

**A qualitative study:
Exploring adherence to bracing in young people with adolescent idiopathic scoliosis**

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Abstract

Background

Adolescent idiopathic scoliosis (AIS) can cause back pain, decrease lung function and reduce quality of life. Bracing can prevent AIS from worsening. However, many young people do not wear their brace for the recommended hours and this is associated with worsening of scoliotic curve and higher chance of requiring surgery. To find ways for improving adherence to bracing, young people's views on what facilitates or hinders adherence were explored.

Methods

A qualitative study was conducted using semi-structured interviews. Young people who were prescribed bracing for AIS and their parents were invited to an online interview. Questions explored their perceived facilitators and barriers to brace adherence. Interview transcripts were analysed using thematic analysis.

Results

Six young people and five of their parents participated in the interviews. All young people were adherent to bracing. Three main themes of facilitators and barriers to brace adherence were generated. 'Knowledge about bracing' shows that adherence is influenced by knowledge about AIS and treatment effectiveness. 'Psychosocial factors' suggests how emotions and attitudes towards bracing affect adherence. 'Practicality' illustrates the physical factors which influence brace adherence.

Conclusions

For young people with good brace adherence, knowledge about bracing facilitates their adherence, suggesting the importance of patient education by healthcare professionals. Parents can play a major role in encouraging adherence by providing emotional and practical support. Young people can be reassured that some barriers to bracing can be overcome. Adherence may be further enhanced by user-friendly brace design. These facilitators can be promoted to maximise brace adherence.

Key points

Knowledge about scoliosis bracing facilitates brace adherence in young people who are adherent to bracing. Brace adherence may be enhanced by emotional and practical support from parents. Physical barriers to brace adherence may be overcome by getting used to bracing, or using different strategies and brace types.

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Introduction

Scoliosis is defined as a 'three-dimensional torsional deformity of the spine' (Negrini et al., 2012). It is diagnosed when the lateral spinal curve exceeds a Cobb angle of 10° on a radiograph, accompanied by axial rotation (Scoliosis Research Society, n.d.). Idiopathic scoliosis specifies the deformity which is not caused by other diseases. Diagnoses made between the age of 10 and 17 are classified as adolescent idiopathic scoliosis (AIS) (James, 1975). The reported prevalence of AIS is between 0.93% and 12%, with more females presenting with larger scoliotic curves (Negrini et al., 2018).

Trunk deformity in AIS may change body appearance, cause pain and limit lung function, consequently reducing quality of life (Negrini et al., 2018). In less severe AIS, curve progression and the health consequences can be prevented by non-surgical management, including observation, physiotherapeutic scoliosis-specific exercise and bracing. Bracing is a rigid support or elastic bands which apply corrective force to the trunk, and a systematic review concluded that bracing is effective in preventing curve progression in patients with AIS (Negrini et al., 2015). This treatment is recommended for skeletally immature patients with Cobb angle above 20° to 25° (Negrini et al., 2018). Most brace types are designed to be worn full-time for at least 18 hours per day, whilst night-time braces should be worn for 8 to 12 hours per day.

Higher adherence to the recommended number of bracing hours is correlated with less curve progression and lower referral rate for surgery (Aulisa et al., 2014). However, when measured by sensors, only 17% of patients reached 70% of the recommended bracing time (Sanders et al., 2014). By exploring the facilitators and barriers to adherence to bracing, treatment adherence and effectiveness may be improved.

Brigham and Armstrong (2017) and Donnelly et al. (2004) identified some facilitators of brace adherence in young people with AIS, including effects of bracing in preventing surgery, curve progression and pain. Brigham and Armstrong (2017) also discovered a barrier to adherence, which was young people's fear of others' comments about their brace. Other possible barriers were physical difficulties such as discomfort, limitations in physical activity and limited choice of clothes; negative emotions due to bracing might hinder adherence too (Brigham and Armstrong, 2017; Donnelly et al., 2004; Law et al., 2017; MacLean et al., 1989). However, previous researchers did not evaluate their participants' actual brace adherence. If young people's perceived facilitators and barriers had been interpreted alongside their actual adherence, it might have enabled the exploration of whether promoting these facilitators or removing these barriers would improve adherence effectively or not. Furthermore, previous studies have only been conducted on girls with a Boston or Milwaukee brace. The experience of boys and young people on different brace types should also be acknowledged, to allow a comprehensive exploration of brace adherence.

This study aimed to explore facilitators and barriers to brace adherence in young people with AIS, including boys and different brace types. The findings may offer insights into how healthcare professionals (HCPs) and people who are close to a young person can motivate young people to adhere to bracing.

Method

A qualitative research design was selected to understand young people's experience of bracing (Green and Thorogood, 2009). This study was based on phenomenology, achieved by bracketing the researcher's prior assumptions, in order to understand 'lived experiences' of bracing from participants' point of view (Eberle, 2014). Interviews were chosen to collect rich data of how young people accounted for brace adherence, and to explore diverse factors of adherence individually (Heary and Hennessy, 2006). To explore participants' in-depth views, semi-structured interviews were employed. Parents/ guardians were also invited to the interviews, which could enrich data about young people's experience and strengthen credibility of the findings (Saldaña, 2011). Ethical approval was obtained from the University College London Research Ethics Committee (Project ID: 19575/001).

Recruitment

Young people and their parents were purposively recruited from eight support groups and scoliosis organisations via an online poster. The inclusion and exclusion criteria for participants are presented in Table 1. Informed consent from parents and assent from young people was obtained from all participants. Recruitment took place in May and June 2021, and was constrained to this period as this was a Masters' research project.

Table 1: Inclusion and exclusion criteria for participants with AIS

Inclusion criteria	Exclusion criteria
On bracing for AIS at the time of interview	Other types of scoliosis
Age between 10 to 15 years	History of spinal operation
Could communicate in English	Could not understand or answer questions in English

Data collection methods

Interviews were conducted and recorded using Microsoft Teams. Reflective notes were taken following the interviews to record the researcher's reflections.

Interview questions

Participants' demographic information and brace adherence were first collected. Then, questions were asked based on the topic guide (Box 1). The guide was developed by the primary researcher to explore how brace adherence was influenced by the facilitators and barriers recognised in the existing literature, including effects of bracing, psychosocial influence and physical difficulties. The influence of HCPs and parents was also asked to understand their role in adherence. The guide was iteratively amended with the project supervisor and other physiotherapists in the Masters' programme to improve its face validity. A pilot interview was conducted with a child on scoliosis bracing, to ensure the topic guide was appropriate for the research question (Roulston, 2014). Her data were not included in this study. Subsequently, a question to ask for participants' advice to other young people on bracing was added to the topic guide.

Box 1: Topic guide for the interview

- Can you tell me about your typical day? When do you wear or take off your brace on a school day, and at the weekend?

Knowledge and understanding about AIS

- What/ how did the healthcare professionals explain scoliosis and your brace to you?
- What do you feel about the effects of scoliosis on you?
 - The effects now, and the potential effects that anyone has told you

Attitudes towards bracing

- Have you not worn your brace on some days? Why?
- What do you feel about wearing your brace?
- Do you think your brace helps you or bothers you?

Physical barriers to adherence

- Do you feel pain in your brace?
- Does your brace stop you from doing something?
- How do you or your parents/ guardians help cope with these problems?
- What advice would you give to other young people on bracing?

Influence of other people

- Who has influenced you to wear your brace?
- Parents/ guardians: What have they done for your brace wear?
- Healthcare professionals: Are they helpful in your brace wear?
 - Have they talked about for how many hours you did wear your brace?
- Peers: Do you have a friend who also wears a brace? Have you told your friends about your brace?

Probing question

- In case of difference in opinions between the young person and the parent/ guardian: How do you usually resolve the difference in your opinions about bracing?

**The topic guide is mainly targeted on young people. Parents/ guardians who accompany the young person during the interview will be asked about the underlined topics.

Data analysis

The interviews were transcribed verbatim by the researcher. The transcripts were sent to parents for member checking to increase credibility (Saldaña, 2011). Four parents confirmed its accuracy while two parents made slight amendments to language use. Data were analysed using an inductive approach, based on the processes of thematic analysis described by Braun and Clarke (2012). Table 2 shows the processes and an example of how a subcategory was generated. During analysis, the primary researcher reflected on her bracketed presumptions about brace adherence (Box 2), which were documented before the interviews. It ensures that generated themes stayed close to participants' responses instead of the researcher's beliefs (Willig, 2014). To enhance credibility, themes were discussed with the supervisor (Green and Thorogood, 2009), and decisions made during the study were recorded in an audit trail (Cope, 2014).

Table 2: Processes of data analysis

Five processes of data analysis	An example illustrating the processes
1. The researcher read the interview transcripts and reflective notes for several times, and highlighted the data possibly relevant to the research question.	The following quote which demonstrated prevention of surgery as a facilitator of brace adherence was highlighted: 'Staying away from having an operation, because I obviously, I don't wanna like, have the operation.'
2. Initial codes were given to label the feature of the participants' responses.	A code 'avoid surgery' was given to label the above quote.
3. Similar codes were grouped together to generate broader themes and subcategories.	The codes including 'avoid surgery', 'reduce curve', 'reduce back pain' and 'unclear about brace effects' were grouped together into a subcategory called 'outcomes of bracing'.
4. A thematic map was constructed to show the relationship between the themes.	
5. Interview transcripts and reflective notes were reviewed to ensure that the themes could reflect the raw data.	

Box 2: Researcher's bracketed presumptions about brace adherence

- Have mild scoliosis, not really affected by it. Parents and dance teacher perceived the 'imbalanced posture' as a bigger problem than I did. Saw a chiropractor for scoliosis during adolescence, but did not want to go to the sessions.
- Saw many young people not adherent to bracing. Had to educate them to adhere to bracing, but felt that the education was passive and ineffective in improving brace adherence-> Want to know how to improve adherence more effectively.
- Think different people may view the same barriers differently. What makes the difference in decision making between people?
- Possible barriers: not promising results of bracing, unwilling to sacrifice for future problems which may not happen, want to be independent, do not like being nagged, hotness.
- Possible facilitators: desire to avoid surgery.

Results

Six young people completed the interview. Table 3 displays the demographic information. There were four females and two males. All participants were adherent to bracing, including Participant 1 (P1), who had just started the treatment and was building up the hours according to his doctor. Five participants joined the interview with their mother.

Table 3: Demographics of participants

Participant	Age	Sex	Country	Ethnicity	Age of diagnosis	Cobb angle before bracing	Latest Cobb angle	Duration on bracing	Type of brace	Number of wearing hours recommended per day	Actual number of wearing hours	Put on and off brace independently	Other conditions
P1	12	M	UK	White	11	60°	/	2 weeks	Boston	22	4(Still building up)	No	Autism spectrum disorder
P2	15	F	US	White	12	17°	37°	3 years	Charleston	10 (night-time)	9 to 10	Yes	Nil
P3	12	F	US	White	10	30°	6°	1.5 years	Providence	12 (night-time)	9	Yes	Nil
P4	15	F	UK	White	13	49°	38°	1.25 years	ScoliBrace	23	22 to 23	Yes	Nil
P5	14	F	US	White	11	43°	14°	3.5 years	Silicon Valley	18	18	Yes	Nil
P6	12	M	UK	White	10	45°	44°	2 years	Gensingen	23	22 to 23	Yes	Hypermobility, on investigation

Key: F – female, M – male, UK – the United Kingdom, US – the United States.

Several new codes were identified in the final interview, implying that data saturation might not have been fully achieved due to the small sample size. Through thematic analysis, three main themes which facilitated or hindered the participants' brace adherence were identified:

1. *Knowledge about bracing*
2. *Psychosocial factors*
3. *Practicality*

Figure 1 presents the subcategories in each theme. Three themes and their subcategories are reported below.

Theme 1: Knowledge about bracing

Impacts of scoliosis

Some participants indicated that knowing scoliosis-associated symptoms facilitated their adherence to bracing:

"I had like lung problems and back pain, because it was so severe, but like that was another motivator." [P5, pre-bracing Cobb angle 43°]

Although other participants were not affected by symptoms of AIS, P2 was worried about pain in case of curve progression, which encouraged her to adhere to bracing.

Outcomes of bracing

Three participants were motivated to adhere to bracing mainly to avoid surgery:

"Staying away from having an operation, because I obviously, I don't wanna like, have the operation." [P2]

P3 and P6 stated that prevention of curve progression facilitated their adherence. Surprisingly, as illustrated by the quote below, P1 thought no outcomes would be achieved through bracing, hence appeared to be not encouraged to adhere to the treatment:

Researcher: "Do you think your brace will help you?"

P1 (diagnosed with autism spectrum disorder): "Like I said, no." ...

P1's mother: "It just takes some moment that he can understand."

Perceptions of surgery

Four participants worried about post-surgical complications, including limitations in activities, pain and nerve damage. Feeling negative towards surgical treatment encouraged them to adhere to bracing:

"It mainly just motivated me to wear my brace, because they (her support group) really like talk about stuff after surgery and ... I don't wanna do that." [P5]

Yet, positive perceptions of surgery can hinder brace adherence, as P2 found surgery faster than bracing:

"I don't want my brace for eight years. Why not just have the surgery?" [P2].

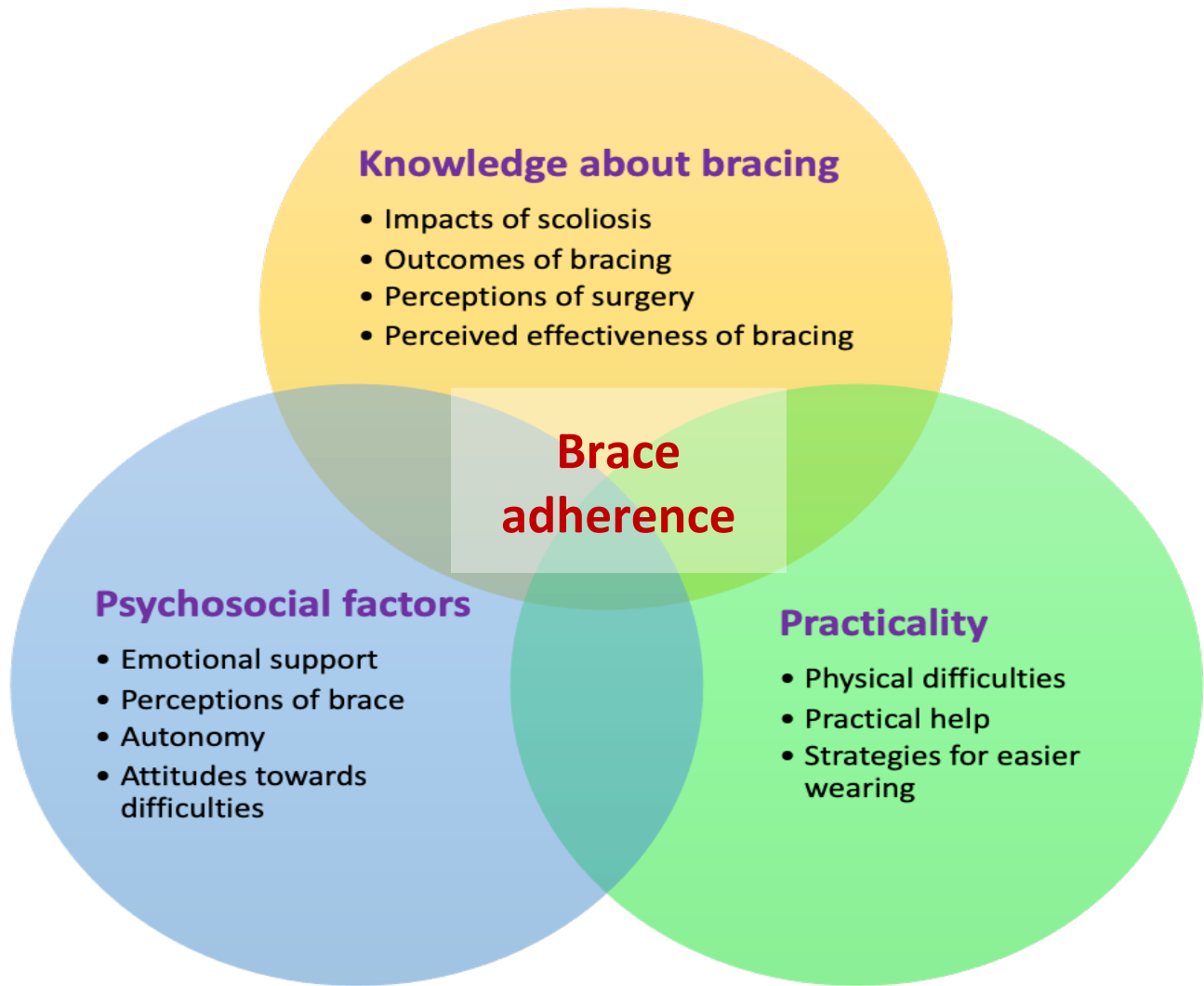


Figure 1: Themes and subcategories for facilitators and barriers to brace adherence in young people with AIS

Perceived effectiveness of bracing

P3 and P5 were confident in the effectiveness of their asymmetric braces, which enhanced their adherence. Their curve reduced during bracing:

"We know that their braces work, so that's also very helpful to know." [P5]

Other participants or their mothers highlighted the uncertainty about the effectiveness of bracing, which was affected by HCPs' explanation. The uncertain effectiveness might be a barrier to brace adherence:

"The size of P4's curves (49°), bracing was highly unlikely to work. ... The surgeon said it would never work." [P4's mother]

"I wouldn't be a supporter of the brace ... I don't see many other people would get significant results." [P1's mother]

The mother of three participants (P2, P4, P5) believed that the symmetrical Boston brace was less effective. When HCPs only offered Boston brace as treatment, they looked for asymmetric braces provided by other healthcare services. This raises speculation that if only Boston brace is available, its low perceived effectiveness may reduce adherence.

Theme 2: Psychosocial factors

Emotional support

Emotional support facilitated all participants' brace adherence. All participants described family support as a significant motivator, especially during the initial adaptation to bracing. Apart from verbal encouragement, some mothers mentioned 'being there' and staying alert to their child's feelings. **P3** and **P5** were encouraged to adhere to bracing by other patients from social media or support groups. **P3** highlighted 'not feeling alone' after owning specially designed animal dolls with braces.

"I also say, 'well done, P1. I'm so proud of you.' " [P1's mother]

"Just be there for you ... Try to understand how he's feeling and give him a break if he needs it." [P6's mother]

"The Curvy Girls meetings. It was helpful to talk to other people." [P5]

"When her sister got her that Higgy Bear ... she made her own little Insta (Instagram) page ... Then, she started talking to other kids ... An absolute game changer." [P3's mother]

Perceptions of brace

Despite good brace adherence, five participants experienced barriers, because they disliked their brace. They recalled emotions like 'upset' and 'annoyed'. Particularly, all four female participants expressed that they were not keen to talk about bracing with their friends. **P4** felt uncomfortable when being seen in her brace, so she hid it under specific clothes. A possible explanation is the worry about others' judgment:

"I wouldn't want to like be known as 'the girl with the brace' ... That's like my main worries like judgment from other teens." [P2]

Conversely, positive perceptions of brace can encourage adherence. **P6** had hypermobility and found his brace 'safe' and 'comfortable', which motivated him to adhere to bracing. Wearing his brace in school also felt 'normal' to him, likely after he explained bracing to schoolmates.

Autonomy

Autonomy in bracing was mentioned by three older participants (age 14 to 15). **P5** felt responsible for 'getting the treatment right' and self-decided what time to wear her brace. **P4** was motivated to wear her brace, partly because her mother supported her decision. The feeling of responsibility and autonomy might have facilitated their adherence.

Attitudes towards difficulties

Even though bracing seems challenging, persistence when facing difficulties enhanced some participants' adherence. Some participants coped with it actively by exploring ways to make brace adherence easier:

"I have to have a hook on the door to hang my brace ... finding ways to make it as easy as possible." [P5]

Theme 3: Practicality

Physical difficulties

Each participant described numerous physical barriers to brace adherence. All of them experienced pain or discomfort, which disrupted sleep for some participants. **P3** had a night-time brace, and stated she would not wear her brace outside her home because of discomfort. This suggests that full-time bracing can be a larger barrier to adherence, because discomfort may last longer.

Some participants mentioned that their brace limited physical activity and everyday activities like bending down. Other barriers included hotness, skin rash, and difficulty in finding chairs and bathrooms at school. Fortunately, five participants overcame the discomfort after getting used to bracing within weeks:

"I've gotten so used to the shape of the brace now, that I can barely feel it anymore." [P6]

Some participants regarded the design of Boston brace as a barrier to adherence, because the straps at the back stopped them from putting on the brace themselves.

Practical help

Brace adherence of all participants was facilitated by physical help, mostly at the beginning when their parents helped them put on the brace. Some parents reminded their child when to wear the brace or monitored their child's adherence. P6 once needed teachers' assistance to put on his brace. His parent also mentioned that HCPs gave suggestions for increasing adherence gradually.

Strategies for easier wearing

All participants used some strategies to make wearing brace easier, which enhanced their adherence. The most common strategy was taking breaks when wearing the brace, followed by doing sedentary activities. Having T-shirt or washcloth underneath the brace helped some participants. P5 loosened her brace for short periods of time, set timers to build up the wearing hours, and stayed indoor during summer. P4's mother bought new clothes for hiding the brace. P6's mother thought adherence would be facilitated by a better brace design, like being 'light-weight' and having straps at the front. It shows that some physical barriers may be overcome using specific strategies or brace design.

Discussion

The aim of this study was to explore the facilitators and barriers to brace adherence in young people with AIS. It has included the views of boys and young people on various brace types. The themes and subcategories generated accord with the existing literature, but reveal more reasons of why young people adhere to bracing. Each theme will be discussed below.

Theme 1: Knowledge about bracing

Impacts of scoliosis

The current study shows that knowing the impacts of AIS, such as back pain and lung problems, facilitates brace adherence in some young people. This finding supports that of Brigham and Armstrong (2017). According to the Health Belief Model, people are more likely to engage in behaviours for disease prevention, when they perceive the disease as severe (Dempster et al., 2018). Young people may perceive AIS as severe after understanding its impacts, and consequently adhere better to bracing.

Outcomes of bracing

Brace adherence can be enhanced by understanding that it helps avoid surgery and curve progression. This result is consistent with that reported by Brigham and Armstrong (2017) and Donnelly et al. (2004). However, education on the bracing outcomes should be tailored to individuals with AIS, as demonstrated by P1's experience. Possibly due to his diagnosis of autism spectrum disorder, P1 appeared to not understand his doctor's explanation of what useful outcomes bracing would bring. He was not motivated to adhere to the treatment. This reflects that some young people may need individualised education to increase their knowledge about the outcomes of bracing, in order to improve their adherence.

Perceptions of surgery

This study illustrates that post-surgery complications can discourage young people from considering surgery and improve brace adherence. On the other hand, P2 found 'one-off' surgery more favourable than bracing, which usually lasts several years. This positive perception of surgery can be a barrier to brace adherence. It is an interesting finding which has not been described previously, possibly because the in-depth interviews conducted here enabled participants to articulate their personal thoughts more easily than questionnaires or focus groups.

Perceived effectiveness of bracing

This is the first study to recognise that perceiving bracing as effective can motivate some young people to adhere to the treatment. It mirrors the Health Belief Model, which states that people are more likely to initiate a health behaviour if they consider the behaviour as beneficial (Dempster et al., 2018). Conversely, the uncertainty of brace effectiveness was a potential barrier to adherence for some participants.

Although the reported effectiveness of Boston brace and asymmetric braces is similar (Costa et al., 2021), some parents in this study believed symmetrical Boston brace was less effective, which may hinder adolescents' treatment adherence (Taddeo et al., 2008). This belief of ineffectiveness might be explained by the fact that all participants lived in the United Kingdom or the United States, where Boston brace is commonly used (Zaina et al., 2014). Among the young people whose curve progressed after bracing, there may have been more people on Boston brace, however this was not evaluated in this study.

Theme 2: Psychosocial factors

Emotional support

While previous studies have not intended to explore parental influence on brace adherence, the current study demonstrates that emotional support from parents can be a significant facilitator. Parental support for emotions remains important throughout adolescence and contributes to the psychological functioning of young people with chronic conditions (Oris et al., 2016), elucidating the role of parents in brace adherence.

Perceptions of brace

Negative perceptions of brace, expressed by most participants, can make brace adherence more difficult. This corroborates the negative emotions mentioned by Donnelly et al. (2004), Law et al. (2017) and MacLean et al. (1989). All the female participants in this study were reluctant to discuss bracing with peers. As the brain develops, adolescents may care more about others' opinions than adults do (Somerville, 2013). To avoid peers' opinions, young people might not wear their brace at school, causing lower adherence. The male participants did not report the same concern, but due to the small sample size, it is uncertain whether this phenomenon is unique to or more common in females.

In contrast to the literature, this study reveals that young people can also perceive their braces positively. **P6** felt safe and comfortable with bracing, which promoted his adherence. His hypermobility might explain why he appreciated the support provided by bracing. Including participants with other conditions in this study might have enabled the exploration of diverse perceptions of braces in different people. Furthermore, wearing a brace at school was not a challenge to **P6** after describing his brace to the whole school. This implies that raising awareness in schools may reduce patients' fear of peer opinions, possibly promoting brace adherence.

Autonomy

Brace adherence may be facilitated when young people have autonomy towards their brace wearing or choosing their own treatment, as suggested by three older participants' experiences. Although autonomy has not been explored in the literature about AIS, its benefit on adherence may be explained by Self-determination Theory, which suggests that autonomy can increase one's own motivation for a behaviour (Deci and Ryan, 2008).

Attitudes towards difficulties

Despite numerous psychosocial and physical barriers to bracing, most participants persisted to adhere to the treatment. Persistence despite obstacles can be important for high brace adherence. This finding has not been described before, likely because previous studies did not evaluate participants' actual brace adherence in relation to their perceived barriers. Persistence in adolescents is associated with authoritative parenting, which emphasises warmth, support for autonomy and reasoning of behaviours (Padilla-Walker et al., 2012). It appears to reinforce the importance of emotional support, autonomy and knowledge about AIS respectively on enhancing brace adherence.

Theme 3: Practicality

The current study confirms the physical barriers to brace adherence identified by Brigham and Armstrong (2017); Donnelly et al. (2004); Law et al. (2017) and MacLean et al. (1989), including pain and activity limitation. Through in-depth interviews, this study acknowledges that some physical barriers can be overcome using specific strategies or as young people get used to brace wearing. What this study also adds is that the back straps of Boston brace may hinder adherence because they make putting on braces difficult, whereas night-time brace seems to reduce physical barriers to adherence due to shorter wearing time. A meta-analysis has shown that the reported effectiveness of night-time bracing is comparable to that of full-time bracing (Costa et al., 2021), so if available, night-time bracing might be a better option to promote adherence.

Implications for practice

- According to a group of young people who adhere to bracing, adherence can be facilitated by knowledge about bracing. Therefore, patient education about the treatment is important. Since parents can influence young people's knowledge, education to parents may also improve adherence. Existing literature may be used to reassure parents about the effectiveness of bracing, including Boston brace.
- The study findings may assist parents and HCPs to better understand the negative emotions associated with bracing. Emotional support from parents may be helpful and supporting young people's autonomy may promote adherence as well. Raising awareness of bracing in schools may reduce patients' worry about peer opinion, possibly encouraging brace wearing at school.
- Although there are physical barriers to brace adherence, HCPs can reassure young people that they may overcome most physical difficulties after getting used to bracing, or manage the difficulties using the strategies identified in this study. Some brace designs may make adherence easier. Parents may also assist brace wearing physically.

Strengths and limitations

This is the first qualitative study to include young people who wore a wide range of braces. It sheds new light on how different types of braces lead to different perceived effectiveness and physical barriers. It is also the first study to include the views of boys. However, it should be noted that the recruitment materials only reached families who joined support groups or particular scoliosis organisations. These families might be more engaged in managing AIS. Furthermore, data saturation was not achieved due to small sample size, and only participants with good adherence were recruited.

There are probably facilitators and barriers to brace adherence left unexplored, especially in young people with low adherence. The results may only be applicable to the population who join support groups and adhere well to bracing. Another limitation is that only participants from the United Kingdom and the United States were recruited, which may be attributed to the greater number of scoliosis organisations in these countries and the interviews being conducted in English. The findings are less transferable to people from other countries which may have different brace types available or different healthcare systems.

Recommendations for future research

The study could be repeated with a wider sample frame, i.e. spinal clinics as well as patient charities and social media groups. Purposive sampling could help ensure that young people who are adherent and non-adherent to bracing are included. A randomised controlled trial is required to establish the effects of combining education by HCPs and parental support on brace adherence. There is also a need for randomised controlled trials or prospective studies to compare the effects of different types of braces. If night-time braces are as effective as full-time braces, night-time braces may be a better option to promote adherence.

Conclusion

This study has explored the facilitators and barriers to brace adherence in a group of young people with AIS with good adherence. Knowledge about bracing, and emotional and practical support from parents have emerged as significant facilitators for adherence. This study has also found that some barriers can be overcome using specific strategies or a more user-friendly brace design.

References

- Aulisa, A.G., Giordano, M., Falciglia, F., Marzetti, E., Poscia, A. & Guzzanti, V. (2014) Correlation between compliance and brace treatment in juvenile and adolescent idiopathic scoliosis: SOSORT 2014 award winner. *Scoliosis*, 9(6), pp.1-9.
- Braun, V. & Clarke, V. (2012) Thematic analysis. In: Cooper, H., Camic, P.M., Long, D.L., Panter, A.T., Rindskopf, D. & Sher, K.J. (eds.) *APA Handbook of Research Methods in Psychology, Vol. 2. Research Designs: Quantitative, Qualitative, Neuropsychological, and Biological*. American Psychological Association, Washington, DC.
- Brigham, E.M. & Armstrong, D.G. (2017) Motivations for compliance with bracing in adolescent idiopathic scoliosis. *Spine Deformity*, 5, pp.46-51.
- Cope, D.G. (2014) Methods and meanings: credibility and trustworthiness of qualitative research. *Oncology Nursing Forum*, 41(1), pp.89-91.
- Costa, L., Schlosser, T.P.C., Jimale, H., Homans, J.F., Kruyt, M.C. & Castelein, R.M. (2021) The effectiveness of different concepts of bracing in adolescent idiopathic scoliosis (AIS): a systematic review and meta-analysis. *Journal of Clinical Medicine*, 10, pp.2145.
- Deci, E.L. & Ryan, R.M. (2008) Self-determination theory: a macrotheory of human motivation, development, and health. *Canadian Psychology/Psychologie canadienne*, 49(3), pp.182-5.
- Dempster, N.R., Wildman, B.G., Masterson, T.L. & Omlor, G.J. (2018) Understanding treatment adherence with the health belief model in children with cystic fibrosis. *Health Education & Behavior*, 45(3), pp.435-43.
- Donnelly, M.J., Dolan, L.A., Grande, L. & Weinstein, S.L. (2004) Patient and parent perspectives on treatment for adolescent idiopathic scoliosis. *The Iowa Orthopaedic Journal*, 24, pp.76-83.
- Eberle, T.S. (2014) Phenomenology as a research method. In: Flick, U. (ed.) *The SAGE Handbook of Qualitative Data Analysis*. SAGE Publications Ltd, London.
- Green, J. & Thorogood, N. (2009) *Qualitative Methods for Health Research*. SAGE Publications Ltd, London.
- Heary, C. & Hennessy, E. (2006) Focus groups versus individual interviews with children: a comparison of data. *The Irish Journal of Psychology*, 27(1-2), pp.58-68.
- James, J.I. (1975) The management of infants with scoliosis. *The Journal of Bone and Joint Surgery*. British volume, 57(4), pp.422-9.
- 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), pp.876-86.
- MacLean, W.E., Jr., Green, N.E., Pierre, C.B. & Ray, D.C. (1989) Stress and coping with scoliosis: psychological effects on adolescents and their families. *Journal of Pediatric Orthopaedics*, 9(3), pp.257-61.
- Negrini, S., Aulisa, A.G., Aulisa, L., Circo, A.B., De Mauroy, J.C., Durmala, J. et al. (2012) 2011 SOSORT guidelines: orthopaedic and rehabilitation treatment of idiopathic scoliosis during growth. *Scoliosis*, 7(1), pp.3.

Negrini, S., Donzelli, S., Aulisa, A.G., Czaprowski, D., Schreiber, S., de Mauroy, J.C. et al. (2018) 2016 SOSORT guidelines: orthopaedic and rehabilitation treatment of idiopathic scoliosis during growth. *Scoliosis*, 13(1), pp.3.

Negrini, S., Minozzi, S., Bettany-Saltikov, J., Chockalingam, N., Grivas, T.B., Kotwicki, T. et al. (2015) Braces for idiopathic scoliosis in adolescents. *Cochrane Database of Systematic Reviews*, (6), pp.CD006850.

Oris, L., Seiffge-Krenke, I., Moons, P., Goubert, L., Rassart, J., Goossens, E. et al. (2016) Parental and peer support in adolescents with a chronic condition: a typological approach and developmental implications. *Journal of Behavioral Medicine*, 39, pp.107-19.

Padilla-Walker, L.M., Day, R.D., Dyer, W.J. & Black, B.C. (2012) "Keep on keeping on, even when it's hard!": predictors and outcomes of adolescent persistence. *The Journal of Early Adolescence*, 33(4), pp.433-57.

Roulston, K. (2014) Analysing interviews. In: Flick, U. (ed.) *The SAGE Handbook of Qualitative Data Analysis*. SAGE Publications Ltd, London.

Saldaña, J. (2011) *Fundamentals of Qualitative Research*. Oxford University Press, Inc., New York.

Sanders, J.O., Newton, P.O., Browne, R.H., Katz, D.E., Birch, J.G. & Herring, J.A. (2014) Bracing for idiopathic scoliosis: how many patients require treatment to prevent one surgery? *The Journal of Bone and Joint Surgery*, 96(8), pp.649- 53.

Scoliosis Research Society. n.d. Adolescent idiopathic scoliosis [Online]. Scoliosis Research Society. Available: <https://www.srs.org/professionals/online-education-and-resources/conditions-and-treatments/adolescent-idiopathic-scoliosis> [Accessed 21 March 2021].

Somerville, L.H. (2013) The teenage brain: sensitivity to social evaluation. *Current Directions in Psychological Science*, 22(2), pp.121-7.

Taddeo, D., Egedy, M. & Frappier, J.-Y. (2008) Adherence to treatment in adolescents. *Paediatrics & Child Health*, 13(1), pp.19-24.

Willig, C. (2014) Interpretation and analysis. In: Flick, U. (ed.) *The SAGE Handbook of Qualitative Data Analysis*. SAGE Publications Ltd, London.

Zaina, F., De Mauroy, J.C., Grivas, T., Hresko, M.T., Kotwizki, T., Maruyama, T. et al. (2014) Bracing for scoliosis in 2014: state of the art. *European Journal of Physical and Rehabilitation Medicine*, 50(1), pp.93-110.