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# Adolescent idiopathic scoliosis: interdisciplinary creative art practice and nature connections

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## ABSTRACT

Scoliosis is an abnormal lateral curvature of the spine with the large majority of cases classed as idiopathic, meaning there is no known cause. Typically, most cases occur in children and young people affecting approximately three per cent of the adult populace with five out of six cases being female. The *BackBone: Interdisciplinary Creative Practices and Body Positive Resilience* pilot research study used arts and humanities methods to measure the impact of adolescent idiopathic scoliosis (AIS) on well-being and body perception. The research aimed to contribute to a better understanding of alternative treatments towards improving quality of life in young women diagnosed with AIS. In particular, concentrating on two highlighted priorities from the Scoliosis Priority Setting Partnership: (1) How is quality of life affected by scoliosis and its treatment? How can we measure this in ways that are meaningful to patients? (2) How are the psychological impacts (including on body image) of diagnosis and treatment best managed. Using established medical techniques, art-based workshops, and focus groups with postoperative participants with AIS and their families we gathered both quantitative and qualitative data. The workshops explored the aesthetics of imperfection through material investigations that focus on the body as both an object and how it is experienced using the metaphor of tree images. Drawing parallels between the growth patterns of trees that, for complex and often unknown reasons, have grown unexpectedly we explored questions around ideological notions of perfect growth through art-making in a non-clinical setting. Uniquely, the pilot project sought to draw on insights from four key disciplines (art, medicine, psychology and human geography), thinking across boundaries to evoke different ways of knowing and understanding the complexities of body perception through image-making.

## BACKGROUND

Despite it not being rare, people either have little knowledge of scoliosis and/or it is poorly understood. An abnormal lateral and twisting curvature of the spine, scoliosis affects circa three per cent of the population and can occur in infancy, early childhood or later in life. However, it is most frequently diagnosed in early adolescence with onset commonly occurring between 10 years and 12 years of age. When other causes are rejected, idiopathic scoliosis is the diagnosis attributed to around 80% of all cases. In general, five out of six cases are female with the American Association of Neurological Surgeons reporting that women

are eight times more likely to progress to a curve magnitude that requires treatment (American Association of Neurological Surgeons n.d). The degree of curvature, measured using the Cobb<sup>1</sup> method (Hornig *et al.* 2019), dictates the treatment plan; a scoliosis curve of 10°–15° would generally trigger monitoring.

Scoliosis can be slow, it can take many years for it to reveal the full impact that it may have on the life of an individual and those they share their lives with. Conversely, the degree of change can be rapid with surgery proposed before the individual has had a chance to fully register and understand their diagnosis. In essence, clinicians, individuals and families wait to see what will happen as the magnitude of the developing curve is disclosed over an unpredictable period of time. A treatment plan is determined by ongoing clinical and radiological mapping in the form of standing spinal X-rays, the frequency of which is dictated by the speed at which the curve appears to be progressing. This takes place until puberty is complete and the individual has stopped growing as commonly the curve does not deteriorate beyond puberty (Core concepts n.d). A curve measurement of 25°–30° is widely accepted as significant with curves in excess of 40° considered to be severe, prompting clinical discussions regarding the need for surgical intervention. Despite reports that differing interpretations of the radiological information can lead to contrary Cobb angles, the system remains the most widely used method to calculate the amount of spinal deformity. Our study concentrated on two highlighted priorities from the Scoliosis Priority Setting Partnership: (1) How is quality of life affected by scoliosis and its treatment? How can we measure this in ways that are meaningful to patients? (2) How are the psychological impacts (including on body image) of diagnosis and treatment best managed?

## LOCATING THE RESEARCH

Bertuccelli, Cantele, and Masiero 2023, 97 state that ‘facets of idiopathic scoliosis have been largely neglected compared to their clinical and genetics determinants’. Anxiety and emotional load are described as the most common social situation issues reported by people with disfiguring conditions and body disfigurement, as seen in adolescent idiopathic scoliosis (AIS) (Misterska, Glowacki, and Latuszewska 2012). Furthermore, it is recognised that AIS is also proven to have a consistent negative effect on the development of a person’s body image (ibid). Bago *et al.* (2010), creators of the Trunk

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Appearance Perception Scale (TAPS)<sup>2</sup> measurement tool used in Scoliosis research, suggest that an ideal methodological position would be achieved if a high correlation existed between the clinical and radiological measures of deformity and the patient's perception of deformity. Yet, it is common to encounter discrepancies between the radiological deformity and the aesthetic deformity 'igniting' a debate as to which aspect 'should be the primordial target of treatment' (ibid, 8). We argue, as do Bago *et al* (ibid), that 'it is crucial to know the patient's perspective in this debate' and hence it was a critical aspect of the *BackBone* research study. A key motivation of the project's conception and design was to use a range of methodological approaches, importantly applied outside of a clinical setting, to stimulate dialogue and generate imagery exploring the gap between the patients' own appraisal of aesthetic deformity and the results of both clinical and radiological evaluation.

Although primarily anchored through art practice methods, interdisciplinarity acted as a theoretical framework for the conception, delivery and review of this unique project. Regardless of the rise of interdisciplinary research methods that seek out diversity and positive collision, Reiff-Pasarew (2022) note that the common conception that the Medical Humanities are 'soft' in contrast to 'hard' biological science obscures the fact that caring for patients from a human-centred standpoint is inexorably more problematic than the scientific question of what to treat and how. In times when both patient (NHS Digital 2022) and clinician (Campbell 2023) mental health increasingly feature in global news reporting, it is not surprising that alternative mixed approaches crafted to foster meaning and thoughtful connection between those who experience illness and/or disease and those responsible for improving their quality of life have gained increasing recognition. Reporting by the Health Evidence Network, WHO and the All-Party Parliamentary Group on Arts, Health and Wellbeing robustly endorses the need to look beyond established clinical practice for new ideas and the Arts has become a notable focus due to its demonstrable results (Creative Health, APPG Inquiry report 2017). In his introduction to the report the Rt. Hon Lord-Howarth of Newport states "It is time to recognise the powerful contribution the arts can make to health and wellbeing. There are now many examples and much evidence of the beneficial impact they can have" (ibid, 4). He goes on to outline three key messages: (1) The arts can help keep us well, aid our recovery and support longer lives better lived; (2) The arts can help meet major challenges facing health and social care: ageing, long-term conditions, loneliness and mental health; and, (3) The arts can help save money in the health service and social care.

As some UK medical teaching institutions are starting to employ a mixture of academics from across non-medical fields of expertise it is clear that times are changing. Yet, what might be considered discerning now will become steadfast and fixed if the transformational benefits and reach of multidisciplinary approaches happens outside of medical institutions. Thankfully, as Kinel *et al.* (2014, 9) point out, 'The level of stress and body self-image perception in girls suffering from [AIS] is the object of interest of the professionals'. Despite the account from Kinel *et al.*, the authors were unable to locate any art-based research projects involving art practice and scoliosis or significantly differing approaches to scoliosis research outside of formal clinical studies. Therefore, the decision to fund the study by the British Scoliosis Research Foundation demonstrates the broad-mindedness essential to bringing about change and new ways of considering treatment plans and the clinical journey for young people diagnosed with AIS.

Along with situating the *BackBone* study in the context of scoliosis, art and health, it is important to stress the philosophical positioning of the ideas that led to the initial conception of the project that drew on notions of human/non-human nature connections. The focus of scoliosis is on the growth pattern of the trunk and so too was the idea behind *BackBone*. Originating from the French word *tronc*, meaning the 'main stem of a tree' and 'torso of the body', both French and Old English references indicate the torso as 'mutilated, cut off'. Scoliosis clinical discussions similarly centre on the torso, the spinal deformity dominates the conversation, disconnecting the clinical encounter from the lived experience of the individual. In a surgical theatre, where the body is mostly covered, it is easy to see how the body and 'the person' to whom it belongs can become distant, no longer individually present but veiled and cut-off. Notions of the phenomenologically distanced individual in illness or disease is widely reviewed by multiple authors (Carel 2013); (Toombs 1993); (Zaner 1988) and therefore, parallels are easily drawn between the experienced *cut-off* and isolated trunk in scoliosis and in nature. After all, a tree trunk separated from its life-giving roots and life-sustaining leaves is a tree disconnected from life; are we not the same if not considered as whole, measured only as a cut-off torso detached from all that makes us who we are?

Essentially in *Aequanimitas*, Osler (Osler, William, Sir 1914) campaigns for the necessity of detachment during serious medical instances, of which we can ascribe spinal fusion surgery, whereby the risks involved demand a 'clearness and judgement' on the part of the surgeon. Despite resulting controversy, there remains a positive recognition for the principles Osler highlighted as desirable, 'imperturbability' and 'equanimity' (ibid, 1914). In the *Conversations about Arts, Humanities and Health* (Declercq and Sabroe 2021) podcast series Dr Alyssa Burgart described that in relation to the qualities Osler advocated, 'There's a place for it, but it's not supposed to be all the time', Burgart (2022 n. p). While recognising Osler's idea she, instead, promotes 'courage' and 'vulnerability' (ibid, 2022) as more desirable characteristics for medical training.

In spinal fusion surgery, an opening in the cover draped over the body marks the site of the skin incision, acting as a corporeal fissure, disclosing the spine to be straightened by adding surgical rods and screws which carries the risk of negative life-altering consequences. Therefore, the surgeon occupies a critical position in the dynamic surrounding both the individual and those with whom they share their life who together, ultimately decide whether to proceed to surgery or not. Although the participants in the *BackBone* study were at least 2 years postoperative it became clear that while their bodies were—in their words—physically 'healed', it had not helped to settle the emotional distress surrounding their treatment. Using notions of growth combined with focusing on the natural world of trees we sought to signpost the very conditions of our existence in the world, and as Ingold (2021, 41) describes, 'it stands to reason that our experience can only be enriched by paying attention to them'.

When asked to draw a tree in a few seconds, most of us will draw either a stick like form with some kind of rounded/cloud-like shape on top or a simple outline tree that is more visually aligned with a Christmas tree like a Norway Spruce with a shorter stick at the bottom. Importantly, it is likely that either option will be straight up and down. However, most growth is not straight and trees in the UK, as opposed to some other countries, generally present a meandering line upwards and/or outwards. Yes, they may exhibit an upright habit but few are strictly straight; trees are unlike the machined wooden telegraph poles, that punctuate our landscapes, despite being made of the



**Figure 1** Straightened Sapling 2018, mixed-media on paper, © Catherine Baker.

same material and anchored in the same ground. Yet our perception is still one of straightness. The artwork (figure 1) consists of a photographic collage showing a staked sapling that has grown apart from its wooden support, taking a different direction from the one intended by staking. However, here it is shown horizontally sliced with the reassembled trunk following a perfect vertical line.

In the same way that the term idiopathic, applied in the context of medical diagnosis, describes a resistance to make known so too can it be deployed in relation to uncharacteristic and unpredictable growth in trees. Much like the irregularities of scoliosis seen in adolescence, some trees in their growth or movement can be difficult to anticipate, twisting and turning in opposition to their projected ontogenesis or environmental situation. A metaphorical approach,<sup>3</sup> using ideas of so-called imperfection in growth were employed in the study enabling participants to make connections with and through the living world around them. Finally, spinal surgery for scoliosis is frequently referred to as corrective surgery, so in order to be eligible for corrective surgery one must assume the status of being incorrect. Importantly, the project sought to consider such positions through art-making.

## METHODS

Ten women diagnosed with AIS (aged 16–24 years) were recruited to take part in this interdisciplinary study; one was accompanied

by her younger sibling (age 14 years) and a parent, three were each accompanied by a parent. The aim had been to recruit 12 participants with AIS, however, a shortened recruitment period for reasons beyond our control impacted on the final numbers. All the recruited participants with AIS were operated on at a mean age of 14.6 years (range: 12.46–17.19 years), were beyond their 2-year postsurgery follow-up (mean: 5.93, range: 2.92–9.17 years), and were drawn from the patient base of Tsirikos at the Scottish National Spine Deformity Centre in the NHS Lothian region of Scotland. A total of 69 project information sheets were sent out via the Service Data Coordinator from the aforementioned centre. All the participants (including sibling and parents) were white and of mixed European origin which is typical of the region. One participant chose to withdraw from the research, along with their parent, partway into the main data collection period which took place over two weekend workshops in September 2022.<sup>4</sup> TAPS data from this participant were not included, however, their Scoliosis Research Society 22r (SRS-22) results were complete as the collection of these data is held in the British Spine Registry.

Prior to the main data collection period all participants were invited to attend a short online meeting where they were able to ask questions about the research and planned activities. In preparation for this meeting, each research team member recorded a brief audiovisual clip introducing themselves and their role in the project.

A mixed-methods approach was used that included radiographic data<sup>5</sup> and SRS-22r<sup>6</sup> Questionnaire data of participants with AIS (presurgery and postsurgery), the completion of a TAPS form by the participants with AIS at the start of the first workshop and at the end of the second workshop, short talks, art sessions with garden walks, focus groups, and an Art School-style 'Crit' session comprising the participants with AIS and the research team. During the first weekend the participants with AIS were split randomly into two groups which stayed together for the art sessions, walks and focus groups. Lunch was taken as a whole group with the researchers. A key objective for the workshops was that they would take place in a non-clinical setting as this would enable the team to ask participants about whether the backdrop impacted on their decision to take part in, and experience during, the research. The workshops took place in the Botanic Cottage located in the grounds of the Royal Botanic Gardens Edinburgh (RBGE). The cottage is a flexible and inviting space with multiple rooms suited to differing activities surrounding a central kitchen space and was ideally suited to the aims of the project enabling us to design the activities around its features and environs.

## Short talks

On Day 1 (Workshop 1), it was necessary to provide some information about art practice as most participants' knowledge of art was based on a bias in the school curriculum which tends to reward the ability to replicate work figuratively rather than encouraging the ability to think abstractly and metaphorically. We endorsed an approach with the participants that made acceptable the notion that their activity might not lead to finished art objects; in essence the journey towards the outcome was considered as equally or more valuable than the artwork. This way of thinking 'more openly' was introduced through a talk using examples drawn from conceptual art practice(s). This helped to dispel the pressure to perform artistically that had been expressed as a concern by some of the participants. In feedback they confirmed that this had indeed made them feel more relaxed:



The art and workshop [were] the thing I was most worried about as I'm not a very confident artistic person but I really enjoyed it and how free it was. [It] has 100% changed my perspective on art and the creation of it. (AIS participant, 2022)

A second talk addressing image manipulation techniques (particularly Photoshop) was also planned, however, we found that such discussions emerged naturally during Day 1 (Workshop 1) art sessions as the participants settled comfortably with one another and conversations began to flow more easily between them. These conversations touched on the proliferation of 'untruthful' images and the culture of bodily misrepresentation that exists across social media platforms. The participants with AIS were fully cognisant of such matters and appeared to understand how easy it is for those with the right materials to alter aspects of appearance using digital software. Despite evidence of their grasp on the presence and influence of digital image manipulation it became clear that they did not so readily understand how we make sense of the world around us through visual perception, how our visual system works, and equally how and why it can be misleading. Consequently, the second talk was altered to extend the idea of 'deceptive' imagery by introducing research on Illusion and Selective Attention (Findlay and Gilchrist 2003) and how much of the world around us can be 'missed' through vision. This talk took place at the beginning of Day 2 (Workshop 1). Feedback from the participants with AIS when relating to the content of this talk, received during *and* long after the workshops, suggested that it had both an immediate and enduring impact on their understanding of such concepts. One participant described the period between the workshops when she was taking a walk,

I said, those trees are so perfect and then realised that I'd described the curved trees as perfect and it showed how it had changed my perspective of them. But I guess I just notice all the curvy trees now.

### Art sessions with garden walks

In Workshop 1 we provided participants with researcher-produced colour A3 and A2 sized photographic prints of tree specimens from the RBGE. Following a demonstration of drawn and collage-based art techniques, the participants were encouraged to experiment for themselves. This included drawing on prints of trees that had curved trunks using the Cobb measurement system to explore how the curve pattern is calculated and measured. Participants deconstructed the images (in some cases, almost entirely) with reconstructing or reordering the image parts to systematically straighten the tree or curve it further; darkening large parts of the image surface to signpost a particular feature or highlight a chosen visual narrative; sometimes attaching other materials to the 2D image using differing cutting and joining methods. Throughout these sessions, the balance between influence and encouraging curiosity were attended to through close observation of the participants' work, talking through the material choices made and what they might (want to) communicate or explore. This included analysing the main features and characteristics within the image and planning how the participant wished to manipulate the content to describe a set of circumstances; an emotional response, a specific memory, and/or a physical or visual condition.

In parallel with the art sessions, the participants undertook researcher-led garden walks during which the participants with AIS took their own photographs for use in Workshop 2. They used their own mobile phone devices and/or digital Single Lens Reflex (SLR) cameras made available by the research team along

with instruction in their use. The walks followed a preplanned route designed to accommodate both the time available and a wide variety of tree specimens. While walking, participants were encouraged, through occasional verbal or physical prompts from the researcher, to become attentive to the growth patterns of the trees and shrubs they passed by, under and through. The researcher also made initial suggestions for photographic vantage points (eg, from a distance, close up, lying down), however, as the walks progressed the participants increasingly discussed specimens and photographic strategy with each other and would occasionally break away from the group in search of alternative stimuli/viewpoints. Multiple photographs were taken by each participant ranging from close-ups of smaller shrub specimens and bark patterns through to larger trees that were either compositionally isolated or selected to highlight an unusual characteristic in comparison to its surroundings, that is, a specific curve pattern or unusually upright. Established trees with guy wires<sup>7</sup> also featured in some photographs. After the walks the participants with AIS reviewed their photography and narratives emerged as each young person selected two or three images to work with in Workshop 2. The objective was to give them greater ownership over the images that they would develop further and gain greater insight into their reasoning. The selected photographs were digitally printed ready for Workshop 2. The parents also participated in a walk; this enabled us to provide an insight into the photographic exercise but also facilitated relaxed conversation out with the formality of the focus group.

Across Workshop 2, as confidence grew among the participants with AIS, they began to discuss individual approaches and the ideas that underpinned the direction and production of their artworks. The dialogue with each other and the researchers often focused on how to construct or craft their artistic ideas in order to communicate visually that which they had been unable to describe verbally at the time of treatment. They experimented freely with a range of techniques exploring complex emotional feelings through the material capacity of art practice to translate a sense of oneself.

### Focus groups

We delivered three focus groups; two for the participants with AIS and a younger female sibling and one for the parents. The focus group discussions were audio-recorded and transcribed. The rules of the focus group were explained regarding confidentiality, that participants would be free from interruption and distraction and that all responses would be anonymised after the completion of the focus group session. The smallness of focus groups provided the opportunity for participants to find similarities across the shared dialogue and feel both encouraged and supported by the other participants. The discussions were fluid with intimate details freely shared. Questions included; what made them participate? We discussed their motivations to be part of the project. During the focus group discussions we explored the impact of AIS on the well-being and body image of young women and their families, the impact of the diagnosis on their life, their family, their social, school life and relationships with friends and family. As the sessions drew to a close the discussions moved towards other issues or concerns about their (or daughter's) treatment, care and future life.

### Art school crit

The final day of Workshop 2 ended with an 'Art School Crit' style session that was audio-recorded and transcribed. This involved all of the participants with AIS and the research team. This

session comprised of sharing and discussing all of the artworks produced across the two workshops. All participants took an active role and the discussion highlighted the artworks that the group felt most closely described their experience of scoliosis diagnosis and treatment. The participants commented on each other's approaches often discussing artistic decision-making, intention and meaning-making. They freely pointed out artistic features that they felt were interpretative of their own thoughts and discussed their communicative ability. They appreciated the diversity of the outcomes signposting originality and that the artwork 'could never be duplicated'. A notable part focused on scars and the way they are 'embedded in your life' and 'that you're not going to forget about it' and the ways in which the artworks 'sh[o]ne a light on it' positively.

### Analysis

Statistical analysis of the radiographic results and SRS-22r outcomes scores was performed using the t-test (statistical significance was defined as  $p < 0.05$ ) and Pearson's correlation-coefficient (strong statistical significance was defined as  $r > 0.5$  or  $r < -0.5$ ). The t-test was used to compare the radiographic measurements of all parameters before surgery and at the 2-year postoperative follow-up. It was also used to compare the SRS-22r outcomes per domain preoperatively and at the 2-year postoperative follow-up. The Pearson test was used to assess possible correlations between the spinal parameters and the SRS-22r Scores across individual domains. The qualitative data were analysed using reflexive thematic analysis (Braun and Clarke 2022) to identify overriding themes and unifying ideas. The quotations and images in the discussion are those that best represent significant constructs that appeared across the data set.

### Patient and public involvement strategy

The research protocol was indirectly developed from an ongoing dialogue with patients with AIS and their families started in 2015 by Baker. These discussions informed the critical decision to use a non-clinical setting and sparked Baker's interest in the shared attributes and terminology used for human bodies and trees.

The voice of patients is often omitted in medical research reporting despite the participatory nature of an increasing number of interdisciplinary research projects that seek to capture their important testimony as experts. The *BackBone* study sought to address this issue highlighting the critical need for patient inclusion in the analysis and dissemination of medical research, and the design of future research. In December 2022, three of the participants with AIS attended a scheduled review meeting with the research team and their contributions are acknowledged in the open-access reporting documents. Their testimony was included in a charity publication whose readership primarily includes patients with scoliosis and their families and some health professionals. The participants with AIS have also been invited to join early discussions regarding the further evolution of the project with a focus on their ongoing potential participation as co-researchers/advisors.

Following the main data collection period, a public-facing exhibition was held at the prestigious Edinburgh Printmakers venue in Scotland in September 2022. This small exhibition of wall-mounted artworks by the participants with AIS was accompanied by information and links to the project aims. The preview event was attended by some of the participants and their families and the works attracted substantial interest from members of the attending general public helping to stimulate wider awareness and debate. This was evidenced via subsequent receipt of

email and postal communications from members of the general public. In August 2023 a show based on the research findings was presented (on two dates) in the Cabaret of Dangerous Ideas (2023) (New Town Theatre) at the internationally renowned Edinburgh Fringe Festival. Again, these events were attended by some of the participants and their families alongside members of the general public further promoting awareness and debate. The majority of the audience present, when surveyed, indicated that they had learnt something new during the shows. Both dissemination activities provided an opportunity for family members, who were unable to take part in the data collection phase, to access the project through the artefacts produced by the participants with AIS.

### FINDINGS

We set out to investigate how quality of life is affected by scoliosis and its treatment, how we can measure this in ways that are meaningful to patients, and how the psychological impacts (including on body image) of diagnosis and treatment might be best managed.

### Psychological impacts

All the young women had good clinical outcomes as assessed by the radiographic measurement parameters with no surgery complications, no reoperations and a good personal perception of the surgical results as expressed in their responses to their preoperative and postoperative SRS-22r and TAPS Questionnaires. However, the SRS-22 reports did indicate that the psychological impact of AIS diagnosis and treatment on participants' self-image and mental health had been adverse. Discussions with the young women revealed four key reasons for this: lost independence, guilt, shame and feelings of isolation.

All the participants agreed that needing someone to help them undertake basic tasks (eg, showering, getting dressed) had been embarrassing and 'dehumanising'. One stated,

The days in hospital, I remember were just awful because I was just lying there, and I was stuck until someone could get me up, [and] I don't want to press the buzzer, [and] want to make someone, like, have to come over and take me to the toilet [to] burden someone.

All but one (the youngest) said they felt a need to regain control, 'to get better', as soon as possible. This was partly because they felt like a burden or nuisance to those tasked with assisting their recovery, be this medical staff;

Whenever I got a shower, I always apologised to the nurse.

or their families;

I'm taking up all your time; you're having to take time off work to take care of me, it shouldn't be like that.

My mum, she was always there. [...] she had a wee cot set up and everything, she was always there. [At] night beside me. And, but obviously, my, what was it [blood pressure monitor], like it kept beeping because I was always at 50 or under, and it would just wake her up all the time [...] I was like, 45, 50, at all times, so it would just be beeping all the time.

But also, because they felt ashamed for complaining about the pain or discomfort they were experiencing. Several said that they had done everything possible to mask their pain and 'be brave' because they 'had *chosen* to have [their] operation (our

emphasis)' when others were in hospital through no fault of their own;

I didn't even cry when I was in the hospital, I didn't cry once. And the nurses always said, "You're allowed to cry, you're going through something really difficult", and I was like "No, I can't let myself feel sorry for myself, because there's people in this hospital that [have] got it so far worse" [...] constantly shutting my own feelings off, because I constantly compare[d] myself to all those little children [...] that were really struggling.

Another felt that she had already caused enough upset,

I definitely had the support of my family but [...] I didn't want to make it worse for them because obviously it's a struggle for them to see their daughter/sibling go through a surgery. So I kind of like, when I was in pain or I was struggling mentally, I didn't, like, confide in them.

Describing the immediate postoperative period, one young woman said, 'I completely didn't allow myself to feel'. Others admitted to only crying when alone and for some this had taken years.

All but one of the young women described feeling isolated at one or more points after diagnosis, during treatment and/or in recovery. All but one (the one who had not felt isolated) had never met another individual with AIS. Although the young women articulated various reasons for participating in the research ('to raise awareness', 'to improve treatment', 'to return the favour' of time invested in them by the medics) they all said that the primary motivator had been the opportunity to meet other individuals who had been through the same diagnosis and treatment. Their families had done everything possible to support them through these stages, they said, but they could never understand what it was like to *live* through it; as one stated,

Obviously the people around me, they're supportive, but no one really understands.

Friends had also proved to be an unreliable source of support, either because the participants could no longer participate in the same activities (eg, sports) or because they were unsympathetic. One recalled,

Before my operation [...] there was a girl in the [school] changing rooms [...] and she was like, "Oh my God, why have you got a bump on your back?" And like everyone, there was like 50 girls in that changing room, and I just remember every single one of them turning round to stare at me [...]. So, after that, [...] they'd all obviously be like, "Oh straighten up, straighten up, you cripple, and all that". And I'm like, you are meant to be my friends.

Although some of the young women had tried to explore and articulate their scoliosis experience through school work (eg, art projects, creative writing) they admitted that they had stopped short of 'making it too personal'. None of these activities appeared to have provided the catharsis or communicative outlet needed to fully process the impact of AIS diagnosis and treatment, during the postsurgery period as emotionally distressing and unresolved.

It is interesting to note that the parents also felt isolated during the process of diagnosis and treatment, although for different reasons. They all blamed themselves for not noticing their child had scoliosis and believed that they were somehow unique in this sense. Likewise, they had all been aware that their child was hiding their feelings, 'bottling-up' fears and worries, but had not known how best to address this. At the time of the surgery

one parent said that they had been scared and could only focus on the day-to-day, not the long term. Another said it seemed as though they were the only ones experiencing it. They had also been motivated to participate in the research because of the opportunity it presented to meet other parents with experience of supporting a child through AIS.

### Safe space

The young women said that, in affirming their experience of scoliosis diagnosis and treatment, participating in the research had given them 'permission' to talk. They described their relief at finally being able to speak unguarded in the workshops;

I've kind of just bottled everything up. I never really speak about it, so it's quite nice to be in a situation where I'm with loads of people that have been through the same thing.

I think it really made me feel okay actually, come on, you're allowed to speak about it, you're allowed to make yourself vulnerable. Whereas before I always tried to be strong [...] it's really not a big deal. But then knowing everyone has gone through the same thing I'm not scared anyone's going to judge what I think.

To be among people with physical similarities;

I saw, I think it was [participant's] scar yesterday and I was like, "Whoa, someone's actually got the same back as me", and it was a key moment because I've never seen anyone in person that has the same scar.

They all described experiencing 'a different kind of bond' with their AIS peers compared with those who did not have it, including members of their family. This feeling of 'shared knowing', of being among people who 'understood deeply' was also felt by the parents, a couple of whom said that right from their arrival at the workshop venue they had felt able to discuss personal matters. This sense of comradeship had intensified as they found similarities among the pain, struggles and ultimate positives which came with their experiences.

All the participants agreed that holding the workshops in a non-clinical setting had helped them to feel more 'relaxed' and willing to share their experiences. Studies have shown that patients are far less forthcoming on clinic visits with prevalent self-concealing behaviour indicating lower psychological well-being (Uysal *et al.* 2012). One young woman confessed that hospitals 'scare[d]' her and another that she would definitely 'be more on [her] guard in a hospital'.

Engaging in art practice, talking through the processes involved and taking part in the focus groups with their peers empowered the participants to disclose and portray aspects of their experience that they had secreted, not fully processed or had not been able to air. Several of the young women said, for example, that they had 'blocked' the operation out of their minds; one commenting,

I'm someone that just kind of gets on with it. So I didn't really, when I had it, I think I just kind of did that thing that people do with, not trauma, but you just kind of completely black it out, so you don't think about it. [...] in the hospital I did find it really hard. And you guys will probably completely understand, it's just a really tough time, especially at such a young age.

It was interesting, then, to see that the fundamental aspects of diagnosis and treatment (in their case, surgery), featured heavily in their artworks. In Workshop 1, several of the young women tried to replicate their original spine curvature cutting and re-arranging the trees to exact specifications. In other





**Figure 2** Participant artwork, Jamielee Stevenson 2022, mixed-media on paper.

cases, the participants (including all the parents) focused on employing artistic processes to create straightened trees out of ones that had grown with a measurable curve in the trunk. Others inserted additional 'foreign' objects into the 2D space of the artwork. [Figure 2](#) shows how one participant inserted a long piece of black foamboard into her reassembled collage of an unusually straight tree, tape 'straps' were crafted to hold the 3D insert centrally within the image. Others also experimented with similar approaches, punctuating the main image by means of cutting slits/openings to fasten the added 'upright' in place.

A further iteration was produced by another participant who opted to make the openings perfectly cut circles that were notably ordered and repetitive. Here the participant developed the concept further by including a red 'backing board' which drew attention to the cut voids causing them to stand out as a prominent red feature within the black and white artwork (see [figure 3](#)). [Figure 3](#) also shows that in the same artwork the



**Figure 3** Participant artwork, Holly Smith 2022, mixed-media on paper.

participant applied words in the branches 'head area', to 'get-out' her feelings. Here there were a mix of surgical and clinical terms intermingled with her personal and intimate feelings about her diagnosis, although, mostly her experience of the treatment and surgical intervention for AIS. Initially, she engaged with developing her idea of using words that were meaningful to her as a solo activity, however, as time passed, she enlisted others to join in; the creative conclusion became a shared event.

It was me trying to get down all my thoughts that I've had throughout my experience and all the other girls' experience. And I think it was more of a healing thing rather than trying to make a piece of artwork that other people would like. [...] So, you've got the poles at the bottom and then a little bit of a curve at the top, just like me, and then you've got branches at the top that kind of represent our thoughts and our feelings in our brains.

Her subsequent artwork was strikingly different in both method and outcome, the process was slower, seemingly more considered, quieter and with less visual complexity ([Figure 4](#)). Her focus notably shifted towards a greater consideration of the creative artefact as a stand-alone entity and how it might function.

In [figure 4](#) we see more of the original photograph left intact, it is important to note that this was produced in the second art workshop and as such she was using her own photograph. Here the image was cropped and she applied a black ink over parts of the surface to reduce colour intensity and contrast in order to draw attention to an untouched area that reveals a small plant





**Figure 4** Participant artwork, Holly Smith 2022, mixed-media on paper.

that has grown with a bend in the stem that is situated amidst other straighter versions. She describes,

I saw it when we were going on our walk, and I just thought it was really nice how the ones around it are all straight, and there's just one in the middle that was quite wonky, kind of like all of us. But I wanted to amplify that and make the surrounding quiet and show that actually we are just as important as everyone else even if we are kind of different.

The process of taking part in the study was described as healing, restoratively wrapping up unresolved and unspoken concerns, that a 'weight had been lifted'. Although, primarily the focus was on using art practice to generate thought through material processes, each of the differing activities coalesced to foster new ways for the participants to think about themselves and what they had been through. Furthermore, the use of the tree photographs and the nature setting provided the means for the participants to build a connection between their visual experiences and the world around them. For some the study helped

to restore a sense of balance by drawing similarities between the trunk of the living tree and the living trunk of the whole person as kindred objects. Recognisably disconnected yet seeking a kind of metaphorical alignment connected through unexpected growth patterns revealed through both time and circumstance.

The workshops evidence that the emotional well-being of young people diagnosed with AIS is not measured in meaningful ways through quantitative methods and that alternative approaches that encourage thoughtful communication are needed. This was further endorsed by the parent group as our interdisciplinary approach revealed that, despite their child's surgery being in the past, there was much that had been held back by the young people that was unlocked through the mixed-methods approach. Some parents described that the resulting artworks had helped them to better understand what their daughters had gone through as, at the time of surgery, their fears had forced them to focus on only 1 day at a time. The reflexive nature of the workshops enabled a deeper understanding of the surgical impact to emerge within the parent group with the artwork acting as a vehicle for an extended, open dialogue to surface with their children.

### Body positivity

The SRS reports illustrate patient self-image improved from mean preoperative 3.16 to 2-year follow-up 4.64 ( $p < 0.001$ ). Patient mental health also improved from mean preoperative 3.67 to 2-year follow-up 4.34 ( $p = 0.004$ ). The young women all obtained a high score on the TAPS indicating smaller perception of deformity and a positive affect and satisfaction with their body image. Online supplemental table 1 however, presents the mean TAPS Scores before and after the participation and completion of the study and shows that their mean score was slightly lower after the end of the second weekend (t-test revealed no statistically significant difference-drop). This suggests a greater self-perception of scoliosis and awareness of their deformity after participating in the research activities. This should not, however, be viewed as a negative outcome.

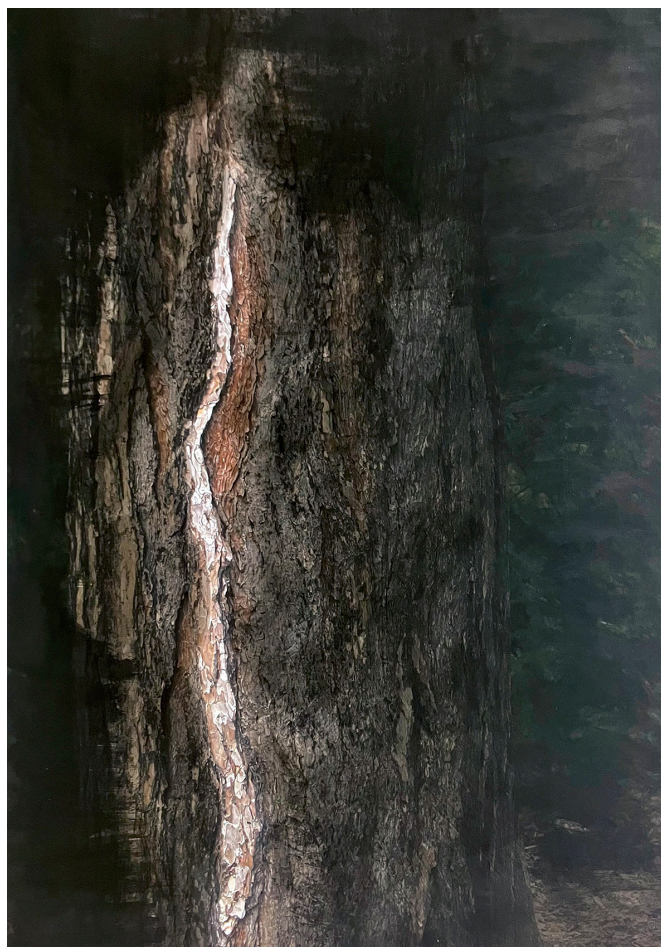
We observed a change across the weekends whereby a greater sense of both ownership and artistic direction emerged in the young women's artworks. The participant who created figures 3 and 4 described this shift as 'healing' versus 'assertion and acknowledgement'. She felt that the first weekend activities provided a healing space for her that, once complete, enabled a more forward-looking and assertive approach to emerge in her subsequent work. This transition had happened without her really realising it but had somehow allowed her thoughts to move on. Further describing one of her artworks from Workshop 2 (figure 4) she expressed a sense of achievement and desire to celebrate her uniqueness,

I see this one as me now [...] like a shining light: I've healed, I've gone through all of that, and now I'm just in the midst of the population just enjoying life.

Most articulated the sensation that 'outstanding closure' resided within them that taking part in the study had resolved.

Another said that the workshops had entirely changed her perspective of herself and the world around her. Talking about how she had been struck by the curved forms of trees while out walking, one young woman emailed to say, "I didn't view it [scoliosis] as a negative before, but I also didn't view it as a positive, least of all a perfection", indicating a positive outcome as the participants described feeling more comfortable with and





**Figure 5** Participant artwork, Melissa McDermott 2022, mixed media on paper.

able to be honest about their curve as many maintain a degree of postoperative curvature.

There was unanimous agreement that one artwork was felt to be the ‘most descriptive’ while also being the ‘most unsettling’ to them (Figure 5).

I love my body. As soon as I got that scar, I was trying to look in the mirror [...] I was just like, “Oh, it’s cool, I like it”. I model, and I always, if I ever have a dress, I’ll always have my scar out.

Relevantly, figure 5 was described by one participant as life-like, ‘because it feels like the tree has gone through something itself’. Of all the artworks the evident bark ‘scar’ has agency as a visible signifier of their shared knowledge and sense of belonging.

## CONCLUSION

It is important to reiterate that the participants had good clinical outcomes as assessed by the radiographic measurement parameters with no surgery complications, no reoperations and a good personal perception on surgical results as expressed in their responses of the SRS-22 and the TAPS Questionnaires. Scoliosis research indicates that overall, the impact of surgical intervention is positive in most studies (Carrasco and Ruiz 2014) which was the case for this small project. However, there was

consensus that the quantitative methods currently used in clinical evaluations feel distant and inadequate.

In the integrative review undertaken by Carrasco and Ruiz they conclude that the ‘predominant clinical symptom of AIS appears to be the negative effect that the spinal deformity exerts on perceived self-image and appearance’ (ibid, 2014). Conversely, our activities indicated that self-image was a lesser concern for our postoperative participants but we recognise that the small cohort result is underpowered. What was confirmed, was the need for individuals to express themselves and their relationship with their diagnosis and that their subsequent treatment plan remained unresolved and continued to be isolating. The known problems identified with AIS can additionally result in decreased self-esteem and social confidence along with increased anxiety, depression and stress (cited in Misterska *et al.* 2013). At a time when mental health issues in young people are on the rise from one in six 17–19 years old in 2021 to one in four in 2022 (NHS Digital 2022) Wave 3 Survey, it is critical that alternative interdisciplinary approaches continue particularly when the psychosocial challenges associated with AIS are globally recognised. Despite signs of poor mental health and suppressed emotions being detected in clinic there remains an absence of referral options and those that are available are frequently overwhelmed. Reported statistics, more generally, indicate a significant rise in mental health referrals for young people (Dorell 2023).

The demonstrable impact of art methods on the individuals’ ability to articulate more than their experience of Scoliosis treatment in meaningful ways was firmly established while the project also evidenced public interest gained through exhibition and public speaking outputs, and the importance of both intergenerational research methods and non-clinical settings. What the artefacts revealed is that the intimate relations that occur across clinical and domestic settings matter greatly because they provide insights into beginning to understand how young people experience and understand health-related distress. The interpretation of such relations through interdisciplinary methodologies and art-based material considerations provided participants with the freedom to tackle, otherwise withheld, unsettled feelings. Cypher 2017 cites Latour (1999) in stating that ‘all artists would recognise that in the act of making, they are not in total control’ and furthermore ‘that they are overtaken by the action’. The condition of going beyond, engaging in the questioning nature of contemporary art practice sees the artwork become more complex and sometimes unfamiliar, but this is actually part of a sophisticated development in the art-making process. For some participants the language of making overtook their ability to explain the material and metaphorical relationships taking place in the image, in words. By using tree metaphors restraint was able to be relinquished allowing unfamiliar ways of thinking to emerge that could be tested through untried material choices.

While their diagnosis happened at a fragile stage of their psychological and body development, it is important that the positive impact of interdisciplinary creative methods should be balanced over the satisfactory outcome of their treatment and the implications of these patients being left long term with an untreated deformity, which could have a major impact on their physical and emotional well-being.

Our interdisciplinary approach, grounded in arts practice, impacted demonstrably on participants’ emotional well-being contributing to positive self-esteem and social confidence. Despite some inevitable overlap with art therapy, it is important to distinguish the differing characteristics that a collaborative art practice approach offers. Throughout the process the specific concern for the maker (artist-participant) can be the artwork

itself and the knowledge revealed through the journey towards it. Ongoing reflection and discussion affect the direction and the aims whereas, 'The arts therapist does not make judgements on the artwork produced by the client' Broderick (2011, 97). The field of arts and medicine has been slow to understand that material practices have agency as forms of knowledge production. While the therapeutic misconception remains somewhat slippery, there are signs that a more balanced form of interdisciplinary collaboration can emerge where an understanding of the epistemological position of arts practice in health is valued. Finally, this study highlighted the need to re-personalise personal aspects of the body which can become alienated through institutional health organisations.

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**Patient consent for publication** Not applicable.

**Ethics approval** This study involves human participants and was approved by NHS REC (Westminster, England) on 14 April 2022 (REC reference: 22/PR/0276, Protocol number: Baker/#9921/sub2/R(C)/2, IRAS project ID:306771). The study also received ethical approval from the HELS Faculty Ethics Committee at Birmingham City University. Further approval was gained from NHS Lothian (Scotland) under the same IRAS and REC reference numbers on 12 July 2022 with a further IG/IT security sign-off (reference: CRD21200). Participants gave informed consent to participate in the study before taking part.

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## NOTES

1. Invented by Dr John Cobb in 1948, the Cobb Angle method is the standard measurement used to verify and track the progression of scoliosis curves. It involves measuring the angle between two lines drawn perpendicular to the upper endplate of the uppermost vertebra involved in the curve and the lower endplate of the lowest vertebra involved (Hornig *et al.* 2019).

2. The TAPS is a tool designed to evaluate subjective impression of trunk deformity in patients with idiopathic scoliosis. It has three sets of drawn outline figures that show the trunk from three different positions: looking towards the back, looking towards the head with the patient bending over and looking towards the front. The last view has two sets of drawings, one for men and one for women. The drawings are scored from 1 (greatest deformity) to 5 (smallest deformity), and a mean score is obtained by adding the scores for the three drawings and dividing by 3. The score ranges from 1 to 15 with lower scores indicating a greater self-perception of scoliosis and higher scores indicating smaller perception of deformity.
3. Despite proving effective for those involved, we later noted that the use of metaphor might be a limitation if teenagers with differing needs had been recruited.
4. Workshop 1 was two full days and attended by the participants with AIS, sibling and parents. Workshop 2 was attended only by the participants with AIS with a full day duration.
5. Radiological parameters were measured on serial digital scoliosis radiographs before surgery and at 2-year follow-up: thoracic scoliosis, thoracolumbar/lumbar scoliosis, apical vertebral translation of thoracic curve apex from the midline, apical vertebral translation of thoracolumbar/lumbar curve apex from the midline, thoracic kyphosis, lumbar lordosis, global coronal balance, global sagittal balance, clavicle angle, shoulder height.
6. The SRS-22r Questionnaire is validated for adolescent idiopathic scoliosis. The SRS-22r measure has six domains which assess patients' function, pain, self-image, mental health, total score and satisfaction. The first five domains are available as part of the preoperative review of patients scheduled for scoliosis surgery. These five domains with the addition of patient satisfaction are also included in the postoperative analysis of outcomes.
7. Various tree-staking mechanisms exist that are aimed at supporting newly planted trees including single, double or angled staking but for larger trees with a diameter of 4 inches or more guying is employed to straighten or support. Guying uses three or four wires that loop around the trunk which are then anchored to the ground at a 45° angle. Guying anchors are usually shorter and stronger.

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