

**How Adolescents who underwent Surgery for Adolescent Idiopathic
Scoliosis experienced their Mental Health and Body Image, an
Interpretative Phenomenological Analysis**

A thesis submitted to London Metropolitan University in partial fulfilment
of the requirements of the Professional Doctorate in Counselling
Psychology

By

Victoria Steele

Student Identification Number: 21040471

Supervised by Dr. Angie Cucchi
School of Social Sciences and Professions
London Metropolitan University

November 2025

Declaration

I hereby declare the work submitted in this thesis is the result of my own investigation, except where otherwise stated.

Acknowledgements

Firstly, I would like to thank my participants for their time and trust in sharing their experiences with me. This research would not have been possible without them.

I am enormously grateful to my supervisor, Dr. Angie Cucchi for pushing me, supporting me, and being a constant presence throughout a difficult three years.

Finally, I would like to thank my family and friends who have always believed in me, even when I did not. My brother for putting up with me, and friends who have kept me going. I would not have been able to do this without my Mum and Dad, listening to my endless doubts, supporting me and reassuring me.

In memory of my Grandpa.

Abstract

Background

Adolescent Idiopathic Scoliosis (AIS) is a curvature in the spine with no known cause (Scoliosis Support and Research [SSR], 2024), diagnosed aged 10-19, with the worst cases commonly treated with spinal fusion surgery. The experience of AIS surgery has been explored revealing psychological difficulties and body image concerns in some adolescents pre- and post-operatively (Motyer et al., 2022; Rullander et al., 2013). Prior quantitative research has shown that those with AIS could be at risk for depression and social anxiety (Baird & Gardner, 2021) and have poorer body image than controls, though body image scores improved post-operatively (Roberts et al., 2011). Following quantitative research identifying mental health and body image as the domains adolescents struggled with most, and qualitative research highlighting further exploration of psychological difficulties, asking adolescents specifically about their mental health was deemed important.

Rationale and Aims

This research aims to explore the psychological experience of adolescents who had AIS spinal fusion surgery, asking how they experienced their mental health and body image pre- and post-operatively.

Method

Data was collected via six semi-structured interviews with female adolescents who had undergone AIS surgery. A qualitative methodology,

Interpretative Phenomenological Analysis, was used to analyse the lived experiences of participants.

Findings and Conclusions

Four Group Experiential Themes emerged from the analysis: Disrupted Belonging and The Search for Normality, Protecting Self in a Social World, Psychological Turmoil and Emotional Disruption, and Emerging Selfhood and Acceptance.

Psychological consequences of AIS appeared tethered to the ability to belong, rather than the experience of major surgery. Participants concealed and sacrificed their physical wellbeing to avoid the psychological implications of not fitting in socially.

Findings revealed surgery does not remove self-consciousness and worries about body image. Concerns and thoughts changed pre- and post-operatively but were not eradicated.

This research illuminated the importance of the social world to adolescents, and how AIS risks that. Implications included providing support for adolescents to allow them space to belong and acknowledge surgery does not and cannot 'fix' everything.

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INTRODUCTION

Major spinal fusion surgery to correct idiopathic scoliosis is the most invasive orthopaedic surgery performed on children (Kotzer, 2000).

Adolescent Idiopathic Scoliosis (AIS) is a curvature in the spine with no known cause (Scoliosis Support and Research [SSR], 2024), diagnosed aged 10-19, with the worst cases commonly treated with spinal fusion surgery. It is acknowledged AIS is not always treated with surgery; however, this study focuses on surgical experiences of AIS and mental health. To ensure surgery provides the best outcomes and patient satisfaction, Gallant et al. (2018) stresses it is imperative physical and psychological impacts are reviewed and managed. Adding the knowledge of a serious health diagnosis to an adolescent dealing with physical and psychological development was described by Sawyer et al. (2007) as an emotional burden, of ongoing stress, anxiety, stigma, possible rejection, and social disruption. Despite this, little research has sought to explore adolescents' psychological experience when going through scoliosis surgery (Motyer et al., 2022) and has not been researched from a counselling psychology lens.

Therefore, this research aims to explore the psychological experience of adolescents who underwent AIS surgery, to 'correct' their curvature, conducting interviews asking how they experienced their mental health and body image pre- and post-operatively. The research question asks:

How do Individuals who underwent Adolescent Idiopathic Scoliosis Surgery experience their Mental Health and Body Image, both prior to and after the Procedure?

Relevance to Counselling Psychology

The aim of counselling psychology is to reduce psychological distress and promote the wellbeing of individuals by focusing on their subjective experiences (Jones Nielsen & Nicholas, 2016), whilst applying critical thinking and reflexivity to evaluate the impact we as practitioners have on our practice, clients, and research. This research is interested in subjective accounts of adolescents as they navigate a deeply personal experience, asking them about their psychological experiences to gain an understanding of how AIS surgery impacted them.

Whiteley (1980) stressed a focus of counselling psychology is helping clients develop their individual potentials rather than the diagnosis they face. In line with the philosophical underpinnings of counselling psychology, the use of ‘mental health’ in the research question is defined as a holistic and contextualised understanding of mental health. It moves beyond purely diagnosable conditions, but incorporates a phenomenological approach, hearing subjective experiences and respecting the complexity and influence of social and developmental contexts. I felt this allowed me to work constructively across contexts and levels of psychological experience, and honour individuals’ understandings of their mental health and body image. Experiences of AIS do not stand alone, so recognising this complexity and incorporating it enabled a more person-centred interpretation of mental health, consistent with Counselling Psychology, my chosen methodology of Interpretative Phenomenological Analysis (IPA) and critical realist standpoint.

AIS diagnosis relies on the objective degree to which the spine deviates from a straight line. Surgery is recommended if the curvature is over 40 degrees or risks progression (worsening curvature) as the individual grows, monitored through regular X-rays (Cambridge University Hospitals, n.d.). Cases over 40 degrees indicate severity, increased likelihood of comorbid medical complications, pain and often a visible curvature.

Surgeons strive to collaborate with patients in treatment planning, but mental health and wellbeing is rarely raised within consultation rooms (Baird & Gardner, 2021). Counselling psychologists can marry scientific-evidence base with embracing the totality of the client (Cooper, 2009) whilst empowering them to know what hurts (Rogers, 1995). The juxtaposition between the positivist medical expectations of AIS with the counselling psychology approach of being led by the patient enables autonomy in adolescents who are searching for their independence (Spear & Kulbok, 2004). The vulnerable age of this subject group, alongside the risk factors of poor mental health and body image (Blakemore & Choudhury, 2006) suggest the need for psychological professionals to assist with mental health research in this field, rather than surgeons alone. Acknowledging the humanistic, and pluralistic underpinnings of counselling psychology (Cooper & Mcleod, 2010) allowed this research to apply those concepts to AIS, drawing on the complexity of the diagnosis, developmental age, and social and cultural factors impacting the adolescents.

As a trainee counselling psychologist and individual who underwent AIS surgery, the use of language is considered throughout this thesis. Previous authors have used stigmatising language when discussing scoliosis

curvatures, such as “deformity”, and “abnormal” (Gallant et al., 2018). I wish to align with Counselling Psychology’s commitment to critical reflexivity and anti-discriminatory practice (Donohue et al., 2024) and avoid the use of such language. However, at times, language has been kept in the authors’ words, in quotations to highlight the use of such terminology.

Theoretical Framework

This research grounds itself within a feminist framework. This study looked to recruit all genders and grounding in a feminist framework allowed an exploration of how one experiences their body incorporating societal ideals and medical interventions. Feminist approaches presented draw on female experiences of their body and society, however principles also highlight how male bodies which do not conform to societal norms are subjected to scrutiny and ‘correction’. It is acknowledged more females will be recruited as AIS impacts females and males at a ratio of 1.4:1 respectively, increasing to 7.2:1 for curvatures over 40 degrees, (Konieczny et al., 2013) making females more likely to require surgery.

Kagan and Tindall (2003) explore principles of feminist approaches to counselling psychology, calling on emphasising gender and sex role stereotyping. De Beauvoir (1956) states the way a woman experiences her body is a direct consequence of her internalising the view of it under the gaze of others. Garland-Thomson (2020) brings the argument back to scoliosis, highlighting how the brace developed in the 1930s to “correct” (p.10) scoliosis is like the nineteenth century corset. Both used to “normalise” (Garland-Thomson, 2020, p.10) female bodies and enforce the standardised female form, suggesting medical interventions can ensure

individuals, particularly women, conform with societal norms of how to look.

Kagan and Tindall (2003) stress how experiences are at the core of feminist work, unmasking and analysing the stereotypes women face, alongside the expectations and roles asked of women at different stages of their life, through socialisation. Whilst scoliosis affects all ages, adolescent surgery is most common (Stitzel, 2024). Recovery is quicker at a younger age, (Cobb, 2016) but the societal pressures on adolescents to have the “ideal” body type for that era (Aniulis et al., 2021) cannot be ignored as another possible factor, upheld by surgeons and adolescents who want to fit in. McCabe et al. (2002) suggest girls go through a period of major developmental transition in early adolescence, between ages 12-14, where gender-role identity, body image and psychological structure is questioned.

Feminist frameworks within counselling psychology aim to facilitate equality in personal power between men and women and seek to help clients recognise their power (Kagan & Tindall, 2003). Lennon and Fischer (2024) looked at feminist perspectives of those with significantly less power than able bodied women. Lennon and Fischer (2024) state general culture associates disability as those with defectiveness, insufficiency, and imperfection, and are routinely overlooked, even within feminist arguments. Those with AIS may perceive themselves or be branded with labels such as “disabled”, weak, different, and “abnormal” compared to society, further exacerbated by male medical professionals stating their “abnormal” body should be ‘corrected’. Consultation rooms for AIS are usually inhabited by a male surgeon, with only 7% of UK orthopaedic consultants being female,

(Ahmed & Hamilton, 2021). Garland-Thompson (2020) agrees with Lennon and Fischer (2024), defining disability as a broad term that devalues bodies not conforming to societal norms. She says: “The unreconstructed female body is persistently cast as having abnormalities that can be corrected by surgical procedures which supposedly improve one’s appearance” (2020, p.12). From a feminist angle, AIS surgery could be rooted in ableism, correcting bodies to conform to societal norms.

However, despite highlighting societal pressures on body shape, it is important not to simplify the decision for surgery, or create a narrative that women are having scoliosis surgery simply to improve appearance. Treatments reduce pain and medical complications of a curved spine. To ground in a feminist lens and counselling psychology allows this research to explore the complex adolescent experiences of their body, body image, and mental health before and after surgery, exploring expectations placed upon them, and value in themselves, whilst allowing them a voice that may be lost within consultation rooms. A critical realist lens is discussed in Chapter 2, allowing the ‘real’ physical condition of AIS to be acknowledged, alongside ‘real’ social systems that value normative bodies, generating the ‘actual’ social scrutiny and medical appointments, and shape the ‘empirical’ human experience.

Alternative frameworks were explored, specifically developmental theories, such as Baumeister and Leary’s (1995) theory on the adolescent Need to Belong. This critical need in social development is interrupted by AIS diagnosis and surgery, and grounding the research within this sensitive timeframe for adolescents would have allowed further exploration around

brain and body changes in adolescence. However, it was felt the theory ignored external forces applying to AIS, such as gender expectations and social norms, which the feminist lens allowed me to explore.

Furthermore, social comparison theory (Festinger, 1954) was considered, detailing how adolescents evaluate their abilities, opinions and worth by comparing to others. This theory would have helped to explore how appearance norms are shaped and potentially internalised by adolescents with AIS. The biopsychosocial model (Engel, 1977) was considered due to its holistic nature aligning with counselling psychology values and would allow the marrying of the biological underpinnings of scoliosis, with the psychological aspects of body image, anxiety and identity, alongside the social lens of peer relationships and cultural ideals. However, neither theory explores how and why bodies become scrutinised by others, where social norms originate, expectations carried by norms and whose interests they serve, and may overlook some individual differences. Feminist theory allowed me to explore comparison, alongside gender norms, power and social expectations of bodies.

Despite the feminist lens used here, the goal is not to devalue male experiences, but instead use the feminist lens to integrate power, the gaze of others and sociocultural constructions into the lived experience of mental health and body image within AIS surgery across genders. Theory is used to guide and ground the research, but I endeavour to allow flexibility in drawing on other theories where appropriate, such as in the findings where development theory is drawn upon.

Reflexive Statement

Reflexivity is a vital cognitive practice, useful in the private and professional lives of counselling psychologists (Mortari, 2015). Within research, reflexivity acknowledges the researcher's role, (Wilhelm, 2013) allowing me to position myself as the knower within the context of my study, observe my subjective biases and viewpoints; whilst analysing my lived reality and its influence on the research (Dixon & Chiang, 2019). This has been particularly important due to my diagnosis of AIS at the age of 16 and surgery aged 17.

Pal (2012) published a paper in the Australian Journal of Counselling Psychology discussing the psychological impacts of AIS, and her surgery. This reassured me counselling psychology input is needed and allowed me to see the benefits of reflexivity within this topic. This research has elicited high anxiety, of not feeling good enough, worries about whether I was doing the right thing, and whether my topic was relevant and appropriate. At times, due to the emotiveness of this topic and to gain perspective, I have had to step away from the research, re-gather my thoughts, lower my anxiety, take reflections to personal therapy, and use my reflective diary (Leech & Onwuegbuzie, 2009). Though still nervous about the importance of this work, these helped to protect my wellbeing which is central to my developing identity as a counselling psychologist and researcher. I feel I have also had to manage multiple roles; a trainee counselling psychologist, trainee researcher and previous AIS patient. Fleet et al. (2016) acknowledge this dual identity can be difficult to untangle, especially within qualitative research, but Gabriel (2005) suggests the use of

self-reflexivity to conquer these difficulties. Giving each of these roles' space within clinical work, my research and personal therapy has helped untangle them and ensure they do not become confused. Feedback from my supervisor and friends helped me to bracket my opinions and emotions and not carry them into my research more than necessary, though I am aware they will be present, as William Morris (1974 /1880) reminds us, our contributions are reflected in every word we write, read, or hear.

During the literature search, prior authors repeatedly used the term "physical deformity", and I found myself using this term when searching for literature. Typing those words was a difficult moment of realisation that my body was, at one time, not "normal". Reading studies about poor body image and its prevalence in females with scoliosis has brought thoughts about my uneven waist to the forefront of my mind. The language of "correct" and "fix" were said by my surgeon to highlight benefits of surgery and, though somewhat reassuring at the time, that language could be incredibly damaging to a teenager, being told they need to "correct" their body.

This literature review has highlighted my self-doubt but allowed me to explore an area I am passionate about as a researcher and previous AIS patient. Dixon and Chiang (2019) share researcher reflexivity is essential, whilst being aware of one's preconceptions towards research topics. My experience is not one I can forget, but bracketing my voice and learning about the experience of others has been enlightening.

CHAPTER 1. CRITICAL LITERATURE REVIEW

1.1 Chapter Introduction

The starting point of this research was a literature review exploring current qualitative and quantitative research into the mental health and body image of adolescents experiencing AIS surgery. The chapter begins by introducing AIS, the context of adolescence and then how the literature search was conducted. Current literature is introduced and critically analysed, organised thematically by methodology, then by temporality of pre- and post-operative. Out of this review, a gap in exploring psychological experiences across the trajectory of surgery was identified and the research question into how adolescents experience their mental health pre- and post-operatively emerged.

1.1.1 Understanding Adolescent Idiopathic Scoliosis

Scoliosis is measured by the Cobb angle, or angle to which the spine deviates from a straight line, with results over ten degrees being diagnosed as scoliosis (Kane, 1977). There are three types of scoliosis: infantile, under the age of three, juvenile, from five to eight, and adolescent, age 10 to 19. The causes of scoliosis can be numerous, but those without specific cause are defined as idiopathic, accounting for eight out of ten cases (National Health Service [NHS], 2019). AIS affects between 0.47% to 5.2% of the worldwide population, with girls affected more than boys with a ratio of 1.4:1, increasing to 7.2:1 for curvatures over 40 degrees (Konieczny et al., 2013). This gender difference is widely accepted across the literature. Ninety percent of idiopathic cases are diagnosed as AIS. Between 10% to 25% of cases can progress to a curvature over 40 degrees (Altaf et al., 2013;

Blanco et al., 2024; Cambridge University Hospitals., n.d.), which can cause medical complications and a visible curvature, resulting in surgery being recommended. Surgery inserts metal rods either side of the spine to stabilize the spinal curvature, lowering the curve degree and “correcting the deformity” (Jada et al., 2017, p.4).

It is acknowledged the diagnosis of AIS impacts a larger group, but this research looks to explore the experience of AIS surgery on adolescents, specifically within this pivotal age group of 10-18 where mental health difficulties may develop.

1.1.2 The Stage of Adolescence

Adolescent brain development causes heightened social sensitivity, greater impulsivity, risk-taking, irritability, and self-consciousness increasing the risk of mental health difficulties (Blakemore & Choudhury, 2006). Hashmi (2013) describes adolescence as a transitional state, where teenagers begin to separate from their parents, placing more emphasis on fitting in with peers, and developing their identity, but lack their clear role in society.

Additional worries about body image and how they look were reported by 52% of adolescents and 63% reported that other people’s perception of them was important, in a survey of 2,000 adolescents (Young Men’s Christian Association [YMCA], 2019). The developmental stage of adolescence causes physical changes in the body which require adjustment, coupled with societal pressures, media influence, peer comparisons, parental expectations, and personal perceptions (Terence et al., 2024). Introspection and body image ideals can influence the psychological wellbeing and self-

esteem of an adolescent, and their place in the world (Pfeifer & Berkman, 2018). Body dissatisfaction consistently links to low self-esteem, heightened vulnerability to mental health disorders, and engagement in unhealthy behaviours (Stice et al., 2021). This is key to this research, where a visual spinal curvature is potentially occurring.

Understanding adolescence as a period of increased risk of mental health difficulties and body image, helps to contextualise the experience adolescents with AIS may be dealing with. If the general population are struggling with identity formulation in adolescence, this research hopes to explore psychological impacts of an additional factor of AIS surgery.

1.1.3 The Literature Search

When we consider the severity of AIS surgery, the vulnerable age, and explicit links with body image, this surgery is unique from other childhood surgeries or illnesses in its presentation and impact, therefore requires specific research and potentially, intervention.

Reviewing this literature began with reading around AIS and mental health. Key terms were searched in Google Scholar, and PubMed search engines. Terms *AIS*, *scoliosis surgery*, *mental health*, *psychological difficulties*, *physical 'deformity'* and useful citations included in previous studies were investigated. Pre- and post-operative studies were read to explore impacts across the experience. Some studies discussing other forms of treatment, such as bracing, were excluded due to this research specifically focusing on AIS surgery and mental health.

The review begins with qualitative studies exploring adolescent experiences of AIS surgery, allowing individual voices to be heard first.

1.2 Qualitative Research on Adolescent Experiences of AIS Surgery

1.2.1 Pre-operative Experiences

Motyer et al. (2022), affiliated with the School of Psychology at University College London, acknowledge the gap within mental health and AIS, identifying there is limited research exploring adolescents' psychosocial experience, specifically pre-operatively. American Psychological Association (2019) defines psychosocial as the interaction of society, culture and environment on the mind and behaviour. Motyer's research acknowledges the contextual implications on adolescents with AIS, as they attempt to use social information to find their place in society (Molleman et al., 2022). Motyer et al. (2022) conducted thematic analysis (TA) following interviews of 14 adolescents who were awaiting AIS surgery. The authors reference how TA has been underutilised and allows an inductive approach, given the exploratory nature of the research. They incorporated reflexivity to self-evaluate their choice of methodology and influence in the analysis (Braun & Clarke, 2019). Themes from Motyer et al's. (2022) semi-structured interviews highlighted how adolescents avoided and missed activities with friends, were unable to join in with things, and sometimes had to rest during the day, leading to feeling down. Avoiding telling friends was driven by fears of being treated differently or misunderstood, however participants who confided in friends reported positive outcomes. Anxiety and fear towards upcoming surgery was noted, the prospect of surgery itself, and falling behind in school, sports, or social activities. Many were keen to have surgery and "move on", allowing things to "go back to normal". Motyer et al. (2022) report negative psychosocial

experiences pre-operatively and help us acknowledge AIS does not occur in isolation. However, attempts to understand the internal impact on the individual are necessary but yet to be directly studied (Essex et al., 2022). The present study will explore the internal and individual distress participants may be experiencing, providing further qualitative research for a richer understanding of participant experiences (Toye et al., 2016).

Motyer et al. (2022) acknowledged how important body image was. Participants used negative language such as “abnormal” to describe themselves, feeling unable to wear certain clothes, feeling different from peers and choosing clothes to hide their body. Participants pinned hopes on surgery to improve their appearance, whilst others believed surgery to be the solution to the problems they were experiencing. Motyer et al. (2022) did not follow-up with participants post-operatively, research which could have explored whether emotions and body image changed. My research question began focusing on pre-operative, as Motyer does. However, evolved as research highlighted less qualitative data post-operatively, and suggestions distress is not resolved post-operatively (Carrasco & Ruiz, 2016).

Carrasco and Ruiz (2016) completed semi-structured interviews with 12 women, aged 15 to 22, in Spain, diagnosed with AIS, who were awaiting surgery. A phenomenological hermeneutical method was used, with a rationale that it captured the essence of lived experience. The age group is wide, given most 15-year-olds are at school, living with parents, with compulsory education ending at age 16 in Spain, whilst 22-year-olds may be living away from home, studying, or working. Acknowledging these life changes may be important when it comes to how young women perceive

their body, alongside the roles society places on different ages. The researchers state their rationale for excluding males is the higher rates of AIS in females and the sample was not intended to be generalisable. AIS males worried less about body image in pre-operative quantitative studies (Roberts et al., 2011), but ignoring male voices feels discriminatory, as men can still be victims of a sexist culture (Kagan & Tindall, 2003).

Carrasco and Ruiz (2016) highlighted, like Gallant et al. (2018) pre-operative body dissatisfaction was the most impactful factor of scoliosis. Carrasco and Ruiz's (2016) participants reported family/friends observed their scoliosis pre-operatively or named their body looked "wrong" prior to diagnosis. Girls said they tried to hide their uneven shoulders or waist in clothing and avoided social activities. The findings of this study led to the present study's inclusion of body image, within the research question.

Carrasco and Ruiz (2016) link back to feminist viewpoints, stating society tells women they have the "unique purpose" of desiring to be like others, be accepted, and succeed. Many AIS patients experienced "relief" at being scheduled for surgery, as Motyer et al. (2022) found. The anticipation of having their curvature "corrected" exceeded concerns about major surgery. However, Carrasco and Ruiz (2016) felt surgery could not resolve negative self-perceptions or the psychological consequences of body dissatisfaction including low mood, social isolation, and low self-esteem, due to the heightened desire for societal acceptance. These speculations prompted the aims for the present study, which will build upon Motyer et al. (2022) and Carrasco and Ruiz (2016) by combining questions around mental health and body image and include post-operative experiences.

1.2.2 Experiences Post-operatively

The studies presented below ask participants post-operatively about their pre- and post-operative experiences. Researchers here report findings over the experience of AIS surgery, acknowledging concerns pre-operatively often remained after the operation. Worries about surgery reduced post-operatively, but new worries formed.

Macculloch et al. (2009) held focus groups for a mixed group of pre- and post-operative adolescents, with the aim to identify support needs of adolescents with AIS. Macculloch et al. (2009) identified key themes of worries of recovery, concerns about post-surgical appearance, maintaining friendships, and people staring, or being unsupportive. Macculloch et al. (2009) concluded themes were expected, but the intensity of concern was higher than anticipated, highlighting how adolescents may be struggling more than previously thought. This reflection highlights the need for louder adolescent voices within AIS to help researchers, parents and surgeons begin to understand the experience of adolescents. However, group dynamics may constrain individual expression, with participants adhering to social desirability, conformity, fear of judgement or choosing to limit disclosures (Hollander, 2004). Additionally, focus groups can limit depth of individual responses (Crabtree et al., 1993). Given the unique nuance of AIS surgery, individual interviews felt more appropriate in this study to capture depth and individual experience.

Rullander et al. (2013) interviewed adolescents two years post-operatively regarding pre- and post-operative experience, which guided the aim for this study. However, Rullander et al. (2013) approached the study

from a medical standpoint, looking to explore impacts of pain, pain management, coping strategies, and physical side-effects of painkillers, noting anxiety pre-operatively and missing out with friends post-operatively. Psychological impacts of surgery may be attributed to physical pain or side effects of medication despite Rullander's humanistic methodology. The present study will explore the trajectory of pre- and post-operative, as Rullander does, but from a psychological viewpoint.

Rullander et al. (2013) used content analysis to interpret text and describe phenomena from a humanistic lens, capturing spoken word and emotional context to analyse the contents of AIS experiences. Content analysis, known as an unobtrusive methodology, can be used in sensitive topics (Prasad, 2008). However, Eatough and Smith (2017) suggest IPA, used here, may be best suited to topics highly important to the participant due to its focus on interpretations of situations and the self. The content of messages around AIS is important, but applying a double hermeneutic to explore interpretations of participant experiences may have allowed the research to expand further. However, Rullander et al. (2013) attempt to hold onto context, as content analysis typically reduces text to concepts (Cho & Lee, 2014), potentially disregarding nuance. Rullander et al. (2013) reported participants paused to cry or compose themselves during interviews. Whilst acknowledged that we cry for multiple reasons, in Rullander et al.'s (2013) study, crying may occur as participants reflect on their suffering and experience an overwhelming emotion (Miceli & Castelfranchi, 2003). Rullander et al. (2013) may implicitly have highlighted the overwhelm and suffering adolescents who underwent AIS surgery experienced which

reinforces the importance of the present study to explore psychological distress in adolescents.

Rullander et al. (2013) named codes including fear of surgery, nervousness, and helplessness prior to the operation and fear, anxiety, nightmares, and sleep difficulties immediately post-operatively. They highlighted the significance of changed body image, and self-consciousness of their scar post-operatively. Loss of friends and social networks were reported as long-lasting, with some participants experiencing social difficulties up to two years post-operatively, due to missing school, clubs, or other hobbies. Rullander et al. (2013) allow us to acknowledge difficulties pre- and post-operatively, which builds on Motyer et al. (2022) as it highlights surgery did not eradicate emotional difficulties or consequences on the adolescent's life post-operatively. A limitation Rullander et al. (2013) acknowledge is memory recall as a limitation with some adolescents being two years post-operative at the time of interview and reported participants aged 15-18 may provide less rich description. Time passed since surgery may impact memory recall in adolescents (Peterson & Whalen, 2001) but emotionally charged events can be deemed more memorable (Kensinger, 2009). Addressing this concern could allow researchers to recognise whether memory recall is a limitation here. This thesis looks to capture an adolescent voice, as Rullander did, to utilise an adolescent perspective of AIS surgery and seeks to value those accounts. The current study will interview adolescents up to three years post-operatively and acknowledges the limitations Rullander et al. (2013) suggest but adopts a humanistic viewpoint to listen and validate experiences despite potential limitations.

Contrasting accounts came from Bilik et al. (2018) who interviewed adolescents on their 2nd and 10th day post-operation. Participants reported nervousness and irritability after surgery, but named a positive body image, contrasting with Rullander et al. (2013), noticing they were taller and could sit straight, suggesting surgery improved poor body image. However, these accounts immediately after surgery may be influenced by confounding factors. It may be hard to see the impact of surgery when participants are still hospitalised and yet to return to daily activities.

Qualitative data has highlighted pre- and post-operative difficulties in adolescents with AIS, with varying states of improvement after surgery. Meaning-making and complex emotions have been highlighted in the methodologies used. Prior studies have shown individually how body image and mental health changes over pre- (Motyer et al., 2022; Carrasco & Ruiz, 2016) and post-operative (Bilik et al., 2018; Mucculloch et al., 2009; Rullander et al., 2013), but accounts from the same participant sharing their experience pre- and post-operative are rare. Though Rullander et al. (2013) studied this, it held a medicalised lens, focusing on pain and physical considerations. Physical considerations are recognised and dealt with (Motyer et al., 2022) so a psychological lens can ensure psychological needs are highlighted. In a systematic scoping review, Essex et al. (2022) reviewed 15 papers and highlighted aside from asking about their experiences, none of the studies reviewed asked patients specifically about their mental health, thus primary concerns of patients may be missed. Specific focus on mental health may allow adolescents to expand on concerns raised in previous studies. Allowing participants to reflect on pre-

and post-operative will help see the trajectory of mental health and body image throughout as a complete lived experience. It is hoped this research will fill that gap.

Quantitative research will now be explored to highlight struggles adolescents with AIS may be experiencing compared to peers and show how quantitative scores shift over the trajectory of the surgical experience.

1.3 Prevalence of Poor Mental Health Among Adolescents with AIS

Pre-Operatively

The above has explored qualitative studies hearing the voices of those who are awaiting or have experienced scoliosis surgery. This research is approached with a critical realism lens, grounding in a feminist framework, whilst acknowledging the medical science behind scoliosis. Qualitative and quantitative methods should be explored to evaluate explanations of the empirical, or impact of AIS surgery (Zachariadis et al., 2010). Quantitative studies can identify the prevalence of poor mental health among adolescents with AIS and compare to controls.

It is acknowledged how clinically mental health diagnoses named in the below paragraphs contradict with the non-pathologizing approach of counselling psychology. The language of clinical diagnoses of mental health was used by the researchers. I aim to use language here descriptively, not diagnostically.

1.3.1 Anxiety and Depression

Baird and Gardner (2021) surveyed 33 adolescents in the UK who were awaiting AIS surgery. Participants completed screening questionnaires, consisting of three questions, to separately evaluate whether

further assessment for depression and social anxiety was needed. Scores showed 18% (6/33) and 59% (19/33) respectively met the criteria for further assessment, with a positive correlation for association between the screening tools. Baird and Gardner (2021), both spinal surgeons, question how well UK surgeons screen for psychological difficulties using appropriate screening tools. Grevitt et al. (1998) agreed, concluding spinal surgeons are poor at noticing psychological distress in patients awaiting surgery, finding 26% of the time, surgeons falsely implied a patient was psychologically “normal”, (P.222; Grevitt et al. 1998) when they were psychologically distressed, as measured by a Modified Somatic Perception Questionnaire and Zung Depression Index. Baird and Gardner’s (2021) report comes 23 years after Grevitt et al.’s (1998) observation, suggesting little has been done to acknowledge or support adolescents’ wellbeing.

These studies build a case for the current research, highlighting some adolescents with AIS are struggling with psychological difficulties (Baird & Gardner, 2021) and emphasises how surgeons may not be the right professional to research or support adolescents with their mental health, as Grevitt et al. (1998) showed. This present research allows focus on the psychological impacts from a counselling psychology lens, rather than surgical professionals attempting to navigate psychological difficulties.

Baird and Gardner (2021) compared data with controls in a US study. Angold et al. (2002) had 6544 children complete the Short Mood and Feelings questionnaire (Angold et al., 1995), a 13-question measure derived from a longer 30-item Mood and Feelings questionnaire. Angold et al. (2002) saw scores for depression in 4.8% for males and 7.2% for females,

compared with the 18% in Baird and Gardner's (2021) study. Despite coming from the US, and subject to cultural differences, comparison to general population highlights how AIS adolescents may be struggling. Comparison data was not available for the social anxiety screening questions. Future research using a standardised social anxiety questionnaire would provide helpful comparisons with the wider population.

Baird and Gardner's (2021) paper, though a small, localised sample, suggests those awaiting AIS surgery are at higher risk for depression compared to a control population, and speculated higher risk for social anxiety. This is relevant to the present study as it highlights how adolescents with AIS may be struggling with their mental health more than controls. My study aims to explore these struggles and interpret how AIS impacted them.

One study which emphasises the need for this research now is Jamnik et al. (2023). They saw mental health scores on the SRS-22 (Scoliosis Research Society) questionnaire have declined over the last 20 years, implying pre-operative adolescents are struggling more with their mental health than previously. Researchers acknowledge the SRS-22 as a valid and reliable tool in assessing AIS patients (Asher et al., 2003), but it is not a standardised measure of mental health. The SRS-22 is useful for surgeons to refer AIS adolescents onto pre-operative psychological support, however, as Baird and Gardner (2021) highlighted, it appears adolescents are currently not being referred despite high scores, and it is not routinely given to adolescents to complete.

Jamnik et al. (2023) raise factors such as social media, online bullying and societal pressures contributing to poorer mental health, which

emphasises the need for a contextualised approach in this field. Jamnik et al. (2023) also saw more appearance scores in pre-operative adolescents dropping below mean scores of “healthy controls” over time. This also raises the contextual, cultural environment pre-operative AIS adolescents are having to cope with, as social media impacts body image (Franchina & Lo Coco, 2018). Gender, age and class could intersect here. Qualitative explorations in the present study will allow conversations around cultural and internal facets of psychological experience to take place.

1.3.2 Body Dissatisfaction

Literature concerning body image uses a range of terminology; body image describes a dynamic mental representation of one’s body (Schilder, 1935), and body dissatisfaction is “negative thoughts and feelings about one’s body” (Grogan, 1999, p.6). Body Image Disturbance (BID; Hosseini & Padhy, 2023) occurs with perceptual cognitive, affective, or attitudinal distortions regarding one’s body size. Most uses of body image within AIS literature appear to refer to body dissatisfaction rather than BID.

Auerbach et al. (2014) acknowledges how important psychological wellbeing is to an individual’s overall health, with increased societal, appearance-related pressure in adolescence with a desperate desire to fit in with friends (Rumsey & Harcourt, 2012).

Gallant et al. (2018) stated AIS adolescents who require surgical treatment may have a “grossly visible deformity” (p.421) in their body shape. Gallant et al. (2018) fails to realise this language could be stigmatising to those with AIS and could offend or increase body image concerns in an AIS population. This language reinforces the need for

counselling psychologists to be involved in AIS research to champion compassionate and collaborative research (Donohue et al., 2024). Gallant et al. (2018) states body image concerns are the most important link between AIS and psychological difficulties. This section will look further into research exploring this claim.

Roberts et al. (2011) gave 621 females and 123 males the SRS-30, a version of the SRS-22 (2006) with eight additional questions, to establish differences in scores pre- and post-surgery. Pre-operatively, body image had the lowest scores of the five domains (mental health, pain, activity, self-image, and satisfaction) for both genders, highlighting the repeated finding that body image is a concern in AIS. Gender figures were consistent with AIS ratios, and body image scores were significantly lower in girls with AIS than boys with AIS. Body image scores were significantly lower in AIS pre-operative adolescents than age-matched controls, allowing us to conclude AIS impacts body image, irrespective of gender. This builds a case, supporting my research question, for further qualitative exploration of body image in adolescents with AIS. Interestingly, preoperative scores of mental health were higher in AIS females than controls in Roberts et al.'s (2011) study. Factors for this were suggested as differing demographic factors between the populations. Male mental health was the same between preoperative and controls.

In a contrasting study, Auerbach et al. (2014) states the SRS questionnaires do not consider the patient's thoughts, emotional wellbeing or ability to function daily, and argue there is a need to assess those with AIS for BID. Auerbach et al. (2014) rationalises by stating body image is

crucial during adolescent development, highlighting the impact of a “visible deformity” (p.2) on body image and the importance of the individual’s psychosocial wellbeing. Auerbach et al. (2014) created the BIDQ-S, a modified version of the BIDQ (Body Image Disturbance Questionnaire; Cash et al., 2004), with the same questions, but asks participants to consider their “back shape” when answering. Auerbach et al. (2014) saw those awaiting AIS surgery with a mean age of 14, had worse body image than age-matched controls, with no gender differences. Auerbach et al. (2014) and Roberts et al. (2011) concluded pre-operative AIS adolescents had worse body image than controls, over two different measures. Research points to AIS impacting body image negatively but the present study will explore specific feelings around body image to begin identifying how and why AIS impacts body image.

Auerbach et al’s (2014) lack of gender difference contrasts with societal and research norms of females, namely adolescent females, being more critical of their bodies and having poorer body image than males (Delfabbro et al., 2011). Auerbach et al. (2014) report the disparity may have occurred due to a lack of male participants within their AIS group. However, the modification of the questionnaire is debateable, as participants are asked to think about their “back shape” as they answer. Carrasco and Ruiz (2016) highlighted how females with AIS were insecure about their back. Asking participants to think about a body part they may be uncomfortable with prior to answering a questionnaire about overall body image may bias results and produce lower scores. However, the research might highlight how males with AIS are struggling alongside females, as

both face idealised body types in media (Brennan et al., 2010). Drawing attention to an insecurity could be a downside to the BIDQ, as participants know the measure is based on scoliosis, but with the SRS-22, questions ask about the appearance of their back alongside wider questions about mood and clothing. Within the present study, asking participants qualitatively about their body image may help to unpick beliefs and draw out themes within an AIS population.

Bertuccelli et al. (2022) conducted a scoping review of 27 articles into body image and body schema in adolescents with AIS. Adolescents with AIS scored consistently lower in self-image than healthy adolescents, and lower scores were seen in those with a more severe degree of “deformity” (p.107) compared to milder cases. Glowacki et al. (2013) agreed, reporting psychological difficulties were higher in those with more severe visible curvatures, with the “deformity” causing body dissatisfaction, anxiety, stress, suicidal thoughts, decreased self-esteem, and social isolation. But Bertuccelli et al. (2022) saw severity of “deformity” did not necessarily correlate with decisions to undergo surgery. However, Bertuccelli et al. (2022) acknowledges the limitations of questionnaires over interviews and Borges et al. (2017) highlights multiple factors influencing the decision for surgery, confirming the need for qualitative research to explore the subjective psychological beliefs and views of adolescents pre- and post-operatively, supporting the present study.

In summary, pre-operative quantitative studies have highlighted a speculated higher risk of poor mental health (Baird & Gardner, 2022) and higher body dissatisfaction within AIS adolescents pre-operatively,

compared to controls (Roberts et al., 2011). This suggests a group requiring support beyond that of teenagers without AIS. What is missing is further qualitative research to fill gaps quantitative research cannot address, such as further exploration of how body image impacts the behaviour of adolescents, and how they are impacted by their body image, and perceptions of their body. The next section will explore post-operative quantitative results to conclude whether surgery does help to erase difficulties as researchers (Roberts et al., 2011) and adolescents (Carrasco & Ruiz, 2016, Motyer et al., 2022) hope for.

1.4 Prevalence of Mental Health in AIS Post-operatively

Zebracki et al. (2013) and Roberts et al. (2011) analysed mental health and body image scores post-operatively. The former surveyed 909 US participants who had undergone AIS surgery. Demographics were consistent with AIS in age (mean age of 14) and gender (80% females) providing good generalisation. They completed SRS-22 (2006) questionnaire, pre- and post-operatively, with 22 questions evaluating five domains; mental health, pain, activity, self-image, and satisfaction. Zebracki et al. (2013) showed participants' mental health and self-image improved two years after surgery when they repeated the SRS-22, but poorer pre-operative scores predicted poorer post-operative scores. Zebracki et al. (2013) concluded identifying adolescents prone to poor self-image and mental health and referring them onto psychological support pre-operatively would optimise surgical satisfaction, outcomes, and may be the best way to improve mental health. Consequently, surgeons should be aware of psychological difficulties in AIS patients.

Zebracki et al.'s (2013) findings potentially suggest surgery does not erase difficulties, though does reduce them, and those who struggle pre-operatively continue to struggle post-operatively. It is necessary to find out why those who struggled continued to do so, to determine whether confounding factors of prior mental health/body dissatisfaction was a contribution, or whether feelings brought on by diagnosis and surgery continued post-operatively.

Roberts et al. (2011) also saw body image and mental health scores improve in the SRS-30 post-operatively in both genders, though female scores were lower in mental health and appearance than males before and after surgery. Roberts et al. (2011) concludes the most beneficial effect of surgery is improved self-image, contrasting with qualitative researchers who felt surgery alone could not resolve negative self-perceptions (Carrasco & Ruiz, 2016; Rullander et al., 2013). Roberts et al. (2011) did not compare results with controls post-operatively, which would have helped identify whether AIS body image matches scores of age-matched controls after surgery.

Whilst quantitative scores show improvement, hearing perspectives from adolescents would help explore why surgery improves self-image and mental health, and what body perceptions continue after surgery.

Danielsson et al. (2001) conducted a study in Sweden exploring health-related quality of life in AIS patients. One hundred and fifty-six participants who had surgery for AIS completed questionnaires and follow-ups 20 years later. The study concluded no mental health differences between AIS patients and controls, but those who reported lower mood

during treatment had significantly lower mental health scores than controls 20 years post-operatively, highlighting, as Zebracki et al. (2013) did, poor pre-operative mental health may lead to further psychological difficulties.

Post-operative quantitative studies provide a mixture of results, some highlighting the positive impacts of surgery, of improved body satisfaction (Roberts et al. 2011; Bertuccelli et al., 2022). Other studies highlight body dissatisfaction remains, even after the visible curvature was “corrected” (Zebracki et al., 2013). The impact of having a visible curvature pre-operatively, no matter the extent, (Bertuccelli et al., 2022) highlighted the importance adolescents may place on body image pre- and post-operatively.

Though useful to see results from large numbers of participants, allowing some generalisation, quantitative studies simplify patient experience, and even reinforce the body ideals, to look and “judge correction” after surgery. It is necessary to gather more information from adolescents, asking why or what changed following surgery, as this study will do, to gain a deeper understanding of changes across the AIS journey.

1.5 Chapter Conclusion

In conclusion, the literature review demonstrates an association between AIS surgery and mental health, in qualitative studies with participants naming low mood, anxiety, social isolation, poor body image and negative self-perception (Motyer et al., 2022; Rullander et al., 2013; Carrasco & Ruiz, 2016). In quantitative studies, mental health and body image scores showed some improvement post-operatively (Zebracki et al., 2013; Roberts et al., 2011) but contrasting long term impacts (Danielsson et al., 2001). Whilst helpful to capture large participant numbers, and introduce

an idea of what changes, they miss the contextual and nuanced detail of why mental health was impacted and how it changed across the trajectory of pre- and post-operative experiences. The literature review highlights mental health and body image are impacted pre- and post-operatively, but further research is needed to explore how adolescents experienced these psychological aspects.

Therefore, this research will qualitatively explore these areas to identify how adolescents experience their mental health and body image and explore what impacts them pre-operatively and what changes post-operatively. Sanders et al. (2018) summarise when the social isolation and age of adolescents with AIS is combined, scoliosis surgery is a risk factor for psychological discomfort. Despite such findings presented here, clinicians currently pay little attention to psychological need (Essex et al., 2022; Baird & Gardner, 2021).

With a changing landscape around naming and addressing mental health (Venters, 2018), the next step is asking adolescents directly about their experience and hearing their account before and after their AIS surgery.

Having identified this gap within the literature, participants will be asked post-operatively about their experience of their mental health and body image pre-and post-operatively to see what they noticed, and if any impacts remained, or changed after the operation.

Therefore, the research question is:

How do Individuals who underwent Adolescent Idiopathic Scoliosis Surgery experience their Mental Health and Body Image, both prior to and after the Procedure?

It is hoped this research will allow for a better understanding of adolescent mental health relating to AIS surgery, whilst advocating for adolescents with AIS, using appropriate and non-stigmatising language.

CHAPTER 2. METHODOLOGY

Chapter Overview

The objective of this research was to explore the psychological experience of adolescents who have experienced AIS surgery to straighten their curvature, conducting semi-structured interviews to ask how they experienced their mental health and body image prior to and following surgery. Interpretative Phenomenological Analysis (IPA) was used to identify themes from individuals and across participants. This chapter will provide a rationale for choices made in respect to the methodology, and describe the method and procedures used.

2.1 Reflexivity on Epistemology and Ontology

Willig (2019) stresses the importance of developing an awareness of one's own epistemological and ontological positions, encouraging researchers to develop a reflexive awareness of ontology, what there is to know, what exists, and epistemology, how we come to know about it. Thus, as a trainee it felt important to reflect and acknowledge my own stance and assumptions. In doing so I acknowledged the objective reality that things exist, however feel these are impacted by our own perceptions and experiences, leaning into critical realist perspectives.

Critical realists retain a realist ontology, there is something real to find out, whilst adopting a relativist epistemology, or understanding different people will come to know things differently (Stutchbury, 2021). As discussed in the literature review, this research is grounded in feminist theory, drawing on the experiences women face, and expectations placed upon them and their bodies. However, this must be combined with the

medical underpinnings of AIS diagnosis and treatment. Critical realism allows the combination of the real, here being the biological condition and social systems that exist, the actual as the diagnosis, treatment and social scrutiny, and the empirical experience of individuals. AIS is a real, biological condition with objective features existing in a society holding onto aspects of ableism (Garland-Thomson, 2020), and critical realism's ontological realism allowed me to recognise this medical and social reality, whilst the relativist epistemology investigates the unobservable dimensions of lived experiences.

To link back to the feminist groundings of this thesis, Gunnarsson et al. (2016) states feminist theory has long acknowledged the importance of epistemological relativism and looks to recruit a variety of vantage points so we can attempt to better understand the reality of others. This perspective allows for subjective experiences to be valued and explore how adolescents make sense of their bodies, and how meanings are shaped by school, peers or medical professionals.

Walsh and Gillett (2011) argue medicine is often positivist, which may have been the viewpoint of prior AIS research, identifying Cobb angles (Kane, 1977) and pain scales (Balagué & Pellisé, 2016). However, I came to this research due to the lack of studies into personal experiences around AIS surgery from adolescents themselves, and critical realism acknowledges the same condition may lead to differing experiences based on culture, gender, social support systems and ones' own perception of events.

Whilst I have discussed the socially constructed aspects of body image and scoliosis treatments aiming to 'correct', it felt a social

constructivist viewpoint may overemphasise perception and meaning at the expense of physical reality, and minimise it to a social construct, rather than a real, objective diagnosis.

This research explored the experience of an adolescent's mental health around the objective medical diagnosis and treatment alongside subjective interpretations. This led me to a qualitative methodology, specifically IPA. Researchers agree IPA is theoretically rooted in critical realism (Farr, 2004) and essential to feminism (New, 1998), aligning with the feminist and medical underpinnings of this research.

IPA enabled me to explore the phenomenon of mental health experiences and AIS surgery; however, I realised my assumption within this research was that such a phenomenon exists, impacted by my experience of AIS and surgery. Acknowledging this was an important step in this research and led me to accept my assumption and reduce it by giving others the opportunity to share their experience via research interviews.

2.2 Rationale for Qualitative Methodology

Qualitative research can be defined as the investigation of a phenomena and aims to provide in-depth insights and understandings of real-world problems, whilst quantitative research typically introduces treatments, manipulates and quantifies predefined variables (Moser & Korstjens, 2017). My aim for this research was to explore the psychological experience of adolescents who had AIS surgery, asking how they experienced their mental health and body image. I was driven by a desire to hear the voices of adolescents and how they made sense of their mental health and body image before and after AIS surgery, which is currently

missing from the field of research. Willig (2019) states qualitative research seeks to provide an understanding of people's experiences and the meanings they give those experiences. I was keen to prioritise the different lived experience of adolescents and hear what they felt was important or what meaning they gave to their accounts. It was felt these subjective and contextualised experiences could not be captured by quantitative data.

Langdridge and Hagger-Johnson (2009) suggest quantitative methods may have been useful had my aim been to quantify or measure mental health and body image in relation to AIS surgery, or predict a cause-effect relationship, however that was not the case, and I was keen to focus on the experience.

2.3 Rationale for Interpretative Phenomenological Analysis

IPA was selected as the appropriate methodology for this research as it offers a framework for exploring experiences. Eatough and Smith (2017) highlight how IPA explores transformative matters of considerable importance for participants alongside its phenomenological, hermeneutic, and ideological underpinnings, which allow researchers to interpret participant lived experiences in depth, appropriate for the emotional, multi-faceted experience of major surgery. IPA is interested in a major experience in a person's life, the reflections that person experiences around what is happening, and research aims to engage in those reflections (Smith et al., 2022). IPA enables a nuanced exploration of how adolescents experienced their mental health and body image, before and after the experience of major AIS surgery. This meets the aims of the research question. It was also felt IPA resonated with feminist arguments presented earlier in this thesis,

empowering those with less power to share their accounts. Acknowledging the subjective lived experiences of adolescents, with IPA's idiographic commitment, alongside sociocultural contexts was important and felt in line with counselling psychology and feminist underpinnings.

However, Willig (2021) critiques how IPA relies on the assumption participants can articulate their experience. Within the study, it was acknowledged adolescents may find it challenging to retrospectively access their experience, share thoughts, and interpretations as their emotional maturity developed (Jobson, 2020). Nevertheless, adolescent participants allowed analysis of adolescent interpretations, rather than adult retrospectives on an adolescent experience. Additionally, Frosh (2007) reminds qualitative researchers, reality is often “messy” and contradictory, making coherent stories of human experiences unlikely, even with adult participants. Instead of making sense of lived experiences (Smith, 2019), Willig (2021) argues focusing on “meaning making” could be more beneficial. The present study looks to align with meaning-making processes. The following will further explore the fundamentals underneath IPA's commitment to meaning making.

2.4 Characteristics of IPA

IPA has been informed by three key philosophies of knowledge; phenomenology, hermeneutics and idiography. The below gives a brief overview of each, and how it relates to aspects of the present study, and my actions as the researcher.

2.4.1 Phenomenology

IPA's phenomenological roots allowed me to explore what participants experienced and how they interpreted those experiences, which aligned with the study's aim of exploring how adolescents experienced their mental health and body image. Phenomenology captures subjective experience in its own terms (Moran, 2002) and allows exploration of the individual's perception, awareness and consciousness, and is key as we try to understand their lived experience (Smith et al., 2022).

IPA is concerned with human lived experience, and Smith et al. (2022) summarise phenomenology within IPA as understanding people do things in the world, reflect on what they did, and understand those actions have meaningful, existential consequences. The participants in the present study faced a major experience of AIS surgery and the multi-dimensional aspect of their response to that experience, choices they made, impacts on others, emotional experiences etc. can be brought to the forefront through IPA.

Additionally, my decisions, actions and understandings are present, Husserl encourages the use of "bracketing" our "taken for granted world" (Smith et al., 2022) to concentrate on our perception of that world, and allow the experience of others in. I recognise the importance of attempting to bracket and ensuring my experiences do not leak into those of my participants. However, Heidegger stated we cannot be meaningfully detached from our "human being", (Smith et al., 2022) reminding me it is impossible to remove myself completely from the data and interpretation of that data.

2.4.2 Hermeneutics

Hermeneutics is the theory of interpretation. Heidegger's formulation of phenomenology is explicitly an interpretative activity, and he articulates a case of hermeneutic phenomenology, emphasising our access to things is always through interpretation (Smith et al., 2022). Giving further evidence that bracketing can only be partially achieved.

Within research, IPA employs the use of the double hermeneutic recognising two layers of interpretation; firstly, the participant making sense of their experience, followed by my endeavours to make sense of their meaning-making process through interpretative engagement with their accounts. Smith et al. (2022) describe the dual role that plays out here. On one hand, the researcher is like the participant; attempting to make sense of the world by drawing on everyday resources. In contrast, the researcher is not like the participant, as the researcher only has access to the participant's experience through what the participant says.

Additionally, Ricoeur (1970) distinguishes between hermeneutics of empathy and hermeneutic of suspicion. Smith et al. (2022) encourage a combination of standing in the participant's shoes and standing alongside the participant to get a different view and question their experience. Successful IPA research combines empathy and questioning by attempting to understand.

With IPA's interpretative roots, it is acknowledged concepts of validity and reliability are reframed under a qualitative lens. I followed Yardley's (2000) criteria (2.10.1) to address validity. Reliability was managed through maintaining notes during the analytic process and taking

pictures of my manual coding process. I acknowledge my own role in the co-construction of meaning, and worked to maintain a reflexive stance throughout, however, recognised the impossibility of removing myself completely as my interpretations generated the research findings.

2.4.3 Idiography

Smith et al. (2022) highlight IPA's commitment to an idiographic approach, operating at two levels. Firstly, the commitment to the particular and depth of analysis. Secondly, to understand how a particular phenomenon has been understood from the perspective of particular people, in a particular context. This commitment allowed me to place value in each participant's account, and interpret their individual perspective of their AIS surgery, mental health and body image. I analysed each participant in isolation of each other to ensure I could commit to their particular world. I attempted to understand their individual reality and acknowledge factors that played a part in their particular experience, such as age, personality, social support and psychological mindedness. I hope my analysis enables shared themes, alongside distinctive voices and variations on those shared themes between participants.

2.4.4 Alternative Methodologies

Alternative methodologies, including Grounded Theory (GT), Thematic Analysis (TA) and Discourse Analysis (DA) were considered.

Foucauldian DA (FDA; Willig, 2013) was considered given the language used throughout prior research into AIS surgery and mental health. When completing the literature review, use of language in research and by surgeons was noted so using FDA could have been helpful to explore how

AIS is talked about and constructed within culture and reality. From the feminist grounding of this research, exploring power between patient and consultant interactions, or how the media or medical texts construct language around surgery, “ideal” bodies and AIS would have been interesting. However, my aim focused around the subjective, lived experience of AIS surgery, hearing from adolescents their experience of mental health and body image, and not how language shaped their experience.

Given its use by Motyer et al. (2022), TA was considered, to identify commonalities among experiences of mental health and body image in adolescents undergoing AIS surgery. TA looks to identify recurring patterns in the interview data via inductive or deductive methods. An inductive approach would have allowed the voices of participants to share their experience. However, classifying idiosyncratic experiences is not the focus of TA (Braun & Clarke, 2012). IPA was able to capture the individual experience of scoliosis surgery, allowing me to explore the unique nuances of individual perspectives, and identify key themes individually, then across participants, highlighting potential common threads in how adolescents interpret their scoliosis surgery and mental health, whilst also valuing the individual experiences.

Finally, Constructivist GT (Charmaz, 2006) was considered, focusing on how participants construct meaning to their mental health and body image (Chun Tie et al., 2019) before and after surgery. Whilst, GT generates in-depth insight and values subjective meaning, it did not fit the research question. Had I wanted to build a conceptual model of why

adolescents experience a change in mental health and body image pre- and post-operatively, GT would have worked well. However, the aim was to understand how adolescents experience their mental health and body image pre- and post-operatively and make sense of their individual lived experience.

2.5 Research Design

Prior to recruitment, I posted a questionnaire on the SSR Facebook page, a charity supporting people with scoliosis (Appendix A). The anonymous questionnaire was for people related to scoliosis, such as those who have had surgery, have the condition without surgery, parents/relatives of adolescents with scoliosis or awaiting surgery. It asked for their thoughts on the research topic, any reservations they would have about participating, if eligible, and for feedback on sections of the information sheet and interview schedule. It was hoped this questionnaire would assist me in addressing any concerns those whom scoliosis research may impact might have in participating and receive feedback on the topic and research design from voices of service users.

Seven people completed the questionnaire. Participants unanimously agreed it was necessary research with mental health regularly overlooked by surgeons. Participants felt addressing body image and giving people a chance to talk about it was important. One participant suggested not focusing on 'early years post-op' rather extending the inclusion criteria. However, for the group to be homogeneous a smaller timeframe was necessary. Participants reflected on the importance of a warm, sensitive researcher, and the use of language for adolescents. Suggestions also

included using prompts in the interview, to help adolescents understand possible impacts of their mental health, and body image, alongside a researcher who understood the topic.

With this feedback, I entered interviews mindful to match the language the participant used, ensuring consistency and clarification of what is meant by various terminology, and an informal, conversational tone to help the participants feel comfortable and able to share their experience.

Hearing the voices of those impacted by the topic enabled me to loosen my assumptions and begin to interpret needs of others within the scoliosis community.

2.5.1 Recruitment

I began recruitment through purposeful sampling via a surgical consultant, an orthopaedic consultant, Mr. Gardner. He volunteered to send the advert (Appendix B) to introduce the study to those who potentially met the inclusion criteria. It was acknowledged adverts would reach the parent/guardian first due to the age of Mr. Gardner's patients. However, Cooper (2020) discusses recruitment as initiating a relationship. Though the research recruited adolescents, parental consent was necessary, therefore building a relationship with parents was vital. However, the advert used age-appropriate language to target both parents/guardians and participants themselves. Interested participants agreed for their contact information to be passed on to the researcher via Mr. Gardner. Mr. Gardner assisted for no personal gain. Seven participants agreed to be contacted for the study via Mr. Gardner and were sent participant information sheets (Appendix

C/Appendix D). Of these seven, two responded and were invited to take part in a pre-screening phone-call with myself (Appendix E).

Alongside this, I used volunteer sampling by using social media platforms to advertise the study (Appendix F). Adverts were posted on the SSR social media page, and other social media pages and groups that targeted the scoliosis community, capturing parents and adolescents directly. Interested individuals were encouraged to contact me via email.

2.6 Participants

Six participants were recruited, all identified as female aged 15-18, with an average age of 16.1. Despite hoping to recruit all genders as AIS impacts males and females, all interested adolescents from Mr Gardner were females and only females volunteered via social media. It was understood AIS impacts a higher number of females, so a female weighted sample was expected, however no males volunteered. Sampling via social media may have captured more females as adolescent girls use social media more than males (Booker et al., 2018) and girls may have been more interested in talking about mental health and body image than males, especially with a female researcher (Arendell, 1997). Limitations of this and recruiting males specifically for future research is discussed further in the conclusions chapter. Two responded via Mr. Gardner and the remaining four participants responded to Facebook and Instagram posts. Two others volunteered but one fell outside of the 12 months to 3-year window of surgery, and the other stopped responding to emails. The pre-screening calls were approximately 15 minutes, with the potential participant and parent/guardian, if participants were under 16. In the pre-screening call, I introduced the study, signed the

consent form with the participant/parent, discussed confidentiality, checked suitability against the inclusion/exclusion criteria, and built rapport. There was a consent form for parental/guardianship consent (Appendix G) and for adolescents aged 16-18, who provided their own consent (Appendix H), an assent form was required for those under age 16 (Appendix I). Conditions surrounding risk and safeguarding, detailed in the ethics section below, were made explicit to participants and parents/guardians at the start of the pre-screening call and again at interview. Participants and parents/guardians were required to sign and return the consent form prior to/during the pre-screening call and made aware that anything concerning shared during the pre-screening call could also be disclosed to relevant people and organisations if necessary.

2.6.1 Inclusion and Exclusion Criteria

The inclusion criteria included participants aged 13-18, who had undergone spinal fusion surgery within the last three years, but not within the last 12 months at the time of interview. Given the emotive topic, it felt necessary to exclude those who had undergone AIS surgery within the last twelve months, as up to 75% of those who develop PTSD develop symptoms within six months of the event (Smid et al., 2009). Some of the questions within the interview related to experiences prior to surgery, the day of their surgery and time post-operatively, therefore it was important participants had had time to recover from the surgery and could speak about the experience. Recall bias was acknowledged here, participants may remember aspects pre-operatively or immediately after surgery differently given the passing of time since their operation. However, the research

question also asked about post-operative experience, and it felt important to protect the participant by allowing time between surgery and interview. Equally, recall bias felt less relevant as the research sought to explore how adolescents experienced their surgery, and not evaluate how well they recalled the event. Additionally, research shows how emotionally charged events are deemed more memorable, (Kensinger, 2008) therefore reducing the impact of recall bias, though its potential presence was acknowledged.

All participants were asked “Please answer yes or no, would you deem your surgery as successful?” The research required successful accounts of surgery, defined by the participant. Though valid, experiences of unsuccessful surgery differ significantly from successful AIS surgery, and compromise homogeneity, as participants would not share a ‘similar lived experience’, an essential within IPA (Creswell, 2013).

Adolescents with additional physical diagnoses, such as neuromuscular disorders, and/or those who experienced surgical complications resulting in medium to long-term implications, deemed by the participant (e.g., paralysis, diagnosed chronic pain, infection) were excluded to ensure homogeneity. No potential participant reported such complications.

Additionally, adolescents were asked at pre-screening if they had experience of mental health difficulties, eating disorders or body dysmorphia disorder, had accessed support, and how they coped. This provided information regarding their mental health, adhering to humanistic counselling psychology principles without relying on questionnaire scores or diagnoses (Lane & Corrie, 2006). It was decided those who named

severe/ongoing difficulties would be, unfortunately, excluded due to ethical considerations. Whilst recruitment was important, removing participants with increased vulnerability limited unnecessary harm (Oates et al., 2021). One participant reported struggles with anxiety and depression, however named helpful coping strategies. They felt able to talk about their surgery and experience. I confirmed with my supervisor that participation was appropriate for this participant and sent the participant the interview schedule prior to the interview so they could prepare and ensure no questions would trigger or cause distress.

Interviews took place with the six suitable participants via video call on Microsoft Teams.

2.7 Procedure

Participants were invited to a Microsoft Teams video-call interview lasting approximately one hour. Participants were not given a choice in the format of the interview. In person interviews were considered due to the emotive topic and vulnerable age range of participants and could have allowed increased protection from harm and quicker rapport building (Shapka et al., 2016), as well as increased ability to manage potential harm, through being able to better observe body language and upset (Moran & Caetano, 2022). However, limitations included finding suitable meeting locations, geographical restrictions, and potential increased risk for young participants travelling to the interview alone. It was felt participants and their parents were able to use video-call confidently, with the contextual factors of Covid-19 and research suggesting adolescents have embraced online communication and may feel more comfortable sharing online

(Shapka et al., 2016). Participants were able to take the call in a familiar space, comfortable for them with confidentiality maintained. Participants under 16 had a parent present to ensure protection from harm. Participants were asked to use their camera during the call, a condition that had been stipulated on the consent form. This allowed me to visually check-in with potential distress and ensured all interviews were consistent with the use of cameras. Participants were invited to have parents/guardians join them during the call. The four participants aged 16 and over chose to be interviewed alone, both participants who were under 16, had their parent join them at the start of the call, before the parent left the room and the participant spoke with me alone. Interviews took place at times during school holidays, ensuring participants did not miss school, and support services were available during the interview in case risk arose.

I followed an interview schedule (Appendix J) of open-ended questions, with prompts for participants and the ability to follow the participant's lead. A distress protocol (Appendix K) and risk assessment (Appendix L) were also available throughout, for times when participants showed distress or named risk, however these were not required. Following the interviews, participants were provided with a debrief form (Appendix M/Appendix N).

2.8 Ethics

This research hopes to increase knowledge of how adolescents who underwent AIS surgery experienced their mental health and body image; however, I was aware interviewing adolescents at the vulnerable age of 13-18 (Oates et al., 2021) may have evoked emotions as participants reflected

on diagnosis, surgery, recovery, and their mental health, thus ethical considerations reflected that. Ethical approval from London Metropolitan University was gained (Appendix O) alongside NHS research ethics via the Health Research Authority (HRA) in June 2024, due to recruitment via Mr. Gardner (Appendix P)

Written informed consent was gained electronically via email during pre-screening, ensuring participants understood the topic (Oates et al., 2021), agreed to be interviewed, and recorded. Participants and parents/guardians verbally reconfirmed consent at interview. Participants under 16 signed an assent form alongside parental written informed consent (Oates et al., 2021). The BPS (Oates et al., 2021) suggest 16- and 17-year-olds can consent unless proven to lack capacity, identified via tests of capacity.¹ Participants aged 18 provided written informed consent in accordance with the age of majority and Mental Capacity Act (2005). Participants were made aware of their right to withdraw consent at any time (Oates et al., 2021).

Participants were informed at pre-screening and interview any risk shared, including but not limited to, self-harm, suicidal thoughts/attempts, harm from others, or plans/actions towards harming others would be shared with parents/guardians and/or third-party organisations if appropriate, as per BPS safeguarding policies up to age 18 (Oates et al., 2021). It was determined that whilst current risk would cause a breach in confidentiality, if the adolescent disclosed historic risk, this could be kept confidential. For

¹ Language of ‘capacity’ is used within the BPS ethics guide (Oates et al. 2021) and it is acknowledged this may not align with Counselling Psychology or my principles.

example, if the current risk was low, the adolescent named healthy coping mechanisms, and/or the adolescent felt disclosing could cause more psychological risk to them in the future, confidentiality could be maintained. It was acknowledged potential disclosures may deter some adolescents from participating, or cause dishonesty in interviews, however protection from harm was a priority. Decisions were based on individuals, and I liaised with my supervisor when necessary. However, this did not arise within the interviews, and no disclosures to parents/guardians or support services were necessary. I had a distress protocol (Appendix K), and risk assessment (Appendix L) available, and participants were asked after the interview if they felt triggered or upset by any questions, none named any concerns. Participants were debriefed (Appendix M/Appendix N) with the research question, study aims, support organisations available and given the opportunity to ask questions.

2.9 Data Collection

Interviews were audio recorded using Audacity software on the researcher's laptop and kept in a password protected folder. Live transcription on Microsoft Teams occurred. This transcript was downloaded, and audio recordings were replayed alongside the transcript allowing me to ensure accuracy and manually edit the transcripts. Transcripts and recordings were anonymised within 24 hours of the interview. Participant names and identifying factors, such as participant's naming their location, surgeon or hospital, or names of friends were masked with tonal sounds in the recordings and were deleted from transcripts, replaced with 'XXX'. These transcripts and audio recordings were then used for data analysis.

2.10 Data Analysis

Analysis began by reading the transcript of one participant, Smith et al. (2022) suggested starting with any interview that was engaging and interesting, but not too long or complex. I noted rapport, and researcher effects (Pietkiewicz & Smith, 2012) exposing my subjective biases and thus hopefully minimising their impact (Larkin & Thompson, 2012). Acknowledging personal preconceptions then allowed for line-by-line, participant focused coding completed on a blank copy of the transcript. I followed the steps laid out by Smith et al. (2022), starting with exploratory noting, colour coding for descriptive, linguistic and conceptual sentences (Appendix Q).

Whilst Smith et al. (2009) suggested this first stage is exploratory, not interpretative, Gyollai (2020) argues IPA is inescapably interpretative from the start. The double hermeneutic, or the researcher's attempts to make sense of participants' sense making (Tuffour, 2017) implies interpretation, led by personal experiences and assumptions. Attempting to bracket preconceptions whilst making sense of the text is an oxymoron (Gyollai, 2020). However, Willig (2021) argues IPA researchers should use their assumptions to advance understanding. Reflexivity and 'dwelling' on data can help separate the researcher's own material from the participant's (Boden & Eatough, 2014).

The next stage was to use the exploratory comments to identify experiential statements to consolidate and crystallise thoughts thus far, these were written in the opposite margin of the transcript. Next, I printed and cut out the experiential statements, to search for connections across them. I

spent time moving and organising them into clusters, and sub-clusters.

Though time consuming, this manual approach was advised by Smith et al. (2022) and helped me to immerse myself in the data and work within it.

Finally, each cluster, or the participant's Personal Experiential Themes (PETs) were given titles and organised into a table (Appendix R). The table organised the PET, followed by the sub-theme of that PET, and the experiential statement brought into developing it. Finally, a quotation was provided as evidence. Some experiential statements, and themes were excluded from the participant's PET table as they lacked evidence within the transcript (Smith & Osborn, 2003) and did not fit once statements were clustered.

Once completed, new analysis started with the next participant to allow individual experiences to be valued. I was aware of assumptions and interpretations from previous PETs and tried to give myself time between analysis with each participant. Larkin and Thompson (2012) suggest sharing assumptions with supervisors may limit bias. I also made personal notes about my own feelings with each analysis.

Following full analysis for each participant, I reminded myself of the PET tables to identify Group Experiential Themes (GETs) (Smith & Nizza, 2022). To explore convergence and divergence across themes and participants, Smith et al. (2009) suggests balancing participant commonality among higher order qualities, and individuality of participants' idiosyncratic characteristics. Once again, I printed and cut all the PET tables for each participant and organised them into groups to identify GETs. IPA is an iterative process, (Smith & Osborn, 2003) so earlier transcripts were

revisited as new GETs emerged throughout analysis. A master table of themes was produced, capturing GETs alongside subthemes and quotations across participants (Table 1).

2.11 Methodology Reflexivity

Throughout all aspects of methodology, I was aware of my own biases and assumptions, as a trainee counselling psychologist, a novice researcher, and an individual who had scoliosis surgery in adolescence.

Surveys conducted prior to the interviews saw those with experience of AIS ask for a sensitive, warm researcher, who allowed adolescent participants to feel comfortable during interviews. I introduced the interview to adolescents as a ‘conversation’ about their scoliosis and mental health. I hoped this change of language would put adolescents at ease, removing the negative connotations and anxiety that may be linked with an ‘interview’. I presented myself as friendly, and used a conversational, warm tone to hopefully help participants feel relaxed, and reduce the potential power imbalance within the interview space to promote participant comfort. I had a range of prompts available to help participants reflect on their experience.

Following my first interview, I felt the participant found it difficult to elaborate on open-ended questions without additional scaffolding, highlighting a limitation in the initial interview schedule. I had underestimated the support adolescent participants might require to engage in reflective dialogue. I revisited my interview schedule and refined it to include additional prompts and clarifications to facilitate deeper engagement whilst maintaining open-ended questions (Smith & Osborn, 2015). I suggested we discuss pre-operative, their surgical experience, then post-

operative, following a logical, temporal sequence (Smith et al., 2022). Some followed this, whilst others needed less structure. In these cases, I allowed participants to lead. Participants often answered in shorter sentences; therefore, my voice was more apparent throughout the interview as I asked for clarification, more information, or offered suggestions as to how different domains of life were impacted by their scoliosis. At times, more directive questions were used to prompt or confirm my understanding of their answers. I felt building rapport and my warm, friendly tone allowed participants to agree or disagree with prompts or suggestions I made, therefore not biasing the interview. Had I presented myself more formally, they may have struggled to feel comfortable and trust me, which may have led to failing to obtain ‘good’, interpreted as rich, detailed and meaningful data (Smith et al., 2009).

Upon sharing early transcripts with peers and supervisors I was made aware of times at which I had unconsciously and instinctively responded to participants with verbal agreement; “excellent” or “perfect” or referenced a shared understanding, specifically with participants I identified with. Whilst unconscious and well-intentioned to encourage participants to continue sharing, I recognised how these instances may have subtly influenced participants and constitutes a form of researcher presence. Whilst my passion for this research and personal experience has inspired me throughout, the interviews highlighted how close I was to the topic. I kept personal notes and pictures during the interview and analysis stage, noting my reflections about what participants were sharing, my memories of surgery, and my grouped themes. I was also able to interpret my reactions as

part of the double hermeneutic of IPA, and how my personal experiences were interpreting the experiences of my participants (Smith et al., 2022).

2.11.1 Research Quality

Whilst reflecting on my own biases, I was conscious of the implications these may have on the validity of the research. Therefore, I chose to ensure I followed Yardley's criteria for qualitative data (2000); sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. I strove to apply sensitivity to context through being aware of emotions the topic may bring up for the participants and conducting interviews in a respectful manner alongside wider awareness of societal and cultural context within the literature review. My personal and professional commitment to the research is hopefully demonstrated in my reflectivity throughout this thesis and detailed literature review, alongside diligence of ethical and good research practice. The coherent links between the research question, aims, links to counselling psychology and theoretical underpinnings are referenced throughout, with transparency of my own assumptions and participant and service user feedback. Member checking following transcription and analysis was not conducted. Whilst I could have given participants' the option to review quotations or transcripts to increase rigour and participant involvement (Lloyd et al., 2024), it was felt member checking would increase time participants were giving to the research (Birt et al., 2016). It may have caused delays, or additional interpretations beyond my interpretations, as the researcher, and participants could have started modifying quotations for personal preference, losing their initial meaning-making. Participants were given the option to be sent summaries of the

findings and results and give feedback, ensuring participants were still involved, if they wanted to be, but without impacting the researcher's analysis.

Finally, I hope this research increases awareness of AIS and mental health among counselling psychologists, and other medical professionals, whilst making an impact on those who may find it most meaningful.

CHAPTER 3. ANALYSIS

Overview

This chapter will present the findings from the analysis, alongside quotations from participants². Four GETs emerged, each with three subthemes. The first; Disrupted Belonging and the Search for Normality identifies the social isolation and desire to belong participants experienced, and how AIS impacted this. Protecting Self in a Social World addresses how participants navigated their social context and how concerns were often internalised to protect themselves. Psychological Turmoil and Emotional Disruption highlights emotions and mental health pre- and post-operatively, finally Emerging Selfhood and Acceptance acknowledges post-operative changes and sense of self.

Whilst presenting the GETs in a temporal sequence of experience through scoliosis diagnosis and surgery was an option at analysis, this felt reductionist for participants and may give the impression the experience through AIS surgery was complete at time of interview as Tess shared “Because it’s now over, everyone just thinks you’re fine, like, but that might not be the case” (1638-1639). I have chosen to present four GETs (Table 1), which highlight the psychological experiences of participants, contextual implications to acknowledge these experiences do not exist in isolation, and coping mechanisms used to manage feelings of distress, whilst acknowledging things are not ‘fine’. However, pre- and post-operative distinctions are referenced throughout, acknowledging how things changed for the participants before and after surgery.

² Participant names are pseudonyms.

It is noted another researcher may have identified different themes.

Table 1.

Group Experiential Themes and subthemes, with supporting quotations

Group	Group level	Supporting Quotations
Experiential Themes (GETs)	Subthemes	
Disrupted	Emotional	<i>Disappointed because, you know, I'm</i>
Belonging and	and Social	<i>at the age where this is the type of</i>
The Search for	Isolation	<i>stuff that- that I'd enjoy and look</i>
Normality		<i>forward to, but I was told that I</i>
		<i>couldn't do it anymore, so it was</i>
		<i>just upsetting as well because, um,</i>
		<i>even though it's something so little,</i>
		<i>it's- it's the only time during school</i>
		<i>where you can just relax. You're not</i>
		<i>writing, you're not doing anything</i>
		<i>like that. So, for me, having to just</i>
		<i>sit there and watch everyone else</i>
		<i>play it was upsetting, but had to be</i>
		<i>done (Flora; 418-423).</i>
	Not Being	<i>I think that really upset me because I</i>
	Allowed to	<i>got told, um, I wasn't, after my</i>
	Belong	<i>operation, I wasn't allowed to do,</i>

like, dance, cheer, gymnastics. I wasn't allowed to do anything. So, I think that actually really affected me more than I thought (Thea; 227-229).

The Search for Normality	<i>I just wanted to, like, have, I wanted to, like, feel normal, I guess because before, like, it felt like I was different from everyone else, and I don't, I didn't like that. But I just wanted to feel, like, normal. I thought after surgery, it would feel, I'd feel normal (Thea; 482-485).</i>
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Protecting Self in a Social World	Keeping it to Myself	<i>I just feel like it wasn't normal to just speak about it, just speak about my feelings. And I didn't really want to say too much anyway. I'd just keep it to myself (Flora; 567-569).</i>
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Performing Fine	<i>I was nervous about the surgery, and like the scoliosis and stuff, because it was like, I'd never really known anyone to have it... But I was just kind of unsure of it all and like, I just tried to not let it bother me and</i>
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*act like it was nothing (Sienna;
419-423).*

Self-Consciousness and Surveillance of the Body *I think, I like, notice things more now
even though I'm, like I'm more
straight now, I feel like I still see
things more than I like even did
when I was like, still had scoliosis
(Tess; 1466-1468)*

Psychological Turmoil and Emotional Disruption Anxiety Caused by Uncertainty *I did some more research. And then I
realised, like, the treatments and
stuff like the bracing and then
surgery. And it made me quite like
anxious, I guess because I didn't
know what to expect (Tess; 255-
259).*

Overwhelm *Very hard for me because I also had
my GCSEs that I had to do. Um,
and I was struggling a lot because
sometimes I have to take time off
school because I just simply
couldn't get up in the morning
(Flora; 121-123).*

Social Withdrawal *They'd still say, like "you went really
quiet, especially after you found
out". And like... "You weren't the*

same bubbly person, you kind of... ” I don’t know... Like I was never the never bubbly out there, but they’re like “you definitely did get quieter for a bit” (Sienna; 387-390).

Emerging	Changed	<i>I think it’s changed massively. Um,</i>
Selfhood and	Body	<i>because before surgery, you know, I really wasn’t happy at all with my body. Now I am happy about my body, but I just get those odd few days, just the whole weight thing, um, that is upsetting for me, but other than that, I think that, yeah, everything’s fine (Flora; 1117-1120).</i>
Acceptance		
	Self-Growth	<i>I think going through something like that, I think it just kind of changes you and changes your perspective on things. It’s helped me with a lot of things. Um, I think I’ve changed as a person, I look at things differently (Flora; 1180-1182).</i>
	Confidence	<i>It just like, well, I’m not going to change it, so there’s no point in,</i>

*like, fussing about it. But it
definitely like made me feel a lot
more confident in myself (Sienna;
1080-1081).*

3.1 GET 1: Disrupted Belonging and The Search for Normality

This GET emerged through participants reporting a strong desire to belong and be ‘normal’, but AIS disrupted this longing. All participants talked about how they experienced disrupted belonging through physical isolation, perceived emotional isolation of missing out, or being separated from friends, with a sense of falling behind and being forgotten pre- and post-operatively.

3.1.1 Subtheme 1: Emotional and Social Isolation

All participants reflected on missing out and the impact of being isolated from peers; physically being absent from school or being separated, unable to participate in activities, occurring before and after surgery.

When discussing how it felt to have to sit and watch her Physical Education (PE) lessons pre-operatively, Thea shared “That made me feel really upset and really excluded because I could see like all my friends having fun on there, like, like doing, taking part in the PE lesson, which I wasn’t allowed to do” (587-589). Her social and emotional isolation is highlighted, as she sat separately from her group of friends, watching them have fun. There is a sense of her as an outsider, looking in, and potentially she feared being forgotten by her friends as she sat physically separated. Her use of “really upset” and “really excluded” intensified the emotional impact

as her body became a barrier to joining in. It is a physical limitation but also evokes a sense of disconnection from the peer group and potential loss of identity.

Flora shared similar sentiment to the same situation pre-operatively: Disappointed because, you know, I'm at the age where this is the type of stuff that- that I'd enjoy and look forward to, but I was told that I couldn't do it anymore, so it was just upsetting as well because, um, even though it's something so little, it's- it's the only time during school where you can just relax. You're not writing, you're not doing anything like that. So, for me, having to just sit there and watch everyone else play it was upsetting, but had to be done (418-423).

Similarly, there is a sense of being an outsider, having to watch others play whilst she was “told” she cannot, acknowledging authority made a choice for her was “upsetting” and “disappointing”. Flora acknowledged missing PE as only a small compromise, drawing on her maturity and an understanding that consequences could be worse. “It had to be done” could suggest she appreciated the bigger picture of having to miss PE to protect her back. But Flora highlighted it was a “relaxing time”, potentially something useful for her mental wellbeing. She mentioned earlier in the transcript being a “sporty person”, and “enjoying PE”, having this taken away and turned into a time of emotional and physical isolation has implications of disappointment, upset, isolation and removal of a potential prior coping strategy.

Flora and Thea highlighted the social and emotional isolation prior to surgery, having to watch friends have fun without them, whilst Olivia raised upset at being off school following her surgery:

I – I was quite upset about, like, like having the surgery in the first place ‘cause like that would mean I’d have like a lot of time off school and umm, like, obviously I couldn’t like, see a lot of my friends (154-156).

All three participants used “upset” signifying a negative emotion, but potentially open to interpretation of frustration, disappointment, as Flora names, or sadness. Olivia emphasised how the surgery, rather than the scoliosis diagnosis, had a bigger impact. Olivia’s hesitation with filler words of “like” and “umm” could give a softening effect, making her words less impactful. One interpretation could be, like Flora, Olivia knew missing school was only a small compromise to make, but equally, she shared how missing friends was important to her, and a significant consequence of her AIS. It highlights school as an opportunity for peer connection and seeing friends, a specific consequence for adolescent surgery that may not be reflected in adult surgery. Missing out on this time could have social and emotional consequences, as Tess remembered:

Some of my friends got a bit closer. So, like, I was in sort of like a trio, kind of. And then they got a bit closer. And then when I went back, it was a bit weird, but it got, it was fine again after that. But when I first went back, it was still a bit weird (933-937).

Tess described her friends developing a closer friendship as “weird” highlighting a sense of unease, and things being unfamiliar upon her return after surgery, potentially due to missing out on things her friends had

experienced together. It, again, gives a sense of her returning as an outsider, separate from others. She stated things were “fine” after that, interpreted as after she returned to school, but her repetition of it being “weird” when she returned highlighted her discomfort at the situation, and perhaps upset they had become closer without her.

One consequence of this social and physical isolation was isolating oneself further because they could not do what they wanted to. Tess recalled going to watch her dance class post-operatively, saying “I think I only watched like two times, and I was like, I’m not watching again, and I didn’t really like it. It’s just, like, felt a bit... Yeah, I’m just frustrated that I couldn’t join in” (1277-1279). Despite being present, she acknowledged it was not the same as being able to join in and made her feel more frustrated and upset. Again, she was physically separated, watching her friends have fun from afar as an outsider, observing a group she used to belong to, but AIS denied her of this belonging. Her use of “a bit” minimises her feelings somewhat, like Olivia and Flora’s understanding of missing PE being “something small”. Participants seemed to feel the need to share “small” compromises, but things they had to sacrifice all the same.

AIS and surgery led to a direct decrease in hobbies, with emotional and social impacts on the participants, leading them to feel excluded and upset. Self-esteem could be affected, as the participants feel outcast. Sienna highlighted how self-esteem could translate into perceptions of being forgotten by others when she takes time off for surgery.

I didn’t think anyone would really notice or care because we’d all just went up. We didn’t have, like, full friendships and the teachers obviously

didn't know us very well, especially with it only being in kind of the January, so I would have only been in the school since the August in the previous year... (480-484).

Sienna reflected on the adolescent experience of moving to secondary school but then taking time off for surgery. The suggestion teachers and peers "wouldn't notice or care" could highlight Sienna's view of herself as forgettable and unimportant. She previously named herself as "one of the quieter ones" (617). Belonging equates to being within the group, but taking time off for surgery challenges that, such that Sienna believed she would be forgotten and left behind.

These experiences may have intensified feelings of difference, and potentially impacted self-esteem and mental health at the time of surgery alongside contextual considerations of their age and autonomy.

3.1.2 Subtheme 2: Not Being Allowed to Belong

This subtheme relates to how all participants repeatedly used language to emphasise isolation was not their choice, but rather AIS prevented belonging, and authorities around the participants enforced this.

I think that really upset me because I got told, um, I wasn't, after my operation, I wasn't allowed to do, like, dance, cheer, gymnastics. I wasn't allowed to do anything. So, I think that actually really affected me more than I thought (Thea; 227-229).

Thea highlighted post-operatively she was limited with activities, and this use of "anything" highlights how, to her, not being allowed to do these hobbies shut down her social world and excluded her from everything, a total loss. Her use of "wasn't allowed" highlights how it was not her

choice to stop these activities but rather an authority. Her omission at naming the authority could suggest it was not important who told her she could not continue, but importance lay in that she could no longer do “anything” she wanted.

Additionally, Thea reflected how her inability to do “anything” affected her more than she thought, using “really upset” to highlight her unhappiness. Her exaggerated use of “actually really” suggests this is not something she has reflected on and retrospectively the isolation and not being allowed to belong was an impactful part of her AIS experience. She reflected further about her unhappiness at being left out and unable to see friends.

I wasn’t able to go outside for break or lunch. I had- I, I think I was only there for break when I was doing half days, so I wasn’t allowed outside, so I was only allowed in like- in like three buildings (1135-1137).

Post-operatively there is a sense of being trapped in Thea’s account, repetition of being “allowed” in only three buildings creates containment, and connotations of being punished, despite her having done nothing wrong. She later described: “I wasn’t able to, like, see anyone else. So, it was kind of hard” (1189-1190). And “It was mainly because they didn’t want me to get hurt. In the end, I ended up just like sneaking out with everybody else, and just going outside, even if I wasn’t allowed to” (1206-1208). “With everyone else” suggests her desire to be with the group and included. There is need to follow authority within the school context, she shares “they”, assuming teachers kept her inside, so she did not get hurt. But Thea engaged in some teenage rebellion and emphasises how her desire to belong,

highlighted by her use of “hard”, overruled authority and any caution regarding her recovery as she “sneaks out” to join her friends.

But a lot of things, like I couldn't do, in the- in the point blank- like I did an acrobatics class which was a lot of the tricks and stuff. And funnily enough it was the teacher who'd noticed it, and she just- any backbends or any like that sort of thing. She was like, “you are not doing it” (Sienna; 266-269).

Sienna's reflection that she could not do a lot of things could be interpreted as her not being allowed to do certain movements, or due to her pain, as Sienna experienced increased pain levels pre-operatively. She shared the dance teacher, who originally noticed her scoliosis, watched her and issued the phrase “you are not doing it”. This suggests Sienna would have done the movement had the teacher not stopped her. Sienna reflected her personality was to do things “110%” and AIS did not allow her to try and do things as she would have liked to. Sienna wanted to do the same as others, and ‘belong’ in class, however again, authority and her AIS did not permit her to.

3.1.3 Subtheme 3: The Search for Normality

All participants craved normality, either through rushing to return to school and hobbies, ignoring medical advice or authority and joining in with peers, or hiding aspects of their AIS to appear the same as others, and ‘normal’. It was apparent within their accounts AIS was a source of difference. There ensued a conflict of mentally wanting to be the same, but their body giving them away, especially if the AIS was visible. The consequences of this crisis could be low self-esteem, or anxiety of

attempting to hide something which made them stand out, particularly heightened in the adolescent world, where being ‘normal’ is key for survival, and a fundamental human motivation (Baumeister & Leary, 1995).

I just wanted to, like, have, I wanted to, like, feel normal, I guess because before, like, it felt like I was different from everyone else, and I don’t, I didn’t like that. But I just wanted to feel, like, normal. I thought after surgery, it would feel, I’d feel normal (Thea; 481-485).

Thea stating she was different from “everyone else” pre-operatively highlighted her sense of being an outsider, outcast from her peers and society. It provides connotations of loneliness, and Thea named not liking being different. This may heighten feelings of self-consciousness and lower self-esteem. Her repetition of “normal” reinforces her desire for normality and its importance to her. It highlights her constant battle of trying to manage AIS symptoms versus blending in. The search for normality appears ongoing, Thea reflected she hoped the surgery would “make her normal”, either visually or behaviourally. Her use of “I thought” could suggest retrospectively she did not “feel normal” after surgery, and her quest continues.

I don't think I like the attention being on me, like it made me feel really like, it made me feel like I was like, I just wanted to blend in, and it felt like I was standing out a lot and I didn't like it (Thea; 1125-1127).

Thea stated her desire to “blend in” and how, post-operatively, she was still “standing out”. Thea’s shy personality contrasts with her difference being a source of attention within her school environment, and led to

negative feelings of self-consciousness, potential embarrassment and discomfort, and directly contrasts to her desire for normality.

Sienna shared a similar mentality of wanting to be normal: “I was trying to like... I was trying to forget about it, and get about like, normal day-to-day. I was... just... I just wanted to do school, do well, hang out with my friends” (396-398). Sienna recalled trying to forget about her upcoming surgery and instead focus on friendships and school, or normal adolescent activities. The potential interpretation here is Sienna was trying to go back to life prior to her diagnosis or news of surgery. There is a sense of her denying her difference by getting on with things unrelated to her diagnosis and surgery and focusing on ‘normality’.

Olivia felt she maintained normality prior to her surgery stating “Honestly, errr, like I- I wasn’t like that affected by it. Like during that time and, umm, like- like I- I just like, I don’t know, enjoyed life (chuckles) like during that moment” (99-100). While Olivia shared she was not affected by the upcoming surgery, this focus on enjoying life could be one way to deny her difference and spend time enjoying things she may have to sacrifice when surgery occurs. Olivia stated she was unable to share the news of surgery with friends due to moving schools. Olivia’s desire to enjoy life and secrecy of her surgery could be interpreted as an unconscious coping strategy to maintain an image of normality and deny her ‘difference’ at a new school.

Participants sought normality by attempting to blend in, and disliked drawing attention.

I didn't like the feeling of having to go, “can I leave?” And they'll be like, “yeah, of course.” And then everyone kinda just looking at you or the standing outside a class for the next period and they'll be like fifth year class has been in it. It just- it wasn't my thing. I didn't like the special treatment and also didn't take a lift pass (Sienna; 865-869).

Sienna's discomfort post-operatively was apparent. She reflected this was a personality trait of not liking “special treatment” alongside the school context of having to ask permission and creates an image of anyone who is ‘different’ sticking out from the crowd. The behaviour of leaving class early goes against ‘normality’. Sienna admitted to only asking to leave for a few weeks before “giving up” and going to lessons with her friends instead, regaining her ‘sameness’ in a continuous bid to belong.

Sienna and Olivia highlighted their desire to be perceived as ‘normal’ externally, with a focus on their behaviours and actions. Thea showed the internal cost of AIS, with an internal feeling of ‘not normal’ and a desire to feel cognitively ‘normal’.

3.1.4 GET Summary and Integration

This theme reflects how the participants' strong desire to belong was disrupted by AIS. Their surgery caused isolation, socially and emotionally pre- and post-operatively. Searching for normality, wanting to belong and ‘be normal’ juxtaposed with disrupted belonging and authority disrupting participant efforts, creating a lack of power and control.

AIS contributed to Disrupted Belonging, participants were then forced to initiate behaviours that protected them from further isolation,

explored under the GET of Protecting Self in a Social World, and consequently experienced Psychological Turmoil alongside that.

Whilst similar, these two initial GETs are distinct. Disrupted Belonging highlights the threat posed to participants, of not belonging and the desired outcome of being normal and included. Protecting Self is the action participants took to mitigate the threat and align with the goal of normality.

3.2 GET 2: Protecting Self in a Social World

This GET emerged through noticing the importance of the social world to participants, and how they behaved to protect themselves from ostracization within the social world. Participants experienced self-consciousness but acted ‘fine’, surveyed their body to appear ‘fine’ and worked hard to keep their AIS and emotions private.

3.2.1 Subtheme 1: Keeping it to Myself

All participants shared aspects of keeping thoughts and feelings to themselves, varying from withholding having surgery or withholding worries, concerns or pain from friends/family. Flora said “I just feel like it wasn't normal to just speak about it, just speak about my feelings. And I didn't really want to say too much anyway. I'd just keep it to myself” (567-569) and “Because I didn’t want to burden anyone with my problems or anything. Um, so yeah, I just kept it to myself. Or I'd speak to my friends about it” (575-576).

Flora used the word “burden” to suggest her feelings would be inconvenient to others, and may worry or discomfort others, therefore pre-operatively, she withheld sharing. Her repetition of “kept it to myself” could

be interpreted as a conscious decision of not sharing and how this potentially burdened her. Flora named she kept things hidden as it “wasn’t normal to speak about”. Desires to be normal may have influenced her decision to share, and she felt talking about AIS, surgery and her feelings emphasised her difference and disrupted her efforts to be normal. This could highlight her cultural or social norms around discussing mental health and emotions.

Flora ended by saying “Or I’d speak to my friends” as a standalone sentence. This could suggest her friends were easier to confide in than family, highlighting adolescent separation from parents. Or it could be an afterthought to share with friends, and worries about burdening others were at the forefront of her decisions.

Thea did not talk about her AIS post-operatively to avoid others “feeling weird about the way it made me feel” (1470) and pre-operatively Sienna did not want “friends worrying” (644). These examples of withholding appeared to be a bid to stay connected with friends. It highlights a particular consequence of adolescent surgery, where peers/friends are an important source of support, especially as they navigate gaining independence from parents. However, participants were aware their friends may struggle to provide support.

When I got told that I’d need the surgery and stuff, I told the rest of my friend group, and they were all kinda, like, not in shock, but freaked out, I th- that’s because we were only 12, some of us weren’t- hadn’t even turned 12 (Sienna; 337-340).

Faye agreed, stating “15 doesn't seem that young, but it is” (821). Sienna and Faye retrospectively acknowledged how young they were and how peers were not attuned to cope with a problem such as surgery. Therefore, the participants chose to keep information to themselves. Whilst a coping mechanism of protecting their social relationships, there could be consequences of suppressing emotions, not receiving support and withdrawing from friends as they internally navigated their worries and concerns.

Faye withheld her difficulties from her Mum:

I did let her know a few times, but in my head I was like, not only- like I didn't let her go home at all in the hospital, like for a break. Um, I just felt bad that she had to deal with all my medical stuff already, which I know she genuinely doesn't mind, because it's like, you know, I'm her kid. I'm going through stuff. She wants to help. But at the time, I just remember feeling really guilty, so I didn't tell her every time it happened (1195-1200).

Faye had nightmares and panic attacks post-operatively. She recalled sometimes sharing but sometimes not because she experienced “guilt”. This highlights an important consideration for adolescent surgery; Faye was old enough to be aware of the implications being a caregiver may have on her Mum, but still required parental support, and potentially did not have anyone else to turn to. This created an internal conflict of needing support whilst being aware of the mental load Mum was dealing with. Faye resorted to keeping some of the nightmares and panic attacks to herself.

There wasn't a lot of support after when I had it, so I wasn't able to talk to, like, the hospital didn't give us, or anyone, didn't give us like places like to go for like things like this. So, like, your mental health. So, I kind of just had to like, figure it out on my own. And I didn't like-, I didn't like talking about the way I felt about it. It just, like, made me feel really weird. So, I just, I never really talked about it. So, I just kept it to myself, and I guess it got worse (Thea;1327-1332).

Thea kept things to herself post-operatively because she did not like talking about it exacerbated by having no-one to talk to. She used "the hospital or anyone" to highlight the lack of support offered. Her use of "just had to figure it out on my own" suggests she had no choice but to keep things to herself, a decision based on the external lack of support. This creates connotations of isolation, loneliness, and internalising emotions. However, it is interpreted that Thea shifts to potentially not wanting to talk. Talking made her feel "weird", potentially because it heightened her difference, drew attention, or she was unfamiliar with doing so. Her standalone of "mental health" could highlight her uncertainty of the topic, she initially called it "this", before naming "mental health", perhaps interpreted as it not being something she is used to discussing or naming, thus she resorted to keeping it to herself.

The participants seemed to withhold their emotions to reduce burden on friends, family, and protect their identity, belonging and limit difference, something Thea realised was not beneficial for her mental health.

3.2.2 Subtheme 2: Performing Fine

Five of six participants expressed a sense of ‘Performing Fine’ despite experiencing pain, discomfort or thoughts about surgery. It is acknowledged this subtheme, at times, intertwines with the Search for Normality subtheme. The distinction emerged with normality being the desired outcome for participants, whilst ‘Performing Fine’ was a behaviour participants relied on to appear ‘normal’.

I was nervous about the surgery, and like the scoliosis and stuff, because it was like, I’d never really known anyone to have it... But I was just kind of unsure of it all and like, I just tried to not let it bother me and act like it was nothing (Sienna; 419, 421-423).

Sienna revealed pre-operatively she did not know anyone she could talk to who understood AIS surgery and what she was experiencing. Sienna stated she “acted like it was nothing”, the use of “act” highlights this was a performance, and perhaps not in line with her actual feelings. Sienna was uncertain of “it all”, perhaps highlighting the enormity of what she was experiencing, and as a coping mechanism decided to “try not to let it bother” her. The use of “try” suggests despite trying, things did bother her. However, she continued “acting” and “trying” to perform fine and avoid risks of standing out.

Pre-operatively Flora tried her best to ‘perform fine’:

I knew that there would be a point where, after my surgery where I would have to (miss school) and I, that wasn’t one of the things that I wanted to do just like, stop my schoolwork and miss out on things, so I tried my

best to just push through, sit in class for however long needed and just get my work done (375-379).

Flora highlights the context of having to remain sitting in a classroom for hour long periods, despite experiencing back pain, something adults with Idiopathic Scoliosis may not have to cope with, with more flexible office environments. She “pushes through” and ‘performs fine’ so she could remain in lessons, without missing out, keeping quiet, respecting authority and working towards her GCSEs.

Post-operatively she shared a similar experience:

I tried my best to, um, get to my lessons after that, I didn’t really want to spend any more time, um, using teams or anything, because I found, like, it wasn’t helping me and I wasn’t really learning anything, and it’s much more better in person so, um, I probably shouldn’t have, but I tried my best to just push myself and just make it to the lessons and everything (953-957).

She “pushes” herself to perform fine by attending lessons in person. School had allowed her to join lessons on Microsoft Teams and sit in the library to avoid busy corridors, but Flora reflected it was difficult to learn by herself online and she preferred being in person. It could be suggested she wanted to be with peers, feeling excluded and different. As before, she forced herself to ‘perform fine’, attending lessons ‘normally’ despite her awareness she “probably shouldn’t”. In neither example did she raise her problems with staff or ask for further provisions to help her, this is interpreted as, again, acting ‘fine’ to protect herself within school and before peers, and “pushing through” possible consequences. This directly links

with the Search for Normality subtheme in the previous GET, as Flora sought to attend her lessons as her peers did. Her goal was normality, and externally ‘performs fine’ to achieve her goal.

Within this subtheme, it was acknowledged how some participants used clothing to hide their body, and ‘perform’ as though their body was ‘fine’. Faye said “At the time I was also quite skinny. So all of my clothes were quite oversized on me, so you couldn’t really tell a difference” (275-276). Faye pre-operatively protected her difference with baggy clothes, stating oversized clothes meant others could not see her visible curvature. She noted “I was like, I- if people can’t see it, then they can’t make fun of it” (686). She revealed a fear of people making fun of her curvature and highlighting her difference. Therefore, she chose baggy clothing to protect herself in the social adolescent world she was navigating. She concealed her difference to ensure she remained the same as others and did not draw negative attention.

3.2.3 Subtheme 3: Self-Consciousness and Surveillance of the Body

One important theme throughout was how participants felt about their body image pre- and post-operatively. This subtheme highlights how participants surveyed and scrutinised their bodies, and feelings about their body were based on how others perceived them.

I'd say because of my body changes, um, I wasn't happy because like, I was very self-conscious about how I looked, especially like with the clothes that I'd wear, so I'd have to change all of that. I'd wear a lot of baggy clothes just to cover up because I was so insecure of my back and everything (Flora; 435-438).

Pre-operatively, Flora attempted to manage her self-consciousness through clothes she wore, hiding her body to ensure others could not see her difference and insecurity. She also could have been covering her body to avoid it. Flora's quotation highlights how her happiness was linked with her body image, and she used "so" and "very" to emphasise her dissatisfaction.

This quotation overlaps with the Performing Fine subtheme, where it is interpreted that Faye used clothing to 'perform fine'. Both used clothing to hide something they were self-conscious about and appear 'fine'. However, Faye used clothing to externally control how others perceived her, hiding her body from the social world, using "they" and "you" pronouns. Flora used "I" pronouns, reflecting internally how "unhappy" she was and highlighting her self-scrutiny.

Post-operatively, self-consciousness and self-surveillance remained but concerns shifted.

I didn't like people seeing it, which was like a problem when I was actually allowed to do PE again, because like a couple of times I had some of the girls like, look at it and just like whisper and, like, stare at it and stuff, and I didn't like that (Thea; 1231-1233).

Thea's post-operative experience of other girls staring and whispering exposed her difference, confirming her beliefs others were looking at her back and increased her self-consciousness and anxiety in public. Thea explained other girls made her "really self-conscious" and she faced different directions and hid herself when changing at school.

This subtheme links back to the theoretical underpinnings of this study. Within the school context, girls are exposed to the judgement of

others, with desires to conform and fit in with ‘ideal’ body types (Aniulis et al., 2021). Alongside self-consciousness, participants showed a surveillance/scrutiny of their body. Pre- and post-operatively, adolescents are left to scrutinise their body for results of whether surgery made their body ‘straight’ enough to be deemed ‘normal’, supporting Garland-Thomson (2020).

Five participants shared imperfections they still noticed post-operatively but used phrases such as “if you look really closely” (Thea; 637).

I've only kind of got uneven shoulder blades and my shoulders are slightly- my shoulders and hips are slightly, but no one notices that apart from me obviously. But I feel like it's 'cause, I'm like hyper aware of it (Sienna; 544-547).

Sienna also said, “I don’t love the fact that my shoulder blades don’t sit even because that’s the really noticeable thing still” (1045-1046). Sienna’s use of “I don’t love” suggests her scrutiny was not extreme and perhaps met levels of normal body dissatisfaction within adolescents. She did acknowledge others did not notice these imperfections, but she did. Her use of “hyper aware” highlights the idea she became accustomed to surveying her body for symmetry pre- and post-operatively.

In contrast Tess shared she felt her body scrutiny is worse now compared to before surgery. She noted “I think, I like, notice things more now even though I’m, like I’m more straight now, I feel like I still see things more than I like even did when I was like, still had scoliosis” (1466-1468). When trying on her prom dress she observed her “uneven shoulders” (1476-1477). Tess’s use of “even though I’m straight now” suggests she felt she

should be happy with her body or not scrutinise it as much, now she's had surgery. For her, it seems AIS heightened the awareness of her body image and could be interpreted as chasing a perfect body that surgery could not provide.

Faye became self-conscious of her movement, scrutinising her walk: I remember like I had an ex who one time was just like "oh, you have like, this kind of waddle when you walk". He didn't mean it in a bad way at all. But then I became really self-conscious about it. And so, I was just kind of like, "oh, we said that that one time, like, am I- am I doing it now, like, am I walking fine. Am I walking weird?" And I just end up walking weird anyway, because I've forgotten how to walk normally (1296-1301).

The comment from someone else, and someone close to her as an ex-partner, highlights how comments, and the gaze of others have an impact on adolescents and a long-lasting effect. Faye began scrutinising her walk, attempting to walk 'normally', but acknowledged this made things worse. She stated "Mostly in my walking, because the curve at the bottom of the spine, especially like, messes with your hips. And then my feet were turning in. So people were just like, oh, like, that one walks funny" (660-662).

The use of "that one" dehumanises Faye, and "people" gives a sense of a group mentality picking Faye out as different. Faye internalised how others view her body and her movements, only feeling conscious of it once a male highlighted it to her. The gaze of others continued to impact her as she reflected on people continuing a commentary on her body, linking back to De Beauvoir's (1956) writings, and the theoretical framework of this

thesis. Faye talked about attempting to practise her walk after surgery, before returning to school, to protect herself against judgement and fit in.

3.2.4 GET Summary and Integration

This GET intertwines with Disrupted Belonging and the Search for Normality as it highlights how participants chose to mitigate their Disrupted Belonging and be perceived as ‘normal’. Self-consciousness highlights a heightened awareness of how one is acting socially, and this awareness constitutes a form of protection, to ensure they are blending in. Psychological Turmoil starts to explore how this self-preservation took an emotional toll.

3.3 GET 3: Psychological Turmoil and Emotional Disruption

All participants reported feeling nervous about surgery, specifically as the surgery date got closer and on the day of surgery. They reported fears of “something going wrong” (Flora, 717), being paralysed, what things would be like after surgery and pain. It is recognised this level of fear is to be expected before a major operation, and, whilst not pleasant for the participants, is not surprising. However emotional disruption was a factor with anxiety, overwhelm and social withdrawal occurring.

3.3.1 Subtheme 1: Anxiety Caused by Uncertainty

Tess and Flora named anxiety caused by a lack of clarity about their diagnosis and need for surgery. They reported having to wait for answers, being given a lack of information by medical staff and having to research things for themselves.

Tess talked about anxiety increasing pre-operatively as she waits for answers regarding her diagnosis and whether she needs surgery. She said “I

did some more research. And then I realised, like, the treatments and stuff like the bracing and then surgery. And it made me quite like anxious, I guess because I didn't know what to expect" (255-259). And "It's just sort of watch and wait to see what would, if it would get any worse. So that, I don't know, made me quite anxious. Like not knowing what was going to happen" (292-295). To cope with the uncertainty, she resorted to researching herself but acknowledged this caused further anxiety as she saw what possible treatments could be. Her repetition across the quotations of "quite anxious" highlights the emotional consequences of this uncertainty.

I mean I don't think it really affected me that much, but sometimes in school I'd have like panic attacks and things cause I don't know, just like daydreaming and thinking about it was like, not very nice and then, but I think other than that it was, I was fine (Tess; 423-427).

Tess initially said she did not feel the news of surgery affected her but then shared she experienced panic attacks at school. This could be interpreted as Tess sharing she felt unaffected but then experiencing panic attacks, or she believed the panic attacks were minor, and un concerning. Alternatively, Tess could be downplaying her panic to me to remain 'normal' and not highlight her difference. Naming panic attacks then stating "other than that, I was fine" in the same sentence could suggest Tess was not processing her emotions, and panic attacks were a result. Tess later shared she has always been an "anxious person" but thinking about the surgery "definitely brought on panic attacks" (534-535). The panic attacks stopped after surgery, suggesting they were directly related to her upcoming surgery. Tess was a participant who admitted "keeping [surgery] to myself" (1037).

Her outward silence and internal struggle may have reflected an internalised coping style. Panic attacks were the cost of internalising emotion and managing the uncertainty and overwhelm of AIS surgery, as her body releases what she was attempting to keep hidden.

3.3.2 Subtheme 2: Overwhelm

Four participants reported factors alongside their surgery that caused overwhelm. Olivia, Thea, and Sienna reported moving school/starting secondary school, managing new friendships and Flora was juggling GCSEs.

Sienna stated, “I definitely got a lot more like nervy and on edge, but I think that was just ‘cause I had so much going on” (375-376) and “I just everything seems like it’s all happening at once and it was all a lot for the time” (409-410). Sienna reflected on how the news of surgery and waiting for her surgery date caused her to feel “more nervy”. Her colloquial wording could be interpreted as increased nerves, anxiety or worry about situations. She later said she “tends to get nervous with things” like Tess above. She reflected surgery was a factor to this, potentially alongside moving to secondary school, making new friends, meeting new teachers, and separating from parents. Alongside these typical adolescent changes, it could be interpreted Sienna was working to conceal her diagnosis, surgery and her changing body. With this adolescent context in mind, it is understandable Sienna felt overwhelmed and “on edge”.

Flora shared a similar adolescent stressor:

Very hard for me because I also had my GCSEs that I had to do. Um, and I was struggling a lot because sometimes I have to take time off school because I just simply couldn't get up in the morning (121-123).

GCSEs are already a stressful experience for teenagers, (Denscombe, 2000) but adding the news of major surgery and Flora experiencing pain in lessons created a sense of overwhelm. Flora's use of "simply couldn't get up" could emphasise even getting up became too much amid other factors overwhelming her. Potentially this turned into a cycle of needing to concentrate on her GCSEs but struggling and missing school, causing her to feel further overwhelm.

I think I just dissociated my way through most of it, so I was like "distance myself from myself, my emotions can't get to me too much, I can't stress too much," like I was either hyper aware of my- of my emotions or I just wasn't at all (533-535).

Faye reflected on her pattern of dissociation, potentially using "I think" to highlight her retrospective awareness. She felt distancing herself from her emotions allowed her to cope and reduce her overwhelm. Her "hyper-awareness" of her emotions could suggest they became overwhelming at times. Faye later spoke about struggling to name emotions and how she felt. Similarly to Tess in 3.3.1, Faye internalised her feelings, containing her distress. Dissociating was one way to get through an experience which she was unsure how to process at a young age.

However, this internalisation seemed to rupture post-operatively as Faye described nightmares and panic attacks.

It's just like I would have the nightmare, I'd wake up back in my room, but it was dark, so I was really disorientated, so like, I would start, erm, freaking out, hyperventilating. I could feel like my heart pounding, my chest felt really tight, I'd just have to like take a few minutes to get my bearings again (1159-1162).

Faye's nightmares included vivid recollections of intensive care and pain followed by panic attacks. Shifting from dissociation to vivid memories and panic may represent delayed processing, or a release of previously suppressed emotion. Dissociation that was once protection from overwhelm had somatic consequences. Her experience highlights the complexity of adolescent coping when overwhelmed by a major event, and potential consequences of attempting to navigate it alone. Faye's use of filler words could be used to delay formulating the rest of her sentence, they may suggest an informality to her cadence of speech, a habit she uses throughout, or could be interpreted as uncertainty, or hesitation. Her "erm" before "freaking out" could reflect her being unsure of how to describe her feelings. It could be interpreted she is unsure whether "freaking out" is appropriate for the research interview setting. She used it reflecting her age and her subjective experience. The word "like" could be used to make her statements less impactful. The intensity of her "heart pounding" contrasts with the softening effect of "like". It was interpreted Faye and Tess experienced different reasons for their panic attacks, but both interestingly downplayed them.

3.3.3 Subtheme 3: Social Withdrawal

The GET of Disrupted Belonging explored isolation, emotionally and socially, but it felt important to note social withdrawal here as a manifestation of psychological turmoil, separate to forced withdrawal from activities and hobbies. Sienna shared her friends noticed a difference in her after finding out she needed surgery.

They'd still say, like "you went really quiet, especially after you found out". And like... "You weren't the same bubbly person, you kind of..." I don't know... Like I was never the most bubbly out there, but they're like "you definitely did get quieter for a bit". (387-390).

My pals were saying to me, they were like "you were already one in the quieter ones" but we're all quite quiet in my group, "That you got even quieter. Not, like you kind of just didn't really talk as much. You weren't having a laugh and like-" There was a difference (376-379).

Friends observed her as "less bubbly", less talkative, not laughing as much. Sienna and her friends acknowledged Sienna's personality was not overly extroverted but noticed a change after finding out about surgery.

Sienna shared she was not aware of her social withdrawal and believed she was "trying to forget about it and get about like normal day-to-day" (396-397). Sienna could have been attempting to 'perform fine', seek normality or defy her difference, but unconsciously withdrew from friends to further disguise her difference, creating distance within her friendships.

Alternatively, her internal conflict on dealing with the news of surgery, and the cognitive load of concealing her difference and trying to 'perform fine' could have caused her to be quieter around friends.

I was quite upset about, like, like having the surgery in the first place 'cause like that would mean I'd have like a lot of time off school and umm, like, obviously I couldn't like, see a lot of my friends and like, they- they just wouldn't know like what happened to me because umm, like I was- I- I wasn't like able to tell them at the time. So, umm, yeah, I was quite sad because I didn't want to worry like all of them about it (Olivia; 154-159).

Olivia shared feeling sad and upset about missing school and not being able to see friends. However, she also stated “they wouldn’t know what happened to me”. Olivia felt unable to tell friends about her surgery because she was moving to a new school. She also reflected on not wanting to worry friends, like other participants who chose to withhold information from friends for fear of worrying them. This concealment causes social withdrawal as she hid a large part of herself from peers and again worked hard to conceal her difference.

Thea recalled isolating herself after surgery: “I hated, like going out and stuff after, like I just didn’t want to do anything. And I think it was more because I couldn’t do anything. It made me not want to do anything or something” (1553-1555). Thea shared a “hatred” of going out and not “wanting to do anything”. She interpreted this feeling was because she “couldn’t do anything”. This acknowledgement could be retrospective as she thinks back, or a realisation she had during recovery. This links with the Disrupted Belonging theme as AIS caused her to miss out. Not being able to do things caused her to not want to do things, leading her to experience

emotional disruption, potentially low motivation, low mood and frustration leading to social withdrawal.

3.3.4 GET Summary and Integration

The psychological turmoil of overwhelm, anxiety and social withdrawal interplay, as overwhelm could have caused anxiety and withdrawal among participants as they struggle with internal chaos. Contextually, school, peers and medical appointments increased this turmoil, alongside aspects of attempting to protect themselves in the Social World, and Disrupted Belonging. In the final GET, participants became self-aware of this turmoil and internal processes and reflected on how these feelings grew into acceptance and a developing sense of self.

3.4 GET 4: Emerging Selfhood and Acceptance

The final GET to emerge was participants retrospectively acknowledging changes since surgery, ranging from participants noticing changes to their body, gaining confidence post-operatively and areas of self-growth caused by the experience.

3.4.1 Subtheme 1: Changed Body

Five participants acknowledged physical changes to their body post-operatively.

I think it's changed massively. Um, because before surgery, you know, I really wasn't happy at all with my body. Now I am happy about my body, but I just get those odd few days, just the whole weight thing, um, that is upsetting for me, but other than that, I think that, yeah, everything's fine (Flora; 1117-1120).

Flora recognised surgery as the reason for her body image changing “massively”. She was unhappy with her body pre-operatively but now accepts and is happy in her body, further highlighted by “everything’s fine”. She acknowledged some concerns about her weight, reporting she gained weight post-operatively because she was doing less sport, but understands weight gain as ‘normal’, and perhaps a shared experience with peers aging into upper adolescence (454-554).

I think like the first sort of, definitely like the first couple months, I’d like, I was really happy about it, like I was really happy about, like how it looked and like just being straight and everything (Tess; 1202-1205).

Tess spoke about the first couple of months post-operatively highlighting how quick the change was following surgery, but also suggests this opinion changed, or lessened after the first months of her recovery. Tess’s repetition of “I was really happy about” highlights her positive emotion but also emphasises how her happiness came from having a “straight”, ‘ideal’ body type and ‘successful’ surgery. Again, leaning into surgical corrections successfully ‘improving’ one’s outward appearance (Garland-Thomson, 2020).

Sienna leant into this feminist viewpoint: “Like it makes me think that it’s, like it was worth it for that reason” (1058). To her, surgery was “worth it” because of the visible change it caused to her body. Despite her internal self-consciousness or having to “push through” difficulties, externally, under the gaze of others, she felt it was worth it.

I wasn’t really warned that like “oh like your self-image might change, the way you think about yourself might change. Um, the mental health

side isn't really talked about. It's more just like “these are the physical side effects. This is what to look at from a physical standpoint.” (Faye; 1346-1349).

Faye reflected she was not “warned” her body image may change or be impacted by surgery, implying missing information and how it would have been helpful to have someone acknowledge this side effect of surgery. Using the word “warning” could also suggest Faye perceived this omission as a failure to protect or prepare her for what was to come. Her physical change was enough to have warranted a “warning”. It highlighted how the change is not always positive, and can be disturbing, upsetting or threatening to the adolescent.

Alongside Faye’s feeling she was not warned about changing body image, she highlighted mental health was not talked about. Her direct quotation from medical professionals emphasised the importance placed on physical side-effects, and how Faye experienced their emphasis on physical outcomes of surgery. The repetition of “physical” further highlighted how from Faye’s viewpoint the physical was important but implied her mental health was not. Her sense of self emerged post-operatively through reflection on how her body image was impacted and how she experienced medical professionals.

Thea reflected on possible consequences of not being “warned”, saying “I just felt like, I looked different. I felt like I looked really weird and stuff and that it wasn’t, like how it was like meant to look or something” (1585-1586). The use of “really weird” and “different” suggests Thea’s body was foreign and uncomfortable to her. Her use of “meant to look” could

reflect her desire to be ‘normal’, society’s desire for the ‘perfect’ body, and her belief that she does not look how she “should”. “Meant to” and “should” also suggest Thea has an idealised image of how she “should” look and feels surgery did not achieve this for her. Her experience of not recognising or liking what she saw in the mirror could be interpreted as a distressing experience in which her outward identity has changed, and she is left with the experience of looking at a stranger in the mirror. Thea struggled with acceptance of her new body, and her emerging selfhood is threatened by someone she does not recognise.

These perspectives highlight how AIS surgery has consequences of a changed body which are celebrated by some but threatening to others.

3.4.2 Subtheme 2: Self-Growth

Four participants named areas of self-growth related to AIS surgery, and how it became a “part of who I am” (Sienna; 1078-1079).

I'd say I have my good days and I have my bad days. A lot of the time I'm not really bothered because I'm so busy with like, being out for the day or college work, coursework so it's like I don't have time to stress about stuff like how I look. Like I have things to be getting on with. But then other times, like I'll catch myself over analysing. Just being like, “oh well, does it look better or worse today?” (Faye; 1280-1284).

Faye acknowledged “good and bad days” around her mental health post-operatively. She reflected being busy with college or “out” meant she did not “have time” to worry about her body image. Her use of “I have things to be getting on with” could be interpreted as her self-growth, of noticing what matters to her and what does not. Additionally, age reducing

worries about her body, where college work became a priority over body image. Davison and McCabe (2006) suggest body image concerns are highest in girls around age 13-16, and increase around early to mid-adolescence, around the time participants were diagnosed and had surgery. Now 18, Faye appears to acknowledge how getting older and self-growth was responsible for less concerns about her body image.

Sienna shared “Definitely, it like totally opened my eyes to like, how... like, things can happen and like, people don’t talk about it as much” (1074-1075). After surgery, she was able to appreciate things and acknowledge how “things can happen”. She reflected how “people don’t talk about it as much”. This could be interpreted as how AIS is not widely spoken or known about, and there is a lack of conversation around it to support adolescents. It could also be an acknowledgement of her own concealment of information, not sharing with friends and keeping things to herself. Sienna could be acknowledging how sharing is useful to gain support and improve relationships.

Also made me really grateful for like, being able to play a sport now, like I'm not the most sporty person, but I will put my all into it because, I do know like, well, that could have been taken away from me fully if I didn't get the operation and stuff and like I... it's just kinda, it's who- part of who I am (Sienna; 1075-1079).

Sienna reflected on how the surgery made her “grateful” for what she can do. She “puts her all in” when playing sport and reflected on knowing how it feels to have the ability taken away from her. It could be interpreted as making the most of what her body can do now after it

betrayed her and took sports away pre-operatively. She reflected on how life could have been without the surgery, potentially suggesting a gratitude her surgery went well, with no complications or long-lasting negative implications, and a gratitude to her body. This appreciation filtered into her emerging sense of self as she “puts her all into” things suggesting a determined mindset to move forward.

I think going through something like that, I think it just kind of changes you and changes your perspective on things. It’s helped me with a lot of things. Um, I think I’ve changed as a person, I look at things differently (Flora; 1180-1182).

Flora recognised how the experience contributed to her self-growth. Her repetition of “changes” highlights her sense of things being different and how far she has come since her diagnosis. She acknowledged “changing as a person, looking at things differently”, with a “changed perspective on things”. It could be interpreted as improved mental wellbeing and being able to manage difficult situations with resilience and strength. When Flora reflected on how she felt pre-operatively, she stated: “I didn’t think that I could do it, or that I was strong enough” (234-235).

From not believing she was “strong enough” to endure surgery, to being able to acknowledge her growth post-operatively highlights her journey, and her ability to cope with a difficult situation.

3.4.3 Subtheme 3: Confidence

Three participants reflected on improved confidence post-operatively. Sienna reflected on how she cannot change what has happened,

her acceptance of AIS surgery and improved confidence, saying “It definitely like made me feel a lot more confident in myself” (1080-1081).

I became more open about stuff and it kinda opened my eyes to like, you don’t need to be so serious, but- because there’s bigger things, but... it opened it to like social situations and stuff. I’m still a total nightmare when it comes to schoolwork, that’s just my downfall (chuckles). That’s- that’s where I get to put all my stress into, now but I don’t stress about social stuff. It’s just there’s no point (1032-1037).

Like Flora, Sienna recognised there are “bigger things” in life and acknowledged she does not need to worry about social situations, therefore she becomes more talkative and shares more about her surgery after returning to school. This contrasted with her social withdrawal pre-operatively, and secrecy, withholding news of diagnosis and surgery from friends and peers. This represents self-growth and surgery providing an increased confidence. Sienna felt she realised there were “bigger things” than worrying about social situations, and maybe realised those worries were no longer relevant. However, her increased confidence could also be due to her changed body shape. Sienna identified her curvature is less visible after surgery, and therefore she could be more talkative and confident as she no longer has to conceal her difference and protect herself socially. She felt her body was the same as her peers, she could stand out more with her personality, compared to hiding and remaining quiet, fearful of detection or others noticing her body.

Tess talked about returning to dance following her surgery and getting better at telling dance teachers anything she cannot do due to her

spinal fusion, saying “I’ve got better now ... I’ll tell them, and then if I put my hand up, they’ll normally clock what I’m about to say” (1314; 1316-1318). Tess reflected how her confidence has improved, stating “I’m better now” suggesting she struggled with doing this at first, perhaps because it led to her sticking out, highlighting her difference. Increased confidence could have come with time since her surgery, a sense of feeling more confidence around her peers, or a self-confidence of her emerging self with AIS surgery as a part of who she is. Flora stated, “And then after a year had gone, I was so much more confident with everything, like, it was all normal to me” (931-932). Flora felt more confident in her body. The use of “normal” could reflect getting used to the way her ‘new’ body moves and feels, whilst also acknowledging her search for feeling “normal” is over. She highlighted it took a year for her to adjust into herself and for this confidence to emerge, like Tess reflecting on being “better now”. Both participants highlight how time helped them to recognise their new sense of self and grow into it.

3.4.4 GET Summary and Integration

This final GET draws on positives of AIS surgery, whilst acknowledging unexpected changes post-operatively. The subtheme of a Changed Body carries links to Self-Consciousness and Surveillance continuing after surgery. However, an increased confidence directly contradicts prior desires to hide, seen in other themes. Self-growth and awareness of who they are as people, including their AIS, appears to end their Search for Normality, as they accept themselves despite their differences.

3.5 Chapter Summary

Overall, this chapter has presented four GETs illuminating how adolescents made sense of their mental health and body image pre- and post-operatively. Whilst each participant navigated their experiences differently, Disrupted Belonging, Protecting Self in a Social World, Psychological Turmoil and Emerging Selfhood surfaced. Across participants, the themes reflected a shared struggle to protect oneself in the context of their adolescent world, alongside an internal conflict of battling to be seen and included by peers whilst hiding their difference so they were not ‘found out’. Consequences of this were standing out, being embarrassed, being exposed and ultimately excluded, feeling catastrophic in the adolescent world.

Across all themes the central concept appears to be a group of participants who prioritised their social status over their AIS, hiding their condition, visually and emotionally to ensure they were the same as others and to avoid psychological consequences of being socially outcast. Participants had a goal of ‘being normal’, and behaved to achieve that goal, through performing ‘fine’, keeping things to themselves and doing self-surveillance to police their body. Their belonging was disrupted by AIS, a factor leading to psychological turmoil of overwhelm, anxiety and withdrawal. Finally, the experience led to an emerging sense of self and realisation of change, perhaps only possible due to the awareness of the previous GETs.

CHAPTER 4. DISCUSSION

Overview

The aim of this research was to explore the psychological experience of adolescents who have undergone AIS surgery, asking about their mental health and body image pre- and post-operatively.

Four GETs emerged from the analysis: Disrupted Belonging and The Search for Normality, Protecting Self in a Social World, Psychological Turmoil and Emotional Disruption, and Emerging Selfhood and Acceptance. It was felt these themes captured the adolescents' psychological experience, highlighting internal conflicts driven by desires to be included and perceived as the same as others externally.

This chapter will discuss the subthemes individually alongside literature previously discussed in the literature review, acknowledging gaps the present study fills, exploring why findings may have emerged, linking to wider theory and identifying critics of this research and prior literature.

4.1 Disrupted Belonging and The Search for Normality

4.1.1 Emotional and Social Isolation

Participants named isolation from their peers, in the form of being socially and emotionally isolated as they felt different from others. Participants reflected on being outsiders, watching friends having fun from afar and missing out on activities, agreeing with Danielsson et al's (2001) findings, which acknowledge adolescents with AIS may be subject to social isolation, depression and reduced participation in hobbies. Participants in the present study acknowledged this reduced participation and how it caused negative emotions, such as upset, frustration and disappointment, like the

pre-operative findings of Motyer et al. (2022) and Macculloch et al. (2009). Macculloch's findings were acknowledged in the present study, with Olivia and Sienna particularly feeling concerned pre-operatively about missing school and falling behind.

In a systematic review, Essex et al. (2022) concluded scoliosis had a negative impact on daily life, reduced physical capacity and prevented socialising. The findings of the present study can be interpreted similarly, with participants unable to join in or socialise, and experiencing the negative impacts of perceived social isolation.

It is well documented humans are social species, and social groups serve many purposes. Laursen and Hartl (2013) define perceived social isolation as an awareness from the individual they are not socially integrated when they want to be, and this leads to emotional distress (Weiss, 1975). This also links to social comparison theory (Festinger, 1954) as participants are potentially making upwards comparisons to peers who can do the things they want to do, such as sports, PE and socialising. Feeling excluded or socially isolated could lead to increased loneliness and a fear of missing out.

Risks of loneliness are heightened in adolescence (Laursen & Hartl, 2013) and potentially more so for adolescents with AIS as they navigate unwanted perceived social isolation. One aspect not explored in this study or prior AIS experience studies (Motyer et al., 2022; Rullander et al., 2013) is the role of social media and how further comparisons may arise, contributing to feelings of missing out and perceived isolation.

Though not discussed in the literature review, following the findings from this study, Motyer et al. (2022) and Essex et al. (2022), it felt important

to explore the consequences of loneliness for adolescents. Vanhalst et al. (2013) found loneliness and self-esteem reciprocally impacted one another in adolescence and perceived social acceptance partially mediated the relationship between self-esteem and loneliness. If individuals with AIS are experiencing lower self-esteem, loneliness and a lack of perceived social acceptance, there are potential risk factors for depression and anxiety disorders.

Baird and Gardner (2021) reported adolescents awaiting AIS surgery scored higher than controls on a criterion for risk of depression scale. Participants of Danielsson et al. (2001) described depressive feelings and 49% stopped all leisure activities. Adolescents feeling lonely could be a factor for these depressive symptoms in both studies.

Vanhalst et al's (2013) associations were seen within these participants, as participants report negative emotions of 'upset', 'disappointment', and 'frustration' when socially isolated, and Tess and Thea report stopping activities because of a lack of motivation to do anything, suggesting depressive feelings (Smith, 2013). It is important to note, in this study, these emotions were seemingly short-lived, explained by their scoliosis and activities restarted once they recovered, were physically able and wanted to. In contrast, Danielsson et al. (2001) highlighted long-term impacts, with those scoring poorly on mental health pre-operatively and scoring worse than controls 20 years post-operatively. Arguably, depressive feelings could ease as isolation is reduced, but other aspects of mental health scored by Danielsson et al. (2001), such as self-esteem, self-

consciousness, or anxiety could remain longer-term, which this study supports further throughout this chapter.

Additionally, participants report aspects which could relate to low self-esteem. Heatherton and Wyland (2003) state those with high self-esteem feel good about themselves, can cope effectively with challenges and believe people value and respect them. Some participants named possible experiences of low self-esteem, such as Sienna stating “I didn’t think anyone would really notice or care” (480) when she left school for surgery and participants reported missing out meant they could not enjoy things they once used to. Heatherton and Wyland (2003) state substantial evidence between low self-esteem and depression, shyness, loneliness, alienation and enjoyment for life, concluding self-esteem is vital for psychological health. Therefore, adolescents with AIS being emotionally and socially isolated, as research seems to suggest (Danielsson et al., 2001; Motyer et al., 2022; Macculloch et al., 2009; Essex et al., 2022) could be at psychological risk of loneliness, emotional distress and low self-esteem that surgery may not eradicate. Cultural factors are also apparent, as Western participants are attending secondary school with PE as part of the curriculum and extra-curricular activities encouraged. Accounting for additional factors of school and authority, it became apparent through language used this exclusion and isolation was not by choice.

4.1.2 Not Being Allowed to Belong

Fitting in and gaining peer acceptance is a primary objective of many adolescents in secondary school (Schall et al., 2014) and was apparent within the interviews conducted in the present study. As defined in the

literature review, adolescence is a transitional state, in which teenagers begin to separate from their parents placing more emphasis on fitting in with peers (Hashmi, 2013). Participants were specifically focused on belonging, fitting in and being 'normal', as characterised by the Disrupted Belonging GET. Specifically, within this subtheme, participants reflected on not being allowed to participate and belong, with others telling them what they could or could not do. Prior studies reported isolation and participants feeling like they did not belong (Danielsson et al., 2001; Motyer et al., 2022). This study found one important distinction of the isolation was it was often not through choice for the participants.

Schall et al. (2014) applied locus of control to social belonging within an American high school. They found youth who felt they had little personal control to influence their own belonging within social situations felt powerless to the perceptions peers placed on them. Those with external locus of control felt more influenced by factors in their environment and felt less in control of their belonging. Those with internal locus of control felt they had more control and ability to influence their belonging and status within school. Schall et al. (2014) therefore suggest locus of control as a variable useful to identify adolescents who are experiencing the negative implications of not fitting in. To apply to those with AIS, it could be argued the participants in the present study are experiencing an external locus of control, where they have little autonomy and control over what they are allowed to do and activities surgeons, teachers and parents may be stopping them from doing. Thus, indirectly authority plays an important role in the participants ability to fit in with peers. This external locus of control could

result in more negative consequences of not belonging, such as distress, disengagement, and helplessness as participants feel powerless to change it, having a negative impact on mental health (Schall et al., 2014). This lack of power relates back to Lennon and Fischer's (2024) arguments on those with less power than able bodied women. The intersectionality of power and age interplay as teachers enforce their power on participants who may already hold less than their female peers.

However, Thea, Flora and Sienna begin to rebel against authority, and gain back their power, making choices of sneaking outside at break, rejoining lessons, and trying new things in PE despite not being 'allowed'. Participants re-establishing an internal locus of control could highlight the strong need to belong. This regained power is displayed post-operatively, perhaps highlighting their power increased post-operatively, once their body held closer resemblance to their able-bodied peers. Siegel (2013) speculates how in adolescence authority loses influence and peer approval becomes more important. Adolescents appear to be aligning with this theory, of 'rebellious' against authority to connect with peers. The risk of injury following surgery could be deemed by adolescents as less important than peer connection, and they are willing to take the risk if the reward enables peer acceptance. Crosnoe (2011) draws attention to a potential discrepancy of how adults view school, as a place for academic learning, compared to how adolescents' importance is placed on navigating peer acceptance and achieving belonging. Flora drew attention to how she was working in the library, attending lessons via Teams after her surgery, however she decided to return to lessons in person, despite reflecting she "probably shouldn't

have”. She stated Teams “wasn’t helping her” and “it’s much better in person”. This highlights the importance of peer connection and belonging Crosnoe (2011) may be referencing. Academically, Flora was being given the information and opportunity to learn, but being separate was unhelpful for her. Being in the room with peers was important to her and allowed her to fit in and re-engage with learning.

The degree to which belonging is disrupted amongst adolescents with AIS is an important finding which is supported across the prior literature (Essex et al., 2022). These findings go further to highlight how participants lose control of their belonging and resort to rebelling against authority to potentially avoid being isolated and experiencing the negative psychological consequences associated with not belonging. Participants had a choice between their social wellbeing and physical wellbeing, and they seemed to prioritise social inclusion and being ‘normal’ above all.

4.1.3 The Search for Normality

All participants used terminology or inferred the desire to be ‘normal’. None described what ‘normal’ meant to them, which meant my assumptions and biases of what ‘normal’ means informed my interpretations here, however Rosenhan and Seligman (1989) define normality by what is acceptable in a particular society under a socio-cultural context. It is interpreted the participants here saw normality as being the same as peers, fitting in, and participating with peers, without having to sit out, be excluded or different. The term ‘normal’ is presented in quotations to honour the participants meaning making and illustrate how normative discourses are internalised, (Smith et al., 2009) but remain consistent with counselling

psychology's commitment to critical reflexivity and anti-discriminatory practice (Donohue et al., 2024) avoiding the use of stigmatising language. The term normality is not quoted as it feels less stigmatising and more subjective, tied to the participant's own experience of their life, routine and habits.

Pre- and post-operatively Thea, Sienna and Olivia reference wanting to be 'normal' prior to surgery, whilst Thea still felt like she was "standing out" after surgery and therefore interpreted as not 'normal'.

As the GET explores, adolescents hold a strong motivation to belong and increased sensitivity to peer evaluation, with the opinions of peers becoming more important than family (Blakemore & Mills, 2014). Participants in the present study emphasise how important being 'normal' is to belong in secondary school. Adolescents aged 13-17 report peer evaluations affect feelings of social and personal worth and peer rejection indicates unworthiness (O'Brien & Bierman, 1988). Being 'normal', or the same as others, reduces the risk of rejection and protects against negative feelings.

The present study supports the findings of Motyer et al. (2022). Their participants thought things would go 'back to normal' after surgery, whilst Thea raised the desire to "feel normal" after surgery. In this subtle difference, Thea highlighted an internalised state, interpreted as her feeling 'abnormal' before surgery, whilst Motyer's participants focused on the external routine AIS disrupted. This could highlight the distinction between Motyer's psychosocial focus and the counselling psychology lens, as Motyer et al. (2022) focus on the social factors related to AIS, and how AIS

interacts with social contexts i.e. disrupting daily routine. Meanwhile the counselling psychology lens allowed Thea to share her lived experience of feeling internally abnormal. Her meaning-making emphasises how she and I interpret her experience as being ‘abnormal’ among peers and this results in a search for normality.

The current study highlights something Motyer et al.’s (2022) study could not; how the current participants may still struggle with searching for normality post-operatively, and potentially for a prolonged period following surgery, with acceptance only coming years later, as seen in the Emerging Selfhood and Acceptance GET.

Maintaining normalcy has been shown to be protective of wellbeing, and arguably mental health, across adolescent populations facing long-term illness or disability (Berntsson et al., 2007). Motyer et al. (2022) and the present study highlights participants are aware of the threats to normalcy AIS surgery poses. This could impact the participants’ sense of self, pre- and post-operatively, as Thea continued to desire “feeling normal” post-operatively. A conflict of being ‘normal’ and having AIS seemed to occur for participants, where the two cannot exist together. This leads to coping mechanisms discussed in the next GET of hiding their AIS to protect themselves and appear ‘normal’ which may or may not be helpful.

4.2 Protecting Self in a Social World

4.2.1 Keeping it to Myself

All participants reported keeping aspects of the diagnosis, surgery, pain and their feelings to themselves. Flora, Olivia and Thea did not want to “burden” or worry friends so kept thoughts to themselves. Tess “wasn’t fond

of talking about it” (1,036), Sienna did not want to make a “big deal”, and Faye reported keeping post-operative nightmares and panic attacks to herself, withholding from her mum, as she felt guilty of how much her mum was already doing to care for her. All participants had an awareness of how their feelings may impact others.

Smolak and Munstertieger (2002) reported girls are socialised to relinquish themselves and are taught likeability and self-sacrifice to make others comfortable and preserve relationships, observed by participants masking their feelings from others. As Thea said: “because I didn’t want, like, people to feel weird”. The present study saw similar behaviours to Motyer et al. (2022) and Macculloch et al. (2009) with participants withholding information from friends, not wanting to hassle them, or struggling to explain their AIS. However, Motyer et al. (2022) also saw positive outcomes once adolescents did decide to share with friends. Some participants in the present study did seek support from friends and enjoyed feeling cared for. However, in contrast, support in the present study mainly included practical support, such as friends helping them carry bags, or move between classrooms, whilst keeping emotions to themselves.

To interpret why participants struggled, here and in Motyer et al.’s (2022) study it could be important to explore the feminist framework this thesis is grounded in, understanding the societal pressures placed on women and attempts to discuss these alongside AIS surgery.

As discussed in the literature review, Carrasco and Ruiz (2016) discuss feminist viewpoints, of society informing women their purpose is to be like others and success is determined by the attractiveness of their body.

Though, in critique of feminist theory, De Beauvoir (1956) draws on the how a patriarchal society may socialise girls to prioritise romantic relationships, here females appeared to act in certain ways to fit in with other females, rather than males. This may link more with developmental theory, highlighting how females in early adolescence, around the age of diagnosis and after surgery, have intimate same-sex friendships and such relationships can reduce depressive symptoms and increase self-esteem (Way & Silverman, 2012). However, feminist theory does highlight society's continued hold over women's bodies and emphasise the impact on their voice also. Cihonski (2005) reported age 11 appears to be the last year many girls speak openly and honestly about their emotions and experiences to anyone, except perhaps their closest friends. Adolescents in the present study may be going through a period of major developmental transition in early adolescence, between ages 12-14, where gender-role identity, body image and psychological structure are questioned (McCabe et al., 2002). Around this time girls may lose confidence and self-esteem, potentially remaining quiet to avoid perceived negative consequences of upsetting others, losing a relationship or standing out (Stern, 1990). This is certainly supported here, as participants kept things to themselves, to ensure others did not feel uncomfortable, burdened and to ensure they blended in. Age intersects with the cultural norms of this study, as Western society favours a pleasing, submissive voice (Cihonski, 2005). As girls move into adolescence, many sacrifice their voices, policing their thoughts and feelings so others will like and approve of them, evidenced here by choices the participants seem to make about sharing their diagnosis and surgery.

Participants silence or compromise their voice, patrolling their responses and feelings so others will continue to accept them, but in attempting to maintain the relationship, they also distance themselves from the relationship through the presentation of an inauthentic self, something Brown and Gilligan (1992) describe as a paradox for adolescent girls. Researchers (Brown & Gilligan, 1992; Pipher, 1998) have documented not speaking up leads to a variety of negative feelings and emotions, such as inadequacy, fear of rejection and humiliation, and consequences of attempting to maintain a sense of self whilst putting the needs of others before theirs. As Thea reflected, she kept her feelings to herself, but things ultimately got worse. Cihonski (2003) reported not expressing oneself led to physical and emotional consequences of feeling helpless, questioning integrity and identity, and deeming their thoughts and feelings as simply not important.

Participants experienced their mental health through keeping things to themselves and these findings offer an explanation as to why the participants withheld information, in the context of their age and adolescent identity shift, as they continuously try to fit in. Silencing their voice in order to remain liked is a coping mechanism used by the participants but could leave them with psychological consequences of negative emotions, maladaptive internalising behaviours, and distanced friendships. Keeping feelings to themselves allowed participants to protect themselves against standing out in the social world, another behaviour for this was ‘performing fine’.

4.2.2 Performing Fine

Another way of protecting oneself in the social world was participants performing or acting fine. Sienna and Flora gave examples of “acting like it was nothing” and “pushing through” to maintain their normality within the social context of school. Motyer et al. (2022) showed similar findings, as participants did not want to dwell on their scoliosis and endeavoured to ‘get on with it’. Hensler and Emmott (2025) found adolescent girls in London associated acting passively and agreeably allowed them to be perceived as feminine and mitigate negative social interactions. Girls were deemed primarily responsible for the outcomes of social interactions, therefore negative social interactions may lead girls to feel responsible and experience worry, anxiety and lower self-esteem (Hensler & Emmott, 2025). Female adolescents with AIS may mask feelings, perform fine and keep problems or discomfort to themselves to avoid being perceived as overly dramatic, high-maintenance or a burden, as Flora, Sienna and Thea reflect in 4.2.1, and conform to gender roles by prioritising the comfort of others (Andrews et al., 2021).

This interpretation is limited in that these potential desires to uphold patriarchal norms could be unconscious, and gender norms are not named by participants. My interpretations could have overstated the feminist lens here, as the hermeneutic circle plays out. Instead, participants reflected “pushing through” was more driven by a desire to ‘blend in’, be the same as others and not stand out, rather than the former suggestion. Based on this finding, it could be argued, contrary to the literature review, the experience of diagnosis and surgery was somewhat secondary to participants, and their

social standing was deemed more important, suggesting any experience, not just AIS surgery, that makes adolescents different can impact mental health. Participants do not want to be different, therefore, implications could be based in allowing participants to fit in socially, rather than increasing support for diagnosis and surgery alone.

Post-operatively Flora worked hard to ‘perform fine’ by returning to lessons quickly, she named her reasons as learning better in the classroom with peers, than working alone. Flora reinforces this idea of being low maintenance by not asking for help, and in doing so she limits attention on herself, and maintains normality. Flora’s behaviour is consistent with research from Lambert and Keogh (2015) who found children with long-term conditions underreported symptoms to appear healthy, reduce attention and maintain normality. ‘Performing fine’ potentially allows participants to reduce potential psychological consequences of not fitting in, such as anxiety, exclusion, self-consciousness and negative feelings. Again, participants are highlighting an aspect of their mental health experience as ‘performing fine’ despite potentially not feeling psychological ‘fine’.

Within this, it was seen how Faye used clothing to ‘perform fine’ and hide her visible difference from others to avoid people “making fun” of her, behaviours Carrasco and Ruiz (2016) also saw. Faye highlighted how society may evaluate the body to determine who is ‘fine’, and a visible difference may suggest a body devalued by society (Garland-Thomson, 2020). Faye worked out how clothing could help her ‘perform fine’.

Within white-centred mainstream Western media, there is a feminine desire to have a young, thin, but not too thin, strong, healthy and active

body, with a slender, flat-stomach and small-waist, commonly referred to as the thin-ideal (McComb & Mills, 2022). Additionally, a fit-ideal has been popularised by social media, encouraging a thin but athletic body type (McComb & Mills, 2022). Faye describes her body as “skinny”, an informal word with negative connotations of being unhealthy, distinctly different from potentially more positive terms used by society, such as ‘thin’ or ‘slim’ (Woodford, 2012), she compares to others, supporting social comparison theory (Festinger, 1956), uses baggy clothing to hide her “skinny” body and attempts to present a ‘fine’, ‘healthy’ body to the world.

This subtheme draws particularly on the feminist grounding of this research, highlighting the cultural norms AIS conflicts with and how the participants attempted to navigate these to avoid consequences. ‘Performing Fine’ and ‘Keeping it to myself’ drew on social behaviours of women. The next sub-theme continues to link back to feminist theory but focuses on the judgement of the female body.

4.2.3 Self-Consciousness and Surveillance of the Body

Participants recognised feeling self-consciousness about their body pre- and post-operatively and surveying it through how it looked and moved. Concerns about their body were mainly contextualised by how others perceived or viewed it, with concerns reflecting what was ‘noticeable’ to others. Baird and Gardner (2021) reported a speculated higher risk for social anxiety among those awaiting AIS surgery. Self-consciousness is a key component to social anxiety and whilst no participants named social anxiety, they related to feeling self-conscious with a strong desire to blend in.

Drawing on De Beauvoir's (1949) view that "one is not born but rather becomes a woman" (p.273), adolescent girls in the present study are grappling with their emerging feminine identity through puberty and understanding what is 'normal' among their peers. This 'becoming' is tied to how their bodies are seen, shaped and judged by others. They slowly realise their AIS is a source of difference, and potentially a threat to being included and valued within society.

Feminist viewpoints are highlighted as participants perceive their body under the gaze of others (De Beauvoir, 1956), and poignant to note, in contrast to feminist theory, how the gaze of other females was as important, if not more, than that of males. The transcripts across participants highlighted school same sex changing rooms as a place in which self-consciousness peaked, a specific and contextual consequence of adolescent age and school life, in which they were able to see and observe bodies of their peers and further understand how their body differed from those around them. As puberty continues, adolescents become increasingly aware of the need to conform to aesthetic and behavioural norms of a patriarchal society (Finne et al., 2020). Those with scoliosis are informed at diagnosis, usually by a male surgeon, their bodies are 'abnormal' and in need of 'corrective' surgery, further reinforcing to adolescents their female body is an object to be looked at, judged and fixed. Bordo (1993) highlights how medicine often pathologizes female embodiment, pushing for correction. This viewpoint may reduce AIS surgery to a purely aesthetic surgery, leaning too far into cultural arguments. However, coupling this theory with the work of Lennon and Fischer (2024), and Garland-Thompson (2020),

referencing less power in less-abled bodies and the norm of appearance allows lived experience and norms to be incorporated. In the case of scoliosis, surgical recommendations address functional concerns but also aesthetic ideals and cosmetic benefits (Gallant et al., 2018).

Carrasco and Ruiz (2016) reported participants attempting to walk straight, which was also a behaviour shown by Faye. Faye realised her feet turned inwards when an ex-partner informed her. She began practising her walk at home, pre- and post-operatively to hide her difference, and reduce the chance others might make fun of her. It is acknowledged how this interpretation overlaps with the ‘performing fine’ subtheme, and how Faye’s use of clothing could be interpreted here as self-consciousness or vice versa. However, it was interpreted clothing was used performatively, to present an external performance, whilst changing her walk was an internal self-consciousness, and something she worked to change physically.

My study builds on Motyer et al. (2022) who reported participants hoped surgery would improve their appearance and remove problems. Within the present study participants reported some positives to their body and how they felt post-operatively, explored further in the ‘Changed Body’ subtheme, but acknowledged continued self-surveillance. Tess recalled how she noticed her body “more than I did before surgery”, observing her imperfections closely and Sienna reflected on being “hyper-aware” of her body, though understood others “wouldn’t notice”. These reflections agree with those of Carrasco and Ruiz (2016) who reported participants were relieved at being scheduled for surgery to ‘correct’ their body, but felt surgery could not resolve negative self-perceptions and psychological

consequences of body dissatisfaction as females have learnt and internalised criticisms of their body, once more aligning with feminist perspectives. Carrasco and Ruiz (2016) interviewed women pre-operatively and made assumptions about post-operative reflections. This study concludes surgery did not remove self-scrutiny, negative perceptions, or awareness of imperfections for these participants, and in some cases made it worse.

This subtheme highlights the impacts diagnosis and ‘corrective’ surgery has on adolescents, impacting their relationship with their body image and their sense of how they are perceived and valued within society, decreasing self-esteem and increasing self-consciousness. The next subtheme moves away from the social world, towards the internal world of the participants and psychological turmoil experienced.

4.3 Psychological Turmoil and Emotional Disruption

4.3.1 Anxiety Caused by Uncertainty

All participants reported feeling nervous and worried about their surgery. Participants reported fears of not knowing what would happen during surgery, things going wrong, pain and worries around what life would be like post-operatively. These findings agree with those discussed in the literature review (Rullander et al., 2013; Motyer et al., 2022; Macculloch et al., 2009), where participants named fear, anxiety and nervousness. One aspect that emerged from the present study and was not captured by previous studies, was how worries were rooted in uncertainty, of not knowing what to expect. Two participants specifically named uncertainty, about whether they would need surgery and when their surgery would be, causing anxiety.

This subtheme directly relates back to the research question, highlighting participants experienced pre-operative anxiety, mainly caused by the uncertainty surrounding surgery. It is widely accepted uncertainty is a central feature in the conceptual model of fear, which leads to anxiety and worry (Gu et al., 2020). The worries Rullander et al. (2013) named can be argued to be rooted in uncertainty, but it is harder to establish for Macculloch et al. (2009) and Motyer et al. (2022) as results did not name roots of fear, simply the emotion.

It could be argued these anxieties are normal when undergoing major surgery and short-lived for participants, however it is important to remember the impacts of surgery and uncertainty may differ for adolescents compared to adults or children. Osmanağaoğlu et al. (2018) state the ability to detect and reason about uncertainty develops across childhood with meta-cognitive skills such as holding multiple possible outcome predictions in mind, delaying making an interpretation about something until further information is gained, or asking for help in response to an uncertain situation developing into adolescence. It could be determined these skills were missing for some of my participants, such as not asking for help, or, in Faye's case, avoiding information as a way of distancing herself from surgery, and attempting to cope. Osmanağaoğlu et al. (2018) reported a strong correlation between low tolerance of uncertainty and anxiety/worry in children and adolescents.

Tess reported anxiety around the uncertainty of her surgery, and experienced panic attacks at school, triggered by thinking about her upcoming surgery, but reported feeling "fine". Similarly to Faye, and in line

with Osmanağaoğlu et al. (2018) it could be interpreted Tess lacked the cognitive ability to cope with the anxiety and uncertainty of her surgery, so she internalised her feelings, stating she was “fine” in a desire to blend in, and this internalisation resulted in panic attacks. Rachman (1980) formulated sudden panic attacks could be a consequence of incomplete emotional processing, and a sign one has failed to process emotion associated with an adverse life event. This could be true for Tess’s experience.

These examples highlight how uncertainty, anxiety and suppression of anxiety and emotion prior to surgery may contribute to worry in adolescents and escalate to panic responses specifically related to AIS surgery.

While there might always be some uncertainty around surgery and diagnosis, reducing the uncertainty as much as possible would be helpful for adolescents experiencing AIS to increase their tolerance of uncertainty, reduce suppression of anxiety and increase coping skills, as Rullander et al. (2013), and Motyer et al. (2022) suggest. Alongside their uncertainties around AIS, participants named situational factors which could give rise to overwhelm (Dael et al., 2025).

4.3.2 Overwhelm

Participants reflected how the diagnosis of scoliosis and surgery caused a sense of overwhelm alongside other aspects of adolescent life they had to deal with. Sienna moved to secondary school just before her diagnosis, and Flora was completing her GCSEs around the time of her diagnosis and surgery. Both stressful times for adolescents, but here the

additional stressor of AIS is added. Participants reported it was “a lot”, and Flora summarised it as “hard”.

Pre-operatively participants reported coping with the diagnosis, but the upcoming surgery had an impact on them and felt overwhelming. As presented in other themes, participants had varying mechanisms to cope with this overwhelm, either ‘Performing Fine’, attempting to be ‘normal’ and blend in, or, as the below subtheme draws on, unconsciously withdrawing from friends. This subtheme relates directly back to how participants experienced their mental health pre- and post-operatively with overwhelm being a common symptom of mental health struggles and a precursor to mental health difficulties.

Ekbäck et al. (2024) researched the association between depression and overwhelm in adolescents. Participants with major depressive disorder, according to the DSM-5, described being subjected to multiple factors caused their depression rather than one single factor. Examples of overwhelming events included health problems limiting their ability to join in. Flora acknowledged PE was something she used to “relax” within school, without it, she was potentially left with the overwhelm of her GCSEs and AIS, with no outlet for relaxation. Ekbäck et al. (2024) continue to describe low mood and overwhelm lead to panic attacks and anxiety, again, symptoms seen in Tess and Faye, one pre-operatively and one post-operatively.

Numerous studies from the literature review highlighted depression/depressive symptoms in adolescents with AIS (Danielsson et al., 2001), or risk for depression (Baird & Gardner, 2021). Findings in the

present study aligned, naming overwhelm, low mood at not being able to join in and examples of withdrawing physically and emotionally, all of which could be construed as emotional distress, or depressive symptoms, as language in previous studies described it.

Faye shared a different experience of overwhelm, due to feeling her emotions were too overwhelming, she dissociated from them. She acknowledged diagnosis and surgery was too much for her to cope with, asking her mum to withhold information about what would happen during surgery from her. No other studies explored here reported episodes of dissociation from participants, but Rullander et al. (2013) acknowledged nightmares. Post-operatively, Faye experienced nightmares and panic attacks about her hospital stay, recalling memories of intensive care and being moved between beds when she was barely conscious. Agargun et al. (2003) report a relationship between dissociative experiences and nightmares, and how childhood traumatic events may factor into this. Faye had prior experience of another spinal surgery when she was younger, which could be a confounding variable, influencing her experience of spinal fusion surgery, as she named aspects of that experience as “traumatic”.

IPA’s idiographic approach allows acknowledgement of dissociation, despite only one participant reporting it. Overwhelm and dissociation reflect the psychological turmoil adolescents with AIS may experience; this emotional disruption may manifest behaviourally through social withdrawal.

4.3.3 Social Withdrawal

Four participants shared examples of socially withdrawing, either physically by not attending activities, not wanting to leave the house, or behaviourally, by becoming quieter with friends.

Rullander et al. (2013) heard participants describe losing friendships due to time off school, and participants not being able to continue sport. Thea described similar withdrawal but identified how this caused an internal feeling of not wanting to do anything. Carrasco and Ruiz (2016) heard accounts of participants avoiding situations, such as swimming and beach trips, because of their body. Rubin et al. (2006) highlight the importance of strong peer relationships for psychological well-being in adolescence, and here it is shown how AIS disrupts that, causing social withdrawal.

Baird and Gardner (2021) completed a quantitative study concluding 59% of participants met criteria for further social anxiety assessment. Barzeva et al. (2020) researched the bidirectional relationship between social anxiety and social withdrawal and how peers influence this relationship. It could be hypothesised Sienna's social withdrawal pre-operatively was a response to feeling socially anxious. She became quieter, was laughing less, and not joking as much with friends. The effort of trying to conceal her scoliosis and feeling anxious about social situations could have caused her to avoid drawing attention to herself, therefore she remained quieter around friends, still physically present, but withdrawing in her behaviours, providing support to Baird and Gardner's (2021) findings. Equally, Sienna's withdrawal could also suggest emotional distress; presenting with less laughter, quieter and withdrawn as she internally dealt

with her diagnosis and upcoming surgery, linking back to Baird and Gardner (2021) and Danielsson et al. (2001).

This interpretation links to the isolation subtheme, however it was felt there was a distinction between social withdrawal being a choice, whilst isolation is unwanted and not chosen by the participant. Qualitative data allows for depth in the interpretation of these behaviours of withdrawal and isolation, that prior studies potentially could not identify (Baird & Gardner, 2021; Danielsson et al., 2001).

This subtheme highlights a behavioural consequence of what participants might be experiencing with their mental health before and after surgery. Whilst participants do not explicitly name clinical labels of mental health, they are occasionally used to align with language used in prior literature (Baird & Gardner, 2021; Danielsson et al., 2001). References to anxiety and depressive symptoms are used descriptively, not diagnostically. The Counselling Psychology lens allows a wider exploration of participants' experience of their behaviour, the social/cultural impact of school, and how these might be impacting their mental health. Counselling psychology also allows an exploration of individual potentials (Whiteley, 1980), moving into the final GET of Emerging Selfhood and Acceptance.

4.4 Emerging Selfhood and Acceptance

4.4.1 Changed Body

This subtheme relates specifically to participants reflecting on how surgery changed their body; reporting positive changes, but also how they had not been 'warned' about their body changes, and the experience of having a 'new' body that they were not used to post-operatively.

Separately, Zebracki et al. (2013) and Roberts et al. (2011) concluded mental health and body image was improved post-operatively when participants repeated the SRS-22 and SRS-30, respectively, leading Roberts et al. (2011) to conclude the most beneficial effect of surgery is improved self-image. However, their data was quantitative and though improved for participants post-operatively, it did not go further to explore what changed, or whether participants still struggled with aspects of their body image, despite scores increasing. Arguably, the way one feels about their body is more complex than single scores, on a single day, and while the present study showed some consistency with Zebracki et al. (2013) and Roberts et al.'s (2011) findings with Flora and Tess reporting being "happy" with their body post-operatively, participants acknowledged surgery did not completely erase body image concerns, aligning with conclusions from the qualitative research of Carrasco and Ruiz (2016) and Rullander et al. (2013). Rullander et al. (2013) found participants reported a changed body image post-operatively, and felt self-conscious about their scar, something participants in my study reported. Faye, Sienna, Tess and Thea shared reflections highlighting they are still aware of their body, scrutinising aspects of it, and surgery did not eradicate these feelings. Tess felt she was more conscious of her body because of having AIS. Thea struggled with how her body felt after surgery, reporting worries it did not look "like how it was meant to look" as she struggled to adapt to a body different from what she was used to. Faye summarised she was not "warned" her body image might change. Prior researchers felt surgery was enough to improve body image but miss that while the body looks different post-operatively, no-one

“warns” adolescents what it might be like to be in a changed, foreign body. There is a sense of adolescents being encouraged to be happy with their changed body and ‘improved self-image’ after surgery, with surgeons highlighting a positive of surgery is the aesthetic, but participants highlight how it may not be that simple, and the counselling psychology lens of this research can acknowledge the complexity of such results, compared to more medical based quantitative research (Roberts et al., 2011; Baird & Gardner, 2021).

Laursen and Hartl (2013) acknowledge adolescent girls are already adapting to a changing body with puberty causing physical changes. Simmons and Blyth (1987) report self-esteem is intractably bound to physical changes and novel romantic experiences. Girls navigating a changing body due to puberty and AIS, dealing with a ‘new’, unfamiliar body shape following surgery and attempting to hide aspects of their difference, as other subthemes have explored, may experience discomfort in learning prospective romantic partners and the opposite-sex are critically evaluating their bodies, though here participants seemed more conscious of other females evaluating them. Managing these changes, self-consciousness and attempting to reintegrate with daily life post-operatively could quickly become a psychological minefield for adolescents.

As Faye suggests, “warning” adolescents about how surgery might change their body, and how these changes might not necessarily feel comfortable or positive could help reduce poor body image post-operatively and increase tolerance and acceptance within changing peer and romantic relationships.

4.4.2 Self-Growth

Four participants in my study reflected on changed mental health post-operatively and this was characterised as self-growth, aligning with counselling psychology definitions of mental health.

New research is explored here given the lack of post-operative qualitative data within AIS literature. Whilst quantitative research showed improved mental health scores (Roberts et al., 2011) it could not highlight what changed, or why mental health improved. This research has highlighted aspects which may improve after surgery. Prior research observed adolescence as a period of self-growth and identity formulation (Luyckx & Robitschek, 2014), as adolescents form who they will become as adults. Flora, Faye and Sienna shared how scoliosis surgery “opened their eyes” to how things can happen in life, helped them reflect on what was important to them, and what was not worth worrying about. Sienna and Flora felt it shaped them as people and became a part of them, highlighting self-growth, and potential positive impacts of the surgery, helping them develop resilience and inner strength.

Cartwright et al. (2015) conducted interviews with adolescents diagnosed with juvenile idiopathic arthritis, whilst not related to AIS, it felt fitting as researchers found adolescents named themes of resilience and this resilience helped them to take control over their body and accept their condition. It is acknowledged adolescents with AIS had surgery to ‘correct’ their curvature and hopefully reduce pain and AIS symptoms. Participants in the arthritis study took medication but their condition was not ‘fixed’. Nonetheless, my participants seemed to resonate a similar resilience and

control; regaining autonomy when they returned to school/lessons, hobbies and understanding they were able to overcome difficult times.

Cartwright et al. (2015) reported acceptance required a combination of maturity and familiarity with the condition, observed within AIS as well. During interviews participants, now older than their initial diagnosis, were able to reflect with maturity, noticing what changed, what was important to them, and some noticed how age was a factor in how they initially dealt with the diagnosis, and how their friends reacted. Being familiar with their ‘new’ body and what they can and cannot do with a fused spine enabled confidence in participants, and an ability to re-engage in hobbies or try new ones. This is information quantitative studies were missing with improved mental health (Danielsson et al., 2001; Zebracki et al., 2013) and body image (Roberts et al., 2011) scores but not seeing why or what remained. This study has explored why participants experienced improved mental health post-operatively, through self-growth and improved confidence, but also what remained difficult socially and around their body image, as Thea shared. This study and Cartwright et al. (2015) highlight how adverse physical health conditions can result in resilience, confidence and self-growth for adolescents.

4.4.3 Confidence

Three participants reflected on feeling more confident after their surgery. Sienna felt more talkative and less socially anxious post-operatively, reflecting the surgery made her see “there’s bigger things”, opening her eyes to not being “so serious”, and made her feel there was “no point” worrying about “social stuff”. Whilst Sienna felt the experience of

diagnosis and surgery helped her see things differently, it could be speculated her change in body shape also helped her to gain confidence, compared to pre-operatively when she was withdrawing potentially to avoid attention or being seen. Javaid and Ajmal (2019) reported 56% of adolescents had low self-esteem because of dissatisfaction with their body image. It is acknowledged that confidence and self-esteem are separate entities, with self-esteem defined as how much a person believes in their own self-worth and their perception of the degree of respect shown to them by others, whilst confidence impacts one's belief about their ability to do certain things. Those with low confidence may also not feel certain about themselves or what they look like (Javaid & Ajmal, 2019). For Sienna, her quieter social self potentially gained confidence once her body changed post-operatively and she could be more talkative and confident in social situations with less risk of ostracization. Sienna may be socially comparing herself to others, experiencing increased confidence when she compares her pre-surgical body to her post-operative self and to peers, and feels increased confidence, aligning with social comparison theory (Festinger, 1956). However, Javaid and Ajmal (2019) and Festinger (1956) reinforce a focus on socially acceptable bodies and how a physical change was the only way to improve confidence. Whilst this research relates to those who have surgery, it may suggest to those who do not have surgery that their body is not socially acceptable without medical intervention, and reinforces a narrative around how confidence can only improve with a physical change, not an internal change.

Danielsson et al. (2001), Roberts et al. (2011) and Mens et al. (2022) report an overall improvement in quality of life, and mental health/body image after surgery, with Mens et al. (2022) showing improved mental health and body image at one year, and somewhat maintained at two years, with a non-clinically relevant decreases from one to two-year follow-up, post-operatively. These studies support the shift in how participants viewed their body post-operatively, including seeing their body more favourably, which could support confidence in their body. Pre-operatively, Flora reported having to miss out on sports and activities, her body failing her. Immediately after surgery, Flora used language of “careful”, and being “cautious” to not hurt herself, or damage her body. Flora described feeling more “confident with everything” a year after surgery, interpreted as her feeling more confidence in her body’s ability and feeling less need to be careful. This aligns with Mens et al. (2022) highlighting the potential recovery period needed for adolescents to adjust and feel confident in their post-operative body.

The present findings help to address the research question, post-operatively participants reported aspects which could be consistent with improved mental health and body image, supported by Danielsson et al. (2001), and Roberts et al. (2011). However, future research could interview participants further on post-operatively, as Danielsson et al. (2001) did to continue to observe trajectory of mental health and body image over time. Post-operatively allowing adolescents to reflect on positives of the experience might boost their mental health and how they feel about themselves.

4.5 Theme Summary

Pre- and post-operatively participants seemed to be faced with a choice between psychological wellbeing versus physical wellbeing. Psychological consequences of AIS were tethered to their social status and ability to belong, rather than the experience of a major surgery itself. Participants concealed and sacrificed their physical wellbeing to avoid the psychological consequences of not fitting in socially and appeared to prioritise their social status over their AIS, desiring to be the same as others. These included returning to school early post-operatively, going outside with peers before they should have, returning to lessons early, “pushing through” pain and trying new things. Body image concerns remained throughout with self-consciousness and self-surveillance; however, acceptance and self-growth shone through, highlighting some positives to the journey participants faced.

CHAPTER 5. CONCLUSIONS

5.1 Considerations for Clinical Implications

The research question aimed to ask participants about their psychological experience of AIS surgery pre- and post-operatively. At analysis, it was decided not to present findings in a temporal manner, with three themes addressing pre- and post-operative experiences. Throughout the analysis, discussion and conclusion, pre- and post-operative differences are acknowledged to illuminate how participant's experiences evolved from pre- to post-operative. Within the frame of clinical implications, acknowledging these evolutions is important, to ensure support is tailored across the experience. This study highlighted how concerns, such as self-consciousness and body image, are not removed by surgery, but may change. Participants may go from concerns about hiding a visible difference to hyperawareness of their body shape, and worrying whether they look 'wrong', as Tess did.

Another clinical implication is the awareness of mental health in the consultation room and use of stigmatising language. Medical staff should be aware how diagnosing a visible difference may impact how an adolescent views their body, and thus this should be done with care. Medical staff and psychological practitioners working with adolescents with AIS could 'warn', as Faye suggested, adolescents about possible changes to their body post-operatively or discuss changes with them. Discussing how their torso may look longer, their waist may change shape, or their shoulders could look different would be a small addition to consultation rooms but allow adolescents to be better prepared for post-operative changes. Discussions

with surgeons and consultants to ensure these topics are being acknowledged in consultation rooms, or adolescents are being signposted to organisations that can help would be a useful update to clinical practice, as well as updated policy on ensuring adolescents are psychologically well enough to go ahead with surgery. Currently, this decision lies with the surgeon, but as Grevitt et al. (1998) highlights, surgical consults may be inexperienced at noticing psychological difficulties. Further conversations and education for surgeons and families around mental health and body image within diagnosis and decisions about surgery would be useful for adolescents.

Offering peer support groups, or web-based forums, as Macculloch et al. (2009) discussed, informal or with a trained practitioner could allow a space for adolescents to discuss their emotions, feelings and fears with others who understand, and reduce consequences of keeping things to themselves. The participants reflected, in hindsight, having a peer to speak to who experienced AIS surgery would have been helpful. These support groups could allow adolescents to build tolerance to uncertainty, talk about their feelings, body image, adjust to a changed body, manage feelings of self-consciousness and gain adaptive coping strategies whilst individuating from parents and achieving a sense of belonging with a group outside of their school or friendships. For participants like Tess who reported high levels of anxiety when in public and feared others were staring at her, psychological support could have been helpful to explore these thoughts.

The charity Scoliosis Support and Research (SSR) have started support groups run by a counsellor, divided by age group, with the aim to

initiate a sense of connection and belonging amongst those with scoliosis. The group is open to pre- and post-operative members. This study has found themes of isolation, self-consciousness, self-surveillance, emotional turmoil and self-growth which could be discussed across pre- and post-operative adolescents. Charities, or the NHS through surgical pathways, may be able to continue/provide such groups, however it is acknowledged funding and availability of practitioners may be limited. The charity may also be able to implement education around how mental health and body image is impacted by a diagnosis of AIS and by surgery, providing peer support and professional support with practitioners who have knowledge of AIS, or an understanding of the condition. Advocating for the adolescent's mental health and body image to be of equal priority to physical health is important to ensure a holistic care plan is enforced. Simply naming mental health and body image may be enough for some adolescents to acknowledge its presence and have the opportunity to discuss it should they wish.

Counselling psychologists could be well placed to offer this support, especially given the findings of participants not framing their experience in terms of mental health diagnoses, but rather emotional and relational processes. The emphasis on subjective and social context aligns with counselling psychology principles of prioritising non-pathologizing perspectives, relational understanding and acknowledging broader social contexts (Strawbridge & Woolfe, 2010; Cooper, 2009) adolescents with AIS are carrying.

5.1.1 Dissemination of Findings

It is important to me to disseminate the findings of this study to ensure it is shared with those to whom it matters.

I have drafted a journal article in line with criteria for the Journal of Paediatric Psychology (Appendix S). The journal's mission is to promote the health and psychological wellbeing of children and adolescents (Oxford Academic, 2023). They describe an interdisciplinary field addressing physical, cognitive, social and emotional functioning in health issues related to adolescents and is a good fit of the interrelationship explored here between physical and psychological wellbeing. Whilst not a counselling psychology specific journal, it was felt the audience reached, of medical clinicians, surgeons and psychological practitioners working in a healthcare setting, would allow the results to be read by those who may be working with adolescents with AIS, and allow them to be aware of the psychological difficulties adolescents may be experiencing. The journal draws on holistic mental health and psychosocial approaches, which leans into counselling psychology principles. Whilst the findings heavily referenced school context and a journal focused on education could have been chosen, it was felt this journal was best placed to address the medical diagnosis and the psychological difficulties as an intertwined relationship. At this early stage of exploring the mental health of AIS adolescents, psychological staff and consultants may be more likely to work together within the healthcare setting to support adolescents with AIS, and provide interdisciplinary care, compared to school staff.

However, disseminating with those who work with adolescents and those directly impacted by AIS was equally important to me.

Participants were given the option to consent to being sent drafts of newsletters and summary sheets, to give feedback on how the findings were presented. One participant consented and was sent one mock newsletter (Appendix T) and one mock information sheet with the findings and a brief discussion (Appendix U). She felt the newsletter and summary sheet were clear and easy to read, had complementary colours, and the information made sense to her.

Four participants consented to being sent the results and discussion after the research is complete. They will be sent a draft article (Appendix V) detailing key findings and discussion points.

Additionally, I have contacted SSR with the newsletter and summary sheet draft to enquire about sharing my research in their quarterly magazine and website. This was important to me as I wanted the findings to reach the adolescents with AIS and their families who have been at the heart of this research. Hopefully sharing these findings will allow them to feel their voices are heard and empowered to reach out and speak about their struggles if they wish to.

5.2 Recommendations for Future Research

Firstly, it is hoped future research will acknowledge how the use of stigmatising language might increase self-consciousness and body image concerns in adolescents with AIS, themes seen here. Whilst language may be used clinically or to highlight the visible difference those with AIS may have, it is important to acknowledge the impact it may have on those with

AIS. Discourse analysis could be used to examine how language is used in the media, society and medical fields around AIS diagnosis and surgery, and how this impacts those with the condition.

Prior research has mostly concluded offering support would be helpful (Motyer et al, 2022; Carrasco & Ruiz, 2016; Zebracki et al., 2013), and participants here agreed, so future research could be implementing this to see how it is received by adolescents. With the positive step of SSR offering free support groups to adolescents, research to explore how adolescents experience the group would help to determine whether the groups are worthwhile. Quantitative data could evaluate the effectiveness of the groups. Qualitative data could inform us what adolescents find helpful, factors they like or dislike about the group, and what topics are most useful to them. There is a risk, as documented in this study, participants may not want to discuss their diagnosis and surgery with others, and revert to ‘keeping things to themselves’, research around support groups could help mitigate this potential barrier to adolescents receiving support.

This research has leaned into feminist grounding, and it is acknowledged no males participated. Future research should seek to explore male mental health and body image around AIS to explore whether the social pressures are similar, and how gender plays a role in the experience. Repeating the study with male participants to ask them similar questions about their mental health and body image may begin to build a picture of gender similarities and differences and generate discussions around how support may be tailored to males with AIS.

Finally, this research focused specifically on those who had AIS surgery one to three years ago. Whilst this allowed for exploration into pre- and post-operative experiences from an adolescent viewpoint, it is acknowledged experiences do not end once the surgery is complete, as Tess highlighted (1638-1639), and difficulties can continue further into adulthood following AIS surgery. Research at different time points after surgery will allow a chronological picture of how mental health and body image is impacted by AIS, and how long-standing these experiences may be. This may then allow support to be implemented at an appropriate time to reduce these concerns or mitigate longer term implications. Additionally, it is acknowledged many live with AIS without surgery. Future research may hear how adolescents diagnosed with AIS experienced their mental health and body image. This research would highlight how not ‘correcting’ the scoliosis may impact mental health and body image. Quantitative research could compare non-operative cases with operative cases to compare mental health and body image satisfaction scores, or qualitative research could gather accounts of how adolescents experience their body without surgery to remove the visible difference.

AIS is a nuanced and specific research area which would benefit from continued research, specifically from a psychology lens to explore mental health and body image implications.

5.3 Limitations of the Study

IPA calls for a small sample size, to allow in-depth exploration of transcripts and participants’ experiences (Smith et al., 2009). The study is not widely generalisable, which can be viewed as a disadvantage. However,

a strength of the research was six participants being able to share their unique experiences, highlighting the nuanced journey adolescents face when going through AIS diagnosis and surgery.

One participant had prior spinal surgery, using Magic Rods to stabilise her scoliosis before having spinal fusion surgery. The participant named this at pre-screening but was still invited to take part as it was deemed she could share her experience of her spinal fusion surgery for her AIS. Prior surgery was overlooked as part of the inclusion/exclusion criteria. It was felt the participant still shared her experience of AIS surgery; however prior treatment should be considered in future.

No males volunteered to take part in the study, meaning a male perspective was not heard despite males being impacted by AIS. No details of male patients were shared via Mr. Gardner and no males volunteered via social media. This could be a consequence of the gender divide within AIS curvatures over 40 degrees, with one boy diagnosed to every 7.2 girls, meaning more girls are likely to require surgery (Konieczny et al., 2013). Despite this known gender divide, under principles of counselling psychology it felt important to provide equal opportunities for all to participate (Tribe & Charura, 2023). I could have advertised specifically for males, once I had several female participants, however time constraints do not allow for open-ended recruitment. Retrospectively recruiting via social media could have appealed to female participants, with females consistently spending more time on social media than males across adolescence (Booker et al., 2018). Furthermore, the research advert highlighted the research topic of mental health and body image, adolescent males may have been less

inclined to want to discuss the topics with a female researcher (Arendell, 1997). Cultural narratives historically position body image as a predominantly female preoccupation (Bordo, 1993). As a generalisation, girls tend to reach emotional maturity before males, and boys with AIS may be struggling with a society giving them less opportunities to develop emotional skills and thus felt less able to participate in research discussing mental health and body image (Feraco & Meneghetti, 2023). However, as Auerbach et al. (2014) found gender differences did not exist, and males with AIS may be struggling as much as females, it felt important to give males an opportunity to take part if they desired, rather than excluding an underrepresented group, as Carrasco and Ruiz (2016) chose to, which does not align with counselling psychology principles (British Association for Counselling and Psychotherapy, n.d.). I was mindful to not generalise ideas of body image as a female preoccupation and ensure all were given the chance to be represented should they wish to. Further research could explore the topic with AIS males as they are heavily underrepresented within AIS research. Asking surgeons to assist recruitment of male participants could move away from recruitment on social media, or appealing to parents of males diagnosed via social media.

Finally, it is acknowledged the GETs were devised under the perspective of myself, as the researcher, and I may have placed higher value on some themes than others, arriving at different conclusions to another researcher. However, it is felt the themes and information presented in the analysis and discussion of this thesis adhere to the unique experiences of the

participants and quotations they shared, placing participants at the heart of the research.

5.4 Relevance to Counselling Psychology

Whiteley (1980) stressed counselling psychology helps clients develop individual potentials rather than the diagnosis they face. This feels particularly poignant after reviewing the findings. Participants reflected on their mental health in relation to contextual, societal, developmental and subjective experiences. Themes relate to coping mechanisms and experiences wrapped in a societal context, with important reflections around how others perceived participants, or how hard they worked to blend in.

The findings of this research highlights AIS does not occur in isolation and cannot be studied as such. This adheres to my critical realist beliefs, the real diagnosis and societal norms occurring alongside the actual events and empirical experiences of individuals. The research highlighted how adolescents are already facing major transitions and challenges as they search for their identity in a period of psychological turmoil and brain development. AIS was an additional pressure to cope with. Recognising and not minimising this feels in keeping with principles of counselling psychology and findings reflect this.

Clinical, pathologizing language or diagnoses were not named by participants. However, terms such as depressive symptoms and social anxiety are used to align this study with prior literature which does use clinical terms. Here the term ‘depressive symptoms’ is used descriptively, to highlight low mood and emotional distress participants may be experiencing. The terms are not used diagnostically. Lane and Corrie (2006)

highlight counselling psychology respects the personal, subjective experience of the client over and above notions of diagnosis, assessment and treatment. Pathologizing experiences to fit a clinical model of psychology does a disservice to the reflections of the participants, the underpinnings of counselling psychology and the foundations of IPA. The idiographic nature of my chosen methodology has been particularly helpful in allowing me to remain alongside the individual participants and interpret their lived experience separately, and then across participants. As a trainee counselling psychologist, I can frame these findings and research within the individual potentials of participants (Whiteley, 1980), and reflect on these contextual, person-centred findings, rather than hunting for clinical mental health diagnoses.

This thesis was grounded in feminist frameworks. The work of De Beauvoir (1956) was specifically drawn on within the findings as participants appeared to experience their body image and mental health as how they were perceived under the gaze of others. Themes highlighted external contexts influencing their internal experiences. One participant, Olivia, reported no concerns with her body image pre- or post-operatively. This highlights how she may have been experiencing different contextual or societal pressures, and for her, AIS did not impact how she viewed herself or how others perceived her. Olivia highlighted how, like everything, AIS is an individual experience. Connecting with humanistic values and principles allows respect of diversity in participants, and shows interest in the subjective truths of participants, no matter how much they differ from each other (Woolfe & Dryden, 1996). Counselling psychologists are well-placed

to embrace the diversity of AIS, supporting adolescents from a person-centred, humanistic viewpoint.

5.5 Conclusions

This thesis was necessary to explore how adolescents experienced their body image and mental health pre- and post-operatively, a study never done before. Prior research highlighted emotional struggles pre- and post-operatively, and elevated mental health/body image scores in adolescents that surgery did not always eradicate.

Themes found participants placed importance on belonging and AIS disrupted this. Participants searched for normality throughout their experience. The social world carried upmost importance, and participants edited their behaviour to protect themselves, hiding their difference through clothing, keeping things to themselves and performing fine. Psychological difficulties were highlighted with anxiety, overwhelm and withdrawal, and finally self-growth and acceptance were acknowledged as part of the journey of AIS.

Participants shared the struggles associated with AIS surgery, but the co-existing context and developmental age seemed important, with participants reflecting how young they were when having to cope with the experience. This intersected with feminist ideas, power and body image. Participants particularly acknowledged their body image concerns were strongly related to how others perceived them, and areas of belonging coincided with how much power they held, with adolescent girls losing their voice and authority, stopping them engaging with activities. Power appeared

renewed after surgery as they rebelled from authority and reclaimed their voice and confidence.

It is believed this thesis has conceptually moved away from clinical outcomes other AIS research may emphasise and a medicalised model of mental health and diagnoses. It explored how adolescents experience the emotional and social aspects of AIS and behaviours participants used to cope with the emotional upset of AIS, not just the physical or visible outcomes. This research could highlight a disconnect where consultants place importance on medical recovery, whilst adolescents aim for social acceptability. Practically, surgeons acknowledging this and working collaboratively with adolescents could aid recovery and ease psychological turmoil.

Hopefully these findings can encourage mental health discussions in consultation rooms and psychological support to be offered to those experiencing AIS surgery. Future research can evaluate support and tailor it to what is most useful for adolescents. Professionally, counselling psychologists may be well placed to offer this support given the non-clinical language adolescents used, and the clear contextual, social and emotional burden participants were carrying. Counselling psychologists can work with this distress without labelling or pathologizing it (Sinacore-Guinn, 1995). Looking beyond diagnostic labels, as this research has done, may help those already trying to hide another label of AIS.

Ultimately, I hope this work has highlighted the importance of asking adolescents directly about their experiences and allowing them space to share what is important to them in the context of mental health and body

image. In a situation where autonomy was removed, I hope this study allowed them to share their experience.

Finally, it is hoped there is continued awareness raised around AIS. Schools, adolescents, surgeons and society need further education to understand the impacts such diagnosis can have on adolescents. As the stigma around mental health breaks down, adolescents experiencing an AIS diagnosis, or who have surgery, should be afforded the same understanding. As Tess reminded us, just because things look “normal”, things may not be “fine”.

5.6 Final Reflexive Statement

Etherington (2004) understands researcher reflexivity as the capacity of the researcher to acknowledge how their experiences and contexts inform the process and outcomes of inquiry. These contexts might be fluid and changing, here, I can reflect on the experience of researching and writing this thesis as challenging and fulfilling. Throughout I have grappled with imposter syndrome, fears I am doing the ‘right’ thing, and wanting to honour the time provided by the amazing participants who shared their experiences with me.

Being able to complete research on a topic so important to me was a privilege but came with additional worries of being too close and having to carefully ensure my biases did not influence participant’s accounts. I managed this through reflection, understanding times when I unconsciously agreed with participants in interviews, or through my interpretations of the transcripts. Etherington (2004) suggests using reflexivity in research allows us to close the illusory gap between researcher and researched, the knower

and what is known. Relationships with participants can be one of collaboration and consultancy. In my methodology chapter I reflected on my participant interviews, and how I aimed for a conversational tone to help my adolescent participants to feel at ease, and more able to engage in the interview. I perceive this reflexivity as my way of collaborating with participants, and ensuring the interviews felt comfortable for them.

At times I notice certain emotions or memories triggered when I analysed the transcripts and explored the findings. I made notes about this, reflecting on why I was experiencing such emotions. Rather than attempt to shut these feelings out, I acknowledged them, explored why I experienced them, revisited the data more aware, and reflected on the interpretation whilst also exploring other possible interpretations the participant might be sharing, rather than my reactions. Smith (2004) encourages transparency and reflexive awareness, not objectivity in IPA research. Despite times I worried I had done the ‘wrong’ thing, I instead tried to reflect on challenges, be transparent about them and explore what I would do differently with my next participant or in future research.

I hope this research resonates with those who have gone through AIS surgery, those recently diagnosed, or awaiting surgery, and those who have an AIS diagnosis in their future. Whilst many aspects of the diagnosis are difficult, I hope this research raises awareness of what the journey may hold and how AIS becomes part of who we are.

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Appendix A

Public/Patient Involvement questionnaire for feedback

Adolescent Idiopathic Scoliosis, Mental Health and Body Image - exploratory questionnaire

Thank you for taking part in the completion of this brief, anonymous questionnaire.

I am a trainee Counselling Psychologist at London Metropolitan University researching Adolescent Idiopathic Scoliosis surgery and mental health and body image. The research will recruit 6-8 participants who have undergone surgery and interview them to ask about their mental health and body image.

However, prior to this research taking place, I would like some feedback from service users to ensure the research captures what is important to patients, parents and those who have or are experiencing scoliosis. The below questions ask for feedback on the research topic, anything you would like to be involved in around the research, questions you would like answered or discussed surrounding mental health and body image within scoliosis diagnosis and surgery, any reservations you would have if you or your child were asked to take part in the research, and the opportunity to give feedback on some of the research materials that have been drafted so far.

The responses will be anonymous and may be reported in the researcher's thesis and final write-up as proof of patient/public involvement.

1. Do you consent to your answers potentially being quoted anonymously as part of the researcher's thesis or write-up?

- o Yes
 - o No
2. Are you a:
- o Parent of an adolescent with idiopathic scoliosis
 - o Adult with scoliosis/adult who has had scoliosis surgery
 - o Adolescent (age 12-18) with scoliosis or adolescent (age 12-18) who has had scoliosis surgery
 - o Other
3. What are your initial thoughts about the research topic, or about the need for research into scoliosis and mental health/body image?
4. The researcher is keen to receive feedback from service users/those with experience of scoliosis in order to ensure the research is representative and meaningful to those experiencing scoliosis.

Answering this questionnaire is a great help, but other things such as looking at draft research materials i.e. interview schedules, information sheets, debrief forms, or reading draft result summaries and discussions, or helping to create newsletters or reports of the results and discussions may be useful too.

5. How would you like to be involved in this research?

6. Are there any particular questions you have regarding the research topic, or aspects that you think are important to discuss regarding mental health and body image within scoliosis?

7. As mentioned, the researcher will be interviewing 6-8 participants, aged 13-18, who have had surgery for AIS within the last three years, but are at least 12 months post-op. This interview will take place via video call on Microsoft Teams, lasting roughly one hour. Interviews will be recorded and transcribed. The interview will be semi-structured, meaning the interviewer has a list of questions to ask but can also ask questions based on what the participant says, asking for more detail or discussing a particular topic. The questions will be based around the participants' perception of their own mental health and body image prior to their surgery.

The researcher is aware that this could be a sensitive topic due to discussing mental health and body image, therefore risk and distress will be managed to the level of best practice, with protocols in place to reduce unnecessary harm.

Imagine you/your child is eligible to take part. Would you have any reservations about your child/yourself taking part in the interview?

8. Do you have any suggestions on how the researcher might address these concerns?

9. Here is a draft section of the information sheet that potential participants will be emailed to read and decide whether they would like to

participate. There will be one aimed at parents/guardians, this one is aimed at the participant (age 13-18).

Hi,

Thank you for taking the time to read this information.

I am a trainee counselling psychologist at London Metropolitan University and am currently carrying out research to discover more about Adolescent Idiopathic Scoliosis (AIS), Mental Health and Body Image.

Research currently suggests that those with AIS struggle with their mental health and body image, and these struggles are usually worse before surgery. However, there is currently very little information about how adolescents experience their mental health and body image prior to surgery.

Having had scoliosis surgery myself, my hope is that by carrying out this research we will be able to gain a better understanding of your and other young people's experience of AIS diagnosis and surgery, so that future research can start tailoring interventions and support for young people should they need help. I am writing to see if you would be interested in sharing your experience of AIS by participating in an interview. The interview would last approximately one hour, conducted via Microsoft Teams, and be video recorded. Data from the interview will then be used for my Doctoral level Counselling Psychology thesis.

Before you decide to participate it is important to understand that the interview will be discussing diagnosis, surgery, mental health, and body image, which may bring up some difficult feelings for you, such as sadness,

or anger. Questions will be asked in a sensitive way, by a researcher who has experience working with children in a mental health setting. You will not be forced to answer any questions and can provide as little or as much detail to questions as you wish. You may stop the interview and leave, ask for breaks, or pause the interview at any time. Your parents are welcome to stay with you during the interview if you wish. Nevertheless, please take your time in deciding whether you wish to take part. You will have the opportunity to discuss any feelings at length post interview with the researcher and be given information on sources of support.

Do you have any feedback on these sections of the information sheet?

10. A semi-structured interview will take place with the participants, meaning there are some pre-written questions that will be asked. Here are some of the questions that may be asked in the interview:

Tell me a little bit about your scoliosis journey? /An overview of your experience?

What was your experience of the time between diagnosis and surgery/pre-operative?

Tell me a little bit about your perceptions of your mental health or wellbeing during this time.

Did anyone ask about your mental health at this time? If so, who and what did they ask?

If not, how would you have reacted if someone had asked about your mental health?

Scoliosis can have an impact on how we physically look. How did you perceive your body image in the time between diagnosis and surgery?

Is there anything else you would like to share that feels important about your experience with your mental health and/or body image prior to surgery?

Do you have any feedback on these questions?

11. Are there any other questions you think need to be asked about the subject matter?/Or questions you would like to be asked as a participant?

12. How would you feel about answering the above questions?

Do you have any further comments about the research, or feedback you would like to provide to the researcher?

Appendix B

Research advert sent by Mr. Gardner via email

Participants needed for scoliosis research

My name is Victoria, and I am a Trainee Counselling Psychologist completing my doctorate research on the mental health and body image of adolescents who have undergone Adolescent Idiopathic Scoliosis Surgery.

I am looking to interview adolescents between the ages of 13-18 who have undergone successful spinal fusion surgery for Adolescent Idiopathic Scoliosis within the last three years.

I am looking for those who consider their surgery to be 'successful', however there are a number of health and wellbeing factors which mean you may or may not be able to take part in this specific study, which we need to discuss in our first conversation. Please see the participant information sheet below for more details.

If you are interested, please email Mr Gardner, giving consent for your details (name, phone and email) to be passed to myself, the researcher. I will then contact you to set up a pre-screening phone call. This will entail introducing myself, telling you about the study, completing the consent form, discussing confidentiality, and asking a few screening questions about your AIS experience and current mental health/body image to ensure you are suitable to take part in the study. You will also be given the opportunity to ask any questions.

I look forward to hearing from you!

Victoria

Jun 25, 2024



Appendix C

Participant Information Sheet – young person



V3.

17/05/2024

Information sheet – for young person/participant

Hi,

Thank you for taking the time to read this information.

I am a trainee counselling psychologist at London Metropolitan University and am currently carrying out research to discover more about Adolescent Idiopathic Scoliosis (AIS), Mental Health and Body Image.

Background for the research

Research currently suggests that those with AIS struggle with their mental health and body image, and these struggles are usually worse before surgery. However, there is currently very little information about how adolescents experience their mental health and body image before and after surgery. Having had scoliosis surgery myself, my hope is that by carrying out this research we will be able to gain a better understanding of your and other young people's experience of AIS diagnosis and surgery.

Benefits of taking part in this research include increasing knowledge of how adolescents who are undergoing surgery for AIS experience their mental health and body image, research never conducted previously.

It will allow you to share your experiences and discuss openly in a way you may have not been able to before, validating your thoughts and feelings, whilst raising the awareness of scoliosis and its potential impact on mental health. Key themes that emerge from your interview may inform future research around how adolescents can be psychologically supported during diagnosis and surgery.

Who is invited to take part?

Adolescents aged 13-18 who have had surgery within the last 1-3 years are being invited to participate in the interview, you should feel your surgery was 'successful' and be happy to talk about your experience and mental health, both before and after surgery. I am looking to recruit six to eight participants for this study.

What do I have to do?

I am writing to see if you would be interested in sharing your experience of AIS by participating in an interview.

If you decide to participate you will be invited to a 30-minute pre-screening phone call. This call will take place with yourself and your parent/guardian to introduce the study to you, give you a chance to speak with me, the researcher, as I will be conducting the interview, complete the consent forms, and ask any questions. This call will also be used to ensure you are suitable to take part; that you fit the inclusion criteria as 12 months post-op but no more than three years post-op. Questions will also be asked about your current mental health and body image. This research involves sensitive

topics, and it is important to reduce risk of harm by excluding those who may be vulnerable, such as if you have a history of mental health difficulties or eating disorders. Taking part in a study like this may be triggering or make things worse if you are already struggling with your mental health. This phone call will be roughly 30 minutes, and you and your parent/guardian can take part.

During the pre-screening call, we will decide together if you are able to go ahead with the research interview.

The research interview is an hour-long interview via Microsoft teams to discuss your experience. This interview will be audio-recorded. After the interview, you can choose to be sent summaries of results and engage in discussion. But no further interviews will be required, and you can choose for your participation to end there.

How will we use information about you?

We will keep all information about you safe and secure. Your interview will be anonymised 24 hours after the interview, and only identifiable from a coding system that I will use. This will be kept for 3 months, so that should you choose to withdraw I can identify your interview.

You can consent for me to send you results and study progress following the interview via your contact information. Confirm your desires on the consent form at the pre-screening call, and I will email you updates. Alternatively, you are welcome to email me to enquire, contact details will be at the bottom of this form.

Once we have finished the study, all contact information will be deleted. We will keep some of the data, the interview transcripts and consent forms, so we can check the results and legality. These will be kept for up to 10 years. Email correspondence will be deleted at this time. Reports will be written in a way that no-one can work out that you took part in the study, such as giving you a fake name, or simply 'participant X'.

If you have further questions regarding your data, please contact:

The researcher: Victoria Steele – vas0397@my.londonmet.ac.uk

London Metropolitan University Data Protection Officer – Tracy Brathwaite
- t.brathwaite@londonmet.ac.uk

What if I do not want to do the study or want to leave?

Participation is entirely voluntary. If you choose to participate you are free to withdraw, or leave the interview at any point, or remove your interview recording from the project write-up until the analysis begins (estimated 3 months from interview) without question. Transcripts from the interview will be used for my Doctoral level Counselling Psychology thesis. Interview recordings and transcripts will be strictly confidential, and only listened to by me and, occasionally my supervisor. All recordings will be kept securely on my university cloud account in a password protected folder and destroyed once the project is completed. We will require written consent from yourself and your parents if you are under 16.

Before I decide

It is important to understand that the interview will be discussing diagnosis, surgery, mental health, and body image, which may bring up some difficult feelings for you, such as sadness, or anger. Questions will be asked in a sensitive way, by a researcher who has experience working with children in a mental health setting. You will not be forced to answer any questions and can provide as little or as much detail to questions as you wish. You may stop the interview and leave, ask for breaks, or pause the interview at any time. Your parents are welcome to stay with you during the interview if you wish. Nevertheless, please take your time in deciding whether you wish to take part. You will have the opportunity to discuss any feelings at length post interview with me and be given information on sources of support.

If you would like to participate, and are age 16 and over, please confirm by emailing me, vas0397@my.londonmet.ac.uk, I will then contact you to arrange the pre-screening call.

If you would like to participate, and are age 15 and under, please get a parent/guardian to confirm your interest by emailing me on vas0397@my.londonmet.ac.uk, I will then contact you to arrange the pre-screening call.

Please feel free to email me directly if you have any questions or queries: vas0397@my.londonmet.ac.uk, and I would be happy to discuss things with you further.

The supervisor for this project is Dr Angie Cucchi;
a.cucchi@londonmet.ac.uk. Please contact Angie if you have any concerns
or complaints to report.

I look forward to hopefully hearing from you soon!

Victoria Steele

Trainee Counselling Psychologist

London Metropolitan University

Appendix D

Participant Information Sheet – parent/guardian



V.3

17/05/2024

Information sheet – for parents.

To whom it may concern,

I am a trainee counselling psychologist at London Metropolitan University and am currently carrying out research into Adolescent Idiopathic Scoliosis (AIS), Mental Health and Body Image.

Background for the research

Prior research suggests adolescents with AIS have poorer mental health and body image than their peers, and this is usually worse pre-operatively.

Despite this research, there is very little out there about how young people experience their mental health and body image before and after surgery.

Having experienced scoliosis surgery myself, as an adolescent, my hope is that by carrying out this research we will be able to gain a better understanding of young people's experience of AIS diagnosis and surgery.

Benefits of taking part in this research include increasing knowledge of how adolescents who are undergoing surgery for AIS experience their mental health and body image, research never conducted previously.

It will allow participants to share their experiences and discuss openly in a way they may have not been able to before, validating their thoughts and feelings, whilst raising the awareness of scoliosis and its potential impact on mental health. Key themes that emerge from participant interview may inform future research around how adolescents can be psychologically supported during diagnosis and surgery.

Who is invited to take part?

Adolescents aged 13-18 who have had surgery within the last 1-3 years are being invited participate in the interview, they should feel their surgery was ‘successful’, and be happy to talk about their experience and mental health, both before and after surgery. I am looking to recruit six to eight participants for this study.

What does participation include?

I am writing to see if your child would be interested in sharing their experience of AIS by participating in an interview.

If your child decides to participate you will both be invited to a 30-minute pre-screening phone call. This call will introduce the study to you, give you a chance to speak with me, the researcher, who will conduct the interview, complete the consent forms, and ask any questions. This call will also be used to ensure the participant is suitable to take part; that they fit the inclusion criteria as 12 months post-op but no more than three years post-op. Questions will also be asked about their current mental health and body image. This research involves sensitive topics, and it is important to reduce risk of harm by excluding those who are vulnerable, such as have a history

of mental health difficulties, or eating disorders. This phone call will be roughly 30 minutes and yourself and your child can take part.

During the pre-screening call, we will decide together if your child is able to go ahead with the research interview.

The research interview will be an hour-long interview via Microsoft teams to discuss your child's experience. This interview will be audio-recorded.

After the interview, you can choose to be sent summaries of results and engage in discussion. But no further interviews will be required, and you can choose for your participation to end there.

How will we use information about you?

We will keep all information about you safe and secure. Your child's interview will be anonymised 24 hours after the interview, and only identifiable from a coding system I will use. This will be kept for 3 months, so that should you choose to withdraw I can identify your child's interview.

You can consent for results and study progress to be sent to you following the interview via your contact information. Confirm your desires on the consent form at the pre-screening call, and I will email you updates.

Alternatively, you are welcome to email me to enquire, contact details will be at the bottom of this form.

Once we have finished the study, all contact information will be deleted. We will keep some of the data, the interview transcripts, and consent forms, so we can check the results and for legal purposes. These will be kept for up to 10 years. Email correspondence will be deleted at thesis submission.

Reports will be written in a way that no-one can work out that your child took part in the study.

If you have further questions regarding your data, please contact:

The researcher: Victoria Steele – vas0397@my.londonmet.ac.uk

London Metropolitan University Data Protection Officer – Tracy Brathwaite
- t.brathwaite@londonmet.ac.uk

What if my child and I want to withdraw?

Participation is entirely voluntary. If your child chooses to participate you are free to withdraw them, or they are free to withdraw up to when analysis begins (estimated 3 months from interview). Transcripts from the interview will be used for my Doctoral level Counselling Psychology thesis. Interview recordings and transcripts will be strictly confidential, and only listened to by me, the researcher and, occasionally my supervisor. All recordings will be kept securely on my university cloud account in a password protected folder and destroyed once the project is completed. We will require written consent from yourself on behalf of your child.

Before my child and I decide

It is important to understand that the interview will be discussing diagnosis, surgery, mental health, and body image, which may evoke some difficult and emotive feelings for your child. Questions will be asked in a sensitive way, by a researcher who has experience working with children in a mental health setting. Your child will not be forced to answer any questions. They

may withdraw at any time, ask for breaks, or pause the interview. Your child will be asked whether they would like you to remain in the interview with them. Nevertheless, please take your time in deciding whether you wish for your child, or whether your child wishes to take part. Your child/you will have the opportunity to discuss any feelings evoked at length post interview with myself and be given information on sources of support.

If your child would like to participate, and is age 16 and over, they can email me themselves to confirm their interest and arrange a pre-screening call.

If your child would like to participate and is age 15 and under, please can you as their parent/guardian confirm by emailing me at vas0397@my.londonmet.ac.uk, we can then arrange the pre-screening call.

Please do not hesitate to contact me directly if you have any questions or queries: vas0397@my.londonmet.ac.uk, and I would be happy to discuss further.

The supervisor for this project is Dr Angie Cucchi; a.cucchi@londonmet.ac.uk. Please contact Angie if you have any concerns or complaints to report.

I look forward to hopefully hearing from you soon.

Yours Sincerely,

Victoria Steele

Trainee Counselling Psychologist

London Metropolitan University

Appendix E

Pre-screening schedule

Pre-screening Questions schedule

Introduce self and the study.

I am a doctoral student at London Metropolitan University, completing my doctorate in Counselling Psychology. This research will explore the experience of AIS surgery on adolescent mental health and body image.

I am contacting you as you have shown an interest in participating in the interview. I wanted to speak with you today to introduce myself and confirm your suitability for the study.

Inform participant about the study, what it will entail, questions that may be asked and answer any questions.

Before we begin, it may be helpful to run through the consent form for the study first, you can ask any questions and sign it now. You will have a chance to review this if we go ahead with the study. Nothing you say today will be used in the write-up or final thesis.

Complete consent form – email back

Before we begin, I wanted to make you aware I may ask some questions about mental health, body image and body dysmorphia. Your responses will be kept confidential, but if you tell me anything that concerns me regarding risk or your safety, I may have to share with your parents, or others in order to keep you safe.

Pre-screening questions

When was your diagnosis and surgery?

“Please answer yes or no, would you deem your surgery as successful?”

Did you experience any complications during and/or after your surgery?

i.e., infection, paralysis, extended hospital stays. Can you share a little more about that with me?

Any long-term implications?

The study is focused on mental health and body image. Would you describe yourself as having anxiety or depression/any mental health difficulties?

If yes, what, how long for, triggers, impact. Have you had professional support for those difficulties?/Are you seeking professional support for these difficulties? Have you ever taken any medication for these difficulties?

If no, have you ever experienced mental health difficulties?

Would you describe yourself as having an eating disorder, body dysphoria disorder or difficulties around eating (eating too much, binge eating, or restricting eating, or excessive exercise, purging etc.)?

If yes, has this been diagnosed by a mental health professional? Have you had professional support?

Do you worry about the way your body looks, hide, or conceal parts of your body? What causes you to do this?

The study asks questions about your mental health and body image. Would you be comfortable answering these questions, giving examples, and sharing your experience?

If yes, are there any questions that you think might cause you distress, upset, or excessive worry?

If no, why not?

Thank you.

Ask participant if they are still happy to take part, offer space to ask any questions or discuss any concerns.

Appendix F

Social Media advertisement

Participants needed for scoliosis research

Research to explore the impact of surgery on mental health and body image is taking place and needs volunteers.

- Have you had successful surgery for Adolescent Idiopathic Scoliosis?
- Are you aged between 13-18?
- Have you had surgery within the last three years, but are at least one-year post-op?

The research involves an hour-long interview conducted on Microsoft Teams asking open-ended questions about AIS, mental health and body image. This interview will be recorded.

If interested, and aged 16 or over, please contact Victoria at **vas0397@my.londonmet.ac.uk**.

If interested and under 16, please get your parent/guardian to email Victoria at **vas0397@my.londonmet.ac.uk**

Appendix G

Consent Form for Parent



V.3

17/05/2024

Consent form – for parents:

IRAS ID: 337745

Title of the study: How adolescents with Idiopathic Scoliosis Experience their Mental Health and Body Image, pre and post surgery: An Interpretative Phenomenological Analysis.

Description of the study: In this research your child will be asked several questions regarding their experience of Adolescent Idiopathic Scoliosis, mental health and body image within a video recorded interview on Microsoft Teams.

- I understand the methods used will be a one-to-one online interview with my child, which will be audio recorded. I understand my child is required to have their camera on for the interview so the researcher can ensure they are not distressed or upset.
- I understand that I can stay with my child for all or part of the interview.
- I understand the researcher has experienced her own scoliosis surgery, however she will not disclose opinions or details of her own

experience until after the interview, to avoid bias or distracting from the experience of my child. I will refrain from asking questions regarding her surgery until after the interview.

- I understand my child is free to withdraw/I am free to withdraw my child at any time during the study without question. The interview data will be anonymised immediately following the interview, however a number will be allocated to my child, used to identify my interview recording and transcript. I understand I must contact the researcher so soon as I, or my child decides they no longer want to take part. I understand I must withdraw my child before analysis starts (3 months from the point of interview) else my child's interview cannot be removed.
- I understand that the researcher will ask for my/my child's personal contact details, such as name, phone number and email. The researcher will keep these details until the end of the research in a password protected folder on the researcher's university cloud at which point they will be destroyed. I can ask for these details to be withdrawn at any time.
- I understand that my child's name will not be used in connection with the results in any way, a pseudonym will be used in the write-up and all information that may otherwise identify my child (e.g.,

school, address, local area, friends names) will be changed/erased prior to transcription.

- I understand that my child's confidentiality will be breached if any information is disclosed that indicates a risk to the safety of themselves or others. This includes both the pre-screening and interview. This could include, but not limited to, suicidal ideation, self-harm, neglect, abuse from/towards others, excessive use of substances, etc. The researcher is duty bound to share or disclosure information to third parties that causes concern, including any information regarding parents/guardians/family members.
- I understand that the results of the study will be written up and accessible to others when completed and that quotations from my child's interview (minus explicit identifying information) may be used within the study.
- I understand that this interview discusses memories of AIS diagnosis and surgery, alongside mental health, and body image, and it may evoke difficult and distressing feelings for my child. My child/I will be offered support and the opportunity to discuss these feelings at length post interview with the researcher. The researcher will also give information on further support available, such as Mind, YoungMinds, Shout and Samaritans.

- I understand that I have the right to obtain information about the findings of the study and details of how to obtain this information will be given in the debriefing form.
- I understand that the interview data will be kept for 10 years after submission on the researcher's university cloud account, in a password protected folder and then destroyed.

The below two questions are optional. It is useful for researchers to liaise with services users and participants when disseminating or writing-up results and discussion. This ensures the results are meaningful to those whom the study may impact, i.e., service users. The below questions ask whether you would like to be involved in the creation of reports, newsletters or reporting the findings of the study, and whether you would like to receive a copy of the results following the write-up.

- My child and I would like to be involved in the dissemination of the findings, this may include reading drafts of newsletters, report summaries or posters that show the results of the study, and providing feedback to make them more accessible or meaningful to service users.
- I would like to receive a copy of the analysis and discussion once the research has finished. This will be in the form of a short document, discussing key themes the researcher has identified, and discussion of the analysis.

Signature of parent/legal guardian of participant:.....

Print name:..... Date:

Signature of researcher:.....

Print name:..... Date.....

Please note, this consent form will be kept securely for up to 10 years in line with standard research practice.

Appendix H

Consent Form for Participant (age 16-18)



V.3

17/05/2024

Consent form – for young person/participant (16-18)

IRAS ID: 337745

Title of the study: How adolescents with Idiopathic Scoliosis Experience their Mental Health and Body Image, pre and post surgery: An Interpretative Phenomenological Analysis.

Description of the study: In this research you will be asked several questions regarding your experience of Adolescent Idiopathic Scoliosis, mental health, and body image within an audio recorded interview on Microsoft Teams.

- I understand that I will have a one-to-one online interview with the researcher, which will be audio recorded. I understand I am required to have my camera on for the interview so the researcher can check I am not distressed or upset.
- I understand that my parent/guardian is welcome to stay with me for all or part of the interview.

- I understand the researcher has experienced her own scoliosis surgery, however she will not disclose opinions or details of her own experience until after the interview, to avoid bias or distracting from my experience. I will refrain from asking questions regarding her surgery until after the interview.

- I understand that I am free to end the interview at any time and withdraw my interview recording from the study without question. The interview data will be anonymised immediately following the interview, however a number will be allocated to me, used to identify my interview recording and transcript. I understand I must contact the researcher so soon as I decide I no longer want to take part. I understand I must withdraw before analysis starts (in 3 months from point of interview) else my interview cannot be removed.

- I understand that the researcher will have my/my parents' personal contact details, such as name, phone number and email. These will be used to contact me for the interview itself. The researcher will keep these details for audit purposes i.e., the consent forms, email trails, until the end of the research, at which point they will be destroyed. I can ask for these details to be withdrawn at any time.

- I understand that my name will not be included in the results in any way, a fake name will be used in the write-up and all information

that may otherwise identify me (e.g., school, address, local area, friends names) will be changed/erased prior to write-up.

- I understand confidentiality will be breached if any information is disclosed that suggests a risk to the safety of myself or others. This includes both the pre-screening and interview. This means the researcher will have to share things I say with other people if they are worried about my safety, or the safety of others around me, this is in line with legal requirements of the researcher. Things may be shared with my parents or GP. These things may include, but not limited to, suicidal thoughts, plans or actions, self-harm (thoughts and/or actions), abuse to/from others, neglect, excessive use of substances, etc.
- I understand that the results of the study will be written up and viewed by others when completed and that quotations/things I say in my interview (minus identifying information) may be used within the study.
- I understand that this interview discusses memories of AIS diagnosis and surgery, alongside mental health, and body image, and that may cause difficult and distressing feelings. I will be offered support and the opportunity to discuss these feelings after the interview with the researcher. The researcher will also give information on further support available, such as Mind, YoungMinds, Shout and Samaritans.

- I understand that I have the right to see the findings of the study and details of how to see this information will be given in the debriefing form.
- I understand that the interview data will be kept for 10 years after submission on the researcher's university cloud account, in a password protected folder and then destroyed.

The below two questions are optional. It is useful for researchers to discuss with services users and participants when writing-up results and discussion. This ensures the results are meaningful to those whom the study may impact, i.e., you! The below questions ask whether you would like to be involved in helping the researcher to make reports, and results accessible to others who might want to read the outcomes of the research and whether you would like to receive a copy of the results following the write-up.

- I would like to be involved in the reporting of the findings, this may include reading drafts of newsletters, report summaries or posters that show the results of the study, and providing feedback to make them more accessible or meaningful to service users.
- I would like to receive a copy of the analysis and discussion once the research has finished. This will be in the form of a short document, discussing key themes the researcher has identified, and discussion of the analysis.

Signature of participant:

Print name:..... Date:

Signature of researcher:.....

Print name:..... Date.....

Please note, this consent form will be kept for up to 10 years, in line with standard research practice.

Appendix I

Assent form for Participant (age 13-15)



V.2

17/05/2025

Assent Form – for participants aged 13-15

IRAS ID: 337745

Title of the study: How adolescents with Idiopathic Scoliosis Experience their Mental Health and Body Image, pre and post surgery: An Interpretative Phenomenological Analysis.

Your parent has given permission for you to take part in this interview, however I also want to check that you are happy to take part. If you do not want to take part in the interview, now or at any time during our conversation, you can choose to not be in the study, leave or end the interview. You simply need to tell me, the researcher, or your parent, alternatively type in the chat.

Important things to note:

The below are things that your parent/guardian agreed to, but are important to make sure you are comfortable with:

- I understand that I will have a one-to-one online interview with the researcher, which will be audio recorded. I understand I am required to have my camera on for the interview so the researcher can check I am not distressed or upset.

- I understand that my parent/guardian is welcome to stay with me for all or part of the interview.
- I understand the researcher has experienced her own scoliosis surgery, however she will not disclose opinions or details of her own experience until after the interview, to avoid bias or distracting from my experience. I will refrain from asking questions regarding her surgery until after the interview.
- I understand that I am free to end the interview at any time, with no consequences. I can also ask the researcher to not use my recording or transcript. I understand I must contact the researcher, or ask my parent to contact the researcher so soon as I decide I no longer want to take part. I understand the researcher will be writing up their findings over the coming months and I must withdraw before analysis starts (in 3 months time) else my interview cannot be removed.
- I understand that the researcher will have my/my parents' personal contact details, such as name, phone number and email. These will be used to contact me for the interview itself. The researcher will keep these details for audit purposes i.e., the consent forms, email trails, until the end of the research, at which point they will be destroyed. I can ask for these details to be withdrawn at any time.

- I understand that my name will not be included in the results in any way, a fake name will be used in the write-up and all information that may otherwise identify me (e.g., school, address, local area, friends names) will be changed/erased prior to write-up.

- I understand confidentiality will be breached if any information is disclosed that suggests a risk to the safety of myself or others. This includes both the pre-screening and interview. This means the researcher will have to share things I say in the interview with other people if they are worried about my safety, or safety of those around me, this is in line with legal requirements of the researcher. Things may be shared with my parents or GP. These things may include, but not limited to, suicidal thoughts, plans or actions, self-harm (thoughts and/or actions), abuse to/from others, neglect, excessive use of substances, etc.

- I understand that the results of the study will be written up and viewed by others when completed and that quotations/things I say in my interview (minus identifying information) may be used within the study.

- I understand that this interview discusses memories of AIS diagnosis and surgery, alongside mental health, and body image, and that may cause difficult and distressing feelings. I will be offered support and the opportunity to discuss these feelings after the interview with the

researcher. The researcher will also give information on further support available, such as Mind, YoungMinds, Shout and Samaritans.

- I understand that I have the right to see the findings of the study and details of how to see this information will be given in the debriefing form.
- I understand that the interview data will be kept for 10 years after submission on the researcher's university cloud account, in a password protected folder and then destroyed.

The below two questions are optional. It is useful for researchers to discuss with services users i.e., you when writing-up results and discussion. This ensures the results are meaningful to those whom the study may impact. The below questions ask whether you would like to be involved in helping the researcher to make reports and results accessible to others who might want to read the outcomes of the research and whether you would like to receive a copy of the results following the write-up.

- I would like to be involved in the reporting of the findings, this may include reading drafts of newsletters, report summaries or posters that show the results of the study and providing feedback to make them more accessible or meaningful to service users.
- I would like to receive a copy of the analysis and discussion once the research has finished. This will be in the form of a short document,

discussing key themes the researcher has identified, and discussion of the analysis.

As stated, you do not have to take part in the interview, if you don't want to, even if your parent has said yes. There will be no consequences, or changes to your care if you decide to not take part. If you have any questions about the things written on this form, or anything else, please ask the researcher, or ask your parent to ask the researcher.

By writing your name, you are agreeing to take part in the interview. You can still change your mind before, during or immediately after the interview.

Your name (participant):.....

Date:

Your Signature (participant):.....

Researcher's name:.....

Date.....

Signature of researcher:.....

Please note, this consent form will be kept for up to 10 years, in line with standard research practice.

Appendix J

Interview schedule

Interview schedule

Italics show prompts that may or may not be asked or may be altered depending on participant's previous answers.

Thank you for joining me today for a conversation around your scoliosis diagnosis and surgery. I will ask you some questions around diagnosis, the time before you had surgery, and how your mental health and/or body image was impacted at this time. I had scoliosis surgery myself, so understand it can be a difficult topic to discuss. Please only answer questions you feel comfortable talking about, we can pause at any time, or you can ask me to move onto the next question.

(Remind participant about consent form, answer any questions, remind participant about confidentiality. Inform participant I am in a private setting. Ensure they are comfortable, feel able to discuss openly and ready to begin).

Tell me a little bit about your scoliosis journey? /An overview of your experience?

How old were you?

When was your diagnosis?

Did you get braced at all?

When was your surgery, how far were you fused?

Tell me how your scoliosis was discovered?

Was it expected?

How long was the process?

How did the diagnosis make you feel? What thoughts/emotions did you experience?

Pre-Operatively

What was your experience of the time between diagnosis and surgery/pre-operative?

Emotions experienced?

Relationship with family/friends?

How long was the wait? What was the wait like?

How did you prepare?

What impact did this have on school, mental wellbeing, friendships, sleep etc?

When we talk about mental health, we can also think about mental wellbeing, or our feelings. And how these feelings impacted the things we do.

Tell me a little bit about your perceptions of your mental health or wellbeing/your feelings and how you coped with those feelings during this time.

Did the diagnosis/upcoming surgery affect your mental health? In what way?

When did you notice these changes?

What made your mental health worse/better? Any triggers that made things better or worse?

Did anyone ask about your mental health before surgery?/Or ask how you were feeling?

If so, who and what did they ask?

If not, how would you have reacted if someone had asked about your mental health?

Ask how you were coping. Whether you wanted to discuss anything about your diagnosis, wellbeing or about your feelings?

Scoliosis can have an impact on how we physically look.

Would you say your scoliosis was visible to others before your surgery?

How did you perceive/ or feel about your body image in the time between diagnosis and surgery?

Did you worry about certain aspects of your body?

Have you ever avoided certain activities because of your scoliosis i.e., swimming, or sports. Getting changed in front of others, if so what and why? If not, why not?

Did you way you felt about your body change following your diagnosis?

Did you receive any support for your mental health/body image before surgery? If yes, what?

If no mental health difficulties reported, what support, if any, did you receive regarding your diagnosis/surgery?

During Surgery

Can you tell me about the day of your surgery?

What emotions did you experience on the day of surgery?

Standout moments that you perceive as important, things you remember clearly.

Who was with you at the hospital?

How long in hospital? Did anyone visit?

Did anyone ask about your mental health in those days after your surgery in hospital?/ or ask how you were feeling?

If so, who and what did they ask?

If not, how would you have reacted if someone had asked about your mental health?

Ask how you were coping. Whether you wanted to discuss anything about your diagnosis, wellbeing or about your feelings?

How was it once you returned home from the hospital?

How long were you off school?

How did it feel?

Where you able to see friends/family?

Post-op

Can you tell me what it was like once you returned to school and you started to feel better?

What was it like going back to school?

What did your friends say?

How did it feel?

Was there anything you couldn't do, or had to do differently? How did that feel?

How did you feel about your new spine? Your scar? Or new body?

Once you were back doing your 'normal' activities, did scoliosis surgery impact your mental health in any way?

How you deal with situations?

Did scoliosis surgery impact your body image in any way?

Has your mental health/body image changed post-operatively, and if so how?

Has your mental health/body image improved, or gotten worse, or stayed the same since your surgery, can you think about what has impacted this?

Has your body image changed post-operatively, and if so how?

Has scoliosis impacted anything positively do you think?

How do you think mental health/body image should be discussed, or acknowledged before and/or after surgery?

What would be helpful, or unhelpful?

Is there anything else you would like to share that feels important about your experience with your mental health and/or body image?

Thank you for taking part.

(Remind participant of right to withdraw, and of the date they must do this by date 3 months after interview]. Provide debrief form, remind them of study aims, highlight support services. Answer any questions. Provide contact details should they have questions at a later date).

Appendix K

Distress Protocol

Distress Protocol

Protocol to follow if participants become distressed during participation:

Due to the emotive nature of this study, this protocol has been devised in case participants become distressed and/or upset during the interview into mental health and body image. The interview will ask participants to reflect on a difficult time of medical diagnosis and surgery, as well as emotions and thoughts that may trigger difficult feelings, memories, or current concerns.

A three-step protocol will help researchers to understand and look out for signs of distress and actions to take should they arise. Extreme distress is not expected as participants will be made aware of the research topic before the interview, and advised not to participate if they are aware of significant mental health difficulties or body image insecurities/diagnosed body dysphoria disorder or eating disorders. A pre-screening call will minimise this risk. The protocol is in case of emergencies should the interview bring up unresolved distress.

Mild distress:

Signs to look out for:

- 1) Tearfulness.
- 2) Voice becomes choked with emotion/difficulty speaking.
- 3) Participant becomes distracted/restless.

Action to take:

- 1) Ask participant if they are happy to continue.
- 2) Offer them time to pause and compose themselves.
- 3) Remind them they can stop at any time they wish if they become too distressed.
- 4) Ask participant if they wish for their parent to join them in the interview/room.

Severe distress:**Signs to look out for:**

- 1) Uncontrolled crying/wailing, inability to talk coherently.
- 2) Panic attack e.g., hyperventilation, shaking, fear of impending heart attack.
- 3) Intrusive thoughts of the traumatic event e.g., flashbacks.

Action to take:

- 1) The researcher will intervene to terminate the interview.
- 2) The participant's parent will be contacted and asked to return to their child/enter the room.
- 3) The debrief will begin immediately.
- 4) Relaxation techniques will be suggested to regulate breathing/reduce agitation.
- 5) The researcher will recognise participants' distress and reassure that their experiences are normal reactions to abnormal events and that most people recover from PTSD.

- 6) If any unresolved issues arise during the interview, accept, and validate their distress, but suggest that they discuss with mental health professionals and remind participants/participants parent's that this is not designed as a therapeutic interaction.
- 7) Details of counselling/therapeutic services available will be offered to participants/participant's parent.

Extreme distress:

Signs to look out for:

- 1) Severe agitation and possible verbal or physical aggression.
- 2) In very extreme cases - possible psychotic breakdown where the participant relives the traumatic incident and begins to lose touch with reality.

Action to take:

- 1) Maintain safety of participant and researcher.
- 2) If the researcher has concerns for the participant's or others' safety, she will inform them that she has a duty to inform any existing contacts they have with mental health services, such as a Community Psychiatric Nurse (CPN) or their GP.
- 3) If the researcher believes that either the participant or someone else is in immediate danger, then she will suggest that they present themselves to the local A&E Department and ask for the on-call psychiatric liaison team.
- 4) If the participant is unwilling to seek immediate help and becomes violent, then the Police will be called and asked to use their powers under

the Mental Health Act to detain someone and take them to a place of safety pending psychiatric assessment (This last option would only be used in an extreme emergency).

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Appendix L

Risk assessment

Identified risks	Likelihood Low/ Medium/ high	Potential Impact/Outcome	Risk management/ Mitigating Factors
Disclosure of risk to self, i.e., suicidal thoughts, intent, plans, action, self-harm.	Medium.	Immediate, urgent, or prompt response may be required by the researcher in breaching confidentiality to share the information and ensure the participant is safe. If suicidal ideation is disclosed – explore intent, plans, and means – if all are known – immediate action required. If intent but no plans, inform parent/guardian	Participants will have been pre-screened prior to interview. Participants will be informed of confidentiality, and that any disclosed risk will be shared with parents/guardians, and/or third-party organisations if appropriate. Parent/guardian will be available during the interview should risk arise.

		and signpost to support services. If self-harm is disclosed – explore what participant uses to self-harm, where, how often, function. Inform parent/guardian and encourage contacting support services. Provide local crisis numbers. If 18-year-olds disclose, the above will be followed if imminent risk to self, and confidentiality will be breached to next of kin or support services. If 18-year-old discloses self-harm, there may be more scope to maintain confidentiality due to	Parents/guardians will be signposted to relevant organisations to contact regarding support and next steps. Researcher can contact local authority anonymously to discuss risk, safeguarding concerns and any action that may need to be taken.
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		age of majority, however judgement will be made based on the individual case, with support of supervisor if necessary.	
		Researcher may experience psychological harm following disclosure.	Researcher will contact research supervisor should they feel they need further support following the interview.
Disclosure of risk from others/to others (i.e., safeguarding, abuse, neglect).	Medium.	Immediate, urgent, or prompt response may be required by the researcher in breaching confidentiality to share the information and ensure the participant is safe.	Participants will have been pre-screened and informed of the confidentiality policy. Researcher can contact local support services anonymously to seek advice if they

		Explore harm – deem who is at risk, of what, when, where. Disclose to parent/guardian, or third-party organisations, if appropriate.	are unsure how to proceed. Discuss with supervisor for additional support.
		Researcher may experience psychological harm following disclosure.	Researcher will contact research supervisor should they feel they need further support following the interview.
Discussion of a sensitive topic, with potential to cause harm to the participant.	Medium.	Participant may experience psychological distress when reflecting on surgery/diagnosis and emotive feelings and memories.	Exclusion criteria excludes those who have had surgery recently, within six months, to decrease chance that participant may not have processed events.

			Follow distress protocol. Ensure participant is aware they can end the interview at any time. Signpost participant and parent/guardian to support services following the interview.
		Researcher may experience vicarious stress from hearing participant reports, Researcher may experience anxiety about conducting the interviews. Researcher may experience own distress remembering	Discuss with research supervisor before/following interviews if necessary. Discuss with personal therapist, and family/friends to ensure managing own

		her own surgery and experiences.	emotions. Ensure researcher is fit to conduct interviews. Discuss with supervisor if feel unfit for interviewer role.
Conducting remote interviews – potential difficulties in managing distress/confidentiality.	Low.	Researcher will follow distress protocol. Ensure participant is comfortable, in a private space before and throughout interview, and aware that they can pause if disturbed. Ensure parent/guardian is available during the time of the interview in home or via phone, so should participant become distressed, researcher can call	Exclusion criteria will limit those who are vulnerable to the subject. Participants will be aware that the interview is online, and they will need to use their camera. Participants will have consented to an online interview and recording. Signpost participant and/or parent/guardian after the interview if they

		parent/guardian for support.	experienced high levels of distress.
		Researcher – use private space and headphones during interviews. Inform participants of this so they feel comfortable. Blur background to reduce distractions.	

Appendix M

Debrief Form for Young People



V.3

Debriefing form – for young person/participant

Thank you to for taking part in this research study!

This is part of a Doctoral thesis that the researcher is conducting.

The research question being explored is:

How do Individuals who underwent Adolescent Idiopathic Scoliosis Surgery experience their Mental Health and Body Image, both prior to and after the Procedure?

The aim of the study was to hear more about the psychological experiences of AIS, and how mental health, and body image are affected pre- and post-operatively. Analysis will pull out key themes that arise from the interview. These themes will hopefully help to explore how scoliosis surgery impacts mental health and body image, and raise awareness, and highlight possible areas for support.

If you are interested in the results of the study, have any questions about this study, or if you wish to withdraw your interview or recording, please contact the researcher on the following email address:

vas0397@my.londonmet.ac.uk.

Please remember that if you do wish to remove your interview from my study it should be done as soon as you decide you no longer want to be included in the study. Interviews cannot be withdrawn once analysis starts, as data will be anonymised, in other words, the researcher will not know which interview was yours. Analysis will begin 3 months after your interview. To withdraw please email: vas0397@my.londonmet.ac.uk.

Your recording and transcript will be anonymised and stored in a password protected folder on the researcher's university cloud account.

Equally, if you have any questions or concerns you are more than welcome to ask the researcher now.

If you have any complaints regarding any aspect of the way you have been treated during the course of the study, please contact my research supervisor, Dr Angie Cucchi on: a.cucchi@londonmet.ac.uk.

Your interview transcript and your consent form/assent form will be kept securely for up to 10 years following the submission of the thesis. This is in line with standard research practice.

As mentioned, the researcher has also had Scoliosis Surgery, if you wish to ask any questions regarding her experience, you may now do so.

If talking about these topics today has raised things that you wish to discuss further, lots of places can provide friendly advice and support:

- SSR (Scoliosis Support and Research) – offers support and advice on scoliosis diagnosis and treatment: <https://ssr.org.uk/> or call them: 020 8964 1166.
- Childline offer free confidential calls, online chat, or email for anyone under the age of 19. Sign up at <https://www.childline.org.uk/registration/> to access their 1-2-1 counsellor chat and email support service. Or call 0800 11 11 anytime, any day.
- Shout are a UK based charity offering free, confidential 24/7 text messaging support to anyone, any age who is struggling to cope or feels at crisis. Text SHOUT to 85258.
- Samaritans provide a listening service to talk through your thoughts and feelings 24/7. Call 116123 or email jo@samaritans.org.
- Visit YoungMinds website for more information on mental health, guidance, advice, and coping strategies. Go to: youngminds.org.uk

Thank you once again for your participation in my doctoral research project!

Appendix N

Debrief Form for Parent/Guardian



V.3

Debriefing form – parent/guardian

Thank you to you and your child for taking part in this research study. This is part of a Doctoral thesis that the researcher is conducting.

The research question being explored is:

How do Individuals who underwent Adolescent Idiopathic Scoliosis Surgery experience their Mental Health and Body Image, both prior to and after the Procedure?

The aim of the study was to hear more about the psychological experiences of AIS, and how mental health, and body image are affected pre and post operatively. Analysis will pull out key themes that arise from the interview. These themes will hopefully help to explore how scoliosis surgery impacts mental health and body image, and raise awareness, and highlight possible areas for support.

If you are interested in the results of the study, have any questions about this study, or if you wish to withdraw your child/your child wishes to withdraw, please contact the researcher on the following email address:

vas0397@my.londonmet.ac.uk.

Please remember that if you do wish to remove your interview from my study it should be done as soon as you decide you no longer want to be included in the study. Interviews cannot be withdrawn once analysis starts, as data will be anonymised. Analysis will begin 3 months after your interview.

To withdraw please email: vas0397@my.londonmet.ac.uk

Your child's recording and transcript will be anonymised and stored in a password protected folder on the researcher's university cloud account.

Equally, if you have any questions or concerns you are more than welcome to address them now.

If you have any complaints regarding any aspect of the way you have been treated during the course of the study, please contact my research supervisor

Dr Angie Cucchi on: a.cucchi@londonmet.ac.uk.

Your child's interview transcript and your consent form/child's assent form will be kept securely for up to 10 years following the submission of the thesis. This is in line with standard research practice.

As mentioned, the researcher has also had Scoliosis Surgery, if you wish to ask any questions regarding her experience, you may now do so.

If participation has raised any concerns or issues that you wish to discuss further, several agencies can provide advice and support in confidence:

- SSR (Scoliosis Support and Research) – offers support and advice on scoliosis diagnosis and treatment: <https://ssr.org.uk/> or call them: 020 8964 1166.

- Childline offer free confidential calls, online chat, or email for anyone under the age of 19. Sign up at <https://www.childline.org.uk/registration/> to access their 1-2-1 counsellor chat and email support service. Or call 0800 11 11 anytime, any day.
- Shout are a UK based charity offering free, confidential 24/7 text messaging support to anyone, any age who is struggling to cope or feels at crisis. Text SHOUT to 85258.
- Samaritans provide a listening service to talk through your thoughts and feelings 24/7. Call 116123 or email jo@samaritans.org.
- Visit YoungMinds website for more information on mental health, guidance, advice, and coping strategies. Go to: youngminds.org.uk

Thank you once again to you and your child for their participation in my doctoral research project.

Appendix O

London Metropolitan University Ethical Approval

Date of approval	11July2024 Updated 4Oct2024
NB: The Researcher should be notified of the review outcome within <u>two</u> weeks of the submission of the application. If the outcome is re-submission of the application because of requests for further information or suggested adjustments of the project, a <u>further two</u> weeks from receipt of the re-submitted application applies, and so on. A copy should be sent to research@londonmet.ac.uk .	
Signature of RERP chair	 Professor Chris Chandler School of Social Sciences and Professions T: 020 7133 2535 E: chris.chandler@londonmet.ac.uk

Appendix P

NHS HRA Ethical Approval



Miss Victoria Steele
Trainee Counselling Psychologist
London Metropolitan University 166-220
Holloway Road
London
N7 8DB

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

27 June 2024

Dear Miss Steele

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title:	How Adolescents with Idiopathic Scoliosis Experienced their Mental Health and Body Image prior to Surgery: An Interpretative Phenomenological Analysis.
IRAS project ID:	337745
Protocol number:	n/a
REC reference:	24/YH/0102
Sponsor	London Metropolitan University

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "[After Ethical Review – guidance for sponsors and investigators](#)", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **337745**. Please quote this on all correspondence.

Yours sincerely,
Rachel Katzenellenbogen
Approvals Specialist

Appendix Q

Section of Transcript with Analysis

Experiential Statements	Transcript	Exploratory notes
Return to normal Pushing herself to try new things – do the same as others? Age - Teenage impulsivity? Being watched by authority – to ensure she doesn't do things she isn't supposed to.	Participant 44:04 Yeah, I went back to PE after my six months check-up. I lit- so the week after my six month check up I was back at dancing, I was back at PE, and my PE teachers, I've still got the same PE teacher that I had in S1, I've had her for four years now, and she's royally sick of me because (chuckles) I tend to push myself too hard, and then she has to deal with it. (chuckles). And she's like, "why did you do that?" And I'm like, "I don't know why I've done that." Researcher 44:33 (chuckles). Participant 44:33 She's, like, got a constant eye on me with it. Researcher 44:38 Yeah. You mentioned	She brings focus on dancing – more important than PE. familiarity with teacher – relationship with her. Sienna's personality Pushing herself, trying new things, doing things she shouldn't do. Desire to do the same as others? Or desire to prove she can do things? Not wanting to be different, or let scoliosis hold her back? Brings memory to life with quote. Impulsivity Being watched to ensure she doesn't do too much. Teenage rebellion/impulsive thought She had brought up dance originally – after surgery – I brought it up. Highlights how it was less important to her after surgery.

Unsure how to navigate her experience of returning to dance.	going back to dance as well. How was that experience?	
Behind compared to her friends because she had missed time dancing.	Participant 44:43 It- I'll- it was a weird one because a lot- we'd moved up to seniors and stuff, and like the set of girls that I'd danced with for years, they'd all done their examination. So I was now a year behind on my grade, like they were sitting. They just sat their Grade 4. Saying I'd be still needing to do it, so they would be doing- and like the jump had just been really a lot and I ended up- I ended up quitting it, but it was kind of I'd already, before everything I started to like think about doing other stuff, and the only thing I'd ever really done was dance, apart from like swimming lessons and stuff.	Confusing, unsure, weird, different – she was unsure how to navigate it.
Decision to quit dance after surgery.		She was behind compared to friends because she had missed time. Friends were ahead of her
Recalls thoughts of doing other activities before surgery and scoliosis diagnosis	but it was kind of I'd already, before everything I started to like think about doing other stuff, and the only thing I'd ever really done was dance, apart from like swimming lessons and stuff.	Doesn't finish sentence – decides against it – no point. Jump to the next level was a lot for Sienna. Decision to quit dance.
Following return after scoliosis surgery, decision to quit.		Doesn't name scoliosis directly – implied. Recalls thoughts of doing other activities before surgery and scoliosis diagnosis. Returning to dance after scoliosis surgery.
Difficult decision for Sienna to quit something she loved.	Erm, but I ended up I went back and then we stopped for the summer, and then I went back	Decision to quit childhood hobby – so important to her before surgery now no longer something she wants to

	bored with it, and I've been playing netball for... nearly two years now.	Introducing new hobby – trying new things, new things she enjoyed.
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Appendix R

Extract of PET table for one participant

PET	Sub themes	Experiential Statements	Quotations
Body image	Pre-op	Self-conscious about body image	<i>I'd say because of my body changes, um, I wasn't happy because like, I was very self-conscious about how I looked,</i> <i>I think it was just my shoulders, um, and my hips. And then obviously if I had turned around, you'd see the- the curvature even more,</i>
Body image	Pre-op	Behavioural changes to hide body	<i>then obviously if I had turned around, you'd see the- the curvature even more, um, depending on the type of clothes I wore, or if I wasn't wearing a top, for example.</i> <i>I was very self-conscious about how I looked, especially like with the clothes that I'd wear, so I'd have to change all of that. I'd wear a lot of baggy clothes just to cover up because I was so insecure of my back and everything.</i>
Body image	Pre-op	Scrutiny of body	<i>And then that was when I just started looking for myself.</i>
Body image	Pre-op	Difficult for Flora noticing changes in her body	<i>it was very hard to begin with. Um, I started noticing changes during secondary school- , I would get changed, erm, with girls in the changing room, so like PE and erm, that's when I started to notice things and it made me uncomfortable</i> <i>it was just that it started off- one of my hips was curved and then as years went by it just got even worse, to the point I had to have surgery</i>

Body image	Pre-op	Belief her spine looked 'bad' pre-diagnosis and continued to get worse	<i>before my diagnosis, I mean, it looked bad, but it didn't look as bad, um, after my diagnosis, because there was quite a big, um, gap. And the curve had progressed and got even worse</i>
Body image	Pre-op	Comparing her body to peers	<i>I would get changed, erm, with girls in the changing room, so like PE and erm, that's when I started to notice things and it made me uncomfortable and I had like this phase where I didn't really want to take part because I could see what was happening</i>

Appendix S

Draft Journal Article for the Journal of Paediatric Psychology

Word limit – 5,000

How Adolescents who underwent Surgery for Adolescent Idiopathic Scoliosis experienced their Mental Health and Body Image, an Interpretative Phenomenological Analysis

Abstract

Objective. This research aims to explore the psychological experience of adolescents who had AIS surgery, asking how they experienced their mental health and body image pre- and post-operatively. **Method.** Data was collected via six semi-structured interviews with female adolescents who had undergone AIS surgery. A qualitative methodology, Interpretative Phenomenological Analysis was used to analysis the lived experiences of participants. **Results.** Four GETs emerged from the analysis: Disrupted Belonging and The Search for Normality, Protecting Self in a Social World, Psychological Turmoil and Emotional Disruption, and Emerging Selfhood and Acceptance. **Conclusions.** Psychological consequences of AIS appeared tethered to the ability to belong, rather than the experience of major surgery. Participants concealed and sacrificed their physical wellbeing to avoid the psychological implications of not fitting in socially. Findings revealed surgery does not remove self-consciousness and worries about body image. Concerns and thoughts changed pre- and post-operatively but were not eradicated. This research illuminated the importance of the social world to adolescents, and how AIS risks that. Implications included providing

support for adolescents to allow them space to belong and acknowledge surgery does not and cannot ‘fix’ everything. *Keywords: Adolescent Idiopathic Scoliosis, surgery, adolescents, mental health, body image.*

Introduction

Major spinal fusion surgery to correct idiopathic scoliosis is the most invasive orthopaedic surgery performed on children (Kotzer, 2000).

Adolescent Idiopathic Scoliosis (AIS) is a curvature in the spine with no known cause (Scoliosis Support and Research [SSR], 2024), diagnosed aged 10-19, with the worst cases being treated with spinal fusion surgery. Gallant et al. (2018) stresses it is imperative physical and psychological impacts are reviewed and managed. Adding the knowledge of a serious health diagnosis to an adolescent dealing with physical and psychological development was described by Sawyer et al. (2007) as an emotional burden, of ongoing stress, anxiety, stigma, possible rejection, and social disruption.

Prior research has explored the experience of adolescents awaiting AIS surgery, (Motyer et al., 2022) and found adolescents reported missing out on activities with friends, experienced feeling of anxiety and fear, fears of falling behind in school, and missing peers. Motyer et al. (2022) highlighted how important body image was, as participants described themselves as “abnormal” and avoided wearing certain clothes. Carrasco and Ruiz (2016) interviewed pre-operative females and again, heard negative feelings about their body image, they felt their bodies looked “wrong”, tried to hide uneven shoulders in clothing, and avoided social situations. However, Carrasco and Ruiz (2016) felt surgery could not erase the negative self-perceptions

participants held. Rullander et al. (2013) addressed this, interviewing participants post-operatively. Researchers concluded participants experienced fear of surgery, helplessness prior to the operation and the significance of a changed body image. Participants lost friends and experienced difficulties up to two years post-operatively. Qualitative studies show participants struggled with the psychological impacts of surgery, alongside the social aspects of missing school and being different. However, such research has explored the general experience of AIS surgery, which is important but with findings highlighting the psychological aspects, it is important to focus attention here.

Quantitative studies have researched anxiety, depression and body dissatisfaction in adolescents pre- and post-operatively. Baird and Gardner (2021) found 18% and 59% of pre-operative participants surveyed met the criteria for further assessment for depression and social anxiety. There was a significant difference when depression scores were compared with the age-matched controls, suggesting adolescents with AIS are struggling with mental health difficulties pre-operatively more so than peers. Roberts et al. (2011) used the SRS-30, and had participants complete before and two years after surgery. Pre-operatively body image had the lowest score of five other domains for males and females, followed by mental health. Following surgery, body image and mental health scores improved in males and females, concluding improved self-image was the most beneficial effect of surgery. Zebracki et al. (2013) saw similar results, with improved body image and mental health scores on the SRS-22, and saw poor pre-operative scores predicted poor post-operative scores. Whilst most studies highlight

improvements in body image and mental health after surgery (Roberts et al., 2011) there is evidence body dissatisfaction and mental health struggles remain (Zebracki et al., 2013). Qualitative research identified challenges adolescents experienced pre- and post-operatively (Motyer et al., 2022; Carrasco & Ruiz, 2016; Rullander et al., 2013), and quantitative research highlighted struggles specifically with mental health and body dissatisfaction pre-operatively, improving post-operatively (Zebracki et al., 2013; Roberts et al., 2011). The next step is therefore to qualitatively explore mental health and body image specifically to identify how adolescents experience their mental health and changes that occur post-operatively. This research will look to answer the research question: *How do Individuals who underwent Adolescent Idiopathic Scoliosis Surgery experience their Mental Health and Body Image, both prior to and after the Procedure?*

Method

This study used a qualitative methodology to explore in-depth insights and explore the lived experience of adolescents who underwent AIS surgery. Willig (2019) states qualitative research seeks to provide an understanding of people's experiences and the meanings they give those experiences. Qualitative methodology felt appropriate given it is underutilised in AIS research, and the unique and nuanced experience of AIS surgery,

Research Design

Prior to recruitment, a questionnaire was posted on the Scoliosis Support and Research (SSR) Facebook Page. The anonymous questionnaire

asked people impacted by scoliosis for their thoughts on the research. Seven service users completed the questionnaire. Participants agreed it was necessary research. They highlighted the need for a ‘warm, sensitive’ researcher and using language appropriate for adolescents.

Recruitment

Following this, recruitment began through purposeful sampling. An orthopaedic consultant, Mr Gardner, volunteered, for no personal gain, to send the research advert out to adolescents on his caseload who potentially met the inclusion criteria. Seven participants agreed to be contacted for the study via Mr Gardner. Of those seven, two responded to emails and were invited to take part in a pre-screening call with the researcher.

Volunteer sampling was used alongside, posting adverts on the SSR social media page and other pages that targeted the scoliosis community, with four participants volunteering.

The inclusion criteria included participants aged 13-18, who had undergone spinal fusion surgery within the last three years, but not within the last 12 months at the time of interview. All participants were asked “Please answer yes or no, would you deem your surgery as successful?” The research required successful accounts of surgery, defined by the participant. Though valid, experiences of unsuccessful surgery differ significantly from successful AIS surgery, and compromise homogeneity, as participants would not share a ‘similar lived experience’, an essential within IPA (Creswell, 2013). Adolescents with additional physical diagnoses, such as neuromuscular disorders, and/or those who experienced surgical complications resulting in medium to long-term implications, deemed by the

participant (e.g., paralysis, diagnosed chronic pain, infection) were excluded to ensure homogeneity.

Adolescents were asked at pre-screening if they had experience of mental health difficulties, eating disorders or body dysmorphia disorder, had accessed support, and how they coped. It was decided those who named severe/ongoing difficulties would be, unfortunately, excluded due to ethical considerations. Whilst recruitment was important, removing participants with increased vulnerability limited unnecessary harm (Oates et al., 2021).

Six participants were recruited, all identified as female, aged between 15-18 (Mean age 16.1). Pre-screening calls took place, lasting approximately 15 minutes, to check participants met the inclusion criteria, to discuss confidentiality, sign the consent forms, and build rapport.

Data collection

Participants were invited to a Microsoft Teams video-call interview lasting approximately one hour. An interview schedule of open-ended questions was followed, with prompts for participants and the ability to follow the participant's lead. Following the interviews, participants were provided with a debrief form.

Ethics

Ethical approval from London Metropolitan University was gained alongside National Health Service research ethics via the Health Research Authority (HRA) in June 2024. Written informed consent was gained electronically via email, during pre-screening calls. Participants and parents/guardians verbally reconfirmed consent at interview. Participants under 16 signed an assent form, alongside parental written consent. Those

aged 16-18 provided their own consent (Oates et al., 2021). Participants were made aware of their right to withdraw at any time. Participants were informed at pre-screening and interview any risk shared, including but not limited to, self-harm, suicidal thoughts/attempts, harm from others, or plans/actions towards harming others would be shared with parents/guardians and/or third-party organisations if appropriate, as per BPS safeguarding policies up to age 18 (Oates et al., 2021). It was determined that whilst current risk would cause a breach in confidentiality, if the adolescent disclosed historic risk and healthy coping mechanisms, this could be kept confidential. However, this did not arise within the interviews, and no disclosures to parents/guardians or support services were necessary. I had a distress protocol and risk assessment available, and participants were asked after the interview if they felt triggered or upset by any questions, though none were.

Data Collection

Interviews were audio-recorded using Audacity software and live transcription on Microsoft Teams occurred. Transcripts and recordings were anonymised within 24 hours of the interview, with participant names, and any identifying factors being removed. These transcripts and audio recordings were then used for data analysis with pseudonyms.

Data analysis

Eatough and Smith (2017) highlight how Interpretative Phenomenological Analysis (IPA) explores transformative matters of considerable importance for participants alongside its phenomenological, hermeneutic, and ideological underpinnings which allow researchers to

interpret participant lived experiences in depth, appropriate for the emotional, multi-faceted experience of major surgery. Analysis began with line-by-line coding of one participant, noting descriptive, linguistic and conceptual sentences. Exploratory comments were used to identify experiential statements in the opposite margin. Experiential statements were then cut out and organised into clusters and subclusters. Finally, each cluster, or Personal Experiential Theme (PET), was organised into a table. This process was repeated for each participant. Once completed, the six PET tables were cut up and again organised into Group Experiential Themes (GETs) identifying convergence and divergence across participants and themes.

Results

Four GETs emerged from the analysis, each with three subthemes (Table 1). Whilst presenting the GETs in a temporal sequence of experience through scoliosis diagnosis and surgery was an option at analysis, this felt reductionist for participants and may give the impression the experience through AIS surgery was complete at time of interview. Tess shared:

Because it's now over, everyone just thinks you're fine, like, but that might not be the case (1638-1639).

GET 1: Disrupted Belonging and The Search for Normality

All participants talked about how they experienced disrupted belonging through social isolation, perceived emotional isolation of missing

out, or being separated from friends, with a sense of falling behind and being forgotten.

Emotional and Social Isolation.

Participants reflected on being physically separated from peers, being unable to participate in activities and gave a sense of being an ‘outsider’. Participants reflected

“feeling really upset and really excluded because I could see like all my friends having fun” (Thea, 587-588).

Thea is physically separated from friends who were doing PE. There is a sense of disconnection from her peers and potential loss of identity as her body becomes a barrier to her joining in.

Disappointed because, you know, I'm at the age where this is the type of stuff that- that I'd enjoy and look forward to, but I was told that I couldn't do it anymore, so it was just upsetting as well because, um, even though it's something so little, it's- it's the only time during school where you can just relax. You're not writing, you're not doing anything like that. So, for me, having to just sit there and watch everyone else play it was upsetting, but had to be done (418-423).

Flora gives a sense of being an outsider, having to watch others play whilst she is “told” she cannot, acknowledging authority made a choice for her is “upsetting” and “disappointing”. Flora acknowledges missing PE as only a small compromise, drawing on her maturity and an understanding that consequences could be worse. “It had to be done” could suggest she

appreciates the bigger picture of having to miss PE to protect her back. But Flora highlights it was a “relaxing time”, potentially something useful for her mental wellbeing. She mentions earlier in the transcript being a “sporty person”, and “enjoying PE”, having this taken away and turned into a time of emotional and physical isolation has implications of disappointment, upset, isolation and removal of a potential prior coping strategy.

Many participants named upset at having to take time off school and missing friends, highlighting the contextual factor of school and peers being important to adolescents. Tess shared a consequence of missing school was two of her friends “*got closer*”, she recalls

“when I went back, it was a bit weird, but it got, it was fine again after that. But when I first went back, it was still a bit weird” (935-937).

Tess repeats “weird” interpreted as how foreign and uncomfortable missing out felt, and her potential upset at friends getting closer without her. Once more there is a sense of Tess returning as an outsider, unable to share the memories her friends made without her.

Not Being Allowed to Belong.

All participants repeatedly used language highlighting the disrupted belonging was not their choice. AIS caused them to miss out and authorities around the participants enforced this. Thea and Sienna emphasised how limited they were with what they could do and shared upset, and frustration at this. Thea reported being unable to go outside at break time, creating a sense of containment and being trapped. After surgery, participants rebelled against authority, as Thea began “sneaking out” to join her friends,

highlighting how belonging was important to them above obeying authority and caution around their back.

The Search for Normality.

Participants craved normality, either through rushing to return to school and hobbies, ignoring medical advice or authority, or hiding aspects of their AIS to appear ‘normal’. Participants attempted to maintain their normality before surgery:

“Trying to forget about it, and get about like, normal day-to-day (Sienna; 396-397)”

“Enjoying life (chuckles) like during that moment (Olivia; 99-100).”

Interpretations of these moments are participants trying to go back to a life before the news of surgery. Their desire for normality is external, doing ‘normal’ things. Thea reflects on her internal feelings of normality, reporting:

“I wanted to feel normal. I felt like I was different from everyone else, and I don’t, I didn’t like that. But I just wanted to feel, like, normal. I thought after surgery, it would feel, I’d feel normal (481-485).”

Thea’s repetition of “normal” reinforces her desire, alongside her hopes surgery would provide this feeling. It is interpreted surgery did not help her to ‘feel normal’, emphasised by her use of “I thought”, and her search continues.

GET 2: Protecting Self in a Social World

The second GET relates with the first but demonstrates the actions participants took to avoid disrupted belonging and seek normality.

Keeping it to Myself.

Participants unanimously shared keeping aspects of their AIS surgery to themselves, either the diagnosis, surgery, or their thoughts and feelings about the surgery. One reason for this appeared to be not wanting to “burden” (Flora, 575), upset, or “*Make others feel weird about the way it made me feel*” (Thea, 1470). Friends/peers are an important source of support to adolescents, and examples of withholding appears to be in a bid to stay connected with friends. Additionally, participants seemed to understand friends may struggle to provide support, given their age. Sienna and Faye reflected on being young at the time of diagnosis and surgery. “*Some of us weren’t- hadn’t even turned 12*” (Sienna, 340) and “*15 doesn’t seem that young, but it is*” (Faye, 821). Consequently, participants keep feelings to themselves to reduce the burden on others and protect themselves socially.

Performing Fine.

It was interpreted participants ‘performed fine’ to appear ‘normal’ and protect themselves socially, despite experiencing pain, discomfort and thoughts about the surgery. Sienna shared

“I just tried to not let it bother me and act like it was nothing (423)”.

The use of the word “act” and “try” highlights this was not how she was feeling, but she was consciously editing her behaviour to ‘perform fine’ and appear ‘normal’ in front of peers, interpreted as a way to protect herself against the social world. Flora shared “*pushing through*” (378) to get her work done, and “*trying her best to push herself to lessons*” (957). Both examples show times participants could have asked for help, or behaved differently, in line with their physical pain or AIS. Instead, participants

prioritise the social world, and ‘perform fine’ to fit in with ‘normal’ behaviours of others.

Self-Consciousness and Self-Scrutiny of the Body.

Participants shared feeling self-conscious of their body before and after surgery, though concerns changed. Flora felt “*insecure of my back and everything*” and used “*baggy clothes just to cover up*” (437-438). It was interpreted her happiness was linked to how self-conscious she felt, highlighting how important her body image was. After surgery participants continued to feel self-conscious,

I didn't like people seeing it, which was like a problem when I was actually allowed to do PE again, because like a couple of times I had some of the girls like, look at it and just like whisper and, like, stare at it and stuff, and I didn't like that (Thea; 1231-1233).

Thea's experience of other girls staring and whispering exposes her difference, confirms her beliefs others are looking at her back and increases her self-consciousness and anxiety in public. Thea explains other girls made her “really self-conscious” and she faced different directions and hid herself when changing at school.

This subtheme links back to the theoretical underpinnings of this study. Within the school context, girls are exposed to the judgement of others, with desires to conform and fit in with ‘ideal’ body types (Aniulis et al., 2021). Alongside self-consciousness, participants showed a surveillance/scrutiny of their body. Pre- and post-operatively, adolescents are left to scrutinise their body for results of whether surgery made their

body ‘straight’ enough to be deemed ‘normal’, supporting Garland-Thomson (2020).

Five participants shared imperfections they still noticed post-operatively but used phrases such as “if you look really closely” (Thea; 637).

Participants used language of “*hyper-aware* (Sienna, 547)” and “*noticing things more now*” (Tess, 1466) after surgery. This language is interpreted as self-surveillance as participants’ study their bodies for imperfections and symmetry. For these participants, despite surgery ‘correcting’ their spines, self-consciousness and self-surveillance remained.

GET 3: Psychological Turmoil and Emotional Disruption

This subtheme relates to the psychological turmoil participants experienced, and emotions they named.

Anxiety Caused by Uncertainty.

One specific cause of anxiety was uncertainty, raised by participants as not knowing whether they would need surgery and when their surgery would be.

“It’s just sort of watch and wait to see what would, if it would get any worse. So that, I don’t know, made me quite anxious. Like not knowing what was going to happen” (Tess; 292-295).

Tess highlights how her anxiety pre-operatively was caused by uncertainty. She combats this by attempting to do “*some more research*” (255) into possible treatments, which she recalls caused further anxiety. Tess goes on to share the consequences this psychological turmoil and uncertainty caused:

“I mean I don’t think it really affected me that much, but sometimes in school I’d have like panic attacks and things cause I don’t know, just like daydreaming and thinking about it (423-426).”

Overwhelm.

Sienna, Olivia and Thea reported moving schools/starting secondary school alongside their diagnosis and surgery, whilst Flora juggled her GCSEs. Sienna summed up the experience:

“I just everything seems like it’s all happening at once and it was all a lot for the time” (Sienna; 409-410).

Sienna acknowledges how *“it all happened at once”* capturing the sense of overwhelm it was interpreted participants were experiencing. Additionally, Flora references things were *“very hard for her” (121)* because of her GCSEs:

“I was struggling a lot because sometimes I have to take time off school because I just simply couldn’t get up in the morning” (122-123).

For her, the surgery, diagnosis, her GCSEs and aspects discussed in the previous themes cumulate in her struggling to get up, it is interpreted this was a result of the overwhelm she was feeling. Surgery alone is deemed stressful and overwhelming, but the participants highlighted other factors they were having to cope with contextually, which cannot be ignored, contributing to emotional disruption and overwhelm.

Social Withdrawal.

Whilst the GET of Disrupted Belonging explored isolation, social withdrawal was also deemed a manifestation of psychological turmoil.

“My pals were saying to me, they were like “you were already one in the quieter ones” but we're all quite quiet in my group, “That you got even quieter. Not, like you kind of just didn't really talk as much. You weren't having a laugh and like-” There was a difference”
(Sienna; 376-379).

It was interpreted Sienna socially withdrew due to the overwhelm and anxiety of surgery. Dealing with the news of surgery, difficult emotions and the cognitive load of trying to “*forget about it*” (396) and ‘perform fine’ could have caused her to become quieter around friends. Thea isolated herself post-operatively.

“I hated, like going out and stuff after, like I just didn't want to do anything. And I think it was more because I couldn't do anything. It made me not want to do anything or something” (1553-1555).

She shares how not being able to do things led her to experience emotional disruption and thus she withdrew from social situations. It's interpreted here, and with the other subthemes in this GET, anxiety, overwhelm and social withdrawal interplay as participants struggle with internal chaos and this is experienced through psychological turmoil.

GET 4: Emerging Self and Acceptance

The final GET to emerge were participants retrospectively acknowledging changes since surgery, ranging from participants noticing changes to their body, gaining confidence post-operatively and areas of self-growth caused by the experience.

Changed Body.

Five participants acknowledged physical changes to their body post-operatively.

“I think it’s changed massively. Um, because before surgery, you know, I really wasn’t happy at all with my body. Now I am happy about my body” (Flora; 1117 – 1118).

Flora recognises the positives surgery left her with, as surgery changed her body image “*massively*”. Tess shares similar, emphasising how “*being straight*” (1205) helped her to feel “*happy*” about her body. Sienna goes further, stating her surgery was worth it because of the visible change to her body:

“Like it makes me think that it’s, like it was worth it for that reason” (Sienna; 1058).

However, Thea highlights how her changed body caused increased self-consciousness and self-scrutiny:

“I just felt like, I looked different. I felt like I looked really weird and stuff and that it wasn’t, like how it was like meant to look or something” (1585-1586).

All participants highlight the complex emotions surrounding a changed body, including happiness alongside a sense of discomfort and fears of looking “weird” confirming continued self-consciousness post-operatively.

Self-growth.

Participants reported a changed perspective on things after surgery, interpreted as self-growth.

“Made me really grateful for like, being able to play a sport now, like I'm not the most sporty person, but I will put my all into it because, I do know like, well, that could have been taken away from me fully if I didn't get the operation and stuff and like I... it's just kinda, it's who- part of who I am” (Sienna; 1075-1079).

Sienna shared feeling grateful for her surgery as she now appreciates things and accepts it as *“part of who she is”*. Because of what she experienced she now *“puts her all into things”*, suggesting a determined mindset moving forward, because she knows how it can feel to have those things removed. Sienna reflected on self-strength. Prior to surgery she stated:

“I didn't think that I could do it, or that I was strong enough” (234-235).

Following surgery, she held an interpreted improved mental wellbeing, and an ability to manage difficult situations with strength and resilience.

Confidence.

The final subtheme was confidence, which appeared to grow in participants after surgery, and continued to the point of interview. Sienna shared:

“It definitely like made me feel a lot more confident in myself” (1080-1081).

“I became more open about stuff and it kinda opened my eyes to like, you don't need to be so serious, but- because there's bigger things, but... it opened it to like social situations and stuff.” (1032-1034)

It was interpreted Sienna gained confidence after her surgery because she was no longer having to conceal parts of herself. Additionally, she was potentially more confident in her body image, once her curvature had been ‘corrected’, this enabled her to worry less about social situations, as she had less to hide. Tess was more confident in sharing things she can and cannot do in her dance classes.

“I’ve got better now ... I’ll tell them, and then if I put my hand up, they’ll normally clock what I’m about to say.” (Tess, 1314; 1316-1318).

“I’ve got better now” highlights how telling dance teachers may have previously been difficult, but she now finds it easier, giving a sense of increased confidence, in emerging self since AIS surgery.

Discussion

Pre- and post-operatively participants seemed to be faced with a choice between psychological wellbeing versus physical wellbeing. Psychological consequences of AIS were tethered to their social status and ability to belong, rather than the experience of a major surgery itself. Participants concealed and sacrificed their physical wellbeing to avoid the psychological consequences of not fitting in socially and appeared to prioritise their social status over their AIS, desiring to be the same as others. Body image concerns remained throughout with self-consciousness and self-surveillance; however, acceptance and self-growth shone through, highlighting some positives to the journey participants faced.

GET 1: Disrupted Belonging and The Search for Normality

Within this theme, three subthemes emerged. This theme saw findings similar to those of previous studies, particularly Motyer et al. (2022), acknowledging reduced participation in hobbies, and how this caused negative emotions. Additionally, this study aligned with Motyer et al. (2022) regarding the participants search for normality. The difference arose in Motyer's participants expressing a desire for things to "go back to normal" after surgery, reflecting the external routine AIS disrupted. This was seen with the present participants. However, Thea shared her desires to "feel normal" after surgery, highlighting her internal sense of abnormality. This highlights the difference between Motyer et al's. (2022) psychosocial findings and the counselling psychology lens here.

GET 2: Protecting Self in a Social World

The results appeared to highlight participants working hard to protect themselves socially, by behaving in ways which concealed their AIS. They kept aspects of their diagnosis, surgery and feelings to themselves, 'performed fine' though behaviours that allowed them to blend in with their peers, felt self-conscious and surveyed their bodies to ensure they hid their visual difference, findings Carrasco and Ruiz (2016) also saw. These findings linked back to feminist underpinnings, with participants perceiving their body under the gaze of others (De Beauvoir, 1956) highlighting the societal pressures girls felt from others to fit in, be accepted and be liked. The participants conformed to social norms to protect themselves from being outcast or rejected.

GET 3: Psychological Turmoil and Emotional Disruption

As seen in previous studies, participants struggled with anxiety, fear and nervousness (Rullander et al., 2013; Motyer et al., 2022). This study went further and explored what caused those emotions. One cause was uncertainty, widely accepted as a central feature in the conceptual model of fear. Osmanağaoğlu et al. (2018) reported a strong correlation between low tolerance of uncertainty and anxiety/worry in children and adolescents, which highlights how aspects of major surgery may be more anxiety provoking for adolescents as they struggle to manage the uncertainty associated with such events. The participants highlighted how contextual factors caused overwhelm and withdrawal. Dealing with moving schools, GCSEs and other pressures of adolescence was acknowledged by participants and some socially withdrew, further highlighting the psychological turmoil they were experiencing.

GET 4: Emerging Selfhood and Acceptance

The final theme highlighted some of the positives of surgery, and aligned with quantitative studies, which highlighted improved mental health and body image after surgery (Roberts et al., 2011; Zebracki et al., 2013) with subthemes of Self-growth and Confidence emerging. However, the Changed Body subtheme went further than these quantitative scores and highlighted positives alongside struggles participants were still coping with, as Carrasco and Ruiz (2016) suggested might be the case.

Clinical relevance

Medical staff and psychological practitioners working with adolescents with AIS could “warn”, as Faye suggests, adolescents about possible changes to their body post-operatively or discuss changes with

them. This would be a small addition to consultation rooms but allow adolescents to be better prepared for post-operative changes.

Offering peer support groups, or web-based forums, (Macculloch et al., 2009) could allow a space for adolescents to discuss their emotions, feelings and fears with others who understand, and reduce consequences of keeping things to themselves, something participants reflected, in hindsight, would have been helpful. This study has found themes of isolation, self-consciousness, self-surveillance, emotional turmoil and self-growth which could be discussed across pre- and post-operative adolescents. These support groups could allow adolescents to build tolerance to uncertainty, talk about their feelings, body image, adjust to a changed body, manage feelings of self-consciousness and gain adaptive coping strategies whilst individuating from parents and achieving a sense of belonging with a group outside of their school or friendships. Charities, or the NHS through surgical pathways, may be able to provide such groups, it is acknowledged funding and availability of practitioners may be limited.

This research highlights how counselling psychologists may be well placed to offer this support, especially given the findings of participants not framing their experience in terms of mental health diagnoses, but rather emotional and relational processes. The emphasis on subjective and social context aligns with counselling psychology principles of prioritising non-pathologizing perspectives, relational understanding and acknowledging broader social contexts (Strawbridge & Woolfe, 2010; Cooper, 2009) adolescents with AIS are carrying.

Further research to explore how adolescents experience support groups would help to determine whether the groups are worthwhile. Quantitative data could evaluate the effectiveness of the groups. Qualitative data could inform us what adolescents find helpful, and what topics are most useful to them. There is a risk, as documented in this study, participants may not want to discuss their diagnosis and surgery with others, and revert to 'keeping things to themselves'. Research around support groups could help mitigate this potential barrier to adolescents receiving support. Future research may seek to explore male mental health and body image around AIS to explore whether the social pressures are similar, and how gender plays a role in the experience, as one of the limitations of this study was the lack of males who volunteered.

Finally, this research focused specifically on AIS surgery, it is acknowledged many live with AIS without surgery. Future research may hear how adolescents diagnosed with AIS experienced their mental health and body image, to raise awareness of another under-researched group.

Conclusions

This research illuminated the importance of the social world to adolescents, and how AIS risks that. Implications included providing support for adolescents to allow them space to belong and acknowledge surgery does not and cannot 'fix' everything. This research could highlight a disconnect in where consultants place importance on medical recovery whilst participants aim for social acceptability. Practically, surgeons acknowledging this and working collaboratively with adolescents could aid recovery and ease psychological turmoil.

Acknowledgements

Thank you to the amazing participants who gave up their time and bravely shared their experiences of their AIS surgery, and Dr. Angie Cucchi for supervising me throughout this project.

Conflict of interest

None declared

Data availability statement

Data available on request.

Table 1.

Group Experiential Themes and subthemes, with supporting quotations

Group	Group level	Supporting Quotations
Experiential Themes (GETs)	Subthemes	
Disrupted	Emotional	<i>Disappointed because, you know, I'm</i>
Belonging and	and Social	<i>at the age where this is the type of</i>
The Search for	Isolation	<i>stuff that- that I'd enjoy and look</i>
Normality		<i>forward to, but I was told that I</i>
		<i>couldn't do it anymore, so it was</i>
		<i>just upsetting as well because, um,</i>
		<i>even though it's something so little,</i>
		<i>it's- it's the only time during school</i>
		<i>where you can just relax. You're not</i>

		<i>writing, you're not doing anything like that. So, for me, having to just sit there and watch everyone else play it was upsetting, but had to be done (Flora; 418-423).</i>
Not Being Allowed to Belong		<i>I think that really upset me because I got told, um, I wasn't, after my operation, I wasn't allowed to do, like, dance, cheer, gymnastics. I wasn't allowed to do anything. So, I think that actually really affected me more than I thought (Thea; 227-229).</i>
The Search for Normality		<i>I just wanted to, like, have, I wanted to, like, feel normal, I guess because before, like, it felt like I was different from everyone else, and I don't, I didn't like that. But I just wanted to feel, like, normal. I thought after surgery, it would feel, I'd feel normal (Thea; 482-485).</i>
Protecting Self in a Social World	Keeping it to Myself	<i>I just feel like it wasn't normal to just speak about it, just speak about my feelings. And I didn't really want to</i>

*say too much anyway. I'd just keep
it to myself (Flora; 567-569).*

Performing	<i>I was nervous about the surgery, and</i>
Fine	<i>like the scoliosis and stuff, because</i>
	<i>it was like, I'd never really known</i>
	<i>anyone to have it... But I was just</i>
	<i>kind of unsure of it all and like, I</i>
	<i>just tried to not let it bother me and</i>
	<i>act like it was nothing (Sienna;</i>
	<i>419-423).</i>

Self-	<i>I think, I like, notice things more now</i>
Consciousness	<i>even though I'm, like I'm more</i>
and	<i>straight now, I feel like I still see</i>
Surveillance	<i>things more than I like even did</i>
of the Body	<i>when I was like, still had scoliosis</i>
	<i>(Tess; 1466-1468)</i>

Psychological	Anxiety	<i>I did some more research. And then I</i>
Turmoil and	Caused by	<i>realised, like, the treatments and</i>
Emotional	Uncertainty	<i>stuff like the bracing and then</i>
Disruption		<i>surgery. And it made me quite like</i>
		<i>anxious, I guess because I didn't</i>
		<i>know what to expect (Tess; 255-</i>
		<i>259).</i>

Overwhelm	<i>Very hard for me because I also had</i>
	<i>my GCSEs that I had to do. Um,</i>

*and I was struggling a lot because
sometimes I have to take time off
school because I just simply
couldn't get up in the morning
(Flora; 121-123).*

	Social	<i>They'd still say, like "you went really</i>
	Withdrawal	<i>quiet, especially after you found out". And like... "You weren't the same bubbly person, you kind of..." I don't know... Like I was never the never bubbly out there, but they're like "you definitely did get quieter for a bit" (Sienna; 387-390).</i>
Emerging	Changed	<i>I think it's changed massively. Um,</i>
Selfhood and Acceptance	Body	<i>because before surgery, you know, I really wasn't happy at all with my body. Now I am happy about my body, but I just get those odd few days, just the whole weight thing, um, that is upsetting for me, but other than that, I think that, yeah, everything's fine (Flora; 1117-1120).</i>

Self-Growth

I think going through something like that, I think it just kind of changes you and changes your perspective on things. It's helped me with a lot of things. Um, I think I've changed as a person, I look at things differently (Flora; 1180-1182).

Confidence

It just like, well, I'm not going to change it, so there's no point in, like, fussing about it. But it definitely like made me feel a lot more confident in myself (Sienna; 1080-1081).

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Appendix T

Draft Newsletter sent to Participant for Feedback

Study into AIS and Mental Health

I am a final year doctoral student, studying Counselling Psychology, finishing my thesis research into Mental health, body image and AIS. I had AIS surgery 12 years ago, and am extremely passionate about the impact AIS surgery may have on adolescents mentally, and with the relationship with their body image. Over the last three years, I have studied this subject and interviewed six participants for my thesis. Participants were aged 15-18 and had had surgery between 1 to 3 years ago at the time of study.

This newsletter gives a brief overview of my findings and discussion. The qualitative research analysed the six participant transcripts, and identified themes from each. Then all transcripts were reviewed and themes across participants emerged. The below shows these themes, and gives supporting quotations. Qualitative data is subjective to the researcher, so you may feel some quotations represent something different!

I wanted to share this with SSR and its readers, to provide information to those who this research really impacts! The findings can hopefully be used to highlight what adolescents are experiencing as they deal with their diagnosis and surgery, but also to see what else can be done to support them.



Findings



Theme 1: Disrupted Belonging and the Search for Normality

This theme highlights how fitting in and belonging was disrupted by AIS. Participants wanted to be 'normal' and searched for their normality after their diagnosis. One particular theme was how AIS meant participants weren't allowed to do what they wanted, which caused feelings of isolation and upset. There were a lot of contextual factors, with participants missing PE, and having to watch others have fun whilst they sat on the sidelines.

Emotional and
Social Isolation

Disappointed because, you know, I'm at the age where this is the type of stuff that- that I'd enjoy and look forward to, but I was told that I couldn't do it anymore, so it was just upsetting as well because, um, even though it's something so little, it's- it's the only time during school where you can just relax. You're not writing, you're not doing anything like that. So, for me, having to just sit there and watch everyone else play it was upsetting, but had to be done (Flora; 418-423).

Not Being
Allowed to
Belong

I think that really upset me because I got told, um, I wasn't, after my operation, I wasn't allowed to do, like, dance, cheer, gymnastics. I wasn't allowed to do anything. So, I think that actually really affected me more than I thought (Thea; 227-229).

The Search for
Normality

I just wanted to, like, have, I wanted to, like, feel normal, I guess because before, like, it felt like I was different from everyone else, and I don't, I didn't like that. But I just wanted to feel, like, normal. I thought after surgery, it would feel, I'd feel normal (Thea; 482-485).



Theme 2: Protection of Self in a Social World

This theme was interpreted based on themes and quotations related to the social world i.e. school, hobbies, friendships and peers. It seemed participants felt self-conscious about their bodies and acted in ways to keep others from knowing about their scoliosis, such as keeping things to themselves or acting like they were fine. It seemed as if participants were attempting to protect themselves in the social world, i.e. school, to make sure others did not make fun of them.

Keeping it to
Myself

I just feel like it wasn't normal to just speak about it, just speak about my feelings. And I didn't really want to say too much anyway. I'd just keep it to myself (Flora; 567-569).

Performing
Fine

I was nervous about the surgery, and like the scoliosis and stuff, because it was like, I'd never really known anyone to have it... But I was just kind of unsure of it all and like, I just tried to not let it bother me and act like it was nothing (Sienna; 419-423).

Self-Consciousness
and Surveillance of
the Body

I think, I like, notice things more now even though I'm, like I'm more straight now, I feel like I still see things more than I like even did when I was like, still had scoliosis (Tess; 1466-1468)



Theme 3: Psychological Turmoil and Emotional Disruption

Here participants reported emotional disruption, and upset. Things like anxiety, feelings of overwhelm and social withdrawal were named. Uncertainty of surgery caused anxiety, and other things going on caused a sense of overwhelmingness. Exams, friendships, moving schools, and starting secondary school was overwhelming, along with having to cope with diagnosis and surgery. Some participants reported withdrawing socially, being quieter around friends, or avoiding hobbies and clubs because they couldn't join in.

Anxiety Caused
by Uncertainty

I did some more research. And then I realised, like, the treatments and stuff like the bracing and then surgery. And it made me quite like anxious, I guess because I didn't know what to expect (Tess; 255-259).

Overwhelm

Very hard for me because I also had my GCSEs that I had to do. Um, and I was struggling a lot because sometimes I have to take time off school because I just simply couldn't get up in the morning (Flora; 121-123).

Social
Withdrawal

They'd still say, like "you went really quiet, especially after you found out". And like... "You weren't the same bubbly person, you kind of..." I don't know... Like I was never the never bubbly out there, but they're like "you definitely did get quieter for a bit" (Sienna; 387-390).



Theme 4: Emerging Selfhood and Acceptance

The final theme is about a sense of self and acceptance that emerged after surgery. Participants talked about a 'changed body' with positive changes to their body after surgery but also some feelings about

their body that they weren't prepared for. Surgery offered a change for growing as a person, and surgery becoming part of them. And surgery helped some participants to feel more confident.

Changed Body

I think it's changed massively. Um, because before surgery, you know, I really wasn't happy at all with my body. Now I am happy about my body, but I just get those odd few days, just the whole weight thing, um, that is upsetting for me, but other than that, I think that, yeah, everything's fine (Flora; 1117-1120).

Self-Growth

I think going through something like that, I think it just kind of changes you and changes your perspective on things. It's helped me with a lot of things. Um, I think I've changed as a person, I look at things differently (Flora; 1180-1182).

Confidence

It just like, well, I'm not going to change it, so there's no point in, like, fussing about it. But it definitely like made me feel a lot more confident in myself (Sienna; 1080-1081).



Discussion

In my thesis, I discussed each of the themes in relation to previous studies and prior research. However, at over 10,000 words that felt a little long to include here!

This study was important to hear the lived experiences of adolescents who had undergone AIS surgery, to gain an understanding of their experience of their mental health and body image as previous studies had not explored these areas specifically, nor asked adolescents about their pre- and post-operative experience.

These findings suggest participants were faced with a choice between psychological wellbeing and physical wellbeing. Not being accepted socially had many psychological consequences. Multiple examples occurred of participants concealing and sacrificing their physical wellbeing in order to avoid the psychological implications of not fitting in socially. These included returning to school early after surgery, going outside with peers before they should have, returning to lessons early, 'pushing through' pain and trying new things. Participants appeared to prioritise their social status over their scoliosis, desiring to be the same as others, and attempting to avoid the psychological consequences of being socially outcast.

These findings, and previous studies highlight adolescents are experiencing psychological turmoil, and challenges of coping with their diagnosis, surgery and social pressures of school, friendships, blending in, and not standing out. Participants reported having someone to talk to who had experienced AIS might help, and clinical implications of this study could explore psychological support and evaluate how

helpful adolescents find it. Further research is needed as these participants were all female, so research asking males would be helpful, as well as research into what support adolescents find or would find helpful.

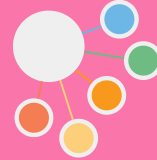
The experience of completing this research was challenging, and difficult to cope with my own emotions as I reflected on my own surgery, but I hope the findings stayed true to the participants, and hopefully raises awareness to support adolescents with their mental health and body image, pre- and post-operatively.

Appendix U

Draft Summary Sheet sent to Participant for Feedback

AIS AND MENTAL HEALTH STUDY ANALYSIS

Research exploring how adolescents experienced their mental health and body image both pre- and post-operatively has recently taken place. This brief document gives a summary of the results. Qualitative analysis of what six participants said took place. This involved making notes on all the transcripts and finding themes in each interview. Then I looked across all the interviews, and interpreted the themes that occurred across everyone who took part. I found these 4 common themes, and 3 subthemes in each main theme, with quotations of what participants shared.



THEME 1: Disrupted Belonging and the Search for Normality

This theme highlights how fitting in and belonging was disrupted by AIS. Participants wanted to be 'normal' and searched for their normality after their diagnosis. One particular theme was how AIS meant participants weren't allowed to do what they wanted, which caused feelings of isolation and upset.

Emotional
and Social
Isolation

Disappointed because, you know, I'm at the age where this is the type of stuff that that I'd enjoy and look forward to, but I was told that I couldn't do it anymore, so it was just upsetting as well because, um, even though it's something so little, it's- it's the only time during school where you can just relax. You're not writing, you're not doing anything like that. So, for me, having to just sit there and watch everyone else play it was upsetting, but had to be done (Flora; 418-423).

Not Being
Allowed to
Belong

I think that really upset me because I got told, um, I wasn't, after my operation, I wasn't allowed to do, like, dance, cheer, gymnastics. I wasn't allowed to do anything. So, I think that actually really affected me more than I thought (Thea; 227-229).

The Search
for
Normality

I just wanted to, like, have, I wanted to, like, feel normal, I guess because before, like, it felt like I was different from everyone else, and I don't, I didn't like that. But I just wanted to feel, like, normal. I thought after surgery, it would feel, I'd feel normal (Thea; 482-485).

THEME 2: Protection of Self in a Social World

This theme was interpreted based on themes and quotations related to the social world i.e. school, hobbies, friendships and peers. It seemed participants felt self-conscious about their bodies and acted in ways to keep others from knowing about their scoliosis, such as keeping things to themselves or acting like they were fine. It seemed as if participants were attempting to protect themselves in the social world to make sure others did not make fun of them.

Keeping it to
Myself

I just feel like it wasn't normal to just speak about it, just speak about my feelings. And I didn't really want to say too much anyway. I'd just keep it to myself (Flora; 567-569).

Performing
Fine

I was nervous about the surgery, and like the scoliosis and stuff, because it was like, I'd never really known anyone to have it... But I was just kind of unsure of it all and like, I just tried to not let it bother me and act like it was nothing (Sienna; 419-423).

Self-
Consciousness
and
Surveillance of
the Body

I think, I like, notice things more now even though I'm, like I'm more straight now, I feel like I still see things more than I like even did when I was like, still had scoliosis (Tess; 1466-1468)

THEME 3: Psychological Turmoil and Emotional Disruption

Here participants reported emotional disruption, and upset. Things like anxiety, feelings of overwhelm and social withdrawal were named. Uncertainty of surgery caused anxiety, and other things going on caused a sense of overwhelmingness. Exams, friendships, moving schools, and starting secondary school was overwhelming, along with having to cope with diagnosis and surgery. Some participants reported withdrawing socially, being quieter around friends, or avoiding hobbies and clubs because they couldn't join in.

Anxiety Caused by Uncertainty	<i>I did some more research. And then I realised, like, the treatments and stuff like the bracing and then surgery. And it made me quite like anxious, I guess because I didn't know what to expect (Tess; 255-259).</i>
Overwhelm	<i>Very hard for me because I also had my GCSEs that I had to do. Um, and I was struggling a lot because sometimes I have to take time off school because I just simply couldn't get up in the morning (Flora; 121-123).</i>
Social Withdrawal	<i>They'd still say, like "you went really quiet, especially after you found out". And like... "You weren't the same bubbly person, you kind of..." I don't know... Like I was never the never bubbly out there, but they're like "you definitely did get quieter for a bit" (Sienna; 387-390).</i>

THEME 4: Emerging Selfhood and Acceptance

The final theme is about a sense of self and acceptance that emerged after surgery. Participants talked about a 'changed body' with positive changes to their body after surgery but also some feelings about their body that they weren't prepared for. Surgery offered a change for growing as a person, and surgery becoming part of them. And surgery helped some participants to feel more confident.

Changed Body	<i>I think it's changed massively. Um, because before surgery, you know, I really wasn't happy at all with my body. Now I am happy about my body, but I just get those odd few days, just the whole weight thing, um, that is upsetting for me, but other than that, I think that, yeah, everything's fine (Flora; 1117-1120).</i>
Self-Growth	<i>I think going through something like that, I think it just kind of changes you and changes your perspective on things. It's helped me with a lot of things. Um, I think I've changed as a person, I look at things differently (Flora; 1180-1182).</i>
Confidence	<i>It just like, well, I'm not going to change it, so there's no point in, like, fussing about it. But it definitely like made me feel a lot more confident in myself (Sienna; 1080-1081).</i>

These findings were then written up into a discussion chapter, which explored other studies which researched AIS. These findings supported previous studies which highlight adolescents do struggle with their mental health and body image, both pre- and post-operatively.

Pre-operatively participants struggled with wanting to fit in with peers, and AIS causing a difference in them compared to others. Participants reported feeling self-conscious and felt isolated.

Post-operatively, participants reported feeling better, able to join in and felt more confident, however some still struggled with their body image, feeling AIS had drawn more attention to how they looked, and surgery did not remove these feelings.

The discussion goes on to talk about what might be done in the future to help those going through AIS diagnosis and surgery, such as having people to talk to who understand AIS, and psychological support offered to those who want it. As well as the understanding that things aren't always easier after surgery.

Appendix V

Article sent to Participants – adapted from Appendix S

Research into AIS surgery, mental health and body image - Findings and Discussion

Approximately one year ago, you/your child took part in a research interview, exploring how adolescents who underwent Adolescent Idiopathic Scoliosis (AIS) surgery experienced their mental health and body image before and after surgery. I have now finished the analysis and write up of the thesis and am submitting it as the final part of my doctoral degree. The below is an adapted copy of the analysis and discussion (the findings), which you consented to receive.

Thank you once again for your participation in the study, and I hope you find the below interesting!

Six participants were recruited, with an average age of 16.1. All had interviews and the transcripts from those interviews were reviewed, analysed, and themes from the interviews emerged.

Below gives an overview of these themes, and some of the quotations and interpretations I made from the quotations. Qualitative data is subjective to the researcher, so you may feel some quotations represent something different, or I may have interpreted something you said differently to how you meant it, which is all part of the research process! All names are fake.

Findings

Four main themes were found, each with three subthemes.

Theme	Subthemes
Disrupted Belonging and The Search for Normality	Emotional and Social Isolation
	Not Being Allowed to Belong
	The Search for Normality
Protecting Self in a Social World	Keeping it to Myself
	Performing Fine

	Self-Consciousness and Surveillance of the Body
Psychological Turmoil and Emotional Disruption	Anxiety Caused by Uncertainty
	Overwhelm
	Social Withdrawal
Emerging Selfhood and Acceptance	Changed Body
	Self-Growth
	Confidence

Theme 1: Disrupted Belonging and The Search for Normality

All participants talked about how they experienced disrupted belonging through physical isolation, feelings of missing out, or being separated from friends, with a sense of falling behind and being forgotten.

Subtheme: Emotional and Social Isolation.

Participants reflected on being physically separated from peers, being unable to participate in activities and gave a sense of being an 'outsider'. Participants reflected:

"feeling really upset and really excluded because I could see like all my friends having fun (Thea, 587-588)".

Thea is physically separated from friends who were doing PE. There is a sense of disconnection from her peers and potential loss of identity as her body becomes a barrier to her joining in. Sienna shared similar upset at not being able to take part in PE, something she used to enjoy. Many participants named upset at having to take time off school and missing friends, highlighting how important school and peers were to adolescents. Tess shared a consequence of missing school was two of her friends *"got closer"*, she recalls:

"when I went back, it was a bit weird, but it got, it was fine again after that. But when I first went back, it was still a bit weird" (935-937).

Tess repeats *"weird"* interpreted as how foreign and uncomfortable missing out felt, and her potential upset at friends getting closer without

her. Once more then is a sense of Tess returning as an outsider, unable to share the memories her friends made without her.

Subtheme: Not Being Allowed to Belong.

All participants repeatedly used language highlighting the disrupted belonging was not their choice. AIS caused them to miss out and authorities around the participants enforced this. Thea and Sienna emphasised how limited they were with what they could do and shared upset, and frustration at this. Thea reported being unable to go outside at break time, creating a sense of being trapped. After surgery, participants rebelled against authority, as Thea began “sneaking out” to join her friends, highlighting how belonging was important to them above obeying authority and caution around their back.

Subtheme: The Search for Normality.

Participants craved normality, either through rushing to return to school and hobbies, ignoring medical advice or authority, or hiding aspects of their AIS to appear ‘normal’. Participants attempted to maintain their normality before surgery:

“Trying to forget about it, and get about like, normal day-to-day (Sienna; 396-397)”

“Enjoying life (chuckles) like during that moment (Olivia; 99-100).”

Interpretations of these moments are participants trying to go back to a life before the news of surgery.

“I wanted to feel normal. I felt like I was different from everyone else, and I don’t, I didn’t like that. But I just wanted to feel, like, normal. I thought after surgery, it would feel, I’d feel normal (481-485).”

Thea’s repetition of “normal” reinforces her desire to feel normal, alongside her hopes surgery would provide this feeling. It is interpreted surgery did not help her to ‘feel normal’, emphasised by her use of “I thought”, and her search continues.

Theme 2: Protecting Self in a Social World

The second GET relates with the first but demonstrates the actions participants took to avoid disrupted belonging and how they sought normality.

Subtheme: Keeping it to Myself.

All participants shared keeping aspects of their AIS surgery to themselves, either the diagnosis, surgery, or their thoughts and feelings about the surgery. One reason for this appeared to be not wanting to “burden” (Flora, 575), upset, or “*Make others feel weird about the way it made me feel*” (Thea, 1470). Friends/peers are an important source of support to adolescents, and examples of withholding appears to be in a bid to stay connected with friends. Additionally, participants seemed to understand friends may struggle to provide support, given their age. Sienna and Faye reflected on being young at the time of diagnosis and surgery. “*Some of us weren’t- hadn’t even turned 12*” (Sienna, 340) and “*15 doesn’t seem that young, but it is*” (Faye, 821). Consequently, participants kept feelings to themselves to reduce the burden on others and protect themselves socially.

Subtheme: Performing Fine.

It was interpreted participants ‘performed fine’ to appear ‘normal’ and protect themselves socially, despite experiencing pain, discomfort and thoughts about the surgery. Sienna shared

“I just tried to not let it bother me and act like it was nothing (423)”.

The use of the word ‘act’ and ‘try’ highlights this was not how she was feeling, but she was consciously editing her behaviour to ‘perform fine’ and appear ‘normal’ in front of peers, interpreted as a way to protect herself against the social world. Flora shared “*pushing through*” (378) to get her work done, and “*trying her best to push herself to lessons*” (957). Both examples show times participants could have asked for help, or behaved differently, in line with their physical pain or AIS. Instead, participants prioritise the social world, and ‘perform fine’ to fit in with ‘normal’ behaviours of others.

Subtheme: Self-Consciousness and Self-Scrutiny of the Body

Participants shared feeling self-conscious of their body before and after surgery, though concerns changed. Flora felt “*insecure of my back and everything*” and used “*baggy clothes just to cover up*” (437-438). It was interpreted her happiness was linked to how self-conscious she felt, highlighting how important her body image was. After surgery participants continued to feel self-conscious, Thea “*didn’t like people seeing it (1231), “I had some of the girls, like, look at it and just like whisper, and like, stare at it” (1232-1233).*

Participants used language of “*hyper-aware (Sienna, 547)*” and “*noticing things more now*” (Tess, 1466) after surgery. This language is interpreted as self-scrutiny as participants studied their bodies for imperfections and symmetry. For these participants, despite surgery ‘correcting’ their spines, self-consciousness and self-surveillance remained.

Theme 3: Psychological Turmoil and Emotional Disruption

This subtheme relates to the psychological turmoil participants experienced, and emotions they named.

Subtheme: Anxiety Caused by Uncertainty

One specific cause of anxiety was uncertainty, raised by participants as not knowing whether they would need surgery and when their surgery would be.

"It's just sort of watch and wait to see what would, if it would get any worse. So that, I don't know, made me quite anxious. Like not knowing what was going to happen" (Tess; 292-295).

Tess highlights how her anxiety pre-operatively was caused by uncertainty. She tries to reduce this by doing *"some more research"* (255) into possible treatments, which she recalls caused further anxiety. Tess goes on to share the consequences this psychological turmoil and uncertainty caused her:

"I mean I don't think it really affected me that much, but sometimes in school I'd have like panic attacks and things cause I don't know, just like daydreaming and thinking about it (423-426)."

Overwhelm.

Sienna, Olivia and Thea reported moving schools/starting secondary school alongside their diagnosis and surgery, whilst Flora juggled her GCSEs. Sienna summed up the experience:

"I just everything seems like it's all happening at once and it was all a lot for the time" (Sienna; 409-410).

Sienna acknowledges how *"it all happened at once"* capturing the sense of overwhelm it was interpreted participants were experiencing. Additionally, Flora references things were *"very hard for her"* (121) because of her GCSEs:

"I was struggling a lot because sometimes I have to take time off school because I just simply couldn't get up in the morning" (122-123).

For her, the surgery, diagnosis, her GCSEs and aspects discussed in the previous themes led to her struggling to get up, it is interpreted this was a result of the overwhelm she was feeling. Surgery alone is deemed stressful and overwhelming, but the participants highlighted other factors they were

having to cope with contextually, which cannot be ignored, contributing to emotional disruption and overwhelm.

Subtheme: Social Withdrawal.

Whilst the GET of Disrupted Belonging explored isolation, social withdrawal was also deemed a manifestation of psychological turmoil.

“My pals were saying to me, they were like “you were already one in the quieter ones” but we’re all quite quiet in my group, “That you got even quieter. Not, like you kind of just didn’t really talk as much. You weren’t having a laugh and like-” There was a difference” (Sienna; 376-379).

It was interpreted Sienna socially withdrew due to the overwhelm and anxiety of surgery. Dealing with the news of surgery, difficult emotions and the cognitive load of trying to “forget about it” (396) and ‘perform fine’ could have caused her to become quieter around friends. Thea isolated herself post-operatively.

“I hated, like going out and stuff after, like I just didn’t want to do anything. And I think it was more because I couldn’t do anything. It made me not want to do anything or something” (1553-1555).

She shares how not being able to do things led her to experience emotional disruption and thus she withdrew from social situations.

Theme 4: Emerging Self and Acceptance

The final GET to emerge were participants retrospectively acknowledging changes since surgery, ranging from participants noticing changes to their body, gaining confidence post-operatively and areas of self-growth caused by the experience.

Subtheme: Changed Body.

Five participants acknowledged physical changes to their body post-operatively.

“I think it’s changed massively. Um, because before surgery, you know, I really wasn’t happy at all with my body. Now I am happy about my body” (Flora; 1117 – 1118).

Flora recognises the positives surgery left her with, as surgery changed her body image “massively”. Tess shares similar, emphasising how “being straight” (1205) helped her to feel “happy” about her body. Sienna goes further, stating her surgery was worth it because of the visible change to her body:

"Like it makes me think that it's, like it was worth it for that reason" (Sienna; 1058).

However, Thea highlights how her changed body caused increased self-consciousness and self-scrutiny:

"I just felt like, I looked different. I felt like I looed really weird and stuff and that it wasn't, like how it was like meant to look or something" (1585-1586).

All participants highlight the complex emotions surrounding a changed body, including happiness alongside a sense of discomfort and fears of looking "weird" confirming continued self-consciousness post-operatively.

Subtheme: Self-growth.

Participants reported a changed perspective on things after surgery, interpreted as self-growth.

"Made me really grateful for like, being able to play a sport now, like I'm not the most sporty person, but I will put my all into it because, I do know like, well, that could have been taken away from me fully if I didn't get the operation and stuff and like I... it's just kinda, it's who- part of who I am" (Sienna; 1075-1079).

Sienna shared feeling grateful for her surgery as she now appreciates things and accepts it as "part of who she is". Because of what she experienced she now "puts her all into things", suggesting a determined mindset moving forward, because she knows how it can feel to have those things removed. Sienna reflected on self-strength. Prior to surgery she stated:

"I didn't think that I could do it, or that I was strong enough" (234-235).

Following surgery, she held an interpreted improved mental wellbeing, and an ability to manage difficult situations with strength and resilience.

Subtheme: Confidence.

The final subtheme was confidence, which appeared to grow in participants after surgery, and continued to the point of interview. Sienna shared:

*"It definitely like made me feel a lot more confident in myself (1080-1081).
I became more open about stuff and it kinda opened my eyes to like, you don't need to be so serious, but- because there's bigger things, but... it opened it to like social situations and stuff." (1032-1034)*

It was interpreted Sienna gained confidence after her surgery because she was no longer having to conceal parts of herself. Additionally, she was potentially more confident in her body image, once her curvature had been 'corrected', this enabled her to worry less about social situations, as she had less to hide. Tess was more confident in sharing things she can and cannot do in her dance classes.

"I've got better now ... I'll tell them, and then if I put my hand up, they'll normally clock what I'm about to say." (Tess, 1314; 1316-1318).

"I've got better now" highlights how telling dance teachers may have previously been difficult, but she now finds it easier, giving a sense of increased confidence, in emerging self since AIS surgery.

Discussion

Pre- and post-operatively participants seemed to be faced with a choice between psychological wellbeing versus physical wellbeing. Psychological consequences of AIS were tied to their social status and ability to belong, rather than the experience of a major surgery itself. Participants concealed and sacrificed their physical wellbeing to avoid the psychological consequences of not fitting in socially and appeared to prioritise their social status over their AIS, desiring to be the same as others. Body image concerns remained throughout with self-consciousness and self-scrutiny; however, acceptance and self-growth shone through, highlighting some positives to the journey participants faced.

Practical Implications

Medical staff and psychological practitioners working with adolescents with AIS could "warn", as Faye suggests, adolescents about possible changes to their body post-operatively or discuss changes with them. This would be a small addition to consultation rooms but allow adolescents to be better prepared for post-operative changes.

Offering peer support groups, or web-based forums could allow a space for adolescents to discuss their emotions, feelings and fears with others who understands, and reduce consequences of keeping things to themselves, something participants reflected, in hindsight, would have been helpful. These support groups could allow adolescents to build tolerance to uncertainty, talk about their feelings, body image, adjust to a changed body, manage feelings of self-consciousness and gain adaptive coping strategies whilst individuating from parents and achieving a sense of belonging with a group outside of their school or friendships. Charities, or the NHS through surgical pathways, may be able to provide such groups, it is acknowledged funding and availability of practitioners may be limited.

Further research to explore how adolescents experience support groups would help to determine whether the groups are worthwhile. There is a risk, as documented in this study, participants may not want to discuss their diagnosis and surgery with others, and revert to 'keeping things to themselves', research around the group could help reduce this potential barrier to adolescents receiving support. Future research may seek to explore male mental health and body image around AIS to explore whether the social pressures are similar, and how gender plays a role in the experience, as one of the limitations of this study was the lack of males who volunteered.

Conclusions

This research illuminated the importance of the social world to adolescents, and how AIS risks that. Implications included providing support for adolescents to allow them space to belong and acknowledge surgery does not and cannot 'fix' everything. This research could highlight a disconnect in where consultants place importance on medical recovery whilst participants aim for social acceptability. Practically, surgeons acknowledging this and working collaboratively with adolescents could aid recovery and ease psychological turmoil.