

CASE REPORT

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Two identical twin pairs discordant for longstanding anorexia nervosa and OSFED: lived experience accounts of eating disorder and recovery processes

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Abstract

Research into the risk of anorexia nervosa (AN) has examined twin pairs to further the understanding of the contributions of genetics, trait inheritance, and environmental factors to eating disorder (ED) development. Investigations of twin experiences of EDs have been biologically-based and have not considered the qualitative, phenomenological aspects of twin experiences. A gap in the literature exists regarding understanding of discordant twins with EDs. This research was developed in response, with the aim to deepen understanding of AN in discordant twins and to create novel ideas for further research and testing. The case studies presented in this article provide lived experience insights of two identical discordant twin pairs: one twin pair discordant for longstanding AN and one twin pair discordant for 'atypical' AN (the twin with AN has recovered). The perspectives and experiences of each co-twin (one with AN and one without) explore a number of factors that may have contributed to twin discordance in these cases, and how each twin has responded to the impact of AN in their lives. Through use of first-person accounts in case study presentation, this article centres social justice values of lived experience leadership and involvement in research. This article aims to extend current knowledge and understanding of EDs in discordant twins, particularly regarding risk for ED development, ED duration, diagnosis and treatment, and recovery processes.

Keywords Anorexia nervosa, Longstanding eating disorder, Severe-enduring eating disorder, Discordant twins, Sibling carers, Lived experience

Introduction

Experiences of eating disorders (EDs) have been studied in siblings and twins, particularly regarding biological risks and correlates for ED development [1–7]. Family, twin, and adoption studies have indicated a pattern of complex

trait inheritance for ED development influenced by a combination of genetic and environmental factors [8–12]. Heritability estimates for AN among twins range from 48 to 74% [13], and approximately 17–46% of the variance in AN may be accounted for by nonshared environmental factors, such as life events (i.e., trauma and adversity), differential parental relationships, peer group experiences, and body weight teasing [14–17]. A multitude of biopsychosocial factors are theorised to contribute to the cause, maintenance, and barriers or facilitators of treatment and recovery of AN, with varying levels of environmental and biological load [18, 19]. A 'perfect storm' of biopsychosocial risk factors may arise whereby an individual is born

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with specific biological, neurocognitive and psychological predisposing traits, that then interact with their environment [18–21]. For example, a person may have a biological predisposition toward anxious, obsessive traits [22, 23]. Early exposure to traumatic or stressful experiences influence structural and functional brain changes; stress regulation; neuroplasticity; sensitivity to reward and punishment; and stress response, including disordered eating [24–26]. Brain changes during and after puberty may contribute to increased worry and perfectionism [18, 27, 28]. During periods of heightened stress, dysregulated stress reactivity may lead to energy and appetite changes, and a person's anxious, obsessive neurocognitive traits may lead to restrictive eating and avoidant behaviours to reduce anxiety [18, 28]. Sociocultural influences (i.e., diet culture), heightened sensitivity to reward and punishment, and the neurobiological effects of malnutrition (i.e., increased anxiety and stress; homeostatic, neuroendocrine, neurotransmitter, and gut microbiome dysregulation) may maintain a cycle of restrictive eating [18, 29].

Emerging research suggests that risk of ED development in twin pairs is elevated by environmental factors that may be common in twin development and birth, such as a restricted intrauterine environment, and pre- and perinatal and obstetric complications [30–34]. These developmental factors may impact brain structure, metabolic and gut microbial development [35–38]. For twins, different exposures during development and delivery [36, 37, 39–42] and differing birth weights [43–46] may be part of environmental factors that influence AN discordance (i.e., one twin has the condition and the other does not; discordance).

The developmental stage at which biopsychosocial stressors occur may determine the timing of onset, type, and duration of stress effects on AN risk, which may influence AN development/non-development in discordant twins. This includes hormone and energy changes during puberty [47–51], and exposure to adversity and trauma [14, 19, 52]. Multiple stress exposures and sociocultural-political factors (i.e., marginalisation, social disadvantage, stigma) may create *additive* effects [53–57]. Individuals may also have a neurobiological predisposition to *susceptibility* to neurobiological changes that occur as a consequence of trauma exposure [19, 26, 58, 59], such as susceptibility through transgenerational trauma via multiple gene–environmental pathways [60, 61] and molecular factors [26, 59]. In identical twins, therefore, despite increased heritability, unique interaction between the biological and psychological vulnerabilities of each individual twin and environmental stressors may lead to discordant development for low- or higher-weight ('atypical') AN, and differing ED duration.

Although perspectives and definitions differ [62–65], longstanding (or 'severe-enduring') EDs have been used to categorise EDs based on illness duration (often a pattern of chronic ED, with various thresholds used ranging from 3, 5, 7 or 10 or more years), differing core symptom profile, a lack of response or lasting improvement to past treatments, clinical and functional impairment [65–70]¹. Building on these understandings from lived experience perspectives have encompassed dimensions of a vulnerable sense of self, global impoverishment, and compromised quality of life [71–73]. Differences in recovery or longstanding course may be influenced by AN subtype (i.e., possible reactive vs. endogenous AN) [74]. Differences may also exist among longstanding patients according to severity and complexity [70, 75]. Recovery processes are complex, precarious, and navigated daily, and may be threatened by social discourses, power structures and other life stressors [73, 76–81]. This may lead to fluctuations in recovery, motivation and hope that favour or threaten healing and wellbeing [73, 77, 82–84]. When twins are discordant for ED, these recovery processes may affect both twins in multiple ways.

The majority of twin studies are biologically focused, and a gap in the literature exists regarding qualitative, phenomenological research of discordant twin experiences of longstanding ED and ED recovery. Lived experience insights in ED research and treatment can improve current knowledge and understanding of ED experiences and highlight complexities and research gaps [85–88]. Lived experience leadership and engagement in mental health research has been progressively recognised as an ethical imperative, anti-oppressive practice, and best-methods approach [85, 89–92]. However, there continue to be gaps and barriers to lived experience involvement in ED research [85, 93]. There have been limited accounts of personally experiencing longstanding EDs and 'atypical' AN in the academic literature [94–97] or of first-person accounts of having a family member with a longstanding ED [98]. No known first-person accounts of discordant longstanding EDs among siblings or twins currently exist. This article expands on the current understanding of the experiences of longstanding EDs, sibling experiences of EDs, and EDs in twins, by providing case study accounts of discordant AN experiences in two identical

¹ Although 7 years duration and non-response to previous treatments has been reported to be the most commonly used definition to categorise longstanding AN [65], differing thresholds of illness duration may be used. Due to differences in how longstanding AN may be defined (i.e., < 7 years duration, > 7 years duration; a criterion of treatment non-response, or no criterion regarding treatment non-response), it may be that SS meets some definitions of longstanding ED (longstanding atypical AN), and does not meet others. This highlights the complexity with concepts, definitions, and prognosis in longstanding ED [73].

twin pairs, authored from a first-person lived experience perspective.

Aims

This article centres the experiences of two twin pairs discordant for AN and explores factors influencing the development and persistence of AN. One twin pair (RE and MW) are discordant for longstanding AN, and one twin pair (SS and ES) are discordant for 'atypical' AN. Experiences of AN between twin-siblings and both discordant twin pairs are compared, to identify aspects of convergence/divergence, as well as factors that may indicate risk for or resilience to AN development, longstanding AN duration, or recovery.

Methods

The co-authors utilised a qualitative phenomenological approach involving: collaborative autoethnography [99, 100] with reflexive thematic analysis [101, 102]. Autoethnographic research methods involve the use of the author/s inclusion of their personal experiences to inform and explore issues within research [103–105]. Reflective personal experiences [103] offer interpretation, nuance, and advancement current knowledge [104]. These personal experiences allow further discussion of the intersections in socio-cultural and political factors that relate to a current issue [104]. Collaborative autoethnography (while an oxymoronic term), involves a duo or team of researchers who 'collectively and cooperatively' [99] "pool their lived experiences on selected sociocultural phenomena and collaboratively analyse and interpret them for commonalities and differences" [106]. Collaborative autoethnography extends the reach of individual autoethnography and addresses some of its methodological and ethical issues through its multivocal approach to data generation, analysis, and writing, and through multidimensional interpretation [99, 100].

Lived experience cannot be captured solely in codes and categories [107], however coding can be used to group and retrieve data with similar characteristics or meaning [108] in order to create themes. Rather than themes emerging clearly from the data, the generation of themes is an active, creative, and interpretative process with authors taking an active role in identifying patterns and clusters [109].

The authors held ten online meetings, to discuss their experiences of AN discordance via the following protocol using collaborative autoethnography and reflexive analysis:

1. Authors purposefully composed written narratives of their experiences of AN. This was done to allow each individual to reflect on aspects of their experience

that were important to them, which could later be identified in thematic analysis. Written narratives were pooled together for collective autoethnography.

2. Five recorded, unstructured online meetings were held for the authors to freely describe and reflect on their experiences of AN. There were no pre-conceived topics to approach their experiences, other than that they were reflecting on the experiences of twin discordance for AN, with attention to how these experienced converged between and within twin pairs. The transcripts, together with free-form written narratives about their experiences, provided the data for analysis.
3. Digital transcripts from the first five meetings were developed and gathered verbatim.
4. 86 pages of digital transcript (a composite of verbal and written narratives) were generated.
5. A novel reflexive analysis was devised for the analysis of the digital transcript in order to generate themes collaboratively between authors, with attention to conferring throughout the process. This included:
 - a. Individual, dyadic and group reflection of co-twin discordance, comparing and contrasting of experiences of AN illness and for twin discordance (RE & SS as twins with AN; MW & ES as twins without AN).
 - b. Co-construction of preliminary themes [110, 111] using inductive semantic (descriptive/meta) coding [102, 109], taking an immersive approach.
 - c. Co-authors agreed upon the conferring, grouping, and consolidation of meta themes and via an iterative process, which evolved via further online meetings and via email. Consensus was established on themes and sub-themes.
 - d. A selection of transcribed quotes and written material were selected to embody these themes and sub-themes (see Supplementary Material).

The process of thematic analysis generated 6 themes and 22 subthemes (Table 3).

Subthemes were categorised into a meta-theme based on how they were connected to this experience. For example, Personal Values and Stigma Resistance influenced insight into illness and motivation for healing. Gastrointestinal and Sensory Factors influenced the experience of food, eating and AN, and AN influenced gastrointestinal problems and food aversions. Sub-themes were also intertwined within a larger meta-theme; for example Diagnosis, Health Literacy, and Stereotypes were intrinsic to insight and acceptance of AN.

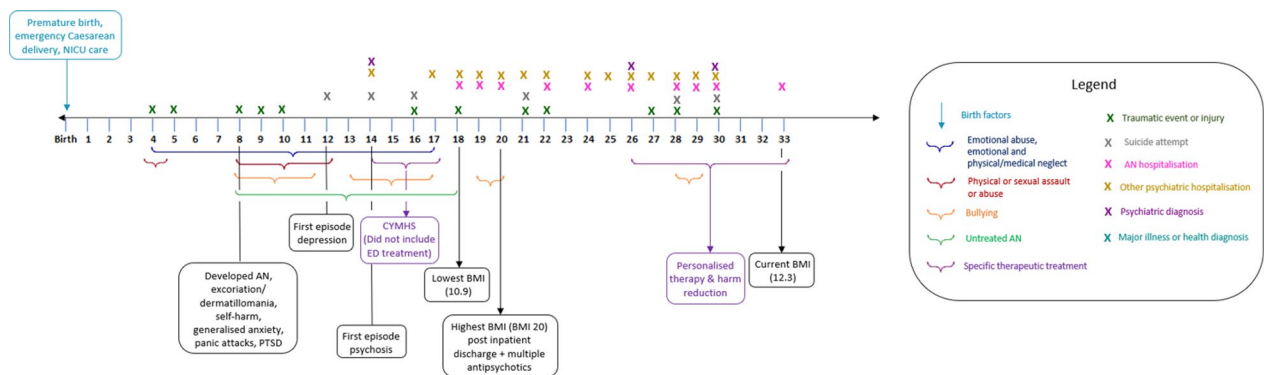


Fig. 1 Life events biography (RE: Living Experience of Longstanding AN)

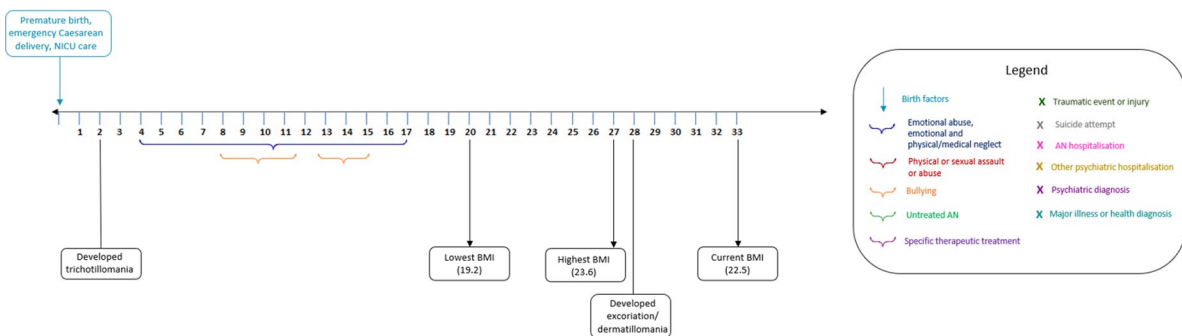


Fig. 2 Life events biography (MW: Discordant for Longstanding AN)

Findings

The following two tables (Tables 1, 2) contain basic background information for both twin pairs that may be relevant for the discordant development of AN, (i.e., premature birth, psychiatric diagnoses, injuries/trauma/illness). Given that developmental weight suppression is known to influence AN development, maintenance, treatment response and recovery [112–121], information on highest/lowest/current BMI, and most recent hospital discharge BMI (if applicable) are also included. Four images accompany the tables as visual representations of the background information, and can be regarded as simplified ‘line biographies’ of factors relevant to AN discordance and duration between co-twins and each twin pair (Figs. 1, 2, 3, 4 and Tables 1, 2).

The excerpts below contain our first-person accounts of the impacts of AN on our lives².

Twin Pair 1 are discordant for longstanding AN: RE has longstanding AN (25 years duration), MW has no lifetime history of AN or ‘atypical’ AN.

Notable aspects of convergence: Anxiety and obsessive-compulsive characteristics.

Notable aspects of divergence for AN development: Exposure to traumatic experiences, gender identity, internalisation of twin trope, body ideals, sensory sensitivity, gastrointestinal problems, co-occurring mental health problems, psychiatric treatment, iatrogenic trauma, self-injury and suicide attempts.

Twin Pair 2 are discordant for OSFED (‘atypical’ AN): SS has recovered from ‘atypical’ AN (6 years duration), ES has no lifetime history of AN or ‘atypical’ AN.

Notable aspects of convergence: Anxiety and obsessive-compulsive characteristics.

Notable aspects of divergence for AN development: Gastrointestinal problems, autoimmune condition, internalisation of twin trope, internalisation of health-related beliefs, and body ideals.

In these two cases, the following themes and subthemes were significantly related to discordant AN experiences in twin pairs (Table 3).

² RE uses they/them pronouns. MW, ES, and SS use she/her pronouns.

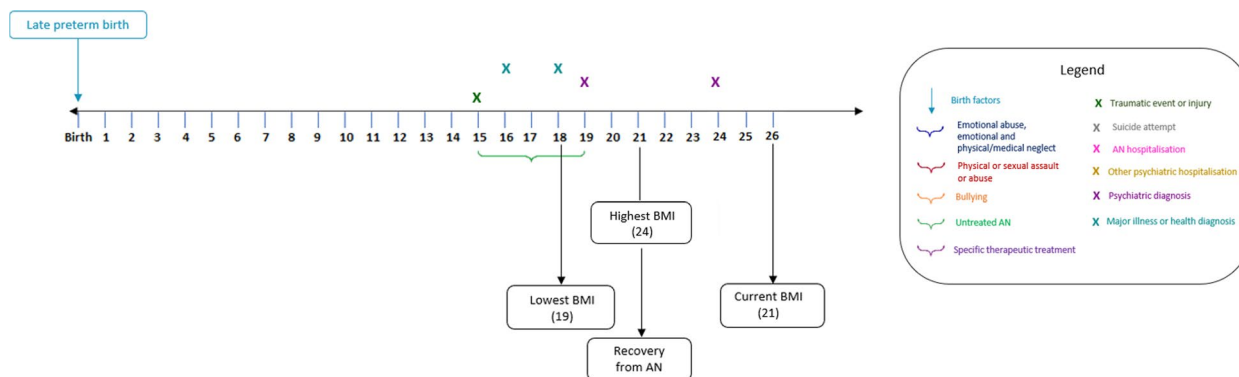


Fig. 3 Life events biography (SS: Lived Experience of 'Atypical' AN)

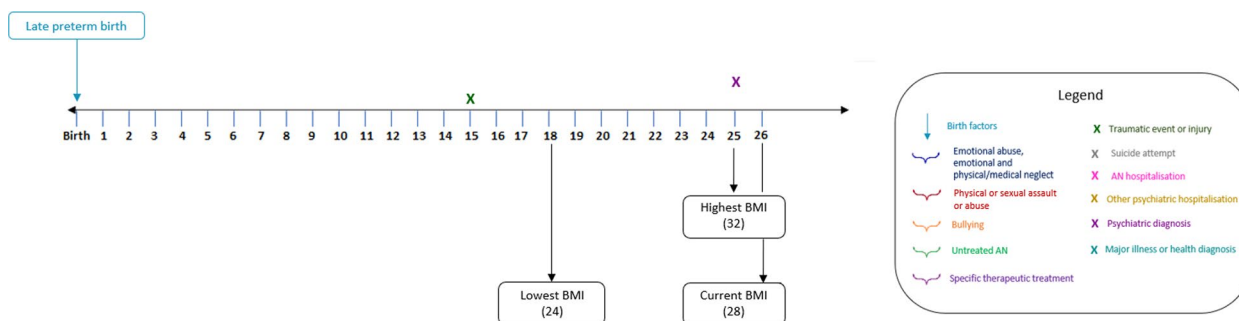


Fig. 4 Life events biography (ES: Discordant for 'Atypical' AN)

Table 1 Background information discordant identical twin pair 1 (RE & MW)

Individual	RE	MW
Mono/dizygotic and handedness	Monozygotic, right-handed	Monozygotic, left-handed
Mode of birth, birth complications, birth weight	Emergency Caesarean delivery 7 weeks premature Required care in the neonatal intensive care unit, separation from twin (returned home earlier from NICU) Birth weight: 2.16kg	Emergency Caesarean delivery 7 weeks premature Required care in the neonatal intensive care unit, separation from twin (longer stay in NICU) Birth weight: 1.50kg
Age and current BMI	Age 33, BMI: 12.3	Age 33, BMI: 22.5
Diagnoses	Longstanding anorexia nervosa (age of first development: age 8, first treated: age 18 years, current age: 33) PTSD and C-PTSD (first developed/post-traumatic responses or 'symptoms' age 8, first treated age 26) Schizoaffective disorder (first psychotic episode age 14, first treated age 14, in remission, age 26) Major depression (first developed age 12, first treated age 14) Generalised anxiety disorder (first developed age 8, first treated age 14) Excoriation/dermatillomania (first developed age 8, untreated, persistent) Coeliac disease, (diagnosed age 14) Recurrent self-harm (first developed age 8, received first therapy age 14) Autism diagnosis (age 30) Suicide attempts (age 12, 14, 16, 21, 28, 30)	No current or historical psychiatric diagnoses Trichotillomania (age 2) Excoriation/dermatillomania (age 28–32)

Table 1 (continued)

Individual	RE	MW
BMI history	Highest BMI: 20 (age 20, reached with NG feeding and multiple antipsychotic treatments) Lowest BMI: 10.9 (age 18) BMI at first hospitalisation: 11.2 (age 18) BMI on last hospital discharge: 14.5 (age 33) Current BMI: 12.3 (age 33)	Highest adult BMI: 23.6 (age 27) Lowest adult BMI: 19.2 (age 20) Current BMI: 22.5 (age 33)
Relevant and major life events	Multiple sources of emotional and medical neglect, emotional abuse (ages 4–17), and physical and sexual abuse (ages 4, 8–12) Bullying at school (ages 8–11, and 13–17), bullying at residential college (ages 19–20), workplace bullying (ages 28–29) Other traumatic experiences and injuries (ages 4, 5, 8, 9, 10, 16, 18, 19, 20, 21, 22, 27, 28, 30) Attendance to Child and Youth Mental Health Service (age 14–17) Participation in multiple courses of ACT, CBT, DBT, MCT, group therapies, art therapies (ages 18–26) Non-AN or mixed psychiatric hospitalisation (ages 14, 17–22, 24–30) Hospitalisation for AN (ages 18, 19, 20, 22, 24, 26, 28, 29, 30, 32, 33) First prescription of anti-depressants (age 16) and first prescription of antipsychotics and mood stabilisers (age 18) Engagement in trauma- and compassion-focused therapy, schema therapy and harm-minimisation (ages 26–present)	Emotional and medical neglect (ages 4–17) Bullying at school (ages 8–11, and 13–15)

Table 2 Background information discordant identical twin pair 2 (SS & ES)

Individual	SS	ES
Mono/dizygotic and handedness	Monozygotic, right-handed	Monozygotic, right-handed
Mode of birth, birth complications, birth weight	Vaginal delivery Born at 36 weeks (late preterm birth) No intensive care required Birth weight: 2.37 kg	Vaginal delivery Born at 36 weeks (late preterm birth) No intensive care required Birth weight: 2.76 kg
Age and current BMI	Age 26, BMI: 21	Age 26, BMI: 28
Diagnoses	OSFED ('atypical' anorexia nervosa) with features of Orthorexia Nervosa) (age of first development: age 15, first treated: age 19 years, recovered age: 21) Ulcerative Colitis (diagnosed age 16) Bacterial <i>C.Diff</i> gut infection (age 18) Obsessive compulsive disorder (diagnosed age 24)	Obsessive compulsive disorder (diagnosed age 25)
BMI history	Highest BMI: 24 (age 21) Lowest BMI: 19 (age 18) BMI at first hospitalisation: N/A BMI on last hospital discharge: N/A Current BMI: 21 (age 26)	Highest adult BMI: 32 (age 25) Lowest adult BMI: 24 (age 18) Current BMI: 28 (age 26)
Relevant and major life events	Moved to Australia from UK aged 9 (end of 2007) Brother diagnosed with Bipolar I Disorder post long hospital stay (2013)	Moved to Australia from UK aged 9 (end of 2007) Brother diagnosed with Bipolar I disorder post long hospital stay (2013)

Table 3 Themes and subthemes related to discordant AN experiences in twin pairs

Theme	Subthemes
Individual and relational identity	The 'Twin' identity Twin tropes
Puberty and maturation	Impact of AN and twin discordance Gendered body ideals and objectification Trauma, puberty and AN In-school weighing and perceived health Developmental age and milestones
Body image	Exposure to trauma and adversity Embodiment disturbance Sociocultural influences and social responses Functional body appreciation and body acceptance
Food and eating	Gastrointestinal and sensory factors Dietary patterns and health-related beliefs Coping strategies and food-related beliefs
Anosognosia, insight and healing	Diagnosis, health literacy, and stereotypes Disconnectedness and insight Self-compassion Comparison and self-connectedness
Service navigation	Personal values, stigma resistance, advocacy and affirmation Familial impact of AN and treatment Weight stigma and iatrogenic harm Sibling role

Individual and relational identity

The 'twin' identity

In both cases of twin discordance, RE and MW; and SS and ES described “negative” experiences in early childhood of being treated as a single entity—“the twins”. They experienced “alienation and othering” as part of being seen as a “package deal”. Twins were often expected to share the same minds, bodies, and lives, which influenced perceptions of their AN discordance by strangers, close others, family members and clinicians.

Whenever MW and my identity and experiences diverged, they accused me of lacking insight and being in denial, and attacked and undermined aspects of my identity as well as the credibility and legitimacy of my AN.

- RE (Living Experience of Longstanding AN)

In childhood and adolescence, RE felt that misunderstandings about twin discordance and stereotypes about AN led to a sense of their “whole identity constantly being pathologised” and their AN being “utterly misunderstood.”

ES described how detailed comparisons made between twins were used as a means to differentiate them. This had a negative impact on sense of self, which led to self-consciousness and a heightened focus on physical traits as “These details weren’t always aspects about

yourself you wanted to hear (e.g. “ES has a rounder face”). Clothing choices were an important part of identity and relationship as twins:

We wanted to be seen as separate people, whilst still dressing and behaving in a way that fortified a look and feeling of twinship.

- ES (Discordant for 'Atypical' AN)

Separation and individuation within the twin relationship were an important part of identity development. This included navigating social dynamics of comparison, having separate space, and making choices about clothing similarity. For RE and MW, the expectation that they would have identical lives led to invalidations of RE’s sexuality, gender identity and AN by family members, friends, and clinicians as “unnatural”, and a misperception that RE’s identity and AN represented an attempt to inauthentically individuate from MW. Expectations of twin identities, experiences, genetics and development led to RE having an identity imposed on them by others, whereby they were not given the space to express their true self and feel accepted.

Twin tropes

In both cases of twin discordance for AN, twin-siblings experienced twin tropes. RE and MW; and SS and ES

described how people would respond to their physical similarities and mannerisms with fascination and an expectation to possess unusual intuition, telepathy, foresight, or some other supernatural powers in connection to each other, such as sensing or predicting each other's pain. Both 'negative' and 'positive' twin tropes related to AN development for both RE and SS. For RE, twin tropes also intersected with stigma for mental health concerns:

From my earliest memories of childhood, I remember being told our birth-story and being shown photos of us in humidicribs in the NICU...photos of us showed our feeding tubes and our tiny bodies—my skin had been translucent, and my body appeared to be a deep red colour...Relatives often joked that this indicated I was the “evil twin”. Although we'd both been premature and a low birthweight, of the two of us, I'd been a slightly higher weight—and a frequent joke was I'd been causing MW to “starve”...as a child, I'd felt that I should spend the rest of my life starving myself to make up for being the “evil twin” and almost starving my sister to death before we were born.

A lot of peers said things like...“You're the crazy one, so she's the good one and you're the evil one”... it was that stigma of mental health problems being equated with ‘bad’ moral character—I was ‘mad’ so I was the ‘evil twin’.

- RE (Living Experience of Longstanding AN)

My family would refer to me as “the healthy one”, which provided more justification to continue eliminating foods I perceived to be ‘unhealthy’.

- SS (Lived Experience of ‘Atypical’ AN)

For RE, being typecast as the ‘evil’ and ‘parasitic’ twin contributed to food-related shame and guilt, reinforcing food restriction as a means to self-punish and atone for inherent moral ‘wickedness’. RE's physical signs of mental/emotional distress was taken as an outward indication of ‘bad’ moral character, which strengthened ‘evil twin’ tropes and acted as a double stigma. For SS, being characterised as the ‘healthy’ twin reinforced orthorexia-type eating beliefs and food restriction.

Impact of AN discordance on the twin identity

In these cases, AN discordance had a complex, multi-layered impact on the twin identity.

Strangers stopped asking if MW and I were twins, and would ask if MW was my aunt, older sister or older cousin... I realised how significantly I physically differed in comparison to MW and my developmental age, which was upsetting and alarming to me. It hurts

both of us in such a complex way. It's a special kind of grief for what you've lost. It's shocking when you realise that the damage has been that great and you differ so much now that people no longer see you as twins. It's really hard on her because it makes her scared and also makes her feel differently about herself, which is really painful, because it's my illness that's done that.

- RE (Living Experience of Longstanding AN)

As we reached our late teens and RE's health declined, the ‘twin identity’ became slightly more complicated...I would often get extremely upset looking at photos of us together...I would also feel worried and scared when I was around RE or would hug them and feel how frail and emaciated they were. It's felt complicated to discuss having a twin sibling with new friends or colleagues. People invariably ask if we look alike, and then I have to navigate a complex, personal, and potentially upsetting conversation.

- MW (Discordant for Longstanding AN)

The ED experience was the first part of our lives that separated ES and I. On the one hand, it was a sad and lonely experience to not share with ES. However, I also remember almost enjoying the fact that the ED distinguished us.

- SS (Lived Experience of ‘Atypical’ AN)

Physical discordance caused by AN led to perceptions of twin-siblings as having different ages and different relationships to one another. Physical disparity led to twin-siblings feeling worried, upset, sad, scared, and lonely, and created a unique sense of “loss and grief”. For SS, physical discordance due to AN also provided a sense of individual identity, which she experienced as positive.

Puberty and maturation

Gendered body ideals

Gendered body expectations, body ideals, and gendered objectification influenced experiences of puberty.

After being aware of MW going through puberty, I felt as though it was a ‘ticking time bomb’...my restrictive eating and exercise intensified...I was actively trying to delay puberty...I wanted to feel androgynous or genderless.

- RE (Living Experience of Longstanding AN)

A complicating factor during puberty was ES and I being avid ballet dancers. The ideal of having fuller breasts as a woman stands in stark contrast to the ideal ‘ballet figure’, where having very small breasts is desirable...losing weight and feeling shame about

my bust was connected to trying to meet both body ideals.

- SS (Lived Experience of 'Atypical' AN)

For RE, distress during puberty was influenced by gender dysphoria, which resulted in restrictive eating as a means to strive toward pubertal suppression, gender congruence, and a non-binary body ideal. For SS, AN development was influenced by perceived pressure to conform to conflicting gendered body ideals which led to body shame.

Trauma, puberty, and AN

For RE, experience of puberty also intersected with trauma exposure which influenced AN development.

I dreaded the thought of female maturation and all that I regarded as being associated with it—namely, being sexualised, objectified, and unsafe... I dealt with constant commentary about minute detail of my body as a twin, and felt frequently dehumanised...I'd experienced abuse, and also dehumanisation and trauma in other ways—such as surviving an abduction attempt by a stranger at the age of 8. Despite escaping and reporting the abduction attempt to adults, I was blamed for having been alone at the time, and was told that it was my fault if the predator went on to victimise others. I did not receive trauma support, and felt deep self-hatred and self-blame over it. I used restriction as an active way to delay puberty in an attempt to feel a sense of control over my physical development and the way other people perceived me. I felt unsafe in a world where I had experienced sexual objectification and violence...and I didn't want that to get worse.

- RE (Living Experience of Longstanding AN)

Trauma exposure led to use of restrictive eating as a coping strategy when there was insufficient support and resources to cope with traumatic experiences. Self-starvation and the physical consequences of AN (i.e., emaciation) provided a method of suppressing pubertal development, and sense of control over the perceptions of others (i.e., attempt to reduce risk of sexual objectification and sexual/physical violence). This highlights the importance of early trauma, lack of trauma support, and internalised blame in AN development in identical twins discordant for AN. As a twin, constant exposure to physical comparisons (i.e., physical similarities and small differences between twin-siblings) may have increased objectification, self-objectification, and dehumanisation in early childhood, which intersected with multiple early traumatic experiences, heightening risk for AN development. Twin comparisons and sense

of objectification may be a specific risk factor within AN development for twins.

In-school weighing and perceived health

Experiences of puberty and perceived health were interlinked with educational influences and experiences, such as in-school weighing and health education. For SS, "normalisation" of weight gain in puberty was "lacking". Having to weigh herself during physical education classes led to "distress". In-school weighing triggered a "focus on weight loss, fixation on BMI, and fear of gaining weight" in association with "perceived unhealthiness".

Developmental age and milestones

All authors were sensitive to developmental age and milestones, and the impact of AN on development.

The misperception clinicians had that I wanted to "remain childlike" was reinforced by a difference in milestones between MW and I during adolescence. However, the reasons behind it were misinterpreted...I didn't want to get my [driver's] licence because I was afraid I'd blackout from malnutrition and injure or kill someone. I also didn't want to leave MW at home alone...opportunities for independence and life experiences always came secondary...if we couldn't both be safe, I did what I could to ensure she'd be away from harm.

- RE (Living Experience of Longstanding AN)

I have found my constant anxiety around RE's intake of food and liquids difficult to 'switch off'...I've found myself repeatedly prompting colleagues to drink water or eat something—purely out of habit—or acted overly 'mothering' to others, which can become annoying to them...It occupies so much space in our lives that it can be easy to lose sight of the fact that these experiences and needs are not common to most people.

- MW (Discordant for Longstanding AN)

I remember having certain 'role-playing personas' in childhood, where I'd act as if I was ES's child, and she often felt like a 'big sister' or even 'mother figure' to me. These roles were further pronounced through my ED.

- SS (Lived Experience of 'Atypical' AN)

The physical impacts of AN led a sense of twins RE and SS being developmentally 'behind' their twin-siblings. AN also affected cognitive-emotional developmental congruence between twins, by impacting achievement

of milestones and sense of role; twins without AN felt “older”, and twins with AN felt developmentally delayed.

Body image

Exposure to trauma and adversity

For RE, exposure to trauma and adversity influenced body image development in AN. When RE experienced early trauma, self-starvation and its consequences were used as an embodied coping strategy to “to look and feel as though my whole body could be knife-like, signalling danger to anyone who was a potential threat. ...I also hoped that my body could signal that I was *in danger*”. Bullying and discrimination also led to AN as a way to “narrow my focus to food, exercise, or self-harm, so I could dissociate from the fear and vulnerability”.

Differential exposure to trauma as twins also affected MW in the form of survivor guilt:

[Spoken to RE] Everything bad that could happen seemed to happen to you...I just felt guilt—why did it always happen to you, and not me too?

- MW (Discordant for Longstanding AN)

Longstanding AN as its own form of ongoing trauma also affected both twin-siblings (RE & MW), indicating the importance of recognising longstanding duration as specific trauma in ED treatment.

As years passed with AN, I felt trapped and traumatised from being unable to heal and recover. I experienced trauma from hospital, suicide attempts and interactions with police and paramedics. The physical damage of the ED, living in ongoing medical instability, going to sleep and feeling as though I may not wake up, and seeing the constant fear and impact of my AN on my sister’s life—has all become its own form of ongoing trauma.

- RE (Living Experience of Longstanding AN)

In these cases, different exposure to trauma and adversity appears to be a significant factor in twin discordance for AN and in longstanding duration. Longstanding AN also creates its own form of specific trauma.

Embodiment disturbance

Differences in embodiment and embodiment disturbance influenced body image in RE’s experience of longstanding AN, but was not described in SS’s experience. RE experienced significant embodiment disturbance, such as “attempting to gauge the proportions of my face and body with body-checking, to check if it was shifting, because I couldn’t get a sense of where my body was in space”, “not knowing what my body’s dimensions were”, and feeling a sense of “shock and disorientation” upon seeing their

reflection or photographs, due to anticipating their body to “more closely resemble my sister’s”. MW described supporting RE to manage this embodiment disturbance by using functional body appreciation strategies and drawing attention to how RE’s AN had created a disparity from their genetic and physical similarities as twins.

Differences in gender identity between twins may lead to differing experiences of embodiment, and influence body dysmorphia and AN. RE described how “intertwined body dysmorphia and gender dysphoria” led to body dissatisfaction and body dysmorphia, which resulted in “using food and water restriction and more exercise to avoid my body, try to control it, or try to feel a better sense of and connection to it”. These experiences may have been interrelated with interoceptive differences as RE described how “this food restriction also intersected with my sensory eating and food aversions”.

Sociocultural influences and social responses

For RE and MW, sociocultural influences and social responses influenced their experience of AN as discordant twins. These social dynamics also affected other family members, who, as described by RE, “felt guilt and shame that they’re being judged as having ‘failed’ at caregiving with one twin (me) and would often say that they felt judged by strangers and clinicians”. For RE, this led to guilt, and created “an additional barrier in seeking treatment”. Sociocultural influences and social responses were particularly significant in the context of longstanding AN. RE and MW described the need to manage stigma and threatening behaviours that negatively impacted RE’s wellbeing and daily functioning:

Strangers have also reached out and felt my ribcage or the ridges of my spine or hipbones or grabbed my wrists and commented on how easy they would be “snap”; “like toothpicks”...I’ve frequently been photographed or filmed by strangers using their mobile phones while they make comments about food—seemingly in an effort to upset me...

- RE (Living Experience of Longstanding AN)

Acquaintances or strangers will frequently feel entitled to comment freely on their body or even touch them...At vulnerable times (e.g. following a hospital admission) it can affect RE’s attempts for recovery.

- MW (Discordance for Longstanding AN)

Negative and threatening social interactions led to RE feeling upset, exhausted, distressed, and scared, “isolating myself afterwards, panicking about leaving the house”. MW felt “anxious”, and “angry” about the “hostile” and “callous” judgments and treatment of RE, leading to her becoming “protective and hypervigilant”, attempting to “shield” RE

from threatening and stigmatising behaviour, and “checking in every few hours” when away from RE. For SS, healthism and diet culture beliefs were a significant sociocultural influence on her AN development as she became “concerned about my size and what it meant for my health”. For SS, initially, “body dissatisfaction and physical appearance was not a driving factor for my ED—I attempted to lose weight because I equated gaining weight in puberty with health problems...although I did hold idealised body-shape beliefs, like believing I needed to have a flat stomach.” For SS, BMI categories became a fixation for health concerns, as she feared being “pushed into an ‘unhealthy’ BMI category”.

Functional body appreciation and body acceptance

For RE, MW’s support helped in decreasing reliance on using layered clothing to hide their emaciation and self-harm scars. This promoted greater body acceptance and “reduced body shame and body dysmorphia”. Awareness of the harmful impacts of AN led to greater functional body appreciation for MW, which improved body dissatisfaction:

Seeing the terrible misery an ED has caused RE and other patients...I resolved to always be grateful for my health and what my body allows me to do...whenever I get into a self-critical or body-hating frame of mind, I’ll remind myself that I love and appreciate my body and that I’m grateful for my health.

- MW (Discordant for Longstanding AN)

For SS, functional body appreciation and body acceptance was an important stage of recovery:

[Spoken to RE] I think accepting my body and thinking about my body more for what it could do rather than what it ‘should be’ and ‘should look like’ was important for me. Also starting to really care about my health and think about what my ED was doing to my health—rather than just connecting my health to aesthetics and weight, shape and BMI was important. I had to learn about how those things weren’t the same.”

- SS (Experience of ‘Atypical’ AN)

Body acceptance and functional body appreciation had protective factors and positive benefits for AN in discordant twins, both for twins without AN, and as a stage of healing for twins with AN.

Food and eating

Gastrointestinal and sensory factors

Although experiences were different, gastrointestinal problems were common to both twins with AN, which

influenced dietary patterns. For RE coeliac disease symptoms impacted AN development—RE became “more highly attuned to gastrointestinal sensations because of the pain and discomfort” and were hypervigilant to coeliac symptoms “from seeing other family members struggle” with coeliac symptoms. Sensory-based eating and food aversions also influenced RE’s longstanding AN, and gastrointestinal problems increased food aversion. RE identified that multiple family members on their paternal side have autistic and ADHD traits and have “strong preferences and routines around food and food aversions”, which may reflect a trait inheritance. For both RE and SS, treatment factors also interacted with AN and gastrointestinal and/or sensory factors. For RE, this resulted in unmet needs, and for SS, AN-related motivations interfered with treatment for gastrointestinal problems:

A frequent issue for me in treatment was the separation between AN and ARFID. My sensory eating patterns, food aversions, interoceptive differences and their relationships with my eating and gastrointestinal symptoms were unexplored in early AN treatment.

- RE (Living Experience of Longstanding AN)

In mid-2016, I became unwell with a gastrointestinal infection...I initially followed the dietitian’s advice post-discharge to restore weight...I’d feared I’d keep gaining weight ‘forever and ever’ if I continued with the meal plan, so I returned to restrictive eating and lost the weight.

- SS (Lived Experience of ‘Atypical’ AN)

The bi-directional relationship of longstanding duration/AN severity, gastrointestinal and physical problems (i.e., starvation syndrome, reactive hypoglycemia, gastroparesis), sensory factors and food aversions also impacted hope for recovery:

After having AN for over two decades now, the physical reactions my body has when I eat solid food often makes me feel hopeless about making progress with eating and moving away from my dependence on nutritional supplements...physical symptoms reinforce food restriction, aversions, and anxiety about feeling sick after eating.

- RE (Living Experience of Longstanding AN)

In these cases, gastrointestinal problems and sensory differences/ARFID intersections appeared to be key factors in discordant AN development in twins, and may have been a factor in longstanding duration or recovery.

Dietary patterns and health-related beliefs

For both authors with AN, dietary patterns and health-related beliefs were influenced by family members. RE recalled their mother having “a strong belief in ‘withstanding pain’ rather than accessing medical help, which I internalised”, eating, making and serving “organic unprocessed food”, and their father “crash dieting repeatedly” and “criticising and commenting on our food choices”. SS recalled her mother “trying weight-loss diets, exercise programs and ‘body sculpting’ technology” and having a “separate dinner because she was always on a specific diet”. SS also cited “diet culture” and “school” as influences that contributed to “orthorexic beliefs” and her ED.

RE developed a belief that their family was financially and food insecure, due to “my parents’ asceticism, thriftiness, and often being told to forage in the garden for food or to drink water to stave off hunger”. Medical neglect formed part of RE’s belief that their family was financially insecure, as RE interpreted their parents’ medical avoidance into a belief that “we couldn’t afford it, and that I didn’t deserve medical treatment because my health wasn’t a priority”. RE “began to associate hunger with guilt and shame” and felt anxiety about using resources, consuming food, and experiencing bankruptcy and houselessness. This led to “learning to delay eating and to override my hunger cues” and a fixation on food:

I often crept into the kitchen at night to open cupboards and stare at ingredients...to hold it and feel comforted that it was still there. I remember hiding a block of palm sugar in my room when I was 8 years old and being comforted by that.

- RE (Living Experience of Longstanding AN)

Vegetarian and vegan diets were related to AN development in both cases. RE was “motivated to consume a plant-based diet for animal welfare and to reduce climate impacts”, however also wanted to “reduce food-related uncertainty and decision paralysis”, and “reduce scrutiny about restrictive eating”. SS described the decision to adopt a pescatarian diet as “a ‘legitimate’ way to restrict food”. Both RE and SS were aware that family members’ and friends’ vegetarianism/veganism would normalise their diet change. For SS, this helped her AN “fly under the radar”, however RE’s family members were concerned that their AN would worsen with a vegan diet. When RE became “too medically unstable” to continue with veganism, they “began consuming nutritional supplement drinks” which led to improved intake. SS gave up her pescatarian diet as part of recovery.

Coping strategies and food-related beliefs

The authors used a variety of coping strategies to challenge food-related beliefs and manage and make changes to their eating patterns. Both RE and SS described processes of “working to unlearn healthism and weight stigma” which supported “healing and rebuilding trust” in food-body relationships. RE also turned to online “neurodivergent and disability spaces” to adopt strategies for sensory needs and food aversions that were not being addressed in their treatment.

MW described how she supported RE as a sibling-carer by modelling “healthy food relationships”, encouraging and eating with them, and discussing “different food options to re-introduce”. MW acknowledged that change was difficult for RE in the context of their longstanding AN due to “physical barriers that exist now—sometimes after eating, it’s like their body goes into shock”. For MW, it was important for both of them to “maintain a sense of hope while navigating the seriousness of RE’s AN”. She and RE used humour and gentle teasing, which helped RE “feel less threatened about having someone try to support them...less judged, blamed, guilty or pressured” particularly in the context of RE’s history of iatrogenic harm and internalised stigma, and helped RE “pay attention to their body cues since they struggle to recognise and then feel as if they ‘should’ attend to these needs”. Together these beliefs and strategies indicate a complex process of navigating life with and recovery from AN.

Anosognosia, insight and healing

Diagnosis, health literacy and stereotypes

Low ED health literacy and stereotypes of AN experiences (both amongst clinicians and in the public) were a barrier to early recognition, early diagnosis, early intervention and treatment access, and also led to difficulties with accepting diagnosis.

RE described how inpatient and outpatient mental health practitioners attributed their AN to depression, suicidality, psychosis, mania, anxiety, or PTSD at varying times. RE was also told by clinicians that they were “reluctant to diagnose me with AN since it was “highly stigmatising”, and I was “too young for an ED”. RE was given other reasons that AN was ruled out as a diagnosis, which included: “I was “too intelligent” to have an ED, I wasn’t “obsessed with appearance”, “had insight” and “knew I was thin” and therefore, couldn’t have AN”. RE was also told that “AN was “highly genetic” and as I was a twin and MW didn’t have AN, my eating problems had to stem from “my psychotic delusions or depression”. Ultimately, RE experienced 10 years of untreated AN—when hospitalised in a critical state, delayed treatment influenced acceptance of AN as a diagnosis: “The inpatient team estimated I was

days from death. I struggled to believe them, after years of being told that AN was something else”.

ED stereotypes also inhibited recognition of SS's 'atypical' AN:

I knew that a lot of her choices and habits led to an overall picture of abnormality around food, exercising and eating, but it was not as 'extreme' as the picture of anorexia or bulimia I held.

- **ES (Discordant for 'Atypical' AN)**

SS experienced 4.5 years of untreated 'atypical' AN before receiving a diagnosis and beginning therapy. Delayed treatment and ED stereotypes influenced acceptance of her diagnosis:

I wasn't 'underweight' according to BMI standards and wasn't engaging in purging behaviours, so I'd ruled out anorexia nervosa and bulimia nervosa diagnoses as a possibility—I was unaware of other ED diagnoses. After being diagnosed with OSFED ('atypical' AN)...it was difficult to reconcile the 'picture' of an ED in my head with my own experience.

- **SS (Lived Experience of 'Atypical' AN)**

These experiences emphasise how ED stereotypes, low ED health literacy, and low genetic/epigenetic literacy in the public and amongst clinicians can result in delayed diagnosis and treatment, and influence illness acceptance/denial.

Disconnectedness and insight

Illness-related insight was a complex experience, involving cognitive/emotional recognition, connection to degree of illness severity, and differing levels of internal/external recognition.

RE described denying illness and refusing treatment out of the desire to avoid consequences:

I felt desperate to hold on to every bit of freedom and independence, and the sense of safety AN gave me...I was terrified of experiencing more trauma in hospital, and often thought I'd rather die of starvation and heart failure than be subjected to the overwhelming fear and powerlessness of being in restraints and seclusion again... Sometimes I'd be scared and want help, but the consequences of acknowledging how ill I was and facing treatment again were scarier than death to me, so I'd say I "felt fine".

- **RE (Living Experience of Longstanding AN)**

Desensitisation was experienced by both the twin with AN, twin discordant for AN, other family members, and medical personnel, which influenced management of longstanding AN. RE described illness-related

desensitisation by clinicians as impacting both their treatment and their own sense of being unwell.

The whole concept of 'insight' becomes really weird, because it depends on other people too. The sense of urgency vanishes for medical professionals when they see you in the same condition all the time...it's something that never really gets talked about when you have a longstanding ED, but other people stop seeing how unwell you are, and that makes it a million times harder to manage it. There's so much self-advocacy involved to even have regular blood tests and ECGs. My GP will literally say "Why are you back so soon? Are you sick?" again and again, and I'm like "Yes! Did you forget? I still have the same life-threatening illness!"

- **RE (Living Experience of Longstanding AN)**

MW described RE's illness-related insight and desensitisation in longstanding AN, and family members' desensitisation as influencing RE's treatment engagement:

During our 20s, things felt very out of control, with RE undergoing multiple hospitalisations...At the worst points in their illness, it felt like the ED would take hold, and RE was trapped behind an iron wall of despair, denial and anger—they felt completely unreachable...completely dissociated from how desperately ill they were.

Although we still get very scared and alarmed by RE's physical state, our family has become slightly desensitised and accustomed over many years to how critically unwell they are, so it can be difficult to recognise the changes that indicate a more dangerous deterioration.

- **MW (Discordant for Longstanding AN)**

Illness-related insight and desensitisation affects not only the individual with AN, but others close to them (carers, clinicians), which influences insight, illness acceptance, motivation for recovery, and treatment engagement. This is an important consideration for longstanding AN and management of chronic illness.

Self-compassion

Self-compassion was a critical factor in improving longstanding AN and an important stage in recovery from 'atypical' AN. To RE, a "major turning point" in "beginning to heal" was starting personalised therapy with a psychologist that involved "trauma-focused and compassion-focused work, schema therapy, and harm-minimisation". Through this therapeutic work, RE described starting to "come out of complete immersion in trauma 'survival mode'" and experiencing greater self-connection, and reconnection "with the world outside of the sense

of sanctuary AN afforded”. Self-compassion for RE also involved acceptance of the impact of their longstanding AN on MW’s life. Acceptance represented an ongoing process of self-kindness and self-forgiveness:

I have to keep forgiving myself and accept and let go...blaming and torturing myself over it does nothing but feed the cycle of the AN, self-destruction, and suicidality—which also causes MW more pain. The best thing I can do is keep showing myself compassion and care, and keep focusing on healing.

- RE (Living Experience of Longstanding AN)

MW described how increased self-compassion had led to RE choosing to go to hospital when for refeeding and medical stabilisation when in a critical state “for the first time...they didn’t have to be under a treatment order”. For SS, self-compassion involved appreciating and “being kind to my body, which meant accepting it for what it was...letting go of controlling it and the thin body ideal”. In these cases, self-compassion was an important part of improved quality of life in AN and recovery from ‘atypical’ AN in discordant twins.

Comparison and self-connectedness

For RE, the comparisons MW made between their bodies as identical twins was a critical supportive strategy in coping with body dysmorphia and desensitisation—increasing self-connection and self-compassion. These comparisons helped RE “break through the depth of my detachment and desensitisation”. When MW would compare their bodies, RE would imagine MW “being in the same physical state...as I connected with the deep sense of love and protectiveness I felt for my sister’s wellbeing...it was as though I was tapping into an ability to feel empathy for my own body and concern for my own survival”. This increasing self-connection led to RE becoming “more motivated about steps I could make in recovery”. RE began to prioritise their health, “developed more caution about my physical limits” and became “more engaged in harm-minimisation” and with medical services.

Body comparisons and twin discordance also impacted MW’s wellbeing in complex ways. MW described how comparing their features and bodies was often helpful in supporting RE to “disrupt ED thoughts” and that “reminding them of their affection for me and my wellbeing can remind RE to care for themselves too”. However, she expressed how RE’s AN had also made her “differently about my own body—occasionally I feel like a giant lumbering creature next to RE, or feel frustrated or embarrassed when strangers assume I am much older or that we have a different relationship (e.g. that I am an aunt or cousin) based on our physical differences.” MW described

managing these feelings and thoughts by “letting them go in the moment”; and shifting focus to “the more important things—health and wellbeing for both RE and I, and how best to support RE’s recovery”. These experiences indicate that making physical comparisons in AN discordant twins can support increased self-connectedness and self-compassion for the twin with AN. Discordance for AN, however, may also lead to negative self-comparisons for the twin without AN particularly in the context of others’ misperceiving the relationship between the twin-siblings due to the physical impacts of AN.

Personal values, stigma resistance, advocacy and affirmation

In both cases of AN, healing, therapy engagement, and recovery were supported by re-connection with personal values, resisting stigma, advocacy, and affirmation. For RE, engaging in “in social justice-oriented work and lived experience work” facilitated re-connection with their values and increased self-compassion by creating a sense of dissonance; “human rights and social justice were critically important values to me, yet I was denying myself the right to safety and fundamental needs”. Connection with LGBTIQ+ community and resources also led to identity affirmation and an increased sense of gender euphoria and body pride. This resulted in reduced “body dysmorphia, body dissatisfaction, and restrictive eating... helped me let go of the highly thin genderless body ideal I held”. MW stated that RE’s involvement in lived experience work and advocacy led to reduced self-stigma and shame and increased openness, resulting in improved understanding among family members: “It became easier for us as a family to support them and understand what they needed from us”.

RE also described a process of combating stigma and decreasing shame about longstanding AN. This involved “reframing AN to myself in the light of chronic illness and disability—looking at how much shame and ableism I’ve internalised”. RE described goals of “feeling less shame about being visible”, and making choices to take part in activities when others expressed a belief that they shouldn’t participate until they recovered (i.e., being photographed with friends/family members, attending events/academic conferences). For RE, it was important to “learn to love and have kindness for the body I’m in now, and the ill, disabled person I *am*—not the theoretical ‘recovered’ body and ‘recovered’ self that doesn’t exist, and may not come to exist”.

For SS, recovery from ‘atypical’ AN involved “educating myself the need for social justice approaches to ED”. SS also described a shift in priorities and reconnection with her “true values”. Reconnecting with personal values, resisting stigma, and affirming identity were important stages in healing and recovery from AN/‘atypical’ AN.

Service navigation

Familial impact of AN and treatment

The impact of AN and mental health and medical treatment had a significant impact on the family, including on the twin relationship (i.e., suicide attempts, feelings of betrayal), and specifically, family members experiencing fear of stigma regarding twin discordance for AN. For authors RE and MW, these impacts shifted throughout the course of RE's longstanding AN.

RE stated that initially, their attendance at CYMHS led to family tension; “frequent arguments, screaming and accusations”, which included a fear of stigma, “Our parents felt any disclosures I made about “family issues” would be a “betrayal”...drawing shame and judgement onto the family”. RE made efforts to increase ED health literacy for their family, by providing their parents and MW with information about research on AN, including epigenetic, biological and environmental factors that “may have contributed to my and MW's discordance”. This information helped RE's parents “feel less as though they might be judged and blamed for my AN development, particularly for having ‘failed at caring for one twin’”. The reduction in perceived stigma resulted in less pressure on MW to act as a mediator between family members and clinicians. Decreased perceived stigma also led to RE's parents advocating for RE to attend medical appointments when acutely medically unwell and to monitor their health, “which marked a huge change from their history of medical avoidance”.

RE's AN greatly impacted MW as a twin-sibling, leading to “constant anxiety”, “frequent panic attacks” and feeling “powerless” particularly when RE was in hospital. When RE self-harmed and attempted suicide, MW described feeling “shocked, hurt, confused and betrayed” and feeling that she had “failed to help them”. She also described feelings of abandonment and rejection: “I felt upset that as their twin and the closest person in their life, I wasn't ‘enough’ for RE to recover or want to stay alive...I didn't think I would ever be able to survive the grief”. Over time, these feelings and perspectives shifted:

I began to think about this situation with less of a focus on myself and our relationship...I gradually understood more about the terrible internal struggle RE was going through...I tried to support RE without thinking of their recovery as a reflection of success or failure on my part.

- MW (Discordant for Longstanding AN)

ED health literacy—with a focus on aetiology and epigenetics that may differentiate AN development, may be particularly important for discordant twins and their families, and support family functioning and treatment engagement by decreasing perceived stigma. Twin siblings also need support for coping with the trauma

of their sibling's ED, and significant gaps exist in the resources and services offered to families.

Weight stigma and iatrogenic harm

Iatrogenic harm occurred in a multitude of ways within ED treatment settings, including weight-stigma, ED stereotypes, lack of compassion, use of restraints and seclusion, over-use of medication, and contradictory expectations regarding treatment engagement (i.e., ED services as reserved for medical crisis only).

RE described how during inpatient admissions, nurses regularly expressed “praise and envy for my ‘thinness’” which occurred even when receiving nasogastric and nasojejunal tube feeding. RE navigated weight stigma in treatment settings by talking directly to nurses about their misunderstandings of AN as a ‘diet’ or ‘extreme willpower’, and resisted trivialisation and stereotypes of AN with the support of MW. For SS, weight stigma reinforced her ‘atypical’ AN when she was praised for her “efforts, ‘willpower’, and ‘healthy lifestyle’” in everyday life, which “reinforced and sanctioned” restrictive eating. SS addressed weight stigma by learning about “social determinants of health and weight science”, which led to an improved relationship with food and an “immense sense of freedom”.

RE and MW experienced other forms of iatrogenic harm over years of treatment for RE's longstanding AN. MW expressed “shock that RE even survived these years of treatment” and “a great deal of regret that I didn't do more to prevent the terrible trauma and impacts of these hospitalisations and medications”, which highlights how internalised blame forms part of the shared trauma of iatrogenic harm for family members. MW stated that lack of treatment options and past traumatic experiences of hospitalisations had become a “huge barrier for RE to continue towards recovery and to re-engage in treatment.”

MW also described feelings of betrayal regarding medical services and staff:

I feel angry and incredulous over the actions of doctors and nurses—using chemical or physical restraints when they were excessive or unwarranted, or making callous or disdainful comments towards RE as their patient...the lack of compassion of medical professionals has often been astounding. I've made formal complaints to several hospitals.

- MW (Discordant for Longstanding AN)

MW described a “catch-22 within the medical system” where RE would be “encouraged to seek treatment and hospitalisation, but then told not to ‘over-use’ or ‘overburden’ hospitals except in a health crisis”. MW stated there was “little support” for ED patients outside of hospitals, “especially for ED patients with a long duration.

We end up searching desperately...there's nothing for patients with chronic ED".

A recent inpatient admission for RE was a crucial step in "repairing some trust in medical services after years of treatment trauma". This involved the treating team collaborating with RE, promising not to subject RE to an involuntary treatment order, agreeing on accommodations to help RE feel safer in hospital and to reduce sensory distress, involving MW in treatment discussions, and allowing MW to sleep in RE's hospital room overnight to increase a feeling of safety. Navigating and addressing iatrogenic harm in AN was important for treatment access and recovery in these cases, particularly in the context of longstanding AN.

Sibling role

Discordant twin siblings (MW, ES) had significant, complex roles in providing support for their siblings with AN (RE, SS) at differing stages. When RE began experiencing hospitalisations for AN, MW "wasn't part of treatment decisions or discussions with clinicians...but our parents would come to me for advice and insight". This led to an experience of being stuck in a difficult and stressful role "as a negotiator, mediator or peacekeeper" and feelings of guilt and moral conflict. MW later had a more active part in RE's treatment as a sibling-carer. RE described how MW provided support around medical appointments and medication, transport, checking in about medical stability, and buying food and nutritional supplements. MW had also helped RE "develop my Psychiatric Advance Health Directive for use in hospitalisations" and assertively encouraged RE to attend medical appointments when they felt "afraid about further trauma" within medical settings. This supported RE to feel "willing to engage with medical services, and steel myself for what I might experience". RE cited that MW did not receive their own support or resources, nor any information on sibling-carer groups. RE also felt doctors "ignored the protective, supportive and healing factors of our relationship and how MW's involvement in my treatment could support my recovery".

ES described how increased ED health literacy helped her to support SS to receive diagnosis and treatment:

After hearing my lecturer talk about EDs, I brought SS in to speak to her. My lecturer (a nutritionist), provided her with a referral to a psychologist and dietitian...it was an important turning point, and I am glad I was able to influence SS's decision to start treatment.

- ES (Discordant for 'Atypical' AN)

These experiences emphasise the important roles of discordant twin siblings in supporting their siblings with AN both to receive diagnosis and treatment, in family relationships, and as sibling-carers.

Discussion

This research expands literature on AN development and epigenetics, by finding that AN in discordant twins was influenced by bio-psycho-social factors, including: differing exposure to stressful, traumatic, and stigmatising experiences [14, 54, 80, 122]; health-related beliefs, diet; autoimmune, gastrointestinal problems; sensory differences; and pursuit of different gendered body ideals. Pre-pubescent and pubertal development were critically important growth periods [48] where heightened exposure to childhood trauma [122, 123], gendered objectification and sexism [79, 124], and in-school focus on weight loss and health [125–127] triggered body-related distress and disordered eating. For RE, longstanding AN became a way of coping with multiple traumatic/adverse experiences, and became traumatic in its own right [123, 128, 129]. In twins with AN, body-related shame (i.e., gender dysphoria [130–137]; bust size [138]) was connected to pressure, conflict and pursuit of gendered body ideals (i.e., 'womanly shape', 'ballerina physique' [138, 139] and non-binary body ideals [131, 135, 140]). Additional factors that differentiated AN development in discordant twins included: gastrointestinal problems [141–146], sensory differences [147–149], health- and eating-related beliefs [150–154], vegetarian/vegan dietary change [155–160], and greater perceived food/financial insecurity [161–166]. Unmet needs in treatment (i.e., AN and ARFID co-occurrence³, trauma, gender dysphoria)[137, 167–172] and the physical impacts of severe and chronic AN [173–175] also maintained severe illness, hopelessness, and longstanding AN duration.

Identity is recognised as important to ED development, maintenance, course of illness, and recovery [71, 176–179]; however, identity amongst twins discordant for ED is a gap in the literature. The expectations of twins RE and MW to have identical identities and lives may have been grounded in cisheterosexism, healthism, stereotypes surrounding twins, and misunderstandings about genetics, and AN aetiology [151, 180–184]. Misperceptions of genetics and identities in identical twins shaped case conceptualisation of discordant AN and negatively influenced treatment expectations, prognosis, and lack of personalised care. Clinicians' misperception of twin development and milestone disparities resulted in failed recognition of key functions of AN and led to significant unmet needs in treatment (i.e., trauma, gender dysphoria) which contributed to longstanding AN duration. Physical disparity caused by AN discordance also affected twins' personal identity and sense of the

³ Diagnostic and Statistical Manual of Mental Disorders-5 trumping system criteria prevents co-occurring diagnosis of both AN and ARFID: Avoidant/Restrictive Food Intake Disorder Criterion C: "The eating disturbance does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no evidence of a disturbance in the way in which one's body weight or shape is experienced".

twin relationship (relational identity). In RE and MW's experience of RE's longstanding AN, the physical disparity between them became a specific aspect of trauma. The physical differences between RE and MW in appearance, body size, shape, and features (i.e., loss of their genetic resemblance) created an ongoing sense of fear of RE's health risk, and sense of loss due to the health impacts of AN.

This research advances current knowledge on ED stigma, identity and AN development by exploring the impact of twin tropes. Twins were frequently compared, and asked questions that subsumed their identities in reference to one another ("who's the evil twin?" [185–187]). Both negative and positive twin tropes influenced AN development, maintenance, and treatment in discordant twins. 'Healthy' twin characterisation reinforced health-motivated restrictive eating [152–154, 182], whereas 'evil' and parasitic twin tropes [185, 187–190] reinforced self-starvation as atonement for 'intrinsic' immorality. Stigma for mental health problems intersected with and reinforced 'evil' twin tropes. AN emaciation and suicide attempt/self-harm scars were used to characterise RE as the 'evil twin', consistent with sociocultural stereotypes of marks/otherness denoting moral 'deviance' or social/moral transgression [191–194]). Twin tropes were also assumed by clinicians to be a factor in twin AN discordance (i.e., AN and ambivalence for recovery representing ego-division and an attempt to control/assume the 'twin' identity) [186, 188, 190, 193–196].

These two case studies extend current literature on barriers to ED treatment. Twins discordant for AN may face additional barriers to early diagnosis and intervention due to stigma and misunderstandings of twin discordance. Family members' and clinicians' recognition of AN in discordant twins was influenced by insufficient ED health literacy and ED stereotypes [197–201], ED diagnostic criteria and treatment cut-offs [202–209], however an additional barrier included misconceptions of genetics and twin discordance. These barriers influenced duration of untreated ED and treatment response [210–213] (in the case of SS, 4.5 years untreated 'atypical' AN; in the case of RE, 10 years of untreated AN despite early mental health treatment due to medical overshadowing and misattribution). Promoting health and genetic literacy, dismantling ED and twin stereotypes, and increasing treatment access (i.e., removing overreliance on BMI, recognising the significance of weight suppression and weight loss speed; [119, 214, 215]) may promote earlier recognition of ED discordance in twins, and increased illness acceptance.

As illustrated in RE's case of longstanding AN, in EDs, illness denial and impaired insight (anosognosia), dissociation, and self-disconnection [216, 217] may be a mechanism of malnutrition and embodiment disturbance [96, 217, 218], trauma, maladaptive beliefs, and suicidality [96,

219, 220]. In psychiatric and legal contexts, illness denial interrelates with treatment refusal or 'compliance' [221–224]. As shown in RE's case, illness treatment refusal should not be assumed to indicate impaired insight, as it can be unintentional or deliberate⁴ [225–231]. Family members' and medical practitioners' desensitisation to RE's condition affected RE's level of desensitisation or sense of urgency to seeking medical care. This finding extends current knowledge on insight and ambivalence in AN and longstanding AN by demonstrating that these experiences are externally influenced and fluctuate with relational dynamics.

Self-processing difficulties may result in individuals with AN perceiving themselves as they would another person or a stranger [232–235]—the body is not "self-related", and therefore, there is no self-directed motivation for protection (i.e., health behaviours). The emotional detachment described by RE may relate to differences in self-processing, such as a lack of activation in the attentional system or insula [232]. For RE, the comparisons their twin-sibling MW made between their bodies as identical twins (i.e., the physical impacts of AN discordance) may have engaged areas of the brain involved in self-processing, resulting in greater self-compassion and insight [232, 236] (i.e., stimulating the insula through compassion [237]). This has indications for the benefits of referential body image (i.e., discordant twins, avatar therapy) for increasing self-compassion and illness-related insight, particularly in severe and longstanding AN presentations.

Longstanding AN duration was influenced by greater disturbance in embodiment [238], body schema [239–242], multisensory integration [240, 243, 244], self-processing, and interoception [234, 245, 246], with interconnecting relationships between body dysmorphia, gender dysphoria, non-binary body ideals, hegemonic expectations of gender expression, body dissatisfaction, and disordered eating [130, 131, 135, 247]). These findings highlight the complex, intersecting relationships involved in embodiment and AN.

RE experienced pressure to conceal their ED [248] due to family members fearing stigma and judgment [249–251] related to their twin discordance for AN (i.e., blame for having 'failed' to care for one twin (RE), and/or as having 'caused' the AN discordance [252]). This resulted in greater family dysfunction [251, 253] and lower family involvement in treatment [254]. Fear of stigma for twin discordance is a previously undescribed aspect of ED stigma, and was a treatment barrier specific to twins

⁴ Unintentional denial involves neurobiologically-based impaired self-awareness, distorted information processing, dissociation, or other unintentional reasons for denying or being unaware of illness states. Deliberate denial and refusal of self-disclosure is intentional and arises from needs that are given higher priority (i.e., avoidance of feared consequences/losses, need for self-determination/autonomy, lack of trust).

discordant for EDs and their family members. RE provided ED health literacy regarding genetic/familial risk, twin discordance, and environmental factors, which supported their parents' understanding and decreased fear of judgement and stigma. In turn, their parents increased support of RE engaging in medical services when in acute medical crisis. This highlights the need for genetic education and genetic counselling for families affected by ED [255], particularly families with twins discordant for EDs.

Siblings may be the first family members to recognise their siblings' disordered eating, as in the case of ES and SS. Siblings may have complex roles in families affected by AN, including acting as a mediator, 'family counsellor', 'protector', and 'problem solver' [256], however, may be under-involved in treatment decisions, and left without adequate resources [249, 251, 256], akin to the experiences of MW. This research extends knowledge on sibling roles in AN-affected families by finding that discordant twin siblings may experience specific family roles connected to ED discordance. The family's perceived stigma regarding RE and MW as discordant twins increased pressure on MW to support family members and 'explain' their discordance to family members and others. The impact of AN on MW was a defining factor in RE's motivation for healing and treatment re-engagement, however clinicians' misconceptions of genetics and the twin relationship resulted in failure to recognise this relationship as protective against AN and suicide, and to involve MW in RE's treatment.

Iatrogenic harm and weight stigma influenced treatment experiences and engagement. Iatrogenic harm led to cumulative trauma and treatment disengagement, maintaining RE's longstanding AN [73, 83, 95, 96, 257–259], and creating distress and additional burdens on MW as a sibling-carer. EDs have been recognised as

shared trauma for family members including siblings [260, 261], however, iatrogenic harm has been under-recognised as part of this shared trauma. Research on addressing and rebuilding trust after iatrogenic harm (i.e., restorative just and learning culture practices [262, 263]) has been a substantial gap in psychiatric research and clinical practice, including for EDs. MW's involvement in RE's inpatient treatment supported medical re-engagement (establishing a sense of safety and helping repair trust with clinical staff). For SS, weight stigma contributed to delayed diagnosis and treatment for 'atypical' AN [202, 208, 209]; whereas dismantling weight stigma supported recovery. For RE, weight stigma reinforced desensitisation, undermined acceptance of their AN as a medical emergency, and eroded trust in clinical staff. In both cases, twins without AN (MW and ES) were vital for service navigation and support during AN, including in recognition, treatment, coping with iatrogenic harm, and recovery processes.

Conclusion

These autoethnographic accounts of twin discordance for longstanding AN and 'atypical' AN provide insights into the impacts of surviving, living with, and healing from AN, including its impacts on the twin relationship, and the importance of the twin relationship for treatment engagement, healing and recovery. Multiple factors may have contributed to discordance in both of these cases (Tables 1 and 2, and Figs. 1, 2, 3 and 4), particularly environmental factors that may have interacted with genetic vulnerability, including higher exposure to traumatic/adverse events, immune and gastrointestinal disturbance, sensory/interoceptive attentiveness/attunement, dietary change, and pursuit of body ideals. These findings of these case studies have both clinical and research implications (Boxes 1 and 2).

Box 1 Clinical implications

Treatments should be expanded to increase focus on aetiological factors

As highlighted by this paper and the bio-psycho-social model, current ED care systems do not adequately cater to the reality of complexity that occurs for many with EDs [14, 19, 71, 168, 169, 264–268]. Research advancements and cultural shifts may not yet be widely translated into improved clinical practice [113, 269, 270]. While medical focus and symptom reversal is important to ED care, a lack of aetiological and psychological focus in treatment is a limitation [71, 271–274].

Increased eating disorder training and professional supervision is needed for clinicians to increase health literacy and deconstruct stereotypes

Stereotypes about EDs hindered early intervention. Increased ED health literacy can facilitate understanding and seeking treatment. For families with discordant twins, ED psychoeducation should include education on genetics, heritability, environmental risk factors, and epigenetics [1, 4, 10, 255, 275, 276]. Clinicians should also receive ED psychoeducation on genetics, epigenetics and aetiological factors that may lead to twin discordance. ED resources and support for sibling-carers is a significant gap in clinical care and an area for future development.

Personalised treatment is needed, including the use of epigenetic framing

These case studies provide support for personalised ED treatment. While discordant twins are the subject of genetics research, no current treatment models address specific approaches to ED discordance for twins and their families—such as use of epigenetic and aetiological framing and genetic counselling [255], which can reduce perceived stigma, self-stigma, hopelessness and genetic fatalism, and support treatment engagement [255, 273].

Box 2 Research implications

Future research could explore the protective role of sibling involvement in ED treatment

This research compared factors in AN development between twins discordant for AN. Aspects of convergence/divergence were explored that may indicate risk or resilience for AN development, and factors that may characterise longstanding AN duration or recovery.

No known literature has explored the *positive* role of sibling/twin relationships in healing and recovery from an ED, development of self-compassion, positive body image, or posttraumatic growth. For twins discordant for AN, sibling involvement in treatment may be support improved quality of life and recovery. Future research could develop educational resources for siblings to promote ED health literacy and early identification to support treatment seeking. Additionally, future research could explore the impacts of sibling and twin-sibling involvement in ED treatment, and aim to develop resources to support siblings and twin-siblings to be safely and effectively involved in ED treatment when a shared goal. Greater carer involvement in ED treatment may be particularly beneficial in longstanding EDs [261], including sibling-carers.

Relational body image may provide new insights into anorexia nervosa

For RE, body schema-in-reference (comparisons to MW) offered a unique strategy to improve embodiment disturbance, insight, and self-compassion. Relational body image has been unexplored in research on embodiment in AN, and development of self-compassion. Future research could explore relational body image in discordant twins and its role on body image, embodiment disturbance, anosognosia, cognitive dissonance, and developing self-compassion while experiencing AN.

Phenomenological methodology can advance understanding of anorexia nervosa

This research can inform future phenomenological studies and member-checking with other twin pairs (concordant or discordant for an ED) which can enhance validity of research findings. Genetic AN studies have had a Eurocentric bias and lacked clear and consistent identification and inclusion of patients with longstanding duration, which may limit identification of diverse genetic factors that may differentiate individuals for longer AN duration and/or greater severity [74, 275, 277–279]. This research indicates that a multidimensional model and/or mixed-methods approach may be beneficial for genetics research; i.e., despite early risk factors for ED development occurring in identical twins (premature/pre-term birth, low birth weight, early trauma), key environmental factors may increase or decrease risk, leading to discordance for ED development and difference in AN duration (multiple trauma exposure, illness, injury, bullying, sociocultural factors).

This article advances current knowledge of longstanding AN and AN recovery. Use of collective autoethnographic methodology and thematic analysis are used to deepen understanding of AN and twin discordance.

Abbreviations

AN	Anorexia nervosa
ARFID	Avoidant/restrictive food intake disorder
C-PTSD	Complex posttraumatic stress disorder
CYMHS	Child and youth mental health service
EKG	Electrocardiography
ED	Eating disorder
EDs	Eating disorders
LGBTIQ+A	Diverse sexual/gender identities (including but not limited to lesbian, gay, bisexual, transgender, gender non-binary and gender diverse, intersex, Two-Spirit, queer/questioning, asexual and aromantic)
NG tube	Nasogastric feeding tube
NICU	Neonatal intensive care unit
PTSD	Posttraumatic stress disorder
SE-AN	Severe-enduring anorexia nervosa
SEED	Severe-enduring eating disorder

Supplementary Information

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Additional file 1

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Reflexive positional statement: The authors of this paper have lived or living experience as twins discordant for longstanding anorexia nervosa and OSFED ('atypical' anorexia nervosa), and are also advocates, professionals, and researchers in the fields of EDs, neuroscience, psychology, biology and ecology. These life experiences informed the approach to this paper. **Contributions:** RE conceptualised this manuscript, researched and wrote all literature contributions, created the figures, and provided projected administration. Narrative autoethnographic inclusions of the case study material were written by the respective authors: RE, MW, ES, and SS, whose personal experiences

they reflect. Transcribed quotes from meetings are direct reflections from the respective authors. All authors: RE, MW, ES, and SS contributed to the overall article planning, collective autoethnography, and thematic analysis. All authors contributed minor grammatical editing of narrative autoethnographic inclusions (which did not significantly alter the meaning or content of the original text) and overall revisions.

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Data availability

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Declarations

Ethics approval and consent to participate

Not applicable. All autoethnographic insights were written by the authors whose lives they reflect.

Consent for publication

This manuscript contains the authors' own personal data as autoethnographic case reports. The authors consent to its publication. This manuscript contains no other individual person's data.

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