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Illness identity on social media: a qualitative content analysis of #bpd

1 Introduction

People living with a diagnosis of borderline personality disorder (BPD) are noted to suffer from identity disturbances, mood swings, difficulties with maintaining interpersonal relationships, and chronic thoughts of self-harm and suicide. Community-based surveys estimate the prevalence of the disorder at 4-16% ⁽¹⁾. It is a common disorder encountered in both psychiatric and general health care settings, and is often associated with stigma and lack of understanding from health professionals ^(2,3). Little is understood about the ways in which people identifying with this diagnosis interact with social media platforms such as Instagram, and how a shared identity is constructed in these virtual media.

1.1 Literature review

The existing qualitative literature on the lives of those with borderline personality disorder is predominantly focussed on verbal or written reports of experience, and frequently focuses on interfaces with health care systems ^(4,5) or the views of health care workers ^(6,7). Ng and Townsend's interviews of 14 women identified "being stuck", "diagnosis" and "strengthening sense of self" as key themes in their recovery process ⁽⁸⁾. Similarly, Carrotte et al interviewed carers and patients with a lived experience of BPD, naming six broad themes in the experiencing of accessing treatment: identity and discovery, (mis)communication, complexities of care, finding what works (for me), an uncertain future, and carer empowerment ⁽⁹⁾. This work suggests that there is a difficulty in patients who identify with a BPD diagnosis communicating with and navigating the health care system, and that identity may be uncertain and fragile.

Taking a more phenomenological view, Dammann et al explored the concept of self-image in BPD among 12 patients admitted to a psychotherapy unit in Sweden, and found that while individuals tended to describe themselves as mostly “friendly” or “sensitive” in comparison with others, they also would make statements with little meaning that highlighted difficulties in self-description and had little relevance to characterisation ⁽¹⁰⁾. This highlights the potential limitations in relying upon verbal descriptions of lived experience. The struggle to communicate is mirrored in health care practitioners’ difficulty in making meaning of patients’ presentations, with shifts between “connection” and “disconnection” being a prominent experience ^(6,7).

A recent discourse analysis of content from the text-based social media site Twitter provides some preliminary ideas on BPD and identity in the social media sphere ⁽¹¹⁾. The authors take a social constructionist stance, and thus identified two strands of identity discourse - one which creates “BPD as the existence of tension”, and the other “BPD as a different existence”. This suggests that users who self-identify with the diagnosis of BPD see themselves as “other”. Although this analysis is of a text-based medium, it assists us in our interpretation of the data presented here.

Image-based social media present a unique opportunity to deepen our understanding of these lived experiences. Instagram is among the most highly-used of these. It is a mobile, social networking application that has risen to prominence since launching in 2010. In 2019 it reached over a billion monthly users, with high numbers of children, adolescents and young adults using it regularly. Users are disproportionately female, particularly in their second and third decade of life, coinciding with the time when borderline personality disorder is most

likely to be causing impairment and distress ⁽¹²⁾. The platform is centred on image-sharing, although users often caption their images with commentary and hashtags, and can choose to make their content publicly available or private.

At the time of this review, there is scarce research into how people who identify with the diagnosis of BPD use images (including photographs, artwork, and other visual forms) to construct and make sense of their experiences. In the related field of self-harm (also frequently referred to as “self-injury” or “non suicidal self-injury”), there has been some investigation of the use of Instagram to share images of self-harm, driven in part by concerns of contagion and promotion of self-harm ^(13–15). A qualitative analysis of Twitter content suggests that a rich and complex social network exists around these symptoms. Five themes were identified including: celebrity influence, self-harm is not a joke, support for and from others, eating disorders and self-harm, and videos and personal stories ⁽¹⁶⁾. However, it is unclear whether use overall contributes to effective coping or exacerbates distress and avoidance.

In the body-image and fitness communities of Instagram and other social media, it seems that images tend to skew towards a particular type of body ideal (toned and thin), which perhaps has dual functions of motivating consumers of media, but also contributing to self-deprecation ⁽¹⁷⁾. Correlational research suggests there is a significant negative effect of viewing these types of images on self-esteem and self-compassion ^(18,19). This may have some overlap with pro-eating disorder and other mental illness communities on Instagram.

The qualitative work in the self-harm and body-image fields was used to inform our approach to understanding borderline personality disorder communities. Creators and consumers of

social media appear to interact with social media in a complex and sometimes ambivalent way, and the resultant community identities likely reflect these contradictions.

2 Aims and objectives

This study aimed to explore the themes related to self- and illness- representations in a public online community. We hoped to respond to the following questions:

- (a) What types of images contribute to a collective identity of illness in borderline personality disorder?, and
- (b) What themes and messages arise in an online community centred around borderline personality disorder?

Based on the existing literature, it was hypothesised that there would be a diverse mixture of types, content, and valence of image, including both positive or supportive content, and negative or devaluing content. It was also hypothesised that there would be significant tensions and contrasts between themes, and that self-representations may be ambivalent or unclear.

It is hoped that this research will contribute to a deeper understanding of the lived experience of people identifying with a diagnosis of BPD, and potentially identify ways in which use of social media may be used for self-management, connection with others, and the creation of online identities. This is particularly relevant for clinicians working with patients who identify as having BPD, and will assist them in understanding the wider experience of this group.

3 Methodological rationale

Content analysis, broadly speaking, has been increasingly recognised as an important tool in sociological and health fields in recent decades. It focuses on the characteristics and context of the data in a manner that is both consciously subjective and systematic, with the aim to understand a phenomenon with information derived from the lived experience ^(20,21). This is in contrast to purely quantitative approaches which tend toward pre-defined, researcher-imposed methods of measuring experiences or outcomes. It is also an approach that has been used successfully to understand visual phenomena in health-related fields, most notably in Instagram “fitspiration” and fitness communities ^(22–25), and to a lesser extent in the self-harm community ⁽²⁶⁾. We believe this is a useful way to begin to understand the internal experience and identities of the #bpd community, which has not been examined in this manner in previous research.

4 Methods

This research focuses on images associated with BPD. The Instagram platform has been chosen for its ubiquity, and richness of the data available. As a mobile social media platform, Instagram is far more common in everyday use than blogs and discussions forums. Most commonly used on personal mobile devices, Instagram facilitates users’ public engagement in a highly personal way. This project utilised an inductive process of data analysis with a phenomenological approach.

4.1 Data collection

Publicly-available images from the “bpd” hashtag (#bpd) from the image-sharing site Instagram were collected from the application over the month of March 2019. Interval sampling (every tenth image) was used to collect a total of 200 images. Based on previous work which has analysed visual social media content, this quantity of data was thought to provide both representative breadth and allow fine-grained analysis of phenomena ^(20,27,28).

4.2 Coding procedure

Images were collated in a Microsoft Excel spreadsheet to assist with analysis. The images were initially annotated with detailed descriptive notes of the content, then coded according to surface content (e.g., words, people, objects, animals) and emotional valence (positive, negative, mixed, ambiguous). The images were then reviewed to manually assign codes to aspects of each. This process of coding was repeated several times to ensure the details of each image were accounted for. The researcher made notes during the coding process which assisted with contextualising the data in existing knowledge.

Following this, the coding units were collated into an adjacent spreadsheet and organised into preliminary subthemes. Subthemes with significant overlap were consolidated, while those with scarce or apparently irrelevant content were put aside. Ultimately codes were organised into a few broader themes which the researcher thought captured the essential aspects of the data set.

The inductive coding process and construction of themes were repeatedly discussed with supervisors, and reviewed with regards to existing literature in order to ensure interpretive

rigour. By cycling through the data, existing literature and reflecting on the analytic process the researcher sought to respond meaningfully to the research questions.

4.3 Reflexivity

The researcher is a psychiatric trainee, with general medical training, working in a major metropolitan city. She has experience working with people with a diagnosis of BPD in public health settings. She was supervised during the project by a consultant psychiatrist with experience in both public and private practice settings, and an anthropologist with research interests in digital media and ethnography. It is intended that this interdisciplinary supervision of the work will enrich the analysis and promote both procedural and theoretical rigour.

4.4 Ethics

The data used for this project is exclusively from publicly-accessible images hosted by the image-sharing website Instagram. No identifying information is included in the report, and description and examples of research data are chosen to maintain anonymity. As the data is considered in the public domain, formal ethics committee approval was not sought.

5 Results

5.1 Overall content type

The data included a wide range of content types, with 41.5% of images including some form of written communication, 24.5% including images of the environment (such as animals, landscapes, and buildings), and 24.0% including single or multiple people. Other content types included artwork, food, and characters from popular culture. Details of this are presented in Table 1.

Table 1: Surface content

Content type	n (number of posts containing these items)	% (percentage of posts containing these items - total >100% as multiple types may be contained within a single image)
Written communication (quotations, comments, information)	83	41.5
Environment (the natural and built environment, animals, plants)	49	24.5
People (single or multiple)	48	24
Art (comics, illustrations, sketches)	22	11
Memes ^a	22	11
Characters (from television, pop culture, etc)	14	7
Food	7	3.5
Other objects (drugs, car, alcohol, medication)	5	2.5

^a An Internet meme is a piece of culture, typically a joke, which gains influence through online transmission ⁽²⁹⁾.

A broad assessment of emotional valence was completed, demonstrating a mixed picture of content, which is shown in Table 2.

Table 2: Emotional valence

Valence	n (total N=200)	%
positive	75	37.5
negative	61	30.5
mixed - both positive and negative aspects	25	12.5
ambiguous	39	19.5

5.2 Description of themes

Five themes were identified from this set of images, ranging in tone from deeply pessimistic to affirmative and hopeful.

5.2.1 The fragmented and obscured self

Users' images of people revealed a tendency to adorn and obscure their appearance with devices such as heavy makeup, unnatural coloured hair dye, and tattoos. Alternatively, users employed image filters that changed the colour scheme, added superimposed items (for example love hearts, bunny ears and noses), or limited the field of view to only a small part of the body. The result of this embellishment and distortion was a heavily modified view of self that suggested a strong motivation to change one's external appearance.

These images occurred alongside comments and written information that pointed to a disconnect between internal and external selves. This was tied to a sense of confusion, driven by a belief that they had been or are “broken”, and had struggled to draw coherent meaning from their experience.

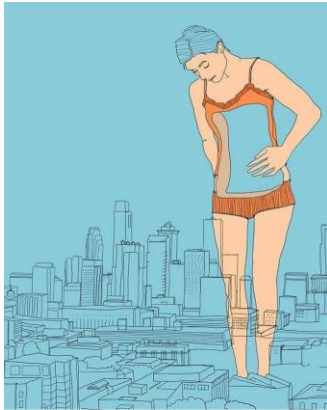


Fig. 1. Illustration of a person missing part of their bodily self

5.2.2 Trepidation and disappointment about the threatening and persecutory world

This theme encapsulated users’ belief that they were, and may continue to be, the target of violence and rejection. Verbal warnings about degrading or dismissive relationships appeared in starkly contrasting colours. Users voiced their disappointment that their emotions were ignored or misunderstood by both individual people (examples included parents, partners, friends and mental health clinicians) and by society at large. At times memes were used to illustrate this sentiment, depicting the villainous “other”. Users described the belief that others were “mad at me”, have “no conscience”, and were indifferent to the users’ inner experience.

Examples of images illustrating this theme included a dark photograph of police at night, pulling over a car at the side of the road, and embellished quotations such as “There is no safe

way to remain in a relationship with a person who has no conscience. The only way is to escape”, and “Be careful what you tolerate. You’re teaching others how to treat u.”

When staff pushes all my buttons to see how I react and later says I'm unstable, blaming me for yelling at them to make them stop



Fig.2. Meme depicting the experience of being blamed and provoked by others

This theme was characterised by a sense of fear verging on paranoia. This component of the #bpd community is imbued by an intense feeling of despair, and reminders to protect oneself from future insults.

5.2.3 An existence built of illness and symptoms

A part of this community was distinguished by illustrations, lists and descriptions of symptoms. The written component appeared to be heavily influenced by the medical model and language of illness.

Images detailed both mental and physical symptoms of BPD, suggesting that users perceived the illness as being of their bodies as much as their minds. Physical exhaustion, pain, and bodily discomfort were intermingled with symptoms of memory and motivational impairment, and emotional exhaustion. Symptoms were often referred to as “invisible”, and those with illness externally indistinguishable from the well.

The influence of other mental disorders was prominent within this theme - images alluding to trauma-related and eating disorders were common. A number of stark, close-up images of somewhat mundane foods suggested a degree of crossover with the eating disorder community, and suggested that users of #bpd may struggle with the idea of self-nourishment.

At times users would share very practical, written advice about how to self-manage symptoms, some of which appeared to derive from formal psychotherapeutic modalities such as dialectical behavioural therapy and cognitive behavioural therapy. Examples of this included a photograph of a handwritten self-management plan, and a list of questions intended to assist reflection. This enhanced the psychoeducational nature of this theme, which appeared to provide information not only on diagnosis and symptoms, but on treatment and self-help.



Fig.3. Image suggestive of distress and pain as a symptom of BPD

5.2.4 Finding comfort in the natural and built environment

Many of the posts in the data set appeared to focus on the outward environment and objects of comfort. Users appeared to use this community to share images that tended to promote a sense of calm or reassurance. Many similar motifs recurred throughout this theme - landscapes of the ocean, forests and fields appeared amongst romantic depictions of long

roads and views from an aeroplane window. These views were stereotypical and relatively simple in their framing and presentation. Users tended to avoid including people in these settings, although a small sub-set of images included domestic animals, frequently pictured returning the gaze of the camera. These animals were not threatening in character, but framed as both the givers and recipients of affection. Users shared images that were gentle, easy to view, and engendered feelings of solace and stillness. The dream-like character of this theme could be read as escapism - a need to turn away from self to fantasy.



Fig. 4. Impressionistic photograph of a road lined by bare trees

5.2.5 Sharing hope and positive experiences of growth

This theme captured users' optimistic reflections on difficult and damaging experiences. In particular a wish for self-awareness and emotional development was expressed through a mixture of quotations and imagery. Many users referenced histories of emotional, physical and relational trauma in reflecting on personal growth, but only occasionally included images of actual people in their posts. Flower and plant symbols, alongside spiritual figures such as the Buddha, featured heavily alongside reassuring quotations. The use of bright and pastel colours throughout these images suggests that users seek to share calming and positive emotional experiences, or to reflect these emotions back to themselves. The contents of this theme contrasts heavily with the morose and pessimistic images described previously.

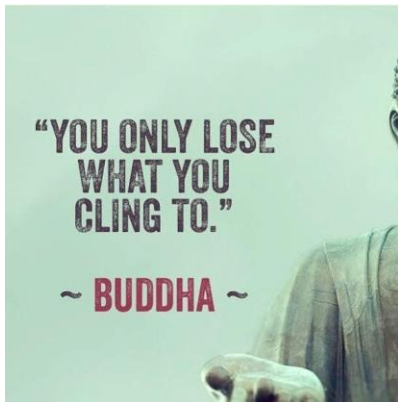


Fig. 5. Philosophical quotation with visual reference to spiritual figure

6 Discussion

The aim of this study was to explore how identities are created in an image-based mental illness community. The five themes identified in our findings suggest that these identities are highly complex and reflect a wide spectrum of experiences within self and in the world. A diverse range of image types were used to illustrate these experiences. The #bpd community depicted their experience as both hopeful and hopeless, and the self as variably broken, shameful, capable and in flux. The world around them could be confusingly polarised - a source of persecution and despair, but also of reassurance and warmth. The dramatic contrast between aspects of personal and relational identities is consistent with Dyson's analysis of BPD "as the existence of tension"⁽¹¹⁾.

The prominence of environmental images may point to safety being located in non-human objects such as buildings, natural landscapes and animals. It may also highlight the relative untrustworthiness of human relationships which were frequently depicted as treacherous. These objects may reflect a need or desire to retreat into fantasy when reality is too difficult to bear. It is postulated that resituating oneself in natural environments may be an important

self-management strategy for people with BPD. Similarly so, the inclusion of animals in images may reflect an ongoing yearning for meaning and attachment ⁽³⁰⁾.

The optimistic aspects of the data found in “Sharing hope and positive experiences of growth” seem to reflect genuinely positive sentiments. However, an alternative reading of this data may be of shallow or overgeneralised platitudes, which may be more in keeping with identified difficulties in self-image and self-description ⁽¹⁰⁾. We suggest that both interpretations can co-exist, and that the contradiction this entails is key to understanding this community.

Symptoms were constructed in ways that deviated from the dominant psychiatric model of illness. Users communicated illness as being situated in physical and social spaces as much as the mental and emotional space. In some cases “medical” language and themes were extended and reinterpreted to include concepts from related experiences such as trauma and anxiety. On the other hand, it is likely that users are strongly informed by their interactions with health care workers and institutions, and part of the way they communicate around their illness is derived from these relationships. It is likely that these illness representations are borne as part of users’ common identity.

A key finding of this research was the theme of “the fragmented and obscured self”. While identity disturbance is considered to be a common feature of BPD, this research points towards some of the specific ways in which this manifests. At times users portray themselves as “broken”, perhaps in response to traumatic events or relationships, and provide a similarly fragmented depiction of their surroundings. It seems that part of the attempt to manage this fragmentation is to cover up or dramatise one’s physical appearance, either by actual means

(e.g., tattoos, unnatural-coloured hair dye) or photo reprocessing (e.g., image filters, colour modification). This may form a means of protection for the “inner” self which is experienced as fragile and incoherent. The tense fragmentation identified in this work contrasts significantly to verbal accounts of self-image in Dammann et al’s study, where descriptions such as “sensitive”, “friendly” and “loving” were more commonly identified ⁽¹⁰⁾. This difference may be related to the mode of communication (visual versus verbal), or the use of a virtual platform to communicate with peers, rather than face-to-face interactions with researchers.

6.1 Limitations

Our findings must be considered in the context of a number of research limitations. Firstly, the researcher did not verify whether users are self-diagnosed, or have formal diagnoses of BPD or other psychiatric disorders. Secondly, data was collected from only one social media platform, which may not be representative of communities on other sites. Such platforms frequently change in their content algorithms, policies, and degree of transparency, which means these communities may be subject to rapid shifts in membership and ways in which users interact on these platforms. The researcher also acknowledge that the study was limited to only one hashtag and did not explore related hashtags such as #EUPD (emotionally unstable personality disorder) or #CPTSD (complex post-traumatic stress disorder). While this ensured feasibility of the study, it also means we must be cautious about the transferability of the research findings to other online mental illness communities.

7 Conclusion

The results of this study demonstrated that #bpd encompassed a variety of content types, with a wide spectrum of emotional tones expressed through photographs, written communication

and artwork. Themes reflected previously identified aspects of the lived experience of BPD, including tension between different parts of identity, and struggles with characterising self-image. This research adds further detail about how self may be modified or hidden in online and real-world representations. This may have ramifications for patients and clinicians, who might use this knowledge to explore identity in a therapeutic context. Similarly, the prominence of medicalised language and illness constructs may be of relevance when approaching psychoeducation interventions. The sense of persecution and fear that features heavily in this community may be yet another reflection of the stigma experienced in health care and general settings. Further research could consider the interrelationship between different mental illness communities, and investigate how individuals respond to the various themes of #bpd, in addition to how clinicians might use these platforms in therapeutic settings.

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