# *“I don’t think that really any of the symptoms of it are my experience”*:

# An Interpretative Phenomenological Analysis of women who disagree with their diagnosis of Borderline Personality Disorder.

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# Abstract.

## Background

Borderline Personality Disorder (BPD) is noted to be a disorder of mood and interaction. This diagnosis is given to more women than men and can be stigmatising, with people being accused of being attention-seeking and manipulative. People have reported feeling that the diagnosis is used when they do not fully meet the criteria for other diagnoses and have reported negative experiences with mental health services after receiving the diagnosis. Some mental health care professionals have also reported finding it difficult to work with people who have this diagnosis. There is also a high correlation between experiencing trauma and receiving this diagnosis, so, a person who has experienced trauma, may then later find it difficult to receive support.

Counselling psychologists are interested in understanding the meaning behind experiences and alleviating distress. Considering that individuals have reported feeling the diagnosis does not match their feelings, and the stigma that they may have experienced, it is important to understand the impact of receiving a diagnosis that is not agreed. This study aimed to explore the experiences of women who have been diagnosed with BPD and have disagreed with their diagnosis, considering what meaning they ascribed to this label, and the impact of this on their mental health and wellbeing.

## Methodology

A qualitative approach was used for this study. Eight women, aged between 21 – 44, took part in semi-structured interviews that were held online via Microsoft

Teams. The transcriptions were analysed using Interpretative Phenomenological Analysis (IPA).

## **Findings**

Five group experiential themes were developed:

1. When did everyone forget that I’m just a normal person?
2. This label made things harder.
3. Society needs order and needs labels to keep this order.
4. Problems within the system.
5. Wanting to feel that I am in control of my life.

These themes highlighted that receiving the diagnosis caused difficulties for the participants, feeling unable to trust themselves and worrying about judgements. Findings supported previous research regarding stigma and negative interactions with professionals and services, often receiving invalidating and unhelpful responses. The findings also discussed misdiagnosis, with some participants later finding out that they were autistic and other participants having trauma-related diagnoses. These findings are discussed in terms of related literature and suggestions are made for implications for practice, and recommended future research.

# Table of Contents

# List of Tables

# Acknowledgements

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# Chapter 1 - Introduction

Borderline personality disorder (BPD) has been called "the twenty-first-century version of the scarlet letter" (Gunn & Potter, 2015, p. 3), a diagnosis that is mainly given to women (American Psychiatric Association [APA], 2013), with an extensive history going back to 1938 (Stern, 1938). This diagnosis is known for having stigmas attached, with individuals describing how they were told that they were just bad people (Reynolds, 2017), manipulative and attention-seeking (Ring & Lawn, 2019). People who have received this diagnosis have described how they feel excluded from services (Stalker et al., 2005). The term "dustbin label" has been used to describe its ability to fit people into a category when their experiences could not fit elsewhere (Horn et al., 2007, p. 262). Despite the difficulties that this diagnosis can bring, it is still widely used today.

There are new perspectives that aim to challenge the use of the medical model to describe psychological or emotional difficulties (Middleton & Moncrieff, 2019; Johnstone & Boyle, 2018). There has been research focusing on disagreements with other diagnoses (Forgione, 2019), with people feeling they were given a diagnosis that did not fit their experience. This study aims to explore the experiences of women, who were diagnosed with BPD and disagreed with their diagnosis. This is explored using the methodology of Interpretative Phenomenological Analysis (Smith et al., 2022), which is a method where the researcher takes an active role in the analysis. To begin that active role, I aim to acknowledge my connection with this diagnosis throughout the thesis, starting with the introduction.

## My experience with this diagnosis.

Throughout my training, working as a support worker, assistant psychologist and trainee counselling psychologist, I have met many people who have this diagnosis. Some felt that their diagnosis explained what they were feeling, but not why. Some also wondered if this meant that they had a problem with their personality, whether their personality was bad somehow. Every person I have met with this diagnosis has experienced some form of trauma or adverse life experience. At the time of writing, I have only met one man who has received this diagnosis, every other person has been a woman.

Across the different settings I have worked in, I have also witnessed the stigma that this diagnosis holds; hearing professionals feeling that certain people are difficult to work with, behavioural or beyond help. I have always strived to look beyond the diagnosis and consider why a person may feel the way they do. I find that after spending time with the person and hearing about their past experiences, the way they 'behave', and feel is usually completely understandable. As a future counselling psychologist, I believe it is important to understand the impact that a diagnosis can have on a person. Considering the amount of stigma that is attached to this diagnosis, and the barriers it causes to treatment; I often wonder whether this actually helps the person. Although I have an understanding of the medical model, I prefer the use of formulation to inform my practice. My knowledge of the medical model enables me to see that, yes, some of their experiences may meet the listed 'symptoms' of BPD; however, they also meet the 'symptoms' of someone who has been through trauma. I often find myself becoming confused and concerned with the amount of people that I meet who have been through traumatic experiences, and now feel that they have 'something wrong' with their responses to this trauma. I used to worry that I was naïve in my viewpoint, as instead of focusing on diagnoses, I focus on experiences and emotions. However, my training and clinical experience have helped me to feel more comfortable with this.

## Rationale of the study.

The literature review will include previous research into the experiences of people who have been diagnosed with BPD. There will be details regarding the stigma and attitudes of others. Research will also include the correlation of trauma and receiving this diagnosis, and the recommended treatment. Despite all the research that has been conducted in this area, there seems to be a void; with no focus on the experiences of individuals who have disagreed with their diagnosis of BPD. There seems to be a lack of understanding of how this can affect a person's life. I feel this is important in my role as a future counselling psychologist. Counselling psychologists understand the medical model; however, they are also concerned with understanding their clients' experiences (Kasket, 2017). The diagnosis could give me ideas of what a person will be (or has been previously) experiencing; however, it does not tell me why they feel the way they do, or how they have felt since receiving the diagnosis. Did they agree with the diagnosis? Did it provide any understanding or explanations? Diagnostic systems are used so mental health professionals can access the information needed to make a diagnosis (Clark et al., 2017); however, I have found myself questioning whether the personal experience is forgotten about. Research has also suggested that there could be a possible 256 different variations of BPD (Critchfield et al., 2007), so can this diagnosis provide any information about a person? Counselling psychologists are concerned with understanding the meaning behind experiences and alleviating distress (British Psychological Society [BPS], 2023), so we need to be able to acknowledge that receiving a diagnosis can also be considered a life experience and be open to trying to understand what this meant for that person.

There have also been discussions, between the BPS and NHS England, regarding prescribing rights for psychologists, and to prescribe, they would be required to provide diagnoses (BPS, 2020). If, in the future, we are required to diagnose, I feel that it is important for us to understand the impact that the diagnosis can have. We are interested in empowering individuals and helping them to manage distress (BPS, 2023) and if we provide a diagnosis which unintentionally causes a person more distress, which reduces their sense of agency, we will be moving away from our values.

## Research questions.

This research attempts to explore the experiences of receiving a diagnosis of BPD and disagreeing with this. This study aims to answer the following research questions:

1. How do the women who participated in this study experience receiving a diagnosis that they have disagreed with?
2. What meaning did the women who participated in this study ascribe to the label of borderline personality disorder?
3. How do the women who participated in this study perceive and experience the impact of this disagreement on their mental health and well-being?

## The structure of this thesis.

Due to my feelings about this diagnosis, I have remained reflective throughout the thesis, and have used a research journal to help with this process. The research journal was used from the very start, keeping note of my thoughts and emotions during the literature review, then throughout each stage of the research. After every interview I would sit and note my reflections and continued this process through the analysis. I have added reflective notes throughout the thesis when it has felt appropriate, beginning with a reflective section in the methodology and followed by additional reflective notes during the findings, discussion and conclusion. This thesis consists of several chapters which cover the following:

The *literature review* will examine the history of the diagnosis and diagnostic systems, with the current diagnostic criteria of BPD. It will then explore critical literature involved with the diagnosis of BPD, before looking at the possibility of gender bias within the diagnosis. The literature will then examine the pathologising of women's experiences, before a consideration of the stigma, beliefs and attitudes attached to this diagnosis. The experiences that people have reported from receiving this diagnosis will be included and the treatment recommended. There will be an exploration of the literature that acknowledges the connection between trauma and receiving this diagnosis. The literature review will conclude with a discussion regarding the viewpoints of people who have disagreed with diagnoses, before moving on to explain the current study.

The *methodology chapter* provides a rationale for choosing a qualitative method, discussing the epistemology and ontology. There will be a description of Interpretative Phenomenological Analysis (IPA), and considerations of other methods, with the rationale for the chosen methodology. An explanation of the interview schedule will be provided, followed by a consideration of using online methods with qualitative research. The participant recruitment process will be detailed, along with the ethical requirements and considerations that were applicable. The chapter will then explain the data collection and analysis process, including the pilot interviews and transcription. The chapter will then conclude with a reflexive paragraph.

The *findings chapter* will begin with discussing the participant's life experiences in relation to their diagnosis, before presenting the group experiential themes. Each group experiential theme will then be explored, within a narrative that uses extracts from the transcriptions. There will be reflective notes added throughout when applicable.

The *discussion chapter* will begin with a summary of findings in relation to the literature. The chapter will then focus on each group experiential theme, discussing relevant literature that could either support, deviate or explain the findings.

The *conclusion chapter* will begin by revisiting the original research questions, before discussing the strengths, limitations and a critique of the methodology used. The methodological integrity of the research will be discussed, before considering the implications for practice and future research. The chapter will close with my final reflections.

# Chapter 2 - Literature Review

## Introduction to the literature review.

This chapter provides a critical overview of Borderline Personality Disorder (BPD) / Emotionally Unstable Personality Disorder (EUPD) literature. The literature review will begin by examining the history of the diagnosis and diagnostic systems, with the current diagnostic criteria of borderline personality disorder. It will then explore critical literature involved with the diagnosis of BPD, before looking at the possibility of gender bias within the diagnosis. The literature will then examine the pathologising of women's experiences, followed with a consideration of the stigma, beliefs and attitudes attached to this diagnosis. The experiences that people have reported from receiving this diagnosis will be included and the treatment provided and recommended. There will then be an exploration of the literature that acknowledges the connection between trauma and receiving this diagnosis. The literature review will conclude with a discussion regarding viewpoints disagreeing with diagnoses.

Although this literature is comprehensive, it is important to note that the current literature surrounding disagreeing with the diagnosis of BPD/EUPD is limited. The chapter will conclude with the aims and rationale for the current study.

## Process of carrying out the literature review.

The purpose of the search was to locate relevant literature relating to BPD, the experience of those who had received the diagnosis and the experience of disagreeing with it. Searches were repeated throughout the years of authoring this thesis to ensure that updated literature was included. Keywords and combinations (Appendix A) were inputted into several databases and websites that utilised Boolean operators to ensure that all possible relevant information was obtained. Several other techniques were employed, for example, allowing for different spelling from other countries.

Searches were mainly conducted using the University West of England, Bristol (UWE) library, which holds access to databases. These databases include (but are not limited to): Directory of Open Access Journals, EBSCO eBook collection, EThOS, PTSDpubs, PsychInfo, SAGE Journals Online, ScienceDirect and Wiley Online Library. UWE library was also used to access books and eBooks, along with Google and Google Scholar. Additional books and resources were also purchased from a variety of websites.

### Defining terminology.

Throughout my training, I have become uncomfortable with the use of the word ‘disorder’ as a means to describe emotional or psychological difficulties; however, the word is used throughout this thesis as it is within the name of the diagnosis involved in this research.

It is important to note that BPD is also sometimes known as EUPD, due to the different classification systems (National Institute for Health and Care Excellence [NICE], 2009a). These terms are sometimes interchangeable, so the literature will consider relevant research using both terms. As the diagnosis originates using the term ‘borderline’, this is the term that will be used predominately throughout this thesis.

## History of Borderline Personality Disorder

Symptoms that could be associated with BPD can be traced back as far as the ancient Egyptians, The Eber Papyrus (1600 BC) documented experiences that described depressive disorders, and historically, female emotional distress was assumed to be the result of the uterus needing to be located back into its original place (Gunn & Potter, 2015).

The term ‘Borderline Personality Disorder’ has an extensive history, starting in 1938 when the term ‘borderline personality’ was first used by Adolph Stern (1938), to describe individuals who did not fit into the psychotic or neurotic categories. It was felt these individuals were on the border of these categories. In the 1940s Robert Knight spoke of ego psychology, dealing with mental functions that allow us to respond effectively to situations, suggesting that those who were seen as ‘borderline’ may have impairment within these functions (Friedel, 2020). At this point, the clinical meaning of ‘borderline’ referred to the individuals who were seen as being ‘borderline schizophrenic’ (Gunderson, 2009).

Borderline personality organisation was then introduced by Kernberg (1975), who used it to refer to instable functioning and behaviour within individuals. These individuals were seen as having fluctuating moods and levels of self-image, fears of abandonment, rejection and periods of suicidal thinking and self-harm (National Collaborating Centre for Mental Health [NCCMH], 2009). Although Kernberg suggested individuals who had ‘borderline personality organisation’ had lapses in reality testing, he proposed that this organisation was treatable with psychoanalytic psychotherapy (Gunderson & Links, 2008).

BPD was first included in the Diagnostic and Statistical Manual of Mental Disorders (DSM) 3rd edition in 1980 (Friedel, 2020). The condition of ‘borderline personality organisation’ had evolved from being considered a result of psychological self-organisation to a disorder with defining diagnostic criteria.

## Diagnostic Systems

There are two main systems commonly used within the diagnosis of mental health conditions, these are the Diagnostic and Statistical Manual of Mental Disorders (DSM) (APA, 2022) and the International Classification of Diseases (ICD) (2023a). Diagnostic systems were developed so that any mental health professional could access the information needed to diagnose. Insurance companies in the United States of America (USA) readily adopted these as they had specific definitions that could be used in their medical model for the reimbursement of care costs required (Clark et al., 2017). The diagnostic systems also provide a common language for clinicians, and attempts have been made to synchronise the information provided in both the DSM and the ICD to allow for more effective communication and diagnosis (van de Water et al., 2016).

Historically, mental health conditions were attributed to supernatural phenomena, such as demonic possession, with ‘treatments’ involving procedures that were thought to ‘release the evil spirits’ (Foerschner, 2010). Today there is more knowledge about the psychological, emotional, physical, and environmental influences that can impact an individual’s life. Within the notion of diagnosing mental health difficulties, there have been some fundamental issues noted such as the aetiology, or the cause of the ‘illnesses. The classification systems are based almost only on observable behaviours and self-reported thoughts and feelings (Clark et al., 2017). Although there is abundant research, which focuses on early childhood experiences and trauma with individuals who have been diagnosed with mental health conditions (Porter et al., 2020; Pohl et al., 2021; Read & Bentall, 2012; Barrense-Dias et al., 2023; Marshall et al., 2020; Banyard et al., 2001), there is still a lack of understanding in the full factors that may contribute to these conditions. Bunston et al. (2017) note that whilst diagnostic systems often influence thinking, research and funding within adult and child mental health services; these systems focus on pathologising rather than exploring causality, ignoring factors such as adverse life experiences.

Classification systems can be interpreted as representing the view that mental health conditions have clear symptoms, the same way that physical health conditions have clear symptoms (Clark et al., 2017). However, with so many ‘disorders’ containing similar symptoms, often being diagnosed after certain behaviours are observed, it calls into question how the person diagnosing can make sense of which ‘disorder’ matches which symptoms. Individuals can be provided with more than one diagnosis, to attempt to explain the range of ‘symptoms’, these diagnoses can change over time, calling into question their validity (Timimi, 2014). The National Institute of Health and Care Excellence (NICE) (2009a) advises that BPD can often be co-morbid with depression, anxiety, eating disorder, Post-Traumatic Stress Disorder (PTSD), substance misuse and bipolar disorder.

Although there have been issues noted with diagnostic systems, there has been research that has stressed the importance of diagnoses within mental health. It has been suggested that a diagnosis can allow a sense of comfort, that others feel or have felt the same way, it also allows the individual to access treatment (Craddock & Mynors-

Wallis, 2014). Research has noted that a diagnosis can allow for individuals to externalise their difficulties, so they do not feel they are to blame for feeling how they do (Eads et al., 2021). There are suggestions that diagnoses prevent individuals from being medicated unnecessarily; without the distinctions between the different diagnoses, it would be possible to provide the incorrect medical treatment, which could further impact the person’s life (Ruffalo, 2019). There are also political reasons for diagnoses being needed, for example, if a person is unable to work and needs to claim state benefits, and in some countries, health insurance companies require a diagnosis for treatment to be accessed (Wykes & Callard, 2010).

As diagnoses can change, not just for the individual but also with the description of the symptoms, both diagnostic criteria from the ICD-11 and DSM-5-TR have been included.

## DSM-5- TR Diagnosis of Borderline Personality Disorder

The current diagnostic criteria for BPD in the DSM-5-TR (APA, 2022, p. 1003–1004) states the following:

A pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity, beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:

1. Frantic efforts to avoid real or imagined abandonment. (Note: Do not include suicidal or self-mutilating behavior covered in Criterion 5.)
2. A pattern of unstable and intense interpersonal relationships characterized by alternating between extremes of idealization and devaluation.

3. Identity disturbance; markedly and persistently unstable self-image or sense of self.
4. Impulsivity in at least two areas that are potentially self-damaging (e.g., spending, sex, substance abuse, reckless driving, binge eating). (Note: Do not include suicidal or self-mutilating behavior covered in Criterion 5.)
5. Recurrent suicidal behaviour, gestures or threats, or self-mutilating behaviour.
6. Affective instability due to a marked reactivity of mood (e.g., intense episodic dysphoria, irritability or anxiety usually lasting a few hours and only rarely more than a few days).
7. Chronic feelings of emptiness
8. Inappropriate, intense anger or difficulty controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights)
9. Transient, stress-related paranoid ideation or severe dissociative symptoms.

### ICD-11 Diagnosis of Borderline Personality Disorder

The ICD-11 has recently changed its definitions of personality disorder, assigning personality disorders as mild, moderate, severe and severity unspecified, these are used alongside categories of personality traits or patterns within its updated version (ICD-11, 2023a). Within the personality traits or patterns category, there is a description of a borderline pattern. This is defined as:

> "The Borderline pattern descriptor may be applied to individuals whose pattern of personality disturbance is characterised by a pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity, as indicated by many of the following: Frantic efforts to avoid real or imagined

> abandonment; A pattern of unstable and intense interpersonal relationships; Identity disturbance, manifested in markedly and persistently unstable self-image or sense of self; A tendency to act rashly in states of high negative affect, leading to potentially self-damaging behaviours; Recurrent episodes of self-harm; Emotional instability due to marked reactivity of mood; Chronic feelings of emptiness; Inappropriate intense anger or difficulty controlling anger; Transient dissociative symptoms or psychotic-like features in situations of high affective arousal." (ICD- 11, 2023b, para. 1).

## Problems with the diagnosis of Borderline Personality Disorder

In 2006, the British Psychological Society published a report looking at personality disorders (Alwin et al., 2006), this report pointed out that around 10% of people could meet the criteria for personality disorder, and clinicians should focus on the formulation and not simply the diagnosis. The diagnosis of personality disorder has been criticised by Pilgrim (2001), who claimed that for any medical diagnosis to be credible, a cause needs to be specified. Although there is a general agreement that personality disorders can be caused by childhood events, there is no consensus or specificity in the aetiology (Pilgrim, 2001). It has been criticised over time for its reliability and validity, it has also been questioned whether the diagnosis captures the experiences of individuals who have been given this diagnosis (NCCMH, 2009). Furthermore, it has been suggested that due to the range of criteria, there could be a possible 256 different variations of BPD, meaning that a group of individuals with this diagnosis may have no common symptoms or experiences (Critchfield et al., 2007). Adding to this issue, BPD often has comorbidity with other diagnoses, so there could be further variations in the presentation, experiences and symptoms with this diagnosis (Critchfield et al, 2007).

Whilst it has been suggested that there are issues with the diagnosis of BPD, the classification does mean that there is evidence-based information available to those involved in the treatment, allowing for a therapeutic framework or pathway within most services (Dickens et al., 2016). There have been suggestions that receiving a diagnosis can reduce prejudices; as diagnoses involving mental health have become more common, therefore individuals are less likely to ‘stand out’ (Paananen et al., 2020). There have been some advantages suggested for the diagnosis of BPD, such as the provision of information for clinicians, those with the diagnosis and their families, and the attempt to predict response to medication (Paris, 2005).

There are concerns that if individuals are not diagnosed with BPD early in life, they may not receive timely support, which may further impact any difficulties faced later in life (Beatson et al., 2016). Some clinicians are reluctant to diagnose individuals due to the amount of stigma, however, it has been suggested that early intervention improves the prognosis (Bozzatello et al., 2019). Although this diagnosis has been criticised, if professionals do not acknowledge the experiences of those who appear to meet the criteria, this affects the individual. Shaw and Proctor (2005) noted that to make a diagnosis, the clinician has to decide whether the emotions are appropriate; so, anger could be considered inappropriate, as opposed to being understood in the context of experiences. Furthermore, it has been noted that those who have been diagnosed with BPD can also find themselves in situations where their feelings about their diagnosis can be used as a diagnostic confirmation, voicing doubt can be seen as a reluctance to engage with reality (Reynolds, 2023).

To address difficulties within this diagnosis, the DSM-5 (APA, 2013) proposed an alternative model for personality disorders, which is characterised by functioning and traits (APA, 2013). The function aspect refers to the intrapersonal and interpersonal affect, whereas the traits are considered in terms of "stable tendencies or dispositions toward particular emotions, thoughts and behaviours" (Vittengl et al., 2023, p. 254). It has been suggested that this model, which takes a more dimensional approach, may help improve therapeutic interventions as it considers other characteristics which do not fit neatly into the personality disorder categories (Krueger & Hobbs, 2020).

## Gender bias within Borderline Personality Disorder.

Since the addition of BPD within the DSM-III (APA, 1980), all subsequent DSM editions have indicated that BPD is present more in females than males (Sansone & Sansone, 2011). The DSM-5 (APA, 2013) stated that BPD is mainly diagnosed in females, with only 25% of diagnoses belonging to males (APA, 2013). The most recent edition, DSM-5-TR (APA, 2022) continues to show an awareness that it is more common in women. The issue of gender bias was proposed by Kaplan (1983) who claimed that the diagnostic team involved with the DSM-III had made assumptions about what female behaviour would seem natural, noting a potential bias within the BPD diagnosis.

Horsfall (2001), suggested gender differences within diagnoses were applied to take note of societal expectations of appropriate behaviour; these relate to what is considered to be accepted masculine and feminine behaviours, therefore the diagnoses become a social construct. Bjorklund (2006) reviewed literature in terms of gender bias with the diagnosis of BPD, claiming women were diagnosed more than men by a ratio of 3:1, suggesting that the gendered nature of society may contribute to women being labelled as borderline more than men.

Skodol and Bender (2003) examined the possibility of biased sampling, considering the higher rate of diagnosis may reflect the higher rate of females seeking help for psychological issues. Skodol and Bender (2003) also looked at biased diagnostic criteria, referring to the possibility that behaviours not consistent with stereotypical gender roles could be pathologised. These beliefs align with earlier theories proposed by Akhtar (1995) who suggested cultural factors may play a part in gender bias. They claimed that females may have more control over their social behaviour, which could explain why males could be diagnosed with Antisocial Personality Disorder (ASPD), whereas females would be diagnosed with BPD (Akhtar, 1995). Further explanations for the difference in the rates of diagnoses have been suggested as biases within the diagnostic constructs, diagnostic criteria and the application of assessment instruments (Widiger, 1998).

It has been suggested that criteria used for diagnosis can be the cause of bias. For example, Samuel and Widiger (2009), found a dimensional model of personality used within diagnosis provides less gender bias than when using a diagnostic criterion. Braamhorst et al. (2015) suggested that the possibility of bias is reduced when a person has enough criteria to meet the threshold of BPD, therefore bias is more present when an individual only has ‘traits’ of the diagnosis. Furthermore, it has been suggested that there is the possibility of a difference in how symptoms present in different genders, similar to how there would be differences in expressions in different cultures (Campon, 2017). Although BPD is diagnosed more in females, there is also a trend of

ASPD being diagnosed more in males (Anderson et al., 2001), so there is the possibility of bias against men with other diagnoses.

## The pathologising of women's experiences

There has been a long-standing history of pathologising women's experiences. The term hysteria was first described by the ancient Greeks, who believed that the womb would detach itself and move through the body, causing emotional difficulties. The recommended treatment was either smelling garlic or putting honey on the woman's vagina, to encourage the womb to return to its regular position (Gunn & Potter, 2015). From the thirteenth century, 'hysterical' women were seen to have bonds with the Devil and were subjected to exorcisms (Tasca et al., 2012), during that period, exorcisms were seen as a treatment method. However, in the late Middle Ages, hysteria was associated with sorcery and those involved in 'witch hunts' would punish women suspected of being witches (Tasca et al., 2012). In 1748, hysteria was described as a condition that mainly affected women, and accordingly, sexual deprivation was often the cause of this hysteria (Ussher, 2013). This theory continued into the 1900s, with psychoanalysis founder Sigmund Freud arguing that hysteria was the result of psychological issues turning into physical symptoms, with an element of erotic suppression. Women who were considered to have hysteria were described as narcissistic, difficult and manipulative (Ussher, 2013).

Burt (1996, 1997) highlighted several issues with the diagnostic systems, suggesting that the classifying of symptoms is not impartial and legitimizes gender stereotyping. Within the DSM-III (APA, 1980), there were no contributions from women or minorities, so the classification relied on the viewpoints of white, middle-class males and although the newer versions do include contributions from women, there have been no significant changes within the description of the BPD symptoms (Eastwood, 2012). Mitchell (2000) noted that symptoms could be read as a variety of hysteria components, which could be interpreted as a description of what would be considered a ‘bad woman’ such as showing extreme emotions. Lester (2013) noted that many of the symptoms go against historical views of what is considered feminine, for example, casual sex is more likely to be considered impulsive in a woman, but not in a man.

Many women in mental health services have been diagnosed with a personality disorder, there is also a high number of women who have reported experiencing trauma and abuse in their lives (Parkes & Freshwater, 2012). Instead of being viewed as experiencing emotional distress due to past events in their lives, they are viewed along a pathological route and given a diagnosis. It has been posited that the diagnosis of BPD reduces the ability to focus on issues such as cultural, gender and socio-economic conditions that women consistently endure, this has been shown within the links between abuse and a BPD diagnosis (Buckland, 2019). Eastwood (2012) expressed that when symptoms are viewed and diagnoses are assigned, considerations need to be made to acknowledge the trauma and realities faced by women. It has even been suggested the symptoms of BPD could be considered survival techniques that were once needed in abusive or invalidating environments (Lester, 2013). Shaw and Proctor (2005) explain the BPD diagnosis from a social constructionist model; where BPD, similar to witchcraft and hysteria, is considered a deviation from the norms. Shaw and Proctor (2005) further explained the diagnosis helps to avoid acknowledging the impact of trauma and abuse. The person with the diagnosis is now distressed as a result of their condition, ignoring the context of the woman's experiences and reinforcing gender inequality.

## Stigma, beliefs and attitudes attached to Borderline Personality Disorder.

Many studies have been conducted exploring the stigma associated with being diagnosed with a mental health condition. In recent years, there have been increased campaigns to try to alter the stigma behind mental health diagnoses, such as the Time to Change (2023) campaign. Despite this, there still are stigmas associated with mental health diagnoses, and studies have focused on some of the experiences with stigma and discrimination. There can be stigma related to the specific diagnosis; for example, Yoshimura et al. (2018) found those with a diagnosis of schizophrenia had experienced discrimination while looking for jobs, compared to those with a diagnosis of depression. Although individuals with depression experienced less discrimination, they were more likely to conceal their diagnoses (Yoshimura et al., 2018). A systematic review also found that individuals anticipated negative consequences with disclosing their mental health difficulties, the fear of appearing weak or being labelled resulted in individuals not disclosing their mental health difficulties and masking their symptoms (Clement, et al, 2015). Individuals were also less likely to seek clinical forms of help, however, they would seek other forms of support such as community groups (Clement et al, 2015).

Attitudes towards mental health stigma can at times be viewed as an opinion of deviation from societal norms, individuals may act against social norms when they are experiencing forms of distress. There are different forms of norms and stereotypes, social norms are often considered as unspoken and informal ideas regarding how different groups of people should behave (Stewart et al., 2021). There are gender-based stereotypes related to the idea of masculinity and femininity, such as physical attributes, temperaments and roles (Stewart et al., 2021). It has been suggested that stigma is a response that the wider society has when individuals fail to conform (Yanos, 2018). Power and competitiveness were considered as a masculine stereotype whereas feminine stereotypes would involve nurturing aspects (Stewart et al., 2021), so a person failing to conform to these could be seen as acting against the norm. Furthermore, stigma has been shown to work in the favour of many, for example, females were once (and possibly still are) stereotyped as being weak to justify not being considered for management positions (Yanos, 2018).

In 2003, in a report published by the National Health Service (NHS), it was revealed that clinicians found the nature of personality disorder difficult, so they were reluctant to work with people who had this diagnosis. Individuals described their diagnosis caused them to be “the patients psychiatrists dislike”, and were called “time-wasters”, “manipulative” and “attention-seeking” (National Institute for Mental Health in England [NIMHE], 2003, p. 20). NICE guidelines were then published, however, there are still reports of stigma from professionals, with one person describing how she was told that she “wasn’t ill” she “was just a bad person” (Reynolds, 2017, Headline). It has been suggested that individuals with this diagnosis are likely to be in a ‘no-win’ situation, being condemned whether they do, or do not, seek help when feeling distressed (Ring & Lawn, 2019). The assumption is that mental health professionals will still consider them to be either “attention seeking” or “manipulative” (Ring & Lawn, 2019, p. 16).

Studies that have focused on the attitudes of staff within mental health services found when staff can understand the person's background, they are more positive or nurturing towards the ‘behaviour’ of individuals with BPD, staff described feelings of both dread and a desire to help (Stroud & Parsons, 2012). It has been suggested further training could help increase understanding and empathy towards individuals with BPD (Weight & Kendal, 2013). This has also been shown in a study by Campbell et al. (2022), who found that experienced mental health nurses who had received training in BPD, reported that although they sometimes found it difficult to work with people who have this diagnosis, they had empathy and hope for their patients.

Recent research has shown that there is a change occurring within some mental health staff attitudes towards people with BPD. Day et al. (2018) carried out two studies, fifteen years apart within the same service, and the later study showed more positive attitudes and language used. They acknowledged that new approaches had been introduced to the service, showing that lessons are being learned. An earlier study found stigmatising attitudes can be reduced by healthcare professionals getting to know the person; this reduces anxiety felt by healthcare professionals and increases empathy (Corrigan et al., 2012).

Although it appears that in some areas attitudes are improving, a recent study suggested that mental health professionals view individuals with BPD as “dangerous” “incomprehensible” and “unworthy” (Papathanasiou & Stylianidis, 2022, Abstract, Results, para. 1). Sheppard et al. (2023) also found that prejudice to people with a BPD diagnosis was higher than those with other mental health diagnoses. Considering that this label may result in individuals receiving less care than others, it is important to try to understand the experiences of those who have received this diagnosis.

## The experiences of receiving a diagnosis of Borderline Personality Disorder.

Lester et al. (2020) reviewed research papers to look into the experience of receiving a diagnosis of BPD. Within the review, a worrying matter was discovered when it was found that some participants had not been informed of their diagnosis and some had found out by accident. Some participants felt that the diagnosis suggested that they were “bad” or “wrong” instead of clarifying their symptoms, however, there were participants who felt that the diagnosis helped them to make sense of their difficulties and connect with other people (Lester et al., 2020, p. 270). Stalker et al. (2005) found participants who found the diagnosis helpful as it worked as a form of communication between professionals, however it was also felt by some that receiving this diagnosis had excluded them from receiving the type of support they needed (Stalker et al., 2005). According to NICE (2009a), people who have been diagnosed with BPD have been excluded from some services as a result of their diagnosis, it is believed that this may be due to a lack of confidence in the staff involved or a lack of skills.

This feeling of being excluded or feeling that the diagnosis was a barrier of some sort, repeats itself within other studies. Rogers and Dunne (2011) carried out a focus group with individuals who had been in inpatient services. It was felt that just having the diagnosis of personality disorder brought a lot of prejudices from the staff, feeling they were often compared to others who had “real/serious” diagnoses such as schizophrenia (Rogers & Dunne, 2011, p. 230). The language used by the staff in this instance indicates a lack of understanding of the difficulties that the individuals involved had and also indicates that those who were diagnosed with BPD were not treated like others who received different diagnoses.

There are reports of people who have found the diagnosis to be helpful, one person felt “the diagnosis had played an important part in her treatment as it gave her something to recover from” (Morris et al., 2014, p. 253). Other people have described the importance of the relationships within services, feeling that those who had listened to them and “treated them like a person” helped to increase their self-esteem and gave them hope (Morris et al., 2014, p. 253). A later study found that some people felt a sense of relief when they were given the diagnosis, however, others felt this was a way to say that their personalities were bad (Gardner et al., 2019). This study also found that some people found group therapy more helpful than individual therapy as it helped to reduce feelings of isolation (Gardner et al., 2019).

Previous research has also highlighted individuals feeling they were given the diagnosis as the professionals involved could not “fit” the symptoms into “other categories” (Horn et al., 2007, p. 262). The term “dustbin label” was used to explain that there seemed to be an urgency to fit individuals into a category, and while their experiences did not fully match the depression or anxiety diagnosis, BPD provided an “answer” to fit someone “in the box” (Horn et al., 2007, p. 262). The same study reported that participants were informed that BPD was “untreatable” and described how this information was like “the killing of hope” (Horn et al., 2007, p. 262). This effect was mediated by the people around them who treated them as a person “rather than a diagnosis” (Horn et al.,2007, p. 262). While there are recommended forms of treatment for BPD, one wonders how helpful it would be to provide an individual with a diagnosis, and then provide the information that it is not treatable. In a first-person account of their experience in services and with their diagnosis, Gary (2018) describes being relieved to receive a diagnosis, hoping it would lead to receiving support; however, an internet search later provided the information that BPD was incurable and that people with this diagnosis were disliked. Some of the listed symptoms of BPD involve chronic feelings of emptiness and potentially self-damaging behaviour (APA, 2022). Informing a person that they have an untreatable diagnosis could lead to that person feeling empty and losing hope, which could then possibly lead to self-damaging behaviours. The information available and provided to individuals could cause a situation where it causes more of the ‘symptoms’ of BPD to be present.

## Treatment of Borderline Personality Disorder

While looking at the recommended treatment options, it appears that some lessons have been learned from previous research, for example, it is stated that when working with an individual who has been diagnosed with BPD “explore treatment options in an atmosphere of hope and optimism, explaining that recovery is possible and obtainable” (NICE, 2009b, para. 2). This is an improvement, considering previous research reported participants were informed that the diagnosis was untreatable (Horn et al., 2007). NICE (2009b) also recommends that it needs to be kept in mind that “many people would have experienced rejection, abuse and trauma, and encountered stigma often associated with self-harm and borderline personality disorder” (para. 3). It is worrying that a diagnosis that has a symptom involving fear of abandonment (APA, 2022), may then add experience of rejection and stigma.

There is no recommended medication specifically for BPD, it is recommended that mental health trusts should develop multidisciplinary specialist teams and services for people with personality disorders (NICE, 2009b). It is also recommended that for women who have been diagnosed with BPD, Dialectical Behaviour Therapy (DBT) should be considered (NICE, 2009c). DBT is a cognitive-behavioural based treatment designed specifically for individuals who have been diagnosed with BPD and provides psychosocial skills training (Linehan, 1993). The typical DBT treatment includes weekly group skills training, weekly individual therapy, and a therapist consultation meeting (Chapman, 2006).

It has been found that in some cases where a BPD diagnosis has been provided, DBT is sometimes the only form of therapy offered, this often involves group therapy and some who attended these groups felt the therapy did not help process trauma experiences (Hodgetts et al., 2007). There were further therapies offered after completion of DBT; however, this period of ‘waiting’ could have further implications for individuals who have previously felt abandoned by services (Hodgetts et al., 2007). Although there are adapted versions of DBT that can be used to treat trauma, it is still recommended that individuals complete the standard version of DBT to address and manage suicidal thoughts or acts of non-suicidal self-injury (Choi-Kain et al., 2021). Although services are following recommendations by providing DBT (NICE, 2009c), it does take away the notion of choice and the possibility of feeling heard. As there is a high correlation between individuals who have suffered trauma and those who receive the diagnosis of BPD, the possibility of further invalidation is something that should be kept in mind.

## Trauma and Borderline Personality Disorder

Several studies have reported significant correlations between trauma and receiving a diagnosis of BPD (Goldman et al., 1992; Helgeland & Torgersen, 2004; Herman et al., 1989; Ogata et al., 1990; Zanarini et al., 2002, Temes et al., 2017). Research by Martin-Blanco et al. (2015) found 75% of participants who were all diagnosed with BPD reported traumatic experiences in childhood, these ranged from emotional abuse, physical abuse, sexual abuse and neglect. Brakemeier et al. (2018) had higher results finding 90% of participants who had been diagnosed with BPD had experienced some form of childhood maltreatment.

De Aquino Ferreira et al. (2018) found sexual abuse played a major role in BPD, especially in women, with child sexual abuse being an important risk factor. Luyten et al. (2020) considered the relationship between trauma and how this could affect the treatment with someone who has been diagnosed with BPD. They reported that trauma disrupts the attachment system, the capacity for mentalizing, the capacity for epistemic trust and the ability to rely on the surrounding environment to recalibrate the mind (Luyten et al., 2020). This can lead to the individual feeling cut off and prevent them from trusting any help and support that is offered, which could appear to professionals as difficult to treat or hard to engage. Difficulties with attachment may involve seeking intimacy, or fear of abandonment, which could in turn result in impulsivity or unstable relationships, which may then lead to feelings of emptiness (Belford et al., 2012). Ball and Links (2009) suggested that childhood trauma should be included in the aetiology of BPD and recommended further implications for treatment, such as future research in trauma-related therapies for individuals diagnosed with BPD.

There is now a wider understanding of the effect that trauma has on the ability to regulate emotions. Emotional regulation can be described as the ability to understand and be aware of one’s emotions, whilst having the ability to control impulsive behaviours when experiencing negative emotions (Fernando et al., 2014). Studies have shown that early-life trauma exacerbates the amygdala response to threatening cues, which affects the ability to regulate responses to emotional conflict

(Marusak et al., 2015). Swaab (2014), noted that if a person's background and developmental experiences have caused heightened emotions, this can result in reduced tolerance of stressful situations. It has also been reported that people who have been diagnosed with BPD are less able to tolerate negative emotions and attempt to suppress or engage in strategies to avoid these emotions (Fernando et al., 2014). The suppression or avoidance of these negative emotions could result in the type of 'behaviours' that are seen as the symptoms of BPD, such as self-harm, and impulsive or suicidal behaviours (Chapman et al., 2011).

Studies have also shown that women who have experienced abuse are at increased risk of experiencing premenstrual dysphoric disorder, so the cyclic monthly changes, which affect mood and cognition, could be more difficult for women who have experienced abuse (Azoulay et al., 2020). The diagnostic criteria for BPD/EUPD involve impulsivity, instability due to a marked reactivity of mood, chronic feelings of emptiness and inappropriate or intense anger (APA, 2022; ICD-11, 2023b). Therefore, a woman who presents with symptoms of BPD may struggle with her emotions as a result of trauma, and the intensity of her emotions may be further impacted by the usual monthly cycles. Mu et al. (2022) studied the menstrual cycle in trauma-related disorders and suggested that clinicians should be mindful of the phases of the menstrual cycle or perform assessments at different times of the month. Mu et al. (2022) further recommended that additional research is needed to understand the influence of the menstrual cycle on trauma-related symptoms. Although this knowledge may not directly alleviate the effects of the trauma, it could help validate the woman, knowing her emotions are understandable, and may lead to more effective treatment or management.

## Looking beyond the symptoms.

The symptoms assigned to the BPD diagnosis can be viewed as the result of growing up in a difficult environment or experiencing trauma. Individuals who have been through difficult or traumatic experiences can develop methods of blocking out or numbing their emotions. This can contribute to difficulties later in their lives, such as affecting their social relationships, the ability to trust and seek out support (Johnson et al., 2007). Some individuals may employ techniques such as avoiding difficult situations, whereas other people may use self-harm as a method to feel anything except emotional turmoil. There is now knowledge available regarding different trauma responses, such as fight, flight, freeze and fawn (PTSD UK, 2023), and some responses may appear to be impulsive. Some people have also experienced difficulties in their early childhood relationships. Attachment theory explains that when an individual has been without secure attachment, this may result in an attachment style that is either anxious, avoidant or disorganised (Bowlby, 1969). A person learns that attachments are not reliable and can therefore be seen as either clingy, avoiding or distrusting, this can be viewed as instability within relationships. Further, if one considers the different environments and systemic factors that an individual experiences, such as race, class and gender, this can also explain some of the presenting symptoms.

A person who has lived in an environment that is threatening, violent or involves low socioeconomic conditions, may develop certain resources for them to survive (Sheffler et al., 2019). These resources may have been helpful at one point; however, they may now cause additional difficulties. They may be seen as impulsive, they may also be seen as having an unstable sense of self, due to the need to behave differently depending on the context or masking their difficulties. They may have difficulties trusting others, which may interfere with their interpersonal relationships. They may have learned to internalise or avoid difficult emotions, so when these emotions are expressed, they can be considered as an outburst. These can all be seen as survival methods, however, within the context of BPD, they are viewed pathologically and considered ‘symptoms’.

When a person has accessed support or therapy, there is the opportunity to learn that their emotions are valid and can be felt without trying to numb them, however, most individuals do not receive any support or therapy until they have reached a crisis point. After being diagnosed with BPD, they may also feel that professionals are more concerned with their behaviour, rather than their emotions and experiences (Ware et al., 2022). This can cause further invalidation, feeling that nobody cares about what they have or are experiencing, and instead, they need to behave more acceptably. Once diagnosed with BPD, ‘normal’ behaviours can then be pathologised. The term ‘splitting’ for example, is often viewed as splitting teams, showing a preference for certain staff members (Bland et al., 2007), however, in usual circumstances, most people have certain people that they feel more comfortable with. If these emotions and behaviours were understood as a result of life experiences, it could be possible to help the person, without the impact of stigma and judgements.

## Disagreeing with diagnoses of psychological distress

Some perspectives have challenged the medical model, since 1977 when Engel (1977) noted that the medical model does not acknowledge the social, psychological and behavioural factors. These approaches consider that there are normal human reactions, instead of diagnoses of mental health (Davies, 2013) and acknowledge relational conflicts, injustices and abuses (Mad in the UK, 2020). They involve hermeneutic approaches, making meaning out of the experiences, and social constructivism, where behaviour or feelings go against what would be considered the social norm (Middleton & Moncrieff, 2019; Thompson, 2019). There is also a movement within some mental health circles that aims to move away from the traditional use of diagnoses. The Power Threat Meaning Framework (Johnstone & Boyle, 2018) was devised by psychologists and service users as a way to help people see themselves in a different light other than being mentally ill. The framework allows people to acknowledge wider social factors such as inequalities, while taking into account trauma and difficult life experiences. It aims to help people understand their difficulties, instead of the medical model of diagnosis where some may find themselves with a label that they feel does not explain why they feel the way they do (Johnstone & Boyle, 2018). More recently, the World Health Organisation (WHO) and the United Nations (UN), published a report calling for a "significant shift from biomedical approaches towards a support paradigm that promotes personhood, autonomy, and community inclusion" (WHO & UN, 2023, p. xvi). The report further stated:

> "A fundamental shift is required within the field of mental health. Stigma, discrimination, and other human rights violations continue in mental health care settings. There is an overreliance on biomedical approaches to treatment options, inpatient services and care, and little attention given to social determinants and community-based, person-centred interventions" (WHO & UN, 2023, p. 4).

This acknowledgement by these two organisations supports the notion that mental health requires further considerations that go beyond the current notion of diagnoses.

Although there has been research into the area of disagreeing with some mental health diagnoses, a search of available databases failed to find research that focuses on the experience of disagreeing with the BPD/EUPD diagnosis, highlighting the need for research in this area. For the purpose of this literature review, studies that have focused on other diagnoses have been included.

There have been several studies published that have focused on the experiences of individuals who have disagreed with the label that they have been given (Elkins, 2015; Everett, 2000; Watson, 2019). These individuals have been seeking to find their own sense of meaning around their experiences without being attached to their diagnosis. Forgione (2019), interviewed individuals who had experiences of receiving either a diagnosis of schizophrenia or a psychotic-disorder diagnosis. It was felt by the participants that they were being given a label that did not fit with their experiences. The participants also felt that after receiving this diagnosis, they had received stigma from friends, family and clinicians, and sometimes being mistreated in hospitals. This study considered the impact as an active response to invalidating the person's experience by assigning a label, which made them feel ignored and misunderstood. Often the term ‘poor insight’ was used during attempts to challenge this diagnosis (Forgione, 2019). These findings raise important questions, such as the types of situations and contexts in which individuals would feel safe enough to disagree and challenge clinical diagnoses.

Van Voohees et al. (2005) looked at individuals who had disagreed with their diagnosis of depression; finding that social norms, beliefs and attitudes were important factors in individuals who had rejected their diagnosis of depression. The participants expressed concerns about employers finding out. These findings show that receiving diagnoses can not only make a person feel powerless but also cause a lot of worry in that person’s life, feeling afraid to talk about their difficulties with those around them and possibly preventing the person from asking for help.

As shown above, there has been research carried out involving different diagnoses and examining why individuals have disagreed with their diagnosis. There appears to be a lack of research looking at the experiences of individuals who have been diagnosed with BPD and subsequently disagree with their diagnosis. Considering the impact of any mental health diagnosis, including treatment, stereotypes and stigma, it is important to consider how an individual has been impacted by their diagnosis and whether they felt the diagnosis was helpful. This study aims to provide a voice to those individuals who did not agree with their diagnosis of BPD.

## The current study

As shown above, there is research available that explores reasons why individuals have disagreed with other diagnoses; however, a search of databases failed to find studies that focused on the impact of disagreeing with the diagnosis of BPD. Psychology often focuses on the narrative of the individual and concentrates on how individuals construct their meaning from their life experiences, trying to ensure that their stories do not get lost among the systems that they are involved with (Adame & Hornstien, 2006). Counselling psychologists are interested in understanding the meaning behind individuals’ experiences, empowering individuals and alleviating distress (BPS, 2023) so this study aims to increase understanding to allow for a more authentic therapeutic process.

In addition, there have been discussions surrounding whether psychologists should be able to prescribe medication, it has been proposed that to do this, psychologists should also be prepared to diagnose (BPS, 2020). So, as a future counselling psychologist, I believe that to stay true to our values, we should be aware of all the implications when a diagnosis is provided. Counselling psychologists work compassionately and aim to provide fairness whilst meeting the psychological needs of others (BPS, 2023). Will we be meeting psychological needs if we are providing a diagnosis that could affect the psychological intervention that is offered?

Considering the above, it is clear that although there is research that focuses on the experiences of individuals who have been diagnosed with BPD, there appears to be a gap, which fails to seek to understand how disagreeing with this diagnosis could affect an individual’s life. In light of the reported experiences that some have had since receiving this diagnosis and considering that it is more diagnosed in women than men (APA, 2022), and after reflecting on my experiences of meeting people with this diagnosis, I felt that this was an important area to concentrate on. People who have tried to disagree with their diagnosis have been seen as ‘difficult’ (Horn et al., 2007) so often would be unable to express their reasoning and have their experiences ignored. I felt that understanding the reasons why people disagree with their diagnosis, and acknowledging the effect that this has had on their lives needed to be considered. As a trainee counselling psychologist working within these services, this will hopefully allow me to understand the impact of this diagnosis and create further awareness. This research attempts to explore these experiences, aiming to answer the following research questions:

1. How do the women who participated in this study experience receiving a diagnosis that they have disagreed with?
2. What meaning did the women who participated in this study ascribe to the label of borderline personality disorder?

3. How do the women who participated in this study perceive and experience the impact of this disagreement on their mental health and well-being?

# Chapter 3 - Methodology

## Introduction

This chapter sets out the methodology used in this research, providing a rationale for the chosen method, information regarding participant recruitment, and how the research interviews were conducted. This section also contains information on how the data analysis was conducted and a reflective statement.

## Qualitative research.

A qualitative approach was used, as this study aims to explore the meaning behind experiences. A quantitative approach would reduce the experiences to a set of numbers without taking into account the nuances and the meaning that can be gained from qualitative interviews. Qualitative research allows access to other people's worlds and allows us to have a subjected view into how their reality is constructed (Braun & Clarke, 2013). Qualitative interviews are particularly useful for research that requires understanding the experiences of others and allows the researcher to critically reflect on what has been said, whilst not having complete focus on the context, instead being curious about the meaning (Braun & Clarke, 2013).

The research questions within this study required an approach that would allow the researcher to explore the meaning and attempt to understand what it may have felt like for the participant (Willig, 2013). Qualitative research allows for this depth that is required. It is also important for the interviewer to be reflexive and have the ability to 'bracket' their feelings during the analysis to not steer the findings to match their personal feelings (Tufford & Newman, 2010).

## Epistemology and Ontology

Epistemology and ontology are concerned with reality and knowledge (Fryer, 2020). This study takes a critical realism viewpoint, which can be seen as a combination of ontological realism and epistemological relativism (Willis, 2022). Critical realism takes the stance that reality exists, but we can only partially know it, accepting that reality is nuanced and will be seen differently by each person (Braun & Clarke, 2013). This stance works well with both IPA research and counselling psychology. Counselling psychologists aim to understand subjective experiences, whilst using self-reflection to understand that there may be different dynamics to the therapeutic context that both the psychologist and client may be unaware of (BPS, 2023). IPA works well with a critical realist stance, as it aims to gain understanding or meaning from an individual’s experience (Braun & Clarke, 2013).

## Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) was chosen as the methodology as it focuses on the meaning that individuals make of their experiences. The assumption is that individuals are constantly trying to make sense of their experiences, and I, as the analyst, would join this process and also attempt to make sense of their experiences (Smith et al., 2009). IPA explores a person’s involvement or understanding of a particular event or phenomenon (Smith et al., 2022), and as the researcher, I commit to the task of describing, interpreting, and exploring the data. This requires the willingness to remain curious, flexible and attempt to enter the participants’ world (Smith et al., 2022). It is recognised that humans try to make sense out of experiences, so IPA acknowledges that although the researcher will have pre-existing ideas, the endeavour remains an interpretative journey (Smith & Osborn, 2015).

IPA is informed by three main concepts: phenomenology, hermeneutics and idiography (Smith et al. 2009). Phenomenology refers to the study of experience and how people make sense of and relate to their experience (Langdridge, 2007). IPA draws from phenomenological frameworks such as the beliefs of Merleau-Ponty, Sartre, Schleiermacher and Gadamer (Miller et al. 2018). Research using a phenomenological method involves the researcher having a curiosity, and remaining open to new understanding, to go past what they already know and ‘bracket’ their feelings about the subject (Finlay, 2012). The phenomenological approach focuses on existential meaning, and the interaction between the participant and the context in which they are involved (Miller et al. 2018).

One of the major theoretical underpinnings of IPA is hermeneutics, which can be understood as the theory of interpretation. Heidegger pointed out in his account of Dasein, that access to our engagement with the world is through interpretation (Smith et al. 2022). Heidegger posited that “things have certain visible meanings for us (which may or may not be deceptive), but they can also have concealed or hidden meanings” (Smith et al. 2022, p. 19). The hermeneutic circle is concerned with the relationship between the part and the whole; “to understand any given part, you look to the whole; to understand the whole, you look to the parts” (Smith et al., 2022, p. 22). Within IPA, the experience is not just simply understood; there is a ‘double hermeneutic approach’ where the researcher is seeking to make sense of the participant making sense of their own world (Peat et al., 2019).

The idiography within this method involves the commitment to the sense of detail and understanding how the particular phenomena have been understood (Smith et al, 2009). This is opposed to nomothetic approaches that make claims about populations (Smith et al. 2022). The intention behind idiography is to value each account instead of prioritising the similarities (Pietkiewicz & Smith, 2014). In IPA, each case is analysed in detail before comparing patterns (Miller et al., 2018). This commitment to detail means that the sample size for IPA research can be small, with Professional Doctorates typically using between 6 and 10 interviews. IPA is concerned with a detailed account to provide rich analysis (Smith et al., 2022). The smaller sample size allows the researcher to maintain the idiographic approach needed for these detailed accounts.

It has been recommended that IPA researchers should approach the data with two aims; firstly, to try to understand what their interviewee's world is like while recognising that 'experience' is both complex and partial. The analyst must try to produce a coherent, third-person view to try to get as close to the interviewee's experience as possible. Secondly, the researcher should try to interpret the analysis, positioning the first description in relation to the wider societal, theoretical and cultural context. This helps the analyst to think about what it may have meant to the individual who was experiencing it at the time (Larkin et al., 2006).

Within scientific research, there is the assumption that generalisability should be a goal; however, with IPA and qualitative research, the aim moves towards the transferability of findings from group to group (Hefferon & Gil-Rodriguez, 2011). Smith et al. (2009), also suggested that the findings can add to existing professional and experiential knowledge. With this in mind, the current research hopes to provide results that could inform professional knowledge. In addition, this research will hopefully provide a way for the participants to voice their experiences, in turn helping others to normalise their feelings about their diagnosis.

## Other considerations and rationale for the use of IPA

During the ‘planning’ stage of this research, although I had decided to use a qualitative method, I deliberated on which method of qualitative analysis to use. At first, I considered using Thematic Analysis (TA). TA “is a method for identifying, analysing and reporting patterns (themes) within data” (Braun & Clarke, 2006, p. 70). This approach appeared attractive at first due to the ability to interpret key features of the data (Clarke & Braun, 2017). However, TA does not focus on the use of language “or the fine-grained functionality of talk” (Braun & Clarke, 2006, p. 97).

After considering TA, I looked for a method that would allow for a deeper analysis. IPA takes the stance that there is “a central role for the analyst in making sense of that personal experience” (Smith, 2004, p. 40). “The researcher is trying to make sense of the participant trying to make sense of their personal and social world” (Smith, 2004, p. 40). I felt this explained exactly the journey that I was about to embark on. IPA has been argued as a method that is participant-oriented and takes the position that making meaning of a person’s experience involves close interpretative engagement (Smith et al, 2009). IPA also examines the data in different levels, allowing for conceptual, descriptive and linguistic aspects, while the researcher tries to generate experiential themes (Smith et al., 2022). It felt that the allowance of these different aspects to have recognition would provide a deeper “commitment to the exploration of personal lived experiences” (Smith, 2004, p. 40).

Furthermore, within IPA, there are different ‘flavours’ during the analysis, assuming that the data can provide us with insight into how a person made sense of the experience (Smith et al., 2022). This required a constant view of curiosity throughout the interviews, not making assumptions about how they received or understood the diagnosis, checking my understanding of their description with each participant and avoiding directing the interviews in a way that would allow for similar codes. Whilst I had research questions, I accepted that these questions may not be fully answered and allowed the participants to express their feelings and experiences throughout the interviews. Within IPA, it is accepted that the study may deviate from its original goal, this was helpful when participants were including experiences that moved away from the original question. These accounts were important to the participants to include in the interviews, and I remained mindful that this was how they made sense of their experience. IPA researchers can ask themselves, is there something meaningful here which was not intended? What is the person trying to tell me? (Pietkiewicz & Smith, 2014). This allows for each person’s account to be interpreted without focusing on directly answering the research questions.

I felt that as this study seeks to explore the experiences of women who have disagreed with their diagnosis, it would be important to use a methodology that allows me to remain open to all possibilities, rather than searching for themes from the outset. The phenomenology acknowledges that I would have pre-conceptions; however, it allowed me to ‘bracket’ my feelings to remain curious during the interviews and analysis stage. Using the double hermeneutic approach meant that I would constantly refer from the text, back to the recorded interviews, focus on what particular words were used and consider them in the context of the sentence. The idiography ensured that I was not just looking at the words that were used; I had to commit to the details, how they were said, and any emotions that were present. I also treated every case as an individual, without trying to look for similarities during the analysis. This process meant that the clustering of the group analysis took some time, as I would continue to refer back to the transcriptions and my initial noting, however, it did mean that every case was given the same high detail of analysis. The ability to commit to every case individually also required that I remained open to all possible themes, which I felt was important considering the literature on the different ways that diagnosis can impact a person. This ensured that I was not looking for themes that would support the literature and allowed unexpected themes to be unearthed.

## Interview Schedule

Semi-structured interviews were used to explore the lived experiences of women who disagreed with their diagnosis of BPD. In accordance with IPA methodology, semi-structured interviews were deemed suitable to explore the opinions of individuals, involving complex and sensitive information and allowing participants to expand on their answers and clarify the information (Barriball & While, 1994). The qualitative interview has been described as a “conversation with purpose” (Smith et al., 2022, p. 54), aiming to help the participant tell their story. The interview questions are used to help answer the research questions, without the research questions becoming part of the interviews. The interview questions were developed by following Smith et al. (2022) guide of considering what I would like to ask the participants and practising the order that would help the interview flow. Supervision was also used to help design the interview questions.

During the interviews, both the interviewer and the interviewee are active participants (Smith et al., 2022). Although there was a design to the interviews, often I would follow the participant's lead, following up with questions regarding new information, even if this deviated from my original question. All my participants were provided with the interview schedule (Appendix B), so they could be fully informed; this also outlined that they may be asked additional questions, based on their answers. I felt this provided structure to the interviews. The interview schedule allowed me to feel more prepared; Smith et al. (2022) advise any anxiety experienced by the interviewer is likely to be picked up by the interviewee and as this was my first qualitative research experience, I remained mindful of this. The interview schedule also included a number of prompts that I could utilise if needed and the questions were listed in an order that would allow for a logical flow of the answers (Smith et al., 2022).

## Using online methods with qualitative research

Previous research has claimed that participants are more likely to provide more open answers when communicating face-to-face (Tracy, 2020). However, due to the COVID-19 government restrictions, it was necessary to offer an alternative means of interviewing so online interviews using Microsoft Teams were offered. At the time of designing the research, the University of the West of England (UWE) provided guidance for using online platforms. The guidance stated that Microsoft Teams and Blackboard Collaborate were the only approved platforms for conducting qualitative research online (UWE, 2021). Guidance was also provided on the storage of data and permitting the use of the tools provided by Microsoft Teams to transcribe the recording. Offering the use of online methods has advantages; for example, it is considered more ethical in terms of sustainable tourism (Hanna, 2012). It also allows to overcome issues with distance and access, while allowing the researcher and participant to both be located within a safe space. The use of Microsoft Teams allowed me the opportunity to not only interview people from different areas of the United Kingdom (UK), but also allowed me to interview people from Australia and the United States of America (USA).

## Recruitment of participants

Participants were recruited from an online support group which seeks an alternative viewpoint on mental health. I first contacted one of the founders of the group to ask permission to advertise for participants. The post was published on 22 October 2021 (Appendix C). Originally the research sought females between the ages of 20 to 30, because this was the age range I had mainly worked with, and I had seen this diagnosis more within these ages. It was also hoped that this age range would allow for a homogenous sample and obtain the experiences of those who have lived with their diagnosis and considered how this may have impacted their life. Four participants were successfully recruited and interviewed, however, during the recruitment phase, I came across other potential participants who questioned the use of age brackets. I reflected on the questions posited and appreciated that individuals can be in similar stages of their lives at any age. An ethical amendment (Appendix D) was then applied for on 05 December 2021, requesting an expansion of the age range to between the ages of 20 to 60. I wanted to interview people who had their diagnosis for some time, so they have had a chance to process what it means to them. It was suggested within supervision that maintaining some form of age range, it would help with the homogeneity of the sample. I also requested to change the inclusion criteria to ‘received a diagnosis based on the symptoms outlined in the DSM or the ICD classification systems for mental disorders’, instead of just seeking participants from the UK. This amendment was requested as individuals outside of the UK may have similar experiences with the diagnosis. This amendment was approved on 09 December 2021. The final inclusion criteria invited women, aged 20 to 60, who had received a diagnosis of BPD based on the DSM or ICD classification.

In the original advert for participant recruitment, my UWE email address was provided. Participants were provided with the consent form (Appendix E), participant information sheet (Appendix F) and privacy notice before the interview (Appendix G). Participants returned the consent form before the interview and further consent was obtained during the interviews.

## Participants

After the initial post seeking participants (Appendix C), fourteen individuals showed interest in taking part so I requested that they email me, so I could send them the information. ten individuals sent emails and two individuals did not respond after receiving the participant information sheet. A final total of eight participants were recruited, the details of the participants are included below in Table 1. Pseudonyms were used for seven participants. One participant requested during the interview to keep her name, she explained this helped her to own her story and she said that she would feel *“empowered to be able to put my name to it”* and that these types of interviews gave her “*that sense of meaning and value to contribute”.* I spoke to my research supervisor to ensure that this would cause no issues with my ethics agreement with UWE, and it was agreed that I would send the participant her transcript, and after reading the transcript, I would use her name if she still wanted. The participant had requested a copy of the transcription during the interview, so I sent this to her, and she replied saying that she had read it, confirming that she still wished to keep her name. This was upheld and her name has been used throughout this research.

Table 1 – Participant Characteristics

| **Name** | **Age** | **Ethnicity** | **Country** |
|---|---|---|---|
| **Anna** | 28 | White | UK |
| **Danielle** | 21 | White | UK |
| **Kelly** | 24 | White | UK |
| **Chloe** | 40 | White | UK |
| **Lauren** | 30 | White | UK |
| **Stephanie** | 37 | White | UK |
| **Louise** | 30 | White | USA |
| **Caroline** | 44 | White | Australia |

## Ethics

Ethical approval (Appendix H) was received by the research ethics committee at UWE on 21 July 2021. An ethical amendment (Appendix D) regarding participant recruitment was provided and approved on 9 December 2021 (Appendix I).

Whilst preparing for the interviews and considering the schedule, I looked at research surrounding interviewing people about sensitive topics (Elmir et al., 2011; Dempsey et al., 2016; Kavanaugh & Ayers, 1998; Adeloye et al., 2020; Dickson-Swift et al., 2008). As I had no personal knowledge of my participants before the interviews, I was not aware of their life experiences. I felt that although the questions were not designed to upset or distress anyone, there was the potential of remembering upsetting experiences.

Previous literature has recommended that for consent to be informed, there should be a full disclosure of the nature of the research and warnings of any emotional topics that could be covered (Dickson-Swift et al., 2008). Research has also noted the power imbalances between the researcher and participants, the importance of attempting to reduce the participant's sense of vulnerability (Elmir et al., 2011), and providing detailed study information to potential participants (Dempsey et al., 2016). Although, as mentioned, the questions were not designed to distress or upset anyone, I could not be sure that this would not happen, so I provided my participants with the interview schedule before sending them the consent form. I felt that along with the participant information sheet, and the research privacy notice, I had provided as much information as possible for my participants to be fully informed of the study. As mentioned, there was an awareness that emotions could be elicited or triggered during data collection and analysis. As face-to-face options were not available at the time of the interviews, video recording was chosen as a method so I could pace the interview and be aware of any distress that the participants may be feeling. It was also agreed with my research supervisor that if there were any times within the interview that I felt concerned or upset, I would contact my supervisor and they would phone me as soon as possible to discuss what had happened and receive a debrief if needed.

## Piloting

Before the participant recruitment took place, I conducted three pilot interviews with peers. These pilot interviews served two purposes:

1) To practice the interview schedules and ensure the questions allowed for the participants to explore their experiences.
2) To gain familiarity with recording on Microsoft Teams.

During the process of these pilot interviews, some aspects came to light; it was realised that some of the later questions could be answered in the first question. I took note of this factor to hopefully prevent myself from asking questions that may have already been answered. The experience also allowed me to ensure that I was allowing participants to elaborate their experiences in depth.

A further aspect that became clear during the pilot interviews, was that the use of the transcription tool was not entirely accurate and appeared to mishear many words. The timing listed in the transcription was also based on the time of the interview, rather than starting at 00:00. Although the transcription tool was used within the interviews, I did not rely on this for the final transcription.

## Transcription and data protection.

As mentioned above, all interviews have been recorded using the Microsoft Teams software, which also provides a transcription tool. However, during pilot interviews, this did not prove reliable, so transcription was performed verbatim. This included significant non-verbal communication, such as pauses, ‘nodding’, emotional effects, and sounds such as ‘hmmm’ were recorded so that I remained close to the dialogue as it occurred in the interviews.

To protect my participants’ identity, I have used a pseudonym and removed all identifying information from the transcripts such as any mention of location and employment. Pseudonyms were used for all apart from one aforementioned participant who requested to keep her name. All transcripts and recordings of the interviews have been saved in a password-protected folder in OneDrive as per UWE guidance (2021).

## Analysis

It has been recommended that to gain rich data for IPA, the number of participants should be between four and ten (Braun & Clarke, 2013). The analysis is ‘bottom-up’, involving generating codes, looking for patterns, experiential statements and group experiential statements (Smith et al., 2022).

The analysis begins with the first ‘case’, immersing myself in the material. I commenced this by first watching the recordings of the interviews, keeping note of any thoughts or feelings that came up. I then listened to the recordings without the visual aspect to see if this brought up any different thoughts or feelings. After doing this, I then began the official first step of the analysis by reading and re-reading the transcripts. I feel that spending so much time with my material helped me to remember how I felt during the interview, and this also helped with bracketing my feelings.

Moving on to step two of the analysis, when I had initially started to learn IPA, I had been using the first edition Smith et al. (2009) book. This provided an example of a table that could be used whilst doing exploratory noting, which helped separate the descriptive, linguistic and conceptual comments. I found this table helpful, however realised that the use of a table meant that I could not add line numbers to the transcript. I continued using the table (and different coloured pens) to organise the comments. I then printed a separate transcript using line numbers to help construct the experiential statements (Appendix J). The following steps have been derived from the more current guidelines provided by Smith et al. (2022).

Step three of the analysis involves searching for connections across the experiential statements. Smith et al. (2022) advise keeping the original transcript (with notes) intact and working with a copy to cut out the experiential statements. I found it helpful to use different coloured paper for this stage, then placing all the statements on the floor and moving them around so the initial order was disrupted (Appendix K). I then moved the statements around to where it felt they related to each other. There were some groups of statements that, at first, I could not explain why they were similar however continued with the process until I felt they were in a cluster that made sense. This step also involved constant referral back to the transcription to ensure that I understood (as much as I possibly could as the researcher) what the participants were trying to tell me.

The next step involves naming the personal experiential themes and organising them into a table (Appendix L). This was a step that I found myself repeating, firstly naming and organising, then referring back to the original transcripts, trying to ensure the names made sense. Many of the names changed throughout this process as I continued to go back to the original transcripts. After I was satisfied with the personal experiential themes of one case, I would then move to the next case and begin from the first step of the analysis for each.

The final step involves working with the personal experiential themes to develop group experiential themes. On a reflective note, I found this step difficult; I worried about putting all of the themes together, after managing to keep them nicely organised. I spent time going through each theme, working out whether what one person had said was similar to another person's. Some themes seemed easy to group, as they had similar statements and my recollections of the interviews helped with this. There were other themes that appeared similar; however, I found it hard to describe what I felt was similar about these themes. After organising the themes, I then utilised peer support to go through the themes with me and help devise initial names for the main group experiential themes and sub-themes (Appendix M). During this stage I also met with my supervisor, who helped with this process, encouraging me to stop seeking professional-sounding names, to re-think about my interviews and to consider whether the names reflected the stories that my participants had shared.

## Reflexivity

I am a 39-year-old woman, who has worked in both inpatient and community mental health settings. I have experience working with both adults and adolescents who have been diagnosed with either BPD, or EUPD. With adolescents, the term ‘emerging’ is added, possibly due to the reluctance to diagnose those under the age of 18 with this label (Papadopoullos et al., 2022). My reason for being interested in this area stems from working with a lady who had been diagnosed with BPD, she had not been given any information after being diagnosed and asked me if this meant that there was *“something wrong with my personality”.* While she admitted to seeing a similarity in her feelings within the criteria, she felt that this also attacked her personality. At the time I was also working with others, who displayed the same “symptoms” or methods of expressing their distress, and they had been given the diagnosis of PTSD. In my experience working within different services, I have come across many women who have this diagnosis, and all have some form of traumatic events that have happened in their lives.

I feel that it is also important to document the effect that conducting this research has had on my personal and professional life. Within the recruitment stage, with the original age range, it was pointed out that by having any inclusion criteria, I was therefore excluding quite a lot of people, and as a result furthering their experiences of feeling ‘shut out’. This made me aware that research can harm people, even when it is not intended. It was also pointed out that many ‘service users’ are recruited for research, or to speak at events, and while ‘professionals’ may be paid for this service, quite often the ‘service users’ are expected to donate their time and knowledge for free. They are often not provided with any feedback regarding their input; it was explained to me that this can make them feel that they have just helped *“tick a box*”, as they are often not given the results of the research. This is something that I have aimed to keep in mind and at the end of each interview I have asked all my participants whether they would be interested in me sending them the results of this research when it has been completed. I explained the length of time that this may take to finish and that I would email them again to check before sending them the finished thesis. All the participants have said that they would appreciate this.

During this research, I have used a reflective research journal, and I have noted my struggles with having a ‘therapist head’ and a ‘researcher head’. At times, I found it difficult to respond to my interviewees as an interviewer and not a therapist, and after re-reading, listening and viewing my interviews, there have been times when I reflected that I may not have had the right balance. I feel that as a beginner interviewer, there were times during the earlier interviews when I may have had the chance to ask further in-depth questions. I do feel, however, that all my interviews provided good insight and rich data to analyse. There have been some emotional experiences during the interviews which made me thankful that I was able to see the person I was interviewing, as opposed to just being able to hear them, this has helped me to ‘check in’ with them and pause the interview if needed. I felt very privileged that my participants have taken part in the interviews and were willing to share their experiences with me. I feel that the interviews have helped me to become more aware of what someone may experience when being diagnosed and to keep this in mind when speaking to my clients within my professional role.

I feel that whilst doing the analysis, additional reflections also emerged. I found myself appreciating that I had chosen IPA as my methodology, as this allowed me the flexibility to include feelings and linguistic comments that I had noted. I feel that this has allowed me to keep my participants in mind throughout. I have found myself feeling stuck at times, struggling with my want to sound professional while trying to develop names for the themes that reflected my participants’ experiences. I have learned when I need to ask for help and have appreciated the support of my supervisor and friends during this time. I find myself constantly reflecting on my interviews and participants and sitting uncomfortably with the knowledge that their experiences are probably not uncommon. I will continue to add reflective notes throughout this thesis when I feel it is appropriate.

# Chapter 4 - Findings

## Introduction

As stated throughout this thesis, the study aimed to explore the experiences of women who disagree with their diagnosis of BPD. To explore these experiences, IPA was used to answer the following research questions:

1. How do women who participated in this study experience receiving a diagnosis that they have disagreed with?
2. What meaning did the women who participated in this study ascribe to the label of borderline personality disorder?
3. How do women who participated in this study perceive and experience the impact of this disagreement on their mental health and well-being?

This chapter outlines the group experiential themes and sub-themes that were generated by using the guides from Smith et al. (2022). It is recommended that the ‘findings’ section of a thesis involving the use of IPA focuses on presenting a clear and detailed narrative of what was learned, drawing on all the material including the transcripts, initial noting, themes and reflective notes (Smith et al., 2022). This section will follow these recommendations. Firstly, there is a brief introduction to my participants and their experiences, followed by presenting the group experiential themes within a table (Table 2) as an overview. The group experiential themes will then be described, using extracts from the transcription to create a narrative. At times, when applicable, reflective notes will be included.

## Participants' life experiences in relation to their diagnosis.

### Reflective note.

Throughout this research, I have constantly kept my participants in mind, with the appreciation that each person has trusted me with their story. Although extracts from their transcriptions will be used when discussing the themes, I wanted to add this introduction, for the reader to hopefully appreciate that they are more than just their extracts. They are someone’s daughter, mother, cousin, auntie, friend, or partner, whose lives have all been impacted in some way by this label and those they have come into contact with. I hope that by adding this brief introduction, any readers will see them as people, all dealing with difficult situations. I think about the fact that if I had lived through the same experiences, I could have found myself in the same situation, being diagnosed and treated the same.

### Anna

Anna was given the diagnosis when she was in inpatient services, she said that she felt this diagnosis *“gave them a free pass to judge me and then send me to a personality disorder unit”* [Anna line 58–59]. At the time of the interview, Anna was trying to get her diagnosis changed, as she has also been given the diagnosis of Complex Post-Traumatic Stress Disorder (CPTSD), and major depressive disorder and anxiety. Anna talked about the judgement that she has felt since receiving the diagnosis of BPD. Anna felt that the time she spent in a personality disorder unit was a waste of time, as it meant that she had therapy targeted to personality disorder, instead of the trauma therapy that she needed. Anna has had some bad experiences within the mental health services, from being admitted into a ward that she described as *"awful"* [Anna line 231] to being dismissed by various members of a crisis team. Anna spent years feeling stuck and that she had no power, before finally having a care coordinator who encouraged her. Now Anna is taking control, she is trying to get her BPD diagnosis removed from her notes and is having trauma therapy, she said that she feels she has *"to give yourself a chance in life"* [Anna line 507] and is now fighting for herself.

### Danielle

Danielle received her diagnosis of BPD when she was seventeen and in inpatient services. She describes being confused at the time, wondering if she should have been eighteen to receive this diagnosis. She talked about how she viewed herself differently and *"was viewed differently by professionals"* [Danielle line 67], Danielle also felt that she could not relate to most of the symptoms. Danielle was referred to a specialist BPD team, she felt that this invalidated a lot of her experiences. Danielle also spent time receiving treatment for an eating disorder and was told that if she exhibited any signs of BPD, then she would be discharged. Danielle experienced that there seemed to be a *"separate set of rules"* [Danielle line 149] for people with this diagnosis. Danielle does not disclose her diagnosis to anyone as she worries that she will be judged and does not want it to affect her future. Danielle is now paying for a private therapist, she said that although she has been in mental health services for a number of years, trauma therapy has never been offered to her. Although she has had to pay for this therapy, and finds it expensive, she feels that it is what she needs so will be worth it.

### Kelly

Kelly had received her diagnosis three years before my interview with her, after being referred to the assessment and treatment service by her GP. Kelly had tried a variety of antidepressants, and they had no effect so her GP suggested meeting with a psychiatrist. Kelly wondered if her diagnosis had been pre-decided, as the psychiatrist came into the room carrying a leaflet that described BPD. Kelly had originally agreed to be referred as she was looking for help, or advice to see *"what else can I do that might help"* [Kelly line 128–129], she also wanted to understand why she felt the way she did. Kelly described being asked questions that appeared to include normal human experiences, for example, *"do you have a fear of abandonment"* [Kelly line 145–146] to which she answered, *"well yeah, but doesn't everyone?"* [Kelly line 146–147]. Kelly also described the symptoms as not fitting her and feeling that it is not good to be told that *"basically your personality is flawed and broken"* [Kelly line 236–237. Kelly further talked about the stigma that she has experienced and witnessed. Kelly avoids disclosing this to others, however, feels disclosing is not needed as she does not feel that her mental health affects her to the point where she needs to talk about it. Kelly finds it hard to listen to the way that others talk about this diagnosis and does not understand why others are so judgemental of those with this diagnosis.

### Chloe

Chloe described looking back on her experience with a feeling of disbelief. She had been looking for ways that somehow explained how she was feeling, and so suggested to the doctor that she thought she may have BPD, the doctor agreed. Later, she suggested to the doctor that she thought she had been trying to survive an abusive relationship, which the doctor also agreed to. Chloe feels that she managed to diagnose herself, then un-diagnose herself, and finds this incredulous. Chloe had experienced a number of difficult experiences in her life, including abuse, and the diagnosis of BPD just seemed to add to this list of difficult experiences. Throughout her life, Chloe has engaged in different types of therapy, however, felt that it was not trauma-informed and therefore did not help her. She described a situation where a woman in her child's playgroup just sat and listened to her and explained how this *"did more for me than trained psychotherapist"* [Chloe line 125–126]. She then attended a domestic violence group and felt that this opened her eyes to what she had been through. Chloe gave different descriptions of how this label had been used against her and how it had affected her family. Chloe does not believe in this label and feels that professionals should look for the reasons why someone has difficulties in certain contexts. Chloe's description of the events that she has experienced felt to me as if they had repeated earlier abuse. For example, when in an abusive relationship she believed she was to blame for everything that felt wrong, just as this diagnosis made her feel she was to blame for the way that she felt. Chloe talked about fears that someone would find out and Google her diagnosis and read about serial killers and judge her the same.

### Lauren

Lauren received her diagnosis of BPD seven years before our interview. She said she felt at the time that she had difficulties with her mood and how she related to other people. Lauren had googled how she felt and came across the diagnosis. At the time, she felt the diagnosis made her feel that she was listened to, however then started to feel that this label affected her sense of agency. Lauren spoke about experiencing *"chronic sexual abuse"* [Lauren line 217] and felt that she wanted something to help with that however at the time was possibly not ready to talk about it. Lauren spoke about being given different medications that did not help, so arranged her own private therapy. Lauren disagrees with her diagnosis as she is a different person now, and does not feel the same, however, this label remains on her record, she also feels the label has done more harm to her than good. Lauren felt that as a result of this label, she was not listened to, at times would be seen as manipulative and told that she did not *“have good insight into your condition”* [Lauren line 329]. Lauren felt that this label causes a *“kind of blacklisting”* [Lauren line 391]. Lauren described times when the label had prevented her from doing certain things and that she was *“looked upon differently”* [Lauren line 477]. Lauren spoke about this experience making it difficult for her to trust NHS services with her mental health.

### Stephanie

Stephanie describes receiving her diagnosis with a lot of confusion, wondering if this meant there was an issue with her personality *“it’s not been disordered before. You know why? Why is it disordered now?”* [Stephanie line 20-21]. She described everything changing for the worse after receiving it. Stephanie received her diagnosis at a difficult time when she had experienced loss and was looking for some help with how to deal with this. It was during an admission to a personality disorder unit that the staff recognised that she had autism. The realisation that she was autistic explained everything that she had felt, having a sensory overload and dealing with emotional distress. Stephanie noticed while she had the BPD diagnosis, that support was withdrawn, and that others were afraid to be seen as caring individuals around her. She noticed that everything was blamed on her and her *“disordered personality”* [Stephanie line 146]. She would hear the thoughts and feelings of professionals, one said that she had *“fucking bitch disorder”* [Stephanie line 227]. When Stephanie’s official diagnosis was changed from BPD to Autism, she noticed how much people were more *“understanding, willing to listen”* [Stephanie line 169]. Stephanie described how she still has to prove to professionals that she no longer has this diagnosis and talked about feelings of *“helplessness and powerless”* [Stephanie line 306]. Stephanie now works as an activist trying to stop others going through the same experience as her, however, her experiences still haunt her, and she worries that this may happen again.

### Louise

Louise received her diagnosis of BPD on her lunch break, over Zoom. Louise lives in America, and was diagnosed by her Psychologist, who then informed her that there were boundaries that would need to be applied now she had this diagnosis. Louise describes the relationship with her Psychologist as being very flexible before the diagnosis, where they would email each other regularly outside of therapy sessions, this flexibility was taken away when she was told she had this diagnosis. Louise described feeling confused about this diagnosis as she did not feel it explained how she felt. Louise wanted to talk about her emotions and *“understand why I’m so sad”* [Louise line 156]. Louise described feeling that the way she was treated after this diagnosis, was similar to how she was abused as a child. At the time that Louise received this diagnosis, she had already been diagnosed with depression, anxiety and PTSD and was not seeking another diagnosis. Louise described the different pathways with diagnoses, and how some result in a trauma pathway treatment route, however, BPD results in a *“behaviourism pathway”* [Louise line 294]. Louise has done a lot of research to understand her own responses and feelings to situations and feels that professionals should look at what people are *"missing in their lives"* [Louise line 373] and is working with a therapist who does *"parts work"* [Louise line 542], she feels that this has been most helpful. She writes about her experiences, hoping that this will help others.

### Caroline

Caroline was seeing a therapist at the time that she found out that she had been given this diagnosis, however, she found out from a mutual acquaintance, not from the actual therapist. So, not only did she find out that this was her diagnosis, but she also found out that her therapist had broken her confidentiality at the same time. At the time, she read about the diagnosis and felt that this explained how she felt and had a sense that she was not alone in feeling this. Caroline said, *"I certainly ticked those boxes"* [Caroline line 60–61]. However, this started a range of *"horrendous experiences"* [Caroline line 75] in relation to this diagnosis. Caroline talked about experiencing loss at a young age and feels that she has just been experiencing unresolved grief. Caroline talked about experiencing stigma from the system and how she was told that she was *"wasting their time"* [Caroline line 267]. Caroline now understands that her *"way of being in the world is a perfectly normal and understandable reaction to a highly abnormal situation"* [Caroline line 343–345]. Caroline also talked about difficulties finding a good therapist and had one therapist who told her that she was *"too fucked up for anyone else to treat"* [Caroline line 478]. Caroline later found out that she is autistic, and explained how this made more sense to her than any other label, and now can understand when she is experiencing sensory overload. Caroline has described how the BPD label affected her work and how she does not share this with others as people are more understanding of autism than BPD.

Caroline now volunteers as an advocate within mental health services, in the hope of making services better for others, however, feels that to cope with this label, it is better to socially withdraw.

## Group Experiential Themes

Themes were generated throughout the individual transcripts, before looking for connections across the cases. There were five main group experiential themes generated, all main themes have sub-themes, as detailed in Table 2 below:

### Reflective note.

I feel it is important to note here that whilst carrying out the analysis, I was very aware that I should not try to search for themes that matched my research or interview questions. At the same time, I was worried about losing the depth of the information that the participants provided, so the analysis took quite a bit of time. I spent time listening and re-listening to the interviews, and during the initial analysis with one participant, my supervisor noted that I had developed a theme that matched my interview question. This was unintentional, so to prevent this from happening again I then blocked out my questions, so I would only focus on the information provided. Whilst creating the group experiential themes I avoided looking at my research questions, so the group experiential themes included information that may not be related to the research questions, however, I feel they have helped my understanding of how this diagnosis affected my participants.

Table 2 – Group Experiential Themes and Sub-themes

| **Group Experiential Themes** | **Sub-Themes** |
|---|---|
| **When did everyone forget that I'm just a normal person?** | Treat me as a person, not a label.<br>Label changed how people saw me.<br>Just want love and belonging like everyone else.<br>I don't matter. |
| **This label made things harder.** | Doubt and confusion.<br>This just made things worse.<br>Do not want to be judged.<br>Lost hope.<br>This label defines your emotions and behaviour. |
| **Society needs order and needs labels to keep this order.** | Not considering the reasons behind these feelings.<br>This label says it's your fault for feeling bad.<br>The need to fit people in boxes.<br>Why does distress need to be labelled?<br>This doesn't fit. |
| **Problems within the system.** | The system and professionals can hurt you.<br>Labels help the services, not the person.<br>This label feels like punishment.<br>Is this a real diagnosis?<br>Misdiagnosis and treated differently. |
| **Wanting to feel that I am in control of my life.** | I just wanted help.<br>There was a name for how I felt.<br>There is a lot of dark power in this label.<br>I'm taking back control. |

### Group experiential theme 1. When did everyone forget that I'm just a normal person?

This theme includes four sub-themes, which are ordered as 'Treat me as a person, not a label', 'Label changed how people saw me', 'Just want love and belonging like anyone else', and 'I don't matter'. I clustered these themes together as they all appeared to indicate that once the participants were given the diagnosis, they were treated differently, with some participants this change was felt almost immediately.

The headline for this theme came from the feeling that this label seemed to change how the participants were viewed and treated by others. The participants appeared to feel that the 'human' part of them was forgotten about as soon as they were diagnosed, and they were treated more as the label than an actual person. Caroline explained *"now I wouldn't even say I'm a person with BPD, I would say I'm a person who has been labelled with BPD"* [Caroline line 691–693]. Anna talked about how this makes her feel, *"it just makes me so angry, like how, you know everyone's still human"* [Anna line number 280–281] *"like no one even bothered having a conversation with me really"* [Anna line number 43–44] and *"it's like you just become BPD instead of Anna, crap"* [Anna line number 288–289]. Stephanie agreed, *"I think you know, when you have this diagnosis you, you're all you're seen as is this diagnosis"* [Stephanie line 234–236].

Other participants echoed the feeling that this label changed the way people saw them and the effect that this had on them, Louise spoke about how difficult this was *"the last three years has been, it was really traumatic, really like. And I don't understand why I was treated the way that I was"* [Louise line 158–160], *"it made no sense to me"* [Louise line 729]. Stephanie stressed that *"everything just changed, you know, for the worst"* [Stephanie line 24–25] and explained how she was treated differently *"So, before people were like, staff was like talking to me"* [Stephanie line 112–113], *"And as soon as I got the diagnosis, they put into place, you know, this sort* *of PD protocol, which meant that, you know, support was withdrawn"* [Stephanie line 116–119].

It felt important for the participants to express that they were just human, with human needs. On a reflective note, I wonder if, as they have experienced judgements, were they worried that I would judge them too. The participants talked about how normal it is to need and want connections in life. Stephanie talked about how she had witnessed some extreme situations in hospitals, coming from *"the extreme need for like relational depth and interaction"* [Stephanie line 681–682]. Stephanie then reinforced this explaining that *"we just need to connect on a human level, I think that, that people need is connection and support and care and love dare I say"* [Stephanie line 705–707]. Lauren spoke about how receiving this label can help someone feel that they have some form of connection, this makes them feel less alone, and it *"made it kind of valid as to why I was feeling that way"* [Lauren line 109], *"they get to relate to other people who have had their label"* [Lauren line 355–356]. Chloe had similar thoughts, feeling that some may *"very easily accept the diagnosis because it helps them. If anything, it helps them fit into that, um sort of find where they fit in the world, where they fit in their mind"* [Chloe line 563–566]. During the interviews, there was a sense that receiving this label at first made some of the participants feel less alone, providing that feeling of belonging, however for some, this made the situation worse, Louise explains *"I already struggled with like not liking certain parts of me, or feeling self-conscious or feeling like I just didn't fit in the world, um, and so getting that diagnosis just made it all worse"* [Louise line 597–600].

The final sub-theme within this group experiential theme involved the participants feeling that they did not matter, this included not being listened to, not being understood, and not being able to have their opinions counted. Kelly described a feeling of being dismissed when she was given her diagnosis *"I just thought well, I don't really agree with this but I can see that nothing I say is going to change what you have already decided"* [Kelly line 50–52], *"I felt powerless as well because I just, there was this overwhelming sense of, I won't achieve anything by saying anything now"* [Kelly line 100–102]. Stephanie talked about not being taken seriously with this diagnosis, and how this impact other areas of health, *"you couldn't get taken seriously if you had another illness, they just see it as attention seeking"* [Stephanie line 201–202]. Stephanie also talked about other healthcare professionals and their responses, *"nobody wants to work with you, you know advocates, CPNs, healthcare assistants"* [Stephanie line 526–527]. Louise also noticed a change in the way she was treated and spoke about the immediate change in her therapist when she was diagnosed, *"she like, completely shifted and her demeanour towards me was different"* [Louise line 89–90]. Caroline talked about how she had been dismissed by other professionals *"the paramedics in the ambulances were telling me how I was wasting their time"* [Caroline line 266–267] and talked about what happens when she reached out for help *"yeah, you go to the hospital, and then they send you home"* [Caroline line 311–312].

Caroline also expressed the seriousness of the possible consequences of not listening to people *"I will rage that people won't hear how much distress I'm in until I'm dead"* [Caroline line 316–317]. Lauren explained how she had been prevented from donating a kidney due to the psychiatrist's opinion being listened to more than hers, *"he said he had concerns about my ability to like, like to reach out for help if something went wrong"* [Lauren 413–415]. Anna spoke about how it did not seem important to give her any information about this diagnosis and *"you're kind of left to figure it out by yourself"* [Anna line 132]. Anna later said that she would be more willing to accept this diagnosis if she felt that someone had actually listened to her *"because at least they would have actually spoken to me and heard my point of view"* [Anna line 320–321].

## Group Experiential Theme 2: This label made things harder.

This theme has 5 sub-themes. I clustered these together as there seemed to be a commonality that receiving the diagnosis appeared to complicate things and make life harder for the participants, instead of providing the help they were hoping for.

Some of the participants talked about the feeling of doubting themselves since being diagnosed and the confusion that having this diagnosis brought. Louise said, *"I can't seem to like stop trying to prove that my story is true"* [Louise line 405–406], *"I'm always questioning, do I have it?"* [Louise line 403]. *"I actually thought it was like bipolar, when I first got it, I remember thinking, ohh she's saying I'm bipolar"* [Louise line 126–128], and later wondering if it was real, *"like if the label is actually a real thing, if the construct actually exists"* [Louise line 342–343]. Chloe talked about constantly doubting her thoughts,

> *"and I would think like, am I being nice because I'm nice, or am I being nice because I'm manipulative? I started believing that, if I did something that was nice or kind, or every time I said, you know, you've got a nice dress on, I thought I was doing it to be manipulative"* [Chloe line 594–599].

This need to question herself involves questioning her personality *"like what parts of my personality are real, and what part of my personality is disordered?"* [Chloe line 653–654].

Danielle also talks about doubting herself and her emotions, wondering *"do I have a right to be annoyed with that person, or is it just because of the diagnosis"*

[Danielle line 206–208]. Danielle talked about trying not to feel her emotions for example, telling herself *“your overreacting, that’s just a BPD thing”* [Danielle line 218], and wondering *“am I nice and caring, or is that part of that?”* [Danielle line 286], *“it’s like your whole self is an illness”* [Danielle line 289], *“how can you have any kind of characteristics that aren’t viewed as being part of this disorder”* [Danielle line 290–292]. Danielle also spoke about receiving the diagnosis and feeling *“so hurt and confused by it, yeah they didn’t really explain it”* [Danielle line 158–159]. Stephanie talked about how she was *“expecting some help, but what I ended up getting was like a diagnosis which just didn’t make any sense to me at all”* [Stephanie line 60–62]. Caroline talked about the confusion of what this meant, *“like what the hell is a disordered personality, like you kinda go, well, if this one’s disordered, what’s the definition of an ordered personality?”* [Caroline line 733–735].

The participants talked about the impact that this has had on their lives, feeling that receiving this diagnosis had been unhelpful. At a time when they were hoping to gain understanding, and possibly receive help, they found themselves in a place where everything felt worse. Danielle described how this felt that she was receiving something bigger than a diagnosis, *“it also felt really frightening”* [Danielle line 34] and being told that *“it might be something that you have for the rest of your life”* [Danielle line 282–283]. Louise talked about how this is hurtful to receive, *“I like my personality, like I have a solid personality, I don’t, I don’t think it's disordered. I think I’m just really sad, like I don’t really understand that, and so I think it’s a really hurtful label”* [Louise line 271–275]. She talked about how this almost repeats a cycle of abuse *“I just don’t see the point of labelling people who have been through so much trauma, with a disordered personality. I don’t think it helps people”* [Louise line 362–

365]. Louise also talked about how this affects her on a daily basis, *"there isn't a day that I don't wake up and think about it "*[Louise line 400–401].

Stephanie also talked about how *"Everything got worse"* [Stephanie line 27] and explained how *"certain people who have undergone certain things in their lives and have certain dispositions and ways of relating and ways of interacting with others when they've experienced deep distress are treated worse than animals basically"* [Stephanie line 177–181]. Stephanie explained, *"You know, I got said that I had fucking bitch disorder"* [Stephanie line 226–227], Stephanie talked about fears that this will always follow her, even though it has now been removed from her medical records, she described how it was brought up just before she gave birth, *"I had to get all the documentation out, I had to show them all the documentation and so that I don't have a personality disorder"* [Stephanie line 268–270], *"there's no escape from it"* [Stephanie line 310-311] and *"I live in fear that it could happen again"* [Stephanie line 364].

All the participants talked about their experiences of being judged and how they fear future judgements. Danielle explained how she is *"worried that it will have an impact on how I'm seen"* [Danielle line 179–180] and if asked questions about her health, for example at work, she will *"just put like mental health or depression anxiety, cos I don't want that to taint the way people see me"* [Danielle line 184–186]. Caroline talked about the judgements that she has received from mental health professionals, *"the real illnesses are your chemical imbalances, bipolar and schizophrenia and that, whereas those people with personality disorders, they're just bad people"* [Caroline line 251–254]. Kelly also talked about judgements within the mental health services, *"the way that people with BPD is spoken about is very much like, oh they're just being PD, or they're being attention seeking"* [Kelly line 249–251].

Anna spoke about specific incidents within the services, such as an unhelpful call to the crisis team where she was told *"It says you have BPD, umm so what do you expect me to say"* [Anna line 245–246], *"it's like just judgement judgement like so unnecessary"* [Anna line 302]. Stephanie explained how she felt that she was *"forever gonna be considered as manipulative and attention seeking"* [Stephanie line 105–107], she also spoke about how staff would talk to her *"they'll say, you're being manipulative, your being attention, stop attention seeking"* [Stephanie line 502–503]. Other participants talked about fear of judgement in their personal lives, Chloe talked about how she is constantly *"in fear that someone will find out"* [Chloe line 632] due to the way that this diagnosis is reported in the media *"because the first things someone's gonna do is Google it, and then they're gonna read about what, how a awful, lying manipulative monster you are"* [Chloe line 821–823]. Lauren spoke about worrying about whether to tell people in her life, *"you're faced with a choice. Do I just ignore, do you, you have to trust that person will understand, that you're not just, you know, mad"* [Lauren line 479–481]. Louise also talked about fears of others finding out *"I just worry that if I were to say that then like, oh, they're gonna do what my psychologist did to me, like putting up walls and then getting rid of me"* [Louise line 518–521].

There was a feeling with some of the participants that this diagnosis caused hope to be lost, either losing hope in themselves or feeling that others lost hope. Some were told that this diagnosis is lifelong, creating some understanding that they would always feel this way. Anna felt *"what hope am I meant to have if you have no idea what to do with me?"* [Anna line 452–453]. Louise talked about losing hope after getting involved with the mental health services,

> *"you think it's gonna be beautiful, it's gonna be an oasis, it's gonna be like this wonderful therapist who's gonna hold your hand. And like, it's gonna be great. But the truth is that that's not true for people who are suicidal, like it's a horrible experience"* [Louise line 605–610].

Chloe explained that the way the diagnosis is described can add to a lack of hope *"If you Google borderline personality disorder and I'll tell you the most insane thing to do with that, and the first thing it would tell you, that is that it's incurable. And so, I felt hopeless"* [Chloe line 195–198]. Chloe was also told *"that because you can't treat it, they basically said that this is the end of the road now for any, um any support"* [Chloe line 465–466], so not only did Chloe feel hopeless in herself, but she was also given the message that the services did not see the point in helping her.

Some of the participants talked about how this label made them afraid to show emotions, as any sign of distress could confirm the diagnosis to others, or the possibility of not being taken seriously. Stephanie spoke about her experiences in inpatient services, where she would experience a sensory overload *"which would result in, like a meltdown, which was happening quite frequently, you know that would result in like restraint and seclusion and in having everything taken away from me"* [Stephanie line 124–127]. Chloe explained how she had been judged for crying *"I got upset and I cried, and I got told that I was unstable"* [Chloe line 676–677] so she learnt that *"I can't cry because I'm unstable, and if I do that, if I show emotions and get upset. So, I wasn't allowed"* [Chloe line 704–705]. Danielle described how she had been told that she was just *"being angry with other people and blaming other people, you can't do that"* [Danielle line 114–115], *"it's never like, oh you feel like that, it's all people with BPD do that"* [Danielle line 126–127]. Danielle talked about feeling that she cannot trust her emotions, or display them, *"like am I allowed to be* *annoyed like? I feel like, feeling or showing any kind of anger is just kind of confirming that I do have it"* [Danielle line 221–223].

> *"Someone assaulted me, and obviously like, people like, oh you must be angry. I'm not angry. It's like, it's like I've, it's pushed down, even more to the point where it's like I'm not allowed to be angry, because if I do, that's just confirming the diagnosis"* [Danielle line 262–266].

So, for Danielle, even when there are times when it would be understandable to feel certain emotions, she feels that she needs to push them down, and not express them as she is afraid that it will just confirm what others think of her.

In addition to the feeling that they could not express their emotions, for fear of confirming the label, there seemed to be another level where being diagnosed can sometimes make them act in a way that could be seen as confirming the diagnosis. Chloe explained how even just questioning the label made her feel that *"you're liar and you're manipulative"* [Chloe line 568], so a person may not be believed by professionals. Chloe also talked about how the way she was treated, and the information provided about BPD made her think *"what a horrible, horrible person I was, and it just fed into that self-hate, which then was makes you self-harm. And then of course, that's evidence that you've got borderline personality disorder"* [Chloe line 906–909]. Caroline also talked about similar experiences, how distress and *"repeated suicide attempts were just attention seeking, just being manipulative"* [Caroline line 232–233]. Caroline explained that there were times when she needed and wanted help, however, was informed *"if you're coming seeking help, then you're not really suicidal, go away"* [Caroline line 286–287] and when she was finally admitted into the hospital, she was *"told by the nurses that I've manipulated my way in"* [Caroline 292–293]. So, receiving this label sometimes results in people not being taken seriously, and therefore needing to go to extreme lengths to get help, which is then seen as one of the symptoms of the diagnosis.

## Group Experiential Theme 3: Society needs order and needs labels to keep this order.

This theme has 5 sub-themes, I clustered these together as they involved considering why this label is needed and why distress needs to be labelled based on the participants' experiences. It also felt that there is something about this label that forgets about the actual person, what they have experienced in life and why they may feel the way they do. Instead of focusing on what could be done to help people, there seems to be a focus on putting people into some form of category to 'explain' the symptoms. Whilst this may serve to provide some form of reasoning to society, it does not appear to serve the person.

Some of the participants talked about how this seems to ignore why they may feel this way, ignoring human experience and how life events can affect people. Chloe talked about how she was diagnosed and then undiagnosed when her situation changed.

> *"I mean, you people have got to see the irony that I was diagnosed with it while in an abusive relationship, and then once I was out of the abusive relationship, all of a sudden, I'm magically cured. You know, you've got to, you've got to question that surely"* [Chloe line 179–184],

*"I think you do have to look at the past"* [Chloe line 852]. Caroline also stressed *"the way a person functions is contingent on their environment"* [Caroline line 981–982]. Louise talked about how others would see her being upset and assume that it was part

of her symptoms, *"it's like this desire to prove that I'm not borderline, that I am emotional for a reason, that I'm crying because somebody hurt me"* [Louise line 413–415]. Louise also talked about how this ignores all the wider issues in society *"like there's so many issues of poverty and racism and so many things' people go through and like and yet we blame the person for having a negative response to really shitty experiences"* [Louise line 637–641].

Lauren talked about how this label almost served as a way for her to not acknowledge her experiences and how previous abuse had affected her, *"it's like oh, if I have this disorder, that's the reason rather than all of this stuff"* [Lauren line 234–235]. *"I have this disorder, I can't f-ing cope, it's not my fault, I don't want to deal with anything you know"* [Lauren line 226–228], *"maybe I wasn't ready to talk about"* [Lauren line 216]. Danielle spoke about how this also prevents people from receiving help for any trauma, *"we're gonna treat it with DBT, to change your behaviour, but what about the trauma?"* [Danielle line 319–320] *"trauma therapies wasn't, it wasn't, it just wasn't offered or even spoken about"* [Danielle line 337–338]. Danielle then found a private therapist who focuses on trauma and feels that *"I'm actually making progress, a lot more than I did when people were just focused on my behaviour"* [Danielle line 233–235].

Some of the participants spoke about how they were made to feel it was their fault that they felt the way they did, *"I remember thinking that everything was my fault, that I was to blame for everything"* [Chloe line 213–215], *"no one can help me because I'm to blame for everything"* [Chloe line 532–533]. *"You know you're blame, you're, you're blamed so, and and and any, anything that you do is interpreted as like something to do with your disordered personality"* [Stephanie line 143–146]. Louise talked about how it blames people for normal human needs *"Attention seeking, like* *we all need attention, every human being needs attention. Like look at Gabor Maté, you like pick up a baby and like, like if you don't pick up that baby, they're gonna die"* [Louise line 422–426]. Caroline also spoke about how telling someone their personality is disordered is blaming *"You've just told me my personality is disordered, how is my personality not me?"* [Caroline line 743–745].

Stephanie talked about how society feels uncomfortable when people display distress *"that's somebody's needs not being met and nobody giving a shit about them. And I think it says more about us as a society than it does about that person"* [Stephanie line 689–692]. Lauren talked about feeling *"boxed and framed"* [Lauren line 323], how *"it's just a rigid framing boxing kind of mechanism"* [Lauren line 585], *"which is mad, you know, you can't describe and you can't explain human, human behaviour in such a stark rigid way"* [Lauren line 591–593]. Chloe felt that this isn't just about psychiatry wanting to fit people in boxes, she felt that it's about:

> *"wanting to explain people that aren't easily explained, people don't, society in general don't like people are a bit different, and they don't like someone with coloured hair or someone that dresses a bit and you like, you know, might wear wacky colours or something"* [Chloe line 322–327].

Some participants wondered why there is a need to label distress, and why distress cannot just be seen and responded to helpfully? Caroline explained that she was asked if her emotional distress *"is that due to the autism or the BPD?"* [Caroline line 854] and wondered why it could not just be seen as distress *"it's so actually, again, that systemic absurdity, not just this is a human being in distress"* [Caroline line 868–869]. Lauren felt that *"most people would experience these symptoms from time to time"* [Lauren line 513–514]. Louise pointed out the normality of the symptoms, *"who likes to be abandoned, nobody likes to be abandoned"* [Louise line 353–354], *"sure like I'm sensitive, who cares, like there's many sensitive people in the world"* [Louise line 653–654]. Kelly was asked questions during her diagnosis such as *"do you have a fear of abandonment, and I was like, well yeah but doesn't everyone"* [Kelly line 145–147], *"And I remember saying to him actually, well everything you've just said surely could apply to everyone, and he said yes, but maybe not everyone suffers as much as you do"* [Kelly line 158–161].

Most of the participants talked about feeling that the diagnosis did not fit them, or feel like them, Caroline spoke about how *"the BPD label doesn't fit"* [Caroline line 573–574], *"none of that makes sense"* [Caroline line 751]. Anna had tried to research and figure *"out where I fit"* [Anna line 142], *"other professionals I've met have said no, that's not right"* [Anna line 146]. For Kelly, *"it didn't feel like it fit"* [Kelly line 186], *"I don't think that really any of the symptoms are my experience"* [Kelly line 190–191]. Louise talked about how she was treated, *"like I was treated really poorly for a label that I feel doesn't even fit"* [Louise line 211–212], *"I just don't feel like I fit it"* [Louise line 361–362]. Lauren talked about how she has processed some of her experiences in therapy and feels different now *"I don't think I'm plagued with the emotions I was experiencing that psychiatrists may have attributed to that diagnosis"* [Lauren line 311–313]. Danielle felt that even at the time of diagnosis, *"I didn't know if it really fit"* [Danielle line 82]. Stephanie also felt that *"back then, I was just thinking about myself, and I was just thinking, this doesn't describe me"* [Stephanie line 671–672] and how this was frustrating *"I suppose I expected them to have some answers"* [Stephanie line 102–103].

### Group Experiential Theme 4: Problems within the system.

This theme has 5 sub-themes. Throughout the interview, all the participants talked about their experiences with mental health services and how people with this label are treated. They talked about feeling that the label made things easier for the services, and highlighted how professionals can make their experience worse. Whilst carrying out these interviews, I was aware that different countries may have different protocols, however, it seems that the experiences are similar despite the different contexts of mental health services.

The participants talked about hurtful experiences from the system and professionals, Caroline talked about how the medical model is not always trauma-informed *"the DSM and diagnosis and evidence-based treatment and all of that stuff, and it's been the these last few years that I've moved away from that and come very much more towards a trauma perspective"* [Caroline line 593–596]. Caroline explained how she talked about her previous therapist with her new therapist, and her new therapist was so shocked by her experience that she made a *"mandatory report"* [Caroline line 459], Caroline explained how damaging this has felt to her, *"what I live with now is due to my experiences within the system, rather than what brought me into contact with the system in the first place"* [Caroline 606–609].

Chloe spoke about the difficulties that she experienced being involved with mental health services, *"you know, when you're in mental health you get shunted around a lot"* [Chloe line 80–81] and *"mental health don't help you, all they do is make things worse"* [Chloe line 760–761]. Chloe also talked about how she was treated, *"Just no one will believe anything you say, even if you're telling the truth"* [Chloe line 248–249] and how she felt *"scrutinized constantly"* [Chloe line 729–730], she explained how *"you have to be this picture-perfect person all the time otherwise* *your unstable or manipulative"* [Chloe line 732–734]. Stephanie talked about how she would be accused of seeking attention from mental health services,

> *"I don't know what sort of attention they think we're getting, like someone's gonna give us, like a bunch of flowers and a box of chocolates, like it's the most awful kind of attention, being in a psychiatric hospital and being treated like that badly"* [Stephanie line 535–540]. *"I constantly feel like quite traumatised by the whole thing, obviously you know, it's just, it's just so inhumane"* [Stephanie line 361–363].

Danielle also spoke about difficulty navigating the system, *"I must have seen between 50-100 mental health professionals, and I literally was like not getting anywhere"* [Danielle line 314–316]. Lauren talked about her experiences that made her reluctant to contact mental health services, *"It's made me shrink away from accessing any support"* [Lauren line 534–535], *"I wouldn't trust the NHS, the NHS in terms of my mental health with a bargepole"* [Lauren line 540–542]. Louise talked about the way her psychologist diagnosed her, *"in my car, on my lunch break, and it was really hurt, it felt really just awful to get a diagnosis like that"* [Louise line 46–48]. Louise expressed, *"I feel like a lot of the psychologists are actually abusers themselves, in the way that they handle this population or work with them"* [Louise line 301–303]. Louise also talked about her experiences with mental health services in America, feeling that they were not concerned with helping people, *"they ask you if you have, questions of like, do you have a firearm, do you have this? And if you don't, they're like, ok, like have a good night"* [Louise line 673–675].

Some of the participants talked about how they felt that this label made things easier for the services, Kelly explained *"it was kind of just a here's your diagnosis,* *here you go kind of thing"* [Kelly line 107–108], Lauren felt that this may be because *"it's a really strained and stressed system"* [Lauren line 351]. Anna expressed *"there's a huge issue with mental health services in general that nothing is person-centred, it's like, oh, you have this label, so you're gonna do this"* [Anna line 367–369], *"you're all treated like a flock of sheep"* [Anna line 433].

This diagnosis felt like a punishment to some of the participants, Danielle talked about how it *"closed things"* for her [Danielle line 141], *"it just feels like a barrier"* [Danielle line 299–300]. Lauren spoke about how this restricted her from doing many things *"I couldn't join the army as an officer"* [Lauren line 464] and how *"it's very, very easy for abuses of power"* [Lauren line 332] and how this *"erodes people's agency"* [Lauren line 132–133]. Stephanie explained how she was treated like *"this untrustworthy, you know, emotionally fucked up person that that could attack them at any moment"* [Stephanie line 415–417], *"all they see is this animal which needs to be, controlled with a disordered personality"* [Stephanie line 434–436], *"your just powerless, no voice, and what you say doesn't matter"* [Stephanie line 521–522].

There was some confusion about this diagnosis, whether it is real, if it serves the person receiving it and how there are problems with the criteria, i.e., the number of different variations that there could be with this diagnosis. Anna talked about how there is a *"like a crazy amount of different symptoms that can make up the same diagnosis"* [Anna line 199–201], *"270 different variations of like symptoms that can make up one diagnosis of BPD, well how can you say that this one pathway, it's gonna treat all these different people the same way"* [Anna line 375–378]. Lauren questioned what this diagnosis does, *"it should be patient serving and client serving however you want to determine it and if it no longer works for the individual and no longer makes* *sense to them, then they shouldn't have those constructs applied to them"* [Lauren line 294–298]. Danielle appeared to agree with this notion, *"I no longer relate to a lot of the criteria of the diagnosis"* [Danielle line 104–105]. Chloe explained how even with other people, she does not feel this diagnosis is real, *"I used to meet women at work that were diagnosed with it and to be honest, I never really recognised it in them"* [Chloe line 828–830] and questioned how she only appears to 'have it' at certain times *"is it borderline personality disorder because it only seems to be related to my ex"* [Chloe line 424–425].

There seemed to be a theme with some participants involving misdiagnosis, there were two participants who had been diagnosed with autism after being diagnosed with BPD, and other participants recognised themselves as having been through trauma. Caroline and Stephanie both spoke about receiving their autism diagnosis, *"I realised this is why I was saying that BPD diagnosis didn't explain stuff, I realised as time went on that it was because of a massive sensory overload"* [Caroline line 648–651], *"the more I read on that, the more I realised that a lot of people, a lot of women, do go through multiple psychiatric labels and then suddenly generally themselves figure out they're autistic"* [Caroline line 561–564]. Stephanie also talked about a similar experience, *"you know what I was having was, you know, a very sort of like emotive reaction to like cognitive and sensory overwhelm, but that was interpreted as like being, you know, emotionally unstable"* [Stephanie line 212–215], *"they realised that that it was actually, you know, an autistic disposition and not, not personality disorder"* [Stephanie line 68–70]. Chloe talked about how it is diagnosed to a lot of people who have gone through trauma, *"I used to support women daily that were in the exact same situation as me"* [Chloe line 296–297] *"You'd start talking to a woman and she said, oh well, to be honest I've got, I've had a diagnosis and you always,*

*always immediately knew what, what diagnosis it was"* [Chloe line 298–301], *"I do believe that it's people that have gone through trauma"* [Chloe line 319–320]. Chloe also pointed out,

> *"if you read the symptoms of borderline personality disorder, I definitely did recognise with some of them, but I think they're also symptoms of someone who's gone through trauma and who is dealing with that trauma in an unhealthy way because no-one ever recognised it or help me try to deal with it in a healthy way"* [Chloe line 445–450].

Some participants also talked about the difference in the way people are treated with other diagnoses, Danielle talked about how it was assumed that "*you have BPD, you have attachment issues"* [Danielle line 136–137] and how there was an *"expectation"* [Danielle line 236] to be suicidal, with people *"constantly saying to you, like are you suicidal?"* [Danielle line 237–238], Danielle felt that at times there would be a *"separate set of rules for people"* [Danielle line 149–150]. Louise talked about how other diagnoses are easier for people to accept *"because it's like people accept that it's related to trauma or something or it just doesn't have the same like stigma"* [Louise line 503–505], *"if I say I have CPTSD, everyone's so kind, it's just a really weird, umm situation"* [Louise line 573–574]. Stephanie has also experienced this difference for herself, *"they try to be accommodating if you're autistic, if you've got a personality disorder, they're quite rude actually"* [Stephanie line 575–577].

## Group Experiential Theme 5: Wanting to feel that I am in control of my life.

This theme has 4 sub-themes. I grouped these together as throughout the analysis there were different patterns of control, feeling that it had been taken away from the participants, control that the diagnosis holds and feeling that some were taking back control over their lives.

The participants talked about their experience of receiving the diagnosis, and how at the time they were looking for help, to understand their experiences and understand their emotions. Louise explained, *"I don't wanna control or like, suppress my emotions, I wanna let them out and like, talk about them and like be able to express them and understand why I'm so sad"* [Louise line 153–156]. Stephanie said, *"I was expecting somebody to give me some tips, maybe to talk to me about it, to help me express like what I was, what I, what was going on for me, what I was feeling you know"* [Stephanie line 78–81]. Lauren also said she was *"looking for some kind of answers"* [Lauren line 41] as she was *"you know, having difficulty, kind of um containing feelings and being able to talk about things and I don't, I didn't feel understood"* [Lauren line 192-194]. Chloe also found herself looking for help, however, now feels that it is *"something I massively regret"* [Chloe line 68] because if she hadn't gone to the doctor *"I would never have had an official diagnosis"* [Chloe line 71].

Some of the participants talked about feeling a sense of relief when they were first given the diagnosis, seeing a name that explained the way they felt, Caroline explained how she saw that it meant that there were *"other people like me out there"* [Caroline line 57–58], *"originally the BPD diagnosis was so validating and then went on this journey where it ended up being awful"* [Caroline line 670–672]. Anna explained that she felt *"well finally, someone has said like you know, this is what's wrong with you"* [Anna line 164–165]. Lauren talked about how it *"kind of alleviated some of the confusion and some of the unknowing and some of the um, um the uncertainty that was with me at that time"* [Lauren line 65–67], *"it made me feel as* *though someone was taking me seriously"* [Lauren line 97–98]. Danielle also explained a similar feeling, *"at the time in part it was kind of a relief to have something, it was kind of like, ok I feel this way because of that"* [Danielle line 32–33].

Most of the participants spoke about the feeling that there was power attached to this diagnosis, Lauren spoke about how she felt *"many people would sooner believe medical professionals over the individual, and I think that goes to the essence of power differential"* [Lauren line 494–495]. Stephanie explained, *"you know about what it means to be somebody that has a personality disorder, you've got no voice, nobody, you just, you just constantly dismissed"* [Stephanie line 302–305]. Kelly also felt *"very frustrated and I felt powerless"* [Kelly line 100–101]. Anna explained *"your just expected to get on with it like, like it isn't even your life"* [Anna line 124–125]. Louise talked about how she feels that she wants to stop this from happening to others,

> *"I'm constantly like arguing with people about this diagnosis or, not just arguing, but just like advocating, and I think it's definitely put me down a different path of like, this is what I'm gonna do now is like make sure this doesn't happen to other women or other trauma survivors"* [Louise line 466–471].

Some of the participants talked about how they were trying to take back control or gain some meaning from their experiences. Stephanie talked about how she spent *"a year fighting against, you know, to try to get it removed"* [Stephanie line 65–66]. Anna spoke about fighting to get trauma therapy, after previously only being offered DBT, feeling that "*actually no, you you do deserve this as well Anna, like you have to give yourself a chance in life and that's why I fought to get this therapy"* [Anna line

506–508]. Caroline spoke about taking part in other research and being asked her opinion about her diagnosis, *"so this kind of gives me that sense of meaning and value to contribute"* [Caroline 1199–1201] and how she gets *a "sense of empowerment"* [Caroline line 1176] from sharing and owning her story.

# Chapter 5 - Discussion

## Introduction

The purpose of this research was to gain an understanding of women's experience when they disagree with their diagnosis of BPD and how this affects them. Semi-structured interviews were used with eight participants to gain this information, which was then analysed using IPA. Five main group experiential themes were clustered. These group experiential themes were: 'When did everyone forget that I'm just a normal person'; this theme involved participants feeling that something about them had changed as soon as they were given the diagnosis, that the label mattered more than they did. The second group experiential theme was: 'This label made things harder'; this diagnosis caused doubt and confusion for the participants, and instead of getting the support or help they wanted, their lives just became harder. The third group experiential theme was: 'Society needs order and needs labels to keep this order'; this theme included the feeling that there was a need to fit them into boxes, feeling that the label ignored the reasons why they felt that way and that it helped to avoid acknowledging that some people are distressed for various reasons. The fourth group experiential theme was: 'Problems within the system'; this involved feeling hurt by professionals, feeling that the diagnosis helped the services more than the person and discussed misdiagnosis. The last group experiential theme was: 'Wanting to feel that I am in control of my life'; this theme felt like it considered the different stages that the participants went through; firstly, seeking help, then feeling that all control had been taken from them, to trying to take back control of their lives.

These themes will all be presented in more depth below, with a discussion showing how the findings either complement, deviate or extend the existing literature.

There may also be reference to literature that was not included in the original review due to unexpected findings, Smith et al. (2022, p. 116) explains "it is in the nature of IPA that the interviews and the analysis will have taken you into new and unanticipated territory". Conclusions will be discussed in the next chapter, with a revisit to the original research aims.

## When did everyone forget that I'm just a normal person?

The first theme involved the participants feeling as if the diagnosis had seemed to change how they were seen and forgetting that they were just normal women who had gone through difficult experiences. They felt that they were seen as different people once they had received this diagnosis and were often judged for having normal human needs, like love and belonging. This is consistent with previous literature that discussed the stigma of this diagnosis, historically the term 'borderline' was used to describe people whom clinicians felt were difficult or disliked (Masland & Null, 2022). Veysey (2014), also found that personality disorders are seen as difficult to treat, and clients with BPD are often seen as 'considerable users of mental health services', so it is possible that once the participants had been given this diagnosis, they were treated differently.

The participants also spoke about the feeling that their human needs were often forgotten or deemed as part of their diagnosis. Participants talked about wanting love and belonging, which is considered a fundamental human need to help achieve esteem needs (Maslow, 1954). A similar theme was reported by Lovell and Hardy (2014), with one person feeling "you're not human, once you have got this disorder you're not a human anymore, that goes, your name goes (p. 233). Chugani (2016) highlighted that some people with BPD feel that their emotions or experiences are judged. However, if the experiences are acknowledged, including the understanding of normal human behaviour, this may facilitate deeper understanding and compassion for those diagnosed (Chugani, 2016). The need for a deeper understanding of expected human wants and behaviour has also been highlighted by Barr et al. (2020) study of peer workers supporting treatment of people with BPD. Participants had received stigmatising responses within services however a peer worker was able to provide hope, validation and understanding of these experiences, helping the individuals to feel less judged (Barr et al., 2020). An important factor within a therapeutic relationship is the need to feel understood and receive empathy (Flora, 2018), along with the need to provide a safe environment to allow the client to develop a safe and trusting relationship (Quinn, 2011). Therefore, it follows that if the participants have experienced judgements, or a lack of understanding of their needs, this could impact trust within services and professionals.

For some of the participants, being given this diagnosis did at first provide that feeling of belonging, possibly helping them to feel less alone. This supports previous research that found connectedness was an important factor in recovery for some diagnosed with BPD (Kverme et al., 2019). Participants found belonging within group therapies, finding that there were people who had similar thoughts and feelings so were able to talk openly without worrying about shame or embarrassment (Kverme et al., 2019). Fromene and Bernard (2014) also found participants who felt that the diagnosis had been useful in some ways, such as helping them realise that they were not alone in the way that they felt.

Despite some participants at first gaining a sense of belonging, participants also felt that they were treated as if they did not matter. Their opinions were not taken seriously, and they were not listened to, this could be consistent with previous research into the discriminatory experiences and the stigma attached to this diagnosis. Veysey (2014) found that some people were seen as attention-seeking and manipulative, being told that they were just doing “things to gain attention” (p. 26), therefore their distress was not taken seriously. Ring and Lawn (2019, p. 17) also found that individuals with this diagnosis are likely to encounter difficulties from mental health professionals, being seen as “attention seeking” and “manipulative”, therefore could struggle to receive the help they need.

### This label made things harder.

Within the ‘clustering’ stage of this group experiential theme, I came across a lot of personal experiential statements that seemed similar but could not be merged into one. This theme encompasses a range of feelings that seemed to be experienced by the participants, including the impact it had on their lives, confusion and the loss of hope.

A sub-theme with some participants involved a level of self-doubt, since being diagnosed and either hearing that they were manipulative, or reading that they may be, some participants started questioning why they did the things they did. This sub-theme is similar to findings by Moltu et al. (2023), where participants described feeling unable to trust themselves “constantly doubting their own inner world, their thoughts and emotions” (Results, Distrusting oneself, para. 1). One person reported questioning herself in every social situation and others reported the feeling of not knowing who they were, this also affected their relationships, worrying how their interactions would appear (Moltu et al., 2023). These feelings could be partly from self-invalidation, there has been research with individuals who have BPD, involving post-event processing. The individuals would scrutinise their actions and then criticise themselves for their emotions (Koivisto et al., 2022); however, it is unclear from the previous research whether their participants would do this before receiving the diagnosis. The participants within my study described this level of self-doubt as being connected to the messages that they had heard about their diagnosis and would therefore wonder if anything they did was somehow in part due to being manipulative. I found this theme interesting, as a lot of the previous research concentrated on how people were treated by others with this diagnosis, however, this suggests that the diagnosis also affected how they saw themselves. A staged model of self-stigma has also been proposed (Corrigan et al., 2011), this involves becoming aware of the stigmatising viewpoints, agreeing with these, applying these views to themselves and suffering lower self-esteem as a result. During the interviews, although it was clear that the participants were aware of the stigmatising viewpoints, it did not appear that they agreed with these. Perhaps as the word ‘manipulative’ is often thought of with BPD, the participants may have been scrutinising their social interactions as a preventative factor against their fears of being manipulative.

On a reflective note, after the interviews, I tried to imagine how it would feel to constantly question your own actions and the difficulties this would cause daily. It feels that there is something bigger than self-invalidation, almost as if the participants found it difficult to trust themselves. I also wonder how many times they had been told that they were manipulative for them to start worrying about paying someone a compliment. I suspect, sadly, that they had heard this message a lot.

Participants also talked about the impact this had on their lives and fear of being judged as a result of the diagnosis. They reported experiences of judgements within mental health services and worried about judgements in other aspects of their lives. This is consistent with previous research by Markham (2003) who found that staff would be more rejecting and desire greater social distance from people diagnosed with BPD than those with schizophrenia or depression. It has been suggested that a lack of training could result in these types of judgements and further training could help staff understand and increase their empathy (Weight & Kendal, 2013). Some participants were also afraid to tell others, worrying that they would be treated differently as a result, considering the wealth of research regarding BPD and stigma (Masland & Null, 2022; Ring & Lawn, 2019; Gray, 2022; Kling, 2014; NIMHE, 2003; Reynolds, 2017; Papathanasiou & Stylianidis, 2022), it is not surprising that people with this diagnosis would worry about the impact of disclosing to others. Research by Carrotte et al. (2019) also reported similar experiences, where people would limit disclosure of their diagnosis out of fear about how they would be treated. Clement et al. (2015) also carried out a systematic review of studies and found that individuals would often worry about negative consequences when disclosing mental health difficulties, so perhaps this applies to other mental health diagnoses.

Participants talked about how they felt that the diagnosis had been unhelpful, sometimes causing confusion and loss of hope. The confusion came from not understanding what this diagnosis meant or what it meant to have a disordered personality. This has appeared frequently in other research, with participants exclaiming “you don’t know who you are with it, cos before I always used to know who I was” (Lovell & Hardy, 2014, p. 233). Gary (2018) described themself as “a non-person, of a walking diagnosis, of a set of symptoms” (p. 70). Participants from previous research also reported the diagnosis not meaning much to them, and not providing a reason for why they felt the way they did (Horn et al., 2007). Loss of hope has also been expressed in previous research, with participants being told that BPD was untreatable (Horn et al., 2007). Ramon et al. (2001) looked into how individuals had experienced receiving the diagnosis of BPD and found views including “a life sentence – untreatable – no hope” (p. 5). Individuals reported the diagnosis as having a negative impact on professionals’ attitudes (Ramon et al., 2001) and it was concluded that the personality disorder diagnosis has multiple negative impacts. Considering the similar themes within previous research, it is possible that participants from the current study were judged or treated differently as soon as they were diagnosed. The additional weight of being told it was life-long and un-treatable, may have contributed to feeling they were fighting a pointless battle.

A final part of this theme involved emotional suppression, along with the feeling that sometimes this diagnosis could make a person act in a way that confirms the diagnosis. Some participants talked about being afraid to show their emotions, either worrying that any display of emotions would confirm the diagnosis or as a result of being told that their emotions were inappropriate. There were experiences that the participants had been through where it would be understandable for them to feel intense emotions, such as Danielle being assaulted, Stephanie having a sensory overload and Chloe being in an abusive relationship. Despite these experiences, participants felt they could not show emotions. There is some research in the area of emotional suppression and people who have been diagnosed with BPD, however, the research is limited. One study did suggest that people with this diagnosis may suppress their emotions as a result of feeling judged for having intense emotions (Beblo et al., 2013). The authors suggested that this may create a vicious cycle where emotional suppression may lead to more intense emotions, and this may expand to a fear of emotional arousal (Beblo et al., 2013).

There is also research regarding emotional numbing and trauma (Feeny et al., 2000), whereby numbing or avoidance is considered a common factor for people who have PTSD (NHS, 2022). Considering the participants’ experiences of trauma, and their experiences of being judged for their emotions, it is understandable that they would either try not to feel emotions or feel unsafe displaying them. Unfortunately for the participants, when they have expressed their distress and their needs, there were times when they were not taken seriously. This too could have contributed to the feeling that they were not able to express or even feel their emotions. This experience of not being taken seriously mirrors findings from previous research, such as Ware et al. (2022) where participants explained that they were not taken seriously until they became very distressed and required admission into hospital. This can also be viewed as emotional invalidation, where interactions communicate, or are perceived to communicate that an individual’s emotions are wrong or inappropriate (Zielinski & Veilleux, 2018). Emotional invalidation can affect how a person experiences emotions and interprets daily stressors (Zielinski et al., 2023), so the feeling of not being taken seriously, could increase the number of difficult emotions that a person feels. This could explain findings from other research where a participant reported that healthcare staff had said or done things that increased their risk (Ware et al., 2022), which was also a finding in the current study. The amount of distress that an individual is feeling could be exacerbated by emotional invalidation, therefore the individual feels more distress as a result of their interactions.

### Society needs order and needs labels to keep this order.

This theme considered the need for diagnosis, in particular wondering why distress cannot just be viewed as distress. The participants felt that the diagnosis only looked at the presenting issue, not why they may feel the way they did and at times blamed them for their feelings.

The participants talked about how they felt that this ignored previous adverse experiences. During the interviews, most of the participants talked about the type of trauma they had experienced in their lives. Some participants also mentioned that they had additional diagnoses of PTSD or CPTSD, indicating that they have been through some form of trauma. As mentioned in the literature review, there have been several studies which have reported correlations between experiencing some form of trauma and receiving a diagnosis of BPD (Goldman et al., 1992; Helgeland & Torgersen, 2004; Herman et al., 1989; Ogata et al., 1990; Zanarini et al., 2002, Temes et al., 2017; Martin-Blanco et al., 2015; Brakemeier et al., 2018). Danielle pointed out that by ignoring the trauma and focusing on the BPD diagnosis, this often prevents people from accessing therapy which could be better suited to them. Barnicot and Priebe (2013) studied the effectiveness of providing DBT for individuals who have PTSD and found that the Stage 1 DBT model does not adequately address the needs of those with PTSD. When an individual has been diagnosed with BPD and has a comorbid diagnosis of PTSD, it is often recommended to provide emotional regulation and distress tolerance skills training before commencing trauma processing therapy (De Jongh et al., 2020). However, research has found that intensive trauma-focused therapy, aimed at processing distressing memories has been beneficial to people with a comorbid diagnosis of BPD and PTSD, without providing prior interventions focusing on emotional regulation and distress tolerance (De Jongh et al., 2020). The authors of the study suggested that the participants may have been more focused on their trauma (De Jongh et al., 2020), which could be understandable considering the effects that it can have on a person’s life. Other research has also suggested that a trauma-informed perspective, which takes into account the broader issues in society would better facilitate recovery (Ferguson, 2016).

There was a theme that involved blame, some participants talked about how they felt blamed for their emotions, and how even the name of BPD implies that there is a problem with their personality. There has been a wealth of research into the stigma that is associated with the diagnosis of BPD, with some professionals believing that individuals with BPD are more in control (Markham & Trower, 2003). If professionals believe that an individual has control over their emotions and actions, it is likely that they could hold them responsible or attribute blame to them. This has also been found in other research, finding that nurses expressed less empathy towards people with BPD, as a result of burnout and lack of training (Bodner et al., 2011). The same study found that negative reactions towards people with BPD decreased as clinicians gained experience (Bodner et al., 2011). So, it could be possible that if the participants had interactions with staff who were unaware of the adverse experiences in their lives, and were working in highly demanding situations, this may have contributed to a lack of empathy and blame.

Some participants spoke about how this feeling was internalised, they would blame themselves for their own feelings, resulting in self-invalidation. Self-invalidation can involve overly self-judgemental thoughts, such as self-blame and may emerge from an invalidating environment (Koivisto et al., 2022). This has also been found in previous research, with participants explaining that they had blamed themselves, and felt they were just difficult to deal with, however through therapy, they learned they were not to blame (Donald et al., 2017). The diagnosis of BPD also holds a lot of stigmas, with studies showing that mental health professionals can have more negative attitudes toward those with BPD than other diagnoses (McKenzie et al., 2022). Due to the stigma that surrounds this diagnosis, it is possible that there may also be an element of self-stigma involved with the participant's experience.

Some of the participants talked about feeling that society feels uncomfortable when people display distress or stand out. This reminded me of a quote in the book Girl Interrupted, “it’s what they call people whose lifestyles bother them” (Kaysen, 1993, p. 123). Recently, there have been many campaigns that aim to reduce the stigma of mental health, and improve societal attitudes (Rethink Mental Illness, 2023; Campaign Against Living Miserably, 2023; Time to Change, 2023; Mind, 2023). There are also a number of ‘celebrities’ or public figures that have been open about their mental health difficulties, so it would be reasonable to assume that attitudes would change. Despite the amount of information that is now widely available, stigma and stereotypes still exist. A study using social media to measure attitudes showed that stigma and stereotyped attitudes were associated more with mental health than physical health (Robinson et al., 2019). It could also be possible to apply Social Identity Theory (Tajfel & Turner, 1979) to this aspect, where categories or stigma results in ‘in-groups’ and ‘out-groups’. Some participants mentioned that just looking a certain way, such as having brightly coloured hair or behaving in a certain way could make them appear ‘different’ to other members of society. Some people who have experienced mental health difficulties feel the need to blend in with others, to act like ‘the norm’ to avoid stigma (Whitley & Campbell, 2014), which adds another level of pressure for them to deal with. Gender norms could also be a factor, Lester (2013) noted that many of the symptoms included within the BPD diagnosis involve going against the historical view of what would be considered feminine. Likewise, Mitchell (2000) suggested that the symptoms could be interpreted as a description of what would be considered a ‘bad’ woman, as historically women who showed emotion would be considered hysterical. Whilst there are some circles or groups of society that would feel comfortable with people expressing themselves freely, it could follow that in some areas, people are less comfortable, and could assign certain aspects of a person as belonging to an ‘out-group’.

Many of the participants also talked about feeling that the diagnosis did not match their experience or did not feel like them. The participants described feeling that they were given a diagnosis that did not match the description of what they felt. Ng et al. (2019) found a theme of non-acceptance within their study of recovery in BPD, however, they also found that for some people, the diagnosis made sense. Horn et al. (2007) found some participants who felt that the diagnosis did not mean much to them and did not provide any understandings of their difficulties. Lester et al. (2020) also found that some felt that the diagnosis did not explain their difficulties, however suggested that one reason could be the lack of information provided during the diagnosis. This sub-theme left me with a lot of thought, the participants were looking for help, or to understand themselves, and received this diagnosis; however, did not feel that this ‘fitted’ them. This may have caused them more difficulties, either feeling frustrated or confused. If, at the time of diagnosis, some felt that this did not explain their experience, would there have been any benefit to providing this diagnosis? Diagnoses can be used to explain symptoms, or guide appropriate treatments, however, the participants in the current study were not provided with the treatment they felt they needed. Some paid for private therapy to access helpful treatment, so receiving the diagnosis did not lead to effective interventions. Perhaps the diagnosis arose from a need to assign a label or categorise the women to enable some form of order.

When thinking about society and the need for order, I considered the notion of emotional norms, and how society has a part in this. It has been considered that emotional experiences can have interactional roots, a person’s close relationships may shape the assessment of what is considered normal as an emotional response (Esala & Del Rosso, 2019). A person, for example, might be told that at times anxiety is normal, and may be told that they should be ‘over’ their trauma, or be able to deal with it differently (Esala & Del Rosso, 2019). The medical model ignores cultural and community ways of expressing, and coping with emotions (Segalo, 2015), so a woman expressing her emotions or feeling distress, could go against these norms. Some of the participants questioned the need to label distress, and wondered why normal human reactions are pathologised. It has been suggested that as a lot of women with this diagnosis have experienced some form of trauma or abuse in their lives, therefore, it would be more helpful to show that their emotions are understandable in the context of how they are experienced (Ussher, 2013).

## Problems within the system

This theme considered the different experiences within the mental health systems, some of these experiences were hurtful to the participants. There was also a theme of misdiagnosis, i.e. participants being given a diagnosis that not only did not make sense to them but was also later changed to a different diagnosis. In these situations, participants noted the way that they were treated differently to people with other diagnoses.

Some participants talked about unhelpful experiences from mental health services and professions; the feeling of not being believed and seen as manipulative or attention-seeking seemed to be a common experience. This is not the first time that this has been discovered in research. Lamont and Dickens (2021) carried out an analysis of literature that focused on the experience of mental health services and found unhelpful interactions with professionals and services. These interactions involved words such as judgemental, dismissive, hostile and being viewed as difficult and challenging (Lamont & Dickens, 2021). A survey also found that two-thirds of respondents with BPD reported being treated disrespectfully by health professionals (Lawn & McMahon, 2015). This raises concerns about whether people who are diagnosed with BPD would feel as though they could seek support when it is needed. Other research has highlighted the difficulties with individuals seeking support, with some finding that services were withdrawn while they were having distressing thoughts, as the service wanted to consider an appropriate pathway (Morris et al., 2014). This also ties into the theme of feeling that the diagnosis makes things easier for the services.

Caroline was not informed of her diagnosis by a professional, instead, this was communicated to her by a mutual acquaintance, previous research has also noted that sometimes individuals have not been told about their diagnosis (Fallon, 2003). It could be reasonable to assume that the diagnosis would have no purpose to the individual if they were unaware of it. Instead, perhaps in this case, the diagnosis served more as a tool of communication between service providers. Anna also spoke about the feeling that the diagnosis defined the treatment pathway. This has also been mentioned in previous research, Katsakou et al. (2012) found a theme of a clash between wanting to focus on their own personal goals and service targets. Their participants felt that therapy would only focus on certain topics, such as self-harm, rather than helping with other aspects, leaving them feeling frustrated (Katsakou et al., 2012).

Some participants talked about feeling that the diagnosis was a punishment, and how it seemed to put up barriers for them. Participants from previous research have reported how services have been withdrawn and were discharged as a result of being in crisis (Morris et al., 2014). It has also been reported that individuals have felt that once they received the diagnosis, they were no longer seen as unwell or distressed, instead they were viewed as difficult (Morris et al., 2014). Moreover, it has been found that sometimes professionals working within mental health services do not offer explanations of their roles or functions of the service; leaving people to find them confusing, frustrating and frightening at times (Fallon, 2003). This lack of communication could be seen as a further barrier, as it adds difficulty to the process if a person tries to contact the services, and also adds to the feelings of unreliability. At times, it has been felt that services can over-respond and take away the independence of individuals (Miller, 1994). It has been suggested that services could be improved if professionals focused on the reasons why a person is distressed, rather than being reactive to the distress (Morris et al., 2014). By over-responding, and taking away independence, this could reduce the amount of personal agency within the individual. It has been recommended to encourage individuals to have an active role in therapy, as collaborating in treatment approaches could help transfer their sense of agency to other areas of their lives (Hashworth et al., 2021).

There was also a lot of confusion surrounding this diagnosis, with some participants wondering if it is a real diagnosis. Some participants also wondered about the purpose of this diagnosis, as there would have been other diagnoses that perhaps would have been more helpful to them. Two of the participants were later given the diagnosis of autism, which they felt not only made more sense to them, but it also seemed to enable more understanding from professionals. It has been noted that due to women learning how to be ‘socially acceptable’, autism can be missed within diagnostic procedures which can result in being given multiple diagnoses, such as anxiety, depression and BPD, before it is recognised that they are autistic (Rasmussen, 2023). It has also been suggested that BPD and autism in women can appear to overlap. Therefore, the diagnosing clinician needs to complete a thorough evaluation (Pires et al., 2023), which would also assist with tailored therapeutic approaches (Xavier et al, 2015). When thinking of the information that the participants in this study provided about their diagnosis, it appears that none of them had a thorough evaluation and were often diagnosed after a short meeting. It has been suggested that autistic women go unnoticed more than men, which increases their risk of being misdiagnosed, suggesting that BPD should not be considered before autism has been ruled out (Rasmussen, 2023). This would provide everyone involved, such as the person, their family and services, with a better understanding of their needs, which would improve the quality of life for the person (Rasmussen, 2023).

There is also a reported overlap between the symptoms of BPD and PTSD (Mosquera & Steele, 2017) and reports of individuals who have experienced trauma and received a diagnosis of BPD (Bozzatello et al., 2020). Most of the participants in this study spoke about traumatic events in their lives, involving abuse, and many also had additional diagnoses such as PTSD. Martin-Blanco et al. (2015) found 75% of their participants, who were all diagnosed with BPD reported traumatic experiences in childhood. Ball and Links (2009) also suggested that childhood trauma should be included in the aetiology of BPD and be recognised within the treatment provided. As noted earlier in this discussion, often people with a diagnosis are only referred to therapies that would focus on specific factors, preventing a focus on what the individual’s actually need. If professionals were more aware of complications caused by misdiagnosis, perhaps individuals would be offered treatment that was better suited to their needs. It has been noted that due to attitudes or care provided, people with the BPD diagnosis can often become involved in a vicious cycle of dropping out of treatment, and being re-referred to services, more commonly known as a ‘revolving door’ (Bodner et al., 2015). If all individuals were thoroughly assessed, which could identify autism or trauma histories, this would not only benefit the individual, but could also release some pressure on the services.

## Wanting to feel that I am in control of my life.

This final theme considers the different experiences involving control, how the participants possibly first felt that they were taking control of their lives by looking for help, how this was taken from them and how they were taking it back.

Most of the participants received their diagnosis from some form of community setting, and they talked about how they were looking for help or to understand their emotions. Some of the participants described feeling a sense of relief when they were told there was a ‘name’ for how they felt and the knowledge that they were not alone with their feelings. This is something that other people have described as well, with one individual describing that the diagnosis provided a focus for recovery (Morris et al., 2014) and others finding that group therapy was helpful as it reduced the feeling of isolation (Gardner et al., 2019). One study found that when they were provided information, such as why BPD might occur and how it may feel for other people, participants felt that it made sense (Richardson & Tracy, 2015). Most of the participants in my study were not provided with much information regarding the diagnosis, many of them received the diagnosis at difficult times in their lives, so it is possible that depending on how it was explained, they may have resonated with some of the symptoms. It is also possible that receiving a diagnosis may have given the participants hope, that it would lead to effective treatment.

Participants later described feeling powerless as a result of the diagnosis, feeling that nobody listened to them and that professionals were more readily believed than them. I feel this speaks to a wider systemic issue within services, and that professionals are often more believed than those living with the diagnosis (Carrotte et al., 2019). The stigma attached to this diagnosis would also not help in this situation, with some people reporting that they were told they were not ill (Reynolds, 2017). Ring and Lawn (2019) also noted that individuals with this diagnosis are often in a situation where they cannot win, as even when they try to seek help, they can be dismissed as attention-seeking or manipulative. In one study, participants felt angry at the restrictions placed on them from the services (Fallon, 2003). In the same study, the feeling of being powerless occurred within the therapy room, where participants felt that their own needs were not acknowledged by the type of therapy provided (Fallon, 2003). As a trainee counselling psychologist, I have been trained to respect the clients' personal therapy goals, however, I have also worked in services where certain forms of therapy were limited. This could be mediated by open communication between the services and the person, having an understanding of what the person needs in terms of therapy, being honest about what is available within the service and creating a plan together.

Finally, some of the participants also talked about taking back control, in some ways, it felt that they were trying to regain ownership of their lives. These methods ranged from focusing on their own needs, becoming activists, and either paying or fighting for trauma therapy. Stephanie actually fought to get the diagnosis removed, however, although the diagnosis had been taken off her record, it was still brought up later. Earlier in this discussion, it was considered that if a person has an active role in their treatment, this could help reduce feelings of powerlessness and increase their sense of agency within other areas of their lives (Hashworth et al., 2021). It would appear that participants in the current study found their sense of agency more out of frustration, possibly feeling that they had exhausted all other options. This is not an isolated experience, Anonymous (2023) explained how they had been diagnosed with BPD without being told, experienced difficulties within the services then found their own forms of treatment. They felt that being able to erase BPD from their medical records would help with healing from iatrogenic harm (Anonymous, 2023). It feels that there is something important to recognise that the participants not only have needed to find a way through the difficult events in their lives, but they have also needed to find a way through their diagnosis.

# Chapter 6 - Conclusion, limitations, and recommendations

## Introduction

This thesis has aimed to explore the experiences of women who have disagreed with their diagnosis of BPD. This chapter provides a conclusion to the thesis, beginning with revisiting the original research questions and discussing which themes were applicable. There will then be a focus on the strengths and limitations of this study, including the method of analysis chosen. I have then provided a framework that involves considering the methodological integrity. Implications for practice will also be discussed and recommendations for future research will be suggested. Finally, further reflections will be discussed, including how I feel that this research has personally and professionally affected me.

## Revisiting the original research questions.

The prior chapters have discussed the findings in relation to previous literature, and insofar, previous literature has either supported the findings or helped to provide explanation. The findings have provided knowledge regarding the experience of women who disagree with their diagnosis of BPD, and there were some themes found that were unexpected.

This study aimed to explore the experiences of women who disagreed with their BPD diagnosis, the original research questions for this study were:

1. How do the women who participated in this study experience receiving a diagnosis that they have disagreed with?

2. What meaning did the women that participated in this study ascribe to the label of borderline personality disorder?
3. How do the women who participated in this study perceive and experience the impact of this disagreement on their mental health and well-being?

The themes that were found after using IPA to analyse the data were:

1. When did everyone forget that I’m just a normal person?
2. This label made things harder.
3. Society needs order and needs labels to keep this order.
4. Problems within the system.
5. Wanting to feel that I am in control of my life.

### How do the women who participated in this study experience receiving a diagnosis that they have disagreed with?

When considering the original research questions, it feels that the experiences of these women involved factors that did not only affect how others saw them, but also their own sense of identity. Participants talked about feelings of confusion and that they had lost control. There seemed to be feelings that this diagnosis changed them, and it was forgotten that they have normal human needs like anyone else. It felt that the participants were all dealing with something difficult in their lives at the time of diagnosis, and this seemed to compound matters. The participants were often not believed by professionals, and they were all exposed to the stigma attached to the diagnosis.

### What meaning did the women that participated in this study ascribe to the label of borderline personality disorder?

For this research question, I find it difficult to pinpoint a particular theme that describes the sense of meaning that the participants had to this diagnosis. The participants described a range of meanings, some found it helpful to begin with, however talked about it being a hurtful label, punishing at times. During the time of diagnosis, many of the participants spoke about feeling out of control, not listened to, and feeling that nobody cared about how they felt. It feels that for some of the participants, the sense of meaning came later when they were taking control of their lives. I feel that for some of the participants, the sense of meaning also involved a lot of confusion and feeling lost within the system.

### How do the women who participated in this study perceive and experience the impact of this disagreement on their mental health and well-being?

It feels that the participants experienced some form of battle that has been present in their lives since receiving this diagnosis. Most of the participants were already dealing with some difficult issues before the diagnosis, and this added another layer that caused more challenges and battles. For some of the participants, it felt that the diagnosis served as a tool between the professionals or helped to create a treatment pathway. However, this pathway often did not involve the treatment that the participants actually wanted, resulting in some of the participants paying for private therapy. There seems to be an impact on some of the participant's identities, with some finding that they judged or invalidated themselves, believing themselves to be manipulative or overreacting. Although some of the participants said that they no longer feel that they have the issues that they used to, it feels that this diagnosis is still something that hangs over them. Some of the participants talked about how it is always on their mind, and that they choose carefully whether to tell anyone about the diagnosis, so this also may affect their feelings of connection with others, feeling that they have a secret that they need to keep.

## Strengths and limitations of this study.

There has been a lot of previous research involving BPD; this has included which treatments are effective (Choi-Kain et al., 2021), experiences within services (Reynolds, 2017), relationships (Dixon-Gordon et al., 2021) and emotions (Fernando et al., 2014). At the time of writing, there was no research into the experiences that women have when they disagree with their diagnosis. This study adds to the body of research that focuses on how mental health diagnoses can have adverse effects on individuals' lives. Although this study at first focused on the experiences of receiving the diagnosis, it unearthed layers where these women explained how this affected their identity, the ability to trust their own thoughts, how it affected relationships and negative experiences from professionals.

This study has indicated how there is a need for services to become more trauma-informed and person-centred, and whilst it is appreciated that all services have pathways, policies and procedures, it should be questioned whether these are helpful. Considering that most of the participants later found private therapists and avoided other mental health services, a systemic review needs to occur.

## Critique of the use of methodology

Whilst considering the chosen methodology for this topic, I feel that IPA was a suitable choice, although IPA does have its criticisms. Firstly, for the role of language used within qualitative research. It has been suggested that language can construct reality, rather than describe it (Willig, 2022), the meanings can reside in the words themselves, so the text describes how a person talks about the experience, not what they actually experienced. It is accepted that whilst the author attempts to understand the experience that the participants are talking about, only the individual can understand how it truly feels.

Phenomenological research has also been critiqued for the focus on lived experience limiting the understanding of what caused the experience (Tuffour, 2017), Smith et al. (2009) however, have argued that the use of hermeneutic, idiographic and contextual analysis helps to understand the experiences that take into account the wider context. I feel that in this study, although there were previous experiences that would have affected my participants, it could be argued that the causation for disagreeing with the diagnosis was receiving the diagnosis in the first place.

It has also been suggested that the meaning and use of cognition in phenomenology require further exploration (Willig, 2022). Smith et al. (2022) claim that the use of cognition within IPA is different to how it is seen in "mainstream psychology" (p. 138). Cognitive psychology can come with certain assumptions and boundaries; however, Smith et al. (2022) explains, "The cognition we are talking about includes the range of layers of reflective activity which make up part of everyday experience and which can therefore form the focus of a phenomenological inquiry" (Smith et al., 2022, p. 139).

It is acknowledged that, within IPA, the researcher plays an active role in the data analysis and the interpretation of the findings (Smith et al., 2022). I recognise that although there has been an effort to 'bracket' my personal feelings, at times this is difficult. In order to prevent my personal feelings and preconceptions from appearing within the analysis, I ensured that I had regular meetings with my supervisor during the analysis stage to go through a process of triangulation. I have also been reflective throughout the thesis, at times adding notes to acknowledge my thoughts at the time. I have aimed for transparency by including extracts from the transcriptions within my findings and discussion for the reader to understand how the themes have been developed.

The homogeneity of my sample could be queried, due to the changing of my inclusion criteria within the recruitment process. One could argue that for a completely homogenous sample, the participants would have needed to be in a small age bracket, having lived with their diagnosis for the same amount of time, including gender and location. However, as my study is regarding the experience of disagreeing with the diagnosis, and this diagnosis can be provided by any country that uses the DSM or ICD, I would argue that it is not location-specific. During the recruitment stage, it became apparent that I would need to widen my inclusion criteria in order to continue with the research. Smith et al. (2022) also suggested that sometimes a researcher needs to be pragmatic and that it is sometimes necessary to expand the recruitment criteria if difficulties arise. I therefore attempted to keep the sample as homogenous as possible despite recruitment challenges.

## Methodological Integrity

There have been many different viewpoints providing guidance into demonstrating validity within qualitative research (Creswell & Miller, 2000). Historically, there has been criticism towards qualitative research for failing in terms of validity and reliability. This has resulted in a shift away from the type of understanding of validity that is often associated with quantitative research (Rose & Johnson, 2020). Criteria used to assess qualitative research incorporate appraising rigour or trustworthiness, one such framework uses the concept of methodological integrity (Levitt et al., 2017). Levitt et al. (2017) considered concepts regarding the fidelity to subject and the utility in achieving goals, the areas of focus are:

- Adequate data
- Perspective management in data collection
- Perspective management in analysis
- Groundedness
- Contextualization
- Catalyst for insight
- Meaning contribution
- Coherence.

When considering the adequacy of the data, Levitt et al. (2017), stress that this does not refer to the number of interviews or participants, moreover, this refers to whether the data collected can provide insight into the phenomenon that is being studied. Although there were some challenges within recruitment, I do feel that the interviews provided rich data to be analysed. My recruitment did lack in diversity in some ways, part of the reason was due to the adherence of attempting to have a homogenous sample. Most of my participants were from the UK, likely as a result of the first recruitment criteria that I employed. All of the participants were white, this was unintended, as this was not part of the recruitment criteria; however, it does mean that I have missed out on possible different experiences and/or viewpoints.

Levitt et al. (2017) explain that fidelity is improved when researchers are transparent about their perspectives during the data collection and analysis, this can involve reflective strategies. Throughout this research, I have been self-reflective, I have utilised a research journal to help with this. The research journal included thoughts and feelings throughout every stage, and even included ‘random’ thoughts, that sometimes made no sense to me at the time. I feel that I have allowed myself to feel vulnerable and open to including these within my reflective notes and discussing this with my supervisors. I decided to add reflective notes throughout the thesis as I felt it allowed for a more honest and transparent style, rather than just adding them to one section. In addition, I felt that not combining them to one section would help the reader gain insight into my thought process during each stage. I utilised supervision frequently during the data analysis stage for the process of triangulation, however our meetings were virtual, so I wonder if having in-person meetings with the raw data in front of us would have made a difference.

Groundedness refers to the meanings that are identified, whether they are rooted in good quality data, this can be demonstrated by using quotes from the data to support the themes (Levitt et al., 2017). Although I have supported my themes with extracts from the transcriptions, I did find this stage difficult. There were a lot of extracts that I wanted to include so spent time considering which ones also involved the emotions or the experiences that the participants were conveying at the time.

Contextualization of the data involves providing sufficient information to enhance the utility of the findings, this involves providing information that allows the findings to be understood (Levitt et al., 2017). I feel that although I have a comprehensive literature review, it was difficult at times to determine which literature to include, as the diagnosis of BPD has been researched extensively for other reasons. As the literature review was carried out before the interviews, I wanted to give the reader an understanding of the various factors that could be involved with receiving this diagnosis. I worried that by only including the extracts that related to the group experiential themes in the findings, that the reader would not have a greater understanding of the participants, so I included some information regarding each participant to hopefully allow greater context. I feel this also helped with the notion of catalyst for insight, in addition to remaining reflective throughout.

Levitt et al. (2017) explain that a meaningful contribution can take many forms. Whilst acknowledging my own biases in this research, I do feel that it could make a meaningful contribution. Firstly, at the time of writing, I failed to find previous research in this area, so this extends knowledge in both an academic and professional context. I feel that the findings should be used to improve practice and awareness that a diagnosis can leave a mark on someone. However, I am aware it will only inform practice if practitioners decide to use it. I would hope that the research will help the participants involved, just with the knowledge that someone has listened to their point of view when they have had so many negative experiences in the past. This could also help normalise the feelings of other people who may be experiencing the same thoughts about their diagnosis.

Finally, Levitt et al. (2017) recommend that there should be coherence among the findings, with explanations into how the findings relate to each other. Strategies can include narrative or artistic representation to demonstrate the complexity of the phenomenon. Although there were some unexpected findings, this is a common occurrence in IPA research (Smith et al., 2022). Whilst defining the names for the themes, I went through a time-consuming process of re-analysing and re-defining the themes until I felt that they would make sense to the reader. During the final stages, I wanted to include a more creative aspect to demonstrate the experiences of those who took part in the study, I decided to include word clouds of the transcripts to help with this (Appendix N – U). I have also included images to show examples of the personal experiential themes (Appendix K), final group experiential themes (Appendix M), a sample from the transcript during the analysis (Appendix J) and a screenshot of the database that I created to organise the themes (Appendix L). I have included all of these details to hopefully help with the coherence of my findings.

## Implications for practice

As there is a high number of individuals being diagnosed with BPD after experiencing trauma, it would be reasonable to assume that individuals will continue to present to services with these symptoms. I feel that before an individual is diagnosed with BPD, there should be time spent assessing the history of the client, not just looking at the presenting symptoms. There should be an awareness of any trauma experienced and considered whether the presenting symptoms can be explained by the person’s life experiences. Time spent talking to the client may also highlight whether there are any indications that the person may be autistic or experiencing sensory difficulties that are presenting as BPD symptoms.

A further implication for practice also involves treatment, the participants spoke about being mainly offered DBT, with no consideration that trauma therapy may be effective. As counselling psychologists, we should be able to assess and formulate, before considering the therapy modality. If we focus on the recommended treatments without taking into account the backgrounds and reasons why a person may feel the way they do, we could be further invalidating the person involved. This could repeat the experience of not listening to them and adding to any feelings of hopelessness if the therapy does not work. Formulation should also be used to help other staff working within services to understand the person they are working with, to be able to see the person, not the label.

These findings have shown that not only was the diagnosis unhelpful for these women, but it also caused more issues, not only within services, but also within their personal lives. This diagnosis caused some of the participants to doubt their own thoughts and made them feel that they were manipulative and attention seeking. This caused further traumatisation to people who had already been through some difficult times in their lives. It also took away their feelings of hope, that the way they feel could change. When considering the above factors, including assessment, treatment and formulation, we need to be aware of this impact. This diagnosis can cause confusion to the person it is given to, and the stigma of the diagnosis can make them feel worse than they originally did. When completing formulations, we should remain curious about the person’s feelings of their diagnosis and how this diagnosis may actually perpetuate their difficulties and cause a further barrier or obstacle for them to overcome.

I think a further, but important implication for practice is having the knowledge that a person with this diagnosis has possibly experienced unhelpful responses from services. They could appear to us as ‘difficult to engage’, however we need to be aware that they may have developed a distrust of mental health professionals due to their previous experiences. Often, different services will have different policies for us to abide by so there may be times when we need to challenge these, so we do not continue to provide further negative experiences and treatment.

I wonder, if as psychologists, we can find a way for our work to continue outside the therapy room. Perhaps we need to become more involved in work that focuses on the systemic issues that people can experience. We need to consider the wider impact, beyond the individual and consider their environments, society, and how we can share our knowledge beyond our practice. This consideration should also focus on the stigma that a person may be experiencing, acknowledging that a person with this diagnosis may now have something else that they may now need to endure. We need to be aware that some people will have more ‘protective factors’ than others. Some areas are considered deprived of resources, so some people may find it difficult to let go of their survival techniques. It feels like there need to be a change within society, to help people gain relational safety and connections to prevent people feeling isolated.

I feel that there needs to be a culture change in all mental health services and society, these diagnoses can be confusing to people, and bring on worries about their identity. There is currently a push for services to become more trauma-informed, however the findings from this study shows that this is lacking in some areas. The women who took part in this research experienced judgements and harmful responses from services, showing a lack of understanding from professionals. Previous research has highlighted that training can help reduce the stigma of this diagnosis from staff groups (Weight & Kendal, 2013), however the participants involved in this study also showed their awareness of the public perception of this diagnosis. So, within the public, there is a message that people who have this diagnosis are manipulative and attention-seeking, rather than acknowledging trauma or difficult life experiences. As the participants have realised, if they had another diagnosis they may have been treated differently, there needs to be greater awareness and understanding of the factors that could contribute to someone receiving this diagnosis. Services and professionals should follow more trauma-informed approaches, with a focus on what can be done to help the person, rather than causing more harm.

## Recommendations for future research.

I am hopeful that one day, we will be able to view distress in a manner that does not hold such a stigma to it. Nevertheless, I feel that this diagnosis, or variations of it will continue to be used in practice. When thinking about further recommendations for research, I am aware that this particular diagnosis has been heavily researched for various factors, such as treatment (Choi-Kain et al., 2021), relationships (Dixon-Gordon et al., 2021), and stigma (NIMHE, 2003). At the time of carrying out this study, there was no prior research on how people experience disagreeing with their diagnosis of BPD. The findings have provided a lot of insight into how the participants were affected by this label. Considering the noted research in the similarity of BPD symptoms with other diagnoses, such as autism, PTSD and CPTSD, and the probable continued use of diagnostic systems; it could be helpful for further research to focus on this area. If these forms of diagnostic systems are continued to be used in the future, the diagnosis provided should be helpful to the person, it should make sense to them and take into account their needs. This would also prevent women from being referred to types of therapy that they do not want and hopefully be able to access support that benefits them.

## Final reflections.

I feel I have learnt a lot from this research and that it has affected me both professionally and personally. Within my role, I work with people who have this diagnosis and they have often asked me if I think they have it. Although I am aware that I should not put my beliefs on others, I do try to allow people the space to consider their ‘symptoms’ as normal responses to their life events. I try to validate the person’s experiences without pathologising. I am also aware now, that people with this diagnosis may have a distrust of ‘professionals’ due to previous bad experiences, so I hold this in mind at all times. This awareness allows me to consider that situations like ‘missed sessions’, may occur due to nervousness or fear. I also attempt to use this knowledge in a variety of team meetings, trying to encourage others to consider the wider context in the individual’s situation.

Personally, I am aware that had I experienced the same situations as my participants, I could have received the same diagnosis. Kelly explained when being asked if she had struggled with her sense of identity, it was explained to her that this could mean that *“some people move away”* [Kelly line 153] and Chloe spoke about how sometimes people *“don’t like someone with coloured hair”* [Chloe line 325]. It occurred to me, as someone who has lived in different countries and currently has bright red hair, how normal experiences are pathologised. The women in my research were not given opportunities for anyone to realise that what they were experiencing were understandable reactions to their life experiences. I have also kept my participants in mind any time I hear the term BPD in the media, such as being used in highly publicised court cases (Hadi, 2022) or movies. I feel disappointed that this term is still being used as a negative aspect about a person and can understand why my participant's spoke of fears of telling people.

Finally, as a trainee, I have at times found this research difficult but needed. I have acknowledged that, at times during the interviews, I found it difficult to switch from being a trainee counselling psychologist to becoming a researcher. Even now at the final stage, I am not sure that I always achieved the right balance. Although I have used the term 'participants' throughout this thesis, I have still wanted to ensure that any reader realises that they are real women, with real lives, and not just research participants. I appreciate that they have trusted me with parts of their lives that they find difficult. All of the interviews brought up different emotions in me; sometimes shock, anxiety and sadness, although I also felt a great deal of respect for my participants. They have all had to deal with a lot of difficult situations and are all still fighting to improve their lives and to get away from this label. I feel that although I have felt uncomfortable at times, and found different parts of the research difficult, I think that has helped me develop as a counselling psychologist, as it is important for us to feel uncomfortable at times to help us reflect on our practice.

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# Appendix A – Search Terms

## Key terms, combinations, and variations of:

Borderline personality disorder, BPD, Borderline,

Diagnostic systems,

Diagnostic and statistical manual of mental disorders,

Disagreeing with diagnosis,

Emotionally unstable personality disorder, EUPD,

Feminist approach,

Gender bias,

History,

International Statistical Classification of Diseases,

Interpretative phenomenological analysis, IPA,

Interviews in psychology research,

Interviews with sensitive topics,

Mental health,

Online interviews,

Pathologizing of experiences,

Post-traumatic stress disorder,

Problems,

Psychiatric,

Qualitative research,

Safety during interviews,

Stigma,

Trauma,

Treatment,

Validity in qualitative research,

Women’s experiences of,

Women's mental health,

Additional terms, combinations and variations include:

Attitudes,

Blame,

Childhood abuse,

Counselling Psychologist,

Depression,

Discrimination,

Emotions,

Emotional invalidation,

Impact,

Issues,

Language,

Positive/negative experiences,

Psychologists,

Reflexivity,

Sexual abuse

Similarities,

Social norms,

Staff,

Stress,

Team.

# Appendix B – Interview Schedule

**An interpretative phenomenological analysis of females who disagree with their diagnosis of Borderline personality disorder.**

**Interview schedule: Version 1**

**Prompts to questions in blue.**

1. Could you tell me what you remember about receiving your diagnosis of borderline personality disorder?
    - How did you receive it?
    - How old were you?
    - Were you expecting to receive a diagnosis?

2. How was that for you?

3. How did it make you feel at that time?
    - Did you agree with it?
    - Did it make any sense to you?

4. Were you given any information at the time about your diagnosis?

5. Why do you disagree with your diagnosis?

6. Has receiving the diagnosis affected your life?
    - Professional
    - Personal/Relational
    - Mental health
    - Identity

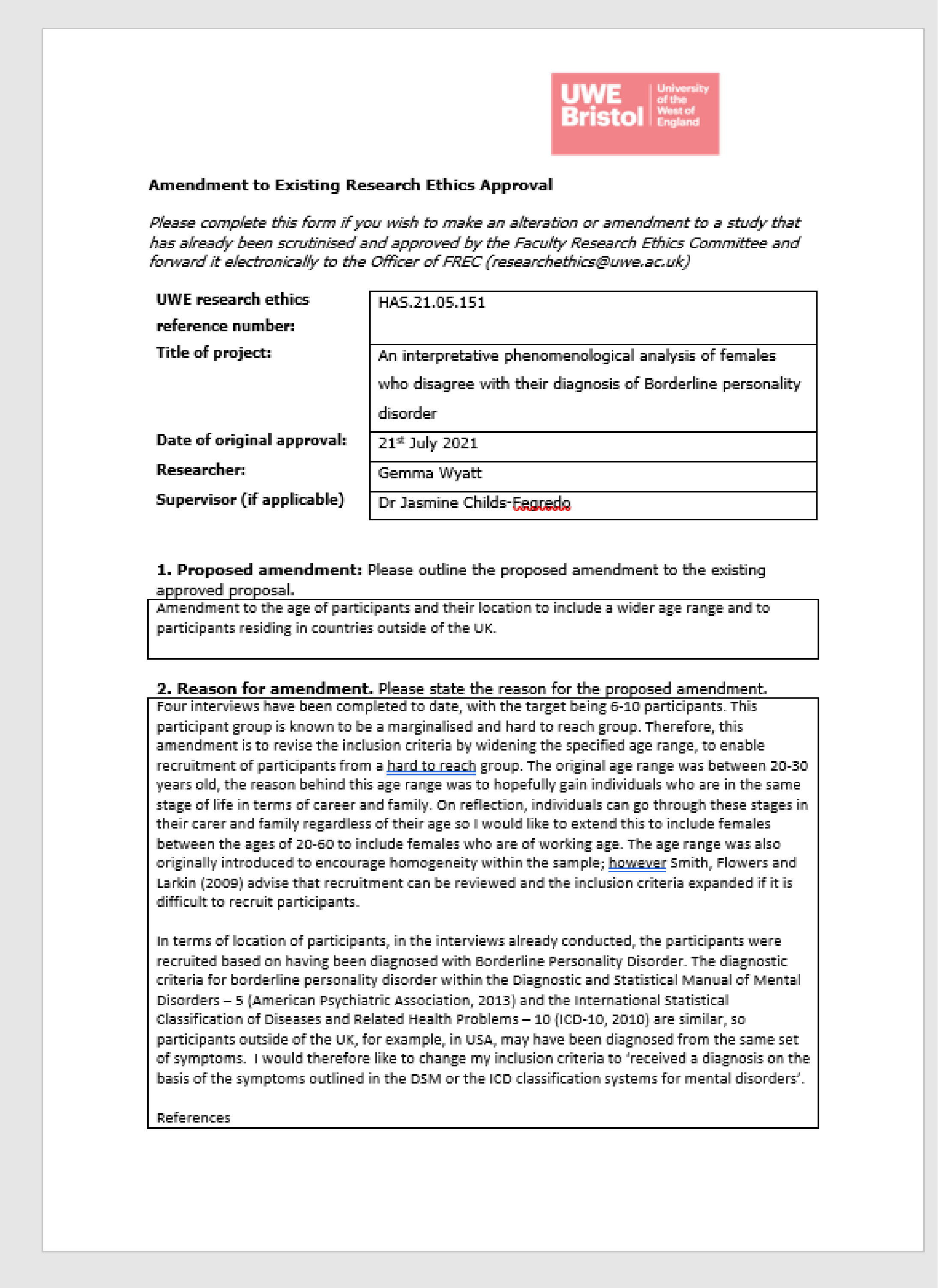
7. How do you cope with living with a diagnosis that you disagree with?
    - Does it bring up any emotions?
    - Have you challenged it?

8. Is there anything else that we haven't talked about? Anything you want to tell me about your experience of disagreeing with your diagnosis or living with your diagnosis?

# Appendix C - Advert

This appendix has been removed as it contains personal information.

# Appendix D – Ethical Amendment Application



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**Amendment to Existing Research Ethics Approval**

*Please complete this form if you wish to make an alteration or amendment to a study that has already been scrutinised and approved by the Faculty Research Ethics Committee and forward it electronically to the Officer of FREC (researchethics@uwe.ac.uk)*

| | |
|---|---|
| **UWE research ethics reference number:** | HAS.21.05.151 |
| **Title of project:** | An interpretative phenomenological analysis of females who disagree with their diagnosis of Borderline personality disorder |
| **Date of original approval:** | 21st July 2021 |
| **Researcher:** | Gemma Wyatt |
| **Supervisor (if applicable)** | Dr Jasmine Childs-Fegredo |

**1. Proposed amendment:** Please outline the proposed amendment to the existing approved proposal.

Amendment to the age of participants and their location to include a wider age range and to participants residing in countries outside of the UK.

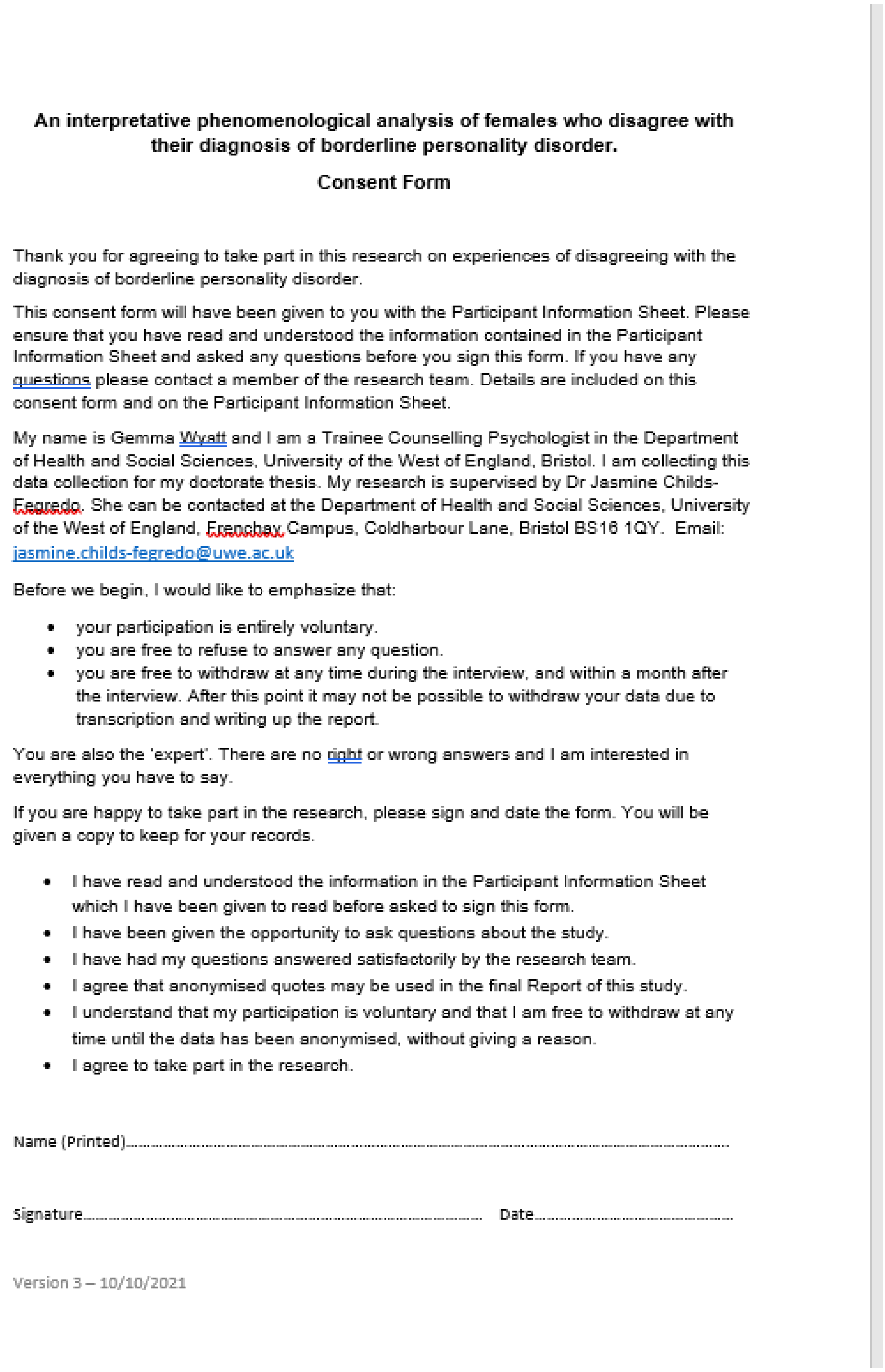
**2. Reason for amendment.** Please state the reason for the proposed amendment.

Four interviews have been completed to date, with the target being 6-10 participants. This participant group is known to be a marginalised and hard to reach group. Therefore, this amendment is to revise the inclusion criteria by widening the specified age range, to enable recruitment of participants from a hard to reach group. The original age range was between 20-30 years old, the reason behind this age range was to hopefully gain individuals who are in the same stage of life in terms of career and family. On reflection, individuals can go through these stages in their carer and family regardless of their age so I would like to extend this to include females between the ages of 20-60 to include females who are of working age. The age range was also originally introduced to encourage homogeneity within the sample; however Smith, Flowers and Larkin (2009) advise that recruitment can be reviewed and the inclusion criteria expanded if it is difficult to recruit participants.

In terms of location of participants, in the interviews already conducted, the participants were recruited based on having been diagnosed with Borderline Personality Disorder. The diagnostic criteria for borderline personality disorder within the Diagnostic and Statistical Manual of Mental Disorders – 5 (American Psychiatric Association, 2013) and the International Statistical Classification of Diseases and Related Health Problems – 10 (ICD-10, 2010) are similar, so participants outside of the UK, for example, in USA, may have been diagnosed from the same set of symptoms.  I would therefore like to change my inclusion criteria to 'received a diagnosis on the basis of the symptoms outlined in the DSM or the ICD classification systems for mental disorders'.

References

# Appendix E – Consent Form



### An interpretative phenomenological analysis of females who disagree with their diagnosis of borderline personality disorder.

### Consent Form

Thank you for agreeing to take part in this research on experiences of disagreeing with the diagnosis of borderline personality disorder.

This consent form will have been given to you with the Participant Information Sheet. Please ensure that you have read and understood the information contained in the Participant Information Sheet and asked any questions before you sign this form. If you have any questions please contact a member of the research team. Details are included on this consent form and on the Participant Information Sheet.

My name is Gemma Wyatt and I am a Trainee Counselling Psychologist in the Department of Health and Social Sciences, University of the West of England, Bristol. I am collecting this data collection for my doctorate thesis. My research is supervised by Dr Jasmine Childs-Fegredo. She can be contacted at the Department of Health and Social Sciences, University of the West of England, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY. Email: jasmine.childs-fegredo@uwe.ac.uk

Before we begin, I would like to emphasize that:

- your participation is entirely voluntary.
- you are free to refuse to answer any question.
- you are free to withdraw at any time during the interview, and within a month after the interview. After this point it may not be possible to withdraw your data due to transcription and writing up the report.

You are also the 'expert'. There are no right or wrong answers and I am interested in everything you have to say.

If you are happy to take part in the research, please sign and date the form. You will be given a copy to keep for your records.

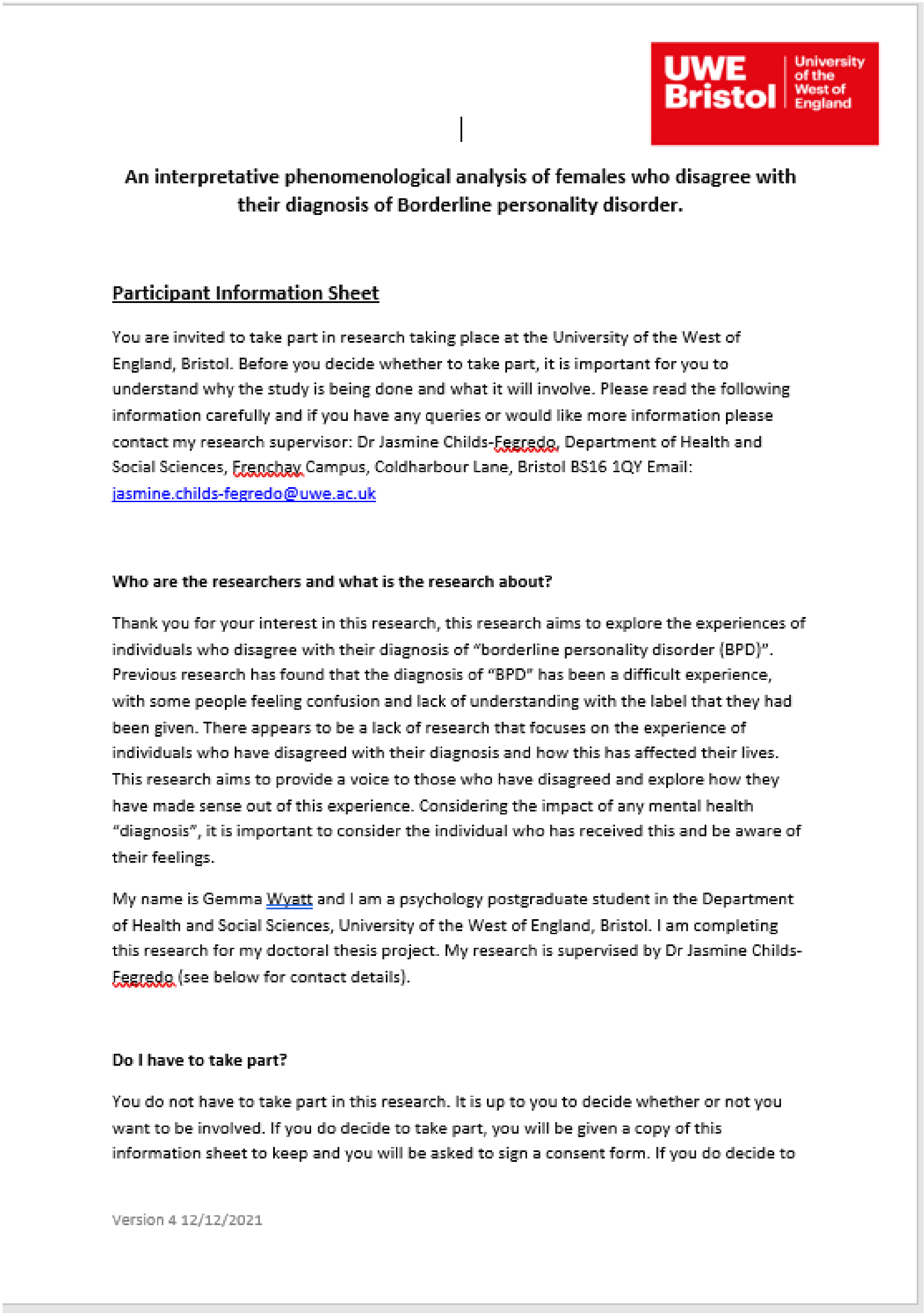
- I have read and understood the information in the Participant Information Sheet which I have been given to read before asked to sign this form.
- I have been given the opportunity to ask questions about the study.
- I have had my questions answered satisfactorily by the research team.
- I agree that anonymised quotes may be used in the final Report of this study.
- I understand that my participation is voluntary and that I am free to withdraw at any time until the data has been anonymised, without giving a reason.
- I agree to take part in the research.

Name (Printed)……………………………………………………………………………………………………

Signature……………………………………………………………………… Date……………………………………

Version 3 – 10/10/2021

# Appendix F – Participant Information Sheet



## An interpretative phenomenological analysis of females who disagree with their diagnosis of Borderline personality disorder.

### Participant Information Sheet

You are invited to take part in research taking place at the University of the West of England, Bristol. Before you decide whether to take part, it is important for you to understand why the study is being done and what it will involve. Please read the following information carefully and if you have any queries or would like more information please contact my research supervisor: Dr Jasmine Childs-Fegredo, Department of Health and Social Sciences, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY Email: jasmine.childs-fegredo@uwe.ac.uk

**Who are the researchers and what is the research about?**

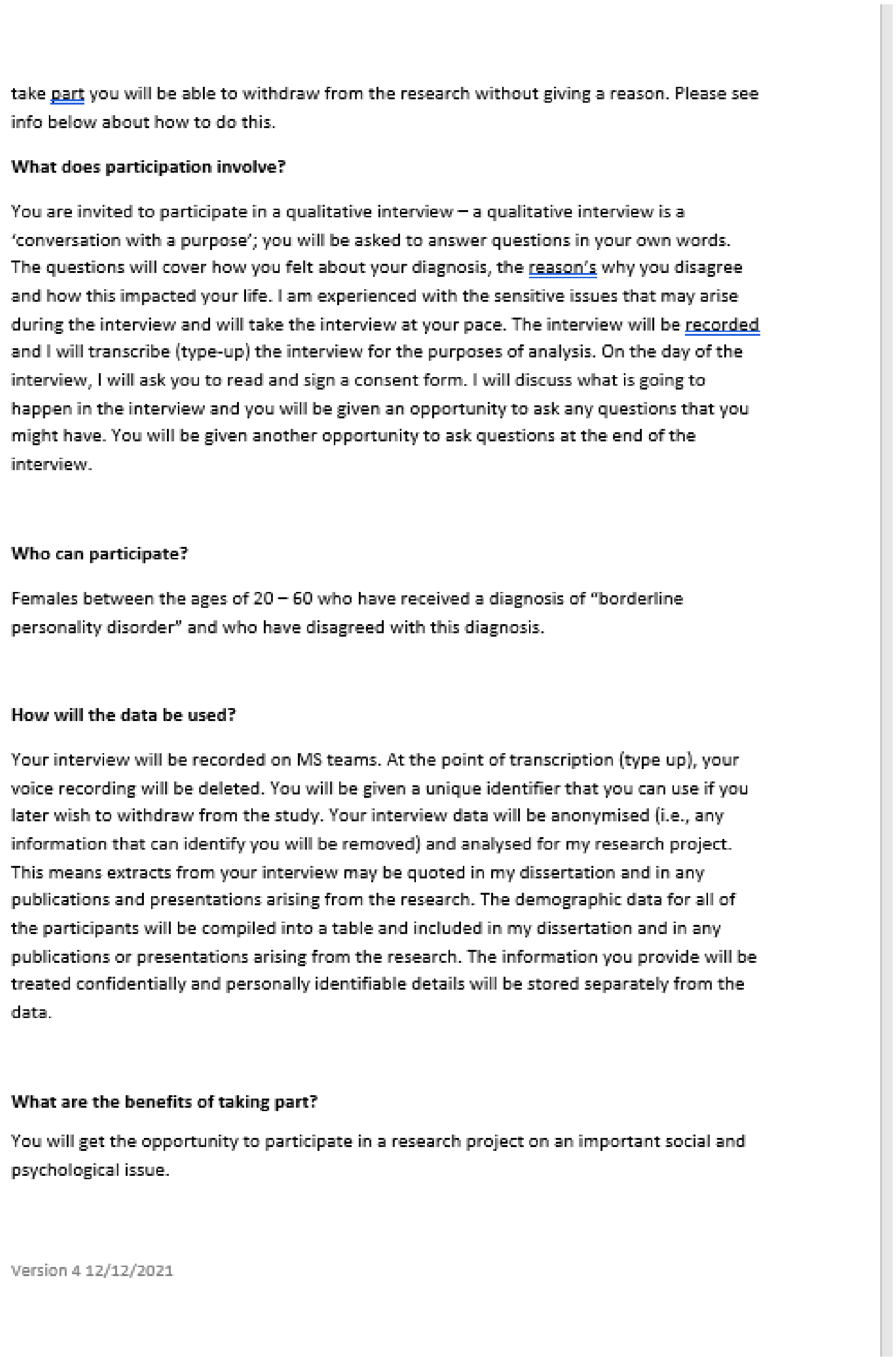
Thank you for your interest in this research, this research aims to explore the experiences of individuals who disagree with their diagnosis of "borderline personality disorder (BPD)". Previous research has found that the diagnosis of "BPD" has been a difficult experience, with some people feeling confusion and lack of understanding with the label that they had been given. There appears to be a lack of research that focuses on the experience of individuals who have disagreed with their diagnosis and how this has affected their lives. This research aims to provide a voice to those who have disagreed and explore how they have made sense out of this experience. Considering the impact of any mental health "diagnosis", it is important to consider the individual who has received this and be aware of their feelings.

My name is Gemma Wyatt and I am a psychology postgraduate student in the Department of Health and Social Sciences, University of the West of England, Bristol. I am completing this research for my doctoral thesis project. My research is supervised by Dr Jasmine Childs-Fegredo (see below for contact details).

**Do I have to take part?**

You do not have to take part in this research. It is up to you to decide whether or not you want to be involved. If you do decide to take part, you will be given a copy of this information sheet to keep and you will be asked to sign a consent form. If you do decide to

Version 4 12/12/2021



take part you will be able to withdraw from the research without giving a reason. Please see info below about how to do this.

### What does participation involve?

You are invited to participate in a qualitative interview – a qualitative interview is a 'conversation with a purpose'; you will be asked to answer questions in your own words. The questions will cover how you felt about your diagnosis, the reason's why you disagree and how this impacted your life. I am experienced with the sensitive issues that may arise during the interview and will take the interview at your pace. The interview will be recorded and I will transcribe (type-up) the interview for the purposes of analysis. On the day of the interview, I will ask you to read and sign a consent form. I will discuss what is going to happen in the interview and you will be given an opportunity to ask any questions that you might have. You will be given another opportunity to ask questions at the end of the interview.

### Who can participate?

Females between the ages of 20 – 60 who have received a diagnosis of "borderline personality disorder" and who have disagreed with this diagnosis.

### How will the data be used?

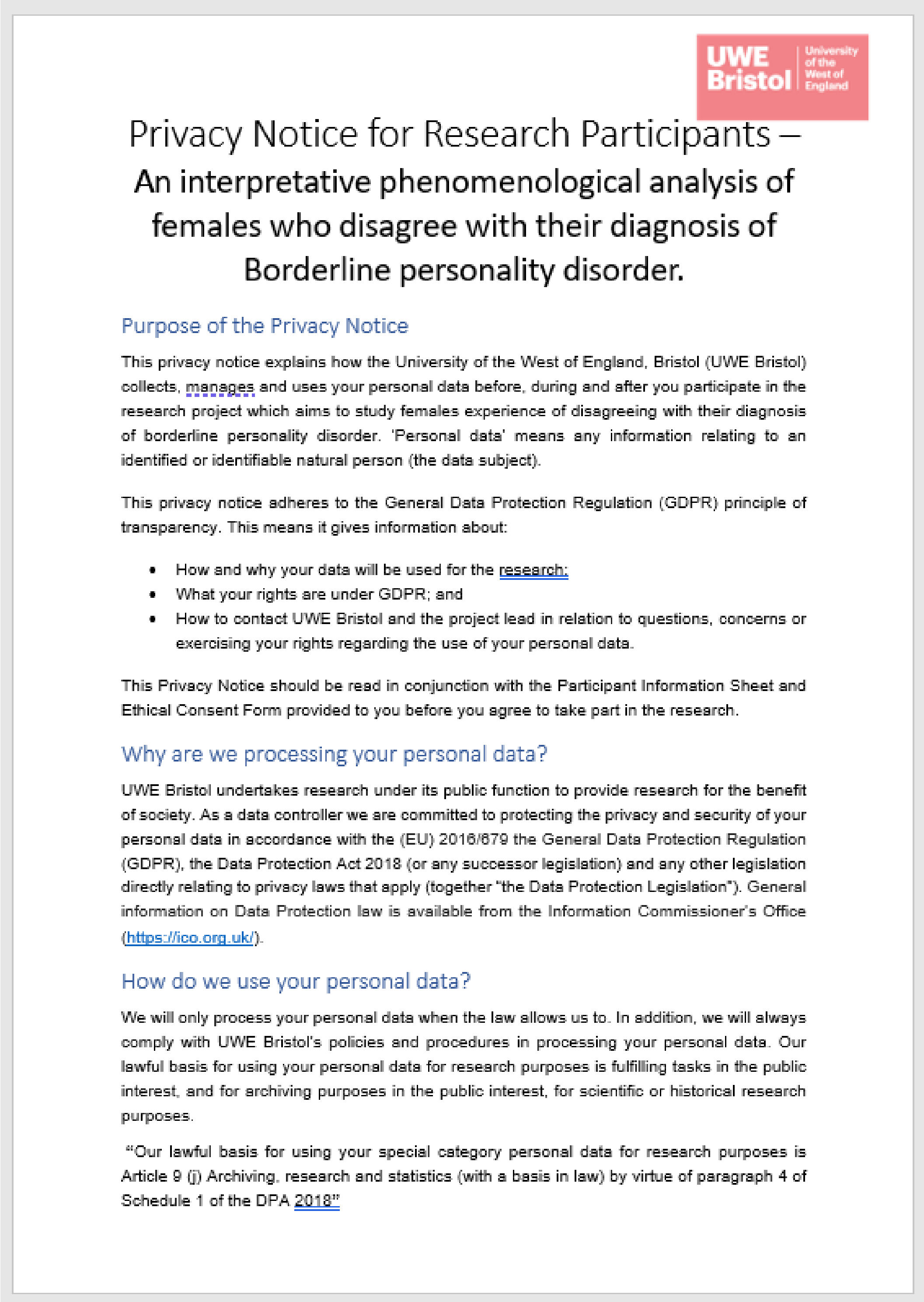
Your interview will be recorded on MS teams. At the point of transcription (type up), your voice recording will be deleted. You will be given a unique identifier that you can use if you later wish to withdraw from the study. Your interview data will be anonymised (i.e., any information that can identify you will be removed) and analysed for my research project. This means extracts from your interview may be quoted in my dissertation and in any publications and presentations arising from the research. The demographic data for all of the participants will be compiled into a table and included in my dissertation and in any publications or presentations arising from the research. The information you provide will be treated confidentially and personally identifiable details will be stored separately from the data.

### What are the benefits of taking part?

You will get the opportunity to participate in a research project on an important social and psychological issue.

Version 4 12/12/2021

# Appendix G – Privacy Notice



UWE Bristol University of the West of England

## Privacy Notice for Research Participants – An interpretative phenomenological analysis of females who disagree with their diagnosis of Borderline personality disorder.

### Purpose of the Privacy Notice

This privacy notice explains how the University of the West of England, Bristol (UWE Bristol) collects, manages and uses your personal data before, during and after you participate in the research project which aims to study females experience of disagreeing with their diagnosis of borderline personality disorder. 'Personal data' means any information relating to an identified or identifiable natural person (the data subject).

This privacy notice adheres to the General Data Protection Regulation (GDPR) principle of transparency. This means it gives information about:

- How and why your data will be used for the research;
- What your rights are under GDPR; and
- How to contact UWE Bristol and the project lead in relation to questions, concerns or exercising your rights regarding the use of your personal data.

This Privacy Notice should be read in conjunction with the Participant Information Sheet and Ethical Consent Form provided to you before you agree to take part in the research.

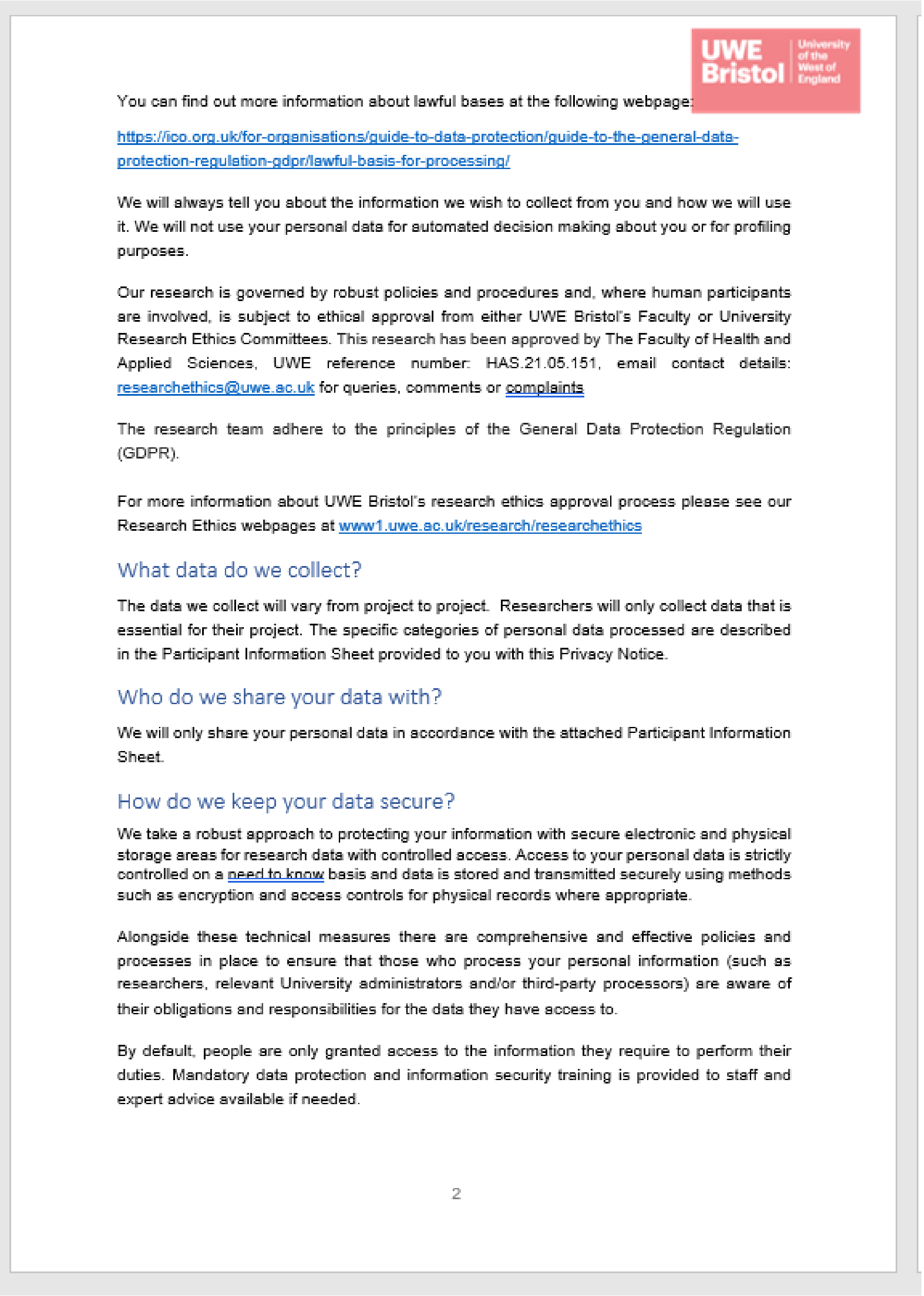
### Why are we processing your personal data?

UWE Bristol undertakes research under its public function to provide research for the benefit of society. As a data controller we are committed to protecting the privacy and security of your personal data in accordance with the (EU) 2016/679 the General Data Protection Regulation (GDPR), the Data Protection Act 2018 (or any successor legislation) and any other legislation directly relating to privacy laws that apply (together "the Data Protection Legislation"). General information on Data Protection law is available from the Information Commissioner's Office (https://ico.org.uk/).

### How do we use your personal data?

We will only process your personal data when the law allows us to. In addition, we will always comply with UWE Bristol's policies and procedures in processing your personal data. Our lawful basis for using your personal data for research purposes is fulfilling tasks in the public interest, and for archiving purposes in the public interest, for scientific or historical research purposes.

"Our lawful basis for using your special category personal data for research purposes is Article 9 (j) Archiving, research and statistics (with a basis in law) by virtue of paragraph 4 of Schedule 1 of the DPA 2018"



You can find out more information about lawful bases at the following webpage:

https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/

We will always tell you about the information we wish to collect from you and how we will use it. We will not use your personal data for automated decision making about you or for profiling purposes.

Our research is governed by robust policies and procedures and, where human participants are involved, is subject to ethical approval from either UWE Bristol's Faculty or University Research Ethics Committees. This research has been approved by The Faculty of Health and Applied Sciences, UWE reference number: HAS.21.05.151, email contact details: researchethics@uwe.ac.uk for queries, comments or complaints

The research team adhere to the principles of the General Data Protection Regulation (GDPR).

For more information about UWE Bristol's research ethics approval process please see our Research Ethics webpages at www1.uwe.ac.uk/research/researchethics

## What data do we collect?

The data we collect will vary from project to project. Researchers will only collect data that is essential for their project. The specific categories of personal data processed are described in the Participant Information Sheet provided to you with this Privacy Notice.

## Who do we share your data with?

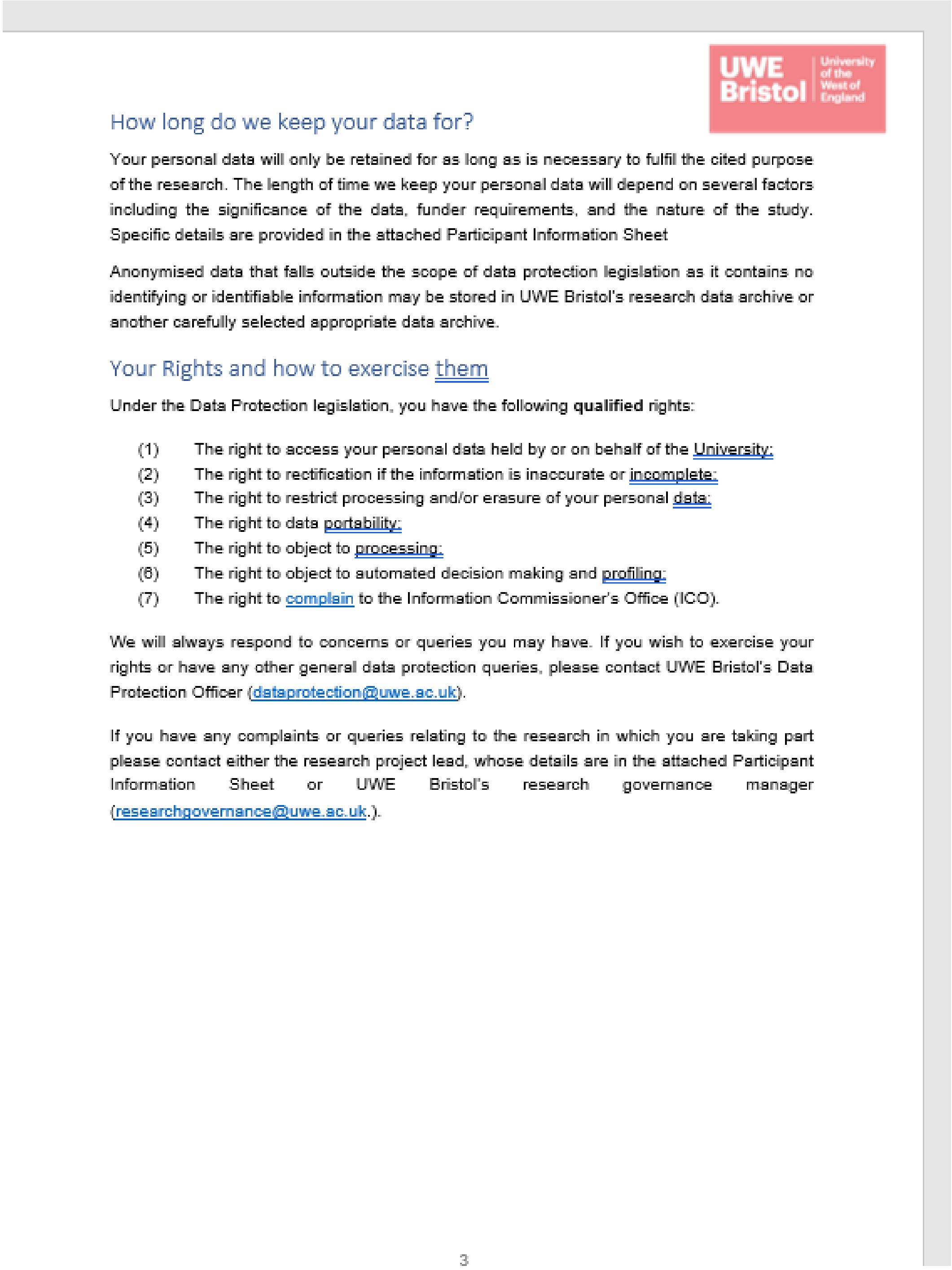
We will only share your personal data in accordance with the attached Participant Information Sheet.

## How do we keep your data secure?

We take a robust approach to protecting your information with secure electronic and physical storage areas for research data with controlled access. Access to your personal data is strictly controlled on a need to know basis and data is stored and transmitted securely using methods such as encryption and access controls for physical records where appropriate.

Alongside these technical measures there are comprehensive and effective policies and processes in place to ensure that those who process your personal information (such as researchers, relevant University administrators and/or third-party processors) are aware of their obligations and responsibilities for the data they have access to.

By default, people are only granted access to the information they require to perform their duties. Mandatory data protection and information security training is provided to staff and expert advice available if needed.



## How long do we keep your data for?

Your personal data will only be retained for as long as is necessary to fulfil the cited purpose of the research. The length of time we keep your personal data will depend on several factors including the significance of the data, funder requirements, and the nature of the study. Specific details are provided in the attached Participant Information Sheet

Anonymised data that falls outside the scope of data protection legislation as it contains no identifying or identifiable information may be stored in UWE Bristol's research data archive or another carefully selected appropriate data archive.

## Your Rights and how to exercise them

Under the Data Protection legislation, you have the following **qualified** rights:

(1) The right to access your personal data held by or on behalf of the University;
(2) The right to rectification if the information is inaccurate or incomplete;
(3) The right to restrict processing and/or erasure of your personal data;
(4) The right to data portability;
(5) The right to object to processing;
(6) The right to object to automated decision making and profiling;
(7) The right to complain to the Information Commissioner's Office (ICO).

We will always respond to concerns or queries you may have. If you wish to exercise your rights or have any other general data protection queries, please contact UWE Bristol's Data Protection Officer (dataprotection@uwe.ac.uk).

If you have any complaints or queries relating to the research in which you are taking part please contact either the research project lead, whose details are in the attached Participant Information Sheet or UWE Bristol's research governance manager (researchgovernance@uwe.ac.uk.).

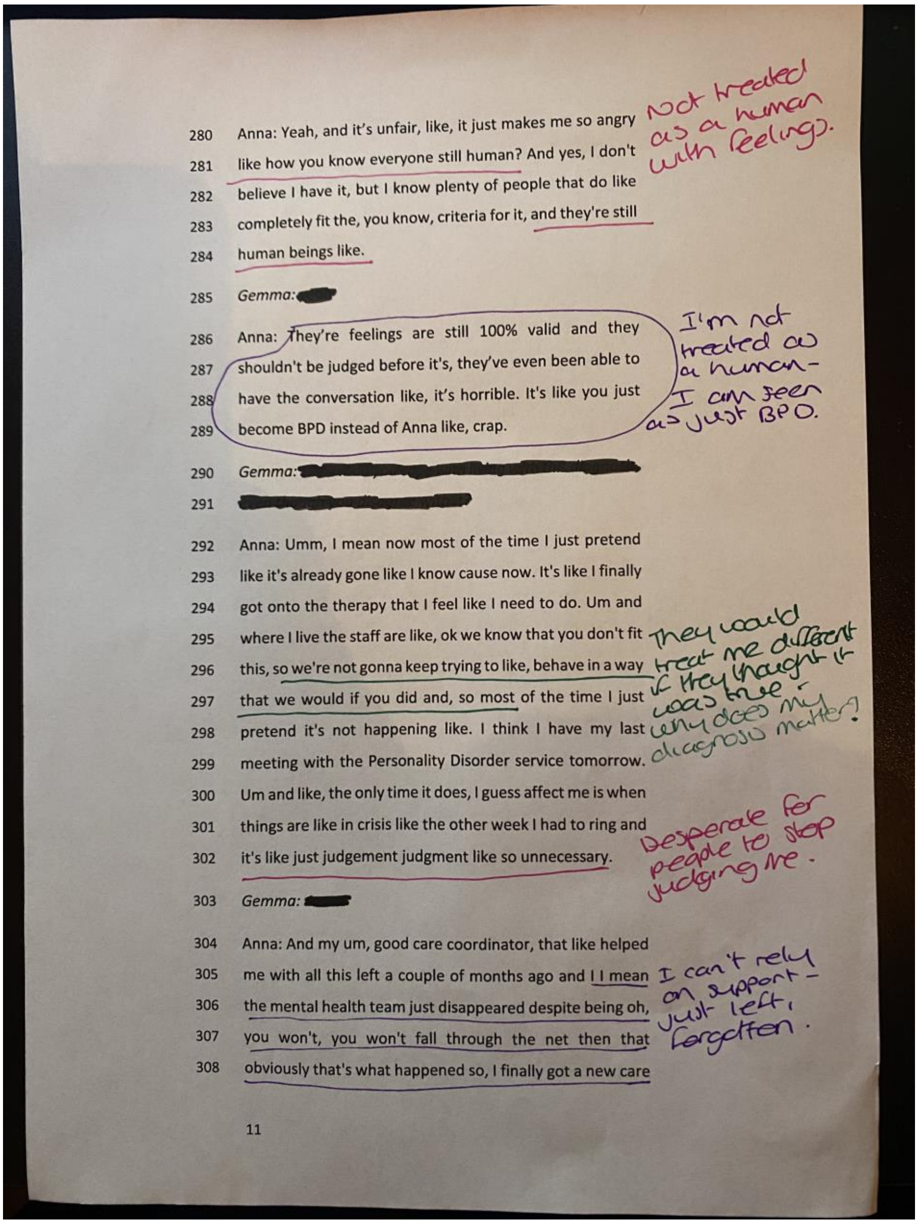
# Appendix H – First Ethical Approval

This appendix has been removed as it contains personal information.

# Appendix I – Ethical Amendment Approval

This appendix has been removed as it contains personal information.

# Appendix J – Example of Initial Noting on Transcript



Anna: Yeah, and it's unfair, like, it just makes me so angry like how you know everyone still human? And yes, I don't believe I have it, but I know plenty of people that do like completely fit the, you know, criteria for it, and they're still human beings like.

Not treated as a human with feelings.

Gemma: [redacted]

Anna: They're feelings are still 100% valid and they shouldn't be judged before it's, they've even been able to have the conversation like, it's horrible. It's like you just become BPD instead of Anna like, crap.

I'm not treated as a human – I am seen as just BPD.

Gemma: [redacted]

Anna: Umm, I mean now most of the time I just pretend like it's already gone like I know cause now. It's like I finally got onto the therapy that I feel like I need to do. Um and where I live the staff are like, ok we know that you don't fit this, so we're not gonna keep trying to like, behave in a way that we would if you did and, so most of the time I just pretend it's not happening like. I think I have my last meeting with the Personality Disorder service tomorrow. Um and like, the only time it does, I guess affect me is when things are like in crisis like the other week I had to ring and it's like just judgement judgment like so unnecessary.

They would treat me different if they thought it was true. Why does my diagnosis matter?

Desperate for people to stop judging me.

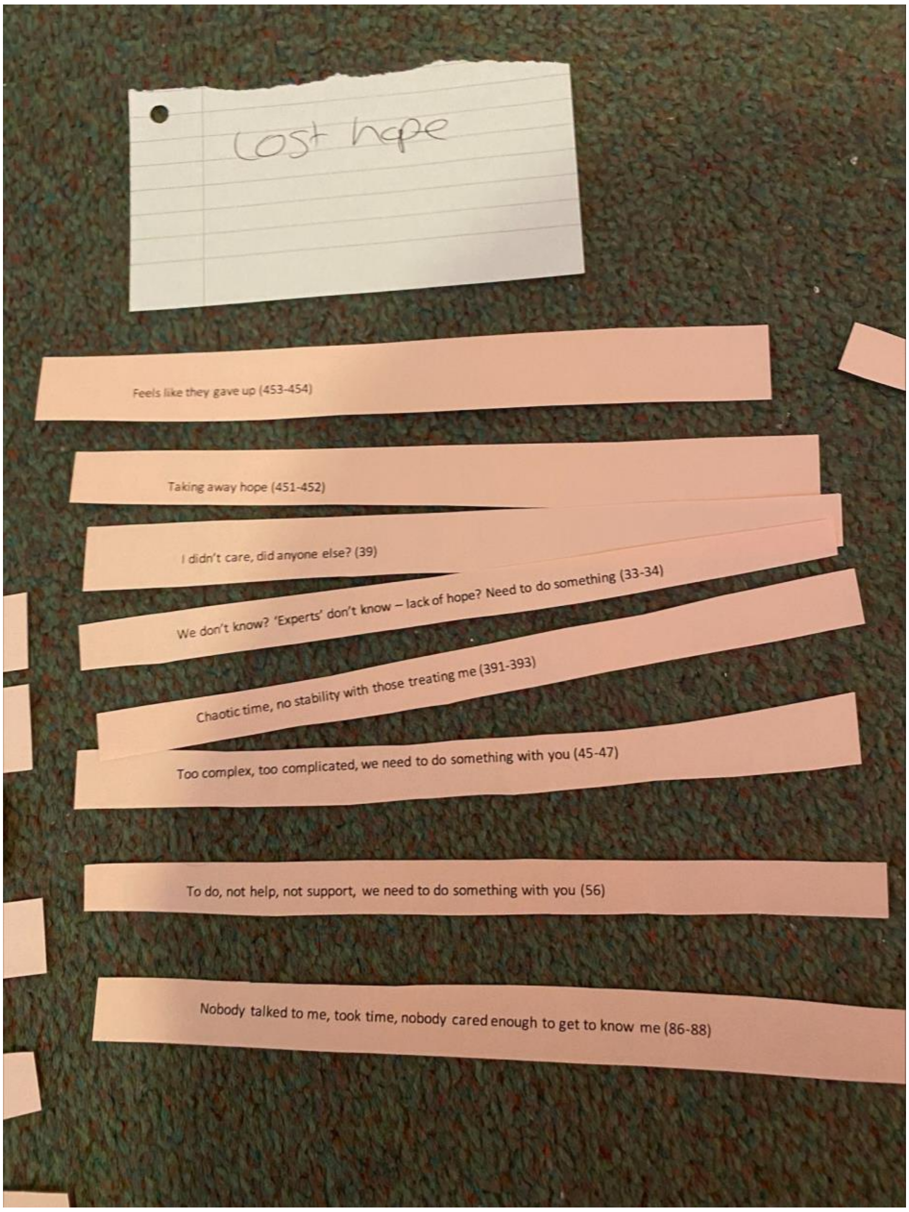
Gemma: [redacted]

Anna: And my um, good care coordinator, that like helped me with all this left a couple of months ago and I I mean the mental health team just disappeared despite being oh, you won't, you won't fall through the net then that obviously that's what happened so, I finally got a new care

I can't rely on support – just left, forgotten.

11

# Appendix K – Image Example of Personal Experiential Statements



Lost hope

Feels like they gave up (453-454)

Taking away hope (451-452)

I didn't care, did anyone else? (39)

We don't know? 'Experts' don't know – lack of hope? Need to do something (33-34)

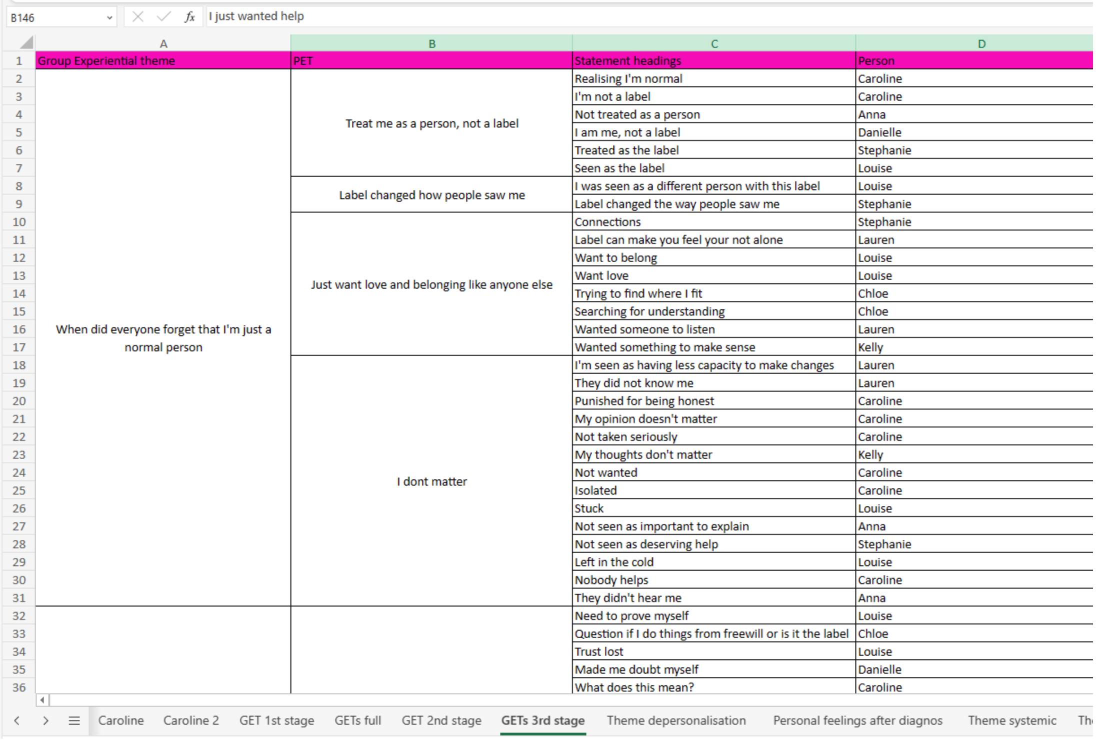
Chaotic time, no stability with those treating me (391-393)

Too complex, too complicated, we need to do something with you (45-47)

To do, not help, not support, we need to do something with you (56)

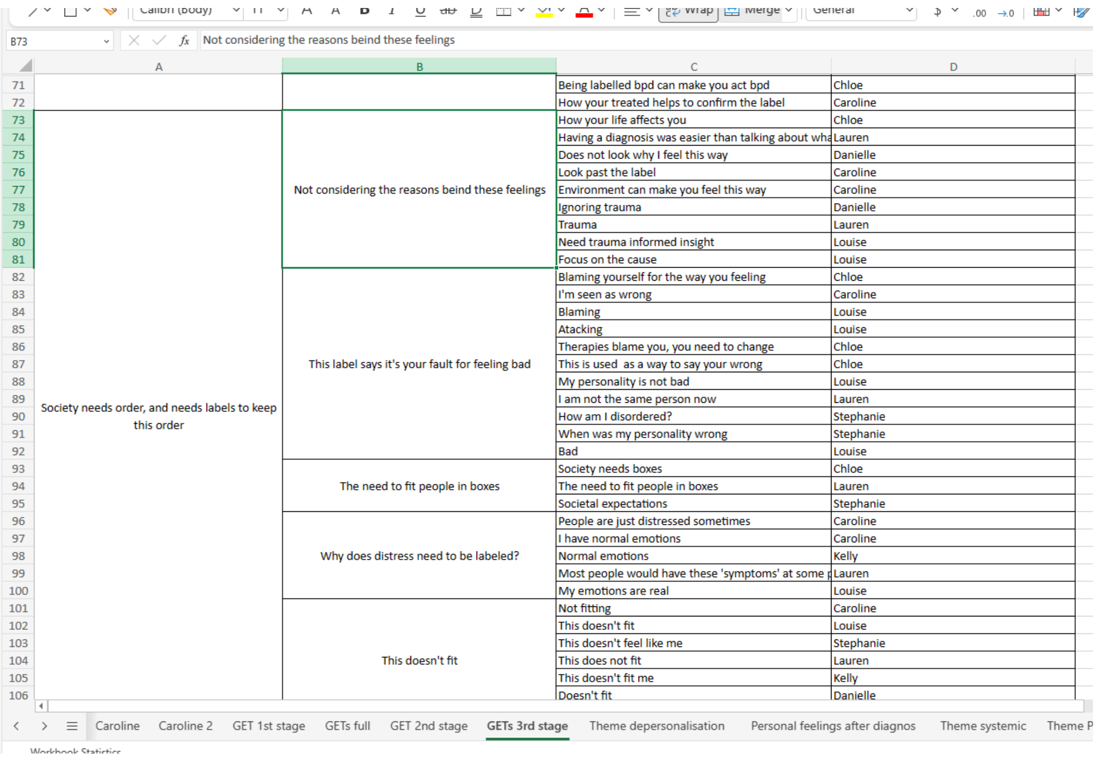
Nobody talked to me, took time, nobody cared enough to get to know me (86-88)

# Appendix L – Screenshot of Tables Used to Organise Themes.



I just wanted help

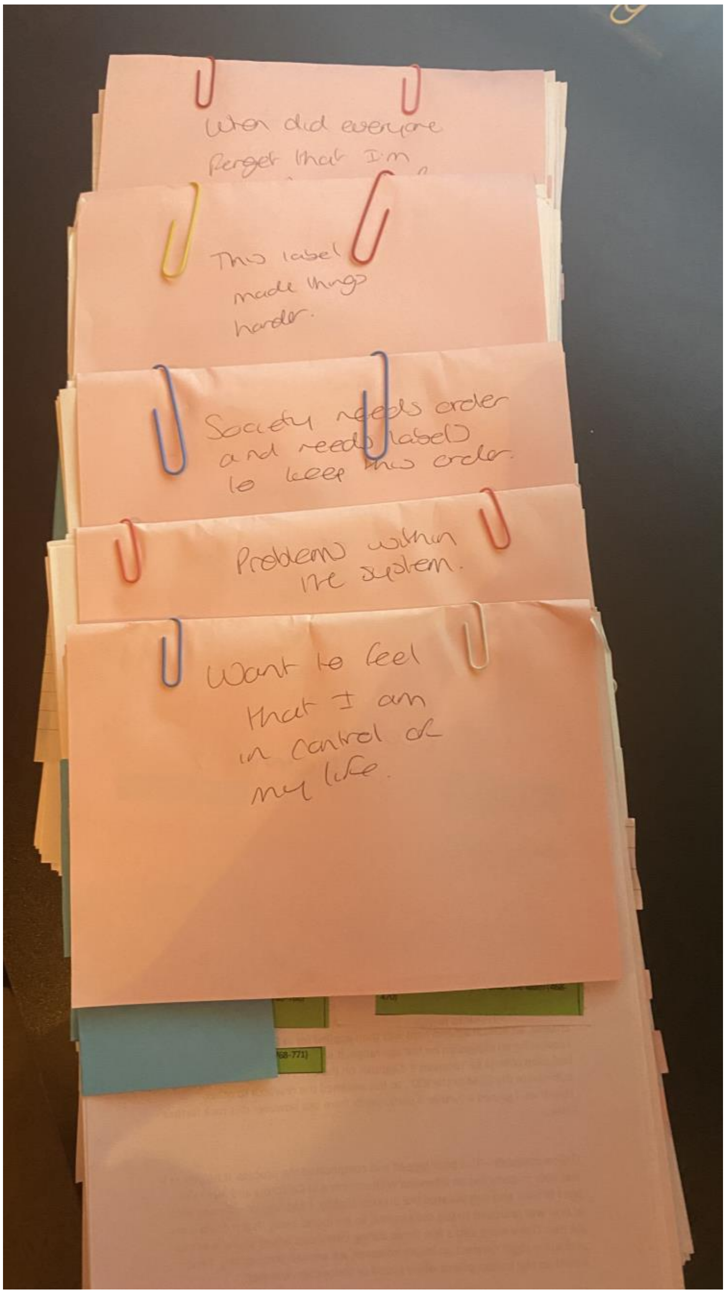
| | A | B | C | D |
|---|---|---|---|---|
| 1 | Group Experiential theme | PET | Statement headings | Person |
| 2 | When did everyone forget that I'm just a normal person | Treat me as a person, not a label | Realising I'm normal | Caroline |
| 3 | | | I'm not a label | Caroline |
| 4 | | | Not treated as a person | Anna |
| 5 | | | I am me, not a label | Danielle |
| 6 | | | Treated as the label | Stephanie |
| 7 | | | Seen as the label | Louise |
| 8 | | Label changed how people saw me | I was seen as a different person with this label | Louise |
| 9 | | | Label changed the way people saw me | Stephanie |
| 10 | | Just want love and belonging like anyone else | Connections | Stephanie |
| 11 | | | Label can make you feel your not alone | Lauren |
| 12 | | | Want to belong | Louise |
| 13 | | | Want love | Louise |
| 14 | | | Trying to find where I fit | Chloe |
| 15 | | | Searching for understanding | Chloe |
| 16 | | | Wanted someone to listen | Lauren |
| 17 | | | Wanted something to make sense | Kelly |
| 18 | | I dont matter | I'm seen as having less capacity to make changes | Lauren |
| 19 | | | They did not know me | Lauren |
| 20 | | | Punished for being honest | Caroline |
| 21 | | | My opinion doesn't matter | Caroline |
| 22 | | | Not taken seriously | Caroline |
| 23 | | | My thoughts don't matter | Kelly |
| 24 | | | Not wanted | Caroline |
| 25 | | | Isolated | Caroline |
| 26 | | | Stuck | Louise |
| 27 | | | Not seen as important to explain | Anna |
| 28 | | | Not seen as deserving help | Stephanie |
| 29 | | | Left in the cold | Louise |
| 30 | | | Nobody helps | Caroline |
| 31 | | | They didn't hear me | Anna |
| 32 | | | Need to prove myself | Louise |
| 33 | | | Question if I do things from freewill or is it the label | Chloe |
| 34 | | | Trust lost | Louise |
| 35 | | | Made me doubt myself | Danielle |
| 36 | | | What does this mean? | Caroline |



Not considering the reasons beind these feelings

| | A | B | C | D |
|---|---|---|---|---|
| 71 | | | Being labelled bpd can make you act bpd | Chloe |
| 72 | | | How your treated helps to confirm the label | Caroline |
| 73 | Society needs order, and needs labels to keep this order | Not considering the reasons beind these feelings | How your life affects you | Chloe |
| 74 | | | Having a diagnosis was easier than talking about wha | Lauren |
| 75 | | | Does not look why I feel this way | Danielle |
| 76 | | | Look past the label | Caroline |
| 77 | | | Environment can make you feel this way | Caroline |
| 78 | | | Ignoring trauma | Danielle |
| 79 | | | Trauma | Lauren |
| 80 | | | Need trauma informed insight | Louise |
| 81 | | | Focus on the cause | Louise |
| 82 | | This label says it's your fault for feeling bad | Blaming yourself for the way you feeling | Chloe |
| 83 | | | I'm seen as wrong | Caroline |
| 84 | | | Blaming | Louise |
| 85 | | | Atacking | Louise |
| 86 | | | Therapies blame you, you need to change | Chloe |
| 87 | | | This is used as a way to say your wrong | Chloe |
| 88 | | | My personality is not bad | Louise |
| 89 | | | I am not the same person now | Lauren |
| 90 | | | How am I disordered? | Stephanie |
| 91 | | | When was my personality wrong | Stephanie |
| 92 | | | Bad | Louise |
| 93 | | The need to fit people in boxes | Society needs boxes | Chloe |
| 94 | | | The need to fit people in boxes | Lauren |
| 95 | | | Societal expectations | Stephanie |
| 96 | | Why does distress need to be labeled? | People are just distressed sometimes | Caroline |
| 97 | | | I have normal emotions | Caroline |
| 98 | | | Normal emotions | Kelly |
| 99 | | | Most people would have these 'symptoms' at some | Lauren |
| 100 | | | My emotions are real | Louise |
| 101 | | This doesn't fit | Not fitting | Caroline |
| 102 | | | This doesn't fit | Louise |
| 103 | | | This doesn't feel like me | Stephanie |
| 104 | | | This does not fit | Lauren |
| 105 | | | This doesn't fit me | Kelly |
| 106 | | | Doesn't fit | Danielle |

# Appendix M – Image of Final Group Experiential Themes



# Appendix N – Anna Word Cloud

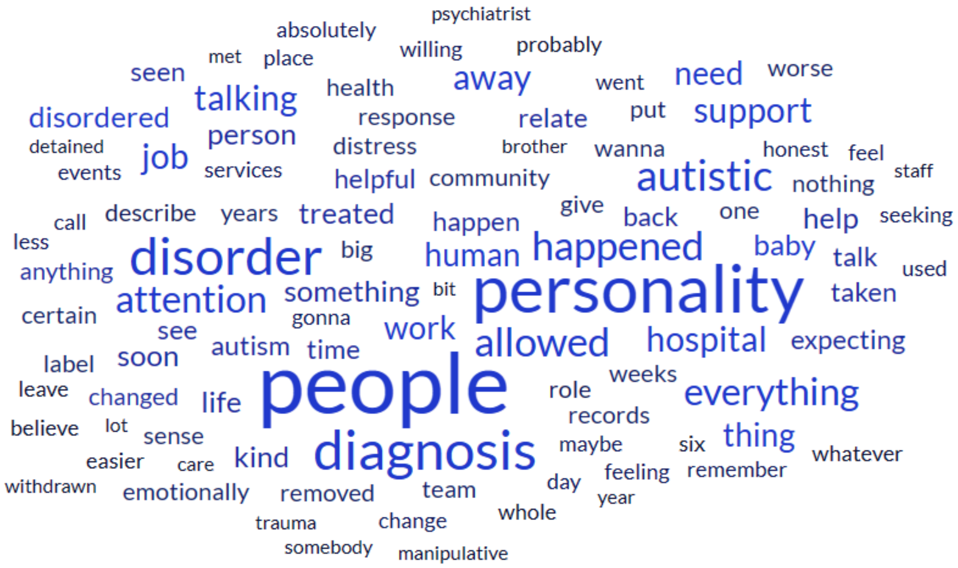
# Appendix O – Danielle Word Cloud

# Appendix P – Kelly Word Cloud

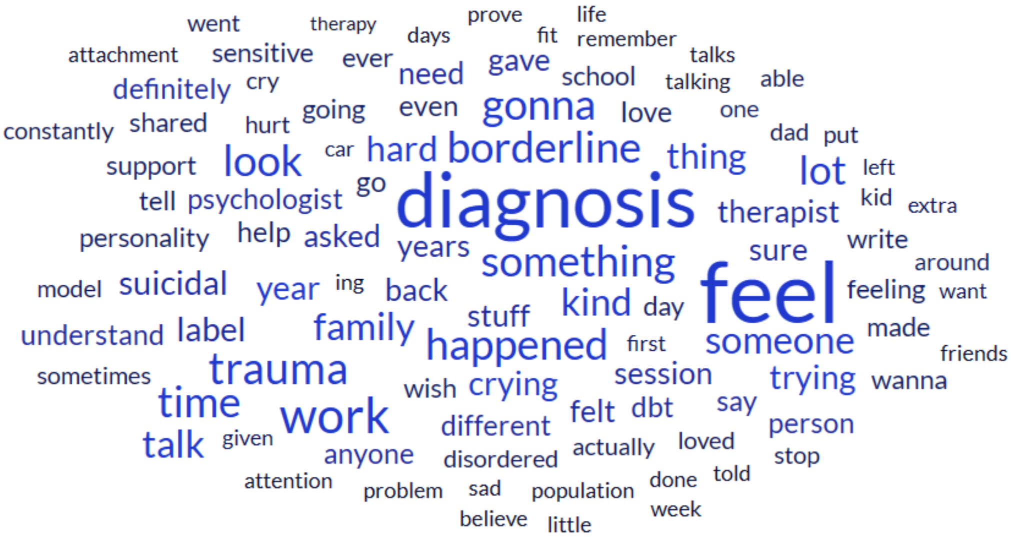
# Appendix Q – Chloe Word Cloud

# Appendix R – Lauren Word Cloud

# Appendix S – Stephanie Word Cloud



# Appendix T – Louise Word Cloud



# Appendix U – Caroline Word Cloud

# Appendix V - Journal Article

## “I don’t think that really any of the symptoms of it are my experience”:

## An Interpretative Phenomenological Analysis of women who disagree with their diagnosis of borderline personality disorder.

**Gemma Wyatt**

## Abstract

### Background

Borderline personality disorder (BPD) is a diagnosis given to more women than men. People who have received this diagnosis have reported feeling the diagnosis is used when they don’t fully meet criteria for other diagnoses, have experienced stigma and have described feeling excluded from services.

### Aims:

This research aims to attempt to explore experiences of women who have been diagnosed with BPD and disagreed with their diagnosis. The research involved considering how they experienced receiving a diagnosis that they disagreed with, the meaning that they ascribed to that experience and how they perceived the impact that this had on their mental health and well-being.

### Methods

Semi-structured interviews were conducted via Microsoft Teams with 8 women. These were analysed using Interpretative Phenomenological Analysis (IPA).

### Results

Five group experiential themes were developed: When did everyone forget that I’m just a normal person? This label made things harder; Society needs order and needs labels to keep this order; Problems within the system; Wanting to feel that I am in control of my life.

### Conclusions

Themes highlighted issues after receiving the diagnosis, participants described feeling unable to trust themselves and experiencing judgements. Findings supported previous research regarding stigma and negative interactions with professionals. Some findings discussed misdiagnosis, involving trauma-related diagnoses, and autism. These findings are discussed in terms of related literature, implications for practice, and recommended future research.

Keywords: Borderline Personality Disorder, Disagreeing, Diagnosis, BPD, EUPD, IPA

## Main text introduction

Borderline personality disorder (BPD) has been called “the twenty-first-century version of the scarlet letter” (Gunn & Potter, 2015, p. 3), a diagnosis that is mainly given to women (American Psychiatric Association [APA], 2013), with an extensive history going back to 1938 (Stern, 1938). The diagnosis has been defined as “a pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity, beginning by early adulthood and present in a variety of contexts” (APA, 2022). The diagnosis of personality disorder has been criticised as although there is a general agreement that it can be caused by childhood events there is no consensus or specificity in the aetiology Pilgrim (2001). It has been criticised over time for its reliability and validity, it has also been questioned whether the diagnosis captures the experiences of individuals who have been given this diagnosis (National Collaborating Centre for Mental Health [NCCMH], 2009). Furthermore, it has been suggested that due to the range of criteria within the diagnosis, there could be a possible 256 different variations of BPD, so a group of individuals with this diagnosis may have no common symptoms or experiences (Critchfield et al., 2007). Adding to this issue, BPD often has comorbidity with other diagnoses, insinuating that there could be further variations in the experiences and symptoms with this diagnosis (Critchfield et al, 2007).

Since the addition of BPD within the DSM-III (APA, 1980), all DSM editions have indicated that BPD is present more in females than males (Sansone & Sansone, 2011). The DSM-5 (APA, 2013) stated that BPD is mainly diagnosed in females, with approximately 75% of diagnoses belonging to females (APA, 2013). The most recent edition, DSM-5-TR (APA, 2022) continues to show awareness that it is more common in women. The issue of gender bias was first proposed by Kaplan (1983) who claimed the diagnostic team involved with DSM-III had made assumptions about what female behaviour would seem natural, noting a potential bias within BPD. Skodol & Bender (2003) also looked at biased diagnostic criteria referring to the possibility that behaviours not consistent with stereotypical gender roles could be pathologized. It has been posited that the diagnosis of BPD reduces ability to focus on issues such as cultural, gender and socio-economic conditions that women consistently endure, this has been shown within links between abuse and a BPD diagnosis (Buckland, 2019). It has also been suggested that symptoms of BPD could be considered survival techniques that were once needed in abusive or invalidating environments (Lester, 2013).

This diagnosis is known for having stigmas attached, in 2003, in a report published by the National Health Service (NHS) it was revealed that clinicians found the nature of personality disorder difficult and were reluctant to work with people with the diagnosis. Individuals described their diagnosis caused them to be “the patients psychiatrists dislike”, and were called “timewasters”, “manipulative” and “attention-seeking” (NIMHE, 2003, p. 20). It has been suggested individuals with this diagnosis are likely to be in a no-win situation, being condemned whether they do, or do not, seek help when feeling distressed (Ring & Lawn, 2019). The assumption is that mental health professionals will still consider them to be either “attention seeking” or “manipulative” (Ring & Lawn, 2019, p. 16).

Previous research has highlighted the issue of some feeling they were given the diagnosis as professionals involved couldn’t “fit” the symptoms into “other categories” (Horn et al.,2007, p. 262). The term “dustbin label” was used to explain the feeling of an urgency to fit into some category, BPD provided an “answer” to fit someone “in the box” (Horn et al.,2007, p. 262). The same study reported that participants were informed BPD was “untreatable” and described how this information was alike “the killing of hope” (Horn et al., 2007, p. 262). There are some reports of people who have found the diagnosis to be helpful, one person felt “the diagnosis had played an important part in her treatment as it gave her something to recover from” (Morris et al., 2014, p. 253). Other people have described the importance of relationships within services, feeling that those who had actually listened and “treated them like a person” helped to increase their self-esteem and gave them hope (Morris et al., 2014, p. 253). A later study found that some people felt a sense of relief when they were given the diagnosis, however others felt this was a way to say that their personalities were bad (Gardner et al., 2019).

A number of studies have reported significant correlations between trauma and receiving a diagnosis of BPD (Goldman et al., 1992; Helgeland & Torgersen, 2004; Herman et al., 1989; Ogata et al., 1990; Zanarini et al., 2002; Temes et al., 2017). Research by Brakemeier et al., (2018) found 90% of their participants who had been diagnosed with BPD had experienced some form of childhood maltreatment. One possible effect of childhood abuse could involve difficulties with attachment, individuals may seek intimacy or fear abandonment, this could result in impulsivity or unstable relationships, leading to feelings of emptiness (Belford et al., 2012). When considering the high level of correlation between individuals who have suffered trauma and been diagnosed with BPD, the presenting symptoms could be seen as normal responses. Supporting this, Ball & Links (2009) recommended further implications for treatment such as future research in trauma-related therapies for individuals diagnosed with BPD.

There are perspectives challenging the medical model, since 1977 when Engel (1977) noted the medical model did not acknowledge the social, psychological, and behavioural factors. These approaches consider that there are normal human reactions, instead of diagnoses of mental health (Davies, 2013) and acknowledge relational conflicts, injustices, and abuses (Mad in the UK, 2020). They involve hermeneutic approaches, making meaning out of the experiences, and social constructivism, where behaviour or feelings go against what would be considered the social norm (Middleton & Moncrieff, 2019; Thompson, 2019). There is also movement within some circles that aim to move away from the traditional use of diagnoses (Johnstone & Boyle, 2018). More recently, the World Health Organisation (WHO) and the United Nations

(UN), published a report calling for a “significant shift from biomedical approaches towards a support paradigm that promotes personhood, autonomy, and community inclusion” (WHO & UN, p. xvi, 2023).

Although there has been some research into the area of disagreeing with some mental health diagnoses, a search of available databases failed to find research focusing on the experience of disagreeing with the BPD/EUPD diagnosis. Considering the noted research into the stigma and the effect that this diagnosis can have on a person's life, the researcher felt that this was an important area to focus on. Counselling psychologists are interested in understanding the meaning behind individual experiences, empowering individuals, and alleviating distress (BPS, 2023), so this study aims to increase understanding to allow for a more authentic therapeutic process. People who have tried to disagree with their diagnosis have been seen as ‘difficult’ (Horn et al., 2007) so often would be unable to express why they disagree and have their experiences ignored. It was felt that understanding the reasons why people disagree with their diagnosis and acknowledging the effect that this has had on their lives needed to be considered. As a trainee counselling psychologist working within these services, this will hopefully provide deeper understanding of the impact of this diagnosis and create further awareness. This research made an attempt to explore these experiences.

## Methodology

### IPA

Interpretative phenomenological analysis (IPA) was the chosen methodology as it focuses on the meaning individuals make of their experiences. The assumption is that individuals are constantly trying to make sense out of their experiences (Smith et al., 2009). IPA explores a person's involvement or understanding of a particular event or phenomenon and is informed by three main concepts: phenomenology; hermeneutics and idiography (Smith et al., 2022). Phenomenology refers to how people make sense of and relate to their experience (Langdridge, 2007). Research using a phenomenological method involves the researcher having curiosity and remaining open to new understanding, to go past what they already know and 'bracket' their own feelings (Finlay, 2012). Hermeneutics can be understood as the theory of interpretation, the hermeneutic circle is concerned with the relationship between the part and the whole; to understand the whole, you have to look at the parts; however, to understand the parts, you need to look at the whole (Smith et al. 2022). The idiography within this method involves the commitment to the sense of detail (Smith et al, 2009), the intention is to value the account of each participant instead of prioritising the similarities (Pietkiewicz & Smith, 2014). In IPA, each case is analysed in detail before comparing patterns (Miller et al., 2018).

## Participants

Participants were recruited from an online group via an advert, they were provided with an explanation of the study, the participant information sheet, consent form and the privacy policy. When participants agreed to take part, consent forms were obtained, and a date was arranged for the interviews. 10 individuals sent emails and 2 individuals did not respond after receiving the participant information sheet. A final total of 8 participants were recruited. Participants were all women, aged between 21 to 44, 6 participants were from the UK, 1 from USA and 1 from Australia.

## Procedures

Ethical approval was gained from the University of the West of England, Bristol (UWE). Due to the COVID-19 restrictions at the time, these interviews were conducted via the use of Microsoft Teams. Consent was further obtained during the interviews and the interviews were recorded using Microsoft Teams. The interviews lasted between 20 minutes to 1 hour and 16 minutes. Transcription was performed verbatim. Pseudonyms have been used for all participants, except one participant who requested to keep her real name. All transcripts and recordings of the interviews were stored as per UWE guidance (UWE, 2021).

## Analysis

The recommended sample size for IPA is 4-10 participants to gain rich data (Braun & Clarke, 2013). The analysis is 'bottom up', involving generating codes, looking for patterns, experiential statements, and group experiential statements (Smith et al., 2022). The analysis begins with the first 'case', immersing oneself in the material. This was carried out by watching recordings of the interviews, taking notes of any thoughts and feelings that came up, then listening to the recordings without the visual aspect, then reading and re-reading the transcripts. Exploratory notes were made, including descriptive, linguistic, and conceptual comments before constructing the experiential statements. The next step involved searching for connections across the experiential statements. This step also involved constant referral back to the transcription and the recordings.

The personal experiential themes were then named and organised into a table. Some of the personal experiential themes resulted in sub-themes. Once a case was completed, the next case would then be analysed. The final step involves working with the personal experiential themes to develop group experiential themes.

## Results

There were 5 main group experiential themes generated, all main themes have sub-themes, as detailed in the Table 1. below:

Table 1.

| **Group Experiential Themes** | **Sub-Themes** |
|---|---|
| **When did everyone forget that I'm just a normal person?** | Treat me as a person, not a label.<br>Label changed how people saw me.<br>Just want love and belonging like everyone else.<br>I don't matter. |
| **This label made things harder.** | Doubt and confusion.<br>This just made things worse.<br>Do not want to be judged.<br>Lost hope.<br>This label defines your emotions and behaviour. |
| **Society needs order and needs labels to keep this order.** | Not considering the reasons behind these feelings.<br>This label says it's your fault for feeling bad.<br>The need to fit people in boxes.<br>Why does distress need to be labelled? |

| | |
|---|---|
| | This doesn't fit. |
| **Problems within the system.** | The system and professionals can hurt you.<br>Labels help the services, not the person.<br>This label feels like punishment.<br>Is this a real diagnosis?<br>Misdiagnosis and treated differently. |
| **Wanting to feel that I am in control of my life.** | I just wanted help.<br>There was a name for how I felt.<br>There is a lot of dark power in this label.<br>I'm taking back control. |

### When did everyone forget that I'm just a normal person?

Within this theme was the feeling that this diagnosis seemed to change how the participants were viewed and treated. The participants appeared to feel the 'human' part of them was forgotten about, and they were treated more as the label than an actual person. Caroline explained *"now I wouldn't even say I'm a person with BPD, I would say I'm a person who has been labelled with BPD"* [Caroline line 691-693]. Anna talked about how this makes her feel, *"it just makes me so angry, like how, you know everyone's still human"* [Anna line number 280-281] and *"it's like you just become BPD instead of Anna, crap"* [Anna line number 288-289]. Stephanie agreed, *"I think you know, when you have this diagnosis you, you're all you're seen as is this diagnosis"* [Stephanie line 234-236].

Other participants echoed the feeling this label changed the way people saw them and the effect this had on them, Louise spoke about how difficult this was *"the* *last three years has been, it was really traumatic, really like. And I don't understand why I was treated the way that I was"* [Louise line 158-160]. Stephanie explained how she was treated differently *"So, before people were like, staff was like talking to me"* [Stephanie line 112-113], *"And as soon as I got the diagnosis, they put into place, you know, this sort of PD protocol, which meant that, you know, support was withdrawn"* [Stephanie line 116-119].

### <u>This label made things harder.</u>

The feeling that this diagnosis made things harder for the participants involved causing a lot of doubt and confusion, Chloe talked about doubting her own thoughts,

> *"I would think like, am I being nice because I'm nice, or am I being nice because I'm manipulative? I started believing that, if I did something that was nice or kind, or every time I said, you know, you've got a nice dress on, I thought I was doing it to be manipulative"* [Chloe line 594-599].

Danielle talked about trying not to feel her emotions, for example, telling herself *"your overreacting, that's just a BPD thing"* [Danielle line 218], and wondering *"am I nice and caring, or is that part of that?"* [Danielle line 286]. Caroline talked about the confusion of what this meant, *"like what the hell is a disordered personality, like you kinda go, well, if this one's disordered, what's the definition of an ordered personality?"* [Caroline line 733-735]. Kelly felt it wasn't good to be told *"basically your personality is flawed and broken"* [Kelly line 236-237]. Chloe felt this took away her feelings of hope, *"If you Google borderline personality disorder and I'll tell you the most insane thing to do with that, and the first thing it would tell you, that is that it's incurable. And so, I felt hopeless"* [Chloe line 195-198].

### Society needs order and needs labels to keep this order.

The participants talked about how this diagnosis seems to help society more than it helps the person, as it ignores the reasons why a person may be experiencing these feelings. Louise talked about how this ignores all the wider issues in society *"like there's so many issues of poverty and racism and so many things' people go through and like and yet we blame the person for having a negative response to really shitty experiences"* [Louise line 637-641]. Caroline also stressed *"the way a person functions is contingent on their environment"* [Caroline line 981-982]. Some participants talked about how they were made to feel it was their fault they felt the way they did, *"I remember thinking that everything was my fault, that I was to blame for everything"* [Chloe line 213-215], *"you know you're blame, you're, you're blamed so, and anything that you do is interpreted as like something to do with your disordered personality"* [Stephanie line 143-146]. Louise talked about how it blames people for normal human needs *"Attention seeking, like we all need attention, every human being needs attention. Like look at Gabor Maté, you like pick up a baby and like if you don't pick up that baby, they're gonna die"* [Louise line 422-426]. Caroline also spoke about how telling someone their personality is disordered is blaming *"You've just told me my personality is disordered, how is my personality not me?"* [Caroline line 743-745].

### Problems with the system

Chloe talked about the difficulties involved with mental health services, *“you know, when you’re in mental health you get shunted around a lot”* [Chloe line 80-81]. Stephanie spoke about being accused of seeking attention from mental health services,

> *“I don’t know what sort of attention they think we’re getting, like someone’s gonna give us, like a bunch of flowers and a box of chocolates, like it’s the most awful kind of attention, being in a psychiatric hospital and being treated like that badly”* [Stephanie line 535-540].

Lauren talked about her experiences that made her reluctant to contact mental health services, *“It’s made me shrink away from accessing any support”* [Lauren line 534-535], *“I wouldn’t trust the NHS, the NHS, in terms of my mental health with a bargepole”* [Lauren line 540-542].

There was a theme with some participants involving misdiagnosis, two participants had been diagnosed with autism after being diagnosed with BPD, and others diagnosed with Post-Traumatic Stress Disorder (PTSD). Caroline and Stephanie both spoke about receiving their autism diagnosis, *“I realised this is why I was saying that BPD diagnosis didn’t explain stuff, I realised as time went on that it was because of a massive sensory overload”* [Caroline line 648-651]. Stephanie also talked about a similar experience, *“you know what I was having was, you know, a very sort of like emotive reaction to like cognitive and sensory overwhelm, but that was interpreted as like being, you know, emotionally unstable”* [Stephanie line 212-215], *“they realised that it was actually, you know, an autistic disposition and not personality disorder”* [Stephanie line 68-70].

### Wanting to feel that I am in control of my life.

The participants talked about their experience of receiving the diagnosis, how at the time they were looking for help, looking to understand their experiences and their emotions. Louise explained, *"I don't wanna control or like, suppress my emotions, I wanna let them out and like, talk about them and like be able to express them and understand why I'm so sad"* [Louise line 153-156]. Stephanie said, *"I was expecting somebody to give me some tips, maybe to talk to me about it, to help me express like what I was, what was going on for me, what I was feeling you know"* [Stephanie line 78-81]. Lauren also said she was *"looking for some kind of answers"* [Lauren line 41] as she was *"you know, having difficulty, kind of um containing feelings and being able to talk about things and I don't, I didn't feel understood"* [Lauren line 192-194].

## Discussion

The first theme involved the participants feeling as if the diagnosis had seemed to change how they were seen and forgetting they were just normal women who had gone through difficult experiences. This is consistent with previous literature that has discussed the stigma of this diagnosis, historically the term 'borderline' was used to describe people who clinicians felt were difficult or disliked (Masland & Null, 2022). Veysey (2014), also found personality disorders are seen as difficult to treat, and clients with BPD are often seen as considerable users of mental health services, so it is possible that once the participants had been given this diagnosis, they were treated differently.

Participants also talked about the impact this had on their lives and fear of being judged as a result of the diagnosis, this is consistent with previous research by

Markham (2003) who found staff would desire greater social distance from people diagnosed with BPD. It has been suggested lack of training could be a reason for these types of judgements and further training could help staff understand and increase their empathy (Weight & Kendal, 2013). Participants also talked about how they felt the diagnosis had been unhelpful, sometimes causing confusion and loss of hope, this has also been a theme within previous research, being told it was untreatable and “killing” their hope (Horn et al., 2007).

During the interviews, most of the participants either talked about the type of trauma they had experienced in their life or mentioned they had also been diagnosed with PTSD. There have been studies reporting correlations between experiencing trauma and receiving a diagnosis of BPD (Helgeland & Torgersen, 2004; Herman et al., 1989; Zanarini et al., 2002, Temes et al., 2017; Martin-Blanco et al., 2015). Previous research has also suggested a trauma-informed perspective, which takes into account broader issues in society would better facilitate recovery (Ferguson, 2016).

There was also a lot of confusion surrounding this diagnosis, with some participants wondering if it is a real diagnosis, and misdiagnosis occurring for some participants. It has been noted that due to learning how to be ‘socially acceptable’, autism can be missed, and multiple diagnoses can be given before it is recognised (Rasmussen, 2023). There is also a reported overlap between symptoms of BPD and PTSD, so the diagnosing clinician needs to complete a thorough assessment (Pires et al., 2023), however the participants in the current study were all diagnosed after a brief meeting. It has been suggested that women go unnoticed more than men, which increases their risk of being misdiagnosed, so BPD should not be considered before autism has been ruled out (Rasmussen, 2023). This would provide everyone involved i.e., the person, their family, and services, with a better understanding of their needs, which would improve the quality of life for the person (Rasmussen, 2023)

Participants later described feeling powerless as a result of the diagnosis, feeling nobody listened to them and professionals were more readily believed than them. This supports previous literature, that professionals are often more believed than those living with the diagnosis (Carrotte et al., 2019). The stigma attached to this diagnosis would also not help in this situation, as Ring & Lawn (2019) noted individuals with this diagnosis are often in a situation where they can't win, as even when they try to seek help, they can be dismissed as attention-seeking or manipulative.

## Conclusion

This research provides insight into how the women who took part in this study experienced receiving this diagnosis. There are implications for both practice and research that can be drawn from the results. This research highlights issues within the therapeutic treatment provided for people who have this diagnosis, participants spoke about being mainly offered DBT, with no consideration of trauma therapy. Counselling psychologists should be able to assess and formulate a person's difficulties, before considering therapy modality. If focus is only given to recommended treatments without taking into account reasons why a person may feel the way they do, this could cause further invalidation. This would repeat experiences of not being listened to and adding to feelings of hopelessness if therapy does not work. Formulation should also be used to help other staff working within services to understand the person they are working with, to be able to see the person, not the label.

An important implication for practice is having this knowledge that a person with this diagnosis has possibly experienced unhelpful responses from services. They could appear as ‘difficult to engage’, however they may have developed a distrust of mental health professionals. Often, different services will have different policies so there may be times when policies need to be challenged or adapted to prevent further bad or harmful experiences and treatment.

Considering the findings and noted research in misdiagnosis, and the probable continued use of diagnostic systems, it could be helpful for further research to focus on this area, to prevent other women from being misdiagnosed. This would also prevent women from being referred to therapy that they do not want and hopefully be able to access the support they need.

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## Declaration of interest statement

No known conflict of interest to declare.

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