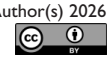
Full-length report

JHP

Journal of Health Psychology
1–19



DOI: 10.1177/13591053261464869
journals.sagepub.com/home/hpq


"A chronic headache and a couple of wonky eyes": Understanding how strabismus relates to body image and body functionality. A thematic analysis of autoethnographic narratives

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Abstract

Strabismus, a condition of misaligned eyes, has the potential to negatively affect quality of life through psychosocial and functional implications. This study adopts an analytical autoethnography to tell my story of living with strabismus and undergoing medical treatments. It considers these experiences through the lenses of body image and body functionality. Five autoethnographic narratives were analysed abductively using thematic analysis and the findings are presented as extracts from the narratives. Six themes were identified: (1) Thoughts and feelings focussed on body functionality, (2) Negative thoughts and feelings related to appearance, (3) Perceptual distortion, (4) Conflicts between functional and appearance elements, (5) Adaptive behaviours related to functionality, (6) Coping behaviours related to appearance. This study demonstrates the conflict between appearance and functional components of strabismus and contributes to the theoretical development of the visible difference literature. The study also highlights the importance of patient voice in visible difference conditions.

Keywords

ophthalmology, squint, visible difference, functional disability, strabismus

Introduction

Strabismus is an ophthalmological condition in which the eyes are misaligned and is sometimes referred to as a squint (Gunton et al., 2015). Colloquially, individuals might refer to strabismus as "cross-eyed" (Eatz et al., 2023). Strabismus can cause the affected eye(s) to turn horizontally and/or vertically (Gunton et al., 2015). Strabismus affects 3.29% of the adult

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Data Availability Statement included at the end of the article

population (Hashemi et al., 2019) and has both functional and psychosocial implications that negatively affect quality of life (Mason et al., 2024), with 68% of strabismic individuals reporting that they would trade a portion of life expectancy to remove strabismus and the associated consequences (Beauchamp et al., 2005).

Strabismus, visible difference, and body image

The physical presentation of the condition (e.g. misaligned eyes) means that an individual with strabismus has characteristics that differ from societal expectations of a "normal" physical appearance, for example, "straight" eyes. Visible difference is the term given to a condition or injury that affects the presentation of the face or body (Changing Faces (n.d.) and is thus applicable to strabismus. Those with visible difference conditions tend to experience increased psychosocial distress (Rumsey et al., 2004). However, the impact of visible differences on quality of life is varied (Rumsey et al., 2004), with psychosocial outcomes impacted by variability in conditions (Zucchelli et al., 2023). There is therefore a need to understand the nuances of different visible difference conditions.

For strabismus specifically, quality of life can be negatively impacted by concerns over how their eyes appear to others, problems with eye contact, interpersonal relationships and self-esteem (Hatt et al., 2007). Strabismic individuals may experience negative thoughts about their appearance, others staring at them, and bullying (Mason et al., 2024). They frequently report feeling embarrassed by their eye misalignment and can regularly engage in behaviours to camouflage their condition (Nelson et al., 2008). Furthermore, they must negotiate the negative preconceptions that others have towards them, such as perceptions of low intelligence (Buffenn, 2021).

Researchers recognise body image as an issue for people with visible differences (Rumsey and Harcourt, 2004), and strabismus is a medical condition where body image is highly relevant (Pruzinsky, 2004). A study of ophthalmic patients reported high levels of distress in relation to their physical appearance (James et al., 2011); however, the study is not specific to strabismus. Related constructs such as self-consciousness have been quantitatively explored (Estes et al., 2020) and strabismic adults have reported shame about their appearance (Mason et al., 2024); however, explicit explorations of body image and strabismus are absent.

Body image is a multidimensional construct (Grogan, 2021), encompassing four components: affective (how you feel about your body), perceptual (how you perceive your body), cognitive (the thoughts you have about your body) and behavioural (the behaviours you might engage in when you experience content or discontent with your body; Riccardelli and Yager, 2015). Body image can capture global characteristics (e.g. the entire body) but can also be site specific (e.g. the eyes; Thompson, 2004). In the current study, it is important to highlight this distinction, as the feelings, perceptions, thoughts and behaviours relevant to eye misalignment are more likely to be considered site-specific.

Strabismus as a functional disability

Strabismus may initially be recognised by others for the appearance-related component, whereby an individual displays a visible difference in their physical features; however, it is also related to a range of physical outcomes. Eye misalignment is associated with physical symptoms such as diplopia, amblyopia, headaches, eyestrain, fatigue when reading (Buffenn, 2021) and issues with depth perception (Hatt et al., 2007). Functional limitations impact daily tasks, such as driving, reading (Kumaran et al., 2019) and perceived efficacy at work (Wang et al., 2018). Moreover, the impact on mobility and sports participation (e.g. impaired ability to throw and catch) has also been recognised (Kumaran et al., 2019). Given these functional limitations, The Royal College of

Ophthalmologists (2017) defines strabismus as a functional disability.

The functional limitations associated with strabismus have recently been highlighted in the mainstream media, where Olympic gold medallist gymnast Stephen Nedoroscik (BBC News, 2024) and England's goalkeeper, and winner of Euro 2025, Hannah Hampton (BBC News, 2025), were positioned as *defying the odds* to achieve in sport. These recent portrayals represent a potential shift in media representations of strabismus, which centre on functional elements of the condition. This can be contrasted with traditional representations (e.g. in children's animated films) that have focussed on stigmatised psychosocial outcomes, for example, unintelligence, villains, followers as opposed to leaders (Liu et al., 2024).

Body functionality and functionality appreciation are important concepts within body image research and are relevant to the study of strabismus. Body functionality describes the capabilities, actions, and processes of the body and becomes a body image construct only when it considers affective, cognitive and perceptual components of what the body can do (Alleva and Tylka, 2021). Functionality appreciation refers to valuing, respecting and being grateful for what the body can do across a variety of domains (Alleva and Tylka, 2021). Research shows that people with physical disabilities often define body functionality in the context of what their bodies cannot do or do differently (Vinoski Thomas et al., 2019), highlighting that body functionality may not always be positive in those with visible physical disabilities.

Functionality appreciation is an important construct for those living with visible difference and chronic health conditions. Functionality-based interventions have shown utility in improving body image in those with visible skin conditions (Adkins et al., 2022) and in adults with visible difference (Guest et al., 2024). While functional appreciation has been explored in those with functional concerns (Alleva et al., 2018) and in people with visible physical disabilities (Vinoski Thomas et al., 2019), body functionality and how it is interpreted has not been investigated in people living with strabismus. This is an important area of exploration, given that the condition has both appearance-related and functional components.

The current study

Due to variability in visible difference conditions, there is a need to consider how specific conditions, such as strabismus, are lived and experienced. Whilst there is literature that considers the psychosocial implications of strabismus, explicit investigations of body image and body functionality are missing. This study adopts a retrospective autoethnography (Buckley and Cooper, 2024) to tell my story of living with strabismus. There is limited research that explores patients' experiences and treatment of ophthalmological conditions (Thurston, 2025). However, this type of research is fundamental to advancing clinical practice and health psychology, as patients are in a unique position to provide information about the lived experience (Li, 2025). In the study, I describe my experiences of living with strabismus and receiving medical care. I thematically analyse these experiences using body image and body functionality theory and present the data as extracts from my autoethnographic stories. This study asks the following research question:

1. How does the lived experience of strabismus and strabismus surgery impact body image and body functionality?

Methodology

This study adopts an autoethnographic approach to answer the research question. Autoethnography is a qualitative method in which the data are primarily derived from storytelling and analyses the data within the broader sociocultural context (Chang, 2016). The process of autoethnography "mimics" that of ethnography, in which in-depth reflective analysis takes place, but with a focus on personal experiences instead of the lives of others (Harrop and Kattari, 2022). This autoethnography is not intended to reflect "the truth of

what happened" but rather provides an insight into "the truth of my experience" (O'Connell, 2023: 265). Thus, the data will centralise my voice to understand the truth of *my* experiences of living with strabismus. In health psychology, autoethnography can provide useful insight into a patient's experience of living with and receiving treatment for health conditions (Li, 2025). Moreover, in ophthalmology, autoethnography is important to tell the "silenced story" of patients' experiences (Thurston, 2025).

The participant

In autoethnography, it is important to position the researcher's identity, allowing readers to understand the perspective of both data analysis and interpretation (Kitto et al., 2023). I am the sole participant in this study. I am a 41-year-old white British female from a working-class background. I am a Senior Lecturer in Sport, Health and Exercise Sciences and obtained my PhD in body image and physical activity over 10 years ago. I continue to conduct research in the area of body image, physical activity and health. My strabismus story started when I was 2 years old and was first diagnosed with a "moderate right convergent squint, which can alternate." I had surgery on my right eye at the age of six and surgery on my left eye at the age of eight. I lived with strabismus without further medical intervention until my late 30s. At 38 I was re-diagnosed with bilateral exotropia and had two unsuccessful Botox treatments. I then had surgery on my left eye at the age of 39.

Autoethnographic approach

This study adopts a retrospective autoethnography, in which my own experiences are used as the basis for the data (Buckley and Cooper, 2024). This type of research provides a narrow but deep approach, in which rich information is obtained from one participant. There are many benefits to autoethnography, including the ability to access personal data that might not be easily observable by other research approaches (Harrop and Kattari, 2022). For example, short interviews may not be able to capture the chronic and personal nature of the condition, particularly in a population where there is an increased prevalence of social fear and social avoidance (Bez et al., 2009).

This study is an analytic autoethnography in which I adopt a structured, theory-driven approach to analyse my experiences (Anderson, 2006). The purpose of an analytic autoethnography is "to gain insight into some broader set of social phenomena than those provided by the data themselves" (Anderson, 2006: 387). Thus, the aim of this study is to consider my stories within the context of body image and body functionality theory. An analytic autoethnography was selected because strabismus remains theoretically underdeveloped within health psychology, especially regarding the intersections of appearance and functionality; thus, this theory-driven approach aims to support theoretical development.

An analytic approach can be contrasted with an evocative autoethnography, whereby the focus is on narrative storytelling (Bochner and Ellis, 2016). However, in positioning the type of autoethnography for this study, I share similar views with other authors, in that evocative and analytical autoethnographies are not mutually exclusive (Sparkes, 2020). Indeed, Tullis (2013) argues a continuum may exist, ranging from highly artistic to highly analytical, with this study being situated towards the analytical end of the spectrum, whilst recognising that my stories cannot be void of emotion. Anderson (2006) suggests that analytic autoethnographies have several characteristics, which have been considered in the study and are outlined in the Supplemental Materials.

Whilst there are benefits to autoethnographies of this nature, it is important to outline the scope and limits of a single-case approach. A single case autoethnography is limited in relation to generalisability, diversity of voice, and subjectivity of the insider perspective. However, these limitations are also central to its strength. A single-case design provides access to longitudinal, personal data that would be difficult to capture through alternative methods (Li, 2025).

However, it is important to note that this study does not aim for statistical generalisability but aims to harness the potential of autoethnographies and their "ability to contribute to researching complex dynamics related to health and illness" (Li, 2025: 2). This study also seeks to provide theoretically transferable insights, with the aim of developing theory and generating new areas for empirical investigation. In their discussion of case studies, Ylikoski (2019) argues for *theoretical generalisation* in single cases, that is, the uncovering of mechanisms that may apply beyond the specific case. Indeed, in an autoethnographic study of identity and illness, the authors recognise the utility of an introspective approach for theoretical development (Harrop and Kattari, 2022). This study is therefore complementary to, rather than a substitute for, future studies using alternative methods.

The data

The data for this study is based on reflective journaling, which retrospectively captures my experiences of living with strabismus. The data used in autoethnographies tends to mirror that of ethnographic research, including "interviews, participant observation field notes, document and artifact analysis, and research diaries" (Wall, 2008: 44). However, existing autoethnographies on chronic illness have focussed on the in-depth experiences of the autoethnographer (e.g. Ciotti, 2023; Ettorre, 2005) or introspective approaches focussed on examining personal experiences and personal artefacts (Harrop and Kattari, 2022), with the approach adopted in the current study reflecting these practices.

Five reflective narratives were written using memory to recall my own experiences, with artefacts (e.g. medical records, photographs, etc.), used as a method of checking my own memories (Ciotti, 2023). These five narratives were constructed in chronological order from childhood to just after my third surgery. The narratives were constructed based on key life experiences associated with my strabismus story: (1) childhood strabismus, (2) living with strabismus as an adult, (3) adult clinical assessment and non-surgical treatment, (4) adult surgery, (5) post-surgery experiences. For each reflection, I started by mapping out key memories associated with the period and then constructed these into longer prose, by asking myself questions such as "What did you think about this event?" and "How did that make you feel?." After the reflections were drafted, I accessed artefacts to support the recall of memories (Ciotti, 2023). Based on reviewing the artefacts, I revisited each narrative and added detail about events and emotions.

As the approach adopted in this study was analytical, my aim was to allow the stories to be an authentic recollection of my lived experiences and to reserve critical, structured analysis for a later stage (Anderson, 2006). The concept of expressive writing and storytelling aligns more with evocative autoethnographic approaches (Bochner and Ellis, 2016). Therefore, the stories are not perfectly written but intentionally reflect my embodied identity beyond academia. Thus, the reflections provide a rich description of my personal life, with less of a concern on writing expressively. Indeed, the stories were constructed in the post-surgery stage when I was suffering from severe eye strain and debilitating headaches. Thus, to reduce screen-time, a dictation device was used to record some of my initial recollections. Whilst I revisited the transcripts to add detail after the artefact stage, I did not want to erode my non-academic identity by changing phrasing or the use of colloquial language (e.g. referring to my "wonky eyes").

Ethical considerations

The data obtained for this study occurred during my normal daily life, and when these experiences and interactions occurred, there was no intention to perform the current research. In line with my institution's ethical procedures, ethical approval is not required for retrospective autoethnography studies. Therefore, the point at which I decided to conduct this research is the

point at which my narratives end. Ethical considerations have been outlined in more detail within the Supplemental Material.

Data analysis

The narratives were analysed using reflexive thematic analysis, and the six steps outlined by Braun and Clarke (2019) were followed. I left a 2-week period between finalising the transcripts and conducting the data analysis (Kitto et al., 2023). This was done to provide distance between my role as a participant and my role as a data analyst. An abductive analysis was conducted, in which the deductive component focussed on making sense of the data in the context of established conceptualisations of body image (Grogan, 2021) and body functionality (Alleva and Tylka, 2021). The inductive component focussed on identifying patterns in the data that may extend beyond the scope of the conceptual framework (Braun and Clarke, 2019) for example, elements that fall outside of standard conceptualisation.

The first stage of analysis involved re-reading the reflections and re-familiarisation with the data. During this stage the reflections were read multiple times, and initial observations about the data were recorded for example, notes were made documenting early thoughts and potential meaning. The data was explored, and preliminary codes were established based on patterns within the dataset and body image conceptualisation for example, affective, behavioural, etc. The codes were then sorted into themes that were refined in the context of the research question. This was an iterative and reflexive process, in which I returned to the transcript's multiple times, to both refine and question early interpretations of the data. The use of multiple researchers in qualitative analysis can reduce bias; however, an autoethnography tends to be an individual endeavour (Kitto et al., 2023). To reduce bias and in an attempt to consider alternative interpretations of the data, I discussed my preliminary coding and themes with a *critical friend* who has experience in qualitative research and body image. Following this process, each theme was then defined and named.

The narratives used in this research *tell* my story, with thematic analysis allowing me to *discuss* my story within the context of body image conceptualisation. Thus, the data presented in this paper are extracts from my autoethnographic narratives, which have been thematically analysed. Thus, the data are presented thematically, as opposed to chronologically. This approach to the thematic analysis of autoethnographical data has been evidenced elsewhere (e.g. Coret et al., 2024; Soleas and Code, 2020) and the use of extracts from data and/or narratives mirrors the approaches of other autoethnographies (e.g. Kitto et al., 2023; Leung, 2021).

Reflexivity

Reflexivity is essential for maintaining quality and rigour in qualitative research and is an ongoing process through which the researcher critically considers their own positionality and acknowledges how it may shape the research and the results (Berger, 2015). I recognise that my dual identity as both a researcher and a participant shaped all aspects of this autoethnography, including what I remembered, how I remembered it, how I told my story and how I analysed the data.

When I began dictating/writing my narratives, I had not yet formulated a research question, nor considered that body image and body functionality would be the framing issues. My initial motivation was more immediate. For example, in the weeks leading up to my last surgery, I began exploring academic literature on strabismus, initially looking for evidence on surgical outcomes, but then looking for research that considered how people like me live with and experience this condition. It became apparent that very few studies centred the voices of people living with strabismus, which partly motivated my desire to conduct this research.

Following my surgery, my recovery was very slow, and my headaches made it difficult to use a computer, read, or watch television. My

frustration at not being able to work on a computer, combined with my earlier frustration of not seeing the voices of people like me represented in the research, led me to start narrating my stories on a dictaphone. At this point, I had little direction, and although body image and body functionality were not explicitly considered, I quickly became aware that much of what I described about my life with strabismus focussed on how my eyes looked and functioned. This awareness initiated the reflexive process. Whilst telling my stories, I developed an awareness of how difficult it was to distance myself from the patterns within the data. I therefore made a conscious decision to keep my narratives broad, with the aim of capturing the full emotional landscape relating to my lived experience. This strategy allowed me to monitor the effects of my identity on the data I was constructing, thus enhancing the quality of the research (Berger, 2015). The research question was only formulated after transcribing my stories, but my dual identity inevitably shaped my storytelling.

Adopting an analytic autoethnography provided me with a structured framework for examining my data (Anderson, 2006). The deductive element of using pre-existing theoretical frameworks allowed me to align the data with established conceptualisations of body image and body functionality. Engaging with theory allowed me to step back from my emotional responses and investigate my own experiences in a more systematic way.

Findings and discussion

To align with the structured, theory-driven approach of analytical autoethnography (Anderson, 2006) the findings and discussion are presented together. Table 1 (Supplemental Material) outlines the themes, example codes, and their links to body image conceptualisation. The following section presents narrative extracts (findings) and situates them within existing literature and theory (discussion). Following the presentation of the individual themes, an analytical synthesis section considers the main cross-theme patterns.

Theme 1: Thoughts and feelings focussed on what the eyes and the body cannot do

This theme reflects the thoughts and feelings associated with perceived lack of functionality (e.g. eye strain and difficulties reading). It also demonstrates the lack of education that I had about the functional limitations of strabismus.

Thematic findings. Light sensitivity and chronic headaches are two physical symptoms that I extensively discuss in my stories; however, in the early narratives, I had not made connections between strabismus and the potential physical symptoms. I was aware that I was experiencing chronic headaches and was trying to search for reasons why my body wasn't optimally functioning:

> "I remember starting to take more and more painkillers for headaches, but it was also the same time that I was doing a PhD. I put the headaches down to stress" (Reflection 2)

I suffered from chronic headaches for over 10 years, and it took me a long time to realise that strabismus could be more than just an appearance-related issue:

> Things started to make sense. Google was telling me that my condition could lead to photophobia and headaches. . . I was relieved that I had an answer to these health issues that were significantly impacting my life, but I was also angry. Why had no one ever educated me? Why had no one ever told me that my squint would "return"? Why had no one ever told me that it had physical symptoms associated with it? (Reflection 2).

My lack of understanding about the potential functional implications stemmed from my childhood experiences, in which strabismus was positioned as a cosmetic issue: "I remember one

particular occasion in which we were sat in a café. The conversation focused on the fact that if I did not have surgery, I might get bullied and might never get a boyfriend." (Reflection 1). Despite making the potential connection between strabismus and physical symptoms as an adult, it still took a long time to get medical help. When discussing my experiences of pain and discomfort, I often felt like a burden: "I always complained a lot to friends and colleagues, but never specifically about the misalignment, just the associated physical symptoms. I am sure they became desensitised to my complaints." (Reflection 3).

I also noted trouble with reading and performance at work. When my body doesn't function like others, it leads to feelings of inadequacy:

> Sometimes, I would send emails and reread them 10-15 times, and then after I press send, spot all the typos. I would deliver lectures and see the typos on the slides. I would worry that people would think it was a lack of attention to detail, or I was lazy, but I guess it is just hard to read sometimes. This job has a tendency to make you feel like you aren't good enough. You constantly question your ability, but also when you look around and see that you aren't making the same progress as other people or doing tasks as quick and efficiently as other people, you do feel inadequate and stupid. (Reflection 5)

In my reflections I continued to focus on what my eyes couldn't do and how this would lead to anger, frustration, and a desire to be *normal*. This poor functioning also led to feelings of isolation:

> I am never going to be "normal" regardless of how much surgery I have. I was also frustrated because I know that no one I know can relate to what this feels like. No one I know can understand what it is like to see words jump all over the place when you switch the fixating eye. No one I know can understand what it is like to live in a world with no depth perception or to always be called clumsy. (Reflection 4)

Interpretation and context. This theme highlights how strabismus can be associated with negative thoughts and feelings in relation to body functionality. Like other research on women with visible physical disabilities (Vinoski Thomas et al., 2019), I too frame functionality in relation to what my body cannot do. Strabismus research also documents similar physical symptoms to the ones I experience (Buffenn, 2021). Although patients without double vision (like myself), experience fewer functional or physical difficulties than those with double vision, issues with lighting (23%), reading (38%), eye fatigue (23%), and headaches (23%) have been reported in a small-scale interview study (Hatt et al., 2007). The current study extends these findings by moving beyond prevalence to report on impact and lived experience.

Furthermore, my experiences align with cross-sectional interview data showing that functional limitations can compromise the completion of day-to-day tasks (Hatt et al., 2007). However, as Hatt et al. (2007) focussed on reporting the frequency of health-related quality of life factors, this study extends existing research by providing in-depth insight into emotional reality and the important role that context may play in perceptions of body functionality. Thus, the emotional reality of living with strabismus is not well documented in existing research. Indeed, although research highlights the impact that strabismus can have on career development (Wang et al., 2018), the in-depth emotional implications are overlooked, with this study providing detailed reflections on feelings of inadequacy at work.

Findings of the current study indicate that a lack of education about the lifelong implications of the condition can delay the seeking of medical support as an adult. This is supported by quantitative evidence that reports lack of awareness as an important factor in delaying strabismus care (Al-Omari et al., 2022). However, this study extends the quantitative evidence by highlighting *why* a lack of education may exist and *how* awareness is developed. This study reports using online sources to learn more about the condition; however, due to the variability in quality of educational

strabismus content online (Ghanekar et al., 2026), it is possible that strabismic individuals may be exposed to misinformation about symptoms and management.

These findings have important implications for future research and practice. Women with physical disabilities have reported how body functionality is an important part of their overall body image (Vinoski Thomas et al., 2019), with the current study emphasising the importance of physical functioning for quality of life in strabismus. Body functionality appreciation interventions have shown initial promise in supporting individuals with visible differences (Guest et al., 2024), and the findings of the current study suggest that functionality support is likely also needed for strabismic individuals. Thes study findings also reinforce the call to promote health education on the lifelong implications of strabismus (Wang et al., 2018), as patients may be seeking support online, with potential exposure to misinformation (Ghanekar et al., 2026).

Theme 2: Negative thoughts and feelings related to the appearance of the eyes

This theme considers the negative thoughts and feelings I experience in relation to the appearance of my eyes, and I reflect on how the appearance component of the condition is not as important as functional elements.

Thematic findings. In reflection 3, I state: "I would say the cosmetic component was a lesser priority. When I did mention the squint, it was usually in the context of the headaches." Further to this, when reflecting on my childhood experiences, I wasn't able to recall a situation in which I felt self-conscious about my eyes, but my medical records clearly state that I was bullied: "She is being teased about the squint at school" (Medical records, dated April 1993). However, in my 20s and 30s I started to feel insecure about the physical presentation of my condition: "I started to physically notice the turn in my eye again. First of all, in pictures and then every single time I looked in the mirror. I started to become self-conscious" (Reflection 2).

This self-consciousness manifested itself in several situations, including when dating:

> I was never self-conscious about my eye when dating until one particular date, when the man randomly said, "Have you ever dated anyone with a lazy eye?". I got flustered. He didn't look like he had a lazy eye, and I immediately thought that he was asking that because he had *clocked* my eye and was waiting for a confession. I managed to quickly change the subject but didn't stop thinking about it. I would have dates where men would say, "oh, you have really nice eyes" and my immediate thought would be, "Are they taking the piss?" "Have they noticed my eye and are just trying to get a confession? (Reflection 2).

But the insecurities were also present at work:

> I remember being in teaching situations and in more situations than I can count on one hand, students say things like "oh, do you mean me?" or "I thought you were looking over there"'. Reflecting on this, I don't think they were ever being mean. It was just genuinely a case of one eye wasn't looking at them, but in those situations, you become incredibly self-conscious. You become even more aware that everyone in the room is looking at you. (Reflection 3).

It appears that I sometimes can forget about the physical appearance component of the condition, but when I am reminded of it, I experience a lot of sadness:

> I clocked myself in the video and immediately noticed how wonky my right eye looked. I have watched this video back, and I see the realisation on my face of the moment when I saw how misaligned my eye looked. In the video, there is an audible sigh right at that point. I looked really sad and then I stopped filming. There are times in your life when you forget about the wonky eyes. After all, you only really see them when you look in the mirror, but those times when you catch a glimpse, and it becomes the only thing you can think about. (Reflection 4).

Interpretation and context. These extracts demonstrate how strabismic individuals can have negative thoughts and feelings about the appearance of their eyes. Previous research shows similar negative feelings about appearance (Hatt et al., 2007) however, in the current study, I reflect in-depth on these negative feelings both in my professional and personal life, highlighting the important nuances associated with contextual variations in lived experience and the significant role that others play in shaping levels of distress. These findings can be compared with research that highlights the self-consciousness that individuals with strabismus experience when speaking in work contexts and developing intimate relationships (Mason et al., 2024). This autoethnography confirms that negative feelings about eye misalignment may develop through socialisation with others, starting in childhood through bullying and extending to adulthood interpersonal relationships. To support this, previous research demonstrates that it is not uncommon for strabismic children to experience bullying, as 40% of young people report peer victimisation (Horwood et al., 2005). However, findings of the current study illustrate how these experiences unfold across the lifespan. Evidence suggests that those with a visible difference may continually anticipate negative reactions from others (Rumsey and Harcourt, 2004), a phenomenon that was echoed in my own experiences of living with strabismus. These findings highlight the emotional reality of living with an appearance that deviates from *normal* and aligns with research that notes the distress that strabismic individuals experience in relation to physical appearance (James et al., 2011). Importantly, this study examines how these experiences are transient across time and context and are shaped by the reactions from others.

Theme 3: Perceptual distortion

This theme considers elements of perceptual distortion that I experience in relation to the magnitude of my eye misalignment. It considers how clinical assessments compare to my own personal judgements. It also outlines the frustration associated with comments from others who seek to reassure me that my misalignment is smaller than I think.

Thematic findings. During a period in my late 20s, I wasn't aware that I still had strabismus, as I was under the assumption it was corrected with childhood surgeries. However, I was receiving comments from others about the appearance of my eyes:

> I never really thought about my strabismus again until my late 20's. At the time I was dating a man, and one day he asked me, "Oh, do you have a lazy eye?", I remember saying to him that I used to, but I had surgery as a child and it was *fixed*. . ..When I looked in the mirror I did not see a misaligned eye, but it was the point at which I became a bit more aware that other people might be able to see something that I can't. (Reflection 2).

Although I initially underestimated the magnitude of deviation, as time progressed, the opposite occurred, and I began to overestimate the turn in my eye. For example, in my adult clinical assessments my squint was always referred to as "small." I felt frustrated that the difference I saw in the mirror wasn't reflected in clinical measurements. This frustration was alleviated when I received a letter from the hospital detailing my referral for surgery:

> One thing that stood out to me in this letter were the words "cosmetically larger than it measures". This was both interesting and reassuring for me because throughout all medical consultations, I had been told that I might not have been suitable for surgery because the measurements weren't quite big enough, yet, when I looked in the mirror or had a picture taken, the turn looks massive! (Reflection 4).

My misjudgement of the scale of the misalignment continued after my adult surgery:

> I was convinced that my operated eye had not changed. In fact, when asked about it in my appointment, I said that I felt it had got worse and

> was turning out more. The measurements were good though. . .I remember feeling shocked when I heard this because when I look in the mirror, I was still seeing a big misalignment. (Reflection 5).

Whilst I thought the deviation was larger than the measurements suggested, people close to me would always try to reassure me that the squint didn't look as bad as I thought. However, these kinds of comments were always perceived as insincere:

> I would refer to them as my wonky eyes. I would say things like "my eye turns outwards" and it was always met with the SAME responses like, "oh, I never noticed", "you can't really tell" or "it isn't that bad". It is a weird thing to get these kinds of responses, because whenever I looked in the mirror or took a photo, I immediately see the deviation. In my head, it is massive. How can they not see it? I know that people say these things to be kind, but I am not sure how helpful it is. I much prefer the honesty of a family member, than a friend who tries to tell me they don't see it. (Reflection 3).

Interpretation and context. These findings highlight the potential importance of the perceptual component of body image, an element that is relatively under-explored in strabismus research. Although researchers understand strabismic individuals can have negative thoughts and feelings about their eye appearance (Mason et al., 2024), the impact of perceptual distortion (i.e. the ability to accurately assess the magnitude of the deviation) is less well understood. Data from this study highlights experiences of perceptual distortion in relation to the magnitude of misalignment, as I move from an underestimation of misalignment in the early narratives, to an overestimation in later narratives. Whilst existing evidence states that objective angle of deviation is not related to psychosocial outcomes (Ritchie et al., 2013), the current study uniquely highlights that subjective perception may be more important and justifies the need for further exploration. To reinforce the importance of perceptual distortion in strabismus, lower health-related quality of life is apparent in those who still report deviations, despite clinically successful surgery (Ji et al., 2020). However, findings from this study uniquely suggest that perceptual distortion is not just relevant post-surgery but is experienced in complex and changing ways over time.

It is also important to understand the emotional invalidation strabismic individuals may experience when discussing perceptions of misalignment, as this was evident within the narratives. Emotional invalidation considers the dismissal, minimisation or contradiction of an individual's affective experiences (Zielinski and Veilleux, 2018) and can lead to intensification of symptoms (Sebring et al., 2023). This study demonstrates emotional invalidation may be experienced by those with strabismus, particularly when friends and peers minimise the magnitude of deviation and when there is a discrepancy between clinical measurements and subjective interpretation. Thus, experiences of invalidation require further investigation in those with strabismus, particularly as this invalidation is associated with negative affective outcomes and psychological distress (Zielinski et al., 2023). Thus, the findings from this theme suggest that perceptual distortion may be a key part of strabismus lived experience that has yet to be explored in-depth. It also identifies how these perceptions may change temporally and suggests that others may shape the emotional experiences associated with this distortion.

Theme 4: Conflicts between functional and appearance-related components

This theme considers the ongoing conflicts experienced between the functional and appearance-related components of strabismus. This includes discussions of my apprehensiveness to not just position strabismus as a cosmetic issue but also feeling unheard in relation to functional issues.

Thematic findings. When thinking about getting medical support, I was conscious not to talk too much about the appearance component and instead focussed on how strabismus impacted my physical well-being. When contacting the Doctor in my 30s I reflected on this: "I carefully crafted the details on the report and felt it very important not to mention anything around physical appearance (again, under the assumption that this would not be taken seriously)" (Reflection 2). Although I initially thought that I wouldn't receive treatment if I didn't focus on the functional issues, after being referred to specialists, I felt unheard in relation to functional issues:

> In all of those medical appointments, no one really asked me in detail about how the condition impacted me functionally, beyond assessments/questions about double vision. I had, of course, mentioned the headaches, but had never been given the opportunity to discuss them in detail. I was never provided an opportunity to say how the functional aspects were sometimes debilitating and severely influenced my day-to-day activities. . .I was never really asked about how the squint impacted my life, other than a question at one appointment that asked something like "Are you concerned about the way it looks?" (Reflection 4).

I reflected on the internal conflict that I experienced when considering the relative importance of functional versus cosmetic aspects of the condition. This tension is evident in Reflection 4: "Because I have to use my eyes to get through 35+ hours of work a week, using them seems more important than how they look.." However, I also reflected on how my experience of both the functional and cosmetic elements seems insignificant when compared to the experiences of other strabismic individuals that I had met during clinical appointments, who had acquired their squints under more challenging circumstances: "Hearing their stories made me feel stupid, like I didn't belong. It felt like they had serious issues, and all I had was a chronic headache and a couple of wonky eyes." (Reflection 3).

Interpretation and context. This study offers a unique contribution by highlighting the possible tension between functional and appearance-related aspects of strabismus, an interplay overlooked in previous research. While studies have documented physical and psychosocial impacts (Hatt et al., 2007), they seldom explore how these components can intersect and diverge in importance depending on individual circumstances. For instance, although I do not experience double vision, which tends to be associated with more functional concerns (Hatt et al., 2007), I place greater emphasis on functional limitations due to their impact on my job performance and identity. This aligns with mixed-method evidence linking strabismus to reduced work self-efficacy (Wang et al., 2018). However, findings from this study suggest that future research needs to investigate the individual contexts of people's lives to understand the relative importance and impact of functional versus appearance-based components. In the UK, surgical priority may be given to patients with double vision (NHS Commissioning Policy Development Team Bristol, North Somerset and South Gloucestershire, 2023), but this may not reflect the potential variability of impact on people's lives. Due to a lack of research that captures the in-depth lived experience of strabismic individuals, clinical decisions regarding surgery may be reductive. This highlights the importance of these study findings in telling the "silenced story" of patients' experiences (Thurston, 2025), with autoethnography having the methodological capacity to capture how functionality and appearance-related tensions unfold across time and context.

Theme 5: Adaptive and avoidance behaviours related to functionality

This theme considers how functional components of the condition can lead to avoidance of activities or unconscious adaptions. The data shows that adaptions to functional impairments are often viewed positively.

Thematic findings. To try and control the impacts of light sensitivity, a symptom I associated with strabismus, I avoid brightly lit environments: "Around my late 20's I started to notice the light sensitivity issue. I have numerous memories of being in brightly lit shopping centres and within a few minutes getting intense headaches" As a result, I adapted by working in the dark:

> People would come into the office and make comments about me sitting in the dark, to which I initially responded that the lights gave me headaches. Most people would make the comment, but it wouldn't just be once. It would be every time they came into the office. It became annoying (Reflection 2).

The adaptations also continued in the post-surgery period: "Sunglasses became my best friend during this period. Initially they were to disguise the eyes, but I found they gave me some relief from the physical symptoms" (Reflection 5). After surgery, I spent a lot of time on social media and had found content creators with strabismus and felt reassurance in the fact that my avoidance behaviours were like other people: "I have never had any desire to drive because I know I would be awful at it. When people ask me why I don't drive, my response is always, a) because I am too anxious, and b) I have no sense of distance and space" (Reflection 5).

Interpretation and context. These extracts from the narratives reflect behavioural components of body functionality, that is, strategies that are adopted to manage functional impairments. Behavioural adaptions have not been well documented in existing studies. Strabismus studies have mentioned "adaptions" or "efforts to reduce symptoms" but focus on interpersonal factors (e.g. avoiding eye contact; Hatt et al., 2007). The current study extends this by identifying functional adaptions and avoidance behaviours embedded in day-to-day life, including working in the dark and avoiding driving. This has important practical implications for considering how strabismic individuals could be supported in education and the workplace (e.g. workplace adaptions).

I displayed positive perceptions of behavioural adaptations within my narratives. This suggests that strabismic individuals may admire their body's capacity for unconscious adaptation and thus may have *functionality appreciation*. Functionality appreciation can be defined as "appreciating, respecting, and honouring the body for what it is capable of doing, extending beyond mere awareness of body functionality" (Alleva et al., 2017: 29). Thus, while strabismic individuals may experience negative thoughts and feelings regarding functional limitations, behavioural functional adaptations appear to be valued. This adds to functionality literature by illustrating how functional appreciation can co-exist with perceived functional impairment. These findings suggest there is scope to develop functionality appreciation interventions across all domains of body functionality (e.g. cognitive, affective, behavioural and perceptual) in those with strabismus.

Theme 6: Checking and avoidance behaviours related to appearance

This theme captures a range of avoidance behaviours that are used to conceal or minimise the physical presentation of strabismus, with coping behaviours allowing more confidence in social situations.

Thematic findings. Coping behaviours are evidenced in Reflection 2: "In social situations I was struggling to maintain eye contact because thoughts would pop into my head that they were judging my eye." In reflection 4, I discuss deleting undesirable photos: "You become pretty good at taking pictures to try and minimise the perceived defect; ensuring you take it at the right angle to try and disguise the misalignment" (Reflection 4) This extended to the photos that I posted online for others to see:

> I carefully crafted my dating profile with a combination of pictures of me straight on in

> sunglasses and a couple of images where I thought my squint was clearly visible. I didn't want to be accused of being a catfish, but the pictures I posted probably didn't fully capture my squint. (Reflection 2).

Although strabismus doesn't stop me from attempting to develop romantic relationships, I have developed coping strategies, as evidenced in reflection 4:

> I adopted a new strategy of telling the people I was dating about my *wonky eyes* pretty much within the first hour of meeting. I suppose it is so I can get in there before they do and be prepared, rather than being caught on the back foot. I feel better prepared to tackle any comments and questions if I am the one who mentions it, and it is usually mentioned in some self-deprecating way. People can't take the piss out of you, when you have already told all the jokes, right? (Reflection 4).

Behavioural strategies extended to checking behaviours:

> In the time leading up to surgery, I became hyperaware of how my eye looked on work Teams or Zoom calls. I know everyone has a little peak at themselves on a video call, but I became fixated on staring at the misalignment and thinking about how awful it looked. (Reflection 4).

Interpretation and context. Unlike the behavioural adaptations associated with functionality, appearance-related adaptions were viewed more negatively and often linked to anticipated judgement from others. Like the findings in other strabismus studies (Mason et al., 2024), behavioural strategies include avoiding eye contact and avoiding photographs. Furthermore, a behavioural strategy of *confession* was evident within the narratives, which has not been explicitly documented in the strabismus literature. This strategy was to *confess* my strabismus to romantic partners and use self-deprecating humour. Self-defeating humour is used to develop relationships with others but can have negative impacts on well-being if used excessively (Martin et al., 2003). Conceptually, these behaviours might be considered body avoidance strategies that link with the behavioural component of body image. Body avoidant behaviours are commonly discussed within the eating disorder literature and include the avoidance of situations where body weight and shape might be visible (e.g. wearing clothes to disguise the body; Rosen et al., 1991). The current study indicates that body avoidant behaviours may also be relevant to strabismus but manifest differently (e.g. avoiding eye contact).

This study identified body checking behaviours may also be applicable to those with strabismus. Body checking relates to the tendency of an individual to check and scrutinise their body (Reas et al., 2002), with my preoccupation with looking at my eyes on video calls, being an example of this. Whilst body avoidant and body checking behaviours impact health-related quality of life in other body image literatures (Latner et al., 2012), the implications for those with strabismus are unclear and warrant further investigation. Given that strabismus is associated with higher levels of anxiety and depression (McBain et al., 2014), it is important to consider the well-being implications of the behavioural adaptions evidenced in this study (e.g. body checking, body avoidance and *confessions*).

Synthesis of findings. The themes indicate that functional and appearance-related components of strabismus are important for lived experience but are largely experienced as distinct dimensions of the condition. The analysis shows that both elements vary with time, context, and social interaction, as does the relative importance of these two components. Whilst both functional and appearance-related consequences of the condition are documented in interviews (Hatt et al., 2007; Kumaran et al., 2019), the temporal, hierarchical and social complexities of these are not easily captured through existing methodological approaches. The ability of autoethnographies to capture the complex dynamics of health has been

acknowledged (Li, 2025). Thus, the current autoethnographic approach provides unique insights into the dynamic nature of living with this condition.

The themes demonstrate how the importance of appearance and functionality vary over time and are shaped by interactions with others, including medical professionals, friends, and family. The responses of others appear to influence not only what is prioritised but how the condition is lived and understood. Therefore, whilst functional and appearance elements can be distinguished conceptually, the analysis suggests that *others* play a significant role in defining what matters, when it matters, and whose voice should be prioritised (e.g. objective clinical measurements vs subjective lived experience). These autoethnographical findings offer novel insights into the shifting priorities of living with strabismus by highlighting the temporal, social, and contextual complexities of the condition.

Strengths, limitations, and future directions

This study offers unique insights into the lived experience of strabismus and provides in-depth personal data that may not have been obtainable by other research approaches (Li, 2025). It is the first known study to make explicit conceptual connections between strabismus and both body image and body functionality theory. In doing so, it contributes to the theoretical development of the visible difference literature by focussing on conditions that affect the presentation of the eyes, which has previously received limited attention. The study also advances theoretical understanding by highlighting the potential complex dynamics associated with conditions that have both appearance-based and functional components.

While this study has several strengths, the findings of the research must be considered within the context of the study limitations. Firstly, as a single case analytic autoethnography, the findings reflect *my* experiences of the condition and cannot be generalised to all people living with strabismus, who may differ in subjective experience and objective clinical presentation (e.g. diplopia, degree of misalignment). It is also important to acknowledge that these accounts reflect *my* experience of how I perceived *my* condition. Although I have drawn on academic literature to situate these experiences, I am not a medical professional, and there may be alternative explanations for aspects of my experiences, for example, chronic headaches. Further to this, my dual role as both a researcher and a participant introduces the potential for bias in my research and the possibility that data may be interpreted differently by others.

As this study foregrounds the challenges and experiences of a marginalised group, whose stories have been overlooked or silenced (Thurston, 2025), it offers a foundation for further empirical or conceptual research. Future complementary research may explore the experiences of others living with strabismus, to consider how functional and appearance-related components intersect depending on socio-cultural context and clinical classification.

Conclusion

This analytical autoethnography provides unique theoretical insight into the lived experience of strabismus and acts as an important bridge between medical research in strabismus and health psychology research in body image. The study identifies how different elements of site-specific body image and body functionality may be experienced by those with strabismus. For body image, this consisted of perceptual elements (e.g. inaccurate judgements of misalignment), behavioural (e.g. avoiding eye contact) cognitive and affective (e.g. negative thoughts and feelings about appearance of the eyes), For body functionality, cognitive and affective components focussed on functional impairments (e.g. eyestrain headaches), whilst behavioural components (e.g. working in dark rooms) focussed on functional appreciation of

unconscious adaptions. The use of personal narratives alongside body image theoretical frameworks, highlight the complexities of aesthetic and functional components that may be experienced by some people living with strabismus. By using my stories as data, I provide an in-depth insight into patient experience to contribute to the development of patient-centred care and theoretical developments in health psychology. Specifically, clinical consideration may need to be given to how functional and appearance components could have differing psychosocial impacts, depending on individual life circumstances. Without fully understanding patient stories, there is a risk that clinical decisions regarding treatment are reductive. This study reflected on the "silenced stories" of ophthalmology patients (Thurston, 2025); thus, by telling my story, I hope to have opened the door for the *silenced*.

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Ethical considerations

In accordance with my university policy on retrospective autoethnographies, ethical approval was not required for this study. However, I have adhered to normal ethical procedures, and these are discussed within the supplementary materials.

Consent to participate

As this study is an autoethnography, I am both the researcher and the sole participant. I confirm that I voluntarily chose to explore and share my personal experiences as part of this research.

Consent for publication

I consent to the publication of this research, including all personal reflections and experiences described within, with full awareness of the implications of sharing autobiographical material.

Funding

The author received no financial support for the research, authorship, and/or publication of this article.

Declaration of conflicting interests

The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data availability statement

Data can be accessed by emailing the corresponding author.

Supplemental material

Supplemental material for this article is available online.

Open access

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