



Experimenting with arts-based methods and affective provocations to understand complex lived experience of a diagnosis of borderline personality disorder

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ABSTRACT

This article draws on arts-based psycho-social research to explore embodied and visceral knowing and feeling in the context of people living with a diagnosis of borderline personality disorder (BPD). It presents a discussion of creative artworks solicited through a nation-wide online survey conducted in Australia in 2021 that generated intimate and affective understanding about living with a diagnosis of BPD. To investigate what lived experiences of distress associated with a BPD diagnosis communicate through sensation, emotion, image and affective capacity, the authors put to work Blackman's (2015) concept of "productive possibilities of negative states of being" and the broader theoretical framework of new materialism. This approach allows a more transformative feeling-with that exceeds the normative affective repertoires and scripts associated with a diagnosis of BPD. The authors recognise the often unspoken and invisible affects of complex mental distress and trauma, and purposefully open the space for affective and symbolic aspects of creative artworks to communicate what is less known or has less presence in dominant biomedical frameworks about living with a BPD diagnosis. The article foregrounds the lived and living experience of participants to generate experiential rather than clinical understandings of the diagnosis.

1. Introduction

Arts-based and creative methods are increasingly deployed by humanities, social science and health researchers to elicit tacit lived experiences of participants (Leavy, 2018). Recently, arts-based methods have been utilised by qualitative health researchers to generate more diverse knowledges as well as for knowledge translation and dissemination (Boydell, 2019; Fraser and al Sayah, 2011). For example, Boydell (2011) utilised research-based dance to examine pathways to care in first episode psychosis; Dalglish (2019) used arts-based methods to explore affordances of art-making for artists living with schizophrenia. The knowledge produced in arts-based research is often more accessible to diverse audiences (e.g., people with lived experience of distress, their

social networks, policy makers, health/social care practitioners, and the general community), and it can foster transformative change in knowledge, attitudes, and behaviour (Boydell, 2019). Creative and arts-based methods are also important components of survivor-led communities engendering peer support through collective and collaborative "making" workshops that challenge psychiatric categories, the experience of psychiatric hospitalization, and the medicalisation of distress. One such example of this is the UK-based 'MadArtClub' who hold art clubs for psychiatric survivors in London. Some members of this group held an exhibition in 2023 titled A Sophisticated Insult specifically exploring the experiences of those who have lived with a diagnosis of BPD. Arts-based methods transmit new knowledges and forms of solidarity and sociality through the capacity of the artworks to articulate wi(th)nessing

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(Ettinger, 2007). This potential exists in and through (displaced) traces, links, and relations, which can be brought into new thresholds of visibility and perception. They are important processes in healing and recovery for survivors and in their invitation to researchers to include them in the modalities of sensemaking that are conventionally part of psychosocial research (interviews, for example). Creative and arts-based methods can generate different kinds of knowledges, facilitate new lines of inquiry, pose fresh questions, or contribute to novel research processes.

Arts-based and creative methods contribute to research landscapes that capture sensory, emotional, and relational dimensions of psycho-social life that have historically been difficult to illuminate. By “generat[ing] insights into lived experiences, sense-making, relational connections and affective forces” (Lupton and Watson, 2021, p. 470) and interrupting the usual modes of knowledge making and translation, creative methods have the potential to make us (researchers, readers, health professionals) feel, think, and act afresh (Hickey-Moody, 2013). They also provide those subjected to the more unspeakable dimensions of health and illness, the means to say something, even if the saying requires speculative methods to attempt to do justice to the sense-making. This potentiality of creative and arts-based methods is mobilised by a growing number of social researchers as a mode of reimagining research landscapes, such as reconceptualising research design, what counts as data, what counts as evidence, and what data, or ‘evidence’ for that matter, can do (Bennett, 2022; Hickey-Moody, 2013; Leavy, 2018).

We draw on arts-based psycho-social research to open a fresh line of inquiry into the embodied and visceral knowing about living with a diagnosis of borderline personality disorder (BPD). We recognise that many people with lived experience have different views about BPD, and that respectful language is essential. In this article, we use the phrase ‘people living with a BPD diagnosis’ to indicate the lived experience of people who have received a diagnosis of BPD, and people who identify aspects of their lived experience with symptoms associated with BPD (with or without diagnosis). The sensitivity to language, combined with arts-based methods, endeavours to “overcome the abstraction of psychology from embodied, lived experience, situated within the social nexus” (Bennett et al., 2022, p. 93). Bennett and colleagues add that arts-based psychosocial research contributes to exploring the subjective aspects of lived experience in relation to social, material, and institutional settings, while simultaneously providing scope for these complex experiences to be re-thought and re-imagined. The creative artworks generated through creative or arts-based methods provide a space for processing and transforming lived experience that can be difficult to sense, feel, or verbalise. Creative artworks might also provide circuits of meaning that circumvent or allow a more transformative feeling-with that exceeds the normative affective repertoires and scripts associated with a diagnosis of BPD, which include feelings of shame, disgust, humiliation and other “negative affects”.

2. Borderline personality disorder: counter-knowledges and contestation

Personality disorders are a site of substantial psychiatric controversy (Manning, 2000), with BPD one of the most problematised psychiatric diagnoses. Broadly, personality disorders (PDs) are clinically understood as long-lasting, maladaptive, and rigid personality traits that differ from cultural standards and usually manifest as inflexible responses to a range of situations (Lehtinen et al., 2022). However, this conceptual foundation may be challenged. Some of the most common problems with defining psychiatric categories such as PDs are historical and contextual trends in delineating what and who fits and differs from normative standards (Lehtinen et al., 2022, p. 4) and the diagnostic overlap between PDs and behavioural responses to traumatic events (Duff et al., 2020). Leyten et al. (2020) problematise the perceived rigidity and stability of “personality” in PD diagnosis and instead propose a

relational way of understanding PDs that focuses on social contexts, relationships, and adaptive strategies developed in response to stressful, complicated life circumstances. They specifically note that PDs, particularly BPD, have been theoretically and clinically linked with attachment trauma and/or complex trauma, with complex trauma often deemed one of the causes of individuals’ problems with self and identity. To this end, Porter et al. (2020) suggest that BPD ought to be framed as a trauma-related disorder due to the high correlation between adverse childhood experiences and diagnosis of BPD.

Problematising and foregrounding trauma further, Redikopp (2018) argues that a diagnosis of BPD is a generative site of knowledge production, particularly about traumatic memory, emotionality, and visceral knowing. As Redikopp (2018, p. 79) writes, “our uncontrollable emotions [are] valid forms of counter-knowledge”. This approach to BPD as a form of counter-knowledge expressed through traumatic memory, emotionality and visceral knowing, echoes what Blackman (2015) calls the productive possibilities of negative states of being and what Ngai (2005) has called “ugly feelings”. Many affect theorists have argued that affects are embodied responses that bring together and express multiple registers of experience, where complex assemblages of material and immaterial relations are felt, carried, and embodied in different ways (see Blackman, 2021). This approach suggests that there is an urgent need to provide more public articulation of what is carried “under the skin” as negative states of feeling, which in the case of BPD arguably can find expression through more medicalized, individualised, and psychologised concepts of disorder.

Johnson similarly sees BPD as an important site of intense emotional and embodied pain, “pain is a useful umbrella for the felt-sensations of BPD” (Johnson, 2021, p. 638), making the lived experience of people diagnosed with BPD marked by intense, confusing, and often unbearable pain. This pain is rarely ever rooted in individual subjectivities but rather stems from socio-material and relational contexts that construct possibilities and impossibilities for individual lives. To this, Lewis (2023) a borderline researcher theorising borderline experience from new materialist and vitalist perspectives, adds a personal note:

I want to reclaim becoming-uncategorisable as an existential feeling of borderline experience, and a central tenet of *autø/gnøsis*. To be unknown and unknowable, because our wants and needs, ideas and feelings are always changing, is to live with the awareness that we do not add up. That empty space at the heart of us will confound the psychiatric gaze that seeks certainty ... The borderline diagnostician knows themselves and their world through an intimate understanding of this unstable and indeterminate space (p. 110).

Autø/gnøsis is how Lewis critically and ontologically engages with an impossibility of researching borderline without validating normative system what produced this diagnostic category, such as the *Diagnostic and Statistical Manual of Mental Disorders*. Instead of diagnosis, Lewis proposes *autø/gnøsis*, a process of knowing a self (any kind of self) in an encounter with its own unknowability: “It is a rejection of a unified self, any kind of fixed truth, and the trap of defining oneself purely to become legible” (p. 107).

2.1. Embodied knowing about living with “borderline”

New materialist ontology focuses on “the materiality of bodies as they engage with other material (natural and cultural) relations” (Fox, 2016, p. 70) to flatten the ontology through which health is analysed and to foster an exploration of productive possibilities of different good-health or ill-health assemblages. If we approach mental health as a process that unfolds within a nexus of relationalities (e.g., Duff, 2016; Fox, 2022; Lewis, 2023), we come to understand a diagnosis of BPD as socially and affectively produced through lived experiences inseparable from multiple contexts that partake in their ongoing production. This premise enables us to consider lived experiences of emotional and mental distress diagnosed as BPD as co-produced while also being

productive in presenting a more nuanced picture of human emotionality, pain, and suffering.

Alongside this productive reframing of bodies, mental health, and relations, this article draws on Blackman's (2015) call for critical scholars to consider the "productive possibilities of negative states of being" (p. 28). Blackman's work (2001) is known for conceptualising the inequalities, oppression and suffering individuals who hear voices experience prior to and following instances of voice hearing. Collaborating with the Hearing Voices Network focuses on the relational possibilities afforded to voice hearers engaging with the network, who had often been failed or let down by an assumption that their voices were meaningless epiphenomenon of a disease-process, such as schizophrenia. Developing an ethnography of peer support groups, Blackman explores how non-pathologising practices central to the network created a setting through which their embodied experience of the voices changed and transformed. Attending to the voices in new ways, as meaningful agents of compossibility (see Venn, 2018), allowed the voices to become-available as modalities of knowing, attention and meaning-making that could speak to the context of a voice-hearer's life and biography (see also Blackman, 2016). The question for researchers' and other participants in the groups, became how to listen in and through another's voice(s) (Blackman, 2023; also see Cho, 2008).

The performative methodology central to the peer support groups enabled a more distributed approach to meaning-making, showing the important need for creative methods that can work across distinctions between somatic, symbolic, affective, cultural and technical. Blackman engages with theories of affect and embodiment to examine the potential of approaches to meaning-making that can attend to "traces, fragments, gaps, silences, submerged narratives, displaced actors, and more inchoate feelings and sensations" (2015, p. 29). Drawing together new materialist ontologies and the generative subtleties of "negative states of being", we emphasise some of the complexities of living with and under a psychiatric diagnosis of BPD, whilst allowing and foregrounding the visceral, deeply affective, and embodied dimensions of living-feeling-becoming with, through, and beyond "BPD".

3. Methods and materials

3.1. Method

The article discusses intimate and creative knowing about living with a diagnosis of BPD generated through a nation-wide online qualitative survey. The survey was conducted in Australia in 2021, as part of a larger interdisciplinary study exploring the lived experiences of individuals diagnosed (or self-diagnosed) with BPD. The focus of the broader research was to explore how a diagnosis of BPD is co-produced alongside sociocultural dimensions, familial and community relations, health care treatments and supports, and interactions between practitioners and those with lived experience. This research addresses a diagnosis of BPD as a socio-material co-produced phenomenon, one that is rooted in social disadvantage, marginalisation, gender inequalities, and complex trauma.

The survey was conducted in an initial phase of the research, followed by a) a series of arts-based workshops with lived experience participants, and b) narrative interviews with lived experience participants and health practitioners. The survey was designed in three parts with an aim to generate distinctive empirical and creative materials that foreground experiential narratives about BPD. The first part included 3 open-ended questions focused on everyday wellbeing and practices of self-care. The second part comprised 13 close-ended questions that collected demographic information and asked participants to share experiences of being diagnosed with BPD, such as the process of receiving a diagnosis, experiences of treatment, questions about care and support systems. The third part of the survey focused on the collection of creative artworks.

The study was approved by RMIT University's Human Research

Ethics Committee and by public hospital in Victoria, Australia. The survey, hosted on Qualtrics, was circulated through partner organisations on the larger study, consisting of key national mental health organisations, and their networks and membership. Individuals aged over 18 years old who had received a BPD diagnosis or self-identified as living with symptoms associated with BPD, and resided in Australia, were invited to participate. Participants were given details on the study, its aims, and confidentiality protocols. Written consent was sought for participation in the survey and for reproduction and analysis of the creative data. The survey was open from August to November 2021 after which the data was screened, and subsequent phases of the research commenced.

Research and analysis were carried by a group of qualitative researchers, with significant experience in researching lived experiences of health and illness (RK, LB, KB, JB), with a particular focus on mental health (JF, ES, RK, LB, KB, JB) and arts-based research (TB, KB, JB). Qualitative data typically capture what is important to participants (Braun et al., 2021), including their preferred language and terminology, which makes it a rich method for analysing lived experience. The data collected via the qualitative survey informed further aspects of data collection. Although surveys are more associated with quantitative data, in this case, the survey was utilised "against the grain", counterintuitively, to create a space of meaning-making that was a supplement or parenthetical to medicalized categories. The purpose of this open-ended space was to capture more visceral, complex, and difficult to narrate lived experiences. The method thus provides a platform for capturing unrestricted, candid, and diverse perspectives, experiences, and complex processes of sense-making (Braun et al., 2021) while keeping participants' identities anonymous. Braun et al. (2021, p. 645) suggest that qualitative surveys can "feel completely anonymous ... which can facilitate participation and disclosure in sensitive research". This anonymity was central in our decision to begin the research with the nation-wide online survey to capture more private and difficult to narrate aspects of lived experience leading to further phases of data collection, which focused on co-design (art-based workshops) and collaborative meaning-making (narrative interviews).

We invited participants to submit a creative artwork that spoke to or illuminated their lived experience via: a) written texts (poem or lived experience narrative); b) photographs; c) short video and audio clips; or d) images (drawing, paintings and digital art), with an option to submit up to three, new or pre-existing creative works. This provided a space where participants could present accounts of their experiences including trauma, distress and mental ill-health in creative and abstract ways, allowing a more transformative feeling-with that exceeds the normative repertoires and scripts associated with a diagnosis of BPD, and provide a platform for experiential and embodied knowledge.

3.2. Participants

Sixty-four people responded to the survey, with 32 participants uploading a total of 61 creative works. The creative artworks submitted varied in genre, including 18 photographs, 12 drawings, 12 stories, 11 poems, 7 paintings and 1 song. Two participants also provided links to their websites, YouTube channels and other social media platforms where they posted their creative works. Out of 32 participants who contributed creative artworks, 26 identified as females, four as males and two as non-binary. They were 21–61 years old, and most lived in three eastern Australian states. All participants except one were diagnosed with BPD by a medical professional and one participant self-identified as living with BPD; all but one had received treatment for BPD (psychotherapy, social support and/or medication). Due to the nature of this method, participants did not specifically voice their relationship to the diagnosis thought at times it manifests through their creative artworks. The following two phases of the larger study explored this issue in more depth and these results are to be published elsewhere (Seal et al., under review).

This article focuses on the 32 participants who submitted arts-based data. We develop our analysis in relation to embodied, creative, and affective knowing about lived experience of BPD. We recognise the multiple affects that circulate across complex mental distress and trauma, and purposefully open a space for emotional and imaginative aspects of artmaking to communicate what is less known about living with BPD. In this way, we shift the gaze to the lived and living experience of individuals diagnosed with BPD. The data submitted for the survey contribute to possibilities for cultivating empathy, conceptualised as the capacity to receive, hear, understand, and support communicated and felt distress (Bennett, 2019).

3.3. Analytical approach

Artistic forms of expression offer different ways of doing and thinking about research processes that lend themselves to diffractive analysis and new materialist ontologies (Barad, 2007; Hultman and Lenz Taguchi, 2010; Mazzei, 2014). This includes mapping insights that respond to a specifically new materialist question: *what data can do* (rather than *what data mean*). Diffractive analysis emerges from Barad's (2007, p. 25) concept of "reading insights through one another" and presents a way of analysing data with theoretical concepts that "[produce]an emergent and unpredictable series of readings as data and theory make themselves intelligible to one another" (Mazzei, 2014, p. 743). Diffractive analysis moves analytical work away from habitual normative readings that focus on sameness toward the production of readings that bring data and theory together, read them through one another, in ways that disperse and disrupt thought. Diffractive analysis takes a rhizomatic (rather than hierarchical and linear) form that leads in different directions and keeps analysis and knowledge production on the move.

The selection of artworks presented in this article draws on diffractive mapping and analysing of this data set – thinking the data carefully through the lens of literature and theory (Mazzei, 2014). The selected artworks facilitate productive consideration of the following questions:

How can data extend, contribute, and unsettle some of the more dominant (biomedical) understandings of what it means to live with the diagnosis?

What could one learn about the productive possibilities of difficult feelings via engaging with artworks created to portray or represent the lived experience?

What affordances are offered by the aesthetic evocation of experience rather than descriptive (often clinical) analysis of symptoms or behaviours associated with a BPD diagnosis?

The selection of artworks that are discussed and analysed are informed by a collaborative analytic workshop where the authors looked at the complete creative artworks data set and identified key emerging insights briefly summarised as: the prevalence of trauma accounts; intensity of complex and difficult feelings; accounts of stigma and isolation; calls for empathy; and focusing on creativity and productive possibilities of living with complex distress. This initial workshop was held online in February 2022. In the next phase, the authors worked together over months to identify a selection presented below – two photographs, two poems and two narrative accounts – due to their capacity to condense the general subjects and mobilise insights that emerged across the survey's creative arts-based submissions, without risking the participants' privacy. This process was iterative, diffractive and dynamic; we agreed on some of the artworks immediately and worked over several months to select the remaining ones. The intention was always to discuss creative accounts that escape 'traditional' narratives and foreground visceral, emotional, and affective dimensions of lived experience. We were led by a shared commitment to present a more nuanced picture of human emotionality, pain and suffering, as

seen in the artworks discussed below, and read closely through the lens of the critical and new materialist scholarship. The diffractive process was led by the first and the second authors with other authors contributing equally to selection, analysis, and discussion of the data.

4. Findings

4.1. A call for empathy

Grieving the arrested self

Sometimes I wonder who I would be if life had dealt me different cards ... if I had grown up in one place or stayed at one school, if I was not bullied, if I had not crossed paths with the people I did. Today I dug up some old songs I used to play on the piano when I was younger. With these songs came memories from those days, washing over me like ripples through the lake. It was my first year of high school at a Catholic college for girls and the school took us to stay at [place anonymised]. I was down by the lake with some other girls, and we were instructed to build a raft using some pipes, ropes, and planks of wood. After building the raft using our amateur skills, we were to test it. We nervously set off into the water on our shonky raft praying it would stay intact; we didn't want to sink, especially as none of us were wearing bathers. The whole exercise was a perfect analogy of what the first year of high school is all about. Like the pieces of the boat, we were all, more or less, scattered, trying to form bonds, coherent groups and a coherent sense of self. Over the years, most of us would eventually find our place, find a group of friends and the security that comes with this, and grow in confidence. [...] I feel like, somewhere, I have missed out on this. While others around me sail into the horizon, I have barely left the shore as my boat keeps falling apart. By the time I reached high school, I had already been to four different schools and my self-esteem had been annihilated. I was also bullied at this school which led me to move again in year nine. When I look at photos of myself, it's as though my colours have been washed away. It's as though a part of me has died. To this day I feel like an outsider. I feel like no one really knows me. I feel like I wear many different uniforms. I feel fragmented, lost, confused, unsure of myself. I feel like a butterfly trapped in a cocoon. Or, as Anneli Rufus puts it, a dud popcorn kernel or bonsai tree. (Participant-Artist 1)

Image 1 and the accompanying prose "Grieving the arrested self" were contributed by a 28-year-old, female identifying participant, who was receiving treatment and dealing with severe symptoms associated with a BPD diagnosis. The image, with its grey colour palette, blurred lines, and dream-like affect, complicates the delineation between real and imaginative. The blurred shapes and ghost-like figure of the silhouette on the bench are in stark contrast with the intensity usually portrayed in relation to how emotions are described in accounts of people diagnosed with BPD. The figure depicted in the image is almost unreal, non-existent; she could be a distant memory from the past, a childhood memory, a reminder of the loneliness associated with complex mental illness, or perhaps rendering the felt sense of emptiness and aloneness.

The painful disturbance in self-experience (Schmidt and Fuchs, 2021), and unstable concept of self, have been central to theoretical frameworks used to understand experiences associated with a diagnosis of BPD (Agnew et al., 2016). In **image 1**, the material world around the girl appears almost more "real" than the girl. Conversely, the existential pain speaking through the prose, the sense of lostness and grief after painful past events, brings the image of girl to life. She is there, after all. The narrative helps contextualise the image as a portrayal of a young woman in search of a sense of self: "*To this day I feel like an outsider. I feel like no one really knows me. I feel like I wear many different uniforms*". A phenomenological perspective claims that a certain alienness regarding a person's affect and responses is an inherent feature of how BPD is currently conceptualised (Køster, 2017), while attaining a coherent sense of self and developing responsibility for one's affect and actions



Image 1. Lone silhouette on a bench (Participant-Artist 1).

are considered facilitators of health. The narrative account above frames this sense of identity confusion differently, though the participant shares: “*I feel fragmented, lost, confused, unsure of myself. I feel like a butterfly trapped in a cocoon*”, she places this feeling in relation to the context of her life - “... *if I had grown up in one place or stayed at one school, if I was not bullied, if I had not crossed paths with the people I did*”. The creative data challenge the notion of identity disturbance and points to individuals’ specific life-worlds. A new materialist framework enables us to think through the materialities and relations that produce health and illness (Duff, 2016), such as the sinking raft, school excursion, lake, peers, loneliness and more. Both the image and the narrative account call for greater consideration of traumatic life events (loneliness, bullying) as they contribute to shaping the “feeling world” of an individual, inextricably interrelated with the social context of one’s life. It brings alive a felt sense of loss and grief that challenges more dominant narratives about uncontrollable, defiant young women and the experiences of distress diagnosed (in her case) as BPD.

4.2. The depth of feeling

Untitled

*I’m not going back to hell.
I closed the doors behind me
and swallowed the key.
Now I suffer from heartburn,*

*but at least my eyes are clear.
As bloody tears roll down my cheeks
I remember
I’m alone.
Even the stars in the black sky
have abandoned me.
My existence was only a madman’s daydream.
Now he’s woken up,
the breath torn from my lungs.
And my twisted thoughts
are no more ... (Participant-Artist 2)*

The poem “*Untitled*” was contributed by a 39-year-old female identifying person diagnosed with BPD over 5 years ago and currently receiving treatment. It focuses on the lived experience associated with a diagnosis of BPD as inseparable from intense embodied and emotional pain (Johnson, 2021; Redikopp, 2018). This emotional intensity is often associated with emotional despair, substance use, self-injury, and suicidality; as Johnson emphatically states, “*BPD hurts*” (2021, p. 637). This pain-centric conceptualisation of BPD requires an embodied understanding that pain also affects *more than* a body. Lived experience of BPD is known for its association with pain: emotional pain; chronic fatigue syndrome/myalgic encephalomyelitis; fibromyalgia; joint and muscular pains are common (Frankenburg and Zanarini, 2004). Understanding the nature and severity of this pain can promote better physical and mental health care supports and outcomes (Biskin et al., 2014), since pain manifests in multiple forms. Yet, the poem above offers more than a visceral rendering of pain; it reads pain and despair with humour and rhythm (*I closed the doors behind me and swallowed the key. Now I suffer from heartburn, but at least my eyes are clear*). The closing of the doors, the swallowing of the key, the felt sense of aloneness and acceptance, the play with existence and non-existence, all bring us closer to the unknowingness and indeterminacy of people’s ever-transforming becomings (Lewis, 2023).

Instead of dismissing the pain or, as Johnson (2021) writes, utilising psychotropic medication to “not feel it”, she proposes understanding pain as a site of knowledge production, particularly the limits of Western epistemologies in understanding emotion, visceral knowing, and traumatic memory. The intention here is to contrast the shame and stigma often associated with the lived experience of a BPD diagnosis, particularly the intensity and lability of emotional pain, relational challenges, and harmful behaviours. The pain in this way cuts across the biological and socio-cultural body (political too) to indicate complicated ways in which materiality of the body and materiality of pain produce possibilities and impossibilities in people’s lives. The existential pain communicated through the poem asks us to reframe how pain is understood and to seek possibilities when encountering affective intensity.

The line “*even the stars in the black sky have abandoned me*” (Participant-Artist 2) generates a different affect to that of saying “*I feel alone*”. Reading this carefully with the notion that emotional pain associated with BPD stems from socio-material and relational contexts that produce (im)possibilities for individual lives, opens productive lines of inquiry. The question of environment, “*what kind(s) of environment is(are) producing this sense of pain*” is useful for a psycho-social understanding of BPD, the question “*why pain*” calls for a more affirmative approach to the lived experience of a BPD diagnosis, while the question “*who needs to read and hear this*” points to the politics of care; how the affective experience of reading the poem can support an empathetic response by those who can respond. The poem affirms the pain as a *palpable* experience of emotional intensity (Redikopp, 2018) while raising questions of inequalities, particularly those socio-material, relational, and health-



Image 2. “Crazy beauty in my mind” (Participant-Artist 3).

related.

4.3. Reflections and dynamic becomings

I painted a dried-out palm tree seed pod branch white and wrapped it in fairy lights and call it “crazy beauty in my mind” ... to depict to myself that inside my mind and emotions is also beauty and although I can't always see it, I can look at this picture and understand myself a little better.

When I was child I started to observe myself, by myself, like I could see myself interacting, critiquing myself, giving myself tips on being in the situation. It developed into me ‘re-creating’ myself several times over in my early adult life. [...] I found it extremely difficult to understand ‘what people wanted from me’ growing up, relationships and friendships were confusing and frustrating, child sex abuse and a very restless and un-emotional father and over emotional mother made it difficult to regulate my understanding of ‘ordinary’ emotions. My other self kept me safe, and would guide me. As I got older my other self was destructive, evil and lurked inside me. My emotions, thoughts and actions, become dark, unsafe, brooding, lashing out [...] I know now this was trauma, from a very young age, and no appropriate parenting to help me know what was happening to me was not my fault.

I am always working on being emotional and [on my] mental level – I embrace my quirks and do activities that bring colour, light, sound, movement, pictures into my everyday life and create constant stimulus of a positive nature. [...] My passion is to help people come back from ‘madness’ and live with mental and emotional diversity with dignity. (Participant-Artist 3)

The participant, a 49-year-old female identifying person, diagnosed with BPD over 10 years ago and currently receiving treatment shares her motivation for creating the visual artwork in the first narrative account above - “to depict to myself that inside my mind and emotions is also beauty” (Participant-Artist 3). [Image 2](#), an illuminated, radiant network of a mind presented against the dark background reflects vitality, acceptance, and radical beauty. A glowing web of lights spreading in unpredictable directions defies the blackness that surrounds this image. There is no system to this grid; nor is there a body hosting the web. The image however still radiates and allows for a different imagining of the borderline, the one where dark and bright light do not oppose each other

but co-participate to create a dynamic experience: “inside my mind and emotions is also beauty and although I can't always see it, I can look at this picture and understand myself a little better.” (Participant - Artist 3). The dynamism of the image and accompanying narrative account embody fluidity, contradiction, and the dynamic production of a self. This notion of a fluid self or multiple selves contradicts the previously discussed notion of the self - central to the conceptualisation of PDs and BPD - as a stable construct ([Agnew et al., 2016](#)). The visceral affect this image evokes escapes simplistic binaries of good or bad, well or unwell, healthy or ill; it opens possibilities of learning to live well with distress, or in the words of the participant-artist: *to live with mental and emotional diversity with dignity.*

4.4. Possibilities for hope and empathy

[Blackman \(2015\)](#) uses the concept of “ordinary suffering” to criticise biomedical approaches that tend to pathologise pain and suffering, and to point to inevitable links between suffering, feeling ill, and the everyday costs of neo-liberalism. For Blackman and other critical feminist and affect theorists (e.g., [Cvetkovich, 2012](#)), there is nothing exceptional or disorderly about suffering in the context of a neo-liberal world marked by a lack of system supports and persistent inequalities. Blackman calls for addressing “the productive possibilities of negative states of being” (2015, p. 28) not to negate the immobilising pains and suffering individuals live with, nor to advise us to look for hope and optimistic futures, but to consider an uneven, processual plane on which suffering is inevitable, ordinary, and potentially sensible. Rather than an aspect of individual pathology, there is productivity in suffering. It is generative. It calls for attention (and sometimes, mobilisation). The author of the poem above is a 24-year-old identifying as female who was in treatment related to her BPD diagnosis and described herself as in remission. She is also, as written in her short narrative account ([image 3](#)), a trained counsellor. The poem reveals the aggregate effects of living with the distress associated with BPD: ongoingness and emotional labour of lived experience, a sense of hopelessness entangled with hope, empathy, intense emotionality (including positive emotion) and sensitivity to human and more-than-human suffering: “BPD gave me the burden of so many things I didn't want, but it gave me the gift of empathy, being able to love whole heartedly, and the want to help others who are in pain” (see [image 3](#), Participant -Artist 4).

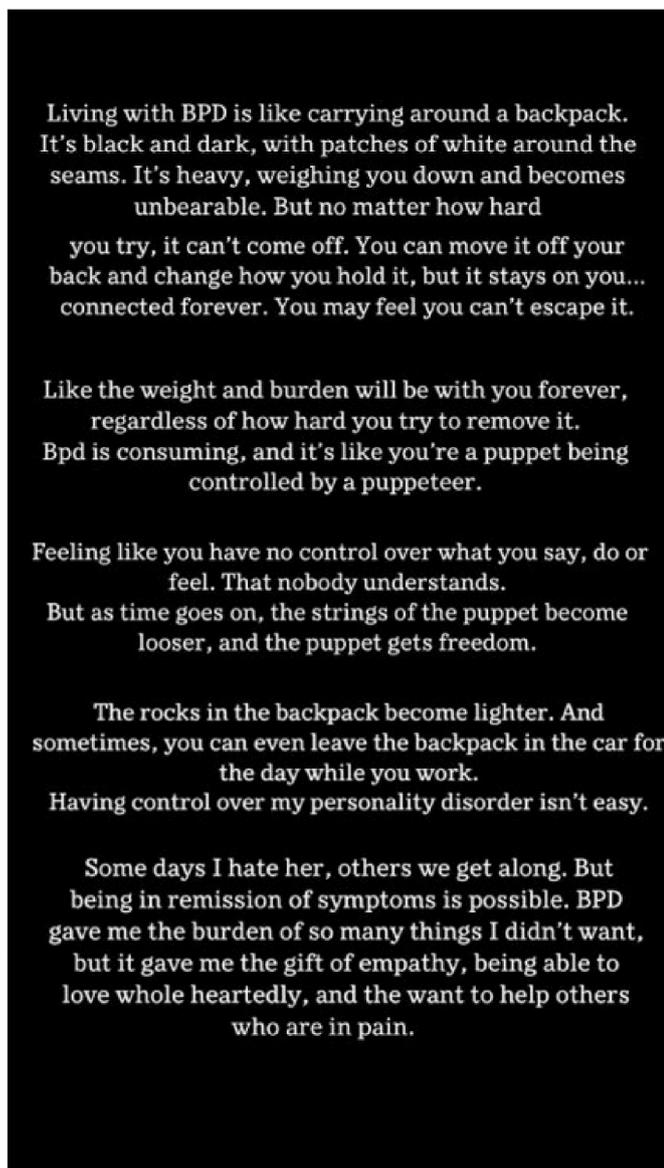


Image 3. "Living with BPD is like carrying around a backpack" (Participant - Artist 4).

Hi! I was diagnosed at 15. Then never got specific treatment and was told to forget about it. I am now a counsellor and was rediagnosed at 21!

The poem reads similarly to another participant's narrative account. This 35-year-old woman, diagnosed with BPD over 10 years ago and receiving treatment at the time of submission, says:

Having BPD has been an amazing journey. It has been full of ups and downs. I have learnt to embrace the diagnosis as I have met so many awesome people on my journey. I don't regret a single moment. It has made me a better person in that I am more compassionate, understanding, and helpful to others. I've learnt so much more about myself which I don't think I'd understand otherwise. I don't see BPD as a life sentence. There is definitely hope and recovery. However, it takes a change in mindset and damn hard work! But it is WORTH IT! (Participant-Artist 5)

The poem and the narrative account introduce possibilities for empathy, compassion, recovery, hopeful futures, and a sense of meaning, connection, and affirmation enmeshed with the experience of mental distress. The narrative data allow the notion of multiple and relational subjectivities to emerge, fleetingly pointing to the possibilities

for transformation e. These possibilities however might not be readily available to everyone, and we would be wise not to rush in advocating for 'recovery' or 'overcoming' while erasing complexities in people's lived experiences of trauma, pain, and marginalisation.

5. Concluding discussion

The diffractive analysis developed in this article considers all kinds of matter, including human bodies, not only as something that is formed by the forces of language, culture, and politics, but also, as something that is formative in itself (Barad, 2007). New materialist scholarship is concerned with dynamic entanglements through which "things" and human beings come to be and continue to become. This focus on "things" includes the materiality of flesh and other physical and biological materialities with which bodies come into contact, along with the sociocultural and political constructs that bear upon bodies materially (Coole and Frost, 2010). To this end, new materialist ontology focuses on socio-material production of the world which enables an exploration of how various matter (bodies, objects, and ideas) provoke, inform, challenge, or produce each other.

Arts-based psycho-social research is particularly well suited to this kind of diffractive analysis, illuminating human dimensions of health and illness by introducing personal, emotional, experiential, and embodied expressions of lived experience (Boydell et al., 2016), while simultaneously providing scope for these complex experiences to be re-thought and re-imagined. The qualitative research discussed in this article aims to contribute to the democratisation of research practices by including non-dominant ways of knowing. In this way, we provide a platform for understanding the emotional toil of mental illness. We respond to Back's and Puwar's (2012) call for research practices, framed as *live* methods, that are attentive to the doings of social life. Our research calls for consideration of the adversity, barriers to progress and inequalities people experience by cultivating empathy and understanding, while also unsettling us as 'researchers'. The connection between participant-artists and audiences that arts-based methods enable fosters communication of more distressing and complicated content.

The arts-based data discussed in this article perform several functions. The data generate profound insights into living with prolonged distress; the sense-making, relational aspects, and affective forces. They make the felt sense of pain, despair and hopelessness more intelligible to those outside of the experience, while also cultivating opportunities for empathetic encounters in which the audience gets to feel and imagine the intimate worlds of people living with intense distress. Not to gaze *at the other* but to sense, feel, and fleetingly grasp what kinds of supports are necessary for adequate care and treatment. Finally, we suggest that the data presented in this article problematise the abstraction of biomedical and diagnostic approaches from embodied, lived experience, situated within the social nexus, and challenge normative notions of health and wellbeing by introducing diversity and multiplicity, and illustrating that living well with the 'disorder' is possible.

Arts-based research often orients towards surprise. It is productive in bringing liminal aspects of the dynamic lived experience of health and illness into the domain of knowledge making and policy work because they are situated at the nexus of subjective lived experience and socio-material contexts. It points to the relations between sensation, emotion, affect and policy (in this case, health care and social care policy). In drawing together new materialist ontologies and the generative subtleties of ordinary suffering ([anonymised], xxxx), we aim to emphasise the visceral, deeply affective, and embodied dimensions of living-feeling-becoming with, through, and beyond BPD. The lived experiences documented in our study bring forth the elusiveness, open-endedness, and unknowingness of the lived experience of a BPD diagnosis. The data provoke a different picture of borderline, one where lived experience of an individual is at the centre, understood as materially, socially and affectively co-produced and inseparable from multiple contexts that partake in its shaping. The visceral effect of arts-based

data communicates the multiple affects of living with a BPD diagnosis; the question is: *who needs to see and hear about this, and who needs to respond to this?*

Our intention is that this arts-based data contributes to broader understandings of the lived experience of distress associated with a BPD diagnosis, particularly for people who might feel isolated in their experience and in their immediate social circles. We advocate that arts-based approaches can contribute to addressing stigma by cultivating empathy among health and social care professionals, policy makers and the broader community, to create better lives for people experiencing distress. In this way, the critical impacts of arts and arts-based research on social and cultural change becomes visible. Finally, arts-based data do not fail to surprise: humour and creativity come through the poems and narratives to paint a different picture of mental ill-health, one where feeling well and being well co-exist with mental illness, alongside joy and pain. In short, this data underscores how the rich experience of 'BPD' cannot be fully 'known'. It continually exceeds its taxonomy; its 'symptoms' are insufficient to capture the breadth and reach of experiences.

5.1. Limitations

While productive in ensuring anonymity and foregrounding aspects of lived experience that at times escape language and dominant modes of knowing, the arts-based online survey method gives limited opportunities for participants' contribution to the analysis process and for collaborative meaning making. We foreground the lived and living experience of participants aimed at generating experiential rather than clinical understandings of the diagnosis, however, in doing so, we rely on our diffractive mapping and analysis of the data. We recognise that this method is imperfect, complex and has often left us wondering and wandering with the data that survey participants-artists generously shared. We are tethered to particular images, sounds, and stories as we bear witness to, and are affected by, experiences of distress, pain, trauma, happiness, elation, fear, doubt, and ambivalence. Much is left unknown about our participants and their life stories. The brief glimpse into their feeling-worlds via their poems, images and stories offers a unique insight into the complex terrain of trauma and mental distress yet leaves many questions unanswered. Further research is needed to determine the doings of stigma on the production of lived experience of BPD and particularly into productive ways of counteracting it.

Ethics declaration

Ethics approval for "Borderline Personality as Social Phenomena: An Interdisciplinary Study" was obtained through the RMIT University's Human Research Ethics Committee (HREC) based in Victoria, Australia, approval number: 23089, approved on May 15, 2020 and Royal Melbourne Hospital Human Research Ethics Committee, approval number: HREC/65990/MH-2020-239433(v2), approved on November 23, 2020.

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Data availability

The data that has been used is confidential.

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