Assessing the BID Taxonomy in the ICD-11

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I will not argue here that BID isn't real, that the diagnosis shouldn't exist, or that the recognition was a mistake. I'm arguing that, in its current form, the provided definition is suboptimal and may have real costs for researchers and those suffering from it.

Historical/Proposed Taxonomies

- **Apotemnophilia**: *paraphilic interest in becoming an amputee*

  (Money et al., 1977)

  - Many cases are devoid of any sexual component (Everaerd, 1983; First, 2005…) and desire actualisation appears successful (Noll and Kasten, 2014)

- **Body Integrity Identity Disorder**: *dysfunction in the development of one's fundamental sense of anatomical (body) identity (First, 2005; First and Fischer, 2011)*

  - Built upon the now outdated Gender Identity Disorder (GID) model, limited evidence base (Lawrence, 2006; De Preester, 2011; 2013)

- **Xenomelia**: *a right parietal lobe syndrome (McGeoch et al., 2011)*

  - Limb/amputation-specific? Neurological evidence cannot yet differentiate cause from effect

International Classification of Disorders 11th Edition (ICD-11, 2019) Code 6c21

Body integrity dysphoria is characterised by an intense and persistent desire to become physically disabled in a significant way (e.g. major limb amputee, paraplegic, blind), with onset by early adolescence accompanied by persistent discomfort, or intense feelings of inappropriateness concerning current non-disabled body configuration.

The desire to become physically disabled results in harmful consequences, as manifested by either the preoccupation with the desire (including time spent pretending to be disabled) significantly interfering with productivity, with leisure activities, or with social functioning (e.g. person is unwilling to have a close relationship because it would make it difficult to pretend) or by attempts to

Essential (Required) Features:

- 1) **Desire**: An intense and persistent desire to become physically disabled in a significant way (e.g., a major limb amputation, paraplegia, blindness) accompanied by persistent discomfort or intense negative feelings about one's current body configuration or functioning.
- 2) **Distress/Harm**: The desire to be disabled results in harmful consequences, manifested by either or both of the following:

  i) Attempts to actually become disabled through self-injury have resulted in the person putting their health or life in significant jeopardy.

  ii) Preoccupation with the desire to be disabled results in significant impairment in personal, family, social,

BID's parent classification is under *Mental, behavioural or neurodevelopment disorders:*

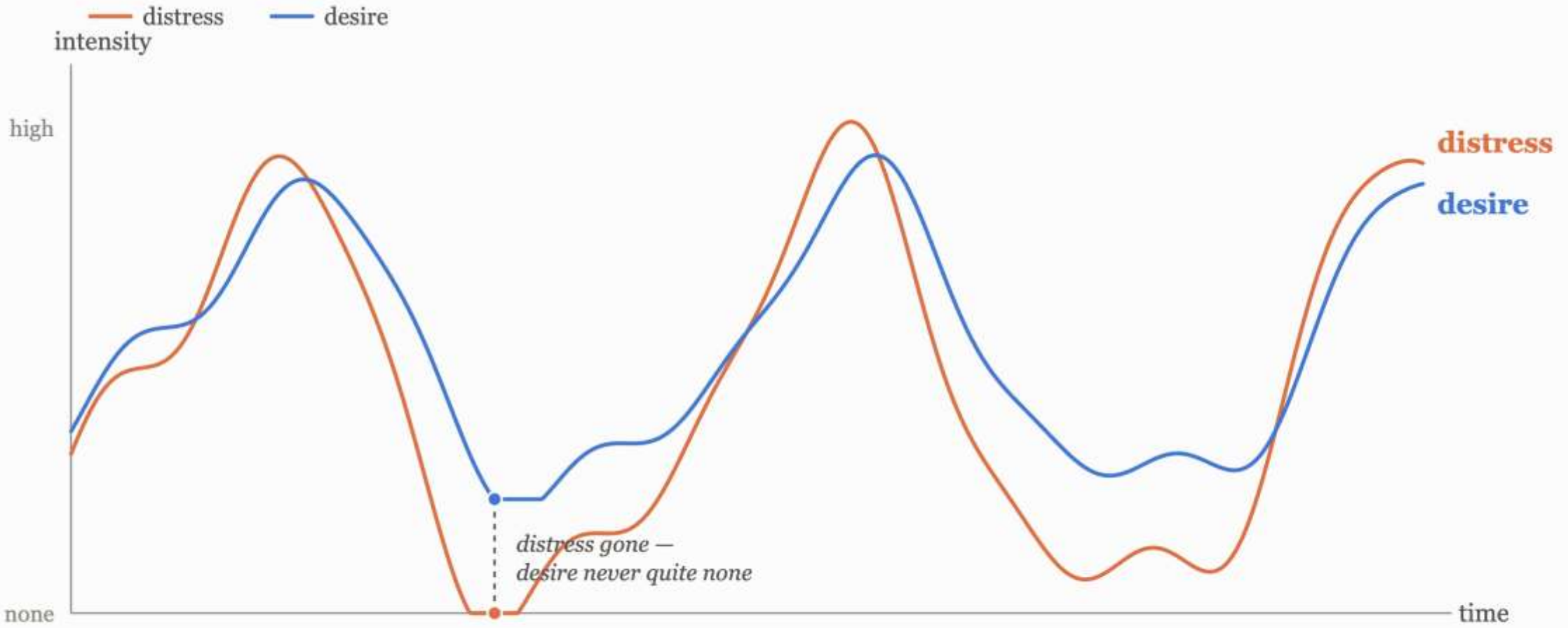
Mental, behavioural and neurodevelopmental disorders are syndromes characterised by clinically significant disturbance in an individual's cognition, emotional regulation, or behaviour that reflects a dysfunction in the psychological, biological, or developmental processes that underlie mental and behavioural functioning. ***These disturbances are usually associated with distress or impairment in personal, family, social, educational, occupational, or other important areas of functioning.*** (ICD-11, 2019, 06)

"The Wave"

- BID is known to operate in "Waves"; its intensity fluctuates greatly through periods (Loriga, 2024)
- 'Suddenly arrive full force upon the individual who can then be overwhelmed with desire … it is so deeply ingrained within the apotemnophilia that she/he cannot restrain or regulate its direction' (Furth and Smith 2002, 68)
- *"Over all of these years, my thoughts about getting rid of my feet would wax and wane. But overall, the feelings were occupying more and more of my headspace. I felt as if a lot of my "processing power" was being used to control or suppress these thoughts. I was constantly trying to distract myself by working harder and harder at my job"* (Kasten, 2024: 4)

The ICD-11 identifies the Wave as a course feature

- *"The typical course is for **the intensity of the desire** to become disabled **and consequent functional impairment** to wax and wane. There may be periods of time where **the intensity of the desire and the accompanying dysphoria** is so great that the individual can think of nothing else and may make plans or take action to become disabled. At other times, the desire to become disabled and the associated intense negative feelings abate, although at no time does **it** completely cease to be present"*

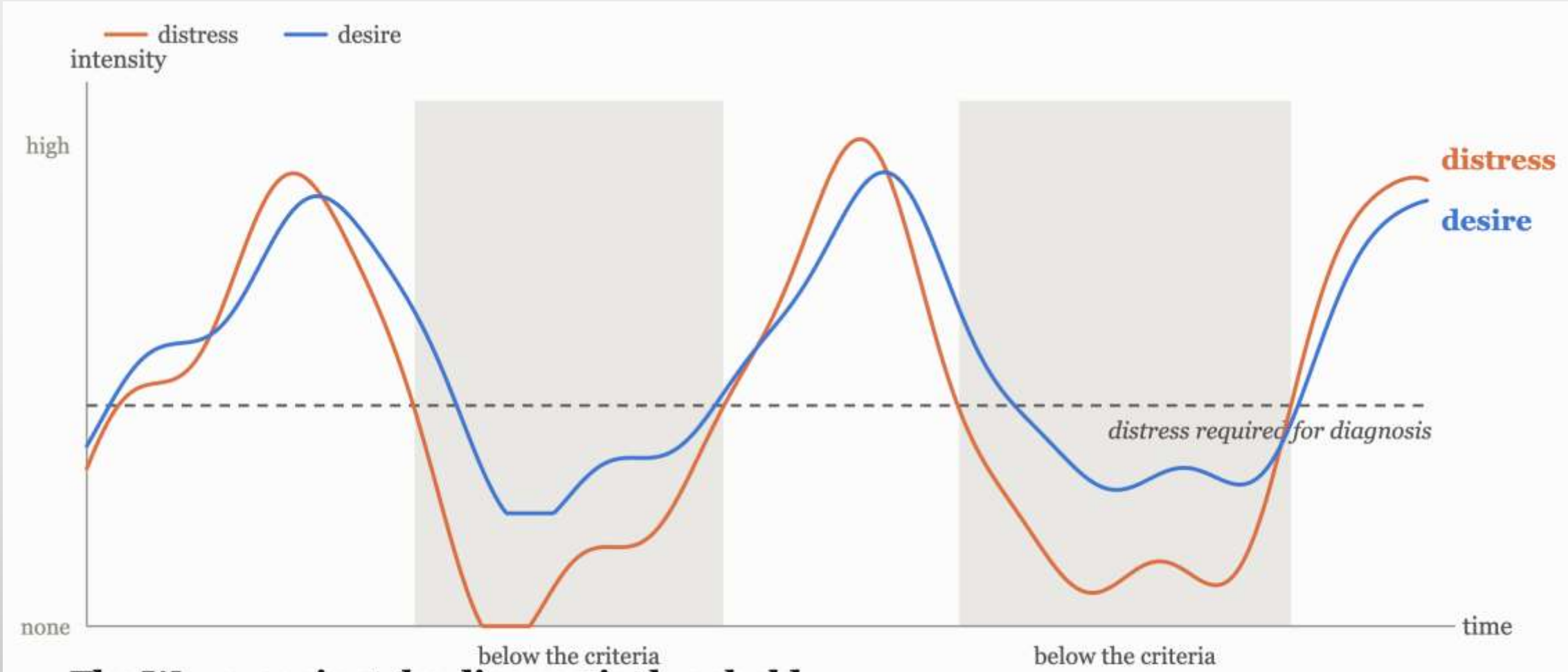


The relationship the taxonomy assumes

Desire and distress rise and fall together — the desire thinning, but never ceasing entirely.

Schematic — illustrative only, not plotted data.

The Wave amid the Harm Criteria



The Wave, against the diagnostic threshold

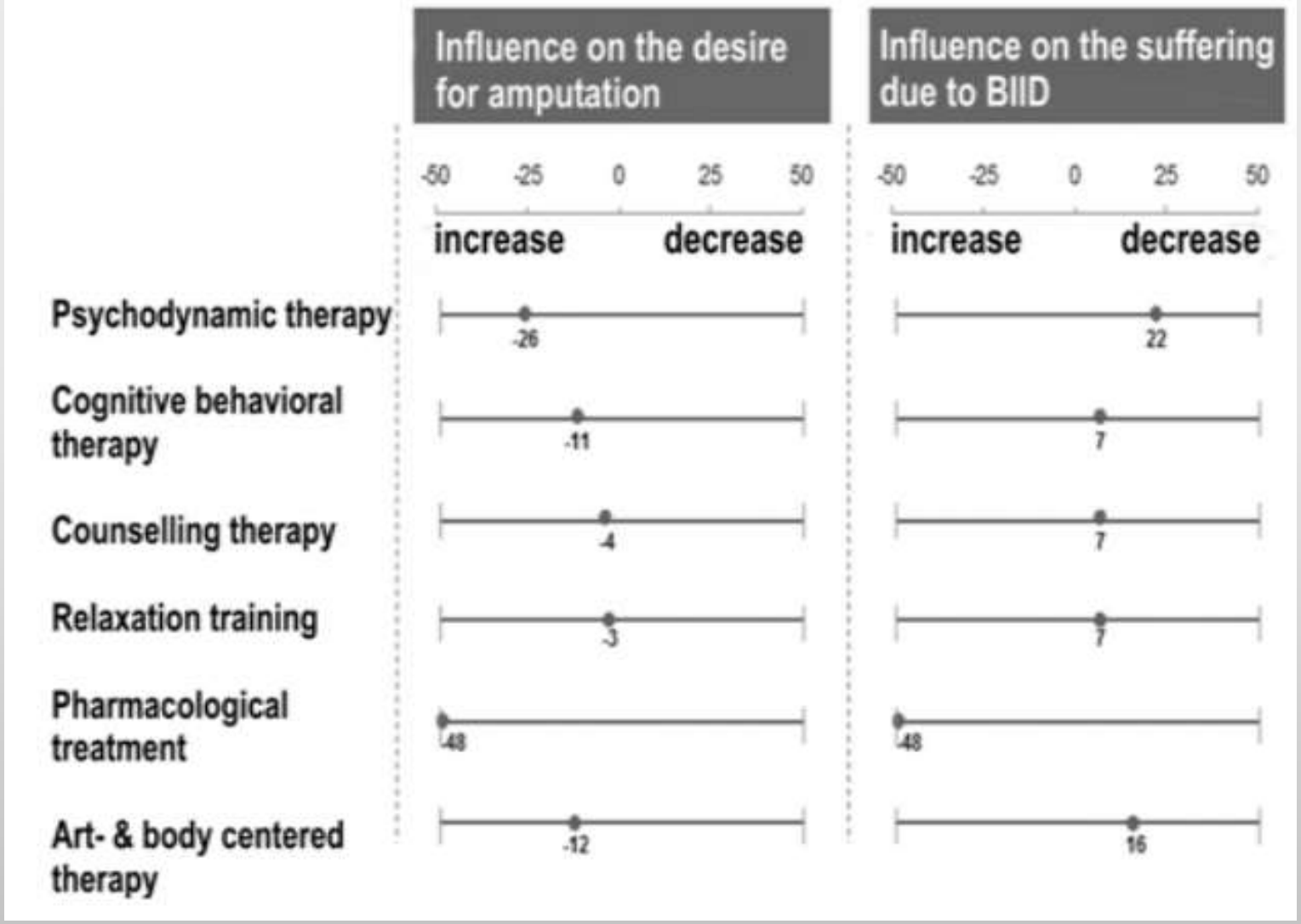
Even on the taxonomy's own account, what remains in the gaps is a desire that does not meet the criteria.

Schematic — illustrative only, not plotted data.

BID's Boundary with Normality

- *Some individuals, especially children and adolescents, may have time-limited periods in which they pretend to have a disability such as blindness out of curiosity about what it is like to live as a disabled person. Such individuals do not experience a persistent desire to become disabled or the harmful consequences associated with Body*

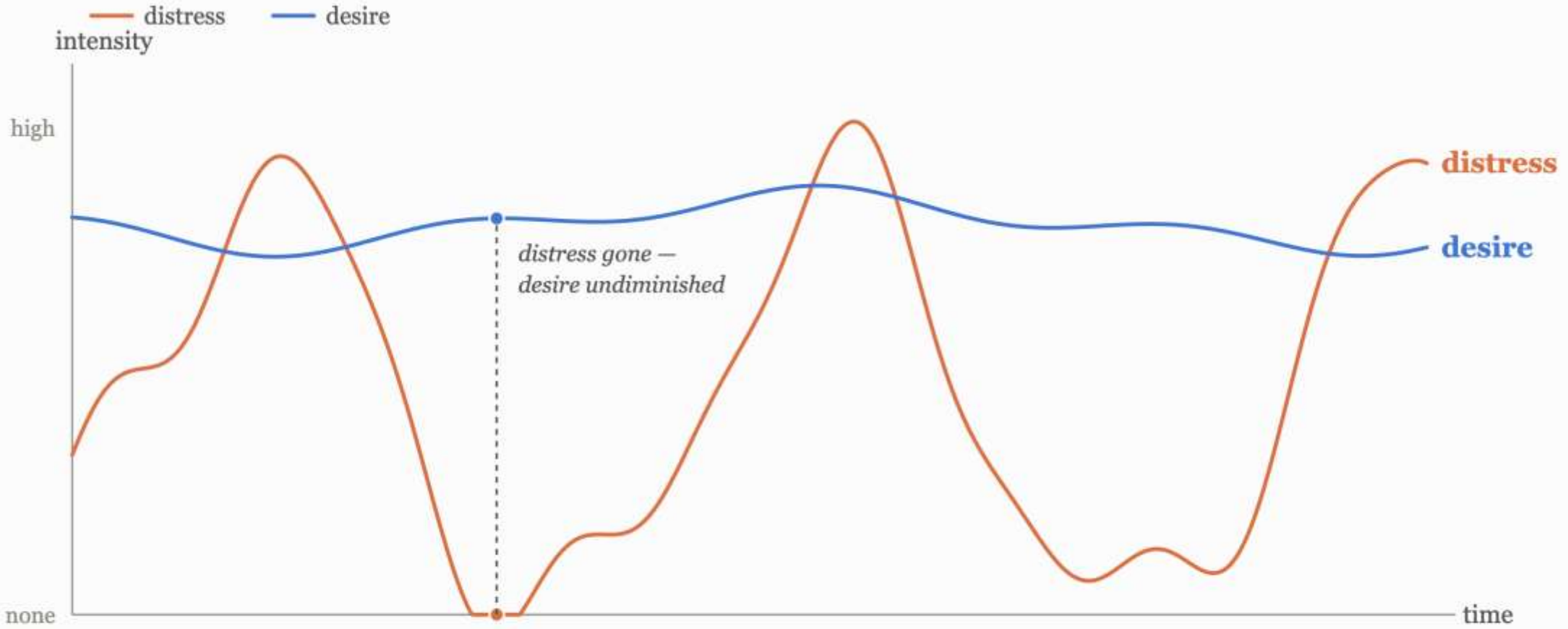
Possible independence of desire and distress



Kröger et al. (2014: 113)

Why is amputation or surgery preferred as optimal?

Why would many reject attempts to be "cured" of BID through less-invasive means (medication or therapy), even if they would be



The relationship the evidence suggests

The desire holds at strength while the distress is turbulent, and persists when it lifts.

Schematic — illustrative only, not plotted data.

What may be the Costs?

Initial research suggests BID's severity distributions are unexceptional (Fischer et al., 2015; Garbos and Kasten, 2022)

- *'16% (1,500 patients) have a very mild form, they feel relatively little pressure and they are often probably not even aware that they are suffering from BID at all. The middle 68% (6,400 patients) from a statistical perspective have a moderate form of BID. […] Serious candidates for an amputation or other forms of*

Those who *cope* better

- BID coping strategies such as disability simulation, distraction, sports and work have been shown to help mitigate BID distress short-term (Helmer and Kasten, 2015).
- Some attempt to cope long-term by living permanently as if they had their desired disability (Stirn et al., 2009; White, 2014).
- Even if these strategies are maladaptive long term, they may enable short-term function and prevent diagnosis.
- Those suffering the most may be those who engage in coping strategies more. The Wave may be turbulent.
- A clinician must consider: "*How would this patient be*

Aggregation of internal and external distress

- Homosexuality and Gender identity Disorder/Gender Dysphoria* were previously considered to be constituted by internal distress.
- Homosexuality went through the process of depathologisation: the distress is now attributed to *external* stigma, and not constitutive of the condition (Meyer, 2003)
- *'He […] explained to the GP that he believed he had a diagnosis of BID, but felt like he was not taken seriously. The patient reported he was not referred for psychiatric or psychological support. He found the response of services very difficult, as he experienced a lot of shame and fear when sharing his experiences of his body. He requested elective surgery, but this was not considered an*

Emotional costs

- A hermeneutical injustice is 'a gap in collective interpretive resources [which] puts someone at an unfair disadvantage when it comes to making sense of their social experiences' (Fricker, 2007; 1).
- Before BID's formal recognition in the ICD, sufferers have lacked a stable diagnostic"psycho-marker" to identify their lived experience (Davis, 2012).
- *'Having BIID documented would . . . ensure us a certain level of legitimacy. Too many people are saying we're "just sick". Being able to point to the DSM and say "yes, we are, but it is not just a fancy, a fantasy, or an invention, it is a REAL condition" would be*

Being told you don't qualify may be experienced as being told your experience is invalid

The Epistemic Cost

- Diagnosis may begin to gate research recruitment. Samples exclude those below the threshold → the evidence base contains only those above it → the criterion looks validated.
- Claims that there is a subthreshold BID population have authority at present.

The Therapeutic Cost

- The risk is that it deprives research of a vital epistemic resource for therapeutic innovation
- Arguably, the subthreshold population is crucial towards devising management strategies.

Possible solutions

- Eliminate the distress criterion?
- Depathologisation?
- Near depathologisation, Gender Incongruence?

- Diagnostic clarity and medical education

Thank you.

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Please get in touch!