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Hartley, Samantha, Baker, Charley, Birtwhistle, Michael, Burgess, Jennifer L, Chatburn, Eleanor, Cobbaert, Laurence, Howley, Maddie, Huggett, Charlotte, MacKenzie-Nash, Charlie, Newton, Alice, Parry, Sarah , Smith, Jee, Taylor, Christopher DJ, Taylor, Peter James and Timoclea, Robyn (2022) Commentary: Bringing together lived experience, clinical and research expertise – a commentary on the May 2022 debate (should CAMH professionals be diagnosing personality disorder in adolescence?). *Child and Adolescent Mental Health*, 27 (3). pp. 246-249. ISSN 1475-357X

DOI: <https://doi.org/10.1111/camh.12586>

Publisher: Wiley

Version: Published Version

Downloaded from: <https://e-space.mmu.ac.uk/630079/>


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Additional Information: This is an Open Access article which appeared in *Child and Adolescent Mental Health*, published by Wiley.

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Commentary: Bringing together lived experience, clinical and research expertise – a commentary on the May 2022 debate (should CAMH professionals be diagnosing personality disorder in adolescence?)

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Background: There is a wealth of evidence to suggest that the Borderline Personality Disorder (BPD, or similar Emotionally Unstable Personality Disorder, EUPD) construct is harmful. We provide a commentary on the ideas expressed in the May Debate issue, highlighting both concerns and alternatives. **Method:** We bring together lived experience, clinical and research expertise. This commentary was written collaboratively drawing on all these sources of evidence. **Results:** We outline evidence that the BPD construct is invalid, harmful, not necessary for effective treatment and a potential block to the development and evaluation of alternatives. **Conclusions:** We ask readers to consider these concerns, perspectives and ideas.

Key Practitioner Message

- There is a wealth of evidence from a range of sources to suggest that BPD can be a harmful, invalid construct that is unnecessary for and might be detrimental to treatment.
- We propose that these risks are even greater in adolescence.
- We highlight alternative forms of practice that warrant further consideration, development and evaluation.

Keywords: Borderline; personality disorder; adolescence; mental health

We are writing in relation to the May Debate issue regarding the diagnosis of personality disorder (PD) in young people (2022). In line with the debate issue, we focus on BPD. In writing this commentary, we bring our varied clinical, research and lived experience of mental health/illness and services. We triangulate evidence from these different sources to critically discuss the assertions made and offer alternatives. The editorial notes that 'it seems remarkable that... we did not receive clear scientific statements for the contra side'. We were surprised that the editors were unable to find such contributions. We would signpost interested parties to the Twitter hashtags #HumanNotPD #TraumaNotPD #PDIInTheBin, the @SurvivorsNotPD and @RITB_

accounts, <https://madcovid.wordpress.com/>, <https://stopsim.co.uk/>, and the recent commissioning report by Lomani (2022). These represent just some of the many communities where the PD construct and associated models of care are actively resisted.

We first outline our stance. We believe that all mental health services, clinicians, frameworks and treatments have the capacity for iatrogenic harm. It is essential that healthcare providers acknowledge this and strive towards mitigating, rather than perpetuating harm. We recognise the significant (research, theoretical, lived experience, clinical) evidence of the harm caused by the BPD construct and ideology. We are not anti-diagnosis per se and believe in the potential value of a plurality of

approaches; utilised with compassion, rigorous evaluation and in collaboration with young people and families. We acknowledge the experiences of young people and families who view this construct as helpful (including those shared in the debate issue itself); we will *always* listen to these voices. We also acknowledge our own blind-spots and are committed to continued learning and listening.

The BPD construct is invalid

The categorical classifications of personality disorders have been heavily criticised for many years as incompatible with the research evidence (Livesley & Larstone, 2018): the categories are not distinct, not temporally stable, poorly operationalised and influenced by the interests of committee members. There are 256 combinations of symptoms which could result in a 'BPD' diagnosis (Watts, 2022). In the *British Journal of Psychiatry* in 1988, Lewis & Appleby concluded that PD 'appears to be an enduring pejorative judgement rather than a clinical diagnosis'. The move to a dimensional model risks applying this same judgement to more people.

Adolescence is a time of developing one's sense of self and identity. Difficulties with self-concept, exploratory and 'risk behaviours', intense emotionality, unstable relationships and impulsivity are the hallmarks of adolescence, constituting critical developmental tasks. Of course, this life stage does also bring rise to difficulties, illness and pain that – if not supported adequately – can persist and escalate into adulthood. We argue that in this developmental context the use of the BPD construct both pathologises normative adolescent experience and presents a stigmatising and pessimistic obstacle to intervening appropriately when needed. Complexities and concerns related to this are recognised across disciplines.

Self-harm is increasingly prevalent in young people (Griffin et al., 2018). There is significant overlap between the presence of self-harm and BPD diagnoses and people with lived experience report that self-harm is frequently used as a reason for applying the BPD construct (Recovery in the Bin, 2016). In this context, we risk diagnosing thousands of young people with BPD, and the associated risks of stigmatisation and iatrogenic harm.

We argue that the BPD construct is culturally situated: psychiatric nosology both incorporates and reflects surrounding social factors such as misogyny, patriarchy, transphobia, homophobia, ableism and colonialism – which it then serves to perpetuate through the weaponisation of pathological 'personality' – the othering and marginalising of difference (Shaw & Proctor, 2005). BPD was introduced in the DSM-III at the same time hysteria and homosexuality-as-mental-illness were discarded. Most people given this label are women (WrenAves, 2020) and there is evidence for biases in the diagnosis of BPD among lesbian, gay and bisexual people (Rodriguez-Seijas, Morgan, & Zimmerman, 2021), and trans people (Anzani, De Panfilis, Scandurra, & Prunas, 2020).

There are also concerns about the misuse of the BPD construct in autistic populations (Au-Yeung et al., 2019; WrenAves, 2022), where women especially are often not served well by the diagnostic processes. Use of the BPD

construct is problematic especially in the context of evidence that autistic people are at a disproportionate risk of experiencing interpersonal violence, trauma, self-harm and suicidal ideation. The notion of a 'disordered personality' is antithetical to the neurodiversity paradigm and pathologises difference (Au-Yeung et al., 2019).

Individuals diagnosed with BPD are 14 times more likely to report childhood adversity than non-clinical controls and three times more likely than other psychiatric groups (Porter et al., 2020). While we acknowledge there is no 'one size fits all' approach to treating mental health difficulties and no framework of understanding should be imposed, it is important that young people are able to access effective and compassionate treatments for traumatic experiences. Diagnosing young people with BPD is likely to provide an additional obstacle to the already difficult process of accessing therapeutic services and trauma-specific therapy (Charlie, 2019; Lomani, 2022; WrenAves, 2020).

The BPD construct is harmful

There can be both positive and negative elements of receiving a BPD diagnosis. Some of the positive aspects of a diagnosis could be connecting with others, feeling validated and increased sensemaking. However, there are also many well-documented negatives, both on a personal and service level. For example, internalising stigma, reduced access to treatments and negative, harmful attitudes from professionals (McKenzie, Gregory, & Hogg, 2022).

The BPD diagnosis is strongly associated with discriminatory experiences that impact negatively on self-image, including epistemic injustice (Watts, 2017). Many professionals openly express contempt in relation to BPD diagnoses (Lester, 2013), which no doubt impinges on treatment success, in addition to causing iatrogenic harm. People with lived experience vehemently and eloquently express the harms that the construct brings (Harvey, 2020; <https://www.bpctestimonyarchive.org/>; <https://warriorwomandlj.wordpress.com/>); seeing beyond diagnosis and connecting with individuals is deemed helpful.

We are concerned that increased use of the BPD construct with young people, where self-image can be more fragile and stigma might be internalised more readily could lead to them internalising the stigma associated with diagnosis, exacerbating any existing difficulties, increasing the effects of trauma (where it is present) and contributing to iatrogenic harm.

We understand the argument that the stigma surrounding BPD in young people is a purely external/social phenomenon, and that the process of clinicians using this diagnosis can somehow challenge this stigma. However, we argue that the construct itself, and the ideology that surrounds it, is inherently stigmatising, because of the way it positions dysfunction within the individual, and encapsulates and legitimises pejorative judgements about 'acceptable' behaviour or personhood. A strength of the Child and Adolescent Mental Health Services (CAMHS) approach is a willingness to bring a holistic understanding to needs and treatments; acknowledging systemic influences – a move towards more diagnostically led pathways risks undermining this. Telling vulnerable and traumatised individuals that

their psychological distress sits with who they inherently are as a person could serve to reify already deep-seated self-hatred and risk re-traumatisation (Harding, 2020).

There is a false link between the need for the BPD construct and effective treatment

There is an argument that the use of the BPD construct can lead to improved treatment. However, we argue that this is an invalid assumption and labelling with the BPD construct often has the opposite effect. Thus, it is not 'diagnosis and treatment' versus 'no diagnosis and no appropriate treatment'; it is possible to intervene with appropriate treatment without labelling an adolescent with 'personality disorder' and risking the harms outlined above.

It has been argued that seeing personality disorder as a spectrum would reduce stigma. We would question whether it should be the burden of young people to carry the label of BPD until society sees fit to separate a contentious and scientifically questionable diagnosis from stigma. We have decades of evidence that stigma is both inherent in and legitimised by the construct itself. We would also question whether a healthcare professional identifying with a spectrum of difficulties from a relatively privileged and safe position is comparable to a vulnerable and relatively disempowered young person being forced to accept a diagnostic construct as a form of understanding or in order to access treatment (c.f. Nell, 2022).

CAMHS are currently not adequately meeting the needs of many young people but the causal link with a 'lack' of PD diagnosis has not been evidenced. We do know, however, that diagnosis does not necessarily equal treatment and can in fact lead to 'off-rolling', denial of care and iatrogenic harm (WrenAves, 2020). We run the risk of people feeling disillusioned by mental health services, thus alienating and harming them further. There will not be a one size fits all approach, but we would strongly oppose any care pathway that is conditional on the acceptance of a diagnostic construct such as BPD.

There are legitimate alternative forms of service provision that warrant investigation

One risk of increasing the use of the BPD construct to organise and provide services is that it risks halting the development, evaluation and implementation of alternatives.

The New Ways of Supporting Child Abuse and Sexual Violence Survivors Report (Lomani, 2022) recognises the re-traumatisation that the BPD construct brings and outlines proposals for trauma-informed, trauma-specific pathways and services that are completely removed from a personality disorder frame of understanding. There is an acknowledgement that across services, access to trauma-informed care is essential for all young people accessing mental health services, and that there should be access to trauma specialist therapy for all young people who have experienced complex PTSD.

In light of the increased use of the BPD construct in the context of neurodivergence, there is a need for improved screening and support for neurodevelopmental differences in CAMHS, especially ADHD and autism in girls (<https://autisticgirlsnetwork.org/autism-in->

girls/) alongside reliable, accessible and effective post-diagnostic support. Services will also need to recognise the cultural context in which their provision is situated and seek to dismantle or mitigate the oppressive societal structures that might predispose or perpetuate suffering, rather than locating them in individuals. Healthcare professionals might seek alternative frameworks, such as relational, feminist perspectives (Harvey, 2020).

More effective, acceptable and accessible treatments for self-harm in young people are sorely needed, although they do not require the use of the BPD construct. Self-harm represents a functional response to essential human needs, the meeting of which is often thwarted by social contexts, therefore more personalised, relational and holistic forms of support are warranted.

I received a 'PD' diagnosis before anyone even mentioned 'trauma' to me. Despite many years of involvement with CAMHS, my childhood experiences were not named as trauma until I went to adult services. Even then, it was only mentioned in passing and I had to do my own research to learn about the effects of trauma and link this with my difficulties because nobody did this work with me.

Initially, the 'EUPD' diagnosis felt validating and like an explanation of something previously not understood, but someone explaining that I was traumatised and helping me to understand how my experiences had affected me would have done the same thing without the extensive harmful effects. The 'PD' label continues to be re-traumatising to me and has irreparably damaged my ability to trust and engage with healthcare professionals, not to mention how it has affected the way I view myself.

I wish I had been given the chance to understand myself and my difficulties in the context of my life experiences and the trauma I went through, rather than being told I had a personality disorder. I was deprived of this opportunity and instead, more trauma was caused to me with and through the 'PD' label – with my response to this ongoing harm being interpreted as yet more proof I had a personality disorder. I was a young person grieving and dealing with the effects of trauma – the one thing I absolutely didn't need was to be told my personality was disordered. [Maddie.]

When young people and families identify a PD diagnosis as potentially helpful, this should be acknowledged, although it is important to note that, historically, often no suitable, alternative diagnosis or framework of understanding has been offered. There might also be ways to meet these needs without the additional burden and obstacles of that construct (Charlie, 2019). Person-centred explanations of one's difficulties that do not rely on diagnosis, such as collaborative psychological formulation, or opportunities to connect with others with similar difficulties through peer support or community-based approaches, provide alternatives that could meet this same need for understanding.

Young people and their families deserve services that meet their needs. These needs will be varied, subjectively experienced and dynamic. Services therefore need to adopt a pluralistic approach whereby interventions can be accessed in a way that honours the sense a person has made of their experiences and the available evidence of the effectiveness of different approaches. The move

towards such approaches will require recognising, repairing, and resolving the harms done by constructs, frameworks and interventions, and developing and evaluating alternatives in true collaboration with those who use services.

Acknowledgements

S.H. coordinated the development and writing of the piece. All authors should be considered to have contributed equally to the contents and are listed in alphabetical order. The authors have declared that they have no competing or potential conflicts of interest.

Ethical information

This study did not require ethical approval as it is a commentary piece and no new research procedures were undertaken nor data generated.

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Accepted for publication: 2 July 2022