

Commentary

Not niche: eating disorders as an example in the dangers of over-specialisation: commentary, Downs

James Downs

Keywords

Eating disorders; lived experience; biology; holistic care.

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Response

The arguments made by Haynos et al in their editorial ‘Not niche: eating disorders as an example in the dangers of overspecialisation’¹ highly resonate with my personal experience as a patient with a long-standing and severe eating disorder. The authors make several pertinent points about the link between perceptions of eating disorders as a niche field within research and the amount of funding available for research and clinical innovation, highlighting some of the possible reasons why. In addition to stereotypical and gendered views about eating disorders and the unique medical risks they may involve, the lived experience of people like myself can provide additional insight into how this overspecialisation is experienced clinically, as well as further potential reasons why. In turn, a broader array of solutions can be alighted upon for addressing the key barrier to equitable understanding and care provision that overspecialisation represents.

Haynos et al’s focus on the interrelationship between eating disorders and other psychiatric concerns reflects the experience of people like myself who often have multiple co-occurring psychiatric conditions. In addition to the medical risks that the authors note, it is also worth stating explicitly that eating disorders are not disconnected from other medical concerns – and not just in terms of risks that result from the physiological consequences of eating disorder symptoms. Emerging research shows that there are many medical factors which may contribute to predisposing risk and development of eating disorders, or be in bidirectional relationship with them, ranging from genetic factors² and neurodivergence³ to metabolic⁴ and autoimmune conditions.⁵

In my lived experience as an individual who also has Ehlers Danlos Syndrome, I experience primary physiological problems as a result of my medical condition (such as gastroparesis) which have directly contributed towards the development and maintenance of anorexia and subsequently bulimia. It has been extremely frustrating to always have medical concerns seen as a secondary consequence or byproduct of the supposedly primary psychological problem – the eating disorder. I have often been told that ‘there is no point’ treating my physical health problems aside from in medical emergencies, as what is needed is to treat ‘the real problem’, which supposedly resides in my psychopathology. Yet, to take an example from my own experience, it is equally important to understand that features of malnutrition such as profoundly low potassium will change one’s psychological state as it is to understand that psychological features may lead to eating patterns causing malnutrition.

At worst, the primacy given to psychology is not just a theoretical problem but has real-world implications in care, whereby my physical health problems have been left undiagnosed and/or untreated as a result of diagnostic overshadowing – sometimes for decades.⁶

This denies opportunities to unlock treatment targets which may be important in the maintenance of illness, as has been the case for me – opportunities which are made more remote by the way in which patients experience care for different components of their condition as ‘siloed’ between multiple specialties which often do not communicate well, or share responsibility effectively and safely.⁷

As such, the over-attribution of illness to psychopathology and understanding of eating disorders as situated within psychiatry alone might be usefully added to the harmful assumptions that Haynos et al rightly identify. The authors’ action-focused and ambitious solutions can therefore be supplemented to include a paradigm shift towards a greater centrality of the role of biology in our conceptualisation of eating disorders – that they are even less niche than proposed. This will allow for a greater range of relevant treatment targets and opportunities for recovery for people like me, where progress has been unlocked by giving greater weight to biological features alongside psychological support and understanding.

Lastly, although factors such as gender are important in understanding the harmful assumptions that confine eating disorders within a niche area,⁸ there are additional prejudices that are important to add to this work which extend beyond the demographics of those who might experience an eating disorder. For instance, assumptions are often made about the psychopathology of those with eating disorders which are not always accurate, evidence-based or helpful, including the idea that eating disorders are centrally concerned with control⁹ or that longstanding eating disorders have an inherent element of untreatability.

Intertwined with some of these ideas are well recognised and deep-rooted stigmas which play a key role in limiting the field. In my own experience, I have felt blamed for my condition, and been left with a sense of hyperresponsibility as a result of being told things like ‘You have to want to get better’, ‘You are demanding special treatment’ and ‘You are too dependent’ on the little care available. Although these are anecdotal examples, ideas that suggest that individuals are in some way not motivated, want to be unwell or are for some reason not able to get better would naturally make anyone question whether it is worth putting efforts into understanding or treating their condition.

In addressing these difficulties, centralising the role of biology can itself go some way to addressing pervasive stigmas that exist around eating disorders. Developing a more comprehensive and integrated understanding that brings together biological, environmental and contextual factors (including those not referenced here such as the food environment, education, food poverty and inequality) will help decentralise the notion of personal responsibility – and thus blame – over food and eating, including for those with eating disorders. I hope these factors together add helpfully to the

authors' efforts to move eating disorders from their current, overly confined niche – a confined space that only restricts the lives and opportunities of people like myself – and towards greater understanding, better treatment and lasting recovery for all.

James Downs , Patient Representative, Royal College of Psychiatrists, Cardiff, UK

Correspondence: jamesldowns@gmail.com

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Declaration of interest

None.

References

- 1 Haynos A, Egbert A, Fitzsimmons-Craft E, Levinson C, Schleider J. Not niche: eating disorders as an example in the dangers of overspecialisation. *Br J Psychiatry* 2024; **224**(3): 82–5.
- 2 Bulik CM, Coleman JR, Hardaway JA, Breithaupt L, Watson HJ, Bryant CD, et al. Genetics and neurobiology of eating disorders. *Nat Neurosci* 2022; **25**(5): 543–54.
- 3 Longhurst P, Clark L. Integrating the autistic experience into existing models for disordered eating. *Front Psychol* 2022; **13**: 926415.
- 4 Yu Z, Muehleman V. Eating disorders and metabolic diseases. *Int J Environ Res Public Health* 2023; **20**(3): 2446.
- 5 Hedman A, Breithaupt L, Hübel C, Thornton LM, Tillander A, Norring C, et al. Bidirectional relationship between eating disorders and autoimmune diseases. *J Child Psychol Psychiatry* 2019; **60**(7): 803–12.
- 6 Downs J, Mycock G. Eating disorders in men: limited models of diagnosis and treatment are failing patients. *Br Med J* 2022; **376**: o537.
- 7 Branley-Bell D, Talbot CV, Downs J, Figueras C, Green J, McGilley B, et al. It's not all about control: challenging mainstream framing of eating disorders. *J Eat Disord* 2023; **11**(1): 1–8.
- 8 Downs J, Ayton A, Collins L, Baker S, Missen H, Ibrahim A. Untreatable or unable to treat? Creating more effective and accessible treatment for long-standing and severe eating disorders. *Lancet Psychiatry* 2023; **10**(2): 146–54.
- 9 Thörel N, Thörel E. Combating the volitional stigma of eating disorders: can empathy reduce the perception that individuals with eating disorders are to blame for their conditions? *Stigma Health* [Epub ahead of print] 13 Jan 2022. Available from: <https://doi.org/10.1037/sah0000355>.

Reflection

Whispers and whirlwinds

Antonio Yaghy 

In the twilight of my own cognition, where thoughts once flowed like a serene river, the waters began to stir and whirl in ways unsettling and unfamiliar. It started with whispers, soft murmurs like leaves rustling in an unseen breeze. These whispers grew into voices, each carrying its own weight, its own colour and its own texture. They told stories that no one else could hear, painted worlds no one else could see.

I walked through days like through a gallery of moving pictures, where reality and imagination blurred in their frames. The familiar faces of friends and family transformed under the gaze of my altered perception, becoming at times unrecognisable, not by their looks but by the essence I felt emanating from them. Their words sometimes reached me across great chasms, distorted by the echoes of my own internal symphony. The diagnosis came like a soft but insistent rain, seeping through the cracks in my carefully constructed umbrella of denial and normality. Schizophrenia, they said, as if naming the storm could tame it. The name was new, but the experience was as old as my earliest memories of the world being too loud, too bright, too much yet never enough. In the heart of this whirlwind, I found moments of unspeakable beauty. The voices, my uninvited guests, sang in harmonies that no composer could conceive. They spoke in poetry, a language born from the deep wells of emotion and experience that I could not otherwise tap. The world, seen through the kaleidoscope of my mind, shimmered with possibilities, with connections that others could not perceive. Living with schizophrenia is like dancing on the edge of a dream. Reality is a concept as fluid as water, and just as hard to hold. I learned to embrace the fluidity, to find my footing in the slipstream. My senses, once overwhelmed, became attuned to a different frequency. I could hear the silent whisper of the trees, feel the soft sorrow of the moon and touch the joy in the rain. Medication and therapy became the lighthouses guiding me back to a shore I could share with others. Yet these tools did not erase the beauty of my experiences; they merely framed them in a context I could navigate and sometimes explain. In my journey, I discovered that my mind, though fragmented, was a mosaic of incredible depth and colour. I paint now, with colours and words, trying to capture the ethereal landscapes of my mind. Each stroke is a dialogue between the world within and the world without. People see my art and find it abstract, beautiful in its complexity. They do not always know that each line, each shade, is a piece of my soul made visible. In this journey, I have lost much but gained something precious: a vision of the world that is uniquely mine.

I stand now under the vast canvas of the sky, no longer trying to separate the voice of the wind from the murmuring of my own heart. I am a traveller in a landscape where the horizons are drawn not by sight but by perception. And in this journey, I have found not just challenges, but a profound, unexpected beauty. For even in the depths of the storm, there is light, and in the complexity of my thoughts, there is a simple, enduring truth: that all of life is a but a collection of unique experiences, and every experience has its place, its purpose and its own unique beauty.

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