Final Revised Report - BackBone: Interdisciplinary Creative Practices and Body Positive Resilience
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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 3% of the adolescent populace with five out of six cases being female. The BackBone: *Interdisciplinary Creative Practices and Body Positive Resilience* pilot research study aimed to use art as a form of interdisciplinary research practice to measure the impact of Adolescent Idiopathic Scoliosis (AIS) on wellbeing and body perception. The research aimed to contribute to a better understanding of alternative treatments towards improving quality of life in young females 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.

Through interdisciplinary art-based workshops and focus groups with post-operative Adolescent Idiopathic Scoliosis participants and their families, objective analytical data plus empirical data from transcripts and artefacts was gathered using qualitative and quantitative methods. 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. By 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. Uniquely, the pilot project sought to draw upon insights from across the combined disciplines, thinking across boundaries to evoke different ways of knowing and understanding the complexities of body perception through image making.

Background
Despite not being rare, people either have little knowledge of Scoliosis and/or it is poorly understood, this section is intended to provide some context for the reader. Scoliosis is an abnormal lateral and twisting curvature of the spine. Scoliosis affects 2-3 percent of the population and can occur in infancy or early childhood, or later in life however, it is most frequently diagnosed in early adolescence with onset occurring between 10 and 12yrs old. When other causes are rejected, idiopathic scoliosis is the diagnosis attributed to around 80 percent of all cases. In general, five out of six cases are female with the American Association of Neurological Surgeons (AANS) reporting that females are eight times more likely to progress to a curve magnitude that requires treatment (AANS, 2023). The degree of curvature measured using the Cobb[1] method dictates the type of treatment and indicates the need for surgical intervention or not. A curve measurement of 25-30degrees is widely accepted as significant with curves in excess of 40degrees considered to be severe.

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, for some the degree of change can happen rapidly with surgery proposed before the individual has had a chance to fully register their diagnosis. In essence, families, clinicians, and individuals wait to see what will happen as time discloses the magnitude of the developing curve or not. A resulting treatment plan is determined by ongoing clinical and radiological mapping in the form of a standing spinal X-ray, the frequency of

which is dictated by the speed at which the curve appears to be progressing. From the radiological diagnostic image, a Cobb angle measurement can be determined. 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.

Locating the research

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) can have a consistent negative effect on the development of a person's body image (Misterska et al, 2012). With regard to the TAPS measurement tool (Trunk Appearance Perception Scale) that is used in Scoliosis research, its creators suggest that an ideal methodological position would be achieved if a high correlation existed between the patient's perception and clinical and radiological measures of deformity however, it is common to encounter discrepancies between the radiologic deformity and the aesthetic deformity (Bago et al, 2010). 'This situation has ignited the debate as to what aspect, the radiologic or aesthetic problem, should be the primordial target of treatment. We believe it is crucial to know the patient's perspective in this debate…' Bago et al, (2010). The issue raised by Bago et al was critical to the *BackBone* (working title) research study. Furthermore, established research claims that body disfigurement, observed in AIS can have a consistent negative effect on the development of an individual's body image leading to a rise in emotional distress. Recently, Bertucceli and Cantele et al stated that 'facets of idiopathic scoliosis have been largely neglected compared to their clinical and genetics determinants' (2023). A key motivation of the projects' 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, as highlighted in the funding application, it should be stressed that interdisciplinarity acted as the main theoretical framework for the conception, delivery and review of this unique project situated within the field of Medical Humanities. Regardless of the rise of Interdisciplinary research methods that seek out diversity and collision, in many disciplines the perception maybe of Medical Humanities as 'soft' in contrast to 'hard' biologic science yet paradoxically, the complex task of caring for patients from a human-centred standpoint is inexorably more problematic than the scientific question of what to treat and how (Reiff-Pasarew, 2022). In times when both patient mental health, and physician burnout increasingly feature in global news reporting, it is not surprising that alternative mixed-approaches crafted to foster meaning, and thoughtful connection between the experience of illness and/or disease and quality of life have gained increasing recognition. Reporting by the Health Evidence Network, World Health Organisation and the All-Party Parliamentary Group on Arts, Health and Wellbeing (APPG) robustly endorses the need to look beyond established clinical practice for new ideas and the Arts has become the focus due to its demonstrable results (Creative Health, APPG Inquiry report 2017). In his introduction to the Creative Health inquiry 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', he goes on to outline three key messages:

- The arts can help keep us well, aid our recovery and support longer lives better lived.
- The arts can help meet major challenges facing health and social care: ageing, long-term conditions, loneliness and mental health.
- The arts can help save money in the health service and social care.

As medical teaching institutions begin to employ a mixture of academics across fields of expertise it is clear that times are changing yet, what might once have been considered insightful will become

steadfast and fixed if it remains closed off to pull of change. Thankfully, 'The level of stress and body self-image perception in girls suffering from adolescent idiopathic scoliosis (AIS) is the object of interest of the professionals', Kinel et al (2014).

Methods

A total of 10 female patients were included in this interdisciplinary study. These 10 patients were operated at mean age of 14.6 years (range: 12.46-17.19). All patients have over 2-year post-surgery follow-up (mean: 5.93, range: 2.92-9.17).
The recruitment period commenced on the 1 August 2022 and closed on 30th of the same month. This was shorter than planned as it was curtailed by delays receiving the full ethical approval from NHS Lothian despite the NHS REC providing a favourable opinion many months prior. Sixty-nine PIS were posted to possible participants from Mr Tsirikos' patient base, those recruited included:
11 AIS participants aged 16 – 24yrs, 4 parents 2 siblings. Feedback indicated that 15 more participants would have been possible had the delays not been experienced. The full recruited cohort was White and of mixed European origin. This is typical of the Lothian region. One participant withdrew the day before the project was due to start and one participant did not complete the exit TAPS survey.

As outlined, we followed a mixed methods interdisciplinary approach that included art workshops, garden walks, focus groups, mini-lectures with AIS participants and their families with follow-on art workshops and a discussion group with only the AIS participants.

Mini-lecture 1

It was necessary to provide some information about art practice as most participants understanding of art was based on the heavily bias school curriculum which rewards the ability to replicate work figuratively rather than the ability to think abstractly and metaphorically that is more typical of higher study across the humanities. This latter approach endorses that all activity might not lead to finished art objects, in essence the journey towards outcomes being frequently more valuable than the end product. This way of thinking more openly was addressed through a mini-lecture style talk by Baker with all participants at the beginning of the first weekend. It helped to dispel the pressures to perform artistically that was expressed as a concern by some of the participants. This proved effective as the group 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. Has 100% changed my perspective on art and the creation of it', AIS participant (2022).

Mini-lecture 2

The second mini-lecture planned for Day 2 was reworked overnight by Baker as day 1 indicated that it would be helpful for participants to understand how we make sense of the world around us through perception. Initially this talk was going to focus on image manipulation techniques, particularly, Photoshop ™ however, such discussions emerged naturally with the YPs in the art workshops on day 1. Our conversations focused on 'untruthful' images and the culture of mis-representation that exists across multiple social media platforms. The YPs were well versed in this and Baker demonstrated how easy it was to alter aspects of ones' appearance through digital software. Despite evidence of their grasp on the presence of digital manipulation, it was clear that all the participants had a limited understanding of perception and how our visual system works so the reworked talk extended the idea of deceptive imagery by concentrating on Illusion and Selective Attention and how much of the world around us (natural world, images) is 'missed' through vision. Again, feedback, received during and much later, from participants evidenced the impact of this talk beyond the projects' timeline.

The TAPS (Trunk Appearance Perception Scale) was carried out at the beginning and the end of all activities and was analysed by Fotakopoulou. The correlation between these findings and the SRS-22 reports provided by Tsirikos will be covered in the next section.

Parallel sessions included Art Workshops with Baker and Parrott; Garden Walks with Morris; and Focus Groups with Tsirikos and Fotakopoulou (max. group size of 6), these sessions were recorded and the transcripts were available to the whole team. The Art Workshops provided participants with pre-prepared photographic prints whilst Morris took groups on the Garden Walks to generate imagery authored by the participants. Additional aims of the garden walks were to engage the participants with the natural world setting looking at the growth patterns of tree and shrub specimens. The photographs were reviewed with participants upon their return, narratives emerged that supported their choices and they each selected two photographs to work with on the follow-on weekend art workshop.

In the first art workshops, participants were introduced to the Cobb measurement system via tree images and Baker demonstrated some art techniques both digital and physical however, the revised funding allowance dictated that access to the computer suite (highlighted in the original funding application) was no longer within budget. This meant that a revised digital manipulation approach was necessary which was covered in part in the small Art Workshops (max. 6) through a Photoshop demonstration and to the whole group in the mini-lecture 2 that focused more on visual perception and how we interpret different types of imagery.

The first art workshops were dominated by collage approaches that were, in part, led by the participants which involved deconstructing the preprepared A3 and A2 digital prints of tree specimens. The deconstruction involved an analysis of the main features and characteristics within the image followed by a plan of 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. The reconstruction of the image was as slight as darkening 80% of the surface of the image to highlight a chosen narrative or a near complete destruction and reordered response often where the tree was forced straight or curved further. What emerged was that other implements were inserted into the 2D image through cutting and joining methods, as shown in Figure 1. This response was made by one participant and it was quickly explored by others as it generated a lively reaction amongst the group.

Figure 1. Initially YP19A7 applied a collaged curve by cutting slices through the original image and reordering them onto card, this was followed by making cuts into the final image whereby tape 'straps' held a piece of black foamboard in place that was centralised in the image.

Other images (shared in the earlier report) show how others explored similar approaches whereby a 'foreign' object, often not an obvious art material was inserted into the space of the tree image and was held in place using other materials including tapes, and card strips. See Figure 2 for close-up details:

Figure 2. Responses by two other participants (detail). The second artwork shows that a bright red layer was placed behind the holes indicating that when the surface was cut a deeper red layer existed. It should be noted that the holes were perfectly cut, were planned and were repetitive.

Artistically, many of the YPs inserted additional objects into the 2D space of the artwork, all of which were centrally located whilst the parents focus was exclusively on straightening the trees through cutting and reassembling. To note, the parent group had access to fewer art workshops which could be remedied with a larger study.

The final day ended with what is described as an 'Art School Crit' style event that was audio recorded and transcribed. This involved all of the YPs and the research team. This session involved showing and discussing the artworks across the group with prompts given by the team. All participants took an active role and the discussion highlighted the artworks that the group felt mostly closely described their experience of scoliosis surgery. There was unanimous agreement that the following image was felt to be the most descriptive whilst also being the most unsettling to them.

Figure 3. The artwork on the right was produced by highlighting a natural curve found within the bark or 'skin' of the tree on the left that YP18A2 described as a scar or wound. The rest of the image was darkened to make the other features become less distinct and accessible. The 'scar' was lightened to provide a higher contrast making it more visually striking taking up nearly the whole length of the paper after being cropped. Note that it was off-set, destabilising the composition.

Patient and Public Involvement Strategy (PPI)

The funding application highlighted early work by Baker in 2015 that led to discussions with Tsirikos so for brevity, it is not outlined here. However, what is important is that the early, but underpowered findings chronicle the ongoing patient and public involvement in the development of *BackBone*.

The research protocol was not directly developed with patients and the public despite being based on the early enquiries that led to the critical decision to focus on a non-clinical setting that enabled participants to explore the natural world around them.
The voice of patients is often omitted in academic writing and research reporting despite, the participatory nature of interdisciplinary research projects that seek to capture their important testimony as experts. The *BackBone* study sought to address this issue, highlighting the criticality of patient inclusion to both participatory reporting and future planning.

One of the final stages of the *BackBone* study included a public facing exhibition held at the prestigious Edinburgh Printmakers in Scotland in September 2022. The small exhibition of works by the YPs was accompanied by information and links to the projects aims and coincided with a solo exhibition by the main author of this report. This was an addition to the main project that was not part of the original funding application however, Baker was able to negotiate financial support from Edinburgh Printmakers to realise the resulting public-facing exhibition. Baker gave a short talk at the opening which was attended by Morris, some of the participants and their families, they described being proud that their work was helping to stimulate public awareness. One parent, who had not taken part in the study described the importance of seeing her daughter's artwork, ''XXXX's art helps me understand more of what she went through. It also opened up a discussion because it has been a while since surgery and in that time, I was scared and only focus[ed] on the day to day, not the long term. So, I can look back now and see how it affected her.'

The full budget was managed by Baker and towards the end of the project contact was made with the Chair of the BSRF Grants committee to use an underspend to invite three of the AIS participants to join the research team to review and assist in the interpretation of the results as part of the PPI strategy. Additional ethical approval was provided by the Health REC at BCU for this amendment. The BMJ dictates that all article submissions should now include a PPI report and their website and blog stresses the need for research to follow the GRIPP2 reporting checklist. Both this study and the future iteration of *BackBone* have/will follow their guidance.

Results:

We set out to investigate 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.

The varied mixed-methods results presented in this report are based on the analysis of radiographic parameters and Health Related Patient Reported Outcomes using the validated for adolescent idiopathic scoliosis, Scoliosis Research Society 22r (SRS-22r) questionnaire, TAPS and Art outcomes. All measurements of radiographic parameters relevant to this patient cohort were made by Mr Tsirikos. The SRS-22r questionnaire information has been produced by Mrs Garcia (the Service's Data Coordinator) for all patients who were surgically treated under Tsirikos' care in the Scottish National Spine Deformity Centre following input of the patients' outcome data in the British Spine Registry.

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.
The SRS-22r outcome measure has 6 domains which assess patients' function, pain, self-image, mental health, total score and satisfaction. The first 5 domains are available as part of the preoperative review of patients scheduled for scoliosis surgery. These 5 domains with the addition of patient satisfaction are included in the postoperative analysis of outcomes.
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 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 2-year postoperative follow-up. It was also used to compare the SRS-22r outcomes per domain preoperatively and at 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. It should be noted that since the number of patients included in this study is small the statistical results are underpowered.

Trunk Appearance Perception Scale

The TAPS includes three sets of figures that depict the trunk from three viewpoints: looking toward the back, looking toward the head with the patient bending over (Adam's test), and looking toward the front. This last view has two sets of drawings, one for males and one for females. Each drawing is scored from 1 (greatest deformity) to 5 (smallest deformity) and a mean score is obtained by adding the scores for the 3 drawings and dividing by 3. The Score ranges from 1-15 with lower scores indicating a greater self-perception of scoliosis while higher scores indicating smaller perception of deformity. Our participants completed the TAPS at the start of the first weekend and at the end and completion of the workshop at the second weekend. They obtained a high score in Trunk Appearance Perception Scale indicating smaller perception of deformity and a positive affect and satisfaction with their body image (please see scores on Table 1, (Appendix 1 TAPS1)). Table 2 below presents the mean scores on TAPS before and after the participation and completion of the study, showing that their mean score was slightly lower after the end of the second weekend (t-test revealed no statistically significant difference-drop) showing a greater self-perception of scoliosis after participating in the workshops and the focus group discussions making them more aware of their condition and deformity.

Table 2: Mean scores on TAPS before and after the participation in the event

	N	Minimum	Maximum	Mean	Std. Deviation
mean_pre	9	3	5	4.26	.572
mean_post	9	4	5	4.11	.408
Valid N (listwise)	9				

Whilst Patient self-image improved from mean preoperative 3.16 to 2-year follow-up 4.64 ($p<0.001$). Patient mental health improved from mean preoperative 3.67 to 2-year follow-up 4.34 ($p=0.004$). The SRS-22 reports indicate that the psychological impact of AIS on self-image and mental health is adverse. This finding correlated with the focus group transcriptions and the discussions that took place throughout the other workshops whereby participants articulated the post-surgery period as emotionally distressing and unresolved. Overall satisfaction increased despite many describing that the isolating experience of scoliosis and its treatments had left them feeling emotionally altered.

The mixed methods revealed that post 2-year the participants were satisfied with their body image. However, the workshops demonstrably evidenced that the psychological impact of diagnosis and surgery for AIS was emotionally distressing due to both the socially isolating experience of scoliosis and its treatments. The workshops further evidence that the emotional wellbeing 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.

Conclusion:

It is important to point out that the participants had very good clinical outcomes as assessed by the radiographic measurement parameters with no surgery complications, no re-operations and a good personal perception on surgical results as expressed in their responses of the SRS-22 and the TAPS Questionnaires.

The demonstrable impact of art methods on the individuals' ability to articulate their experience of Scoliosis treatment in meaningful ways was firmly established whilst the project also evidenced public interest gained through exhibition outputs, and the importance of both inter-generational research methods and non-clinical settings.

Further demonstrated was that body-image was a lesser concern for most participants however, the need to express themselves and their relationship with their diagnosis and treatment 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 Misterka 2013). At a time when mental health issues in young people are on the rise from 1 in 6 17-19yr olds in 2021 to 1 in 4 in 2022 (NHS Wave 3 survey 2022), it is critical that alternative, interdisciplinary approaches continue particularly when the psychosocial challenges associated with AIS are globally recognised.

Whilst 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 major impact on their physical and emotional wellbeing.

Our interdisciplinary approach, grounded in arts practice, impacted demonstrably on participants emotional wellbeing contributing to positive self-esteem and social confidence. Furthermore, this study highlights the need to re-personalise personal aspects of the body which become alienated through institutional health organisations.

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Notes:

1. The Cobb Angle is used as a standard measurement to determine and track the progression of scoliosis. The method was invented by Dr John Robert Cobb 1948 and involves locating the most tilted vertebra above and below the apex vertebra on a standing x-ray of the patient's spine. Where drawn perpendicular lines extending from these most titled vertebrae meet dictates the Cobb angle.

Appendices:

Appendix 1 TAPS1

Appendix 1 - Trunk Appearance Perception Scale

BackBone Final Report

The TAPS includes 3 sets of figures that depict the trunk from 3 viewpoints: looking toward the back, looking toward the head with the patient bending over (Adam's test), and looking toward the front. This last view has two sets of drawings, one for males and one for females. Each drawing is scored from 1 (greatest deformity) to 5 (smallest deformity) and a mean score is obtained by adding the scores for the 3 drawings and dividing by 3.
Score ranges from 1-15 with lower scores indicating a greater self-perception of scoliosis while higher scores indicating smaller perception of deformity.

1 greatest deformity to 5 smallest deformity

Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
pre-intervention set 1	9	4	5	4.44	.527
pre-intervention set 2	9	3	5	4.00	.866
pre-intervention set 3 (females)	9	3	5	4.33	.707
post-intervention set 1	9	3	5	4.22	.667
post-intervention set 2	9	3	5	4.00	.707
post-intervention set 3 (females)	9	3	5	4.11	.601
Valid N (listwise)	9				

Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
mean_pre	9	3	5	4.26	.572
mean_post	9	4	5	4.11	.408
Valid N (listwise)	9				

The TAPS assesses:
Insight
Negative affect
Patient satisfaction
Positive affect
Quality of life