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Coping and mental health among teenagers with adolescent idiopathic scoliosis: a qualitative study

Background

Adolescent idiopathic scoliosis (AIS) is the predominant spinal deformity in the pediatric population, affecting 0.93% to 12% of teenagers aged 10 to 18 years globally (Negrini et al., 2018). In Hong Kong, the estimated prevalence of AIS reached 4.7%, with an average annual increase of 0.61% (Fong et al., 2015). During adolescence, the progression of spinal curvature can result in physical deformity, pain, pulmonary complications, and even disability (Kan et al., 2023; Wong et al., 2019). To prevent curve progression, conservative treatments like bracing and physiotherapy are commonly prescribed. When teenagers develop severe curvatures exceeding a Cobb angle of 45-50°, surgery is recommended to correct the deformity (Bettany-Saltikov et al., 2015).

AIS and its treatments can lead to various challenges or stressful situations, including impaired self-image (Rushton & Grevitt, 2013), back pain (Wong et al., 2019), and low activity levels (Misterska et al., 2013), which may result in psychosocial distress for teenagers with AIS. Specifically, they are more prone to have problems in social interactions because of body image disturbance (Auerbach et al., 2014). Furthermore, adolescence is a critical period of personal development during which half of all lifetime mental disorders may emerge (Solmi et al., 2022). Therefore, the significant disease-related stress experienced by teenagers during adolescence may increase their susceptibility to developing mental health problems (Mitsiaki et al., 2022). In a 5-year retrospective analysis of 37,044 teenagers with AIS, approximately 7% were found to have psychiatric disorders, exhibiting a significantly higher risk (ORs=1.47-1.74) compared to individuals without AIS (Lee et al., 2021). A population-based study also showed that 7.2% of young adults with scoliosis developed clinical depression in a 5-year follow-up, which almost doubled the risk of healthy counterparts (Chang et al., 2016).

Based on the stress and coping theory developed by Lazarus et al., coping is a process in which individuals constantly change themselves to deal with stress according to the requirements of specific internal and external environments (Lazarus & Folkman, 1984). Coping is vital for psychological adjustment to physical disabilities and significantly impacts mental health (Li et al., 2019; Li et al., 2020). Indeed, teenagers' coping ability affects not only their mental well-being but also their personal development and future adulthood life (Compas et al., 2012). Specifically, research has indicated that young adults with disabilities can experience improved mental health outcomes by adopting adaptive coping strategies (Xu & Liu, 2020). Similarly, compared to healthy controls, teenagers with AIS tended to adopt more negative coping strategies, resulting in poor family quality of life (Cyran-Grzebyk et al., 2023). However, despite the potential importance of coping in promoting well-being in AIS teenagers, the understanding of coping strategies and their association with mental health in this population remains limited. To the best of our knowledge, only one study reported that when teenagers with AIS used more emotion-focused coping strategies, their emotional distress was more intense (Beka et al., 2006). Therefore, it was critically important to better understand the role of coping strategies in managing psychological symptoms and mental health among teenagers with AIS.

Given the above, the current qualitative approach aimed to comprehensively and thoroughly explore the specific stressors related to this disease and its treatment, coping strategies, and mental health among teenagers with AIS.

Methods

Design

Qualitative description design allows for a direct and comprehensive depiction of a phenomenon, enabling participants to express their perspectives and ensuring a detailed presentation of their experiences (Kim et al., 2017). This approach is suitable and effective for describing the nature of experiences that have not been extensively explored or well comprehended (Sandelowski, 2000, 2010). Consequently, in alignment with the study objective, a qualitative descriptive approach was employed in the current study.

Recruitment and study participants

The participants' information was obtained from records derived from a previous survey conducted by the research team at a local non-government organization specializing in AIS treatment. Following the consent of both the organization and participants, a total of 133 records were initially evaluated for eligibility. Subsequently, eligible teenagers were contacted through mobile messages and telephone invitations. Prior to the commencement of the study, consent forms were obtained from both the participants and their guardians (for participants under 18 years old). A small cash coupon was provided to compensate participants' time and energy for the study participation. The recruitment phase occurred from December 2022 to January 2023.

Participants needed to be aged 10-18 years, capable of communicating in Cantonese, and possess the ability to comprehend and respond to interview questions. This study focused solely on participants who received conservative treatments (physiotherapy, observation, or bracing) to better understand their coping abilities and mental health. To achieve maximum variation (Sandelowski, 2010), a purposeful sampling method was adopted to recruit participants of different genders, ages, and receiving different conservative treatments. The required number of participants was determined based on the principle of data saturation, which means that all codes and themes were well developed and no new data were obtained (Saunders et al., 2018). Data saturation was achieved with nine participants during concurrent data analysis and three additional participants were interviewed for cross-validation.

Data collection

The semi-structured interview guide was developed by an experienced qualitative researcher, incorporating a comprehensive literature review and theoretical understanding of the research question (Essex et al., 2022; Tones et al., 2006). The interview guide was validated by AIS experts and teenagers with AIS before utilization.

Feedback received via email or mobile messages led to modifications in the questions to enhance clarity and relevance. For instance, the question "How do you think AIS affects your identity?" was revised to "Does scoliosis affect the way you see yourself as a person?" following feedback from teenagers who found the initial version unclear. The final interview guide comprised open-ended questions and probes to elicit participants' experiences of living with AIS, including its effects on daily activities, social relationships, mental health, and how they coped with unexpected situations. The sample questions of the interview guide are presented in **Appendix A**.

To facilitate open communication and capture the personal experiences of the participants, interviews were conducted without the presence of parents or guardians. One co-investigator (YPL), a registered social worker with a master's degree in childhood education conducted the individual interviews. The interviews lasted for 31-60 (Mean=39) minutes and were digitally audio-recorded to facilitate verbatim transcription. To ensure confidentiality, identifying personal information was removed from the transcripts. The bilingual corresponding author conducted checks to ensure accurate translation and transcription. Data collection occurred between February and March 2023.

Ethical considerations

The study obtained ethical approval from the research ethics subcommittee of the corresponding institution (Ref No: HSEARS20221121001). The research team does not have a therapeutic role within the organization from which the participants' information was obtained. Prior to the study, informed consent forms were obtained from all participants and their guardians (for those under 18 years old) through mobile messages. The consent process involved providing a comprehensive explanation of the research objectives and participant rights. Participants were informed about the voluntary nature of their participation and assured that they had the freedom to withdraw from the study at any time without facing any penalties.

Data analysis

The interview data were analyzed using the principles of thematic analysis, which involves the identification, analysis, organization, description, and reporting of themes found within a dataset (Braun & Clarke, 2006; Braun & Clarke, 2019). A combination of inductive and deductive approaches was employed in the thematic analysis (Braun & Clarke, 2006; Sandelowski, 2010). Broad themes were initially developed based on the fundamental components of stress and coping theory (stressors, cognitive appraisal, coping, and outcomes) (Lazarus & Folkman, 1984). Through an inductive analysis, a prominent theme centered around social support, along with specific sub-themes within the broader themes, was identified from the data.

Data analysis utilized NVivo 11 (QSR International [Americas] Inc.), with final transcripts uploaded for coding. Two independent authors (JYL and MQL) performed open coding to identify similar word meanings. Any discrepancies were resolved through mutual agreement and support from a senior co-investigator (YL). Codes with similar meanings were collated and merged into themes iteratively. Interviews were initially analyzed in Cantonese, and relevant quotes were translated to support the findings. The study is reported following the guideline of the Consolidated Criteria for Reporting Qualitative Studies (Tong et al., 2007).

Trustworthiness of the research

Constant comparisons were made between excerpts within and across themes to ensure consistency in capturing the same aspect (Boeije, 2002). In line with the post-positivist paradigm, the values, experience, and background knowledge of the principal investigator (JYL, a first-year female PhD student, who shared a similar sociocultural background with the participants) can influence the analysis and interpretation of data. Consequently, two research meetings were held for peer debriefing and vetting of theme development to ensure a thorough and rigorous analysis (Nowell et al., 2017). Memos and a reflective journal were continuously documented during data analysis to foster reflexivity through critical self-reflection on the researcher's influence (Braun & Clarke, 2019). Additionally, thick descriptions regarding recruitment and data collection were provided to increase the transferability of the findings.

Findings

The final sample comprised seven females and five males, with eight participants wearing orthotic braces as the primary treatment and the remaining four receiving physiotherapy with follow-ups. Participant characteristics are summarized in **Table 1**.

Table 1. Participant Characteristics (N=12)

	Number of participants	%
Gender		
Female	7	58.3
Male	5	41.7
Curve type*		
Thoracic	3	27.3
Thoracolumbar	8	72.7
Treatment		
Bracing	8	66.7
Non-bracing	4	33.3
	Median	Range
Age (years)	15.5	14-18
Duration of diagnosis (months)	43	16-69
Cobb angle for the major curve*	28.9°	20°-40°

* N=11, data from participant 7 was missing

Five key themes were identified that reflected pertinent aspects of participants' lived experiences following a diagnosis of AIS. The text provides exemplary quotes to illustrate these findings.

Theme 1: Disease- and treatment-induced changes and stressors

Participants reported that AIS had affected life in various ways, ranging from physical limitations to changes in body image. Furthermore, participants experienced extra burden and discomfort from treatments.

Physical activity restriction and body image changes

Some participants reported limitations in simple daily activities; *"Sometimes, if the shoelaces are loose, it's difficult to bend down and tie them. The brace might press against my waist, making it hard to bend down." (P10; Female; 14 years)*. Participants also found that AIS and bracing limited their flexibility during sports activities. This may impact their efficacy in performing physical exercise; *"My physical strength is limited [because of AIS] ... wearing the brace might affect my breathing and make it less smooth." (P8; Male; 15 years)*.

Many participants acknowledged the impact of the illness and bracing treatment on truncal asymmetries, such as uneven shoulders or hips, which could adversely affect their self-image and clothing choices; "*I feel like my shoulders are uneven…you can tell at a glance. (P6; Female; 17)*.

Burden and demand from bracing

Wearing a brace was a major stressor for most participants, which included loss of appetite, oppression, numbness, cramping, and pain; *"The brace has a sponge that presses against my neck ... This causes my hand to feel numb and sometimes I even get cramps." (P3; Female; 14 years)*.

Several participants expressed that managing the brace not only was demanding for themselves but also for their surroundings; *"During physical education classes, I have to take off the brace, and sometimes, the school staff helps me with it. I find it can be bothersome for them as well." (P12; Female; 14 years)*.

Pain and time-consuming from non-bracing treatments

Three non-bracing participants also experienced pain, often due to maintaining prolonged fixed postures. Two participants considered physiotherapy and follow-up appointments to be time-consuming; *"Physiotherapy does [reduce my time] ... I had less time to study because of physiotherapy." (P2; Male; 17 years)*.

Theme 2: Cognitive assessment and personal perceptions

As participants faced the stressors, they developed varying cognitions and perceptions toward AIS and its treatments.

Feeling different from others

Some participants perceived their condition as abnormal, and they felt different from their peers; *"Others can carry out activities normally ... But there are some restrictions for me… Feeling like wearing a brace makes me different from other people." (P5; Male; 15 years)*. Activity restrictions and appearance changes were two main contributors to feeling different; *"There may still be a little difference, that is ... my spine is crooked." (P4; Female; 16 years)*.

Normalizing and looking at the bright side

A certain number of participants tried to normalize the illness and looked at the positive meaning of living with AIS. One participant compared AIS to myopia; *"It's just scoliosis like it is impossible because I have myopia, others will say, oh you, why* *do you wear glasses like this. Well, others will not." (P1; Male; 17 years)*. One participant expressed acceptance of wearing a brace, stating that *"[wearing a brace] is just a physical need, so I didn't pay too much attention to this aspect." (P6; Female; 17 years)*.

Some participants perceived it positively. A girl perceived wearing a brace from an optimistic view, seeing it as beneficial for maintaining good body shape; *"The brace has been pressing my waist, so my waist will not become very thick, it has been kept very thin, so I feel very ok." (P10; Female; 14 years)*. Three participants recognized the importance of wearing a brace to prevent further curvature progression in the long term.

General acceptance after psychological adjustment

After undergoing a period of psychological adjustment, many participants accepted the challenges posed by AIS, with a few emphasizing the importance of accepting things they cannot change; *"Knowing that I have this illness, I accept it, because I didn't think there was any way to solve it, so it's better to accept it." (P11; Female; 14 years)*.

In addition, some participants demonstrated acceptance towards tolerable impacts or negative consequences of the illness; *"I'm not going to blame and say I didn't get a good grade [climbing rock] because of my scoliosis." (P1; Male; 17 years)*.

Theme 3: Behavioral and emotional coping strategies

Participants utilized various coping strategies, which encapsulated both behavioral and emotional aspects, to deal with the stressors they encountered.

Adaptive coping and engagement in treatments

Some participants perceived the benefits of adhering to medical staff's advice, which included correcting body posture, wearing the brace for over 20 hours a day, and committing to physiotherapy; *"When doing physiotherapy, I found it very helpful. Sometimes I also do some physiotherapy at home, and now it has become a habit." (P6; Female; 17 years)*. Besides, participants were skillful in dealing with the negative impact of AIS. When it came to how to visually mask body image changes, one participant stated; *"Sometimes I wear a jacket…the right shoulder is relatively low, so I will put the phone in the left pocket to balance it." (P9; Female; 15 years)*.

Likewise, engaging in exercises that can help prevent curvature progression was another active coping strategy used by some participants; *"Swimming is good for the waist, so the exercise I usually do after taking off the brace is just swimming." (P10; Female; 14 years)*. Some participants requested personalized support and information, such as explaining their physical activity limitations to teachers for exemptions and searching for AIS-related information online; *"But because I told the school [about my condition], the school allowed me to skip doing some strenuous things in physical education class." (P12; Female; 14 years)*.

Emotional expression and modulation

Participants utilized emotional expression as a coping strategy. While many confided in close friends and family, its effectiveness varied among participants. Some felt it had limited impact, stating; *"If I don't feel uncomfortable, then it doesn't matter whether I talk to others or not." (P1; Male; 17 years)*. While others might find that confiding in others can make them feel more at ease; *"[Talking to people around] is useful, because at least they all know that [I have AIS], and they won't feel strange or surprised when they see me wearing a brace in the future." (P10; Female; 14 years)*. Participants also adopted some emotional modulation methods when facing distress and setbacks, such as sleeping, staring off into space, and playing with mobile phones.

Maladaptive behavioral coping and emotional suppression

Non-compliance with the brace was common among many participants who felt discomfort and inconvenience; *"After wearing the brace for 9 months [I didn't wear it anymore]. Because the skin would always be broken after wearing it, so I didn't want to wear it ... There is also the fear of others knowing that I wear a brace." (P5; Male; 15 years)*.

Several participants exhibited avoidant behaviors, including concealing their condition and refusing to communicate with their doctors; *"[The doctor] would also say a few words [about my non-compliance]. But I didn't pay much attention to it, anyway, it wasn't him who was wearing the brace." (P3; Female; 14 years)*.

In terms of maladaptive emotional coping, several participants reported that they habitually repressed or ignored their negative emotions instead of letting them out; "*I don't express [negative emotions], I still suppressed them, they are only in my heart*."

(P5; Male; 15 years).

Theme 4: Social interactions and social support

Participants' social relationships and social support play crucial roles in their psychological adjustment, mental health, and overall well-being.

Changes in social interactions and relationships

Several participants showed a tendency to social withdrawal due to the physical limitations and changes in body image caused by wearing a brace; *"I dare not meet new friends, and reduce the number of outings with old friends." (P5; Male; 15 years)*.

Contrary to some participants, a girl discovered that wearing a brace had a positive impact on her social interactions; *"My friends say that I wear a brace now as if I am wearing armor, then they'll play with my brace all day." (P10; Female; 14 years)*. A boy described that his social network had undergone "unexpected changes". Spending less time outdoors and more time surfing the internet at home, he has formed connections with some online gamers.

Excessive attention and psychological control

Unexpectedly, several participants expressed feeling overly concerned by people around them, which brought them a sense of unease; *"They think that [AIS] is very serious, and they make it look like I have some kind of malignant tumor, and then take special care of me, which I feel like unnecessary ...this is a little troublesome." (P12;*

Female; 14 years).

Some participants reported experiencing unpleasant feelings due to excessive psychological control exerted by their family members; *"It [Uneven shoulders] will not affect my choice of clothing. But if the clothes I choose can't hide the uneven shoulders, my mother will say you have even shoulders, choose another one ... So I, I don't have the freedom to choose clothes." (P11, Female; 14 years)*.

Sufficient instrumental support

Most of the participants reported receiving sufficient practical assistance from their surroundings. This kind of support included help with daily activities, assistance with managing treatments, and access to free medical resources. It was provided by family members, friends, schools, and healthcare providers;*"The support of family members will not be manifested ... They won't directly say that they support you like a friend, it will be silently helping you behind the scenes." (P3; Female; 14 years)*.

Insufficient professional psychological support

Most participants did not engage in any AIS-related psychosocial care programs, with only one participant receiving a home visit from a social worker. With adequate tangible support, many participants indicated that the emotional support from families was limited; *"Because my mother is that kind, she thinks, I'm just talking, she just let me stop so caring about those [troubles] ... So, so I'll forget it [chatting with mother] right now." (P11; Female; 14 years)*.

Some participants received emotional support from friends and teachers which made them feel understood and accepted; *“I have a friend who has known each other for 10 years ... she has always been there for me and supported me. Then I met some friends in middle school, and they have always taken care of me.” (P3; Female; 14 years)*.

Theme 5: Deteriorating or thriving in psychological development and well-being

Participants experienced stressful situations that might cause psychological distress, while some of them also adapted successfully with positive gains. Participants' health conditions differ from each other consequently.

Psychological distress and emotional reactions

Many participants expressed their distress when newly diagnosed or braced; *“At first, I felt very tired [wearing the brace]. The whole person was very negative.” (P3; Female; 14 years)*. As AIS progresses, participants developed worries about its impact on their growth and development and potential deterioration over time; *“If there is a sore situation, I will feel, could it be that it [AIS] has become aggravated, and I have this kind of worrying mentality.” (P7; Male; 18 years)*. Some participants felt uncertain about the effectiveness of their treatment. One girl, upon realizing that the brace treatment did not yield the expected results, expressed; “*It seems to make me lose confidence.” (P3; Female; 14 years)*. In social environments, such as schools, participants also experienced fear of discrimination from others; *“At the beginning, I* *just didn't want to be known [I wear a brace] … Others may mock me because of this.” (P8; Male; 15 years).*

Low self-esteem and depressive symptoms

Some participants appeared to experience a decline in their self-esteem while living with AIS. A boy expressed *“feel ashamed”* for wearing a brace (P5; Male; 15 years). Additionally, a girl also stated that; *“When family members or friends around me mention [I have AIS], I feel a little inferior.” (P11; Female; 14 years).* Due to the various challenges they faced, several participants exhibited depressive symptoms. One participant required psychological treatment to address his symptoms; *“I am always very unhappy, I am not happy doing many things… I used to love playing basketball, [now] I'm not happy at the thought of having to wear a brace after I've played basketball.” (P5; Male; 15 years).*

Development of a peaceful mindset and psychological resilience

Many participants in our study ultimately embraced the changes brought about by AIS and chose to move forward. Some developed a peaceful mindset, and some attained psychological resilience after navigating through various emotional challenges; *“I will not be depressed, sad, or afraid of this [AIS], at least I will accept this reality … When people ask me, I will also tell them that I have mild [AIS] … Which means I won't be too sad.” (P9; Female; 15 years).*

Different spinal curve progression outcomes

At the time of the interview, participants in our study demonstrated varying degrees of progression. Many participants maintained stable Cobb angles, whereas a few teenagers showed increased severity. Aligning with empirical studies, non-compliance with treatment was found to contribute to illness progression. This was evident in one participant who experienced a significant curvature increase and subsequently required surgery; *"It's [degree increased] because I'm lazy ... At the beginning, I wore the brace, but I didn't wear it for a while, so the [situation] was bad." (P5; Male; 15 years).*

Discussion

This study represents the first in-depth exploration of stressors, coping strategies, and psychological well-being among teenagers with AIS. The rich information obtained enhances our understanding of AIS experiences and sheds light on clinical care and psychosocial support.

Disease- and treatment-induced changes and stressors

Consistent with previous evidence (Weinstein et al., 2008), our study found that participants frequently experienced physical activity limitations and body image concerns due to the impact of AIS on spinal mobility, respiration, and aesthetics. The long-term use of braces, identified as a significant stressor, further exacerbates body image disturbances, aligning with previous findings (Cheung et al., 2007). However, these psychosocial concerns of the AIS population are currently overlooked in clinical care and follow-ups, despite their crucial role in personal development and holistic well-being (Essex et al., 2022; Gallant et al., 2018). Therefore, ongoing psychosocial need screening is crucial in this population to enable clinicians to provide individualized care and predict therapeutic outcomes (Talic et al., 2016). Additionally, our study raised concerns regarding brace management and demand in time for physiotherapy and follow-ups. Addressing these issues requires collaboration among healthcare providers and relevant agencies, such as partnering with schools to provide brace management resources and teaching students time-management skills.

Cognitive assessment and personal perceptions

Variations in participants' cognitive appraisals of AIS-related stressful situations led to diverse illness perceptions, which can be attributed to differences in their medical diagnoses, physical symptoms, past experiences, and support systems (Leventhal et al., 2016). Consistent with existing evidence (Rivera et al., 2020), our research indicated that positive perceptions, including normalizing the disease and establishing treatment expectations, can enhance treatment engagement and psychosocial adjustment. Thus, future research could focus on developing cognitive-based psychoeducational interventions as they have effectively fostered positive perceptions in adolescents with chronic diseases (Douma et al., 2019). Notably, participants often held negative perceptions regarding activity restriction and body image due to bulky spinal braces, underscoring the importance of considering mobility and aesthetic factors in brace design. The use of lighter and thinner 3D-printed orthoses holds promise for enhancing school activity participation among teenagers with AIS, while maintaining comparable clinical effectiveness and quality of life to conventional orthoses (Lin et al., 2022). Furthermore, user acceptance, compliance, and psychological distress may be improved by teenagers' participation in the co-design of visually appealing braces (Law et al., 2017).

Behavioral and emotional coping strategies

Participants tried to adopt problem-focused strategies, such as engaging in spine-beneficial exercises and seeking information to address personal needs. However, non-compliance to brace treatment was observed in some participants. Electronic monitoring, health counseling, and psychotherapies like mindfulness are feasible and effective in improving brace adherence, which can be integrated into psychosocial interventions and/or clinical orthotic management (Karol et al., 2016; Li et al., 2023; Miller et al., 2012). Some participants concealed their AIS conditions or emotions from those around them. Promoting peer communication among individuals with the same condition can be beneficial as it enables experience sharing and coping skill acquisition, which may help diminish stigma and psychosocial distress (Chaudoir & Quinn, 2010; Kaushansky et al., 2016). Additionally, it is crucial for parents and attending doctors to cultivate effective communication skills to facilitate emotional expression in AIS teenagers, while actively caring for the condition.

Social interactions and social support

The diagnosis of AIS during early adolescence can disrupt normal developmental processes, impacting social interactions with peers, family, and the outside world (Baird & Gardner, 2021). Our study identified social withdrawal among participants, highlighting the need for social skills training to promote healthy relationships and seek social support for AIS teenagers. Parent-child interactions were also crucial for teenagers' psychosocial adaptation, suggesting the importance of parental programs that teach a balance between maintaining authority and allowing independence (Salisbury et al., 2007; Wang et al., 2019). Additionally, insufficient emotional support was reported by some participants, indicating a lack of available psychosocial resources. To establish a more comprehensive support system, integrating new strategies into the AIS care continuum is essential. This can involve partnering with rehabilitation centers to share services, integrating social workers into AIS clinic teams, and collaborating with school counselors (Provost et al., 2022).

Deteriorating or thriving in psychological development and well-being

The emotional burden of living with chronic diseases during adolescence is well documented (Sawyer et al., 2007). Participants' development of psychological resilience and peaceful mindset can be attributed to adaptive coping strategies and active engagement in treatment, which also served to prevent curve progression (Weinstein et al., 2013). This highlights the interconnectedness of psychological well-being and physical health. Conversely, employing ineffective coping strategies may have contributed to psychosocial distress. Therefore, early assessment of the mental health status of AIS teenagers is crucial, as it can offer valuable insight into early treatment (Chang et al., 2016). As psychosocial interventions for AIS individuals are limited, nurses can serve as care team coordinators to facilitate the implementation of holistic care (van Niekerk et al., 2023).

Practice implications

Healthcare providers should gain a comprehensive understanding of the obstacles and their evolution throughout the AIS journey to improve clinical interactions, communication, and overall care for AIS teenagers. In light of the valuable insights gained from this study regarding the social skills and support required for AIS teenagers, future research should prioritize the crucial aspects of psychosocial support for this population. Coping-based psychosocial interventions should be implemented by health support organizations to facilitate changes in maladaptive coping behaviors and promote adaptive coping behaviors, thereby enhancing the overall well-being of the AIS population.

Strengths and limitation

This study addresses a notable gap in the literature by conducting the first comprehensive exploration of stressors, coping strategies, and mental health among teenagers with AIS. Through the use of qualitative methods, the study provides in-depth insights into the lived experiences of AIS teenagers. This study’s findings offer valuable insights that can inform and guide improvements in clinical practices and support systems specifically tailored to the needs of individuals with AIS.

Several study limitations should be acknowledged. First, the study was conducted in Hong Kong with Chinese participants, so the findings may not be transferable to teenagers with AIS of different ethnicity in other countries. Second, the purposive selection of study participants may restrict the representation of broader populations in primary care settings. Finally, although efforts such as asking direct questions and active listening were made to encourage open communication, limited verbal expression was observed in several participants during interviews. As parents, peers, or health professionals may possess valuable insights into the lived experiences of AIS teenagers, future research could consider collecting information from these sources to gain a more comprehensive understanding.

Conclusion

Teenagers living with AIS encountered a challenging journey marked by various physical and psychological stressors. Utilizing positive appraisal techniques and adopting adaptive coping strategies, in addition to activating social support, were crucial for achieving optimal overall health.

Appendix

Appendix A. The sample questions of the interview guide

Data availability statement

The data that support the findings of this study are available on request from the corresponding author.

References

Auerbach, J. D., Lonner, B. S., Crerand, C. E., Shah, S. A., Flynn, J. M., Bastrom, T., Penn, P., Ahn, J., Toombs, C., Bharucha, N., Bowe, W. P., & Newton, P. O. (2014). Body image in patients with adolescent idiopathic scoliosis: validation of the Body Image Disturbance Questionnaire--Scoliosis Version. *J Bone Joint Surg Am, 96*(8), e61. https://doi.org/10.2106/jbjs.L.00867.

Baird, C., & Gardner, A. (2021). A report of the number of adolescents screened as warranting further investigation for depression and social anxiety in a pre-operative cohort with idiopathic scoliosis. *Surgeon-Journal of the Royal Colleges of Surgeons of Edinburgh and Ireland, 19*(5), 263-267. https://doi.org/10.1016/j.surge.2020.07.009.

Beka, A., Dermitzaki, I., Christodoulou, A., Kapetanos, G., Markovitis, M., & Pournaras, J. (2006). Children and adolescents with idiopathic scoliosis: emotional reactions, coping mechanisms, and self-esteem. *Psychological Reports, 98*(2), 477-485. https://doi.org/10.2466/pr0.98.2.477-485.

Bettany-Saltikov, J., Weiss, H. R., Chockalingam, N., Taranu, R., Srinivas, S., Hogg, J., Whittaker, V., Kalyan, R. V., & Arnell, T. (2015). Surgical versus non-surgical interventions in people with adolescent idiopathic scoliosis. *Cochrane Database of Systematic Reviews*(4), Article Cd010663. https://doi.org/10.1002/14651858.CD010663.pub2.

Boeije, H. (2002). A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Quality & Quantity, 36*(4), 391-409. https://doi.org/10.1023/A:1020909529486.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sports Exercise and Health, 11*(4), 589-597. https://doi.org/10.1080/2159676X.2019.1628806.

Chang, W. P., Lin, Y. L., Huang, H. L., Lu, H. F., Wang, S. T., Chi, Y. C., Hung, K. S., & Chen, H. Y. (2016). Scoliosis and the Subsequent Risk of Depression A Nationwide Population-based Cohort Study in Taiwan. *Spine, 41*(3), 253-258.

https://doi.org/10.1097/BRS.0000000000001187.

Chaudoir, S. R., & Quinn, D. M. (2010). Revealing Concealable Stigmatized Identities: The Impact of Disclosure Motivations and Positive First-Disclosure Experiences on Fear of Disclosure and Well-Being. *Journal of Social Issues, 66*(3), 570-584. https://doi.org/10.1111/j.1540-4560.2010.01663.x.

Cheung, K. M. C., Cheng, E. Y. L., Chan, S. C. W., Yeung, K. W. K., & Luk, K. D. K. (2007). Outcome assessment of bracing in adolescent idiopathic scoliosis by the use of the SRS-22 questionnaire. *International Orthopaedics, 31*(4), 507-511. https://doi.org/10.1007/s00264-006-0209-5.

Compas, B. E., Jaser, S. S., Dunn, M. J., & Rodriguez, E. M. (2012). Coping with chronic illness in childhood and adolescence. *Annu Rev Clin Psychol, 8*, 455-480. https://doi.org/10.1146/annurev-clinpsy-032511-143108.

Cyran-Grzebyk, B., Perenc, L., Wyszynska, J., Kolodziej-Lackorzynska, G., & Majewska, J. (2023). The Influence of Family Crisis Coping Strategies on Family Quality of Life in the Assessment of Patients with Idiopathic Scoliosis. *International Journal of Environmental Research and Public Health, 20*(2), Article 1177. https://doi.org/10.3390/ijerph20021177.

Douma, M., Joosten, M. M. H., Scholten, L., Maurice-Stam, H., & Grootenhuis, M. A. (2019). Online Cognitive-Behavioral Group Intervention for Adolescents With Chronic Illness: A Pilot Study. *Clinical Practice in Pediatric Psychology, 7*(1), 79-92. https://doi.org/10.1037/cpp0000274.

Essex, R., Bruce, G., Dibley, M., Newton, P., Thompson, T., Swaine, I., & Dibley, L. (2022). A systematic scoping review and textual narrative synthesis of the qualitative evidence related to adolescent idiopathic scoliosis. *Int J Orthop Trauma Nurs, 45*, 100921. https://doi.org/10.1016/j.ijotn.2022.100921.

Fong, D. Y. T., Cheung, K. M. C., Wong, Y. W., Wan, Y. Y., Lee, C. F., Lam, T. P., Cheng, J. C. Y., Ng, B. K. W., & Luk, K. D. K. (2015). A population-based cohort study of 394,401 children followed for 10 years exhibits sustained effectiveness of scoliosis screening. *Spine Journal, 15*(5), 825-833. https://doi.org/10.1016/j.spinee.2015.01.019.

Gallant, J. N., Morgan, C. D., Stoklosa, J. B., Gannon, S. R., Shannon, C. N., & Bonfield, C. M. (2018). Psychosocial Difficulties in Adolescent Idiopathic Scoliosis: Body Image, Eating Behaviors, and Mood Disorders. *World Neurosugery, 116*, 421-+. https://doi.org/10.1016/j.wneu.2018.05.104.

Kan, M. M. P., Negrini, S., Di Felice, F., Cheung, J. P. Y., Donzelli, S., Zaina, F., Samartzis, D., Cheung, E. T. C., & Wong, A. Y. L. (2023). Is impaired lung function related to spinal deformities in patients with adolescent idiopathic scoliosis? A systematic review and meta-analysis-

SOSORT 2019 award paper. *Eur Spine J, 32*(1), 118-139. https://doi.org/10.1007/s00586-022-07371-z.

Karol, L. A., Virostek, D., Felton, K., & Wheeler, L. (2016). Effect of Compliance Counseling on Brace Use and Success in Patients with Adolescent Idiopathic Scoliosis. *Journal of Bone and Joint Surgery -American Volume, 98*(1), 9-14. https://doi.org/10.2106/JBJS.O.00359.

Kaushansky, D., Cox, J., Dodson, C., McNeeley, M., Kumar, S., & Iverson, E. (2016). Living a secret: Disclosure among adolescents and young adults with chronic illnesses. *Chronic Illness, 13*(1), 49-61. https://doi.org/10.1177/1742395316655855.

Kim, H., Sefcik, J. S., & Bradway, C. (2017). Characteristics of Qualitative Descriptive Studies: A Systematic Review. *Res Nurs Health, 40*(1), 23-42. https://doi.org/10.1002/nur.21768.

Law, D., Cheung, M.-c., Yip, J., Yick, K.-L., & Wong, C. (2017). Scoliosis brace design: influence of visual aesthetics on user acceptance and compliance. *Ergonomics, 60*(6), 876-886. https://doi.org/10.1080/00140139.2016.1227093.

Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal, and Coping*. Springer.

Lee, S. B., Chae, H. W., Kwon, J. W., Sung, S., Lee, H. M., Moon, S. H., & Lee, B. H. (2021). Is There an Association Between Psychiatric Disorders and Adolescent Idiopathic Scoliosis? A Large-database Study. *Clinical Orthopaedics and Related Research, 479*(8), 1805-1812. https://doi.org/10.1097/CORR.0000000000001716.

Leventhal, H., Phillips, L. A., & Burns, E. (2016). The Common-Sense Model of Self-Regulation (CSM): a dynamic framework for understanding illness self-management. *J Behav Med, 39*(6), 935-946. https://doi.org/10.1007/s10865-016-9782-2.

Li, X., Lau, E. N. S., Chan, S. K. C., Lam, T. P., Cheng, J. C. Y., Lee, E. K. P., Wong, S. Y. S., & Yip, B. H. K. (2023). Effects of Mindfulness-Based Intervention to Improve Bracing Compliance in Adolescent Idiopathic Scoliosis Patients: a Randomized Controlled Trial. *Mindfulness*. https://doi.org/10.1007/s12671-022-02021-3.

Li, Y., Bressington, D., & Chien, W. T. (2019). Pilot evaluation of a coping-oriented supportive program for people with spinal cord injury during inpatient rehabilitation. *Disability and Rehabilitation, 41*(2), 182-190. https://doi.org/10.1080/09638288.2017.1386238.

Li, Y., Chien, W. T., & Bressington, D. (2020). Effects of a coping-oriented supportive programme for people with spinal cord injury during inpatient rehabilitation: a quasi-experimental study. *Spinal Cord, 58*(1), 58-69. https://doi.org/10.1038/s41393-019-0320-2.

Lin, Y. M., Cheung, J. P. Y., Chan, C. K., Wong, S. W. F., Cheung, K. M. C., Wong, M. R., Wong, W. C., Cheung, P. W. H., & Wong, M. S. (2022). A Randomized Controlled Trial to Evaluate the Clinical Effectiveness of 3D-Printed Orthosis in the Management of Adolescent Idiopathic Scoliosis. *Spine, 47*(1), 13-20. https://doi.org/10.1097/BRS.0000000000004202.

Miller, D. J., Franzone, J. M., Matsumoto, H., Gomez, J. A., Avendano, J., Hyman, J. E., Roye, D. P., & Vitale, M. G. (2012). Electronic Monitoring Improves Brace-Wearing Compliance in Patients With Adolescent Idiopathic Scoliosis A Randomized Clinical Trial. *Spine, 37*(9), 717-721. https://doi.org/10.1097/BRS.0b013e31822f4306.

Misterska, E., Glowacki, M., Latuszewska, J., & Adamczyk, K. (2013). Perception of stress level, trunk appearance, body function and mental health in females with adolescent idiopathic scoliosis treated conservatively: a longitudinal analysis. *Quality in Life Research, 22*(7), 1633-1645. https://doi.org/10.1007/s11136-012-0316-2.

Mitsiaki, I., Thirios, A., Panagouli, E., Bacopoulou, F., Pasparakis, D., Psaltopoulou, T., Sergentanis, T. N., & Tsitsika, A. (2022). Adolescent Idiopathic Scoliosis and Mental Health Disorders: A Narrative Review of the Literature. *Children (Basel), 9*(5). https://doi.org/10.3390/children9050597.

Negrini, S., Donzelli, S., Aulisa, A. G., Czaprowski, D., Schreiber, S., de Mauroy, J. C., Diers, H., Grivas, T. B., Knott, P., Kotwicki, T., Lebel, A., Marti, C., Maruyama, T., O'Brien, J., Price, N., Parent, E., Rigo, M., Romano, M., Stikeleather, L., Wynne, J., & Zaina, F. (2018). 2016 SOSORT guidelines: orthopaedic and rehabilitation treatment of idiopathic scoliosis during growth [Review]. *Scoliosis and Spinal Disorders, 13*, Article 3. https://doi.org/10.1186/s13013-017-0145-8.

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods, 16*(1), 1-13. https://doi.org/10.1177/1609406917733847.

Provost, M., Beauséjour, M., Ishimo, M.-C., Joncas, J., Labelle, H., & Le May, S. (2022). Development of a model of interprofessional support interventions to enhance brace adherence in adolescents with idiopathic scoliosis: a qualitative study. *BMC Musculoskeletal Disorders, 23*(1), 406. https://doi.org/10.1186/s12891-022-05359-w.

Rivera, E., Corte, C., DeVon, H. A., Collins, E. G., & Steffen, A. (2020). A systematic review of illness representation clusters in chronic conditions. *Research in Nursing & Health, 43*(3), 241-254. https://doi.org/10.1002/nur.22013.

Rushton, P. R. P., & Grevitt, M. P. (2013). Comparison of Untreated Adolescent Idiopathic Scoliosis With Normal Controls A Review and Statistical Analysis of the Literature. *Spine, 38*(9), 778-785. https://doi.org/10.1097/BRS.0b013e31827db418.

Salisbury, M. H., LaMontagne, L. L., Hepworth, J. T., & Cohen, F. (2007). Parents' Self-Identified Stressors and Coping Strategies During Adolescents' Spinal Surgery Experiences. *Clinical*

Nursing Research, 16(3), 212-230. https://doi.org/10.1177/1054773807302732.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health, 23*(4), 334-340. https://doi.org/10.1002/1098-240X(200008)23:4.

Sandelowski, M. (2010). What's in a Name? Qualitative Description Revisited. *Research in Nursing & Health, 33*(1), 77-84. https://doi.org/10.1002/nur.20362.

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & Quantity, 52*(4), 1893-1907. https://doi.org/10.1007/s11135-017-0574-8.

Sawyer, S. M., Drew, S., Yeo, M. S., & Britto, M. T. (2007). Adolescents with a chronic condition: challenges living, challenges treating. *The Lancet, 369*(9571), 1481-1489. https://doi.org/10.1016/S0140-6736(07)60370-5.

Solmi, M., Radua, J., Olivola, M., Croce, E., Soardo, L., Salazar de Pablo, G., Il Shin, J., Kirkbride, J. B., Jones, P., Kim, J. H., Kim, J. Y., Carvalho, A. F., Seeman, M. V., Correll, C. U., & Fusar-Poli, P. (2022). Age at onset of mental disorders worldwide: large-scale meta-analysis of 192 epidemiological studies. *Molecular Psychiatry, 27*(1), 281-295. https://doi.org/10.1038/s41380-021-01161-7.

Talic, G., Ostojic, L., Bursac, S. N., Nozica-Radulovic, T., & Stevanovic-Papic, D. (2016). Idiopathic Scoliosis from Psychopathological and Mind-Body Medicine Perspectives. *Psychiatr Danub, 28*(4), 357-362. https://www.ncbi.nlm.nih.gov/pubmed/27855426

Tones, M., Moss, N., & Polly, D. W. (2006). A review of quality of life and psychosocial issues in scoliosis. *Spine, 31*(26), 3027-3038. https://doi.org/10.1097/01.brs.0000249555.87601.fc.

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19*(6), 349-357. https://doi.org/10.1093/intqhc/mzm042.

van Niekerk, M., Richey, A., Vorhies, J., Wong, C. N., & Tileston, K. (2023). Effectiveness of psychosocial interventions for pediatric patients with scoliosis: a systematic review. *World Journal of Pediatric Surgery, 6*(2), Article e000513. https://doi.org/10.1136/wjps-2022-000513.

Wang, H., Li, T., Yuan, W. S., Zhang, Z. P., Wei, J., Qiu, G. X., & Shen, J. (2019). Mental health of patients with adolescent idiopathic scoliosis and their parents in China: a cross-sectional survey. *BMC Psychiatry, 19*, Article 147. https://doi.org/10.1186/s12888-019-2128-1.

Weinstein, S. L., Dolan, L. A., Cheng, J. C. Y., Danielsson, A., & Morcuende, J. A. (2008). Adolescent idiopathic scoliosis. *The Lancet, 371*(9623), 1527-1537. https://doi.org/10.1016/s0140-6736(08)60658-3.

Weinstein, S. L., Dolan, L. A., Wright, J. G., & Dobbs, M. B. (2013). Effects of Bracing in Adolescents with Idiopathic Scoliosis. *New England Journal of Medicine, 369*(16), 1512-1521. https://doi.org/10.1056/NEJMoa1307337.

Wong, A. Y. L., Samartzis, D., Cheung, P. W. H., & Cheung, J. P. Y. (2019). How Common Is Back Pain and What Biopsychosocial Factors Are Associated With Back Pain in Patients With Adolescent Idiopathic Scoliosis? *Clinical Orthopaedics and Related Research, 477*(4), 676-686. https://doi.org/10.1097/CORR.0000000000000569.

Xu, N., & Liu, Y. Y. (2020). Coping strategy mediates the relationship between body image evaluation and mental health: A study with Chinese college students with disabilities. *Disability and Health Journal, 13*(1), Article 100830. https://doi.org/10.1016/j.dhjo.2019.100830.