



# Exploring stigmatisation among people diagnosed with either bipolar disorder or borderline personality disorder: A critical realist analysis



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## ABSTRACT

This study explores experiences of stigma and discrimination amongst people diagnosed with bipolar disorder (BD) or borderline personality disorder (BPD). Inspired by Margaret Archer's morphogenetic sequence and the ontological depth of critical realism, a temporal framework for stigmatisation, incorporating structure and agency, is developed and used to situate these experiences. A literature review found very little existing research on the subjective experience of stigma amongst these diagnostic groups. Indeed, most mental illness stigma research is quantitative and focussed on schizophrenia and depression. In-depth interviews were conducted with twenty-nine people diagnosed with BD or BPD, along with five 'friendship' mini-focus groups within the UK. Participants were recruited via charities and participant networking. Using thematic analysis, along with abductive and retroductive inference, experiences and anticipation of stigma and discrimination for participants with one of the two diagnoses in various contexts of social interaction were found to coincide with 'four faces' of oppression: cultural imperialism (pathologisation, normalisation and stereotyping), powerlessness, marginalisation and violence. Such experiences implied a range of antecedent social and cultural structures. Implications for the stigma concept are discussed.

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## 1. Introduction

### 1.1. Stigma theory as applied to mental illness

Fifty years ago Goffman (1963) emphasised that human attributes, characteristics or traits were not shameful in themselves, but could have discrediting effects if they were considered incongruous with cultural expectations placed on their bearers in social interaction. It was these discrediting effects, he argued, that made a particular feature a stigma.

Since then, the stigma concept has developed considerably. Scambler and Hopkins (1986), for example, made the distinction between *stigma* as an ontological deficit (i.e. implying bearers are 'imperfect beings') and *deviance* as a moral deficit relating to 'doing wrong'. Within the context of mental illness stigma, both the labelling of mental distress (Link et al., 1987, 1989; Scheff, 1966) and the cognitive, affective and behavioural responses to *behaviour*

indicative of mental disorder (Corrigan et al., 2000; Crocker et al., 1998; Hinshaw, 2007; Jones, 1984; Thornicroft, 2006) are considered germane (Link et al., 1999, 2013; Pescosolido and Martin, 2007; Siltan et al., 2011). Moreover, during the last decade or so, attempts have been made to expand and reorient stigma's theoretical lens to focus on meso and macro socio-cultural structures and power (Link and Phelan, 2001; Link et al., 2004; Parker and Aggleton, 2003; Pescosolido et al., 2008; Scambler, 2006a, 2006b; Schulze and Angermeyer, 2003). Link and Phelan's (2001) and Link et al. (2004) stigma concept, for instance, consists in the co-occurrence of labelling, stereotyping, separating 'us' from 'them', negative emotional reactions of others and those labelled, status loss, and discrimination, within a power situation that allows these processes to unfold. Power was incorporated into the stigma concept in response to criticism from disability theorists who argued that stigma was not about 'personal tragedy', but rather the social oppression of difference (Oliver, 1992). And oppression, as one of the functions of stigma (Phelan et al., 2008), is conceived by Young as having 'five faces': exploitation, marginalisation, powerlessness, violence and cultural imperialism (1992). Although Young's idea of oppression has been regarded as theoretically important to stigma (Scambler, 2011), empirical data linking the two are so far lacking.

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Whilst recent advances in the *general theory of stigma* discuss the processual importance of ‘structures’, some theorists in the *mental illness stigma field* appear to treat ‘structure’ as synonymous with ‘institution’ (e.g. Corrigan et al., 2004), rather than see it as a variety of relatively enduring relational elements of the social world, emergent at different social levels (Archer, 1995). Consequently, there is perhaps a need to consider more fully the effects on stigmatisation from multiple structural elements such as social roles, social positions, institutions, and the systemic relations between them, alongside their intertwining with cultural/ideational forms. This requires a conception of the temporal interplay between structure and agency hitherto lacking in the stigma field. When referring to agency, a useful distinction can be made between actors (individual people), primary agents (collectivities of individuals similarly placed in a socio-cultural system without their choosing) and corporate agents (groups organised around shared concerns) as distinctive ways of being human which are constrained and enabled by structures (Archer, 2000). And to understand the structure-agency interplay, Archer’s morphogenetic sequence can help explain how structure and agency “emerge, intertwine and redefine one another” over three stages of *structural conditioning, social interaction, structural elaboration/reproduction* (Archer, 2011, p. 68). A turn to Archer’s work, which utilises Bhaskar’s (1989) critical realist social ontology, also helps to provide a metatheoretical corrective in the mental illness stigma field which is largely situated in the positivist-empiricist tradition.

### 1.2. The effect of mental illness stigma

Stigmatisation leads to numerous negative consequences for people with mental illness (Arboleda-Flórez and Sartorius, 2008; Corrigan et al., 2003; Okazaki, 2000; Sartorius and Schulze, 2005; Thornicroft, 2006; Thornicroft et al., 2009; Wahl, 1999) including reduced self-esteem (Wahl, 1999; Wright et al., 2000), hurt and anger (Wahl, 1999), social withdrawal (Link et al., 1989), rejection, avoidance, delayed healthcare seeking (Sirey et al., 2001), unemployment and reduced income (Link et al., 1987), poorer quality of life (Markowitz, 1998) and less social support (Perlick et al., 2001). Stigma also results in impeded policy formation and lower levels of treatment resources and research funding (Pescosolido and Martin, 2007). However, most mental illness stigma research has been conducted in relation to schizophrenia and depression, or a generalised category of mental illness. Indeed, most of this consists of quantitative surveys measuring public attitudes towards people with mental illness. Hence, subjective experiences of people diagnosed with an array of alternative psychiatric disorders are relatively under-researched and under-represented (Link et al., 2004). Two diagnostic groups to which this applies are borderline personality disorder (BPD) and bipolar disorder (BD).

### 1.3. Stigma and BPD

BPD is clinically defined as “a pattern of instability in interpersonal relationships, self-image, and affects, and marked impulsivity that begins in early adulthood” (APA, 2000). However, the conceptual validity of BPD, and other personality disorders, has been questioned by psychiatrists (Lewis and Appleby, 1988; Tyrer, 2009; Vaillant, 1992), sociologists (Manning, 2011; Pilgrim, 2001, 2002), clinical psychologists (Bourne, 2011; Proctor, 2007) and survivor activists (Shaw and Proctor, 2005).

It has been claimed that BPD is the most stigmatised psychiatric diagnosis (Nehls, 1998). Yet, virtually all accounts of public stigma involve healthcare worker social roles, suggesting public unawareness of the diagnosis (Aviram et al., 2006; Black et al., 2011; Bodner et al., 2011; Commons Treolar and Lewis, 2008; Deans

and Meocevic, 2006; Fraser and Gallop, 1993; Gallop et al., 1989; Markham and Trower, 2003; Nehls, 1998; Ross and Goldner, 2009; Westwood and Baker, 2010; Woollaston and Hixenbaugh, 2008). For instance, nurses commonly view BPD patients as difficult, annoying, manipulative, treatment-resistant, dangerous, attention-seeking, nuisances, and timewasters. They also report fear and frustration in reaction to self-harming behaviour (Wilstrand et al., 2007) and tend to view those diagnosed as ‘bad’ rather than ‘ill’. However, public unawareness of the *diagnosis* does not mean that *people* with the diagnosis are socially invisible; self-harm scars can render illness ‘visible’ in social interaction, possibly increasing exposure to stigma (Schulze et al., 2010).

Beyond clinical interactions, BPD is marginalised at the levels of policy, planning, staff training and service delivery, perhaps representing social oppression (Kealy and Ogrodniczuk, 2010) or institutional abuse (Warne and McAndrew, 2005).

Measurement of stigma amongst people with a BPD diagnosis is rare (Ramon et al., 2001; Rüsich et al., 2006; Schulze et al., 2010). A small qualitative literature has explored the subjective experience of BPD (Fallon, 2003; Horn et al., 2007; Miller, 1994; Nehls, 1999; Ramon et al., 2001; Rogers and Dunne, 2011; Stalker et al., 2005), most of which has paid some attention, at least, to stigma or discrimination, although these concepts are rarely defined, not the focus of inquiry, and never critiqued or reviewed in the light of the study’s empirical evidence. Themes from this literature on BPD and the stigma experienced or anticipated by people with the diagnosis can be divided into two broad categories: *the stigma surrounding the act of diagnosis and the label itself* (Horn et al., 2007; Nehls, 1999; Ramon et al., 2001; Stalker et al., 2005) and *the stigma experienced and anticipated in the context of healthcare* (Stalker et al., 2005) including being stereotyped (Haigh, 2002; Nehls, 1999), being subjected to psychological abuse (Castillo, 2003; Haigh, 2002) and having the diagnosis withheld (Castillo, 2003; Crawford et al., 2007; Fallon, 2003; Haigh, 2002; Horn et al., 2007; Rogers and Dunne, 2011) which is linked to being excluded from treatment (Horn et al., 2007; Nehls, 1999; Ramon et al., 2001; Stalker et al., 2005) and explicitly contradicts professional guidance (NICE, 2009; NIMH, 2003).

### 1.4. Stigma and BD

BD – formerly manic depression – is classified as a mood disorder (APA, 2000; WHO, 2007). Whilst the general public endorse stigmatising attitudes towards people with BD (Wolkenstein and Meyer, 2008), few studies have focused exclusively on this diagnosis and stigma, or examined stigma experiences of people diagnosed with it (Brohan et al., 2010a; Hayward et al., 2002; Kelly and Jorm, 2007). However, perceived stigma is high amongst people with the diagnosis (Brohan et al., 2010b) and is associated with lower self-esteem in depressive episodes (Hayward et al., 2002), low autonomy, workplace difficulties, poor cognitive functioning, adverse financial issues, fewer interpersonal relationships (Thome et al., 2012; Vázquez et al., 2011) and increased avoidance of social interactions (Perlick et al., 2001). Having a mood disorder is also associated with an increased likelihood of endorsing stigma as a barrier to help-seeking (Alvidrez and Azocar, 1999).

A small qualitative literature has considered the subjective experiences of people diagnosed with BD, though stigma is more often a theme within, rather than a focus of, such research (Jönsson et al., 2008; Lim et al., 2004; Michalak et al., 2006; Proudfoot et al., 2009; Sajatovic et al., 2008; Wilson and Crowe, 2008). Stigma is usually mentioned with respect to disclosure decisions (Jönsson et al., 2008; Michalak et al., 2011, 2007; Proudfoot et al., 2009; Wilson and Crowe, 2008), though reported stigma experiences include stereotype application, distress, frustration and isolation within family,

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