# (Re)Negotiating Narrative Identity: The lived experience of women diagnosed with Borderline Personality Disorder

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# Abstract

Borderline Personality Disorder (BPD) has a long history as a controversial psychiatric diagnosis. It is frequently criticised by feminist scholars for its gendered nature and for reinforcing an endemic tendency to deny or obscure the social causes of distress. The failure of the psychiatric profession to respond to the frequent traumatic antecedents of BPD, combined with the extent to which the diagnostic label implicitly frames the source of the ‘disorder’ as being situated within an individual’s own personality functioning has resulted in a widespread perception that individuals with BPD are ‘untreatable’. It is therefore a highly stigmatised diagnosis that can have significant implications for treatment, understandings of recovery and identity. This research draws upon feminist, critical realist, contextualist and narrative theoretical and methodological approaches to explore the personal meaning of diagnosis to women with a BPD diagnosis in the context of their life histories and wider societal attitudes towards women and mental health. It examines the ways in which these factors influence their understandings of self and identity and the function, purpose and meanings associated with the creative coping strategies that women with a BPD diagnosis use to negotiate distress. It also explores the systems and structures that are helpful and (unhelpful) in fostering concepts of recovery and supporting individuals to (re)build a sense of identity within or outside of the framework of diagnosis.

The research was carried out in two stages. Stage one involved a qualitative secondary analysis of eight interviews conducted with women with a BPD diagnosis as part of a research project examining experiences of being detained under Section 136 of the Mental Health Act. Building upon the themes identified in stage one, the second stage of the research explored experiences and attitudes towards diagnosis and treatment, conceptions of identity and the experience and meaning of creativity to four women with a BPD diagnosis who self-identified as having an involvement in artmaking or other creative activities. This was done using a collaborative approach that offered participants the flexibility to share their stories in the way that best suited them. All participants chose to take part in one or two face-to-face interviews, with the majority sharing examples of their creative outputs during or after the interview to illustrate the feelings and concepts discussed. The data were analysed using an approach to thematic narrative analysis that was sensitive to the feminist idea of ‘voice’ and the inter-subjective experience of the research process. Visual data are included in the thesis where appropriate to illustrate themes.

The findings reveal a strong theme of invalidation that pervades participants’ accounts of their early childhood experiences and is often perpetuated in adolescence and adulthood by stigmatising attitudes towards their experiences of distress and the diagnostic label of BPD. Experiences of invalidation and complex histories of trauma occupy a privileged position in participants’ narratives and have a profound effect on how they form and maintain their identities in the context of diagnosis. Receiving a diagnosis of BPD can intensify or exacerbate an already unstable or uncertain sense of self and being given a diagnosis frequently results in a denial of access to treatment or referrals to services which further compounds experiences of trauma or invalidation. The study finds support for an alternative perspective which challenges psychiatric positivism, acknowledges the experiential reality of events and emphasises the meaning attributed to these events, rather than focusing merely on what is considered wrong or ‘disordered’ in an individual’s behaviour. It argues that this is best reflected in the work of Johnstone & Boyle (2018), who developed the Power Threat Meaning Framework as an alternative way of conceptualising mental distress and distressing behaviours as adaptive responses to childhood trauma in order to maintain personal survival.

The research finds that progress towards self-defined concepts of recovery amongst women with a BPD diagnosis appears to be realised through the combination of a supportive and appropriate therapeutic environment and an individual exploration of creative ways of expressing and understanding identity and emotional distress. The findings show that, both in a therapeutic and everyday setting, creative activities can be a powerful way of alleviating distress and renegotiating identity by providing a platform for women with a BPD diagnosis to render different aspects of their identity visible, thus enabling them to build a more coherent and holistic sense of themselves. The thesis provides practical recommendations for services supporting women with a BPD diagnosis that focus on the need to provide a validating and empowering space to explore and identify not only the individual experiences that have contributed to their distress, but, crucially, the response and meaning associated with them and how they have shaped their sense of selves.

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# Acknowledgements

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# Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author.

The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed: Ashley Tya Austin

Dated: 26th November 2023

# Chapter 1: Introduction

This research has its foundations in the wider programme of work led by former lead supervisor Professor Gillian Bendelow, which was developed in response to rising concerns over the consistently high rates of detentions under Section 136 of the Mental Health Act. Section 136 (S136) of the Mental Health Act, 1983, amended in 2007, is set apart from the main body of mental health legislation in that it makes provisions in relation to people experiencing mental distress in public places. Furthermore, it provides police officers with a legal mandate to initiate compulsory detention on the basis of making a value-based judgment on an individual's mental health. The use of S136 is perceived to have become a 'default response' by which police manage highly distressed individuals in public places and has been subject to much government and media attention, in particular with regard to the use of police custody as a place of safety (Menkes and Bendelow, 2014).

The research conducted by Bendelow et al (2016) identified significant numbers of 'repeat detainees' who inflated the detention figures for 2012 by 13%. Of note amongst this group was an overrepresentation of women with a diagnosis of Borderline Personality Disorder (BPD), who had in common overwhelming traumatic histories of sexual abuse/domestic violence and a lack of access to appropriate forms of support which have led to them becoming 'trapped' in a cycle of extreme emotional and often public displays of distress.

The diagnosis and subsequent treatment of BPD has for some time been subject to scrutiny and controversy and is considered problematic on a number of levels with regards to its reliability, validity, aetiological specificity and utility for treatment planning (Pilgrim, 2001, Widiger et al, 2002). The current diagnostic criteria rely heavily on a contested concept of personality that is arguably neither stable nor measurable (Newnes, 2014) and requires an inherent moral and social judgement in order to ascertain what is considered abnormal and therefore 'disordered' (Mann and Lewis, 1989). It has been argued therefore that the only clear agreement that exists in relation to BPD is that it comprises an extensive range of behaviours that serve to constitute role failure or rule breaking in a social context (Blackburn, 1988). Indeed, the Diagnostic and Statistical Manual of Mental Disorders (DSM) refers to personality disorders as being defined by pervasive and inflexible patterns of inner experience and behaviour that are markedly different from cultural expectations (APA, 2022). Furthermore, the inherently gendered nature of the diagnosis, whereby women typically outnumber men 3:1 in clinical settings (APA, 2022), and the extent to which those diagnosed with BPD have experienced sexual abuse means that the diagnostic construct has been criticised for ignoring the social factors that precipitate distress and labelling what are regarded as typically ‘feminine’ responses to this distress as mental ‘illness’ (Shaw and Proctor, 2005).

The ontological perspective guiding the thesis is concomitant with the criticisms of the prevailing biomedical model of mental distress outlined above. It is particularly critical of the tendency of the biomedical model to rely on limiting empiricist notions of experience at the expense of an understanding of the laminated systems of culture, context and interpretation that underpin personal experience and meaning (Bhaskar, 1993). Thus, this study is underpinned by a critical realist ontology that draws upon feminist, contextualist and narrative theoretical and methodological approaches to explore the personal meaning of diagnosis to women with a BPD diagnosis in the context of their life histories and wider societal attitudes to women and mental health. Critical realism recognises the reality of individual experience and so allows for BPD to be conceptualised as a ‘real’ entity whilst acknowledging that it is only constructed as such within a specific personal, cultural and historical context. Using this framework, the thesis examines the ways in which these multiple factors influence participants’ understandings of self and identity and their relationship with the BPD diagnosis. Drawing upon sociological theories of biographical disruption (Bury, 1982) and narrative reconstruction (Williams, 1984) it seeks to privilege the voice of lived experience to understand how women with a BPD diagnosis negotiate their experiences of distress. It is specifically concerned with exploring the function, meaning and purpose associated with the creative coping strategies used by women with a BPD diagnosis to make sense of their experiences, alleviate negative emotions and renegotiate their identities in the context of diagnosis.

The researcher acknowledges the considerable academic and emotional challenge involved in undertaking this research – not least because of the contested nature of many of the concepts it seeks to understand and disentangle, including understandings of self, identity, and the diagnosis of BPD itself. Lived experience research, particularly that which focuses on experiences of mental distress, is inherently emotionally demanding and requires a continuous commitment to ethical practice and self-reflection. This thesis is the product of many years work and represents the researcher’s best attempt at disentangling a number of complex concepts to contribute new knowledge and present a coherent response to the research questions outlined below.

## 1.1 Original Contribution to Knowledge

Despite the existence of a growing body of research that has begun to examine the phenomenology of BPD from a lived experience perspective, the literature continues to be dominated by a biomedical and inherently gendered model of BPD as defined by diagnostic tools such as the Diagnostic and Statistical Manual of Mental Disorders (DSM), and the International Classification of Diseases (ICD), developed and perpetuated by the psychiatric profession. This thesis contributes to a growing body of knowledge offering support for an alternative perspective on mental distress which challenges psychiatric positivism, acknowledges the experiential reality of past events and emphasises the meaning attributed to them and their impact on emotions, behaviours and conceptions of the self, rather than focusing merely on what is considered wrong or 'disordered' in an individual's behaviour. Rooted in critical realism, it aims to destigmatise and challenge the marginalisation of those with experience of mental distress by privileging the voices of women with a BPD diagnosis as experts of their own experience.

Central to this is an exploration of conceptions of identity in the context of BPD. Although 'identity disturbance' is widely recognised as one of the key characteristics of individuals with a BPD diagnosis, there is limited research exploring the mechanisms underpinning this and the bi-directional relationship between identity and diagnosis. Drawing upon illness narratives and concepts of narrative identity, this research generates new knowledge about the ways in which identity both shapes and is shaped by subjective understandings of diagnosis as well as the cultural, social and relational contexts in which individual experience occurs.

The application of concepts of biographical disruption (Bury, 1982) and narrative reconstruction (Williams, 1984) provides an alternative way of understanding the disruptive life events that contribute to the emotions and behaviours associated with a diagnosis of BPD and the ways in which individuals with the diagnosis negotiate identity and reconstruct narratives to help them make sense of the complex personal, social and organisational challenges with which they are faced. Whilst a focus on the management of 'problematic behaviours' has largely dominated treatment discourse, this thesis provides evidence for how an understanding of the perceptual and emotional experiences of those experiencing BPD and the everyday strategies they use to negotiate distress can be used to develop effective treatments which are holistic and responsive to individual concerns.

Within this, the research contributes new knowledge to the evidence base on creativity and mental health by filling gaps in the qualitative literature regarding the meaning and function of artmaking amongst women with a BPD diagnosis, both in an everyday and therapeutic context. Furthermore, drawing upon Kaufman & Beghetto's (2009) Four C model of creativity, the thesis considers the role of creativity outside of the artistic domain, applying these ideas to the novel ways in which women with a BPD diagnosis manage and cope with their distress.

The research also adds to the scant literature regarding the relationship between creativity and identity through an exploration of the role of creativity in the development and renegotiation of identity amongst women with a BPD diagnosis. Drawing upon Csikszentmihalyi's (1975) theory of flow and Bion's (1970) concept of reverie, it explores how these concepts interact with identity development processes to support women with a BPD diagnosis to create and narrate stories about their selves that move beyond traditional narratives of mental ill-health and support them in building a more coherent sense of narrative identity.

The thesis provides recommendations for policy and practice which emphasise the need for mental health professionals to provide a validating and empowering environment which offers space for individualised and creative explorations of the factors underpinning distress and a more explicit focus and reflection on the construction (or reconstruction) of identity in the context of past experiences, current understandings and conceptions of recovery. The research generates new evidence to support the more widespread application of the Power Threat Meaning Framework (Johnstone & Boyle, 2018) as an alternative way of conceptualising mental distress and distressing behaviours which can support women with a BPD diagnosis to reconceptualise their behaviours as adaptive responses to childhood trauma and construct a sense of meaning, identity and coherence within the context of their experiences. Furthermore, the research findings also have practical implications for those working in the creative wellbeing space, building on existing understandings of art therapy and everyday creativity to discuss how the mental health benefits of creativity can be realised in more informal settings.

The methodological framework guiding this research combines qualitative secondary analysis with primary data collection, influenced by the concerns of participatory research. The primary data collection aims to involve women with a BPD diagnosis in a collaborative way, using narrative and creative methods to provide a flexible and dynamic space for participants to contribute in a way that feels meaningful and allows them to articulate their embodied experience. Combining this with a reflexive approach, guided by the tenets of critical realism, the thesis also adds to the methodological literature regarding the use of creative and narrative methods in the study of mental distress.

## 1.2 Research Questions

Taking all of the above into account, the research questions that have been developed to guide this study are as follows:

- How do women diagnosed with BPD understand and conceptualise their diagnosis in relation to their life histories and sense of self?

- How do women with a BPD diagnosis use creativity to make meaning of their experiences, negotiate identity and manage distress?

- How can an understanding of the 'lived experiences' of women with a BPD diagnosis be used to contribute towards an understanding of effective and appropriate treatment strategies for the management of distress?

### 1.3 Thesis Structure

The thesis is presented across ten chapters.

Following this introduction, chapter two provides an overview of the biomedical model of mental health and an explanation of the common conception of BPD that sits within it. It discusses the biomedical literature regarding the diagnostic criteria, aetiology, prevalence and comorbidity associated with BPD and uses this as a framework with which to highlight some of the key criticisms and controversies surrounding the biomedical approach. It then goes on to highlight some of the alternative approaches to understanding BPD, focusing predominantly on feminist and critical realist approaches to understanding mental distress and providing an overview of the Power Threat Meaning Framework (Johnstone and Boyle, 2018) and its application. The literature review also discusses findings from existing research that privileges the standpoint of individuals with lived experience of BPD before moving on to explore service users' perspectives on treatment and recovery. Finally, adopting a narrative approach, existing research relating to the disruption and reconstruction of identity is critically analysed in the context of BPD and the concepts of biographical construction and narrative reconstruction are introduced.

Chapter three presents a review of the literature relating to creativity, situating it in the context of mental health and identity. It outlines the various definitions of creativity and discusses the evidence supporting the link between creativity, 'genius' and conceptions of 'madness.' Returning to theories of identity discussed in chapter two, it summarises the limited evidence regarding the ways in which creativity can contribute to identity development. Finally, the review explores the benefits of creativity to mental health and wellbeing, focusing both on the formal use of art therapy and the function of everyday creativity. It draws upon Kaufman and Beghetto's (2009) Four C model of creativity, Csikszentmihalyi's (1975) theory of flow and Bion's (1970) concept of reverie to consider the role of creativity outside of the artistic domain as a way of exploring identity and coping with distress.

Chapter four outlines the research questions developed to guide the study and summarises the two stages of the overall research design and the principles guiding them. It outlines the critical realist onto-epistemological framework underpinning the research and its influence on the project design and methodology. It presents a detailed account and justification for the methods used to collect and analyse data in the two stages of the research, as well as an overview of the participants, ethical concerns and methods of analysis for each stage.

Chapter five provides a reflexive account of the researcher's own personal journey and relationship with the research, underpinned by a theoretical account of the importance of a reflexive approach to the research enquiry. In line with the critical realist ontology of the thesis, it presents an account that situates the researcher within the study and makes explicit the values, beliefs and contextual experiences that will undoubtedly have influenced the research.

Chapter six offers a brief introduction to the four participants who took part in the second stage of the research. In line with the narrative approach adopted throughout the study, this chapter aims to provide the reader with the context needed to feel connected to participants' individual stories and to enable them to situate their stories within the context of their biographies.

Chapter seven represents the first of three analysis chapters, which present the findings and themes from both stages of the research in a broad chronology according to participants' life course and their journey through the process of diagnosis, treatment and recovery. The first of these focuses on participants' early experiences of trauma and invalidation and their impact on identity formation, relating this to Winnicott's (1960) concept of the 'false self'. It also analyses participants' narratives regarding their initial interactions with mental health services, and the impact of this both on their understanding themselves and their relationship with the label of BPD.

Chapter eight goes on to present a thematic analysis of participants' accounts of their sense of selves in adulthood, situating these conceptions of identity within the context of living with a diagnosis of BPD. It explores the meaning that participants ascribe to the BPD diagnosis and the impact it has on the stories they tell about who they are and how they have come to be. It also explores the reactions and attitudes to BPD experienced by others and the effect of these on participants' feelings towards themselves and the diagnosis.

Chapter nine, the final analysis chapter, explores the themes identified from participants' stories about the meaning and experience of 'recovery'. It investigates the elements of both formal treatment and informal coping strategies that have proven to be helpful to them, returning to the themes of trauma and invalidation discussed throughout the analysis. It offers a detailed exploration of the role of creativity in alleviating distress and fostering a sense of identity congruent with notions of recovery. This is positioned within a wider discussion of the ways in which participants renegotiate identity and build a new, more coherent and authentic sense of themselves that is located within but not dominated by the framework of BPD.

Chapter ten concludes the research by presenting a discussion of the key themes and conclusions drawn from the analysis. It highlights the effect of trauma and invalidation on identity development, the role of the biomedical model of BPD in perpetuating invalidation and obscuring trauma, and discusses how biographical disruption can be understood as a threat to the 'false self'. It then goes on to illustrate the mechanisms which contribute to a 're-storying' of the self, with particular reference to the concept of validation and the integration of the BPD diagnosis into understandings of identity. It discusses the key ingredients of effective services and support and, crucially, the role of creativity in recovery and identity negotiation. Finally, this concluding chapter ends with some of the key recommendations for policy and practise drawn from the research, as well as highlighting the limitations of the study and recommendations for further research in the field.

### A note on terminology:

The thesis aims to avoid the use of medicalised language to describe the emotional experiences referred to in this study to reflect its broadly critical view of the biomedical approach to mental health. Following the *Guidelines on Language in Relation to Functional Diagnosis* issued by the British Psychological Society's Division of Clinical Psychology (2015), the thesis refers to emotional or mental distress or emotional difficulties as opposed to 'mental illness' or 'disorder'. Instead of 'patient', the terms 'service user' or 'person with lived experience' are used to describe people who have received mental health interventions. When referring more broadly to emotional experiences, the terms 'mental health' or 'wellbeing' are used interchangeably.

It is acknowledged that much of the literature related to the subject of enquiry, particularly that referred to in the initial literature review chapters to provide context, is positioned within a medical framework and therefore uses medicalised language to describe the experiences and behaviours associate with a BPD diagnosis. When discussing this work, or when medicalised terms are used elsewhere in the thesis to refer to the perspectives of those operating within a more medicalised framework, single quotation marks are used to acknowledge the problematic nature of these terms.

The term ‘borderline personality disorder’ is used throughout the thesis to reflect the most commonly understood label used to describe the experiences discussed. This is considered appropriate due to the focus of the enquiry on the implications of the diagnostic term. However, the thesis refers to individuals ‘with a borderline personality disorder diagnosis’ rather than ‘people with borderline personality disorder’ throughout in order to challenge the biomedical assumption of the term as a distinct underlying ‘illness’ and reflect the argument presented in this thesis that the label represents a subjective construct. Instead of ‘symptoms’, the thesis refers to the ‘behaviours’, ‘difficulties’ or ‘challenges’ associated with a diagnosis of borderline personality disorder.

# Chapter 2: Literature Review

Perspectives on Borderline Personality Disorder, Identity, and Recovery

## 2.1 Introduction

Understandings of emotional distress and mental wellbeing have, and continue to be, dominated by a ‘technological paradigm’ of psychiatry that operates within a positivist orientation (Bracken et al, 2012). This paradigm assumes that mental health problems can be understood and treated using the same logic as in traditional biomedicine. Thus, great importance has been attached to the development of classification systems such as the Diagnostic and Statistical Manual of Mental Disorders [DSM] (American Psychiatric Association [APA], 2022) and the International Classification of Diseases [ICD] (World Health Organisation [WHO], 2022) which are used to identify specific ‘syndromes’ or ‘symptoms’ at which interventions can be targeted. However, there are many, both outside of and within the psychiatric profession, who contest this medicalised approach, arguing that the psychiatric profession is experiencing a crisis brought about by its failure to recognise and respond to the ‘non-technical’ aspects of clinical care, particularly those that relate to the building of human relationships with service users (Bracken and Thomas, 2017). Critics of the biomedical paradigm advocate for a model of diagnosing and treating mental health problems that prioritises the ethical and hermeneutic aspects of care and acknowledges the importance of socio-political values in understanding mental distress (Bracken et al, 2012).

The current classificatory systems for diagnosing mental health problems have been both created and shaped by the biomedical model of mental ‘illness’ which has dominated popular discourse. As such, they have been subject to significant challenge by those who advocate for an alternative way of understanding psychological distress (e,g. Johnstone and Boyle, 2018). Personality disorders are among the most controversial of these medicalised classifications and are often rejected by both academics and service user organisations. It is argued that they rely heavily on a contested concept of personality that is neither stable nor measurable (Newnes, 2014) and require an inherent moral and social judgement in order to ascertain what is considered abnormal and therefore ‘disordered’ (Mann and Lewis, 1989).

Personality disorders, as defined by the DSM (APA, 2022) are characterised by abnormal patterns of inner experience and behaviour that affect cognition, emotion, interpersonal functioning, and impulse control; are inflexible and pervasive, lead to clinically significant distress or impairment; are stable and of long duration; and have an onset in adolescence or early adulthood. As such, individuals with a personality disorder diagnosis feature highly in instances of anti-social, self-harm and suicidal behaviour, issues that attract a great deal of public concern (Bendelow, 2010). Borderline Personality Disorder (BPD) is one of ten personality disorders that are included in the DSM-5-TR (APA, 2022) and is arguably the most contentious (National Collaborating Centre for Mental Health [NCCMH], 2009).

In order to understand the complexities associated with the BPD diagnosis and the context in which they originated, this chapter begins with an overview of the biomedical model and understanding of BPD and highlights some of the criticisms associated with it. It then goes on to examine alternative approaches to understanding BPD, rooted in a feminist body of literature that aims to privilege the 'lived experience' of those experiencing distress. Adopting a narrative approach, existing research relating to the disruption and reconstruction of identity is critically analysed in the context of BPD. This chapter also identifies and discuss gaps in the literature relevant to this thesis, which have been central in the development of this research. These will be summarised at the conclusion of this review and drawn together in chapter four in a set of research questions that have guided this research.

## 2.2 Borderline Personality Disorder: A Contested Diagnosis

Borderline Personality Disorder (BPD) is one of ten personality disorders that are included in the DSM-5-TR (APA, 2022). The term 'borderline' was originally coined in the early 1900s by American psychoanalyst Adolph Stern in an attempt to make sense of a growing population of individuals whose 'symptoms' lay somewhere in between the oversimplified diagnostic categories of 'neuroses' or 'psychoses' used to conceptualise mental distress at that time (Masterson, 1988). It has been argued that the "borderline" concept was created in an attempt to define "a heterogeneous group of patients that did not fit elsewhere" (Manning, 2000, p. 632). This emergent concept was influential to the inclusion of Borderline Disorder Personality to the DSM-3 in 1980, but was a term not widely used in the UK until the mid-1980s (NCCMH, 2009). Borderline Personality Disorder is often referred to interchangeably as Emotionally Unstable Personality Disorder (EUPD) and has also more recently sometimes been described as Emotional Intensity Disorder (EID) (Mind, 2022).

In order to receive a diagnosis of BPD, individuals must meet five of nine specified criteria. These include: 'frantic' efforts to avoid real or imagined abandonment; identity disturbance (e.g. unstable self-image or sense of self); a pattern of unstable and intense interpersonal relationships; impulsivity in at least two areas that are potentially self-damaging (e.g. substance abuse, sex or binge eating), recurrent suicidal or self-mutilating behaviour; affective instability due to marked reactivity of mood; chronic feelings of emptiness; inappropriate or intense anger (or difficulty in controlling anger) and stress-related paranoid ideation or severe dissociative symptoms (APA, 2022). In practical terms, individuals diagnosed with BPD typically receive the diagnosis as a result of chronic suicidal tendencies and repeated self-injurious behaviour, which leads to frequent interactions with healthcare professionals and utilisation of mental health resources (Gunderson and Links, 2014). However, using the current DSM criteria, there are 246 different combinations of symptoms that can result in an individual being given a diagnosis of BPD. As such it is a label that covers a vast range of diverse and often contrasting experiences, which calls into question the validity and utility of diagnosis (Tyrer, 1999).

This criticism is addressed to some extent in the latest version of the ICD (WHO, 2022) which seeks to align itself to the DSM-5 Alternative Model for Personality Disorders (APA, 2013). Whilst the latter continues to remain secondary to the official DSM classification outlined above, both approaches represent the beginning of a paradigm shift, considered necessary due to the unnecessary complexity of previous approaches to diagnosing personality disorders and the lack of consideration to the severity of what is described as ‘personality disturbance’ (Mulder, 2021). The ICD-11 (WHO, 2022) abolishes all individual categorisations of personality disorder in favour of a general description of personality disorder that can be further described in terms of severity as either ‘mild’, ‘moderate’ or ‘severe’. There does, however, remain the option of specifying a ‘borderline pattern’ qualifier which largely mirrors the nine DSM criteria outlined above (Mulder, 2021).

The new ICD criteria for the diagnosis of personality disorders (WHO, 2022) represent an attempt to acknowledge the dimensional nature of personality and categorise personality disturbances according to well-established traits in the broader study of personality (Swales, 2022). Whilst there is some suggestion that this approach could result in a more compassionate understanding of personality disorders if underpinned by an understanding of how personality develops in the context of life experience (Swales, 2022) it remains arguable that the process of being diagnosed with BPD is based on subjective judgements which are rooted in cultural definitions of what is considered ‘normal’ behaviour (Paris, 1996). As there can be no truly objective test for diagnosing an individual with BPD it can be argued that the basis of the diagnosis itself is questionable at best (Tyrer and Ferguson, 1987).

A further challenge to the diagnostic criteria occurs when considering the argument that a diagnosis can only be useful if it provides a framework with which to guide, specify or clarify effective treatment interventions (Pilgrim, 2001). Whilst some studies have demonstrated encouraging evidence that psychotherapeutic interventions show promise in reducing general distress and some of the behavioural ‘symptoms’ associated with a BPD diagnosis (Bateman and Tyrer, 2004, McMain et al, 2009), there is no strong evidence to suggest a clear and definitive treatment pathway that is effective in consistently and significantly alleviating what are considered to be the ‘problematic’ behaviours associated with the diagnosis. (Dolan and Coid, 1993). Furthermore, there are a vast range of approaches, underpinned by varying degrees of evidence, currently in use to treat BPD worldwide, including various types of medication, hormone-based and psychological therapies (Choi-Kain et al, 2017). This highlights the lack of treatment specificity associated with the BPD diagnosis, which calls into question the validity of its categorisation as a mental ‘illness’ in the biomedical sense of the word (Tyrer et al, 2003, Pilgrim, 2001). This can be extended to include a critique of the biomedical model of mental health more broadly. Rocca and Anjum (2020) submit that once a problem is categorised as a biomedical issue, it is natural to focus on locating a biomedical solution to it. However, evidence indicates that, despite offering some relief from the ‘symptoms’ associated with mental distress, pharmacological treatments targeting specific brain systems or processes do little to resolve the underlying causes or alter the long-term course of what the biomedical model terms as ‘psychiatric disorders’ (Ivanov and Schwartz, 2021).

Returning to the focus of this study, current National Institute for Health and Care Excellence (NICE) guidelines in the UK recommend psychological treatment for individuals diagnosed with BPD and specify that drug treatment should not be used specifically for BPD or for the individual symptoms or behaviours associated with the diagnosis (NICE, 2009). Given the commonly held belief that drug treatment is ineffective and inappropriate for the treatment of many mental health problems, including BPD, there is a strong argument for reconceptualising our understanding and response to psychological distress (Ivanov and Schwartz, 2021). Some of the alternative methods which have been developed to frame or categorise the experiences and behaviours which are typically perceived to be symptomatic of mental ‘illness’ are discussed in greater detail later in this chapter. However, firstly, in order to provide a comprehensive overview of the BPD diagnosis as it currently exists, the following section touches upon the complex body of literature which has attempted to explain its aetiology.

### *2.2.1 Aetiology*

Early attempts to explain the development of BPD were largely focused within the psychoanalytic community and had their roots in the theories of Kernberg (1975), Adler and Buie (1979) and Masterson (1976). They suggested that disruptions in early childhood, such as problems with care-giving or intense environmental frustration contribute towards difficulties in the development of an enduring sense of self and a fear of abandonment. Since that time a sizeable body of evidence has emerged in support of the argument that the foundations of BPD lie in disorganised and insecure attachment patterns (Agrawal et al, 2004). Originating from Bowlby's (1958) seminal attachment theory, which underlined the importance of early caregiver bonds in a child's development, insecure attachment patterns are characterised in infancy by avoidant, clingy or distressed behaviour when subject to the 'Strange Situation' test (Ainsworth et al, 1978). This test involves observing the behaviour of an infant during a period of interaction with an unusual environment, followed by the introduction of a stranger and the temporary departure of and subsequent reunification with the primary caregiver.

Ainsworth's (1978) typology of infant attachment behaviours originally included three organisations of attachment behaviour: secure, avoidant and ambivalent attachment. However, this was expanded to include a fourth category, labelled as disorganised or disorientated attachment, the behaviours of which were typically associated with increased parental risk factors, such as poor mental health, conflict or mistreatment directed towards the infant (Main and Solomon, 1990). It is this disorganised attachment that is most commonly linked to a diagnosis of BPD in adulthood (De Zulueta, 1999). In a review of the relationship between attachment and personality disorders, Lorenzini and Fonagy (2013) describe the stable nature of attachment styles which can account for the ways in which early attachment behaviours can give rise to enduring strategies to regulate social and emotional contact in adulthood. Whilst securely attached individuals generally operate from a position of trust and are therefore better able to process emotions in a responsive and non-defensive way, those with a history of insecure or disorganised attachment are more likely to experience emotional instability, unstable relationships, feelings of emptiness and bursts of rage; some of the 'symptoms' associated with a BPD diagnosis (Sandstrom and Heurta, 2013).

The main childhood risk factors typically associated with a later diagnosis of BPD can be loosely categorised as trauma, early separation or loss, and difficulties in parental bonding (Paris, 1994). Up to 90% of individuals with a diagnosis of BPD report maltreatment in childhood and the co-occurrence of physical, sexual, emotional abuse and neglect has been strongly associated with the diagnosis (Carlson et al, 2009). Multivariate studies have illustrated that a history of childhood sexual abuse is frequent in those diagnosed with BPD (around 70% of those diagnosed with BPD have been subject to sexual abuse) and that this is demonstrated independently of other factors such as neglect or loss. In light of these findings, trauma has been proposed as one of the primary explanations for the aetiology of

BPD. This is supported by theories linking some of the frequent symptoms of BPD with those related to posttraumatic disorder and long-term effects of childhood sexual abuse (Van der Kolk et al, 1991; Browne and Finkelhor, 1986).

In her influential research on the biosocial factors relating to BPD, Linehan (1993), broadens the definition of trauma beyond physical and sexual abuse, proposing that an invalidating developmental context is a key factor underpinning the development of behaviours associated with BPD in adulthood. This invalidating environment is thought to be characterised by the dismissal, punishment and/or trivialisation of private emotional experiences, especially when they are not linked to observable events. The effect of this, according to Linehan, is that, whilst extreme expressions of emotion are intermittently reinforced, the message that is communicated to the child is that these emotional displays are unwarranted and that emotions should be processed internally and without parental support. Thus, the child does not develop the ability to make sense of, identify, label, regulate or tolerate natural emotional responses to external events, or develop skills in solving the problems that contribute to these emotional reactions. This results in behaviour which oscillates between emotional inhibition and extreme emotional sensitivity (Linehan, 1993; Crowell et al, 2009).

An understanding of the role of trauma in the development of symptoms associated with a diagnosis of BPD can be useful in promoting an understanding of BPD that moves away from the concept of the innately ‘disordered’ personality. However, when situated in the current biomedical paradigm, there is a lack of specificity in relation to what is termed the ‘trauma variable’, which renders it problematic. This means that the presence of trauma does not accurately discriminate those meeting the criteria for a BPD diagnosis from those without (Paris, 1994). Proponents of the biomedical model would argue that this means the presence of trauma alone cannot be considered to lead to or cause the ‘symptoms’ of BPD, as the presence of trauma is also associated with a wide range of other psychopathology (Paris et al, 1994). The tension between the diagnostic criteria of BPD and its relationship to trauma will be explored in more detail later in this chapter.

Some research has suggested that it is the interaction between the traumatic event and individual personality traits that determine how trauma is experienced, processed and the resulting long-term consequences (Sigal and Weinfield, 1989). However, there is limited evidence as to how this mechanism operates. It has been hypothesised that the core dimensions of personality underlying BPD are impulsivity and affective instability and there exists a small degree of biological support for this theory (Siever and Davis, 1991). However, there is little evidence to suggest any stable biological or genetic risk factors for BPD (Chanen and Kaess, 2012) and these studies typically ignore contextual factors that may contribute towards personality development. Amad et al (2014) conducted a systematic review of the literature regarding the genetic influences on BPD. They concluded that the development of behaviours and feelings associated with a diagnosis of BPD is best understood through an integrative model which links a potential genetic predisposition with developmental, social and environmental factors which in turn trigger a neurobiological response. This is further complicated by the extent to which a BPD diagnosis frequently coexists alongside other diagnoses, thus making it even more challenging to establish cause and effect.

### *2.2.2 Comorbidity*

The diagnosis of BPD has consistently been found to have a high level of comorbidity with a range of other so called psychiatric ‘disorders’ (Eaton et al, 2011). The degree to which the feelings and behaviours associated with BPD and the factors underpinning it overlap with other diagnoses has contributed heavily to debates with regard to the validity of the diagnosis as a distinct entity in its own right and is therefore something that requires further consideration in the context of this thesis.

Biomedical research has demonstrated high levels of comorbidity amongst individuals diagnosed with BPD and a number of Axis 1 (mental health and substance use) ‘disorders’ in both clinical and community population samples (Eaton et al, 2011; Tomko et al, 2014). The strongest associations are typically seen with diagnoses relating to chronic mood and anxiety, especially major depressive episodes, mania, panic disorder, agoraphobia, generalised anxiety disorder and post-traumatic stress disorder (Coid et al, 2006; Tomko et al, 2014). The prevalence of these disorders, it is argued, may predominantly be influenced by some of the internalising features of BPD, such as affective instability and feelings of emptiness (Tomko et al, 2014). With regard to externalising disorders, previous research has established a strong link between diagnoses of BPD and substance use disorders (Coid et al, 2006; Sher and Trull, 2002; Trull et al, 2000). This is particularly pertinent as substance use is often considered to be a barrier to receiving adequate help for mental distress (Bendelow et al, 2016). Attempts to explain this relationship have focused on impulsivity and negative emotionality – two of the personality traits associated with a diagnosis of BPD that are believed to be most likely to result in externalising behaviour (Skodol et al, 2002). As well as Axis 1 disorders, significant levels of comorbidity have also been established between a diagnosis of BPD and a range of other personality disorder diagnoses, particularly schizotypal (Coid et al, 2006), narcissistic and dependent (Tomko et al, 2014) These findings are again consistent across community and clinical samples (Lenzenweger et al, 2007; Paris, 2009) and suggest that BPD is rarely diagnosed alone.

Tomko et al's (2014) research found that high levels of comorbidity amongst those diagnosed with BPD were associated with what they describe as severe 'impairment and dysfunction' (p.10) across almost all areas examined. This, they felt, may contribute to the relatively high incidence of mental health help seeking behaviour amongst those meeting the diagnostic criteria for BPD in community samples. As well as reported difficulties within interpersonal relationships, emotional functioning and general mental health, BPD was also found to be a significant predictor of impairment in physical functioning, and difficulties in this area were observed in the areas of increased bodily pain, poor general health and decreased vitality (Tomko et al, 2014). More recently, a nationwide Swedish study found that a diagnosis of BPD was associated with the majority of more than 30 indicators of psychiatric disorders, somatic illness, trauma and 'adverse behaviour' examined. (Tate et al, 2022).

Indeed, there is a large body of evidence to support a link between physical and mental health, although little is still known about the pathways from one to another (Ohrnberger et al, 2017). Various studies have demonstrated both how poor physical health increases the risk of being diagnosed with a mental health problem (Braam et al, 2015; Ostergaard and Foldager, 2011), and how those experiencing mental health problems suffer an increased risk of early mortality and disproportionate burden of physical health complaints across their lifespan (Chang et al, 2010; Fok et al, 2012; Henderson et al, 2011). This has been linked to a number of factors such as unhealthy lifestyle, social disadvantage and unequal access to physical health services (Fok et al, 2012). Whilst there is scant research which examines specifically the interaction between personality disorders and physical health, there is, unsurprisingly, some evidence to suggest that individuals with personality disorder diagnoses demonstrate an increased risk of comorbid health problems (Fok et al, 2014; Frankenburg and Zanarini, 2006). In the first study of its kind to date, Fok et al (2014) screened a randomly selected community sample of 1,662 individuals for personality disorder traits and collected self-report data on a range of physical, lifestyle and mental health variables. Even after accounting for a range of covariates, a greater proportion of those screening positive for personality disorders reported a number of specific longstanding 'illnesses', including depression, asthma, other chest problems, rheumatism or arthritis, migraines, back problems and 'other illnesses'. This sample was also considered more likely to report 3 or more illnesses than those who did not meet the threshold for a personality disorder diagnosis.

Fok et al (2014) argue that there are several mechanisms that may underlie this association and that these have significant implications for public health policy and understanding of personality disorder functioning. As personality disorders frequently occur in partnership with mood disorders such as depression, a strong predictor of poor physical health (Rugulies, 2002), a cause effect relationship cannot be ruled out. However, receiving a diagnosis of personality disorder has also been found to have a negative impact on the treatment and prognosis of concurrent medical illness (Pollock-BarZiv and Davis, 2005; Wuerth et al, 2005). It is argued that this occurs both as a result of challenging relationships between individuals with a personality disorder diagnosis and health care providers and difficulties complying with treatment (Pollock-BarZiv and Davis, 2005; Wuerth et al, 2005). Although not the focus of this thesis, there clearly remains a gap in academic understanding of the complex underpinnings of this relationship.

It is clear from the biomedical literature outlined in this section that the diagnosis of BPD is strongly associated with a range of other diagnoses and behaviours. However, controversy arises when considering what this means for the validity of BPD as a unique diagnostic entity, and for the utility of the biomedical model as a whole. (Lewis and Grenyer, 2009). Section 2.3 of this chapter will delve further into this to explore alternative approaches to understanding BPD which are less reliant on distinct behavioural and diagnostic criteria and more focused on individualised understandings of distress. Prior to this, the remainder of this section will provide an overview of the literature regarding the prevalence of the BPD diagnosis and the relevance of this to the ontological position underpinning the thesis.

### *2.2.3 Prevalence*

As well as aetiology and comorbidity, examining the prevalence of a diagnosis can also provide valuable context with regards to its origins and antecedents. Whilst data on the prevalence and incidence of BPD remains limited, current estimates suggest that diagnoses of BPD have a weighted prevalence (adjusting elements to provide an accurate reflection of population demography) of between 0.5% and 2% in the general community (Samuels et al, 2002). Although far from being the most common personality disorder in community samples (Samuels et al, 2002), research indicates a high prevalence of BPD compared to other personality disorders within a clinical setting; those diagnosed with BPD making up 27% of psychiatric outpatients with a personality disorder diagnosis (Widiger and Sanderson, 1997) and 50% of inpatients (Widiger and Weissman, 1991). This disparity may be partially accounted for by specific behaviours associated the diagnosis such as impulsive, suicidal and/or self-mutilating behaviour which are considered particularly high risk and difficult to manage in community settings (Bjorklund, 2006).

Similarly, whilst it is currently estimated that there is little difference in gender between the 8-12% of the general population that meet the criteria for one of the 10 personality disorders outlined in DSM 5 (Lenzenweger et al, 2007), when it comes to BPD diagnoses women typically outnumber men at a ratio of 3:1 in clinical settings (APA, 2022). This has been supported by a body of research which suggests that 70–77% of those diagnosed with BPD are reported to be women (Swartz et al, 1990, Widiger and Weissman, 1991, Widiger and Trull, 1993). Whilst this may not seem surprising given that antecedents of sexual and physical abuse which precede it are most commonly experienced by women, it is generally acknowledged that there is little gender difference in prevalence in community samples (Torgersen et al, 2001; Coid et al, 2006) and it has been suggested that these results are likely a result of sampling bias rather than a reflection of a higher female propensity towards the behaviours and emotions associated with BPD (Silberschmidt et al, 2015). The overrepresentation of women with a BPD diagnosis in clinical settings and the impact of this therefore warrants further investigation and will be discussed in greater detail in the next section.

In terms of cultural prevalence, it is notable that BPD is most frequently reported in North America, Europe and the United Kingdom (Bjorklund, 2006). For example, only 1-3% of psychiatric outpatients in Ethiopia and India receive a diagnosis of BPD, compared to 32% of British outpatients (Khandelwal and Workneh, 1988). This is perhaps unsurprising given that the symptom indicators and diagnostic criteria defining BPD have been developed from the perspective of mainstream Western society, and as such are inherently shaped by the culture in which they were created (Ryder et al, 2002). There is a small amount of evidence to suggest that the behaviours commensurate with a BPD diagnosis may be universal in their prevalence (Akhtar, 1995; Pinto et al, 2000). However, the lesser extent to which these behaviours come to clinical attention outside of western society is indicative of a range of cultural differences which shape the context in which such behaviours are perceived, experienced and constructed as mental 'disorders'. (Ryder et al, 2002) Critics of the universalist perspective warn against the dangers of ethnocentrism, particularly with regard to the 'category fallacy' (Kleinman, 1997). This is the tendency towards the imposition of categories from one's own culture – for example, mental health diagnoses – on behaviours observed in other cultures. Proponents of the relativist approach argue that psychodiagnostic systems often neglect the unique contextual elements present in non-Western societies and are applied subjectively by clinicians within these cultures who have limited understanding of the cultural, gendered and racial elements that contribute towards individual experience and symptomology (Castillo, 1997). It is argued that, because of this, it is impossible to say with any certainty, that the 'disorders' identified within the DSM exist or present in the same way in other cultures, thus calling into question the validity of the diagnostic systems developed in the West as universal constructs (Draguns, 1996). Some, such as Bjorklund (2006) take this further to suggest that the cultural construction of psychiatry, as it relates to the diagnostic entity of BPD, is sufficient to render it obscure, and suspect as anything other than a social construction based on an increasing tendency towards the medicalisation of distress in contemporary western society.

## 2.3 **Alternative Approaches to Understanding BPD**

Whilst the biomedical paradigm has dominated understandings of mental 'health' and 'illness' for many years, there are a variety of other perspectives that dispute the biomedical model and offer alternative understandings of the factors and frameworks that contribute to what is typically perceived as 'mental illness' (Bergin et al, 2008). However, it is argued that the philosophies underpinning these competing perspectives are often incommensurable and lack a common language with which to communicate (Littlejohn, 2003). This means that the field of mental health, particularly when it comes to highly controversial diagnoses such as BPD, remains polarised and lacking consensus.

In order to foreground the current research, this chapter highlights a number of alternative perspectives on mental distress that offer a critique of the prevailing diagnostic model and suggest other ways of understanding the set of behaviours and experiences that are typically referred to as BPD. This section will begin with an overview of feminist critiques of the diagnostic criteria of BPD as defined in the DSM. It will then explore the development of the Power Threat Meaning Framework [PTMF] (Johnstone and Boyle, 2018) as an alternative to the current diagnostic framework, before touching upon the role of critical realist frameworks in understanding mental distress.

### *2.3.1 Feminist Critiques*

The extent to which the concept of BPD is considered to be a gendered construction has been subject to much curiosity and debate. It has been suggested by many that cultural factors may be largely responsible for the greater representation of women with this diagnosis in clinical settings (Bjorklund, 2006). Gendered expectations with regard to emotional and relational behaviour have, it is argued, led to extremes of what are typically regarded as 'female' traits being labelled as 'mental illness' (Wright and Owen, 2001).

Horsfall (2001) highlights the cultural tendency to conflate the social construct of gender with biological issues of 'sex' and argues that dominant cultural and societal assumptions regarding gender are firmly embedded in the medical discourse of psychiatric knowledge. Bias in diagnostic constructs therefore occurs when the criteria for diagnosis are closely aligned with traditional gender stereotypes or "involve gender related behaviours that can complicate equal application of diagnostic criteria to males and females" (Bjorklund, 2006, p.12). The diagnostic characteristics of BPD, such as 'emotional instability' and 'interpersonal difficulties' are arguably perceived as typically 'feminine' traits and their definition as problematic occurs in the context of a society in which typically male behaviour is considered the norm (Ussher, 2011). This creates gendered expectations around the context in which BPD is situated and creates a bias which makes it more difficult for men to meet the criteria for diagnosis.

Becker (1997) writes of BPD as a patriarchal construct designed to oppress those (women) who seek to achieve independence and identity in western culture. Wirth-Cauchon (2001) argues that the symptoms of BPD, as defined in the DSM, can be best understood as "exaggerated or extreme forms of some of the cultural contradictions of gender in late modern society" (p.30). By applying diagnostic categories to behaviour that is both considered to fall outside of the realms of the typical feminine role and that which is regarded as an extreme display of archetypically feminine traits it serves to create a discourse of femininity as itself psychologically unhealthy (Ussher, 2011). This provides a framework for distress which ignores the cultural and societal factors that may have contributed to its occurrence. Thus, the distress can now be attributed to something that is specifically 'disordered' within the individual, obstructing a recognition of the context in which it occurs and continues to be reinforced. This in turn promotes a sense of identification within the individual of themselves as 'mentally ill' (Linnet, 2004). From a feminist social constructionist perspective, this is problematic in that it exists in a mutually reinforcing relation with gender inequalities; ignoring the context of women's distress and serving to deny histories of abuse by situating the root of distress within the woman herself, defining her as 'defective' for failing to confirm to societal norms in a patriarchal society (Shaw and Proctor, 2005).

For feminist critics, the BPD diagnosis reflects the long-standing tendency within society to deny the extent and impact of childhood sexual abuse specifically, and the social causation of distress more generally (Shaw and Proctor, 2005). This, it is argued, is harmful at both an individual and societal level. Whilst the focus within psychiatric services remains on the management of behaviours associated with BPD, there remains little opportunity for treatment strategies which address the causal underpinnings of the distress (Warner and Wilkins, 2003).

Labelling these unique and complex behaviours as 'BPD' removes the need to associate them with the trauma or abuse that preceded them and allows the individual distress to be reframed as occurring *as a result* of the disorder (Shaw and Proctor, 2005). In addition, the diagnostic category is felt to obscure a greater societal awareness of the extent and impact of violence and abuse committed against women and girls, as well as reinforcing an endemic status-quo of sexual violence against women (Armstrong, 1991).

### *2.3.2 The Power Threat Meaning Framework*

In light of the criticisms highlighted above, it has been suggested that 'symptoms' of conditions typically framed as mental health 'disorders' might be better understood if viewed as adaptive responses to childhood trauma in order to maintain personal survival (Johnstone, 2000). However, this approach, it is argued, is fundamentally incompatible with the traditional classification systems as outlined in the DSM and ICD, which are underpinned by the question "What is wrong with you?", rather than asking "What happened to you?" (Johnstone and Boyle, 2018).

In 2013, the Division of Clinical Psychology (DCP) of the British Psychological Society highlighted what they regard as 'significant conceptual and empirical limitations' (DCP, 2013, p.1) to the current approach to diagnosing mental distress and called for a paradigm shift towards an alternative conceptual system which is not based on a medicalised disease model. The result of this call to action was the development of a framework which is underpinned by the principle that people's thoughts, feelings, and behaviours should be understood in relation to their cultural, relational, social and biological contexts and reflect the importance of personal meaning in shaping experiences and expressions of distress.

The Power Threat Meaning Framework (PTMF; Johnstone and Boyle, 2018) proposes that to do this requires not only an understanding of what these individual circumstances are ('What happened to you?') but also of the impact that they had and the meaning that they held ('How did it affect you?' and 'What sense did you make of it?'). They argue this meaning is the key ingredient to understanding what are currently commonly regarded as psychiatric 'disorders'. One of the core principles of the PTMF therefore centres on identifying and privileging meaning-based threats and restoring the links with the protective mechanisms and behaviours developed in response to them. It is suggested that services should seek to explore and validate these experiences in order to assist in the development of personal narratives that are more effective than the current medicalised diagnostic criteria in providing explanations for distress (Johnstone and Boyle, 2018).

The challenges, principles and recommendations laid out in the PTMF have been subject to some controversy and mixed responses from those working in psychiatry, psychology and those with lived experience of mental distress (Johnstone et al, 2019). It has been argued that, by placing a disproportionate focus on trauma. the PTMF leans towards a linear view of causality that is reductive and reduces mental distress to a simplistic interplay of power and threat, thus invalidating the reality and experience of 'madness' amongst those for whom this does not resonate (Morgan, 2023). In response to these criticisms, the authors of the framework reassert the importance of meaning, suggesting that the traditional psychiatric paradigm can obscure an understanding of the importance of this. This can result in less obvious links between threats and threat responses to be overlooked, for example when the threat is subtle, cumulative, and/or considered socially acceptable – as it often is when violence is perpetrated against women and girls (Johnstone and Boyle, 2018). Thus, the definition of what is considered trauma can and should be broadened to include the everyday features of life which can generate and perpetuate distress, with the PTMF having a key role to play in elucidating the mechanisms and meanings behind these experiences, even when more 'obvious' forms of trauma are not evident (Johnstone et al, 2019). The PTMF proposes that the focus of mental health services should be on understanding and restoring the links between threat and threat response in the same non-pathologising way that grief would naturally be understood to be a consequence of the death of a loved one, or terror as a reaction to a threat to physical safety (Johnstone and Boyle, 2018).

However, critics such as Morgan (2023) and Rashed (2023) argue that, contrary to this, the PTMF actually invokes a similar degree of pathologisation to the DSM through the imposition of a 'master narrative' (Rashed, 2023, p.69) that is inherently value laden yet does not acknowledge its rationale for judging experiences of mental distress *as* distress and therefore something troubling or out of the ordinary that requires intervention. In response, Barnes (2023) submits that. unlike psychiatry, where the application of a 'disorder' removes the context of distress and replaces it with implied pathology, the PTMF offers a way of making experiences of distress understandable and normalising them within the context in which they occur. Furthermore, the PTMF advocates an approach where these narratives and meaning making processes are not imposed by mental health professionals but are co-created with service users as a means of promoting shared sense-making and faciliating support that is individually beneficial (Barnes, 2023).

Due in part to its relatively recent publication, there is limited published research exploring the practical application of the PTMF or the success in instigating a paradigm shift and challenging the psychiatric hegemony. However, there is a small amount of promising evidence to suggest that the application of the framework in a structured way through guided discussion can result in the development of new perspectives which challenge the dominant perception of people with experience of mental and emotional distress as ‘abnormal’ and ‘disordered’ (Self Help Inspiring Forward Thinking, 2020). Members of the Self Help Inspiring Forward Thinking (SHIFT) Recovery Community described how responding to the questions outlined in the framework and sharing their life stories with each other was a deeply therapeutic process which made them feel hopeful, validated and understood and prompted them to reconceptualise their ‘symptoms’ as understandable reactions to abnormal and threatening life events (SHIFT Recovery Community, 2020). One member of the community, a female with a diagnosis of BPD, shared that prior to becoming aware of the PTMF and completing the exercise, she had previously been told that there was no treatment that would meet her needs, had felt hopeless about any prospect of recovery and had been using large quantities of medication to numb her emotions. After taking part in the exercise, she now understands her problems to be a result of neglect in childhood and her behaviour as an understandable response which has arisen out of the circumstances in which she was placed. This has been beneficial in providing her with the confidence to explore her emotions in a non-shameful way and re-engage in options for addressing her behaviour (SHIFT Recovery Community, 2020). Whilst this research offers an important insight into the application and lived experience of the PTMF, caution should be taken in drawing conclusions from individual case study evidence. Clearly, more research is needed to understand how the PTMF operates in an applied setting and its impact on people with a wide range of mental health, sociocultural, relational and biological experiences. Nonetheless, its emphasis on lived experience and contextual factors over symptomology and the challenge it presents to the biomedical paradigm make it of particular relevance to this thesis.

### *2.3.3 Critical Realist Perspectives*

The Power Threat Meaning Framework is part of a wider shift towards a critical realist perspective which challenges psychiatric positivism by acknowledging the experiential reality of events and emphasises the meaning attributed to them, rather than focusing merely on what is considered to be wrong or ‘disordered’ in the behaviour of those experiencing mental distress (Pilgrim, 2020). Critical realism is concerned with the nature of causation and the ways in which agency, structure and relations operate within the realities in which they exist (Archer, 2016). Unlike social constructionism, ontological realism accepts the existence of realities which are present and act independently of our descriptions of them; but posits that that we can only know them under particular circumstances (Bhaskar, 1975). Critical realism reflects the position that all knowledge is local, provisional and situation-dependent (Jaeger and Rosnow, 1988) and always situated within a historical, social and cultural framework that is transient and ever-changing (Archer, 2016). It follows, therefore, that social mechanisms and their effects cannot be understood in isolation but rather should be viewed as “laminated systems whose internal elements are necessarily ‘bonded’ in a multiplicity of structures” (Bhaskar, 1993, p.25).

It is the complex relationship between experiential accounts and the social and historical context in which they are produced that is particularly important within a critical realist framework. The critical realist perspective contends that individual experiences and views are real entities and therefore understanding them is essential to a broader understanding of society, and vice versa. It posits that whilst experience is inherently defined by interpretation, meaning it is, to some degree, constructed (and therefore flexible) rather than determined and fixed, it exists in reality to the person experiencing it (Willig, 2008). In the context of this research, a critical-realist analysis allows for the acknowledgement of the reality of the psychological and somatic distress experienced by individuals with a diagnosis of BPD, whilst enabling it to be conceptualised as a complex and multifaceted phenomenon that is only constructed as BPD within a specific historical and cultural context (Ussher, 2011). A critical realist approach provides space for an understanding and acknowledgement of the integration and interaction of various social, cultural, historical and biological factors, which might contribute towards psychological distress, help-seeking, the development of diverse coping strategies and the conceptualism of behaviour. Critical realism allows for the incorporation of findings from research spanning a range of theoretical perspectives into one framework without having to reconcile competing epistemological assumptions or privilege one level of analysis over another (Williams, 2003).

There is currently very little research that explicitly adopts a critical realist perspective to studying the experiences of individuals with a BPD diagnosis. In Bonnington and Rose’s (2014) research, experiences of stigma and discrimination amongst people diagnosed with bipolar disorder (BD) or BPD were explored using a critical realist ontology to develop a temporal framework which situated these experiences within the context of both structure and agency. In doing so, the research was able to privilege the subjective reality of stigma and discrimination whilst identifying and acknowledging the antecedent social and cultural structures underpinning it, identified in the research as cultural imperialism (pathologisation, normalisation and stereotyping), powerlessness, marginalisation and violence (Bonnington and Rose, 2014). The literature would benefit from more studies that privilege subjective experience whilst also recognising the cultural frameworks within which that experience exists.

## 2.4 The ‘Lived Experience’ of BPD

A central tenet of critical realism, as applied in the context of mental distress, is the notion of embodiment, which, it is argued, allows for a more sophisticated understanding of the experience of distress within a biological and social context without privileging one domain over the other or denying the material reality of individual experience (Bergin et al, 2008). Historically, the field of research exploring mental distress has been dominated by a discourse of medicalisation that has prioritised the knowledge and opinions of academics and professional groups working within the field. Increasingly though, there has been a shift in recent years towards the recognition of the role of experiential knowledge or ‘lived experience’, which is defined as “knowledge that arises from personal participation in the phenomenon and incorporates a reflective stance on this experience” (Cotterell and Morris, 2012, p.58). The lived experience perspective offers an additional resource for understanding and re-conceptualising, giving rise to new responses to distress, and developing useful, more collaborative research methodologies in this field. Traditional social science research has generally excluded the experiences of both women and mental health service users in favour of a collective professional opinion underpinned by assumptions regarding the nature of what it is to be female and ‘mentally ill’ (Cotterell and Morris, 2012). However, research conducted from the standpoints of neglected groups can seek to redress the balance of power by attempting to engage from the point of view of those who identify themselves as being part of these groups and hold belief and trust in their own knowledge through having experienced these phenomena directly (Beresford and Boxall, 2013).

An enduring interest across the recovery movement, and the growth of personal and public involvement (PPI) in health care settings has led to the development of a body of literature that has attempted to understand the contested phenomena of BPD from the perspective of the individual experience of those diagnosed with it. This research has largely demonstrated consistent similarities in experiences between individuals, but also reveals marked difference between these and clinical descriptions of the disorder. In a pioneering study, Miller (1994) obtained life story data from ten patients with a diagnosis of BPD in a series of interviews in which they were asked only to talk about themselves. The resulting narratives highlighted common themes of estrangement, inadequacy and despair and revealed participants’ predominant coping strategies to be dissociation and avoidance of self-disclosure. In addition, preoccupations with suicide and self-harm appear to dominate participant discourses in this area, which suggests that the way in which death is conceptualised is an important feature which may prove useful to explore within therapeutic interventions (Birch et al, 2011). This has been mirrored to some extent in Black et al's (2014) study investigating the phenomenology of BPD from the perspective of the individual diagnosed with it. In this study, close relationships were regarded by many as a reason for continuing to live but also frequently resulted in a concealment of symptoms which exacerbated feelings of isolation. Whilst the defining clinical features of BPD are largely interpersonal, research has indicated that distressing emotions, such as chronic anger, distorted perceptions and suicidal ideations are more common and result in significant detriment to psychosocial functioning (Taulke-Johnson, 2010), indicating a need to develop a greater and more nuanced understanding of perceptual and emotional experiences to inform treatment development (Black et al, 2014).

### *2.4.1 Diagnosis – Helpful or Harmful?*

The social and personal consequences of mental health diagnosis have been extensively researched and it is widely acknowledged that being labelled as 'mentally ill' can have far reaching effects in relation to stigma, social isolation and discrimination, as well as on internalised negative views of self which can significantly impact upon recovery (Horn et al, 2007). Much of the usefulness in diagnostic categories is believed to stem from their ability to inform and direct effective treatment. However, as BPD is often considered by mental health professionals to be unresponsive to treatment or therapy (NIMH, 2003) it has been argued that the label itself is little more than a sophisticated insult (Herman, 1992) indicating an enduring personality fault.

It has been claimed that BPD is the most stigmatising psychiatric diagnosis (Nehls, 1998), particularly with regard to clinical interactions. Research has consistently identified that mental health staff perceive individuals with BPD as 'bad' rather than 'mad' and react with less empathy towards them as a result (Horn et al, 2007). Nurses commonly view them as difficult, manipulative, treatment-resistant, dangerous and attention seeking and report fear and frustration in relation to self-harming behaviour (Wilstrand et al, 2007). The impact of this, and the dominant perspective of the disorder as 'untreatable' (Adshead, 2001) is that individuals with this diagnosis are often excluded from treatment or become trapped in a cycle of distress whereby the only way they feel able to obtain help is through public enactments of extreme distress which often lead to emergency service intervention (Bendelow et al, 2016).

Rivera-Segarra et al's (2014) study investigated stigmatisation experiences of individuals with BPD diagnoses in Puerto Rico, highlighting themes of stigmatisation associated with severe mental distress (e.g. being out of control) as well as those associated with less severe distress (e.g. an assumption of personal responsibility and over-reacting). Their research suggested that individuals with BPD are likely to experience a sense of being simultaneously perceived as if they are both out of control and as if they can control their behaviour to manipulate others. It is acknowledged that diagnosis plays a very powerful role both within the psychiatric system and in society at large. When a diagnostic label, rather than individual needs and desires, determines how an individual experiencing distress is treated and perceived, there are implications not just for the treatment of that individual but for their own individual self-perceptions. In addition, this can contribute to reinforcing social and cultural structures that contribute to oppression (Kealy and Ogrodniczuk, 2010).

Whilst criticisms of the biomedical model emphasise the detrimental effects of situating mental distress solely within the realms of an individual's own pathology, it is also important to acknowledge the lived experience of those for whom it is a  very tangible and distressing reality. For some, a specific diagnosis may be useful in terms of both validating the existence of their distress and allowing them access to resources and support which may assist in its negotiation (Ussher, 2011). Lester et al's (2020) systematic review of research exploring people's experiences of receiving a diagnosis of BPD found that the way in which the diagnosis is delivered is fundamental to how it is interpreted and understood and is instrumental in shaping their views on treatment and recovery. Horn et al's (2007) research found that positive experiences of diagnosis were, unsurprisingly, most frequently reported when the assignment of the BPD label was perceived to have led to access to service, support and therapy. However, positive responses to diagnosis were also described in terms relating to a feeling of 'relief' and the idea of finally 'knowing' what was wrong with them, giving them something tangible to grasp on to and focus on in relation to their distress. This, they said, enabled them to take a step back from their problems and gave them a sense of containment which allowed for consideration of the specific aspects of diagnosis that they identified with. Horn et al (2007) suggest this is suggestive of the narrative process of 'externalisation', which Payne (2000) describes as being useful in allowing for a person to conceive of their difficulties as a product of circumstances or interpersonal processes rather than a direct result of an innate pathology of personality or psychological functioning. These findings are also mirrored to some extent in Ng et al's (2019) research into the lived experience of recovery amongst women with a borderline personality disorder diagnosis. They found that receiving a diagnosis was often regarded as a 'turning point' which provided participants with a sense of validation and relief and helped them to conceptualise their experiences and move towards recovery.

Nevertheless, whilst there is clearly some utility to be found in the diagnostic label of BPD, these positive aspects appear to be frequently compounded by negative experiences of diagnosis which leave individuals feeling rejected, uncertain and devalued (Bonnington and

Rose, 2014; Horn et al, 2007, Ng et al, 2019). For those given the diagnosis, the label of BPD can represent a suggestion of permanent dysfunction and a reinforcement of the idea of ‘not fitting’. Participants in both Bonnington and Rose’s (2014) and Horn et al’s (2007) studies reported experiencing confusion with regard to the diagnosis and an uncertainty regarding its meaning, brought about predominantly by a lack of appropriate information or explanation from clinicians. Many participants felt that BPD was a “dustbin” label (Horn et al, 2007, p.262), assigned to those unable to fit into a clear category of ‘mental illness’ by a mental health system preoccupied by fitting people into boxes in order to offer or deny treatment. Once attributed to the BPD diagnosis, it was felt that misconceptions regarding its reality and treatability led to a wholesale withdrawal of support services which left individuals feeling rejected and marginalised.

Service users in Bonnington and Rose’s (2014) study also described experiencing negative stereotyping as a result of the BPD label, consistent with the findings of Wilstrand et al’s (2007) study. Many had what they considered to be their ‘illness’ dismissed as illegitimate by both friends/family members and healthcare staff and/or constructed as morally transgressive. Even more worrying was that many participants reported experiences of physical and psychological violence, predominantly in healthcare settings, which was perceived as being a result of being pathologised or stereotyped by the BPD diagnosis. Clearly, in order for the diagnosis of BPD to be considered a useful construct, it must be accompanied by trusting, supporting and accepting relationships, appropriate treatment and a recognition of the individual experience (Horn et al, 2007). In order for this to occur, there must be a greater understanding of the way in which BPD is understood and enacted by those to whom the label is ascribed, informed not just from an academic perspective but by those living with the diagnosis as a daily reality.

Furthermore, there appears to be a strong awareness of social roles and an understanding of the stigma of diagnosis amongst those diagnosed with a personality disorder. This idea emerged in Horn et al’s (2007) study through the themes of ‘diagnosis as rejection’ and ‘diagnosis as not fitting.’ This study also explored individual understandings of diagnosis and the relationship to participants’ own sense of self and identified that ways of understandings consistent with a social constructionist perspective were typically more helpful to participants than those that privileged the realist approach represented by the diagnostic category of BPD. This was also reflected in Gillard et al’s (2015) research exploring understandings of the concept of recovery in the context of the lived experience of personality disorders. Participants in this study articulated feelings of extreme isolation and alienation and demonstrated uncertainty and vulnerability in their conceptions of their sense of self, reporting that they were unsure who they are or what is ‘normal’.

### *2.4.2 Female- focused research*

In the context of the wider body of personality disorder literature, women have featured relatively highly in research exploring the lived experience of a BPD diagnosis; likely due to their overrepresentation in clinical settings. However, few studies have focused exclusively and/or explicitly on the experiences of women living with a BPD diagnosis.

Lovell and Hardy (2014) used interpretative phenomenological analysis to explore the experiences of eight women who were detained in private secure units in the UK and had been given a diagnosis of BPD. The findings echoed the emergent themes of similar studies incorporating both men and women, highlighting identity, power, protection and containment and confusion as key concepts. However, the theme of identity in this study was particularly pertinent and central to all participants’ accounts, tying in strongly with the theme of confusion which led to the creation of the sub-theme, ‘who am I?’. The label of BPD for these women would appear to be a pervasive one, although attitudes towards it were polarised, with some accepting that BPD was their identity and others feeling that it had taken over or taken their identity from them, leading to uncertainty with regard to their sense of self. Many of the women demonstrated an understanding of the social implications of being diagnosed with a personality disorder, with many viewing it as a shameful label which invites judgement and others feeling that it was something that had been assigned to them against their will and that they were now not able to escape from – a dehumanising label that contributed to a loss of identity. Reflecting similar findings from previous studies, some of the women in Lovell and Hardy’s (2014) research conversely articulated a sense of gratitude at being offered an explanation for their experiences and viewed the diagnosis as an important and integral part of themselves that helped them to make sense of who they are. As highlighted in the previous section, this study shows that lived experience research is important in feeding into wider debates about the usefulness and legitimacy of diagnostic criteria as well as informing clinical practise and training programmes.

In the wider framework of mental health research, feminist studies that prioritise the lived experience of women experiencing mental distress have communicated a strong message to challenge dominant discourses of medicalisation and contributed to new strategies for understanding and prioritising mental health care in a community setting. What has emerged from this body of research, which privileges the importance of recognising the validity of experiential knowledge in order to create a sense of social justice and citizenship for this marginalised group (Lister, 2002), is a strong collaborative female identity. This manifests itself in a desire for an increase in mental health services that respond to and address the specific needs of women, as well as the creation of environments which foster reciprocal trust and allow two-way dialogue to occur between users and providers in the context of ongoing therapeutic relationships (Barnes et al, 2006).

Research of this nature has important implications for the design of services and development of policy, but also offers a collective view which lends its focus towards practical solutions rather than an acknowledgement of individual subjectivity and in-depth contextual understandings of social, emotional and cultural factors that have led to a requirement for the utilisation of mental health services. The critical realist perspective underpinning this thesis contends that both elements are important to provide a framework with which to understand both the context and meaning of mental distress and offer tangible support to help alleviate it. It is therefore important to consider the lived experience perspective in researching and designing treatment approaches that are effective in reducing mental distress. Accordingly, the next section outlines the findings of existing research treatment research that is driven by the principles of user consultation and involvement.

## 2.5 Service User Perspectives on Treatment and Recovery: What Works?

As previously mentioned, BPD has traditionally been considered to be unresponsive to treatment, (NIMHE, 2003). However, in recent years attempts have been made to challenge the hegemonic biomedical discourse by shifting the focus from ‘curative’ measures towards a concept of wellbeing and personal recovery (Ng et al, 2019). Quantitative studies have focused primarily on the measurement of reduction in the behaviours associated with BPD, such as suicide attempts and self-harm. Whilst they have demonstrated encouraging evidence for the efficacy of specialist psychotherapies such as Dialectical Behaviour Therapy (DBT) and Mentalisation-based Therapy (MBT), there has also emerged a body of qualitative literature which seeks to prioritise the views of service users in evaluating the appropriateness and effectiveness of treatment options.

In terms of the concept of ‘recovery’, as it relates to mental distress, research indicates that perceptions of recovery expressed by individuals with a diagnosis of BPD are generally consistent with definitions of recovery expressed within the wider recovery literature (Ng et al, 2019). They reflect the concept of recovery as an open-ended journey which involves learning how to cope effectively with the difficulties associated with a diagnosis and developing a meaningful life within its limitations (Katsakou et al, 2012; Slade and Hayward, 2007). Katsakou et al's (2012) research contributes greatly to the literature in this field by providing valuable insights into the way in which those diagnosed with BPD relate to their own recovery and the tools they consider helpful in contributing towards positive change. Whilst some of the recovery goals expressed by service users with BPD such as improvements in self-acceptance, relationships and employment have been widely documented among users of general mental health services, more specific goals such as gaining control over difficult emotions and progress in the management of clinical systems (e.g. self-harming) appear to be more specific to those diagnosed with BPD. Despite this, some service users in Katsakou et al's (2012) study felt that the specialist therapies offered (e.g. DBT and MBT) were too heavily focused on specific behaviours and did not allow for individual consideration of issues they perceived to be equally important, e.g. past traumatic experiences and eating problems.

In Ng et al's (2019) research, fourteen narratives of women with a BPD diagnosis were analysed using qualitative interpretative phenomenological analysis, with the aim of understanding recovery experiences. Similar to Katsakou et al's (2012) research, they found that recovery is an ongoing and non-linear process that occurs as a result of the interaction between the three stages and four processes identified from their analysis. These stages were defined as 'being stuck', 'diagnosis' and 'improving experience' and the processes included 'hope', 'active engagement the recovery journey', 'engagement with treatment services' and 'engaging in meaningful activities and relationships' (Ng et al, 2019).

Participants in Katsakou et al's (2012) research also described difficulties with the semantic usage of the word 'recovery', reasoning that the implication of a dichotomous classification between either having *or* not having problems is not appropriate to the BPD diagnosis. The hegemonic discourse of BPD as innate personality dysfunction means that for some, separating themselves from the disorder is particularly difficult and it is felt that to 'recover' from BPD would have to mean becoming a different person altogether. As such, full recovery in the sense of no longer experiencing any of the symptoms was perceived as unrealistic, especially as many could not remember a time when they had not experienced emotional problems, and felt, that to some degree, BPD was a 'part' of them. Building an awareness of the meaning of recovery and the concept of identity amongst individuals with a BPD diagnosis is therefore particularly important in understanding the particular social and contextual processes at work and developing treatment programmes which are relevant and appropriate.

This is particularly relevant given that the label of BPD can still frequently result in exclusion from or withdrawal of treatment options, which often results in an exacerbation of distress and some of the symptoms associated with it. Research has indicated that when appropriate treatment is able to be accessed, service users typically report more positive attitudes towards the diagnosis (Horn et al, 2007; Bendelow et al, 2016). In 2003, the National Institute of Mental Health in England (NIMHE) published a list of characteristics that individuals with a personality disorder diagnosis had found helpful when accessing mental health services. This table is reproduced in figure 2.1 below.

**Figure 2.1 Helpful features for personality disorder services (NIMH, 2003, p.22)**

- Early interventions, before crisis point
- Specialist services, not part of general mental health
- Choice from a range of treatment options
- Individually tailored care
- Therapeutic optimism and high expectations
- Develops patients' skills
- Fosters the use of creativity.
- Respects strengths and weaknesses
- Good clear communication

- Accepting, reliable, consistent
- Clear and negotiated treatment contracts
  Focus on education and personal development
- Good assessment/treatment link
- Conducive environment
- Listens to feedback and has strong voice from service users
- Supportive peer networks
- Shared understanding of boundaries
- Appropriate follow up and continuing care
- Involves patients as experts
- Attitude of acceptance and sympathy
- Atmosphere of truth and trust

Mirroring one of the findings from Ng et al's (2019) research highlighted above, many of the characteristics referred to by the NIMH (2003) relate to the importance of interpersonal relationships in the treatment and recovery process and support many of the prevailing assumptions with regard to what is considered 'good practise' in recovery-focused mental health services (Repper and Perkins, 2003). The participants in Horn et al's (2007) study described the most useful aspects of their BPD diagnosis as relating to the development of trusting, supporting and accepting relationships which served as a counterpoint to both the external and internal stigma of diagnosis. Similarly, Bowen (2013), in his study of a specialist personality disorder service echoed the previous findings of Krawitz (2004) and Commons Treloar and Lewis (2008) that a strong level of empathy amongst mental health staff acted as a strong catalyst for positive change. This can have implications for training and supervision which promotes shared values of inclusion, optimism and negotiation (Bowen, 2013).

What also emerged from the focus groups which informed the NIMH (2003) research findings illustrated above was the importance of fostering creativity within treatment settings. The use of art has a relatively long tradition within the specialised treatment of BPD, and the process of interchange between the making and sharing of artwork has been found to produce positive outcomes, particularly in mentalisation-based treatment programmes (Johns and Karterud, 2004; Springham et al, 2012b). Other studies have identified a range of diverse creative interests, particularly amongst women with a BPD diagnosis (Bendelow et al, 2016) and there is an indication that this creativity, if managed appropriately, can assist in the management of distress and negotiation of identity (Eastwood, 2012). The role of creativity and the evidence relating to the use of art therapy in the treatment of BPD are discussed in more detail in the next chapter. The remainder of this chapter will expand further on the concept of identity and its relationship to BPD, and reflect upon how this relationship has been conceptualised through the framework of illness narratives.

## 2.6 Understanding Illness Narratives and Identity

The conceptual framework of illness narratives has become a widely used tool by which to aid academic understandings of the experience of physical illness. It has been argued that the construction of these narratives allows for the creation of subjective, personal accounts that enable individuals to make sense of their condition and the perceived reasons for its occurrence outside of or in opposition to the traditional biomedical discourse of symptomology and the management of practical implications (Bury, 2001). Frank (2000) asserts that telling the story of illness can help to provide some distance from the fear and dislocation experienced during the illness experience and offer a sense of liberation from medicine as well as articulating a sense of abandonment from it. He emphasises the social character of these narratives and their therapeutic importance for the teller in negotiating the disruption caused to this sense of self by the onset of illness. This relies on an understanding that the ‘self’ is a narrative construct (Ricoeur, 1986) which is shaped by the personal and social history of the teller as well as the immediate relational context and the broader socio-cultural context of which the individual is a part (Langellier, 2001). As well as the conception of the self, this also influences the wider narratives individuals create, for example, in response to illness. Thus, one of the key strengths of narrative analysis can be defined as its ability to examine the complex ties between individual stories and the cultural and social contexts within which they occur (Plummer, 2001).

### *2.6.1 Defining Identity*

The question of what makes up a person’s identity and the nature of the self is one that has been addressed many times, and contemporary psychology and sociology offer a vast range of perspectives on, and conceptual understandings of personal identity. Broadly speaking, the concept of identity can be described as a way of understanding attempts to differentiate and integrate a consistent sense of self along different social and personal dimensions (Bamberg, 2011). The definition of identity that underpins this thesis is derived from and brings together a number of traditions, including psychodynamic, narrative and critical realist approaches. It has its basis in the work of Erikson (1959) who described it in a number of separate yet connected ways, namely as: a conscious and subjective sense of oneself; an unconscious striving for continuity of personal character; a necessary criterion for the synthesis of the ego; and as an inner connection and identification with the values, ideas, and (self-) images of a social group.

Jorgensen (2010) builds upon Erikson's work to distinguish four distinct yet interconnected levels of identity:

1) Ego identity - considered to be related to basic personality structure and functioning, continuity, and to stable and firmly integrated images of the self and others.
2) Personal identity – concerned with personal goals, values, belief systems, personality traits and preferences that are outwardly articulated.
3) Social identity – a consciously and deliberately constructed expression of identity, built upon an individual's sense of solidarity with specific social groups and elements of identity and demonstrated through impression management and the enactment of social roles.
4) Collective or large group identity – grounded in the internalisation of cultural norms, ideals and values, the membership or larger social groups or communities, ethnic background or religious identity.

Identity and sense of self are typically something individuals are said to *have,* e.g., some essential or fundamental thing that defines human beings at a deep rooted and unchanging level. The concept of the 'true self' has featured strongly in psychological research as a way of describing the authentic (and typically morally 'good') thoughts, feelings, values and desires that make up an individual's personal identity (Strohminger et al, 2017). However, identity is not something individuals are born with, or that can be pre-determined. As such, it can be considered not only a subjective construction, but one that is open-ended and influenced by a wide range of social and environmental factors (Jorgensen, 2006).

According to the psychodynamic perspective, the ability to form a coherent sense of the self is based on the capacity to integrate contradictory elements of the self and others and develop mature and adaptive personal, social and collective identities (Kernberg, 2004). This is typically achieved through a process of socialisation that begins in childhood and adolescence, whereby the individual is integrated into a community with a common set of behavioural norms, ideals, values and guidance on how to realise one’s personal and social identity (Habermas, 1981). Disruptions or challenges to the socialisation process can result in an inability to internalise key aspects of one or more of the levels of identity described above and a failure to establish a common frame of reference by which to conceive of the self (Jorgensen, 2006).

Winnicott’s (1960) theory of the ‘false self’ will be drawn upon in this thesis to refer to one of the ways in which an inescapable disruption to the socialisation process can impact upon the formation of a stable and integrated sense of identity. Winnicott suggests that when a child is subject to early caregiver relationships which do not prioritise or validate their needs and experiences, they learn to respond in a way that seems necessary to fulfil their inherent desire to be cared for and develop a bond with the caregiver. In doing this they come to understand that their internal and emotional reality is less important than that of the caregiver (Cooke, 2009). The consequence of this is described as a ‘splitting’ of the self into two – a public ‘false self’ which exists to meet the needs of others and serves to protect the vulnerable ‘true self’. Between these two, often polarised, selves, lies a divide which is confusing and difficult to navigate.

Whilst Winnicott’s theory draws upon the popular vernacular of the ‘true self’, he does not use this to mean a complete and functioning ‘core’, but rather as an individual set of potentials or possibilities that may or may not be realised, and the ‘human individual’s capacity for creative living’ (Winnicott, 1971, p.68). His theory is compatible with a critical realist ontology because, whilst it reflects the reality of individual experience, it also considers the relational aspects of context and behaviour and the ways in which power is exerted in the social structures in which we come to be. He suggests that the process of becoming a ‘true self’ is one that begins in childhood but continues and develops throughout life in our relationships with proximate and significant others. The critical realist perspective contends that, in the broadest sense, an individual’s continuous awareness of the self is ‘ontologically inviolable’ (Archer, 2000, p.2), experienced as reality, and is present independently of social constructions of the world. This lived experience of identity manifests in various conscious and unconscious ways; through an individual’s subjective experience of who they are, their basic needs, the way in which their temporal understandings of their pasts, presents and futures form together to make a more or less meaningful whole, and through their behaviour and internal interpretations of the world (Jorgensen, 2010).

The emergence of a social self, which exists in dialectical relation with personal identity, occurs as a result of the relationship between the internal self and the structures and cultures within which an individual exists (Archer, 2000). Understanding this social world and being present within it requires an awareness of the structures and narratives through which core identity is formed and it is through this process of narration and narrativity that we constitute our social selves and construct and reconstruct ourselves through the accounts that we provide to others (Butler, 2005).

### *2.6.2 Narrative Identity*

Narrative identity refers to the individual life stories that are created by individuals in order to create ‘unity, purpose and meaning’ (McAdams and McLean, 2013, p. 233) out of the synthesis of past autobiographical episodes and imagined futures. Life narratives and self-conceptions are continually changing in response to actions, events and acquired knowledge (Gergen, 1994). Narrative identity allows people the mechanism with which to convey to themselves and others who they are, how they came to be and their perceptions of the future (McAdams and McLean, 2013). However, given that our understanding of life is intertwined with the specific time, place and social context in which we are present, the narrative of ourselves that is conveyed does not exist within a vacuum, but is inevitably governed by traditions which influence its telling (McAdams, 1985). Thus, it is impossible to separate the understanding of the self from the context in which it occurs and any analysis of individual or collective stories of identity must consider the importance and reality of these stories to the individual as well as the underlying processes and structures that they represent (Bamberg, 2011).

The development of a well-formed narrative identity is understood to occur over time, influenced through repeated social interactions and wider cultural understandings which are integrated and adapted within the narrative framework (McAdams and McLean, 2013). It has been argued that it initially emerges in late adolescence/early adulthood as a response to societal expectations regarding identity and as a vehicle by which to begin to make sense of some of the key questions that arise as a result of these, most notably, ‘Who am I?’, and ‘How did I come to be?’ (Erikson, 1963). To cultivate it requires an understanding of the dynamics of sharing stories within particular cultural, familial and social contexts, and the early parental relationship is believed to be an important factor in the development of this understanding (Fivush et al, 2006). The story that an individual constructs in relation to their life is therefore thought to represent a distinct level of personality (McAdams and Pals, 2006).

Research on narrative identity has typically examined both the internal dynamics of private life narration and the external factors that contribute to the shaping of stories about the self, and this is often done by inviting participants to tell extended stories about scenes or periods in their own lives and coding these accounts for dimensions and features common amongst them. In general, research on narrative identity suggests that the way in which individuals make sense of and articulate suffering in their lives can impact upon their continued psychological well-being (McAdams and McLean, 2013). Those who demonstrate the capacity to articulate and commit to a positive resolution of a negative experience or construct narratives that emphasise learning, growth and positive transformation are found to score consistently higher on indices relating to happiness, maturity and psychological well-being (Tavernier and Willoughby, 2012; King and Hicks, 2007; Bauer et al, 2005). In addition, research by Adler (2012) has demonstrated that narrative accounts which include high levels of self-reported agency have been associated with continued positive mental health amongst individuals with experience of psychotherapy. Participants who developed stories that increasingly emphasised elements of control over their world and the ability to make self-determined decisions and take responsibility for their own difficulties showed significant decreases in negative coping behaviours and overall increases in mental health (Adler et al, 2008; Adler, 2012).

Whilst the causal relationship between features of life stories and positive psychological adaptation requires further research (McAdams and McLean, 2013), research concerned with the constructions and conceptions of narrative identity provides an important contribution to the understanding of personality beyond an emphasis on dispositional traits and biomedical markers of mental health (Adler et al, 2012).

### *2.6.3 Identity Disruption and BPD*

Psychodynamic theorists have emphasised the importance of what they define as identity to the structure and dynamic organisation of personality functioning (Clarkin et al, 2006). Individuals with a consolidated identity; that is one where the component parts are sufficiently well integrated in the organisation of the whole to create the effect of a single consistent unit (Greenacre, 1958), are considered more able to adapt and modulate their behaviour within different contexts and act in ways that are relatively coherent and predictable (Jørgensen, 2006). Additionally, a stable and integrated sense of identity is strongly associated with the development of self-acceptance and self-esteem and is considered essential for an individual’s conceptualisation of themselves as an autonomous agent with a balanced internal locus of control (Crawford et al, 2004).

A disturbed sense of identity has long been considered one of the key features of the BPD diagnosis (Clarkin et al, 1983; Spitzer et al, 1979). However, few studies have been dedicated to examining its specific characteristics and origins, particularly in relation to understanding its potential social and cultural underpinnings. Research grounded in the work of Erikson (1959) has been able to identify disruptions in identity unique to those diagnosed with BPD when compared to other respondents (Jørgensen, 2009; Wilkinson-Ryan and Westen, 2000), which supports the assertion that, irrespective of its aetiology, individuals with a BPD diagnosis have difficulty in developing and maintaining a strong sense of self (Heard and Linehan, 1993; Westen and Cohen, 1993). However, these studies have relied heavily on questionnaire data and clinician reports, which, whilst often valuable in the assessment of 'symptomology' and social functioning, can often be lacking in insight when it comes to understanding the complexities and subjectivities of personality (Adler et al, 2012).

Alder et al (2012) adopted a more experiential method of studying identity disturbance which involved studying the personal narratives of those diagnosed with BPD, in order to distinguish those aspects of narrative identity which differ from 'non-pathological' identity processes. The findings of their study indicated that the narrative identities of individuals meeting the diagnostic criteria for BPD contained significantly less agency, communion fulfilment (the degree to which their need for attachment was met) and overall coherence than in a matched sample of participants without a BPD diagnosis. Whilst both sets of participants articulated life stories that contained a certain amount of difficult and distressing experiences, the focus of this study was not so much on the specific life events that contributed towards the resulting narrative but on the common thematic and structural elements that distinguished participants diagnosed with BPD from those without. The life stories articulated by those diagnosed with BPD typically depicted a disempowered protagonist who is a victim of external circumstances is consistently unable to fulfil the need for stable intimate connection. Furthermore, the narratives themselves were found to be lacking in sequence, a broader sense of subjective personal reflection over meaning and appropriate affect.

Whilst these findings support general consensus with regards to the importance of identity disturbance in BPD and contribute to an understanding of the disorder that originates within the individual's own conceptualisation of self, there is little space in the research for an examination of the contributory factors that result in this disturbance. Jørgensen (2006) argues that the development of personal identity is better understood if considered in relation to early psychological development and some of the elements of modern culture on which identity can be considered to be dependent. As has previously been discussed, there is a strong argument that BPD originates out of insecure attachment patterns in childhood, something that is also associated with identity diffusion (Erikson, 1968). Masterson (2000) suggests that a lack of support for a child's 'emerging self' during the separation-individuation process can result in separation anxiety and strong feelings of abandonment which could negatively affect the normal development of personal identity. This, combined with an understanding of how changing social organisation and cultural dynamics can shape and influence human psychology is considered by Jørgensen (2006) to be the key to understanding identity development and the disturbed sense of identity experienced by individuals diagnosed with BPD.

Adler et al (2012) acknowledge that their study, whilst having some utility for the development of therapeutic techniques which address the particular features of identity disturbance, does not allow for an assessment of the directional relationship between identity disruption and diagnostic status. According to Jørgensen's (2006) assertions above it would be reasonable to assume that the application of the diagnostic label of BPD itself, in a society where medicalised discourses are privileged and the labelling of atypical behaviour as 'illness' is considered the norm, could contribute to some of the confusion and identity disturbance experienced by those to whom a BPD diagnosis is ascribed. This thesis aims to contribute towards furthering knowledge in this area by applying the frameworks of biographical disruption and narrative reconstruction outlined below to explore the bi-directional relationship between identity and diagnosis and the way that it is shaped by social, cultural and individual factors.

### *2.6.4 Biographical Disruption and Narrative Reconstruction*

Illness narratives, as they are traditionally understood in relation to experiences of physical illness, are inherently personal, subjective and vary in individual significance. However, in the sociological study of heath and illness, illness narratives are commonly recognised as an essential process in the recognition of the self as ill and the acceptance of this (Williams, 1984). The concepts of 'biographical disruption' and 'narrative reconstruction' were developed by Bury (1982) and Williams (1984) respectively to understand the ways in which illness narratives are constructed in response to the sudden or significant change brought about by the onset of chronic or severe illness.

The concept of biographical disruption was developed as a result of Bury's (1982) work with a group of adults ranging in age from early 20s to late 60s with rheumatoid arthritis. He developed the idea of biographical disruption in response to findings which illustrated the disruptive effects of arthritis to what was considered the 'normal' trajectory. Bury (1982) noted that there were three aspects to this biographical disruption. Firstly, taken for granted behaviours are disrupted, as well as the typical explanatory systems used by individuals. This leads to a reconsideration of the biography which in turn manifests as a mobilisation of resources and response to the disruptive event. Contained within is the assumption that self-identity relies on the maintenance of a consistent personal narrative of the self and that illness represents a threat to this consistent self through an undermining of the everyday structures and assumptions about the world that underpin it (Bury, 1982; Reeve et al, 2010). In order to attempt to maintain this coherent account of the self (Giddens, 1991), the experience of illness is reconstructed in such a way that it renders 'intelligible the biographical disruption to which it has given rise' (Williams, 1984, p.197). These reconstructions are situated largely outside of traditional medical discourses, but are nonetheless shaped by their influence in the wider social contexts in which illness occurs. Narrative reconstruction occurs in a bid to reorganise and reassemble the discrepancies between the embodied experience of illness, the self and the social world by the forming links and interpreting events in such a way as to realign events and self-conceptions with societal norms (Williams, 1984).

Reeve et al (2010) suggest that for a particular incident or event to be viewed as 'disruptive', there is an inherent supposition of the shared concept of a 'normal' state as well as an understanding of the significance of change, something that has not always been demonstrated in practise. The accounts analysed by them in relation to the diagnosis of terminal cancer did not demonstrate evidence of a continuous effort to maintain a meaningful self-narrative, but rather an acknowledgment of the embodied and emotional experience that underpinned individual coping mechanisms allowing them to maintain continuity. This is particularly pertinent when considering the concepts of biographical disruption and narrative reconstruction in the context of chronic mental distress, especially in the case of contested diagnoses such as BPD, which contains an inherent assumption of dysfunction as being located within an individual's core personality functioning, rather than as a result of a specific biological malfunction (Mann and Lewis, 1989). Given the extent to which this thesis is critical of the biomedical model of mental distress, there is some reservation with regards to the application of literature relating to physical illness on concepts of mental distress. However, adopting a critical realist perspective, it is interesting to explore how personal meaning around experiences of mental distress is created in the context of a prevailing biomedical discourse, and the extent to which these processes align with or deviate from those employed in relation to physical health.

Arthur Frank, a sociologist and cancer survivor, has suggested that the act of storytelling can assist in restoring what may have been cast adrift by those experiencing a loss of health or bodily function (Frank, 1995). He identified three broad types of narrative – 'restitution', 'chaos' and 'quest', which he suggested are likely to be present (both singularly and interchangeably) in stories told about personal experiences of health and illness. In the restitution narrative, the ill person is framed as a passive recipient of treatment or medicine designed to return them to their former healthy selves. Restitution denotes a solution, end, or resolution to the problem of illness, with the hope and promise of a return to a prior state of normality (Nosek et al, 2012). On the other hand, the quest narrative situates the ill person as the agent, whose goal is not to return to health but to learn to live with illness; the experience of illness being reworked by the narrator to depict a transformative process in which the self is placed at the centre and grows and changes in response to the illness (Frank, 1995). Narratives characterised by chaos are often more difficult to distinguish (Chandler, 2014) in that they are typically defined by a lack of narrative and an absence of coherence relating to the events or experiences being relayed (Frank, 1995). Chaos narratives are categorised by a sense of 'incessant present with no memorable past and no future worth anticipating' (Frank 1995: 99) and are more frequently told retrospectively, as lived chaos presents a significant challenge to the storytelling process (Nosek et al, 2012; Chandler, 2014).

The narrative, biographical approach offers a strong theoretical basis on which to further understandings of the impact of illness on personal meaning and for conceptualising illness and recovery (Lawton, 2003). However, it has been suggested that this approach may serve to distance the accounts from the lived experience of individuals and that narrative construction and reconstruction may be best described as an artefact of the research process rather than the given 'reality' of individual experience (Bury, 2001). Whilst the stories told about illness are, by definition, 'enacted' (Frank, 1995, p.116), in that they are representative of a particular point in time and are constructed in relational response to the listener, they can still offer valuable insight into the construction of meaning. Furthermore, they can serve to illuminate the reflective embodied relationship between lived experience and how it is constructed and woven into narrative (Chandler, 2014).

### *2.6.5 Biographical Disruption and Narrative Reconstruction in the Context of Mental Distress*

There is very little in the literature that reflects upon the concept of biographical disruption as far as it can be applied to chronic experiences of mental distress. Research by Perry and Pescosolido (2012) exploring the effect of long-term mental 'illness' on an individual's social network employed some of Bury's (1982) ideas on biographical disruption to relate the destabilising and subsequent mobilisation of the social network in response to a disruptive event to the experience of mental ill-health. Their findings demonstrated a degree of support for Bury's (1982) argument as it relates to chronic illness, in the sense that individuals at the onset of psychiatric treatment reported larger and more functional social networks than individuals in the population at large. However, over time, the number of network ties were observed to decrease in contrast to those without experience of mental distress who generally showed an increase in social connections. One of the explanations offered for this relates to the elevated levels of stigma and rejection previously discussed as being experienced by individuals labelled as mentally ill (Perry, 2011; Link et al, 1994). An alternative argument however is offered which suggests that a reduction in the social network may be reflective of a pattern of adjustment to chronic illness. Thus, the initial influx of support rescinds as the individual adjusts or is forced to adapt to their new identity as a person with a mental health diagnosis (Perry and Pescosolido, 2012).

These ideas are echoed in research that focuses on the concepts of narrative reconstruction or 'narrative re-storying' as a response to the interruption of daily life through mental distress (Richardson, 2000; Grant et al, 2015). Academics in this area argue that the action of re-storying significant events in one's life in order to make sense of the past and guide the present can be both therapeutic and transformational (Frank, 1995; Grant et al, 2015). The importance of psychotherapy in facilitating narrative reconstruction has been documented in literature that attempts to understand the importance of storytelling to the achievement and maintenance of therapeutic gains (Josselson, 2004; Neimeyer, 2000; Singer, 2005; Spence, 1982). Psychotherapeutic approaches, including existential, Jungian, and transpersonal therapies are designed to cultivate Frank's (1995) quest narrative, as described in the previous section, in which the experience of distress is viewed as an opportunity for development and adaptation, rather than as a loss of control or passive experience over which the individual experiencing distress has no influence (Singh and Ochitill, 2006).

Whilst the unique process of telling one's story through therapy can undoubtedly assist in the renegotiation of disruptive life events that resist incorporation into an individual's existing self-story, Adler and McAdams (2007) assert that the way in which individuals' construct stories about the experience of therapy itself can also assist in the negotiation of identity and have powerful transformative effects. Stories about therapy, they argue, can help people to understand the ways in which they have suffered and the mechanisms which they have employed to manage and overcome distress and can assist in preserving the positive gains achieved through treatment. Their research demonstrated that individuals who were unable to relate coherent stories about their therapeutic experience generally scored lower on both ego-development and well-being measurements, possibly suggesting that they were unable to render their experiences meaningful. Conversely, individuals who scored highly on these measurements typically narrated stories high in personal agency and self-insight, with the therapist portrayed as a supportive but not overbearing figure in the treatment process. This research has implications for the psychotherapeutic relationship and highlights the longitudinal importance of the therapist as a vehicle for the facilitation of co-constructed narratives of the therapeutic journey (Bruner, 1990; Adler and McAdams, 2007).

According to McLeod (1997) and Baldwin (2005), successful therapeutic interventions for individuals with mental health problems allow opportunity to create and maintain personal stories which reinstate a sense of meaning, identity and coherence within the context of both their experience and the cultural narratives available to them. Carless and Douglas (2008) identified sport and exercise as important tools in allowing for a positive 're-storying' following experiences of severe mental distress. The narratives expressed by the (all male) participants of this study about their experiences of participating in sport and exercise marked a departure from the dominant 'restitution' narrative focused on restoring a past state of 'wellness' in the future (Frank, 1995). Whilst a restitution narrative may be appropriate for some experiences of illness, for which a return to a previous state of health may be forthcoming, stories of restitution are not sustainable in the context of long-term impairment, to which a severe mental health problem can arguably be equated (Carless and Douglas, 2008). Smith and Sparkes (2005) suggest that for individuals experiencing chronic illness, it is necessary to develop alternative narrative resources by which to story their lives in order to maintain or reinstate a sense of self, identity, and positive mental health. In Carless and Douglas' (2008) research, the experience of sport and exercise was found to have enabled a new narrative framework by which to convey the present and embodied experience, based on the notions of action, achievement and relationships. Whilst this study represents only a limited perspective, its findings have implications for the development of treatment interventions that can initiate similar effects on the narratives of those experiencing mental distress.

Chandler (2014) also applied Frank's (1995) typology of illness narratives in the context of mental distress, in her research exploring narratives of self-injury. Although not a straight-forward 'illness', the analysis of participants' accounts of both the act of self-injury, and their reflections on the aftermath highlighted the diverse meanings associated with self-injury and its resulting scars. The chaos, restitution and quest narratives, as outlined by Frank (1995) offered a useful alternative means by which to explore these meanings and structures, with participants' accounts often containing elements of all three (Chandler, 2014).

The research highlighted above suggests that existing typologies of illness narratives and concepts of biographical disruption and narrative reconstruction may be appropriate for exploring the construction of meaning and the importance of storytelling amongst those with experience of mental distress. However, further research is needed in order to understand the extent to which these concepts are applicable to the specific experience of BPD, given the particular controversy around its status as an 'illness' in its own right (Bjorklund, 2006).

## 2.7 Summary and Conclusion

This chapter began by providing an overview of the biomedical model of BPD which continues to dominate the discourse before examining the ways the ways in which feminist, critical realist and narrative approaches have challenged the medicalisation of mental distress in this context and promote alternative understandings grounded in the lived experience of those to whom the diagnosis of BPD is a distressing reality. The literature regarding identity disturbance amongst individuals diagnosed with BPD has provided a useful framework by which to conceptualise some of the challenges of diagnosis. Whilst it is clear that identity disturbance is considered a central characteristic of the BPD diagnosis and that therapeutic interventions which help to create an integrated sense of self and encourage the development of personal agency promote positive wellbeing, there is no clear consensus with regard to the origin of this disturbance and the mechanisms that reinforce it. This thesis aims to further understanding in this area by exploring the impact of diagnosis itself on narrative identity in the context of the wider social and cultural climate, grounded in the subjective experiences of individuals with a BPD diagnosis.

Life history methods and illness narratives provide an effective way of understanding 'the inner experience of individuals, how they interpret, understand and define the world around them' (Faraday and Plummer, 1979: 776). The concepts of biographical disruption and narrative reconstruction allow for conceptualisations of chronic illness which create awareness of how meaning is both created and made sense of. The application of these concepts to the experience of chronic mental distress could provide alternative ways of understanding the disruptive life events that contribute to the emotions and behaviours associated with a diagnosis of BPD and the ways in which individuals with the diagnosis negotiate identity and reconstruct narratives to help them make sense of the complex personal, social and organisational challenges with which they are faced. Whilst a focus on the management of acute interpersonal symptoms has largely dominated treatment discourse, there is an increasing awareness of the need for greater understanding of the perceptual and emotional experiences of those experiencing personality disorder and how these experiences can be used to develop effective treatments which are holistic and responsive to individual concerns.

Existing research has begun to examine the phenomenology of personality disorder from a service user perspective, and feminist critics have offered valuable insight into the gendered construction of the diagnosis borne out of a wider cultural tendency to pathologise manifestations of distress, particularly against women (Shaw and Proctor, 2005). There is however little to be found in the literature that acknowledges and explores both the social construction of personality disorders and the way in which they are understood and experienced first-hand by those to which the diagnosis is ascribed, taking into account the political and social climate which privileges certain discourses. Whilst lived experience research in this field has generally been focused on women as a result of the higher diagnostic rates amongst this group, there is an absence of feminist-orientated research which privileges the experiences of women and focuses on how they are constructed and interpreted in a wider cultural context. Research of this nature can be useful in producing new ways of understanding which are informed by cultural constructions and perceptions of those with experience of mental health problems and, perhaps more importantly, how they perceive themselves.

This study aims to fill some of the gaps highlighted above and contribute new knowledge to this area of research by focusing its attention specifically on the lived experience of women with a BPD diagnosis and the ways in which they interpret and create personal meaning out of their diagnosis. Furthermore, it builds upon the existing body of recovery literature informed by service user perspectives to develop understandings of ‘what works’ to alleviate distressing symptoms of BPD and promote a concept of personal recovery that is meaningful and achievable. The next chapter expands on this concept of recovery further to explore the origins of art-therapy and other creative treatment approaches, as well as their effectiveness in providing meaningful outcomes for women with a BPD diagnosis. Furthermore, it provides a summary of the existing literature in relation to the function of creativity and its relationship to identity, including an exploration of the ways in which creative activity can provide an alternative way of telling stories about mental ill-health which go beyond a traditional biomedical narrative.

# Chapter 3: Literature Review

## Creativity, Identity and Mental Health

### 3.1 Introduction

Creativity is a broad and complex domain, and the study of it spans many different disciplines and methodological approaches (Shiu, 2014). Despite the large body of research centred on isolating and explaining the processes involved in creativity, there remains little consensus on how to define and measure such a concept with many disparate parts (Vilanova and Cunha, 2020). Before embarking on an exploration of creativity, it is important to first understand the context within which previous research has been situated and the scale and complexity of the debates regarding its study. This chapter begins therefore by summarising the various definitions of creativity used in the literature and highlighting those relevant to this study. This then leads to an overview of the ways in which creativity can be measured, with the aim of building a broad foundation of multi-disciplinary knowledge upon which to refine the focus of this research.

Narrowing the focus of the review, the chapter will then go onto explore the neuroscientific, psychological and sociological literature regarding the relationship between creativity and mental wellbeing in order to further ground the context of the current research and highlight the gaps in existing knowledge which this study seeks to fill. It explores the function of creativity and its interaction with identity processes and highlights relevant literature with regard to the role that creativity and artmaking can play in recovery from mental distress, both as a formal therapeutic tool and as an everyday activity.

### 3.2 Defining Creativity

Creativity is difficult to define, and there is little in the way of consensus in the literature as to what it is, the role it plays and how it should be measured (Weilgosz and Imms, 2007). However, the most commonly accepted way of defining creativity is in terms of the creative output, with an emphasis on the ability to produce work that is novel, effective and appropriate (Sternberg and Lubart, 1999). In a similar vein but with more of a focus on internal traits, Weston (2007) defines creativity as the ability to go beyond the obvious and to be imaginative, innovative, practical and persistent. He argues that whilst creative thinking requires a level of playfulness, it also necessitates a disciplined and critical approach. This is a perspective also articulated by Lane (2006), who speaks of a creative way of life as being one defined by an ability to be unselfconscious and spontaneous whilst also maintaining a sense of discipline.

Emphasising this playful approach, Bohm (2004) describes a creative state of mind as something that can be cultivated through a wholehearted, childlike involvement in an activity and an openness to new perspectives, orders and structures. Weston (2007) supports this, asserting that to think creatively requires an attitude of exploration and a willingness to explore different angles and ideas. He outlines the role of creativity as a powerful tool for social change, but also emphasises its importance as a practical, everyday activity.

Many theorists and psychologists suggest that creativity is central to human existence (e.g. Csikszentmihalyi, 1996; Nelson, 2005) and something that distinguishes us from other species. It is generally perceived to be an intrapsychic process – an individual psychological trait or combination of traits (Northfield, 2014), and much of the research about creativity has sought to identify common characteristics and constructs that define creative people. Much of the literature relating to creativity has positioned it as something exceptional, linking it to artistic genius or madness, rather than exploring it in an everyday context or as existing outside of the domain of the arts (Northfield, 2014). However, scholars such as Richards (2007, 2010) have highlighted the significance of creativity in daily life, emphasising its importance as both a cause and effect of human flourishing. Studies have also found a significant correlation between emotional wellbeing and involvement in everyday creativity, linked to participants' experiences of creative self-expression and their enjoyment of the activity itself (Wright, 2022). This is of particular relevance to the thesis and is explored in more detail later in this chapter.

Everyday creativity is often understood in term of little and mini 'c' creativity, which separates it from the Big and Pro 'C' creativities associated with professional and elite artistic disciplines (Kaufman and Beghetto, 2009). Whilst little-c creativity is more concerned with tangible and recognisable expressions of creativity in everyday life, mini-c creativity is personal in nature and focused on the genesis of creative expression. Mini-c creativity is described by Kaufman and Beghetto (2009) as "the dynamic, interpretive process of constructing personal knowledge and understanding within a particular sociocultural context" (p.3). This is of particular relevance considering the critical realist and feminist approaches discussed in the previous chapter and the ontology underpinning this thesis which posits that the reality of experience cannot be understood without also understanding the context in which it occurs (Bhaskar, 1975).

The hierarchical nature of the 'Four C' model of creativity which places little-c and mini-c creativity below Big-C and Pro-C creativity reflects the fact that traditionally, limited attention has been paid in the literature to conceptualisations of creativity that prioritise process over output (Richards, 2012). However, when it comes to everyday creativity, research finds that participants rarely make clear distinctions with regard to their involvement in specific creative activities, tending to focus more on how the creative process makes them feel rather than what is produced or achieved (Benedek, Bruckdorfer and Jauk, 2019). Armstrong (2007) argues that what is missing from much of the research seeking to define and measure creativity is ‘the meaning of life aspect’ (p.22) – that is, the significance of the creative process at an individual and socio-cultural level, especially on an everyday basis. The current research aims to further understandings of the role and value of everyday creativity, particularly with regard to the novel and meaningful processes experienced by individuals with a diagnosis of BPD, both within and outside of the artistic domain.

### *3.2.1 Flow, reverie and escape in the creative process*

Theorists concerned with exploring and describing what occurs during the creative process have typically focused on identifying the ideal conditions under which creativity can occur, rather than the function of creativity for the individual (Armstrong, 2007). These studies generally define creativity primarily in terms of artistic output and the objects of study are often artists, writers or musicians who are deemed to be exceptional in their field.

Csikszentmihalyi’s (1975) theory of ‘flow’ is considered one of the most influential theories of the creative process. In his studies of art students, and later, musicians and chess players, many reported a trance-like state of total immersion, which occurred when they were taking part in their chosen creative activity. This led him to surmise that creativity is premised on the idea of intrinsic motivation – that is, being totally involved in an activity for its own sake, in such a way that nothing else seems to matter. He theorised that a state of flow was not present in habitual or routine activities, but that a degree of challenge and an exertion of skill is required in order for action and awareness to merge to achieve a sense of order over the expression of one’s inner life (Debold, 2002). Csikszentmihalyi later refined his theory of flow by conducting research with 91 people considered experts in their creative field (Csikszentmihalyi, 1996). In this, he examines the cultural and social elements of creativity and suggests that creativity manifests itself through the way that an individual interacts with the symbolic rules of their chosen activity (the cultural domain) and the social field in which it exists and is validated.

Similar to Csikszentmihalyi’s theory of flow, artist and psychoanalyst Marion Milner described, in her 1957 book, a state of what she called ‘reverie’ that occurred whilst she was drawing and painting. This is referred to as a state of ‘liveness’, experienced as a feeling of being both fully present yet somehow separate from one’s surroundings, and can be summarised as the kind of concentration which results in being totally lost in an activity. Expanding upon this, Ravetz (2019) describes reverie, like Csikszentmihalyi's flow, as being inherently relational, and requiring an environment that fosters safety, security and the ability to be vulnerable. She draws upon Bion's (1970) concept of reverie, as the ability to tolerate a level of uncomfortable uncertainty without becoming overwhelmed or frustrated, to argue that the ability to be creative comes as a result of being able to liberate oneself from rules and expectations of seeing, being and doing and to embrace new growth (Ravetz, 2019). Building upon these ideas, some creativity researchers (e.g. Dissanayake, 2019) have suggested that the creative process represents an avenue of escape from what is described as the mundanity, tedium and challenges of day-to-day to life and an opportunity to exist temporarily in a more desirable alternative world. This is likely to be particularly pertinent when considering the function of the creative process to those experiencing mental distress.

These ideas of reverie, flow and escape are relevant not only when considering how creativity is manifested and experienced, but also in investigating the relationship between creativity and individual identity or sense of self. The remainder of this literature review, will outline the relatively scant literature linking creativity and identity, before moving on to explore the far larger body of evidence regarding creativity and the role of artmaking in mental health and wellbeing, with a particular focus on how art and creativity can be useful for individuals diagnosed with BPD.

## 3.3 Creativity and Identity

Anecdotally, there are many examples of creative individuals who describe their art as being an expression of their self or as being inherently linked to their identity (Dollinger et al, 2005). Drawing upon elements of the theory of flow referred to in the previous section, Cupchik (2013) posits that the creative process involves a complementary relationship between what he terms the 'Thinking-I' and the 'Being-I' and that artistic expression involves the combination of conscious decisions about matters such as colour, composition or texture and unconscious representations of feelings and emotions associated with the self. He suggests that the 'Being-I' is related to a search for meaning in one's life and as such manifests itself in the creative process through what Cupchik (1992) refers to as expressive embodiment. This is described as being comparable to Ekman and Friesen's (1969) theory of nonverbal leakage (cited in Cupchik, 2013) - that is, when an individual controls one channel, such as their facial expression, but displays emotion subconsciously through their nonverbal behaviour, e.g. by nervously tapping a foot.

The majority of the literature examining the relationship between creativity and identity has focused on the ways in which personal identity is represented through creative outputs or the extent to which identity processes shape the development of creative activity. Drawing upon Erikson's (1959) conception of identity as referenced in the previous chapter, Albert (1990) suggests that to be creative involves being in control of, and having a clear understanding of, one's own identity. Creative behaviour can therefore be understood as a way of indicating the legitimacy of that identity. Erikson himself has relatively little to say about creativity, but an analysis of his unpublished writings suggests that he associated it with a playful quality that allows children to explore new elements of their identity (Hoare, 2002).

Dollinger et al (2005) conducted a study with 250 university students with the aim of establishing whether identity and creativity are empirically related. Using measures of identity style, creative potential, creative accomplishments and creative products, they assessed the extent to which identity style correlates with creativity. Like the concept of narrative identity discussed in the previous chapter, identity style refers to the way in which individuals construct, revise or maintain their sense of identity. Dollinger et al (2005) hypothesised that an exploratory identity style would be associated with higher levels of creativity amongst adolescents and young adults. They found that those who emphasise their inner personal identity (rather than their outer or social identity) and actively seek out and process information before making identity-relevant decisions seem to exhibit greater potential for creativity, showing more evidence of creative accomplishments. These findings mirror previous research in which creativity is consistently correlated with openness to experience (e.g. Feist, 1998, Dollinger et al, 2004) as well as personality traits such as independence of judgement and inner-directedness that are associated with personal identity and an information seeking style (e.g. MacKinnon, 1962).

Whilst the quantitative literature clearly demonstrates a relationship between creativity and identity processes, what remains unclear, and thus warrants further exploration, is the directionality of influence within this relationship. Whilst Dollinger et al (2005) claim that identity processes shape the development of creative activity, other researchers (e.g. Waterman and Archer, 1979) argue that creative activity, especially in early life, can lead to changes in identity status. This is particularly relevant to this study in that identity disruption and a lack of a consistent and stable sense of self is a key feature of the BPD diagnosis (Clarkin et al, 1983). Returning to Cupchik's (2013) article on expression in life and art, he submits that when an identity is fully formed, the artistic output can offer an embodiment of this sense of being that is clearly visible and understood by the artist and viewer. However, he suggests that an artistic output can also be part of what he terms a person's 'becoming' (Cupchik, 2013, p.86) in that the act of producing the creative work can enable an individual to find or resolve a sense of their own identity. Jorgensen (2006) suggests that we are yet to fully understand how creative processes can enable self-discovery and/or the development of a coherent sense of identity, especially amongst individuals who have experienced early relational trauma and/or disruptions to the socialisation process which can affect identity development. This thesis aims to contribute towards building this understanding by exploring the function and meaning of creativity to women with a BPD diagnosis, particularly in relation to the relationship between creativity and narrative identity.

### 3.4 Creativity, Genius and ‘Madness’

The existence of a relationship between creativity and mental health has been speculated on for centuries (Becker, 2014) and is typically conceived of in two ways. Historically, the stereotypical idea of ‘creative genius’ and its link to what was then regarded as ‘madness’ dates back to the 1830s (Becker, 2001). Since then, various attempts have been made to evidence a link for an association between the traits that underscore creativity and those related to emotional distress (Fisher, 2015). On the other hand, there has been a growing contemporary interest in the role of creativity, and particularly participation in the arts, as a way of promoting positive mental health and wellbeing, social connection and inclusion (All-Party Parliamentary Group on Arts, Health and Wellbeing, 2017).

‘Genius’ is an ambiguous construct that is frequently linked to creativity (Battersby, 1989) and studies of creativity and ‘madness’ have typically focused on individuals considered to possess what is conceptualised as creative genius – that is, demonstrating exceptional talent in a creative field (Northfield, 2014). Numerous studies have examined eminent figures in disciplines such as art, literature and music and attempted to diagnose so called ‘symptoms’ of mental ‘illness’, often retrospectively (e.g. Simonton, 1997; Post, 1994; Jamison, 1994). Whilst these studies have concluded a higher incidence of poor mental health amongst these exceptionally creative individuals than the general population, they have been criticised for failing to consider the social, political and cultural context and are typically male-dominated – a characteristic suggested to be reflective of the far more limited extent to which women are considered to possess ‘genius’ qualities (Northfield, 2014).

The supposed link between creativity and psychopathology has also received some support through empirical studies that have sought to identify shared personality traits and functions between creative individuals and those experiencing mental distress. Eysenck’s (1995) ‘psychoticism dimension’, a personality construct characterised by coldness, aggressive and impulsive behaviour and a lack of empathy, has been found to be positively associated with a number of creativity-related demands (Acar and Runco, 2012). There has also been some evidence to suggest that individuals exhibiting mild to moderate symptoms of schizophrenia display heightened levels of creativity (e.g. Abraham, 2014; Nelson and Rawlings, 2010). However, these studies have also shown that individuals with severe symptoms related to a diagnosis of a schizophrenia perform worse than so called 'healthy' controls on a broad range of creativity-related tasks. This lends some support to Rothenberg's (1994) argument that the relationship between psychosis and high-level creativity is a predominantly superficial one and that creative thinking typically occurs through a conscious, rational process rather than in an altered or pathological state. Comparing this to the common definition of creativity described in section 3.2, scholars such as Fink et al (2004) have emphasised that the creative performance of individuals with certain types of psychopathology is frequently limited to novelty generation and they are less likely to score highly on the measures of appropriateness and effectiveness that are deemed to make an individual 'highly creative'.

Nevertheless, the idea of an ambiguous association between creativity and poor mental health continues to be pervasive, supported to some degree by brain imaging studies, qualitative case studies and behavioural research studies that all demonstrate some shared characteristics between varying degrees of mental 'illness' and the creative process (Leutgeb et al, 2016). There is some evidence from magnetic resonance imaging to support the idea that similar mental processes may be involved in the originality component of creativity and so-called 'schizotypy.' Fink et al (2014) investigated functional patterns of brain activity during creative ideation amongst groups individuals categorised as having high or low 'schizotypy' and found an association between reduced deactivation of right parietal brain activity in both originality processes and psychosis proneness. There is also some evidence to suggest that heightened impulsivity, a primary trait of so called 'disorders' such as Bipolar Disorder and BPD, is linked to enhanced creativity, both through self-reported levels of creativity amongst those experiencing hypomanic episodes, and also through quantitative measures of creativity (e.g. McCraw et al, 2013; Srivastava et al, 2010, Johnson et al, 2012).

There are very few studies examining the specific link between creativity and the diagnosis of BPD. However, on the basis of the personality traits and functions considered to be associated with heightened creativity (e.g. impulsivity, risk taking and low inhibition) it would be reasonable to assume that individuals with a diagnosis of BPD are more likely than the general population to possess above average levels of creativity (Leutgeb et al, 2016). Despite this being a commonly-held perception, studies of creative functioning amongst individuals with a BPD diagnosis have produced mixed results. Fink et al's (2012) study of females with a diagnosis of BPD showed comparatively high levels of originality during an idea generation task relative to a control group of individuals without a diagnosis. However, other neuroscientific studies involving individuals with BPD have revealed smaller volumes in the physical composition of brain regions typically linked to creativity-related demands (e.g. Rossi et al, 2013), indicating the likelihood of lower levels of creativity amongst individuals with BPD.

Leutgeb et al's (2016) study compared different psychometrically-determined facets of creativity amongst 20 females diagnosed with BPD compared to 19 individuals without a mental health diagnosis. They also conducted an analysis of grey matter amongst both groups and found no indication of a significant link between creativity and psychopathology in either domain. The sample of females with a diagnosis of BPD in this study displayed a pronounced reduction in grey matter in brain regions which support cognition and emotion (including the bilateral orbital inferior frontal gyri and the left superior temporal gyrus), indicating severe psychopathology. This supports the assertions of others (e.g. Rothenberg, 1994; Abraham, 2014) who suggest that the relationship between psychopathology and creativity exists as an inverse U-shape, whereby certain characteristics, sometimes associated with mental 'illness' can enhance creativity, but the experience of severe mental 'illness' is detrimental to the creative impulse (Nettle, 2001).

The ambiguity about the relationship between mental health and creativity exists in part because of the challenge in defining and measuring creativity outlined earlier in this chapter (Fisher, 2015). Despite a wide body of research spanning across the cognitive sciences, there remains no conclusive scientific understanding of creativity as a distinct or localised mental process which makes it difficult to objectively determine who is and is not deemed to be creative (Fink et al, 2009). It is argued that focusing on establishing shared determinants of creativity and mental distress can obscure an examination of the cultural, social and relational underpinnings of both creativity and mental distress as well as the lived experience and function of creativity. Therefore, this thesis is not concerned with measuring or judging participants' creative abilities or outputs, but rather on exploring the meaning, function and process of creativity amongst women with experience of mental distress. Furthermore, it also offers some insight into the impact of the commonly-held belief of a link between poor mental health and creative ability on participants' attitudes towards and expectations of their own creativity.

The next section explores the growing body of evidence examining the role of creativity and the arts in promoting positive mental health and wellbeing which goes some way to redress some of the limitations highlighted in the literature referred to above.

### 3.5 Understanding the positive impact of creativity and artmaking on mental health and wellbeing

In 2017, the All Party Parliamentary Group on Arts, Health and Wellbeing published a report detailing the findings of a detailed inquiry into the interactions between the arts, health and wellbeing across the life course. In it, they highlight a number of ways in which participation in the arts can be beneficial at both an individual and societal level, including through exposure and participation in the arts in health and social care settings, participatory arts programmes, the inclusion of community art programmes in social prescribing initiatives, arts therapies, and through participation in everyday creativity (APPG, 2017). The World Health Organization's (WHO) Health Evidence Network (HEN) produced a synthesis report on arts and health in 2019 which references over 900 publications relating to arts and health, including 200 reviews covering over 3,000 studies. Their report finds evidence of the overwhelming positive contribution of the arts in promoting good health and helping to prevent, treat and manage a range of mental and physical health conditions. Furthermore, the report finds that the arts have a vital role to play in addressing complex health challenges in a multisectoral, holistic and person-centred way (Fancourt and Finn, 2019). More recently, the Centre for Cultural Value (Wright, 2022) published a review of the current evidence relating to the impact of everyday creativity on individual and collective wellbeing. They found a significant positive correlation between engagement in everyday creative and positive emotional states, as well as a tendency towards a greater sense connection to others amongst those involved in creative activities in the community.

Griffiths (2003) suggests that the benefits of participation in creativity and arts can be understood at three levels, which are described in the following broad terms:

- Enhancing the psychosocial, coping and life skills of an individual by building or enhancing abilities such as stress or anger management, self-efficacy, self-expression or relaxation.

- Increasing social support and resilience through participation in shared or community creative practice.

- Improving wider access to resources and services that promote and protect positive mental wellbeing, e.g. financial services, employment opportunities and formal mental health services.

Cassandra (2004) suggests that the artistic achievements of those within the user/survivor movement have also provided a way for those with mental health diagnoses to create a sense of meaning and pride in their ‘madness.’ Gillam (2012) adds to this by highlighting the importance of self-expression through the arts as a tool for creating meaning and storytelling, particularly for those who are marginalised within society. This is of particular significance to this research, given the stigmatised nature of the BPD diagnosis.

Whilst the evidence in this field is vast, and covers a range of different formal and informal interventions, disciplines and activities, the remainder of this review focuses on the two areas most pertinent to this research – namely, exploring the role of formal art therapy in mental health recovery (with a particular focus on BPD), and the functions and therapeutic benefits of the less formal process of creativity and artmaking for people experiencing mental distress.

### *3.5.1 The principles and benefits of art therapy in mental health settings*

The practice of art therapy was developed as a response to the development of knowledge about human emotional, social and behavioural development (Junge, 1994). It has been used formally alongside traditional psychotherapeutic methods to treat a variety of mental health problems since the 1940s, and can incorporate a wide range of creative approaches, such as music, dance art and creative writing (Lamont et al, 2009). The benefits of art therapy are reported to stem from its focus on nonverbal means of communication as a way of expressing powerful and deep-rooted emotions in an environment that is safe and supportive (Harnden et al, 2004). Taking part in this creative process is said to result in increased clarity, self-awareness, self-acceptance and a general sense of overall psychological well-being (Crawford and Patterson, 2007). As well as in formal clinical settings, the principles of art therapy have also been used to inform a broader gamut of community-based ‘participatory’ arts groups and projects that work with individuals with mental health needs on a more informal basis to increase factors such as self-esteem and confidence and improve social inclusion (Hacking et al, 2008).

Whilst there has been a great deal of interest in the therapeutic benefits of the creative arts, scholars (e.g. Reynolds et al, 2000) have pointed towards a lack of reliable outcome data to demonstrate its value as a valid approach to responding to mental distress. The wide application of different art therapy techniques across a range of different populations and mental health settings means that it is difficult to produce generalisable empirical findings as to its effectiveness (Reynolds et al, 2000). The next section provides an overview of both the quantitative and qualitative literature relating to the effectiveness of art therapy, before discussing more specifically the application of arts-based approaches in the treatment of BPD. Finally, consideration will be given to the role of creativity outside of formal therapeutic settings and its relationship with concepts of the self.

Reynolds et al (2000) conducted a review of the published empirical evidence regarding the effectiveness of art therapy. Their literature search identified 17 published studies that assessed the impact of art therapy on a measurable outcome (e.g. self-esteem or depression) and included an assessment of the impact on a sample or treatment group. These were reviewed with the aim of identifying any trends in outcomes and their association with study design. They concluded that, whilst positive effects of art therapy were demonstrated across the three types of study designs reviewed (single group, nonrandomised controlled trial and randomised controlled trial), there appeared to be no demonstrable additional benefits of art therapy when compared to other therapeutic approaches. This, they attributed in part to a lack of descriptive data regarding the goals and procedures of art therapy, the lack of standardised reporting measures and the vast heterogeneity in the sample. Elsewhere, the lack of a developed literature base regarding the therapeutic benefits of art therapy in hospital settings is often explained by the transient nature of these populations (Luzzatto, 1997).

A review of arts-based interventions in community settings (Hacking et al, 2008) has demonstrated more encouraging results, with participants across 22 participatory art projects showing improvements in standardised measures of empowerment, mental health, and social inclusion. The authors of this paper acknowledged that whilst further investment in high quality, large scale empirical research is needed to increase the evidence base, there is also a need for ongoing qualitative research to understand the benefits that are not able to be captured by the questionnaire measures used, for example participants' self-defined aims and goals.

A further systematic review, conducted by Uttley et al (2015) of the clinical effectiveness of art therapy among people with non-psychotic mental health problems adopted a mixed method design that explored the acceptability, relative benefits and potential harms of art therapy. Findings of the quantitative review were similar to those expressed by Reynolds et al (2000), however the qualitative aspect of the study identified a number of major themes relating to the benefits of art therapy to service users. These included an increased understanding of self, sense of personal achievement, ability for self-expression, empowerment, relaxation, expression of feelings, distraction from illness and the importance of the therapeutic relationship. The significance of the therapeutic relationship has also been emphasised by

Luzatto (1997) who suggests that the role of the art therapist must extend across several different domains in order for the therapeutic benefits to be felt. As well as acting as a therapeutic ally, the art therapist must act as a facilitator to the artistic process, which may not occur naturally, as well as be able to demonstrate the connection between the artistic output and the individual’s mental functioning to illuminate new perspectives and understandings. Areas of potential harm identified in the review by Uttley et al (2015) were also related to the role of the art therapist, in particular where the practitioner was considered to not have the required skills. Concerns were also expressed in some studies with regard to the potential for activation of emotions that were then left unresolved and the negative effects that could occur if art therapy was suddenly terminated.

It is clear that there are a wide variety of approaches to the practise of art therapy and that arts-based interventions can be utilised in the treatment of a diverse range of mental health problems in both community and clinical settings. In the context of this study, the focus will now shift to consider the existing literature in relation to the utility of arts-based approaches to women with BPD.

### *3.5.2 Art Therapy with Women with BPD: The Lived Experience Perspective*

The use of visual art therapy is relatively well established within BPD treatment programmes and in 2012 a special interest group of the British Association of Art Therapists published a set of 10 clinical guidelines for art therapists based on the first UK consensus on practise in this clinical area (Springham et al, 2012a). These were developed using empirical research evidence from the National Institute of Clinical Excellence (NICE) guidance on psychological therapy with BPD (NICE, 2009). It was acknowledged however in creating these guidelines that they were significantly limited by a lack of service user perspective in their design. Since then, some degree of effort has been made to conduct further research on the utility of art therapy which reflects the views of those with lived experience of BPD. Whilst the literature in this area is currently reasonably limited in its scope, it provides a useful framework from which to examine the meaning of art and the creative process to women with a BPD diagnosis.

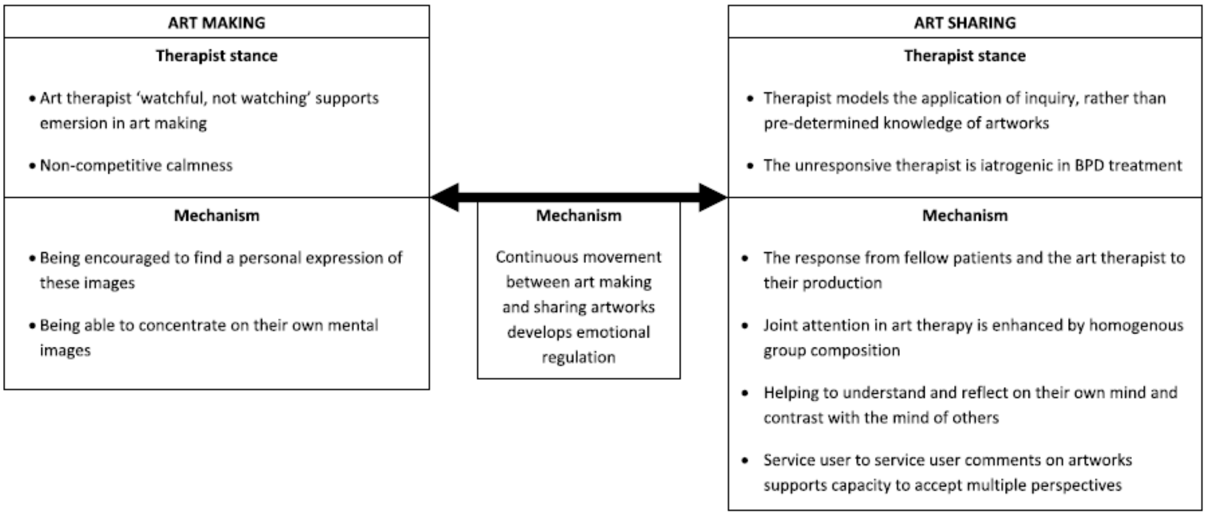
Morgan et al (2012) reflect on some of the complexities and challenges of the BPD diagnosis that were iterated in the previous chapter and their relationship to the therapeutic process. They emphasise that the challenges faced by anyone with experience of BPD will be unique and that it is crucial that any therapeutic intervention is tailored to the individual needs of participants rather than regarding those with a BPD diagnosis as a homogenous group. This is echoed by Eastwood (2012) who offers a feminist perspective on art therapy with women with BPD and suggests that an approach to art therapy that values the individual’s entire story and considers the personal, social, economic and political positions of those it is seeking to engage is necessary for a multidimensional understanding of experience.

Nevertheless, drawing on participants’ shared experiences of taking part in visual art therapy as women with BPD, Morgan et al (2012) were able to highlight some core themes pertinent to the utility of the approach. As alluded to in the previous section, the authors suggest that art therapy can be particularly useful in opening up new possibilities for dealing with emotions in ways that had not previously been considered. They discuss the difficulties in verbalising emotion associated with BPD and consider that art therapy provides an alternative, healthy channel for communication that can assist in accessing core emotions and expressing them in a way that avoids some of the anxieties and risks associated with purely verbal expression. This is also observed in the findings of Lamont et al (2009) who present a case study of the art psychotherapy journey of a 46-year-old woman diagnosed with BPD. Reflecting on the chronological art portfolio produced over the course of eleven sessions of art therapy, it was clear that the process of artmaking allowed for the expression of traumatic experiences that were not able to be verbalised, suggesting that images may be more accurate and appropriate representations of inner ‘being’ and clearer indicators of experience than words alone. Eastwood (2012) argues that as well as this, art therapy in a group environment can allow for a shared acknowledgement of the origins of trauma whilst developing strategies towards empowerment.

Furthermore, Lamont et al (2009) highlight the benefits afforded to the therapeutic relationship through the introduction of art as a way of engaging in a non-confrontational manner within the therapeutic environment. Morgan et al (2012) argue that the introduction of art as a ‘mediator’ can assist in navigating some of the challenges of interpersonal relationships and allows for connections and interactions to occur naturally, *‘based on the external medium and not the complexity of emotion that is projected between the individuals’* (p. 94). Eastwood (2012) also suggests that process of art-making in a group setting can be instrumental in fostering a sense of community and understanding. It can also assist in the diffusion of intense feelings related to personal trauma. Discussing the personal meaning associated with artwork produced in a group environment can lead to a greater understanding of relationships through discussion and development of social constructs, such as motherhood and marriage, as well as through representations of the self. Eastwood (2012) argues that *“artmaking and the consequent product is well equipped to expose, explore and challenge the suppressed and disguised”* (p. 112).

Springham et al (2012b) drew upon service-user experiences in their evaluation of a pilot mentalisation-based treatment programme for BPD and highlighted some core values related to the mentalisation approach that were translated to produce an emerging picture of the mechanisms considered valuable in art therapy programmes. This diagram is replicated in Figure 3.1 (below).

**Figure 3. 1 Service user valued mechanisms in art therapy with BPD (Springham et al, 2012b, p126)**



**ART MAKING**

**Therapist stance**

- Art therapist 'watchful, not watching' supports emersion in art making
- Non-competitive calmness

**Mechanism**

- Being encouraged to find a personal expression of these images
- Being able to concentrate on their own mental images

**Mechanism**

Continuous movement between art making and sharing artworks develops emotional regulation

**ART SHARING**

**Therapist stance**

- Therapist models the application of inquiry, rather than pre-determined knowledge of artworks
- The unresponsive therapist is iatrogenic in BPD treatment

**Mechanism**

- The response from fellow patients and the art therapist to their production
- Joint attention in art therapy is enhanced by homogenous group composition
- Helping to understand and reflect on their own mind and contrast with the mind of others
- Service user to service user comments on artworks supports capacity to accept multiple perspectives

It is suggested that it is the repeated explicit process of art-sharing and artmaking that is most effective in supporting mentalisation in BPD, and that this process assists in differentiating between self and others and allowing for the organisation of thoughts and feelings at a manageable pace. This is particularly interesting to explore in the context of this thesis, given that the majority of participants in the current research have not had the opportunity to engage in formal art therapy and therefore the processes described particularly that of art-sharing, occur on a much more informal basis.

Morgan et al (2012) reflect on the benefits of engaging in art making as a way of reconnecting with one's sense of self, however they also warn against the dangers of self-denigration in the artistic process, particularly with regards to a self-imposed pressure to create meaningful representations leading to reinforcements of a sense of the self as inherently 'flawed'. Morgan et al (2012) offer a perspective that the process of creativity itself can be more beneficial to women with BPD than the formal 'art therapy' approach to reflecting on symbols and meanings within the artistic creation. They suggest that refocusing emphasis on the experience of creating art rather than the art itself can allow for a more embodied process of creative absorption, and an opportunity to disconnect from difficult and painful emotions. Findings from a study by Turner et al (2011) also lend support to this perspective, reflecting that many individuals with BPD who have taken part in art therapy express a desire to continue to engage in arts-based activities once the therapeutic programme has ended. They submit that the level of stimulation experienced by taking part in creative activities not only serves as a useful distraction but allows for the creation of meaningful connections, described as ‘attachment to art’ and ‘attachment through art’ which allow for the growth of relationships both within the self and the outside world. This leads to the final section of this chapter, focusing on a broader examination of the function of participating in creative and/or artistic pursuits outside of a therapeutic setting, particularly for individuals with experience of mental distress.

### *3.5.3 Exploring the mental health benefits of everyday creativity.*

In a study of over 1,200 Australians commissioned by the Australia Council in 2000 to explore the meaning of the arts to Australians, 80% of participants said that they felt good when they expressed themselves creatively, 66% agreed that the arts are “good for my inner self” (Costantoura, 2000, p.12) and 66% of artists derived enjoyment from creating art for themselves. The 2017 APPG report on the arts for health and wellbeing draws attention to the 49,000 amateur arts groups that exist in England, involving 9.4 million people – 17% of the population (APPG, 2017). Whilst it is clear then that creativity and the arts have a valuable role to play at both a societal and individual level, what is less clear from the existing literature is how the transformative power of the arts is realised, particularly for those with experience of mental distress who may struggle to know and express themselves through more traditional verbal means.

The Centre for Cultural Value’s recent rapid review of the evidence relating to everyday creativity (Wright, 2022) explored the impact of engaging in creative and cultural activities both at home or in community settings on individual and collective wellbeing. They found that everyday creativity encapsulates a broad range of activities, ranging from traditional ‘artforms’ such as music, photography, and painting/drawing to those less typically perceived as ‘art’, such as cosplay, eyebrow art and DIY. Often, participants did not make clear distinctions between different types of activities, preferring to focus on their motivations for and feelings associated with each activity rather than the creative output (Wright, 2022). This is particularly pertinent to this study considering that not all participants in the current research referred to their experiences of creativity in terms of their participation in artmaking or other distinct creative pursuits.

The review found that the primary motivation for engaging in everyday creativity was simply enjoyment, with this then being linked to positive impacts on mental health and emotional wellbeing (Wright, 2022). Of particular relevance to this study is the focus of the review on creativity in the home environment, with the evidence pointing towards the importance of creative self-expression as a primary motivator for home based creativity (e.g. Gibson and Edwards, 2013). The review also points towards an increasing trend towards the importance of everyday creativity in fostering social connection through the act of sharing creative outputs outside of the home environment but cautions that there is a clear gap in the evidence regarding understandings of the function of creativity in homes and the policy implications of this (Wright, 2022). Given that the majority of the participants in this research were engaged in everyday creativity in a home environment (as opposed to formal art therapy) at the time of the research, and that many also shared their creative outputs online, this thesis aims to add to what is currently a limited evidence base exploring the drivers, function and benefits of everyday creativity at a personal and social level.

Research with people experiencing mental health problems has drawn upon the theories of flow, escape and reverie referred to earlier in this chapter to provide a framework for understanding how creativity and artmaking are experienced and the feelings invoked by the creative process. In her PhD thesis exploring the role and meaning of artmaking to women with experience of mental distress and/or trauma, Northfield (2014) found that many of the women involved in her research described some of the elements of Csikszentmihalyi's (1975) theory of flow as being central to their experience and enjoyment of artmaking. This was articulated as a sense of deep involvement that creates distraction from worries, fears and anxieties, as well as a feeling of being part of some greater totality that allows them to transform chaos into order. However, unlike Csikszentmihalyi's theory, which emphasises a sense of control and a constant process of feedback and monitoring success, the women in Northfield's (2014) research described their experience of artmaking as a more fluid, dynamic and evolving process which is entangled with cultural, relational, and embodied processes and meanings.

Similarly, Langer (2005) observed that, in agreement with the theory of flow, interviews she conducted with women living in the United States often highlighted feelings of feeling suspended in time and as though 'nothing else matters' when engaged in artmaking. She concluded that the purpose of creative activity is to feel alive and connected to oneself and described the role of artmaking in her own life as being 'not for art's sake, but art is for life's sake (Langer, 2005, p.206). In her 2010 book, 'Diary Drawings: Mental Illness and Me', Bobby Baker, an artist with a diagnosis of BPD, describes the therapeutic benefits she experienced from drawing and painting throughout her recovery journey. Again, in keeping with aspects of Csikszentmihalyi's theory of flow, she speaks of the soothing effects of the intense concentration she experiences when making art – describing the experience of painting as 'sensuous' and 'blissful' (Baker, 2010, p.214). She also speaks of the connection she has experienced between the regularity with which she engages in artmaking and the act of self-reflection, believing that the creative process has helped her to develop greater levels of self-awareness, acceptance and understanding – both of herself and the wider world in which she exists as a woman with a diagnosis of BPD (Baker, 2010).

Ravetz (2019) conducted research with ten participants with experience of substance misuse, who, as part of their recovery journeys, were invited to participate in a photographic self-portraiture project, culminating in the production of self-authored 'artists' books' documenting their journeys. Ravetz (2019) reports that participants in this project experienced a state of being safely lost in an activity, consistent with an understanding of reverie as described by Bion (1970). The six participants who remained until the end of the project described how participation and engagement in photography helped them to feel more connected and self-accepted. Some said that it had profoundly changed how they process and express emotions and feelings – giving them a more embodied understanding of how they relate to themselves and others (Ravetz, 2019). Related to this, Stuckey and Nobel (2010) suggest that creative and artistic processes allow for an engagement with identity which occurs outside of the conception of the self as 'ill' and that the more that is understood about the relationship between these two factors, the more that can be discovered about the healing power of the arts.

Returning, as was discussed in the previous chapter, to the concept of narrative identity as a mechanism for people to convey to themselves and others who they are, how they came to be and their perceptions of the future (McAdams and McLean, 2013), it is suggested that the process of creativity and artmaking could be beneficial not only as a therapeutic tool but as a means of developing, connecting with and expressing narrative identity in an alternative, more embodied way. This is consistent with findings from Gibson and Edwards's (2013) research with young people in care, which found that having the freedom to express themselves creatively supported young people to develop an understanding of their place in the world. This study aims to build an understanding of how experiences of flow, reverie and escape interact with identity development processes to produce the benefits outlined above.

## 3.6 Summary and Conclusion

This chapter has outlined the various definitions of creativity and highlighted some of the challenges associated with defining and measuring it. Building upon this, it discussed the presumed association between creativity, genius and conceptions of ‘madness’, concluding that the relationship between mental distress and a propensity towards creativity is ill-defined, inconsistent and can potentially have implications for how individuals with mental health diagnoses perceive their own creativity in relation to their identity or their relationship with creative pursuits. Furthermore, the cultural, social and relational underpinnings of both constructs are poorly represented in the existing literature, as is research examining the process and meaning of everyday creativity.

Returning to Erikson’s (1959) theory of identity discussed in the previous chapter, the relatively scant literature linking identity to creative processes was summarised and gaps in the evidence regarding the ways in which creative processes can enable self-discovery and/or the development of a coherent sense of identity highlighted. This is especially pertinent for individuals who have experienced early relational trauma and/or disruptions to the socialisation process which can affect identity development, as is often the case amongst women given a diagnosis of BPD (Jorgensen, 2006).

Finally, the review expanded on the concept of recovery outlined in the previous chapter to explore the literature regarding the benefits of creativity and artmaking to mental health and wellbeing. The final sections summarised the origins of art-therapy and other creative treatment approaches and their effectiveness in providing meaningful outcomes for women with a BPD diagnosis, outlining a number of benefits that appear to occur both within a formal art therapy and everyday creativity domain. Drawing upon Csikszentmihalyi’s (1975) theory of flow and Bion’s (1970) concept of reverie, the ways in which people with experience of mental distress experience creativity and artmaking and the impact it has on their conception and expression of their sense of self were explored. A further gap was identified in the literature regarding the extent to which these experiences of flow and reverie interact with identity development processes to support women with a BPD diagnosis to create and narrate stories about their selves that move beyond traditional narratives of mental ill-health and support them in building a coherent sense of narrative identity.

This study aims to contribute new knowledge to the evidence base on creativity and mental health by filling gaps in the qualitative literature regarding the meaning and function of artmaking amongst women with a BPD diagnosis, both in an everyday and therapeutic context. Furthermore, drawing upon Kaufman and Beghetto’s (2009) Four C model of creativity, the thesis will consider the role of creativity outside of the artistic domain, examining novel ways of coping and the processes underpinning them. The research also adds to the scant literature regarding the relationship between creativity and identity through an exploration of the role of artmaking and other creative pursuits in the development and renegotiation of identity amongst women with a BPD diagnosis.

In the following chapter, the key findings and evidence gaps highlighted in the previous two chapters are drawn together in the context of this thesis to outline the research questions guiding the study as well as the methodology and theoretical framework underpinning it.

# Chapter 4: Methodology and Methods

## 4.1 Introduction

Having conducted a detailed review of the literature which identified gaps and areas that would benefit from further research, the following three research questions have been developed to guide this study:

(i) How do women diagnosed with BPD understand and conceptualise their diagnosis in relation to their life histories and sense of self?

(ii) How do women with a BPD diagnosis use creativity to make meaning of their experiences, negotiate identity and manage distress?

(iii) How can an understanding of the 'lived experiences' of women with a BPD diagnosis be used to contribute towards an understanding of effective and appropriate treatment strategies for the management of distress?

This chapter is divided into three sections and will be used to present a detailed explanation of and rationale for the methodology and method employed to answer the questions above. The initial section will provide an overview of the research design and the principles guiding it. The remainder of the chapter will focus on an explanation and justification of the research strategies adopted in the two distinct stages of the research. It will provide insight into the methods used to collect and analyse data, the research participants and the theoretical framework guiding data interpretation. It will also consider some of the relevant methodological and ethical challenges.

## 4.2 Overall Research Design

In this initial section, the overall research design will be outlined, detailing the approaches used to answer the research questions detailed above and structured according to the two key research stages (see figure 4.1 below). Stage one involved a qualitative secondary analysis of eight interviews conducted with women with a BPD diagnosis as part of a research project examining experiences of being detained under Section 136 of the Mental Health Act. The second stage built upon the themes identified in stage one and explored attitudes towards and experiences of diagnosis and treatment, conceptions of identity and the experience and meaning of creativity to women with a BPD diagnosis. The second stage of the research employed a collaborative and flexible research approach with the aim of allowing for subjective and reflexive enquiry and empowering participants to generate new knowledge and contribute towards social change.

**Figure 4.1 Research Design**

| ***Research stage*** | ***Research questions addressed*** | ***Data source*** | ***Data collection methods*** | ***Data analysis method*** |
|---|---|---|---|---|
| 1. | (i)<br>(iii) | Eight women with a BPD diagnosis who have experience of being detained under Section 136 of the Mental Health Act | In-depth unstructured interviews conducted by Professor Gillian Bendelow in 2013 and 2014 as part of research into experiences of being detained under S136 of the Mental Health Act. | Secondary analysis of interview transcripts, analysed using narrative thematic analysis (Braun and Clarke, 2006) |
| 2. | (i)<br>(ii)<br>(iii) | 4 women with a diagnosis of BPD who self-identify as having an involvement in artmaking or other creative activities. | Unstructured interviews combined with creative elements such as drawings, paintings, photographs or creative writing. | Narrative thematic analysis (Braun and Clarke, 2006) |

## 4.3 Onto-Epistemological Framework

The thesis is underpinned by a critical realist ontology which occupies a contextualist position that sits between the poles of realism and constructionism (Braun and Clarke, 2006). Critical realism is concerned with the nature of causation and the ways in which agency, structure and relations operate within the realities in which they exist. (Archer et al, 2016). Unlike social constructionism, ontological realism accepts the existence of realities which are present and act independently of our descriptions of them; but posits that that we can only know them under particular circumstances (Bhaskar, 1975). Critical realism reflects the position that all knowledge is local, provisional and situation dependent (Jaeger and Rosnow, 1988) and always situated within a historical, social and cultural framework that is transient and ever-changing (Archer et al, 2016). It follows, therefore, that social mechanisms and their effects cannot be understood in isolation but rather should be viewed as "laminated systems whose internal elements are necessarily 'bonded' in a multiplicity of structures" (Bhaskar, 1993, p25). The current research reflects the critical realist perspective of reality as being determined by multiple factors, with no single mechanism causing or being solely responsible for determining events (Bhaskar, 1975). It is therefore concerned with teasing out multiple causes from a detailed exploration and explicit articulation of the personal and cultural perspectives from which the analysis is approached (Wilkinson, 1998), including, but not limited to, participants' own experiences, researcher context and interpretation, cultural systems underpinning meaning making, and value judgements inherent within communities (Pidgeon and Henwood, 1997).

It is the complex relationship between experiential accounts and the social and historical context in which they are produced that is particularly important within a critical realist framework. The critical realist perspective contends that individual experiences and views are real entities and therefore understanding them is essential to a broader understanding of society, and vice versa. It posits that whilst experience is inherently defined by interpretation, meaning it is, to some degree. constructed (and therefore flexible) rather than determined and fixed, it exists in reality to the person experiencing it (Willig, 2008). In the context of this research, a critical-realist analysis allows us to acknowledge the reality of the psychological and somatic distress experienced by women with the diagnosis of Borderline Personality Disorder, whilst enabling us to conceptualise it as a complex and multifaceted phenomenon that is only constructed as BPD within a specific historical and cultural context (Ussher, 2011). It provides space for an understanding and acknowledgement of the integration and interaction of various social, cultural, historical and biological factors, which might contribute towards psychological distress, help-seeking, the development of diverse coping strategies and the conceptualism of behaviour, and allows for the incorporation of findings from research spanning a range of theoretical perspectives into one framework without having to reconcile competing epistemological assumptions or privilege one level of analysis over another (Williams, 2003). This thesis uses the material-discursive-intrapsychic model, as defined by Ussher (2000), to attempt to understand how participants' experiences of, and narratives constructed around BPD and identity, exist and are articulated in the context of their whole life stories, including the relationships, sociocultural frameworks, temporal and embodied experiences that shape them. This sits in contrast to the biomedical approach, which privileges biological discourse and from which the diagnosis of BPD is arguably constructed, and this is tension which will be explored throughout the research.

The approach to critical realism adopted in this thesis is underpinned by many of the principles of feminist epistemology. Feminism invites researchers to consider and be sensitive to the idea of 'voice', particularly in relation to who is being heard and who is being excluded (Kralik and Van Loon, 2008). At its core is an ambition to allow for voices that have typically been excluded to become central to generating knowledge that will illuminate new ways of understanding that challenge hegemonic discourses. Sitting neatly alongside critical realism, feminist research places emphasis on the validity of personal experience, illuminated within the whole life context and the social world that predicates it (Speedy, 1991). Historically, the field of mental health research has been dominated by a discourse of medicalisation that has prioritised the knowledge and opinions of academics and medical professionals and excluded the experiences of both women and those with experience of mental distress to generate 'collective solutions' based on a fixed set of assumptions regarding the nature of that distress and of femininity itself. The feminist critical realist perspective underpinning this study argues that the value of experiential knowledge cannot be invalidated or rejected "*because if something was felt then it was, and if it was felt it was absolutely real for the woman feeling and experiencing it"* (Stanley and Wise, 1983, p53). Focusing exclusively on what is arguably a marginalised demographic, this study draws upon these values to contribute towards a body of knowledge that privileges the personal experience of women with a BPD diagnosis. It is centred on their own interpretations of their lives, acknowledging agency and authentic subjectivity in the way that meaning is constructed around the social context in which their story has come to being (Roets and Goedgeluck, 1999).

Adherence to the principles detailed above typically results in the use of research methods that are unstructured in nature and allow for a reciprocal relationship between participant and researcher that aims to break down hierarchal distinctions and create a sense of empowerment (Hammersley, 1994; Millen, 1997). A critical realist approach emphasises the importance, not just of the context in which the observed exists, but also of the inevitable influence of the researcher's own culturally influenced humanity on that which they observe. (Madill et al, 2000). Bhaskar (2002) states that *"not only must the observer include himself in the field in which he observes, the agent must live his life in awareness, that is self-awareness of his own activity, the continuing witness of everything he does"* (p.329). Like critical realism, feminist epistemology also recognises the research scenario as an ‘inter-subjective’ experience (England, 1994) and argues for a reflexive and collaborative approach which creates an environment for the discovery of authentic knowledge (Reinharz, 1983). This idea will be woven into the remainder of the thesis through the inclusion of a reflexive account which renders visible the researcher context and assumptions which underpin the analysis of the data.

Many feminists define their research as emancipatory in nature, with a common thread lying in a commitment to working towards action that will challenge and create change within oppressive structures and forces (Maguire, 1996). Jackson (1997) argues that feminist principles are political, transformative and transparent and therefore appropriate for research that aims to create social change. It is important to acknowledge that change is in itself a subjective construct that can be experienced at a range of different levels, but Speedy (1991) identifies ‘consciousness raising’ as a foundation of feminist research used to initiate change. Consciousness raising is defined as the experience of a shared sense of reality which gives way to a conscious understanding of a collective, rather than individual problem (Henderson, 1995). This research aims to raise consciousness and initiate change by drawing upon the experiential knowledge of women with a BPD diagnosis to redress the balance of power and contribute towards new understandings of distress and appropriate treatment that are socially and contextually informed.

## 4.4 Stage One: The ‘lived experience’ of women diagnosed with Borderline Personality Disorder

The first stage of this study is concerned with an examination of the lived experience of women diagnosed with BPD, specifically with regards to how meaning is created and negotiated in relation to identity and the ways in which distressing symptoms are managed and understood. This was executed by way of a secondary analysis of existing interview data from eight women with a BPD diagnosis who took part in Bendelow’s (2016) research into experiences of being detained under S136 of the Mental Health Act. This section will provide an overview of secondary data analysis, along with a rationale for its use in this context. It will also consider and address relevant ethical issues pertinent to this stage of the study.

### *4.4.1 Qualitative Secondary Analysis*

Whilst secondary analysis of quantitative data has long been regarded as a regular and respected practise, it is only relatively recently that there has been a move to address some of the challenges inherent in analysing existing qualitative data and a recognition of the utility of such an approach. This is borne out of an acknowledgement amongst academic researchers of the analytic potential available within existing qualitative data sets that frequently contain an abundance of rich material that is often underused or remains un-analysed (Long-Sutehall et al, 2011). The aim therefore of secondary analysis is to use existing data to answer new research questions that differ from those from those asked in the primary study (Hinds et al, 1997). The next section will provide justification for the use of qualitative secondary analysis and outline the key approaches and some of the challenges associated with it, situating these within the context of this research.

#### *4.4.1.1 Why do Qualitative Secondary Analysis?*

Although the use of qualitative secondary analysis (QSA) has only gained more widespread interest and momentum relatively recently, its potential benefits were being posited as far back as 1963, with Bernie Glaser suggesting, amongst other things, that independent secondary analysis could be utilised to “lend new strength to the body of fundamental knowledge” (Glaser, 1963, p.11). The Economic and Social Research Council has long advocated the archiving of qualitative data for future use by others and has laid out an expectation that new data only be collected where it can be demonstrated that there is no existing data suitable for the research purpose (Irwin and Winterton, 2011). Qualitative data collection is time and resource intensive, and it therefore stands to reason that there is benefit in ensuring that the resulting data is maximised in potential to become an important source of information for more than one study or purpose where appropriate. Time and resource constraints may make secondary data analysis an appealing prospect for researchers who are unable to negotiate lengthy ethics and research approval processes. Furthermore, QSA can be particularly valuable in providing access to what has been referred to as an ‘elusive’ population (Fielding, 2004) – that is those individuals or groups that are hard to access due to their vulnerability, location or the sensitive nature of the research. Gladstone et al (2007) suggest that QSA can allow researchers the ability to generate new knowledge in an appropriate and productive way whilst “limiting the overall burden placed on particular participants, especially to ‘talk’ more” (p.440).

A key justification for the use of QSA in this study was in limiting intrusion and potential harm to participants that could be caused by continued questioning around sensitive and distressing issues that generally were already been covered in some depth in the primary research. QSA has specific utility in facilitating access to vulnerable or marginalised populations that require particularly sensitive handling and the approach adopted in the current research has allowed for an exploration of a sensitive and specific area of mental health with an underrepresented population whilst avoiding the difficulties associated with participant recruitment and the potential risk of harm involved in interviews of this nature.

#### *4.4.1.2 Approaches to Qualitative Secondary Analysis*

There is limited discussion amongst the qualitative research community with regards to qualitative secondary analysis, which has led historically to it being referred to as an ‘invisible enterprise’ for which there is little clear methodological guidance (Gladstone et al, 2007). There are however a number of ‘key’ approaches to QSA which have been outlined and developed by those working in the field (Hind et al, 1997; Irwin and Winterton, 2011). Whilst these are by no means exhaustive, they serve to form the basis of a discussion and contextualisation of the breadth of different ways in which secondary analysis of qualitative data can be applied and utilised within the social sciences.

The first approach that can be employed by QSA researchers involves amending the unit of analysis so that it differs from that of the primary study. For example, Deatrick et al (1993) conducted a reanalysis of existing interview data, the original purpose of which was to investigate the familial definition, management and evaluation of having a child with a chronic illness through reports from individual family members. The secondary analysis approached the data from the point of view of an examination of individual management behaviours employed by family members and focused its analysis on just 4 of the 63 families which were studied in detail. The primary data set of 63 families was then utilised again by Knafl et al (1994) to present an analysis of critical events preceding diagnosis which was used to outline five pathways to diagnosis. Similarly, Gladstone et al (2007) have reported on their decision to conduct a reanalysis of parental interview data gathered as part of a research project designed to examine the subjective experience of motivation amongst young people suffering a first episode of psychosis and the psychosocial factors that influence it. In the original study, in-depth interview data were obtained from individuals identified as having either ‘recovered’ from schizophrenia, or those experiencing a first episode of psychosis, as well as mental health professionals and parents of family members experiencing mental distress. Although it was not the focus of the original research question, the richness of the narratives contained within the interview data obtained from the parental sample led the researchers to reanalyse the data using an interpretative interactionist framework which allowed for the emergence of a greater understanding of the factors involved in mental health help-seeking behaviour.

This also serves as a useful example of how QSA can be undertaken with the aim of prioritising a concept or issue that appeared to manifest itself in the original data but was not specifically addressed or the focus of analysis at that time (Hinds et al, 1997; Irwin and Winterton, 2011). Vallerand et al (1995) utilised this approach in their secondary analysis of a data set that was initially collected by Ferrell et al (1993) to investigate the experience of pain in the home, as understood by the patient, primary family caregiver, and home care nurse. The researchers became aware of the presence of the concept of control within the data, and so conducted a reanalysis of ten of these 'triads' of transcripts against an existing typology of control. Similarly, in Williams and Collins (2002), the potential for social construction of disability was explored through the secondary analysis of data originally collected by the researchers as part of a grounded theory investigation into the subjective experience of schizophrenia (Williams and Collins, 1999). Previously transcribed interviews were reanalysed using a coding system informed by but distinct from the original enquiry whereby specific search criteria were applied and subsequently investigated. Whilst the authors of this paper acknowledge the importance of establishing a more direct approach to the exploration of disability construction in schizophrenia, the QSA study allowed for valuable foundations for and justification of further research in this area.

The last approach to QSA outlined by Hinds et al (1997), and arguably the most pertinent to the current research, is the extraction of a subset of cases from the primary study for a more in-depth analysis relative to but distinct from the original research. This is similar to the previous approach in that it is typically brought about by the emergence of concepts or themes within the original data that warrant investigation, however it may also be used to narrow the research focus to a more detailed examination of a set of distinguishing characteristics or participant demographic present within the wider data set. Some who have conducted QSA in this way have referred to this process as a 'tentative conceptualisation' (Thorne, 1990) when the original study was not conducted with the phenomenon or demographic under scrutiny in mind. In Thorne's (1990) research, a subset of transcripts were selected for review from a larger study documenting personal experiences of chronic illness with the aim of understanding health care relationships. Sixteen transcripts from mothers who described the experience of motherhood whilst living with a chronic illness were subject to further contextual analysis. Similarly, Emslie et al (2006) selected sixteen cases from a primary study investigating the experiences of thirty-eight men and women who had been diagnosed with depression. Through an in-depth analysis of interviews conducted only with the male study participants the researchers were able to conduct an in-depth investigation into the emergent issue of male gender identity in the context of depression.

The approach to QSA adopted in this study was chosen to fulfil the aim of conducting a more focused analysis, relevant to, but distinct from, the original enquiry, on a subset of eight interviews selected from Bendelow et al's (2016) study on Section 136 in Sussex. As well as the ethical justifications for the use of QSA referred to at the beginning of this section, the decision to undertake a secondary analysis of existing data at this stage was taken in response to an emerging theme of the primary study that there exists a high incidence of women diagnosed with BPD who are repeatedly detained by police in public places under S136 of the Mental Health Act. Although the research questions in the primary study were exclusively focused on experiences of S136, the loosely structured interview approach resulted in interview data that represented a whole spectrum of life events, emotions and observations considered significant to the participants which extended far beyond their experiences of being detained under S136. Thus, the data were considered sufficiently rich and detailed to answer the new research questions posed by this study.

#### *4.4.1.3 Challenges and Debates around Qualitative Secondary Analysis*

Whilst the variety of approaches to QSA outlined above illustrate the potential for wide utility, there remains a degree of debate and concern over its practical application within the social sciences. Critics of the approach have argued that its only value lies in its ability to generate retrospective methodological insights, dismissing its capability for enabling advancements in theoretical and applied knowledge (Mauthner et al, 1998). Other sceptics have highlighted contextual and ethical difficulties around the re-use of existing data, which may serve to limit the potential benefits of such an approach (Hammersley, 1997). Whilst advocates of QSA warn against perpetual academic introspection (Mason, 2007) limiting the ability for methodological advancement in the field, it is important to address potential challenges and key debates and situate them within the context of the current research.

##### Researcher proximity and contextual understanding

Qualitative research draws much of its strength from its ability to produce data that is firmly rooted in the wider social, political, biographical and political context in which it occurs. Thus, qualitative data is considered to be inherently subjective; influenced by and as a result of the environment and relationship dynamic in which it is constructed. It is notable therefore that one of the key debates surrounding QSA centres on the impact of researcher proximity on the generation of valid insights from the re-use of existing data (Irwin and Winterton, 2011). Critics of QSA suggest that it is only through direct and personal involvement in data production and the unique reflexive relationship created between researcher and participant that the original context can be understood in such a way as to enable the data to be effectively interpreted. In a reflection of their experiences of subsequently revisiting their own research in an attempt to generate new theories, Mauthner et al (1998) document particular difficulties in the ability to evoke the contextual understanding in which their previous research occurred and conclude that this distance equates to a 'loss of privilege' (Mauthner et al, 1998, p. 742). Hammersley (2010) echoes some of these concerns, suggesting that implicit understandings, feelings and memories generated by primary researchers during the course of data collection will permeate analysis in ways that are not always apparent but nevertheless play an important role in making sense of data. Without these implicit understandings, it is argued that those approaching data retrospectively lack the sensitivity required to conduct a valid subsequent analysis (Hinds et al, 1997).

It is particularly important to acknowledge this tension given the contextualist and critical realist framework underpinning the research and it is true to some extent that having not conducted the interviews personally there was felt to be a degree of 'separation' between the researcher and participants which undoubtedly will have impacted upon analysis. Hammersley (2010) however suggests that QSA need not be constrained by issues of context as long as there is an awareness of the 'unknowns'. Nevertheless, it is typically recognised that evidential documentation illustrating contextual aspects of primary research in a practical sense can provide valuable assistance to researchers approaching data retrospectively. Whilst guidance around the conduct of secondary analysis remains relatively limited, Van Den Berg (2008) offers a useful framework to assist in the acquisition of appropriate contextual information. These include: having access to information regarding interviewer/interviewee interaction, preferably in the form of audio recordings and/or transcripts, information about participant recruitment, the time, date and setting of the interview(s) and relevant background information about the interviewer, including age, race, gender and social class. Bishop (2006) expands on this by identifying multiple levels of context – the interactional, situational, and cultural/institutional and suggesting ways in which information can be documented in these respects.

In the context of the current study, these criteria were able to be addressed through close collaboration with the primary researcher, Professor Bendelow, who conducted the interviews personally, as well as through access to the original audio taped interview data, some of which was personally transcribed for the purposes of the secondary analysis. Gladstone et al (2007) document a concern with the 'flat' quality of transcripts that has been echoed by other qualitative researchers (Lapadet and Lindsay, 1999, Poland, 2002). Whilst Watson (2006) provides a convincing argument for the advantages of working with transcribed data on the basis of facilitating a more constructive and ‘dislocated’ analytical relationship to the data, it is generally accepted that being able to listen to oral interview data in conjunction with a reading of the transcript allows for a more ‘complete’ situational and relational understanding.

Whilst it is recognised that the arguments illustrated above reflect valid concerns and warrant further consideration prior to undertaking any secondary analysis project, it is suggested by those more amenable to the benefits of conducting QSA that a degree of distance from the primary study may not necessarily preclude an effective and worthwhile analysis. The concept of context is in itself complex, with its interpretation based on a number of factors – not least the theoretical and disciplinary approach of the researchers involved in its production. Context therefore cannot be regarded as a ‘fixed’ notion that we should aim to recreate in secondary analysis (Moore, 2006). Furthermore, whilst it is accepted that primary researchers are able to demonstrate unique insights as a result of proximal understanding of the data itself, this does not necessarily equate to privilege with regards to explanation and/or interpretation of that data (Hammersley, 2010). To suggest as much may be to deny alternative theoretical explanations and encourage a tendency towards description rather than exploration.

Through an acceptance and understanding of the differing methodological, analytical and political purposes in which it is embedded, secondary analysis can allow space for valuable insights into the various ways in which a body of data can be amenable to more than one analytic interpretation. In Fielding and Fielding (2000) the secondary analysis of Cohen and Taylor’s (1972) *Psychological Survival* offers a very different set of conclusions about prisoners’ experiences and understandings of prison life than the primary study. However, by providing a detailed account of the context underpinning the construction of meaning in their study they were able to justify the use of QSA as a complementary alternative rather than a competing approach to the primary study. Applying these principles to this study, the thesis includes a reflexive account of the researcher’s own experience of conducting the analysis which includes discussion of the personal, social and theoretical context within which the research was approached. Focusing the gaze upon the researcher’s own subjectivities in this way allows space for the emergence of an analysis that is truly exploratory, multi-faceted and holistic, grounded in explicit contextual understandings and embodied experience.

### *Assessing suitability*

Hinds et al (1997) outline two key methodological challenges that warrant consideration prior to conducting a secondary analysis. The first of these is the degree to which individual qualitative methods can produce data that is amenable to secondary analysis. This involves an acknowledgement and understanding of the potentially selective process of data collection and an assessment of the degree and extent of what Hinds et al refer to as ‘missing data’ (Hinds et al, p.411). This is used to refer to a topic or issue that is not uniformly addressed across the entire participant sample or scope of the study. Missing data in itself does not necessarily constitute a problem for QSA. However, understanding the reasons for it is important for an accurate assessment of the suitability of a particular data set for further investigation. Some researchers (Hinds et al, 1997, Thorne, 1994) have suggested that specific qualitative approaches, such as grounded theory, are less suitable for secondary analysis due to the way in which the initial questions are narrowed and refined over time, meaning that the reasons for missing data may be subject to (mis)interpretation, potentially resulting in false conclusions being drawn. Methods that involve asking the same open-ended or semi-structured interview question(s) to all participants are generally considered more appropriate for secondary analysis due to the relative ease by which missing data can be attributed to a specific source. In the current study, the secondary data under analysis was generated as a result of in-depth narrative interviews, in which the participants were asked open-ended questions about their experiences of detention under Section 136. This ensures minimal researcher influence over the themes and topics addressed within the wider context of the interview topic and therefore renders the data amenable to further investigation for the purposes of this study.

The second consideration is the degree to which the primary dataset has the potential to answer the secondary questions being asked of it. Research questions relating to similar or closely related subjects of interest to the primary study are generally regarded as more suitable for QSA. However, an assessment of the data contained within the primary data set is required in order to determine whether it is has suitable and sufficient detail in relation to the phenomenon under scrutiny (Charmaz, 2006) to be able to fulfil the secondary purpose. Practically speaking, this means that the data should contain sufficient depth and richness of information pertinent to the study purpose to reasonably assume that enough new information can be solicited from it to answer the research questions (Long-Sutehall et al, 2011). It stands to reason that primary research methods that ask exploratory rather than closed questions and invite participants to talk openly around their views, perceptions and experiences are more likely to yield data of the requisite depth for a secondary analysis (Hinds et al, 1997). Whilst the research questions in the primary study were designed to elicit information about experiences of being detained under S136 of the Mental Health Act, the loosely structured nature of the interviews allowed participants opportunity to talk freely and uninterrupted, thus allowing for the emergence of connected themes which are explored in more detail in this study.

Gladstone et al (2007) provide an outline of the assessment process that was undertaken in order to establish quality and suitability of the primary data prior to their secondary analysis of help-seeking behaviour in the prodrome to psychosis. They conclude, amongst other things, that the presence of a secondary research question that has emerged directly from the primary data can be regarded as a strong indicator of quality in the sense that it serves to validate the importance of the issue under examination. The research questions guiding this study were drawn from directly from themes that emerged in situ within the primary study conducted by Bendelow et al (2016) and were developed in conjunction with a preliminary analysis of the data alongside a detailed review of the literature. It is argued therefore that the data serve as a strong fit for further analysis around these themes. Whilst the original focus of this study was intended to result in a more nuanced understanding of the factors contributing towards high rates of S136 detentions amongst women with a BPD diagnosis, the accounts obtained through interview represented a diverse range of in-depth and complex narratives that represented a whole spectrum of life events, emotions and observations considered significant to the participants which extended far beyond their experiences of being detained under S136. As such, the research focus was developed and expanded to allow for an examination of the wider themes evident within the data that had not previously been subject to analysis. The resulting research questions, as highlighted at the beginning of this chapter, reflect a more holistic focus on the ways in which women (re)negotiate their identities as a result of and in response to a BPD diagnosis and the social and cultural mechanisms that contribute towards shaping their perceptions, understandings and interpretations of both themselves and the world in which they exist.

### *4.4.2 Ethical Considerations*

Whilst the use of existing data for secondary analysis may not require the same lengthy ethics processes applied to the collection of primary data, there are documented ethical concerns specifically associated with this approach. The most pertinent issue to the current research appears to be that of informed consent; that is, the suggestion that consent given at the time of the original study can be violated in the course of asking new questions of previously collected data (Hinds et al, 1997, Thorne, 1998). It is recommended that for secondary analysis to be considered ethical, a thorough assessment of the scope of the original consent and the appropriateness of the secondary research questions be conducted to ensure no harm to the participants. Furthermore, anonymisation is considered necessary to protect participants’ identities (Gladstone et al, 2007).

It was not deemed necessary to obtain further consent from participants in relation to the use of their interview data for the current secondary analysis as all had agreed to and actively encouraged the continued use of their data for other purposes at the time of the primary study. The themes and questions addressed in the secondary analysis are also considered to be sufficiently related to those of the primary study to ensure that initial consent is not violated. Where transcribed data was provided, it was done so in an anonymised form and although the researcher had access to the original audio-taped data for some of the interviews there was no information contained within that allowed the identification of individual participants. Whilst there was a risk that participants may have been able to be identified from their voices, this was considered minimal, and all participants had given consent for their recordings to be made accessible to a third party for the purposes of transcription and analysis.

As participants had already been assigned pseudonyms during the primary research, the same pseudonyms have been used in reporting of the secondary research findings. There are no personal data included within the analysis or contained within the interview extracts that will allow for identification of individual participants. As such it can be reasonably suggested that all necessary precautions have been taken to ensure ethical guidelines in relation to the re-use of the primary data have been adhered to.

### *4.4.3 Participants*

Interview data for secondary analysis was provided by the lead researcher on the primary study, Professor Gillian Bendelow. All participants in stage one of the research had initially been recruited to take part in an unstructured interview with Professor Bendelow in 2013/14 as part of her research project exploring experiences of being detained under S136 of the Mental Health Act. The overall sample of participants for the original research comprised of a self-selecting sample of 37 individuals who responded to a letter inviting them to take part in the research. This letter was sent to a total of 1142 individuals who had been detained or assessed by street triage during 2012 and for whom a viable address was available.

Interviews were selected for inclusion in this study on the basis of participants' shared characteristics of being female and having received a formal diagnosis of Borderline Personality Disorder. Whilst the presence of a BPD diagnosis was not always explicitly referred to within the interviews, Professor Bendelow had ethical consent to access additional data (e.g. medical history notes) which verified the presence of a BPD diagnosis.

In total, eight interviews were selected to be included in the secondary analysis. Participants ranged in age from 19 to 55 (at the time of interview). The interviews varied in duration, from 43 minutes to 1hr 55 minutes in length, with the average interview length being 1hr 8 minutes.

## 4.5 Stage Two: Exploring the meaning of creativity and identity to women with a Borderline Personality Disorder diagnosis

The focus and design of stage two of the research was heavily influenced by the findings of the secondary analysis carried out in stage one; in particular, the emerging theme of creativity as a coping strategy in the management of distress and the negotiation of identity. This finding led to an in-depth review of the literature pertaining to creativity, identity and mental distress which precipitated a reframing of the research questions to incorporate a greater focus on the relationship between creativity, identity and meaning making in the context of mental distress.

The second stage of the research was thus concerned with building upon this emerging theme to facilitate an in-depth exploration of the meaning of creativity and identity to women with a Borderline Disorder Diagnosis. This was done through the application of a flexible, creative and (as far as is possible) collaborative methodological framework, influenced by the concerns of arts-based and participatory research approaches.

The following section will provide an overview of the principles underpinning this second part of the study, an overview of the study design and a discussion of the relevant ethical issues. The approach to data analysis, which was the same for both stages of the research, will then be discussed in the following section.

### *4.5.1 Collaborative Research*

Collaborative approaches to research are grounded in the idea of reconceptualising participants as co-researchers and blurring the boundaries between scientific practitioners and those on the receiving end of scientific enquiry (Beresford and Croft, 2012; Nowotny et al, 2001). Collaborative research can occur across disciplines and across fields and acknowledges the expertise that can be brought to the research process and resulting knowledge outcomes from people with differing realms of experience and skill sets (Jones, 2012).

Collaborative research has, as its aim, the ‘coproduction’ of knowledge and advocates of this approach argue that creating knowledge in this way allows for the illumination of multiple layers of subjectivity and inter-subjectivities that ultimately result in richer and more critical meaning-making which can challenge mainstream assumptions that are typically taken for granted (Chang, et al, 2013). As such, it is particularly useful in engaging marginalised and minoritised groups in research that seeks to enable their voices to be heard by audiences that would not typically be accessible to them. It can also provide a basis for influencing social change and furthering awareness and understanding of under-researched topic areas (Fenge et al, 2016). Research conducted from the standpoints of these neglected groups can however seek to readdress the balance of power by attempting to engage from the point of view of those who identify themselves as being part of these groups and hold belief and trust in their own knowledge through having experienced these phenomena directly (Beresford and Boxall, 2013).

Within the field of mental health research, it has been argued that those with experience of mental health problems should be respected as experts on their own lives and therefore that the knowledge base in this area should be informed by a ‘marriage of expertise’ of both professional and experiential knowledge (Faulkner and Thomas, 2002). Gillard et al (2012) suggest that the involvement of those with lived experience of mental distress in research around supporting self-care not only added expertise by experience to the research process but also challenged some of the underlying assumptions about the processes associated with conducting academic research. One outcome is that research professionals lose something of their exclusive status as arbiters of knowledge (Gaventa and Cornwall, 2015).

Gillard et al (2012) illustrate how an essential component of the success of this type of research lies in its ability to be flexible in its methodological approach to encourage joint involvement and collaborative decision making at all stages of the research process. It is considered that one of the challenges in conducting research in this way relates to the degree to which knowledge in this context can truly be considered co-produced. Whilst it is possible to challenge who has the authority to create knowledge, research is a *“social and human practice that embodies institutional, personal and political factors that influence its design, impact and acceptability”* (Orr and Bennett, 2009, p85). As such, it is important to examine reflexively the social and political dynamics of collaborative research endeavours in order to acknowledge where certain contributions have been privileged and power relations are inherently unequal (Durose et al, 2011). Pertinent to this research, it is acknowledged that due to the independent nature of doctoral study, ethical requirements and the extent to which research planning had already been undertaken prior to recruitment of participants, it was never going to be possible to produce co-produced research in the true sense of the word. However, the research was influenced by the concerns of participatory and coproduction approaches in an attempt to produce new knowledge that is both relevant and contributes towards a growing democratisation of the research process. How these elements were woven into the research design will be discussed later in this section.

Durose et al (2011) draw attention to the importance of appropriate research tools in the facilitation of co-produced research and draw upon research which indicates that a reliance on text can exacerbate a sense of exclusion amongst research participants (Ravensbergen and Van der Plaat, 2010). It is suggested that tools which move beyond text to engage participants in creative ways throughout the research process can assist in empowering participants and allow for greater reflection on the lived experience of those involved (Jones, 2006). In the next section, the concept of arts-based research and it's relevance to this study is briefly introduced and discussed.

### *4.5.2 Arts-based approaches*

The term 'arts-based research' reflects a wide range of approaches that, loosely speaking, refer to those that seek to incorporate the arts in some way as tools for data collection, analysis, and/or dissemination (Gregory, 2014). Arts-based research is multi-disciplinary and epistemologically diverse but generally speaking seeks to challenge the positivist conceptualisation of 'fact-based' objective research and present an alternative, more accessible and 'human' way of knowing that is rooted in the principles of inter-subjectivity (Jones, 2006).

Typically therefore, the outputs of arts-based research seek to incorporate creative techniques such as music, visual art or poetry into traditional academic discourses, or communicate research findings in alternative ways such as through performance or film (Gregory, 2014). As well as presenting research differently, arts-based research also encourages the expression of different forms of knowledge that are less able to be articulated through traditional means (Eisner, 2008). Leavy (2011) argues that in order to understand the nuance of lived experience and enable effective dialogue we need to be able to see in different shapes and to produce knowledge in different shapes (Leavy, 2011). One of the benefits of arts-based research lies in its ability to give space to experimentation and explore alternative ways of interpreting the realities of personal experience, bringing to light 'vivid realities that would otherwise go unknown' (Eisner, 2008, p.11) Thus, arts-based methods are particularly useful in exploring lived and embodied experiences of sensitive issues and can help to produce deep, holistic narratives that privilege the voices and emotions of participants and help to redress the balance of power between researcher and participant.

It was considered that, with the focus of enquiry during this stage of the research on the meaning of creativity to women with a BPD diagnosis, there should be space within the research design to allow for the emergence of more creative ways of knowing which are not constrained by what can be obtained through interview data. It was felt that encouraging participants to respond to the research question in creative ways would enable the discovery of new knowledge about how women with BPD create meaning around creativity and identity grounded in the rich representations of creative embodied experience.

The next section will outline the data collection methods, recruitment and inclusion criteria refer to relevant ethical considerations at this stage of the research.

### *4.5.3 Data Collection Methods*

In line with the approaches detailed above, data collection was driven by a two-way dialogue with participants which allowed them to directly influence the research design; thus, enabling the creation of an environment where they were comfortably and openly able to share their views and experiences in a way that felt appropriate to them. Contact with participants was initiated by email and the background and purpose to the research explained. Participants were then encouraged to engage in discussion with the researcher with regards to their individual understanding of the research aims and their preferences and desires regarding their participation/contribution.

It was the aspiration that data collection would be an organic process, achieved through the telling of back-and-forth stories between participant and researcher, and thus allowing for a self-reflective re-narration of subjective experience. Participants were invited to consider their creativity in relation to their BPD diagnosis and express their interpretation of the connection between them in a way that they felt most adequately represents their views and experiences. Participants were encouraged to utilise their creativity in their responses and were advised that they were not required to take part in a traditional interview if it did not feel like the easiest or most comfortable way to convey meaning. Despite this, all four participants opted to be interviewed face-to-face, with one participant choosing to take part in a second follow-up interview shortly after the first as they did not feel they had fully answered the research questions in the first. Some participants chose to show examples of their creative outputs to illustrate their responses during the interview, whilst others preferred to refer to these in their interview and share them afterwards.

### *4.5.4 Recruitment*

Participants for the second stage of the research were selected using purposive targeted sampling – appropriate due to the specificity of the research questions. It was the original intention to recruit between four and six participants, with the sample size being deliberately small in order to support the depth of case orientated analysis fundamental to the inquiry.

Individuals were invited to take part on the basis of being female, having a diagnosis of BPD, and an involvement in creative pursuits. Recruitment began with a period of online research which identified several individuals who met the inclusion criteria and published their creative work online, as well as a charity (Borderline Arts) whose mission is to raise awareness and understanding of BPD through arts-based activities. An invitation to take part in the research was published on the charity's Facebook page which generated some interest in the project, and the researcher attended an art exhibition hosted by the charity which provided an opportunity to speak informally about the research to potential participants. This led to the recruitment of two individuals keen to take part in the project. A further participant expressed an interest in taking part to a contact of the researcher and was subsequently introduced through mutual consent and the final participant was identified via a public Twitter profile showcasing her photography and approached via email using contact details that were published in the open source (online) domain.

Whilst it can reasonably be supposed that the publication of contact details in a publicly accessible forum indicates a favourable attitude towards the initiation of contact, BPS guidelines for internet-mediated research highlight potential difficulties in determining which online spaces people perceive as 'private' or 'public', and thus in what context(s) individuals and groups are happy to be approached (BPS, 2013). In order to mitigate this, initial email contact began with an explanation of how contact details were obtained, after which the nature, purpose and intended outcomes of the research was clearly outlined.

### *4.5.5 Participants*

Participants for the second stage of the research were selected on a self-identification basis. Unlike participants whose interview transcripts were selected to be included in the secondary analysis, all of the participants who agreed to take part in an interview were aware that the research was intended to explore experiences of having a diagnosis of BPD. Thus, all identified with the diagnosis to the extent that they felt it to have had a significant impact on their lives. Participants were also selected on the basis of their participation in creative or artistic pursuits. However, what constituted this was not explicitly defined in order to allow for a broad exploration of creativity and to avoid excluding potential participants for whom the concept resonated.

The interviews conducted with the four women who took part ranged in duration from two to five hours, and, due to their unstructured nature, were able to bring about a rich understanding of their unique experiences, diverse histories and complex personalities. Although the analysis has been conducted and will be presented thematically, it is the intention of the research to preserve a sense of participants' individual narratives throughout so as not to obscure their personal and situated individual experience (Gillard et al, 2010). In order to ground the analysis within this context and enable the reader to feel more connected to the accounts presented therein, a short introduction to the analysis chapters will provide a brief background to the four participants who shared their stories to inform this research. Firstly though, the ethical considerations pertinent to this stage of the research will be discussed and an overview of the analytical approach given.

### *4.5.6 Ethical Considerations*

This section explores some of the key ethical considerations pertinent to this stage of the research and the steps taken to address them in the study.

#### *4.5.6.1 Considering Vulnerability*

Moore and Miller (1999) define a vulnerable person as 'an individual who is diagnosed with an illness and due to that illness lacks the ability to maintain autonomy, personal independence and self-determination'. For this reason, under the prevailing biomedical model, individuals with experience of mental distress are typically recognised as a vulnerable population, which can present challenges in conducting research. Some of these challenges however are believed to originate from common misconceptions regarding the nature of mental distress and reservations regarding the ability of individuals with a mental health diagnosis to accurately comprehend the research process and provide informed consent for their involvement (Keogh and Daly, 2009).

It is considered that in the context of this project, the risk of conducting research with a vulnerable population is reduced by the application of a collaborative approach and measures put in place during the research encounter to recognise and respond appropriately to participant distress. This ensured that the research methodology was a mutually-agreed process, which not only felt safe and secure, but was directly influenced by the individual preferences of each participant. Whilst the discussion of a sensitive subject matter (mental distress) could provoke memories and emotions which participants may find upsetting, participants were invited only to share what they felt comfortable with.

#### *4.5.6.2 Informed Consent*

It is considered that in light of the collaborative and evolving nature of the research that consent should take the form of ‘a mutually negotiated process that is on-going throughout the course of the research’ (Smythe and Murray, 2010, p. 320). Enabling a process of clear two-way communication between participants and researcher throughout the research process helped to ensure that participants were not only aware of what they were providing consent for and why but had the ability to directly influence and shape their involvement. Participants were encouraged to discuss any concerns regarding the research process with the researcher. However, they were also be made aware that they had the right to withdraw from the study at any time without giving a reason and without consequence.

The sample size of the study was kept deliberately small to allow for the research findings to reflect an in-depth exploration of participants’ narratives and life histories and to give space for the relationship between researcher and participant to develop within the research process. Due to the small sample size of the study, participants were contacted individually and communication was tailored accordingly to ensure that each participant was aware of the reasons they had been contacted and how their details were obtained. Initial contact (appendix 1) also included a brief overview of the research and its aims and objectives, written in language appropriate for a layperson. Further contact was dependent on initial response but typically took the form of a two-way process of discussion regarding the direction of the research process. During this stage a participant information sheet (appendix 2) was also circulated, and participants were given the chance to ask any questions regarding the research and their continued participation in it. Initial consent was obtained verbally, or via email. Written consent (appendix 3) was obtained as a formality prior to interviews taking place and was signed by participants before commencing the interview.

It is particularly important in research of this nature that participants are cognisant of the way in which their stories are to be presented and accept them as an accurate and appropriate re-interpretation of their views and experiences in the context of the research aims and objectives. It is the duty of the researcher to take care to ensure that these re-interpretations do not compromise the subjectivity of the participants to become a singular authoritative interpretation and that meaning is not imposed without consideration of its impact (Smythe and Murray, 2010). Whilst it was intended that a two-way dialogue be maintained with participants throughout the analysis process in order to promote the creation of knowledge that was grounded firmly in the user experience, the long duration over which the analysis occurred (which included a number of periods where study was suspended) meant that it was difficult to maintain engagement with participants and facilitate their continued involvement in the research process. As such the analysis cannot be considered to be co-produced – something that will be discussed in more detail in the discussion.

#### *4.5.6.3 Confidentiality and Anonymity*

Given the sensitive nature of the topic area and some of the ‘problematic’ behaviours typically associated with a diagnosis of BPD there was perceived to be a greater than average risk that participants may discuss behaviour which constitutes a desire to harm themselves or others. Participants were made aware that if such an intention was disclosed, completely confidentiality could not be guaranteed. All participants were made aware of the responsibility of the researcher to inform relevant services of anything disclosed during the research that indicates a desire to harm themselves or others or constitutes a criminal offence.

The majority of participants in this phase of the study were recruited using information publicly available on the internet and located through Google using simple search terms (e.g. “personality disorder artist”). Those recruited through a third-party organisation or individual were invited to contact the researcher directly. As a result of the recruitment process, some participants had an active online (web) presence at the time of recruitment, and as such it is not possible to guarantee anonymity where participants have chosen to include creative work that is accessible in the public domain and directly attributable to them. Participants were made aware of this at the time of the recruitment.

Traditional ethical guidelines tend to be based on a central premise that whilst research respondents should be able to recognise themselves, the reader should not be able to identify them (Barnes, 1979). Thus, the application of pseudonyms and the removal of identifying characteristics has become an integral feature of ethical research. There has been some indication however that, when consulted, many respondents have indicated a desire to retain their identities within research publications, attributing anonymisation of data as a ‘loss of ownership’ (Grinyer, 2002). Some participants in this study have decided to publish either their creative work and/or their diagnosis in the public domain. With this, and the above argument in mind, it was felt appropriate to give participants the choice whether they would prefer to retain their identities or to have their accounts anonymised. It is felt that, particularly in light of the research focus and its emphasis on negotiation of identity, it would not be appropriate to 'strip' participants of their identifies by imposing a singular process of anonymisation. However, the importance of giving participants the choice to remain anonymous is acknowledged and understood.

Of the four participants in the second stage of the research, two chose to retain their identities and have their real names included in the thesis and two chose to remain anonymous. Those who wished to remain anonymous were assigned a pseudonym and any identifying information was removed. Participants were also advised that should they choose to publish any of the creative work they provided for inclusion in the research within the public domain in an attributable way, then their continued anonymity could not be guaranteed. Participants who chose to have their real names and other identifiable information included in the thesis were required to sign an anonymity waiver (appendix four).

#### *4.5.6.4 Debriefing and protection of participants*

Participants in the study were asked to reflect on the relationship between creativity and their own personal mental health, particularly in relation to their diagnosis of BPD and the concept of identity. It is apparent that these are extremely personal and sensitive issues and that discussing these topics could produce an emotional response amongst participants. There was also potential that the process of being a participant in the study may bring to the fore memories and emotions which may cause an element of distress.

The collaborative nature of the research methodology went some way to mitigate this risk by allowing the issues under discussion to be largely participant-driven. Participants were invited to take breaks as required throughout the interview and to engage in any self-care routines necessary to make them feel comfortable. Participants were questioned prior to taking part with regards to what (if any) mental health and/or other support they were currently receiving and advised that their participation in the study should be discussed with a mental health professional if they were currently receiving treatment/on-going support. Whilst participation in the study was unlikely to impede upon any existing programme of treatment, it was important to ensure that any involvement in the study was appropriate in the wider context of participants' on-going mental health and that the risks were fully understood. As the majority of contact between researcher and participant took place via email or telephone there was some difficulty in monitoring participants' reactions and behaviours for potential signs of distress and that any distress may not manifest itself immediately (BPS, 2013). All participants received a follow up email/telephone call the day after the interview to check on their general welfare. Debriefing took place at all stages of the research process and participants were encouraged into a relationship of trust between themselves and the researcher whereby they felt able to voice any anxieties or issues comfortably and openly. Participants were given ample opportunity to discuss any concerns and the appropriateness of their continued participation in the research and were directed towards formal support pathways where it was deemed necessary and appropriate. Participants were also provided with details of specialist telephone/online support channels that they could contact should they feel upset after the interview by any of the issues/topics discussed.

It is believed that the process of reflection, knowledge exchange and the elements of co-production present in the research may have had mutual benefits for both the researcher and participants. Although not intended to be a therapeutic process, participants in similar studies exploring emotive topics have reported experiencing a sense of catharsis which has proven beneficial to their psychological well-being (Lowes and Gill, 2006). Participants in stage one of the research articulated feeling a sense of empowerment as a result of being given the opportunity for involvement in research that may be used to help others or influence future policy and practice (Bendelow, 2006) and this was also reflected in feedback from participants who took part in stage two.

## 4.6 Data Analysis

Interview data from both the first and second stages of the research were analysed using a thematic narrative analysis approach grounded within the feminist and contextualist epistemologies underpinning the thesis. Chapter two presented an overview of the narrative approach, particularly in relation to the extant literature on illness narratives and narrative identity which guided the research questions in this study. This section will briefly describe what is meant by narrative analysis and how it sits within the overarching theoretical framework of the research. It then discusses the utility of adopting a thematic approach to narrative analysis and provide an explanation of how this method of analysis was applied in the context of the research.

### *4.6.1 What is Narrative Analysis?*

Whilst there is some variation amongst academics with regards to a clear definition of what constitutes a ‘narrative’, Riessman (2008) provides a useful definition of the term as ‘events [that] are selected, organised, connected, and evaluated as meaningful for a particular audience' (p.1). The creation of stories is a daily occurrence in everyday social interaction, as well as in formal settings such as the interviews that form the basis of this study. In narrative analysis, the focus of the investigation is on the stories themselves, the meaning that is communicated through these stories, and the purpose behind the telling of a particular story at a particular time to a particular audience (Riessman, 2008).

Narrative analysis in this context therefore is concerned with the life events that are considered to be significant within the lives of the participants and how the stories that they construct to evoke them demonstrate their own perspectives, understandings and interpretations of both themselves and the world around them. The focus of the analysis is therefore not so much on details of specific events but predominantly on how those events are experienced and made sense of by the individual and how the resulting narrative functions for the teller (Coffey and Atkinson, 1996). Narrative analysis fits within a feminist critical realist perspective in that it allows for a relational view of self-conception that identifies story telling as a means by which an individual constructs his or her identity based on ongoing relationships and social interchange, meaning that life narratives and self-conceptions are continually changing in response to actions, events and acquired knowledge (Gergen, 1994).

Furthermore, narrative analysis does not purport to be a method of objectively observing a singular process, but acknowledges that stories are often retold in multiple forms directed by context, with Mishler (2004) noting that *'we story our lives differently depending on the occasion, audience, and reason for the telling'* (p.103). With regards to a research setting, this is also reflected in the analytical process through the degree to which the researcher is involved in the selected re-telling of stories to a new audience through their own contextual lens (Riessman, 2003). Instead of viewing this partiality as a limitation to narrative analysis and a barrier to producing generalisable research findings, the theoretical underpinnings complementing this approach acknowledge the inherent subjectivities as ubiquitous and inescapable, but reflect that embracing this ultimately allows for the presentation of tentative ideas that may be richer and thicker in descriptive meaning than methodologies that demand certainty in their results. (Stubbs, 1983).

### *4.6.2 Thematic Narrative Analysis*

Thematic narrative analysis is arguably the most common and straightforward method of narrative analysis, however being theoretically, epistemologically and methodologically diverse there is little concrete agreement on what exactly it entails and how it should be carried out. Broadly speaking, thematic narrative analysis is concerned with the identification and coding of stories to illustrate general patterns and underlying assumptions. Unlike other forms of narrative analysis, thematic analysis is less concerned with the structure and language of storytelling but more on what is being said and the meaning that can be attributed to it. This interpretation is typically influenced by a number of factors, such as existing and/or emergent theory, the purpose of investigation, the data itself and the wider sociocultural background in which it is situated (Riessman, 2008).

Unlike grounded theory, to which it is most frequently compared, a thematic narrative analysis approach aims to preserve ‘stories’ intact for interpretative purposes, remaining *‘sensitive to the sense of temporal sequence that people, as tellers of stories about their lives or events around them, detect in their lives and surrounding episodes and inject into their accounts’* (Bryman, 2015, p.589). As Fraser (2004) and Riessman (2008) note however, there can be considerable challenge involved in the demarcation of specific stories and sections of narrative, not least because the narratives produced by speakers are rarely clearly defined and contained; typically flowing seamlessly from one story to the next or shifting from one subject to another. This process is therefore open to a considerable degree of interpretation but is loosely concerned with identifying sections where sets of ideas are expressed or a scene is described where a degree of plot or chronology is evident (Fraser, 2004). Furthermore, because the aim is to preserve the sense of individual narrative meaning, the analysis is case-centred and typically illustrates themes from within cases rather than across cases. This is illustrated, for example,in Williams’ (1984) study of illness narratives, where he presents three cases that demonstrate the different ways in which individuals make sense of the genesis of disability. Preserving the essence of the case allows for the preservation of personal meaning within stories but provides a platform from which to compare stories to illustrate patterns and create theories around this meaning. In the case of Williams’ (1984) study, the common theme of rejection of medical formulations of aetiology, and the tendency across all cases to construct new explanations for the genesis of arthritis provided support to Williams’ theoretical argument that the arrival of chronic illness initiates a process of cognitive reorganisation where an individual attempts to reconstruct a sense of order and meaning to repair an identity fragmented by its onset.

Because of this case-based process and its emphasis on preserving individual narrative accounts, thematic narrative is labour intensive and so best suited to a focus on in-depth analyses of a relatively small numbers of accounts (Fraser, 2004). It is also particular suited to analysing data generated from interview methods which are informal and conversational in style and engage participants in ways that allow for the emergence of stories that may not appear to be immediately relevant to the research question (Hollway and Jefferson, 2000).

Whilst the interviews subject to analysis in the first stage of the study were not carried out by the author of this thesis or tailored for the purpose of this analysis, they were carried out in an informal and unstructured way and designed to elicit narrative accounts from participants. In Williams' (1984) study, many interviewees told long and detailed stories in response to the brief and simple question "Why do you think you got arthritis?" and expanded upon these as the research developed. In Bendelow's (2016) study preceding this research, the women interviewed were initially asked just to talk a little about themselves. Even this simple question generated a range of stories revealing rich insights into conceptions of identity and the personal meaning ascribed to experiences of mental distress. Throughout the interviews, the conversational and 'interviewee-orientated' (Reinharz and Davidman, 1992, p.38) approach allowed for the women being interviewed to share the experiences and narrate stories deemed to be meaningful and relevant to them in the context of the interview environment. Thus, it is considered that this data is particularly amenable to a thematic narrative analysis approach, as is the data from the second stage of the research that was gathered in an unstructured way with the intention of being analysed in this way.

Narrative analysis is typically guided by theory and is suited to this study at an epistemological level in that it provides a framework to consider both the individual experience of mental distress and personal meaning as well as allowing space to consider the different domains in which this experience occurs. Narrative analysis can assist in producing insights about how people interact with the various dimensions of their environment and Fraser (2004) advocates a feminist approach that includes an exploration of the intrapersonal, interpersonal and cultural aspects of stories to link 'the personal with the political' (Jackson, 1998). This allows for an understanding and awareness of the ways in which dominant discourses and social frameworks influence the ways in which meaning is created and interpreted (Riessman, 2003).

In the context of this study and the critical realist ontology underpinning it, thematic narrative analysis is useful as a method both to reflect the reality of experience and to unpick the underlying constructs of this reality. Whilst the analysis can be said to be inductive in that themes are generated from the data on the basis of participants' experiences, it is also deductive in that it draws upon theoretical constructs from feminist and narrative traditions to render visible issues that participants did not explicitly articulate. One of the tensions between narrative and thematic approaches lies in the extent to which the latter tends towards decontextualising data by 'cutting and pasting' themes across cases to examine broader issues (Riley and Hawe, 2005). The current study attempts to address this through an explicit recognition of the impact of temporality and context on participants' interpretations of and the meanings ascribed to the events they describe, whilst also acknowledging the similarities and differences between participants' accounts and the broader implications of this. Similarly, the tension between thematic analysis' tendency to fragment stories for the purpose of illustrating themes versus the narrative tradition of preserving stories intact is addressed in the analysis chapters through a commitment to retaining a sense of participants' individual narratives where possible. This is achieved by retaining the sequence. structure and detail contained within the individual stories presented insofar as possible and by way of the short introductions to participants' presented in chapter five; the aim of which is to render them visible as individuals and situate the reader within the context of their stories.

### *4.6.3 How data were analysed in this study*

Fraser (2004) and Riessman (2008) provide useful practical guidance on conducting narrative analysis and this was drawn upon extensively throughout the process of conducting the secondary data analysis. Interviews were subject to repeated listening, and this was particularly useful in the secondary analysis, as it enabled a 'sense' of the interviews and the emotions experienced in hearing them (Fraser, 2004). Whilst some of the interviews had already been transcribed for Bendelow's (2016) research, transcription of some of the interview material by the researcher allowed for a process of feeling 'closer' to the stories contained within.

The process by which interview data were analysed was broadly similar during both stages of the study, though the primary and secondary data were initially analysed separately (with the secondary data being analysed first). In both cases, a framework template was created in Microsoft Excel for the purposes of carrying out and documenting the analysis. This was laid out with individual cases running vertically, and themes/subthemes on the horizontal axis. Each transcript was analysed line by line to identify the types of stories and experiences articulated and consider the emerging themes. During this initial analysis, several perceptible larger themes were noted on the horizontal access and named for the purposes of organising the data. Stories that were considered to relate to each theme were identified and entered verbatim under the relevant heading, with emerging subthemes noted in the framework. As the second stage of the research was directly influenced by the findings of the secondary analysis, the initial framework used in the analysis of the primary data was guided by the broad themes identified from the secondary analysis. These were expanded upon and revised as new themes emerged from the primary data and themes that were not reflected in the second stage of the study were removed in subsequent iterations.

Following an initial analysis. each transcript was revisited a number of times to explore the different domains of experience contained within; focusing on the sociocultural, relational and political aspects of the stories to facilitate an understanding of the dominant discourses underpinning them. At this stage, the themes and subthemes were reviewed and refined to ensure the most accurate representation of the data and findings from both stages of the research were also compared with each other to identity crosscutting themes and divergences.

Visual data was analysed in conjunction with interview transcripts in recognition of the importance of participants' own interpretations of their images and the challenge in identifying and analysing complex discourse based on imagery alone (Murray and Nash, 2016). The analysis of the visual data was particularly concerned with respecting and privileging the meaning participants' ascribed to their images and examining the extent to which the images reinforce, contradict, or add something new to the themes generated from the interview data (Trombeta and Cox, 2022). To this end, visual data was analysed after the interview data and is predominantly included in the findings to illustrate or add meaning to themes identified from the primary data.

The analysis was guided by the principles of reflexivity, and recognition of the dynamic relationship between researchers and participants and the inevitable influence that this relationship exerts (Orr and Bennett, 2009). The next chapter provides a reflexive account of the research process and the position of the researcher within it.

# Chapter 5: Who am I?

A reflexive account of my personal journey through the research process

## 5.1 Introduction

We do not exist in a vacuum. Qualitative research, by its nature, typically requires researchers to bring something of themselves to the research process and engage on an emotional level with both research participants and the subject of inquiry (Gabriel, 2018). It is inherently contextual, a product of the relationship between researcher and research participant, occurring within a specific time and place (Dodgson, 2019). Reflexivity is the process of making this context visible for the purposes bringing integrity and authenticity to the research process. Being reflexive means to turn inwards, investigating one's own values and beliefs and how they have impacted the research (Etherington, 2007).

In this chapter I briefly outline why reflexivity is an important element of knowledge production and how it relates to the ontological position of the research. I then reflect on my own relationship with the research, the personal journey I have experienced and the various facets of myself that have shaped and been shaped by the research process. In doing so, I aim to situate myself explicitly within the research process as a person with a history, a self and a complex set of emotions and beliefs, in the hope that what follows thereafter is a complete and authentic account of participants' lives and experiences, made possible by an awareness and understanding of my own.

## 5.2 Why is reflexivity important?

Reflexivity is an established practice within qualitative research, where the goal is not to generate objective and absolute knowledge about cause and effect, but to produce narrative knowledge about the meanings, motivations and links between actions, behaviours and emotions (Gabriel, 2018). In qualitative research, it is often said that 'the researcher is the instrument' (Patton, 2002, p.14). Like any other research instrument, it is therefore important to examine the researcher for bias and to understand their positionality, so that there is transparency and clarity about who the researcher is and how they may have impacted the research Dodgson, 2019). In practising reflexivity, qualitative researchers increase the trustworthiness and credibility of their work, whilst deepening understanding and making it easier to determine the relevance and applicability of the research findings (Berger, 2015; Teh and Lek, 2018).

Reflexivity requires the researcher to be able to identify and articulate, through an intersectional lens, the context in which they are situated, and their relationship, both to the phenomena under scrutiny, and the research participants (Dodgson, 2018). It involves an examination of identity across several dimensions, e.g., race, socio-economic status, age, cultural background and an exploration and careful monitoring of the role of the self in the creation of knowledge (Berger, 2015). It also necessitates an awareness and understanding of our unconscious biases, inviting us to challenge how our pre-existing beliefs can impact upon how we interpret and value research findings (Buetow, 2019).

Berger (2015) outlines the importance of identifying and making explicit the extent to which the researcher shares characteristics or experiences with research participants and the effect of this positioning on the research. She suggests that the degree to which the researcher is regarded as an ‘insider’ or an ‘outsider’ can impact upon the researcher/participant relationship and power dynamic as well as potential access to the ‘field’ (e.g. participants may be more willing to share their experiences with a researcher who they feel may be empathetic towards their situation by virtue of their shared experiences). The extent to which the researcher relates to and identifies with the experiences and characteristics of participants will also inherently affect the lens through which the information gathered is interpreted and made sense of.

Reflexivity, therefore, is a conscious and deliberate effort to reflect on and elucidate the ways in which the research account is constructed from the researcher’s own worldview, rendering this visible so that this tension can be monitored and deliberated. As well as enhancing the accuracy and credibility of qualitative research, maintaining a reflexive practise also helps to ensure ethical rigour by reducing the negative effects of power in the researcher/participant relationship and acknowledging that whilst “interpretation of findings is always done through the eyes and cultural standards of the researcher, the effects of the latter on the research process is monitored” (Berger, 2015, p.221).

## 5.3 Approach

### 5.3.1 *Reflexivity in the context of a critical realist ontology*

As outlined in the previous chapter, this thesis is underpinned by a critical realist ontology which occupies a contextualist position that sits between the poles of realism and constructionism (Braun and Clarke, 2006). Unlike social constructionism, ontological realism accepts the existence of realities which are present and act independently of our descriptions of them; but posits that that we can only know them under particular circumstances (Bhaskar, 1975). Critical realism reflects the position that all knowledge is local, provisional and situation-dependent (Jaeger and Rosnow, 1988) and always situated within a historical, social and cultural framework that is transient and ever-changing (Archer et al, 2016).

It follows, therefore, that social mechanisms and their effects cannot be understood in isolation, but rather should be viewed as ‘laminated systems whose internal elements are necessarily “bonded” in a multiplicity of structures’ (Bhaskar, 1993: p25). The current research reflects the critical realist perspective of reality as being determined by multiple factors, with no single mechanism causing or being solely responsible for determining events (Bhaskar, 1975). It is therefore concerned with teasing out multiple causes from a detailed exploration and explicit articulation of the personal and cultural perspectives from which the analysis is approached (Wilkinson, 1998). This includes but is not limited to, participants’ own experiences, researcher context and interpretation, cultural systems underpinning meaning making, and value judgements inherent within communities (Pidgeon and Henwood, 1997).

A critical realist approach necessitates a commitment to reflexivity, to understand how the reality of the researcher is felt and contributes to the multiplicity of factors affecting the phenomenon under investigation. Adopting many of the principles of feminist epistemology, this study is also sensitive to the idea of ‘voice’, particularly in relation to who is being heard and who is being excluded (Kralik and Loon, 2008). It has at its core an ambition to allow for voices that have typically been excluded to become central to knowledge production. To do this requires hearing and understanding *all* the voices that are present in the research process, including the voice of the researcher, and an explicit acknowledgement of the dynamics of power that have shaped the research process and findings. (Ackerly and True, 2008).

### *5.3.2 Reflexivity in practise*

To be reflexive requires a continuous process of self-questioning, evaluating and reflecting on one’s own values, beliefs and standpoint (Gabriel, 2018). Whilst there is no prescribed way to engage in reflexive practice, researchers are encouraged to engage in reflexivity throughout the research process through activities such as journaling, keeping a detailed record of decisions made in the research process and the rationale for them, and through a process of self or guided supervision.

Over the past seven years of conducting this research, I have woven reflexivity, almost instinctively through every stage, as I have explored my own identity, mental health and traumatic past alongside the evolution of this thesis, and as my understanding of the concepts and issues the research seeks to explore has developed. This has involved examining, re-examining and re-framing my own beliefs and values, and it has led me to question my own sense of self in the context of interpreting participants' narratives about theirs. I regularly discussed these questions and reflected upon my values and belief systems in my weekly therapy sessions, with my supervisors, in my work life and in my own personal reflections. As my knowledge of the experiences, arguments and debates pertinent to this thesis has grown, so too has my knowledge of myself and many of the theories discussed in this research have formed the basis of my therapy sessions over the last six years. Conversely, in conversations with my supervisors and professional colleagues I have reflected and challenged myself on the extent to which I allow my own personal experiences and opinions to shape the direction and arguments presented in the thesis.

Whilst I have endeavoured to apply and demonstrate a reflexive approach throughout the research process, I observed that my voice and personality are notably missing from the majority of the thesis, which is written in traditional academic prose; reflective of my traditional academic background and career in third sector research. To attempt to counteract this and balance it against my aim to privilege the voice of lived experience of the participants in my research, I chose to include this chapter which tells the story of who I am, where I came from, and how this research has shaped me, as well as I it. In containing my story within this chapter and situating it prior to my analysis of participants' narratives I hope to provide the reader with the context needed to bear my positionality in mind throughout the remainder of this thesis, without detracting from the voices and stories of the women who contributed to the research.

### 5.4 Where did I come from?

When I was 11 years old, I contracted salmonella, and later pneumonia. I was unwell and absent from school for ten weeks, at a time when friendships were developing and identities were forming. For many years, in my narrative of my life, this was the 'biographical disruption' that catalysed a lifelong struggle with my mental health. I grew up in a home with an alcoholic and a narcissist, but I did not know this until I was well into my 20s, and it is something that, now in my late 30s, I am still coming to terms with. As a child, I was not encouraged to express my emotions, but was constantly exposed to the unpredictable and confusing emotions of my parents, which I internalised and adopted as my own. My worth was defined by my academic achievements, and my desire to be accepted, seen and valued, which manifested itself in perfectionism, crippling anxiety, self-deprecation and an obsessive interest in anyone who showed me kindness. Consequentially, my teenage years were long and painful, punctuated by intense crushes (often on teachers or people in positions of power) and a phobia of vomiting that led to a diagnosis of obsessive-compulsive disorder and my first experience of therapy at age thirteen.

Whilst this initial experience of therapy went some way to reducing my compulsive behaviour, at least for a time, it was not a hugely validating or empowering experience. The causal underpinnings of my obsessive thoughts and complex emotions were never explored and I never spoke with anyone else (even my parents) about my mental health – not having the language or the permission to do so. Consequently, I often felt lonely and isolated and internalised a perception that there was something ‘wrong’ with me that needed to be fixed. In the absence of a supportive space in which to be myself and express my feelings, I looked for outlets through which to channel my intense emotions, which led to me discovering a passion for music and a penchant for melancholic poetry which has travelled with me to adulthood.

What I did have however, was the benefit of an excellent education and a supportive school environment that allowed me to flourish and explore my creative and academic passions. As well as encouraging my love for theatre, music and writing, this environment also facilitated my introduction to the study of psychology and instilled in me a deep curiosity and desire to make sense of the way we experience and interpret the world, which resulted in a decision to study psychology and drama studies at university. It was also around this time that one of my longstanding crushes developed into something more tangible, setting me off on a path of co-dependency that would prevent me from acknowledging or addressing the implications of my upbringing for many years to come.

My university experience was uneventful and uninspiring, but it cemented my desire to pursue the study of psychology and uncovered an interest in the criminal justice system which I took forward through the completion of a master’s degree in criminology and criminal psychology. It was here that I first began to explore the world through a gendered lens, completing my dissertation in cultural criminology on the subject of media representations of violent women. After university, I secured a job as an intelligence analyst with the police, bought a house, filled my life with achievements and material things and generally buried my head in the sand, refusing to acknowledge or reflect on the deeply-rooted sense of anxiety, insecurity and unfulfillment I felt almost daily. This continued unabated until my mid-20s when my Mum’s mental health started to deteriorate, eventually culminating in the revelation that she was addicted to alcohol and had been throughout my childhood. Despite my father and I both purporting to have been unaware of my Mum’s drinking, my diary entries from age twelve indicate at least a subconscious, if not explicit, awareness of the issue. However, even with this knowledge, it would still be many years before I was able to explore the impact of this on my own thoughts, feelings and behaviours. I coped with the news of my Mum's alcoholism by embarking on an affair with a married father of three, and later, a further affair which catalysed the end of my ten-year relationship and a move to Brighton. This began a period of chaotic emotions and behaviours through which I tried desperately to seek validation and a sense of self through romantic relationships, but found neither.

Like many things in my life, I stumbled upon my PhD in a way that seemed like an accident, but now makes perfect sense in retrospect. Still working in the police, myself and my other female colleagues were being subjected to misogynistic and sexist behaviour at the hands of our supervisors, and my mind was preoccupied with thoughts of everybody's mental health except my own. I was exploring several options, including retraining as a forensic psychologist, when I came across the studentship opportunity, and was drawn to the subject, as it was then, because of my (now somewhat distant) background in criminal psychology, an aspiration to contribute towards an increased awareness and understanding of mental health, and a vague desire to elevate the voices of women to drive change in policy and practise.

## 5.5 My journey from outsider to insider

When I began this research, I had very little understanding of either BPD or S136. Despite the personal and professional experiences I have outlined above, both concepts felt alien to me, likely due to my refusal to acknowledge my own distress and the persona I had created for myself which centred me firmly as an 'overachiever', or someone 'with their shit together'. Thus, I initially approached the research from the position of an outsider, placing the participants very much in the space of 'other'. I am almost ashamed to say now that at this point, I did not even consider myself a feminist.

In the process of conducting an initial literature review and drawing up my research plan, I became more attuned to the gendered nature of mental health diagnosis and began to reflect upon my own experiences as a woman, particularly with regard to my relationships with men, both in my personal life and in the workplace. Transcribing and carrying out a secondary analysis of my then supervisor, Professor Gillian Bendelow's, interviews with women with a BPD diagnosis who had been detained under S136 allowed me to gain a more nuanced understanding of the experience of BPD. However, their accounts felt removed from my own experiences and only served to reinforce the idea that I occupied a position outside of their realities. Although I was aware of, and could articulate, my own experiences with what I then conceptualised as anxiety, I felt as though my mental health was 'under control' in a way that theirs was not.

Nevertheless, it is clear to me now that there was a bi-directional relationship between my analysis of these interviews and a shift towards reconceptualising my own experiences, which led to the evolution of the research away from a focus on S136 toward an exploration of identity, trauma, invalidation and creativity. Whilst these themes emerged organically from the data and are supported by the literature, my own experiences and interests (subconscious though they may have been) undoubtedly shaped the lens through which I interpreted the findings, and, in turn, the elucidation of these themes allowed me a platform through which to explore their presence and impact on my own life.

Outside of the research environment, whilst I appeared to be functioning well on the surface, my personal life was becoming increasingly chaotic and unmanageable, and, catalysed by my increased exposure to and awareness of some of the issues I was experiencing through my research, I made the decision to invest in long term private therapy. My initial aims upon entering therapy were to deal predominantly with my feelings and behaviours in the context of my romantic relationships, but what followed was the beginning of an ongoing exploration of identity and selfhood, and a journey towards reconceptualising my own challenges in the context of my past experiences.

In approaching the primary data collection, I did so through the eyes of someone who was neither wholly insider nor wholly outsider. It is telling that the ‘about the researcher’ section on the website I created to recruit participants remains blank, and I recall coming to some realisations in therapy about the extent to which my sense of self was shaped by the perceptions and expectations of others rather than my own thoughts, feelings and experiences. My reflexive practice at this time centred around the degree to which I was able to relate to the women that I interviewed for the study. All four came from a similar background to myself and shared many similar experiences, and, although I was not explicitly aware of it at the time, I suspect now that I approached these women to take part either because I perceived something in them I could relate to, or because the inclusion criteria were inherently relatable to me.

Adhering to the principles of critical realism and a feminist epistemology underpinning the study, I adopted an unstructured methodology in terms of the format of the interview process and my engagement with participants, the aim of this being to enable a reciprocal relationship between participant and researcher that would break down hierarchal distinctions and create a sense of empowerment (Hammersley, 1994; Millen, 1997). My aim was to create a comfortable and validating space for participants to share their experiences and talk about what was important to them, but I struggled to know how much of myself to bring to the interview process and how much self-disclosure to engage in, especially in the light of my uncertainty about the extent to which I could be considered an insider in the researcher/participant relationship. What I found was that, in spite of the unnatural environment and inherent power dynamics created in a research interview, conversation with all participants flowed freely and naturally. Being of a similar age and background to participants appeared to allow them to feel comfortable to share their experiences with me without me feeling compelled to give too much of myself away. Nevertheless, upon transcribing the interviews, I became aware of the extent to which I became noticeably more animated when participants articulated opinions which resonated closely with my own worldview and the biases I hold, particularly as someone critical of the biomedical model of mental 'illness'. In the process of carrying out the analysis, I was careful to analyse not only what participants were telling me, but how I was responding, to understand the extent to which I might be influencing the conversation and imposing my own views. Whilst it is difficult to say with any certainty what effect my reactions will have had on participants' responses to my questions and the direction of the conversation, my analysis has led me to conclude that for the most part my presence was encouraging rather than dominating, and I am confident that despite my inherent bias I was able to offer a space where participants felt comfortable to share their views and experiences, even if they differed from my own.

I found the process of analysing and making sense of the primary data I collected extremely challenging, both because of its depth and complexity in relation to the research questions, but also the degree to which much of what I was told penetrated and took residence within my own conception of self. When I talk about my research, especially to other researchers, I am often asked the question 'Have you diagnosed yourself with BPD yet?' and the answer to this is that for a time, I thought of little else. The following extracts from my annual progression reviews in 2018 and 2019 go some way to describing the profound and prolonged impact that conducting the research had on me:

> *"I have found that the process of hearing about participants' experiences is one that has had a profound effect on me personally and has led to me challenging my own preconceived ideas about what it means to be mentally unwell. I have been blown away by the openness and honesty with which people have been willing to share their stories with me, and the levels of insight that those participating in my research have shown in relation to themselves, their struggles, and experiences. I have also spent significant time reflecting on my own mental health and have been surprised by how much of what participants have shared with me has resonated with me. I feel a huge sense of empathy towards the participants in my research and a desire to 'do justice' to their stories and experiences, but this passion and sense of duty has made the*

> *process of transcription and data analysis one that has often been emotionally challenging."*
>
> *(APR Report, 2018)*

> *"I have spent a significant amount of time reflecting on my own mental health during this process, and the sense of empathy I feel towards the participants in my research has only grown as I have progressed through my own journey of recovery and exploration through therapy. This however has meant that many of the themes that have emerged out of this research have felt very 'close to home' which has sometimes been challenging and meant that progress has not always occurred at the rate I would like. I feel that it is vitally important to protect my own mental health during this process and I hope that by giving space to and acknowledging my own feelings and the impact they have had on this research, it will allow me to produce something that is authentic and truly grounded in lived experience."*
>
> *(APR Report, 2019)*

Through the process of engaging in therapy, supervision and reflexive practice, I was eventually able to separate myself from participants' accounts enough to conduct an analysis that was both inductive, in that themes were generated from the data on the basis of participants' experiences, and deductive, in that I drew upon theoretical constructs to render visible issues that participants did not necessary explicitly articulate. The themes were added to, revised and developed throughout the analysis process as consideration was given to the similarities and differences between the transcripts and how they aligned with the initial assumptions of my research and the existing literature, as well as my own assumptions and biases.

I am still uncertain as to whether I was perceived as an 'insider' or 'outsider' researcher by participants, or in fact, which I identify myself as. However, as Davis (2020) notes, regardless of who is conducting research on whom, *"the qualities of a good interviewer, for example listening, being sensitive and compassionate to the information shared, may help to form the building block of any relationship; these in turn would demand honesty, reciprocity and trust – integral to data collection.*" (Davis, 2020, p.6). I am reassured by feedback I received from participants which indicated that they felt heard and validated that I provided a space for them to share openly and, as such, reflect that perhaps these qualities are more important than the positionality of the researcher in terms of creating a safe and empowering experience for participants.

### 5.6 Where am I now?

Reflecting on this journey now, the experiences, outlook and ambition that shaped the research and brought me here seem obvious. However, the fact that it was not obvious to me until relatively recently indicates the extent to which my own identity and sense of self had been obscured for many years.

I have now been attending weekly therapy for almost seven years years and am in the privileged position of having had the same therapist throughout this time and the financial means to pay for it. I am acutely aware that the majority of the participants in this research have not had this luxury and it remains a slight tension in my reflexive journey as I reflect on the extent to which I am equipped to write about their experiences. At this point in my therapeutic journey, I have come to understand my own difficult emotions, relationships and behaviour as a product of the relational trauma I experienced in childhood and adolescence, and through acknowledging and examining this am renegotiating my own identity and learning to give myself the acceptance, validation and support that I never had previously and seek out relationships that empower rather than subsume me.

Alongside my research and personal journey, my career has also developed, and I now hold a senior position in a feminist charity, leading intersectional and participatory research to campaign for young women's economic justice. My identity as a feminist is another aspect of myself that has developed over time, but my core beliefs about the importance of equity and elevating the voices of lived experience underpin every aspect of this research. My original aspiration to drive changes in policy and practise affecting women experiencing emotional distress has only been strengthened by my work in the charity sector.

My own relationship with creativity is also something that has remained fairly constant. For me, creativity is auditory rather than visual, and I have always said that I feel most 'myself' when I am singing, playing or listening to music. Being active in two bands allows me the space to connect with myself through that creative outlet, but as I learn more about myself, I find that I don't 'need' it in quite the same way I once did. Through my understanding of what it means to be creative, I hope I am able to accurately represent participants' creative journeys and convey something of the emotional weight and meaning they hold.

## 5.7 Conclusion

In this chapter, I have attempted to render myself visible in the context of the research by sharing my own personal journey through the research process and highlighting the implications of this for the research. It is my aim that, as Davis (2020, p.12) suggests, 'the very act of acknowledging the researcher voice and threading the researcher positionality throughout the thesis endorses the inter-subjectivity paradigm of qualitative research.'

In the three substantive analysis chapters, I present a thematic analysis of participants' accounts from both the primary and secondary data. Just as I have recounted my own story chronologically, the analysis will also be structured in such a way to reflect the chronology of narratives expressed by participants and their journey from diagnosis (situated in the context of their life histories) through to understandings of 'recovery' and (re)negotiation of identity. As the majority of the participants are artists/photographers, this will be illustrated with examples of their artwork with descriptions in their own words where possible.

I have privileged my own voice in this chapter, so that the voices of participants can be privileged in the analysis. However, I hope that in doing this, the reader will bear my own journey in mind when considering the context in which participants' journeys are presented and discussed and acknowledge it as an integral part of the process of knowledge production. I return to the subject of reflexivity in the discussion chapter, where I examine the implications of my own perspectives, experiences and beliefs on the findings and conclusions I have drawn.

# Chapter 6: Who are they?

Introducing the research participants and setting the scene

## 6.1 Introduction

The previous chapter provided a detailed account of my own background and the reflexive journey I have taken throughout this thesis, with the aim of raising the reader's consciousness of my positionality and its impact on the resulting research. The importance of personal and situated individual experience is central to the critical realist ontology underpinning the thesis and the rationale for adopting a thematic narrative approach to analysis was discussed at length in chapter four. However, whilst it has been the intention throughout the analysis to retain a sense of participants' individual journeys and narratives, it can be difficult to preserve stories intact when analysis is presented thematically as it is done here.

This short chapter therefore serves to provide a brief introduction to the participants who took part in the research. This aims to provide the reader with a degree of context to enable them to build an initial picture of each of the participants as individuals and help to situate and feel more connected to their stories.

## 6.2 Participants in Stage One.

As discussed in chapter four, the interview data analysed during stage one of the research were obtained by way of a secondary analysis of transcripts originally collected by Professor Gillian Bendelow for a research project examining participants' experiences of being detained under Section 136 of the Mental Health Act. As such, biographical information for participants in stage one of the research is limited to that contained within the interview transcripts and thus contains less detail than that of participants who took part in the second stage of the research. Nevertheless, short biographies for each of the participants are included below to foreground the stories and experiences referred to in the following chapters.

### *6.2.1 Chrissie*

Chrissie was 39 at the time of interview. She was born in Wales, adopted by devout Catholics and grew up in Wrexham. She has an academic background in Criminology and has previously worked with young offenders and disabled adults. She is dyspraxic and was not working at the time of interview. Chrissie has been detained a number of times under S136 and has had a number of periods of inpatient psychiatric treatment and living in a therapeutic community. She says life has got better since receiving more specialist support to manage her distress and she enjoys doing puzzles, colouring, and playing with her cats.

### *6.2.2 Holly*

Holly was born in London, in 1962, making her 52 at the time of interview. She was brought up in a large family – the youngest of five and the only girl. Her father was an alcoholic who left when she was two and she moved around a lot as a child as her Mum struggled with financial difficulties which made it difficult for her to feel settled. She met her husband when she was 15 and has four children of her own. Holly loves animals and has four dogs, four cats and two horses. Holly previously worked as a Community Psychiatric Nurse but stopped working when she began to experience mental distress. She has struggled with an addiction to alcohol and also has a diagnosis of PTSD in addition to a diagnosis of BPD.

### *6.2.3 Martina*

Martina was 47 at the time of interview and living in a small town in East Sussex. She has worked as a Senior Night Carer with elderly people and previously worked as a retail manager, but was signed off work at the time of interview. She is not married and has no children. Martina first began to experience mental distress around two and a half years prior to the interview, which she says was triggered by antisocial behaviour from her neighbours. Since then, she has attempted to end her own life a number of times and been detained repeatedly under S136. In addition to BPD, Martina has also been diagnosed with PTSD and Major Depressive Disorder

### *6.2.4 Brigid*

Brigid grew up in Germany and came to the UK in 2006 to work as an au pair and a teaching assistant, before having to stop work due to an injury to her foot which has required multiple surgeries. She was 32 at the time of interview. Brigid experienced a number of concurrent challenges, including being made redundant, being involved in a car accident and experiencing severe pain in her feet, which contributed to her attempting to take her own life and subsequently being detained under S136. She has had periods of inpatient psychiatric treatment but is now getting support to manage her mental distress and physical disability and enjoys swimming, going to the library and volunteering with the help of her support worker.

### *6.2.5 Siobhan*

Siobhan was 36 at the time of interview. She grew up in Brighton as one of three children and describes her childhood as ‘very difficult.’ She went to university in the north of England and began training as a teacher before moving to a course specialising in Disability and Community Studies. She describes being actively involved in political campaigning at university which led to a career in advocacy within the health and social care sector. She has worked in strategic leadership roles in service user involvement for large national charities but at the time of the interview was taking some time off work to focus on her recovery. Siobhan has been involved with mental health services since she was 13 and has a number of diagnoses, including PTSD, Bipolar, a Major Depressive Disorder, in addition to her BPD diagnosis. She describes herself as having a lot of ‘creative energy’ but struggles with agoraphobia and dissociative episodes which have made it difficult for her to put her creative ideas into practise.

### *6.2.6 Sally*

Sally was born in the Westcountry and describes moving around a lot whilst growing up and finding it difficult to settle. She moved to Surrey at 18 where she trained as a nurse working with people with learning disabilities. She was 42 at the time of interview and had lived in East Sussex for the last 13 years where she previously founded and ran a charity supporting women and children who had experienced childhood trauma. She has also studied law, psychology and sociology and at the time of interview was studying for diplomas in integrative counselling and canine psychology. She loves animals, music and poetry, but describes herself as being ‘rubbish at art’. Sally has experienced various challenges to her physical and mental health which means she was not able to work at the time of interview and has been diagnosed with an eating disorder, Dissociative Identity Disorder and Major Depressive Disorder in addition to BPD.

### *6.2.7 Naomi*

Naomi was 21 at the time of the interview and describes coming from a ‘fairly big family’. At the time of the interview she was living with her parents, two older sisters, younger brother and live in nanny in West Sussex. She left school before doing her GCSE’s but sat one GCSE and her A-Levels at home and at the time of interview was studying Natural Sciences with the Open University. Naomi has been detained 24 times under S136 of the Mental Health Act and has been in contact with mental health services since she was 14. She has been diagnosed with BPD, PTSD and Recurrent Depressive Disorder and at the time of interview was receiving inpatient treatment in a specialist BPD unit.

### *6.2.8 Sonia*

Sonia was also 21 years old at the time of interview. She lives alone but is cared for by Mum, whose health she expressed concern over. She is particularly close to her Grandad who has dementia and is in a care home. She describes him as ‘her life’ and enjoys visiting the care home, referring to the other residents as her ‘family’. Sonia has never been able to work due to her mental health but has done some voluntary work. She has been under the care of mental health services since she was around 15 and has been detained under S136 more than ten times. She started drinking at 14 and has made numerous attempts to end her own life, In addition to BPD, she also has a diagnosis of PTSD and Bipolar Disorder and experiences regular dissociative episodes.

## 6.3 Participants in Stage Two.

### *6.3.1 Katy*

Katy describes herself as ‘an artist who has BPD’ rather than ‘a person with BPD who is an artist’. At the time of the research she was in *her early 30s and was living in East London with her two cats. The following is taken with Katy’s permission from a website on which she was a regular contributor, and provides an introduction to Katy in her own words:

> *I am an art school dropout, with a PhD in Psychology (which I mostly use as a doorstop) and a cacophony of mental health disorders. I have spent the last 3 years in intensive therapy for my primary diagnoses (Borderline Personality Disorder and Complex Post Traumatic Stress Disorder), and I also live with Major Depressive Disorder, Generalised Anxiety Disorder and Eating Disorder. I'm a hearer of voices, a recipient of intrusive thoughts, and my mind is host to a number of identities, who are learning to get along with one another.*
>
> *I'm also a kitten lover, an avid reader, a lover of nature and night-time, and an artist and writer. For approximately 3 years, I have been documenting my life with mental illness through an art journal sketch series. The pieces in the series are "one draft" drawings, created during or as close as possible to the cognitive or emotional event they depict. My method is not to plan my drawings beforehand. Rather I practice a method I calls "free drawing", which, similarly to "stream of consciousness" writing, involves simply holding the pencil in front of a blank piece of paper, and focusing inwardly on my emotional state. The resultant drawing is often a surprise, even to myself. This method helps me not only to communicate how I am feeling to others (an*

> *ability I struggle with verbally), but it also helps me to work out how I am feeling for myself (another thing I find difficult).*

At the time of the research, Katy managed a number of social media platforms, including an Instagram account for her art, and a Facebook account which featured articles about BPD and complex trauma as well as her own artwork recording her therapeutic progress. Her artwork has been featured in a number of exhibitions, including one which she curated herself. She describes herself as having a streak of ‘toxic perfectionism’ which has resulted in a history of over-achieving that contributed towards the ‘breakdown’ that eventually led to her being diagnosed with BPD as well as the other diagnoses outlined above.

### *6.3.2 Emily*

Emily was also in her 30s at the time of the research and was living in the north of England. She describes her background in terms of growing up in a ‘settled’ family but says she has always been ‘sensitive’ and experienced difficulties with her mental health from an early age, starting to self-harm and restrict her eating in her early teens. After leaving school, she spent some time working abroad, before returning to the UK, firstly on a temporary basis to undergo inpatient treatment for her mental health, and then permanently. She has a degree in Creative Arts, and after spending some time in eating disorder units and acute mental health wards, where she was first diagnosed with BPD, she set up a charity to help raise awareness of BPD and attempt to break down the stigma surrounding it.

Art and photography are a big part of her life and is involved in many different aspects of artmaking, including printing, stamping, clay, paper modelling, decoupage, scrapbooking, felting and jewellery making. She describes herself as a ‘jack of all trades, master of none’ but states that the two mediums that have remained constant throughout her ‘phases’ are collage and photography. She used to think that she was bad at art but since beginning art therapy has found it to be a useful tool for emotional expression. She particularly finds that selecting words and images for collage and ordering them onto paper helps her to work out how she is feeling and communicate this to her therapist.

Emily is also an avid Lego fan and likes to combine her passion for photography with her passion for Lego. She regularly takes photos of her Lego figures on ‘adventures’ and considers this a form of escapism and playfulness. She enjoys how art can both be a vehicle for communicating deeper meaning and raising awareness and also sometimes ‘just a bit of fun’.

She is passionate about helping to change the stigma associated with BPD and finds that her artwork helps people to gain insight and understand her and others with the diagnosis better.

As well as a diagnosis of BPD, Emily also has a diagnosis of anorexia. Emily considers her experience of anorexia to be closely linked to her BPD diagnosis, describing it as a destructive coping mechanism to manage the intense unbearable emotions and difficulties that come as a result of BPD. She describes her involvement in creativity and artmaking as being vital to maintain reasonable health and a much healthier coping mechanism.

### *6.3.3 Claire*

Claire was in her late thirties at the time of the research and was living with her partner of 14 years in West Sussex. She describes growing up in a relatively stable, although rather 'adult' environment, with two sisters who are ten and twelve years older than her respectively and parents who described her as being 'dramatically different' to raise than her sisters. She describes herself as a 'complicated' child who was very interested in politics and world events and began writing letters to the Sri Lankan government (in crayon) at ten years old about issues relating to animal welfare. Claire describes how she has always been 'obsessive' about things and experienced intense and unstable relationships from early adolescence. She began self-harming aged 11 and had her first interaction with CAMHS aged 14.

She did not go to university but spent some time travelling in Australia and Asia and had a stable job for a number of years working as a support worker for young men with experience of the criminal justice system. Her declining mental health and increasing difficulties with substance misuse and alcohol meant that she eventually had to stop working and she has spent some time in private therapy and a residential rehabilitation centre, where she was eventually diagnosed with BPD. At the time of interview, she had also recently been diagnosed with Bipolar Disorder.

Claire describes herself as 'quite an academic person' and enjoys reading, learning new things and engaging in political debate. She also enjoys music and feels a deep connection to the lyrics of songs by Joy Division and the Manic Street Preachers. She also enjoys yoga, which she refers to as 'therapy for the body'. She and her partner have been experimenting with role playing during sex as a way of exploring different aspects of identity in a safe way – 'a place to play and invent and be somebody else'. She has found this to be a helpful creative coping mechanism which has reduced the degree to which she feels compelled to engage in self-harming behaviours.

### *6.3.4 Victoria*

Like the other participants, Victoria is also in her 30s and lives alone in the south of England. She was sexually abused by a family member when she was a child and has experienced difficulties in relation to her mental health from a very young age – describing her first interaction with mental health services aged around eleven or twelve. Victoria's life history has been punctuated by periods of inpatient care, frequent interaction with crisis services and continued interaction with mental health services over the years, and her ongoing mental health challenges have prevented her from undertaking regular work. However, she has studied psychology and philosophy at university and has a keen interest in the subject of consciousness and the self.

Victoria first experimented with photography a number of years ago when she was dating an artist who also had an SLR camera which she was able to borrow and experiment with. She noticed that she could spend hours taking photographs and that she felt soothed by it, so pursued it as a hobby and now has a successful website and social media pages where she exhibits and sells prints of her photographs. Her photographs are predominantly self-portraits, and she finds that seeing herself in photographs helps her to feel grounded.

Victoria finds it difficult to describe herself but says that she is compassionate and becomes angry when faced with unfairness and injustice. She has been told that she has a good moral compass, cares a lot about human beings and always tries to behave ethically. She says that her personality has been described by others as 'cute, but kick arse' and describes her favourite photograph of herself which she feels reflects this:

> *There is a picture of me in Berlin, in the Ramones museum – just like, punk stuff everywhere. But also smiling and looking quite giggly and childlike, but kind of… had my DMs on, in a Ramones museum, so there was that kind of, energy. I've, like… of… you know, rebellion.*

Victoria finds it useful to look back and reflect on the images that she has taken, although she sometimes finds this difficult. She would love to have the opportunity, in future, to talk through her photographs with a therapist.

## 6.4 Conclusion

This short chapter has served as an introduction to the accounts contained within the analysis and provides a short description and background to the participants who took part in the research. The following three chapters present the main body of analysis that has informed this research.

# Chapter 7: How did I get here?

The impact of early childhood experiences on identity formation and the road to receiving a BPD diagnosis

## 7.1 Introduction

As discussed in chapter two, there is a large body of literature linking the development of symptoms typically categorised by the biomedical model as ‘BPD’ to disruptions in early childhood (Kernberg, 1975; Adler and Buie, 1979; Masterson, 1976). The main childhood risk factors typically associated with a later diagnosis of BPD are suggested to be trauma, early separation or loss, and abnormalities in parental bonding (Paris, 1994). There is also a well-documented link between insecure attachment behaviours in childhood and the emotional instability and unstable sense of self associated with a BPD diagnosis in adulthood (Fonagy et al, 2013; Sandstrom and Heurta, 2013). Despite this, a detailed exploration of early childhood experiences and the meaning attributed to them is often missing from biomedical discourses surrounding BPD and other psychiatric ‘disorders’. (Johnstone and Boyle, 2018).

In contrast, this thesis is concerned with building on existing understandings of how women with a diagnosis of BPD make meaning out of their experiences and narrate and negotiate their identities in the context of the stories they tell about their whole lives and the relationships, sociocultural frameworks, temporal and embodied experiences that have shaped them (Ussher, 2000). Thus, this, the first of three chapters that present the analysis from the primary and secondary data, is concerned with exploring similarities and differences in participants’ early childhood experiences and early conceptions of identity and selfhood and the meaning attributed to them in relation to their diagnosis of BPD in adulthood. It discusses how, despite marked differences in the childhood experiences of participants and the extent to which they experienced what is typically regarded as trauma, the analysis reveals a pervasive theme of invalidation running throughout their accounts of their early years. These accounts of invalidation give way to themes of internalisation, masking and early understandings of the self as ‘bad’, which are discussed in relation to Winnicott’s theory of the ‘false self’ (Winnicott, 1960).

Drawing upon Bury’s (1982) theory of biographical disruption this chapter also explores the effect of disruptive life events on repressed trauma; conceptualised as a threat to the ‘false self’ (Winnicott, 1960), which is created in childhood and adolescence to meet the needs of others in an invalidating and emotionally unsupportive environment. Underpinned by this early relational and sociocultural context, the chapter concludes by examining participants' experiences of navigating mental health services and eventually receiving a diagnosis and the extent to which this can exacerbate existing feelings of invalidation and perpetuate an unstable sense of self.

## 7.2 Mental health in early childhood and adolescence

All four participants in the second stage of the research articulated a narrative which framed the challenges they have experienced in relation to their mental health in the context of their early childhood and adolescence. Mental health was referred to as something that had always been a challenge. However, the degree to which they were aware of this at the time and the ways in which it played out in their actions and behaviour varied considerably. As will be demonstrated throughout this chapter, the way in which these early difficulties were conceptualised and manifested themselves impacted upon the stories participants told about the attitudes and treatment they received from others as well as their early interactions with mental health services.

In Katy's narrative, she describes an awareness of having difficulties with her mental health throughout childhood and adolescence, but being unable to conceptualise them as being something that required support because she always appeared to be coping.

> *"I don't think I've ever not struggled with my mental health. Erm…. to…. to some extent, it's a strange thing, because it's something I've always been aware that I struggled with, but also not aware of at the same time. Because I was always coping, but the ways I was coping were extreme and… completely non normal."*
>
> (*Katy*)

Like Katy, Emily describes having an incomplete awareness as a child of things that she now understands to be related to her mental health. She describes having obsessive thoughts from a very young age but being unable to understand the significance of them or of passing them off as just 'being sensitive.'

> *"I had quite a lot of, kind of beliefs, like – when I was a kid as well like. Like you know, if you touch one finger – like obsessive behaviours, like I had to touch all of them. And if I didn't I felt really really anxious. And so I had - as a child I was quite like that anyway. Like, so, looking back, you can kind of see how there was stuff kind of going on in my head but I didn't know it was unusual.*
>
> *(Emily)*

Claire also describes having intense and often polarised views from a very young age, which, looking back, she now believes to be related to the emotional intensity and ‘black and white thinking’ she continues to struggle with.

> *“I mean – you can look back to when I was a kid. Really young. 4 or 5. And look at things, you know – I either loved things or I hated them. If I loved them I had to do them over and over and over again. You know, my Mum still talks about things like – she had to hide the biscuits from me, because I couldn’t have one, or two – I would eat the entire pack.*
>
> *(Claire)*

At the time of interview, Claire had very recently been diagnosed with bipolar disorder in addition to her existing diagnosis of BPD; something that she acknowledged she was still processing and attempting to make sense of in the context of her life history. Being given this new diagnosis less than two weeks prior to the interview will no doubt have impacted upon the construction of her narrative in relation to her history of mental health.

It is also acknowledged that participants’ accounts of themselves in early childhood will have been shaped by their experiences of adult life; and viewed retrospectively through the lens of diagnosis are likely to take on new meaning. The action of ‘re-storying’ the past in order to make sense of and guide the present is a common response to events that are considered to challenge and disrupt the ‘normal’ trajectory (Bury, 1982). The experience of illness is reconstructed in such as way so as to attempt to maintain a consistent personal narrative and a coherent account of the self (Williams, 1984).

### *7.2.1 Experiences of childhood trauma and invalidation*

As was reflected upon in chapter two, the co-occurrence of physical, sexual and emotional abuse and neglect, particularly in childhood, has been strongly associated with a diagnosis of Borderline Personality Disorder in adulthood (Carlson et al, 2009). All of the women whose interview transcripts were subject to secondary analysis in stage one of this research relayed histories of traumatic experiences that had, in some cases, been repressed for many years. Reflections on these traumas were privileged in the stories articulated by those participants, far above and beyond any reference to specific mental health diagnoses. For example, Sonia reveals the following account within the first few minutes of the interview:

> ***Interviewer:*** *When were you first in contact with mental health services then?*

> *Well my Mum and Dad had to pay for me to go private I was 15/16, because CAMHS wouldn't take me on, and my Mum had to have an operation, and I took an overdose. And so that's when I first… like when, I was 15/6*
>
> ***Interviewer:*** *And what was happening then?*
>
> *I've had loads of traumas since I've been six. I can just tell you what it was – I don't want to go into like…*
>
> ***Interviewer:*** *Yeah, fine, whatever you feel safe…*
>
> *It was abuse from my so-called brother. Sexually, physically and mentally. And then I had a boyfriend when I was like 14, who – I used to have seizures, and he raped me when I came around from a fit and used to get me in front of a mirror and call me loads of stuff.*
>
> *(Sonia – S136 Research Participant)*

Of the eight women whose interviews were subject to secondary analysis, half referred explicitly to having been sexually abused within the dialogue without ever being directly asked to reflect upon this. A further participant, Brigid, made frequent references to having a phobia of men. Of the remaining three women, one, Naomi, referred to having had discussions during therapy around post-traumatic stress disorder (PTSD) but did not explicitly state what this was related to except to say that it was not related to her sister's diagnosis of Paranoid Schizophrenia (which she had previously described as being traumatic for her). The other two women, Chrissie and Sally, reflected upon their childhoods in ways which indicated a lack of stable attachments, which it is suggested can contribute towards a failure in the development of an enduring sense of self and a fear of abandonment (Masterson, 1976), both 'symptoms' of BPD. As Chrissie describes;

> *I was forced to do things and I didn't bond with my Mum… that, probably a mixture of adoption anyway, because you talk to adopted people these days and, even if they've been in, you know, really really the best of families, they still didn't… couldn't bond to the actual adoptive parents. So there's still that emptiness inside.*
>
> *(Chrissie – S136 Research Participant)*

For the younger participants, Sonia and Naomi, the trauma that they experienced had manifested itself at a relatively early age, and this was reflected to some degree in the narrative of Siobhan who related a complex history of interactions with mental health services that began when she was at school. However, in the older women's narratives there emerged a distinct theme relating to the long-term repression of trauma which was eventually no longer able to be contained, and manifested itself in severe outpourings of distress, self-harm and attempts on their own lives, often conceptualised as a cry for help. This will be discussed further in section 7.3.3.

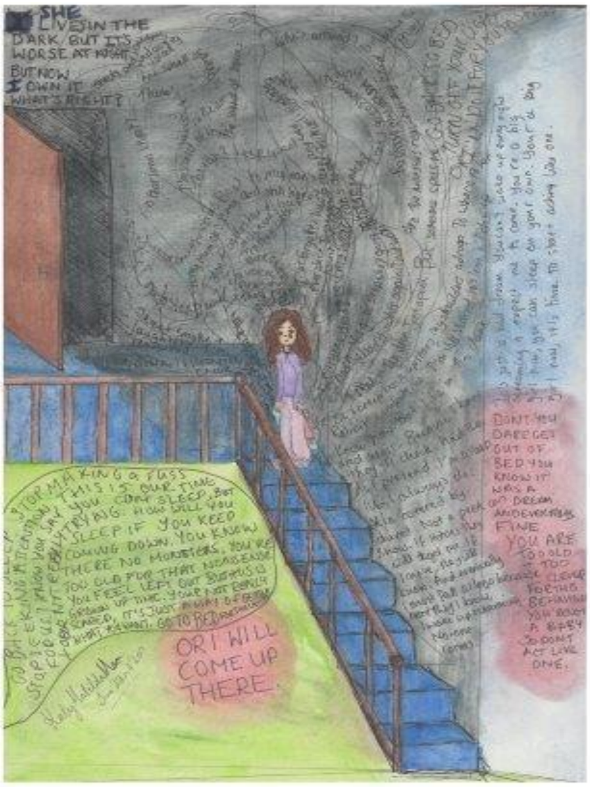
As in the interviews which produced the secondary data, the interviews with Emily, Victoria Claire and Katy did not seek to ask explicitly about experiences of trauma. However, the in-depth nature of the conversations allowed for a greater exploration of early childhood experiences which revealed a range of complex narratives pointing towards varying degrees of trauma, neglect and invalidating experiences which, for most, were felt to have contributed towards the difficulties which later came to be regarded as ‘symptoms’ of BPD.

The link to trauma was most clearly apparent in the narratives of Katy and Victoria. Whilst Katy did not talk in depth during the interview about the trauma she experienced as a child, she makes frequent references to having a secondary diagnosis of complex post-traumatic stress disorder (CPTSD) and alludes to an invalidating and challenging relationship with her parents, where her needs were not prioritised:

> *“Nothing got picked up when I was younger, because nobody really gave a shit, so nobody really noticed anything.”*
>
> *“My Dad definitely has narcissistic personality disorder and my Mum was not very good at noticing stuff in general. My sister had a lot better time than I did growing up, but… erm… mostly because of me.”*
>
> *(Katy)*

The artwork and associated caption shown in image 6.1 are taken from Katy’s art journal and were published on the Borderline Arts website. The image provides a powerful sense of what Katy experienced as a child, with the solitary figure representing Katy as a child appearing small against the vastness of the black background – suggestive of her vulnerability and the isolation she felt. The title of the image – ‘she lives in the dark’, suggests a feeling of being trapped and that she cannot escape from the darkness, even in her waking hours. The harsh and dismissive words of her parents in response to her need for comfort are written prominently around picture, whilst her own feelings and emotions swirl around her against the black backdrop, perhaps indicating the extent to which they were not prioritised or heard by her parents.

**Figure 7.1 'She lives in the dark' (Katy)**



*"I struggle a lot with nightmares and night terrors. I wake frozen with terror and in desperate need of reassurance and comfort. To me 'the dream' feels real. When I was a young child, my parents soon lost patience with this "behaviour", me continually getting out of bed was "not acceptable". I used to sneak to the edge of where the pool of light from downstairs hit the darkness of the landing. No one could or would keep me safe." - Katy*

Victoria was sexually abused by her father from a young age – something that she was too scared to disclose and was not detected or acknowledged by her family or through her early interactions with Child and Adolescent Mental Health Services (CAMHS).

> *"My Dad… sexually abused me for years and years, and emotionally and physically… just tortured me basically…*
>
> *So when I was growing up, I was kind of a problem child, but actually I was trying to show people in the best way I knew, without telling them because I was too scared for my life to actually tell them what was going on at home"*
>
> *(Victoria)*

For Emily and Claire, the traumatic antecedents to their diagnosis are less clear cut. Emily describes coming from a 'settled' family – her parents were happily married, and she did not experience what she would describe as any trauma or abuse growing up. However, her parents led busy lives and were heavily involved in church activities, and she reflects that the time she was able to spend with her parents on a one-to-one basis was limited. She also describes having very limited opportunities to express her feelings within her family unit and feeling pressure from her parents to present a positive image of their family to the outside world.

> *And we didn't really talk about feelings and stuff. And like, erm, it was just sort of like 'oh, we'll just be positive. We'll just forget about it' and that sort of thing, so there was a lot of invalidation in that sense, basically just ignore your feelings and get on, there's lots to get on and do. I remember one particular Sunday, it happened other times as well I'm sure, but this one particular week they'd been shouting in the car on the way – shouting and screaming – well not screaming but just shouting at each other. And then literally when we got out the car my Mum, it was either my Mum or my Dad said 'right, well, we've got to be positive now, we're going to church.' It was literally like 'church face', and erm, so, yeah, it was, that was quite difficult sometimes, because people didn't necessarily see the angry side of my Dad.*
>
> *(Emily)*

Claire also describes growing up in a relatively stable environment, with parents who she describes as being 'on a very even keel'.

> *My father describes himself as having a thermostat that's set permanently at room temperature.*
>
> *(Claire)*

Claire's parents had her later in life and she had two sisters who were ten and twelve years older. She grew up in quite an 'adult' environment, being surrounded by people who were much older, and was encouraged to participate in conversations at a level above what would typically be expected of a child.

> *I've always been a rather precocious talker because, as I said, my sisters are so much older, so there was no baby talk. So I was always encouraged to talk about, from a really young age, I was always encouraged to give my opinions on the stories of the day. And, you know, I can remember writing a diary about, erm, my concerns about the run up to the first Gulf war, I was 10. You know, I mean I've got it somewhere – it's written in bloody crayon. So yes, very serious child – very serious child (laughs)*
>
> *(Claire)*

Claire's account differs somewhat from that given by Victoria, Katy and Emily, who mostly describe feeling ignored, isolated from or abused by their primary caregivers. Overall, Claire paints a predominantly positive picture of her family and the environment she grew up in. However, despite having grown up in relatively secure homes, both describe a family environment where what they felt to be their legitimate concerns were often dismissed as 'melodramatic', where feelings and preferences were dismissed as a 'phase' and where they felt under pressure to conform to expectations of behaviour placed upon them.

> *"Don't be so dramatic Claire, don't be so dramatic Claire – you're being melodramatic Claire. Erm, this is a refrain I've heard over and over"*
>
> *(Claire)*

Whilst the early experiences of the research participants clearly vary greatly in terms of nature and severity, the common thread running through them appears to be a lack of ability to express feelings, emotions and reactions in a way that was heard and validated by those whose role it was to protect and support them. This mirrors findings from Linehan's (1993) research on the biosocial factors relating to a diagnosis of BPD, which proposes that an invalidating developmental context is a key factor underpinning the development of symptoms related to BPD in adulthood. This invalidation is described by Linehan (1993) as being characterised by the dismissal, punishment and/or trivialisation of private emotional experiences – all elements that can be observed to varying degrees in the accounts of Katy, Claire, Emily and Victoria and also within some of the accounts of the participants in stage one of the research. The effect of this, Linehan suggests, is that the child does not develop the ability to make sense of, identify, label, regulate or tolerate natural emotional responses to external events, resulting in behaviour that fluctuates between emotional inhibition or repression and extreme displays of sensitivity. The next section will discuss the impact of early experiences of trauma and invalidation on participants' early emotional responses and the effect this had on their developing identities.

### *7.2.2 Internalising trauma: reflections on early identity*

The early impact of these experiences of trauma and invalidation appears to be most clearly articulated through participants' descriptions of their own sense of their childhood identities. The critical realist ontology underpinning this thesis posits that all knowledge is local, provisional and situation-dependent (Jaeger and Rosnow, 1998) and as such it is acknowledged that participants' accounts of their identities as children and adolescents will undoubtedly be shaped by the current lens by which they understand themselves and the world around them. For the participants in the second stage of this study, their descriptions of their early feelings and behaviour help to provide a sense of the impact of the experience of being invalidated in childhood. These tangible descriptions of childhood thoughts and actions can help to build a fuller understanding of how narratives about themselves and their identities have formed and developed in the context of their whole life stories.

Emily describes a vivid memory of playing games with her sister as a child and the feelings she associated with those games even at a very young age:

> *It's really bizarre but when we used to play games with me and my sisters - I always wanted to die. And I always wanted to have a horrible name. Because I felt like that was who I was. Like what I deserved or something. This was like – I mean I remember one of the times we were playing, and that was at my gran and grandad's house when*

> *they were at the first house, so that would have been probably when I was like, five, so it's – I was quite young to be thinking that.*
>
> *(Emily)*

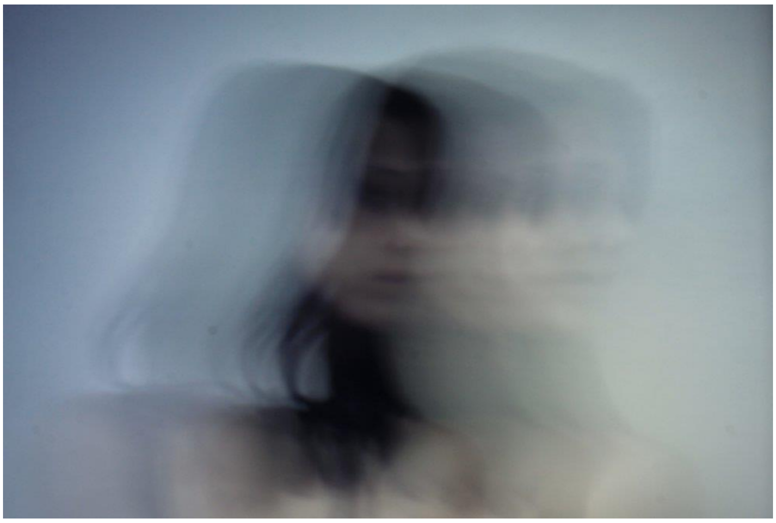
This powerful verbal imagery clearly reflects Emily's understanding of herself as being 'unworthy' or 'not good enough'. This mirrors findings from McCormack and Thomson's (2017) research exploring participants' subjective interpretations of childhood trauma, in which 'unworthiness' was a key theme linked to receiving a psychiatric diagnosis in adulthood. For a young child, it is inconceivable that a caregiver on which they are reliant could be fallible, therefore negative emotions are internalised and reflected through negative self-beliefs (McCormack and Thomson, 2017).

Victoria's childhood was marked by fear, uncertainty and the constant threat of abuse at the hands of her father, and so it was necessary for her to be adaptable to protect herself in an uncertain environment.

> *For me, like growing up, I.. never had a solid sense of self. I basically lived in an environment where I had to be whoever I needed to be so my Dad wouldn't hurt me or my Mum or my sister. So I never developed a sense of self. So I was constantly fluid.*
>
> *(Victoria)*

The photography that Victoria creates seeks to make tangible this sense of fluidity and dissociation of the self she experienced as a child and continues to feel as an adult:

**Figure 7.2 Self Portrait (Victoria)**



Claire also describes having intense and often polarised feelings as a child and adolescent which contributed towards feelings of uncertainty and a sense of herself as 'unstable.' She describes experiencing particular insecurities around relationships and a fear of being abandoned that began in early adolescence and continued into adulthood.

> *I must have you near me at all times, but then fuck off and leave me alone, but don't actually go anywhere because I'm frightened of being abandoned. But, you know, I'd had that pattern of relationships going back to… my whole life, from like 13, where you're first a vaguely pubescent sexual being.*
>
> *(Claire)*

These patterns are typical of what the biomedical model would describe as 'symptoms' of BPD (APA, 2022) and Claire's explanation for these feelings is generally more firmly grounded in biomedical understandings than the other participants. However, there is some tentative indication in her account that she experienced some degree of invalidation in her childhood and was not encouraged to freely express her emotions in an age-appropriate way by her primary caregivers. It is possible that growing up in an environment where she was encouraged to behave as an adult from a young age and where her emotions were dismissed as 'melodramatic' contributed towards difficulties in developing an enduring sense of self as well as a fear of abandonment (Kernberg, 1975).

This 'fluidity' of self is a theme that emerged from both the primary and secondary data and will be explored in more detail in relation to the BPD diagnosis in the next chapter. However, broadly speaking, it is clear from the narratives of participants who took part in this research that all have experienced, to some degree, an unstable and uncertain sense of their own identities and sense of self which began in childhood, potentially as a result of what can conceivably be described as trauma or invalidation.

### *7.2.3 Developing strategies to cope in an unstable environment*

As well as internalising negative emotions, having limited opportunities to express themselves and have their feelings heard by those around them appears to have led to a need to find alternative ways of coping with the things that were happening to them and the emotions they were experiencing. For Katy and Victoria, one of the ways of doing this was dissociation, a common stress response frequently linked to experiences of trauma and a common coping strategy amongst individuals with a diagnosis of BPD (Miller, 1994).

> *"When I was being sexually abused, basically… my way of coping with it was to dissociate and climb inside my bedroom wall and watch it happening."*
>
> *(Victoria)*

Katy’s description of her early experiences of dissociation also included reference to her first attempts at using art and creativity to cope with distressing situations and emotions.

> *“That was pretty much how I coped with my life was to imagine myself in other worlds through reading about them, drawing them, writing about them.”*
>
> *(Katy)*

A clear theme emerging from the stories of all four participants is a sense that the early struggles they experienced were often conceptualised by those around them as bad, problematic or unwanted behaviour rather than legitimate attempts to cope with their own difficult emotions or the distressing behaviour of others. This was true both when this behaviour was regarded as being symptomatic of mental health problems, or when, as was the case for Katy, the underlying distress was not acknowledged by others.

> *So when I was growing up, I was kind of a problem child, but actually I was trying to show people in the best way I knew, without telling them because I was too scared for my life to actually do that, what was going on at home.*
>
> *(Victoria)*

> *The only people who were noticing my behaviour or whatever, just treated me as if I had behaviour problems… just like I was bad or whatever, not like… hurting or, you know, never looked beyond the behaviour they didn’t want. And I was very aggressive when I was younger, I was really angry, so, a lot of externalising stuff… so it just looked, to school and stuff, it did look like behavioural problems.*
>
> *(Katy)*

The narratives of all four participants in the second stage of the research indicate that feelings of anger featured strongly throughout their childhoods and adolescence. For Emily, Claire and Victoria, their accounts suggest that not having a mechanism to express this anger towards those either directly responsible or contributing towards their distress caused them to internalise those feelings, projecting them inwards and expressing them as self-harm behaviour.

> *It’s not a healthy coping strategy. But it’s a protective one in the sense that you are harming yourself, rather than somebody else. And I certainly felt that. That it was – anger was the primary emotion that I felt when I first started to self-harm.*
>
> *(Claire)*

> *And that (self-harming) caused a lot of tension and my Mum was really upset and stuff. And then, erm, so I was trying not to do that and then that’s probably when the eating disorder got worse because I was finding a more secret – a more kind of hidden way of – I don’t know – expressing that anger at myself in a way.*
>
> *(Emily)*

In Claire's narrative, she talks in some detail about the pressure she felt as a young woman to conform to society's expectations of how she should behave. She feels that harming herself allowed her to relieve some of those 'unwanted' feelings without drawing attention to herself as being fundamentally different from her peers.

> *Men are taught It's okay to externalise your anger, but women are told it isn't. At least, I feel I was taught, as a woman. I shouldn't speak for all women. But you know, I could never have screamed or shouted at anybody, or beat my fists against something. I couldn't envisage doing anything like that, but hurting myself, you know – scratching myself and then seeing the blood for the first time was hugely calming and helped me to remain unseen in a way. So not to stick out as the oddity, as the freak. As the one who's different. Because I knew, even at 11, that it wasn't normal.*
>
> *(Claire)*

This lends some support to arguments illustrated in feminist discourses of mental health which draw attention to the tendency of the biomedical model to pathologise behaviour which both falls outside the typical realms of 'femininity', e.g. anger, and is considered to be an extreme display of 'feminine' traits, e.g. the stereotype of the 'hysterical woman' (Usher, 2011).

Emily also talks about how the fear of upsetting her family and present an image of the 'perfect family' led her to going to great lengths to hide her behaviour and the distress she was experiencing.

> *When I did talk to her (Mum) - it was really awkward. So then after that I just kind of pretended to be okay because it was just easier. But I wasn't. I was so ill I walked down to Argos and bought all of these weights that you put round your arms and wrists, carted them home. I was nearly like dead by the time I got back! I had to wait until my Mum had gone out so that I could go and get them. I was drinking loads of water, putting stones in my pockets – anything to just make my weight so much more. I think my Mum was so desperate to believe I was getting better that although I was losing weight, she wanted to believe the number on the scales.*
>
> *(Emily)*

After the extent of her eating disorder was revealed when she was refused an operation on her jaw at the age of 17 due to her weight being too low, Emily worked hard to regain the weight she had lost in order to create the perception of being visibly 'well'. Being keen not to cause further upset she began to make herself sick after eating, a form of self-harm she felt would be less visibly obvious to those around her.

> *I'd tried avoiding hurting my Mum by not cutting myself, which led to not eating. And then I realised that that upset my Mum too. And then the eating and myself sick – it was almost as though I went to that because I knew there was no evidence, if that makes sense.*
>
> *(Emily)*

The early coping strategies discussed by Emily, Claire, Katy and Victoria demonstrate some support for Winnicott's (1960) theory of the 'false self', which suggests that when a child is subject to invalidating relationships in childhood they internalise an understanding that their emotional reality is of secondary importance to that of their caregiver(s) (Cooke, 2009). This results in what is described as a 'splitting' of the self, whereby the 'false self' exists to meet the needs of others and protect the vulnerable and invalidated 'true self' (Winnicott, 1960). In the accounts that informed this study, this is demonstrated through the extent to which participants described their attempts to mask their emotional distress by engaging in attempts to appear 'well', often at expense of their own physical and emotional wellbeing. This desire to prioritise the needs and emotions of others over their own and protect the 'true' self is further compounded by what Shaw and Proctor (2005) describe as a need to confirm to societal norms in a patriarchal society which denies experiences of abuse and invalidation by locating distress as something 'defective' within the individual. As is demonstrated in the next section, this is also evidenced by the way in which the behaviours and emotions associated with a diagnosis of BPD are understood and dealt with by mental health services and professionals.

## 7.3 Threats to the 'false self': Understanding biographical disruption in the context of BPD

### *7.3.1 Navigating (a lack of) diagnosis in Child and Adolescent Mental Health Services (CAMHS)*

For Emily, Claire and Victoria, interaction with formal mental health services first began during adolescence, typically as a result of the self-harm or eating disordered behaviour highlighted in the previous section. Emily began self-harming and restricting her food intake in her early teens and eventually sought a referral to Child and Adolescent Mental Health Services (CAMHS) through a local youth leader. Victoria started to experience issues with food at the age of eight, but states that these were not properly diagnosed until she was sent to a psychologist at the age of 11 or 12. For Claire, her first contact with CAMHS came at the age of 14 as a result of her continued self-harm.

Whilst the experiences and recollections of the three women in relation to their early interactions with mental health services vary considerably, none feel that the framework of CAMHS was particularly helpful or sympathetic to their individual needs. Victoria's account of her experience reflects her wider rejection of the current diagnostic approach (something that will be explored in more detail subsequently) and highlights what she believes to be one of the main issues with the problematisation and medicalisation of distress in a system which often operates in isolation from other health and social care services.

> *I was being abused at home during this time, so the treatment I got wasn't very helpful because I was just going back to an abusive environment. Erm… then I got put in an adolescent unit, where – at that age you couldn't be diagnosed with BPD, but, erm, that's where they were going with it. I've had labels chucked at me from a very young age, when really, what should have happened is social services should have said 'oh, she's being abused, poor kid, let's put her somewhere safe,' you know.*
>
> *(Victoria)*

Claire's experience of CAMHS was somewhat different but also serves to highlight one of the key criticisms of the biomedical model of mental health, particularly in relation to the BPD diagnosis. Whilst Claire did not become aware of the term 'borderline personality disorder' until she was in her 20s, with the benefit of hindsight she, like Victoria, now believes that she was already being treated according to the BPD label even from her first interaction with mental health services at 14. Like Victoria, Claire feels that there was very little attempt by CAMHS to understand the individual context in which her distress was occurring. However, unlike Victoria, in whose case the abuse she was experiencing at home was overlooked, Claire reports that the psychiatrist assessing her seemed to place a disproportionate focus on questioning her around her experiences of abuse, something that she found both confusing and profoundly invalidating.

> *That's how CAMHS had made me feel, like there WAS something terrible that had happened, but that I just didn't remember it. Or I wasn't recalling it, or I was suppressing it, or repressing it, or… and that it was all out there waiting for me. So I had this feeling for a while that the abuse was out there waiting for me and I used that to tell rather elaborate lies about things that had happened to me, or not happened to me, or… you know. So there was that phase of it, where my identity became associated with abuse in some way. So I looked for it, I searched my past for it, I scrutinised. I scrutinised all the men who had been a part of my childhood – up to and including my closest relatives. I used to Google my teachers, when Google first appeared, to try and find out whether any of them had ever been convicted or… investigated for sexual activity with children. So for a while my identity was almost sort of subsumed by this desperate search for abuse which had never happened.*
>
> *(Claire)*

Considering studies show that around 80% of those given a diagnosis of BPD have experienced severe child abuse (e.g. Carlson et al, 2009; Herman et al, 1989) it is not surprising that professionals coming into contact with those exhibiting 'symptoms' suggestive of BPD are likely to be attuned to, or on the lookout for, experiences of trauma that may serve to cement their views on diagnosis or offer an explanation for a patient's behaviour. Arguably, for people like Victoria, who had or were being subject to abuse, being given the opportunity to disclose and discuss this would likely have been extremely valuable. However, the difficulty exists when there are clear underlying assumptions with regards to contributing social and environmental factors relating to a ‘disorder’ which are not integrated into (or are fundamentally opposed to) to the framework which informs diagnosis and treatment (Johnstone and Boyle, 2018).

The tension between the diagnostic criteria for BPD and the prevalence of trauma amongst those who meet it will be explored in greater detail in the next chapter. However, it is clearly relevant here in the sense that both Victoria and Kate experienced a disjuncture in how the context surrounding their childhood experiences was (or was not) addressed in their early interactions with mental health services.

### *7.3.2 Holding it together: Denial, expectations, and pretending ‘I’m ok’*

After experiencing initial mental health difficulties in adolescence and (with the exception of Katy) their early experiences with CAMHS, an analysis of the chronological narratives of participants appears to show a period during early adulthood where all appeared to be, at least, outwardly, functioning at a level equivalent to, or in some cases above the traditional expectations of society. Emily achieved a place at university and travelled to Australia to complete a gap year at a Christian organisation. Victoria completed two years of a Philosophy degree before transferring and completing a degree in Psychology. Despite intermittent difficulties with drugs and alcohol, Claire spent some time travelling and was able to hold down a job as a support worker with young offenders. Katy dropped out of a degree in art but went on to study psychology and gain a PhD at the same time as holding down a full-time job.

The women whose stories were subject to secondary analysis for this research also described their backgrounds in terms of successful and often diverse career paths, with many going into caring professions, some directly related to mental health. This appears to be mirrored to some extent in the life histories articulated by participants in the second stage of the research and is not necessarily surprising given the current hegemonic discourse which discourages open conversation about trauma, abuse, denies the social causation of distress and reinforces gendered expectations of acceptable behaviour (Shaw and Proctor, 2005).

This discourse is so effective and deeply engrained that the majority of the participants in both stages of the research, were able to effectively repress and deny their own distress for many years, even when working directly with others experiencing similar problems or obtaining high levels of knowledge in a related field.

> *"I had no insight… despite studying psychology, despite reading about it, despite being aware that I struggled with my mental health, I also wasn't aware of it at the same time. Erm, and I didn't… even though I knew the things that I did and experienced were… would be symptoms of mental illness in other people, I was still like… they're not… because I'm still ok. And I really wasn't ok."*
>
> *(Katy)*

> *"I recognised that I was not healthy, and I was… I had become very unwell, I recognised that. But perhaps I blamed it all on my drug use at the time, whereas I think a lot of it – looking back, I think a lot of it was really mental health, not because I wasn't… I was certainly using drugs, but there was only a very short period when I was actually abusing drugs, and there is a difference."*
>
> *(Claire)*

Katy 'coped' with the distress she was experiencing by channelling it into her academic achievements and career, leaving little time to consider the implications on her own mental health.

> *"I've got this perfectionist mindset so I was kind of pushing pushing pushing down this career path. Did a PhD, did a couple of research jobs, all of that."*
>
> *(Katy)*

Emily also found herself gravitating towards an environment where there was little time, space or encouragement to reflect on her own mental health challenges. She travelled to Australia to complete a gap year at a Christian organisation but found the environment to be quite restrictive, which, she reflects retrospectively, allowed her to remain in denial about her feelings and emotions for many years.

> *"It turns out that they (the organisation) are a little bit extreme. And they're… basically they kind of make you feel like, really, like accepted and all the rest of it. But if you start to go out of line with their kind of, rules and regulations, they start saying 'oh you're being rebellious, and rebellion is a sin as bad as witchcraft', and mental health issues were demonic and needed to be cast out of you. And I thought that they were right – erm – anyway, I ended up staying there for four years. Because I felt like, as long as I adhered to their rules, I fit in. And the structure was… flipping… structured…. And you know, it was so busy, you didn't have time to stop. It was just go go go, and, so yeah – I did that."*
>
> *(Emily)*

The theme of 'fitting in' also emerged in quite a tangible way in Claire's narrative, where she describes how she went to great lengths to ensure that those closest to her were not aware of the difficulties she was experiencing:

> *"I managed to live with my sister for a period and hide it quite effectively. I would pretend, you know – in the morning, we would get up together, and I would shower and she would go to work at the museum, and I would then sit, at home – not going into uni. Not doing any academic work. You know, weeping a lot to Channel 5 television movies about women getting cancer and, you know. And then at about 5pm, when I knew she was on her way home, I would get up, you know, get dressed, put myself together, you know – take myself to Sainsbury's and have dinner cooked by the time she got home. And that worked – I kept that up for about six months, seven months – so she really didn't know when she lived with me just what was going on."*
>
> *(Claire)*

As was demonstrated in section 7.2.3, the complex trauma and sense of invalidation that all four participants experienced in early childhood and adolescence led them to them develop internalised coping strategies which carried over into adulthood and manifested as a need to appear, at least on the surface, to be conforming to society's expectations of 'normality'.

### *7.3.3 'Opening the floodgates': The effect of disruptive life events on repressed trauma*

For some, particularly the older women whose interviews contributed to the secondary analysis, these strategies of denial and repression which fuelled their attempts to conform remained unchallenged and, to a degree, proved successful for many years. However, for all of the women interviewed, there came a point where they were unable to 'hold it in' any longer and became overwhelmed with intensely distressing emotions which they were unable to regulate or negotiate. For many, this 'tipping point' was typically associated with what can be conceptualised as a 'disruptive event', or series of disruptive events, which either provoke the resurfacing of painful memories or represent a challenge to what is considered the 'normal' trajectory of their lives (Bury, 1982).

In the interviews subject to secondary analysis, these disruptive events are articulated quite clearly and distinctly, often in a way that highlights the stark contrast to their previously 'successful' lives. Those referenced in the interviews included: the death of a brother from alcoholism, a conflict with neighbours, a car accident, problems at work, and the development of complex physical health problems. Whilst the events themselves are very different, what all of the narratives appear to have in common is a sense of them acting as a catalyst to confront past (repressed) trauma, and an opening of emotional floodgates that had often been sealed firmly shut for many years:

> *"It was too much stuff coming out, because all my life I'd never spoken about things, I've just kept things a secret."*
>
> *(Martina – S136 Interview Participant)*

> *“And that’s when I first had contact with my, the other brother, who was my sexual abuser. But of course nobody knew anything. Nobody found out until five years ago, so everybody was very shocked, my family, my best friends, everybody…*
>
> *So that’s when it all started really. What I was doing, I was taking all of this in. I wasn’t dealing with any of it, It was sort of like I was drawn into this thing I couldn’t get out of”*
> *(Holly – S136 Interview Participant)*

For the participants in the second stage of the research, as well as the younger participants who took part in the interviews about their experiences of S136, the sense of a single, initial, disruptive event marking a transition from ‘well’ to ‘unwell’ is slightly less clear cut, perhaps due to the age in which their emotional difficulties first manifested. However, with the possible exception of Victoria, who was under the continued care of mental health services from a very young age, all of the women’s narratives including reference to a ‘tipping point’ which resulted in something of a breakdown and led to them seeking or being forced to accept more formalised help to manage their mental health.

In Katy’s case, this tipping point came about, not so much as a result of a particular event or occurrence, but more due to the unhealthy mechanisms that she had been using to avoid confronting her distress, and the subsequent removal of these mechanisms which allowed the thoughts and feelings that had she had been supressing to come into focus.

> *“I have this persona, who I call superwoman, who is like this perfectionist self who can do anything. And she was just ripping through life, dragging the rest of me behind her, until literally, my body fell apart and I couldn’t do it anymore. I was writing up my PhD at the same time as working full time, erm… and, I’d just had this horrific job that I’d left and I went into a better job… finished my PhD, erm, and then… it was kind of like after I’d done that – I think I’d kind of had this idea in my head that when I finish it, it will get better, because I’ll have time to rest. So I took some time off – my work, the work that I was in at that point were really understanding. I took some time off to kind of recuperate, and I just didn’t recuperate, and then all my… all of the symptoms that I’d had at various points in my life in isolation just kind of came back at once. So I went through a massive eating disorder relapse, I was self-harming like crazy, I was dissociating all over the place, so I was kind of like – I was manic, I was so depressed I couldn’t move, I was, like, just… everything.”*
>
> *(Katy)*

Claire had her first experience of reaching crisis point whilst travelling in Australia in her early 20s. Despite receiving advice from mental health services there who advised her to seek a psychiatric assessment, she (as previously referred to) attributed this episode to her excessive use of recreational drugs and did not seek further help for some time.

> *“A crisis mental health worker told me, in Australia – we would section you if you could, or whatever the equivalent is – erm, but basically, they said to me, erm, if you were*

> *Australian and you didn't have a ticket out the country, we would put you in hospital, but we can't do that, so what I am advising you to do is to fly home immediately and seek a psychiatric assessment. But I was determined to reject their advice to fly home, because I had been saving and preparing for this trip for some time, and, you know, it was my intention that I was going to do that, whatever the bloody hell they said basically. It was a rejection of… I don't need your help, I don't need that, I can sort myself out, I can make myself healthy."*
>
> *(Claire)*

What Claire refers to as her 'breakdown' did not then come until some years later, after she had already begun to seek help for what was being treated as 'depression'. She describes the events that led up to her eventual breakdown as the result of a 'perfect storm' of her continued challenges with her mental health, drug and alcohol misuse and her feelings of guilt and paranoia over an affair she was having with a close friend of her long-term partner. Claire frames this narrative in the context of the new diagnosis of bipolar disorder that she has recently received.

> *"Looking back now I believe that I had a hypomanic episode which contributed to my having an affair, which contributed to my increased use of stimulants as I became paranoid and terrified that the affair would be discovered, and I realised I'd done something which was sort of irrevocable. I knew we were all heading for disaster basically – like, we were in a high-speed car and there was a wall coming towards us. I didn't know how far away the wall was, erm, but I knew it was coming. And so I got more and more wound up. More and more intense, more stressed, more frightened of being discovered, frightened of not being discovered – wanting to be discovered, because wanting it to all be over and out in the open.*
>
> *And that's very much the point I got to with the affair. Where I just couldn't. And I just broke one night and I said, this is what's been happening. Erm, and it all came tumbling down. But I couldn't have gone on like that anymore. I was literally going to kill myself through – either through killing myself, or the amount of drugs and alcohol and lack of food, and the lack of sleep. I think I was literally trying to drive myself insane so I could… as a way out… I genuinely think that's what I was trying to do."*
>
> *(Claire)*

Bury's (1982) concept of biographical disruption rests on an assumption that self-identity relies on the maintenance of a consistent personal narrative of the self and that illness represents a threat to this consistent self through an undermining of the everyday structures and assumptions about the world that underpin it (Reeve et al, 2010). However, as was previously discussed in section 7.2.3 (and will be explored in the more detail in the following chapter) the participants in this research have largely lacked this consistent personal narrative and sense of stable identity – instead being forced to craft an external 'false self' based on the expectations and desires of those around them in order to survive or be accepted by their primary caregivers (Winnicott, 1960). The 'disruptive events' described above that led to Katy's and Claire's breakdowns can therefore perhaps be seen to represent a threat, not to their consistent and coherent sense of selves, but rather as a threat to these 'personas' (e.g. the unstoppable perfectionist or calm and subservient woman) they have created in order to avoid engaging or acknowledging the 'true' self.

This idea can be seen clearly in Emily's story of her breakdown, which was sparked by her feelings for, and developing relationship with another woman - something that was considered a sin in the church community in which she was desperately trying to fit in.

> *"One day she said to me 'Do you like me?', I was like 'Of course I do'. And she was like – 'I mean, do you like me?' And I was like 'No!' - like really defensive, because being gay was a sin. Like a terrible terrible sin. You could not be. So I flat out said no. But then I started to think – oh gosh I did. I do. Like what's wrong with me, I'm a terrible person blah blah blah. So I was like praying and repenting and saying I won't do this ever again and all that. And then I went back to Australia – but not long before I went back, I freaked out because I thought I can't accept that I've done this, it's horrible. It was almost like, to avoid accepting that I was like that, I was like – well she was the one that wanted to do it. I didn't want to do it. And then it ended up that people were like 'well why, in what way?' So then it kind of almost, basically became that I was saying that I was abused. And so then it became this big thing. So then this girl, she was at the [religious organisation] base in LA – her leaders were informed, and then as it happened they then caught her in the act with another girl. So she was sent home from LA and she wasn't allowed to be there any more because she'd broken the rules. And meanwhile I was in a right pickle because I was like, feeling awful that I was lying about this and it was affecting her. But I also felt so guilty and sick about it that I couldn't accept it, I couldn't tell the truth. So I was kind of stuck in that I couldn't stop lying – but I couldn't live with myself lying. So then I actually took an overdose when I was out in Australia."*
>
> *(Emily)*

Emily had repressed her sexuality for many years in order to be accepted by her family (who were active members of the church community of which she was a part), but being forced to acknowledge it in this way led to feelings of distress which she was unable to express or regulate due to the fear of being rejected and the lack of certainty around her 'true' identity.

The only participant, across both the primary and secondary research, whose narrative does not contain reference to an event or series of events representing a tipping point in their mental health experience is Victoria. Victoria describes having been involved with mental health services since the age of 12 and being sectioned a number of times in her 20s, but does not go into detail about the catalyst for these detentions, instead preferring to talk more broadly about her experiences of treatment and diagnosis. It is interesting then that Victoria is also the only one of the four participants who vehemently rejects the Borderline Personality Disorder diagnosis – something that will be discussed subsequently.

## 7.4 The road to diagnosis: Navigating the complexities of mental health services

Despite experiencing many of the same ‘symptoms’ and there being similarities in the antecedents to their involvement with mental health services, the process and experience of receiving a diagnosis of Borderline Personality Disorder was very different for all of the women who shared their stories to inform this research. This is likely partly a result of how and when they each came into contact with services - but is also reflective of the lack of a consistent approach to diagnosis evident in the UK’s mental health system, likely to be at least partly as a result of the wide range of experiences and symptomology that the diagnosis covers (Tyrer, 1999).

Katy’s experience of receiving an initial diagnosis of BPD was arguably the most straightforward. She had not had any previous contact with mental health services and was able to self-refer online to her local Community Mental Health Team after taking the advice of a friend who had recently completed a course of CBT.

> *“I emailed, because that felt like a safe way to do it, and they had self-referral, which was… so my local CMHT have self-referral and it’s for everything, it’s all points of access, so they’ll refer you to IAPT, they’ll refer you to… they’ll put you in inpatient… they’ll put you in… anything. Literally, anything. So I was like, that feels safe, because if they’re just like, oh you’re just a bit depressed, they’ll send me to IAPT and it won’t be embarrassing.”*
>
> *(Katy)*

After undergoing an initial assessment over the phone, Katy was surprised at how quickly things escalated and she was soon referred to a specialist unit for further assessment.

> *“They rang me and did a phone assessment, and then it just all… it all spiralled from there. Because once I was saying the things I was saying, people were just like… we’re going to pass you and pass you and pass you. Because the first nurse I saw was like… she got about half way through, and then she was like… ‘I’m going to let you say everything you need to say, but I’m also going to tell you now that I really won’t be able to like, tell you anything right now about what any of this means, because it’s already way beyond my level, and I’m passing you straight to psychological services’ – and I was just like, whhaaat? So then it all just ran away without me.”*
>
> *(Katy)*

Soon after this she received a diagnosis of BPD and was told by the person assessing her that she was ‘basically a textbook case’. Nevertheless, in addition to the BPD diagnosis, she also received around five ‘other labels’, including Complex PTSD and Dissociative Identity Disorder.

Emily received some treatment following an overdose in Australia but was not diagnosed with BPD until a few years later. By this time, she had returned to the UK, having spent four years in Australia, and was in her second year of a creative arts degree when the patterns of disorder eating that she had experienced in adolescence resurfaced. This led to a lengthy period of hospitalisation during which she feels as though she was 'passed back and forth' between services.

> *"In my second year though I got a bit poorly again – not eating. So then in between my second and third year I had a year when I was in hospital. In an eating disorders unit first, and then I got discharged because my weight was up, but all of the, kind of, more BPD type symptoms flared up. But I didn't know I had BPD at the time, so I ended up in the acute ward in Derby. And then that was like – literally I was out of hospital for like a day or something. And then, erm, I was transferred from there to Leicester to the eating disorders unit, because, erm, they weren't able to manage the eating in the acute ward. So I went from Oxford to Derby to Leicester – like straight on – and altogether it was about 11 months I think."*
>
> *(Emily)*

It was whist she was in the eating disorders unit in Leicester that Emily was eventually given a diagnosis of BPD.

> *"He basically said to me that looking back over my time that I'd been in hospital and all of the notes and everything like that and my history as a whole, he said I think that your symptoms and your difficulties can be summed up by a diagnosis that's called Borderline Personality Disorder. Well, I think he said Emotionally Unstable Personality Disorder."*
>
> *(Emily)*

Victoria and Claire also describe frustrations at being 'passed around' services and a lack of clarity in relation to their diagnoses. Victoria has been under the care of mental health services for so long that she is unable to recall exactly when and how she received the BPD diagnosis. However, she feels as though BPD is a label that has been associated with her from a young age, even before she was formally diagnosed.

> *"I was put in an adolescent unit, where – at that age you couldn't be diagnosed with BPD, but, erm, that's where they were going with it.*
>
> *(Victoria)*

This was also the experience of Siobhan, one of the participants in the first stage of the research:

> *Interviewer: When did you get that, the diagnosis of Borderline?*

> *They never… well, I'm not sure they ever actually quite stated it. The official diagnosis didn't come until much later.*
>
> *(Siobhan – S136 Interview Participant)*

Claire's journey to receiving a diagnosis is particularly lengthy and complex. She first heard the term 'Borderline Personality Disorder' whilst being assessed by mental health services in Australia and has a vague recollection of researching it online at the time, but did not pursue this further. Upon returning to the UK she visited the GP and was initially medicated for depression – something that she was reluctant to accept but did so on their advice. However, she was not offered any sort of therapeutic intervention or additional support from the NHS so sought help from a psychotherapist who she saw privately for around four years. Eventually, having moved from London to Brighton and feeling like she was making little progress, she ended the psychotherapy and approached the NHS to ask for a course of Cognitive Behavioural Therapy. This was around the time that she was having the affair that she feels contributed to her breakdown as well as engaging in various forms of self-harm behaviour, including the misuse of drugs and alcohol. In response to her request for CBT, she describes how she received a letter from the NHS which she feels acted as a diagnosis of Borderline Personality Disorder by proxy.

> *"They [the NHS] wrote me a letter saying – you're not suitable for CBT, you need DBT, but we don't offer it, thank you, goodbye. To me, that letter read – 'Dear Claire, you have Borderline Personality Disorder, good luck with that, love the NHS', basically, that's how I read that letter, once I Googled DBT. So, I get this letter from the NHS saying you need DBT. I say to them, are you going to diagnose me with Borderline and treat me for it, and they say… we are not going to do that because we can't treat you because we don't do DBT.*
>
> *(Claire)*

Claire's breakdown occurred shortly after receiving this letter and she was admitted to the Priory Clinic where she was told initially that she did not meet the criteria for BPD. She then started an addiction treatment programme, but whilst others around her seemed to be improving, her mental health deteriorated.

> *'There's that initial relief of, phew, well I'm not mad then – I'm just addicted. And these people are telling me we can deal with that, we can fix – it's hard work but we can help to make you better. And then I'll go… so my view of the future at that point is that I'll go out, into the future, you know, clean and sober and everything will be wonderful – you know, sunshine and… gambolling lambs and happy kittens, and you know, it'll all be like that. And then, you know, I'm getting worse and worse and worse, and I'm getting more distressed, and I'm having to harm myself, and I'm having to be really sneaky to harm myself, which feels awful"*
>
> *(Claire)*

Three weeks into her stay at the Priory, Claire was formally assessed by a psychiatrist and officially received the diagnosis of Borderline Personality Disorder – her reaction to which will be discussed in the following chapter.

The general sense of confusion and complexity associated with receiving a BPD diagnosis was mirrored in the narratives of the participants whose interviews were subject to secondary analysis. Typically, especially for the older women, a formal diagnosis was not received until after they had already experienced multiple and complex mental and physical health problems that they had difficulty in resolving or coping with effectively. A diagnosis of BPD was often unclear to participants and closely intertwined with other diagnoses:

> *"I've been under the community mental health team since I was 17, and there's been backwards and forwards about diagnosis and that sort of thing. I've been diagnosed with Borderline Personality Disorder and depression and they've kind of alternated"*
>
> (Naomi – S136 Interview Participant)

The apparent reluctance to issue a formal diagnosis of BPD may be as a result of the contentious nature of the diagnostic label, acknowledged by many psychiatrists, and the poor treatment prognosis and stigma historically associated with it (e.g. Nehls, 1998). It could however also be reflective of its status as a 'dustbin label' (Horn et al, 2007, p262) assigned to those with complex needs who are unable to fit into a clear category of mental 'illness' or who are unresponsive to conventional treatment options.

> *"They said that I've got, um, what's it called, Emotionally Unstable Personality Disorder. Yeah, I think they just give you that sort of title really, when they don't know what to say really."*
>
> *(Holly – S136 Interview Participant)*

Indeed, all of the participants in both stages of this research have, over the course of their involvement with mental health services, acquired a number of, often overlapping, diagnoses, including, Bipolar Disorder, PTSD (or Complex PTSD), Major Depressive Disorder (otherwise known as Clinical Depression), Eating Disorder, Dissociative Identity Disorder, Substance Use Disorder and other types of Personality Disorder. This is reflective of the high level of comorbidity typically associated with BPD. Previous research suggests that BPD is rarely diagnosed alone (Fyer et al, 1988, Eaton et al, 2011), a fact that has contributed heavily to debates with regards to its validity as a diagnosis in its own right.

In the experiences of the majority of the women who took part in this research, the lines between the various diagnoses they have received are blurred and contribute towards a sense of confusion around the meaning and purpose of diagnostic criteria.

> *"I've obviously had Bipolar for as long as I've had Borderline, and yet my Bipolar diagnosis is literally two weeks old at this point. Yeah. So I think a lot of people get those… get slightly wrong diagnoses, or incorrect diagnoses – or the not-quite diagnoses, or actually you've got aspects of two."*
>
> *(Claire)*

> *"So, my second highest score, which was borderline high enough to get a diagnosis, but I didn't get one because I was like 'Please don't give me one' and he said 'No, I'm not just going to give you one for the sake of it' was Avoidant Personality Disorder."*
>
> *(Emily)*

Victoria, who is arguably the most critical of the diagnostic criteria, believes that the high levels of comorbidity and blurred lines between diagnoses are reflective of an arbitrary set of criteria that are essentially reflective of the same or similar struggles and therefore not a useful way of conceptualising distress.

> *And they've kind of changed their mind between BPD, or EUPD as they sometimes call it now, Bipolar Type 2… Complex PTSD, because basically, they're all the same.*
>
> *(Victoria)*

Emily and Katy, however, consider, that whilst their diagnoses are closely linked and contain some overlap, the BPD diagnosis does have some utility in terms of describing or explaining specific aspects of their difficulties.

> *"I got like, five other labels, but erm… the main secondary, or overlapping label that I got was Complex PTSD, which makes a lot more sense in terms of a narrative for the difficulties that I have. It doesn't… it doesn't cover the entire spectrum of things that BPD covers though."*
>
> *(Katy)*

> *"So like, I think the eating disorder is a symptom of BPD. And it's a way that I, like, shut down all of the BPD stuff is like, if I restrict that's all I can think about so nothing else matters. All of the BPD stuff calms down."*
>
> *(Emily)*

In the next chapter, the analysis will return to these concurrent and overlapping diagnoses to explore the value of different labels, how they are perceived by others and their impact on participants' conceptions of their own identities. It will also begin to explore how an alternative framework of understanding distress may be helpful in order to move away from categorising mental distress on the basis of a fixed set of criteria towards a more nuanced understanding of individual experience.

## 7.5 Conclusion

This initial analysis has explored the stories told by participants about their experiences in childhood and adolescence and the ways in which they shaped and influenced their early conceptions of identity. Despite marked differences in participants' early caregiver relationships and variation in the severity and degree of trauma experienced, a consistent theme of invalidation was identified, characterised by the dismissal, punishment and/or trivialisation of private emotional experiences in childhood (Linehan, 1993).

There is evidence from participants' accounts that these early experiences of invalidation led to what is conceptualised as the development of a 'false self' (Winnicott, 1970), borne out of an internalised understanding that their emotional reality is of secondary importance to that of their caregiver(s) (Cooke, 2009). This manifested as attempts to mask their emotional distress through self-harm behaviour and an emerging sense of self that was fluid and unstable. For many, this fluidity of self-perpetuated into adulthood, defined by the creation and maintenance of personas designed to present the illusion of wellness.

However, the accounts of the majority of participants in both the first and second stages of the research contained reference to a 'tipping point' which catalysed a sense of overwhelming distress that they were no longer able to contain. This was typically associated with a disruptive event or series of events representing a challenge to the 'normal' trajectory of their lives or provoking the resurfacing of painful memories (Bury, 1982). Building upon Bury's (1982) concept of biographical disruption, the analysis showed how, in the absence of a consistent personal narrative of self, the 'threat' experienced by at least some of the participants in this research can be understood as a threat to the 'false self' – that is, the personas created in order to appear well and avoid acknowledging the vulnerability of the 'true self'.

This forcible dismantling of the 'false self' and the resulting inability to continue to mask experiences of emotional distress led to participants relaying complex and varied accounts of their experiences of mental health services and diagnosis. For many, BPD was just one of many diagnostic labels afforded to them, and the lines between their various diagnoses were often blurred and confused, symptomatic of the high levels of comorbidity associated with the biomedical understanding of BPD which has led to questions about its validity as a diagnosis in its own right (Eaton et al, 2011). Whilst one participant described having a relatively positive and straightforward experience of diagnosis, for the majority the road to diagnosis involved being passed around services and subjected to attitudes which exacerbated existing feelings of invalidation and unworthiness by ignoring the context of their distress.

In the next chapter, the themes of invalidation and the ‘false self’ will be explored further in the context of a more detailed analysis of the impact of receiving and living with a BPD diagnosis on participants’ constructions of identity and understandings of self. This will be situated within the context of the treatment and support they have (or have not) received to manage the challenges they experience and located within key debates about the utility of the BPD label and the biomedical framework within which it is treated.

# Chapter 8: Living with a diagnosis of BPD

Navigating complex stories of identity, perception, and society

## 8.1 Introduction

In keeping with the chronology of the analysis, this chapter investigates the implications of participants' early identity development on their sense of selves in adulthood. It highlights how many of the themes discussed in the previous chapter perpetuate in participants' narratives of their adult selves, including a sense of the self as fluid and unstable and a deeply rooted notion of themselves as intrinsically 'bad'. The implications of the 'false self' (Winnicott, 1960) are discussed in relation to the formation and maintenance of relationships with the self and others in adulthood and the impact of this on experiences and understandings of mental distress.

The analysis then goes on to situate these conceptions of identity within the context of being diagnosed and living with a diagnosis of BPD, exploring the meaning participants ascribe to the diagnosis and the impact it has on the stories they tell about who they are and how they have come to be. It explores how experiences of diagnosis and treatment grounded in the biomedical model have influenced participants' perceptions of both themselves and the diagnosis itself, exploring themes of power and control, semantics and the obfuscation of trauma, as well as how, for some, diagnosis can be a validating experience in a world of invalidation. The analysis finds that, for all participants, irrespective of their experiences of treatment or diagnosis, BPD has become a large and important part of their identities, and one which they struggle to conceive of themselves without. It discusses the implications of this for concepts of recovery and begins to explore the role that individuals and mental health services can play in either perpetuating or challenging feelings of invalidation, worthlessness and instability of self.

## 8.2 Who am I? The relationship between identity and BPD

### *8.2.1 Fluid identities: The role of the 'false' self and its implications in adulthood*

As was discussed in the previous chapter, all four of the women whose stories form the basis of the second stage of this research describe lacking a solid sense of their own identities from a young age. Masterston (2000) suggests that a lack of support for a child's 'emerging self' during the key phases of their development can negatively affect the development of personal identity by creating separation anxiety and feelings of abandonment. Furthermore, insecure attachment patterns in childhood are said to be associated with identity diffusion in adulthood (Erikson, 1968). It is perhaps unsurprising then, given the childhood experiences referred to in the previous chapter, that this sense of their identities as fluid and changeable is something that all of the women who took part in the second stage of the research describe still feeling to some extent in adulthood. This was a theme that was also present in the narratives that informed the secondary analysis.

Reference to this sense of fluidity quite often emerged in response to participants' difficulties in describing themselves, with many across both stages of the research referring to not really knowing who they were or feeling in some way incomplete.

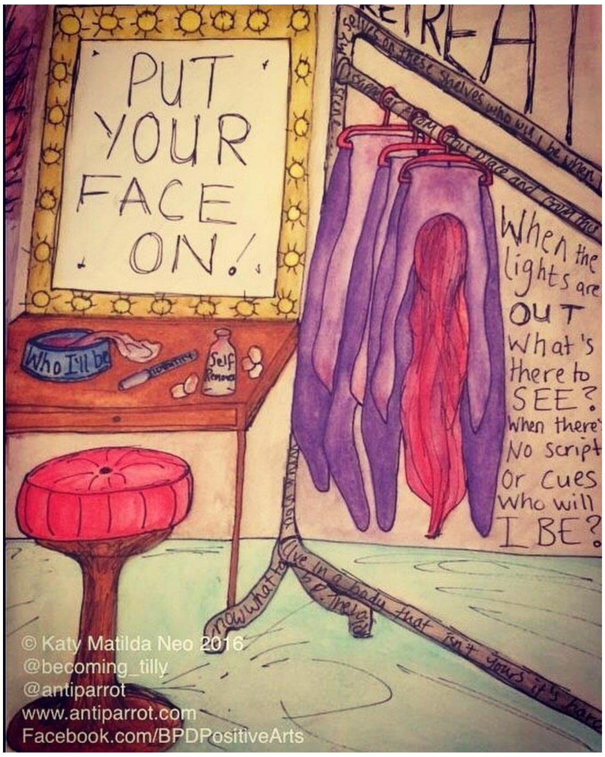
> *"I genuinely don't know who to answer who I am, like, I don't know."*
>
> *(Siobhan – S136 Interview Participant)*

For Katy, this incompleteness has manifested itself in taking on a variety of different external identities, none of which she has felt particularly connected to.

> *"Identity for me is an incredibly fluid thing, and because of the… because of the dissociative identity thing that I have slightly as well… I have this concept of being able to be different identities. And having been different identities at different parts of my life as well. And none of those have been… they've all been kind of hollow, and I've always felt a bit like an actor."*
>
> *(Katy)*

This idea of feeling like an 'actor' is represented visually by Katy in the image below. The image shows a set of three seemingly identical costumes hanging up and a mirror displaying the words 'put your face on' – suggestive of a need to put on a 'mask' to present to the outside world. The image also includes the words *'When the lights are out, what's there to see? When there's no scripts or cues who will I be?'.* This illustrates Katy's uncertainty about her sense of identity and her tendency to adopt different identities to be accepted by those around her.

**Figure 8.1 'Curtain Call' (Katy)**



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This can be related to the idea of the ‘false self’ (Winnicott, 1960) and the ideas of invalidation referred to in the previous chapter. Typically, the formation of a coherent and stable sense of self is achieved through a process of socialisation and secure attachment in childhood and adolescence where the individual is supported to integrate contradictory elements of the self and develop their personal, social and collective identities (Kernberg, 2004, Habermas, 1981). However, disruption to identity development can occur when a child is subject to early caregiver relationships which are not adequately immersed in their needs and experiences, particularly when the development of a child’s ‘emerging self’ is not supported or encouraged (Masterson, 2000). Winnicott suggests that the consequence of this is a ‘splitting’ of the self into two – a public and a private self. In coming to understand that their internal and emotional reality is less important than that of the caregiver, the ‘public’ self exists to meet the needs of others and the ‘private’ self is considered less important and often shameful (Cooke, 2009). These two ‘selves’ are often polarised and between them lies a divide which is confusing and difficult to navigate. This results in an uncertain or unstable (or non-existent) sense of the ‘true self’ – that is, a stable and integrated sense of identity (Winnicott, 1960).

Victoria’s narrative expresses clearly how the uncertainty she experiences about who she is manifests itself as a feeling of not being fully present in a world in which others around her seem more ‘real’ than she is.

> *"I think most people know who they are no matter what life throws at them. Even if someone makes them feel shit, still, somewhere in them they know who they are. But I don't, really… so, there's kind of… I feel quite ghostly – not fully present, quite changeable and fluid. There's that Alice in Wonderland quote, where the caterpillar says 'Explain yourself' and she says… 'I'm afraid I can't explain myself sir, because I'm not myself, you see' and everyone's like, what? But I'm like, no, I get it."*
>
> *(Victoria)*

Claire's narrative also contains reference to what can be interpreted as the presence of a false self. She describes many occasions throughout her life, particularly within romantic relationships, where she has unconsciously 'adapted' her identity to reflect the needs and preferences of another person – both as a way of gaining their affection and in an attempt to fill the emptiness within her sense of self.

> *"And obviously an unstable sense of identity is one of the core… you know – it used to happen to me a lot more. In relationships – I would take on the other person's interests, and the other person's personality to a certain extent."*
>
> *(Claire)*

Despite, or perhaps as a result of, the lack of a solid or consistent sense articulated by all of the women who took part in this research, there are some common themes that emerge in the (often fragmented) stories of identity contained within their narratives and in the ways that the invalidating experiences of their childhoods and adolescence manifest themselves in adulthood. These include feelings of unworthiness, understandings of themselves as 'bad' and an internalisation of certain aspects of the BPD diagnosis. These will be explored and discussed in the context of the previous literature in the remainder of this chapter.

### *8.2.2 "The Monster Within"*

Previous research has demonstrated an association between a stable and integrated sense of identity and the development of self-acceptance and self-esteem (Crawford et al, 2004). The trauma experienced by all the participants in various forms and degrees in childhood and adolescence, appears to have led to an inability to form a sense of self that is resistant to both external and internal critique and challenge. Compounded by a lack of validation of their emotions and early displays of distress, this appears to have manifested itself in adulthood as a deeply-rooted perception of themselves as fundamentally flawed, unworthy or a 'bad' person.

The false self, who in Katy's case is described as 'Superwoman' – a perfectionist who is unstoppable and relentless, develops into adulthood to serve a secondary purpose, of hiding from the outside world what is believed to be the true 'badness' within. This is illustrated in the image and caption below:

**Figure 8.2 'The Monster Within' (Katy)**

*"I call it in The Monster Within, and I've drawn this picture of… one of the characters I drew to represent myself – she's kind of screaming, kind of scared, kind of angry, and just has this monster coming out of her chest. That's what I thought of myself. And it wasn't something that I understood as an opinion about myself, that's what I thought was the truth. I just thought, that is what I am, and all the good things that I do are to try and make up for this – for this thing that's underneath me, that I can't control, that's terrifying."*

*(Katy)*

Both Emily and Claire also articulate a perception of their 'true selves' as being 'horrible', 'terrible' or 'evil' and reflect that this perception is what often lay at the root of their distress.

> *I attempted suicide loads of times. And it was often – not always but often, related to that I couldn't cope with myself. I couldn't cope with who I am – I'm a terrible person for being like this, for doing that. I'm disgusting, like – I should be dead basically.*
>
> *(Emily)*
>
> *"There's that strong feeling of – there's nothing wrong with me, I'm just a horrible person. There's no, erm – there's no, sort of, psychiatric element at play here – I'm just plain evil, you know. Me and Stalin and Hitler and Pol Pot are right up there, you know…"*
>
> *(Claire)*

One of the primary criticisms of the BPD diagnosis is in its implicit framing of the 'problem' as being located within the personality of the individual (Herman, 1992). The detrimental effects that situating distress solely within the realms of pathology can have, both through the obfuscation of contextual factors and in its implications for treatment and recovery are well documented in the literature (e.g. Horn et al, 2007; Shaw and Proctor, 2005; Warner and Wilkins, 2003). Alongside this, being given a diagnosis that can be seen to imply that one's personality is inherently ‘disordered’ is likely to reinforce existing negative perceptions of the self.

This has certainly been the case for Victoria, who, of the four women, has had her diagnosis the longest and is the most critical of both it and the psychiatric profession as a whole.

> *“Until recently, it made me feel like a problem. Like the problem was located in me.”*
>
> *(Victoria)*

After Claire received the letter from her local NHS trust recommending her for DBT – something that she understood as an implied diagnosis of BPD, she initially took this to be confirmation of all that she believed to be intrinsically and fundamentally wrong with her.

> *The word personality is so fundamental, it’s who you are. It’s not – so it’s not saying, it’s not saying you’re unwell, or, erm, you’re ill, or you’re sick, or you need treatment. It’s saying, you’re wrong, you’re bad, there’s something wrong with you, there’s something disordered about you – all of you. And that’s a horrible feeling, simply – especially if you have spent, like I have, spent the whole of my life feeling like you’re an awful person. So then you’ve got a label, and it’s official – so you’re officially a bad person, officially a nasty person.*
>
> *(Claire*)

However, as will be discussed in the following section(s), it is clear, particularly from Claire’s story, that the way that the Borderline Personality Disorder diagnosis is framed by professionals, particularly in the early stages of diagnosis, and the subsequent treatment that is received seems to have a significant impact on the way that it is perceived and internalised and consequently the way that it interacts with and adds to existing conceptions of identity.

### *8.2.3 Making it feel real: Diagnosis as validation*

Despite being aware of the controversies surrounding the BPD diagnosis and experiencing their own challenges in relation to it, Emily, Katy, and Louise all felt as though the process of receiving it provided them with a degree of validation of their experiences of distress and helped them to situate them outside of their existing narrative of themselves as inherently bad or unworthy of treatment or support.

Whilst Claire still has issues with the BPD label itself (something that will be discussed subsequently), after finally receiving a formal diagnosis during her time at the Priory, she now believes that the diagnosis was necessary in order for her to be able to admit to herself that she was unwell and move away from the perception of herself as fundamentally flawed. She feels that the extent to which she identifies with the criteria allowed her to reframe her experiences as something tangible and gave her something to relate to.

> *I think they [diagnoses] can be massively helpful. And I think I needed mine. I needed mine, because part of my disorder is the desire to deny that I am in any way ill. Even if you don't feel like you meet all the criteria, or some of the criteria aren't quite right for you, erm, you know – to me, I just recognised it as myself, you know. A pattern of intense and unstable relationships – absolutely describes my past. You know, the list of things, you know – overspending or substance misuse, or drinking, all of that, sort of, fit. Repeated self-harm or suicidal gestures, erm, yeah – all of that fit.*
>
> *(Claire)*

For Katy, one of her biggest fears with regards to seeking help and support health was that she would not be taken seriously by mental health professionals.

> *"I thought they'd just think I was stupid for even thinking I could have a problem, and I thought straight away they'd be like 'but you've got a PhD, you've got a proper job, and you advise people on how to design research… how can you have any of these problems, you're just making it up…'*
>
> *(Katy)*

Therefore, when her case was quickly escalated to a specialist personality disorder service who assessed her and gave her a diagnosis which subsequently allowed her to access an intensive programme of treatment, she felt a huge sense of relief and validation of the distressing experiences and unhealthy coping mechanisms which she had previously believed originated from something fundamentally flawed within herself.

> *"It just felt like such a relief. I still went through the assessment expecting at the end to be told that there wasn't… it was just normal stuff, and so to be told that… yeah… it was relief, because even though… some people might be like, it's a terrible diagnosis to have or whatever, it's kind of… like, well, yeah, but it's worse to have all of the symptoms of it and think that you're just a normal person like everyone else and your internal world is just like everyone else's, because then you feel like a terrible person… you feel like a failure at being a human.*
>
> *And it gave me complete validation. Things I'd just thought I was imagining, were suddenly like… no, these things are real, they're actually happening to you."*
>
> *(Katy)*

Emily experienced similar feelings when she received her diagnosis of BPD after almost a year as an inpatient in eating disorder and acute services.

> *"When I was being passed back and forth between acute side and the eating disorder and having people say I wasn't being compliant, and this and that. And when I was*

> *told that the thing that I was struggling with was actually a thing, and I wasn't being non-compliant, it was actually that I was trying to cope with this thing, and I needed help to cope with it better. It didn't matter what it was called, the fact that there was something that was concrete actually really helped me."*
>
> *(Emily)*

The idea of Borderline Personality Disorder as something 'concrete' is an interesting one, given that many of the criticisms regarding the diagnosis stem from the lack of consensus regarding both its aetiology and its very existence as a distinct condition in its own right (Bjorklund, 2006). However, for Emily, Katy and Claire, whose sense of their own selves was both fragile and arguably distorted, being able to conceptualise their difficulties as something both tangible and situated outside of themselves provided a sense of hope and relief, and will be demonstrated, provided them with a useful framework with which to understand both themselves and the challenges they experience.

Emily is the only one of the four participants to describe in detail exactly how she received her diagnosis and how it made her feel:

> *"It was when I was in Leicester that I was diagnosed with BPD by the psychiatrist there. And he's got a lot of understanding about BPD and eating disorders. And he's really lovely. And he explained what it was, and he said, like, it's not to say that that's who you are at all. It's just basically, that's just – it quite well sums up your difficulties and struggles that you have. And now that we are aware of that we can look at how we can tackle it. And all of that sort of thing. So it actually gave me hope. Because I think I had been passed from like, eating disorder services to just general psych stuff, like, no one was looking at it as a whole."*
>
> *(Emily)*

Being treated compassionately and having her diagnosis explained to her in such a way that did not imply that she was complicit or responsible for it helped Emily start to construct a new narrative of herself as unwell rather than fundamentally bad. The framing of the diagnosis as a starting point from which to discuss treatment options also helped to create a perception of it as useful construct representing something tangible which could be 'fixed.' However, unfortunately for Victoria, and the majority of the participants interviewed about their experiences of S136 in the first stage of the research, their experiences of diagnosis and subsequent treatment were not so positive, and they did not experience the same sense of validation felt by Emily, Claire and Katy.

Victoria's experience of psychiatrists and the treatment she has received by professionals as a result of her BPD diagnosis, combined with her interest and experience in psychology, has led her to largely reject the BPD label and created a deep mistrust of services. Her story of unhelpful, and often damaging experiences of treatment will be discussed later in this section; however, her response to the notion that for many, receiving a diagnosis can be a validating experience, clearly brings into focus the impact that mental health services can have, both on an individual's own perceptions of themselves and of the diagnoses that they are given.

> *A lot of people do say they find it validating. They're generally the people who haven't been sectioned like 20 odd times though, and had their human rights been taken away from them because of it. Or, you know, been treated so disgustingly in AandE and things. But no, I don't want to dismiss their experiences – well, I just did, but I cannot imagine why you would, because, to me, it's not… they're not pathological issues. They are mental health issues, but they're actually normal for so many people.*
>
> *(Victoria)*

This supports findings from previous research (Horn et al, 2007; Bendelow et al, 2016) which suggests that when appropriate treatment is able to be accessed, individuals typically report more positive attitudes towards diagnosis. The treatment received from others is also an important factor in the way identity is reconceptualised in the context of diagnosis, and this is explored in the following section.

### 8.3 The biographical disruption of diagnosis: Re-storying the self in the context of a BPD diagnosis

Bury (1982) suggests that the onset of illness represents a threat to the self, and so in order to maintain a consistent sense of self, individuals must attempt to make sense of their experiences of illness in ways that preserve their core beliefs about who they are (Williams, 1984). This is arguably more straightforward when the site of the illness is visible and fits neatly within a biomedical framework, allowing for causal links and explanations to be made that are generally accepted within the dominant (medicalised) discourses of society. However, one of the controversies surrounding the BPD diagnosis is the extent to which it is both labelled as an 'illness' within a biomedical framework but also locates the origins of that illness within an individual's core personality functioning (Mann and Lewis, 1989). This tension makes it more difficult for individuals to make sense of their diagnosis in such a way which preserves the stability of the narrative identity and reflects the sense of self as it was prior to the disruptive effects of the illness. Compounding this further is the lack of an existing stable sense of identity articulated by participants in this study, and often associated with a diagnosis of BPD (e.g. Clarkin et al, 1983; Kernberg, 2004; Spitzer et al, 1979).

One of the key critiques of Bury's (1982) model of biographical disruption argues that it assumes a shared concept of a 'normal' state (Reeve et al, 2010). As was discussed in section

8.2.1, this does not appear to be the case for the participants in this research, who describe a sense of themselves as fluid and changeable. Given that the central tenants of Bury's (1982) and Williams' (1984) concepts of biographical disruption and narrative reconstruction lie in the idea of a need to preserve a consistent self, it is interesting to consider the impact of biographical disruption on identity when the self that is disrupted is already fragile, or in some cases, felt to be lacking entirely.

The previous chapter began to explore the concept of biographical disruption in the context of the disruptive life events that preceded the 'breakdown' experienced by the majority of participants, and which could be seen to represent a threat to the 'false self' (Winnicott, 1960) created in response to the invalidation experienced in their early lives. In a similar way, being given a diagnosis of Borderline Personality Disorder can also be understood as a biographical disruption in that it represents a disruption to the existing systems used to explain feelings and behaviour and challenges the conception of the self (Bury, 1982). For many of the women who took part in this research, whose existing explanatory systems had been grounded in the idea of themselves as fundamentally bad and whose notion of the self was fragmented and unstable, being given a diagnosis of BPD could be interpreted as an opportunity for them to attempt to construct, (rather than maintain) an alternative and more coherent account of the self (Giddens, 1991) based on the diagnostic criteria.

As has already been noted, Katy, Victoria, Claire and Emily all described very different experiences of diagnosis and treatment, and all were at different stages in their journey at the time of interview. However, to varying degrees, the stories that they told about their identities all contained a sense that BPD had come in some way to define who they were and/or how they perceived themselves, and these stories are explored in more detail in the following section. This was also seen, in an even greater degree, within the narratives of the women who discussed their experiences of being detained under S136. These women largely articulated identities that had become so dominated by mental distress that they were unable to conceive of themselves outside this diagnostic framework.

> *"My life has been dominated by my mental health for, many many years of my life, but – and I, and particularly the last few years, so I think I've lost all other identity, rather than a service user"*
>
> *(Siobhan – S136 Interview Participant)*

These narratives are congruent with the identity disturbances associated with a diagnosis of BPD (APA, 2022) and are supportive of findings from Lovell and Hardy's (2014) research whereby participants absorbed the diagnosis of BPD into their identities to such an extent that they either accepted it as their identity or felt that it had taken their identity from them. This idea is also discussed further in the following section.

### *8.3.1 Building an illness narrative: Negotiating multiple and conflicting identities in the context of BPD*

As was described in Section 8.2.3, the sense of relief and validation that some participants described feeling upon receiving their diagnosis was largely a result of them being able to conceptualise their experiences of distress as being a result of something external and tangible rather than an enduring personality fault. Being given a diagnosis appears to provide the space, and permission, for the reframing of behaviours and experiences in the context of the biomedical paradigm of which the BPD diagnosis is a product. Linked to the idea of illness identities (Charmaz, 1995) this leads to the creation of illness narratives where thoughts and behaviours are attributed, both by the individual themselves, and (as will be demonstrated subsequently) more widely by family, friends and mental health professionals, to the disorder, thus potentially obscuring a sense of self outside of the BPD diagnosis or creating a disjuncture between the ‘ill’ and ‘well’ identities.

This is particularly evident in the secondary analysis, where a key characteristic of participants’ narratives was a lack of agency and the depiction of themselves as disempowered victims of an ‘illness’ over which they have no control. Many of the participants described dissociative symptoms of their emotional difficulties which were clear in accounts that situated their actions and behaviours separately from what could be considered their core selves and therefore rendered it outside of their awareness or control. For Chrissie and Martina, this manifested in potentially harmful behaviour that they felt afraid of and unable to regulate.

> *“But I’m just also worried when I’m in that state of being by the sea. In case I like, go out and just swim out into the sea.”*
>
> *(Chrissie – S136 Interview Participant)*
>
> *“I just went really downhill and everything and I started collecting knives and I really was becoming quite afraid of my behaviour.*
>
> *It only occurred to me when I was driving along the seafront and I saw Beachy Head, and I thought ‘oh, of course’. You know, I hadn’t intended. It wasn’t my intention to go and commit suicide.”*
>
> *(Martina – S136 Interview Participant)*

In this regard, distress is conceived as an ‘illness’ that disrupts what is perceived as normal functioning and reflects an ‘ill’ identity that is separate from an alternative, rational, thinking self.

> *“I feel as though as I’m living two parallel lives. I feel as though on the one hand I’m trying to be normal and do normal things every day, that kind of stuff, and the on the other I’m leading this lie where I… know that I’ve got access to this gun and Beachy Head is always there…”*
>
> *“I do feel like I’ve become a different person. And I don’t particularly like the person I’ve become.”*
>
> *(Martina – S136 Interview Participant)*
>
> *“I used to be very efficient, but I started doing things like – I’d have all the files under my arm and I’d go into the office and I’d just say ‘I’m going home’ and she’d say ‘It’s not time to go home – and you’ve got all the folders under your arm’. I was not aware that I was, you know. And some of the nurses found me in the staff room, just like laying on the settee holding files. Lots of different things I didn’t realise I was doing”*
> *(Holly – S136 Interview Participant)*

The four women who took part in the second stage of the research had generally had more positive experiences of mental health services or were further advanced in their journeys of recovery. They also typically had a higher level of formal education and had a greater awareness of the arguments and controversies surrounding the BPD diagnosis. Perhaps as a result of this, or because of the focus of the interview, their narratives in relation to their BPD diagnosis typically contained more nuance, self-awareness and acknowledgement of a variety of contributing social and environmental factors than those whose interviews informed the secondary analysis. This is consistent with previous research (e.g. McCay and Seeman, 1998; Oris et al, 2018) that has demonstrated a negative association between ‘engulfment’ (the extent to which chronic illness dominates a person’s identity and daily life’) and factors such as hope, self-esteem and physical and psychological functioning, occurring as a result of a lack of illness integration (Oris et al, 2016).

However, the awareness of participants in the second stage of the research of these environmental and social factors and the controversies surrounding the diagnosis combined with a degree of integration of the diagnosis into their illness identity appears to result in the emergence of complex, and often confused narratives. In these, attempts are made to negotiate multiple and conflicting identities amid a sense of uncertainty as to whether behaviours, thoughts and feelings should be positioned internally within the ‘self’, externally as ‘illness’ or as coping mechanisms developed in response to adversity.

Having recently made good progress in her recovery, Emily concedes that for many years her understanding of her identity was entirely dominated by her perception of herself as ‘ill’:

> *“You kind of get into that, almost like, patient mode, and it becomes kind of like who you are.”*
>
> *(Emily)*

With hindsight, she is able to reflect on the potential origins of this identity as a coping mechanism in early childhood and adolescence and is beginning to understand its utility in terms of getting her the care she needed:

> *“It’s kind of been like that on and off throughout my life. I think a lot of the time because I only, sort of, got the care and the one to one time if I was ill, it almost became a bit of an automatic fall back – not like, consciously, but it was almost like I’d become more ill when I needed support. Being the ill person made me feel safe. I didn’t like it but it felt safe, I knew it, there wasn’t as many expectations.*
>
> *(Emily)*

However, she also describes herself as ‘naturally sensitive’ – an inherent trait of her personality that she feels was not shared with her siblings, and suggests that this, apparently more biologically-based factor, may have contributed to the way in which she reacted to the challenges she experienced.

> *“But I was always very sensitive, just naturally, so I think I tend to take things very personally and always have done. And I think I always used to question, why am I like that? Why am I affected by that, but my sisters aren’t?”*
>
> (Emily)

Katy’s narrative is suggestive of an understanding of her difficulties as being largely grounded in a medicalised model of ‘illness’, despite having an awareness and understanding of the trauma she experienced as a child. She does not subscribe to the idea of being defined by a diagnosis and feels that the utility of the label is primarily in presenting a consistent image of the self to the outside world. However, she does feel as though her various diagnoses currently make up a large part of who she is and in describing this seems to be suggesting that many of her behaviours occur as a *result* of having BPD, rather than as a natural response to trauma as suggested by critics of the biomedical model such as Johnstone (2000).

> *“I’d say to some extent at the moment it makes up quite a lot of my identity, because I’m in this kind of really insular phase where I’m not really interacting with the world. And while I’m doing that… reflecting a personality that almost is defined by the diagnosis because it’s… it’s almost an easy buffer for the world. That doesn’t mean that I’m a diagnosis, because nobody’s a diagnosis…It’s… like saying that somebody’s… I don’t know… it’s like saying that being a doctor actually defines who*

> *somebody is. It doesn't, it defines what they do. And BPD defines a lot of the things that I do, and a lot of the reasons I do them, but it doesn't define who I am…"*
>
> *(Katy)*

In addition to this, Katy also refers to genetic factors which she feels may have contributed to what she describes as her 'illness'.

> *I think social and environmental factors are a huge part, but I don't necessarily believe that you can invalidate all biological aspects of it. My Dad definitely has narcissistic personality disorder, which is one of the red flag… genetic heritability things. And my sister's autistic, which is another red flag.*
>
> *(Katy)*

This reference to genetics is also present in Claire's narrative, and is used as a way of explaining the early onset of what she perceives to be behaviours symptomatic of a diagnosis of BPD.

> *I certainly think that there must be a genetic factor to it, because I have had aspects of it for so long, I mean – you can look back to when I was a kid. Really young. Four or five.*
>
> *(Claire)*

Whilst there is little evidence to suggest any stable biological or genetic risk factors for BPD (Chanen and Kaess, 2012) there has been some suggestion that BPD is best understood through an integrative model which links a potential genetic predisposition with developmental, social and environmental factors which in turn trigger a neurobiological response (Amad et al, 2014). It appears that, to some extent, a degree of assumed biological causation has been helpful in shaping participants' narratives around their diagnoses, particularly, as in Emily's case, as a way of understanding why they may have been affected differently to their siblings. Nevertheless, it is interesting, though perhaps not unsurprising given the focus of this research, that biological factors do not feature heavily in the stories that participants constructed to explain their difficulties, despite many of these stories drawing frequently from biomedical constructs of language and meaning.

Of the four women who took part in the second stage of the research, Claire's narrative is arguably the most firmly grounded in the biomedical model of mental 'illness'. In spite of (or because of) this she is also the participant who most strongly identifies with the diagnosis, although she prefers to use the term 'Emotional Intensity Disorder' rather than BPD to describe it. This semantic change has helped her to be able to reconceptualise it as an illness rather than an inherent character defect:

> *It is an illness, to my mind, of emotional intensity – that’s what makes sense to me. Erm, it doesn’t have the word personality in it, so you don’t feel like you’re being told that your character is under attack, or your character is flawed.*
>
> *(Claire)*

The meaning and value of language in relation to the diagnostic label itself will be discussed in more detail in section 8.4.5. However, Claire’s use, and subsequent correction of the word ‘disease’ below highlights both the degree to which medicalised language has become subsumed in her framing of the diagnosis and, to an even greater degree, the impact that certain words and phrases can have on how it is understood and perceived by the self and others.

> *Obviously I can only speak for myself, but to me, it is a disease of emotional intensity, or an illness – maybe I shouldn’t use the word disease, that has terrible connotations doesn’t it – makes me think of fleas and the bubonic plague.*
>
> *(Claire)*

Claire feels as though a lot of who she *is* comes as a direct result of the illness that she *has.* This includes not only the things that she struggles with, but also aspects of her personality that she regards as positive.

> *So I think I get a lot from the illness. I think my passion comes from the illness. I’m very passionate about the things I care about. The things I love, I LOVE the things I love. Erm… everything about me that is intense I think, I get from it. So, erm… yes, my intense passions – the intense highs, the love for things, and the intense lows as well, and that’s, erm… loathing of certain people and policies… I think my greediness is something I get from the illness – my inability to stop with things. Anything I like. So I feel strongly that everything that is particularly intense about me, passionate – both ways, both in good and in bad ways comes from the illness.”*
>
> *(Claire)*

In contrast to Claire, Victoria firmly rejects the biomedical model and does not regard herself as ill. She acknowledges that her understanding of herself is largely affected by how other people respond to her and treat her, and reflects that that it is for this reason that she has, until recently, regarded her difficulties as being situated predominantly within her own, in her opinion, flawed, personality. Nevertheless, like Claire, Victoria believes that there are positive and negative aspects of her identity that are intrinsically linked to what she still describes as ‘symptoms’ of BPD despite her rejection of the diagnostic label.

> *“I wouldn’t want to get rid of the empathy. Erm, actually, maybe a little bit. Because, it can be - if you can feel something – if you can feel someone else’s pain too much, it’s just – you can’t really actually help them. But yeah, I wouldn’t want to – the empathy is a positive. And also, the passion and the, you know, having… you know, interest in*

> *things and strong feelings for people, and loving people very hard, you know, it's quite a nice part of it. But then there are, there's always flipsides, so yeah."*
>
> *(Victoria)*

Previous research exploring empathy in individuals with a diagnosis of BPD suggests that enhanced empathetic sensitivity can develop in childhood in response to confusing or neglectful parenting, and for this reason is more prevalent amongst those diagnosed with BPD in adulthood (Krohn, 1974; Carter and Rinsley, 1977). However, in a systematic review of the evidence investigating empathy in BPD, Dinsdale and Crespi (2013) found comparable levels evidence demonstrating enhanced, reduced and preserved empathetic skills amongst individuals with a diagnosis of BPD. The implications of associating certain personality traits and skills with a specific mental health diagnosis are discussed in the next section. However, what all of these accounts demonstrate, to varying degrees, is the challenge of forming or maintaining a coherent sense of self that is distinct from the illness - in this case the diagnosis of BPD, that represents a disruption to the 'normal' trajectory (Bury, 1982).

This disruption represents an opportunity to reorganise and reassemble the discrepancies between the embodied experience of illness, the self, and the social world (Williams, 1984), but, in the absence of an existing personal narrative of the self that is stable, consistent and intelligible, there is a risk that the illness *becomes* the self, and vice versa. As was also found in Lovell and Hardy's (2014) study of eight women with a PD diagnosis detained in a secure unit, there are some people for whom the diagnosis is viewed as an important and integral part of themselves which has helped them to make sense of who they are. However, there remains a tension between the seemingly binary, but undoubtedly interlinked concepts of BPD or as a fundamental part of an individual's personality functioning which are both implicit within the biomedical understanding of BPD. This is particularly brought into focus when considering participants' views on recovery and moving beyond the BPD label.

### *8.3.2 What will be left of me? Worries about moving beyond BPD.*

With the possible exception of Victoria, the women who took part in this research appear to, at least in some way, subscribe to the idea of BPD as an illness and as such believe that, with the right support, it is possible for them to be 'well'. However, the extent to which they have absorbed the diagnostic criteria into their sense of selves means that they are understandably concerned about losing a large part of their identities in the process of recovery. Whilst Emily is now able to reflect on the potential origins of her 'illness identity' in early childhood and adolescence and its utility in terms of getting her the care she needed, she feels that, even with this understanding, it is difficult to move beyond her understanding of herself as ill because she does not feel she has a solid enough sense of who she is outside of the framework of the BPD diagnosis.

> *"And one of the really difficult things about moving forward, and moving into life away from, kind of, BPD, is not knowing who you are without it – it's scary. It's really scary."*
>
> *(Emily)*

As was referred to in the previous section, Claire attributes both positive and negative aspects of her personality to her diagnosis and therefore currently struggles to conceive a sense of herself without it:

> *"It's a fear of – if I change this illness, if I cure this illness, if I manage this illness – what's left of me? What's going to be left of me? Am I still going to be me? Especially when I do feel there are positive attributes to it. I do feel… I mean, I love being passionate about things."*
>
> *(Claire)*

This mirrors findings from Gillard et al's (2015) research exploring the concept of recovery amongst those with a PD diagnosis whereby individuals reported being unsure of who they are and what is considered 'normal' outside of their experience of having a personality disorder. This has clear implications for clinical practise and treatment programmes. Katy is currently working closely with a therapist who is helping her to understand her thoughts, feelings and behaviours and encouraging her to start to build a sense of self outside of the illness but, like participants in Gillard et al's (2015) study, still reflects a sense of uncertainty and vulnerability in relation to her sense of self and its relationship to the outside world.

> *"But I think that there will come a time where… it's what my therapist calls 'post traumatic growth' which I think will be the point where I move beyond needing that as much to define myself because I'll have a new language of understanding, a new framework. And I don't intend to stay… well I don't want to stay locked in this, erm, kind of self-encapsulating, self-defeating cycle of being within this illness, because if I choose that then I will never be anything else. So I'm trying to be open… I'm not very good with uncertainty and with openness to change, and to things just happening, but I'm trying to be open to the idea that I will become something, and I don't know what that is, and that's ok, because that's what's everyone's doing."*
>
> *(Katy)*

In the next chapter, the analysis will further explore the concept of recovery as it is understood by participants and reflect on the treatment approaches and tools that are considered to have been helpful and effective by the women who took part in this research. Prior to that though, the remainder of this chapter focuses on participants' experiences of the attitudes and treatment they have received from friends, family and mental health professionals as a result of their diagnosis, and the impact that the perceptions of others have on their own conceptions of themselves and their feelings towards the diagnostic criteria as a whole.

## 8.4 Who do people think I am? Preconceptions, power and control in mental health services and society.

It has been claimed that BPD is the most stigmatising diagnosis (Nehls, 1998), particularly in the context of clinical interactions. Previous research has identified a number of dominant and enduring stereotypes which are typically associated with the diagnosis (e.g. Horn et al, 2007; Wilstrand et al, 2007) and highlights the implications of these both for the treatment that individuals with the diagnosis receive and their own internalised self-perceptions (Kealy and Ogrodniczuk, 2010). However, there has been little research which offers an in-depth exploration of the ways in which the reactions towards diagnosis and treatment received from others can impact upon perceptions of the diagnostic label of BPD and the identity that is then crafted around it.

The women who took part in both stages of this research, many of whom have lived with a diagnosis of BPD for many years, articulated long histories of interactions with both in-, and out-patient mental health services, psychiatrists and friends and family, all of whom have undoubtedly contributed to shaping their perceptions both of themselves and of the diagnosis as a whole. Despite having very different journeys of diagnosis and experiences of services, a number of consistent themes emerged, many of which echo those identified in previous research. The analysis in this chapter will predominantly focus on unpicking some of the negative stereotypes surrounding the BPD diagnosis, the barriers these stereotypes create in respect of accessing treatment and their contribution to shaping the personal narratives and identities discussed earlier in this chapter. Following this, the next chapter will move beyond this by emphasising factors that contribute to a positive experience of services and support and assist in the process of negotiating an identity outside of the diagnostic label of BPD.

### *8.4.1 Not waving but drowning: The impact of conceptualising distress as 'attention seeking'.*

The term 'attention seeking' is one that frequently appears in research relating to perceptions of clinicians towards those with a BPD diagnosis (e.g. Wilstrand et al, 2007). This is typically expressed in relation to external manifestations of distress, such as self-harm and suicide attempts, actions that often lead to frequent and repeated interactions with mental health and emergency services (Sansone and Sansone, 2011). Victoria, Kate and Claire have all experienced the invalidating effects of having not only their behaviour, but also their thoughts and feelings labelled as ‘attention seeking’ by nurses, psychiatrists, and to a lesser extent, family and friends. This is consistent with previous research which revealed a commonly held view amongst nurses that individuals with BPD are difficult, manipulative, treatment-resistant, dangerous and attention seeking (Wilstrand et al, 2007).

> *“I mean, I’ve been told I’ve been attention seeking all my life. I’ve been called attention seeker – and melodramatic is the other word. And I’m sure most people with BPD have as well.”*
>
> *(Claire)*

The fear of not being believed or taken seriously was one of the main factors that contributed to Katy’s initial reluctance to seek help for her mental health:

> *“And there were times, there were definitely numerous times in my life where I wished that someone would help me, but it was always from a kind of like… I want someone to come in and tell me that I’m not ok, and, I didn’t know how to even begin unpicking that or getting any help because I also, like truly believed that I would be laughed out of the building if I asked for help.”*
>
> *(Katy)*

Even after having a positive experience of referral and diagnosis and receiving appropriate and helpful treatment, Katy describes how she still found it difficult to move beyond the preconceived notion of herself as someone who ‘creates’ issues in order to seek attention from others.

> *“I was refusing to accept there was anything wrong with me, on a lot of levels. And he [the therapist] would just be like: ‘Well, why would you make this up? Let’s assume you’re making this up then – why?’… I don’t know… ‘Whose attention do you want?’… I don’t know, I didn’t know you before, but maybe yours? And he was like, I don’t really think that’s it… like… he was just like, I’m not really buying that, you’re not really buying that. So, it took me a long time to really convince myself”*
>
> *(Katy)*

The above interaction demonstrates how pervasive stereotypes and deeply ingrained social understandings can be in unconsciously shaping people’s own perspectives of themselves and others. Illustrating this further, Claire’s narrative contains a particularly vivid account of her own preconceptions of the BPD diagnosis, which appear to be firmly rooted in Victorian notions of femininity and echo the views of feminist critics (e.g. Ussher, 2011; Wirth-Cauchon, 2001) who suggest that the medicalisation of ‘extreme’ displays of femininity or behaviour which falls outside of the traditional feminine role has had the effect of obscuring the cultural and societal factors that have contributed to its occurrence.

> *"I had a picture of it by the time that I was eventually diagnosed, which I think is a picture that is very prevalent within the NHS, which is that of a difficult woman. A very difficult, erm, you know – brings to mind to me, almost 19th century images of the hysterical woman needing to be confined, and erm – what does it make me think of? It makes me think of a book called 'The Yellow Wallpaper' Do you know it? It makes me think of that. That idea that women are overly excitable and need to be contained. And need to be physically contained within corsets and clothing. And need to be contained within, erm, within medical – within a medical sort of structure."*
>
> *(Claire)*

The theme of containment and control referenced here will be explored in more detail later in this chapter, but what is clear in both Claire's and Katy's accounts is a dominant perception that the 'symptoms' experienced by people with a diagnosis of BPD are not legitimate manifestations of distress, but merely attempts to disrupt, manipulate or garner attention that is undeserved. Fortunately for Katy, the treatment she was offered helped her to challenge some of the negative preconceptions that she had internalised even before she received her diagnosis. However, for the other three women who took part in the second stage of the research, as well as the majority of the women who were interviewed about their experiences of being detained under S136, their interactions with mental health services have only served to compound this further.

Victoria, Claire and Emily all describe having their feelings and behaviours frequently dismissed by mental health professionals as being an overreaction. Victoria explains that whilst she understands that her emotional responses can be extreme, she struggles when they are not taken seriously as it reinforces her deeply held belief that her 'symptoms' are her fault and something she should be able to control:

> *"Well, what is not helpful is being invalidated… basically being told you're overreacting. Because the fact is, if you have a strong emotion, you have a strong emotion, you can't just magic that away."*
>
> *(Victoria)*

Similarly, Emily considers that the lack of empathy amongst staff and unwillingness to fully engage that she has experienced from some staff in mental health services has often had the effect of minimising the severity of her distress and making her feel as though her problems are insignificant:

> *"A lot of the time, like the staff or CPNs or whatever, they don't necessarily really listen to you. Or if you say 'I'm feeling suicidal' they'll just be like 'Oh, do you want some PRN? ['when required' medication] or just like 'Oh, just do some breathing exercises".*
>
> *(Emily)*

This account appears to reflect a limited understanding or awareness by professionals of the reality of emotional distress as experienced by the people under their care. This could be, as Kealy and Ogrodniczuk (2010) suggest, a result of the diagnostic label obscuring individual needs and desires, or potentially due to the stigmatising attitudes of mental health professionals towards those with a BPD diagnosis (Nehls, 1998). It could also be a result of systemic issues in mental health care such as lack of funding and pressure on staff resources which foster a less than ideal environment for the provision of compassionate care. Whatever the reason, the consequence of this lack of understanding or unwillingness to listen serves to further invalidate the thoughts, feelings and emotions of individuals who, as has been evidenced, typically have long histories of abuse, neglect or invalidation spanning back to childhood.

Claire believes it to be a commonly held view that people with a BPD diagnosis deliberately and purposefully harm themselves in order to garner attention and that they do, or should have, the capacity to be able to self-regulate their emotions. She feels that the focus of professionals' attention should be less on the behaviour itself than the very real emotions underpinning it:

> *"Or, it's the classic 'just calm down' – 'just calm down!' And I'm not being funny but, these experiences are not fun! You know. Nobody repeatedly harms themselves because going to AandE and being stitched up, by pissed off people is fun. And there's also a view, as well of the difficult, hysterical woman, who repeatedly self-harms or makes suicidal gestures. Which I think is such an awful term, by the way! An awful term. Because the feelings of distress, even if it only a gesture. Even if you have only swallowed, you know, 15 paracetamol, or, you know, cut your wrists, but not very badly – the feelings there are genuinely as real and as terrible as – as somebody who jumps off a bridge, or, you know."*
>
> *(Claire)*

Bendelow et al's (2016) research suggests that a further consequence of the minimisation and/or lack of acknowledgement of expressions of distress by professionals is to create a situation whereby the only way people feel they can obtain help is through (often public) enactments of extreme distress which often lead to emergency service intervention. This was the case for the women whose interviews were analysed in stage one of the research who were also participants in Bendelow's (2016) research and as such had all been detained by police under S136 of the Mental Health Act, often repeatedly.

All of the women whose narratives have informed this research present as eloquent, intelligent and self-aware, something that could be conceived of as a strength, especially when it comes to engaging in dialogue about their thoughts and feelings. However, both Victoria and Claire reflect that this level of self-awareness and ability to articulate their distress has often contributed to the perception of them as attention seeking and prevented them from receiving the help they need because they appear too ‘well’.

> *“They [mental health professionals] see it as attention seeking, because how can you be feeling like you might kill yourself, but also talking to me about it, and, you know… so they would label that as attention seeking.”*
>
> *(Victoria)*

> *“That’s been my problem throughout my entire psychiatric history, is appearing too well. I’m too articulate, erm… So I turn up in your office, I’m showered, I look bright-eyed and bushy tailed. And I talk to you quite intently and quite articulately, and you know, tell you how I’m feeling, and you go away and think – well she’s not in any trouble is she? And then I’m left exactly where I was.”*
>
> *(Claire)*

This reflects the findings of Rivera-Segarra et al’s (2014) study investigating stigmatisation experiences of individuals with BPD in Puerto Rico, which highlighted themes of stigmatisation associated both with severe mental distress (e.g. being out of control) as well as those associated with less severe forms of mental distress (e.g. an assumption of personal responsibility and over-reacting). Thus, their research suggested that individuals with BPD are likely to experience a sense of being simultaneously perceived as if they are both out of control and as if they can control their behaviour to manipulate others.

Chugani (2016) proposes that the enduring stigma experienced by those with a diagnosis of BPD may be perpetuated both by misguided assumptions about the behaviour associated with the diagnosis alongside a failure to appreciate the context underpinning the emotional or behavioural response. For example, suicidal thoughts and self-injurious behaviours that are typically perceived as “attention-seeking” could be better understood as a maladaptive means of regulating emotions and/or a consequence of a dysfunctional and invalidating environment (Linehan 1993). Both Claire and Victoria reflect that, when a particular behaviour is interpreted or dismissed as attention seeking, it not only serves to invalidate the experience of distress, it also obscures an understanding of the genuine function of the behaviour.

> *“Well, it’s help seeking, it’s not attention seeking. It’s help seeking – it’s help me, I am drowning, not waving. Help me.”*
>
> *(Claire)*

> *But if someone is seeking attention then they need attention. We all need attention. And it’s a valid issue.”*
>
> *(Victoria)*

This understanding of the function of behaviour, situated in the context in which it emerged and continues to occur is thought to be crucial in reducing dysfunctional behaviours in those with a diagnosis with BPD through the selection of treatment options that effectively target the behaviour (Chugani, 2016). However, this is particularly challenging when there remains a dominant perception of individuals with BPD as being difficult, resistant or unable to be treated, something that is both borne out of and contributes to an unwillingness to see beyond the diagnostic label (Wilstrand et al, 2007).

### *8.4.2 Treating labels, not people.*

The narratives of the majority of participants who took part in this research suggest that the emphasis within mainstream psychiatric services continues to be on the management of behaviours associated with BPD and there remains little opportunity to engage in treatment strategies that address the causal underpinnings of distress. Their experience, particularly with regard to their interactions with psychiatrists, has been of a system whereby they are perceived, and therefore treated, within the confines of the diagnostic label and the, often stigmatising, preconceptions associated with it.

> *"Once a psychiatrist, in my experience… once a psychiatrist sees your label, they will obviously… they will just think of whatever kind of ideas they have about that label and apply that to you and treat you accordingly."*
>
> *(Victoria)*

> *"I did find it helpful to get a diagnosis, in a way, but what I hate about it is the way that people then perceive you because of the diagnosis."*
>
> *(Emily)*

One of the criticisms with regard to the utility and validity of the BPD diagnosis relates to the broad range of criteria associated with it – of which five (of nine) need to be met in order to receive a diagnosis. Whilst, practically-speaking, those diagnosed with BPD typically come into contact with psychiatric services as a result of suicidal or self-injurious behaviour (Gunderson and Links, 2014), there are in fact 246 different combinations of symptoms that can lead to a diagnosis of BPD (Tyrer, 1999). It is a label, therefore, that covers a vast range of diverse and often contrasting experiences – something that is particularly problematic if, as the participants in this study suggest, people with the diagnosis are often regarded and treated on the basis of the label, rather than in response to their individual presentation and circumstances.

> *"It's just too many different types of people. How can you use one label for all those different types of people?"*

*(Victoria)*

*"It's a super broad diagnostic category. It's massive. Crazy big."*
*(Emily)*

Victoria was diagnosed with BPD over 10 years ago and still retains the same diagnosis, despite feeling as though she has changed a lot since she first received it.

> *"I had the diagnosis… I still have the diagnosis… and I'm a completely different person to what I was 10 years ago. But you wouldn't know that on paper because it would just say the same words. You wouldn't have a clue… you know, I'm completely different in so many ways, and I think I will be completely different in another ten years, if I last that long! And, you wouldn't… on paper you wouldn't know that."*
> *(Victoria)*

For her, being labelled with a diagnosis that covers such a broad range of symptoms is particularly problematic because her father, who was responsible for abusing her as a child, also has a diagnosis of BPD:

> *"My main problem with the diagnosis, like I said, is the variety of symptoms. But also, that my Dad… who sexually abused me for years and years, and emotionally and physically… just tortured me basically… fits the same criteria. So, to tell someone who has been abused that they're abuser has then… I don't really want, do you know what I mean? To be included in the same… I never… like, I'm not an abusive person. I'm not violent, I'm not cruel, I'm not… I'm not anything like him. But to be lumped under the same category as him, which is the same for a lot of people who've been abused, you know, that's really unhelpful and actually really distressing."*
> *(Victoria)*

The distress and internal conflict arising as a result of being diagnosed with the same condition as her abusive father is likely to have contributed to the development of Victoria's understanding of her problems as being situated within her, as well as her rejection of the illness model. Whilst Victoria's relationship with her father was not explored in detail in the interview, it was clear that she feels, understandably, a lot of anger towards him, which she has never been able to express in a healthy way. Instead, this anger has been turned inwards and directed towards herself, manifested in self-harm behaviours and suicidal thoughts. Unlike Katy, Emily and Claire, for whom being given a diagnosis of BPD afforded them an opportunity, at least to some degree, to reconstruct a new narrative of themselves as 'ill' rather than fundamentally flawed, for Victoria, the need to navigate the tension of sharing a diagnosis with her father only served to reinforce the perception of herself further. She considers that there is little space within the diagnostic category for a nuanced understanding of the self and its development and argues that the reductionist nature of the label serves to obscure the individual (and often very different) thoughts, feelings and experiences of people who are given it.

> *"I hate labels. I don't think of people as labels. You know, several friends of mine have a BPD diagnosis. I don't think of them as my 'BPD friends'. They all have different struggles, they're all really different. You know, all of my friends have their own issues, their own emotions, their own experiences and reasons. When people say 'what's your diagnosis?' I just think… it doesn't matter, it doesn't matter… ask me what I'm like, ask me what I feel, you know, ask me what I struggle with."*
>
> *(Victoria)*

Emily's experiences have also led her to believe that mental health services need to move away from treating people on the basis of their diagnosis towards a model more focused on exploring and dealing with the underlying causes of distress.

> *"The attitude just needs to change around it, and erm, the way it's dealt with in terms of looking at why you're doing what you do, or why you're feeling how you feel, rather than how does that fit into the diagnosis."*
>
> *(Emily)*

Nevertheless, there is an overwhelming sense from both the primary and secondary data that this change is not taking place – or at least not quickly enough, and that there still exists a disproportionate focus on controlling the unwanted behaviours associated with the diagnosis, primarily through the use of medication. Despite recent evidence indicating a growing number of effective psychotherapeutic interventions for the treatment of BPD (Choi-Kain et al, 2017) the experiences of the women who took part in this research suggest, that to some extent at least, there still remains a perception of the diagnosis as untreatable – something which is thought to contribute to the over-reliance on medication and lack of access to appropriate forms of support (Adshead, 2001).

> *"And for me, it always… it has been a diagnosis of exclusion, it has been one, when psychiatrists decide they can't treat you, they just stick that label on you."*
>
> *(Victoria)*

This is sometimes implicit, but on occasion, as Victoria describes, it can be overt and insensitive:

> *"And I remember a nurse specifically saying to me when I was sectioned once, she was newly qualified, and she said 'what's your diagnosis then?', and I said, well, BPD, at the moment… she said 'Oh, that's so sad, that means you're never going to get better.' And yeah, I mean, that was an explicit… but it's said implicitly by lots of people."*
>
> *(Victoria)*

Claire received her diagnosis of BPD three weeks into a residential addiction programme at the expensive Priory clinic. Although she received some support to manage her mental health after receiving her diagnosis, she feels as though the minimal treatment she was offered did not sufficiently address the emotional underpinnings of her distress and was predominantly focused on medicating her, which came with unpleasant side effects.

> *"I was in a very desperate place where I felt like I'd been treated, we'd spent all this money, and I wasn't any… I knew I wasn't any better. I was just medicated now, erm… and I didn't like the feeling of being medicated either, you know – the initial anti-psychotics they put me on, which were for the Borderline, erm.. I hated them. They put me on Olanzapine where I couldn't stop eating, they switched me to Quetiapine, I still couldn't stop eating...:*
>
> *(Claire)*

The consequence of being on the receiving end of treatment that is inappropriate and/or ineffective can be both to create and reinforce negative perceptions of the self as being fundamentally damaged and therefore untreatable, thus creating a cyclical process and to some degree, a self-fulfilling prophecy. This mirrors findings from Katsakou et al's (2012) research whereby participants were unable to conceive of themselves as 'recovered' due to the extent to which they had internalised the BPD diagnosis as being a 'part of them'. Shaw and Proctor (2005) argue that the tendency of psychiatric services to focus on the management of behaviours associated with BPD obscures an understanding of the causal underpinnings of distress and thus situates the problem as being located within the individual.

This was particularly felt amongst the women who were interviewed about their experiences of being detained under Section 136. They described how the limited support they received after being detained, and the disproportionate focus on medication as a short-term solution, exacerbated feelings of powerlessness and often resulted in repeated cycles of extreme distress and public displays of help-seeking behaviour (Bendelow et al, 2016).

> *"Actually I was falling through the tracks. Again. And that was kind of my life story. That each time, I'm reaching out for help. And I didn't get any help. I was just being put on medication that would make me go completely crazy."*
>
> *(Brigid – S136 Interview Participant)*

> *"Like the nurses just, all they do is just come to you for a cup of tea and then go, and it's just, that ain't treatment. Go and see a doctor and they'll change your medication or up it, or change it, and like, that's all they ever do, medication, fixed on medication"*
>
> *(Sonia – S136 Interview Participant)*

> *"I feel like I've got no voice. I don't feel like I matter or my wishes matter. It's only what they want that matters. Erm, and you know, the thing that I want, or the thing that I feel I need anyway, is the therapy. Because that is the one thing where I was making the biggest progress and yet they're insistent locally about taking medication. You know, even my keyworker goes on and on about medication, every time I have a low bit it's*

> *‘Oh, Antidepressants.’ It’s like that’s their cheap fix solution. And they think very much short term.”*
>
> *(Sally – S136 Interview Participant)*

Typically, a stable sense of identity is associated with a perception of a sense of agency that is located within the self, rather than being controlled by external variables (Bamberg, 2010). It is unsurprisingly therefore that the narrative identities of those diagnosed with BPD typically contain significantly less agency than those without (Adler et al, 2012). However, whilst identity disruption is typically regarded as a symptom of BPD, it is suggested that it could also be a consequence of the disempowerment experienced by those who are subject to inappropriate treatment over which they have little control (Jørgensen, 2006).

### *8.4.3 Power and control.*

Both Claire’s and Victoria’s accounts reference the imbalance of power and lack of control they have experienced within the psychiatric profession and their apparent preoccupation with issuing medication at the expense of taking the time to understand or discuss the experiences of those with a BPD diagnosis.

> *“They [psychiatrists] are, erm…. deeply superior. They are unwilling to listen to your theories, even if you are somewhere who is capable of doing academic level research. You know, I am someone who can do that. I read a lot of scholarly articles about my condition, about medication. And yet I’ve never yet found an NHS psychiatrist who is genuinely willing to engage in a dialogue with me about my illness.”*
>
> *(Claire)*

> *“Psychiatrists, obviously, are very… obviously they stick with their DSM manual, and… are very focused on medicating you. Often consultant psychiatrists will sit on a ward round – they never mix with the patients - they’ve never sat on the ward and watched… you know, what people are like day to day. They’re just on the ward round with their notes and their booklets and their prescription pads, and it makes me really angry.”*
>
> *(Victoria)*

The issue of control, particularly in how it relates to the stigma associated with the diagnosis, is also referred to by Emily. During her time in in-patient mental health services, Emily was frequently referred to as a ‘non-compliant’ or ‘difficult’ patient – a term that is often used by mental health professionals to describe the behaviour of those with BPD in in-patient settings (Wilstrand et al, 2007). She reflects that the intense emotional responses she experienced whilst hospitalised were a reaction to what she felt was the removal of what little sense of control she felt she had.

> *“It was more like, I was being seen as I was being a non-compliant patient, because when that control was taken away from me, I couldn’t, like, cope with it.”*

*(Emily)*

In her experience, the imbalance of control between staff and patients, particularly in in-patient services, can result in stigmatising views going unchallenged or becoming further engrained and, even more worryingly, exclude the voices of service users in both shaping and feeding back on their care.

> *"And when there's things like, if you make a complaint about a service, who are they going to believe? You, the patient with BPD, who's clearly manipulating everyone because that's what people with BPD do apparently, or the nurse who's got the control."*
>
> *(Emily)*

This feeds into a wider debate regarding the social construction of diagnosis, which suggests that medicalised labels can act as a useful form of social control. This is borne out of the tendency of the medical profession to deal with behaviour that is considered 'non-conformist' by labelling it as illness. (Broom and Woodward, 1996) and the acceptance of a medical perspective as the dominant framework within which to understand mental 'illness' (Conrad, 1979).

Victoria alludes to this debate in explaining some of the issues she has with current psychiatric practise.

> *"I'm quite anti the whole labelling thing, but I also understand why it exists. But I also think it exists for kind of… erm… pretty prejudiced reasons really, and, you know, for the convenience of psychiatrists, who, let's face it, earn a lot of money and… they're very powerful. Power is a big issue in mental health. There's also a kind of, political… there's an advantage to labelling people"*
>
> *(Victoria)*

As Bracken et al (2012) note, the 'technological paradigm' - that is, the assumption that mental health problems can be understood, categorised and therefore treated using the same causal logic as is dominant in other areas of medicine, has led to the psychiatric profession becoming entangled with the pharmaceutical industry. It has been suggested that the move towards community health care represents a major challenge to psychiatric power, and that in order to attempt to maintain this power, the profession has renewed its efforts to align itself closely to its biomedical identity (Thomas, 2014). Thomas (2017) argues that, what has been referred to as the crisis of psychiatry has arisen as a result of the failure of the profession to recognise and respond to the 'non-technical' aspects of clinical care, particularly those that relate to the building of human relationships with service users.

### *8.4.4 Obscuring traumatic histories and perpetuating a diagnosis of exclusion.*

Related to this then, is the tendency, as has previously been noted, to ignore or invalidate the traumatic antecedents that often provide the foundations of what comes to be known as BPD in adulthood. Given the extent to which people diagnosed with BPD are thought to have experienced childhood trauma - up to 90% in some studies (e.g. Carlson et al, 2009) and the links between disorganised and insecure attachment patterns in childhood and the development of 'symptoms' of BPD in adulthood (e.g. Fonagy et al, 2013; Sandstrom and Heurta, 2013), it would seem reasonable that treatment of those with the diagnosis should include some focus on addressing the traumatic histories underpinning their distress. However, the stories of almost all of the women who took part in this research suggest that there is little space within the mainstream psychiatric community to discuss and truly understand trauma, and even fewer services which offer the long-term support necessary to begin to address and process it.

> *"I was told you've just got to get over what's happened to you. You've just got to forget it, blah blah blah"*
>
> *(Sonia – S136 Interview Participant)*

The accounts of the women who contributed to research suggest that it is not the case that the awareness of the prevalence of childhood trauma in people with a BPD diagnosis that is lacking. Rather, there appears to be a failure or reluctance to explore the context of individual experiences and recognise distress and troubled or troubling behaviours as intelligent responses to adversity. As Johnstone and Boyle (2018) note, the focus within mental health services continues to be on asking "What is wrong with you?" rather than 'What happened to you?" The effect of this can be to reinforce existing feelings of shame and self-blame, and, by locating the deficit internally, also serves to deny histories of abuse and inequality (Shaw and Proctor, 2005).

This is clearly evidenced in Victoria's account of her experience with CAMHS, which was discussed in the previous chapter. Victoria was unable to disclose her abuse at the hands of her father for fear of what would happen if she did. However, she conceptualises her troubled behaviour in childhood and adolescence as a 'cry for help', and when this was not acknowledged and she was institutionalised whilst her abuser remained free, she internalised this as confirmation of her wrongdoing and her perception of herself as a 'a fuck up'.

> *"In terms of my identity, until the last few years when I've become, I guess, a bit surer of myself, it's [the BPD diagnosis] just made me feel that I'm a fuck up, that I'm a*

> *problem, you know, I'm a pain in the arse, I'm a nightmare… you know. I was the one that got carted off to the psych ward, my Dad didn't get taken… you know, so I was the problem. So, BPD, I feel like it's kind of, well you're the problem, you've got behavioural issues."*
>
> *(Victoria)*

In contrast to Victoria's experience, in which she feels little attempt was or has been made to uncover or acknowledge the impact of the abuse she was subjected to, Claire and Emily both describe how an implicit assumption of abuse in those with a BPD diagnosis can also be invalidating and led them to question their own memories of past events. As was also discussed in the previous chapter, Claire describes how, whilst under the care of CAMHS, she was questioned at length about whether she had experienced abuse, something which she internalised and searched for even as she developed into adulthood, believing somehow that discovering it would legitimise the distress she felt and help her to move forwards.

> *"Fourteen-year-old me, going into CAMHS and being led to believe there's some hideous abuse that has happened to me that I hadn't remembered. You know, like I say – throughout my 20s it was just out there, like it was coming for me. Like, any day, I was just going to wake up and like, be smacked in the – or, or – I'd walk past someone and be like… yes… you know – one of my teachers would be in the paper, like, you know – exposed as a paedophile, or, erm – a summer camp I went to a couple of times – I was obsessed with that place. Because my parents told me that the first time I went there I was about seven, and they were really worried because I was really young, but I did really well and I absolutely loved it. But they sent me again like two summers later and they said I'd lost all my confidence and I cried every night and I wanted to come home. So, for years I was like – something happened there…! And it just didn't, it just didn't – but I just kept looking for it."*
>
> *(Claire)*

Emily also describes interactions with nurses which have focused disproportionately on seeking out experiences of trauma in order to explain or validate a diagnosis of BPD, something which she feels demonstrates a poor understanding of individual experience and also demonstrates the imbalance of power within some mental health services and the impact this can have on conceptions of self and identity.

> *"I've literally had some nurses be like 'so, erm, did you experience abuse as a child?' and I'd be like, no, and they'd be like 'are you sure?' and it's almost like they're trying to fish it out of you. And I'm like, no, I really didn't. And like, and they're like 'sometimes you block out trauma'. And I'm thinking stop convincing me that I've been through trauma. You're literally like, they're the nurse, I'm the patient – they must be right."*
>
> *(Emily)*

Many years after the experience she describes above, Claire was admitted to the Priory following her breakdown and assessed by a psychiatrist. She describes how she was told almost immediately that she did not meet the criteria to be given a diagnosis of BPD, a decision that she feels was made primarily on the basis that she had not experienced abuse as a child.

> *"So initially the diagnosis was, there is no borderline. He told me that within like 20 to 40 minutes of meeting me. And he said that off the back of very interestingly – it's what a lot of people think, or the view is… he said you don't have it because there was no childhood trauma. So I think, he just instantly took the view that no trauma equals no borderline, equals addiction only really."*
>
> *(Claire)*

Whilst countless studies have undoubtedly demonstrated a link between experiences of trauma and the symptoms associated with BPD (e.g. Paris, 1994; Carlson et al, 2009, Van der Kolk et al, 1991), childhood trauma is not one of the DSM criteria used to inform its diagnosis, and therefore a lack of abuse should not, on the basis of the current biomedical model, preclude a diagnosis of BPD. The experiences of Emily and Claire described above arguably demonstrate an unsophisticated and simplistic understanding of trauma whereby the presence (or not) of a generic definition of abuse is applied in a binary way to both inform and confirm the legitimacy of the BPD diagnosis. Whilst it is promising to see a greater awareness and recognition of the role of trauma within the psychiatric profession, this one-dimensional understanding can have the effect of obscuring or invalidating the experiences of those whose challenging circumstances or adversities may be less clear cut.

Johnstone (2000) suggests that the symptoms of conditions such as BPD may be better understood if viewed as adaptive responses to childhood trauma in order to maintain personal survival and that an understanding of the meaning of the traumatic event and its impact on the individual is more important than its objective 'severity'. This approach could assist in reducing the sense of invalidation experienced by those such as Claire and Emily who have typically relied more on illness narratives to explain their distress and situate their identities – a result perhaps of the trauma they experienced in childhood being less marked or perceived as less serious than others with the diagnosis.

> *"And I think that a lot of people can… get caught in the trap of self-invalidation, because they can compare themselves to some of the stories of trauma and things that people have been through, and they say, 'well nothing like that ever happened to me…' You know, my family… my parents are still together, my… we basically had enough money, you know, I wasn't starving, I wasn't beaten, I wasn't sexually abused, I wasn't anything… so how am I still struggling with the same thing as this person who's had all these things happen to them?"*
>
> *(Katy)*

> *"I know it sounds weird, but actually I do feel sorry - not that I'd want them to have been abused, but I think – especially in group therapy, you have some people who do*

> *not know why they're like why they are. I have the privilege of – oh well, look at that, that and that – no wonder she's like this, you know."*
>
> *(Victoria)*

The tension between the behavioural criteria underpinning the BPD diagnosis, as demonstrated in the DSM, and the high incidence of trauma amongst those who receive the diagnosis is borne out in the tales of frustration expressed by many of the women who contributed to this research in response to the lack of services equipped to provide longer term support to address and process trauma, even when it is acknowledged that this is both helpful and necessary.

> *"In my [Section 136] assessments quite often it was recommended that I have long term psychotherapy – so like, years' worth. But my CMHT as standard you get 12 sessions and at most you might be able to extend it to 18 if you've got a flexible therapist. It's not what has been recommended. Erm, and it's kind of, erm, for skills-based stuff… erm, whereas what my consultant at the moment is recommending is kind of, psychotherapy, where you talk over stuff and you look at patterns."*
>
> *(Naomi – S136 Interview Participant)*

> *"Loads of doctors have said I need to go somewhere residential to go through my traumas, but there's nowhere in the NHS anymore"*
>
> *(Sonia – S136 Interview Participant)*

> *"He didn't have a lot he could do for really, except for up my dose all the time, because I kept saying 'I'm suicidal. I'm suicidal. I'm suicidal.' And he didn't really have any talking therapy to offer me."*
>
> *(Claire)*

Often, as demonstrated above, this is because appropriate services are simply not available – a consequence of a predominating discourse of medicalisation which focuses disproportionately on treating the tangible behavioural 'symptoms' of mental distress rather than the underlying cause (Shaw and Proctor, 2005) and therefore does not prioritise funding for longer-term or trauma-focused therapies.

In the rare cases where therapy that attempts to deal with the trauma and/or abuse at the root of their difficulties is or has been made available, it is often considered unsuitable or has to be terminated due to participants being deemed too 'unstable' to cope with the effects of processing trauma and there not being appropriate support in place to adequately respond to this.

> *"I was out-patient with my therapist who I've got back in contact with, like about a year ago, who I see now and again. But I can't go into detail with her about stuff because she says it's too risky because I'm unpredictable and it will mess my head up."*
>
> *(Sonia – S136 Interview Participant)*

> *"I was referred to somebody who only dealt with child abuse psychology. And I only had one session with her and she just said I was too, what was the word… she felt that if the information came out, that I would end up, you know, keep self-harming or drinking… she thought something bad would happen and she didn't want to continue"*
>
> *(Holly – S136 Interview Participant)*

> *"**Interviewer:** Have you ever had any therapy that's dealt with that trauma, side of things?*
>
> *No, because I'm too unstable (laughs). No. Because, the thing is… trauma… trauma-based services are, again… they're quite limited in what they can offer. So obviously, I'm not wealthy, so I'm talking about NHS services here. But, yeah…no… anything you want therapy for you get it for a limited amount of time and you get whatever happens to be available in that area."*
>
> *(Victoria)*

These experiences appear to be indicative of a mental health system that is both underfunded and ill-equipped to deal with the complexities of trauma. There is also evidence of a lack of a centralised approach to coordinating services and support across NHS based care which means that individuals with the same diagnosis can have very different experiences depending on where in the country they are located. Katy reflects that she feels very lucky to have received the level of trauma-focused support that she has (something that will be expanded upon in the next chapter) but is aware that is predominantly because of the services available in the area that she lives and that many others have not been afforded the opportunities she has.

> *"Just by pure chance I happened to be living in this part of London, but in North East London, erm, NHS have like a really well developed personality disorder service, and that's because they have… it's a research service that's like researching implementation of DBT and all sorts of things. So, for a start I happened to just walk into the mental health services where that's happening. And secondly, the therapist I was allocated… his specialist interest is complex trauma, so he was looking at BPD through the lens of that…*
>
> *I think anyone who was first picked up by that service would have had a similar sort of experience, but I don't think many people are."*
>
> *(Katy)*

Emily's account of transitioning between services and attempting to access treatment shows how the 'postcode lottery' regarding the availability of support can exacerbate feelings of powerlessness, contribute to confusion and uncertainty around the diagnosis and its meaning and create situations whereby the only way to receive help is to become 'more ill'.

> *Leicester's got quite a good personality disorder treatment thing, erm, and when I was discharged from Leicester it took ages for me to get sorted to have a CPN in Derby, because the transition was horrendous as usual. And when I did they were saying there*

> *is no DBT, there is no treatment or whatever for BPD. And it turned out that there was, but basically it was only – you had to have – be based in the Derbyshire postcode, not the Derby City, and it was all to do with that kind of thing. There was literally nothing for people with BPD in Derby City at that point. Then they were saying you can't have that, but you can access like, the counselling sessions or whatever. But when you had an assessment for them they'd say, oh, you're too complex, and that kind of thing. It was a bit of a kind if difficult area, because I was too complex for some, not complex enough for others, and they were saying to me at one point – 'well, you know, if you were sectioned you'd be able to get the treatment' or ' if you were in prison'. Yeah, I'll commit crime, I'll erm, get myself sectioned or whatever – I'm not really willing to do that to get some treatment.*
>
> *(Emily)*

All of the experiences described above demonstrate how privileging the diagnostic label above the individual can contribute to distancing those diagnosed with BPD from their distress, leading to a confused sense of their relationship with themselves, their diagnosis and the trauma that has preceded it. Whilst the process of being diagnosed certainly has meaning and utility for some, the label of BPD is laden with value judgements and assumptions (Mann and Lewis, 1989) which, combined with the treatment received from others on the basis of it, clearly impact upon individual conceptions of identity and sense of self. This is most evident when attitudes towards the semantics of the BPD label are considered and the value of the diagnosis compared against other labels used to describe manifestations of distress.

### *8.4.5 What's in a name? The challenge of semantics and the value of different labels.*

As outlined in chapter two, the Borderline Personality Disorder label has its origins in the work of American psychoanalyst Adolph Stern who coined it in the early 1900s to make sense of a growing population of individuals whose presentation lay somewhere in between the oversimplified diagnostic categories of 'neuroses' or 'psychoses' used to conceptualise mental 'illness' at that time (Masterson, 1988). Since then, it has come to be known by a number of different names, including Emotionally Unstable Personality Disorder (EUPD) and more recently, Emotional Intensity Disorder (EID).

The 'personality disorder' label is often considered to contribute towards the stigma associated with the diagnosis in that it seems to indicate that it is the whole person (or personality) that is flawed. It has been argued that the label itself constitutes little more than a sophisticated insult (Herman, 1992). It is therefore useful to briefly examine participants' experiences and reflections on the language associated with their diagnoses in order to contribute an understanding of the value and meaning of different labels and how they are integrated into the identities of those to whom they relate.

Katy, Emily, Victoria and Claire's narratives all reflected an understanding and awareness of the negative connotations associated with the label and the challenges surrounding it. For Claire and Victoria, the BPD label is the most problematic, largely because of the way that it is portrayed in popular culture, the misunderstanding and confusion surrounding it and the implication that the individual is in some way responsible for their own distress.

For Claire, the label of BPD is evocative of Victorian notions of femininity as dangerous and something to be contained.

> *"The true origin of it [BPD] is that you're on the borderline between a psychotic and neurotic, is that right? Psychotic and neurotic. You know, I dislike that a lot, because a neurotic is another word that brings to mind hysterical women, the wandering womb theory, you know – all that bollocks, all that medieval, you know, child birth… women are dirty, dangerous and must be shunned during their periods. It brings all that to mind, that really really profoundly anti-feminist, anti-woman… medical history of which is there is a great deal."*
>
> *(Claire)*

This interpretation reflects the implicit assumption within the diagnostic label of the problem as occurring somewhere within the non-conforming or damaged self, as well as notions of femininity as being in itself psychologically unhealthy (Ussher, 2011). Claire considers this to be deeply problematic:

> *"And that's, you know, the difficulty with telling someone that their personality is disordered. Erm… I mean, I just think it's such a problematic term. I struggle to think of another diagnosis where, erm, where the diagnoses implies that you are complicit in your own illness."*
>
> *(Claire)*

Victoria is critical of, and feels badly treated by the psychiatric community, and therefore strongly believes that there is little space for diagnostic labels of all kinds within modern society. However, she feels that the BPD diagnosis is particularly problematic because of the confusion it causes and the way that negative portrayals in the media can reinforce stigmatising attitudes and negative perceptions towards people who are given it.

> *"Borderline Personality Disorder is too confusing for the general public, because they're like – you've only got a bit of a personality disorder…? And I think if you Google it, it'll be like, films about Borderline Personality Disorder, like single white female, and… there'll be those forums that are like 'Oh, my partner's got BPD and they're such a pain in the arse.' Like 'Just leave them, nobody can be in a relationship with a Borderline." You know, they're… so if we relabelled it, and least when people are Googling they might not come up with… I dunno but, sorry, I'm being long about it. But yeah, they all piss me off, yeah…"*
>
> *(Victoria)*

> *"Borderline, you know, because it sounds like you've almost got a personality disorder, Borderline is meaningless. I mean, nobody – literally nobody knows what it means. I've met so many women who are diagnosed with it who have no idea that it means you're on the borderline between psychosis and neurosis. I've met so many women with it who have no clue that that's what it actually means."*
>
> *(Claire)*

However, Emily suggests that the confusion and uncertainty surrounding the meaning of BPD may actually be a strength of the label and an argument for using it instead of the frequently used (and often preferential) alternative of EUPD, which she believes is overly reductionist and potentially creates more stigma than BPD.

> *"I hate Emotionally Unstable Personality Disorder too, because if you tell somebody you've got that they're just 'Oh, ok, stay away from you' whereas if you tell someone you've got Borderline Personality Disorder at least they don't really know what it means (laughs). I'd rather they just didn't really know and asked than, think, oh, she's emotionally unstable, be careful."*
>
> *(Emily)*

Victoria's criticism of the EUPD label stems from its inability to accurately portray the complexity and severity of the emotions and behaviours associated with the diagnosis. She does, however, feel that it is slightly more useful in that it does contain a descriptor which gives some indication of the nature of the condition.

> *"I think the emotionally unstable is more accurate in terms of describing the moods, but is also a bit dismissive, it doesn't describe – it just makes you sound like you're a bit wobbly, you know. It's way more than that, it's more intense.*
>
> *(Victoria)*

Claire also agrees with the view that EUPD is more descriptive but also echoes Emily's concerns regarding the (self and external) stigma associated with being labelled as both fundamentally disordered *and* unstable.

> *"EUPD I think is… I mean it's… it's better in the sense that it's descriptive, so it does… emotionally unstable has some meaning. But in a way it's even worse – they've managed to get the personality in there, and unstable as well."*
>
> *(Claire)*

Claire was introduced to the term 'Emotional Intensity Disorder' a number of years ago when exploring treatment options. She believes that this terminology is both more accurate in terms of reflecting her experiences and contains less implicit bias which has helped her to begin to reconceptualise her sense of herself as someone who is ill rather than inherently defective.

> *“When I first came across the EID diagnosis was through a lady who is the Trust lead for personality disorders, and is particularly interested in BPD/EID. And she’s the one who introduced me to the term emotional intensity disorder. And I like that term so much better, because that’s what makes sense to me. Erm, it doesn’t have the word personality in it, so you don’t feel like you’re being told that your character is under attack, or your character is flawed. It’s simply that you have more intense emotions, both positive and negative, than other people.”*
>
> *(Claire)*

Claire’s account of how a reframing of the BPD diagnosis on the basis of semantics has fundamentally changed her positioning of herself in relation to it demonstrates the function of diagnostic labels can have on how people understand and form identities and create stories about themselves on the basis of these labels. This is particularly the case when, as is typical amongst those diagnosed with BPD, individuals’ have a disrupted or unstable sense of themselves prior to diagnosis (Clarkin et al, 1983; Spitzer et al, 1979). Given the confusion and controversy surrounding both the BPD and EUPD labels expressed by the participants in this research, there is support for Jørgensen’s (2006) claim that the application of the diagnostic label could contribute to or further exacerbate confusion and identity disturbance, therefore potentially rendering an unstable sense of identity both a symptom *and* a consequence of BPD.

To illustrate this, it is useful to consider participants’ attitudes towards other mental health diagnoses, their perceived value and how they are understood to impact on treatment received by professionals. The primary concern emerging from these discussions seemed to be a sense that conceptions of the diagnosis of BPD, as the name suggests, lie somewhere on the border between more medicalised diagnoses such as Bipolar, which are typically regarded as being more a product of neurochemistry, and diagnoses such as Complex PTSD which place more emphasis on trauma and therefore contextualise the dysfunction within the environment in which it occurred. It is the experience of the women who took part in this research that attitudes towards diagnoses that sit more neatly at either end of the spectrum are more favourably and compassionately perceived than BPD, which is poorly understood and therefore widely stigmatised.

> *“Schizophrenia is one thing – it’s got frightening connotations because of the fucking media, but it’s one thing – and you can tell what it is, and you know it’s brain chemistry, and you know it’s not somebody’s fault, because you can scan the brain and you can see it’s a schizophrenic brain – you can scan the brain and see it’s schizophrenic. So that to me says, oh it’s medical, oh it’s medical – it’s definitely medical. Bipolar is still relatively new. But again – at least it sort of does what it says on the tin. Erm, it is bipolar – it’s descriptive – it’s not unipolar, it’s bipolar. It’s only when you get into the personality disorders that you really feel like, actually this is nasty. This is nasty to be told that your personality – and especially, especially – I’ve never, I mean – as far as I*

> *know, I’ve never met one. But, erm – to be told you’ve got narcissistic personality disorder – god knows what that feels like.”*
>
> *(Claire)*

Victoria has a diagnosis of Bipolar in addition to her BPD diagnosis and has more recently also been diagnosed with Complex PTSD, something that will be discussed in more detail in the next chapter. Although she feels that all of her diagnoses essentially represent the same set of difficulties, she considers that when she has spent in hospital as a result of the symptoms more closely aligned with the Bipolar diagnosis she has generally been met with a perception of being more legitimate and deserving of in-patient care.

> *“When I’ve been sectioned because I’ve got ‘bipolar’, in inverted commas, I… yeah, there’s an acceptance that you need to be in hospital. They see it as kind of a neurochemical thing, not realising that all emotions are basically neurochemical.”*
>
> *(Victoria)*

Within the disability community, there is a widespread understanding that the use of negative language can have a major influence on public and professional attitudes and impact upon the treatment received by people with the associated conditions (Dahl, 1993). Katy and Victoria both have a diagnosis of Complex PTSD, and although Katy feels as though there is some utility in also having the BPD label and is generally fairly positive about it, she recognises that Complex PTSD is a more straightforward label that does not carry with it some of the difficulties associated with BPD.

> *“Complex PTSD, if you say to somebody, you know, I’ve got PTSD, they’re kind of just like, well, ok, something bad has happened to you, and so you have difficulty managing stuff because of that, and it’s much more… it’s a more forgiving diagnosis in a lot of ways.*
>
> *(Katy)*

Victoria also believes that Complex PTSD is a much more compassionate diagnosis which more accurately acknowledges and reflects the contextual factors that contribute to experiences of distress.

> *“When someone talks about me having PTSD, I feel that that’s a compassionate diagnosis, it’s an acknowledgement that something happened to you and you’re having a reaction to it, and it’s not your fault.”*
>
> *(Victoria)*

She also believes that having a diagnosis of Complex PTSD can open up more doors with regards to accessing appropriate forms of support to effectively process trauma, but, having had her BPD diagnosis for so long, now feels some solidarity with it, suggesting that despite her criticism of it she does still feel it to be in some way part of her identity.

> *"If I get rid of enough of the symptoms then I'll have a Bipolar Type 2 diagnosis, or just a Complex PTSD diagnosis – they said they're refer me to trauma therapy after. But a bit of me wants that, because I'd be taken more seriously by services. But another part of me wants to say, no… I'm diagnosed with BPD and kind of, I feel… in solidarity with other people who, should hang on to it and try and explain to people what it actually is."*
>
> *(Victoria)*

The above accounts lend weight to previous research which suggests that the diagnosis of BPD is based on subjective, value-laden judgements which ignore the contextual underpinnings of distress and have led to an enduring perception of it as a diagnosis of exclusion (Paris, 1996). The experiences of stigma participants describe having encountered as a result of the diagnosis indicate a strong argument for a moving away from the current diagnostic framework towards a more compassionate and individualised understanding of distress which is not beholden to rigid labels or categories (Johnstone and Boyle, 2018). However, this is clearly an ambitious undertaking which will take time to implement. This research has begun to show that the labels people are given have a significant impact both on how they perceive themselves and how they are treated by mental health services. In the meantime, therefore, it is recommended that more thought should be given to how diagnostic labels are understood and assigned, particularly when there are overlapping symptoms and histories of trauma that may be better served through a diagnosis of PTSD or Complex PTSD rather than BPD.

## 8.5 Conclusion

This chapter has offered a detailed exploration of the complex stories constructed by participants in relation to their sense of selves and their relationship with the BPD diagnosis. There is some evidence from participants' accounts to suggest that identity disturbance, as well as being a 'symptom' of BPD thought to originate from insecure attachment patterns in childhood (Masterson, 2000), can be exacerbated by its diagnosis. For all participants, even those who rejected the diagnostic label of BPD and saw little utility in it, BPD was a strong feature of their identity. To varying degrees, all had internalised aspects of it as being fundamental to their sense of self – unsurprising, given that the very nature of diagnosis situates the 'problem' or distress as being implicitly located within the personality of the individual (Herman, 1992). However, the complex and fluid stories participants told about their identities were further complicated by the tension between the conceptualisation of BPD as something intrinsic to the individual and the traditional biomedical notion of a ‘illness’ that can therefore be cured. Some participants found a sense of validation in having a framework and label with which to explain and situate their difficulties. However, the tension identified above means that participants struggled to conceive of themselves outside of the diagnosis and therefore expressed fears about ‘what would be left’ of them if they were to become well. This has clear implications for treatment practices and understandings of recovery that will be explored further in the discussion.

This chapter also explored the impact of mental health services and professionals on participants’ feelings towards both themselves their diagnosis, and explored themes of power and control, the conceptualisation of distress as attention seeking and the tendency for the diagnostic label of BPD to obscure an understanding of the individual experience. This can lead to inappropriate forms of support which do not address root causes of distress as well as exacerbating existing feelings of invalidation and worthlessness. Finally, the analysis concluded with an exploration of the role of language and semantics on attitudes towards diagnosis. Whilst participants had their own personal preferences with regards to the label they chose to use to describe their difficulties, their accounts highlighted the lack of compassion afforded to the BPD diagnosis in comparison to, for example, CPTSD. The experiences participants relayed in terms of the discrimination experienced at the hands of friends, family and most crucially, professionals demonstrates that stigmatising attitudes around the diagnosis of BPD still perpetuate and can have huge implications for recovery as well as identity and selfhood (Horn et al, 2007).

The next chapter will continue to navigate the broad chronology of participants’ journeys and conclude the analysis by exploring the ways in which the women who took part in this research have started to move beyond the BPD diagnosis and reconceptualise their identities in a way that is not so reliant on the ‘illness’ identity created in response to BPD. It also offers an analysis of the ingredients of effective and appropriate forms of support that have assisted participants in negotiating these identities and addressing the traumatic antecedents of their distress.

# Chapter 9: What works? Moving beyond a diagnosis of BPD

Understanding ‘recovery’ and the role of creativity in renegotiating identity

## 9.1 Introduction

In the previous chapter, a tension was identified between the conceptualisation of BPD as something intrinsic to an individual’s personality functioning and the popular biomedical understanding of a ‘illness’ that can therefore be cured. As was outlined in chapter two, this is a tension that underpins many of the debates and controversies surrounding the BPD diagnosis and has clear implications for how individuals with the diagnosis are treated by mental health professionals as well as for how they relate their own identities to the diagnosis.

Keeping this tension in mind, this chapter explores the meaning of ‘recovery’ to women with a diagnosis of BPD, including the application of this in practical terms. Based on this definition of recovery, it then investigates the elements of treatment and therapeutic relationships that are contributing to making it a reality – returning to the themes of invalidation and trauma discussed in the previous two chapters. Taking this further, this final analysis chapter then goes on to provide a detailed exploration of the role of creativity in managing some of the ‘symptoms’ associated with BPD and in fostering a sense of identity that is congruent with notions of recovery expressed by participants, drawing upon the literature regarding the benefits of creativity to mental health to support this.

Finally, this chapter concludes with an analysis of how the various factors discussed have enabled participants to begin a process of reconstructing a sense of identity that is not so heavily dominated by the medicalised label of BPD. Drawing upon elements of Frank’s (1995) quest narrative and Williams’ (1984) theory of narrative reconstruction, the analysis will discuss how participants in this research are developing a new, more coherent and authentic sense of themselves that is located within but not dominated by the framework of BPD and functions to serve their own needs rather than meet the needs of others.

## 9.2 Towards a concept of ‘recovery’: Understanding the ingredients of effective services and support

### *9.2.1 Compassion, resilience and letting go: Definitions of ‘recovery’*

Echoing previous research in this area, participants' narratives reflected their understanding of 'recovery' as an open-ended journey involving firstly an acceptance of, and secondly, a desire to create a meaningful life within the limitations of the challenges associated with their mental health (Katsakou et al, 2012). Claire's, Victoria's and Emily's initial responses to the question of recovery further demonstrates, as was discussed in the previous chapter, the extent to which the diagnostic category of BPD blurs the boundary between 'illness' and identity. Mirroring (and perhaps reflective of) the viewpoint of many in the psychiatric profession that individual with BPD are 'untreatable', they consider that, for them, recovery is unlikely to mean being completely free of the symptoms that make up the diagnosis. However, they express an optimism that it is possible to develop more positive ways of coping that allow them to manage the intense emotions they experience.

> *"I think emotional intensity will always be a part of my life. But I think I can learn to deal with it in a way that is completely healthy, and therefore I can be… I believe I can be completely healthy."*
>
> *(Claire)*

> *"I don't think I will ever fully recover from the symptoms that are included in the label, erm, and I'm not sure I want to either."*
>
> *(Victoria)*

> *"I don't think all of it can go, and I think a lot of it is genetic. So, I think it'll always be… there, but I definitely can have better control of it."*
>
> *(Emily)*

According to previous research, the recovery goals expressed by people with a diagnosis of BPD typically include improvements in self-acceptance, relationships and employment, as well as more specific goals such as gaining control over difficult emotions and the behaviours (e.g. self-harm) associated with them (Katsakou et al, 2012). The depictions of life in recovery expressed by participants each contained elements of some of these previously identified factors. Victoria's understanding of recovery is centred primarily on building emotional resilience and gaining some control over the strong reactions and behaviours that are a product of her emotional intensity.

> *"I suppose for me recovery would mean… being… being less reactive, so… not, you know, not feeling so emotionally raw that the tiniest thing would set you off. I mean, I think that would be a… almost being a bit more resilient. Like, more waterproof to psychological weather I guess, you know like. Also, that I would have some control, yeah, in, how quickly emotions come, how strong they are, and how quickly they escalate. How quickly – how long, you know, it takes to get rid of them. And also have control over the behaviours that are a response to those emotions, most of the time."*
>
> *(Victoria)*

Emily's perception of recovery also focuses on being able to gain control over her emotional reactions, something which she believes is linked to self-compassion. She considers that moving beyond an understanding of herself as a 'terrible person' will enable her to react in more appropriate ways to situations that challenge her perception of herself and manage what she describes as her sensitivity in healthier ways.

> *"One of the things I've sort of done, is I've learnt to like, physically hug myself, or like put the Lego characters together in a hug to say, it's ok, it's to feel hurt by that, it's ok to be sensitive, but it's what you do then with that pain. Do you internalise that to say, it's my fault, I'm a terrible person, or do you say that really hurt me, but what they're saying isn't really real, it's not true or whatever, and sort of dealing with it a little bit better. So, I definitely want to learn to deal with it better, I want to be in control of it."*
>
> *(Emily)*

Claire also recognises the importance of self-acceptance and compassion in her journey of recovery and, like Emily and Victoria, would like to develop healthier ways of coping with the emotions that are difficult and overwhelming.

> *"The most important thing that recovery means to me is having – is not loathing myself anymore. It's having sympathy, and empathy, for myself. So, it's about trying to have sympathy and empathy for myself. That's such a fundamental part of recovery for me. I think if I can do that – I think if I can be kind to myself, I can be healthy. I can live with this illness and be healthy. And that means not self-harming anymore - but dealing with those difficult emotions in a different way. Erm… it means, you know, accepting that I have self-destructive urges, and letting myself occasionally indulge them in a safe way, in a safe space."*
>
> *(Claire)*

However, in contrast to Claire's, Emily's and Victoria's accounts of regaining control, Katy's vision of recovery is one where she is able to let go of her hypervigilant need to control and manage all aspects of her life and be more open to uncertainty and emerging possibilities. This is a clear example of the way in which similar 'symptoms' can be understood depending on the context in which they are framed, which, as will be discussed later in this chapter, can be one of the functions of effective treatment as well as a consequence (as was demonstrated in the last chapter) of stigmatising views and inappropriate forms of support.

> *"I think that is what recovery looks like… not needing to know what's going to happen, because people have goals, and people have aims, and people have paths that they're on, but people don't have to know exactly where something's going to end in order to take the first step. And I think for me, a recovery will mean having a mindset where I'm not so afraid to just let life happen to me. Because at the moment I'm making life happen, and by doing that I'm stagnating it, or I'm sending it down bad tracks because I don't know how to do anything better. I think it's being able to drop my anxiety to a level where I can just let life happen."*
>
> *(Katy)*

Practically speaking, both Claire and Victoria consider that a desirable outcome of recovery would be an ability to work. For Claire, this extends to using her time in a meaningful way, something that she does not currently feel able to do, and for Victoria, recovery would mean being able to have what she considers to be a healthy romantic relationship and be stable enough to look after a pet.

> *"So yeah, and… my idea of how I would behave if I was recovered is that I would be able to work, I'd be able to have a relationship with someone without going through their phone and emails, and things like that. And I've have a dog. But yeah, that's my little picture of recovery and what it looks like."*
>
> *(Victoria)*

> *"It [recovery] means some form of gainful employment. It means, erm – doing something with my time that is meaningful to me. Whether that's my gainful employment or whether that comes from somewhere else, because I'm so dramatically underqualified and now have such a spotty work history that my options are severely limited."*
>
> *(Claire)*

Whilst there are clearly differences in the way that all four participants describe their ambitions and visions for recovery, their narratives share one key similarity, in that they all reflect a sense of living *with* a diagnosis of BPD, rather than overcoming it or indicating a desire to return to a 'pre-illness' state (Nosek et al, 2012). This aligns closely with Frank's (1995) quest narrative, whereby the experience of illness is reworked by the narrator to depict a transformative process in which the self is placed at the centre and grows and changes in response to the illness. Given the degree to which participants' identities appear to be closely linked to those elements which can be seen to represent 'symptoms' of BPD, and the difficulty they have in expressing a sense of their identity prior to receiving a diagnosis, it is of little surprise that understandings of recovery are based on a desire to develop within the framework of BPD rather than remove all of the elements of it completely. This quest narrative manifests as a bringing to the fore the things that are regarded as the 'positive' aspects of the diagnosis. These are typically the more desirable personality traits, e.g. empathy and passion, which some participants feel have developed or are present as a consequence of what they understand to be BPD.

> *"Erm, it [recovery] means retaining the positive aspects of the illness, erm, without… letting the negative aspects of it rule my life."*
>
> *(Claire)*

> *"I don't want to be happy. Because a lot of people say, 'I just want you to be happy'. Erm, I don't actually want to be happy; I just want to be able to deal with whatever it is I happen to be feeling. So, I'm not saying I don't ever want to be happy. But for me,*

> *being recovered isn't about just being happy non-stop. It's about being able to feel all kinds of different emotions. One of my cousins is super functional. You know, on paper, she's psychological perfection. But she – there's nothing – it sounds really cruel, but from my opinion, I get nothing out of talking to her. There's nothing to her, because everything she feels is uniform and appropriate. And I'm like, does nothing make you angry? Does nothing make you like, so excited you want to wee? (laughs) Like, I dunno, I wouldn't want to be someone with no kind of flair, or… weirdness to them."*
>
> *(Victoria)*

> *"I think, because some parts of BPD are kind of related to personality, those things I don't think will change. Like, being a really sensitive person, but, and I don't – I do and I don't want that to change, because it does my head in, but at the same time it means that I can be more sensitive with other people if I need to be."*
>
> *(Emily)*

The previous chapter identified how invalidating experiences of mental health services and a lack of control over the treatment received can lead to feelings of powerlessness and exacerbate the identity confusion associated with a diagnosis of BPD. Unlike Frank's (1995) restitution narrative, in which the ill person is framed as a passive recipient of treatment or medicine designed to return them to their former healthy selves, the quest narrative situates the ill person as the agent, whose goal is not to return to health but to learn to live with illness.

### *9.2.2 Choice and control: Fostering a sense of agency in a treatment setting*

A sense of agency is strongly associated with the development of a stable and integrated sense of identity (Crawford et al, 2004), one of the things that individuals with a BPD diagnosis often do not have experience of. It follows, therefore, that listening to the voices of those with a BPD diagnosis and allowing them the space to shape their own treatment could be an important step in rebuilding disrupted identities and developing a sense of self-acceptance and self-esteem.

As outlined in the previous chapter, the majority of the women whose interviews about their experiences of S136 were subject to secondary analysis had, at the time of interview, not been fully able to negotiate a way out of the cycle of distress which punctuated their experiences of living with BPD. A principal theme of their narratives was a lack of agency which led to depictions of themselves as disempowered victims over an 'illness' over which they had no control. Most had been offered little in the way of effective support to manage their symptoms, something which undoubtedly contributed towards this perspective. However, in the few cases where participants described experiences of treatment which provided them with appropriate tools to regain a sense of control over their mental health or allowed them to exert a degree of influence over the care they received, their stories contained significantly more agency and situated them more centrally to their own recoveries.

> *"And then I got a tool and she was working with me and giving me tools that I didn't have before, and that was making such a difference, and it made this hospital stay a positive because I got tools – because the first time I didn't get anything. There was nothing. And she also gave me different, other tools, about controlling my emotions. Because I never learnt how to control my emotions"*
>
> *(Brigid – S136 Interview Participant)*

> *"So, she agreed that what we'd do was make a completely new care plan that was me and her, you know, devised ourselves, and we'd put in things like, if I get ill this will happen, and…*
>
> ***Interviewer:*** *So you feel like you've got some ownership of it?*
>
> *Yeah.*
>
> *(Holly – S136 Interview Participant)*

> *"It's like anything in life… you've got to put the work in. You've got to know, you've got to be prepared. And even my care coordinator said last time she saw me that I've got the right support now so… And I'm willing to use it as well."*
>
> *(Chrissie – S136 Interview Participant)*

The NIMH (2003) recommend involving patients as experts in designing services and interventions appropriate for those with PD diagnoses and highlight the importance of clear and negotiated treatment contracts. Katy feels that having a therapist who has provided a space for her to openly discuss her treatment and has respected her opinions and decisions regarding what she considers beneficial has allowed her to regain a degree of self-confidence and helped build a sense of herself as an autonomous agent in her own recovery.

> *"Where I've had difficulties with therapists has been, erm, when they've stuck too rigidly to like the manual, and been like 'no, this WILL work for you.' I had this one therapist that I just couldn't like… I just argued with her constantly – and I'd go to my individual therapist and I'd be like 'she said this, blah blah blah' and he'd just be like 'Well just don't do it then, you don't have to do it. If it's going to harm you to do it, don't do it, it's your life.' And it's really helped me to develop self-efficacy and those sorts of things, instead of just deferring to everyone all of the time about what's going to help me…"*
>
> *(Katy)*

Emily also considers that having a variety of treatment options available is important to ensure that services reflect individual needs and preferences and allow for a degree of choice and control.

> *"And I think different things are going to help different people. So I think having different ways is really important."*

*(Emily)*

Prior to the Cognitive Analytic Therapy (CAT) she was receiving at the time of interview, Claire completed the STEPPS (Systems Training for Emotional Predictability and Problem Solving) course, a practical treatment for people with BPD which is based on Cognitive Behavioural Therapy (CBT). As well as being the place where she was first introduced to the term Emotional Intensity Disorder as an alternative to BPD, she found the STEPPS programme useful because it provided her with practical tools that allowed her to feel more in control over the trajectory of her 'illness'.

> *"And for me, because I am quite an academic person – the classroom environment, you know – I did all my homework, and I got it all in on time, and, you know – and so that felt good for me. It felt like taking control, and that's what I wanted – I wanted to feel like I had some control over my destiny in this. Like, my destiny wasn't going to be written by the illness."*
>
> *(Claire)*

However, she reflects that the group-based classroom environment may not be the most appropriate setting for everyone and that that the proscriptive nature of the workbooks and exercises could be overwhelming. She considers that CAT is more effective because it allows a greater degree of collaboration between herself and the therapist. Echoing findings from Katsakou et al's (2012) research, she also suggests that the STEPPS course is too heavily focused on specific symptomology and does not allow for individual consideration of the underlying causes of distress.

> *"It is work. It's a classroom. It's not a therapy room, it's a classroom. But it's a classroom where you're being asked to share things that are quite emotional and personal. I think Steps has a lot to offer, I really do. I think it gave me a lot. But it didn't quite get me there. It's very focused on the behaviours, it's not really interested in the causes."*
>
> *(Claire)*

### *9.2.3 'What happened to you?': Privileging traumatic histories and understanding threat responses.*

The previous chapter discussed the effect that mental health services that focus exclusively on asking 'What is wrong with you?' can have on the way in which those with a BPD diagnosis understand and relate to their own identities. The stories told by participants about their experiences of interacting with the psychiatric profession indicated that when the presence of trauma was acknowledged, this was often in an attempt to identify straightforward causal pathways rather than inform a nuanced understanding of the underlying factors and meaning making contributing to distress. One of the core principles of the Power Threat Meaning Framework (PTMF; Johnstone and Boyle, 2018) therefore centres on identifying and privileging meaning-based threats and restoring the links with the protective mechanisms and behaviours developed in response to them.

Katy's story reflects the most tangible example of how therapeutic services that acknowledge and privilege experiences of trauma can impact on service users' perception of themselves and their diagnosis. Katy had no prior experience of accessing mental health services prior to referring herself online to her local CMHT. After making initial contact and receiving her various diagnoses (including CPTSD in addition to her BPD diagnosis) she was quickly referred to a specialist personality disorder service where she received 18 months of treatment, including individual therapy and Dialectical Behaviour Therapy (DBT). At the time of interview, she was continuing her treatment with the same therapist through Mind (the mental health charity), despite having been discharged from the personality disorder service itself. Her account suggests that, unlike some of the treatment described in the previous chapter, the service she accessed has adopted a trauma-informed and compassionate approach which seeks to understand the experiences that have contributed to distress rather than focusing exclusively on the troubling or 'unwanted' behaviours and locating them solely within the rigid framework of diagnosis.

> *"The whole service is formed around the understanding that all behaviour is caused, and they don't assume that everyone has been through some kind of… what you might think of classically as trauma, but they… like the whole DBT programme is taught from the point of view that everyone who's there is the product of their environment, and their environment must have been invalidating, and must have been in some way emotionally neglectful in order for them to develop the coping mechanism they developed. Because those are the result of that type of environment.*
>
> *(Katy)*

Of all the participants who contributed to this research, Katy's narrative undoubtedly reflects the most positive attitude towards the BPD diagnosis. Her experience echoes the findings of previous research, whereby service users who have been able to access to treatment that is considered to be helpful and appropriate typically report more positive attitudes towards the diagnosis (Bendelow et al, 2016; Horn et al, 2007).

> *"There's a label for it and that label will enable you to get help for it."*
>
> *(Katy)*

For Katy, one of the consequences of having a consistent therapeutic framework which both acknowledges and privileges her trauma has been to foster a greater understanding and explanation for her negative perception of herself. Whilst she considers her recovery very much still a work in progress, Katy reflects on the progress she has made which has allowed her to understand that this negative perception is just that, and she is optimistic of future changes which she hopes will enable her to view herself in more compassionate ways.

> *"And that's not to say I've moved to a place where I completely dismiss that negative self-image all the time. But I understand that it is a self-image and that it can be changed. And that it is a product of the things that have happened to me and the ways that I've been made to think about myself. Erm, and that's a massive amount of progress and change."*
>
> *(Katy)*

Victoria's experience of accessing services and support to help her understand and manage her distress has been less straightforward, and far less positive than Katy's. However, at the time of interview, she had recently begun DBT and was finding it useful in helping to validate her experiences and reverse the perception of herself as fundamentally bad that she had internalised as a child. This negative perception, she felt, had been reinforced by the diagnostic label of BPD, and in turn by the majority of psychiatric services she had accessed so far.

> *"And most therapy is like, you need to do this, whereas DBT is a bit more compassionate. I mean, they will say, that was awful, that's not fair, but, anyway, you're here now so you've got to do this, this and this. Like the whole point of DBT is to validate, yeah, like any individual that has gone through this, this and this, would feel like this, this and this. However, the way you respond to that isn't very helpful."*
>
> *(Victoria)*

Specialist therapies such as DBT have often been criticised for focusing too heavily on specific symptomology and thus not allowing for consideration of other issues that are perceived as important by those with a BPD diagnosis, including individual experiences of trauma (Katsakou et al, 2012). Victoria now has a Complex PTSD diagnosis in addition to her BPD diagnosis, a clear acknowledgement of the traumatic antecedents to her distress, but has been told that she will not be referred for specialist therapy to help process and address her trauma until she has 'got rid' of enough of the symptoms regarded as being part of her BPD diagnosis, something which she hopes DBT will help with. Whilst she acknowledges that the DBT model can be proscriptive, she feels that its trauma-informed approach has been helpful in validating a gradual shift towards a reconceptualising of her distress and distressing behaviours as a product of her traumatic childhood rather than an innate personality fault.

> *"But I still do have a lot of… the way that I make sense of my symptoms, that are called BPD, is that they are… they all make sense in the context of my upbringing, my life. They are actually trauma reactions, they're normal responses. They're textbook responses to… to childhood abuse. So, from my point of view… that's how I would explain my symptoms I suppose. But it took… I don't think… that took a lot of hard work and… I think I'm lucky that I managed to get to that stage, because for most of my life I felt, no… I was, it was me. There was something wrong with my personality, and there was always going to be, so what was the point."*

Whilst she is still critical of the diagnostic label of BPD, she accepts that it currently has utility in enabling her to gain access to support that she considers helpful.

> *"I've accepted the label so I can have DBT, because it does help with the symptoms that I suffer from."*
>
> *(Victoria)*

Despite NIMH guidance published in 2003 which heralded personality disorder as being 'No longer a diagnosis of exclusion' (NIMH, 2003, p.1), Emily's more recent experience of accessing DBT indicates that positive changes have taken some time to implement and that there are still some barriers to accessing specialist treatment.

> *"It's funding, it's all funding, you can only get funding if you've got a diagnosis. I was offered DBT, and I think I was the first Derby City person to be offered it. And Lucy was then, not long later, offered it. And then it's become the norm now…"*

Having completed a course of DBT, Emily is now receiving 1:1 therapy as an outpatient, which is based on the transactional analysis (TA) model founded by Eric Berne in the 1950s (Steiner, 2005). TA focuses on identifying and explaining the patterns and functions of communication and relationships, which includes exploring the origins of the relationship with the self. (UKATA, 2016). Emily reflects that approaching her difficulties in this way, and using visual ways of representing the different aspects of the TA model, has helped her to feel more connected to the feelings and emotions underpinning her distress and allowed her to reflect, in a constructive way, on the way in which her early relationship with her parents has impacted both on her perception of herself and the way that she thinks, feels and acts.

> *"And I think now I'm having therapy as an outpatient and he [the therapist] often mentions attachment and stuff like that, and I've found it quite helpful to look at it in those sorts of ways. And I'm actually using Lego, and – you know the characters from erm, Inside Out. I've got a little house that I've made that they live in and like, I've created their little control room of the emotions, and I move them around and take pictures of them and that sort of thing. And all the characters represent like, different parts of the transactional analysis model, and it's just so helpful. Just really looking at why I feel how I feel and what's going on – when is the critical parent in control, and why are they, and how have they got that power. And the free child is kind of, a product*

> *of the nurturing parent. And my experience of the nurturing parent has been quite… conditional. And obviously that's kind of, all the internal… stuff, but often how then does that relate to external situations and stuff, like, erm, yeah – like, I've been doing that for over a year and we're going to carry on doing it. And just, yeah, seeing the characters and stuff helps me to understand it so much more. Understand myself and connect with it more."*
>
> *(Emily)*

Emily does not explicitly frame her early experiences as trauma, and, as was discussed in the previous chapter, has found that the tendency of the psychiatric profession to focus on identifying the tangibly traumatic antecedents of BPD can be invalidating. The extent to which participants relate their early experiences to the 'symptoms' of BPD they experience in adulthood is one of the key differences in their accounts, but, as Johnstone and Boyle (2018) note, the need to identify specific causal pathways (e.g. the presence of physical or sexual abuse) can obscure an understanding of the importance of meaning, and cause less obvious links between threats and threat responses to be overlooked. This is particularly true when the 'threat' is subtle, cumulative, and/or considered socially acceptable, as is arguably true of Emily's and Claire's early experiences of invalidation. Claire's narrative in particular remains largely grounded in the biomedical model of illness and, despite being able to articulate her experiences of having her emotions invalidated in childhood and the pressure she felt to conform, she generally does not link these experiences to her diagnosis of BPD in adulthood. However, at the time of interview, Claire had recently begun Cognitive Analytic Therapy (CAT), something which she feels is enabling her to gain a greater understanding of how her patterns of emotions and behaviour have been influenced by her past relationships and experiences.

> *"It's patterns of – it's sort of identifying patterns of behaviour, and patterns in relationships. So, it starts off very much in the past. You spend the first four or five sessions talking about your family. They start with grandparents – and very detailed descriptions of your grandparents. Erm… then your parents, your parents' relationship with their parents, so all very, sort of focused on the past initially. And then it says, ok, so that's the past – here are the patterns that the past has created – let's find a way to move past them. Very much your own narrative."*
>
> *(Claire)*

Unlike CBT, which arguably focuses primarily on addressing the problematic behaviours associated with feelings of distress, CAT is concerned with identifying the underlying causes of these problematic behaviours and building an understanding of the mechanisms of relating to the self and others that were employed to maintain survival in the face of feelings and situations that were often intense and unmanageable (Association for Cognitive Analytic Therapy, 2020). Although she is still in the very early stages of her recovery, for Claire, exploring the past and being supported to make and legitimise the connection between the feelings and behaviour of her childhood self and the way in which she experiences life as an adult has helped her to approach her difficulties in a more compassionate way and begun to change the way she relates to herself.

> *“We’ve been working on this a lot in CAT, and talking about – we keep talking about ‘little Claire.’ And I’ve been using my niece, who has just turned 11, to try and visualise myself at that age, because that is the age at which I started self-harming. And to say, you know what… you’re not a bad person. You know, an eleven-year-old child who is self-harming, they’re not a bad person. They’re in pain. They’re a little girl. There’s a little girl there who’s in pain. And it’s really hard, because my instinct is to smack that child around the face, and say ‘sort yourself out girl before you ruin the rest of your life’. Erm, yeah – but, erm – I’m working really hard on that. On trying to feel empathy for ‘little Claire’ as we’re calling her.”*
>
> *(Claire)*

The PTMF proposes that the focus of mental health services should be on understanding and restoring the links between threat and threat response in the same non-pathologising way that grief is naturally understood as a consequence of the death of a loved one, or terror as a reaction to a threat to physical safety (Johnstone and Boyle, 2018). In order do to this, it is necessary to take the time to explore the individual experiences of those who present to services in order to identify not only those factors which have contributed to their problematic feelings and behaviour, but, crucially, the response and meaning associated with them. Whilst an understanding of the impact of trauma is certainly important, the experiences of Claire and Emily in particular suggest that a generic awareness of the presence of trauma amongst people with a BPD diagnosis is not sufficient to make them feel heard and validated. Rather, it appears that, as the PTMF suggests, the creation of an environment which fosters and privileges an individualised understanding of ‘What happened to you?’ is more helpful in terms of explaining distress and distressing behaviour that is situated outside of an individual’s own pathology and, therefore, in reducing some of the self-stigma associated with the current diagnostic label (Johnstone and Boyle, 2018).

Emily articulates this idea by highlighting the importance of treating individuals with a BPD diagnosis as individuals and taking the time to understand the thoughts and feelings underpinning their behaviour rather than just focusing on the behaviour itself and attributing it to the diagnosis:

> *“And asking ‘why?’ as well, because I think often like, there isn’t that. And I think it’s because either there isn’t enough time, there isn’t enough staff, or they don’t really want to go there because it’s difficult. It’s much easier to just, you know, give someone some drugs and calm them down a bit. It might help in the short term, but in the long run it’s not going to do anything. “So rather than people going ‘oh, it’s BPD behaviour again’ or ‘oh, it’s self-harm’ or it’s this or it’s that, looking at why it’s happening. Asking that person what’s going on.  Like, what’s happening, how are you feeling?”*

*(Emily)*

### *9.2.4 Validating the invalidated: The importance of feeling heard and treated as an individual*

The women who took part in this research all told very different stories about their lives, their upbringing and their relationship with their BPD diagnosis. However, as was noted in chapter seven, underpinning all of their stories appears to be a shared history of emotional invalidation, typically first experienced in early childhood as a result of dysfunctional or abusive parental relationships, and often perpetuated by mental health services that focused on behaviour and diagnosis rather than taking the time to build an individual understanding of distress. Linehan's (1993) research into the characteristics, development, and treatment of BPD identified invalidation in childhood as one of the key contributing factors to the development of BPD symptomology, a link that has since been supported by other research in this field (e.g. Robertson et al, 2013; Selby et al, 2008; Sturrock et al, 2009). Experiences of invalidation form a common thread throughout the narratives that informed this research, with Emily going as far to say she believes it to be the primary cause of BPD.

> *"I think if you're going to pick one thing that causes BPD, it's not being validated in some way."*
>
> *(Emily)*

Invalidation occurs when the expression of private experiences and emotions is punished, ignored or trivialised, rather than heard and acknowledged (Robertson et al, 2013). The previous chapter demonstrated how many of the psychiatric professionals that participants have encountered during the course of their interactions with mental health services have done just that, compounding feelings of invalidation that have been internalised over many years. It also explored how being treated on the basis of a diagnostic label rather than as an individual has contributed towards distancing participants from both their experiences, and an understanding of their identities outside of the diagnostic label. It follows, therefore, that when participants described helpful aspects of services and support, they typically referred to therapeutic relationships which made them feel heard, validated their experiences, and treated them as individuals.

Often, this is articulated simply as having someone who is willing and able to take the time to bear witness to their distress in a compassionate, non-judgemental way and accepting way.

> *"Actually, I just want – for me – what I'd want is someone with compassion and intelligence to just sit with me, talk it over until the emotion is at a more manageable level."*
>
> *(Victoria)*

> *"And they [staff at the crisis house] were just brilliant with me the whole time I was there, even when I tried to self-harm, they didn't make an issue. They just sat and chatted, like in the middle of the night when I was feeling really bad. They'd just sit and chat and they were just lovely people you know."*
>
> *(Holly – S136 Interview Participant)*

Victoria expands on this to echo Horn et al's (2007) findings that the presence of trusting, supportive and accepting relationships can serve as a useful counterpoint to both the internal and external stigma of diagnosis.

> *"And the main thing that makes me feel better, more than anything, is having someone who will listen, without judgement – but not kind of a stone-cold therapist who just sits there like a rock. You know, that may as well be a robot. You know, someone intelligent, someone compassionate. So, talking to people who are intelligent, compassionate, want to understand, aren't judgemental, aren't trying to fix you, and… also people who are willing to – the main, the most helpful thing for me is someone who is willing to accept the level of pain you're in or what you're going through. So, someone who will kind of, look that situation in the eye with you, and… is willing… that to me, is the most helpful thing. So, someone who will accept your reality and face it with you. Erm, and isn't scared or, yeah… put off by that, that's the most helpful thing for me."*
>
> *(Victoria)*

For Victoria, having someone available to 'look that situation in the eye' with is an important element of being able to acknowledge that what she is feeling is difficult, and that the intensity of those feelings is real and legitimate. Emily also describes how receiving a tangible reaction to the distress and suicidal thoughts she experienced whilst in hospital helped her to feel validated and cared for and reassured her that the feelings she was experiencing were genuine and worthy of help and support.

> *"And I think I needed that response. I needed someone to say, 'Whoa, ok, how you're feeling is really really tough', and kind of like validate how I was feeling because otherwise I felt like, well, they're not bothered, so probably I should kill myself if they don't seem to care. Just having somebody acknowledge that it's real… And I think, I mean, certainly for BPD, one of the many issues is the lack of validation for your feelings. And so, you know, people, I think if people with BPD have their feelings validated, then that's going to stop a lot of problems."*
>
> *(Emily)*

It has been claimed that one of the functions of mental health diagnoses is to validate distress (Ussher, 2011). Whilst there is some evidence to support this in relation to the diagnosis of

BPD, both from within this research and other research exploring reactions to diagnosis (Horn et al, 2007), more frequently this is compounded by subsequent treatment that privileges the features of the diagnostic label over and above individual experience. Where the women who took part in this research have received treatment considered to be helpful, this is mediated by supportive and collaborative relationships in which they are treated as individuals rather than on the basis of their diagnosis or behavioural symptoms.

> *"So I think what's been most helpful has been, erm… that my individual therapist has, regardless of his orientation or his views on any of my diagnoses, or what I should or shouldn't be doing with my life, he's never seen me as a set of symptoms. He's always seen me as a person with a story who needs to, like, divert into a path that's kind of happy and healthy for me."*
>
> *(Katy)*

> *"When I've had therapy, it's tended to be with outside individuals in a non-clinical setting, and to be honest that's what I find works for me. I don't like feeling like I'm on a conveyor belt, or I'm just the next number through the door"*
>
> *(Sally – S136 Interview Participant)*

> *"The way [my therapist] talks about it – we never talk about having BPD. We just talk about what's going on and stuff. But it's not saying 'you are this'. It's saying, this is a thing that's difficult…"*
>
> *(Emily)*

The benefit of individually-tailored care is acknowledged by the NIMHE (2003) in their list of characteristics that individuals with a PD diagnosis have found helpful when accessing mental health services. The PTMF also advocates for a shift towards supporting the construction of personal narratives as an alternative to diagnosis, which can lead to more nuanced understandings and effectively tailored care (Johnstone and Boyle, 2018). Katy's story demonstrates how the availability of services and support which privilege the individual experience can be a strong catalyst for positive change, over and above any one particular therapeutic technique or approach.

> *"I can see recovery as being something that actually happens for me. And I wouldn't have seen that, I couldn't have seen that six months ago, I was in such a hopeless place. Erm… and, so I think that that's an important thing to kind of get across. That it's only because of the specific support that I have had really, that's helped me to heal and move forward. And I don't think it's any one therapeutic approach, rather than having a therapeutic approach that's about me."*
>
> *(Katy)*

## 9.3 The role of creativity in recovery

Outside of the therapeutic environment, the women who shared their stories to inform this research articulated a number of outlets and coping strategies that they found helpful for managing their distress. These ranged from rearranging the furniture, going for walks, listening to music, yoga and mindfulness activities such as adult colouring and puzzle books. The function of many of these appeared to be primarily in providing a healthy distraction from unwanted feelings and behaviours and a way of disconnecting from difficult and painful emotions (Morgan et al, 2012).

> *"And when, say I'm at home, ok, I'm ruminating, or something triggers me on the television, you know, say, something triggers me. And basically, I now just go for my puzzle book, or a colouring book, or go and play with the cats.*
>
> ***Interviewer:*** *And that will distract you?*
>
> *Yeah. Whereas in the past I'd have gone for the pills, and taken more."*
> *(Chrissie – S136 Interview Participant)*

The four women who were interviewed during the second stage of this research were recruited because of their interest and involvement in creative forms of expression, to enable a more in-depth exploration of the relationship between creativity, identity and mental health. For Katy, Victoria, Emily and Claire, having a creative way to express themselves was seen both as an important part of how they made sense of their feelings and experiences, a healthier alternative to more harmful coping mechanisms such as self-harm and restrictive patterns of eating, and a safe way to explore their inner world.

Like their stories of mental health and BPD, each of the women articulate different views and interpretations of their creative journeys and how they came to be. Katy initially studied art at university but dropped out two years into her course and instead chose to 'push' herself down what she describes as a more traditionally 'academic' route, studying Psychology and then going on to complete her PhD. She started drawing again when she became unwell and found it a helpful coping mechanism when things became overwhelming.

> *These books are where I do most of my work – this is about the fourth or fifth of them. So, I started out just in the book, I wasn't even showing them to anybody, erm, but I was taking them with me everywhere and it was kind of my lifeline at that point. I couldn't – when I couldn't cope with the environment I was in; I would go into the book and I would kind of be scribbling away.*
> *(Katy)*

Emily studied photography at AS Level and found it to be useful medium to express herself. Prior to that, she had disliked art because she did not feel she was good at it, but through discovering photography and then going on to receive formal art therapy she realised that there were other ways to express herself artistically that were not reliant upon her ability to draw.

> *And I found that doing photography I could really express myself through art, which I'd never done before because I thought 'I hate art, I'm no good at it', like – yeah, so that was quite an eye opener. So, then I had art therapy as well. So that, again, and then using clay and realising that I don't have to be good at drawing, I don't have to be you know, this incredible artist. I can really like, powerfully express myself using art.*
>
> *(Emily)*

Victoria first became interested in photography through an ex-boyfriend who had a digital SLR camera. She noticed that she could become easily absorbed in taking photographs and that this seemed to have a calming effect.

> *I had a boyfriend at the time who was – he's an artist, he's still an artist, an amazing artist. He was a painter, is a painter, he also had a camera, in his first year of his art degree he had a digital SLR, and erm, I, used to play around with his camera, and do it for hours, and notice I was very soothed by it.*
>
> *(Victoria)*

For Claire, the concept of creative expression has manifested itself in a slightly different way. In her narrative, she discusses how her lack of artistic ability made her feel like she had missed out on what she considers to be one of the more positive elements of the BPD diagnosis. This understanding of the supposed relationship between BPD and creativity is reflective of typically held views on the link between mental health and creative genius (Becker, 2001).

> *Because I tell you, when I first got the diagnosis, I felt like I'd been really jipped. Like I'd been really… because I kept hearing about all these people with Borderline who were amazing writers and painters and potters and sculptors, and I kept thinking – well I've been totally fucked over then haven't I? I've got all of the illness and none of the fucking talent.*
>
> *(Claire)*

However, after taking some time to consider her own understanding of the meaning of creativity, she concludes that, for her, the way she chooses to express herself sexually is a creative outlet that has helped her to cope with some of the challenges she experiences. This is more in line with Kaufman and Beghetto's (2019) 'mini-c' theory of creativity which focuses on the personal nature and meaning associated with creative expression.

> *I don't know how you'll feel about me saying this, but I think my sexuality has been a big part of my creativity. And I think it's one of the ways that I've tried to cope with my diagnosis. I'm quite a submissive person sexually, which you wouldn't think to meet*

> *me. But being submissive has allowed me to explore some of those negative feelings about myself in a safe and pleasurable environment.*
>
> *(Claire)*

There is a wide range of literature which explores different definitions of creativity, and to a lesser degree, how it relates to mental health. Some (e.g. Sternberg and Lubart, 1999) focus on the creative output, linking it to originality and suggesting it should be appropriate and effective in fulfilling a desired purpose. Others, however, suggest that creativity is merely about going beyond the supposedly obvious and being imaginative, inventive, disciplined and persistent in approach in order to present a new view of the world (Weston, 2007). Bohm (2004) defines a creative state of mind as an openness to learning as opposed to staying within familiar structures as well as a wholehearted involvement in an activity or pursuit, which in turn can help to overcome what he refers to as the 'unsatisfying narrowness and mechanicalness of life' (Bohm, 2004, p3.). Whilst Victoria, Emily and Katy's artistic interests may be considered to represent a more traditional idea of creativity in that they result in a tangible visual output, as will be demonstrated, the outlets that all four women describe can be seen to signify an imaginative approach to learning about and understanding the world through the enthusiastic and committed involvement to a particular activity, and thus constitute creativity as per Weston's (2007) and Bohm's (2004) definitions above. However, as Claire's creativity manifests itself somewhat differently to that of the other three women, it could be argued that its function is slightly different – something that will be explored throughout this chapter.

### *9.3.1 Feelings with no words: Using art and photography to convey complex and distressing emotions*

A central theme to Katy's, Emily's and Victoria's narratives is the idea of using art and photography as a means of expressing thoughts, feelings and experiences that are difficult or impossible to verbalise to others.

> *Because I'd never been very good at – I still struggle with talking about emotions. Partly on the shame side of things, but more, I just don't have the words, I don't know how to describe those things. But I don't really know how to tell somebody – this is how I'm feeling, because I can't put the words on it, but I can draw it.*
>
> *(Katy)*

> *It's not as if I'm shit with words. I can write on other topics, no problem. I like writing essays. But when it comes to talking about myself, it's very confusing. I see the mind as something a bit, kind of – it's not tangible is it, you can't touch it, it's, I dunno… yeah… it's something I'm really fascinated by, I love reading about it, but I couldn't necessarily write it about it myself, I find that difficult, but I can take pictures of it.*

*(Victoria)*

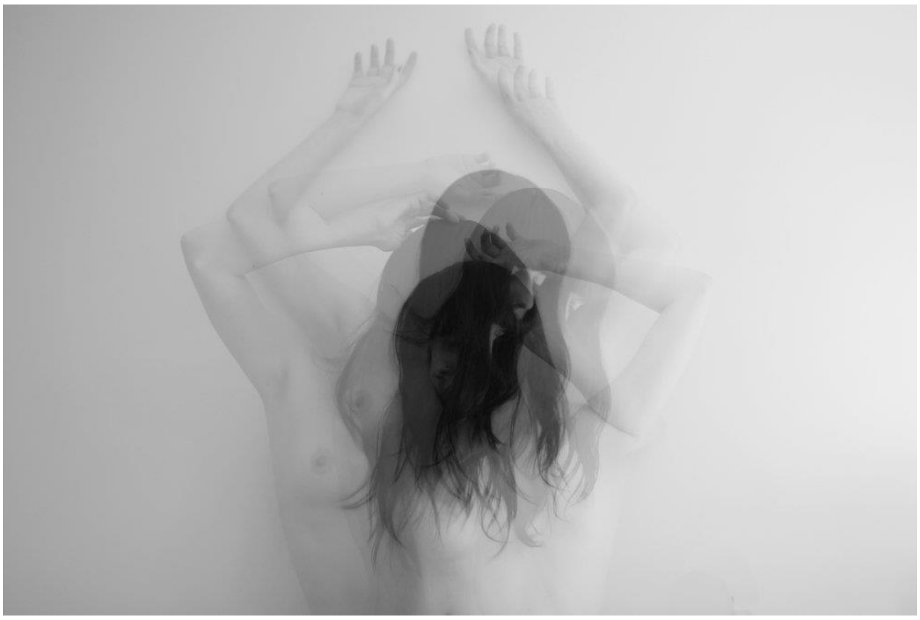
Unlike the other three women, Claire describes herself as articulate and verbose, and whilst she feels that her ability to accurately describe the complexity of her feelings in detail has sometimes made her appear ‘too well’ and created barriers to accessing treatment, she offers this as an explanation for why she does not feel the same need to create tangible representations of her distress in the same way as the other participants.

> *“I think sometimes, actually, the fact that I have the vocab actually fails to get my distress across. Because I’m just not just sitting there saying ‘I can’t take it. I can’t take it. I can’t take it.’ I’m saying, ‘I feel like this, but then sometimes I feel like this.’ You know, so… but it just occurred to me that since I’m able to express verbally what I feel, that, erm – that I don’t need to create something to show it.”*
>
> *(Claire)*

Because of this, the way Claire describes her creative expression is primarily as a tool to explore and express her feelings and identity in a safe and pleasurable way and as an alternative to self-harm, something that will be discussed in more detail later in this chapter. This section, therefore, will focus predominantly on how the remaining three participants, Emily, Victoria and Katy, use their artwork as a way of communicating with others.

As was discussed in chapter seven, Victoria’s dissociative episodes began when she was a child as a way of protecting herself emotionally from the sexual abuse she experienced at the hands of her father. She finds it difficult to verbalise how it feels to be ‘not fully present’ in a way that she feels accurately conveys the experience to others, but has found that through photography, such as in the image below, she has been able to create images which she feels accurately depicts how she feels when she dissociates.

**Figure 9.1 Self Portrait (2) (Victoria)**



> *I feel quite ghostly – not fully present, quite changeable and fluid, which is why… dissociation is really hard to describe in words, so when I learnt how to show it with a camera, I think, you know – it is one of the criteria on the BPD list, erm, that not feeling real. You know, how, just how fragile that sense of self is. How easily kind of, it can be sent flying. You know, like, and so a lot of my images are kind of ghostly, wispy, kind of, I'm only half present, erm…and that's kind of what I'm trying to… I do struggle to say it in words, whereas if I was to show you a picture of it, well you've seen my pictures – that's what it feels like – that's what I feel like…*
>
> *(Victoria)*

Although it can be distressing to see her feelings reflected back in such a tangible way, Victoria finds that being able to effectively convey the reality of her distress to others provides some comfort and relief.

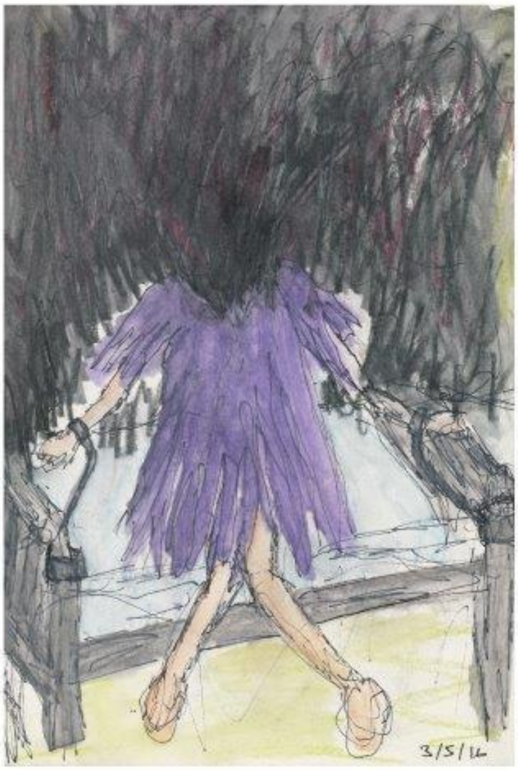
> *"It's like me trying to show people what that actually looks like. And it's helpful for me to see it. It's very strange when you make something – make art about something so kind of, painful, and then it's staring back at you. And often, it can actually be quite distressing – but it can also be comforting, to look at the picture and think, yeah, that's how it feels, I can show someone that, then they're like 'yeah, I know what you mean'."*
>
> *(Victoria)*

Throughout Katy's narrative she describes having difficulty both in engaging with her emotions and having the verbal language to articulate them. She suggests that not having the ability to recognise or describe her experiences has often exacerbated her distress and contributed to the development of unhealthy coping mechanisms, as well as preventing her from seeking help in the past. Katy has found that representing her emotions visually in her sketchbook has been a more effective way to demonstrate to her therapist how she has been feeling and has provided a framework with which to start to understand and verbalise them.

> *It's kind of supported me to learn more of a verbal emotional language. Because I've used it a lot with my therapist as well. Because he's always like "What are you feeling? What are you feeling? What are you feeling now?" At the start I'd just be like… Just trying to start sentences, and there were no words. And I got so frustrated with that that I took out the sketch book because I always had it with me, and I was like, this is how I've been feeling this week. And then he started, like, naming the things for me, and this helped me to build up a language around it, and with other people as well, in a less formal setting.*
>
> *(Katy)*

Previous research by Morgan et al (2012) has discussed the difficulties in verbalising emotion often associated with a BPD diagnosis and suggests that art therapy can provide an alternative, healthy channel for communication that can assist in accessing core emotions in a safe and constructive way. Whilst Katy's interaction with her therapist does not constitute formal art therapy, it is clear that elements of this practice are at play here, and that the act of producing art has allowed Katy a means of expressing and processing traumatic experiences that were not able to be verbalised. Lamont et al (2009) suggest that images can be more accurate and appropriate representations of inner 'being' and clearer indicators of experience than words alone and can be used in a therapeutic setting to strengthen the therapeutic relationship and build a shared understanding of distress. The harsh black lines obscuring the face of the figure in Katy's image below provide a powerful representation of what she describes as her 'meltdowns' and illustrates how she is able to use her art practice to convey emotions and experiences she does not feel able to describe verbally.

**Figure 9.2 'Extremes of Mood - A Total Meltdown' (Katy)**



Emily did take part in formal art therapy whilst receiving in-patient care and, like Katy, found the process of art-making helpful both to make sense of and to provide a framework to express her distress. Emily found that the process of talking about her emotions through her art reduced some of the anxieties and risks associated with purely verbal modes of expression (Morgan et al, 2012).

> *"I think often I didn't know how I felt. And I quite often did collages and so I'd be kind of looking through magazines and picking things out that I could relate to. And the things that jumped out of me were things that I could relate to in that moment. And when I then had all of the pieces, put them together, organised them, and then looked at the picture as a whole, it was like, oh gosh yeah, that's what I'm feeling right now, that's what's going on. So, then I could see it, I could use that – I could talk about that image to the therapist, whereas I found it more hard to talk about myself, even though I was talking about myself, but via an image which made it less difficult. And yeah, I think I just found that really helpful."*
>
> *(Emily)*

The image below illustrates the process of collage making described by Emily above:

**Figure 9.3 ' The Journey' - Magazine Collage (Emily)**

Victoria describes a more mixed experience of art therapy which highlights the importance of both the therapeutic relationship, and of adopting an approach which encourages personal expression in a way that feels comfortable, achievable and valuable to the service user.

> *"I had a very positive year of art therapy and when I was in a therapeutic community we did art therapy. I actually found it a little bit irritating, because I can't… there's certain mediums I can't use and things like that, and also the therapist would interpret the art rather than you. It was all quite like 'oh, that's red, are you feeling angry today….?"*
>
> *(Victoria)*

This mirrors Springham et al's (2012) research, which drew upon service users' experiences to identify the mechanisms considered valuable for people with BPD when engaging in art therapy. In sharing artwork created during art therapy sessions, the role of the therapist offers the greatest value when their stance is one which encourages self-reflection and understanding rather than one which imposes meaning on the artwork created. Furthermore, Springham et al's framework suggests that art making is most beneficial when the participants are supported to engage in a way that allows them to focus on the process in a way that feels personal, engaging and non-competitive. For Victoria particularly, the creative process cannot be forced, and it is the organic and embodied nature of her photography that allows her to express herself with the greatest degree of clarity.

> *“I often do it by accident. That’s the best way to do it I find. I need to be on my own. I can’t do if I’ve been around other people. So I need to be on my own for a good few hours. And just not have any kind of expectations from kind of anyone else on me, and then it just comes out.”*
>
> *(Victoria)*

Part of the benefit of expressing emotions that are difficult to verbalise in a visual way appears to come from the external validation of those emotions by others when they are presented in this way. Emily reflects on how using imagery has helped her to demonstrate the extent of her distressing emotions to mental health professionals and shift the power back to herself. She has found this particularly useful in a hospital setting where nurses may be desensitised to the language used to describe distress, especially, as was discussed in the previous chapter, when often those with a BPD diagnosis may be perceived to be functioning well.

> *Also, I think, a lot of the time, like the staff or CPNs or whatever, they don’t necessarily really listen to you, whereas if you present them with an image that’s clearly full of emotion, and you know, very graphic, and almost sort of disturbing, actually it makes them stop and listen.*
>
> *(Emily)*

Emily considers that the function of her self-harming behaviour has often been an attempt to demonstrate to others the extent of the pain and distress she was feeling, especially given that, as was discussed in the previous chapter, her verbal pronouncements of suicidal ideation have often been met with dismissive and invalidating attitudes. In building her relationship with art and photography, Emily has been able to find a way to convey her thoughts and feelings to others without having to physically harm herself to receive the validation and attention she craves.

> *“There have been times when I’ve been in hospital or I’ve been at home and I’ve felt unsafe and like, you know, getting that out on paper. Even though it’s not a nice image, I can show that to somebody to show how I’m feeling. I can do that and they can see, kind of, really really how I’m feeling without me having to do that to myself. And I remember [therapist] saying to me one time, ‘I’d much rather you killed yourself on paper than in reality’ and that really just was like, yeah, really powerful.”*
>
> *(Emily)*

In the previous chapter, it was suggested that one element of the stigma frequently experienced by those with a BPD diagnosis from mental health professionals may occur as a result of being perceived as in control of their emotions, and thus their behaviour is interpreted as manipulative and attention seeking (Rivera-Segarra et al, 2014). It appears, from an analysis of Emily’s, Katy’s and Victoria’s experiences above, that when distressing thoughts and feelings are communicated visually, often in graphic ways, the resulting response is more likely to be one that acknowledges that distress and reacts to it with an appropriate level of sympathy and concern. This is reflective perhaps of the more embodied and visceral experience of art making which is better able to permeate through the mask of ‘normal’ functioning which often serves as a protective mechanism for those with a BPD diagnosis as well as serving as a tangible manifestation of emotional dysregulation which can more easily be understood by others (Hamden et al, 2004).

### *9.3.2 Exploring the inner world: Making sense of and reframing emotions in creative ways*

As well as being a useful tool to help them express and convey the reality of their emotions in a tangible way to others, participants also reflected on how having a way of expressing their internal thoughts and feelings externally helped them to make sense of their experiences and could sometimes enable them to see alternative perspectives they had not previously considered.

Katy considers that her creative process exists in relation to the process of making sense of the emotion that she is trying to express. Often, when she begins to draw, she is not fully aware of what she is thinking or feeling. However, in allowing herself to create freely, she finds that she is typically able to render visible the underlying, and often repressed, emotion and thus in acknowledging it is able to return to the creative output with a greater level of understanding and begin the process again. This is consistent with findings from previous research which has found that the process of artmaking can profoundly change how individuals experiencing emotional distress process and express emotions and feelings (Ravetz, 2019).

> *“And sometimes what I, what will come out will be exactly what I had in my head, but often it will be something completely different. But it will express that thing that I was kind of holding to try and kind of get in there. And quite often it will take three or four drawings to get a concept down. So I have a lot of bits that kind of like – three or four drawings that go together because it takes me that length of time to process the emotion or the thought or the journey that I’m trying to understand within myself.”*
>
> *(Katy)*

Katy describes how she often creates images as a ‘first attempt’ at expressing something that she does not yet have the words to describe. Her creative meaning-making process has been supported by her therapist, who typically works with her in a collaborative and iterative way to help her make sense of and find the words to describe the things she has drawn. Because of this she feels that she is making rapid progress in her recovery and is developing a new language with which to understand the complexities of her inner world. However, even without formal therapeutic input, the narratives of Victoria, Emily and Claire suggest that creative forms of expression can still be helpful in providing them with a tangible way to make sense of their emotional distress.

Being able to depict the experience of dissociation through her photography has not only enabled Victoria to articulate to others a sense of how she feels, but has also helped her to validate her own existence as someone who is real and present through the process of reflecting a consistent (albeit fluid) physical self in her photographs and seeing the reality of her visible self.

**Figure 9.4 Self Portrait (3) (Victoria)**

*"You can see it's the same person in all the photographs however much it varies. There is a consistency, yeah. So, I guess it does soothe me with some of those feelings that I'm not, like, I'm not solid. So, in a way, even the pictures of me being fluid, it's not fluid because there's all real. It's a bit weird." (Victoria)*

Victoria finds that the process of channelling her emotions into a photograph can enable her to both make sense of and achieve some sort of containment or control over feelings which are difficult to process internally. By making a conscious decision to frame a photograph in a certain way she considers that she is often able to displace or reframe the emotion so that it is both more comprehensible and less intense and distressing.

> *"Emotions can… emotions are so intoxicating you can't really think, so to see something… literally in black and white usually, erm, is more containable. You know, it's in an image, it's framed, it's composed – I can choose how it's composed. So I can almost, it's a bit like psychological reframing but it is literal reframing of a feeling or an experience. And that can be therapeutic I think. Erm… Yeah. It feels like… it just makes more sense. You can see it. It's in a picture. But also sometimes you can change what's happening. Like you can… say I feel a certain way but I want to feel a different way, you know, I can take a picture that changes the way I look, and that's the emotion*

> *gone, like, I've done it with that, erm… does that make sense? It's really hard to explain.*
>
> *(Victoria)*

Through photography, it appears that Victoria has been able to regain a sense of agency that is not present in her narratives surrounding her early childhood experiences or in the majority of her interactions with mental health professionals. Uttley et al (2015) suggest that empowerment is one of the key benefits of art therapy expressed by service users and it appears that even outside of the therapeutic environment, creative expression has a useful function in allowing for the self-directed navigation and exploration of complex thoughts and feelings and can, in a sense, act as a form of personal 're-storying' in the way that it allows for a making sense of the past in order to guide the present (Grant et al, 2015).

Emily has also found the process of making meaning through photography empowering, particularly in helping her to explore different options and ways of reacting, and exploring, in a safe and controlled way, how they might play out and what they might feel like in reality. She has been able to use tools learned in therapy to apply elements of the transactional analysis model to hypothetical situations which represent aspects of her inner world and has found it helpful to represent these in a tangible way using Lego characters.

> *"I often feel that, just life, is too overwhelming, there's just too much going around in my head – things I need to do, things I should do, things that I shouldn't do, expectations, how I'm feeling – just everything. And I had this image of like, me just standing there, you know like in the dome in the Crystal Maze, and all of the gold tickets and the silver tickets. And it was almost like I was stood in the middle of this dome and the fans were on and there were all these tickets swirling around me. And I couldn't get them all – I was trying to and I couldn't get them. And I had this image of like, this is how I'm feeling and like, I suddenly thought – Super Mum can switch the fan off and we can calmly sort through them and stuff like that. And I found this little dome and it's got a cork thing – like a cork lid. And I made a hole in the cork and got a hairdryer and put my little Lego character in there with all the bits of paper like swirling around, so I could have that visual image. So, like, to see it actually happening. And like actually physically turn off the fan. So, I find like kind of doing all that kind of thing really helpful."*
>
> *(Emily)*

Emily's narrative suggests that the process of telling and engaging with her story visually, through photography, offers a mechanism with which to render the different aspects of her identity visible. In situating them outside of herself, she is able to observe and analyse the individual elements with a greater degree of clarity and objectivity, enabling her to understand the impact of those which are harmful, and consider ways of addressing them.

> *"I did a Lego picture – this was a BPD related one. And I set up, I had this toy mini boxing ring, and I got like, there's Lego boxing characters. So I had like Maleficent in the ring, and Super Mum in the ring and they were having a boxing match. And it was*

> *showing like, actually Super Mum won, and Maleficent's on the floor, and like – physically seeing and thinking how like, when I stop and think – well actually if she was on the floor, how different would life be."*
>
> *(Emily)*

**Figure 9.5 'Boxing Match' (Emily)**

In a similar way, Claire feels that embracing and developing her understanding of her sexual orientation has allowed her space to recognise and explore different facets of her identity, as well as helping her to gain some control over those that have typically resulted in unhealthy and damaging behaviour.

> *"I have used being submissive to have a space with which to play with some of these negative feelings about myself in a way that is not harmful to me. In a way that doesn't damage me the way my self-harm does. The way my drug abuse has. Erm, yeah, so I wanted to mention that, because that feels creative to me. It's a playful space. It's a place to play and invent and be somebody else, or somebody different – somebody slightly different."*
>
> *(Claire)*

In this sense, in the same way as art or photography, the experience of being sexually submissive can be seen as a vehicle through which to process difficult emotions by externalising and rendering them visible in such a way as to reframe them in a more positive light. Like Emily, who described the powerful realisation of understanding that it is better to kill herself on paper (through her artwork) than in reality, Claire has found a way to channel and act out her negative thoughts and feelings in a way that is not harmful to her. Finding creative and constructive ways to access and express difficult emotions can help to reduce feelings of shame associated with harmful behaviour and foster the development of strategies that lead to a greater sense of agency and empowerment (Eastwood, 2012).

### *9.3.3 The embodied experience: Purging and displacing difficult emotions*

Previous research exploring the benefits of art therapy for women with a BPD diagnosis has identified that, as well as allowing for the organisation of thoughts and feelings, the embodied process of creative absorption can be a useful tool in disconnecting and distracting from difficult and painful emotions (Morgan et al, 2012; Turner et al, 2011). The experiences of the women who took part in this research tend to support this and reflect the wider body of literature relating to the benefits of mindful activity and everyday creativity in reducing feelings of distress

Consistent with the theories of reverie (Bion, 1970) and flow (Csikszentmihaly, 1975), Emily, Katy, Victoria and Claire all describe how their various creative outlets soothe them by captivating and focusing their attention. For Katy, drawing in her sketchbook enables her to engage with her inner world in a more visceral way – a process which both helps to provide clarity and alleviates feelings of distress and confusion.

> *"It's hard to describe… it's completely captivating, like, erm, it's like… being kind of taken over by something and then if you actually manage to create the… the concept that you had in mind that wasn't formed into anything then it's really gratifying as well to kind of see that process through."*
>
> *(Katy)*

Like Katy, Emily experiences photography as a therapeutic activity because it absorbs her attention and allows her to shift her focus away from negative emotions or stressful situations, providing her with a sense of control and a fun and creative outlet. The description and accompanying image below illustrate how, as Dissanayake (1998) suggests, the creative process can represent an avenue of escape to an alternative (sometimes more desirable) world:

> *"It's very therapeutic because you're going into, just this world, that's just… fun. And you can create the world. It's like, it's escapism, I think. I went on holiday to Tenerife - I went on my own, and it was quite a big deal. And if I hadn't had that Lego with me, I don't think I'd have enjoyed the holiday very much being on my own, because I'd just have felt quite lonely, but it was just like I was in this other little world with my Lego characters. And I just loved it. And it was just a complete escape from reality, from stress, from anything I had to do, it was brilliant."*
>
> *(Emily)*

**Figure 9.6 Tenerife (Emily)**

Victoria finds that, for her, taking photographs can be both grounding – allowing her to focus on the present rather than the post - and a process which allows her to disconnect (or dissociate) from negative emotions. Having learned that photography helps her to feel better, Victoria finds that she is resorting less to self-harm behaviours and is more able to manage her own anxiety and distress on a day-to-day basis. She describes how creating and composing images like the one below can be particularly soothing and something that she can easily do to distract herself and make herself feel better.

**Figure 9.7 Window (Victoria)**

*"It's very grounding. Or, you're also – also, it can be, you can dissociate. But either way you feel nicer. I guess now I habitually know that it will make me feel better. So yeah, but I feel – I feel very soothed when I'm editing photos and taking pictures. And actually, one thing I do all the time, like when I'm sitting here – that window frame and those two chimney posts, like, all the time I constantly sit and compose it so that it looks like a good photograph."*
*(Victoria)*

The ability to 'self-soothe' is something often found to be lacking in individuals with a diagnosis of BPD (Hooley and Murphy, 2012) – likely as a consequence of invalidating childhood relationships and/or traumatic experiences which leave them unable to effectively regulate their emotions and therefore make them vulnerable to engaging in harmful behaviours in an attempt to displace negative emotions (e.g. Holmes, 2004). One of the core components of DBT aims to help participants learn to effectively nurture and parent their 'inner child' (Vaillant, 1992) and provide them with the skills to soothe and validate their own emotional distress in a safe and healthy way. The accounts above suggest that having this creative outlet is one way that participants engage in self-soothe behaviour and, in this way, their art making can be seen to serve a similar function to other self-soothing or mindfulness activities, such as yoga, music or playing with a pet, which the participants in this research also engage in and find to be helpful and can also be understood as examples of everyday creativity.

> *"I use the DBT self soothe skill loads, when I really can't cope with anything. I use – I distract myself - or try to. I knit, just rearrange… I rearrange the house when I'm really stressed. And going for walks, things like that"*
>
> *(Katy)*

> *"Yoga is strangely therapeutic. I'm not really sure what it is, it's weird, you know – and people told me to do yoga for years and I just saw it as really dismissive and invalidating, and I thought, yoga's not going to cure me, but it's surprisingly helpful actually."*
>
> *(Victoria)*

> *"The yoga is a huge part of my treatment plan at the moment. I've got [my CAT therapist] for my mind and then I've got my yoga therapist, which is like having a therapist for your body"*
>
> *(Claire)*

The ability to self-soothe appears to be an important factor in recovering (as it is understood in this context) from the negative symptoms associated with a BPD diagnosis, and supporting and fostering the development of those skills is considered to be a useful and practical element of DBT. However, the stories of the women who took part in this research also reflected a related, yet distinct, benefit of the embodied creative process which is articulated in terms of a purging or displacing of emotions. Unlike other mindfulness activities, which seem to provide relief through a process of absorption or distraction from the painful emotion, activities which allow for a direct expression of the negative emotion appear, at least in some cases, to have the added benefit of providing a sense of emotional transference as described by Victoria below:

> *"Sometimes it almost displaces it. So, if it's in the image – so if there's, say, the image is related to some kind of strong emotion, you've put it in the image and you can leave it in the image. And I think that's a really helpful part of art and creativity, is that you can just purge it basically – it's there instead of in you. I can take a picture that changes*

> *the way I look, and that's the emotion gone, like, I've done it with that, erm… does that make sense? It's really hard to explain."*
>
> *(Victoria)*

In a similar way, Emily finds that, whilst not all of photography and art that she creates is directly related to her emotions, having a creative outlet when she is feeling agitated or overwhelmed helps to release and displace negative thoughts and feelings that might otherwise become 'trapped' in her head, or manifest themselves in self-harm or destructive behaviour. The image below is an example of the sort of picture that Emily creates to release or express feelings of frustration:

**Figure 9.8 'Psycho Me' (Emily)**

> *"Often I think when I get quite angry or like, agitated, doing a really scribbly kind of picture or something really helps to get out some of that frustration"*
>
> *(Emily)*

Whilst Claire's experience of creativity is slightly different to the other women who took part in this research, her narrative suggests that there is a similar mechanism at play in terms of the sense of catharsis she experiences whilst engaging in submissive sexual role play with her long-term partner. Like Emily, Katy and Victoria's experience of art making, Claire finds that being submissive allows her to displace, reframe and purge her negative emotions in a way that feels healthy and pleasurable.

> *"To a certain extent, experiencing pain – and particularly experiencing pain as pleasure is cathartic. There are aspects of it that you could relate to self-harm. But I don't like to, because it's such a different space for me. One is done in a state of despair and anger and hurt. And the other is done in a pleasurable, intimate, sexual environment. It's definitely about self-expression, yeah, it's about all those things I think. It allows –*

> *and I do think it's been a way… it's been a coping mechanism for me, just as much as the self-harm has.*
>
> *(Claire)*

Katy, Emily and Victoria's artmaking are clear examples of 'little-c' creativity (Kaufman and Beghetto, 2009) in that they are concerned with tangible and recognisable expressions of creativity. However, it is argued that all four participants' accounts also contain elements of 'mini-c' creativity in the way that their expressions of creativity serve to assist in the construction of personal knowledge and understanding within the context of having a BPD diagnosis. The potential healing power of this 'mini-c' creativity is certainly something that warrants further exploration. The next section offers a more in-depth exploration of the role of creativity in the healing process and the ways in which participants' stories of creativity are told alongside and intertwined with stories of recovery.

### *9.3.4 Growing through creativity: The evolution of the creative process and the role of looking back in moving forwards*

As well as being a way to express, make sense of and displace thoughts, feelings and emotions in the present, having a tangible outlet can also allow for the ability to look back and reflect on past experiences – a process which can assist in building a coherent narrative and fostering a sense of personal agency and self-insight. Baldwin (2005) suggests that the most successful therapeutic interventions are those which provide an opportunity to develop personal stories which reinstate a sense of meaning and Adler and McAdams' (2007) research indicates that the way individuals construct stories about their experiences of therapy can assist in the negotiation of identity and have powerful transformative effects which can help to preserve positive gains achieved in treatment. In this research, the way that participants narrated their creative journeys was closely linked to the stories they told about their mental health and the process of recovery and their creative or artistic development often mirrored their development of new skills to understand and better manage their mental health.

Katy's story reflects the extent to which artistic expression has become intertwined with her progress in recovery, and how her artistic skill has grown alongside and become something of a metaphor for her emotional development.

> *"The art itself is the journey. It's not just the progression in the emotional, it's also the skill reflects the emotional skill that I have as well that I didn't have when I started. So it's… it's almost poetic that I started with kind of these two dimensional figures where I really struggled with perspective, I struggled with facial features, I struggled with all these things… limbs, shapes – I still struggle with hands and feet… But yeah, it's just*

> *like, the change that's happened. Because I can draw now at a level I never thought I'd be able to draw at, and it's not… I still don't consider myself good at drawing, but I know that the improvement that I've seen is immense."*
>
> *(Katy)*

Whilst Katy suggests that her emotional progression is reflected in the technical skills she has acquired to be able to express herself effectively through drawing, Emily feels that her emotional development is most clearly reflected in the changing content and process of her artwork over time. As she progresses in her recovery, she notes that the mood and themes of her artwork have changed in response to the changes in her own mood.

> *"Oh gosh! Some of the artwork – when I was in hospital, not the last time but the time before, was just like, looking back at it, it's cringey. Like, I literally used to paint with my own blood and stuff. And it was just – it was just, all very… dark. Very dark. Whereas now, if I'm having a difficult time, I might do some dark pictures, but not like that. And, erm, generally speaking there's a lot more of a mix. So, you might have some more positive things, erm, so I think it's just a lot more balanced now."*
>
> *(Emily)*

Emily also finds that, as she has developed skills to manage her mental health and her relationships with others, she has been able to render them visible in her artwork, and has often used art as a way of testing or practising some of these skills in a safe and contained way.

> *"Back then – I had no control at all, in my emotion – you could see it was literally like, so dark. When I was in hospital the last time – loads of my art work – I got really obsessed with doing lift the flap collages, so, a lot of the kind of, really, kind of difficult things or the things that were kind of hard to hear or look at, you had to look for. But it was almost like I'd found this way of saying, no, I've got a boundary here, and if I let you open that door, you can see it, and if I don't then you can't. And erm, actually that was a lot healthier, and it's almost like… as long as I let the people that need to be in to see it."*
>
> *(Emily)*

Claire's creative exploration of her sexuality has also developed alongside her understanding and exploration of her mental health and the way in which she relates to her identity. She reflects that, as she has come to a greater understanding of who she is and has begun to feel more secure and validated in a stable relationship, she has felt more comfortable to explore certain aspects of herself that she had previously repressed.

> *"It's taken a long time for me to comfortable with it. So, it's only relatively recently – it's only during like the period of my relationship with [my partner] basically. We've sort of been on this journey together. We've been on this journey very much together. So, it started off really just as this vague sense of… of tendencies that I had, and tendencies that maybe he had. And we sort of developed it together."*

*(Claire)*

Katy finds that looking back on her previous artwork can help bring about new understandings and provides an opportunity to reflect on her emotional development as well as a tangible way of rendering visible and acknowledging progress and change.

> *"Sometimes when I look back on it, sometimes months, sometimes a year or so later, I'm like oh… that makes sense, because now I've got a lot more understanding of emotions and… erm, and how they link to kind of my behaviours and thoughts and things."*
>
> *(Katy)*

Whilst this process of looking back can sometimes bring about mixed feelings, Katy feels that it is ultimately a positive one which brings about a sense of compassion for the distress experienced by her former self and provides her with a feeling of optimism about the direction of her recovery.

> *"I've been doing a series on my website, just sporadically, where I look at a piece and write a reflection on what it meant to me then and how things have changed. So, looking back – sometimes it makes me feel… I don't know what it makes me feel, but it can make me… it rarely makes me, it's rarely a negative experience. Sometimes it can make me sad about how I used to think or feel, or sad that things haven't changed as much as I want them to yet sometimes as well, but it always shows me that change has happened, and that's really positive."*
>
> *(Katy)*

Victoria experiences similarly mixed emotions when looking back over old photographs but finds that seeing old emotions rendered visible in black and white can make them feel less threatening and overwhelming and provides her with a sense of containment. Unlike Katy and Emily, Victoria has not had the opportunity to talk through the meaning and emotion conveyed in her photographs with a therapist. However, she feels that this is something that would be beneficial in helping her to make sense of the images she creates and her feelings towards them.

> *"Sometimes it makes me feel sick. Sometimes, I, erm… I don't want to remember, that… yeah. Other times it's helpful, erm… but, yeah… I think there's a certain satisfaction in… because emotions can… emotions are so intoxicating you can't really think, so to see something… literally in black and white usually, erm, is more containable. I'd love to sit with my photographs with a therapist and go through them. I'd love to have that opportunity, but I can't afford it."*
>
> *(Victoria)*

It appears that the process of reflecting and looking back on past manifestations and expressions of emotion and experience can contribute to building self-esteem, self-compassion and understanding and can help to foster feelings of empowerment and optimism around future recovery. Given the extent to which the process of storytelling is suggested to be important in achieving and maintaining therapeutic gains (e.g. Josselson, 2004; Singer, 2005), supporting women with a BPD diagnosis to undergo this reflected process in a structured way, through therapy, could be beneficial in both restoring a sense of agency and in allowing space to make sense of and construct a sense of meaning, identity and coherence within the context of their experiences (Baldwin, 2005).

## 9.4 Re-storying the self: Renegotiating identity through creative forms of expression and constructing new narratives beyond BPD

Whilst the four women who took part in the second stage of this research have all had different creative and therapeutic journeys, and are at different stages in their understanding and experience of recovery, all have come some way in beginning to build a new narrative of their selves and their identities, both within and outside of their BPD diagnosis. For Emily, Katy, Claire and Victoria, making progress towards recovery has meant investing time and effort in building self-awareness, as well as being able to reflect more compassionately on the factors underpinning their behaviour. The extent to which they have been supported to do this appears to impact upon both the relationship they have with themselves and their relationship with their BPD diagnosis.

### *9.4.1 Who else am I? Building a relationship with the self and exploring alternative identities*

In the previous chapter, the concept of the 'false self' (Winnicott, 1960) was discussed and applied to the ways in which the women who took part in this research were required to adapt to caregiver relationships in which their emotional reality was not prioritised or validated. The narrative accounts of participants appear to suggest that understanding and dismantling this false self is an important element of recovery and a key part of beginning to understand and build a relationship with themselves where their own needs and desires are prioritised. Katy describes this process as a deconstruction of the false self and a gradual rebuilding of a new, more compassionate narrative that reflects the traumatic and invalidating experiences she has endured.

> *"I would say that I'm, at the moment, in a kind of period of synthesis in terms of… I… have spent a long time deconstructing everything that I've become, and… building up a new narrative that reflects what I've actually been through."*
>
> *(Katy)*

In the previous chapter, Katy described how the function of her perfectionist ‘false self’ was to hide what she believed to be a fundamentally flawed ‘true self’. Although she describes it as a ‘work in progress’, through therapy Katy is beginning to build a more nuanced understanding of the concept of the self, as well as learning to explore and value her own thoughts and feelings in a positive and constructive way.

> “I understand about the concept of a self. I understand that I have a self about which I can form an opinion, and I understand that my self is neither good nor bad, it’s just a self. Because I thought that therapy would change me from bad to good, erm, or bad to better – or teach me ways to manage the bad more. And I realise now that it’s not, it’s about changing how I… changing my relationship with myself.”
>
> (Katy)

Like Katy, Emily is also at a stage of her recovery where she is able to deconstruct and reflect on the role of her ‘false self’ and make a conscious effort to challenge and move forwards from it. Understanding the function of her own illness narrative and the purpose that casting herself as an ‘ill person’ served in terms of affording her the care and attention she craved has enabled her to explore new ways to provide that care and attention to herself that does not rely on self-harming behaviours.

> *“Even as a teenager and whatever - all of that time I think I still very much saw myself as an ill person. Being the ill person made me feel safe. I didn’t like it, but it felt safe, I knew it, there wasn’t as many expectations. Whereas going away from that, I didn’t know who I was, I didn’t think I was strong enough. It was scary. But I think building up that sense of identity away from that helps you move away from that illness role, almost, and you know, a lot of I think, for me, has been just through discovery – play and discovery and stuff really.”*
>
> *(Emily)*

She describes how making a conscious of effort to explore interests and activities that are not related to BPD, particularly those which engage her creative passions, have enabled her to feel more confident to explore and express an identity outside of her mental health diagnosis, purposefully taking steps to move away from the illness identity that made her feel safe throughout childhood and adolescence.

> *“I’ve spent a lot more time doing purposefully – purposefully doing things that aren’t related to my illness. So, like, doing, learning sign language and erm, I did some art classes, like last year, that just were completely unrelated – it was just like doing printing and different things like that. And, like, a lot of the photography I do isn’t related to BPD – it’s just sort of taking funny pictures of Lego. Some of it has an underlying meaning – might have an inkling, kind of, some sort of link with BPD, but a lot of it is purely just having fun.”*
>
> *(Emily)*

Katy's, Victoria's and Claire's stories also reflect the extent to which, as they progress in their recoveries, they have been able to achieve a greater degree of self-awareness which has enabled them to begin to build a more holistic sense of themselves which is not as reliant on a diagnostic label or the external validation of others. Whilst this emerging sense of identity is (to varying degrees) in the relatively early stages and still fairly entwined (again, to varying degrees) with their experiences and understandings of emotional distress, it is clear from the narratives of all of the women that tentative steps are being taken to understand more about who they are, what motivates them and what they like and dislike.

Victoria still struggles to articulate who she is, but when asked to describe herself as a person, highlights some key qualities which she feels are consistent features of her identity:

> *"It's hard to describe in words. I'll try. Erm, I don't know. I think. I think I've… I guess… changeable. But, I think – compassion is quite a consistent quality in me. Most… yeah. There's also quite a… there's anger in there, but quite a… mainly about injustice. I'm quite concerned with things being fair and just. I care a lot about human beings. And… I guess I would say I'm passionate. Erm… and… this is what I've been told by several therapists, and family members, so I'm not sure… but I have a good moral compass apparently, but I don't always feel like – I wouldn't always say I'm a good person, but I try. I'm very concerned with ethics. I try and behave ethically. I don't know. It's such a hard question, I don't know."*
>
> *(Victoria)*

Emily also describes a range of different identities that she believes make up who she is and reflects on how the development of these has enabled her to feel more 'whole' and to overcome some of the fears associated with moving beyond the illness narrative described above.

> *"I think a lot of my identity has got a lot to do with Lego. I'm quite well known as the 'Lego lady'. Yeah, that and, also, cats, and just creativity generally, and animals, I love cats, and stuff like that – I see that as a pretty big part of my identity. And learning languages, and being an aunty, and being a sister, and being a friend – all of those different things now are all parts of who I am, and things that make my life and me feel more like a person – like a whole person. Rather than just feeling like if I'm not a patient, if I'm not BPD or I'm not an eating disorder, then who am I? What am I? I'm nothing."*
>
> *(Emily)*

Whilst, as reflected in Victoria and Emily's accounts above, there are indications of the development of broader and more consistent narratives of the self, it is their creative identities which emerged most strongly and with the greatest degree of certainty amongst the participants in this research. Interestingly, these creative identities were also the ones most closely linked and related to participants' experiences of poor mental health, creating something of a dichotomy which is explored further below.

### *9.4.2 Does creativity keep me unwell? The relationship between creativity and mental health and the fear of letting go*

The previous chapter discussed how the label of BPD carries particular connotations regarding the nature of personality and how the integration of that label into their understanding of their identities could often make it challenging for participants to conceive of themselves outside of their diagnosis. The section above illustrates how, through the combination of a supportive therapeutic environment and creative self-exploration, the participants in this research have been able to start to build a relationship with themselves that is not confined by the framework of BPD. However, the extent to which their creative abilities are felt to be intrinsically linked to and motivated by their experiences of mental distress is apparent in some of the women's narratives and feeds into the wider thoughts, reflections and concerns about what will be left of them if they become 'well' discussed in the previous chapter.

This is particularly true for Victoria, who feels that her ability to produce meaningful artistic outputs is dependent on her turbulent emotions.

> *"When I was happy in a relationship about two years ago, erm, I couldn't take photographs. I could take photographs, but I couldn't make art if you know what I mean. Yeah, I can't do it when I'm happy."*
>
> *(Victoria)*

Being a photographer is an important part of how Victoria conceives of her identity. The degree to which she feels it is intrinsically linked to the intense and challenging feelings associated with her poor mental health means that there are some aspects of her mental health difficulties that she is reluctant to move on from.

> *"Because when I'm… when I'm with my niece for example is when I'm at my most happy. Pure, pure happiness. I love her, more than anything. And I could not make, I couldn't make art… I make art with her, but it's like… trees and sky and sea – but yeah, yeah… it does make me reluctant to give up some things, definitely."*
>
> *(Victoria)*

This has the potential to create something of a paradox, whereby creativity exists both as a function for alleviating and managing distress whilst also preventing a focus or engagement with longer term 'recovery'.

Emily also feels as though her identity as an artist grew from her experiences of poor mental health and that she discovered what she describes as her creative 'spark' through a process of understanding how she could use art and photography to express herself. However, unlike Victoria, Emily feels that she has been able to retain that spark and apply it to art that is not created directly as a result of, or to make sense of, her mental health.

> *"Like, I know when I started doing photography – the first kind of assignment we were given or something. I had, like, I wasn't connecting with my feelings or my emotions at all. And it was like 'lines' or something like that. And I just went out and literally like, there's a line, take a picture. And it was quite dead, if that makes sense. There wasn't a sense of…And it was like, just seemed – it didn't seem alive if that makes sense, It didn't evoke anything if you looked at it. Whereas by the end, and I was kind of realising I could use art to express how I was feeling, erm, my art almost told a story. And, erm, it – one of the images that I did – I used Barbie dolls and I set up scenes – and one of the images was, erm, like Barbie dolls on a playground, so I like chalked a little playground and stuff, and, erm, there was one Barbie doll sat on her own and the others were like laughing at her in the background, you could see. So, when I look at those images or think about those images, there's a lot more to them, and even now I think that with my silly images, I found that kind of creative spark that I can now use even if it's not something… I'm not necessarily depicting something difficult. They can still be – it can still be quite alive and… but I don't think I would have found that had it not been for that and having art therapy and that sort of thing. I think it was through doing all of that that I found that. So, I probably wouldn't really be doing art if it wasn't for my mental health to be honest."*
>
> *(Emily)*

**Figure 9.9 'Autobiography - I was bullied at school' (Emily)**

For Katy, who has always had an interest in art, but dropped out of studying it at university in order to pursue a more traditionally academic path, what she describes as her 'breakdown' and the subsequent rebuilding of herself, provided her an opportunity to re-engage with her creative interests. Whilst Victoria and Emily feel as though their identities as artists came to being as a result of, and developed alongside their mental health identities, Katy believes that creativity has always been a part of her identity but has been repressed by the perfectionist ‘false self’ as she described in the previous chapter.

> *“That’s how I’ve kind of come back to being an artist, but I would say that’s always been part of what I’ve been underneath, I think I kind of ran away from it for quite a long time. Because I think I was scared of what it meant. What it meant to kind of do something – to pursue something I was actually interested in, as opposed to something I thought I should do… to be good enough, you know.”*
>
> *(Katy)*

Like Victoria, Katy has struggled to separate her ability to create meaningful art from her experiences of poor mental health. However, over time, and with the support of her therapist, she has been able to start to critically analyse and challenge this belief and hopes that being able to reflect on these insights will prevent it from holding her back in her recovery.

> *“There was definitely a time when I feared that it [creativity] couldn’t exist without being unwell, and that’s still a fear at times… that’s one of the, one of the… so I feel like at the moment I kind of go right in this loop, where I have like new hope, I can see recovery, and then I come back down and I’m like, no it’s not possible or… and one of things that drags me down there is the idea that outside of what I know I won’t be able to create, and that feels like… at times that feels like the truth. But it’s not, it’s a lie that keeps me unwell, because it also says that about everything else, and I know that I will be able to function better at lots of other things when I’m better.”*
>
> *(Katy)*

Whilst BPD is undoubtedly still a significant part of how Katy currently understands and describes her identity, developing and nurturing her creativity, and being supported to do so, has allowed her to reach a place where she can confidently privilege her identity as an artist and understand that this aspect of herself can exist in isolation from her mental health.

> “I would say I am an artist who has BPD. Not… erm, a person with BPD who is an artist. It’s more of a… constant of my identity than anything else actually, because I think it’s something that will be there whether I’m well or sick, I think. Erm, it’s always going to be a thing that I’ll have to express myself through.”
>
> (Katy)

## *9.5* Conclusion

The women who shared their stories to inform this research are undoubtedly all at different stages in their recovery and have had unique experiences of diagnosis, treatment and support which have influenced how they make sense of themselves, their mental health and the social world of which they are a part. Their varied and multifaceted journeys provide an opportunity to understand the ways in which different external and internal mechanisms operate and influence their attitudes and experiences of the mental health system and how it relates to women with a BPD diagnosis.

As demonstrated in the previous chapter, participants' perceptions of the diagnosis of BPD and the extent to which they accept and integrate it into their identities appears to be influenced by a number of factors, with the greatest and arguably most obvious of these being the reactions of and treatment by others in response to their distress. In this chapter, the narratives of the women who took part in this research demonstrate that receiving a BPD diagnosis can represent a meaningful experience, if it is precipitated by compassion and understanding and if it leads to effective and appropriate forms of support that allow for choice and control as well as individual meaning making, particularly with regards to experiences of trauma and invalidation.

Katy, Victoria, Emily and Claire have all, to varying degrees, been able to find a way to understand and make sense of their diagnosis in a way that works for them. They have also began to create new, more compassionate narratives of the self that weave this understanding together with other aspects of their emerging selves. Their creative interests and activities have been instrumental in this process by providing them with a framework with which to explore, make sense of and communicate their emotions. Despite differences in the medium of creative expression, there were many consistent themes running throughout their accounts that are congruent with the "dynamic, interpretive process of constructing personal knowledge and understanding" that defines 'mini-c' creativity (Kaufman and Beghetto, 2009, p.3). Participants described how their experiences of creative expression helped them to purge or displace distressing emotions and offered them a way to make sense of, reframe or make visible thoughts, feelings and experiences of distress. In addition, consistent with research demonstrating the mental health benefits of creative activity (Ravetz et al, 2019) and elements of Csikszentmihalyi's (1975) theory of flow and Milner's (1957) description of 'reverie', the process of engaging in everyday creativity provided a sense of escapism and a feeling of being soothed or grounded. Participants' creative outlets often acted as an alternative to self-harm or other 'unhealthy' or 'problematic' coping behaviours and, as well as assisting with personal sense making, also provided them with an alternative way of communicating the intensity and complexity of their emotions that they found was often responded to in a more validating way than their attempts to verbalise or 'act out' their distress.

It is the validation of this distress, both internally and by others, that appears to have the most fundamentally transformational effect in allowing for a reconstruction of the self which is based on nurturing (rather than suppressing) of individual needs, desires and interests. This chapter has shown that, despite the implicit assumption of personality dysfunction inherent in the diagnostic label of BPD and the extent to which this is internalised, it is possible for new conceptions of the self to emerge within an understanding (and to some degree, acceptance) of the label. It has also demonstrated how engaging in creative activities can support this process by offering a means to explore and make sense of different aspects of identity and render them visible, in essence acting as a form of personal ‘re-storying’ in the way that it allows for a making sense of the past in order to guide the present (Grant et al, 2015).

The next, and final, chapter will bring together the themes identified in the analysis, discuss their implications, and make some practical recommendations for the mental health sector.

# Chapter 10: Discussion and Conclusion

## *10.1* Introduction

This study set out to investigate the lived experience of 12 women with a diagnosis of Borderline Personality Disorder (BPD) through a thematic analysis of the narrative accounts obtained through both primary and secondary data collection. In doing so, the research has drawn on a diverse body of existing literature, including service user and survivor research, sociological concepts of health and illness narratives, feminist scholarship and a vast body of identity and creativity literature. An initial review of the literature revealed a field of study that is still heavily dominated by biomedical and inherently gendered models of mental ‘illness’ that fail to take an in-depth look at the traumatic antecedents of BPD. Furthermore, it identified gaps in the evidence pertaining to the ways in which women who receive this controversial diagnosis make sense of and conceptualise it in relation to their understanding of their own identity and sense of self. Lastly, the study aimed to contribute to a growing body of literature that challenges traditional approaches to the diagnosis and treatment of BPD. Valuing women with a BPD diagnosis as experts of their own experience, it aimed to make recommendations for effective and appropriate treatment options that are informed by their experiences and preferences.

Underpinned by a feminist critical realist ontology occupying a contextualist position that sits between the poles of realism and constructionism (Braun and Clarke, 2006), the key questions that this study has sought to answer are as follows:

- How do women diagnosed with BPD understand and conceptualise their diagnosis in relation to their life histories and sense of self?
- How do women with a BPD diagnosis use creativity to make meaning of their experiences, negotiate identity and manage distress?
- How can an understanding of the ‘lived experiences’ of women with a BPD diagnosis be used to contribute towards an understanding of effective and appropriate treatment strategies for the management of distress?

This final chapter discusses the key findings and addresses the conclusions drawn from the research - contextualising them within the existing literature. It will outline the contributions this study has sought to make in the field of applied social science, address the limitations of the research and provide recommendations for future research as well as for policy and practice where appropriate.

## 10.2 Storying the self

The women whose stories have formed the basis of this research gave rich and complex narrative accounts of their lives, their journeys and their relationships with themselves and the diagnosis of BPD. To reduce these accounts to a set of overarching themes for discussion feels somewhat reductionist, given that, as will be discussed, one of the key conclusions of this research is the need for individualised and contextualised understandings of distress that go beyond the traditional biomedical model of mental 'illness'. However, whilst bearing this in mind, it is important to acknowledge the similarities (and differences) in participants' accounts of themselves, their life histories, and their journeys through diagnosis and treatment. Reflecting on what these accounts can tell us about how identity is formed and negotiated and more importantly, how its development can be supported, can help identify the key ingredients of appropriate and effective treatment options that are tailored to their needs.

### *10.2.1 The effect of trauma and invalidation on identity development*

Given that the link between attachment issues and/or trauma in childhood and a later diagnosis of BPD has been widely researched and documented (e.g. Agrawal et al, 2004; Carlson et al, 2009; Paris, 1994), it is unsurprising that the life history accounts of the majority of participants contained reference to experiences of abuse, neglect or mistreatment in childhood, even when these were not explicitly asked about in interview. However, what was striking, particularly in the primary accounts, was that even when these experiences were not clearly defined as trauma, there was a persistent sense of invalidation which began in childhood and was frequently perpetuated into adulthood. Underpinning this sense of invalidation, participants articulated stories of caregiver relationships in which their thoughts, feelings and emotions were dismissed, or in which their legitimate distress or reactions to abusive situations were characterised as 'bad' behaviour or patently ignored. This focus on invalidation mirrors the results of Linehan's (1993) study which highlighted an invalidating developmental context as one of the key factors underpinning the development of BPD symptoms. Linehan's research primarily focused on the extent to which an invalidating emotional environment can preclude a child from developing healthy ways to process and express emotions externally which can lead to extreme emotional sensitivity and difficulties in making sense of and identifying emotions. However, this study is primarily concerned with the impact of invalidation and early childhood trauma on the development of identity and conceptions of the self.

This study provides support for Masterson's (2000) theory that a lack of support for a child's 'emerging self' can result in separation anxiety and create feelings of abandonment which can negatively affect the typical development of personal identity. Participants in the current study described intense feelings of uncertainty in childhood, combined with fears and insecurities around relationships and a pervasive sense of themselves as 'fluid'. Furthermore, growing up in an environment where their emotional reactions were conceptualised as problematic or undesirable led them to internalise a perception of themselves as fundamentally 'bad' – catalysing a desire to suppress parts of themselves considered to be undesirable and present a more 'acceptable' version of themselves to the outside world, something that is conceptualised in this study using Winnicott's (1960) theory of the 'false self'.

Participants in the current study spoke of the extent to which, as children and teenagers, they felt it necessary to behave or act in certain ways in order to be accepted by, or in some cases, kept safe from their primary caregivers. Thus, the 'false self' can be seen to emerge as a coping or survival mechanism in childhood and adolescence, with attempts to meet and respond to the needs and emotions of the 'true self' carried out in private through acts of control such as self-harm and disordered eating. In adulthood, this 'splitting' of the self, as described by Winnicott, results in what is described by participants in this study as a sense of 'fluidity', or of not having a strong sense of their own selves, emotions, or desires. This supports Winnicott's (1970) suggestion that when a child is subject to early caregiver relationships that do not prioritise or validate their needs and experiences, they learn that their emotional reality is less important than that of the caregiver. This leads to the development of a public 'false self' which acts as a mechanism by which to elicit care and attempt to develop a bond with the caregiver and protects the vulnerable and invalidated 'true self' (Cooke, 2009).

### *10.2.2 The role of the biomedical model of BPD in perpetuating invalidation and obscuring trauma*

Much criticism has been levied on the prevailing biomedical model of mental 'illness', and particularly the diagnostic category of BPD, for being highly subjective, value-laden and for placing the emphasis on individual pathology (Paris, 1996). This typically occurs at the expense of understanding the context in which distressing thoughts, feelings and behaviours originate or are perpetuated (e.g. Johnstone, 2000, Shaw and Proctor, 2005). The research findings broad support for these criticisms, whilst acknowledging that some aspects of the

BPD diagnosis were considered helpful for some participants; a nuance that will be discussed in more detail later in this concluding chapter.

Many of the participants in the current study describing experiences of stigma and discrimination at the hands of mental health professionals, reinforcing the assertions of previous research that BPD is the one of the most stigmatised psychiatric diagnosis (e.g. Nehls, 1998; Horn et al, 2007). For participants in this study, these unsympathetic interactions with CAMHS and adult mental health services are reminiscent of the dismissal and invalidation they experienced at the hands of their caregivers, and as such, serve to further invalidate their emotional distress and reinforce internalised notions of themselves as fundamentally bad.

Furthermore, participants described feeling confined, and sometimes controlled, by the structures and frameworks underpinning the biomedical model of mental ‘illness’. This was especially felt with regards to the rigid and reductionist diagnostic classification system and the disproportionate focus of services on managing behaviour at the expense of acknowledging and treating the underlying causes of distress and the function of the behaviour itself. Feminist critics of the biomedical model, such as Ussher (2011), Wirth-Cauchon (2001) and Shaw and Proctor (2005) argue that BPD is a patriarchal construct which medicalises behaviours perceived as ‘extreme’ displays of femininity and obscures an awareness of violence and abuse against women and girls by locating the source of distress as something ‘disordered’ within the individual. The findings from the current study support this view and highlight the extent to which many women with a BPD diagnosis feel that the current approach to diagnosis and treatment serves to deny both their agency and their individual experience. Despite being a diagnosis that covers a vast range of diverse and often contrasting experiences (Tyrer, 1999) participants in the current study often reported feeling stereotyped, treated as a label or ‘lumped in a category’. This led to internalised perceptions of themselves as ‘difficult’, ‘non-compliant’ or ‘hysterical’ – all words associated with Victorian notions of femininity and reflecting a wider societal tendency to control, contain or suppress overt displays of behaviour which falls outside of the traditional notions of what it means to be a woman in a patriarchal society (Ussher, 2011).

Participants also reflected a disproportionate focus by mental health professionals on the external presentation of ‘symptoms’ such as self-harm behaviours rather than a desire to listen and understand their thoughts, feelings, and experiences. In addition to having their external expressions of distress dismissed and categorised as problematic behaviours at the expense of understanding their function, participants also spoke of being overlooked and disregarded for appearing ‘too well’ when they attempted to articulate their distress in a clear and rational way. Thus, many participants described being caught in a situation where they are stigmatised and dismissed both for being unable to control or articulate their distress (except through seemingly unwanted or extreme behaviours) and for appearing as though their distress is not serious enough to deserve help. This finding supports assertions made in Rivera-Segarra et al's (2014) research which suggests that individuals with BPD are likely to experience a sense of being simultaneously perceived as if they are both out of control and as if they can control their behaviour to manipulate others. This leaves women who are placed in this position feeling confused, disempowered, and unsure of what to do to get the help they need. Exacerbating this is the systemic underfunding in mental health services in the UK which has led to huge pressure on services, chronic understaffing and significant levels of unmet need (TUC, 2018).

A further consequence of the apparent overreliance on the diagnostic criteria of BPD which has become clear from this research is the extent to which one-dimensional understandings of trauma can also serve to obscure and invalidate important contextual understandings and underpinnings of distress. This study shows that a disproportionate focus on 'uncovering' a single traumatic event responsible for causing the symptoms associated with BPD can be just as invalidating as a failure to acknowledge or treat the traumatic antecedents of distress. This lends support to Johnstone and Boyle's (2018) assertion that the need to identify specific causal pathways can obscure an understanding of the importance of meaning, and cause less obvious links between threats and threat responses to be overlooked, for example when the threat is subtle, cumulative, and/or considered socially acceptable.

The accounts of some of the women who contributed to research suggest that it is not the case that the awareness of the prevalence of childhood trauma in people with a BPD diagnosis that is lacking, but rather that there appears to be a failure or reluctance to explore the context of individual experiences and recognise distress and troubled or troubling behaviours as intelligent responses to adversity. Even when the presence of trauma was acknowledged or linked to BPD symptomology, participants were rarely given an opportunity to discuss the more subtle impacts of and meaning attributed to their experiences or supported to understand how their coping strategies originated in response to it. This is indicative of a mental health system that is dominated by a discourse of medicalisation which focuses disproportionately on treating the tangible behavioural 'symptoms' of mental distress rather than the underlying cause (Shaw and Proctor, 2005) and is ill-equipped to deal with the complexities of trauma. Thus, this supports previous assertions by Johnstone and Boyle (2018) that the definition of what is considered trauma can and should be broadened to include the everyday features of life which can generate and perpetuate distress, such as experiences of invalidation and emotional neglect. Services should focus on elucidating the mechanisms and meanings behind these experiences, even when more ‘obvious’ forms of trauma are not evident (Johnstone et al, 2019).

To return to the exploration of identity central to this study, the research finds that the inconsistency with which trauma is acknowledged, discussed, and treated in the context of the BPD diagnosis can compound confusion and uncertainty with regards to understandings of the self. Whilst the presence of trauma is often implicit in a diagnosis of BPD (despite not being part of the diagnostic criteria), the stories of almost all the women who took part in this research suggest that there is little space within the mainstream psychiatric community to discuss and truly understand the implications of their trauma. Beyond this, few services are available which offer the long-term support necessary to begin to address and process it. As Johnstone and Boyle (2018) note, this is reflective of a mental health system which continues to ask, “What is wrong with you?” rather than ‘What happened to you?” and which has at its core an aim to treat and manage behaviours rather than address the underlying causes of distress.

It is suggested that this tendency towards pathologisation and medicalisation can prevent women with a BPD diagnosis from answering one of the questions Erikson (1963) defines as being central to the development of a coherent narrative identity; that is – ‘How did I come to be?’ by obscuring an understanding of the historical and social context in which distress occurs and instead positioning it as an internal deficit or core part of an individual’s personality functioning. Thus, it is argued that the way in which BPD is currently diagnosed and treated could be exacerbating identity instability; a notion which supports claims made by Jorgensen (2006) that an unstable sense of identity could be both a symptom *and* a consequence of BPD. This will be examined further later in this chapter in the context of the illness narratives formed by participants in response to their diagnosis.

### *10.2.3 Biographical disruption as a threat to the ‘false self’*

So far, there has been little research which has attempted to apply Bury’s (1982) concept of biographical disruption to understandings of chronic experiences of mental distress. This study therefore offers a new way of understanding how identity is shaped by, and negotiated, in the context of a diagnosis of BPD. The study finds two key ways in which the common experiences of participants can be said to represent a biographical disruption - that is, a disruption to the typical explanatory systems or behaviours used by individuals and a threat to the self, brought about by experience of illness (Bury, 1982).

The first of these is reflected in the extent to which almost all the women who took part in the research described experiencing something of a ‘tipping point’ or breakdown. This marked, to varying degrees, their transition from being (at least outwardly) ‘well’ to ‘unwell’ and forced them to seek or accept more formal support for their distress. This ‘tipping point’ typically occurred as a result of a disruptive event, or series of events that provoked the resurfacing of painful memories or represented a challenge to the coping mechanisms that participants had been using to hide their distress and portray an image of ‘success’ to the outside world.

The second is the way in which receiving a diagnosis of BPD can also be understood as a biographical disruption in that it represents a disruption to the existing systems used to explain feelings and behaviour and challenges the conception of the self. As outlined by Williams (1984), this challenge precipitates a renegotiation of identity and a process of narrative reconstruction which aims to render this biographical disruption intelligible, the implications of which will be discussed in more detail in section 10.3.

Bury’s (1982) original theory of biographical disruption rests on an assumption that self-identity relies on the maintenance of a consistent personal narrative of the self and that illness represents a threat to this consistent self. This threat to the self must be made sense of in a way that preserves an individual’s core beliefs about who they are (Reeve et al, 2010). It is interesting and novel therefore to consider how biographical disruption operates and is experienced, as is the case for participants in this study, when the self that is being disrupted is already considered to be fragile, fluid, or changeable. Instead of the consistent personal narrative outlined above, participants in the current study largely reflected uncertain and unstable understandings of themselves. As previously outlined, these were underpinned by early experiences which forced them to craft external ‘false’ selves (Winnicott, 1960) based on the expectations and desires of those around them. These ‘false’ selves functioned as survival mechanisms in the face of neglect and abuse or as attempts to be accepted by their primary caregivers. On this basis, this research concludes that the experiences of biographical disruption outlined above can be conceived of in two ways. Firstly, as representing a threat to the ‘false self’, created to meet the needs of others and protect the vulnerability of the ‘true’ self. Secondly, as a disruption to the existing systems used to explain distressing feelings and harmful behaviours. For the women who took part in this research, whose existing explanatory systems had been grounded in the idea of themselves as fundamentally bad, and whose notion of the self was fragmented and unstable, being given a diagnosis of BPD could be interpreted as an opportunity for them to attempt to construct, (rather than maintain) an alternative and more coherent account of the self, based on the diagnostic criteria. However, the findings from this research demonstrate that the extent to which these experiences of biographical disruption give rise to and create space for a more stable and consistent narrative of the self is dependent on a number of factors, discussed in more detail in the following section.

## 10.3 Re-storying the self

The narrative accounts of the women who took part in this research are complex and multifaceted. However, all contain a degree of linearity which reflect, to some degree, Bury's (1982) and William's (1984) concepts of biographical disruption and narrative reconstruction, and the importance of sense making to the experience of mental ill-health. The fundamental difference between the stories articulated by participants in this research and William's (1984) original concept of narrative reconstruction appears to manifest through the lack of a consistent personal narrative of the self to return to. Thus, in order to render the biographical disruption of mental distress intelligible, it is necessary to construct a new sense of self which can exist alongside the framework of their BPD, and various other diagnoses. Whilst the four women who took part in the second stage of this research all articulated different recovery journeys, all had come some way in beginning to build a new narrative of their selves and their identities, both within and outside of their BPD diagnosis. An in-depth analysis of the accounts of participants in this research reveals that this process is influenced by a variety of complex factors, the main findings of which are summarised and discussed below.

### *10.3.1 Diagnosis as validation*

It is important to note that, despite the controversies surrounding BPD, at least some of the participants in this research described receiving their diagnosis as a validating experience. This was largely articulated as a sense of relief at being provided with an explanation for their distress which felt tangible and was also considered a welcome challenge to their existing conceptions of themselves as inherently bad or unworthy of treatment or support. This supports findings from Horn et al's (2007) and Ng et al's (2019) research, where some participants described receiving a diagnosis of BPD as being relating to a feeling of 'relief' at finally 'knowing' what was wrong with them and being able to situate this outside of themselves, leading to a greater engagement with concepts of recovery.

It has not gone unnoticed that this lies in contrast to the discussion in section 10.2.2, where the invalidating effects of the BPD diagnosis, and its tendency to obscure trauma were discussed at length. Given that one of the primary criticisms of personality disorder diagnoses is the extent to which they perpetuate a notion of distress and perceived dysfunction as being situated within the realms of an individual's own pathology and personality functioning (Linnet, 2004) it is interesting that there is still some relief to be gained by conceptualising the diagnosis in a typically 'biomedical' way – that is, as an 'illness' with a possible cure. Both findings potentially warrant further exploration to understand more about the mechanisms underpinning them and how they are experienced. However, in the context of this study, the tension between them provides further evidence of the complexity and conflicting feelings and experiences interwoven across and often within participants' narratives and the extent to which they are governed by the biomedical model, even when participants were individually critical of it.

Broadly speaking the findings from this research show that receiving a BPD diagnosis can represent a meaningful and validating experience, but only if it is precipitated by compassion and understanding and if it leads to effective and appropriate forms of support – a finding also replicated in Horn et al's (2007) study. When, as was the case for many of the participants in this study, receiving a diagnosis of BPD leads to experiences of stigma, discrimination, and an enduring perception that they are 'untreatable', the diagnosis itself is considered largely unhelpful and can serve to reinforce negative perceptions of the self as being fundamentally damaged. However, if accompanied by an empathetic understanding and access to support, diagnosis can provide a useful alternative framework within which to begin to renegotiate and re-story the self. This typically involves a reframing of behaviours and experiences in the context of the biomedical paradigm of which the BPD diagnosis is a product. This leads to the creation of illness narratives, which, as will be discussed below, can serve a variety of purposes and be both helpful and unhelpful in the reconstruction of identity within the context of diagnosis.

### *10.3.2 Building illness narratives and a 'BPD' identity*

Illness narratives are inherently personal, subjective and vary in individual significance, but are commonly recognised as an essential process in the recognition of the self as 'ill' and the acceptance of this (Williams, 1984). This study sought to build upon existing literature (e.g. Chandler, 2014) exploring the extent to which existing typologies of illness narratives are appropriate for understanding how meaning is constructed and articulated amongst people with experience of mental health problems. More specifically, the research aimed to understand how the stories women tell about their experiences of BPD can be understood using these concepts, especially considering the controversy around the status of the BPD diagnosis as a definable 'illness' category (Bjorklund, 2006).

The study found that participants' perceptions of the diagnosis of BPD and the extent to which they accept and integrate it into their identities appears to be influenced by several factors, with the greatest, and arguably most obvious of these being the reactions of, and treatment by, others in response to their distress, as outlined above. However, what is clear from all the narrative accounts is a sense that BPD had come in some way to define who they were and/or how they perceived themselves. This theme was present amongst all participants but was most notable within the narratives of the women who discussed their experiences of being detained under S136 who articulated identities that had become so dominated by mental distress that they were unable to conceive of themselves outside this diagnostic framework. Particularly for the four women whose stories formed the basis of the second stage of the research the negotiation of social and environment factors alongside biomedical understandings of the diagnosis appears to result in the emergence of complex, and often confused narratives, where attempts are made to negotiate multiple and conflicting identities amid a sense of uncertainty as to whether behaviours, thoughts and feelings should be positioned internally within the 'self', externally as 'illness' or as coping mechanisms developed in response to adversity. This supports the findings of Lovell and Hardy's (2014) research, where the theme of identity was linked closely with the theme of confusion, leading to the creation of the sub-theme 'who am I?' which highlighted strong feelings of uncertainty with regards to participants' sense of their own sense of selves and the influence of the BPD diagnosis on their understanding of their own identity.

The research findings demonstrate, to varying degrees, the challenge of forming or maintaining a coherent sense of self that is distinct from the 'illness' - in this case the diagnosis of BPD, that represents a disruption to the 'normal' trajectory (Bury, 1982). This disruption represents an opportunity to reorganise and reassemble the discrepancies between the embodied experience of illness, the self, and the social world (Williams, 1984), but, in the absence of an existing personal narrative of the self that is stable, consistent, and intelligible, there is a risk that the illness *becomes* the self, and vice versa. As was also found in Lovell and Hardy's (2014) study of eight women with a PD diagnosis detained in a secure unit, there are some people for whom the diagnosis is viewed as an important and integral part of themselves which has helped them to make sense of who they are. However, there remains a tension between the seemingly binary, but undoubtedly interlinked, concepts of BPD either as an 'illness' with a cure, or as a fundamental part of an individual's personality functioning. This is particularly brought into focus when we consider participants' views on recovery and moving beyond the BPD label.

The majority of women who took part in this research appear to, at least in some way, subscribe to the idea of BPD as an 'illness' and as such it follows that, with the right support, it is possible for them to be 'well'. However, the extent to which they have absorbed the diagnostic criteria into their sense of selves, potentially as a way to reconcile some of the 'fluidity' of self they describe, means that they are understandably concerned about losing a large part of their identities in the process of recovery. This theme supports findings from Katsakou et al's (2012) research understanding concepts of recovery amongst people diagnosed with BPD. Building upon research by Chandler (2014) and Carless and Douglas(2008), the application of Frank's (1995) typology of illness narratives allows for a nuanced understanding of how stories of recovery are constructed within the context of chronic or long-term experiences of mental health problems and how different experiences of support can be instrumental in shaping these.

Whilst there are clear differences in the way that participants describe their ambitions and visions for recovery, their narratives share one key similarity, in that they all reflect a sense of living *with* a diagnosis of BPD, rather than overcoming it or indicating a desire to return to a 'pre-illness' state. This aligns closely with Frank's (1995) quest narrative, whereby the experience of illness is reworked by the narrator to depict a transformative process in which the self is placed at the centre, and grows and changes in response to the illness. Given the degree to which participants' identities appear to be closely linked to those elements which can be seen to represent 'symptoms' of BPD, and the difficulty they have in expressing a sense of their identity prior to receiving a diagnosis, it is of little surprise that understandings of recovery are based on a desire to develop within the framework of BPD rather than remove all of the elements of it completely. This quest narrative manifests as a bringing to the fore the things that are regarded as the 'positive' aspects of the diagnosis. These are typically the more desirable personality traits, e.g., empathy and passion, which some participants feel have developed or are present as a consequence of what they understand to be BPD.

However, comparing these narratives with those of the women whose stories were subject to secondary analysis in stage one of the research indicates that the development of a quest narrative appears to be reliant on positive experiences of services and support that enable individuals to reflect on the deeper meaning represented in the experience and apply the lessons learned to accept and grow alongside the experience of illness. This supports previous research (e.g. McLeod, 1997; Baldwin, 2005) which suggests that successful therapeutic interventions for individuals with mental health problems allow opportunity to create and maintain personal stories which reinstate a sense of meaning, identity and coherence within the context of both their experience and the cultural narratives available to them

For those who have not been supported to negotiate a way out of the cycle of distress that has resulted in their (often multiple) detentions under S136, their stories reveal a dominant chaos narrative (Frank, 1995) in which there is little indication of hope for long term recovery or reliable treatment and a focus on the management of behaviours and a sense of disempowerment.

It is clear from this research that, despite not being clear-cut, concepts of recovery are of great importance to women with a diagnosis of BPD. Support systems which allow for an individual exploration of the meaning attributed to recovery and assist in the renegotiation of identity in response to it are potentially central in meeting the recovery goals defined by these women. It follows therefore that the next section will summarise and discuss the findings from the research in relation to the things that women with a BPD diagnosis find helpful to support them to alleviate distress and negotiate complex understandings of identity in the context of their diagnosis and the wider societal context that underpins it.

### *10.3.3 Renegotiating identity: ingredients of effective services and support*

The stories articulated by participants in the current research highlight several ingredients and principles of effective and appropriate treatment strategies for women with a diagnosis of BPD. These mirror some of the characteristics published by the National Institute of Mental Health in England (NIMHE) in 2003, including the importance of having a degree of choice and control in shaping their own treatment, individually-tailored care and specialist service provision, supportive and collaborative relationships, a space where they feel heard, validated and accepted and an environment that fosters the use of creativity.

The theme of invalidation is central to this research, underpinning and running throughout the narrative accounts of the women who shared their stories to inform it. It follows therefore that one of the key components of effective treatment which has supported participants to build a more compassionate understanding of themselves is a validating environment where they are heard, valued and accepted. Building upon findings from Horn et al’s (2007) study, the research finds that crucial to this validating space is the presence of trusting, supportive and accepting relationships in which they are treated as individuals as opposed to a diagnostic label, set of symptoms, or behaviours.

As early experiences of invalidation in childhood gave rise to disrupted and ‘fluid’ identities, later compounded by invalidating support services and stigmatising views, so too it follows that being validated, heard and understood can have a transformational effect on how women with a BPD diagnosis perceive themselves. The current study finds that receiving support that is empathic and acknowledges (rather than dismisses) their distress can help women with a BPD diagnosis to navigate and challenge internalised feelings of being unworthy and legitimises feelings of distress. As well as being hugely validating, more individualised and tailored forms of support can help service users conceive of themselves outside of the confines of the BPD label. These findings reflect many of the helpful features of personality disorder services outlined by the NIMH (2003) which include the importance of individually tailored care, an attitude of acceptance and sympathy and an atmosphere of truth and trust. Participants in this research described the transformational effects of receiving support that was about them rather than their diagnosis and conveyed how this was often more important in advancing their recovery than any specific therapeutic approach or model. This has important implications for service delivery which will be discussed in section 10.4.

Earlier in the discussion, the role of the biomedical model of BPD in obscuring important contextual understandings and underpinnings of distress, including trauma, was reflected upon, and the potential impacts on identity construction outlined. Similarly, to the finding above, participants in this study reported the positive effects of therapeutic services that provide space for them to explore, process and understand their diagnosis in the context of the things they have experienced in their lives. The research finds that participants who have had access to trauma-informed support are more able to conceptualise their distress as a product of traumatic, distressing or invalidating experiences in childhood rather than an innate personality fault. Being supported to reframe problematic behaviours as legitimate (and often necessary) coping or survival strategies can help women with a BPD diagnosis to reflect more compassionately on their manifestations of distress and feel more connected to and aware of themselves and the emotions they are experiencing.

This finding lends support to the assertions underpinning the Power Threat Meaning Framework (Johnstone and Boyle, 2018) which suggests that the creation of an environment which fosters and privileges an understanding of ‘What happened to you?’ is more helpful than the prevailing framework of asking ‘What is wrong with you?’ in terms of offering an explanation for distress and distressing behaviour that is situated outside of an individual’s own pathology and reducing some of the self-stigma associated with the diagnostic label. The current study has shown that being aware of the traumatic antecedents of BPD is not enough, especially when, as Johnstone and Boyle (2018) suggest, the trauma or threat is less obvious or has accumulated or taken root over time. Instead, what is needed is a nuanced understanding of the threat and the function of the threat response, and to do this requires time to explore the individual experience and the meaning associated with it. The findings from this study suggest that the best way to do this is to empower and support women with BPD to tell their stories in a safe and validating environment which in turn can give rise to new constructions of the self.

### *10.3.4 The role of creativity in recovery and identity negotiation*

The mental health benefits of participation in creativity and artmaking are relatively well understood and documented in the literature, and there is some evidence to support a link between creative expression and identity processes (e.g. Cupchik, 2013). This study makes a valuable contribution to this creativity literature by exploring how creativity can be useful, both in a therapeutic setting, and as an everyday tool for renegotiating identity amongst women with a diagnosis of BPD.

Participants in the current study described several ways in which creative forms of expression had a positive impact on their mental health. The first of these is through the way that everyday creativity can offer women with a BPD diagnosis an alternative way of communicating and conveying the intensity and complexity of their emotions that is often met with a greater degree of validation than their attempts to verbalise their distress. This builds upon findings from Morgan et al's (2012) research in an art-therapy context suggesting that the benefits Morgan et al observed are also realised outside of the therapeutic setting through engagement in everyday creative activities such as drawing, painting and photography. Participants in the current study found that having a creative outlet through which to express themselves often prevented them from engaging in unhealthy coping mechanisms such as self-harm behaviours and provided them with an alternative way to communicate their distress that is less stigmatised and more socially accepted than the 'problematic' behaviours typically associated with BPD. This also mirrors findings from previous research (e.g. Morgan et al, 2012; Lamont et al, 2009) who highlight how art therapy can provide an alternative, healthy channel for communication and expression and can support individuals to access and express core emotions in a safe and supportive environment. Once again, the theme of validation is also relevant in this context. Participants in the current study reported the validating effects of receiving responses to their creative outputs that represent an acknowledgement or understanding of the distress which precipitates it.

Similarly, participants in the current study regarded creative expression as being a useful way of purging or displacing difficult emotions and artmaking often assisted them in making sense of or reframing thoughts, feelings, and experiences in such a way as to make them more tangible or less distressing. Again, this appears to occur both within and beyond a formal therapeutic environment and was described in the current study even when the creative outlet did not result in an artistic output. This is congruent with Kaufman and Beghetto's (2009) 'four-c' model of creativity, which explores the personal significance of what can be understood as everyday creativity. Regardless of how creativity was expressed outwardly, all participants' accounts contained elements of "the dynamic, interpretive process of constructing personal knowledge and understanding within a particular sociocultural context." (Kaufman and Beghetto, 2009 p.3) which defines 'mini-c' creativity. This finding also lends some support to Uttley et al's (2015) suggestion that empowerment is one of the key benefits of art therapy expressed by service users and it appears that even outside of the therapeutic environment, creative expression has a useful function in allowing for the self-directed navigation and exploration of complex thoughts and feelings and can, in a sense, act as a form of personal 're-storying' in the way that it allows for a making sense of the past in order to guide the present (Grant et al, 2015).

Returning to Csikszentmihalyi's (1975) theory of flow and Milner's (1957) description of 'reverie', participants in the current study describe experiences of feeling soothed and 'captivated' when engaging in creative activities which are consistent with these processes. Participants in the current study also reflected on the positive and grounding effects of having their attention absorbed in a creative activity and described how it provided a sense of escapism and a distraction from negative thoughts and feelings. This is consistent with the literature exploring the mental health benefits of everyday creativity, supporting findings from studies such as Ravetz et al (2019) and personal accounts (e.g. Baker, 2008) which suggest that creativity and artmaking provide a way of becoming safely lost in an activity that may be particularly helpful for people who struggle to disconnect from difficult thoughts and feelings and/or build a connection with the self.

It is the relationship between creativity and conceptions of the self that provides the most relevant and interesting insights in relation to this research. Cupchik's (2013) article on expression in life and art suggests that artistic output can be part of what he terms a person's 'becoming' – providing an individual with the opportunity to find or resolve a sense of their own identity. For participants in this study, whose sense of themselves was typically fluid and uncertain, the creative process appears to provide a way in which to explore and render different aspects of identity visible and, notably, to build a more coherent and holistic sense of themselves that is not as reliant on the diagnostic label of BPD or the external validation of others. There is some tension here with regards to the extent to which participants associate their ability to be creative with their experiences of poor mental health and thus integrate their creative identities into their illness narratives to the extent that they fear they would be unable to be creative if they were ‘well’. However, the research finds broad support for Stuckey and Nobel’s (2010) suggestion that creative and artistic processes allow for an engagement with identity which occurs outside of the self as ‘ill’. This is demonstrated in the extent to which participants in the current study found that, even when they felt their artmaking was intrinsically linked to their diagnosis, exploring their creative passions empowered them to explore and express their identities as artists. This often gave them the confidence to pursue other forms of creative expression that were not directly linked to their experiences of poor mental health.

Although the process of identity renegotiation is clearly mediated by a number of factors, many of which have been outlined in this thesis, the research finds overwhelming support for the idea that creative expression can function not only as a way of reconnecting with one’s sense of self (Morgan et al, 2012) but as a means of dismantling and challenging the ‘false self’ (Winnicott, 1960) and rebuilding a new, more compassionate narrative. The implications of this with regards to services and support for women with a BPD diagnosis will be explored in the next section.

### 10.4 Recommendations for policy and practice

For the participants in this research, progress towards recovery appears to have been mediated through the combination of a supportive and appropriate therapeutic environment and an individual exploration of alternative and creative methods of expressing and understanding emotional distress. For Emily, Katy, Claire and Victoria, making progress towards recovery has meant investing time and effort in building self-awareness, as well as being able to reflect more compassionately on the factors underpinning their behaviour, thoughts and feelings. The extent to which they have been supported to do this appears to impact upon both the relationship they have with themselves and their relationship with their BPD diagnosis.

The themes and findings of this research make it clear that the current biomedical model of diagnosing and treating BPD is frequently not meeting the needs of women to whom the diagnosis is ascribed. Experiences of stigma and discrimination are reflected both here, and in the wider literature (e.g. Horn et al, 2007, Bonnington and Rose, 2014) and being given a diagnosis frequently results in a denial of access to treatment or referrals to services which further compound experiences of trauma or invalidation. In line with its critical realist underpinnings, the study finds support for an alternative perspective which challenges psychiatric positivism, acknowledges the experiential reality of events and emphasises the meaning attributed to these events, rather than focusing merely on what is considered wrong or 'disordered' in their behaviour. It argues that this is best reflected in the work of Johnstone and Boyle (2018) who developed the Power Threat Meaning Framework as an alternative way of conceptualising mental distress and distressing behaviours as adaptive responses to childhood trauma in order to maintain personal survival. The small amount of evidence that currently exists in relation to the implement of the PTMF suggests that supporting individuals with experience of mental distress to reflect on what has happened in their lives, how it has affected them and the meaning attributed to it can have a profoundly validating effect and can support service users to reconceptualise their 'symptoms' as understandable reactions to abnormal and threatening life events (SHIFT, 2020).

A move towards the practical application of this framework within mainstream mental health services could help to lessen the extent to which (often unconscious) value judgements are applied and inform responses to stories of adversity and play a key role in elucidating the mechanisms and meanings behind these experiences, even when more 'obvious' forms of trauma are not evident. The current study supports recommendations made in the PTMF that the focus of mental health services should be on understanding and restoring the links between threat and threat response in the same non-pathologising way that grief would naturally be understood to be a consequence of the death of a loved one, or terror as a reaction to a threat to physical safety (Johnstone and Boyle, 2018).

In order do to this, it is necessary to take the time to explore the individual experiences of those who present to services, to identify not only those factors which have contributed to their problematic feelings and behaviour, but, crucially, the response and meaning associated with them. Whilst an understanding of the impact of trauma is certainly important, the research findings suggest that a generic awareness of the presence of trauma amongst people with a BPD diagnosis is not sufficient to make them feel heard and validated. Rather, it appears that, as the PTMF suggests, the creation of an environment which fosters and privileges an individualised understanding of 'What happened to you?' is more helpful in terms of explaining distress and situating distressing behaviour outside of an individual's own pathology. This therefore has the impact of reducing some of the self-stigma associated with the current diagnostic label (Johnstone and Boyle, 2018).

The findings from this research suggest that this individualised approach is also crucial in a treatment setting. Consistent with the feminist values of this research, services supporting women with a BPD diagnosis should aim to provide a validating and empowering space in which they are supported to explore their experiences, tell their stories and have their voices heard. Given the extent to which the process of storytelling is suggested to be important in achieving and maintaining therapeutic gains (e.g. Josselson, 2004; Singer, 2005), supporting women with a BPD diagnosis to undergo this reflective process in a structured way, through therapy, could be beneficial in both restoring a sense of agency and in allowing space to make sense of and construct a sense of meaning, identity and coherence within the context of their experiences.

The extent to which concepts of identity appear to underpin both the illness and recovery narratives of participants in this study suggest that there is space for a more explicit acknowledgement of the impact of identity disruption and the transformative effects of renegotiating identity within therapeutic services. This is also supported by the findings of Sajjadi et al's (2022) recent study which associated higher levels of fragmentation in narrative identity with features related to BPD. Supporting women with a BPD diagnosis to reflect on their own identities and how they have been constructed in the context of their experiences (including their BPD diagnosis), as well as encouraging them to engage in an exploration of alternative identities which prioritise compassionate understandings of the self could potentially enable more women diagnosed with BPD to move beyond dominant illness narratives and conceive of themselves outside of the diagnostic criteria.

Previous research (e.g. Morgan et al, 2012; Lamont et al, 2009; Eastwood, 2012) has demonstrated the positive effects of art therapy for women with a BPD diagnosis and the findings from this study support a recommendation that formal art therapy can be a useful tool for helping women with a diagnosis of BPD to express themselves, organise their thoughts and feelings and build connections with themselves and others. The research also finds that engaging in everyday creativity also has a role to play in recovery from BPD – both as a therapeutic or mindful activity that serves to distract from difficult emotions, and through some of the same mechanisms as formal art therapy which assist in the negotiation of identity.

Whilst the therapeutic relationship is considered to be an important aspect of formal art therapy (Uttley et al, 2015), it is clear from this research that many of the same processes are at play in this formal setting as can occur whilst engaging in everyday creativity. Given that the expense and resource associated with delivering art therapy is high and services for women with a BPD diagnosis are already underfunded (Paris and Black, 2021) this research recommends a less formal approach to engaging women with a diagnosis of BPD in creative pursuits and encouraging them to express themselves creatively, perhaps through a social prescribing model or similar (Camic, 2016).

This reflects Gilam's (2012) research highlighting the importance of self-expression through the arts as a tool for creating meaning and storytelling, particularly for those who are marginalised in society. In this research, the way that participants narrated their creative journeys was closely linked to the stories they told about their mental health and the process of recovery, and their creative or artistic development often mirrored their development of new skills to understand and better manage their mental health. Fostering understandings of these processes amongst individuals and services who support women with a BPD diagnosis could potentially lead to new ways to understanding how recovery is experienced and the effect of this on the relationship with and expression of the self.

## 10.5 Further research

This study explores the various ways in which women with a diagnosis of BPD make sense of and navigate their diagnosis in the context of broader understandings of their historical, social and environmental contexts. Crucially, it explores how these factors also influence their understandings of self and identity. It has sought to prioritise the voice of lived experience and the stories that participants tell about their lives to elucidate an understanding of the function and purpose of the strategies that are used to negotiate distress and the systems and structures that are helpful (and unhelpful) in fostering concepts of recovery.

Whilst the research did not explicitly set out to explore how trauma is experienced by women with a BPD diagnosis, it is clear that experiences of invalidation and complex histories of trauma occupy a privileged position in participants' narratives and have a profound effect on how they form and maintain their identities in the context of diagnosis. Given how pertinent the theme of (in)validation is to this research, it would be beneficial for further research to focus on a more detailed qualitative exploration of how this is experienced by women with a BPD diagnosis and its centrality to identity development and disturbance. Following on from this, it would be interesting to explore the extent to which Winnicott's (1960) theory of the 'false self' could represent a useful construct for women with a diagnosis of BPD to conceive of the effect of early experiences of invalidation on identity formation.

The findings of the research suggest that the wider application of the Power Threat Meaning Framework (Johnstone and Boyle, 2018) could represent a useful alternative to the current biomedical model of mental health. However, there is currently limited evidence about how the PTMF operates in an applied setting, and how it is perceived by women with a BPD diagnosis. Given the extent to which the narratives and identities of the participants in this study were shaped by their experiences of diagnosis within the prevailing biomedical model, it would be useful for further research to understand what effect this alternative explanatory framework could have on how women with a diagnosis of BPD perceive themselves and situate their difficulties and the impact this has on journeys and stories of recovery.

Following on from this, it would also be helpful, as other researchers (e.g. Adler et al, 2012) have suggested, to focus research on the directional relationship between identity disruption and diagnosis. The current research offers some explanation of how receiving a diagnosis of BPD can intensify or exacerbate an already unstable or uncertain sense of self, but there is also evidence to support a suggestion that diagnosis can support in the construction of more stable sense of identity if perceived as a validating experience. This highlights the importance of lived experience research in feeding into wider debates about the usefulness and legitimacy of diagnostic criteria as well as informing clinical practise and training programmes. A more nuanced understanding of this process, the factors that mediate identity disturbance and the extent to which this differs depending on experiences of diagnosis, would help to build a better understanding of the function of diagnosis and its impact on identity.

The current research provides a unique exploration of the extent to which Bury's (1982) concept of biographical disruption can be applied to the narrative accounts of women with a diagnosis of BPD. It finds that there are two key ways in which participants' experiences can be understood as disruptions to their typical explanatory systems and/or a threat to the self, but that the absence of a consistent personal narrative means that this process can be conceived of slightly differently than when applied to more straightforward medical experiences of illness. Whilst this research has provided a useful starting point from which to examine the utility of the concept of biographical disruption in understanding narratives of chronic mental distress, it would be worthwhile for research to take this further to understand the extent to which it is applicable to other experiences of diagnosis and to examine its utility in a more applied (e.g. therapeutic) setting.

Finally, this research has contributed to the literature on everyday and therapeutic experiences of creativity by exploring how creative forms of expression can support women with a BPD diagnosis to achieve therapeutic gains through the renegotiation of identity. It would be interesting to explore this further with a broader group of women who do not identify as artists and to develop more nuanced understandings of how everyday creativity can function as a tool for renegotiating identity. Whilst it is clear that the stories that people tell about their experiences of diagnosis and mental ill-health have an important purpose, there is more for us to learn about the significance of how these stories are told and the personal and social consequences of them.

## 10.6 Limitations and reflections on the research process

The research acknowledges the limitations of qualitative secondary analysis as outlined in chapter four and is cognisant of the challenge of integrating primary and secondary data in such a way that renders a coherent analysis. Given that the research questions underpinning the primary and secondary collection differed, it is important to reflect upon the limitations of directly comparing them and the effect this may have had on analysis and the resultant discussion. It is hoped that the methodological discussions presented in this thesis render this process sufficiently clear for it not to have had a detrimental effect on the findings. Indeed, the findings from the secondary analysis guided the primary data collection in such a way as to build upon findings of interest, rather than acting as an attempt to replicate or offer a direct comparison.

The findings from the second stage of this research were informed by only four participants, and as such, the results cannot be seen to be generalisable. However, this was never the intention of the research and is compatible with the methodology used (Braun and Clarke, 2006). Nevertheless, the findings from this study represents the experiences of only a small number of women, and further research is necessary to understand whether these themes are replicated in a wider population.

The thesis set out to provide a narrative analytic account of participants' data. However, the extent to which it was able to do this is limited by the degree to which the analysis was able to go beyond the content of participants' narratives to consider their function, particularly in relation to their socio-political contexts. It is acknowledged that, although unstructured in nature, the interview environment is an artificial construct that is likely to produce narratives that are rehearsed, polished, and bound by particular socio-cultural constraints (Watson, 2012), thus potentially obscuring the function of the narrative for the teller and the wider context within which it operates. As Schiff (2012) notes, it is important to consider then that the stories people tell are not directly representative of experience itself, but of the meaning given to experience in the particular context of the telling, which may be limited by factors such as power dynamics, language, relevance or unconscious conflicts or desires.

Furthermore, it is acknowledged that participants' experiences of selfhood are inextricably enmeshed with the psychologisation of Western society that shapes language, meaning and narrative. As Rose (2002) surmises, "when our culture provides us with narratives couched in psychological terms, our lives really do become psychological in their form." (p.237). Whilst the current study makes some attempt to render this context visible, it is challenging to disentangle meaning, context, form and function, particularly when dealing with complex concepts such as identity, selfhood and mental distress. A further challenge occurs when considering the tendency within narrative research to promote a reified understanding of self, the truth of which it is proposed can be illuminated through autobiographical accounts or stories of personal experience (Wood, 2011). Whilst self-narratives are clearly a useful tool for understanding meaning and self-conception, it is important to acknowledge them as artefacts of a shared social world not an exhaustive authentic or universal account of selfhood (Zahavi, 2007).

Narration is an ideological process which requires us to impose a particular way of thinking about experience (Hendry, 2007), and this is true both of the narratives of personal experience constructed by participants and also for the research narratives constructed in response. Thus, it is important to remain reflexively cognisant of the context in which narration occurs; a process that is made explicit in this thesis through the inclusion of an in-depth reflexive account of the researcher's own positionality and sociopolitical background. The approach to reflexivity taken throughout this research has involved the constant examination and re-examination of the relationship between the researcher and the research and the personal and cultural perspectives from which the analysis is approached. With this comes an acknowledgement that conducting this research over many years means that many of these perspectives have changed and evolved, both as a result of, and alongside the research process. The researcher's own journey can therefore, to some degree at least, be seen to be reflected in the selected re-telling of participants' narratives which form the analytical process, a nuance which would perhaps be more visible if the reflexive account was woven throughout the analysis rather than contained with a distinct chapter.

In a thesis underpinned by a feminist ontology that is sensitive to the idea of voice, it is important to acknowledge whose voices are being heard and those which are absent. It was the intention of this research to work more collaboratively with the participants in the second stage of this study to co-produce narratives which confidently and reliably reflected their experiences. However, due primarily to the time that has elapsed between conducting fieldwork and completing this analysis, and the difficulty in maintaining relationships remotely, there has been no engagement from participants during the analysis and reporting stage of this research. This means that the way in which participants' narratives are portrayed in this thesis is influenced and shaped to a greater extent than was anticipated by the researcher's own subjective understandings and experiences which are undoubtedly present throughout the analysis and resulting discussion. Linked to this, attention is turned to a brief discussion of the tensions between the critical realist ontology underpinning the thesis and the feminist narrative approach, with reference to the concept of epistemic injustice. Critical realism recognises the reality of individual experience, accepting the existence of realities which are present and act independently of our descriptions of them. but posits that we can only know them under particular circumstances (Bhaskar, 1975). However, it is important to reflect upon who gets to decide what constitutes 'reality' and the systemic inequalities at play within the field of knowledge production. Epistemic injustice is common within mental health research, whereby individuals with 'lived experience' of mental distress are diminished or excluded from the process of creating knowledge or meaning in favour of clinical, academic or professional knowledge (Okoroji et al, 2023). Whilst this research had the co-production of knowledge as its aim and a commitment to privileging the voice and reality of lived experience at its heart, there remains a fundamental imbalance of power whereby the researcher bears the ultimate responsibility for shaping and defining the production of knowledge.

### 10.7 Concluding thoughts

This research has furthered understandings of the lived experience of women with a BPD diagnosis by privileging their narratives and challenging dominant discourses that perpetuate stigmatising stereotypes of mental distress. It has explored the stories women tell about their childhoods, their experiences of diagnosis, the coping strategies they use to negotiate distress and their stories of hope and recovery.

The thesis has contributed to a growing body of knowledge offering support for an alternative perspective on mental distress which challenges psychiatric positivism, acknowledges the experiential reality of past events and emphasises the meaning attributed to them. It lends support to a more widespread application of the Power Threat Meaning Framework (Johnstone & Boyle, 2018) as an alternative way of conceptualising mental distress and distressing behaviours which can support women with a BPD diagnosis to reconceptualise their behaviours as adaptive responses to childhood trauma and construct a sense of meaning, identity and coherence within the context of their experiences.

Furthermore, the research has generated new knowledge about the ways in which identity both shapes and is shaped by subjective understandings of diagnosis as well as the cultural, social and relational contexts in which individual experience occurs. It has explored the meaning and function of creativity as a way of coping with mental distress and added to the scant literature regarding the relationship between creativity and identity. Drawing upon Csikszentmihalyi's (1975) theory of flow and Bion's (1970) concept of reverie, it has demonstrated how these concepts interact with identity development processes to support women with a BPD diagnosis to create and narrate stories about their selves that move beyond traditional narratives of mental distress and support them in building a more coherent sense of narrative identity.

Using these findings, it has provided evidence for how an understanding of the perceptual and emotional experiences of those experiencing BPD and the everyday strategies they use to negotiate distress can be used to develop effective treatments which are holistic and responsive to individual concerns. Finally, it has provided recommendations for policy and practice which emphasises the need for mental health professionals to provide a validating and empowering environment which offers space for individualised explorations of the factors underpinning distress and a more explicit focus and reflection on the construction (or reconstruction) of identity in the context of past experiences, current understandings and conceptions of recovery.

If I were to draw only one conclusion from this research, it would be to highlight the transformative effect of feeling heard and validated on participants' perceptions of themselves and their diagnosis. Despite the complex narratives and concepts explored in this thesis, it is this simpler notion that resonates with me most, and which I would urge us all to apply in our interactions with each other – particularly those who are marginalised and furthest from power. The stories that we tell play a vital role in shaping who we are and the society that we live in. It is my hope that bringing the stories of these women to life will help foster more compassionate understandings of the BPD diagnosis and support the development of effective services and formal and informal support networks that assist with the renegotiation of identity and recovery – whatever that means to the individual.

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# Appendices

## Appendix 1 : Initial Email to Potential Participants

Good [Morning/Afternoon]

I am a postgraduate researcher from the School of Applied Social Science at the University of Brighton, carrying out research on the experiences of women with a personality disorder diagnosis as part of my PhD. Part of the research aims to examine the individual experience of and meaning of creativity amongst women with BPD. I am aiming to understand how women with BPD make sense of their diagnosis and the individual coping mechanisms that can help to manage some of the symptoms. I am particularly interested in ideas around creativity and identity and how creativity affects or is affected by mental health.

I hope you don’t mind me contacting you directly, but I came across your [website/blog/artwork etc. – give details] during my initial background research and am contacting you using the email address you provided there to ask if you would be interested in being involved in my research. I have contacted you as your postings online suggest that you have been given a diagnosis of personality disorder and have creative interests. I apologise if this information is incorrect or no longer the case.

The exact nature of your participation in the research is negotiable as it is my aim for it to be a collaborative process which allows you to the opportunity to share your experiences, thoughts and opinions in whichever way feels comfortable and appropriate for you. However, it is anticipated that your involvement may involve a degree of interviewing (either face to face, over the telephone or via email exchange). I would also be keen to use examples of your creative work in my research and/or to allow you to respond to questions in a creative way if you choose.

If you are interested in participating please contact me by replying to this email or by telephone on the number below and we can discuss your involvement in further detail. I will also then send you further information about the research and answer any questions you might have.

Thanks and kind regards,

Ashley Austin

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## Appendix 2: Participant Information Sheet

## Participant Information Sheet

The Lived Experience of Women diagnosed with Borderline Personality Disorder

I am a postgraduate researcher from the School of Applied Social Science at the University of Brighton, carrying out research on the experiences of women with a Borderline Personality Disorder (BPD) diagnosis as part of my PhD. Part of the research aims to explore the experience of creativity and what it means to women with a BPD diagnosis.

I would like to invite you to take part in this study. Before you decide, I would like to tell you why I am carrying out this research and what you would be required to do if you were to take part. Please read this information sheet, which should take around 10-15 minutes and feel free to ask any questions if there is anything that is not clear.

### Why is this research being carried out?

The research that I am inviting you to be involved in is about the experience of being a woman living with a diagnosis of BPD. I am aiming to understand how women with BPD make sense of their diagnosis and the individual ways of coping that can help to manage some of the symptoms. I am particularly interested in your ideas and feelings towards your own creativity and how it affects or is affected by your mental health.

It is intended that the research will increase knowledge of how women understand and experience BPD and how they view themselves in relation to their diagnosis. It is also hoped that it can contribute towards the development of treatment strategies and appropriate forms of support for women with BPD.

### Why have I been invited to participate?

You have been selected to receive an invitation to participate in this study because either;

1. During the course of my background research I have found public information on the Internet that suggests you are someone who identifies themselves as a woman with a BPD diagnosis and who has an interest in creativity and/or the arts, OR
2. You have been referred to me as someone who may meet the criteria and be interested in taking part in the research by an organisation/individual that you are involved with.
3. You have expressed a direct interest in being involved in the research.

If you are unsure how your details were obtained then please contact me and I will be able to provide specific information.

If you know of any other person who you think meets the above criteria and would be keen to participate in this study, then please feel free to forward my contact details to them. However, due to time and resource constraints, there are a limited number of participants required for this study and participants will be recruited on a first come, first served basis.

### Do I have to take part?

Taking part in the research is entirely voluntary. If you are willing to take part you will be asked to sign a consent form before any information is collected, however you are free to withdraw from the study at any time without giving a reason. In this case, I will ask whether the information already provided can be still be used or whether it should be deleted. You are encouraged to talk about any concerns you might have at any time during the course of taking part in the research.

**What will I need to do if I decide to take part?**

If you decide you would like to take part in the research then I will be in touch to discuss how you would like to be involved. I would like to provide you with the opportunity to tell your own story and am interested in hearing your ideas about how you would like to do this. I would like to talk to you in an informal way about your experiences and this can take place via email, over the telephone, or face to face in a private location. However I am also interested in creative ways of sharing stories and experiences and would like to invite you to respond in a way/ways that you feel best able to express yourself. Some examples may include (but is not limited to) through artwork, video, poetry or song, or a combination of some or all of the above.

If you choose to be interviewed face to face or over the telephone I would like to record the interview in order that I am able to have a full record of our conversation that I can analyse in depth at a later stage. A record of the interview will be typed up by myself, after which the original recording will be destroyed. It is your choice whether our conversation is recorded and if you do not want the interview recorded it will not affect your participation in the study.

Whilst there are some particular topics I am interested in and will ask questions about, you will also be encouraged to ask questions and talk about things that are meaningful and important to you during our discussions. This is so that we can explore and develop the themes of the research together and will help me to best represent your views in my analysis.

**Can I claim any expenses?**

I will do my best to accommodate your preferences in terms of how and where the research is carried out as much as possible but unfortunately I am not able to pay for expenses incurred as a result of taking part in the research (e.g. travel costs or childcare).

**What are the potential disadvantages or risks of taking part?**

During the course of the research you will be given the opportunity to share your experiences of living with BPD and may be asked specific questions relating to past events or your understanding of certain aspects of yourself/your diagnosis. It is hoped that this will be a positive process, however there is the potential that you may find yourself reflecting on upsetting memories or distressing incidents or require additional support.

Before taking part in the research I will ask what mental health and/or other support you currently have available to you and encourage you to make them aware of your participation in the research in the event that you require additional support. I will be available to discuss any concerns you may have and will also provide you with contact details of organisations that may be able to help you if you experience any distress as a result of participation in the research.

**What are the potential benefits of taking part?**

The research is an opportunity for you to share your experience of living with a BPD diagnosis and discuss what creativity means to you. It is intended to provide a voice for women with a BPD diagnosis and contribute towards improving understanding and treatment of others in a similar position.

**Who will know I have taken part?**

It is up to you who you tell about your participation in the research. Any correspondence or interview will take place in private and your personal information will be treated as confidential. The only exception to this is if you tell me of any intention to cause harm to yourself or someone else. In this case I will talk to you first about the best thing to do before taking any further action.

The information that you share with me will form part of my PhD thesis and, with your permission, may include direct quotes from interviews and/or examples of your creative work. You will be asked whether you would like your real details to be used in the thesis or whether you would prefer to remain anonymous. If you would prefer to remain anonymous you will be given a fictitious name, which are you free to choose, and any details that may identify you will be changed.

### Who is organising and funding the research?

The research is fully funded by the University of Brighton

### What if there is a problem?

You are encouraged to discuss any issues or concerns with myself, the researcher, in the first instance, using the contact details listed below. However if you do not feel able to do so then please contact my supervisor, Professor Gillian Bendelow.

**This study has been reviewed and approved by the School of Applied Social Science Research Ethics and Governance Committee of the University of Brighton**

Thank you for taking the time to read this information.

Signed: ………………………………………………………………………… (Lead Researcher)

Date: …………………………………………

### Contact information

| Researcher | Lead Supervisor | Independent contact (not associated with the research) |
|---|---|---|
| **Ashley Austin**<br>College of Applied Social Science<br>Mayfield House<br>University of Brighton<br>BN1 9PH<br><br>**Telephone:** 07792027058<br>**Email:** A.T.Austin@brighton.ac.uk | **Professor Gillian Bendelow**<br>College of Applied Social Science<br>Mayfield House<br>University of Brighton<br>BN1 9PH<br><br>**Telephone:** 01273 643960<br>**Email:** G.Bendelow@brighton.ac.uk | **Dr. Mark Erickson**<br>College of Applied Social Science<br>Mayfield House<br>University of Brighton<br>BN1 9PH<br><br>**Telephone:** 01273 641085<br>**Email:** M.Erickson@brighton.ac.uk |

## Appendix 3: Participant Consent Form

### Participant Consent Form

The Lived Experience of Women diagnosed with Borderline Personality Disorder

| | Please initial or tick box |
|---|---|
| I agree to take part in this research about my experiences of living with a personality disorder diagnosis and my ideas and feelings towards the role of creativity in my life. | ☐ |
| I am happy that the researcher has explained to me the reasons for the research, what I will be required to do and the possible issues involved. | ☐ |
| I have been given the chance to ask any questions or discuss any concerns I have about the research. | ☐ |
| I have read the information sheet and understand the purpose of the study, what is involved and the possible risks. | ☐ |
| I understand that some of the information generated from this research will be published and that I will be given the choice whether I wish to remain anonymous. I understand that I will be required to complete an additional consent form should I wish to waive my right to anonymity. | ☐ |
| Where interviews are to be conducted over the telephone or face-to-face, I consent to a recording being made of the interview. I understand that this recording will be destroyed once the content of the interview has been transcribed. | ☐ |
| I know that confidentiality cannot be guaranteed should I provide information that indicates a desire to harm myself or others. | ☐ |
| I understand that I am free to withdraw from the study at any time without giving a reason. | ☐ |

Name (please print) ………………………………………………………………………

Signed ……………………………………………………….. Date ……………………….

If you have any questions about this form, or relating to the research itself, please contact myself, the researcher, in the first instance, using the contact details below;

**Contact information**

| Researcher |
|---|
| **Ashley Austin**<br>College of Applied Social Science<br>Mayfield House<br>University of Brighton<br>BN1 9PH<br><br>**Telephone:** 07792027058<br>**Email:** A.T.Austin@brighton.ac.uk |

## Appendix 4: Anonymity Waiver

### Anonymity Waiver

The Lived Experience of Women diagnosed with Borderline Personality Disorder

*Please read the declaration below and make sure you consider it carefully before signing. You should sign two copies of this form – one is yours to keep and the other will be retained by the researcher. If you have any questions about this form, or relating to the research itself, please contact myself, the researcher, in the first instance, using the contact details at the bottom of the page.*

I understand that I have the right to remain anonymous and that unless I give permission my name and any identifying details will be changed in any publication relating to the research.

By signing this form, I am voluntarily electing to waive my right to remain anonymous and authorise the researcher to use my real/preferred name and personal details in the thesis and any further resulting publications.

I understand that these publications may be accessible to the general public and that by consenting to the use of your personal details you may be identifiable as a result.

Name (please print) …………………………………………………………………………..

Signed ……………………………………………    Date ………………………………..

**Contact information**

| Researcher |
|---|
| **Ashley Austin**<br>College of Applied Social Science<br>Mayfield House<br>University of Brighton<br>BN1 9PH<br><br>**Telephone:** 07792027058<br>**Email:** A.T.Austin@brighton.ac.uk |

## Appendix 5: Sample Topic Guide

Interviews will be unstructured, allowing space for participants to influence discussions so that wherever possible the position of the researcher is not privileged above that of the researcher. It is hoped that this will allow for a two-way dialogue within which to explore emerging themes and issues in the context of lived and subjective experience.

The following is intended as a rough guide to the topics of interest to the researcher that may be used to guide conversation;

### *Background/Introductions*

- Explanation of how the research has been developed – emerging as a result of Gillian Bendelow's work on S136 and some of the findings of the QSA.
- Contextual/background information on participants
    - Age?
    - Domestic situation?
    - Are they currently working? Etc.
- Who are they? How do they describe themselves?

### *Diagnosis*

- When were they first diagnosed with a personality disorder?
- Do they have any other physical/mental health diagnosis? Are they taking any medication?
- Explore understandings of diagnosis – what does it mean to them and their concept of identity. Has it helped them or made things difficult? How did other people react to their diagnosis? Do they believe it is correct?

### *Living with BPD*

- How has their life changed since being diagnosed with BPD?
- What does it mean for them to live with BPD on a daily basis?
- What treatment/support have they been offered? What has been helpful and what has not been so helpful?
- What do they think the reaction of society is to people with a BPD diagnosis?

### *Creativity*

- Explore what creativity means to them – in a general sense and more specifically in relation to themselves and their PD.
- How does art/music/photography etc. help them to express themselves?
- How does being involved in creative pursuits affect their mental health? Or what effect do they believe having BPD has on their creativity.

### *Going forward*

- What treatments/support networks do they think are helpful for women with BPD?
- What would they like other people to know about themselves/their lives?
- Have their experiences/observations/perceptions changed over time?
- How is their life different now to when they were first diagnosed?