisons were conducted using the Mann–Whitney U test. $p \leq 0.05$ was considered significant.

^aThe psychosocial health summary score represents the sum of the items in the *Emotional*, *Social*, and *School Functioning* scales divided by the number of items answered.

^bA total scale score ≤ 60 indicates weak SOC, 61–75 indicates moderate SOC, and ≥ 76 indicates strong SOC.

Ethical considerations

The study was executed in accordance with the Declaration of Helsinki [28]. Permission to access the rehabilitation centers was granted by the Palestinian Ministry of Health, while permission to contact the schools was given by the Palestinian Ministry of Education. Parents signed a consent form and adolescents gave their assent. The adolescents were informed that their participation was voluntary and all information would be treated confidentially.

Results

Demographic and clinical characteristics (Table 1)

Mean age for the SB group was 14.6 years (SD 1.6) and for the reference group 14.5 years (SD 1.4). There were no significant differences between the groups with respect to age, gender, or area of residency. Two-thirds of the adolescents with SB had mid-to-low lumbar lesions and 12% had high lumbar lesions. Almost 42% used a wheelchair full-time, 54% needed help using clean intermittent catheterization to control the bladder, and 34% needed help using an enema to control the bowel.

Self-perceived health and SOC (Table 2)

Adolescents with SB had significantly lower PedsQL total scale score (median 55, IQR 42–67), than those in the reference group (median 85, IQR 74–90), $p < 0.001$. The findings also showed that adolescents with SB had significantly lower scores for physical health summary score (median 42, IQR 28–59), and psychosocial health summary score (median 59, IQR 44–76), as compared to the reference group (median 89, IQR 78–93), $p < 0.001$, and (median 83, IQR 70–90), $p < 0.001$, respectively. SOC total scale scores were significantly lower in the adolescents with SB (median 47, IQR 44–50), compared with the reference group (median 55, IQR 44–61) $p < 0.001$. In one of the three SOC dimensions, manageability, there was no significant difference between the groups.

Table 3. Correlations between demographic characteristics, clinical characteristics, self-perceived health (PedsQL™ 4.0), and sense of coherence in adolescents with spina bifida ($N = 50$).

Physical characteristics	PedsQL™ 4.0 Total scale score		SOC Total scale score	
	r_s	p	r_s	p
Residency	–0.14	0.3	–0.30	0.1
Gender	0.24	0.08	–0.88	0.54
Lesion level	–0.11	0.4	–0.20	0.08
Impairment in mobility	–0.61	<0.001	–0.28	0.01
Impairment in bladder function	–0.17	0.21	–0.42	<0.001
Impairment in bowel function	–0.38	<0.001	–0.27	0.05
Hydrocephalus	–0.60	<0.001	–0.32	0.02

PedsQL™ 4.0: Pediatric Quality of Life Inventory, version 4; SOC: Sense of Coherence scale; r_s : Spearman's correlation coefficient.

All correlations were calculated on the total scale score for each instrument and were analyzed with Spearman's correlation coefficient. Correlations with $p \leq 0.05$ were considered significant.

Correlations between self-perceived health, SOC, and level of impairment (Table 3)

No significant correlations were found between demographic characteristics, SOC, and PedsQL score. An inverse correlation was found between the PedsQL total scale score and level of impairment in mobility ($r_s = -0.61$, $p < 0.001$), where lower PedsQL score was associated with a higher level of impairment. Lower PedsQL score was also associated with the presence of hydrocephalus ($r_s = -0.60$, $p < 0.001$) and impairment in bowel function ($r_s = -0.38$, $p < 0.001$). Inverse correlations were also found between SOC total scale score and level of bladder dysfunction ($r_s = -0.42$, $p < 0.001$), the presence of hydrocephalus ($r_s = -0.32$, $p < 0.02$), and impairment in mobility ($r_s = -0.28$, $p < 0.01$). However, no significant correlation was found between the lesion level and PedsQL total scale score or SOC total scale score. A positive correlation was found between SOC and PedsQL total scale scores ($r_s = 0.57$, $p < 0.001$).

Discussion

In the present study, self-reported data were obtained using the PedsQL and SOC instruments to examine self-perceived health and SOC among adolescents with SB in the West Bank, Palestine,

as compared to a reference group of healthy peers of the same age. In addition, the study examined the relationships between demographic characteristics, level of impairment and PedsQL, and SOC scores in the adolescents with SB.

The self-perceived health of the adolescents with SB was significantly lower than that of the healthy reference group. This finding is consistent with a previous systematic review of HRQoL in children with myelomeningocele by Bakaniene et al. [29]. However, the adolescents with SB in the present study reported lower PedsQL scores than children and adolescents with the same condition in USA [30,31] and Sweden [32].

It is worth noting that studies on HRQoL of children with SB are mainly derived from Western cultures (i.e., Europe and North America) [29], and there is an apparent lack of such studies in countries of the Middle East, particularly Arab cultures. To the best of our knowledge, there is only one previous study, by Arabiat and Al Jabery [33], exploring self-perceived health in children and adolescents with SB in an Arab Muslim country. Arabiat and Al Jabery [33] compared adolescents with chronic illnesses with healthy controls in Jordan. One of the diagnoses within the chronic illness group was SB, and the PedsQL total scale scores for the adolescents with SB were even lower than in the present study. The authors attributed this finding to the serious effect of SB on children's health together with the impact of environmental barriers.

Bakaniene et al. [29] revealed that children living with SB in developing countries may report worse scores of HRQoL than in developed countries for a number of reasons, including the cultural attitudes, environmental barriers, economic aspects, and ineffective rehabilitation systems. Reasons that have shown a significant impact on the Palestinian children with disabilities [17], and may be an explanation for the lower PedsQL scores among the adolescents in the present study than among peers in countries of North America and Western Europe (e.g., USA and Sweden).

The physical domain of PedsQL was the most affected aspect of self-perceived health in the Palestinian adolescents with SB, which is consistent with what Bakaniene et al. [29] found in their systematic review. However, the heavy impact on the physical domain not only depended on the physical characteristics and the complexity of SB, but modifiable environmental factors also had a great impact [29]. For example, the physical layout of the environment, economic status, and access to public transportation were considered as potent predictors of HRQoL for adolescents with SB [29]. All these factors are problems in the Palestinian context. The environment is not adapted to ease of access for impaired persons, neither is the public transportation. Further, the lack of money to overcome these problems is evident both on an individual and public authority level.

We cannot disregard the possibility that the findings in the present study might reflect the sociocultural and political conditions of the country. The political strains related to instability, closures, checkpoints, and separation wall, may negatively impact the daily life of the adolescents in present study, and leads to heavy burden on health and suffering [17]. Children and adolescents with disabilities in Palestine are especially affected by the deteriorated infrastructure of health care services and the restricted access to social and educational organizations [14], which challenge their health and their possibility to take part in the society, and thereby put their psychosocial adjustment at risk [15]. To support these adolescents and their families, it is of great importance for the health care providers to understand their views and needs in order to enable their resilience and to cope

with their daily challenges. Further, adequate attention should be given to the inclusion of political domain in measures of HRQoL due to its important contribution to people's health in societies with a political instability [34].

A further explanation of the low self-perceived health scores in the present study might be the stigma of disability and the consequent psychosocial difficulties which have been considered as major influences on health and self-concept for children with disability in Palestine [14,15]. The harmful effects of stigma on the Palestinian children with SB has been seen in a variety of psychosocial challenges (i.e., emotional, sociocultural, peer relations, financial, and political) that impact their health and wellbeing [7]. These challenges appear to give rise to psychosocial difficulties for all family members including stigmatization and constant feelings of anxiety, particularly upon the mothers who are often blamed for giving birth to a child with SB [16]. Future studies should examine the influence of stigma on a variety of elements in the life of youth with SB such as educational attainment, work opportunities, economic stability, social cohesion, and future family life.

However, previous studies in the Palestinian context have shown the important role of the traditional Arab collectivist family in caring for and supporting both family members and the child with SB and disability [7,16,35]. Although the contribution of the extended family produced a positive feeling for children with SB [7], it entails risk of the overprotective role that can make the development of independency more challenging for the adolescents [35]. The adolescents with SB in Palestine face difficulties in self-care, and adherence to medical regimens and self-care measures (e.g., appropriate catheterizing, and bowel program) [7]. To promote the adolescents' possibility to develop their independency, health care providers should give adequate attention to the families of children with SB, focusing on strategies to improve self-perceived health and self-care measures of these children.

We found a significant correlation between PedsQL score and the clinical characteristics of SB, in which both hydrocephalus and impairment in mobility were inversely associated with self-perceived health. These two characteristics were particularly pertinent and have, more than other clinical characteristics of SB, had an impact on HRQoL and wellbeing in previous studies [36–38]. Several studies in the systematic review of Bakaniene et al. [29], have examined the impact of incontinence, lesion level, and the number of shunt revisions on HRQoL of patients with SB, but most have found no association.

Regarding SOC, our study revealed lower scores in the adolescents with SB as compared with the healthy reference group, indicating a weaker SOC. It is notable that our reference group itself demonstrated weak SOC [27]. To the best of our knowledge, there are no other studies of SOC in adolescents with SB. However, research on adolescents with chronic illness found that a strong SOC among these adolescents is shaped by their coping abilities, self-care autonomy, and adherence to therapeutic regimens [39]. Such factors can be considered important challenges for adolescents with SB, because their autonomy might be hindered due to their medical care needs, mobility challenges, and lack of social support in school or the wider community [7,40].

Moreover, the cultural norms of the Arab Muslim families and their beliefs about bearing full responsibility to meet the needs of children with disability, have an important influence of the adolescent's self-care autonomy [35]. In such culture, children will learn to rely on the family members for their medical regimens and needs which might adversely impact their psychosocial coping and their SOC. Addressing these challenges may be especially

pertinent and important for adolescents with SB in Palestine, and might promote their health and improve their SOC.

The notably weak SOC reported by both the adolescents with SB and the healthy reference group in the present study might be explained on basis of the political conflict and negative influences upon the Palestinian population in general, eroding their rights and exposing them to traumatic events and distress [41]. Previous studies of SOC in different cultures have reported that being constantly exposed to political violence and living with instability and inconsistency could weaken SOC scores in adolescents who have grown up under these conditions [42–44].

Our findings showed no significant difference between the two groups regarding manageability, one dimension of SOC that refers to the support or resources individuals have, enabling them to meet the demands posed by external stimuli and helping them to feel that things are within their control [18]. This finding might reinforce the impact of the political conflict upon these adolescents in Palestine. They might have negative feelings about the unpredictable situation and might feel loss of confidence or control over the surrounding environment.

The SOC scores within the SB group in the present study showed a negative correlation with the investigated physical characteristics. Those adolescents with severe physical impairments showed a weaker SOC. This finding is interesting and merits further studies to establish whether the weak SOC demonstrates maladaptive coping behaviors of adolescents with SB. According to Moons and Norekval [45], children with chronic illness who successfully cope with their disease and the associated progressively stressful situations might develop a strong SOC. Unfortunately, studies examining the association between SOC and the level of physical impairments among adolescents with chronic illness or disability are scarce. In addition, we know little about the factors associated with SOC in adolescents with SB. Identifying these factors is critical to building interventions aimed at facilitating SOC. With regard to the association between the SOC and PedsQL scores, our findings are consistent with a previous systematic review published in 2007 [46], which pointed out the potential impact of SOC on perceived health, arguing that the stronger the SOC, the better the perceived health and wellbeing.

It should be mentioned that, in the present study, the generic version of PedsQL 4.0 was used, as it was a suitable instrument, applicable to adolescents with chronic health conditions and available in a validated Arabic version. However, this instrument may not be sufficiently sensitive to capture the impact of specific characteristics of SB on self-perceived health, particularly in items like (walking around the block, running, and bathing). In response to these perceived limitations, the development of SB-specific PedsQL instrument has been emphasized [30,37], but there was no SB-specific instrument measuring self-perceived health available in Arabic. Further, the generic version is found to be suitable when comparing the burden of SB with a healthy population [29], and a disease specific instrument might preclude the ability to compare findings of self-perceived health across diverse populations [47]. Nevertheless, a disease-specific instrument with a greater sensitivity to clinical changes is of utmost importance, for example, when evaluating certain interventions in the population under study.

Limitations and strengths

The major limitation of this study is its cross-sectional design, hence the findings support an association rather than causality. Another limitation for this cross-sectional study is that an

individually matched sample was not used. The convenience sampling technique used can lead to selection bias. To limit this possibility, our data include adolescents from different areas of the West Bank, Palestine, and no significant differences between the SB-group and reference group, with regard to the demographic variables (age, gender, and residency), was found. For the future, we recommend replicating this study with a randomized sampling technique that will improve generalizability to the entire population, or in lack of that possibility an individually matched sample could be used.

The major strength of this study is its use of standardized instruments, available in validated Arabic versions and suitable for adolescents in the age range 13–18 years. Despite the study limitations, the results are interesting because of the useful information they provide for clinical practice, underlining the particular impact of mobility problems and hydrocephaly on the self-perceived health of adolescent with SB. Although this study only provides information about the self-perceived health and SOC of adolescents with SB, it does provide a framework for further studies concerning adolescents with other chronic illnesses and disabilities.

Conclusions

This study revealed lower levels of self-perceived health and SOC in adolescents with SB compared with a healthy reference group. Levels of impairment in adolescents with SB were inversely associated with both self-perceived health and SOC. Moreover, weak SOC was associated with low self-perceived health in adolescents with SB in Palestine. These results imply that raising awareness about the essential physical and psychosocial needs of adolescents with SB in Palestine is imperative. Health care providers should support adolescents with SB to improve their self-perceived health and SOC. The social and political hindrances to the adolescent's health, wellbeing, and SOC could in part be alleviated by collaboration between health care providers and the family members to address these issues.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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