

Parents' information needs, treatment concerns, and psychological well-being when their child is diagnosed with adolescent idiopathic scoliosis: A systematic review

Gillian Motyer^{a,*}, Barbara Dooley^a, Patrick Kiely^b, Amanda Fitzgerald^a

^a School of Psychology, University College Dublin, Belfield, Dublin, D04V1W8, Ireland

^b Department of Orthopaedics, Children's Health Ireland at Crumlin, Crumlin, Dublin, D12N512, Ireland

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ABSTRACT

Objective: We systematically reviewed the experiences of parents who have a child with adolescent idiopathic scoliosis in order to understand their needs and concerns related to their child's healthcare, and assist health professionals in supporting parents of this paediatric patient group.

Methods: A systematic search strategy identified eighteen relevant studies published between 2000 and 2020. Quality was assessed using the Mixed Methods Appraisal Tool and the literature was narratively synthesised.

Results: Three main themes were evident across the literature including information needs, treatment concerns, and psychological well-being. Studies predominantly focused on the surgical treatment of scoliosis.

Conclusion: Parents face challenges such as acquiring appropriate knowledge about scoliosis to participate in healthcare decisions and coping with their child undergoing invasive spinal surgery. Throughout this time, their psychological well-being can be negatively impacted. Considering parents' experiences and support needs throughout this anxiety-provoking time is an important step in delivering family-centered care and promoting better outcomes for paediatric patients.

Practice Implications: Providing parents with appropriate resources and addressing concerns around surgical complications, postoperative pain, and how they can best support their child before and after surgery, may alleviate some of the emotional burden that parents experience.

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* Corresponding author.

E-mail address: gillian.motyer@ucdconnect.ie (G. Motyer).

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1. Introduction

Adolescent idiopathic scoliosis (AIS) is a lateral curvature of the spine that develops with no known cause in approximately 1–3% of adolescents. The condition is more common in females, and is typically diagnosed around the onset of puberty when it can progress rapidly [1,2]. In addition to the physical implications of AIS such as postural changes, altered appearance and pain, research has shown that this patient group can experience other quality of life issues and psychosocial difficulties [3,4]. While minor to moderate scoliosis is kept under observation or treated conservatively with a brace, curvatures that progress to a Cobb angle exceeding 45–50° can require surgical intervention [5,6]. Scoliosis surgery is known as one of the most extensive elective procedures performed on adolescents, and can be a distressing experience for patients throughout the pre- and postoperative period [7].

Health professionals involved in the treatment of AIS will also be aware of the difficulties that parents face following a diagnosis of scoliosis in their child. Paediatric health conditions can introduce additional challenges to the parenting role, related to the emotional impact of the diagnosis, integrating the child's needs into family life, and parents' primary role in managing healthcare treatment [8–10]. Parents of children with AIS can face specific stressors including unpredictable progression of the spinal curve and the possibility of invasive spinal surgery. Parental reactions vary, and while parents of children with health complications often cope well, some research reports increased levels of stress, depression, and adverse health compared to parents of non-affected children [8,11,12]. It is also acknowledged that the way parents respond to their child's condition has potential to promote or confound the child's health outcomes [13], therefore, supporting them in their parenting role is a primary concern for their own well-being, and for their child's.

To support parents over the course of their child's scoliosis and provide family-centered care, an understanding of parents' key concerns, stressors, and associated needs is required. Understanding parents' experiences is recognised as an important topic in the field of paediatric healthcare [14] and as a result, literature reviews relevant to parents of children with various health complications are increasingly evident [9,15–17]. However, no literature review specific to parents of patients with AIS is available. The current study was therefore undertaken to provide the first systematic review focused on parents' experiences of their child's AIS, in order to collate the body of evidence, assist health professionals in supporting families, and guide future research on this topic.

2. Methods

This systematic review was conducted in line with the Preferred Reporting Items for Systematic Reviews and Meta-analyses guidelines [18], and included research studies that reported on parents' experiences of their child's AIS. We conducted a mixed studies systematic review, whereby all study designs were eligible for inclusion in order to accurately represent the scope of the research on this topic [19].

2.1. Search strategy

A systematic search, developed in consultation with a research librarian, was performed on the MEDLINE, CINAHL Plus, PsycINFO,

Scopus, and EMBASE databases. The search strategy combined key terms 'parent', 'scoliosis', 'child or adolescent', 'experience', and their variations (see Appendix A for the search strategy). Additionally, we manually searched the reference lists of included studies, ProQuest Digital Dissertations, OpenGrey.eu, Google, and Google Scholar for further eligible studies and grey literature. The search dates were from January 2000 to September 2020 in order to reflect current paediatric healthcare.

2.2. Screening

The search results were imported into Covidence Systematic Review software [20], where any duplicates were removed. A total of 302 unique records were identified through the database searches, and an additional 5 relevant records were identified by handsearching reference lists and by searching the other grey literature sources. Using the eligibility criteria detailed in Table 1, titles and abstracts of 307 studies were screened by two independent reviewers, and 49 were chosen for full-text examination. There was strong inter-rater reliability during screening ($\kappa = 0.93$). Following full-text examination, 31 studies were excluded. Main reasons for exclusion were; (1) children had conditions other than idiopathic scoliosis or, (2) study focus was not on parents' personal experiences or was predominantly focused on the child. A total of 18 studies were eligible for inclusion.

2.3. Quality appraisal

The Mixed Methods Appraisal Tool (MMAT) [21], developed to allow concurrent assessment of qualitative, quantitative, and mixed-method studies, was used to provide information on quality of study reporting and design. Included studies were assessed against two universal screening criteria, and five criteria specific to the research design. Appraisal criteria related to issues such as selection bias, measurement validity, and integrity of results. The MMAT is increasingly used in systematic reviews [17,22], demonstrates good interrater reliability [23], and content validity [24]. No studies were excluded on the basis of this assessment.

2.4. Data synthesis

For all included studies, details of the research objectives, study context, sample, research design, methodologies, and main findings were extracted from the original papers and tabulated. As we included both quantitative and qualitative research designs and explored a broad range of parental experiences in the current review, narrative synthesis was chosen as an appropriate method of synthesising study findings. Guidance on conducting a narrative synthesis in systematic reviews developed by Popay et al., [25], informed the process of identifying patterns across the literature, clustering studies into overarching themes, and producing a synthesis that 'tells the story' of the included studies.

3. Results

A total of 18 studies were included. A PRISMA flow chart [18] illustrating the review process is shown in Fig. 1.

Table 1
 Inclusion and exclusion criteria for study selection.

Characteristic	Inclusion criteria	Exclusion criteria
Study Design	Primary studies (Quantitative, qualitative or mixed-method designs)	Not applicable
Population	Parents who have a child with adolescent idiopathic scoliosis	Parents of children with scoliosis of a non-idiopathic cause or other significant co-morbid medical conditions
Outcome	Studies investigating an aspect of parents' personal experiences over the course of their child's scoliosis	Family history or genetics studies

3.1. Study characteristics

An overview of the included studies is presented in Table 2. Studies were categorised as qualitative (n = 2), mixed-methods (n = 1), and quantitative (n = 15). A variety of quantitative research designs were represented, including non-randomized controlled studies, cross-sectional surveys, and case series. The majority of studies recruited parents from clinical settings, while three collected data via support groups [26–28]. Within the twelve studies reporting parent gender, mothers made up an average of 85 % of the samples. Studies spanned various stages of scoliosis treatment, but there was a predominant focus on parents whose children were undergoing surgical intervention. The mean age of children reported in studies ranged from 11.9 to 17.3 years. Two studies included a small number of early onset scoliosis cases in their analyses [26,29], however these studies were included as the majority of the samples were AIS.

3.2. Study quality

All studies met the MMAT screening criteria. Within their respective study design categories, two thirds of the included studies (n = 12) did not meet, or reported unclear information in relation to at least one criterion. The two qualitative and one mixed-methods studies demonstrated no major methodological or reporting bias concerns, whereas a number of issues arose within the quantitative studies. Six studies did not report basic demographics including the gender of their parent samples, making it difficult to generalise findings to mothers and fathers. Another issue was risk of non-response bias in five studies, whereby missing or incomplete data was problematic or not explained, while one of the two non-randomized controlled studies reported they did not account for potential confounding factors in their design. The MMAT assessment summary is presented in Appendix A.

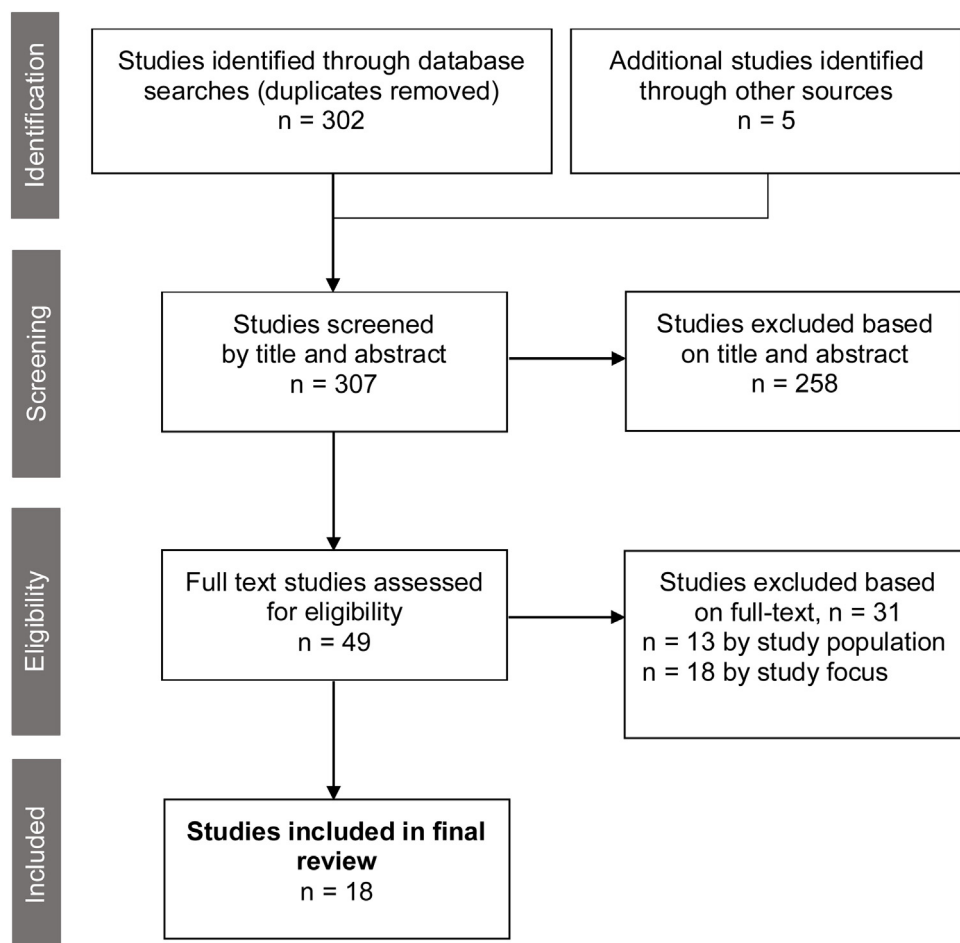


Fig. 1. PRISMA flow chart illustrating study selection.

Table 2
Summary of included studies.

Citation	Parents Age (M) Gender	Children Age (M) Gender	Treatment Status	Study Design	Measures used	Findings
Information Needs						
Khetani 2008 Canada	n = 30 – –	n=34 11–18 (14.7) 94 % F	Braced & Post-op	Survey	Scoliosis Knowledge Questionnaire	Parents scored higher than children on the scoliosis knowledge survey. >70 % of parents incorrectly answered questions on curve progression, radiation exposure, non-union, and long-term postsurgical concerns.
Baker 2012 Ireland	n = 168 – 81 % F	– 1–19 (11.9) –	All outpatients	Survey	Internet Usage Questionnaire	58 % of parents reported using the internet for scoliosis information. 77 % of responses indicated that the internet was helpful. 29 % of responses showed that the internet created more anxiety for parents, while 30 % encountered confusing websites.
Lysenko 2016 Canada	n = 71 (45.9) –	n = 74 10–18 (14.3) 90.5 % F	Pre-op	Case series	Scoliosis Knowledge Questionnaire; MIQ; CHIP	91.2 % parents previously searched online for scoliosis information, with 63.9 % rating it as somewhat helpful and 18.1 % as very helpful. Scoliosis knowledge improved after exposure to website intervention ($p < .05$), while parents also demonstrated a small increase in negative attitude toward illness and a small decrease in positive attitude towards illness ($p < .05$).
Schwieger 2016 USA	n = 300 – 92 % F	– – –	All stages	Content analysis	Purpose-made coding frame	Parents with newly diagnosed children were most likely to seek information. Parents most often exchanged information about the causes and progression of scoliosis (48 % of online posts), brace types (25 %), brace effectiveness (21 %), and doctors/hospitals (21 %).
Treatment Concerns						
Bridwell 2000 USA	n = 93 – 82 % F	N=91 9–18 82 % F	Pre-op	Survey	Concerns and Preferences Questionnaire	Neurologic deficit, pseudarthrosis, and wound infection were ranked as greatest surgical concerns. Main reasons/expectations for surgery were to prevent scoliosis progression and future pain, and cosmetic correction. Patients ranked postsurgical lifestyle adjustment as more concerning and return to function as more important than parents ($p < .05$).
Donnelly 2004 USA	n = 10 – 80 % F	n = 12 13–18 100 % F	Braced & Post-op	Qualitative	Semi-structured Interview	<i>Decision making:</i> Parents felt they had a responsibility to proceed with bracing as a less invasive treatment over surgery. <i>Effect on life & compliance with brace wear:</i> Parents reported that brace fitting was traumatic, fights with child over brace wear, difficulty finding clothing, and a difficult recovery from surgery.
Salisbury ^a 2007 USA	n = 92 – 100 % F	– (13.6) 80.4 % F	Pre – to post-op	Mixed methods	Semi-structured interview; WCQ	Presurgical stressors (in order): <i>parental role loss, possibility of poor surgical outcomes, uncertainty about recovery, pain, and accepting reality.</i> Postsurgical stressors (in order): <i>pain, parental role loss, uncertainty about recovery, concerns about care, and complications</i> Most frequent pre- and postsurgical coping strategies were social support, positive reappraisal, and playful problem solving.
Narayanan 2008 Canada	n = 55 – –	n = 55 12–18 (14.3) 87 % F	Post-op	Survey	Concerns/ Expectations Questionnaire	Parents had higher levels of overall concern about surgery than children ($p = .001$). 91 % parents were ‘very’ or ‘extremely’ concerned about child’s appearance pre-op. Highest surgical concerns were pain (M = 4.45/5), stiffness (M = 3.98), & paralysis (M = 3.91). Strongest desires were to prevent deformity progression (M = 4.6/5), prevent future health problems (M = 4.38), & reduce pain (M = 4.25).
Bull & Grogan ^b 2010 UK	n = 13 (46) 91.6 % F	– 3.5–18 (12.9) ^c 92 % F	Post-op	Qualitative	Semi-structured Interview	Themes: 1. <i>Information</i> (parents lacked knowledge, often used the internet); 2. <i>Parenting role</i> (fear/anxiety related to diagnosis and treatment threatened protector role); 3. <i>Confidence in professionals</i> (importance of relationship with consultant & nursing team); 4. <i>Pain</i> (pain management was major source of stress); 5. <i>Effect on life</i> (living in a state of uncertainty & emotional upheaval).
Chan 2017 USA	n = 48 – –	n = 48 10–19 (14.2) 90 % F	Pre-op	Survey	Concerns questionnaire	Parents had higher presurgical concern (M = 6.9/10) than children (M = 4.6). Age of child was correlated with parents level of concern ($r = -.37, p = .009$). Parents listed top three surgical concerns as pain, neurologic injury, and amount of correction. Patients listed pain, ability to return to activities, and neurologic injury.
Lonner 2020 USA	n = 44 – –	n = 44 10–18 (14.3) 84 % F	Pre-op	Survey	PGI	Parents’ primary operative aspirations were to improve sleep, self-esteem, and pain, while patients most wanted to improve pain, self-esteem, and sports. Parents reported they would be most regretful about surgery if sleep (M = 8.6/10), future health (M = 7.3), and appearance (M = 6.75) were not improved.

Table 2 (Continued)

Citation	Parents Age (M) Gender	Children Age (M) Gender	Treatment Status	Study Design	Measures used	Findings
Psychological Well-being						
LaMontagne 2001 USA	n = 74 – –	n = 74 11–18 74 % F	Pre- to post-op	Case series	STAI; VAS-P	Parents' anxiety decreased from the presurgical clinic visit to the second postsurgical day ($p < .01$). Parents' and children's anxiety positively correlated at presurgical ($r = .28, p = .01$) and postsurgical ($r = .32, p > .01$) timepoints, but parents' anxiety was not related to children's pain.
LaMontagne 2003 USA	n = 60 – 100 % F	– (14) 85 % F	Pre- to post-op	Case series	LOT; STAI; WCQ	Parental anxiety decreased from pre- to post-op ($p < .01$), but was still moderately high. Seeking social support was the most common coping strategy used at pre- and postsurgical timepoints, followed by positive reappraisal, and playful problem solving.
Kasai 2006 Japan	n = 30 (40.4) 100 % F	n = 30 10–26(15.1) 80 % F	Pre- to post-op	Case series	MPI	Parents reported reduced neurotic tendencies from the presurgical period to one year after surgery ($p < .001$). No significant correlations were identified between parents and patients psychological states (extroversion, neuroticism).
Flynn 2007 UK	n = 41 (47.2) 90 % F	– (17.3) 75 % F	All stages	Survey	FDC	Parents most frequently mentioned predominant life stressor was the health of their child with scoliosis (constituting 34 % of all 103 life stressors listed). Three most frequently reported coping styles for parents were emotional social support, instrumental social support, and optimism.
Hines 2015 USA	n = 54 –	n = 54 9–17(14.1)	Referred to clinic	Non-randomized cross-sequential	STAI	Parents and children referred from school scoliosis screening experienced elevated levels of anxiety pre-appointment compared to controls ($p = .02; p = .04$). Those diagnosed with scoliosis continued to report elevated anxiety levels post-appointment while anxiety declined for those not diagnosed.
Kwan 2016 Malaysia	78 % F n = 96 – 51 % F	74 % F – –	Pre- to post-op	Non-randomized cohort	VAS-A; HADS	Over 70 % of parents rated the SSS evaluation as helpful. Intraoperative text messages (SMS) were effective in reducing parental anxiety during children's spinal fusion surgery. Compared to controls, parents receiving SMS had significantly lower anxiety during surgery ($p < .05$) and one day post-surgery ($p < .05$).
Wang 2019 China	n = 64 (42.4) 73 % F	n = 64 11–18(14.3) 92 % F	Braced & pre-op	Survey	PHQ-9; GAD-7	Parents of children with AIS were more likely to report moderate to severe levels of depressive symptoms and generalized anxiety compared to a controls (14.1 % vs. 4.7 %, $p = 0.045$, & 14.1% vs. 3.5%, $p = 0.019$, respectively). Parent and child depression & anxiety scores were correlated ($r = .45–.5, p < .01$). Scoliosis Cobb angle $\geq 50^\circ$, child depression, and low parental education level were independent risk factors for parental depressive symptoms.

Studies are placed under the theme they aligned with most and ordered by date of publication. ^a Contributed to treatment concerns and psychological well-being. ^b Contributed to treatment concerns and information needs. ^c 2 of 13 cases were early onset scoliosis. Abbreviations: MIQ: Meaning of Illness Questionnaire; CHIP: Coping Health Inventory for Parents; WCQ: Ways of Coping Questionnaire; PGI: Patient Generated Index; STAI: State-Trait Anxiety Inventory; VAS-P/A: Visual Analogue Scale for Pain/Anxiety; LOT: Life Orientation Test; MPI: Maudsley Personality Inventory; FDC: Functional Dimensions of Coping; HADS: Hospital Anxiety and Depression Score. PHQ-9: Patient Health Questionnaire; GAD-7: Generalized Anxiety Disorder Scale.

3.3. Narrative synthesis

The included studies were heterogenous with respect to design, research questions, and children's stage in treatment. Despite the variability observed, we identified three main themes that were evident across the literature: 'Information needs' (n = 4), 'Treatment concerns' (n = 7), and 'Psychological well-being' (n = 7).

3.3.1. Information needs

A number of studies investigated parents' scoliosis knowledge and associated behaviours as they sought to gather information about their child's condition, which is evidently a significant aspect of their experience. Khetani et al., [30] developed a reliable and valid 'Scoliosis Knowledge Questionnaire' to investigate parents' treatment knowledge, and found that more than 70 % of 30 parents lacked information about topics such as curve progression and postsurgical issues. To access more information about scoliosis, many parents turn to the internet, as identified in an outpatient department survey by Baker et al. [29], and a presurgical case series by Lysenko et al. [31], where 58 % and 91.2 % of parents respectively, reported searching online for this purpose. While the

majority of these parents found the internet at least somewhat helpful, almost a third of parents in one study indicated that sites were confusing and caused them greater feelings of anxiety [29].

Qualitative accounts support the findings of these quantitative studies, as parents reported that they lacked knowledge about scoliosis and searched online as their main source of information [26]. However, learning about the implications of scoliosis online seemed to cause further anxiety and distress, suggesting that caution is required if recommending e-health resources for parents. Lysenko et al. [31], investigated the effectiveness of their purpose-built scoliosis website, which was informed by evidence and needs assessments [32,33]. Parents' knowledge scores on the 'Scoliosis Knowledge Questionnaire' significantly improved after using the website, while they also reported a minor increase in negative attitudes towards their child's condition. The evidence-based, user driven website was an advantage in this study, however, risk of non-response bias and the lack of a control group for comparison limited the results.

As well as searching for informative websites, some parents seek information through online support networks. Information sought and shared in an online support forum was examined by

Schwieger et al., [28], who found that the most frequent topic discussed by parents was the causes and progression of scoliosis. Bracing and its effectiveness were also frequently discussed, and parents were found to exchange significantly more information regarding doctors and hospitals compared to adolescents who participated in the forum [28].

3.3.2. Treatment concerns

Seven studies explored parents' concerns about medical treatment for scoliosis, highlighting the considerable fears, stressors, and emotional consequences they experience. Of these, one study by Donnelly et al., [34] interviewed parents whose daughters were undergoing brace treatment. Parents felt a responsibility to choose bracing as a less invasive treatment than surgery, despite difficulties with brace wear compliance and conflicting evidence regarding its effectiveness. They reported issues including the traumatic nature of brace fitting, conflict with their child over compliance, and difficulty finding clothing.

The remaining six studies focused on parents whose children were undergoing spinal surgery. Bridwell et al., [35] and Narayanan [36] had parents score predetermined concerns and expectations, while Chan et al., [37] and Lonner et al. [38], asked parents to indicate their greatest concerns or operative aspirations with an open-ended question. Both Salisbury et al., [39] and Bull & Grogan, [26], interviewed parents about key stressors.

Despite differing methods of data collection, there were similarities across study findings. Overall, parents were found to be more concerned about the surgery than their children [36,37]. Specific surgical concerns that were common across studies were the possibility of complications, particularly neurologic injury, and the amount of pain their child would experience [26,35–37,39]. Another primary stressor described by parents was the pressure of their parenting role, including the responsibility of supporting their child before surgery [39], and their inability to protect their child in such an uncertain situation [26]. Parents were also concerned about the amount of correction that surgery could achieve and possible failure of the spinal fusion [35–37]. Focusing on what they hoped would be achieved by surgery, parents' top aspirations and expectations centred around preventing progression of the spinal curve and associated future health problems, improving pain and sleep, as well as improving appearance and self-esteem [35,36,38].

Postoperatively, concerns about fulfilling the parenting role continued, as parents experienced fear and uncertainty about whether their child was recovering as expected [26,39]. Some parents felt unprepared for the amount of pain their child experienced following surgery, and identified this as a main stressor [26,39], while parents' whose children had complications self-identified this as their main cause of stress [39]. Some parents were concerned about the level of care their child received postoperatively [39], and it was suggested that parents' trust in the medical and nursing staff was key to them feeling supported [26]. They recalled living in a state of uncertainty and intense emotional upheaval when waiting for a surgery date [26], and during their child's recovery [39].

3.3.3. Psychological well-being

As well as concerns directly related to medical treatment, other stressors reported by parents included the shock of diagnosis, explaining scoliosis or bracing to their child, treatment delays, lack of clarity about treatment options, worry about curve progression, and concerns about their child's quality of life [27]. Such stressors may have an impact on parental well-being, as a recent study by Wang et al. [40], found that parents of children who were undergoing treatment for AIS had higher levels of mental health difficulties in comparison to a control sample. Parents in the

scoliosis group were three times more likely to report moderate to severe depressive symptoms, and about four times more likely to experience moderate to severe generalized anxiety. Maternal depression scores were also found to be significantly higher than fathers [40].

Three studies measured parental anxiety at specific times throughout their child's scoliosis treatment [41–43]. Firstly, a controlled study by Hines et al. [41], found parents whose children were referred to the orthopaedic clinic from a school scoliosis screening experienced increased state anxiety prior to their appointment and after confirmation of the diagnosis. For parents whose children were undergoing surgery, two case series by LaMontagne et al. [42,43], found that parents reported high levels of state anxiety at the preoperative clinic visit before their child's surgery, and while anxiety decreased two days following surgery, it was still classified as moderately high [43]. Two studies also reported that parental anxiety and depression were weakly and moderately correlated with their children's anxiety and depressive symptoms [40,42]. One further case series [44] measured personality characteristics in mothers from the pre- to postoperative period, with findings suggesting that mothers felt a strong sense of anxiety pre-surgery and a sense of relief afterwards.

An intervention study by Kwan et al., [45] sought to alleviate parental anxiety during surgery, as the intraoperative waiting period is known to be a particularly anxious time for family members due to uncertainty surrounding surgical outcomes. Parents who received intraoperative text messages with surgical progress updates experienced significantly lower levels of anxiety during, and on the day following surgery, compared to a control group of parents who received no messages. While the authors recognise some constraints, (e.g. limited information is conveyed via text compared to face-to-face interaction), this represents a promising strategy for keeping parents informed and improving their surgical experience.

Three of the included studies explored parents' coping strategies for dealing with the stress of their child's scoliosis [27] and at the time of their child's surgery [39,43]. In all studies, seeking social emotional support (e.g. from friends, family) was the coping strategy used most often by parents. After this, positively reappraising the situation or optimism, playful problem solving, and seeking expert advice (e.g. from doctors) were among parents' three most common strategies reported across studies [27,39,43]. At the time of surgery, it was also found that seeking social support decreased postoperatively, while positively reappraising the situation increased [39,43].

4. Discussion and conclusion

4.1. Discussion

This systematic review included eighteen studies that investigated parents' experiences when their child is diagnosed with AIS. The identified literature was synthesised into three meaningful themes which reflect the experiences of this parent group, including parents' information needs, their concerns about their child's treatment, and the impact on parents' psychological well-being. Despite the relatively limited amount of studies contributing to each theme, the current review provides insight into these facets of parental experience. Within paediatric healthcare, parents of children with AIS face specific challenges including the uncertainty of scoliosis progression, the diversity and varied evidence surrounding treatment approaches, and the severity of elective spinal fusion surgery for scoliosis. Furthermore, considering the burden of lengthy wait times for orthopaedic consultations and procedures which are evident in many healthcare systems [46], parents managing their child's AIS may be under particular

strain. This review synthesises the available evidence to assist healthcare professionals involved in the care of families affected by AIS, and provides a basis for future research to build upon.

Parents report having little or no knowledge about scoliosis before their child was diagnosed [26]. In particular, research suggests that some parents may lack certain knowledge about surgery for scoliosis [30], which is important to address given the significant role they play in their child's surgical decision making. To assist with identification of topics where further information is required, tools such as the Scoliosis Knowledge Questionnaire [30,31], could be used collaboratively with parents in practice if their child reaches the stage of surgical consideration. This questionnaire could also benefit from being cross-culturally validated and updated as advancements in scoliosis treatments occur [47].

Accessing scoliosis information online appears to be a convenient strategy for meeting parents' information needs outside of the clinical setting. However, variation in the quality or presentation of information online may contribute to feelings of confusion and distress in parents [26,29]. A previous review of scoliosis-specific websites indicated that overall, information quality was poor, with academic and physician-provided sites shown to contain better quality information in comparison to social media sites [48]. This highlights that where possible, healthcare professionals should direct parents and their children to appropriate, evidence-based resources. There are a number of reputable resources available, such as those associated with hospitals and spinal organisations [e.g. 49–51]. Given parents increasing use of e-health resources [52], further research evaluating effective online scoliosis information provision for parents is timely. Some level of distress may be unavoidable when viewing information resources [26], as topics such as potential complications are likely to cause concern to parents. However, equipped with the appropriate knowledge, parents would be in a better position to offer support to their child before surgery [39], which could contribute to less anxiety and stress, and a better operative experience for families [26,31].

Studies exploring parents' treatment concerns related to their child's AIS have primarily focused on surgery. Understandably, parents indicate many concerns about the surgical treatment of scoliosis, such as the possibility of surgical complications, their child's level of pain, and fulfilling their parenting role both pre- and postoperatively [26,35–37,39]. Preoperative counselling and preparation addressing these main areas of concern may help to improve the surgical experience for parents and their children [37]. In addition to addressing concerns, it may be beneficial to consider parent and patient priorities for surgical outcomes (e.g. cosmetic correction), as these may have implications for postoperative satisfaction. We identified only one study that considered parents' experiences of their child's brace treatment [34]. Parents reported considerably different issues compared to those expressed in relation to surgery, such as conflict with their child over brace wear compliance. Previous research has investigated factors related to non-compliance with brace wear, such as increasing age of the patient, setting (e.g. in school, during summer), and appearance concerns [53–55]. Future research could explore the role of healthcare providers in supporting parents throughout the management of their child's bracing treatment.

Studies highlight heightened anxiety levels in parents at the time of their child's scoliosis diagnosis [41], and throughout surgical treatment [42,43,45], which could potentially be reduced using novel interventions [45]. Furthermore, parents of children receiving treatment for AIS were shown to have significantly higher levels of anxiety and depressive symptoms in comparison to parents of non-affected children, with mothers and parents of children with curves exceeding 50° more vulnerable to depressive

symptoms [40]. Importantly, it is often recognised in practice that parents' reactions to their child's scoliosis and medical treatment may influence how their child copes with the condition and in line with this, two studies in the current review reported correlations between parent and child anxiety [40,42], and depressive symptoms [40]. In the clinical setting, it is important to gain insight into parental mental health, in order to identify families that may benefit from increased support or intervention. Future research could also seek to evaluate aspects of resilience which may serve as protective factors for parental well-being [56], as well psychosocial support needs relevant to this parent group.

Positive reappraisal of the situation was a commonly used coping strategy among parents, particularly during their child's surgical recovery [27,39,43], suggesting their attempts to remain optimistic at this difficult time. However, the most frequently reported coping strategy, seeking emotional support, highlights the importance of parents' social networks as they manage the impact of their child's AIS on their lives. Decreases in this strategy postoperatively may reflect parents presence in hospital with their child, and consequently, removal from normal support systems [39,43]. Healthcare staff therefore play an important role in supporting parents during this postoperative period [26].

Reviews of parental experiences in the context of paediatric health complications are increasingly evident [e.g. 57], highlighting the importance of family-centered healthcare. Notably, the holistic approach of the current review was advantageous. As well as synthesising research related to parents' practical and information needs, their main concerns and psychological well-being were key considerations. Parents' mental health and well-being over the course of their child's treatment for AIS is evidently an important topic to consider within healthcare provider-parent communication. Other strengths of this review included the rigorous search strategy and strong inter-rater reliability at screening which reduced risk of reporting bias [58], while inclusion of all study designs resulted in comprehensive coverage of the research topic [19]. It is notable that qualitative methodologies, such as interviews, are increasingly valued in the medical literature to understand personal experiences [59]. The qualitative and mixed-methods evidence provided by three studies in this review supplemented the quantitative findings by providing rich detail on parents' treatment concerns [26,34,39].

We also conducted a quality appraisal of included studies using the MMAT [21]. An important issue identified by this assessment was inconsistent reporting of demographic information for parent samples. Of the studies that did include information on parent gender, the majority were mothers, which is in line with reports that fathers are typically underrepresented in research concerning paediatric health conditions [60,61]. As a result, the review primarily reflects mothers' experiences and highlights the need to encourage future participation of fathers.

4.2. Conclusion

This systematic literature review provides insight into the information needs, treatment concerns, and psychological well-being of parents who are accessing medical care for their child's AIS. Parents face challenges such as accepting the diagnosis of scoliosis, acquiring appropriate knowledge to participate in healthcare decisions, and coping with potentially invasive medical treatments for their child. Navigating their children's spinal surgery is a stressful and anxiety provoking experience pre- and postoperatively for parents, who may need additional support at this time to assist them in their parenting role.

While the research to date provides insight to the experience of parenting a child with AIS, we acknowledge that the literature predominantly focuses on the operative treatment of scoliosis and

parents' needs, concerns, and anxieties throughout this time. Further research is required to extend current knowledge by exploring the experience of both mothers' and fathers' throughout all stages of scoliosis progression and treatment, including the broader psychological and social implications, as well as their perspectives on improving the delivery of family-centered care. To build on the knowledge presented in this systematic review, we are conducting a subsequent qualitative interview study to further explore aspects of parents' psychosocial well-being and support needs throughout the treatment of their child's AIS.

4.3. Practice implications

In collaboration with healthcare providers, parents play an important role in managing the treatment of their child's AIS and supporting their child throughout this potentially difficult time. The findings of this review demonstrate how strategies such as directing parents to appropriate resources about scoliosis, keeping parents updated regarding their child's treatment, and preoperative counselling and education may improve parents' experiences. This review also emphasizes the importance of prioritising a child and family-centered approach in healthcare provision [62]. While caring for a child with AIS, healthcare professionals can be encouraged to communicate and collaborate with parents and to consider how they can be best supported in their parenting role throughout their child's treatment.

Declaration of Competing Interest

The authors report no declarations of interest.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.pec.2020.11.023>.

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