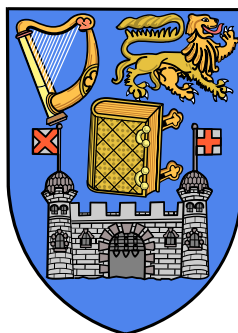


Women's Experiences of Diagnosis and Disclosure of Borderline Personality Disorder: A Narrative Inquiry

**A thesis submitted to Trinity College Dublin, The University of
Dublin in fulfilment of the requirements of the degree of
Doctor of Philosophy in Nursing and Midwifery**

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2025



Declaration

I declare that this thesis has not been submitted as an exercise for a degree at this or any other university and it is entirely my own work.

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Date: _____

Dedication

To each of the fourteen women who trusted me to tell their story

To my supervisors who believed in me when I failed to believe in myself

To Richard, my soulmate, for your loving, generous and steadfast support

To my family and friends who mean everything to me and keep me going

I am indebted to you all and hope that I have done you proud

To each of you, and to Sharon, my 'twin'

I dedicate this Thesis

Thank you

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My most heartfelt thanks to the women who participated in this study and whose experiences form the heart of this thesis. I am truly grateful for their courage in sharing their stories and their generosity in sharing their time with me. I have learned so much from them that makes me a better nurse, a better researcher, and a better educator.

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*We can only be said to be alive in those moments when our
hearts are conscious of our treasures*

~ Thornton Wilder

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List of acronyms

ACE	Adverse childhood experience
ACT	Acceptance and commitment therapy
ADHD	Attention Deficit Hyperactivity Disorder
APA	American Psychiatric Association
APMS	Adult Psychiatric Morbidity Study
BDM	Biosocial Developmental Model
BPD	Borderline Personality Disorder
CAMHS	Child and Adolescent Mental Health Services
CFT	Compassion Focused Therapy
DBT	Dialectical Behaviour Therapy
DoH	Department of Health (Ireland)
DSM	Diagnostic and Statistical Manual of Mental Disorders
ECM	Emotional Cascades Model
EUPD	Emotionally Unstable Personality Disorder
GP	General Practitioner
HCA	Healthcare Assistant
HRB	Health Research Board
HSE	Health Service Executive (Ireland)
ICD	International Classification of Disease
LG	Listening Guide
MHA	Mental Health Act (Ireland)
NI	Narrative Inquiry
NHS	National Health Service (UK)
RTA	Reflexive Thematic Analysis
VCRM	Voice-centred Relational Method
WHO	World Health Organisation

Epigraph

*Words mean more than what is set down on paper. It takes the human voice
to infuse them with deeper meaning.*

~ Maya Angelou

I Know Why the Caged Bird Sings

Summary

Background: Since the borderline personality disorder diagnosis (BPD) diagnosis was first introduced in 1980 its use has continued to increase. Even as critical debates rage regarding its validity and utility, both inside and outside of psychiatry where it was first constructed, it continues to be used in biomedically dominated systems to individualise, medicalise, and label distress, firmly locating the “disorder” in the person independent of their social context. 75% of people diagnosed with BPD are women, their voices and experiences of diagnosis and disclosure of BPD therefore need to be better heard and understood.

Aim: The aim of this inquiry was to explore the lived experiences of women in receiving the diagnosis of BPD, or emotionally unstable personality disorder (EUPD), in the Irish context, to gain an understanding of the meaning they attach to that diagnosis. The inquiry furthermore aimed to garner an understanding of the experiences of women in disclosing their diagnosis to others.

Methodology: A narrative inquiry methodology that draws on feminist and critical perspectives was employed. Participants consisted of 14 women diagnosed with BPD/EUPD who were resident in the Republic of Ireland. Data were gathered using in-depth narrative interviews. The narrative analysis was conducted using a dual-level analytic strategy employing the Listening Guide (LG) and a Reflective Thematic Analysis (RTA).

Findings: The synthesised findings developed through the RTA enhanced the accessibility of the narrative findings translating them into three main themes. The themes identified include: life before being diagnosed as “borderline:” women’s early life experiences; the diagnostic moment: women’s stories of being diagnosed with BPD/EUPD, and; life after diagnosis: women’s stories of disclosure and living with the diagnosis of BPD/EUPD. Dyadic relationships were identified as an overarching concept in the narratives.

Conclusions: The unique contribution of this inquiry is its focus on the women’s voices as they navigate their lived experience of life before the diagnosis of BPD, the diagnostic moment, and life after the diagnosis living with the borderline label. Within each stage the voices of the women illuminate potential points of intervention that will inform the practice of mental health nursing and other disciplines, policy, education, and research.

Chapter 1: Thesis introduction and overview

1.1 Introduction

This chapter presents an overview of the thesis and an introduction to this inquiry that explores women's lived experiences of being diagnosed with borderline personality disorder (BPD), or the analogous diagnosis of emotionally unstable personality disorder (EUPD) and of disclosing that diagnosis to others in the Irish context. BPD is a contentious (Campbell et al. 2020; Duff et al., 2020), highly stigmatised (Klein et al., 2022; Navarre, 2025; Ring & Lawn, 2019) and gendered (Özel et al., 2024; Shaw & Proctor, 2005) psychiatric diagnosis that has significant prevalence in clinical settings (Eaton & Greene, 20218; Ellison et al., 2018). People diagnosed with BPD typically experience difficulties with: affect regulation; impulsivity; maintaining stable relationships, and; unstable self-image and identity (Bohus et al., 2021; Leichsenring et al., 2024; Lieb et al., 2004;). A detailed discussion of the evolution of the BPD diagnosis and how it is currently classified in diagnostic taxonomies is presented in Chapter 2. In this chapter I begin my overview of the thesis by recounting the impetus for this inquiry and my positionality as the researcher. Next, I outline the rationale for selecting a narrative inquiry (NI) methodology. I then set out the aims and objectives of the inquiry. The chapter concludes with notes on the use of language in the inquiry and an outline of the thesis chapters that follow.

1.2 Coming to inquire about the “*borderline*” diagnosis

My interest in the *borderline* concept and women's lived experiences of diagnosis and disclosure of BPD developed during my time as an undergraduate mental health nursing student. While in college as a mature student I worked part-time, on an agency basis, as a healthcare assistant (HCA) in a number of different healthcare settings. With no previous experience of working in healthcare, up to the age of forty when I entered nursing, I felt that my role as a HCA working in various general hospitals would provide an excellent opportunity to develop my care skills. I was also keen to learn more about the various physical illnesses that I

might encounter among service users in my mental health nursing practice. However, I soon discovered that I would also learn a lot there about mental health and how mental health problems are often perceived. Working in those general hospital settings, particularly in busy emergency departments (ED), I admired and rated highly my hard-working, skilled and dedicated colleagues. I learned a lot from them, particularly the nurses, who worked under almost-constant pressure in over-crowded and under-staffed conditions that were less than ideal. However, I also witnessed a tendency for very negative comments to surface among healthcare colleagues when people, mostly women, presented following incidents of self-harm or attempted suicide, particularly those who were diagnosed with BPD/EUPD. The negative and stigmatising remarks that I witnessed were made by only a minority of staff but nevertheless it was a persistent issue. The types of remarks that were directed towards me as a mental health nursing student relating to specific patients included for example: “*here’s one of yours*”, or “*you can take her*”, or “*don’t worry she’s a frequent flyer*” and most commonly “*she’s a roaring PD*,” inferring that the person awaiting care and treatment had a diagnosis of BPD/EUPD. I was appalled at the attitude and behaviour that seemed almost to have been normalised in that environment; most staff did not speak like that but those who did typically went unchallenged. It was much later that I recognised these comments were reflective of the dominant narratives that were in circulation related to BPD/EUPD. I regret that I failed to challenge those narratives that I encountered even though I found them abhorrent. Upon reflection perhaps this was due to naïveté, a lack of confidence, or a desire to fit in within a new and temporary work environment.

As I repeatedly encountered a deep and abiding sense of negativity among healthcare professionals towards the BPD/EUPD diagnosis and specifically the stereotype of the “*borderline woman*,” who was typified as *difficult*, *angry*, and *manipulative*, I ruminated on it. How was this acceptable in a modern healthcare setting and why was this disdain reserved only for certain people, mostly women? The seed was sewn, I wanted to understand more and, in some way challenge the stigma that I felt was cruel and unjust. As I continued my training and later

working as a mental health nurse, I was dismayed at times to find that similar narratives circulated in various mental health settings around the diagnosis of BPD/EUPD and the stereotypical *borderline woman*. I became determined to gain a better understanding of the diagnosis from the lived experience and also the feminist perspective and so enrolled for my PhD in 2016. I had much to learn too, grounded as my understanding of BPD/EUPD was in the biomedical model of psychiatry with a tacit acceptance of the diagnostic construct. It has been disappointing too, in my time as a doctoral student, that more than a few times when asked by other mental health nurses about my PhD topic the response has been something like: “*rather you than me, you’re welcome to them.*” However, this has spurred me on to gather the stories of the women in my inquiry and to best represent them in the retelling so that together we might in a small way challenge the dominant narrative through the construction of counterstories.

1.3 Positionality of the researcher

I came to this inquiry as a researcher and a mental health nurse and as I completed the final two years of my PhD journey I had moved, full-time, into mental health nurse education; each role has had a bearing on the final thesis as is borne out in my reflexive writings that are threaded throughout. In that final two-year period I was also diagnosed with attention deficit hyperactivity disorder (ADHD) and so came to personally understand a little of what it means to be diagnosed and come to terms with a contentious diagnosis, this too had an effect. This inquiry had its genesis in the space between the dominant narratives that circulated in the healthcare settings where I worked about BPD and the “*borderline woman*” and what I was learning as a student about best practice in ethical, person-centred, and recovery-oriented care. As a person who values justice and fairness in all aspects of life I was drawn to explore, through a feminist lens, what was it that led to a seemingly tacit acceptance of such negative stereotyping, prejudice, and casual discrimination. I came to perceive the diagnosis of BPD as highly stigmatised and began to question its validity. In this thesis and in my everyday work in teaching I aim to challenge those dominant narratives through sharing the counterstories of women that deserve to be heard.

1.4 Selecting narrative inquiry

Intent on exploring the lived experiences of women of receiving a diagnosis of BPD/EUPD and, as an extension of that, of disclosing that diagnosis to others I knew that I would need to select an appropriate qualitative methodology. Excited to begin I set about learning as much as possible about different research methodologies that might be suitable for use in my study. Other methodologies that I considered might be appropriate to explore my chosen topic included hermeneutic phenomenology and interpretive phenomenological analysis (IPA). Hermeneutic phenomenology offered a methodology that incorporates aspects of phenomenology, or the study of subjective lived experience and the meanings people derive from them, with hermeneutics, which centres upon the theory and practice of interpretation (Godden & Kutsyuruba, 2023). However, the primary focus of phenomenology relates more to discerning the essence of the particular phenomenon and is less about the participants experiences and how they make meaning of the phenomenon. IPA was another option as a methodology that seeks to uncover the unique meanings individuals assign to their lived experiences often focusing on emotionally-significant or transformative events (Smith et al., 2009). IPA emphasises the researcher's interpretation of the participant's meaning-making and the individual's specific context while NI identifies the individual as a storyteller and emphasises how narratives shape individual identities and meaning-making. NI is premised on the assertion that human beings have stories about particular phenomena and it is the responsibility of the researcher to elicit that story and present it in an organised and meaningful manner so that the reader can draw an understanding of that phenomenon from the storyteller's perspective (Cresswell, 2015). NI looks beyond the individual context and explores how people's experiences and meaning-making processes are influenced by the broader social and cultural context. Kim (2016) emphasises that in NI the researcher uses multiple lenses through which to view and make sense of the phenomena of interest. The nuanced nature of NI resonated with me and the purpose of my research and I therefore chose to adopt this methodology.

Having identified NI as my chosen methodology I was very interested in looking beyond existing conceptualisations of the BPD/EUPD diagnosis and unearthing the meaning that women attached to their experiences of diagnosis and disclosure. NI offered a sensitive means of discerning how the women made sense of those experiences as they embedded them in narrative. It follows in NI that the analysis occurs at two levels of interpretation. In this inquiry the first level of interpretation occurs as the women interpret their lived experiences of diagnosis and disclosure of BPD/EUPD through the construction of narrative. The second level of interpretation occurs when I, as the researcher, interpret their construction of that narrative. Intuitively, I felt that NI was a very suitable methodology to meet my aim of gaining a better and more nuanced understanding of women's lived experiences of BPD/EUPD. Focusing on how the women narrated and made sense of their experiences within their social and cultural contexts would afford me the opportunity to examine the broader socio-cultural factors that impacted and shaped those lived experiences. This would in turn inform my interpretation and recommendations for future practice, policy, education and research. To achieve these aims I chose to use the Listening Guide (LG) as a voice-centred relational method of analysis (VCRM; Gilligan et al., 2006; Doucet & Mauthner, 2008). Using the LG method I developed a bespoke analytical framework that worked well given my experience as a mental health nurse practised in listening to people's stories in an effort to understand their distress.

I chose this approach specifically for the clarity that it offers in preserving the women's individual voices and stories as I interpreted their narratives of lived experience in the context of a contested diagnosis. The current debates surrounding the diagnosis of BPD/EUPD are outlined in Chapter 2 (2.7). Having conducted an individual vertical analysis of each narrative the LG method of analysis is also conducive to adding a further optional level of horizontal analysis across the narrative accounts for the purpose of identifying similarities and/or disparities between the narratives. This is an important aspect of this inquiry in terms of gaining an understanding of what is particular versus what is shared, or

indicates a potential pattern, in the experiences of this group of women who share a diagnosis of BPD/EUPD.

1.5 Aims and objectives of the inquiry

1.5.1 Aims

The aim of this inquiry was to explore the lived experiences of women in receiving the diagnosis of BPD, or EUPD, in the Irish context and to gain an understanding of the meaning they attach to that diagnosis. The inquiry furthermore aimed to garner an understanding of the experiences of women in disclosing their diagnosis to others.

1.5.2 Objectives

The objectives of the inquiry were to:

- inform the practice of mental health nursing and other healthcare professions by
 - exploring the subjective experiences of women in receiving a diagnosis of BPD/EUPD
 - eliciting the meaning of that diagnosis to each woman
 - exploring the experiences of women in disclosing their BPD/EUPD diagnosis to others
 - exploring the women's thoughts, feelings, and decision-making regarding disclosure
- contribute to the theoretical knowledge and the body of research on women's lived experiences of the diagnosis and disclosure of BPD/EUPD

1.6 Notes on terminology and use of language

In this section I outline the rationale for the use of certain terms and language in the thesis particularly terminology that is of biomedical origin and orientation.

1.6.1 BPD and EUPD diagnostic labels

Given the interchangeable nature of the diagnostic labels that are written thus far as BPD/EUPD it is important to clarify from the outset how this terminology is used in the context of this inquiry. For ease of reading I will switch now to primarily use the BPD label, as the more commonly used diagnostic term in research, throughout the rest of the thesis. BPD should be taken in that context to also represent the analogous diagnosis of EUPD. The EUPD term is retained however in certain instances, for example, in the outline plots of the women's stories in Chapter 7 (7.1) where the women identify that they were given a diagnosis of EUPD and in subsequent findings chapters where that is the terminology used by the women. The use of the relevant diagnostic term is intended as a means of authentically representing the women's individual stories.

1.6.2 Use of terms for persons accessing healthcare services

It is also important to acknowledge here that the use of terms in this thesis including "patient," "client," "consumer", or "service user" to describe persons accessing healthcare services is not value-free and that in recent years the use of these and other alternatives including the "survivor" term have been the subject of much debate (Costa et al., 2019). Where I have used a term other than the "woman", the "person," or the "individual" this is indicative of the term used in the literature cited or the language used by the women as directly quoted.

1.6.3 Use of borderline terminology

The use of the various *borderline* terms in the thesis is intended to reflect common usages and does not imply an acceptance or endorsement, on my part as the researcher, of the *borderline* concept or of the label that is primarily construed as pejorative, as discussed by Masland and Null (2022). For that reason, other than the diagnostic term of BPD and the language that is reflected in the women's direct quotes, all other *borderline* terms referenced in the thesis are denoted using an italicised font.

1.6.4 Use of biomedical language

Much of the large volume of literature that examines the topic of BPD is written from the biomedical perspective and as a result the language used is typically replete with biomedically-oriented terminology. In the context of discussing the BPD diagnosis, for example its epidemiology, aetiology, history and diagnostic criteria, such terms commonly arise and therefore have been incorporated into the thesis. Examples include terms such as *mental disorder*, *impairment* and *hysteria*. Again the inclusion of such terms is not intended to legitimise their use and does not reflect a biomedical orientation on my part as the researcher. I have endeavoured to denote all such terms also using an italicised font.

1.7 Overview of the structure of the thesis

In this chapter I provided an introduction to the inquiry and a brief overview of the thesis that concludes with an outline of the remaining chapters as follows:

Chapter 2 provides the background and context to the inquiry beginning with a detailed discussion of the history of the borderline concept and the evolution of the BPD diagnostic construct from the 1930s to its current classification. The global prevalence for personality disorder and guidelines and policy related to the care and treatment of people diagnosed with personality disorder are explored with an emphasis on BPD.

Chapter 3 presents a narrative review of the theoretical and empirical literature related to the diagnosis and disclosure of BPD. The chapter opens with an overview of contemporary aetiological theories of BPD. The empirical literature that explores the diagnosis and disclosure of BPD from the lived experience perspective is presented under the following themes: the lived experience of receiving the diagnosis of BPD; diagnostic and structural stigma relevant to BPD; perceptions of healthcare in the context of BPD, and; BPD and perceptions of recovery.

Chapter 4 describes the ontological, epistemological and methodological propositions that underpin the inquiry. This methodology chapter makes explicit

the alignment of my chosen NI research design with my social constructionist epistemology. The narrative analysis strategy that comprises two stages of analysis is also presented.

Chapter 5 as the first of two methods chapters provides a detailed description of the narrative methods employed in generating the data to address the research problem. The processes related to participant recruitment and collection of the narrative data are made explicit. The ethical considerations that inform the inquiry and the methods employed to maintain rigour and quality are also discussed.

Chapter 6 as the second methods chapter makes explicit the application of the two levels of analysis in accordance with the analytic strategy.

Chapter 7 as the first of four empirical chapters provides a brief abstract of each of the 14 stories shared of diagnosis and disclosure of BPD. The stories, presented in the form of anonymised summary plots, were a product of the first vertical level of LG analysis and their inclusion serves to maintain the integrity of the individual stories told.

Chapters 8, 9, and 10 constitute the key findings of the inquiry each representing a theme, and constituent subthemes, identified during the second level horizontal RTA analysis. Chapter 8 depicts the findings related to the women's early-life experiences. Chapter 9 describes the findings related to the women's experiences of receiving the diagnosis of BPD. Chapter 10 presents the findings related to the women's experiences of living with and disclosing the diagnosis of BPD.

Chapter 11 comprises a critical discussion of the inquiry's key findings as they relate to the extant theoretical and empirical literature.

Chapter 12 outlines the inquiry's strengths and limitations. Drawing from the findings and the arguments presented in the inquiry the implications of the inquiry are considered and the recommendations in terms of research, education, policy and practice are set out in closing.

Chapter 2: Background and context

2.1 Introduction

The focus of this chapter is on providing background and context to this inquiry. I begin with a brief history of the *borderline* concept. I then explore the social construction of the borderline personality disorder (BPD) diagnosis and trace its development in terms of its psychiatric nosology. Next, I discuss the global prevalence rates and current guidelines and policy related to personality disorder with an emphasis on BPD. To conclude this chapter, I make explicit the feminist and critical psychiatry discourses and the alternative frameworks for understanding mental distress that inform my inquiry.

2.2 A brief history of the “borderline” concept and BPD

Prompted by Jones (2023, p. 118) who cautions that while BPD is clearly identifiable as a “*product of psychiatry*,” tracing its history should not be confined to an examination of the various editions of the psychiatric classification manuals. Rather it should incorporate close consideration of the broader socio-cultural contexts in which the diagnosis emerged and continues to prosper. Following the example of Jones (2023), I chose to trace and present chronologically, in the sections that follow, the key contributions to the development of the BPD construct from the 1930s through to the present day. From a sociological perspective Jones (2023, p. 117) suggests that to “*appreciate some of the conundrums and puzzles*” that surround the diagnosis of BPD it is necessary to develop an understanding of its history and the cultures and contexts in which it “*arose, consolidated and proliferated*.”

2.2.1 The origins of the *borderline* psychological concept

The earliest use of the *borderline* term in modern psychiatric literature is attributed to Hungarian-American psychoanalyst Adolph Stern who described a “*borderline group of patients*” whom he considered were on the border of psychosis and neurosis (Stern, 1938,

p. 467). Later, American psychoanalyst Robert Knight described as *borderline* patients whom he considered had *impaired* mental functions related to their: (i) realistic perception of events; (ii) successful integration of thoughts and feelings, and; (iii) ability to respond effectively to life events. Knight (1953) concluded that these *functional impairments* could be understood as *borderline states*. The concept of a *borderline personality* thus emerged at a time when the psychoanalytic paradigm was the dominant one in psychiatry and modern psychiatric nosology was in its infancy (Mayes & Horwitz, 2005). The next major development in the evolution of the borderline construct involved Austrian-American psychoanalyst Otto Kernberg who conceptualised *borderline personality organisation* (BPO) as a mid-level of personality organisation that existed on a spectrum with *sicker* patients who were deemed to have a *psychotic personality organisation* at one end and *healthier* patients who were labelled as having a *neurotic personality organisation* at the other. Influenced by the work of Mahler (1971), Kernberg developed a theory of BPO based on a developmental disruption from an object-relations perspective of psychodynamic theory where the child became stuck in the separation-individuation stage of development. He believed that due to emotional unavailability of the mother a child's ability to internalise the object (person) was affected and resulted in disturbed relationships and fears of abandonment (Gunderson, 2010; Kernberg, 1967). This concept of BPO as a *psychopathology* was characterised by primitive psychological defence mechanisms that included splitting and projective identification, identify diffusion and lapses in reality testing (Gunderson, 2010; Yalch & Levendosky, 2014). Kernberg (1968) went on to suggest that BPO was *treatable* using psychoanalytic psychotherapy.

Roy Grinker as an early advocate of a more descriptive approach to the classification of *mental disorder* actively sought to establish diagnostic criteria for BPD. In their landmark book "*The Borderline Syndrome*" Grinker et al. (1968) set about describing *borderline patients*. Later in the mid-1970s John Gunderson, who had a background in medicine and psychoanalysis, led out on synthesising earlier works to form an overview of this *borderline syndrome*. This synthesis resulted in the publication of a highly

influential paper “*Defining Borderline Patients: An Overview*” that effectively converted the extant descriptive literature into a diagnostic entity (Gunderson & Singer, 1975). This was followed by the development of a diagnostic interview, a tool designed to help set a consistent standard for the assessment using defined criteria (Gunderson & Kolb, 1978). Later, the *borderline* concept was hypothesized as being on the borderline of an affective rather than psychotic disorder (Shea et al., 2004; Stone, 1979; Tyrer, 2009).

2.2.2 The influence of critical psychiatry

Up to the mid-1960s psychiatry remained committed to a psychoanalytic approach that up to that point was highly regarded. However, from the mid-1960s and through the 1970s psychiatry came under increasing scrutiny and its legitimacy began to be questioned within and without the profession. Challenges arose in terms of the emergence of alternative therapies to psychoanalysis including a steep rise in new psychopharmacological interventions that will be discussed in the next section (2.2.3). Research also revealed a significant problem of inconsistency in psychiatric diagnosis (Cooper et al., 1972; Gurland et al., 1972; Rosenhan, 1973). A further threat to the status of psychiatry was the so-called “anti-psychiatry” movement that was popularised at the time across Europe and the United States in an era of counterculture and anti-establishment sentiment. The names of leading critical thinkers at the time that became synonymous with the movement include: psychiatrists Thomas Szasz, R.D. Laing, and David Cooper; sociologists Erving Goffmann and Thomas Scheff, and; philosopher and historian Michel Foucault. However, many of these proponents of what was essentially the first wave of critical psychiatry eschewed the anti-psychiatry label that was originally coined from within the profession by David Cooper (Middleton & Moncrieff, 2019). As psychiatrists, Szasz and Laing each oppose coercive practices and compulsory treatment within their own profession, however, in other ways they differ significantly in both perspective and approach. Szasz challenges the psychiatric establishment by radically denouncing mental illness as a “myth” and psychiatric treatments as means of social control. He asserts that, unlike physical diseases of the body and brain, mental illness is

a destructive social construct that medicalises people's "*problems in living*" (Szasz, 1960, p. 117, italics in the original). While Laing does not deny the existence of mental illness he views it very differently to most of his contemporaries. He originally considered the experience of psychosis understandable in the context of dysfunctional family life associating poor parenting with the onset of schizophrenia, although he later revised his opinion on this (Laing, 1967). From the perspective of labelling theory Goffman (1961, 1963) and Scheff (1963, 1964, 1974) each contend that mental illness constitutes a means by which society labels and controls those who do not conform to societal expectations and norms.

Much of Foucault's original and highly influential work focuses on his analysis of knowledge and power as intimately related concepts (Foucault, 1967, 1969, 1973; 1978; 1979). Foucault employs the metaphors of "archaeology" and "genealogy" to describe his analytic approaches (Karim, 2021). He identifies his archaeology as the methodological framework for his analysis of various discourses that are analysed as events or sets of events (Karim, 2021). The aim of his archaeology is the critical analysis of systems of knowledge to determine the rules and societal structures that influence knowledge formation (Foucault, 1967, 1969, 1994). His core argument is that discourses, for example the discourse of madness, should be thought of as "practices." His conceptualisation of discursive practice incorporates "things said" and the "rules" that govern knowledge. Foucault's (1967) analysis of the discourse of madness that involved thorough examination of the archives and practices of psychiatry, psychoanalysis, and medicine illustrates how these discourses equated madness with mental illness and thus labelled people experiencing madness as "abnormal" or mentally ill. He argues that discourses of madness define people using negative language that represses, excludes, and others those who are not part of the dominant discourse and deprives them of a voice.

Foucault's genealogical approach extends into an examination of discourses and power and how discourses become established as norms and legitimate forms of knowledge.

The notion of a “disciplinary power” emerged from his analysis of the organisation of asylums and prisons (Foucault, 1979). When Foucault refers to psychiatry as a discursive practice he infers that psychiatric knowledge is not neutral in that it intertwines with power to shape how people experiencing distress are classified, treated and controlled (Foucault, 2000; Roberts, 2005). He argues that the use of diagnostic labels in psychiatry leads to the reification of mental illness and is an example of exercising power to determine what is “normal” and “abnormal.” The use of such diagnostic power can result in individuals being objectified and reduced into norms, categories, and diagnostic labels as opposed to being considered as complex human beings (Roberts, 2005; Hoffman, 2011). From the 1970s onwards Foucault began to challenge those traditional understandings of power as a wholly negative force that suppressed, conquered, and silenced and began writing about how power could alternatively be considered a positive, productive, and enabling force in everyday lives (Foucault, 1978; 1979). He proceeded to explore a “genealogy of ethics” in which power is recognised as a subjectivising as well as an objectivising force. Foucault herein proposes that individuals have agency and are therefore capable of transforming and modifying themselves to shape their own identity using “technologies of the self” as a means of navigating and resisting power in their everyday lives (Foucault, 1988).

In the face of this maelstrom of critique, American psychiatry sought ways in which it could become re-medicalised and grounded in empirical research with the aim of *legitimising* the discipline. This led to the radical revision of the DSM in an attempt to increase the consistency and reliability of psychiatric diagnosis, both clinically and in terms of academic research, through the application of a biomedical model and a standardised nosology (Kirk & Kutchins, 1992; Suris et al., 2016; Whooley, 2014). Jones (2023, p. 129) argues that this move to a positivistic system of identifying *disorder* led to BPD existing on “*a significant fault line within the discipline of psychiatry*” between the biomedical understanding of disorder on one side and psychoanalytic understandings of the mind on the other. In accordance with the developmental theory of Winnicott (1984), Jones (2023) suggests that BPD might better be understood from a relational perspective

as a problem that exists not solely within the individual nor simply in the social world but in a transitional space between the two.

2.2.3 The impact of psychopharmacological advances

Significant developments in the science and business of psychopharmacology, particularly through the 1950s and 1960s, led to the introduction of a range of new classes of psychotropic drugs designed for the pharmacological treatment of *mental disorder*. These drugs, that were quickly adopted in psychiatry as first-line treatment options, included first-generation antidepressant and antipsychotic medications and benzodiazepines (Baldessarini, 2014). The advent of this psychopharmacological era heavily impacted psychiatry not only in terms of *revolutionising* treatment but also in terms of influencing a change in orientation within the profession towards a biomedical conceptualisation, categorisation and symptom-based diagnosis for most psychiatric disorders (Baldessarini, 2014). Mayes and Horwitz (2005, p. 252) observed how the radical move to a more descriptive psychiatric nosology was thus influenced stating that a “*symptom-based manual also met the needs of pharmaceutical companies to have specific diseases for their products to treat.*” The pervasive influence of psychopharmacology on clinical practice in psychiatry may also explain why, despite the fact that there are no medications licensed or approved specifically for the treatment of BPD (Hancock-Johnson et al., 2017), a systematic review and meta-analysis of 21 randomized controlled trials found that up to 96% of people diagnosed with BPD were prescribed at least one psychotropic drug (Gartlehner et al., 2021).

2.2.4 The evolution of BPD as a diagnostic category

While personality and its perceived *dysfunction*, or *abnormality*, have been contemplated and theorised by humankind for millennia the modern concept of personality disorder is relatively recent and can be traced back to the 1950s in America (Crocq, 2013; Gunn & Potter, 2014). The first edition DSM-I (APA, 1952) included a

category of “personality disorders” that were grouped under three headings: (i) personality disturbance, (ii) personality trait disturbance, and (iii) sociopathic personality disturbance. The second category of personality trait disturbance included a diagnosis of “emotionally unstable personality” that could be considered a precursor to the diagnosis of BPD and that was defined as follows:

“In such cases the individual reacts with excitability and ineffectiveness when confronted by minor stress. His judgement may be undependable under stress, and his relationship, to other people is continuously fraught with fluctuating emotional attitudes, because of strong and poorly controlled hostility, guilt, and anxiety” (APA, 1952, p.36).

Jones (2023) observes that while the male-centric description in this DSM diagnostic category reflects the convention of a masculine norm there is also no indication, at this time, that the diagnosis was directed towards women.

As a WHO Member State, the United States, is required to have a classification system for mental disorders that aligns with the ICD, or at least does not contravene it. As a result the DSM (APA) and ICD (WHO) systems of classification, as described by First et al. (2021, p. 34), have “*separate and intertwining histories*” as is evident in the case of the diagnoses of BPD and EUPD. The second edition DSM-II (APA, 1968) was designed to address inconsistencies between the DSM and the ICD which was then in its eighth edition (WHO, 1966). This second edition retained its psychodynamic approach and the influence of psychoanalysis remained evident. In DSM-II (APA, 1968) the appendix indicated that the “emotionally unstable” construct had been replaced by diagnosis of “hysterical personality disorder”, or histrionic personality disorder, as defined in Figure 2-1. Jones (2023) draws attention to the fact that the male centric language is no longer in use here. He considers that the use of the “hysterical” term, that is associated with historical notion of *hysteria* as a feminine problem, indicates that this had become a gendered diagnosis. Jones (2023) also notes that the histrionic personality disorder

diagnosis remained as a separate diagnosis even after BPD was introduced in DSM-III (APA, 1980).

Figure 2-1: Definition of hysterical personality disorder (APA, 1968)

301.5 Hysterical personality (Histrionic personality disorder)

These behaviour patterns are characterised by excitability, emotional instability, over-reactivity, and self-dramatization. This self-dramatization is always attention-seeking and often seductive, whether or not the patient is aware of its purpose. These personalities are also immature, self-centred, often vain, and usually dependent on others.

The publication of DSM-III (APA, 1980) represented a radical departure from previous versions moving away from psychodynamic approaches and terminology to a new categorical, biomedical model that was no longer tethered to aetiological theories (Kirk & Kutchins, 1992; Rogler, 1997). The diagnostic criteria published in DSM-III were widely considered, by clinicians and researchers, to be far superior to those contained ICD-9 (WHO, 1978). The Committee for the Development of ICD-10 therefore made the unusual decision to modify the manual's diagnostic criteria to be consistent with the DSM classification instead of the other way around (Fischer, 2012). This resulted in the inclusion of ten personality disorder diagnoses in ICD-10 (WHO, 1994) that were conceptually very similar to those listed in DSM-III. The new DSM manual also had its critics, for example, in a vehement critique Vaillant (1984, p.542) declared that although well-intentioned DSM-III was "*parochial*," "*reductionistic*," and "*adynamic*" adding that "*it has consistently sacrificed diagnostic validity on the altar of diagnostic reliability*." The APA on the other hand attributed the success of DSM-III to the power of *scientific knowledge* as their medical director Melvin Sabshin claimed it represented the victory of "*science over ideology*" (Sabshin, 1990, p. 1272).

Mayes and Horwitz (2005), however, contested this notion that great scientific advancement underpinned the move to a symptom-based model arguing that DSM-III

simply provided psychiatry with a standardised system of measurement that was beneficial to a number of stakeholders. In their critique Mayes and Horwitz (2005) point out that influential psychiatrists involved in research gained a reliable means of measuring mental illness. They added that for clinicians the categorical system provided the evidence that the *disorders* they were engaged in treating were real. They noted also that as an atheoretical system for the classification of illnesses, that relies only on symptoms independent of cause, it was suitable for use by all clinicians regardless of their theoretical orientation. They concluded that this new classification system also conveniently facilitated reimbursement from insurance providers and met the needs of the burgeoning psychopharmacology industry. Other critics argued that this new system of classification negatively impacted patients through the increasing medicalisation of social ills that inevitably led to the widespread and inappropriate prescribing of psychotropic drugs (Kutchins & Kirk, 1988; Szasz, 2007). Regardless of the critics, supporters of DSM-III (APA, 1980) revelled in its success as it was widely adopted by stakeholders that included clinicians, researchers, insurance companies, and the pharmaceutical industry. In this way DSM-III did in effect serve to *legitimise* psychiatry as a specialist branch of biomedical practice (Fischer, 2012; Whooley, 2014).

In their critique of the BPD diagnostic construct Zanderson et al. (2019) argue that the operational impact of DSM-III that resulted in a seismic epistemological shift, from a diagnostic process grounded in psychoanalytic theory to a system of diagnosis that involves identifying the correct number of criteria from a list of specified signs and symptoms, is often underestimated or goes unrecognised. Using the example of the BPD diagnosis the authors assert that the so-called operationally defined criteria are not operational in any scientific or theoretical sense since they comprise only brief lay-language descriptions that are devoid of narrative context, lack any conceptual framework, and are open to multiple interpretations. They add that to distinguish the diagnostic categories commonly co-occurring phenomena, including anxiety or depressed mood, were mostly removed. This led to the pared-back criteria that remained

becoming unduly reified as they were considered to provide a comprehensive view of the disorder (Zanderson et al., 2019).

A new hierarchical system of multi-axial coding was also incorporated in DSM-III (APA, 1980) wherein personality disorders were coded on the second axis indicating their conceptualisation as pervasive and enduring. Under Axis II personality disorders were grouped into three clusters (A, B, and C) based on similarity of symptoms. Together with antisocial, histrionic, and narcissistic personality disorders BPD was subsumed under Cluster B. This sub-group of personality disorder diagnoses is characterised in terms of *emotionality* or *unpredictability* (Campbell et al., 2020; Sheehan et al., 2016). The description of Cluster B personality disorders in DSM-III (APA, 1980, p. 307) states that “*individuals with these disorders often appear dramatic, emotional, or erratic.*” This characterisation of Cluster B personality disorders as a “dramatic-emotional-erratic” group persists through the subsequent revisions of the DSM and therefore permeates the published literature and media content related to the Cluster B diagnoses (Kraus & Reynolds, 2001; Vanta, 2024; Young et al., 2018). This is a significant issue in terms of potential stigma since recent studies have found that the descriptors and specific terms used in diagnostic manuals may contribute to negative and pejorative attitudes among clinicians towards people diagnosed with personality disorders which may in turn result in discriminatory behaviours (Hein et al., 2024; Lagunes-Cordoba et al., 2021).

Eight diagnostic criteria, developed based on groups of *symptoms*, were agreed for the diagnosis of BPD in DSM-III (APA, 1980). Said to emerge in adolescence, or early adulthood, these criteria span the domains of affectivity, interpersonal functioning, impulsivity, and cognition. Where a person consistently met a minimum of five of those criteria the diagnosis of BPD was given (Goldstein, 1983). A ninth criterion of transient dissociation was added as a minor revision in DSM-III-R (APA, 1987). There were some minor changes made to the wording for the diagnosis of BPD in DSM-IV (APA, 1994) the criteria for which are set out in Table 2-1.

Table 2-1: Diagnostic criteria for BPD (APA, 1994)

Diagnostic criteria for BPD in DSM-IV (APA, 1994)
A pervasive pattern of instability of interpersonal relationship, 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
2. A pattern of unstable and intense personal relationships characterised by alternating between extremes of idealisation 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)
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 in controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights)
9. Transient, stress-related paranoid ideation or severe dissociative symptoms

The multi-axial diagnostic structure was later discontinued as no longer relevant in DSM-5 (APA, 2013). Otherwise, the diagnostic criteria for BPD have remained essentially intact through successive revisions spanning more than 40 years through to the latest edition DSM-5-TR (APA, 2022) as defined in section 2.3.1.

2.3 Defining the diagnoses of BPD and EUPD

As is evident from the complex nosological histories previously outlined in this chapter (2.2.4) the psychiatric diagnoses of BPD and EUPD are closely related core concepts which although constructed within different psychiatric taxonomies have shared origins. Until recently either of these diagnoses could be employed to diagnose what is described,

from a medical perspective, as a *severe mental disorder* that is characterised by pervasive patterns of emotional dysregulation, identity disturbance, and interpersonal difficulties (Bohus et al., 2021). Since ICD-11 (WHO, 2019) became fully enacted the diagnosis of EUPD is no longer given as discussed later in this chapter (2.3.2). Because these similar, though not identical, diagnoses share numerous overlapping diagnostic criteria and describe similar patterns of mental health difficulties, that are discussed in the following sections, they are often used interchangeably both clinically and in research.

2.3.1 BPD diagnosis defined

The most recently revised edition of the psychiatric taxonomy DSM-5-TR¹ (APA, 2022) retains the traditional polythetic system for diagnosing BPD that requires five out of nine criteria to be present to make the diagnosis. The use of this diagnostic system that Fowler et al. (2021, p. 203) describe as “*far from optimal*” allows for 256 possible combinations of criteria that can result in a diagnosis of BPD. The lack of specificity and high degree of heterogeneity in the BPD diagnosis is the subject of ongoing debate among clinicians and researchers (Cavelti et al., 2021; Rufino et al., 2017; Skodol, 2014). A discussion of the ongoing development of an alternative model for conceptualising personality disorder within the DSM follows in section 2.4.1. Currently, however, BPD continues to primarily be diagnosed under Section II of DSM-5 (APA, 2013, p. 663) where it is characterised 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.*” Briefly, the diagnostic criteria include: fear of abandonment, patterns of unstable relationships, identity disturbance, impulsive behaviour, suicidality, affective instability, chronic feelings of emptiness, *inappropriate* intense anger, and transient stress-related paranoia or severe dissociation.

¹ The changes in terms of DSM-5 diagnosis of BPD discussed in this thesis were first introduced in DSM-5 (WHO, 2013). The latest text-revision DSM-5-TR does not make any updates to the diagnostic system for BPD. Details are available here: <https://www.psychiatry.org/psychiatrists/practice/dsm/about-dsm>

2.3.2 EUPD diagnosis defined

Introduced in ICD-10 (WHO, 1994), the diagnosis of EUPD is conceptually very similar to the diagnosis of BPD and is characterised by:

“a definite tendency to act impulsively and without consideration of the consequences; the mood is unpredictable and capricious. There is a liability to outbursts of emotion and an incapacity to control the behavioural explosions. There is a tendency to quarrelsome behaviour and to conflicts with others, especially when impulsive acts are thwarted or censored” (WHO, 1994, p. 323).

Two subtypes of EUPD were identified within the classification: the impulsive type and the borderline type. The impulsive type is categorised as “*emotional instability and lack of impulse control*” while the borderline type is characterised “*in addition by disturbances in self-image, aims and internal preferences, by chronic feelings of emptiness, by intense and unstable interpersonal relationships, and by a tendency to self-destructive behaviour, including suicide gestures and attempts*” (WHO, 1993, p. 323).

In what Tyrer et al. (2019) describe as a radical change to the classification of personality disorder in ICD-11 (WHO, 2019) the categorical system was replaced with a new dimensional model which led to the abolition of the ten personality disorder categories that were previously classified in ICD-10 (WHO, 1994). An overview of this new model for the diagnosis of personality disorder and an outline of the relevant *borderline pattern descriptor* as a predominant trait is presented in section 2.4.2. Following a three-year period of transition, as the WHO member countries migrated from ICD-10 (WHO, 1994) to ICD-11 (WHO, 2019), the provisions of ICD-11 are now fully enacted and it is operational across 35 countries since early 2022. It follows that the EUPD diagnosis is now defunct, however, in the context of this inquiry EUPD remains relevant as the diagnosis given to most of the women each of whom was diagnosed prior to the introduction and implementation of ICD-11.

2.4 Current taxonomies and the BPD diagnosis

The classification of personality disorders, in both the DSM and ICD taxonomies, has long been criticised by both clinicians and researchers for its lack of utility due to high levels of overlap with (multiple) other diagnoses, within-diagnosis, and an over-reliance on a not-otherwise-specified (NOS) diagnosis (Clark et al., 1997; Skodol et al., 2002; Widiger & Trull, 2007). A shift to a dimensional approach was therefore considered by many as long overdue (Benzi et al., 2020; Krueger, 2013; Tyrer, 2012). The latest editions of both taxonomies developed through extensive, and often contentious, periods of consultation promised significant change each heralding new and more dimensional approaches to personality disorder diagnosis. As a result there are currently three systems of classification for personality disorder across Sections II and III of the DSM-5-TR (APA, 2022) and in Chapter 6 of ICD-11 (WHO, 2018) as outlined in Table 2.2. It is evident, however, in the following sections that the final published versions of each of the new models fell somewhat short of the anticipated level of change (Pickersgill, 2014; Tyrer et al., 2019). Of note each of the three classifications currently in use allows for the diagnosis of BPD in adolescents from the age of 12 years.

Table 2-2: DSM-5-TR (APA, 2022) & ICD-11 (WHO,2019) BPD classifications

DSM-5-TR (APA, 2022) Classification systems for the diagnosis of personality disorder:	
1.	The categorical model for the classification of personality disorders appears in DSM-5-TR Section II: <i>Diagnostic Criteria and Codes</i>
2.	The alternative model for personality disorders [AMPD] appears in DSM-5-TR Section III: <i>Emerging Measures and Models</i>
ICD-11 (WHO, 2019) Classification system for the diagnosis of personality disorder:	
1.	The new model for the classification of personality disorders appears in ICD-11 Chapter 6: <i>Mental, behavioural or neurodevelopmental disorders</i>

2.4.1 The DSM classifications of BPD

It was expected from the outset of the revision process for DSM-5 that the classification of personality disorders would change to incorporate a dimensional component (Zachar et al., 2015). The Personality and Personality Disorders Work Group developed an initial proposal that was rejected as too radical. They proceeded to develop an alternative hybrid model of personality disorder (AMPD) that retained six categories of personality disorder but also adopted a dimensional approach that assesses the severity of *maladaptive personality functioning* as opposed to merely identifying the presence or absence of criteria using a categorical approach (Benzi et al., 2020). However, in its final deliberations the Board of the APA also ultimately rejected the AMPD for inclusion in the main section (II) of DSM-5 as it was considered overly-complex and its clinical utility was called into question (Oldham, 2022). The Board chose instead to retain unchanged the categorical model contained in DSM-IV (1994). However, the AMPD was included as an alternative classification in Section III “Emerging Measures and Models,” ostensibly so that it may be further researched and used clinically to diagnose BPD, using the criteria outlined in Table 2-3.

Table 2-3: AMPD criteria for BPD DSM-5-TR (APA, 2022)

Diagnostic criteria for BPD in AMPD DSM-5-TR: Section III		
Criterion A: A pervasive pattern of instability of interpersonal relationship, self-image and affects, and marked impulsivity beginning by early adulthood and present in a variety of contexts, as indicated by 5 (or more) of the following:	Criterion B: Four or more of the following seven pathological personality traits, at least one of which must be 5, 6 or 7	
1. Identity	1. Emotional lability	5. Impulsivity
2. Self-direction	2. Anxiousness	6. Risk taking
3. Empathy	3. Separation insecurity	7. Hostility
4. Intimacy	4. Depressivity	

*Table adapted from Leichsenring et al. (2024)

2.4.2 THE ICD-11 classification of personality disorder

In ICD-11 (WHO, 2019) the categorical system for the classification of personality disorder was replaced with a new dimensional model (Mulder et al., 2020; Tyrer et al., 2019). This new model is described as providing an opportunity for clinicians to direct their conceptualisation of a person's emotions, thoughts and behaviours towards a psychological case formulation that considers these patterns as the person's best attempt at functioning in what are often suboptimal environments (Swales, 2022). The new model has a requirement of two steps for assessment and two optional additional steps if required. As described by Swales (2022) the model first directs the clinician to assess whether the difficulties the person is experiencing in terms of *disturbances* in aspects of both self and interpersonal functioning meet the general requirements for a diagnosis of personality disorder as that include disturbances that are enduring for a minimum of two years as follows:

- *self-dysfunction* may include: persistent problems in maintaining a stable sense of identity; a persistent perception of an over or under-valued sense of self-worth; an inaccurate perception of self; or difficulty with self-direction and decision-making
- inter-personal difficulties that include: ongoing challenges with establishing and maintaining close relationships; problems understanding the perspectives of others, and/or; managing conflict in relationships

Maladaptive patterns of cognition, emotional response and behaviour associated with these two primary features must be evident across a number of social or personal contexts. If this threshold is met the clinician's next step is to assess the *impairment* according to level of severity that ranges from *personality difficulty* to mild, moderate or severe *personality disorder*. The clinician may then choose to specify one or more trait qualifiers, that are deemed to contribute to the *personality impairment*, from across five domains of: negative affectivity; detachment, dissocialise, disinhibition, and anankastia.

This new model for the classification of personality disorder was originally intended to end with the identification of the trait domains. However, on foot of extensive lobbying by the clinical and academic communities regarding the proposed changes the new model was amended to include the option to add a *borderline pattern descriptor* (Reed, 2018; Tyrer et al., 2019). The demand for the retention of the *borderline* diagnosis ostensibly related to concerns regarding equity and continued access to specialised treatments for people who needed them (Herpertz et al., 2017). As a result of this change once the level of severity of *personality dysfunction* and domain traits have been determined a *borderline pattern specifier* may be applied that essentially has the same diagnostic criteria for BPD as those in the DSM, as outlined in Figure 2-2. The primary reason given for allowing this change was so that no one was disadvantaged by the removal of the borderline/emotionally unstable personality disorder diagnosis since in some jurisdictions payment for some specialist treatment is contingent on having a BPD diagnosis (Tyrer et al., 2019).

Figure 2-2: Borderline pattern specifier in ICD-11 (WHO, 2017)

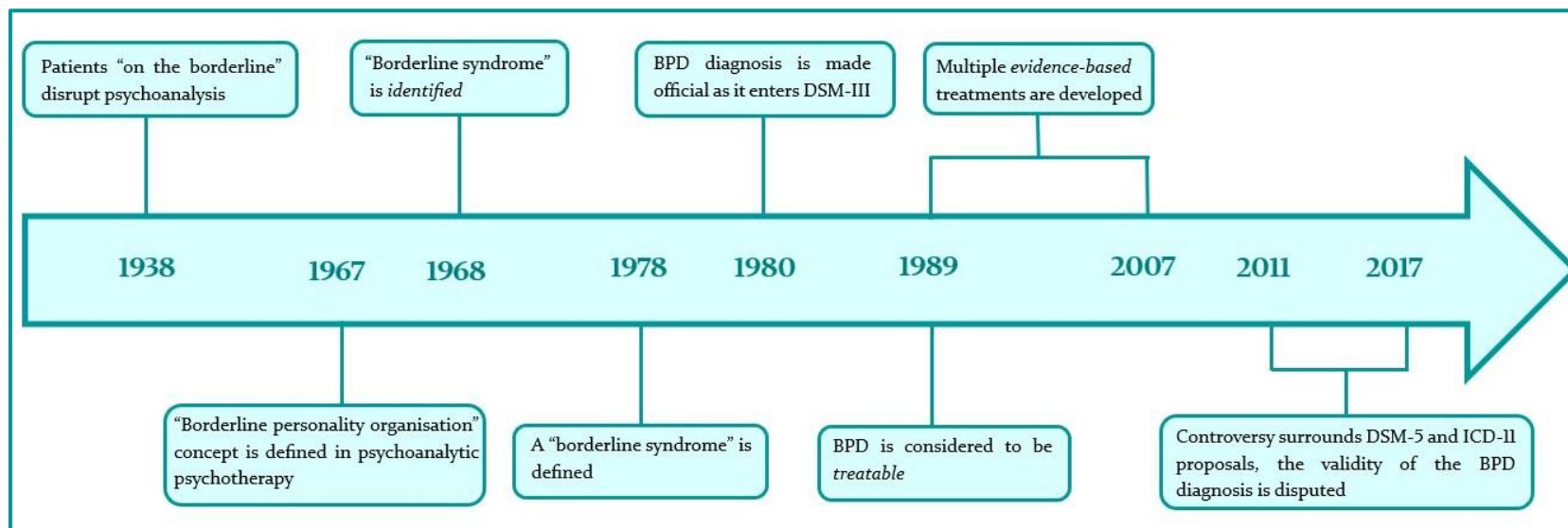
Borderline pattern specifier in ICD-11 (WHO, 2019)
The borderline pattern specifier may be applied to individuals whose pattern of personality disturbance is characterised by a pervasive pattern of instability of interpersonal relationships, self-image and affects, and marked impulsivity, as indicated by five (or more) 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
Coding Note: This category should ONLY be used in combination with a Personality disorder category (Mild, Moderate, Sever) or Personality difficulty

There is also an option to consider during the diagnostic process three additional *manifestations of the borderline pattern*:

- (i) a view of self as inadequate, bad, guilty, disgusting and contemptable
- (ii) an experience of the self as profoundly different and isolated from other people; a painful sense of alienation and pervasive loneliness
- (iii) proneness to rejection hypersensitivity, problems with trust, and misinterpretation of social signals (WHO, 2019).

Overall, it appears that little has changed in terms of personality diagnosis despite the advent of two new models of classification. The significant U-turns made at the behest of powerful interest groups during the most recent major revisions of both the DSM and the ICD have meant that neither system fully embraced the adoption a new dimensional approach to the classification of personality disorder and the BPD diagnosis remains. In a commentary published in *The Lancet*, lived experience activist and consultant clinical psychologist, Dr Jay Watts argues that there is lack of scientific evidence for the inclusion of the *borderline pattern* in ICD-11. Watts (2019, p.462) emphasises this point by quoting Tyrer et al. (2019, p.494) who found “*a notable absence of sound scientific evidence that it is a unified syndrome.*” Watts (2019) adds that the retention of the *borderline* diagnosis undermines the scientific legitimacy of the new dimensional classification model while disadvantaging those who find diagnosis validating by perpetuating a highly contested diagnosis. Furthermore, the author challenges the notion that the inclusion of the *borderline pattern* is a pragmatic compromise that is universally acceptable as claimed by Tyrer et al. (2019). Watts (2019) argues vehemently against its acceptability for patients, predominantly women who have experienced trauma, whose voices mostly remain unheard and who remain subjugated by this misogynistic diagnosis. A timeline depicting the major milestones in the evolution of BPD is illustrated in Figure 2.3.

Figure 2-3: Milestones in the development of the *borderline* construct



2.5 Prevalence of any personality disorder diagnosis and of BPD

In a psychiatric system dominated by the biomedical model personality disorders, although contested in terms of construct validity, continue to be recognised and diagnosed and therefore are reported in the literature as being among the most commonly experienced *psychiatric conditions* (WHO, 2009; Trull et al., 2010; Winsper et al., 2019). The most recent and comprehensive systematic review and meta-analysis of the prevalence of personality disorders in the community, conducted by Winsper et al. (2019), examined data from 46 studies from 21 countries across six continents (Africa, North America, South America, Asia, Australia/Oceania, and Europe). The pooled prevalence for any personality disorder was found to be significantly lower in low- and middle-income countries (LMIC) than in high-income countries. The review authors suggest there could be a number of explanations for this finding. First, they suggest that there is a potentially lower level of population risk in LMICs that possibly relates to social or cultural factors, for example, variations in behavioural expectations across countries that have individualistic versus collective societies. Next, they consider that varying levels of social control across countries may inhibit antisocial behaviours. The review authors argue further that some diagnostic criteria may not be relevant or meaningful across countries and societies. Their final argument is that variations in assessment tools and the heterogeneity of included study designs could also be a factor in the disparity of prevalence rates for personality disorder between LMIC and high-income countries (Winsper et al., 2019). The final meta-analysis revealed a global pooled prevalence rate for any personality disorder of 7.8%. This exceeds the global prevalence for mood disorders of 5.4% and anxiety disorders of 6.7% as established in a systematic review and meta-analysis, conducted by Steel et al. (2014), that included 174 studies published between 1980 and 2013 across 37 LMICs and 26 high-income countries. In comparison to other psychiatric labels personality disorder diagnoses are among the most stigmatised (Hein et al., 2024; Sheehan et al., 2016). The life expectancy of people diagnosed with personality disorder is also estimated to be shorter, by almost 20 years, in comparison to the general population (Fok et al., 2012; Temes et al., 2019). The suicide rate among people

diagnosed with BPD, for example, has been estimated at 5-10% (Black et al., 2004; Broadbear et al., 2020; McGirr et al., 2007; Paris, 2019).

From a national perspective, the Health Research Board (HRB) in Ireland produce an annual report that provides comprehensive data on all admissions, length of stay, and discharges (including deaths) across all 67 Irish psychiatric hospitals and units that are registered as Approved Centres for the reception and treatment of patients by the Mental Health Commission (MHC) under the Mental Health Act 2001 (MHA; Department of Health and Children [DoHC], 2001). Although this document does not report specifically on rates of hospital admission for individuals with a primary admission diagnosis of BPD the statistics presented in their most recently published report (Daly et al., 2023) under the category of “personality and behaviour disorders” are indicative of the prevalence and significance of personality disorder diagnoses in inpatient mental health settings in Ireland. In total across all mental health diagnostic categories there were 15,631 admissions to adult psychiatric units and hospitals in Ireland in 2023. This represents a rate of admission of 303 per 100,000 total population. Of those 5,838 were first admissions (37%) and 9,793 were re-admissions (63%). 7,771 (49.7%) of all admissions were identified as male and 7,860 (50.3%) were identified as female. 13,130 of all admissions (84%) were voluntary and 2,501 (16%) were involuntary. Under the category of “personality and behavioural disorders” there was a total of 1,282 admissions reported in 2023 representing a rate of admission of 24.9 per 100,000 total population and 8.2% of all admissions. Of those, 290 (22.6%) were first admissions and 992 (77.4%) were readmissions. 340 (26.5%) of those in this group were identified as male and 942 (73.5%) were identified as female. 1,184 (92.4%) of those admissions were voluntary and 98 (7.6%) were reported as involuntary. In terms of length of stay 674 (48.1%) of those admitted in this category were discharged in under 1 week, 253 (18%) were admitted for 1-<2 weeks (13.9%), 194 for 2-<4 weeks, 234 (16.7%) for 1-<3 months, and 42 (3%) were admitted for between 3 months and 1 year. The total number of discharges (including deaths) for this group in 2023 were reported at 1,400 representing 9% of all discharges and the total number of inpatient days reported was 31,075 (4.2% of all inpatient days), the average

number of inpatient days per admission was 22.2. It is evident from these statistics that the prevalence of personality disorder diagnosis among people accessing inpatient mental health services in Ireland is significant, women in this category outnumber men in a ratio of almost 3:1, and for most of those admitted their admission is brief (<1-2 weeks) which may be indicative of crisis admissions.

2.5.1 Prevalence of BPD

An internationally recognised guidance document for the treatment and management of BPD commissioned by the National Institute for Health and Clinical Excellence (NICE) and developed and published by the National Collaborating Centre for Mental Health Services (2009) found only three methodologically rigorous surveys that examined the community prevalence of BPD (Coid et al., 2006; Samuels et al., 2002; Torgensen et al., 2001). Although methodologically diverse these three surveys arrived at very similar prevalence rates and a median prevalence rate for BPD of 0.7% was determined. This aligns with the lower end of prevalence rates for BPD in the general adult population estimated respectively in more recent reviews by Eaton and Greene (2018) at 0.7-1.2% and Ellison et al. (2018) at 0.7-2.7%. Prior to the publication of those reviews a lifetime prevalence rate of 5.9%, that was determined in a large epidemiological study conducted in the United States with more than 40,000 participants, was commonly cited (Grant et al. 2008). However, this rate was subsequently revised downwards to 2.7% by Trull et al. (2010). This revised prevalence rate emerged as a result of the researchers' adjustment to the original algorithms to ensure that the scoring reflected whether there was a significant level of distress or impairment present for each of the BPD criteria. The "Adult Psychiatric Morbidity Survey" (APMS) is a cross-sectional survey that is conducted every seven years on behalf of National Health Service (NHS) Digital in England. Using consistent methods the survey screens for a range of "*common mental disorders, substance disorders and self-harm behaviours*"(McManus et al., 2016, p. 8). The purpose of the APMS is to provide statistics for the monitoring of mental illness and treatment access in the nation's household population. The fourth and most recently reported

APMS survey was conducted by NatCen Social Research in collaboration with the University of Leicester in 2014 during which a representative sample of the household population of 7,500 people were screened. As a component of the survey the self-completion Structured Clinical Interview for DSM-IV Personality Disorders (SCID-II) screening tool (Gorgens, 2010) was administered among 16-64 year old participants to screen for BPD and for antisocial personality disorder (ASPD). The results reported by Moran et al. (2016) show that 2.4% of people in the 16-64 age group screened positive for BPD. The difference in the prevalence rate between men and women screened was not statistically significant. Lewis et al., (2019) emphasise the high rate of healthcare utilisation among people diagnosed with BPD. Prevalence rates for BPD in clinical settings as reported by Ellison et al. (2018), from their review of community and clinical epidemiology of BPD, were 10-12% in outpatient psychiatric clinics and 20-22% within inpatient settings.

BPD is widely perceived as a predominantly female disorder both within clinical settings and from a research perspective as indicated by Qian et al. (2022) and Bozzatello et al., (2024) in their respective reviews that consider gender, or sex, differences in the diagnosis of BPD. Qian et al. (2022) highlight by way of example the DSM-5 (APA, 2013) assertion that 75% of people diagnosed with the disorder are women. However, both reviews indicate that more recent epidemiological studies have revealed conflicting data and a lack of conclusive evidence on the differences in prevalence rates for BPD between men and women. This aligns with earlier findings on gender differences reported in the NICE guideline on BPD (NICE, 2009). In Chapter 3 (3.3.2) I explore further the issue of gender bias in the diagnosis of BPD.

In the Irish context a lack of information on the overall prevalence of *mental health disorders* among the general adult population in Ireland prompted a study by Hyland et al. (2022) that examined the prevalence of 12 *common mental disorders* by measuring the proportion of adults from a nationally representative sample (n = 1100) who screened

positive using self-report measures for any of the 12 *disorders* under consideration including four *personality disorders*. Overall, 42.5% of those screened met the criteria for a mental health diagnosis. Item measures derived from “The Structured Clinical Interview for DSM-IV Axis II Disorders” (First et al., 1997) were used to screen for the prevalence of specific personality disorders with the following results: (i) avoidant personality disorder (14%), where the diagnostic threshold was met if six of seven symptoms were indicated; (ii) BPD (6.8%) if seven of nine symptoms were indicated; (iii) schizoid personality disorder (5.7%) if six of seven items were indicated, and; (iv) histrionic personality disorder (1.7%) if all six *symptoms* were indicated. Hyland et al. (2022) acknowledge the limitations of this study, firstly, in terms of sampling they recognise that although efforts were made regarding representativeness the results may not generalise to the entire adult population in Ireland. Secondly, they accept that self-report measures are recognised as producing higher prevalence rates than structured clinical diagnostic interviews (Levis et al., 2020). In an effort to mitigate this effect the researchers stringently applied cut-off scores for each measure ensuring the strictest possible criteria for reaching the diagnostic threshold, however, they acknowledge that their findings may represent an inflated prevalence of mental health disorders in the Irish population. Despite its limitations this study is important in the context of this inquiry in that it provides the most recent and the most comprehensive assessment of the community prevalence, from a biomedical model perspective, of BPD in Ireland.

2.6 National and international guidelines and policies

Given the global significance of the issues related to personality disorder diagnoses Wong et al. (2023) recognised the importance of systematically identifying and synthesising the recommendations from the evidence-based guidelines available internationally for the treatment and care of individuals diagnosed with personality disorder. In their review Wong et al. (2023) included 29 guidelines and consensus statements drawn from across 11 countries and one that was developed by an international organisation. The breakdown of guidelines per country was reported as: UK (n = 10), Australia (n = 5), the Netherlands

(n = 3), Spain (n = 3), and one each from Canada, Denmark, Finland, Italy, Sweden, Switzerland, and the United States. The majority of the guidelines reviewed were produced by government agencies (n=24) and the remainder were published by voluntary organisations (n=5). Twenty of the guidelines selected for inclusion in the review addressed personality disorder generally, eight specifically focused on BPD, and one provided guidance on antisocial personality disorder. Wong et al. (2023, p.8) identified four “organising domains”, that encompassed 27 themes, from among the recommendations of the different guidelines: (i) recipients of services, (ii) service delivery, (iii) staff, and (iv) treatment.

The key principles for which they found consensus in the guidelines included: continuity in care, equitable access, accessible services, provision of specialist care, prioritising a whole-systems approach, a trauma-informed perspective, and collaboration in care planning and decision making. However, while the review found that the themes identified in the guidelines aligned with the needs and priorities of individuals diagnosed with personality disorder as identified by Rains et al. (2021) and Trevillon et al. (2022) most participants in those studies reported negative experiences in services. The reviewers concluded therefore that the problem is not with the guidelines’ recommendations per se but rather with their dissemination and implementation in services. Another issue identified in the review related to the variation of quality in the guidelines only twelve of which were assessed as high quality. A lack of evidence to support the development of evidence-based guidelines was identified and most of the guidelines scored low on quality in relation to the evidence base for their recommendations. This prompted Wong et al. (2023) to call urgently for more high-quality research in the area of personality disorder treatment and the further development and dissemination of high-quality guidance. This would support the development of an internationally recognised consensus on best practice for mental health care provision for people diagnosed with personality disorders.

In the Irish context a position paper published by the College of Psychiatrists of Ireland (2021) identified as significant the level of unmet need in terms of service provision and treatment options for people diagnosed with personality disorder. The authors indicate that Ireland lags seriously behind other comparable countries specifically in the provision of evidence-based treatment options for people diagnosed with personality disorder. The paper therefore calls upon the country's public health service, the Health Service Executive (HSE), and government policy makers to develop a national strategy for the treatment of personality disorders. In reviewing current mental health policy provision for the care and treatment of people diagnosed with personality disorder in Ireland the authors are critical of recent developments. They highlight positive advances made under the previous national policy for mental health "A Vision for Change" (Department of Health [DoH], 2006) that made specific recommendations regarding the provision of evidence-based treatment for people diagnosed with BPD and the development of clinical expertise which led to the promotion of DBT training among mental health staff that was resourced through the National Office for Suicide Prevention. However, the position paper is critical of a perceived regression in the current Irish mental health policy "Sharing the Vision – A Mental Health Policy for Everyone" (DoH, 2020) that is evident in its failure to include any recommendations for the provision of services for people diagnosed with personality disorder, nor is there any reference to personality disorders in the section on suicide prevention.

Having highlighted, from the biomedical perspective, the current issues in treatment provision for personality disorder the key recommendations of the College of Psychiatrists of Ireland (2021) included: (i) the development of a national strategy for the treatment of personality disorders in Ireland, (ii) the establishment of evidence-based treatment services, and (iii) the development of clinical expertise in personality disorder treatment. The proposed development of a national strategy for people diagnosed with personality disorder would ensure that adequate resources would be made available to develop an appropriate model of care and a national clinical programme. This would in turn support the development of standardised structured services for the provision of

evidence-based treatments delivered by appropriately trained and resourced clinicians in line with the existing care pathways for other mental health diagnoses in Ireland so delivering on the promise embedded in “Sharing the Vision: A Mental Health Policy for Everyone” to deliver a mental health policy “for all of the population” (DoH, 2020, p. 13).

Another factor that impacts access to acute care for individuals diagnosed with BPD in Ireland relates to mental health legislation and the fact that a person may not be involuntarily admitted to an approved centre for treatment under Section 3 of the MHA 2001 (DoHC, 2001), solely on the basis of their personality disorder diagnosis. Under Section 8(2) of the Act the involuntary admission of a person to an approved centre is expressly prohibited by reason only of the fact that the person:

- (a) is suffering from a personality disorder
- (b) is socially deviant; or
- (c) is addicted to drugs or intoxicants

Individuals diagnosed with BPD, or other personality disorders, therefore may only be admitted involuntarily if there are also deemed to be experiencing a mental disorder and meet other additional criteria also set out Section 3 of the Act. Reidy and Kelly (2021) suggest that one of the arguments for considering personality disorder as separate to “mental disorder” in this context relates to the perception of some personality disorders as chronic and enduring in nature which has sometimes meant they have traditionally been considered untreatable. Another argument for the exclusion is related to the widespread belief that involuntary hospitalisation is unlikely to provide a significant therapeutic benefit for people diagnosed with personality disorder who do not have any comorbid mental health diagnosis. This relates to the perception that personality disorder treatment is typically long-term and so should be community based. However, James (2006) argues that given the high rates of attempted suicide and of suicide completion among people diagnosed with BPD the exclusion of people with a personality disorder diagnosis from involuntary admission would appear to contravene suicide prevention objectives. The provisions of the New Mental Health Bill, published in Ireland

in July 2024, that are based on the recommendations of an Expert Review Group of The Mental Health Act 2001 indicate that personality disorders remain on the exclusion list for involuntary detention (Butler, 2024).

2.7 Current debates

My initial exploration of the published literature on BPD revealed a wealth of studies that carry a fundamental a priori understanding of BPD as a *true entity* from the biomedical perspective. Looking critically at BPD, from a social constructionist standpoint, I sought to engage more broadly with the literature to capture the critical discourses that challenge the dominant narratives surrounding BPD. This section of the chapter briefly explores the contemporary critical debates that influenced my approach to this inquiry.

2.7.1 The medicalisation of distress

Looking at the concept of psychiatric diagnosis from a sociological perspective led me to consider the critical arguments that exist around psychiatry's medicalisation of distress that becomes labelled as mental illness (Busfield, 2017; Conrad & Bergey, 2015; Maj, 2012; van Dijk et al., 2019). In their paper that reassesses the concept of medicalisation and confirms its contemporary relevance Busfield (2017) traces its origins from the field of medical sociology from the late 1960s when medicalisation was defined by Pitts (1968, p. 391) as "*one of the most effective means of social control.*" Busfield (2017) and van Dijk et al. (2019) identify other significant early contributions to the concept of medicalisation as a form of social control from: Zola (1972) who believed that as it expanded medicine was set to replace religion and law as the new arbiter of social control, and; Illich (1975) who was highly critical of medicine arguing that medicine's power over people's lives led to iatrogenic harm, he also adopted the term "medical colonisation." Busfield (2017) also examines how Foucault (1967, 1973, 1974) conceptualises medicalisation by asserting that one of the key features of medicine's history was the drive to increasingly bring elements of the human body and human behaviour under the realm of medical practice and

discourse. More recently Conrad (1992, p.211) defined medicalisation as: *“defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to treat it.”* Busfield (2017, p.768) makes clear that questioning medical legitimacy in certain domains does not imply a general critique of medicine as a whole stating that: *“[I]t is essential to distinguish the evaluation of particular instances from any general critique of medicine. Indeed description and explanation, not critical evaluation, are often the prime aim of medicalisation research.”*

Busfield (2017) further discusses how the concept of medicalisation was quickly adopted by three diverse groups whose ideas sometimes overlapped: Foucauldians, feminists, and critics of psychiatry. Academics influenced by the ideas of Foucault explored medicalisation, medical surveillance, and the notion of the “medical gaze” that describes how doctors adapt the patient story to fit the biomedical paradigm while filtering out non-biomedical information. This is exemplified in the works of Rose (1994; 2007) who emphasises the cultural impact of psychiatry and critically explores the notion of medicalisation of social space and of the family as examples of how medicine infiltrates people’s lives and meaning-making. From the 1970s onwards concerns grew from the feminist perspective regarding ever-increasing medical control and the power held by doctors, who at that time were typically male. Numerous feminist scholars from diverse backgrounds began to speak out explicitly on the concept of medicalisation. Busfield (2017) cites a study by Caplan et al. (1992), that queries whether *premenstrual syndrome* should be legitimised as a psychiatric disorder, as an example of how feminist authors began to examine the impact of medicalisation on women in relation to their mental health. My interpretation of the women’s narratives in this inquiry is influenced by feminist thinking as discussed in section 2.7.3 and by the critical discourse of postpsychiatry explored in the next section.

2.7.2 The postpsychiatry discourse

Thomas and Bracken (2004) describe having adopted the term “postpsychiatry” to describe the emergence of a new post-modern philosophy that was intended to promote the possibility of and bring to fruition new ways of thinking about mental health practice. In their seminal work that provides a conceptual critique of psychiatry Bracken and Thomas (2001) argued from the postpsychiatry perspective that psychiatry must seek to set aside its positivistic modernist roots to adapt to a postmodern environment. Key to the philosophy of postpsychiatry is the opening up of spaces in psychiatry where alternative perspectives can be accepted as valid and the prioritisation and centrality of the voices of service users or survivors. Postpsychiatry, as conceptualised by Bracken and Thomas (2001), aims therefore to democratise mental health, its goals are outlined as: (i) to recognise the importance of contexts incorporating social, political and cultural realities as central components to the understanding of madness; (ii) to adopt an ethical rather than a technological orientation to mental health practice keeping values to the fore and being open to ways of working with people that explore hermeneutically the meaning of their experiences rather than labelling them, and (iii) to rethink the politics of coercion in mental health practice. Crucially, the philosophy underpinning the postpsychiatry perspective that prioritises the voice of the person with lived experience and takes into account their social, political and cultural contexts is fully congruent with the principles of NI and the LG method (Gilligan et al., 2006; Doucet & Mauthner, 2008) employed in my analysis as discussed in Chapter 4 (4.3.5).

2.7.3 The feminist discourse

BPD is considered a feminised diagnosis given that it is diagnosed in a ratio of 3:1 of women to men (APA, 2013). Given that feminist frameworks seek to locate the individual problem in the broader socio-political context (Berger, 2014) I was motivated to explore the literature to gain an understanding of how the diagnosis of BPD is conceptualised from a feminist perspective. I was drawn first to the seminal works of Ussher (1991, 2011, 2013) on women and *madness*. In her early, often-quoted, book “*Women’s Madness:*

Misogyny or Mental illness?” Ussher (1991, p. 7) argues that “*labelling us mad silences our voices . . . the rantings of the mad woman are irrelevant, her anger impotent.*” In a paper that examines gender bias in psychiatric nosology Ussher (2013) critically examines, from a historical perspective, the medicalisation of femininity over many years and how psychiatric diagnosis has served as a technique to regulate “difficult” women. Ussher (2013) discusses how changes in Western society in the 1960s and 1970s that saw women entering the workforce in huge numbers for the first time led to a change in gender roles and a loss of relevance for the historical diagnosis of hysteria. She agreed with Jiminez (1997) that this did not signify the end of the pathologisation of what both authors refer to as “exaggerated femininity” since hysteria was simply replaced by the diagnosis of BPD. However, as noted by Jiminez (1997), BPD differs from the diagnosis of hysteria in terms of its diagnostic criteria that comprise *symptoms* including emotional lability, impulsivity, and identity disturbance that could be characterised as “feminine” but also the more “masculine” criterion of “intense anger” that is associated with the notion of “dangerousness.” This is an important concept in terms of the perceived stereotype of BPD as someone who is “rageful.” Jiminez (1997, p. 162-3) further describes how the typical person diagnosed with BPD is perceived as a “*demanding, angry, aggressive woman*” who is labelled with a *mental disorder* for behaving in a manner that would be considered acceptable for a man.

In navigating the literature I was also influenced by the work of Potter (2009). In her ground-breaking book “*Mapping the Edges and the In-between: A Critical Analysis of Borderline Personality Disorder*” Potter (2009, p. 4) identifies the book’s core purpose as “*to press questions of to what extent the symptoms of the classificatory disorder BPD represent pathology or, instead, cultural disapproval or social disvalue.*” The author questions the validity of the diagnosis and argues that the diagnosis is significantly influenced by cultural and gender norms. Potter also asserts that clinicians’ preconceptions of the person diagnosed with BPD negatively impacts ethical and therapeutic engagement. My own values and motivations in undertaking this inquiry very much align with this clearly articulated position. Shaw and Proctor (2005) perceive

the diagnosis of BPD as a form of social control. They argue that women who are considered difficult, deviant, or defiant, for having challenged cultural and gender assumptions and norms, are devalued by labelling them with BPD. This demonstrates how the process of individualisation that locates the problem as a *pathology* within the person fails to take into account that, for many women, the *symptoms* of BPD represent a complex coping strategy in the face of abuse or oppression.

The pathologisation of normative femininity will be an important lens through which to filter the findings of this inquiry. Furthermore, deconstructing the concept of madness Ussher (2011) simultaneously recognises and acknowledges the reality of women's distress. She argues that upon close examination of the origins of distress in the context of women's lived experience it could be construed more as a reasonable response than as an indicator of an inner pathology. She recognises also the importance of being sensitive to the notion that even a contested diagnosis, such as BPD, can serve to validate a woman's experiences as "real," dispelling any doubts that they might be "malingering" and that their problems are not the result of "personal failings." These sensitivities are important in the context of my inquiry to make explicit that in denouncing the validity of the BPD diagnosis my intention is not in any way to dismiss or negate the pain and distress that most certainly exist for those to whom this label is applied and neither would I wish to deny that for many people there is utility in the diagnosis on a personal level.

2.7.4 Alternative frameworks for understanding mental distress

In this section I briefly examine two complementary alternatives to the medical model for understanding mental health difficulties that each embrace a holistic and person-centred approach.

2.7.4.1 The Power Threat Meaning Framework: an alternative to functional psychiatric diagnosis

In line with the critical approach in mental health the Division of Clinical Psychology of the British Psychological Society published The Power Threat Meaning Framework (PTMF) in 2018 (Johnstone & Boyle, 2018). The PTMF proposes an alternative framework to existing biomedical psychiatric systems of classification that dominate Western mental health systems. Co-produced with service users the PTMF is built upon psychological, social, and biological research. It proposes a broad framework for the initial identification of patterns that could be employed to make sense of people's problems. A key assumption of the PTMF is that emotional distress and associated troublesome behaviours are understandable responses to certain situations and adversities in life (Johnstone & Boyle, 2018). The PTMF essentially aims to step back from medicalisation and diagnostic labelling to focus on the roles of power, threat, and meaning that shape people's experiences and their responses. It aims to support the construction of non-diagnostic, non-blaming stories about strength and survival, and to inform practice at all levels, from individual to social policy.

The authors envisaged, and embraced, the wider application of the framework outside of clinical and therapeutic settings including research. As an overarching framework, it does not out rule other models of understanding distress. The framework of thinking presented by the PTMF is intended to differ from the predominant psychiatric diagnostic model of such phenomena. Where the latter tends to focus on medicalising human experiences and behaviours, the former aims to position human experiences and behaviours within the various biological, psychological and social contexts that surround them (Johnstone et al., 2019). The basic premise of the framework is to replace the traditional psychiatric approach that asks essentially "what is wrong with you?" with a series of four core questions, depicted in Table 2-4, that aim to elucidate "what happened to you?" For clinical work additional strengths-based questions may be added in accordance with the provisions of the framework.

Table 2-4: The PTMF core questions (Johnstone & Boyle et al., 2018)

The Power Threat Meaning Framework (Johnstone & Boyle et al., 2018)	
1.	‘What has happened to you?’ [How is Power operating in your life?]
2.	‘How did it affect you?’ [What kind of Threats does this pose?]
3.	‘What sense did you make of it?’ [What is the Meaning of these experiences to you?]
4.	‘What did you have to do to survive?’ [What kinds of Threat Response are you using?]

The PTMF is not without its critics, the argument has been made that there is an over-emphasis on trauma that invalidates other experiences of mental illness and madness (Morgan, 2023). The evidence-base and its potential political motivations have been questioned and, overall, initial responses to the PTMF, across various clinical and research fields were mixed as evaluated by Johnstone et al. (2019). However, the use of the PTMF has continued to grow and five years after it was first published Gallagher et al. (2024) conducted a scoping review, the first to look at the body of published PTMF-based studies. The review sought to identify and synthesise the entire body of empirical research that specifically utilized the PTMF in their methodologies since its inception in 2018 (Gallagher et al., 2024). The authors were interested in the characteristics of the included studies, the different ways in which the PTMF had been incorporated in the study methodologies, and the studies’ key findings. Seventeen studies were included in the review, eleven of which were reported in published manuscripts and six of which were reported within three individual doctoral theses. The diversity of included studies in terms of discipline, research methodology, and population was notable. Most studies were conducted within the sub-disciplines of psychology including: clinical psychology (n=7), forensic psychology (n=3), and educational psychology (n=1). The remaining studies focused more broadly on mental health (n=3) and education (n=3). Study populations included: prison officers and prisoners, psychology professionals, mental health service users, and the general public. Of note there were no nursing studies identified (Gallagher et al., 2024). The authors note that the heterogeneity of the

included studies limited the conclusions that could be drawn. What the review did find was that the evidence-base identified had merit. The findings also indicate that the use of the PTMF was valued by the researchers and/or participants. Research studies that employed the PTMF, up to that point, predominantly used qualitative methodologies. Among the qualitative studies included in the review, four adopted the PTMF to inform both data collection and analysis, while six studies used the PTMF to inform data analysis phase only. Eight of these studies used a bespoke hybrid approach to apply inductive and deductive thematic analysis methods. The authors conclude that the initial interest in the PTMF, over the first five years, and the broad span of its application across populations, disciplines, and methodologies is very promising and warrants further research attention.

2.7.4.2 The recovery model in mental health

The recovery model has been hugely influential in reorientating mental health services globally over the past twenty years. Gradually during that time the emphasis has shifted from a wholly biomedical approach that operated from a *deficits* perspective and that was focused on *symptoms* and *functional impairment* towards the adoption of a recovery model that fosters hope and empowerment. The concept of recovery that emerged from the survivor movement in the 1980s grew to become a central component of mental health discourse and a foundation for a more person-centred and holistic approach to mental health policy and practice internationally (Barker & Barker, 2011; Pilgrim, 2008). Recovery in mental health is a multifaceted concept that may be categorised into three types: clinical recovery from medical symptoms; functional recovery meaning improvement in social and occupational skills, and; personal recovery indicating improved self-efficacy (Higgins & McGowan, 2014). Chester et al. (2016) similarly describe clinical and personal recovery and add the dimension of service-defined recovery that refers to the organisation's recovery orientation in terms of policy and vision. Pilgrim (2013) adds that the lack of a single definition and the multiple meanings applied to the concept of recovery have led to confusion and a sense of ambiguity that hinders efforts to operationalise recovery in practice.

In Ireland the publication of *A Vision for Change* (DoH, 2006) policy document signalled a radical change as the recovery model was identified as the preferred model going forward in terms of mental health service provision. The aims of the policy in relation to developing recovery-oriented mental health services were positively received, however, progress in translating recovery from policy into practice was slow due to a lack of guidance or implementation strategy (Higgins & McGowan, 2014). Important developments in the Irish context since the introduction of the recovery model in mental health include the establishment of Advancing Recovery Ireland (ARI) in 2012 and the publication in 2017 of the first national framework for the development of recovery-oriented services (HSE, 2017) which has recently been updated (HSE, 2024). ARI was an initiative designed to bring together service providers, service users, and their families and community supports to work collaboratively on developing mental health services that are more recovery focused. ARI has since merged with the Office for Mental Health Engagement to form the Office of Mental Health Engagement and Recovery whose mission is to ensure the voices of the service users, family members and carers inform the development of mental health services including their design, delivery and evaluation. The literature pertaining to mental health recovery from the perspective of people diagnosed with BPD is explored in the next chapter (3.3.5).

2.8 Chapter summary

This chapter provided context to the inquiry beginning with a brief exploration of the history of the *borderline* concept and the evolution of the BPD diagnosis from the 1930s through to the present day. The contentious diagnoses of BPD and EUPD, as core concepts in this inquiry, were defined and the contemporary classifications of the BPD diagnosis were made explicit. The prevalence and global significance of personality disorder diagnoses, including BPD, were outlined. Extant policy and guidelines relevant to the provision of standardised high quality care for people diagnosed with BPD were examined from a national and international perspective. Each of the discourses and frameworks explored offers a discrete lens through which I review the literature and filter

the analysis and discussion of findings of this inquiry as presented in subsequent chapters. My review of the theoretical and empirical literature is presented next in Chapter 3.

Chapter 3: Literature review

3.1 Introduction

The purpose of this chapter is to present a review of the extant theoretical and empirical literature relevant to this inquiry. Chenail et al. (2010) critically discuss the debate surrounding the role of the literature in qualitative research. They identify how some experts (Creswell, 2003; Lichtman, 2010) recommend a minimal approach to reviewing the literature to avoid bias and any potential influence on the researcher's interpretation of the data while other authors including Marshall & Rossman (2006) and Haverkamp & Young (2007) favour a more conventional approach to reviewing the literature in advance for the purpose of providing context and situating their study within the contemporary research landscape. The purpose of this literature review chapter is twofold as it serves to situate this inquiry within the existing body of research on BPD diagnosis and disclosure and it identifies the gap in knowledge that justifies this inquiry.

3.2 Aetiology of BPD

It is not feasible within the scope of this thesis to examine in detail the numerous theories that have been developed and the multiple aetiologies of BPD that have been proposed. However, it is important to draw from the literature to briefly outline the principal contemporary aetiological theories of BPD for the purpose of providing context to the current discourses that surround BPD in clinical settings. As outlined in a review by Winsper (2018) there has been a significant change in how the aetiology of the BPD diagnosis is understood and theoretical models have evolved from the early research focus in the 1980s on childhood trauma and childhood sexual abuse as major risk factors for BPD. In the 1990s a broad range of new multifactorial diathesis-stress models were developed that considered cognition, attachment, emotion, and social context as well as trauma with each recognising the relevance of these psychosocial risk factors. Winsper (2018) adds that from the mid-2000s the diathesis-stress models were further

developed and expanded with a new focus on exploring developmental antecedents to BPD. Genetic, neural, behavioural, familial and social factors are considered and these theories commonly assert that these risk factors negatively impact psychological processes and impair personal and interpersonal functioning across developmental stages. The principal contemporary theories, as identified by Winsper (2018), that are explored in the sections that follow include the Biosocial Developmental Model (BDM; Crowell et al., 2009), the Emotional Cascades Model (ECM; Selby & Joiner, 2009), Hughes Developmental Model (2012), and the Epistemic Trust and Social Learning Theory (Fonagy et al., 2017).

3.2.1 The Biosocial Development Model

The Biosocial Developmental Model (BDM) of BPD developed by Crowell et al. (2009) builds upon the seminal Biosocial Model of BPD that was developed by Linehan (1993). Linehan's (1993) original model describes BPD as a disorder of emotion regulation that results from *maladaptive responses* that occur when an individual's *biological vulnerabilities* interact with an invalidating environment. An invalidating environment is described by Linehan (1993) as one in which the caregiver's response to a child's expressed emotional needs are erratic, extreme, and inappropriate. This combination of environment and emotional vulnerability results in: hypersensitivity to emotional stimuli; highly intense emotional reactions, and; a delayed return to emotional baseline. Crowell et al. (2009) expand the model by adopting a lifespan approach that identifies impulsivity as a trait linked to early vulnerability. Impulsivity and emotional vulnerability are thought to emerge independently and interact with environmental risk factors which over time contributes to negative social and cognitive outcomes and the development of *maladaptive coping mechanisms* in adolescence that invoke negative reactions and further disrupt development.

3.2.2 The Emotional Cascades Model

The Emotional Cascades Model (ECM) builds upon BDM theories by integrating findings from clinical studies that explore emotional and behavioural dysregulation to further understand the BPD construct. This model suggests that individuals diagnosed with BPD tend to ruminate on negative affect which leads to behavioural dysregulation experience and this in turn results in the individual experiencing what the authors describe as an “*emotional cascade*” (Selby & Joiner, p.2). As emotional cascade is conceptualised as a positive feedback loop wherein emotional intensity is increased by high levels of rumination on negative affect and in turn the increased level of emotional intensity leads to increased rumination. As a result even a low level of emotional stimulus may ignite an intensified emotional response and this cycle may persist over an extended time period. The authors further suggest that because emotional cascades have the potential to engender such negative emotional responses one of the most effective ways for individuals diagnosed with BPD to deal with negative affect is to engage in behaviour that induces physical response, including for example pain related to self-injurious behaviour. Selby and Joiner (2009) furthermore suggest that in this way dysregulated behaviour perhaps functions as a distraction from negative affect for individuals diagnosed with BPD and a means of bypassing the emotional cascade.

3.2.3 Epistemic Trust and Social Learning Theory

Fonagy’s Epistemic Trust and Social Learning Theory builds upon the theory of mentalising which may be defined as the ability to perceive and interpret the mental states of self and others including goals, feelings, beliefs, intentions, needs and desires as a prerequisite to effective emotional regulation. The link between mentalisation and emotional regulation can be traced in part to early developmental experiences and particularly to attachment relationships (Fonagy et al., 2004). As a socially-oriented model of BPD this model expands on the developmental perspective to incorporate the influence of social learning and the impact of cultural knowledge on psychological development (Fonagy et al., 2017;

Fonagy & Luyten, 2018). The role of epistemic trust, meaning the capacity to recognise information or knowledge from others as reliable, trustworthy, self-relevant and transferable to other contexts, and the ability to judge whether to trust or mistrust another is identified as critical to interpreting communication which relates to mentalising ability. Failure to establish epistemic trust whether related to impaired mentalising or adverse experiences impacting trust, or both, can lead to epistemic mistrust. This can lead to guardedness and suspicion related to the actions and motives of others and ultimately a rejection of socially transmitted knowledge (Fonagy & Allison, 2023). BPD is therefore hypothesised to develop from a communication failure that is linked to the loss of capacity at an early stage to form learning relationships. In the case of infants with abusive or negligent caregivers epistemic trust may fail to develop and epistemic mistrust may ensue as an adaptive process (Winsper, 2018). As the infant develops epistemic hypervigilance may ensue in response to over-interpreting (hypermentalising) the actions and motives of others. This can lead to a persistent cycle of *social dysfunction* and mentalising problems that result in a level of emotional dysregulation that is associated with the diagnosis of BPD.

3.2.4 Hughes' Developmental Model

Hughes et al. (2012) developmental model examines BPD from a neuroscience perspective emphasising both emotional and social domains as they consider the how a child's lack of proximity to, or responsiveness from, their caregiver disrupts they development and their ability to form a healthy attachment and self-regulate. The model operates within the context of Coan's (2008, 2010) social baseline theory (SBT). Briefly, SBT suggests that human beings are adapted biologically to seek social connection through proximity to other humans and therefore social isolation has a negative neurobiological effect. The authors argue that emotion regulation is not only an individual but also an interpersonal process which is important given that many of the difficulties encountered by individuals diagnosed with BPD are interpersonal in nature. Hughes et al. (2012) emphasise the importance of relationships and the ability of caregivers to appropriately

respond to and help co-regulate a child's emotional distress (Belsky and de Haan 2011; Mead et al., 2010; Roth and Sweatt 2011). Hughes et al. (2012) further emphasise the importance of the development of effective co-regulation during infancy, achieved through secure attachment relationships, as a prerequisite for successful co-regulation later in life since it strengthens the neural structures underpinning self-control. They argue, for example, that children with low levels of self-control may be rejected by peers which reduces opportunities for developing co-regulation across the lifespan. Hughes et al. (2012) recognise that social isolation is a significant risk factor that relates to loneliness, self-harm, and suicide for individuals diagnosed with BPD. The authors suggest that social isolation in adulthood relates to early attachment issues, including temperament and parenting interactions, and lifelong experiences of inefficient co-regulation.

Winsper (2018) makes an important observation about the future direction of research in light of the new wave of developmental aetiological theories that have emerged in recent years. The suggestion of "*early origins and a developmental unfurling*" of BPD has directed attention towards and prompted prospective research studies in younger community populations with a view to early tracking of populations, assessing for environmental and individual risk factors, and testing for potential mechanisms that contribute to the early development of BPD (Winsper, 2018, p.108). In light of the fact that both diagnostic taxonomies currently in use allow for the diagnosis of BPD in adolescents from the age of 12 this sway in aetiological research towards identifying a developmental model will result in young people, at a very sensitive age, being increasingly at risk of being brought swiftly and controversially into the diagnostic net in the name of research.

3.2.5 A biopsychosocial critique of the aetiology of BPD

A systematic review conducted by Cameron et al. (2019) that comprehensively critiques the literature on the aetiology of BPD using the ecological systems theory

lens considers: (i) the individual including their physical and/or mental health, (ii) the microsystem that includes the individual's immediate relationships, (iii) the mesosystem in which various aspects of the individual's environment interact, (iv) the exosystem that includes the community the individual lives in and their extended family, and (v) the macrosystem that includes the social, cultural and political policies and practices that influence the individual's life (Bronfenbrenner, 1992). Cameron et al. (2019) infer from their review that the predominant discourse surrounding the aetiology of BPD is generated from within the fields of psychology and biology. This drives clinicians to respond from a biomedical model perspective of treating *symptoms* rather than examining the behavioural complexity or social construction of the diagnosis. The authors conclude, from an ecological systems perspective, that the narrow focus in the literature on identifying the aetiology of BPD from a psychological or biological perspective limits understanding. BPD is reduced to a phenomenon that develops in the individual as a disorder and that presents within the micro-system of their intrapersonal and interpersonal relationships. As a result many potential risk factors have been identified including: childhood adversity, genetic factors, temperament, and neurobiological factors. Cameron et al. (2019) suggest that looking at BPD through the ecological systems lens prompts consideration of how structural, political, cultural, and historical factors may also have impacted the individual. Cameron et al. (2019) identify the need for further research to examine the meso, exo, and macro systems of those living with the diagnosis. This model is relevant to my inquiry that seeks to explore the systemic and sociopolitical factors that may be at play alongside the commonly reported psychological, biological and sociological factors.

3.3 Lived experiences of diagnosis and disclosure of BPD

The specific objective of this part of the literature review is to identify and critique the literature that explores the lived experience of diagnosis and disclosure of BPD. The related themes derived from my narrative review of the literature include: the lived experience of receiving the diagnosis of BPD; diagnostic and structural

stigma relevant to BPD; perceptions of healthcare in the context of the diagnosis of BPD; BPD disclosure and decision-making, and; BPD and perceptions of recovery.

3.3.1 The lived experience of receiving the diagnosis of BPD

The debate surrounding the diagnosis of BPD has generated a body of literature that examines both the perceived advantages and disadvantages of this controversial diagnosis. Advantages discussed include a reliable classification for research and for some service users a perceived sense of clarity and validation, and a pathway to accessing treatment (Campbell et al., 2020; Ng et al., 2019). Disadvantages of the diagnosis are discussed in critiques that decry the diagnosis as stigmatising, pathologising and misogynistic (Berger, 2014, Recovery in the Bin, 2019). Despite these ongoing debates and the fact that BPD is the most well-researched of all personality disorders Lester et al. (2020) found that the lived experience of receiving the diagnosis of BPD was poorly reported and therefore embarked on a systematic review of qualitative evidence with the aim of synthesising what was known about the subjective experience of receiving the diagnosis and gaining insight into how people diagnosed with BPD understand and interpret the diagnosis. The inclusion criteria for the review stipulated the following: (i) study data was from the service user perspective; (ii) study data reported specifically on the subjective experience of receiving a diagnosis of BPD, and; (iii) study participants must have a formal diagnosis of BPD. The review included 12 papers, published between 1999 and 2017, that reported data from 172 individuals diagnosed with BPD, 129 of whom were female and 43 of whom were male. The two overarching themes derived from the evidence were identified as positive and negative experiences of receiving a diagnosis of BPD, the subthemes of which are discussed in the sections that follow.

A qualitative thematic synthesis by Sheridan Rains et al. (2021) that includes 47 papers from 44 peer-reviewed studies reporting data from 1,531 service users on

their experiences and perspectives on good community mental health care for adults with complex emotional needs (CEN) also provides evidence relevant to the lived experience of receiving a diagnosis of personality disorder including BPD. The rationale for including this synthesis is that while it does not exclusively focus on BPD nonetheless it includes 28 studies that report data from people diagnosed with BPD, 12 studies whose samples include people with mixed personality disorder diagnoses, four studies with mixed samples of people with either a personality disorder diagnosis or those who self-identify with the diagnosis, two studies that include service users of a specialist personality disorder service whose specific diagnosis is not revealed, and one study whose participants have a history of repeated self-harm. It can be argued therefore that the findings are very relevant to this inquiry. And, although service users' experiences of receiving their diagnosis was not the main focus of their synthesis the authors reveal that many of the included studies discuss service users' perspectives on receiving a personality disorder diagnosis adding that the impact of the diagnosis on the provision of care in mental health services was often reported as profound. The included studies were conducted in the United Kingdom (n=28), Europe (n=8), Australia (n=5), the United States (n=3), and the rest of the world (n=3) and were published between 2003 and 2019 (Sheridan Rains et al., 2021). Of the 34 studies that reported on the sex of the study participants the statistics are as follows: 100% female (n=9); >80% female (n=13); >70% female (n=9), >60% female (n=1), and; >50% female (n=2), samples reported indicate a typically low rate of male-identified participants and none of the studies reported a higher ratio of male to female participants. Other relevant findings from this comprehensive synthesis of international evidence are also discussed in the sections that follow.

A recent co-produced qualitative study undertaken by Tedesco et al. (2024) sought to explore the lived experiences of adults receiving the diagnosis of BPD with the aim of gaining a better understanding of the complexities of living with this diagnosis and informing best practice for the delivery of the diagnosis in an informative, compassionate, and non-stigmatising manner. Interviews were

conducted with 15 participants who were living with the diagnosis of BPD, 14 of whom of whom were female. The study found that although most of the participants (n=14) reported the onset of their mental health difficulties occurred during adolescence, from an average age of 12.1 years, there was a significant delay in receiving their diagnosis, the average age of receiving the diagnosis of BPD was 30.2 years. Most of the participants (n=13) stated that they would have benefitted from an earlier diagnosis of BPD at that time. Tedesco et al. (2024) as a result propose the controversial notion of routine screening for personality disorder in adolescence and suggest that giving the diagnosis in adolescence should at least be considered, on a case by case basis. The rationale put forward for early diagnosis in adolescence is that diagnosis is important in terms of accessing timely and appropriate treatment. This is in line with the thinking of Chanen et al. (2017) who propose a major change for youth mental health services with the recommendation that early detection and specialised treatment for BPD in youth (age 12-25 years) should become a major focus globally in clinical practice. Allison et al. (2022), however, argue against this recommendation pointing to the low quality of evidence for the efficacy of treatment of BPD in adolescence as found in a systematic review and meta-analysis of randomised controlled trials undertaken by Jørgensen et al. (2021). Allison et al. (2022) argues that this limits the potential to develop evidence-based guidelines for treatment and therefore negates the case for early intervention. Hartley et al. (2022) also caution against professionals in Child and Adolescent Mental Health Services (CAMHS) expanding the diagnosis of personality disorder in adolescence due to the potential for iatrogenic harm. They argue that research evidence shows that the BPD diagnostic construct is invalid, potentially harmful, unnecessary for effective treatment, and that it could be a barrier to treatment and alternative conceptualisations of distress. They emphasise that these problems that are associated with the BPD diagnosis are elevated in the context of adolescent mental health. Similarly to the review findings of Lester (2020) and Sheridan Rains et al. (2021), the findings from the study by Tedesco et al. (2024) relevant to receiving the diagnosis of BPD included both positive and negative experiences. Other related findings from this study add to the discussion in the sections that follow.

3.3.1.1 Communication of the diagnosis

The quality of the diagnostic communication appears to be key to how people understand and interpret the diagnosis of BPD and it shapes their view of the diagnosis going forward. Under the theme of negative experiences Lester et al. (2020) reveal that participants in nine of their included studies knew very little about BPD at the time of their diagnosis and that they were provided with little or no information. The findings indicate that the manner in which the diagnosis was given brought about confusion, anger and upset for many of the participants who described feeling dismissed and having to struggle to get more information. Lester et al. (2020) also reveal a reported reluctance among clinicians to impart the diagnosis of BPD. The review authors were concerned to discover that at least six participants, across five separate studies, had not been made aware of their diagnosis until they were recruited to the study and others reported to have discovered their diagnosis accidentally. The synthesised findings reported Sheridan Rains et al. (2021) indicate that attempts by clinicians to avoid or withhold a diagnosis of personality disorder were negatively perceived by service users who felt that this portrayed a negative attitude on the part of the clinician towards the diagnosis that was invalidating for them.

Lester et al. (2020) found overall that while a well-delivered diagnosis was typically perceived quite positively, in comparison a poorly-delivered diagnosis resulted in a typically negative perception of the diagnosis. Participants in one study described a sense of relief when the health professional took the time and care to explain the diagnosis relevant to their individual context. Sheridan Rains et al. (2021) similarly found that the way in which service users were informed of their diagnosis appeared to significantly impact how they later perceived it. Positive diagnostic experiences were reported where the diagnosis was delivered by a clinician who clearly understood it, who was open to and had time for discussion, and who demonstrated optimism in relation to the effectiveness of treatment options and the possibility of recovery.

3.3.1.2 Impact of the diagnosis

Lester et al. (2020) found that participants in several of their included studies were conscious of the controversy that surrounds the validity of the BPD diagnosis and the social stigma that is associated with it. A significant number of participants in three of the included studies felt that the diagnosis was given to them by the clinician only because they didn't know what other diagnosis to give them. Negative reactions to being diagnosed with BPD were reported in five of the studies reviewed by Lester et al. (2020, p.270) as some participants likened the experience to being labelled as "*bad, wrong, or child-like.*" Participants in those studies perceived the diagnosis as unhelpful and thought it did little to explain their difficulties. Similarly, some of the papers reviewed by Sheridan Rains et al. (2021) discussed how some service users viewed the diagnosis as pathologising their responses to the trauma they had experienced over their lifetime. This in turn was perceived as retraumatising and led to feelings of victimisation. The reviewers also found that, for some, the controversial and nebulous nature of the diagnosis was challenging in terms of the myths and misinformation that were in circulation. In the study by Tedesco et al. (2024) some participants similarly rejected the label of BPD either in terms of not identifying with it or refusing to be defined by it. Others recognised the utility of the diagnosis in terms of accessing treatment or listing symptoms to be overcome.

Stigma related to BPD in society and within mental health services and possible rejection and exclusion by healthcare staff were also identified as significant service user concerns by Tedesco et al (2024). A qualitative descriptive study by Motala and Price (2021) that explored service user perspectives on the impact of the EUPD diagnosis on self-concept found that exposure to stigma was a serious issue. This study found that the immediate first response of each of the 10 participants who received their diagnosis in community settings was to research the diagnosis online. The volume and consistency of online hatred toward people with the diagnosis that they found online had a profound effect in their self-concept. The participants interpreted the content that they found as saying that

they were essentially “*emotionally abusive, manipulative and incapable of having functioning relationships.*” The impact on the participants engendered deep feelings of despair and distress (Motala & Price, 2021). A study undertaken by Moltu et al. (2022) that explores how people recently diagnosed with BPD experience relationships with self and others used RTA to analyse data collected using in-depth lifeworld interviews with 12 women. The findings further suggest that women recently diagnosed with BPD struggle with feelings of insecurity and fear. The authors found that the women experiences revolved around finding and developing strategies to protect themselves and their vulnerabilities. Self-harm, suicide attempts and addiction were implicated as means of coping with chaotic and difficult emotions. A narrative study by Lambert (2018) found that women experienced a range of emotions related to their diagnosis of BPD that vacillated between feelings of validation to feeling defeated and hopeless.

In terms of positive impact Sheridan Rains et al. (2021) found that some included studies reported that service users found their diagnosis useful for reflecting on their feelings and reactions and for engaging with treatment. This was particularly true where the diagnosis appeared to fit with service users’ experiences and where helpful information was provided about the diagnosis and the treatment options. Where the diagnosis led to therapy that was perceived as helpful, the diagnosis was seen as validating and providing a sense of relief. Lester et al. (2020) similarly found in seven of their included studies reports of positive diagnostic experiences that offered validation, an explanation for problems, a means of forging connections with others, a renewed sense of identity, and hope for the future. Tedesco et al. (2024) also report positive impact in terms of the diagnosis bringing initial relief and validation and a perceived improvement in self-understanding and insight. The opportunity to forge connections with shared experiences and the potential access to treatment were also identified as positive outcomes.

Overall, the literature on receiving a diagnosis of BPD reveals that the diagnostic process and the perception of the diagnosis itself have significant potential to

profoundly impact those diagnosed. The diagnosis may be perceived as useful for understanding and contextualizing distress, providing a sense of validation and relief, particularly when communicated sensitively. The diagnosis may also provide a pathway to accessing effective specialist treatment. However, stigma associated with BPD may negatively impact service user's sense of self-worth, their self-concept and their hope for recovery.

3.3.1.3 Recommendations for improving the diagnostic process

In conclusion Lester et al. (2020) emphasised that the way in which the diagnosis of BPD is shared with people can ultimately shape their views about it, their hope for recovery, and their subsequent engagement with services. They identify the need for openness and transparency in communicating the diagnosis and the importance of meaningful relationships that promote hope and recovery. Support that fostered a sense of trust, acceptance, reassurance, and respect and feeling heard and understood were identified as vitally important. A synthesis of participant recommendations for improving the diagnostic process drawn from the findings of Tedesco et al. (2024) included the following steps: explain the diagnostic process; make a thorough assessment; explore the symptomology in the context of everyday life, and; link the diagnosis to an evidence-based treatment plan. The authors conclude with a call for improved diagnostic processes and support for those diagnosed with BPD.

3.3.2 Diagnostic and structural stigma relevant to BPD

Building on the seminal work of Erving Goffman (1963), Link and Phelan (2001) developed a conceptualisation of stigma that comprises five essential convergent components, without which stigma is judged not to be present. Link et al (2004) expanded on that original definition to include the component of individual negative emotional reaction on the stigma. As a result, for there to be stigma the following six components must converge: labelled differences, stereotypes, separation, status loss and discrimination, power, and emotional reaction. Link

and Phelan (2004) claim that stigma exists as a matter of degree and that the degree of separation can vary (Anderson et al., 2022). Stigma associated with mental health has long been recognised in the literature as very prevalent and highly problematic. As a result people with mental health problems are at high risk of experiencing stigma in the form of discrimination, prejudice, and stereotypes (Boysen et al., 2020; Ferguson, 2016). While anyone living with a mental health diagnosis is therefore at significant risk of experiencing stigma, people who live with a diagnosis of BPD are at increased risk since BPD has been considered for many years to be the most stigmatised mental health diagnosis (Gunn and Potter, 2015; Masland et al., 2023; McKenzie et al., 2022; Stiles et al. 2023; Nehls, 1998).

Masland et al. (2023) argue that stigma disproportionately affects women who live with the label of BPD asserting that negative attitudes towards the diagnosis exist at the nexus of misogynistic attitudes toward women more generally and negative views related to mental illness and/or emotionality. In their article that voices concern regarding the potential for research and editorial processes to propagate stigma and as a result inflict harm on those diagnosed with BPD the authors examine the gendered nature and the consequences of BPD stigma. They discuss and cite examples of how gendered, sexualised and deeply stigmatising ideas and language have been perpetuated in the media and more worryingly in published scientific research citing for example a study published by Blanchard et al. (2021, p.2) that examines sex differences in partner preferences using the “*hot crazy matrix*” to rate attractiveness in relation to BPD on a scale of “*hot crazy*” women. Masland et al. (2023) further argue that such gendered and sexualised conceptualisations of BPD are also potentially damaging to men who according to more recent epidemiological research are equally likely to meet the criteria for a diagnosis of BPD. The authors add that it remains that women are disproportionately diagnosed with BPD (APA, 2022) which may be due to gender bias on the part of health professionals. Women are, however, more likely to seek treatment than men (Dehlbom et al., 2022) and differences in presentation occur

between men and women who seek help. Men tend to present with more antisocial traits while women typically present with more depressive, anxious or somatic difficulties (Silberschmidt et al., 2015). Masland et al. (2023) conclude that these differences in presentation may lead health professionals to assign different diagnoses. Commenting on the difference between community prevalence rates and diagnostic rates reported in clinical settings Masland et al. (2023) deduce that this may relate to sampling bias in research since the majority of BPD studies are populated almost exclusively with White female samples (Cristea et al., 2017). This perpetuates the notion that BPD is a “female disorder” and negates potential differences in experience that might occur across the gender spectrum. The resulting feminised view of BPD has contributed to a lack of available help and significant barriers to treatment for men diagnosed with BPD (Dean et al., 2024). In terms of pejorative and stigmatising language used in reference to women diagnosed with BPD Masland et al. (2023) argue that words including “manipulative” and “attention-seeking” spring easily to mind, however, they caution the reader to think carefully about the subtleties of language chosen to describe the experiences of people diagnosed with BPD where the nuances of the words chosen can, even inadvertently, add to the stigma. Examples cited from previous studies of words that may have this effect include: “dramatic,” “immature,” “hysterical,” “flailing,” and “gestures” (Brazandeh et al., 2018; Kramer et al., 2013; Conklin et al., 2006; Southward et al., 2018; Heilbron et al., 2010).

A co-produced study by van Schie et al. (2024) that explores the use of language in relation to BPD and the effect that it has on people living with the diagnosis and their carers reveals that all 63 participants had been exposed to stigmatising language. Approximately 90% of each of the participant groups were identified as female. The aim of the study was to understand the effect of language on individuals with BPD and their carers and to provide recommendations for reducing stigma through more positive, affirming and compassionate communication. The findings indicate that BPD language is heavily stigmatised and language was recognised as playing a significant role in perpetuating stigma.

Hurtful language can lead to feelings of inadequacy, frustration, guilt, despair and self-stigma among individuals with BPD and their carers. Words such as “attention-seeking,” “manipulative,” and “crazy” were perceived as common, hurtful and unhelpful. Phrases that were considered helpful were described as “validating”, “understanding”, and “acknowledging of effort.” Patterns of communication that were unhelpful left service users feeling small and misunderstood and rejected as individuals. They expressed the desire to be seen as people, understood, and supported. The study recommendations include using language that is accepting, connecting, empowering, and hopeful. Reflective positive language can improve therapeutic relationships and outcomes. The study emphasises the importance of mindful language use to reduce stigma and support the recovery for people with BPD and their carers. It calls for increased awareness and education among clinicians and the public. It emphasizes the need for reflective practice and compassionate communication in mental health care.

As discussed by Bryant (2024) the majority of research studies that examine stigma related to BPD are focused in micro-level processes, those that involve the person who is stigmatising and the person who is stigmatised with few studies focusing on meso and macro level processes with the exception of the scoping review undertaken by Klein et al. (2022). This comprehensive scoping review that includes 57 studies that examine the impact of structural stigma on healthcare for people diagnosed with BPD, their families, and health professionals. The review identifies a broad range of micro- and macro-level structural factors, challenges and barriers that contribute to the stigma encountered in the context of BPD. Structural stigma occurs at societal level and involves cultural norms, organisational policies, practices and culture that negatively impact the opportunities, resources, and wellbeing of those who are subjected to the stigma. The key structural mechanisms identified that negatively impact the provision of appropriate services for BPD included pervasive BPD-related stigma and the dominance of the biomedical model in healthcare.

3.3.3 Perceptions of healthcare in the context of a diagnosis of BPD

Accessible and comprehensible mental health services where the staff are perceived as well-informed and welcoming, where service users have the opportunity to become meaningfully involved in their own care, and where they can avail of high quality appropriate treatment are valued and identified as optimal by individuals living with a diagnosis of personality disorder including BPD (Sheridan Rains et al., 2021). However, many of the studies reviewed indicate significant variations in the availability of high quality care for this population and reports of good quality care within generic mental health services were significantly fewer than for specialist services. Gaps in the provision of appropriate treatment pathways and exclusion from a range of mental health services on that basis of personality disorder diagnosis were reported in numerous studies. Service users described care that was limited to a series of hurried outpatient appointments and reported feeling excluded from important aspects of decision-making regarding their care. The absence of proactive knowledgeable staff was disappointing for some service users and led to feelings of rejection and potential disengagement. Sheridan Rains et al. (2021) found overall that the attitudes of staff, standard of treatment and choice, and the active involvement of service users was typically rated much better in specialist personality disorder settings than in generic mental health services. Access to specialist services, however, was identified as much more limited which is challenging in terms of long-term care. Continuity of care was further identified as an issue and transitions and termination of care that were sometimes abrupt were also identified as challenging.

3.3.3.1 Perceived attitudes of healthcare professionals towards BPD

The therapeutic relationship between mental health nurses and individuals diagnosed with BPD is considered vital to successful treatment and achieving personal recovery. However, not all mental health nurses succeed in establishing a positive therapeutic relationship with service users living with this diagnosis often due to the impact of their own negative emotional reactions to the diagnosis

or associated *symptoms*. Romeu-Labayen et al. (2021) therefore sought to explore, using a qualitative descriptive methodology, the perspectives of people diagnosed with BPD who had experienced an improvement in their mental health on the role of the attitudes of mental health nurses in building a positive therapeutic relationship. They recruited 12 participants (aged 20-46 years) to the study, all of whom identified as female and who self-reported an improvement in their mental health since embarking in treatment. Five key attitudes that support the development of a positive therapeutic relationship were identified in the thematic analysis of interview data: (i) confidence in their ability to recover; (ii) non-judgement; (iii) humour; (iv) availability, and; (v) humanity. Each of the attitudes identified was valued by the participants in terms of supporting their recovery journey beginning by displaying confidence in their ability to recover. The ability to withhold judgement and having a sense of humour were important factors in establishing trust and rapport. Being available to care for the person when required built confidence and being treated in a humanistic way was very much welcomed. This study makes an important contribution to the nursing knowledge on the factors that may enhance the therapeutic relationship since attitudes are amenable to change, particularly through the process of reflective practice.

The importance of therapeutic relationships and good service user-healthcare professional relationships were commonly identified by service users as core components of good mental health care in the synthesis by Sheridan Rains et al. (2021). The positive attributes of healthcare professionals that were valued by services users overlap with those identified by Romeu-Labayen and include warmth, trustworthiness, honesty, openness, acceptance, being non-judgemental, having an interest in their role and in the service user as a person. Where these attributes were evident service users reported that they felt supported, valued, understood, listened to, and cared about. Where these attributes were absent, service users felt that they could not be honest with their clinician, that the clinician would be unable to help them, or that their treatment would be poorly tailored to their needs. Positive qualities were described in many

papers as being more frequent among clinicians working in specialist services, potentially as a result of good/advanced training and increased understanding of the difficulties associated with the diagnosis of personality disorder.

The risk of stigma for people living with BPD is very significant at the interface of healthcare. For example a qualitative study conducted in the UK by Bonnington and Rose (2014) explored the lived experiences of 29 participants, who were diagnosed with BPD or bipolar disorder (BD), in relation to stigma and discrimination. The thematic findings indicate that both participant groups experienced what are described as “four faces of oppression” that include: cultural imperialism, powerlessness, marginalisation, and violence (Bonnington & Rose, p. 7). In terms of healthcare and employment participants diagnosed with BPD more often faced healthcare discrimination and exclusion from services while those diagnosed with BD experienced greater discrimination at work. Participants diagnosed with BPD were stereotyped as manipulative and attention-seeking. Both groups described experiencing powerlessness that impacted their treatment and marginalization in a number of social contexts, including family groups and employment. Both groups of participants reported physical and psychological violence, particularly within healthcare settings. The authors conclude that the interaction of structure and agency is important to understanding the stigma experienced by people diagnosed with BD and BPD and calls for more comprehensive approaches to address these issues.

Recognising the significance of the issue of stigma within healthcare settings for people living with a diagnosis of BPD, Ring and Lawn (2019) undertook a comparative review of the literature. In their review they compare and contrast perceptions of stigma in the mental health care context, from the perspective of patients and mental health professionals (MHPs), and how this is operationalised and maintained at the interface of health care. The literature search identified 329 papers and 30 were included in the final review. Of those 12 include patient perspectives and 18 are from the perspective of clinicians. The six themes

identified include: (i) stigma related to diagnosis and disclosure; (ii) perceived un-treatability; (iii) stigma as a response to feeling powerless; (iv) stigma due to preconceptions of patients; (v) low BPD health literacy, and; (vi) overcoming stigma through enhanced empathy. The authors propose a conceptual framework to explain the perpetuation of stigma and BPD that suggests that stigma towards people with BPD is perpetuated due to a lack of BPD health literacy by patients and MHPs that negatively impact engagement and effective treatment, disempower all and defer responsibility to others. The authors further suggest multiple strategies are required to address the problem that incorporates targeted education, and promotes empowered advocacy and leadership.

Negative experiences were more common outside of specialist personality disorder services according to Sheridan Rains et al. (2021). Difficulties reported in some of the included studies included exclusion from services and treatments by virtue of the diagnosis and encountering stigmatising attitudes both with clinicians and in the community. Some studies reported that the personality disorder label led to service users being viewed as “difficult” rather than distressed or mentally unwell and for some symptoms being dismissed as false. Negative attitudes of others, including healthcare professionals, were commonly identified in the review including that notion that personality disorders are untreatable and that acts of self-harm and other behaviours are indicative of manipulation and attention-seeking. Other perceived negative attitudes identified related to stereotypes that those with the diagnosis tell lies, are unreasonable or difficult, and monopolise resources. Service users reported an increased sense of isolation and marginalisation and associated feelings of abandonment or rejection as a consequence of those negative attitudes.

While much of the literature related to the lived experience of BPD stigma relates to mental health settings and contexts, individuals living with the diagnosis of BPD are also recognised as having an increased likelihood of experiencing significant physical healthcare needs that necessitate more frequent contact with

the medical health professions in medical settings compared to the general population (Álvarez Tomás et al., 2024). Concerns regarding the potential consequences of the pervasive stigma experienced by people diagnosed with BPD in terms of impaired access to quality care and treatment in medical contexts prompted a qualitative study by Navarre (2025). This study explored participants BPD stigma experiences while attending medical settings and engaging with medical professionals other than for mental health purposes, for example for wound care, accidents, or medical problems. The aim was to gain an understanding of the frequency and impact of stigma on the quality of care provided and patient outcomes. Participants were recruited from within a larger study that explored the overall lived experiences of BPD among 81 adult participants using a qualitative survey method. Of those surveyed approximately one third of the participants (n=29) confirmed that they had experienced stigma related to their diagnosis of BPD or related symptoms specifically in a medical context. Those 29 participants were invited to disclose their experiences of stigma in the medical setting by participating in this additional study that involved the completion of a supplemental qualitative survey. A total of 16 participants volunteered to participate who ranged in age from 22 to 40 years. The study reports that 11 participants reported their sex at birth as female (69%) and five participants (31%) reported their sex at birth as male, 7 participants (44%) identified as cisgender women, 5 participants (31%) identified as cisgender men, and 4 participants (25%) identified as nonbinary, transgender, genderqueer, and/or genderfluid. The participants written responses described a range of stigmatising experiences in the context of seeking medical care that impacted their perceived quality of care, their physical and psychological wellbeing and their medical outcomes. A critical realist reflective thematic analysis of the data reported identified six related themes: (i) dismissal and misattribution of physical symptoms; (ii) delayed or inappropriate medical diagnosis and intervention; (iii) communication and advocacy challenges; (iv) invalidation of emotional wellbeing and distress; (v) self-harm stigma, and; (vi) presumed drug-seeking behaviour. The themes identified align with previous research on healthcare-associated BPD stigma that is grounded in mistrust of the patient and a perceived lack of

credibility and trustworthiness that relates to the BPD label (Aguirre, 2016; Aviram et al., 2006; Masland et al., 2022; Ociskova et al., 2017).

The findings from Navarre's (2025) study contribute to the knowledge surrounding the problematic impact of BPD stigma specifically in the context of medical settings where stigma was found to create barriers to accessing quality care and treatment for people diagnosed with BPD that in turn negatively impacted physical and mental health outcomes. The findings from the study indicate stigma led to a risk to disengagement from treatment, challenges with medical adherence, an erosion of trust between patients and medical professionals. The author emphasises from the findings the importance of supporting patients with BPD as they navigate stigmatizing health care systems. Participants consistently reported feeling of invalidated, experiencing distress, and they found communication difficult. The author suggests patient advocacy, increased supports for patients, enhanced education and training for medical professionals specific to communication and the intersections of BPD and physical health outcomes might be beneficial. The author advocates that future research should be undertaken in collaboration with the impacted population in order to adequately and appropriately address issues and needs of marginalized individuals.

Navarre (2025) further concludes from the findings that the typically higher rates of physical healthcare utilisation among patients with BPD in comparison to the general population should perhaps be considered in terms of elevated or unmet physical and mental healthcare needs challenging the perception of "overuse" of medical services by individuals diagnosed with BPD. This aligns with the findings from a qualitative study undertaken in Canada by Vandyk et al. (2019) who explored frequency of ED use, related to mental health needs, by people diagnosed with BPD. Frequent use was determined as more than 12 visits in one year. Six people, five women and one man aged 22-66 years, were interviewed. The findings indicate the main drivers for the participants ED use were: loneliness and

a strong desire to forge human connection; the failure of crisis services; self-harm; concerns regarding suicidal ideation, or; substance misuse. Stigma encountered in the ED was also identified as a significant issue. The authors conclude that unmet needs due to a failing system and a lack of community supports are significant contributors to the frequency of use of the ED.

3.3.3.2 Factors that influence good quality mental healthcare for people living with the diagnosis of BPD

The need to develop appropriate models of care and to establish pathways to high quality community mental healthcare for people living with a diagnosis of personality disorder, including BPD, is emphasised in the review paper by Sheridan Rains (2021). The authors of this comprehensive co-produced review provide a solid evidence base from the lived experience perspective to guide the development of good quality community mental healthcare for people living with a diagnosis of personality disorder that is highly relevant to the provision of care for individuals living with the diagnosis of BPD. Importantly, the authors clearly state that the development and design of mental health services for people diagnosed with personality disorder should be informed by the views of service users articulating a position that aligns with the recovery model of mental health and the global drive towards the provision of recovery-oriented mental health services.

The findings from a number of studies included in this metasynthesis indicate the importance of individualised holistic person-centred care and a preference for the provision of a suite of options in terms of treatment that focus on achieving personal goals rather than focusing on the diagnosis and relying on heavily manualised therapies. Service user participants in some studies reported that the therapies available to them were not designed to deal with issues of trauma and the difficulties they encountered in daily living were but instead focused on dealing with specific challenges for example relationships or self-harm which was frustrating. Learning to adapt skills developed in therapy to their own individual

context was identified as important by service users in some studies. Sheridan Rains et al. (2021) further identify that some studies in their review indicate ambivalence among participants towards therapies that focus specifically on treating self-harm since self-harm was typically considered as a coping strategy, or survival mechanism, for enduring significant emotional pain and distress that is perceived as almost unbearable. Service users expressed a preference for supportive, compassionate, and empathetic exploration of alternative coping strategies over eliminating self-harm. Recognition in services that service users sometimes struggle psychologically with engaging with treatment and that emotional overwhelm can be a barrier to employing skills and strategies learned in treatment was identified as important. Service users further reported that emotional overload brought on in therapy sessions sometimes impacted their future attendance even when they recognised the importance of processing adverse reactions. They added that this potential impact should be taken into consideration by service providers.

3.3.4 BPD disclosure and decision-making

The literature pertaining to self-disclosure of BPD is sparse with only one study identified that was recently undertaken in the United States (Dong, 2024). In that doctoral study, that is currently available only as a preview, the researcher uniquely explores decision-making related to self-disclosure of BPD as a highly stigmatised but invisible health condition. Dong (2024) specifically explores how individuals diagnosed with BPD navigate their decision-making on disclosure in romantic relationships using a phenomenological research design. The study population includes 14 participants with an age range of 21-37 years. Twelve inter-related themes were identified that are conceptualised as “barriers” and “motivations” to diagnostic self-disclosure for people diagnosed with BPD. From the preview, examples of the barriers identified include “the fear of stigmatisation,” and, “the worry of being pigeonholed by BPD.” Examples of the motivations to disclose include “the perceived prognosis of BPD,” “the manifestation and interpersonal relevance of BPD,” “the positive relational quality” of disclosure, “disclosure

efficacy,” and “BPD as a critical part of the self.” The “anticipate disclosure reaction” was identified as both a disclosure barrier and a motivation. The role of mental health professionals was also identified as a theme in terms of facilitating disclosure decision-making. The breadth of the findings in this contemporary study, that is not yet published, points to the important establishment of evidence for the complexity of decision-making regarding diagnostic self-disclosure for individuals living with a diagnosis of BPD.

3.3.5 BPD and perceptions of recovery

The lived experience perspective specifically related to the concept of recovery in BPD has not been widely explored. A study by Ng et al. (2019) that explores the phenomenon of recovery among 14 women with a self-reported diagnosis of BPD using an IPA methodology reports perspectives drawn from opposite ends of the recovery spectrum, seven recovered and seven not recovered. The study found that recovery occurred for these women in three stages that were conceptualised as involving four processes. The stages included: (i) being stuck, (ii) diagnosis, and (iii) improving experience. The processes identified were: (i) hope, (ii) active engagement in the recovery journey, (iii) engagement with treatment services, and (iv) engaging in meaningful activities and relationships. The differences in experience between participants in the recovered and the non-recovered groups were most evident in the improving experience stage. Ng et al. (2019) conclude from their findings that recovery in BPD is experienced as non-linear and ongoing and that it is navigated through the interaction of stages and processes. They advocate that clinical services foster hope, motivation, activity and relational and therapeutic engagement to ensure a holistic approach to recovery.

The metasynthesis by Sheridan Rains et al. (2021) reveals that service users across numerous studies described mixed feelings in relation to the notion of recovery being a primary goal for services and the implication of gradual progression towards either clinical or personal goals. A commonly reported opinion on what

was realistic in terms of recovery centred upon an improved capacity to cope with difficulties as opposed to the resolution of these difficulties, or alternatively, a reduction in their negative impact. Service users widely reported patterns of experiencing periods of improvement interrupted with setbacks. The review further found that service users across many studies recognised gradual improvements in their ability to regulate their emotions as they came to understand in treatment the emotions underpinning their difficulties and learned to respond to them differently. Health professionals' expectations in terms of a relatively swift period of recovery were considered unrealistic by service users in some included studies whose experiences led them to be cautious regarding the pace of change and their ability to maintain it. Service users in a number of the studies reviewed by Sheridan Rains et al. (2021) also spoke of how their relationships with others gradually improved over time as they began to better understand through treatment the feelings, perspectives and behaviours of other people. They felt the benefit of reflecting on how their own behaviour might impact others and the reported feeling supported to assess the behaviour of others in a more balanced way. Positive therapeutic relationships were identified as instrumental in promoting ways to make positive changes in personal relationships. Relationships with peers in services were identified as providing important opportunities to practice and develop good communication skills. Service users reported the gradual strengthening of their relationships with friends and family as a consequence of good quality care.

3.4 Chapter summary and conclusion

This chapter provides a narrative review of the theoretical and empirical literature relevant to this inquiry. The extant literature related to the diverse range of contemporary aetiological theories of BPD was outlined. The empirical literature presented focuses on the lived experience of BPD in relation to receiving the diagnosis, perceptions of stigma, experiences of healthcare, decision-making around self-disclosure, and perceptions of recovery. Overall, the review reveals a lack of in-depth studies that critically explore women's experiences of receiving

the diagnosis of BPD. Studies that specifically examine the lived experience of self-disclosure of the diagnosis of BPD and related decision-making processes are notably absent from the literature with only one relevant study identified. This means that there is limited evidence to guide health professionals' understanding of women's experiences of diagnosis and disclosure of BPD. A better understanding of those lived experiences may contribute to further development and improvements in the fields of healthcare practice, policy, education and research related to the care of those labelled with BPD. Crucially, new knowledge may contribute to improved diagnostic and healthcare experiences for women which in turn may influence their decision-making related to disclosure. The literature review therefore establishes the need for this inquiry that explores women's lived experiences of diagnosis and disclosure of BPD in the Irish context and influences its design. In the next Chapter (4) I make explicit the philosophical assumptions that underpin my inquiry and discuss the methodological choices that underpin its design.

Chapter 4: Methodology

4.1 Introduction

This chapter sets out the philosophical and methodological positions that underpin this inquiry. It is of fundamental importance that researchers carefully consider and make explicit the philosophical framework for their research including their ontological and epistemological perspectives. This promotes informed decision-making regarding the methodology and strengthens the rationale for the chosen research design. Making clear the philosophical assumptions that underpin the inquiry and justifying the chosen methodology strengthens the rigour of the inquiry and allows the researcher to better defend the inquiry outcomes (Jackson, 2013). This inquiry adopts a social constructionist paradigm to critically explore and gain a deep understanding of the meanings women in Ireland construct around their lived experiences of being diagnosed with borderline personality disorder (BPD) and of disclosing that diagnosis to others. In the first section of this chapter, I identify my ontological position of constructionism and make clear my epistemological position of social constructionism as appropriate underpinnings for this inquiry. In the second section of this chapter, I outline the history and core principles of NI and discuss how it aligns methodologically with the principles of social constructionism. In outlining the fundamental theoretical perspectives of NI, I provide a strong rationale for its use in my study.

4.2 Ontology and epistemology

Guba & Lincoln (1994, p.105) define paradigms in the research context as “*the basic belief system or world view that guides the investigator, not only in choices of method but in ontologically and epistemologically fundamental ways.*” Choosing the appropriate paradigmatic framework is challenging for the novice researcher as there are numerous paradigms to consider (Ashgar, 2013). Kivunja & Kuyini (2017) describe the research paradigm as influencing how the researcher sees, interprets, and acts in the world. They further define paradigms as the conceptual lens through which the researcher explores the methodological aspects of their study including the decisions on what research

methods to use and how to analyse the study data. The research paradigm thus influences what should be studied, how it should be studied, and how the results of a study should be interpreted. Accordingly, the social constructionist paradigm that underpins this inquiry aligns well with the chosen methodology of NI (Squire, 2013). Each paradigm has its own unique combination of ontological and epistemological assumptions. Ontology refers to the study of the nature of reality. Ontological assumptions, as defined by Guba & Lincoln (1989, p.83), are those that answer the questions “*what is there that can be known*” or “*what is the nature of reality?*” The ontological position that underpins this inquiry is constructionism. Bryman (2016) depicts ontological constructionism as inferring that social phenomena are created through social interaction. Viewed through the lens of ontological constructionism, social reality is considered an ongoing accomplishment of social actors. Bryman (2016, p.20) further describes culture as “*an emergent reality in a continuous state of construction and reconstruction.*” A constructionist ontology is fitting for this inquiry that examines women’s lived experience of BPD diagnosis which can, I believe, be legitimately construed as an inherently social phenomenon produced as an accomplishment of social actors that includes healthcare professionals in mental health and general settings and academics active in BPD research. Epistemology considers the nature, origins, and scope of human knowledge (Creswell & Poth 2018). Epistemological assumptions are those that answer the questions of how we acquire knowledge. Epistemology, therefore, according to Guba and Lincoln (1994), addresses how we come to know what we know, what is the truth, what constitutes legitimate knowledge, how are claims regarding knowledge justified, what is the relationship between the researcher and what can be known and is knowledge value neutral? The epistemology that underpins this inquiry is social constructionism.

4.2.1 Social constructionism

The epistemology of social constructionism that underpins my inquiry emerged less than sixty years ago from the seminal publication “*The Social Construction of Reality: A Treatise in the Sociology of Knowledge*” authored by sociologists Berger and Luckman ([1966], 2016). Their principal assertion was that social reality is constructed through the actions and interactions of individuals. The work of Berger and Luckman (1966) was

heavily influenced by philosophers Karl Marx, Emile Durkheim and particularly George Herbert Mead's work on symbolic interactionism (Batiuk & Sacks, 1981). It is evident therefore that the origins of social constructionism can be traced, at least in part, to interpretivism. However, social constructionism is a distinct approach to thinking that views knowledge and truth as created through interactions between people in their social world rather than discovered by the mind. It is also argued that social constructionism is compatible with realism in that one can believe that a concept is constructed rather than discovered but can still correspond to something in the "real" physical world (Andrews 2012, Schwandt, 2003). The BPD diagnostic construct is an example of just such a social construction that has been much contested since it was first inducted into DSM-III (APA, 1980) as a diagnosable *psychiatric disorder* as previously discussed in Chapter 2 (2.2.4). That is not to say that if that diagnosis were to be immediately abandoned that the real and significant issues and distress that individuals labelled with that diagnosis typically experience would similarly disappear.

Constructionists claim that knowledge and meaning is constructed by "*human beings as they engage with the world they are interpreting*" (Crotty, 1998, p.43). Social constructionism differs from constructivism in that it focuses on the collective generation of meaning, influenced by language and other social processes, whereas constructivism centres upon the notion of the individual mind as being independently active in meaning-making (Schwandt 1998). Crotty (1998) suggests that constructivism focuses upon the unique experience of the individual upholding each individual's sense of the world as equally valid and worthy of respect. Conversely, Crotty (1998) views social constructionism as emphasising the power of culture and how it influences how we see the world. He concludes that "*constructivism tends to resist the critical spirit, while constructionism tends to foster it.*"(Crotty 1998, p.58).

In the seminal paper "*The Social Constructionist Movement in Modern Psychology*" Gergen (1985, pp.266) describes social constructionism as "*principally concerned with explicating the processes by which people come to describe, explain, or otherwise account*

for the world (including themselves) in which they live.” Acknowledging that no single definition or description of social constructionism exists Burr (2015), drawing on the work of Gergen (1985), identifies four key assumptions that underpin and unify social constructionist approaches.

1. A critical stance toward taken-for-granted knowledge

Burr (2015, p.2-3) argues that social constructionism demands critical examination of otherwise accepted or “*taken-for-granted*” ways of understanding the world and self. A social constructionist approach challenges the positivist notion that the nature of the world can be objectively observed.

2. Historical and cultural specificity

Social constructionism asserts that the way in which we understand the world, including the concepts and the categories that we use varies both historically, over time, and culturally, from place to place. We each, therefore, encounter the world from our own social location (Burr & Dick, 2017).

3. Knowledge is sustained by social processes

Social constructionists believe that knowledge is constructed through interactions between people in their social world. The social interactions between people as they go about their everyday lives, particularly the use of language, are viewed as the practices through which our common understandings of the world are constructed and the means by which our shared knowledge is fabricated (Burr, 2015).

4. Knowledge and social action go together

Burr (2015) supports the idea that social constructionists accept that social processes and interactions can result in a variety of potential social constructions of events. Each alternative construction demands a different type of action or response from human beings.

Social constructionism asserts that as individuals exist, and make sense of phenomena they encounter in the world; they do not do this in isolation but in the “*social milieu in which a system of intelligibility prevails. We inherit a system of significant symbols*” (Crotty, 1998, p.54). Language is a key consideration in social constructionism; language is not neutral since it emphasises certain things and disregards others (Vinney et al., 2019). Burr and Dick (2017, p.59) identify a key principle of social constructionism is that how we understand and perceive the world does not necessarily reflect “*the nature of that world*” but instead reflects how the world is depicted through language and is dependent upon the society and era that we live in. Social constructionism places heavy emphasis on meaning and power (Galbin, 2014). Social constructionism thus adopts the position that reality is constructed through human activity and is shaped by politics, history, culture, and social norms (Ankers et al., 2023). The BPD diagnostic construct in psychiatry, often described as a new “female malady” (Showalter, 1985), has evolved and endures as a direct consequence of the patriarchal power of psychiatry as discussed in Chapter 2 (2.7). BPD further exemplifies the dominance of a Western neo-liberal discourse of identity that values goal-directed actions and productive labour and the medicalisation of women’s behaviours that are considered to breach the boundaries of normative femininity (Ussher 2013, Berger 2014).

As I have identified the research paradigm that underpins this inquiry is social constructionism. My constructionist ontological position reflects my belief that people’s understanding of reality is something that is constructed through social interaction with others especially through language and that there are multiple realities rather than one unassailable truth. As identified by Varpio and McLeod (2020) epistemology builds upon ontology to put the nature of reality into practice to develop knowledge that is valuable and legitimate. My epistemological position is that of social constructionism and so I believe that knowledge is constructed by and between people and that understanding is impacted by time and place. An important consideration for me embarking on this inquiry was that a social constructionist approach opposes taking knowledge for granted and advocates a critical approach where all knowledge must be questioned. This tenet was applied to the conceptualisation of BPD which, from a social constructionist

perspective, has been shaped by shared meanings, language, social interaction, issues of gender and medical/psychiatric tradition.

Two principal forms of social constructionist theory and research exist and are evident in the literature (Burr, 2015; Cruickshank, 2012). Burr (2015) describes micro social constructionism as that which focuses upon the micro-structures of language that are used in interactions, the common or everyday talk used in social interaction. Macro social constructionism focuses more on the macro linguistic and social structures that underpin the productive power of language. Adopting a micro constructionist approach to my inquiry I attended to the language of the narratives. I listened for linguistic cues, or flags, inherent in storytelling that supported the story being told and that gave clues to the function of the language and the meaning of the individual story and experience. Adopting a macro social constructionist approach, I attended to how societal structures, the discourses of mental illness and of BPD, and cultural norms surrounding femininity impacted the women and shaped their experiences of diagnosis and disclosure.

A social constructionist philosophical position is appropriate for my inquiry because it offers a framework through which I can better understand the subjective experiences of the women participants in being diagnosed with BPD and in disclosing that diagnosis to others. Social constructionism facilitates an exploration of the meaning that each individual woman ascribes to those lived experiences as determined by their own beliefs and knowledge and what they perceive to be the truth arrived at through the social processes of language, discourses, and power. Since the knowledge generated through social constructionism is culturally, historically, and politically situated it is not value free (Scotland, 2012). The principles of social constructionism demand that I examine my own suppositions, taken-for-granted beliefs, thought processes, feelings, and intentions through a process of reflexivity (Gergen, 2009; Swords & Houston, 2021). This is important in the context of this inquiry that explores the lived experiences of a diagnosis that is highly stigmatised within healthcare as evidenced in the literature in Chapter 3 (3.3.2). To meet the identified objectives of this study required a methodology that directly engaged with and prioritised the perspectives of women diagnosed with BPD. To

dovetail with a social constructionist philosophy the methodology must, as previously discussed: allow for a critical stance; interrogate powerful social, cultural, and political influences; consider the social processes through which knowledge is constructed, and; have the potential to accommodate social action. To appropriately meet the objectives of the study in line with the paradigmatic assumptions of social constructionism the methodology chosen was that of NI, as described in the next section.

4.3 Narrative inquiry methodology

In this section I discuss my chosen NI methodology first briefly exploring its history and then discussing the central role of stories and storytelling. I outline the qualities of narrative research and the process of data generation. I conclude with a discussion of narrative data analysis and provide an outline of my analytic framework for the inquiry.

4.3.1 History of narrative inquiry

NI describes a very diverse field of research, spanning many disciplines and theoretical perspectives, that is popular yet highly complex (Riessman 2007, Bamberg 2012). Early proponents of narrative research included Mishler (1986), Polkinghorne (1988), and Riessman (1993) who advocate that researchers in the qualitative paradigm ought to listen to the stories their participants tell and strive to understand the context and ways in which their stories are constructed and positioned (Hickson, 2016). Inspired by the work of Dewey (1938), it was Connolly & Clandinin (1990) who first conceived of the term “narrative inquiry” as a research methodology in the field of education. They proposed to return “the person” to the centre of research to ensure the individual’s voice was not lost in translation. Connolly and Clandinin (1990) heavily emphasised the study of the lived experience of individuals but recognised that this should not be done in isolation but rather should incorporate the study of socio-cultural factors that impact that experience. NI in essence is a qualitative methodology that examines oral or written texts that provide accounts of events that are connected chronologically (Czarniaskawa, 2004). The core components of NI are the participants’ stories of particular experiences and an

exploration of the personal meaning implicit in those stories (Ntinda, 2020). NI is further described by Framp et al. (2019, p.43) as belonging more to the critical rather than the interpretive paradigm of qualitative research in that it aims not only to explore and understand human experience, but also focuses upon being “*empathic, participatory, and empowering*” through unveiling, using in-depth analysis, aspects of experience that may not have been previously considered. Adopting a critical stance acknowledges that narratives are socially created and are heavily influenced by social, cultural, and political values and that the resulting power dynamics often result in marginalisation (Gavidia & Adu, 2022). This was an important consideration in this inquiry that aimed to engage empathically with women labelled as having BPD and to co-construct narratives that reflect their lived experiences in a way that is empowering in that it privileges their own voice and their position as an expert in their own life.

4.3.2 Stories and storytelling in narrative inquiry

A key assumption that underpins narrative inquiry is that human beings live storied lives implying that people ascribe meaning to their experiences through storytelling (Riley & Hawe 2005, Holloway & Freshwater 2007). The stories told typically represent the narrators’ past, present, or future behaviours (Hiles et al., 2010). Proponents of NI assert that human beings instinctively share stories through storytelling for the dual purposes of communicating their experiences and of bringing order and structure to those experiences (Moen 2006, Holloway & Freshwater 2007). The structure of the story provides the basis for the individual to contemplate and assign meaning to their experiences (Patton, 2015). Storytelling as a process further facilitates individuals to engage in identity construction (Reissman 2005). It furthermore allows individuals to position themselves culturally and socially in their environment (Stapleton & Wilson 2017). Storytelling is a key feature that makes NI distinctive among qualitative methodologies as discussed in Chapter 1 (1.4).

Although often used interchangeably in the literature there is a distinction between a narrative and a story as explored by Nasheeda et al. (2019). Stories also typically comprise a struggle or conflict, a protagonist, and some form of sequenced plot (Nasheeda 2019). Stories are defined as comprising the three dimensions of form, function, and phenomenon (Kurtz, 2014). Narrative is described in its basic form as continuous stories that incorporate problem, plot, and a cast of characters. Elliott (2005) emphasises the importance of three key features that define narratives. Firstly, that narratives are chronological and so represent a temporal sequence of events. Secondly, narratives are meaningful and therefore have a plot. Thirdly, narrative is fundamentally social in that it involves the narrator, the researcher and the reader. Moen (2006, p.62) defines the concept of narrative as “*a process that organizes human experiences into meaningful episodes*” adding that the “*raw material*” for narratives emerges from the innermost mental experiences and mental images of the individual that cannot be directly observed. The stories told by the individual that contribute to the narrative are however observable and open to interpretation (Polkinghorne, 1998). Simply stated temporality suggests that stories evolve in a way that is sequential, implying three linked sequences of a beginning, a middle, and an end (Holloway & Freshwater, 2007). Stories are explicit and tend to be told and retold. Narratives by comparison are an amalgam of many stories, may comprise many problems, or none, and may not have a clear end. Narratives often go unnoticed and yet can powerfully influence human experience. In the social world dominant narratives, conscious or unconscious, serve to maintain existing power dynamics. They applaud or excuse groups who hold power while demonising or censoring those who are marginalised (Morrison et al., 2019). In the case of the BPD diagnosis the dominant narrative favours locating an individual’s problem and difficulties in life within the individual versus examining the historical, social, or cultural factors that might contribute to those problems perhaps representing a form of social control (Dyson & Gorvin, 2017).

4.3.3 Qualities of narrative research

Carless and Douglas (2017) suggest six qualities of narrative research that I identified as important in choosing a design best suited to answering my research questions. First, the authors propose that narrative research provides rich insights into the lived experience of participants. It prioritises the participant's experience of events and embraces the complexities of those lived experiences. The telling of those experiences in story form allows the researcher to understand the participants' responses to recounted events. This was an important factor in my inquiry as I sought to understand the women's various responses to their diagnosis of BPD. Second, Carless and Douglas (2017) suggest that narrative research elucidates the meaning/s of personal experience allowing the researcher to gain an understanding from the participant as the expert on their own life. Arriving at a co-constructed meaning occurs through a process of reciprocal and dialogic interaction. As the women's stories unfolded in the interviews, and more fully unfurled in the analysis, I began to understand on a much deeper level what it meant to them to receive the diagnosis of BPD and to disclose, or not disclose, the diagnosis to others. Third, the authors describe how narrative research allows the researcher to explore the participants story over time meaning that consequences may be revealed versus a "snapshot" approach that merely encapsulates a fixed timeframe. This was significant in my inquiry as a phenomenon of interest in the study was how the women attributed meaning to their diagnosis and disclosure experiences at the time and later in their journey. Fourth, Carless and Douglas (2017) state that narrative research allows for an exploration of both the personal and the social. In my inquiry this facilitated close examination of the very personal nature of the phenomenon of psychiatric diagnosis while also considering the social world, social circumstances, social interactions, and societal issues that impacted the women in terms of their diagnosis and disclosure. Fifth, the authors advocate narrative research as a means of depicting how life is experienced by the participant as an embodied human being who lives, breathes, and experiences feelings and emotions. Storytelling is conceived of by Carless and Douglas (2017, p. 305) in this context as "*an embodied act that draws on one's experience of the world through one's body.*" The insights generated in narrative research thus challenge reductionist representations of human experience by revealing more deeply emotional and holistic

perspectives. This is an important factor in my inquiry that explores women's lived experiences of diagnosis and disclosure of BPD where there is a lack of published literature. Sixth, Carless & Douglas (2017) in conclusion highlight the importance of relational engagement that upholds the highest ethical standards in narrative research, a level of engagement that is developed over time. The values of openness, acceptance, empathy, and trust between the researcher and the participant are emphasised as key in narrative research. The concept of relational engagement and these values resonate with me both as a mental health nurse and as a researcher. Reflecting upon these qualities of narrative research as outlined helped me navigate the unknown territory of doctoral research as I undertook this inquiry.

4.3.4 Data generation and narrative interviewing

Creswell (2013) describes NI as the study of methods of generating, as well as analysing and reporting upon, stories that depict lived experience. Riessman (2005, p. 474) points out that storytelling “*pivots on relationship – between teller and listener, researcher and researched, reader and writer.*” The researcher engaged in NI does not take an objective stance but rather takes a subjective approach to connect relationally with the participant's perspective (Pinnegar & Daynes 2007). The relational nature of NI offers both the researcher and the individual participants a means to engage closely and develop connections that foster a deeper understanding of the phenomena under consideration. Qualitative interviews have traditionally been categorised as structured, semi-structured and unstructured. Semi-structured in-depth interviews are well established and widely used as a reliable method of data collection in qualitative research (DiCicco-Bloom & Crabtree, 2006). Individual in-depth interviews provide a space for the participant and the researcher to co-create meaning by engaging in a “*personal and intimate encounter in which open, direct, verbal questions are used to elicit detailed narratives and stories*” (DiCicco-Bloom & Crabtree, 2006, p. 317). The data collection for this inquiry was conducted using narrative interview. Narrative interviewing is a specific method of data collection that facilitates the researcher in accessing the participants stories (Holloway & Freshwater, 2007). It is important to remember that perfect congruity between the interviewee and interviewer is probably neither possible nor even desirable

(Riessman, 1987). Paying close attention in the interview with minimal interruption and attending to the participants' cues is of vital importance in eliciting their experiences in their own words.

Drawing on the earlier work of Benney and Hughes (1956), Elliot (2005, p. 17) discusses the idea that the interview is conceived not only as a tool for collecting data but may also act as a site for the production of data and therefore may be considered not only a resource but also a "*focus for enquiry in its own right*." Narrative interviews are designed to elicit a story as the researcher guides the participant in telling how their experience unfolded over time (Anderson & Kirkpatrick, 2015). The goal in narrative interviewing is identified by Riessman (2008, p. 23) as "*generating detailed accounts rather than brief answers or general statements*." Narrative interviewing prioritises the collection of participants' stories about their experiences and depends on preserving the integrity of the story told (Josselson & Hammack 2021). The core focus of NI research is to sensitively elicit that personal experience and crucially the meaning the individual ascribes to those experiences (Anderson & Kirkpatrick, 2015). The focus of the narrative interview is on the flow of talk from the participant. The researcher strives to encourage the participant's talk by resisting the urge to talk and by choosing a setting and creating an atmosphere that is conducive to spontaneous talk (Holloway & Freshwater, 2007). The number of questions should be limited adopting an almost unstructured approach. Other than the use of occasional prompts, researcher interruptions are minimised to avoid breaking the flow and the participant potentially losing the thread of the story being told. Josselson and Hammack (2021, p. 22) term such prompts in the narrative interview process as "*pocket questions*" that can be used to return to issues not covered in the participant's initial narration.

The narrative interview process may be described as "recursive" indicating that the direction that the research takes may change as the study progresses. The interview process should be flexible with the ability to adapt if required. A social constructionist epistemology means differences that may arise across the data set as a result in NI are not problematic since the aim is to explore meaning rather than identify universal experience

or singular truth (Josselson & Hammack, 2021). Beuthin (2014, p. 131) in examining the researcher's role in narrative interviewing, identifies tensions that occur in the process and encourages researchers to use these tensions as "*catalysts to keep the interview process dynamic.*" The tensions identified are described as potentially arising between "*presence and performance, equality and power, leading and following, being an insider and outsider, influence and neutrality, and the tension between trust and responsibility.*" (Beuthin, 2014, p. 132). In the next chapter (5.5) I discuss how the interviews for my inquiry were planned and conducted.

4.3.5 Narrative data analysis

Narrative analysis is described by Phoenix et al. (2010, p. 3) as "*a technique that seeks to interpret the ways in which people perceive reality, make sense of their worlds, and perform social actions.*" Through the process of narrative data analysis participants' stories are "re-storied" to produce narratives that are a co-construction between the researcher and participant. The role of the narrative researcher is described by Cunliffe et al. (2004) as an interpreter of stories. The narrative researcher in analysing the participants narratives should "*attend to their forms and meanings, letting our subjects voices speak from themselves*" (Riessman 1987, p. 191). Polkinghorne (1988) identifies the organising theme that identifies the significance and the role of the individual events as the "plot" of the narrative. The plot acts to transform an account of events into a coherent whole by acknowledging and emphasising the impact of specific events on the development and outcomes of a story. The plot brings together a complex series of events to form a complete story taking account of the historic and social context and acknowledging the importance of extraordinary occurrences (Polkinghorne, 1988, p. 18). Emplotment, as defined by Brooks (1985), is an active process in which individuals engage creatively to uncover what is happening and what is likely to happen as the story unfolds. Ricoeur (1980) uses the term emplotment to describe the how a series of diverse events are drawn together to form a meaningful whole that is a story. Connelly & Clandinin (2006, p. 379) assert that events under consideration in the analysis are in "*temporal transition.*" Clandinin et al. (2011) suggest that attending to temporality in NI directs the researcher to consider the past, present, and future of the people, places, phenomena, and events

under study. Portraying the relational element of NI involves acknowledging the influence of the researcher on the participant's narratives and the re-storying of those narratives as this demands researcher visibility in the study findings. It is important therefore that the researcher makes explicit the co-produced nature of the narrative by clearly identifying the roles of the participant and the researcher as they come together in the narrative interview to co-construct the narrative data. The role of the researcher in the interpretation of the narrative data produced and their responsibility for the presentation of findings in the inquiry must also be made clear (Haydon et al. 2018).

Riessman (2006, p. 186) defines narrative data analysis as a *"family of approaches to diverse kinds of texts, which have in common storied form."* A distinctive feature of narrative analysis that differentiates it from other forms of qualitative data analysis is its sole focus on the single genre of discourse, the story (Smith, 2016). In the broad arena of narrative research, although there have been numerous typologies over the years, there remains a lack of consensus and neither has a unified guideline or approach to the conduct of narrative analysis been developed (Mishler, 1995; Lieblich et al., 1998; Riessman 2005, 2008). The diversity and complex nature of available methods makes it challenging for the novice narrative researcher to decide which form of analysis to use to analyse their narrative data and best represent the participants' voices. Smith (2016, p. 203) recognises that undertaking narrative analysis is difficult and describes it as a craft that develops slowly through practice and experience adding that narrative analysis calls for a measure of *"phronesis,"* a philosophical term that translates as "good sense" or "practical wisdom".

4.3.5.1 Analytic framework

Having read widely on approaches to narrative data analysis I chose to adopt the Listening Guide (LG) method as a voice-centred relational method of analysis that was originally developed by Brown and Gilligan (1991). The method traditionally involved four listening stages during which the researcher is tasked with focusing on a different element of the narrative, these stages include:

1. Listening for the plot (this includes listening for the reader/researcher response)

In this stage the researcher concentrates on identifying the plot in the participants interviews. An important element is that the researcher also listens for their own “reader response” which is similar to the reflexivity process

2. Listening for the “I” (this involves the creation of I-poems)

The focus in this listening is on how the speaker speaks about themselves, their use of the “I” voice. The “I” voice is singled out and used to make an I-poem, by isolating each utterance that begins with “I” and as few as possible adjacent words to make a poem, a brief example is included in Chapter 6 (6.3.2). This is a creative way of focusing closely upon how the person narrates themselves. The resulting I-poems are often incorporated creatively in the research article or thesis as part of the findings although I chose not to do so due to the word count involved with 14 participants. Undertaking the step was nonetheless very useful as a means of focussing attention very closely on the participants narrations of themselves. The method is often used to also examine the “we” or the “you” voice to get a sense of the participants interpersonal relationships but also to observe where the participant steps away from the “I” voice.

3. Listening for the contrapuntal voices (these may be in harmony or in conflict)

In this listening the researcher listens for the contrapuntal voices (this is a musical term). It involves being attuned to the different voices/tones that the women adopt as they speak in relation to the research question. Multiple voices may be heard in the narratives, for example, the voices of loneliness and regret.

4. Listening for the voice of self in relation

In this listening stage the researcher is listening for the voice of the participants in relation to others in the story. This offers an window into the interpersonal relationships that are relevant to the participants’ story.

The LG method, therefore, involves a minimum of four “listening” stages which, in practical terms, also involves reading and annotation of the transcripts. Each stage typically involves more than one cycle of listening and reading, often there are several more listenings at each stage. In the early stage as I began working on the analysis I realised that while I was satisfied that the LG offered a creative and in-depth method for analysing the narrative data set I had some concerns about how I was using it very much at the micro level and therefore its overall applicability in terms of the inquiry aims and my social constructionist approach. I decided in the end that I should seek a structured means of incorporating an analysis of the wider cultural, structural and societal influences on the data. This led me to the work of feminist researchers Doucet and Mauthner (2008) who had further developed and adapted the LG model. Their first two stages that they describe as “readings” rather than “listenings” are similar to those of Gilligan et al. (2006) that seek to identify the plot and the voice of self, however, in their model they incorporated two alternative steps that allowed for listening/reading for social interaction between the participant and their social network at the micro level and then another reading for the interaction at the macro level of wider society. I considered those steps particularly relevant to my inquiry objectives and made the decision to adapt my use of the LG to include them. Following the example of McKenzie et al. (2021) I adapted a bespoke framework for the LG analysis of my data set that incorporates 6 steps drawn from both models (Doucet and Mauthner, 2008; Gilligan et al., 2006).

The LG method that is primarily based on the vertical analysis of single narratives also allows for an additional optional level of horizontal analysis across the individual narrative accounts. Conducting an additional analysis across the narratives is often useful to the research design particularly where there is an intention to inform practice as it brings the narrative evidence from the participant group together in an easily accessible form. I chose therefore to incorporate this second level of analysis by conducting a horizontal reflexive thematic analysis (RTA) across the women’s narrative accounts. This was incorporated as the seventh step in my bespoke analytical framework, see Table 4-1. I chose to use RTA guided by the seminal work of Braun and Clarke (2006) in accordance

with the updates advocated by Clarke and Braun (2012, 2019). I intentionally chose this relational method of analysis as it fit well with the reflexive nature of my narrative methodology and the LG method used during the first-level vertical analysis. Once the second-level horizontal RTA is complete the final step in the analytic framework involves the producing the “report” which in this inquiry forms a substantive and integral part of thesis in the analysis and findings chapters (6-10).

Table 4-1: Analysis framework

	1st Level: A vertical analysis of the 14 individual women's narratives using a hybrid Listening Guide method adapted from the methods of Gilligan <i>et al.</i> (2006) and Doucet & Mauthner (2008).
	Listening to and reading sequentially (in steps 1-5) each interview to explore:
	1. the plot and reader response
	2. the voice of the “I” (self-voice)
	3. contrapuntal voices in relation to the diagnosis and disclosure of BPD/EUPD
	4. voices of self-in-relation to others
	5. voices in relation to cultural contexts and social structures
6.	In this step an analysis is composed for each individual narrative by synthesising the summaries created for each listening step (1-5). The researcher considers where and how the voices analysed interact and overlap and interprets the major themes in each woman's individual narrative.
	2nd Level: A horizontal thematic analysis is applied across the women's narratives. The incorporation of this additional 7 th step is congruent with my inquiry objectives, my narrative inquiry methodology, and with the Listening Guide analysis methods of Gilligan <i>et. al.</i> (2006) and Doucet and Mauthner (2008) that inform this analysis.
7.	A cross-case analysis is conducted following the six stages of the reflexive thematic analysis method of Braun and Clarke (2006, 2019) that include:
	1. familiarisation with the data
	2. generation of codes
	3. generation of themes
	4. reviewing the themes
	5. defining and naming the themes
	6. producing the report

This highly structured approach to the analysis worked well for me as a novice researcher in terms of developing my understanding of the uniqueness of the NI methodology and the nuanced nature of narrative analysis while, in practical terms, it provided a very good level of structure for ensuring a detailed and in-depth analysis of each woman's story. The application of each stage of the analytic framework is described in detail in Chapter 6 supported and illustrated with examples from the data analysis process.

4.4 Chapter summary

This chapter examined the philosophical and methodological framework that underpins this inquiry that explores the lived experiences of women in being diagnosed with BPD and in disclosing that diagnosis to others. The adoption of a social constructionist paradigm was explored, and my philosophical assumptions were outlined. The social constructionist approach was identified as providing a conceptual space in which the world can be viewed from multiple perspectives. NI was identified as the chosen methodology for the inquiry. It was demonstrated as compatible with a social constructionist approach and an appropriate methodology to meet the objectives of the study. The nature and origins of narrative research were briefly outlined, and the key features identified. The unique qualities inherent in NI were emphasised. Using NI to address the research problem opens up opportunities to shed light on the experiences of women labelled with BPD. The findings from an inquiry of this nature have the potential to unveil counternarratives that challenge existing stereotypes and stigma that fuel outdated narratives that should be unacceptable in contemporary society. In Chapters 5 and 6 that follow I discuss the application of the NI methodology in the conduct of the inquiry.

Chapter 5: Generating the data

5.1 Introduction

In this chapter I present a detailed account of the processes involved in generating the rich narrative data required to meaningfully answer the research questions and meet the aims and the objectives of this inquiry as outlined in Figure 5-1. I begin by outlining the sampling and recruitment strategies employed. I describe in detail the process of recruiting the women to the inquiry and the challenges encountered that necessitated a two-phase recruitment process. Next, I provide an initial introduction to the women by presenting an outline of their participant characteristics and a description of the sample. I then discuss the process of generating the narrative data with the women through single in-depth interviews. I provide a detailed description of the ethical considerations that informed all aspects of the inquiry thus safeguarding all involved. The chapter concludes with a description of how quality was maintained in the conduct of the inquiry.

Figure 5-1: Aims and objectives of the inquiry

Aims

The aim of this narrative inquiry was to explore the experiences of women in receiving the diagnosis of borderline personality disorder (BPD), or emotionally unstable personality disorder (EUPD), and to gain an understanding of the meaning they attach to that diagnosis. The inquiry furthermore aimed to garner an understanding of the experiences of women in disclosing their diagnosis to others.

Objectives

The objectives of the study were to:

- inform the practice of mental health nursing and other healthcare professions by
 - exploring the subjective experiences of women in receiving a diagnosis of BPD/EUPD
 - eliciting the meaning of that diagnosis to each woman
 - exploring the experiences of women in disclosing their BPD/EUPD diagnosis to others
 - exploring the women's thoughts, feelings and decision-making regarding disclosure
- to contribute to the theoretical knowledge and the body of research on women's lived experiences of the diagnosis and disclosure BPD

5.2 Sampling strategy

The sample size in qualitative research is typically not pre-determined and is often, although not always, quite small. A recent systematic review of sample sizes in qualitative research revealed typical sample sizes ranged from 9-17 participants (Hennink & Kaiser, 2022). The aim is to achieve a sample size that is sufficient to provide a depth and richness of data to adequately answer the research question (Josselson & Hammck, 2021; Subedi, 2021). It follows that in narrative research it is not necessary to have a large sample as it is a methodology that is based on information-rich cases (Josselson & Hammack, 2021). The uniqueness of the participant's stories or the depth of the phenomena under consideration is more significant than the breadth of the study (Holloway & Freshwater 2007). Creswell (2013, pp. 73-74) indicates that "*narrative research is best for capturing the detailed stories or life of a single individual or the lives of a small number of individuals.*" In discussing the concept of adequacy of sample size in narrative inquiry Josselson and Hammack (2021, p.21) add that having too few participants could result in "*thin interpretation*" whereas having too many participants could potentially be overwhelming in terms of the management and analysis of data. In my inquiry I was satisfied as to the sufficiency of the original sample of 15 participants with whom I succeeded in generating a wealth of rich data replete with thick description that adequately answers the research questions.

There are numerous sampling strategies that are applicable in qualitative research and among these purposive sampling is considered an appropriate method for identifying information-rich cases for in-depth study (Patton, 2015; Robin et al. 2021). Purposive sampling involves procuring a sample from a specific group of people who share common characteristics. Tracy (2020, p.82) emphasises the suitability of a purposive sampling strategy that allows qualitative researchers to "*purposefully choose data that fit the parameters of the project's research questions, goals, and purposes.*" I therefore adopted a purposive sampling strategy for this inquiry that allowed me to select participants who could provide rich information relevant to the lived experience of diagnosis and disclosure of BPD.

Patton (1990) identified 16 strategies for purposeful sampling. The strategy that I used, to best meet the objectives of my inquiry was that of criterion sampling in which all potential participants that meet pre-determined criteria are selected for inclusion in the inquiry. This meant that I procured a sample of adult women living in Ireland who had experience of living with a diagnosis of BPD for six months or more as per the eligibility criteria outlined in the next section. The development of the inclusion and exclusion criteria that determined participant eligibility and the application of a criterion sampling strategy ensured that the participants recruited could provide rich and detailed stories of their experiences to answer the research questions.

5.2.1 Eligibility criteria

I elected to have a minimum requirement of six months post-diagnosis for recruitment to this inquiry. This was to allow time for the woman to sit with and begin to assimilate the diagnosis and to have had the time and opportunity to perhaps have made a disclosure of the diagnosis to others. Due to the nuanced nature of NI, I choose not to include women who do not speak English fluently. I considered that the use of an interpreter may have resulted in a loss of sensitivity to the individual's story. The use of an interpreter also raises issues of confidentiality and has significant cost implications. The decision to confine eligibility for participation to women resident in the Republic of Ireland relates to the aim of the study that sought to explore the lived experiences of women in relation to the diagnosis and disclosure of BPD specifically in the Republic of Ireland context. The further objective of the inquiry in seeking to inform policy and practice meant that it was important to ensure the data gathered would be relevant in terms of mental health services and social factors in the Republic of Ireland. The inclusion and exclusion criteria for participation in the inquiry are presented in Figure 5-2.

Figure 5-2: Inclusion criteria

Inclusion criteria Eligible participants were required to be:
➤ women aged 18 years and over
➤ capable of providing written informed consent to participate in the inquiry
➤ formally diagnosed with BPD/EUPD by a psychiatrist
➤ diagnosed with BPD/EUPD more than six months prior to the time of recruitment to the inquiry
➤ fluent in the English language
➤ resident in the Republic of Ireland
Exclusion criteria Women were deemed ineligible to participate in the inquiry if they:
➤ were aged less than 18 years
➤ did not have capacity to provide written informed consent
➤ did not have a formal diagnosis of BPD/EUPD
➤ were diagnosed less than six months prior to the time of recruitment to the inquiry
➤ were not fluent in the English language
➤ were not resident in the Republic of Ireland

5.3 Recruiting the women

This section describes the recruitment strategy for the inquiry and the recruitment process that was undertaken in two phases to ensure the successful recruitment of the women to the inquiry.

5.3.1 Recruitment strategy

From the outset of my inquiry I wanted to reach out to women diagnosed with BPD wherever they were living in the Republic of Ireland. I also wanted to reach women who might not be currently engaged with mental health services and therefore I intentionally chose not to recruit via mental health services. With these factors in mind I made the decision to devise a digital recruitment strategy to conduct the recruitment process wholly online. I was very aware of how social networking has evolved in recent years from

the original basic online sites that digitally connected individuals to ever-more sophisticated and intricate systems that facilitate connection, communication and sharing between individuals, groups, and organisations across diverse social networks. Dworkin et al. (2016, p.551) conceptualised this new era of social networking as “*a new digital town square*.” With burgeoning levels of online engagement, research recruitment via social media has become a preferred option among researchers with benefits that include speed and efficiency, cost reduction, and the opportunity for real-time interaction with potential participants (Admon et al. 2016; Chu & Snider 2013; Kapp et al. 2013; Khatri et al., 2015; McCarthy & Mazza 2019).

A systematic review by Sanchez et al. (2020) examined a total of 176 unique studies that used social media recruitment for mental health research. Of the studies reviewed 92.6% opted to recruit via Facebook and 60.8% of those used paid advertising for their recruitment. The review found that in 68.3% of included studies social media recruitment was as effective, or more effective, than traditional recruitment methods, for example postal methods, in terms of numbers recruited and costs per participant enrolled. However, the review also found that the representativeness of the sample recruited via social media must be taken into consideration since gender, age and education level were more likely to be imbalanced than when using traditional methods. This issue was evident in their analysis of study samples that were recruited via Facebook that typically had an overrepresentation of younger females. In terms of seeking to address such issues of representativeness in social media recruitment one of the recommendations from a multi-stakeholder study by Goldman et al. (2023) is to recruit via several platforms. In this study that examined the practical benefits and challenges of social media recruitment in clinical and non-clinical health research the use of multiple social media platforms was found to improve the study’s reach and the representativeness of the sample.

As previously described my recruitment strategy was based on the use of multiple social media platforms for similar reasons to broaden the reach and potential participation. To further maximise visibility and promote my inquiry I developed a logo and set up a dedicated Twitter (now known as X) account called the “Experiences of Diagnosis and

Disclosure of BPD (EDD Study)” with the Twitter handle @theeddstudy. The primary purpose of the Twitter page was for recruitment but it was also a useful means of following the activity of leading authors, academics and activists in the field. Next, I designed a digital recruitment poster specifically for use on social media platforms. The recruitment poster incorporated a call for participants, details of the aim of the inquiry, and the inclusion criteria. The poster invited interested women to contact me on my personal mobile number by calling, sending a What’s App or SMS message, or by emailing to a designated EDD Study email address. With a solid digital recruitment strategy in place I was excited to begin the recruitment process in the late autumn of 2019. What I could not have envisaged at that time was the unprecedented disruption that would ensue shortly afterwards due to the outbreak of the SARS-CoV-2 (Covid-19) global pandemic in the spring of 2020. The impact of the pandemic was significant and as a result the recruitment of women to the inquiry was conducted in two phases some two years apart.

5.3.2 Recruitment Phase 1 - October 2019

Phase 1 of the recruitment process was launched online in October of 2019 prior to the outbreak of the first recorded cases of Covid-19 in Ireland in March of 2020. I initiated the digital recruitment process by posting the recruitment poster on the EDD Study Twitter page. I promoted the post by tagging, and asking directly, mental health charities and my networks to share my recruitment poster across their social media platforms including Facebook, Instagram, Twitter (X), and LinkedIn. A screenshot of the recruitment posting is presented in Figure 5-3. This initial recruitment drive was successful. With just one posting and some sharing of that post I was contacted by seven women who were interested in participating in the inquiry.

Figure 5-3: Screenshot of digital recruitment poster posted on social media



5.3.3 Screening for eligibility

Using an eligibility form devised using the inquiry's inclusion criteria, I conducted screening to determine women's eligibility to participate, see Figure 5-4. Two of the women who were interested in participating were resident in the Northern Ireland and were therefore ineligible to participate in accordance with the eligibility criteria previously discussed. I was sorry to have had to exclude two potential participants and regretted having to disappoint those two women. I realised that I had underestimated the reach of social media and therefore had not anticipated this issue when devising the recruitment poster that did not specify the Republic of Ireland criteria. As a result I revised the poster to make it explicit that participants must be currently residing in the Republic of Ireland (see appendix 1). The remaining five women who contacted me

during that first phase of recruitment were deemed eligible to participate and were recruited to the inquiry. I scheduled an interview with each of the five women and had completed three of those interviews before the implementation, nationally, of Covid-19 pandemic restrictions and eventual lockdown that meant all research field activity was put on hold. Regretfully, the two remaining scheduled interviews could not be undertaken at that time as a result.

Figure 5-4: Participant eligibility screening form

	EDD Study Eligibility for Participation			
PARTICIPANT NAME: _____				
INCLUSION CRITERIA (<i>Must be "yes"</i>*)		Yes	No	
1. Are you aged 18 or over?				
2. Have you been given a formal diagnosis of borderline personality disorder (BPD) / emotionally unstable personality disorder (EUPD) by a psychiatrist using the DSM or ICD classifications?				
3. Have you been given this diagnosis more than 6 months ago?				
4. Do you speak and understand English fluently?				
5. Are you currently resident in Ireland?				
*Potential participants who do not meet all of the inclusion criteria will be excluded				

5.3.4 Recruitment Stage 2 – November 2021

With the lifting of Covid-19 pandemic restrictions and the resumption of research field activity, Phase 2 of recruitment for this inquiry took place in November of 2021. In the wake of the pandemic having a digital recruitment strategy proved to be hugely beneficial since more traditional methods of recruitment, for example, the placement of posters in health centres, family resource centres, or mental health service outpatient departments may not have been feasible due to ongoing restrictions and limited access. In advance of launching Phase 2 of my recruitment I emailed a major Irish mental health charity, whom I felt had a very positive online presence, to ask if they would consider sharing my inquiry

recruitment poster. They responded to confirm that they would promote the study and they suggested a specific date on which they would share the poster across all of their social media platforms. This was hugely advantageous in terms of reach since the poster would be shared across multiple social media platforms by a reputable organisation with a high level of visibility online that included their own dedicated website and social media accounts on Facebook (8K+ followers), Instagram (3K+ followers), and Twitter [X] (13K+ followers). Figures published by the Central Statistics Office (CSO) from the “Information and Communications Technology (ICT) Household Survey” (CSO, 2021), carried out in Quarters 1 and 2 of 2021, indicate that 90% of people in Ireland aged 16 years and over had used the internet in the previous three months. 70% of those internet users reported engaging with social media. The statistics show that in Ireland at that time 89% of internet users aged 16-29 years, 85% of those aged 30-44 years, 72% of those aged 45-59 years, and 45% of internet users who were aged 60-74 years used social media platforms. Given the proliferation of internet and social media use across the age ranges I was optimistic that having the recruitment poster shared across multiple platforms would be fruitful and would maximise the inquiry’s reach.

This second phase of recruitment was very successful. As a direct result of that single-day multi-platform posting I was contacted, within one week, by an additional 15 women who each expressed an interest in participating in the inquiry. Out of that group of 15 women, 14 initially agreed to be interviewed and 12 interviews were completed. Although every effort was made in terms of trying to agree a suitable date and time to meet it was not possible to arrange interviews with the remaining two women, who had expressed initial interest, due to their busy schedules. During this recruitment phase I also reached out to the two women whose interviews were cancelled at the end of Phase 1, however, they both declined to participate. One of the women explained that her decision not to participate was due to a change in her personal circumstances and the other woman felt she had too many other commitments. The decision by both women not to participate was of course understandable given the time lapse since they had first expressed an interest in participating. In total, the two phases of recruitment resulted in a sample size of 15.

5.4 Introducing the women: participant profiles

At the outset of each interview the women were invited to complete an optional short form on key characteristics (see appendix 2) that would contextualise the data and provide for a description of the sample. As per the inclusion criteria all of the participants recruited were adult women who: were resident in Ireland at the time of interview; were fluent in English, and; had been diagnosed with BPD/EUPD more than six months previously. It is important to mention at this point that one of the 15 participants who were interviewed later withdrew from the inquiry, as will be discussed in section 5.6.2, therefore the number of participant profiles is 14. From the analysis of the participant characteristic data gathered, all 14 of those participants identified as female, none identified as being transgender female. Regarding sexual orientation: eight of the women reported being attracted to members of the opposite sex, four reported being attracted to both men and women, and two opted not to complete that question. The age range of the women was 23-40 years, with an average age of 30 years. The average age at which this group of women were diagnosed with BPD was approximately 26 years old. The length of time since diagnosis ranged from 11 months to 13 years. All 14 women reported their marital status as single: eight of them reported to be in a relationship; one identified as single and dating, and; the remaining five described themselves as single and not dating. One of the women reported to have a child/children. In terms of educational achievement four of the women reported to have completed upper second level, while the remaining ten had attained a level of higher education including two who had achieved doctoral level. Regarding the employment status of the women at the time of interview: six reported to be working in paid employment; two worked in a voluntary capacity; two reported that they were unable to work as a result of illness or disability, and; one woman reported to be taking care of home/family. Finally, 13 out of the 14 women reported to be currently attending, or to have previously attended, a mental health service. Ten of the women reported to be currently prescribed medication in respect of their mental health, while four were not. An overview of the women's individual profiles is presented in Table 5-1.

Table 5-1: Participants characteristics (1-7)

Name	Gender and sexual orientation	Age*	Have any children* (Y/N)	Marital status*	Romantic relationship status*	Education level completed*	Occupational status*	Time since diagnosis*	Attends / attended mental health services*	Prescribed psychotropic medication*
Una	<i>Female attracted to the opposite sex</i>	33	No	Single	Single and not dating	Upper secondary level	Unable to work due to illness / disability	2+ years	Yes	Yes
Anna	<i>Female attracted to men/women</i>	24	No	Single	In a relationship	Upper secondary level	Unable to work due to illness / disability	1 years, 10 months	Yes	No
Fay	<i>Female attracted to opposite sex</i>	29	No	Single	Single and not dating	Doctoral level (PhD)	Working in paid employment	3 years	Yes	No
Leah	<i>Female attracted to opposite sex</i>	23	No	Single	In a relationship	Third level	Working in paid employment	3 years, 6 months	Yes	Yes
Val	<i>Female attracted to opposite sex</i>	37	No	Single	Single and dating	Third level	Working in paid employment	13 years	Yes	No
Brooke	<i>Female attracted to opposite sex</i>	23	No	Single	In a relationship	Third level	Student	3 years, 1 months	Yes	No
Jane	<i>Female attracted to men/women</i>	35	No	Single	In a relationship	Third level	Working as a volunteer	6 years	Yes	Yes

*Denotes the age of the participants at time of interview 2019/202

Table 5-1: Participant characteristics (8-14)

Name	Gender and sexual orientation	Age*	Have any children* (Y/N)	Marital status*	Romantic relationship status*	Education level completed*	Occupational status*	Time since diagnosis*	Attends / attended mental health services*	Prescribed psychotropic medication*
Ava	Female attracted to men/women	27	Yes	Single	In a relationship	Upper secondary school	Looking after home/family & Unable to work due to illness/disability	7 years, 4 months	Yes	No
Rose	Female attracted to opposite sex	40	No	Single	Single and not dating	Third level	Working in paid employment	11 months	Yes	Yes
Mya	Female, sexual orientation not stated	26	No	Single	In a relationship	Third level	Student & Self-employed	2 years	Yes	Yes
Pia	Female and straight (preferred term)	30	No	Single	Single and not dating	Third level	Student & Working in paid employment	1 year. 2 months	No	Yes
Kym	Female attracted to men/women	31	No	Single	In a relationship	Upper secondary level	Working in paid employment	2 years, 3 months	Yes	Yes
Zoe	Female attracted to opposite sex	36	No	Single	Single and dating	Third level	Working as a volunteer and unemployed	6 years	Yes	Yes
Stella	Female , sexual orientation not stated	26	No	Single	In a relationship	Third level	Working in paid employment	3 years, 6 months	Yes	Yes

5.5 Generating the data

As discussed in Chapter 4 (4.3.4) my methodological approach to answering the research questions outlined was to gather narrative data using single in-depth narrative interviews. The settings in which these interviews were conducted were important as was the effective use of interpersonal skills to put the women at ease. It was important to me when designing the inquiry to ensure that the setting for each interview was conducive to conversation and afforded each woman the privacy and level of comfort necessary to facilitate them in telling their story in an atmosphere of calm and quiet with an attentive listener as advocated by Holloway and Galvin (2017). At the recruitment stage when participation was confirmed I offered each of the women the opportunity to participate in the interview in their own home if preferred, only one of the women availed of this option. The remaining women opted to meet for interview at an alternative location. I was keen to provide an appropriate venue to ensure the smooth running of the interviews and felt that in doing so it demonstrated respect for the women and acknowledged the importance of each woman's contribution to the inquiry.

In consultation with each of the women, I sourced venues that were reasonably convenient for them to meet for interview. I offered at the outset to reimburse travel or parking expenses, however, each of the women declined. For the interviews that took place pre-pandemic sourcing an appropriate location was not too difficult. In Phase 2, post lockdown but still in the Covid-19 era, sourcing appropriate venues was more challenging. For example, one venue regrettably needed to cancel a booking due to limited access to the building and having limited staff on-site. However, without exception the community-based centres, venues, and hotels that I chose were most accommodating and worked very well. Of critical importance, each venue had in place a suite of health and safety measures in relation to preventing the transmission of the Covid-19 virus. In the interest of health and safety, and specifically preventing the spread of Covid-19 infection, I provided each of the women with a "comfort pack" that included two disposable masks, a small bottle of hand-sanitiser gel, a packet of paper tissues,

and a bottle of water. I showed each of the women a copy of my Covid-19 vaccination record and I wore a mask for the duration of each interview, masks were optional for the participants. My efforts to mitigate risk in relation to the potential transmission of Covid-19 that included maintaining appropriate social distancing as per government guidelines and wearing masks did impact the quality of the interpersonal communication reflecting the findings of a study by Mheidly et al. (2020). Social distancing and the muffling effect of face masks meant that it was sometimes difficult to hear each other clearly in the interviews. To mitigate these communication issues during the interviews both the women and I made every effort to ensure clear enunciation and asked for clarification when necessary. The masks also obscured the facial expressions, specifically of the middle and lower face, that typically form an integral part of communication and the relaying of emotion, for example through smiling or grimacing. I noted in my research journal having noticed the impact of mask-wearing on picking up more subtle cues in the interviews, for example a lip quiver that might indicate upset. I noted that the difference in non-verbal communication was more noticeable since not all participants chose to wear masks.

5.5.1 In-depth narrative interviews with the women

“The aim of a narrative research interview is to enter the world of the participant and try to understand how it looks and feels from the participant’s point of view. This occurs through empathic listening. (...) We reach an empathic attitude through highly attuned, focused, careful, attentive listening.” (Josselson, 2013, p.80)

Conscious of the potential impact of mask-wearing on communication I was motivated to ensure that I achieved a good level of empathic listening as I engaged with the women throughout each of the interviews, as described by Josselson (2013) in this brief quotation. I aimed to achieve this by becoming attuned to the women, by staying focused, and through active listening. I felt my experience as a mental health nurse would be advantageous in regards to the skills of active and empathic listening. I entered the process of data generation with some trepidation in terms of my novice status as a narrative researcher and with a modicum of

confidence in terms of my communication and interpersonal skills that I will discuss later in this chapter in terms of researcher reflexivity (5.7.4). As a woman interviewing women I hoped, from the outset, that gender congruity would contribute positively to my understanding and analysis of the experiences of the participants. I feel that this was an important consideration, but I was cognisant that many other factors including differing backgrounds, or ethnicity, can impact interviewer-interviewee congruity and can result in bias within the interview process. Regardless of efforts to create an equal relationship between the researcher and the participant it remains that there is an inherent power differential reflected in the fact that the researcher determines the research topic and question and crucially the way the data produced in the interviews is ultimately used and presented (Briggs, 2007; Thambinathan & Kinsella et al., 2021).

The narrative data was “generated,” a term coined by Elliot (2005) for the gathering of narrative data, by using in-depth, audio-recorded, one-to-one interviews. Before commencing each interview and in accordance with the ethical conduct of the inquiry, that is discussed in detail in the next section of this chapter (5.6), I confirmed the women’s agreement for the interview to be audio-recorded. I reiterated assurances regarding confidentiality and I secured their written consent in accordance with best practice (Bold, 2012). I also explained the aims and objectives of the inquiry and described the format of the interview. I explained that once I began recording I would invite them to share their story of their experience of being diagnosed with BPD and their experience of disclosing that diagnosis to others if they had chosen to disclose. I encouraged the women to answer in their own words and at their own pace, beginning and ending at whatever point they chose. Oral storytelling, as described by Riessman (2005, p.474), is a relational practice that takes place in “*an evolving and often intimate conversation*” between the narrator and the listener. She cautions that the performance element may pressurise the participant to divulge more than they had intended or were comfortable to tell. I was conscious therefore not to exert any pressure upon the women to elaborate where they were not naturally inclined

to do so. I reminded the women that we could stop at any point for a break but also that there would be no pressure to resume the interview if that was too difficult. I also explained that I might make some occasional notes during the interview just as a reminder to follow up on points of interest or to make a clarification. In fact I made very few notes during the interviews as I was intent on actively listening to the narration. I did note some keywords that helped me remember key aspects of the interview that I later wrote up as field notes.

The interviewing style that I adopted, while not considered fully unstructured, was intentionally concentrated around a small number of questions to allow for a flow of talk from the women. I therefore compiled a brief interview guide that comprised open-ended questions that were designed to elicit the woman's narrative (see appendix 3). I included some questioning and clarification phrases and prompts and some notes as reminders for concluding the interviews. In line with an experience-centred approach I began the recorded component of the interview by asking the following question:

"Beginning wherever you wish can you tell me about being given the diagnosis of borderline personality disorder, or emotionally unstable personality disorder, and about telling others about that diagnosis. Please feel free to give me as much detail as you would like as everything you tell me about your story is important." [Tracey]

As is evident in the open nature of the question posed, as we began the interview I was keen to avoid interrupting the flow of the women's stories (Kvale, 2007). As previously mentioned, for me active listening was vitally important, however, narrative interviews are recognised as interactive as together the participant and the researcher generate the data (Barbour, 2014; Riessman, 2008). In accordance with the emergent nature of narrative interviewing there were some instances where the use of additional pocket questions, as described by Josselson and Hammack (2021), was helpful. They facilitated probing a little deeper during the interviews where issues that I felt warranted further exploration arose in the narration. For example, in some of the interviews I took the opportunity to

explore, from a feminist perspective, the women's perceptions of whether the gender of the clinician impacted their diagnostic experience or their mental healthcare experiences as is exemplified in this extract from my interview with Ava where I asked:

"Is it difficult to ... deal with a medical professional who's a man? Do you think that's ... do you think that's relevant? Is it easier perhaps to talk to a woman?" [Tracey]

Ava replied indicating that while she was reluctant to say that the gender of the clinician made a difference to her experience in fact it did as she explained:

"I wanna say no ... because whenever I see a man-doctor I never think 'get me the woman-doctor' [...] I question that now, I really question that because I know in my GP clinic the two women doctors they're a lot more understanding [...] and even my psychologist, she's very nice and understanding and [...] not insensitive at all [...] while the man-psychiatrist [...] he's the kinda doctor that he'd say [...] just don't be anxious [...] like he has said stuff like that. [...] I do wonder that, unfortunately, I'd like to say that's not the case but I question that a lot. [...] It's a lot easier to ... to open up to ... to [named female clinician], for example, than it would be to him because I know [female clinician] is not really gonna say something that will really upset me and ... she doesn't really say things that I take up the wrong way, you know, not that you have to tiptoe around me but ... while the other doctor, the male doctor, he does say quite insensitive things like [...] he doesn't even seem to try." [Ava]

In the interviews where the women disclosed that their (male) partner also had a diagnosis of BPD and had difficulty managing anger I probed further to explore their perceptions around the differences between how men and women experience and express anger and how they felt women's anger is perceived at a societal level. For example, in my interview with Leah as she spoke about how women tend to turn anger inwards on themselves rather than be perceived by others as being aggressive or a "bitch" whereas men are "almost forced to be aggressive." I was interested to hear more about her perception of societal

expectations around women's behaviour as I commented on what she had said and asked a question:

"Yeah ... there's a really interesting thing that you're saying there ... it's a little bit about societal expectation isn't it? [...] With what society expects ... how they expect a woman to behave [...] or how they expect a man to behave and to process, as you said, what ... what seems to you to be very similar thoughts and feelings?" [Tracey]

Leah took a moment before answering and her response was a little hesitant as she considered the challenges for both men and women in expressing anger and the impact of gendered roles and expectations on men and women in society:

"Yeah [...] I think so [...] like I don't think one is ... it's not better to be either ... 'cos I'm sure men would sometimes wish they could be more sensitive and sad and not have to lash out when they're upset ... but it's annoying when you're a woman and like sometimes you're right to be angry and you're right to have like eh ... an aggressive ... well not an aggressive ... but you know an angry reaction to something and it's like jees she'd want to settle down like she's ... why is she acting like such a bitch, why is she being so crazy? So we're kind of expected to just be quiet and internalise things. And then you hurt yourself, or you do something, and it's "where did that come out of?" But you know you were upset the whole time but we were just being seen as being emotional or being seen as sensitive ... I dunno" [Leah]

I asked in response:

"Does that create a pressure?" [Tracey]

Leah replied:

" Yeah, I think so, I feel like I can't be assertive without being a bitch or I can't be assertive without people thinking negatively of me ... I'm afraid to be assertive like ... but it's my own perception as well like [...] me being afraid is my own thoughts of what I should be but it doesn't help the way I think society is as well." [Leah]

As I have shown in these excerpts it was useful to have the scope to ask additional questions that helped open up the conversation further to enhance the richness and depth of the narrative data generated.

The women that I interviewed were incredibly generous with their time and forthright in sharing their stories. Each individual story revealed a unique pattern of difficult, painful, and traumatic experiences. The telling of those stories was highly charged with emotion and the way that each of the women managed that and still continued to share their story was admirable. I felt they each demonstrated courage and fortitude. The length of interview, which was determined by the women, varied from 45 minutes to 100+ minutes, most lasted approximately an hour. At the end of each interview, I reflected briefly with the woman on the story shared and thanked them for their contribution to the inquiry, reminding them that I would forward a copy of the interview transcript which could be amended, if necessary, with any corrections of to remove any text if they were unhappy with any of the content. Only a few very minor amendments were requested to avoid potential recognition of people, or setting, or a specific incident that might be identifiable and could therefore potentially compromise anonymity. While each interview experience was unique, a common feature among the interviews was that the women appreciated the opportunity to tell their stories and share their experiences. This is reflective of the findings of a review that explored the value of narrative inquiry as a methodology in nursing research in which the authors conclude that *“stories heal and soothe the body and spirit, provide hope and courage to explore and grow. The process of storytelling, a fundamental element in narrative inquiry, provides the opportunity for dialogue and reflection, each intertwined and cyclical”* (Wang & Geale, 2015, p.198).

Once the interviews were complete and the women had left, I dictated my field notes to quickly and efficiently capture my initial impressions. I later transcribed my field notes into my research journal that I used to track my thoughts, observations, and decision-making processes throughout the inquiry. My field notes served to record my initial impressions of the story told, the topics discussed, the language used, the body language, and any notable emotion or nonverbal communication. In this way I supplemented the data gathered in the audio-recording of the interview by documenting, for example, nonverbal

behaviours such as tearfulness. My carefully recorded field notes were particularly useful in the first step of the analysis using the Listening Guide method as discussed in Chapter 6 (6.3.1).

5.6 Ethical considerations

As with all other forms of research in health and social care contexts that involve human beings as research subjects, NI warrants ethical consideration from the planning and design phase through to dissemination (Bold 2012). Ethical approval for this inquiry was granted by the University of Dublin Trinity College Faculty Research Ethics Committee in December 2018 (see appendix 4). While the process of applying for ethical approval provided a useful framework to initially tease out the ethical issues pertaining to the inquiry, I soon learned that institutional approval was just the first step on the journey towards conducting an ethical inquiry. It was important that I developed an ethical attitude that permeated each stage of the inquiry from recruitment through to publication.

From the outset I was mindful of my ethical obligations in relation to recruitment. Gyure et al. (2014, p.2) describe an approach they define as “*recruitment etiquette*” that prioritises ethical considerations of respect for persons, beneficence, and justice emphasising the values of responsibility, compassion, and cultural sensitivity. They argue that these values should consistently underpin the interactions between the researcher and those who participate in the study. The researcher’s proactive use of interpersonal skills is recognised as a vitally important factor in successful recruitment and retention in research (Patterson et al., 2011; Penckofer et al., 2011). In the recruitment phases of my inquiry, I was keen to model good recruitment etiquette by drawing on the interpersonal skills that underpin my nursing practice. Throughout this process of engaging with women who were interested in participating in the inquiry I endeavoured to be approachable, respectful, and tactful and to convey compassion and empathy. During each phase of the online recruitment as each woman contacted me, I

arranged a telephone call with them for the purposes of introducing myself, providing additional information about the inquiry, outlining my interest in the research topic, and answering any questions they might have. I was conscious of maintaining an ethical approach to safeguard potential participants and to ensure the integrity of the inquiry. Therefore, as I enrolled each woman in the inquiry, I was careful to adhere closely to the relevant ethical procedures and principles identified here.

5.6.1 Protection from harm

Lee (1993, p.4) offers a simple definition of sensitive research in describing it as *“research which potentially poses a substantial threat to those who are or have been involved in it.”* He expands on this definition to discuss how there is always a cost to those who engage as participants in research if only in time and perhaps inconvenience. However, the human cost for the participant and sometimes too for the researcher involved in sensitive research can be much more significant. The risks of harm to the participant that are inherent in narrative research, including exploitation, distress, and the perception of being wronged or deceived are outlined in the previous chapter (4.3). The risk of exploitation is considered significant given the nature of the research and the level of relational engagement. Given the personal and often intimate nature of the stories that were being told by the women, in a relatively convivial setting, I was pro-active in maintaining a professional researcher-participant relationship to minimise the risk of exploitation.

There is always potential for distress in narrative inquiry as the participant narrates potentially sensitive topics that have the capacity to unleash powerful emotions (Pascoe Leahy, 2021). In advance of starting each interview, I addressed directly with each woman the potential for distress arising from her engagement in the interview process and advised her that the interview could be paused, or stopped entirely, at any stage. We agreed a hand signal to indicate the woman's desire to stop the recording if she became upset and felt unable to speak. This

worked well as several of the women did become upset and a little overwhelmed during the interview and so availed of a short break to regain their composure. On each occasion the woman opted to recommence the interview and brought the session to its natural conclusion. Where the woman hesitated before sharing an element of her story, or when I asked a follow-up question on a point of interest, I was careful to remind her that she did not have to answer or to share anything that made her feel uncomfortable.

I also observed that these interviews appeared to be very physically draining on the women who had become very emotional and upset. I checked with each woman interviewed that she had a support system in place should she become distressed later in relation to having participated in the interview. Furthermore, each of the women was provided with a contact sheet that listed support services that might be of help in a crisis (see appendix 5). Before concluding each interview, I agreed a mechanism for me to “check-in” with them over the following couple of days as a means of follow-up. This check-in was conducted by telephone, What’s App or text message. Each of the women responded positively to the check-in and all reported at that stage to have been happy with the interview process and to have had the opportunity to participate in the study.

5.6.2 Voluntary participation and informed consent

Nelson et al. (2011) in their concept analysis of voluntariness argue that voluntary consent is one of three pillars identified in the literature that underpin the protection of human beings engaging as participants in research, the other two being fairness in the selection of participants and an adequate balance of risk versus benefit to the study participants. Nelson et al. (2011, p. 14) essentially suggest two “*necessary and jointly sufficient conditions*” both of which must be achieved for an action to be considered voluntary; the action must be “*intentional*” and “*substantially free of controlling influences.*” I revisited the subject of the voluntary nature of research engagement and the right to withdraw from the inquiry at each point of engagement with the participants. This included our

initial contact at recruitment stage and each stage thereafter through to the transcription and analysis stages where participants had any queries or concerns related to their contribution to the inquiry. Following one of the interviews and prior to the transcription of the audio file one of the women contacted me to withdraw her interview from the inquiry for personal reasons. I agreed to do so immediately reiterating the participants' absolute right to withdraw. I provided reassurance that the audio file would be destroyed and later that day I emailed confirmation of the destruction of the audio file and the personal information gathered at the interview.

An open and transparent process of ongoing informed consent is a key component of all research that involves human beings. The rationale for informed consent is that it facilitates a clear understanding of the research and its inherent risks for the participant (Kylkkinen, 2021). The informed consent process promotes a research relationship that encourages trust and establishes research integrity (British Sociological Association, 2017). Appelbaum et al. (2009) assert that informed consent is founded on three components: adequate information, a competent decision-maker, and a voluntary decision process. Bearing in mind the guidance from the British Psychological Association (2017) I provided, from the outset, clear and unambiguous information for the women who participated in my inquiry. I began this process by providing each of the women deemed eligible for participation with a comprehensive participant information pack. The pack detailed the aims and conduct of the inquiry and emphasised the voluntary nature of participation in the research and their absolute right to withdraw at any stage. The information pack included a cover letter outlining the study (see appendix 6), the participant information leaflet (see appendix 7), and an expression of interest form (see appendix 8). I was meticulous in gaining the informed consent of each of the women prior to each interview. I included a copy of the consent form (see appendix 9) in the information pack to allow sufficient time for the women to fully consider their decision on consent. I allowed a minimum of seven days between providing the pack and seeking consent. I made the women aware that I was available to answer any questions during that time.

At the outset of each interview, the purpose and process of the inquiry were clearly outlined verbally. The expectations around the women's involvement and contribution were clearly defined in terms of participation in the narrative interview and the option to review their interview transcript. I outlined the content and implications of the consent form and the legal limitations regarding confidentiality and disclosure. I assured the women of my commitment to professional conduct throughout the inquiry and to addressing any queries they might have. The gathering and use of narrative data in an ethical manner requires the acquisition of informed consent both in advance of the interview and through a continuous process of renegotiation of consent as required throughout the inquiry. Therefore having confirmed consent I was committed to renegotiating it at each appropriate point in the inquiry. For example, I reconfirmed consent with the women who chose to review their interview transcript and at any point where queries were raised as discussed later in this chapter. I thus remained open in my communication around consent throughout the inquiry.

5.6.3 Confidentiality

Confidentiality is a core principle of research ethics wherein the researcher has a significant obligation to uphold the privacy and confidentiality of the research participants (Surmiak, 2019). Issues of privacy and confidentiality can be problematic in NI since the data comprises individual and unique stories that render the participants potentially more readily identifiable than those who participate in research that employs other methodologies (Wiles, 2012). I therefore took several steps to ensure the privacy and confidentiality of the women in my inquiry was maintained throughout. First, potential participants contacted me directly to express their interest in participating in the inquiry. Second, following each interview the woman's identity and biographical information was anonymised prior to transcription as previously mentioned. Third, the data generated in the inquiry was encrypted for storage on my computer and secure cloud storage was used in accordance with the provisions of the General Data Protection Regulations (GDPR) (EU) 2016/679. Fourth, hard copy consent forms

and demographic forms were filed and stored in a locked filing cabinet in my home office in accordance with data protection requirements. Fifth, the anonymised audio recordings and hard copy transcripts were stored in a locked filing cabinet separate from other hard data to ensure confidentiality and to protect the women's identities.

The nature of the narrative interviews through which the women revealed personal experiences, discussed their relationships, and described significant life events meant that participants might be recognisable in ways other than just by name. It was my responsibility as the researcher to consider this potential risk and to comprehensively address this challenge to maintaining anonymity in the inquiry. As I drafted the inquiry findings I took great care to avoid using quotes, or relaying certain incidents, that could potentially render the woman identifiable and therefore jeopardise the confidentiality of the inquiry and the woman's anonymity (Lingard & Watling, 2021). This involved some compromise and sometimes having to omit a significant incident or poignant quote to include a less identifiable alternative. I knew that anonymity was a particular concern for some of the women, three of whom had contacted me with some questions having read their transcripts. They each voiced concerns in relation to how their narrative would be presented and that potentially they might be recognisable. I provided reassurance to each of the women that while a summary account of each of their stories would be included in the final thesis and quotes from each of their transcripts would be used to illustrate the findings the thesis would not directly connect the details of their individual stories and experiences in a way that would render them recognisable. I explained that the findings presented would reflect my interpretation of the stories shared by all 14 women who participated in the inquiry and that their data would contribute in that way to answering the research question. I also assured them of the absolute confidentiality of the original full transcripts. Before ending the conversation I ensured that the women were still consenting to participate and they each confirmed that they were happy to continue as participants in the inquiry. Having those conversation made me more keenly aware of my responsibilities, as the researcher, in relation to potential

issues of confidentiality arising from the presentation of findings. I continued to carefully screen each thesis chapter draft to ensure that none of the women who participated, nor any other individuals or organisations mentioned in the narratives, could be identified in any way.

5.6.4 Vulnerability

The notion of vulnerability that is central to research ethics emanated from the Belmont Report in the United States in 1979 which highlighted the possibility that certain participants might be at increased risk of harm (Bracken-Roche et al., 2017). While there is general consensus that some research participants may be particularly vulnerable in certain circumstances much debate exists around the exact meaning of the term that is somewhat nebulous. Traditionally, there are many reasons why an individual or group may be defined as vulnerable in terms of research participation and those vulnerabilities span the physical, psychological, and social domains of wellbeing. Those who are stigmatised, marginalised, or socially excluded, and individuals living with mental health difficulties are among the groups of people who are considered vulnerable in the research context. Such blanket conceptualisation of whole groups of people as *vulnerable* is problematic in that it is paternalistic, stigmatising, and contradicts positive dimensions of autonomy, empowerment, and agency (Mackenzie et al., 2014).

An important ethical consideration in terms of this tendency to characterise whole groups of people as vulnerable is that researchers can contribute to a deficit discourse when conducting research with populations labelled as vulnerable (Mollard et al., 2020). A deficit discourse is one that locates the blame for a problem or difficulty in the person who is experiencing it while disregarding larger systems of oppression and systemic inequities including for example medicalisation, paternalism, and sexism. Mollard et al., p.803 asserts that vulnerable populations are often characterized by *“a deficit discourse, a disempowering narrative that emphasizes deficiency, risk, and failure. This discourse ignores the social and structural determinants of health and the*

strengths of individuals.” It was important in the context of my inquiry to avoid contributing to and reinforcing the dominant deficit discourse that abounds relating to the “*borderline woman*” by automatically attributing a vulnerable status to the women and instead to adopt a strengths-based approach to the inquiry. Having a background as a mental health nurse I value the principles of a strengths-based approach in research that focuses upon empowerment. The strengths-based strategy I adopted was to seek out in the narratives evidence of individual strengths and capabilities and to identify the social context and resources that positively impact the women’s lives. I sought to engage respectfully with the women who have agency and are expert in their own lived experience.

5.6.5 Issues of vulnerability in sensitive research

While adopting a strengths-based approach to the inquiry it remained important for me to keep to the forefront of my mind the ethical issue of potential participant vulnerability since this inquiry has at its core the sensitive topic of BPD diagnosis. This inquiry had significant potential to elicit stories that might retraumatise the women in the telling. As indicated by Delaunay et al. (2020) an individual’s level of vulnerability in research relates directly to the nature and sensitivity of the research. A review conducted by Alexander et al. (2018) interestingly found substantive evidence that participants considered vulnerable in research were very willing to discuss sensitive issues and that they often welcomed the opportunity to engage on topics that others were not interested or willing to explore with them. Benefits to participants that were identified by Alexander et al. (2018), in their synthesis of findings from 11 published studies, included: a sense of catharsis; the development of new knowledge; feelings of altruism; and; the development of new insights or personal meanings in relation to events that they had discussed in the research interview. Many participants across the studies described a sense of relief at having told their story to an interested and empathetic listener and the findings overall were reported as very positive. In respect of the *truth* of the stories told within this narrative inquiry I respected the principle that the stories told reflected the women’s subjective truth. There may have been some incongruence and

certainly stories were not always told in sequence but it was important to respect and represent the women's telling of their stories.

5.6.6 Vulnerability of the researcher

According to Riessman (2005) the listener engaged in narrative research can be significantly affected by the stories that they hear. The listener may as a result have difficulty dealing with the emotions that ensue. The blurring of roles, or a sense of role conflict, that may also occur while conducting fieldwork is identified as a significant researcher vulnerability in the realm sensitive research (Bloor et al. 2010; Sikic-Micanovic et al. 2019). Sikic-Micanovic et al. (2019) emphasise the importance of foregrounding one's role as a researcher and acknowledging and communicating the emotional challenges to mitigate risk. Hanna (2019) points out that there is little discussion in the literature of the emotional labour of the researcher involved in researching sensitive topics. Bloor et al. (2010, p.25) observe that the *"face-to-face proximity of researchers to people whose stories are heavy with loss, sorrow, disappointment, or grief make it easy to understand that there will be an emotional cost to undertaking these kinds of studies."* The way in which Bloor et al. (2010) describe the potential impact of the stories told on the researcher speaks to my experience of interviewing the women in my inquiry. I reflect upon the somewhat unanticipated level of emotional reaction that I experienced during the process of data generation and my experience of balancing conflicting roles of researcher and nurse in the next chapter (6.3.1). While undertaking the inquiry field work it was important for me to put in place a plan to access support in respect of dealing with the emotional impact of bearing witness to the women's often difficult accounts and managing conflicting roles in terms of my responsibilities as a researcher and my natural inclinations to respond as a nurse. My academic supervisors were hugely supportive and provided for me a safe space to debrief while maintaining the absolute confidentiality of the research encounter.

5.7 How quality was maintained in the inquiry

Credible research demands a critical stance and a rigorous approach (Holloway & Freshwater, 2007). In her paper that problematises the issue of determining quality in narrative Andrews (2020) sets out a checklist of quality indicators for high-quality narrative research (see appendix 10). The list is not intended to be exhaustive and was developed based on the authors extensive experience in the field of narrative research. Although the criteria are not exclusive to narrative research, it is useful to have the checklist that draws together quality indicators that are most relevant for the narrative researcher. Each of the ten criteria included in the checklist has been written about by Andrews and other narrative scholars.

- Truthfulness
- Trustworthiness
- Critical reflexivity
- Scholarship and accessibility
- Ethical sensitivity
- Co-construction of meaning
- Attention to the untold
- Awareness of temporal fluidity
- Multilayered stories

In the interest of demonstrating my commitment to quality and maintaining rigour in the inquiry, I briefly discuss the criteria listed as each relates to my inquiry in the sections that follow.

5.7.1 Truthfulness

Andrews (2020) makes clear her use of the term “truthfulness” to distinguish from any claims of a single factual “truth” which are seldom claimed in narrative research. Earlier in this chapter (5.6.5) I acknowledge that the stories shared with me in this inquiry are a reflection of the women’s subjective truth in accordance with the principles of narrative inquiry.

5.7.2 Trustworthiness

Andrews (2020) likens her use of the trustworthiness criteria to Riessman's (2008, p.191) conceptualisation of "*persuasiveness*" that asserts that the interpretation of data should be "*plausible, reasonable and convincing*". The researcher strengthens the persuasiveness of their inquiry by: supporting their theoretical claims with evidence from the narrative/s, by including discussion of dissonant voices (negative cases), and through the consideration of other potential interpretations. Riessman (2008, p.191) adds that trustworthiness is supported by "*making sense analytically of both convergence and divergence*." In my inquiry I comprehensively discuss and clearly present the analytic framework that guided the two levels and methods of analysis. In the chapters that follow I support the theoretical findings with extensive illustration using representative extracts from the data that tell the story. I attend to the dissonant voices in the narratives and I examine in detail the points of convergence and divergence in the narratives. The presentation of the summary plots in Chapter 7 (7.1) that provides context in the form a brief abstract of each woman's story is intended to add to the persuasiveness of the findings in terms of demonstrating that the interpretation of the women's collective experiences is plausible, reasonable and convincing.

5.7.3 Critical reflexivity

Commensurate with a social constructionist approach, and the requirement for the researcher to scrutinise his/her own taken-for-granted beliefs, reflexivity is crucial in narrative inquiry as a means of recognising and addressing the inseparability of the researcher the research and interpretation (Riessman, 2015). Reflexivity involves careful consideration of subjectivity within the research study and demands the researcher's continuous reflection upon their own values (Palganas et al. 2017; Parahoo, 2014). It is a process therefore that locates the self within the research (Hesse-Biber & Leavy, 2010). The reflexivity process encompasses the recognition, examination and understanding of how the researcher's personal background, their location, and their assumptions impact

upon their research (Hesse-Biber & Leavy, 2010). Reflexivity is an important component in narrative inquiry that demands the researcher reflects upon the reflections of the participants (Holloway & Freshwater, 2007). Riessman (2015, p.233) considers multiple definitions and modes of reflexivity summarising the practice as involving “*entering a hall of mirrors that illuminates a social phenomenon from many angles.*” Riessman (2015) asserts that adding a mere rhetorical flourish by contributing something personal is not adequate but rather the researcher must account for his/her situated self to lend credibility and validity to the study. The researcher must use reflection and self-awareness to understand how his/her own experiences and interactions influence and are influenced by the research (Chan, 2017). Reflexivity therefore involves an ongoing process of internal dialogue and critical self-evaluation of positionality on the part of the researcher (Berger 2015). In the interest of transparency and upholding the rigour of the study I engaged in reflexivity from the outset of the inquiry. I maintained a reflexive research journal for the duration of the inquiry to record and reflect upon my thoughts, ideas, emotions, insights, reactions, doubts, and achievements. I intersperse some short excerpts from my reflexive research journal, where relevant, throughout the thesis as examples of the reflexive approach that underpins my research.

5.7.4 Reflexivity in data collection

When I had completed and transcribed the first three interviews, that comprised phase one of the data generation, I reflected on my performance as a novice to narrative interviewing and determined that I would benefit from some additional training and preparation to enhance my skills. I sought online training and accessed additional online resources through the Social Research Association (SRA, n.d.) to further develop my narrative interview skills and technique and I revised my interview guide to develop better prompts.

Today is the first time I felt really comfortable in the research interview. I felt I picked up on some cues that I might have previously missed. I felt more at ease and yet more tuned in. There was just a good flow, and everything just seemed to click. From our chat afterwards it seems that the young woman that I interviewed felt that it was very positive too although certainly there were some incredibly difficult moments. I feel very privileged and a bit nervous too, I hope that I can do a good job and not let her down. [Tracey, Nov. 11th 2021]

It is important to put into context when writing reflexively about the data collection for this study the major disruption that was brought to bear by the onset of the Covid-19 global pandemic. When I began data collection in late 2019 I could not have envisaged that a short few months later my research would grind to a halt for a period of eighteen months. This extract was taken from my reflexive research journal, dated November 2021, shortly after I had recommenced my interviews in phase two of my data collection:

Today the manager from the Centre where I was due to conduct my next research interview next week phoned to inform me that they must cancel the booking due to Covid-19 restrictions. Hearing this I understood of course that safety must come first but, somewhat selfishly, I worried whether we were facing another full lockdown and feared that my inquiry (and I) would once more lose momentum. [Tracey, Nov. 15th 2021]

Fortunately, my fears were unfounded and although restrictions remained in place, I completed the interviews that were scheduled without further interruption.

5.7.4.1 Reflexivity in data analysis

My positionality as the researcher was established from the outset in the thesis. Researcher reflexivity is a fundamental principle that underpins both of the methods of analysis used in the inquiry. Accordingly the analysis was conducted with a high degree of reflexivity built in across both levels. As a mental health

nurse and educator I have always valued the practice of self-reflection in clinical practice and in undertaking this inquiry I have come to appreciate the value and importance of reflexivity in research as a method that ensures quality and as a self-care mechanism when working on sensitive or difficult topics.

5.7.5 Scholarship and accessibility

In terms of achieving an appropriate level of scholarship while maintaining accessibility this was constituted a significant learning experience for me. Getting the balance right between writing a thesis to an academic standard that demonstrated my theoretical engagement with the narratives and the literature and producing a thesis and findings that are engaging and understandable was challenging. In my efforts at times I veered from over-complicating to over-simplifying. I was very well supported in supervision throughout the inquiry and through the process of examination of the thesis to develop a balance and to enhance my scholarship in writing.

5.7.6 Ethical sensitivity

Working with the women in the co-construction of their narratives I maintained a high degree of ethical sensitivity throughout the inquiry as previously discussed in this chapter (5.6). Protection from potential harm (5.6.1) and upholding confidentiality (5.6.3) also warranted significant consideration. Working from a strengths-based approach with the women as they told their stories, while remaining attuned to the potential for distress, led to the development of a good rapport that appeared to engender in the women a high degree of trust in our participant-researcher relationship.

5.7.7 Co-construction of meaning

My social constructionist epistemology coupled with a NI methodology recognises that knowledge is jointly produced. I acknowledge in the inquiry my

active role in knowledge production and remain sensitive to the ways in which as an interviewer, listening and speaking, and occasionally interjecting with additional questions in the interviews I also contribute to shaping the narrative produced. For example, raising some questions in relation gender differences in BPD as a topic of interest that naturally arose in some of the women's stories. As a transcriber and analyst I also contribute to shaping the narratives accounts through interpretation. Researcher subjectivity is acknowledged and is in fact crucial in the LG (Gilligan et al. 2006; Doucet & Mauthner, 2008) and the RTA methods of analysis (Braun & Clarke, 2006).

5.7.8 Attention to the untold

Andrews (2020) draws attention to the need for narrative researchers not to limit the scope of their research starting with the design. In the design of my inquiry I aimed to recruit women from all over the Republic of Ireland through the use of a digital recruitment strategy making the intentional decision to recruit outside of mental health settings so as to include women who may not be engaged with services. From the perspective of the data analysis the LG method of narrative analysis employed in the inquiry specifically attends to silences, the unheard voice, and the untold story. Specifically, the use of the concept of contrapuntal voices in the presentation of findings is intended to draw attention to what is left unsaid.

5.7.9 Awareness of temporal fluidity

Andrews (2020) adopts a literary term to represent the subjective nature of time and the interconnectedness of past, present, and future. I recognise in my inquiry that there are a number of levels of temporality at play also in the stories told and in my interpretation of them. First, the stories told by the women are told at a certain point in time, the time of the actual interview (2019/2021). Next, are the times in the stories themselves that can be broadly divided into: (i) the time of diagnosis, conceptualised as the "diagnostic moment" (ii) pre-diagnosis, women's early-years and "life before being diagnosed", and (iii) post-diagnosis, or "life after

being diagnosed” (also includes disclosure). Finally, there is the present time when I will bring this inquiry to a close. Andrew’s points out that these temporal dimensions impact the interpretation of the stories. The temporality of the women’s stories is acknowledged in the presentation of the key findings chapters (Chapters 8, 9 and 10), in terms of the temporal order in which the women told their stories, and in the discussion in Chapter 11.

5.7.10 Multilayered stories

In this narrative inquiry I make clear my quest to investigate the multilayered stories of the women who have been diagnosed with BPD. In both levels of analysis discussed in the next chapter (6.3 and 6.4) I make explicit the search for points of connection between the micro-level narratives and the macro-level social structures, cultural narratives, and socio-political discourses and ideologies that speak to my social constructionist epistemology. The key findings chapters (8-10) represent an in-depth analysis of the multilayered stories told by the women that reflect the complexity of their difficult experiences. My interpretation of the multilayered nature of the stories told in terms of impact and meaning for the women is explored in structured way in the Chapter 11 using the principles of the PTMF framework.

5.7.11 Contextualisation of the research

The context of the research is made explicit in the inquiry demonstrating that the women’s stories are produced in a specific context at a particular point in time and for a particular audience. Before presenting the key thematic findings the women are introduced to the audience (the reader) using the plot summaries presented in Chapter (7.1) as a means to helping the reader understand the stories of the women that informed the findings. The findings are contextualised in the extant theoretical and empirical literature in Chapter 11.

5.8 Chapter summary

In this chapter I set out the methods employed in the conduct of this inquiry in accordance with the NI design described in the previous chapter (4.3). I discussed the sampling and recruitment strategies and described in-depth the process of recruitment. I explained the circumstances that resulted in the recruitment being undertaken in two phases. I provided a description of the sample and an overview of the women's characteristics pertaining to the inquiry. I then described my approach to the narrative interviews as the means of data generation. Next, I made explicit the ethical considerations pertaining to this inquiry and my approach to addressing appropriately the important issues of protection from harm, voluntary participation and informed consent, confidentiality, and a brief critique of the concept vulnerability and its relevance in sensitive research. I concluded this chapter with a structured discussion on how quality was maintained in the conduct of this inquiry in accordance with the quality indicators for narrative research set out by Andrews (2020). In the next chapter (6) I will make explicit how I carried out each level of analysis in accordance with the analytic strategy previously set out in Chapter 4.

Chapter 6: Producing the narratives

6.1 Introduction

In Chapter 4 (4.3.5.1) I introduced the analytic framework that I devised for my narrative inquiry. I further provided the rationale for my methodological choices that led to the design of a bespoke analytic framework that was appropriate to the narrative analysis of the interview data generated in my inquiry as described in Chapter 5 (5.5.1). In this chapter I make explicit how I carried out the analysis in accordance with my analytic framework. I provide a detailed description of how I conducted the two levels of analysis that were designed specifically to answer the research questions at the centre of this inquiry. I begin with a discussion of the process of transcription as an important precursor to the two formal levels of analysis undertaken. I further discuss my use of a qualitative data management and analysis software package to: (i) manage and organise my suite of analytic products and resources, and (ii) support the conduct of certain aspects of the analysis at each level. I then describe how I used the hybrid LG method, adapted from the methods of Doucet & Mauthner (2008) and Gilligan et al. (2006), to conduct an in-depth vertical analysis of the narrative data that was co-constructed between myself and each of the women during the relational narrative interview process. Next I discuss how, in accordance with the final step in my analytical framework, I undertook a horizontal RTA across the 14 women's individual narratives guided by the methods of Braun & Clarke (2006, 2012, 2019). I complete the chapter with a brief overview of the thematic findings.

6.2 Application of the narrative analysis framework

Josselson and Hammack (2021) describe the process of moving from audio-recorded oral interview data to text as interpretive. Next to the preliminary analysis that occurs naturally in the mind of the researcher, during and immediately following qualitative interviews and while constructing the field notes, one of the first steps in the narrative analysis of interview data is transcription, as identified by Rubin (2016).

6.2.1 Transcription

Mero-Jaffe (2011) identifies five factors that may influence the quality of research transcripts: (i) the researcher; (ii) the interviewer; (iii) the interviewee; (iv) the transcriber, and; (v) the equipment and place of transcription. In this inquiry I undertook the roles of researcher, interviewer, and transcriber thus reducing the conflicting influences that might otherwise have affected the quality of the transcripts. Further, I made every effort to ensure the comfort of the interviewee, to establish rapport, and to create an ambience conducive to the interview process by choosing quiet, private, and comfortable settings for the interviews (Ortiz, 2015). Furthermore, I took great care to ensure the quality of the recordings with the careful use of an appropriate, good-quality recording device. I was fortunate to have the option to conduct the transcription, uninterrupted, in the privacy and quiet of my home-office.

Verbatim transcription by the researcher is recommended for the novice researcher as a means of immersing oneself in the data and becoming sensitised to the most important emerging issues (Holloway and Galvin, 2017). This is a time-consuming and sometimes frustrating process; however, it does result in the fullest and richest data for analysis (Davidson, 2009). Holloway and Galvin (2017) caution that while more experienced researchers are often more selective with their transcriptions, transcribing only the more relevant data, verbatim transcription is preferable for the novice researcher lest they inadvertently omit some significant data. For these reasons I opted to transcribe the data verbatim, beginning slowly but improving with practice. My transcription was conducted using a naturalistic approach and I therefore included all verbal and audible cues which I bracketed in the text, for example, instances of: nodding, sighing, and laughing. In my original transcription I also retained in the text all extraneous utterances, for example, “ehms” and “hmms.” However, in the presentation of findings I made the decision to remove these together with any repetition of words or short phrases that occur naturally in speech. I took this decision in the interest of managing word count due to the volume of data. A summary table of the transcription conventions that I applied and that are visible in the certain quotes in the thesis are presented in Figure 6-1. The process of verbatim transcription and subsequent checking of the transcripts for accuracy against

the audio files allowed for a good level of familiarisation with the stories told (Davidson, 2009; Nasheeda et al., 2019).

Figure 6-1: Transcription conventions

Symbol used	Purpose
...	The use of ellipses indicates a pause of a few seconds
[pause]	Indicates a more significant pause of more than a few seconds
[laughs]	Denotes an instance and mode of non-verbal communication
<u>Underline</u>	Indicates the speaker placed emphasis on the word/s underlined
[...]	Bracketed ellipses are used to indicate that in between the lines quoted one or more line/s from the original transcript have been omitted for brevity or because I considered them less relevant to the point under discussion

During the interview process, and later as I worked on the transcriptions, I noticed that several of the interview recordings included some directly identifiable information in relation to place names and the names of various healthcare services. I took great care to ensure that this information was anonymised at the point of transcription. An important ethical consideration identified in the previous chapter (5.6.3), that further informed my transcription strategy is that the storied nature of narrative interview data means it carries a higher risk of participants being identifiable (Saunders et al., 2015). I therefore considered that the standard approach to anonymising qualitative data of simply applying pseudonyms, as I had done, to replace the women's names might not suffice to protect the identities of the women in my inquiry. Keen to maintain the ethical conduct of my inquiry, I took action to mitigate the risk of recognition in the narratives that could potentially compromise the privacy and confidentiality of the women. I did this by making careful note of any segments of narrative data that I thought might potentially be identifiable. Using the line numbers in the transcripts as reference points I kept a record of the sections that warranted further consideration. Working systematically in this way I completed the transcription and followed best practice in the anonymisation of each interview. I was thorough in my approach as I was determined to

ensure that the women, the specific events that they described, and the stories that they told would not be recognisable in the thesis thus upholding my ethical commitments.

My immersion in the data, by virtue of this thorough process of verbatim transcription, was very useful in terms of preparing to undertake the first level of my analysis of the women's stories using the LG method (Gilligan, 2006' Doucet Mauthner, 2008). Outside of the transcription and the formal analysis phase, described in the sections that follow, naturally the process of analysis also continued organically through contemplation of the women's stories outside of dedicated "work time", as is to be expected in qualitative research (Rubin, 2016). To keep track of the ideas, insights, and questions that occurred to me at times when I was busy doing other things, I typically sent myself an email to my EDD study email address for later consideration and follow up. Some of these electronic "notes" later formed the basis of analytical or reflexive memos.

6.2.2 Use of qualitative data management and analysis software

The practice of using qualitative data analysis software (QDAS) in the conduct of qualitative research is not without its critics, the principal argument being the risk of distancing the researcher from the data (Mortelmans, 2019). However, QDAS packages are increasingly becoming vital tools in the work of qualitative researchers. My choice to use NVivo Version 12 (NVivo-12) software (Lumivero, 2017), as a data management and analysis tool in my narrative inquiry, was a pragmatic one. This user-friendly software package offered me a flexible, reliable and convenient means of managing and organising the data files generated during the inquiry. It also offered a number of functions that I considered would be useful to me while undertaking particular steps in my analysis. Having opted to use NVivo-12 (Lumivero, 2017), I undertook basic professional training and proceeded to create a dedicated EDD Study project page. I first uploaded my audio files and later added the interview transcripts and my transcribed field notes. The creation of these composite data files, for each woman's interview, facilitated ease of access and storage of files during the analysis phase. The capacity of qualitative data analysis software packages to link digital audio files and transcripts to facilitate

simultaneous listening and reading is highlighted by Kiegelmann (2021) as a helpful feature when using the LG method of analysis. I made extensive use of NVivo-12 (Lumivero, 2017) for this purpose during the first level of my analysis. It was also very useful for the purpose of annotating the transcripts, creating summaries, and for storing related documents that I produced during the first five steps of the LG analysis. These documents included: plot summaries, concept maps, I-poems, reflexive and analytic memos, and analytic summaries of each listening step. It was important to file carefully these products of the analysis process since they constituted the building blocks for the composition of the individual LG narrative analysis documents as the end-product of the first level of analysis, as discussed in the next section. As I progressed through the second level of analysis I relied less on the use of software and leaned instinctively towards more traditional methods of generating, labelling, reviewing and organising themes, as described later in this chapter.

6.3 Listening Guide: How I listened to the women's narratives

In this section I provide the detail of how I undertook the first level of analysis in my inquiry using the purposefully adapted version of the Listening Guide method that I developed, following the example of McKenzie et al. (2015) as previously discussed in Chapter 4 (4.3.5.1). Having devised an analysis method that was specific and appropriate to achieving the aims and objectives of my inquiry it was important then to develop a systematic approach to support the authentic application of the method. Inspired by a useful table, published in the narrative inquiry paper by McKenzie et al. (2015), I used its design as a basic template to devise a similar table to use as a working document to guide my analysis. The document lists each analytic step alongside a concise description of its aim and purpose in accordance with the original methods of Gilligan et al. (2006) and Doucet and Mauthner (2008). These descriptions served as a useful quick reference guide as I worked sequentially through each step of the analysis. As this was my first time using the LG method of analysis, which is flexible, creative, and nuanced, I relied on this working analysis document as a guide to remind me of the purpose of each step and to maintain a tight focus on achieving its aim. As I moved sequentially through the steps

this working document proved very useful as a guide and I also used it as a means of recording the actions taken. As I completed each step of the analysis of the first interview I added a brief note under the description. Therein, I outlined the actions I had taken to achieve the aims of that step, as appropriate to my inquiry, thus maintaining an audit trail.

As an overview of how I applied each of the specific steps (steps 1-5) that facilitated the composition of the individual LG narrative analyses of the women's stories (step 6), I present a copy of my LG working analysis document in Figure 6-2. In the sections that follow, I expand narratively on the concise descriptions that are included in the working document. My practical application of the LG method is made transparent by drawing on selected examples of the following:

- my creative use of concept maps as a visual means of tracing the plots in the women's narratives
- the construction of I-poems as a unique feature of the Listening Guide method
- the use of figures to present my reflexive interpretation of the voices adopted by the women that relate to the research questions, illustrated with brief quotes
- brief excerpts from the transcripts that illustrate explicitly, or by inference, how the women speak to the meaning of their experiences of BPD diagnosis and disclosure in the social context
- my reflexive approach to the interpretation of the women's individual narratives, illustrated using excerpts from my reflective writings that are delineated using text-boxes

Figure 6-2: Listening Guide method - Working analysis document

Step	Description
Step 1: <i>Exploring the plot. What is happening here? Who are the main characters? What are the main events?</i>	This focus of this listening is on identifying the plot of the woman's story regarding their experience of diagnosis and disclosure of BPD/EUPD. An important element of this listening is to listen for the researcher's reflexive response in relation to the participant and the story told (Gilligan et al., 2006). This prompted me to listen for my own voice and to distinguish it from that of the woman. I did this by making brief annotations in the transcript, using Nvivo-12 (Lumivero, 2017), and then by making a related entry in my reflexive journal.
Step 2: <i>Exploring the voice of "I" (self-voice)</i>	This listening focuses upon the voice of "I", or self, with the aim of identifying how narrators speak about themselves (Gilligan et al., 2006). The creation of I-poems, in this second key step of the Listening Guide (LG) method, emphasises the voice of self with a focus on the "I" and not the plot (Koelsch, 2015). Following the example of Koelsch (2015), I created an I-poem for each of the women's narratives that is intentionally sparse. To do this I stripped out most of the contextual details, pushed the plot to the background to foreground the woman's narration of self. I highlighted relevant sections of the transcript and identified the "I" statements. I constructed each I-poem sequentially from selected passages in the transcript that reflects the woman's own voice in relation to their experiences of BPD diagnosis and disclosure, using their own words.
Step 3: <i>Exploring contrapuntal voices in relation to the diagnosis and disclosure of BPD/EUPD</i>	This step of listening for contrapuntal/different voices focuses attention on hearing the voices used by the women that relate to the research question/s (Gill et al., 2006). This involves analysing how the participant speaks in terms of tone and the language that they use and how that relates to their own self-voice. I adapted this step to accommodate two separate listenings for the voices that the women used in my inquiry to represent themselves and others in relation to (i) being diagnosed with BPD/EUPD, and (ii) disclosing their BPD/EUPD diagnosis to others. I listened first for the different voices that the women used to speak about themselves in relation to their experience of being diagnosed with BPD. I highlighted those voices, in a digital copy of the transcript, using different colours and noted how they related to one another. In the next listening and reading, I sought to hear the voices that the women used relating to their disclosure of the BPD. I also digitally highlighted those, in the transcript, again using different colours and considered them in relation to each other.

Figure 6-2: Listening Guide method - Working analysis document p.2

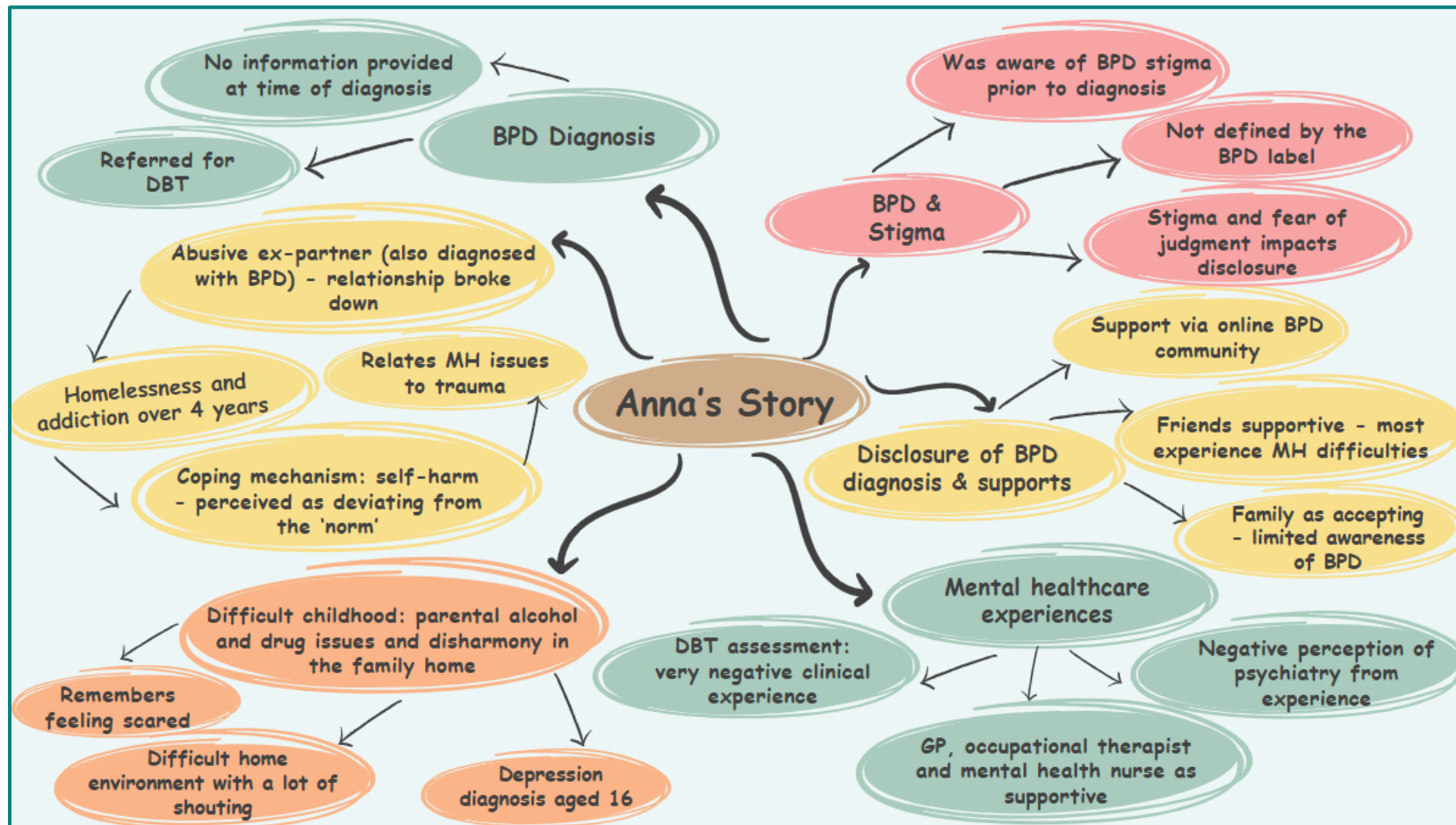
Step	Description
Step 4: <i>Exploring voices of self-in-relation to others</i>	Following the example of McKenzie <i>et al.</i> (2021) I incorporated this step and the next (step 5), that align with the LG method of Doucet & Mauthner (2008), into my framework. This fourth step focuses attention on listening and reading for participants' social interactions within their social networks including their intimate relationships. I listened for the women's voice of the self-in-relation to family, friends, colleagues, and healthcare professionals. I listened to how the women narrated their interactions with others, in a range of contexts, and analysed the voices used when describing how others responded to them in their early-life years and later as a "borderline" woman.
Step 5: <i>Exploring voices in relation to cultural contexts and social structures</i>	This fifth step focuses attention upon linking micro-level narratives with macro-level social processes and structures. From a social constructionist perspective, I was highly motivated to explore in-depth the voices used by the women in relation to their social context and whether and how they voiced or inferred, ways in which social structures, culturally dominant narratives, and/or socio-political discourses and ideologies impacted their lived experiences as women diagnosed with BPD/EUPD. This was important in terms of understanding the meaning women attributed to their lived experiences of diagnosis and disclosure of BPD/EUPD in the wider social context.
Step 6: <i>Composing an analysis</i>	In this step the researcher composes an "in-case" analysis of the individual woman's narrative by drawing together summaries of each listening step (1-5) and analysing where each voice identified interacts or overlaps. Bringing together and synthesising everything that they have learned about the person interviewed, in relation to the inquiry's research question/s, the researcher forms an interpretation of the major themes for each narrative. Following this step I drew together my summaries of each step and composed an LG analysis for each woman's narrative. These individual LG narrative analyses then became the data source for the next level horizontal analysis.
Level 2 Analysis	Description
Step 7: <i>"Cross-case" thematic analysis</i>	This final step is incorporated into the analysis framework to accommodate a horizontal analysis of the LG narrative analyses produced during the vertical analysis (step 6). The application of this six-stage reflexive thematic analysis following Braun and Clarke (2006, 2019), was recorded using a separate working analysis document.

6.3.1 Step 1: Exploring the plot

Modelled on the method of Gilligan et al. (2006) the first step I took in the LG analysis involved simultaneous listening and reading to explore: (i) the main plot of the narrative, and (ii) the reflexive researcher-response. While undertaking this first step my attention was focused upon the narrative content that was co-constructed between myself as the interviewer and the women during each of the interviews. During the first listening my primary focus was upon identifying the plot, or the main events, of each narrative. This involved the creation of a descriptive analysis that identifies who is speaking and to whom (the major characters) and what is happening (the plotlines in the narrative). By working systematically through the woman's narrative account and by staying attuned to the patterns in the language used, the gaps and the silences, and the nuances of emotion I discovered who the main characters were, what was happening, and what the main events were as I identified key elements of the plot. To help me clearly visualise the plot inherent in each woman's story I created an individual concept map onto which I carefully mapped out the various aspects of their story that were striking in terms of: relationships; trauma; diagnosis and disclosure; successes, and; challenges encountered. To illustrate how I applied this technique to visually trace the plots I present, in Figure 6-3, a sample concept map that represents an outline of the plot of Anna's story.

Having derived the plot from the stories told, my next challenge was to decide how best to represent the women's individual narratives in the thesis. I needed to strike a balance between (re)presenting the unique stories told, that in their whole form could potentially be identifiable, and editing to the point where there was a risk that women's individual stories might be lost. Montgomery (2012) described facing a similar dilemma regarding the presentation of plots for their narrative inquiry that explored the care experiences of women who were sexually abused in childhood, which they resolved satisfactorily with the development of plot summaries to include in the thesis. Following the example of Montgomery (2012) I decided to include, in the next chapter (7), a brief summary of each woman's story that encapsulates the plot.

Figure 6-3: Concept map tracing the plot of Anna's story



In summarising the individual story the order in which the events were recounted by the woman was typically changed to provide a brief, yet coherent, account. Some significant, but potentially recognisable events, were omitted as discussed in the previous chapter (5.6.3). The finalised summaries are presented in Chapter 7 (7.1) as a foreground to the inquiry's key findings. This exposition of the plots is intended to provide context for the findings and make each individual woman's lived experiences of diagnosis and disclosure of BPD more visible in the thesis. The plot summaries also honour each woman's unique contribution to this inquiry.

Having listened for and traced the plots in the women's narratives the next element of this step involved listening for my reflexive researcher-response in accordance with the LG method (Gilligan et al., 2006). The aim was to listen to and read for the ways in which each woman's story resonated for me during both: (i) the interview, as I listened empathetically and engaged in the process of co-production of the narrative data, and; (ii) the later analysis of the interview transcript. Intentionally listening and reading for my own voice in this step, I actively observed my own researcher-response to the story I was hearing. In writing my response, as I undertook this step, I added to my initial interview responses and reactions that I had previously recorded in my reflexive journal. Crucially, hearing and writing my response in this way allowed me to more deeply consider how my own thoughts and feelings affected both my understanding and my interpretation of the story and how I wrote about the woman who had shared it with me. This was important since this step, that is fundamental to the LG method, expressly calls upon researchers to locate themselves socially, emotionally and intellectually for the purpose of retaining "*some grasp over the blurred boundary between the respondent's narrative and our interpretation*" (Mauthner & Doucet, 2008, p.419). Therefore, in the interest of establishing trustworthiness, as discussed in Chapter 5 (5.7.2), examples of my reflexive researcher-responses while engaged in both the stages of active listening in the interviews, and later in the analysis, are interspersed in this chapter.

Following the methodological guidance of Tolman and Head (2021), I listened to and read each woman's account paying close attention to anything in the story that seemed

out of place, to any recurring words, phrases, or metaphors that arose and to anything that stirred my curiosity as a researcher. An example that I consider interesting, regarding the women's use of metaphor in their stories, was that of having been "put in a box" by virtue of being labelled with the diagnosis of BPD. This metaphor was all the more interesting in that it was adopted, at different stages during their interviews, by three of the women as they narrated their stories. For example, in the interview with Val looking back on her diagnostic encounter, that took place some thirteen years earlier, she used the metaphor, for the first time.

In this short extract Val described the negative impact of her BPD diagnosis that made her feel as though she had been labelled for life:

"So I was apprehensive about it because I knew if I'd been labelled then that's it ... I was put into this box and that was it ... I had no choice out of it ... that was going to be my life." [Val]

I recall that, even during the interview, I reflected on the aptness of Val's metaphor as I envisaged a box with a "BPD" label attached. Later, in the first step of the LG analysis, as I heard the words again, I reflected on a different image that the metaphor conjured up for me, that of a doll in a box. This image raised questions, for me, in terms of how women labelled with BPD are perceived in society and how women living with this label perceive themselves. [Tracey]

Later in the interview, Val expressed dissatisfaction at the lack of opportunity for progression in her employment that related to the structure of the supported employment programme through which she was employed.

Although Val enjoyed her job, having worked in the role for the past seven years, she felt labelled and devalued in the system:

"There's no opportunities [...] and there never will be because we are what we are ... so we're ... we're stuck in a box again. [...] You're stuck in a box [...] you're not important [...] you're not valued." [Val]

As I listened to Val's description of the limitations of her current job I could hear the frustration in her voice that was reflected in her repeated use of the metaphor to describe feeling unimportant and perhaps shoved aside, or shelved. [Tracey]

As I analysed each of the women's stories I sought to become attuned to any part of the audio or text that "*glows*" or lights up with intensity to become an "*emotional hotspot*", as suggested by Tolman and Head (2021, p.157). An example of an emotional hotspot, triggered by inconsistency in healthcare, arose in my interview with Kym who described how, when attending her monthly mental health clinic appointments, she typically met with a different new medical registrar each time.

When I asked Kym how it felt to have to see a new doctor each month she replied indicating how frustrating and upsetting it was since it was obvious the doctors had not taken the time to read her file:

"I get reset every time ... so I've gone in numerous times to my ... sessions and I feel like they don't even read the ... the file, they just call out ... oh eh ... 'Jane Doe' [...] I go in and they're like 'oh so you're Jane Doe?' ... 'Yeah' ... 'and can you tell me a little bit about yourself?' They clearly haven't read any of the file and [...] I have to restart everything every month." [Kym]

During the interview I felt empathy for Kym and I could imagine how distressing it must have been to be constantly asked to repeat her history that was difficult and painful to recount. Reflecting later on Kym's experience, during the first listening step of my analysis, I could understand her frustration at the futility of a system that allowed this to happen in an era of trauma-informed care. [Tracey]

During this first step of my LG analysis it was also important, in my attempt to remain true to the principles of the method, to take note of any gaps or ruptures, in other words to consider what was not said or that which was absent (Gilligan, 2015). An example of where I noted that something was not said, occurred in the telling of their stories by some of the women who had experienced a particularly difficult relationship with one parent

during their childhood. I noticed that three of the women spoke, in general terms, more highly, of their other parent in comparison to the parent who was difficult or abusive which was understandable. However, what I thought on reflection was interesting was that they did not expand to say whether in fact that parent had acted in any way to actively protect or support them. This was something I had not picked up on in the interviews, as the data was generated, but rather it was something that I noticed later as I worked through the first step of the analysis.

As advocated by Hutton and Lystor (2021), it was also important for me to listen for the physical silences in each transcript that were evident in the pauses, the lowering of the woman's voice, and instances where sentences trailed off as incomplete. I noticed, for example, that silences permeated my interview with Ava who described feelings of despair as she came to terms with complex co-morbid diagnoses of BPD, ADHD, anorexia nervosa, and potentially, a diagnosis of autism spectrum disorder (ASD) for which she was undergoing assessment around the time of our interview. As depicted in the previous chapter (5.5.1) Ava experienced challenges in her relationship with her psychiatrist.

The silences in Ava's narrative are evident in this excerpt where she talks about how she felt it would have been beneficial if her psychiatrist had shared some information on the BPD diagnosis with her during the diagnostic process as the content she later found online was not helpful:

"But [pauses] well [whispered] ... I think it would have been a ... like a good idea if maybe he'd explained to me a bit what it is ... because now I know that reading stuff on Google was ... kind of ... it kind of made me push it way [...] but then [pauses] I'm sorry [whispered softly]." [Ava]

During the interview with Ava I realised at an early stage that she might need some additional time to process difficult thoughts and emotions that appeared to surface as she told her story. I felt comfortable to wait and was keen not to rush Ava, or to exert any pressure on her to continue. Upon reflection I felt that my experience, as a mental health nurse, helped me to sit with the silences and difficult emotions that arose. What felt different for me during the interview was not being in a “helping” role, however, I did work empathetically with Ava and I did also offer a contact list for support services. [Tracey]

Having carefully mapped out and summarised the plot and listened closely for my own voice, as the researcher-response, I completed this step by filing the concept map, summary, and reflexive memo using NVivo-12 (Lumivero, 2017). I then turned my attention to undertake the next step in the analysis.

6.3.2 Step 2: Exploring the voice of “I” (self-voice)

Following the second step of my LG analysis I explored the voice of self in the woman’s story by listening and reading for the voice of “I” in accordance with the method of Gilligan et al., (2006). This step is undertaken for the purpose of understanding “*people’s inner worlds as they navigate, experience or live with conflict, their challenges, their relationships, and their social and material worlds*” (Tolman & Head, 2021, p.156). While this step of listening for and tracing the voice of self is fundamental to the unique LG method of analysis, the creation of I-poems is optional (Gilligan, 2006; Koelsch, 2015). I chose to include the construction of I-poems in my analytic framework as a powerful means of understanding each woman’s experiences, sense of self, and “*turning up the volume*” on how the woman is representing themselves (Tolman & Head, 2021, p.157). Gilligan and Eddy (2021) remind would-be I-poets that there are two rules that must be followed: (i) every “I” phrase within the selected text must be highlighted, and; (ii) the phrases extracted must be retained in the same order as they appear in the original text.

To construct the I-poems, first I listened to and read through the full interview intent on hearing the voice of “I”. Listening and reading for a second time in this step I then located

and highlighted the sections in the transcripts that spoke directly to the woman's experience of diagnosis and disclosure of BPD. I chose to highlight the transcript digitally in NVivo-12 (Lumivero, 2017). Next I traced the "I" statements in the highlighted texts and copied and pasted to draw these together in a word document to form the I-poem. Listening for tone and emphasis in the voice was important to differentiate what was said from how it was said. The I-poems use only the woman's own words, albeit that these are framed through my interpretation and selection of the text.

In Figure 6-4, I present a brief extract from the I-poem that I constructed that speaks to Una's experience of receiving her diagnosis of EUPD. At the time of the interview, more than two years had passed since Una was informed of her diagnosis of EUPD during a mental health clinic appointment where she was asked by the medical registrar, as a member of the mental health team, whether she knew what their diagnosis was. Using the I-poem technique I focused my listening on hearing the self-voice of the woman (narrator), in this example Una. I was interested in hearing Una's thoughts, feelings, and actions rather than focusing directly on her story. I sought to hear and understand where the self-voice was confident, or unsure, indicated for example in Una's I-poem where she used phrases like "I just thought" and "I didn't know." Listening carefully to Una's voice as she tells the story of her diagnosis her tone is one perhaps of resignation and a level of acceptance.

As Una portrays her "not knowing" position in the story, she also describe her actions, for example "I went home" and "I googled it". Una also makes clear the impact of hearing about her diagnosis in this way by indicating that she was shocked emphasising that she "froze." Listening in this step for the self-voice and constructing the I-poems for each woman in relation to her BPD diagnosis and disclosure experiences helped me attune to and prioritise the self-voice of the woman in the analysis. I completed this step by reflecting on the I-poems before composing a brief summary, incorporating extracts from the I-poem, that would inform the composition of the individual LG analysis. As previously discussed in Chapter 4 (4.3.5.1) the I-poems are not included in the

presentation of findings but nonetheless their construction supported my deep engagement with the women's stories and their positioning of self.

Figure 6-4: An extract from Una's I-poem

*I just remembered
I saw one of the registrars
I was like, no
I haven't been told
I just thought it was like
I just thought

I went home
I ... I ... like ... I froze
I didn't know
I froze
I went home
I googled it

I think
I got my diagnosis
I don't know
I'd say
I don't know*

Reflecting on the time-consuming and sometimes challenging process of creating the I-poems I was pleased that I had chosen to do so because it was only by attempting this novel technique that I learned what could be revealed by stripping the narratives back to their "bare bones" to reveal the skeleton that holds them together. I envisaged presenting creatively a selection of extracts from the women's I-poems at a future narrative research conference. [Tracey]

6.3.3 Step 3: Exploring contrapuntal voices related to the diagnosis and disclosure of BPD

Having completed my exploration of the self-voice and the production of the I-poem, next I turned my attention to listening for contrapuntal voices in the woman's narrative. For clarity, I engaged in separate rounds of reading and listening for the contrapuntal voices in the interview as they related to the two strands of the research question that sought to explore the lived experience of women in Ireland in:

- (i) being given the diagnosis of BPD and
- (ii) disclosing the diagnosis of BPD to others

This step involved listening to and reading each interview at least twice more to identify the different elements of the story and the different voices used by the woman to tell the story. It was difficult at first to comprehend this step due to the "*cacophony*" of voices at play in the women's accounts but by focusing on the requirement in this step to listen for the voices that directly related to answering a single research question the voices became much clearer (Tolman & Head, 2021, p.158). Listening for at least two contrapuntal voices in each woman's account I first identified each potential voice and wrote a brief description. I then read through the transcript listening for only one potential voice at a time and highlighting that voice in colour. Once I had identified the different contrapuntal voices in the transcript, each highlighted in a different colour, it was clearly visible how the different voices related to each other and to the first person voice. In this way it was possible to identify the voices that were in harmony, the voices that were in tension, and the dissonant voices that are also important in narrative inquiry (Josselson & Hammack, 2021; Riessman, 2008).

6.3.3.1 Contrapuntal voices related to being given the diagnosis of BPD/EUPD

Listening for the contrapuntal voices in each woman's account offered me a unique insight into the multiple different voices, or means of expression, employed by the women to relay their experiences and how these voices interplayed with each other. To illustrate this step I present, as a brief worked example, details of the two contrapuntal

voices that I identified in Fay's interview that related to being diagnosed with BPD. The two distinct voices that I interpreted were the "Voice of Relief" and the "Empowerment Voice." Fay's voice of relief laughingly recalled the initial relief, excitement and pure delight when she received their diagnosis of BPD. Implicit in Fay's words, and her wry tone, is a sense at times of self-deprecation. It seems as if it is almost difficult for Fay to believe how pleased she was at time given how she felt at the time of interview. Fay's voice softened audibly and became more emotional as she recalled the gradual onset of emotion and diminished contentedness as she began to come to terms with the diagnosis. Conversely, Fay's empowered voice sounded strong and confident as she rejected the validity of the diagnosis of BPD. Her voice had a tone of righteousness and towards the end of her statement she adopted a more quizzical, questioning tone, that I thought might indicate that the diagnosis doesn't make sense to her. The worked examples of the contrapuntal voice of relief and the empowered voice that I interpreted as meaningful in Fay's account are presented in Figure 6-5. For practical purposes in the thesis each sample voice that I present is illustrated with a representative quote from only one of the women's narratives. However, it is worth noting that each voice was adopted by more than one of the women as they each narrated their stories. The contrapuntal voice of relief, that related to the diagnosis of BPD, was commonly employed in the initial period after diagnosis. This voice was heard in six other accounts. The empowered voice, empowered in terms of rejecting the diagnosis on grounds of validity, was heard in three other accounts.

Figure 6-5: Contrapuntal voices in relation to receiving the diagnosis of BPD

B P D D I A G N O S I S	The Voice of Relief [Fay]	
	<i>I remember the first few hours just being so relieved and I think that relief came from years of thinking there was something like really wrong with me, like really, that I was just was not normal at all [...] I remember when she said it, I was just like ok that's something I can latch on to. [...] then it was just this huge wave of re awh, just the relief [...] I was [Fay laughs] delighted with myself and [...] then I think the relief became a bit more emotional. [...] the general contentedness with the diagnosis... this lasted mmm... maybe a couple of months I'd say</i>	Fay's voice has a tone of wry amusement as she recalls the feelings of relief that she experienced when initially diagnosed. I was a little surprised in the interview to hear that she was so relieved, I had not anticipated such a huge sense of relief and I reflected that perhaps I had assumed on some level that the diagnosis would be "bad news". Her tone and demeanour changes to become more emotional at the end of this account as she recalls a difficult time.
	The Empowered Voice [Fay]	
	<i>[...] And now I have very strong views on the whole idea about personality disorder I don't think they are a thing really. I don't think they should be in the DSM as they are I don't think we should be just trying to identify like maladaptive ways of living and then saying alright well that's in that box and that's in that box [...] treating it as a disorder. I don't agree with that at all actually [...] I don't think I have a personality disorder in that sense do you know? [...] I don't think it's a thing anymore so therefore I can't have it [...]</i>	I reflected on the point Fay makes here about the tendency in psychiatry to try to fit everything into neat boxes and how that is not a good way to try and understand people's emotions, behaviours and coping mechanisms. Her analogy speaks to the notion of labelling. Fay demonstrates strength of character and also makes an interesting point when she states that since she denies the validity of the BPD diagnosis she can't have it.

6.3.4 Contrapuntal voices related to disclosure of the diagnosis of BPD

In this second stage I listened to and read each interview several times to hear and identify potential voices that each woman adopted related to the disclosure of their diagnosis of BPD. Tuning in carefully to the woman's voice I identified at least two contrapuntal voices in each of the accounts that spoke to the question of disclosure and disclosure strategies. For the purpose of illustrating this step I present a worked example that details the contrapuntal voices that I located in one of the women's interviews. I analysed four contrapuntal voices in Brooke's story related to disclosure that include: the "Voice of Openness," the "Voice of Support," the "Voice of Invalidation," and the "Paternal Voice." These four voices that I interpreted as meaningful in Brooke's account are therefore presented in Figure 6-6. Brooke was the only one of the 14 women in the inquiry that declared to be very open about disclosing her diagnosis of BPD. She sounded cheery as she discussed the usefulness of the diagnosis in terms of providing an explanation for past behaviours. Brooke felt that her diagnosis was well received with the exception of a few friends who felt it wasn't a fit for her. The voice of invalidation is connected to this discussion where Brooke feels invalidated by her friends who don't seem to understand her diagnosis or problems. Frustration and self-doubt are evident and Brooke's voice wavers towards the end of her narration as she ask plaintively how she can get help.

It didn't occur to me in the interview, however, I reflected later as I listened to her speak on the audio file that the frustration and sense of invalidation that Brooke describes here in relation to her friends lack of "seeing" her difficulties could be reminiscent for her in ways of not feeling heard in her early-life experiences within CAMHS. [Tracey]

Figure 6-6: Contrapuntal voices in relation to the disclosure of BPD (1/2)

D I S C L O S U R E	The Voice of Openness [Brooke]	
	<i>[...] from the get-go, I was very open about my diagnosis [...] not that I'd like shout it from the rooftops but I told everyone in my life about it 'cos I feel [...] I wanted to them to understand why not to like excuse kind of negative things I've done but I want I felt like it explained, it explained things to me and I wanted to be able to explain it to them. So from the get-go I kind of told everyone kind of around me, not And I was pretty lucky I don't think it had any like no-one in my life was negative about it, really, they were all quite understanding. [...] a few kind of say less closer friends but that would find out [...] they were like "oh really, I don't think that suits you" 'cos I think I'm quite good at like masking my symptoms to people that aren't very close to me [...] but other than that I think it was I honestly can't think of any negative experience I had</i>	Brooke speaks very positively and sounds quite upbeat as she describes being very open with friends and family about her diagnosis. She seems to welcome the diagnosis in some respects because she feels it offers some explanation for her in relation to struggles she has had in the past in terms of negative behaviours that she alludes to here. There is a hint of regret or sadness or perhaps disappointment in the way that she discussed how some friends didn't seem to understand and that she masks her difficulties.
	The Voice of Support [Brooke]	
	<i>My Mam's not a very emotional person, she wouldn't discuss emotions very much, but she she's very supportive [...] she's very good at supporting and trying her best to understand, so [...] I can't remember much of what she said or anything but she was like really supportive of me getting the help and like ... even to this day ... if I'm in a really distressed way ... like, she understands and she tries her best to kind of ... At first there was a few hiccups where she just couldn't like wrap her head around some of the parts of it and stuff but now she yeah, she was she reacted really well, I think ehm yeah. [...] Sorry... [emotional]</i>	Brooke speaks softly and kindly when she speaks about her Mum and sounds very appreciative of all the support that her mum has given her and she emphasises that her mum "tries her best". Mentioning that her Mum is not very emotional Brooke appears to appreciate the care and feedback she does get from her mum. Brooke implies that their relationship may not always have been easy but and becomes emotional when she talks about how her mum reacted to her diagnosis.

Figure 6-7: Contrapuntal voices in relation to the disclosure of BPD (2/2)

DISCOURSE	The Voice of Invalidation [Brooke]	
DISCOURSE	Kind of throughout my life everyone has invalidated me, [...] even for example the couple of friends that I said that kinda said “I don’t think that diagnosis fits you” it’s kind of this ongoing trend of because I do hide I hide my symptoms very well unless you’re like extremely close to me. So I try my best to like put forward like the best person I can be and kind of squish down the BPD symptoms [...] so it’s always it feels like this trend of I’m suffering so much inside that other people don’t see it and then it’s this whole thing of like there’s a few feelings around it I suppose it’s like feeling invalidated but then I also go on to the flip side of maybe I’m not doing enough to express myself but I feel like I’m trying to but maybe it’s not enough kind of thing like I’m feel like I’m I don’t know, yeah I guess this issue of like how do I how am I supposed to show these people how much help I need ‘cos they’re not seeing it.	Brooke speaks here with an air of resignation in terms of feeling consistently invalidated throughout her life referring to this issue as an ongoing trend more than once. Brooke sounds both sad and frustrated as she talks about putting her “best foot forward” and trying to “squish down the symptoms” in a way perhaps embodying her difficulties. She sounds anguished in terms of suffering on the inside while people around her can’t see it – and wavering between feeling invalidated and then sounding out the idea that perhaps she is not doing enough to express herself. There is an element of frustration in her voice towards the end of this excerpt.
	The Paternal Voice [Brooke]	
DISCOURSE	Yeah [...] I see him on and off so [...] it’s a bit of a strained relationship [...] I did tell him [...] my dad is he has a lot of issues but he like he jokes a lot and stuff ehm I can’t remember the exact interaction but basically my dad has been in like psychiatric wards and stuff [...] he has severe problems, he has no diagnosis because aside from being forced to go to these wards he doesn’t believe in he doesn’t believe in doctors like he wouldn’t go to a GP even. [...] So he has no diagnosis, in my it’s not my place to say but in my opinion, I think he has BPD but ehm more outward than mine would be My dad is very aggressive, ehm very bad substance abuse problems [...] yeah, he kind of checks all all the boxes. [...] I’ll just say real quick [...] the joke he made was like he said “to be honest I think I have” to be honest he kind of mumbled it he said it very quietly he was like “to be honest I think have that personality thing” like he doesn’t know what it’s called “that you have”. Ehm “so that’s my gift to you, that’s your inheritance” he kinda made a joke like that so I think he acknowledges himself that he has that [...] which is a bit weird.	Brooke maintains a calm and measured voice as she discusses having disclosed her BPD diagnosis to her Dad. Her relationship with her Dad is difficult and he has been abusive towards her. It is interesting that Brooke perceives her father’s way of dealing with his problems as more “outward” in comparison to her own and that she thinks he would perhaps meet the criteria for a diagnosis of BPD because he “checks all the boxes”. Brooke sounds perplexed when she talks about her Dad’s “joke” about him having the same diagnosis. Reflecting on this I’m not sure whether the idea of that her father has revealed a diagnosis is “a bit weird” or whether it’s that they both would have the same diagnosis.

The voice of support is emotive and relates to Brooke's Mum who is as supportive as possible. There may have been some issues but there is a strong bond evident. The paternal voice relates to Brooke's Dad with whom she has a difficult father-daughter dyadic relationship. Brooke remains calm and speaks openly about the strained relationship with her Dad. The issue of her Dad revealing that he also has a diagnosis of BPD is interesting and the context in which he revealed it framing it a "gift" to his daughter.

Although I did not pick up on it in the interview, reflecting on Brooke's comment related to her Dad's disclosure of his diagnosis of BPD as being "weird" I thought perhaps it may have felt weird for her in a number of ways: (i) he had never previously revealed any diagnosis; (ii) the way in which he framed the diagnosis as a gift/inheritance, and/or; (iii) the fact that they both now shared the diagnosis of BPD. I could imagine that this would be difficult to come to terms with given the problematic nature of their relationship. I was struck by Brooke's strength conveyed through her calm and thoughtful narration. [Tracey]

Having completed the analysis of the contrapuntal voices during this step for each of the women's narratives, related first to receiving the diagnosis of BPD and then to disclosure, I developed a summary, illustrated with extracts from the transcript, that would contribute to their individual LG analysis.

Through this complex process of identifying, analysing and interpreting the contrapuntal voices related to receiving the diagnosis and to the disclosure experiences of each of the women I developed a vital understanding of how the women were impacted by the diagnosis and their dilemmas around disclosure and how they made sense of those experiences in their lives that would inform my interpretation of their stories. [Tracey]

6.3.5 Exploring voices of self-in-relation to others

This step, developed based on the method of Doucet and Mauthner (2008), explores the women's social interactions by tracing their voices of self-in-relation as they interact with family, friends, colleagues, and healthcare professionals in a wide range of contexts. I

undertook this step by listening and reading for the voices used by each woman as they narrated their interactions with others and by paying particular attention to the ways in which they described how others responded to them, both in their early-life years and later relation to their BPD label. In this listening voices of “early-life trauma” and of “difficult relationships” were expressed, to a greater or lesser extent, within each of the women’s narrative accounts. Further, voices of “rejection” and “stigma” could be heard in each woman’s narrative related to their interactions within their personal and/or social networks. Furthermore the voice of “coping”, expressed in a myriad of ways by the women was also embedded within each individual narrative. By listening to and individually analysing the diverse voices of trauma, difficult relationships, rejection, stigma, and coping that were enmeshed in each of the women’s narratives and by further considering how those voices related to each other I crucially developed my understanding of the meanings that each woman attributed to their own unique relationship experiences.

Other voices that were less ubiquitous in the narratives were also significant in developing a nuanced understanding of the meaning in the stories told. For example, the voice of “articulation” through which some of the women spoke about the challenges of feeling heard in terms of their mental health difficulties. This voice was more commonly heard in the accounts of women who had experienced care in CAMHS as a young person. As a mental health nurse engaged in research the voice of “despair” was difficult to hear and the voice of “ambivalence” was worrying, in the moment. Importantly, there were also positive voices evident in the women’s relationships interpreted as voices of “support” and of “care” that sustain them in life. Having analysed the voices-in-relation in each woman’s account I created a summary, that included excerpts from the transcript, for inclusion in the LG narrative analysis. As a means of demonstrating the approach taken in this step I have devised a sample table of voices that I identified drawn from across my analyses of the individual women’s narratives for presentation. This table incorporates some brief examples illustrated with quotes from the transcripts, see Figure 6-8.

Figure 6-8: Voices of self-in-relation to others

R E L A T I O N S H I P	The Voice of Adversity [Una]	
	<i>[...] things weren't great like kind of growing up [...] with my Mum and Dad [...] my Mum was sick [...] I kind of had to take charge because my Dad he kind of [brief laugh] never grew up.</i>	Una describes challenging family circumstances in a calm voice that sounds both resigned and understated.
	The Voice of Rejection [Val]	
	<i>So she [Val's mother] just she didn't want me she made it she made it quite clear, she still does make it quite clear she never wanted me.</i>	Val voices her mother's rejection of her in a very matter of fact way with little evidence of emotion.
	The Voice of Understanding [Fay]	
	<i>Eh so she [Fay's mother] she had a very difficult upbringing herself eh much more difficult than she gave me.</i>	Fay recognises the effect of intergenerational trauma and voices, hesitantly, empathy for her mother.
	The Voice of Professional Care [Brooke]	
P	<i>[...] the psychologist I got in my local service, she was very eh I immediately felt comfortable with her, she was very validating and she listened very well and like I had [...] I was seeing her for over a year I think and the whole time I just I really enjoyed seeing her.</i>	Brooke speaks with warm appreciation of the care she received in her local service where she felt heard.
	The Voice of Support [Pia]	
	<i>I'll start from the start so I had very pleasant childhood great upbringing really caring mammy and daddy was very loved. And I really excelled in primary school.</i>	Pia's is the only narrative that opens with emphasis on a happy home. Trauma and bullying voiced later.

Overall, reflecting on the privileged experience of hearing the women's voices-in-relation that were variously embedded in the women's narratives afforded me the opportunity to develop a more nuanced interpretation of each woman's individual narrative. [Tracey]

6.3.6 Exploring voices in relation to cultural contexts and social structures

Following the fifth step in my LG analysis, devised in accordance with the method Doucet and Mauthner (2008), I focused upon exploring the links between the micro-level narratives of the women's lived experiences and the macro-level social processes and structures that shape their lives. I did this by directing my attention to the social contexts embedded in the women's stories. As is suggested by Eddy (2019) it is often possible, during this step in the LG method, to identify a potentially overwhelming multiplicity of voices. Therefore, it was important that I used my research questions to steer my listening for voices that inferred social context that was relevant to answering those specific questions. With this in mind, as I embarked on this step of analysis I listened and read for the voices that the women used that reflected dominant cultural narratives, and/or socio-political discourses and ideologies, that related to their experiences of diagnosis and disclosure of BPD.

During the inquiry I have struggled with how I would meaningfully draw from the narratives, and adequately represent, the influence of the social context. My struggle related to the complexity of the narratives but mostly my lack of experience. I knew what I needed to do but not quite how to do it and no amount of reading or helpful suggestions from my supervisors seemed to really "click" for me. I experienced the type of overwhelm discussed by Tolman & Head (2021). It was through the incorporation of this vital step in my analysis that I could "turn down the volume" on the voices and find those that would answer my inquiry questions, this was my "Eureka" moment. [Tracey]

In listening and reading closely for social context I identified a range of voices, both implicit and explicit in the narratives, that reflected the impact of: (i) the medicalisation of trauma; (ii) gendered power relations; (iii) individualism, and; (iv) negative BPD narratives on the women's lives and sense of self in the context of being labelled as *borderline*. For example, the effect of having internalised an individualist master narrative that locates full responsibility for wellbeing, employment, and home-ownership firmly within the individual regardless of their socio-economic circumstances, thus absolving the state of welfare obligations, is evident in some of the women's stories. An example of having internalised this cultural master narrative, that I interpreted from my analysis of Jane's narrative, arose in relation to her personal circumstances at the time of the interview. Jane spoke about her living circumstances with an apparent sense of self-blame for her situation that I interpreted as being reflective of the dominant discourse of individualism of a neoliberal society that dictates that each person is responsible for themselves and must manage themselves to ensure self-sufficiency without relying on the state (Brockman & Garrett, 2022).

Jane, who had endured a difficult upbringing and was living independently alone, expressed a sense of not meeting societal expectation that is evident in this excerpt from her narrative:

"So it's even more apparent now that, you know, I'm not really functioning ... I don't have a home, I'm pregnant now and I don't have a stable environment. I live in tiny bedsit and you know my relationship isn't very stable either." [Jane]

Another example that I interpreted as being related to the influence of an individualist-leaning society occurred in my analysis of Val's story. As will be discussed further in Chapter 8 (8.2.1) Val compared herself, a number of times in the course of her storytelling, quite negatively to her siblings, specifically in terms of educational achievement and employment. I noticed that Val's tendency to compare herself to others appeared to be rooted in two ways to: (i) her mother's persistent criticism and disapproval, and; (ii) the perceived expectations in her extended family in relation to education, employment, housing, and marriage as markers of success.

Val's interactions with her extended family appeared to be fraught with similar negative comparisons:

"So, I was never like them ... I always felt very inadequate whenever there was weddings or anything like that I never liked going to them because they'd be like ... oh, what do you do? ... how do you feel? ... what are you up to? ... and if you didn't have a good job, or you weren't married, or you weren't getting married [...] there was war [...] the back'd be cut off ya by [laughs]." [Val]

Having identified the voices in this step I created my final summary that would contribute to the individual LG narrative analyses. Listening and reading for social context, particularly that which was latent in the women's stories was a labour-intensive process that revealed important underlying socio-cultural influences that impacted their lived experiences of the diagnosis and disclosure of BPD. Further examples related to the dominant discourses and ideologies identified as influential in the individual LG analyses were assimilated in the process of reflexive thematic analysis and appear in the thematic presentation of findings in Chapters 8, 9, and 10.

6.3.7 Composing an analysis

This first level of narrative analysis, comprising five sequential "listening" steps, was key to "hearing" the voices that would inform my interpretation of the stories told and my composition of an individual LG analysis of each woman's narrative. In this step I was tasked with composing an "in-case" analysis of the woman's narrative as the analytic output for this first level of analysis. In this step I composed the individual analysis report by drawing together summaries, as the products of each listening step in the analysis (steps 1-5), and then analysing where each of the voices interact and overlap. Gilligan and Eddy (2021) suggest that the best place to begin composing the analysis is to start with the "wow" moments by asking what was surprising. They advocate looking back, using the summaries, at each step of the analysis to find what was surprising and why. In the final step I brought back in my voice as the person composing the analysis to demonstrate, using the evidence gathered in each listening, how the narratives were developed on my "*journey of curiosity*" (Gilligan & Eddy, 2021, p.142). This process allowed

me synthesise everything that I had learned in the process about the woman that I had interviewed related to my research question to form my interpretation of the themes that were significant in their narrative. The end-product of this first level narrative analysis was 14 individual LG narrative analyses that then became the source of the “*narratives for further analysis*” as defined by Mischler (1995, p.95), since they constituted the data source for the next level horizontal analysis. Having completed this vertical analysis of the women’s stories, that resulted in a deep and nuanced interpretation of the women’s individual narratives, I then proceeded undertake the second level of thematic analysis outlined in the next section.

6.4 Thematic Analysis: How I analysed across the narratives

In accordance with the final step of my analytic framework I embarked on a horizontal RTA of the fourteen narrative analysis documents produced using the LG method. I undertook the RTA guided by the six-stage method originally developed and recently updated by Braun and Clarke (2006, 2019, 2022). The rationale for using RTA, as a philosophically and methodologically congruent method, in the final stage of analysis is outlined in Chapter 4 (4.3.5.1). An overview of the six stages of the RTA, that describes the aim of each stage and the action that I took to achieve it, is provided in the form of my RTA working analysis document, see Figure 6-9. It is important to add that while the stages are laid out, for clarity, in a linear fashion RTA is very much a recursive process (Braun and Clarke, 2019).

Figure 6-9: RTA method: Working analysis document p.1/2

Stage	Description
Stage 1: <i>Familiarisation with the data</i>	The first stage in the reflexive thematic analysis (RTA) requires that researcher becomes familiar with the data through a dual process of (i) immersion to begin to understand its depth and the breadth, and (ii) distancing that allows for critical reflection. Since the individual LG narrative analyses, that I composed in the final step (step 6) of my Level 1 vertical analysis, constituted the data source for the horizontal thematic analysis I was already very familiar with the “narrative for analysis”. Nonetheless, I immersed myself in the LG narrative analyses (the texts) to re-familiarise myself and to orientate myself to the thematic content. I read each text afresh made some annotations in the transcripts, using NVivo-12 (Lumivero, 2017), noting my initial thoughts regarding potential thematic content. I also engaged reflexively with the texts, using my field notes and my reflexive research diary, to reflect on my own thinking and responses that occurred during the interviews and later during the first level of analysis.
Stage 2: <i>Generation of codes</i>	The second stage of the RTA calls for the generation of initial codes as a means of organisation of the data. In this exploratory stage the researcher begins to identify elements of the data that stand out. Through reflexive engagement with the data the researcher begins to not only uncover insights and patterns inherent in the data but also considers further how their own perspective might influence the findings. Working diligently through the individual analysis documents, using NVivo (Lumivero, 2017), I identified and labelled both semantic (descriptive) and latent (interpretive) codes and organised them to create meaningful groups. In line with the social constructionist paradigm the generation of codes latent in the narratives that related to the social context was important.
Stage 3: <i>Generation of themes</i>	Braun and Clarke (2019, p.593) emphasise that themes do not “emerge” since they are not “in the data, pre-existing analysis, awaiting retrieval” but rather themes are actively generated by the researcher who identifies interesting patterns in the data (narrative) and alerts the reader (audience) to them. The third stage of the RTA facilitates the development of initial themes that are generated in the data by thoughtfully and creatively clustering together related codes to encapsulate patterns of shared meaning that occur across the dataset. Reflecting on my social constructionist perspective I actively sought to identify patterns in the latent codes generated to form coherent themes that reflected the influence of social structures and contexts on the construction of the women’s narratives.

Table 6-5: RTA method: Working analysis document p.2/2

Stage	Description
Stage 4: <i>Reviewing the themes</i>	At this fourth stage of the analysis as I worked to make sense of the women's stories, as a whole, as I compared and contrasted them to identify both the similarities and the differences in these unique texts. I began mapping out the themes visually, to create a graphic display. By doing this I could see clearly identify where many of the themes I had generated reverberated across the women's collective narratives but, equally importantly, I could also identify themes that were unique and represented a dissonant voice. During this stage of the RTA the researcher revisits the data to ensure that the themes generated accurately represent coherent patterns in the data. During this stage themes may be merged, refined, or if necessary discarded. The aim is to ensure that the analysis remains grounded in the data. I therefore sought to ensure that there was sufficient evidence in the narratives to support the themes identified. The richness of the narrative data meant that I had a wealth of quotes from which to draw examples to illustrate the analytic points made.
Stage 5: <i>Defining and naming the themes</i>	The fifth stage of the RTA is concerned with defining and naming the themes. The researcher is tasked with creating a concise summary for each theme identified to define clearly its core meaning. Naming the themes is a creative process and the name assigned should convey the essence of each theme in a way that is concise and engaging. I aimed for clarity and conciseness in the naming of the themes.
Stage 6: <i>Producing the report</i>	In the final sixth stage the researcher is required to draw together the analysis to tell the story of the findings in a way that is both engaging and accessible and that demonstrates the richness, depth and breadth of the reflexive thematic analysis undertaken. By using creatively conceptual maps and tables and incorporating representative quotes and my reflections in the substantive chapters that follow (chapters seven, eight, and nine) I aimed to provide findings that are both interesting and accessible to a wide audience. Conscious that this reflexive thematic analysis is an analysis of previously interpreted narratives, I have illustrated each theme and sub-theme with the liberal use of direct quotes from the women's narratives. This use of direct quotes serves to tell the women's stories in the thesis using their own words, while I acknowledge that they are framed using my interpretation.

It is also important to clarify that in this RTA the diverse term of “theme” is conceptualised as: “*capturing a core idea or meaning (what is shared and unites the observations in the theme is meaning), and the telling of an interpretative story about it*” as emphasised by Braun and Clarke (2023, p.2) in their editorial commentary on good practice in thematic analysis. While undertaking the RTA I frequently moved forward and back between the generation of codes and themes and revisited both when defining and naming the themes and producing the report (findings). In the sections that follow I expand on the specific stages to discuss points relevant to my inquiry and this second level of analysis.

6.4.1 Familiarisation with the data

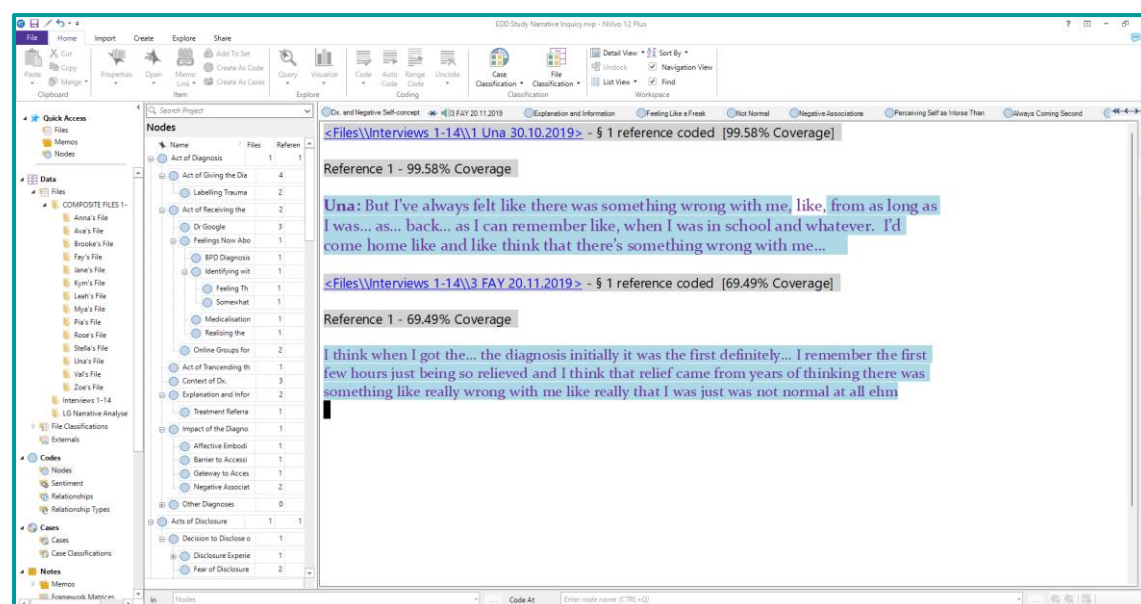
Having first conducted an in-depth vertical LG analysis, as previously discussed, I was very familiar with the data at the outset of this second level of analysis. It was important, however, in this first stage of the RTA, to step back from the individual analyses in which I had become so immersed to re-orientate myself towards looking thematically across the women’s accounts to begin observing patterns in the narratives.

6.4.2 Generation of codes

In this phase of the analysis I worked according to the RTA method to generate codes as a means of identifying and labelling features in the narrative data relevant to my research question (Braun & Clarke, 2012). This was a slow and iterative process as I worked systematically with the narratives to generate a mix of descriptive (semantic) and interpretative (latent) codes, using NVivo-12 (Lumivero, 2017). Given the social constructionist framing of my inquiry it was important in this stage to look in-depth in the narratives to interpret the meanings that lay beneath the more easily-identified semantic, or surface-level, codes. This was achieved slowly as I learned the skill of generating latent codes that spoke to the cultural context and social structures that impacted the women’s lived experiences of BPD diagnosis and disclosure.

I present here a brief example of how I worked to generate meaningful codes in the narratives to fuel the development of the themes and sub-themes that would constitute my final interpretation of the women's stories. Many of the women narrated initial feelings of relief associated with receiving the diagnosis of BPD whether in terms of accessing potentially effective treatment or of gaining some understanding of the problems they were experiencing. Two of the women who expressed feelings of relief in that context, Una and Fay, related their sense of relief to having always felt there was "something wrong" with them. Staying close to the women's own use of language I labelled this descriptive code accordingly as "something wrong." None of the women in this inquiry spoke directly in terms of "negative self-concept," at any point in their narratives. However, looking interpretatively beneath the surface, as I did with this example and with other instances of self-critical descriptive codes, I labelled "negative self-concept" as latent a code. This interpretative code subsequently contributed to the sub-themes of "diagnosis and disclosure dilemmas" as the women worked out how they felt about themselves in relation to the diagnosis and the broader theme of "living with the diagnosis." This brief example of how I coded the women's narratives is represented using an extract drawn from my record of codes (nodes) in NVivo-12 (Lumivero, 2017) that illustrates, in Figure 6-10, the coding of quote's drawn from each of the women's narratives.

Figure 6-10: RTA generation of codes in NVivo



6.4.3 Generation of themes

On a practical level, following the guidance of Braun and Clarke (2012) I sought to develop themes that ideally: (i) have a singular focus; (ii) relate to each other without overlapping, themes that build on one another but should not be repetitive, and; (iii) directly answer the research question. In the initial generation of themes I leaned towards being very descriptive. Through the reflexive and recursive process of revisiting the narratives numerous times to generate a more comprehensive range of interpretative codes I crucially expanded and developed the sub-themes that constituted the major themes in the narratives. In this way I developed the themes and sub-themes to better align with the inquiry's social constructionist framework that was designed to theorise about how socio-cultural contexts and social structures impact on women's lived experiences of distress labelled as BPD and their disclosure strategies.

I reflected in this initial stage of generating the themes, on the feeling that I was really only "scratching the surface" of the "collective" narratives with many of the themes. By focusing too soon on the structure of the findings, I realised that I had been working "hard" but not "smart" and so I was falling short in my attempts to reflect the richness of the individual narratives. I realised that I needed to revisit the latent codes and work on developing more interpretative themes that delved further below the surface. [Tracey]

6.4.4 Reviewing the themes

The critical and interpretative development of sub-themes was useful in my RTA that identified three major themes (patterns) in the narratives as each of these themes was conceptualised in a number of different ways. In this stage of reviewing the themes (and sub-themes) I realised that in the "busyness" of generating my themes I had lost focus on how the themes I identified answered the research question in terms of telling the story of the women's experiences of diagnosis and disclosure of BPD. I include here a verbatim extract from my reflexive journal that illustrates how I paused to consider my direction and to reorientate my RTA.

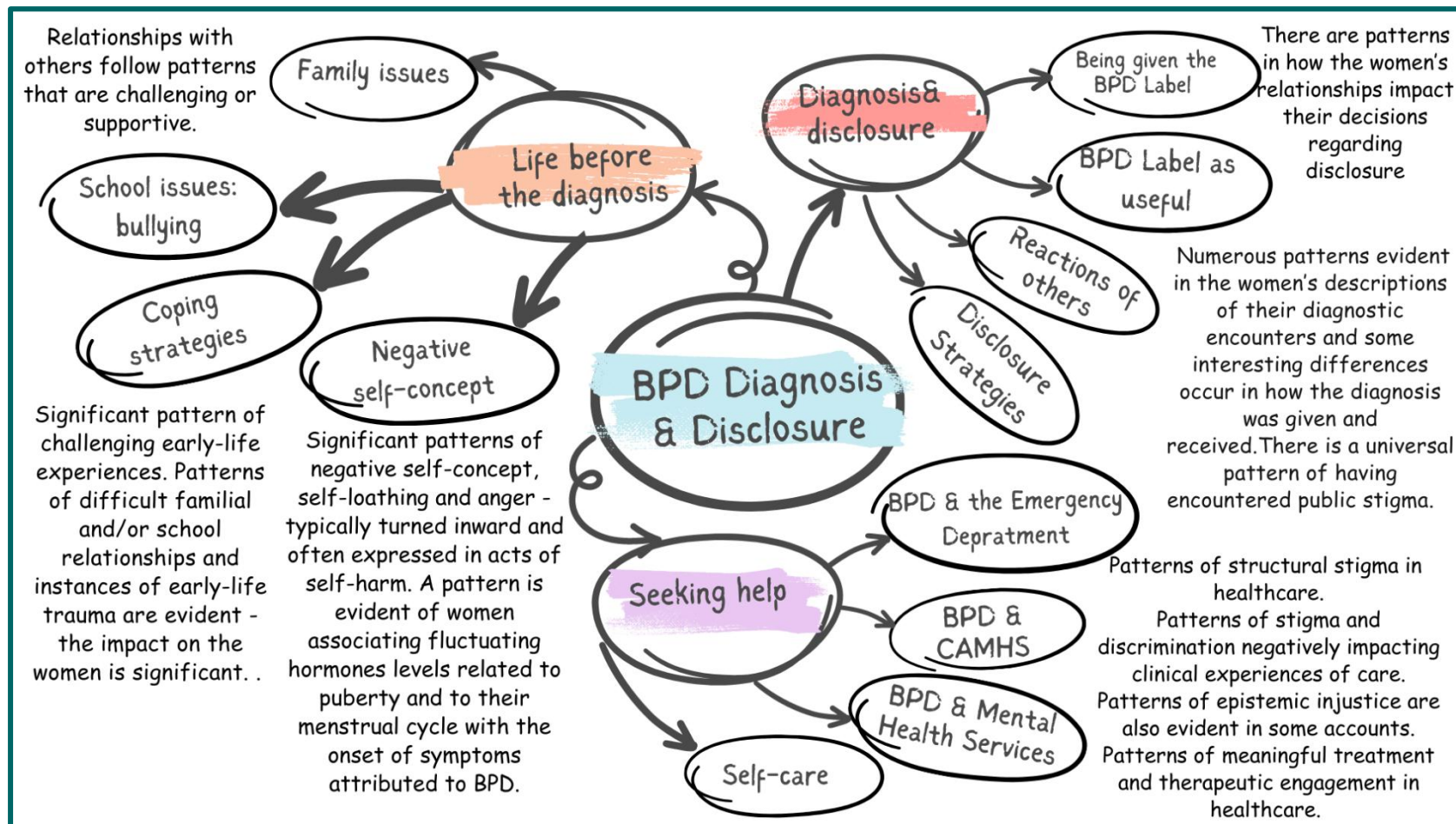
I am a little lost: I need to take a step back to reflect on what this “collection” of narratives is telling me and how I can represent them as authentic meaning-united stories in my thesis. I need to think about what I “know” [what I learned about the women’s experiences from what they told me in the interviews and how I interpreted those stories] and now look across the narratives to see how they connect and what “they” were “collectively” telling me about: what it means to be diagnosed with BPD as women living in Ireland in the personal and the social context, how they experienced disclosing the diagnosis to others, and what were the factors that impacted their disclosure decisions. [Tracey]

Taking a step back was a useful strategy as I realised that I had captured in my themes answers that addressed the research questions, what I needed to do next was to develop a structure to those themes, (re)label them and illustrate them in a way that told the story in an interesting and accessible way that was congruent with the narrative inquiry methodology and scholarly endeavour. A concept map representing a relatively early stage in the process of generating and developing the themes is presented in Figure 6-11.

The key questions that I asked myself as I reviewed my themes in this stage and at later stages as I completed the RTA were those proposed by Braun and Clarke (2012, p.65)

- Is this a theme (it could be just a code)?
- If it is a theme, what is the quality of this theme (does it tell me something useful about the data set and my research question)?
- What are the boundaries of this theme (what does it include and exclude)?
- Are there enough (meaningful) data to support this theme (is the theme thin or thick)?
- Are the data too diverse and wide ranging (does the theme lack coherence)?

Figure 6-11: RTA – Early-stage in the generation of themes



6.4.5 Defining and naming the themes

In this stage it was important to first clearly and specifically define the unique aspects of the themes generated by identifying the focus and purpose of each and by demonstrating how they build on each other to form a coherent story about the narratives co-constructed. It became very obvious as I conducted the interviews and later as I worked through the LG individual analysis that the stories fell naturally into three temporal stages of before, during, and after diagnosis, this was very evident in the RTA as I analysed across the narratives. This drew me back to reflect on my reading around diagnosis and the work of Jutel (2009, 2016, 2019) on the sociology of diagnosis. Central to this inquiry the concept of diagnosis is portrayed as a “*story in itself*” by Jutel (2019, p. 2) who explains that “*the moment a diagnosis is named is a moment in which a story is told.*” Jutel (2019) described how in a seminal essay on the language of illness and disease philologist and linguistics scholar Susan Fleischman (1999), who wrote from a lived experience perspective having been diagnosed herself with a rare and ultimately fatal illness, powerfully described how diagnostic language and the diagnostic moment have the power to transform lives:

“The language of diagnosis illustrates perhaps better than anything else the “vertical rhetoric” ... of medical language and the transformative power it has over patients. ... Moreover, the utterance marks a boundary. It serves to divide a life into ‘before’ and ‘after,’ and this division is henceforth superimposed onto every rewrite of the individual's life story” (Fleischman, 1999, p. 10).

Fleischman’s argument regarding the transformative impact of diagnosis and the notion of the diagnostic moment imposing a boundary on the life of the recipient really resonated for me as I thought about the collective experiences of the women in this inquiry. Having mulled over how I could represent explicitly in the thesis my interpretation of a theoretical divide in the lives of the women into “before” and “after” their diagnosis of BPD while remaining true to the thematic findings I chose to name the themes using three headings that represent not only the women’s lives before and after their diagnosis but also the “diagnostic moment,” as conceptualised by Jutel (2009), that lies between and that is central to the research question in this inquiry. The key findings of the inquiry are therefore presented in the following sections under these three

chronological headings: (i) life before being diagnosed as “borderline,” (ii) the diagnostic moment and women’s responses to the *borderline* label, and (iii) life after being diagnosed, living with the *borderline* label. An excerpt from my reflexive journal illustrates my thinking as I developed the three themes, see Figure 6-12.

Figure 6-12: Extract from my Reflexive Journal

What does it all mean? - Diagnosis

I thought too about life before the diagnosis as a connecting space:

It is a space where the women, as children and young people, should have been safe in:

their family relationships and their family home

their peer relationships and their schools

This is where they are harmed, where their “illness” is constructed or “done to them”

This is where relationships were not always safe, secure or reliable

This is where women learned to cope and how to survive

I thought about the diagnostic moment as a connecting space and what its purpose is:

It is a connecting space but also a medical space which is important

It is a connecting space between doctor (diagnostician) and patient/service user

It is a connecting space between “life before” and “life after” the diagnosis

It is a space that should welcome the woman in with her story from her life before

It is a conversational space, an information centre, a communication space

It should be a comfortable space for the woman seeking help

Thinking then about life after the diagnosis as a connecting space:

It is an adjusting space and a sense-making space

It is a decision-making space and a disclosure space

Next, I identified the particular sections of narrative to incorporate as extracts in writing up the findings. I carefully selected extracts that I thought offered a “*vivid and compelling account of the arguments being made by a respective theme*” (Byrne, 2021, p.1407). I used a number of extracts, drawn from across the women’s narratives, to illustrate how the narratives inform each theme. Adopting this approach I aimed to make explicit the diverse ways in which the women voiced and constructed meaning from their experiences to demonstrate how each sub-theme related to the major theme identified and the overall research questions. Following the guidance of Braun and Clarke (2014) I aimed to name the themes in a way that was clear and concise and where possible to use some short quotes in the titles to indicate the content and remain true to the women’s own words.

6.4.6 Producing the analysis for the thesis

The reporting stage of RTA is a dynamic process and does not necessarily take place right at the end but rather using a recursive approach; much as the codes and themes change and evolve the written report is also flexible (Braun & Clarke, 2012; Byrne, 2022). Therefore, as I engaged in writing up the analysis I noted any minor changes using analysis memos while any major changes over the course of the analysis were also noted in my research journal. The purpose of the reporting stage in RTA is to produce a “*compelling story about your data*” that is based on the analysis (Braun & Clarke, 2012, p.69). It is important that the story is clearly told but with sufficient complexity appropriate to the academic field. The reporting must extend beyond description to make a convincing argument that addresses the research question/s. Braun and Clarke (2012) argue the importance of the order in which the themes are presented: themes ought to connect in logical and meaningful way.

There were three themes identified in this RTA: (i) Life before being diagnosed as “*borderline*”: Women’s early-life experiences; (ii) The diagnostic moment: Women’s stories of being diagnosed with BPD/EUPD, and; (iii) Life after diagnosis: Women’s stories of disclosure and living with the diagnosis. I had a choice to make in terms of the

order of presentation of the themes. These three major themes broadly represent: (i) themes arising related to women's early-life challenges in terms of relationships and childhood adversity (pre-diagnosis); (ii) themes related to the diagnostic encounter, and; (iii) themes related to life after being diagnosed with BPD (post-diagnosis). In thirteen of the interviews the women began their story at the point of diagnosis, moving back temporally to talk about their early-life experiences and forward again temporally to talk about life after the diagnosis. I could have followed a similar pattern in the presentation of findings by beginning with the theme entitled "The diagnostic moment: Women's stories of being diagnosed with BPD/EUPD" and by moving backward and forward then to the other two themes. However, I chose to present the story of the women's narratives following the natural order of the lives and events depicted by starting with the early-life challenges, moving on to the diagnosis and subsequent disclosure decision, and finishing with the experiences in healthcare related to the BPD diagnosis. Presenting the themes in this order foregrounds the women's early-life experiences that are so significant in the narratives.

6.5 Concluding the analysis and an overview of the findings

The detailed account provided in this chapter of how the two levels of analysis were applied to the narrative data demonstrates the robust nature and appropriateness of the inquiry's analysis framework. The use of the LG method facilitated an in-depth analysis of the women's individual stories and afforded a depth of understanding of the nuances of the narratives that strengthened the RTA. The application, across the women's narratives, of a second level of analysis using RTA, following Braun and Clarke (2006, 2012, 2019), resulted in the development of a set of findings that represent both the women's individual and unique lived experiences and the commonalities and dissonances in their collective narratives. The analysis undertaken served the dual purpose of (i) developing an in-depth and nuanced interpretation of the women's lived experiences of BPD in the Irish context, and (ii) ensuring wider accessibility and application of the inquiry's findings. This unique set of findings, therefore, contributes

new knowledge that may inform practice, policy, education and research as discussed in Chapter 12 (12.2).

The three major themes developed in the analysis and their constituent sub-themes are unfolded and presented in detail, supported with selected illustrative quotes drawn from the women's narratives, over three chapters as follows:

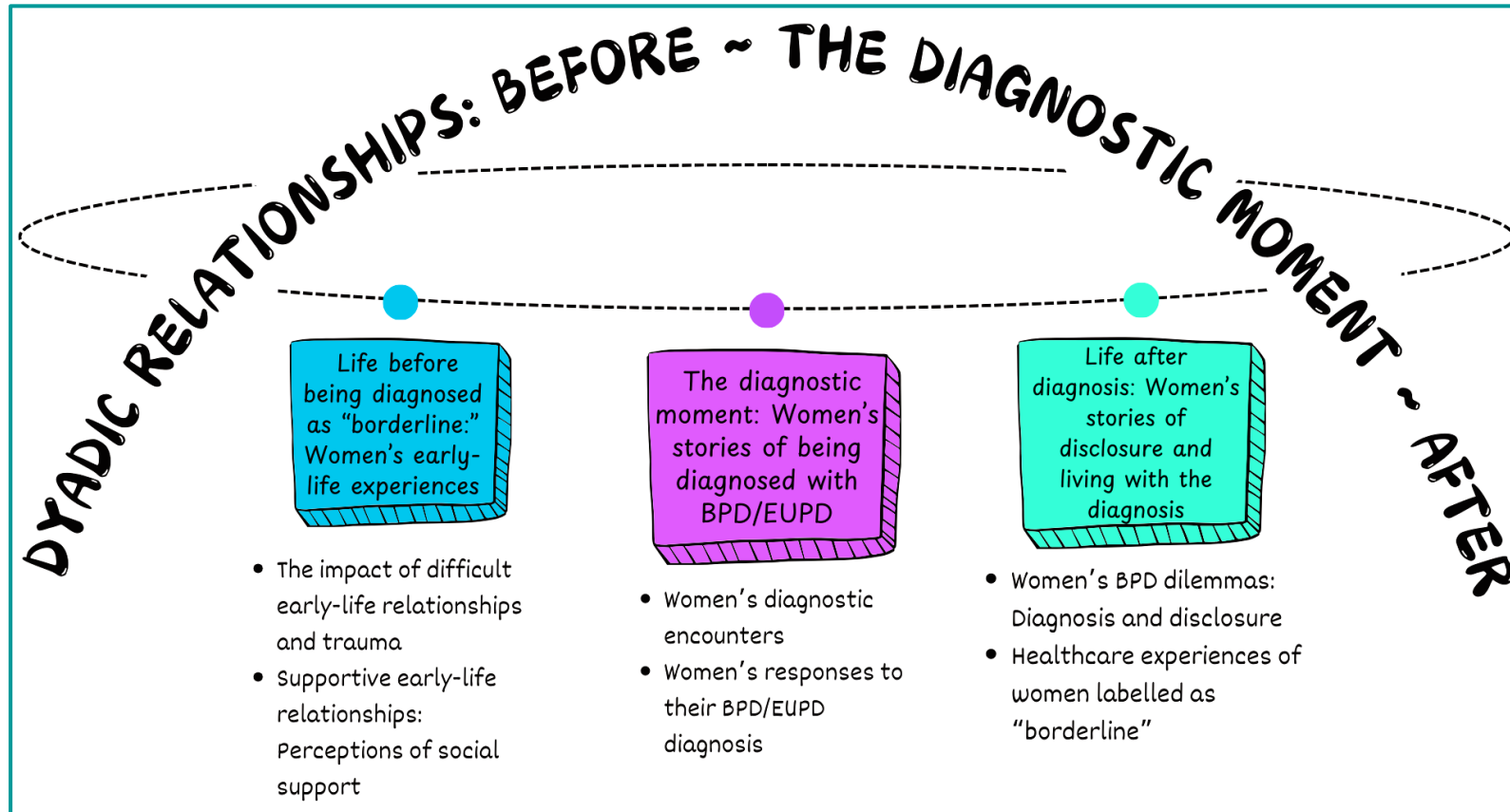
- **Chapter 8:** Life before being diagnosed as “borderline:” Women's early-life experiences
- **Chapter 9:** The diagnostic moment: Women's stories of being diagnosed with BPD/EUPD
- **Chapter 10:** Life after diagnosis: Women's stories of disclosure and living with the diagnosis

A conceptual map depicting the three themes and each of their constituent sub-themes is presented in Figure 6-12. The overarching theme that I interpreted as binding the narrative findings was “dyadic relationships” that is discussed further in the next chapter (7.2)

6.6 Chapter summary

In this chapter I described in detail my approach to the analysis of the data generated in this inquiry using a robust analytic framework that incorporated two levels and methods of analysis. The application of each method was made explicit supported with examples drawn from the narratives. In the next chapter I present an overview of the women's narratives in the form of individual plot summaries (7.1).

Figure 6-13: Conceptual map outlining the inquiry findings



Chapter 7: Summary plots

As previously outlined the findings of this inquiry are presented across four substantive chapters beginning in this chapter with a brief overview of the women's individual narrative accounts. A key feature of narrative inquiry and of research conducted from a feminist perspective is that the researcher maintains a focus on the participants' individual stories. It is essential therefore that each of the 14 women remains visible in this thesis and that each story is heard. I chose therefore, as discussed in the previous chapter (6.3.1), to open the presentation of findings with an introduction to the women and a brief overview of their individual stories. These are presented using the summary plots that I constructed from the first stage of the Listening Guide (LG) analysis. It is important to reiterate that I was careful when constructing these summaries to omit any specific details or personal information that could potentially render the women identifiable. These accounts therefore are not first-hand and they provide only brief abridged versions of the women's complex stories. Nonetheless, they serve to orient the reader to the participants context and offer a window into the women's unique lived experiences.

7.1 Introducing the women and their individual stories

In this section I aim to preserve the integrity of the women's individual stories with the presentation of the women's individual plot summaries. I include a brief commentary. The chapter concludes with a summary and a discussion of the overarching theme of "dyadic relationships" that ties together the three themes identified in the analysis.

7.1.1 Una's story

Una, who was aged 33 at the time of interview, discovered her diagnosis two years earlier when a doctor asked her during a mental health clinic appointment whether she was aware of her diagnosis of EUPD, which she was not. Una

compared herself negatively to her siblings in terms of being able to make friends or “*hold down a job.*” She described being bullied throughout her school years which resulted in a deep sense of loneliness and rejection. She also described complex family problems including financial hardship. Una attributed this to the perceived immaturity and indifference of her father who prioritised his own personal spending over providing for his family. When Una was aged 11 her mother developed a serious physical illness which, coupled with her alcohol dependency, led to her premature death ten years later. Her mother’s illness resulted in a significant care burden for Una. Una referred briefly to not having any friends and to never having had a romantic relationship. Her social circle was limited and she was reluctant to go out other than with family members. Una encountered problems at work and described “*clashes*” with work colleagues and with peers and staff in a mental health support service. Una believed her performance in work situations was hindered by being “*too slow*” and she felt under pressure to “*speed up.*”

Una disclosed her diagnosis to her sister, who was usually supportive, and to her peers in the mental health support service. Her peers were accepting, however, her sister’s response was that Una should avoid using the diagnosis as an excuse. Una felt this meant that her sister did not understand her mental health difficulties. Una’s relationship with her father, who was a heavy drinker, remained difficult and she chose not to disclose her diagnosis to him as she feared an angry response. Una discussed a recurring pattern of conflict with her siblings and her extended family with whom she often argued via text and social media. She described her tendency to react angrily and become upset when she perceived she was being rejected by others. Una enjoyed good clinical support and excellent therapeutic relationships with both her community mental health nurse and her occupational therapist.

7.1.2 Anna's story

Anna was aged 24 at the time of interview and she had been given the diagnosis of BPD almost two years earlier. She had some awareness of the stigma surrounding the diagnosis and was initially upset about it. Because Anna's ex-partner, who was abusive and controlling, also had a diagnosis of BPD she felt initially that perhaps this meant that she was also "*like that*". She worried in terms of getting into relationships that people might see her differently. Anna disclosed her diagnosis of BPD to her family without issue; she considered that they might not know much about the diagnosis. Anna benefitted from the positive support of an online community of people diagnosed with BPD and she confided in her friendship group, most of whom had lived experience of mental health problems. Those supports were helpful in terms of assimilating and living with the diagnosis of BPD. Anna chose only disclose to those she was close to due to the stigma surrounding the BPD diagnosis. Anna came to consider the diagnosis as "*just a label*" and she made it clear that it didn't define her.

Anna briefly described her childhood as being negatively impacted by her parents habitual drug and alcohol misuse and she recalled that most days she witnessed a lot of shouting and arguing in the family home that frightened her. She was diagnosed with depression at the age of 16. In hindsight Anna thought that the reason she had tolerated an abusive relationship, as a young adult, was due to low self-esteem. She reflected on not having had any expectation of being treated well since childhood. Following the breakdown of that abusive relationship Anna became homeless and developed a drug dependency. She described using self-harm as a coping mechanism and she resented the fact that the ways in which people cope with trauma are often labelled as disorder. Anna discussed the medicalisation of trauma, and questioned the validity of the BPD diagnosis. Anna discussed instances of structural stigma and her concerns surrounding the potential for being treated unfairly in mental health services by virtue of her diagnosis.

7.1.3 Fay's story

Fay, who was aged 29 at the time of interview, was diagnosed with BPD three years earlier. Fay, who has a background in the broad area of mental health, knew little about the diagnosis at the time and welcomed it as an explanation for her difficulties. However, as she learned more about the diagnosis and the stigma attached to it she came to resent it. Fay had also been diagnosed with an eating disorder at the age of 19. She described a difficult and complex relationship with her mother that she felt led to her own mental health problems. She described her mother as having a bad-temper, being clingy and inappropriate, and very controlling. Fay suggested that if assessed for BPD she believed her mother would meet the criteria. Her mother was dependent on alcohol and had issues with eating and weight. Fay was estranged from her mother for five years at the time of interview and she described conflicting feelings of abhorrence and empathy towards her mother who also had a very difficult upbringing.

Fay described experiencing attachment issues from early childhood that led her to become overly-attached to older women including teachers and friends. She also spoke of deep-rooted shame relating to her own "*dark thoughts*" and coping mechanisms some aspects of which she has never spoken about to anyone. She described a deep need to continue self-harming and a fear of stopping. Fay enjoyed a good relationship with her father although she did not disclose her BPD diagnosis to him. Fay's mother resented her relationship with her father and was possessive of her. Fay chose to disclose her diagnosis of BPD to one family member, her cousin with whom she was close, and to her best friend from childhood. She also disclosed to six colleagues, with whom she was friendly, as she felt they would be understanding and non-judgemental. Fay ultimately rejected the BPD diagnosis completely and questioned its validity. She described not feeling comfortable to disclose the BPD diagnosis to anyone else, even a future boyfriend, due to the huge level of stigma.

7.1.4 Leah's story

Aged 23, Leah was one of the youngest women who participated in the inquiry. At the time of interview she had lived with the EUPD diagnosis for more than three years. She felt that the diagnosis "*clicked a little bit*" and that some of the criteria resonated for her. Leah described having been under the care of CAMHS as a teenager and how she felt that her diagnosis of social anxiety didn't address everything that she was experiencing but she didn't have the words to explain it. She described feeling as if she had not been heard and how she began to doubt herself and think that maybe she was just being "*real sensitive and over-dramatic*". She was discharged from CAMHS at the age of 17 and two years later was referred, via an ED, to adult mental health services following an overdose.

Leah described experiencing attachment issues as a result of her father's absence throughout her life. When Leah was aged 15 her mother developed a terminal illness; she died two years later. Leah was supported in her mental health by other female family members. She was happy to disclose her EUPD diagnosis to them as she felt it offered an explanation for some of her problems and behaviours. She mentioned that she had not disclosed the diagnosis to her step-father but that her sister might have done so. Leah disclosed her diagnosis to her friends who were very supportive. In her workplace Leah disclosed having mental health issues but not her BPD diagnosis due to the stigma attached to it. Leah's boyfriend, whom she met in a therapy group, also had a diagnosis of EUPD. Leah encountered significant issues related to her mental health care specifically regarding interactions with her consultant psychiatrist whom she felt had a "*stereotypical image of borderline women*." Leah described how when she was first diagnosed that, for a time, she almost "*lived up*" to the diagnosis by not even trying to self-regulate her emotions. She found that moving out of home and taking on responsibilities was helpful and that Dialectical Behaviour Therapy (DBT) was very beneficial for her.

7.1.5 Val's story

Val, who was 37 at the time of interview, had been diagnosed with BPD 13 years earlier. She described a difficult childhood where she felt rejected and disregarded by her mother. Her father was physically abusive towards Val and her siblings as children although she described him as having mellowed in later years. She described her father as supportive regarding her mental health whereas her mother was not accepting of her mental health difficulties. Val spoke several times about how she was compared negatively to her siblings in terms of academic achievement, employment, housing, and marital status. She described her first encounter with mental health services where she was admitted to a psychiatric unit following an incident where she had been drinking heavily and had been in an accident.

Val was diagnosed at that time with depression and she described reacting badly, physically and psychologically, to the prescribed medication with the result that she could not function. As an alternative Val chose to begin psychological treatment with a psychologist whom she described as “*excellent*.” Following the retirement of her consultant psychiatrist her new consultant conducted a review and full assessment and amended Val’s diagnosis to BPD and Bipolar II. Val was very grateful to him; she felt that he was very thorough and that he saved her life. Val underwent an extensive range of psychological treatments over a five-year period and stated that as a result she “*no longer hated*” herself or “*felt inferior*” to her siblings.

When Val disclosed her diagnoses to her siblings one of her sisters didn’t believe she had any mental health problems, her other three sisters were “*okay about it*” and her younger brother was very supportive. Val encountered stigma with a boyfriend, of one year, who ended their relationship when he found out about her diagnosis. Val concluded that she would only disclose her diagnosis of BPD to a future partner after a long period of time. She also lost her friends following her hospitalisation due to stigma but she made new friends some of whom had lived

experience of mental health difficulties. Val spoke about how her mental health issues had impacted her education because it was difficult to concentrate and she was proud of having successfully changed track and completed courses part-time. She undertook advocacy work in mental health to support others. She resented being labelled with the BPD diagnosis and regretted getting involved with a supported employment programme because there was no opportunity to progress. Uniquely, Val described how her religious faith was also seriously challenged for a time due to her mental health problems.

7.1.6 Brooke's story

Brooke, who was aged 23, was one of the youngest women participating in the inquiry. She had lived with the diagnosis of BPD for more than three years at the time of interview. Brooke described having been diagnosed in CAMHS with generalised anxiety disorder and depression which she felt didn't make sense. Therefore the treatments, in the form of medication and psychological therapy, felt inappropriate to Brooke. She described not having the words at that time to articulate her issues and how therefore she perceived that she had not been heard. At the age of 18 Brooke was deemed ineligible to be referred on to adult services and she took this to mean she "*wasn't bad enough*." She struggled to cope over a two-year period before being referred to adult mental health services, via ED, following an overdose. The liaison psychiatrist that Brooke met in the ED suggested a potential diagnosis of EUPD. At the follow-up appointment the diagnosis was confirmed by the consultant in the mental health service. Brooke, having anticipated the diagnosis, was "*excited*" that it offered her a pathway to treatment beginning with psychology sessions that were helpful while she awaited DBT.

Brooke described a very strained relationship with her father who was abusive to her in the past. Her father had complex issues related to his mental health, aggressive behaviour, and serious issues with substance misuse. When Brooke disclosed her EUPD diagnosis to him he revealed that he also had a diagnosis of

EUPD. She was open regarding disclosure of her EUPD diagnosis to her friends and family as she wanted them to understand some of her issues and past behaviours. Brooke felt that the diagnosis offered an explanation and overall she found that most people were understanding. Some “*less-close*” friends expressed doubts about the diagnosis and didn’t see that it “*suit*ed” Brooke. Her mother, sister and boyfriend were very supportive. Her mental health issues almost cost her relationship, at the outset, as her boyfriend had some doubts, but they worked at it by communicating clearly with each other. Brooke expressed some worries for the future related to living with the EUPD diagnosis in terms of potential heredity factors and a possible negative impact on her desired career in mental health.

7.1.7 Jane’s story

Following the death of her father Jane was linked back in with mental health services through an ED referral following an incident of self-harm. She was aged 29 at the time of interview and had been given a diagnosis of BPD six years earlier. However, it later emerged from her case notes that she had been diagnosed much earlier with BPD in another service but she had never been told. She disclosed the diagnosis to two friends and when they looked it up together Jane felt very “*shamed by the diagnosis*.” While Jane identified the diagnosis as validating in a way because she met many of the criteria she was conflicted about it because she also felt it was unfair to label trauma-response as a disorder as if it “*was the person’s own fault*.” Through working hard in therapy Jane developed self-compassion. She was bullied at work and was unable to work full-time. She moved to work part-time in the mental health field and found her colleagues there were non-judgemental in relation to her diagnosis.

Jane disclosed her BPD diagnosis to her mother who showed little interest. Jane proceeded to describe a childhood impacted by intergenerational trauma; she and both of her parents had experienced childhood sexual abuse. Jane and her mother were both sexually abused by her maternal grandfather. Although she did not wish to discuss the details Jane indicated that her father had been forced out

of her life when she was nine years old. Jane felt that her parents were “*both very sensitive*” and possibly emotionally unstable. Jane carried a lot of responsibility for the day-to-day care of her younger siblings who were born when she was a teenager. She had a difficult relationship with her mother whom Jane believed didn’t appreciate her efforts. Jane left home aged 22 and was estranged from her mother for a few years. Jane was pregnant at the time of interview and she was determined to take good care of her baby although she was concerned that she her housing situation and her relationship lacked stability. Jane considered that her partner might also have an issue with emotional instability. Jane had recently begun rekindling her relationship with her mother who was looking forward to becoming a grandmother.

7.1.8 Ava’s story

Ava was aged 27 at the time of interview and had been diagnosed with BPD for less than two years. Prior to her diagnosis Ava was attending college as a single parent and was really struggling emotionally. She was planning her suicide but sought help from her GP and was referred to her local mental health service. Ava was assessed and given the diagnosis of BPD. As previously discussed in Chapter 6 (6.3.1) Ava also had a diagnosis of ADHD, anorexia nervosa and was undergoing assessment for ASD. As Ava became aware of the stigma surrounding the BPD diagnosis she began to reject it, however, she some found some aspects quite validating in that she felt the diagnosis explained, for example, her feelings of chronic emptiness. Ava also described sometimes feeling as though her brain is in a “*heavy fog*” that makes it “*difficult to breathe*.”

Ava described issues of abandonment and neglect in childhood and having first attempted suicide at the age of 12. She described a lack of understanding and awareness of mental health issues among her family. It was Ava’s understanding that in the country where her parents grew up mental health was not a priority and was poorly understood. Ava was therefore reluctant to disclose her BPD

diagnosis to them. Her relationship with her mother was difficult and although she had a good relationship with her father he was very dismissive of matters related to mental health. Her partner, who also had a diagnosis of BPD, was supportive. She disclosed her BPD diagnosis to her friends who were also supportive. Ava was determined to work hard in therapy to ensure she that she would break the cycle of intergenerational trauma for her daughter. She was careful therefore not to belittle or demean her as her mother had done to her. She recalled feeling unwanted by her parents and experiencing a lot of instability. Ava felt that her mother would have benefitted from support and intervention as a young woman and that she may have also met the criteria for a BPD diagnosis if assessed. Ava described jealousy in her romantic relationship as a significant issue that she worked on successfully using skills developed in her skills group.

7.1.9 Rose's story

Rose, who was aged 40 at the time of interview, was diagnosed with BPD the previous year at the age of 39 which was quite a bit later in life than the other women in the inquiry so she had been living with the diagnosis for just eleven months and was still coming to terms with it. Rose spoke fondly of her parents while she recounted the difficulties she had endured in her early life including the prolonged absence of her father due to his enduring mental health difficulties. Rose as a result was very conscious, all through her childhood, of the stigma attached to mental ill health. She described a happy home life with her mother and grandparents and friends to play with "*on the road*" who became lifelong friends. However, Rose was bullied in primary school and didn't have any friends there. She subsequently found it difficult to make friends in secondary school and she began to hate school so she stopped going. Rose also clashed with her mother at this time and felt guilty for upsetting her. Rose described how the only person she had ever displayed anger towards was her mother.

Rose enjoyed great support in two different jobs, one was a small family business where she grew in confidence in speaking to people and the second was with a

community organisation where she was surrounded by strong, independent, working-class women who were very supportive of her. She worked there for 11 years at which point she left to go back to college. Rose attempted college a number of times but found it too difficult to complete. Rose became mentally unwell at that point and began to display signs of mania. She split up with her fiancé and spent a lot of money, over a short period of time, that she had saved for her mortgage. Rose contacted her GP who suggested she might have bipolar affective disorder. While Rose was happy to share a bipolar diagnosis, which she felt people understood, she felt that it wasn't correct. Rose described asking her GP to refer her for a mental health assessment which led to her being diagnosed with EUPD. Her consultant psychiatrist offered Rose an admission to hospital to do a formulation; her hospital experience was very good. It was suggested that the manic episode was related to past trauma. Rose experienced some memories/flashbacks related to possible abuse but with no certainty or clarity. Rose described the EUPD diagnosis as shameful and she disclosed it to only two family members. She later regretted the disclosure as she felt paranoid that they might think badly of her and question her behaviour and ashamed because of the stigma attached to the diagnosis. She decided not to disclose the diagnosis to her mother as it would upset her. Rose concluded that overall she was glad to have been given the diagnosis as it explained some things for her.

7.1.10 Mya's story

Mya was aged 26 at the time of interview and she was diagnosed with BPD two years earlier. Mya's story in relation to her diagnosis of BPD differed somewhat from the other women in that she sought the diagnosis from an early stage having read about BPD and having come to the conclusion that this was a diagnosis that fit for her in terms of the difficulties she was experiencing. Mya described difficult early-life circumstances in terms of a broken attachment as a result of her beloved childminder moving away, when Mya was aged 3. Later Mya was ostracised at school as a result of an incident where she had hurt a playmate. Mya continued to be excluded by her classmates throughout primary and secondary school. At the

age of 18 Mya experienced an unplanned pregnancy and she was strongly encouraged by her mother to have a termination which she did. There were physical and emotional complications that were traumatic and this had a detrimental effect on Mya's mental health; she experienced post-traumatic stress.

When she had recovered physically Mya spent time living abroad with her boyfriend who was abusive. When she returned home she ended the relationship. A short time later she met her fiancé who was very supportive. Having set up home with her fiancé Mya began having panic attacks and sought help via her GP in two different medical practices having moved house. Having been treated, unsuccessfully, for anxiety and depression Mya was eventually referred to her local mental health service for assessment. Being diagnosed with BPD resulted in a sense of satisfaction for Mya who felt vindicated that she was "*right all along*". Her diagnosis led to a short period of treatment, similar to DBT, that Mya found helpful. However, she also came to understand the stigmatised nature of the diagnosis. Mya disclosed her diagnosis to her mother who was supportive. Mya did not tell her father directly, as she felt he would simply dismiss it, but she assumes that her mother told him. When Mya told a couple of friends they had no issue with the diagnosis but found it difficult to believe that she had BPD, Mya attributed this to her ability to mask her difficulties.

7.1.11 Pia's story

Pia, who was aged 30 at the time of interview, was diagnosed with BPD 12 years earlier. Pia began her narration by describing a very happy childhood in terms of her homelife and a loving relationship with her parents. However, Pia experienced trauma in a medical context as a young child that had a lasting negative impact. To explain briefly, while maintaining confidentiality, Pia had a physical health condition that resulted in her being subjected to two medical examinations, against her will, at the age of 7. Because Pia would not cooperate with the medical examination she was effectively restrained for the purpose of the examination. As

a result of these incidents, Pia felt very ashamed and she developed a negative self-image that persisted into her teenage years.

Pia did well in primary school although she was very shy. She had picked up on some rituals from her mother, who had a diagnosis of obsessive compulsive disorder (OCD), and she was bullied in school as a result. She also experienced significant difficulties in secondary school due to anxiety and depression. Pia experienced persistent low mood and suicidal ideation in her early teens. Over a one-year period she also engaged in cycles of restrictive eating, bingeing and purging. Pia also engaged in self-harm and used drugs and alcohol in an effort to cope with her problems from the age of 14 to 16. Her mum supported her and paid for private healthcare treatment. She left school at the age of 16 as she could not tolerate sitting in the classroom due to heightened levels of anxiety. She got a job and later undertook a training course and got a qualification in healthcare. Pia was referred to adult mental health services at age 18 and was given the diagnosis of BPD. Her parents attended a support group for families of individual diagnosed with BPD. In the context of a previous employment Pia encountered, under the auspices of occupational health, significant discrimination related to her diagnosis of BPD. She was required to undergo a number of reviews of her mental health to ensure she was not a danger to the patient/client. The suggestion that she might be a danger to another person was devastating for Pia and when she returned to work all of her colleagues knew what had happened, she left soon afterwards and moved back home. Pia was grateful for her BPD diagnosis as it opened up a pathway to DBT which she felt saved her life. Pia described working hard in therapy to build a good life and to achieve recovery.

7.1.12 Kym's story

Kym, who was 31 at the time of interview, had been living with the diagnosis of EUPD for two years. She was still coming to terms with the diagnosis and she was very frustrated at the idea of being diagnosed with a personality disorder. Kym had been attending mental health services since the age of 18 and had been previously

diagnosed with depression and anxiety. There had been very little consistency of staff in her treatment team which was frustrating and as a result she disengaged from treatment. Kym was referred back to the mental health team when she became overwhelmed due to pressure of postgraduate study and work. Kym disclosed her EUPD diagnosis to her partner and her parents. Her partner was supportive. Her father disregarded her diagnosis and her mother's response was "*do you really think you have this?*" Kym felt this indicated how little her mother actually knew about her. Kym encountered significant discrimination in the context of her work when she chose to indicate on an occupational health form that she had a diagnosis of BPD/EUPD. She was prevented from taking up the post immediately and she had to undertake a significant mental health treatment programme to prove that she was well and stable enough in her mental health to do her job, a job that she had been doing successfully for ten years. Kym undertook the treatment programme and later took up the post.

Kym described painful early-life experiences that centred upon the abusive behaviours of her father and strong feelings of parental rejection. Kym felt that she was a constant disappointment to her parents either because she failed some college exams or because she came out as a lesbian, which at the time they questioned by asking "*are you sure?*" Her father was physically and emotionally abusive to Kym and her brother. Kym found it difficult to interact with people in authority in her job and she associated this with not being able to talk to her own parents; she felt intimidated. She found it difficult also to make small talk in the work environment due to feeling perpetually "*awkward.*" Kym became involved in a new sporting hobby through a childhood sports coach and this provided her with a good social outlet. Kym had to push herself to engage socially with her teammates. Overall Kym was disappointed that she still felt the need to hide her

mental health problems because she thought that if she let people know her diagnosis it would be as she was “*wearing a scarlet letter*.”²

7.1.13 Zoe’s story

Zoe was aged 36 at the time of interview and was diagnosed with EUPD, six years earlier. Her consultant at the time wasn’t sure that the diagnosis was accurate but he later confirmed the diagnosis following Zoe’s assessment with a psychologist. She was relieved at first to be able to put a name on her problems but she soon realised how stigmatised the diagnosis is. Zoe, who is the eldest of four children, has a good relationship with her family. However, she found it difficult over the years to confide in her parents and her siblings around her mental health. She described her father as dependable and she was protective of her mother who had been bullied in the past by her own sisters. Zoe was diagnosed in her late teens with an eating disorder and she described how she later “*replaced the eating disorder with self-harm*.” She described herself as introverted and explained that she found socialising difficult. Zoe was made redundant from a job that she loved and she identified this as having significantly impacted her mental health as she felt very invested in the organisation for whom she worked first as a volunteer and later as an employee.

Zoe rejected the diagnosis of BPD and felt that it was not a good fit for her. She felt strongly that hormonal fluctuations related to her menstrual cycle had a significant impact on her mood. She also felt she was treated completely

² Published in 1850, *The Scarlet Letter* written by Nathaniel Hawthorne is one of the most compelling stories in American Literature. With deep insight into human nature, Hawthorne depicts a Puritan woman named Hester Prynne who arrives alone in New England.

What the Scarlet Letter Symbolizes

The most significant symbol in Hawthorne’s story is the scarlet letter itself. Hester wears a large, red letter ‘A’ on her chest, a letter marking her as an adulteress. She must wear the letter out of shame for her sin. It is red to indicate an indelible stain of sin, like blood upon her character. Hester becomes the object of shame, anger, and ridicule by the townsfolk around her. By facing her accusers and openly bearing the shame of adultery, however, Hester’s character is strengthened in such a way that the scarlet letter, at first, represents her sin but later becomes a mark of her grace and high, almost angelic, character.

differently by healthcare professionals since she had been given the EUPD diagnosis; she felt as if she was wasting their time. Zoe described feeling a responsibility, as the eldest in the family, to set a good example and she didn't want her siblings to know that she wasn't coping. She felt guilty that her younger sister had also developed an eating disorder. She felt a deep sense of shame regarding feeling suicidal and in relation to having taken an overdose. Zoe found the diagnosis itself to be isolating and she likened it to being told that you're the "*bad kid at school and you will always be the bad kid.*"

7.1.14 Stella's story

Stella, who was aged 26 at the time of interview, discovered at the age of 23 that she had a diagnosis of EUPD. While she was engaged in treatment for an eating disorder Stella noticed the EUPD diagnosis written on her notes alongside her eating disorder diagnosis and she later asked her psychologist if she had been given a diagnosis of EUPD. Her consultant later reluctantly confirmed that she did have a diagnosis of EUPD. Stella felt a sense of validation that she was not just "*being dramatic*", or "*not trying hard enough*," and that the diagnosis was a good fit when it came to emotions. Overall, she felt the diagnosis was positive as it meant that she got access to DBT which she rated as "*excellent.*" Stella discussed encountering stigma related to the diagnosis in her workplace where she works in a medical environment as a member of the administration team. Hearing staff make passing comments about patients made Stella feel that she could never disclose her diagnosis to them. Stella was worried about her partner reading about the diagnosis online because although he was aware of her mental health difficulties she had not specified the diagnosis.

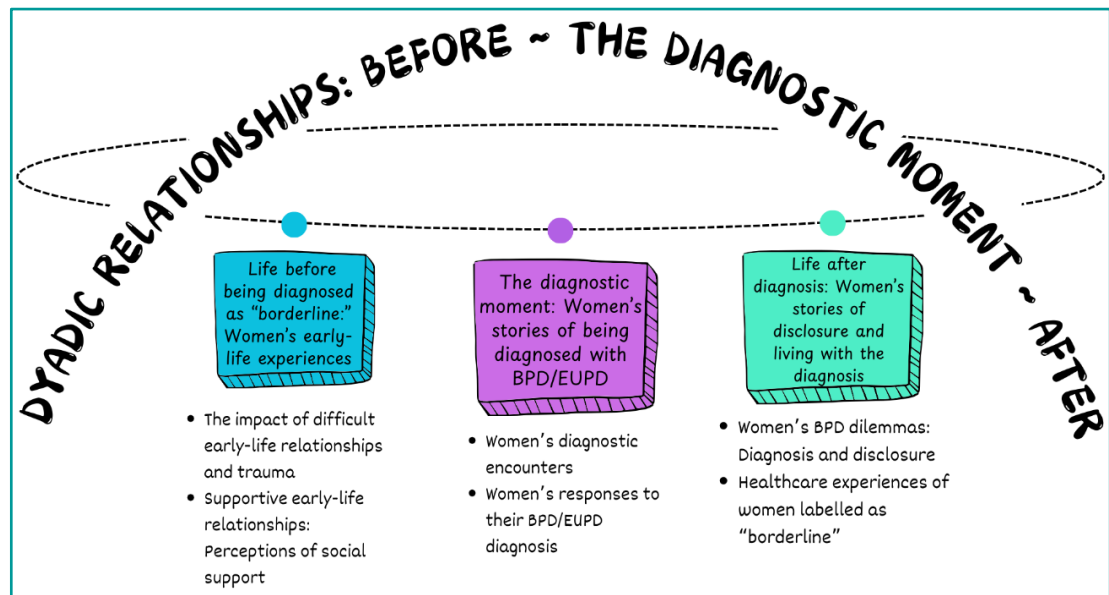
Stella described experiencing feelings of anger from early childhood and encountering a lot of difficulties in primary school. Stella also described a persistent sense of invalidation due to her parents apparent lack of understanding of her difficulties that led to them dismiss her feelings and expressions of distress. She later discovered that she had sensory issues and was very sensitive to light and

heat. She experienced further problems from the age of fifteen, that she associated with the onset of puberty, when began self-harming and developed an eating disorder. Stella also clearly articulated a real lack of identity, or sense of self, that compounded her difficulties as an adolescent. Worried about this lack of a sense of identity Stella decided she needed a hobby and she took up dance. She adopted the identity of “*the dancer*” and when she finished school she went abroad to study but she also had an intense eating disorder and so it did not work out. Stella returned home and entered a successful treatment programme. She emphasised the importance of maintaining self-care to avoid a relapse of mental health.

7.2 Chapter summary and conclusion

The summaries outlined represent a brief overview of the individual experiences of the 14 women. Presenting these accounts allows me to foreground the women’s stories while providing background and context for the thematic findings that follow. Having analysed across the individual narratives the overarching concept that unites the women’s stories is “dyadic relationships,” see Figure 7-1. A dyad comprises two people in relation with each other, for example parent-child, who directly interact with each other. There is an interdependence in the dyad where the members depend on each other for the continuation of the relationship (Brauer & Proyer 2019). Dyadic relationships can be emotionally intense due to their personal nature which can result in closeness and affection, or, conflict and hostility. Power issues can occur within dyads that challenge equity in the relationship (Edwards, 2024). The stories that the women told are replete with examples of dyadic relationships that impacted their lives, at each stage: before, during, and after diagnosis. Some of the relationships described had a very positive impact on the women’s lives and many of them were very challenging. Many of those relationships appeared influential in terms of how the women experienced diagnosis and disclosure. Examples of the dyads that are significant in the women’s stories include the mother-daughter and the father-daughter dyads. The discussion of findings, therefore, pays particular attention to the dyadic power and influences that were at play in the women’s narratives.

Figure 7-1: Overview of themes



Although each woman's story is unique there are numerous similarities evident between the stories and these are presented thematically in the following three chapters. Beginning with Chapter 8, that explores women's early-life experiences, the women's own voices are prioritised in these three chapters and in keeping with the presentation of narrative research findings each is well-represented through the liberal use of direct quotes from the interview transcripts. In this way the women's lived experiences of diagnosis and disclosure of BPD are vividly and legitimately depicted using their own words

Chapter 8: Life before being diagnosed as “borderline”

8.1 Introduction

This chapter presents the findings from the first theme identified in the analysis that relates to the women’s early-life experiences before being diagnosed as “borderline.” Although I did not explicitly ask the women about their early-life experiences they each gravitated back temporally in their narrations towards their early-life experiences as they sought to put their diagnosis in context. The term “early-life” is defined for the purpose of this inquiry as the time from birth to early adulthood (0-25 years). An outline of the themes as they relate to each other and the overarching theme of “dyadic relationships” is provided in each of the findings chapters, see Table 8-1.

Table 8-1: Theme 1 in context

DYADIC RELATIONSHIPS: BEFORE ~ THE DIAGNOSTIC MOMENT ~ AFTER		
THEME 1	THEME 2	THEME 3
Life before being diagnosed as “borderline:” Women’s early-life experiences	The diagnostic moment: Women’s stories of being diagnosed with BPD/EUPD	Life after diagnosis: Women’s stories of disclosure and living with the diagnosis of BPD/EUPD

This theme comprises two related subthemes that are explored in the sections that follow: (i) the impact of difficult early-life relationships and trauma, and; (ii) supportive early-life relationships: perceptions of social support, see Table 8-2.

Table 8-2: Theme 1 and subthemes

THEME 1: Life before being diagnosed as “borderline:” Women’s early-life experiences	
The impact of difficult early-life relationships and trauma	Supportive early-life relationships: Perceptions of social support

8.2 The impact of difficult early-life relationships and trauma

This subtheme focuses on my interpretation of the stories the women told in relation to their early family life and life at school. The findings are presented under the following headings: (i) difficult familial relationships and trauma, (ii) difficult school relationships and experiences, (iii) psychological support needs in the early-life stage.

8.2.1 Difficult familial relationships and trauma

Most of women described having endured very difficult and complex family circumstances as they were growing up. It seemed important to them, however painful, to expose the foundations of their story by telling about the difficulties they encountered in their younger lives before being diagnosed with BPD. Three of the women's early-life experiences were marred by particularly difficult maternal relationships.

Jane described a complex history of intergenerational childhood sexual abuse, forcible separation from her father, and a challenging relationship with her mother. While Jane demonstrated compassion for her mother she also appeared hurt and somewhat resentful towards her. Jane resented her involuntary estrangement from her father and her mother's perceived failure to act when she disclosed her abuse as a teenager at school:

"I had been traumatised at a young age, I was sexually abused by my mother's father [...] my dad was completely pushed out of my life when I was nine [...] she [Jane's mother] told me at one stage [...] that she felt suicidal once and she has had some counselling because, like that, she was also sexually abused by her father [...] she possibly had some sort of diagnosis. [...] she knew that I was abused because [...] I came out with that when I was 14 and I was talking to a guidance counsellor in school and then I got brought into Child and Adolescent Services [...] So she knew I had stuff going on [...] I don't think she understood it fully and didn't really have a grasp ... and didn't want to know." [Jane]

Jane reflected vehemently on how she believed she was perceived by her mother. Amidst the angry words there was a sense of rejection in her story as she describes feeling as if her mother had often pushed her away. The contrapuntal voices of self as good or bad could also be heard in Jane's account as she struggled to reconcile her mother's perceived perception of her as inherently bad with her own innate feeling that she was a good daughter/student who was doing her best. Jane also seemed upset that her mother lacked appreciation for her significant contribution to the care of her young siblings while she was also struggling to study, recover from trauma, establish a social life, and work part-time:

"I was just lazy and bad and wrong and a bitch and all these negative words and she pushed me away numerous times and we constantly would clash and argue [...] when I think back ... I was really good, I was a straight A student for my Junior Cert, but she had two more kids when I was a teenager and I minded them for four hours every day and I got up to their cries during the night and I had to work part-time and I was in full-time education and I was dealing with my trauma and trying to have boyfriends and friends and all the rest of it. So, no wonder I was tired early, I was like, 'fu*k this like' it was so much at the time and it wasn't a bit appreciated ... I was still a lazy bitch and I was still an ungrateful bitch. I was still not good enough, you know?" [Jane]

Val made it clear from the outset, as she told her story, that she and her mother are not close and have never been close. She talked about how her mother was not very accepting of her mental health problems and would prefer that it remained a secret. Val adopted the voice of self-confidence as she projected strength and self-assuredness, both in her tone and the way that she described the ongoing problems, and surely painful issues, that she had endured since childhood in her relationship with her mother. However, listening back to our interview I detected the contrapuntal voice of self-doubt at times in Val's narrative as she repeatedly mentioned how members of her family, particularly her mother, very often compared her negatively to her siblings in terms of academic achievement, and; marital, housing, and employment status:

“I was very close to my father more so than my mother [...]. Myself and my mother don't really get on very well [...] she's not very accepting of my situation. [...] My father was far more accepting of it than my mother and whenever anything happened with my mental health problems my father was the one that talked to me ... my mother, no [...] could not handle that at all [...] would not discuss it ... didn't want anybody knowing about it. She felt it was [...] a family defect because all my siblings were highly educated, academics and high end jobs and there was me ... didn't go down very well in that household at all. But my father was far more accepting.” [Val]

The contrapuntal voices of family loyalty and resentment could be heard in competition throughout Val's story as she narrated feelings of maternal rejection that appeared to underpin her considerably difficult relationship with her mother:

“I do love my mother very much she is my mother at the end of the day. But she doesn't [...] I mean she hasn't accepted that [Val's mental health difficulties] [...] I think the turning point for her is when [Val's psychiatrist] brought her in [...] to talk to her about my past and she didn't want to talk about it [...] my childhood life was not good in any way shape or form. [...] she had me eleven months after my sister and she sent me to live with my grandmother [...] she didn't want me [...] she made it quite clear, she still does make it quite clear she never wanted me. [...] it's a major sore point with her. [Val]

The interplay of voices of compassion and rejection was also significant as Val spoke about the perceived pressure on her mother that led to her having six children which Val believed was too many for her. Yet, the voice of rejection is clarion as Val emphasised her depth of feeling on the matter by suggesting that her mother should have terminated some of her pregnancies, including her own:

“I just think that she [...] had too many children ... she shouldn't have had too many children and that's where the problem lies ... she should have stopped after two I think and left it at that [...] she should have aborted me and a few other of my siblings [...] she should never have had six kids. I think the pressure on women back then to have a son was huge and she had five girls and one boy. So she was pushed in to that and she shouldn't have been ... because Dad had this thing about land and property that it had to be left to a boy.” [Val]

Fay's narration was punctuated by contrapuntal voices of accusation and compassion that could be heard in the description of her relationship with her mother. Fay's voice was accusatory as she described her mother's seemingly erratic, aggressive, and inappropriate behaviours. Fay also spoke very candidly about how her mother treated her very differently to brothers. Fay described how while her mother would also fight and argue with them, she reserved her harshest treatment for Fay as her only daughter. Speaking at times with the voice of compassion, Fay acknowledged her mother's difficult upbringing. She described extensive issues that were indicative of a mother whose own lack of skills, and ability to cope, resulted in the perpetuation of an intergenerational cycle of trauma and abuse:

"She had a very difficult upbringing herself ... much more difficult than she gave me but so she's an alcoholic now so she drinks every day [...]. She has this thing [...] that there's something different about the relationship that a mother has with her daughter as opposed to her sons [...] 'cos I was the only girl I got everything [...] she was either clung to me [...] or we'd have these big, huge arguments and she'd be screaming her head off and then wouldn't talk to me for a few weeks [...]. I can handle that one in your kinda late teens but not when you're a child. [...] Even the fights she'd have with my brother [...] she had a big temper and stuff and couldn't [...] control her [...] temper really ... but the arguments she'd have with my brothers they were never the same [...] with me [...] it would get really nasty like and personal". [Fay]

Fay's mother's perceived lack of boundaries and possessiveness were problematic for Fay as an adolescent. She described how her mother preferred to think of herself and Fay as friends who shared everything including intimate details of each other's life. Fay described how she struggled to maintain any privacy. She also spoke of the difficulty she had in maintaining her good relationship with her father unhindered, as her mother was possessive and seemingly jealous:

"And then she hated when I tried to put up any boundaries [...] if I came out of the shower as a teenage girl with a towel on me she would take offence to that and think like well like we're all girls [...] why do you have to put a towel [...] just no boundaries just like at all [...] would tell me [...]"

details of her sex life and all that kind of stuff with my Dad [Fay laughs] which was really fu*ked up [...]. I think she just wanted a best friend and had this idea that girls and their mothers should be best friends as opposed to like a parent and a child [...] she always had this weird thing that I loved my Dad more than her and she'd always be shouting that at me [...] and then I got to love my Dad way more than her [...] if anything she kind of made me that way [Fay laughs] [...] she hated anything that would make me deviate from her really." [Fay]

Fay invoked the voice of family loyalty as she acknowledged in her story her feelings of conflict regarding her lack of a close relationship with her mother. She spoke empathetically about her mother, as someone who was abused as a child, and described occasional feelings of guilt and regret about being estranged from her. Adopting the voice of compassion, she reasoned that her mother married and had children at a young age while at the same time she had never dealt with her own trauma. However, thinking then about how her mother had treated her Fay adopted the voice of self-preservation as she asserted that she could not maintain a relationship with her because it was too difficult. Fay's negative feelings regarding her mother appeared to be very strong and seemed to have significantly impacted her self-concept. Fay talked about sometimes experiencing thoughts, or fantasies, where she wished she could go back in time and do something to ensure she had never been born:

"I feel bad now, every now and then I get this glimmer of intense empathy for her [...] I'll get this wave of guilt that I've cut her out of my life and this intense empathy for how she grew up. [...] But most of the time I just ... I despise her [...] I either despise her for making me this way and sometimes when it gets really far I despise her for conceiving me. I'm like if I could just go back [...] to when [...] she was pregnant with me if I could just do something that would make me not viable as a foetus. [...] she just should never have had kids but like back in those days like I suppose people just weren't really aware. They just got married young, had kids young [...] it's weird 'cos even though I blame her for everything that's wrong in my life I also think she was only a child as well when she settled down and started having kids [...] and had all these horrendous experiences in her life no one taught her how to deal with them [...] what's she supposed to do like? Like she had the kids like what's she supposed to do? [...] sometimes I'm like she did her best and then I'm like no she didn't [...] so I like I go back and

forth all the time [...] it was a long road with her [...] but yeah, she's kind of out of my life." [Fay]

Fay adopted the voice of self-disgust as she revealed how significantly she was impacted by her difficult relationship with her mother. She vividly described embodied feelings of self-loathing that manifested in a physical sense of revulsion whenever she saw in herself physical resemblance to her mother:

"I've become so averse to her and she's not even in my life anymore but sometimes I'll be talking to people or I'll be sitting a certain way or I'll have a certain facial expression on me, or whatever, and I just feel like I am her ... like that I look like her, or that I talk like her, and I would just ... my skin crawls like ... it actually crawls. And I'm like 'oh my God' or [...] I can see parts of my body changing to look like ... that look like hers and I'm just like ... it just makes me wanna [...] just crawl in my skin [...]" [Fay]

Fay used the voice of self-awareness as she further described having been heavily influenced, in her early-life, by her mother's attitude and behaviours in relation to food and weight to the point where she developed an eating disorder in her mid-teens:

"She had horrendous issues with food which she also passed on to me [Fay laughs]. [...] she never really taught me to eat well and like allowed me to ... not eat good things and would reward me with food [...] as a child I would like be hiding food [...] so that no-one else could find my junk food [...]. I would watch her go on these intense yo-yo diets like she'd be a size 22 and then she's be a size 10 [...] always dieting and everything was about like how you look and if you were fat you were disgusting [...]. Just all these really unhealthy [...] cognitions [...]. Looking back now it's madness [...] just some of the things she allowed me to do and taught me as like a child or a teenager [...] I was about fifteen I'd say I went on my first like diet and she would be the one bringing me up to the chemists so that I could weigh myself and go on these [...] crash protein diets [...] like allowing me to do that and of course then [...] I developed an eating disorder, of course [Fay laughs]. I suppose it started really mid-teens [...] I've had that now for ten years [...] that's another thing I credit her for." [Fay]

For seven of the women patterns of difficult paternal relationships emerged in the analysis. Representative examples of how the women narrated difficult and abusive paternal relationships are drawn from Una and Kym's accounts and the damaging effects those relationships had on the women are discussed.

Una told the story of how, when her mother first became physically ill, she was burdened from the age of just 11 with considerable domestic responsibility. She described having felt an obligation to take charge in the family as a result of her mother's illness. Adopting a voice of resignation, in her narration, Una described her father as being immature and irresponsible as she referred to her mother having had to take over the mothering role with him when she married him. Una adopted the voice of regret as she described the resulting hardship that her mother, and she and her siblings, endured as a result of her father's actions. Notably, Una appeared more accepting of, or resigned to, his behaviours than angry or resentful as is evident in this excerpt:

"My Mum was sick, she had [a serious illness] and like I kind of had to take charge because my Dad he kind of [Una laughs briefly] never grew up. [...] when my Mum and Dad got married she kind of took over the role of being his mother. [...] So when she went into the hospital [...] she had to organise for like all her sisters and his sister to take turns coming over [...] to help him look after us, she had to show me how to use the washing machine. I had to wash up you know that kind of stuff when she was in hospital [...]. I don't think anything was the same after she got sick [...] things were difficult, like my Mum had to like save like every penny she got for us like my Dad like made it difficult for her 'cos he always [...] spent the money on himself [...] and he'd let the bills go into arrears [...] so my Mum [...] numerous times ... she would have to rely on [relatives or charity] to help with the bills." [Una]

In telling the story of her early-life challenges Kym spoke of how her father's aggressive and uncaring demeanour led her to feel that he only provided care for her and her brother out of a sense of duty rather than out of wanting to do so and

how she thought he probably resented it. Adopting the voice of regret Kym depicted her father's parenting as harsh and she also described him as physically, verbally, and emotionally abusive, implicit in her story regarding their daily lives is the absence of her mother:

"My brother [...] needed a lot of extra supports in school and he got all those extra supports and my dad hated it. [...] He, yeah he was mean [...] he was a mean parent. I always got the impression he never wanted kids. [...] he would have been physically abusive to us in the past, he would have been emotionally abusive, I wouldn't say he was neglectful [...] but I think he met our needs out of having to do it as opposed to wanting to look after us. So when we left the creche, at eleven, because he retired early from [his career] he became, you know, our primary carer and my mother worked. [...] so she would be home late so he was the primary carer and he was kind of put in a position where he had to look after us, two people he didn't particularly want to look after, didn't want to know [...] my brother struggled with reading, writing and maths and my Dad would just shout at him as if shouting at him would [...] make someone learn something faster so my brother got worse and it became an issue but then [...] that was how he tried to teach and it just didn't work." [Kym]

While many of the women described having encountered very challenging issues with one of their parents, four of the women described having experienced major issues with both parents. Examples drawn from Anna, Ava and Stella's early-life stories are discussed to illustrate this theme.

Anna adopted the voice of regret as she described living in a home surrounded by drugs and alcohol in an atmosphere of family disharmony that meant she grew up feeling afraid in her own home which she associates with her own subsequent drug dependency that spanned a period of four years:

"I didn't always have a very good time growing up. I was around a lot of drugs and drinking as a kid so I think that probably explains why that's the way I went as well ... and just there were family issues [...] a lot of arguing and shouting most days in the house and that made me feel very scared [...] it was difficult [...]. I became homeless and then I started using drugs because that was a way to escape and not be in my reality 'cos my reality

was too much to deal with and yeah kinda continued using drugs every day for four years.” [Anna]

Ava’s account offers a poignant example that is representative of the feelings expressed by of a number of the women whose early lives were defined by experiences of perceived rejection and abandonment. In this brief excerpt Ava adopted the voice of abandonment as she described feeling unwanted by her young parents. She also made reference to how her life was significantly negatively impacted by their poor parenting choices, reflecting on the unfairness of her situation. She recalls how, as a young child, she was left behind to stay with her grandmother when her mother first emigrated to Ireland, the sense of abandonment is palpable:

“I think it was mainly just ... not feeling wanted by my parents ‘cos they ... they just made silly choices and continued making them ... and I had to suffer ... they were young parents that decided to have the child and give the child to anyone who’ll have her [...] it’s just not really fair is it? [...] I didn’t learn how to regulate my emotions [...] My mam [...] when I was a child she left my home country [...] and she came to Ireland. And I just remember, as a child, having nightmares [...] I’d wake up crying, covered in tears from those dreams.” [Ava].

The contrapuntal voices of invalidation and reconciliation were evident in Stella’s story as she described having experienced social anxiety as a child and the difficulty she had in managing her feelings. She describes her parents as having a casual and dismissive attitude and an apparent lack of understanding of her problems and needs. However, Stella adopted the voice of reconciliation as she reasoned that a lack of emotional intelligence, rather than a lack of care, was at the root of the problem. Stella appeared to be coming to terms with how she was treated by her parents, as a child, but had not yet fully forgiven them:

“I’m not quite yet at the point yet where I can totally forgive [...] the invalidation [...] even when I was really, really sick just before I was hospitalised like I was still being told like ‘there’s nothing wrong with you’

and [...] looking back I'm like 'you were literally phoned by the hospital telling you I had to be admitted' and then you were like 'ah, it's fine, you'll be fine just don't go it'll be fine' [Stella laughs]. It was not fine [Stella laughs]. I just don't think my parents had the emotional like language [...] I don't think it was ever from a lack of caring [...] it was just that they just didn't know [...]. When I was in primary school [...] I'd be so nervous going to like a birthday party [...] I'd be in the car bawling my eyes out and it was [...] 'you're going to a party ... like get yourself together [...] this is fun, go.' They [...] just didn't have that understanding [...] I wasn't being difficult I [...] literally could not handle what I was feeling." [Stella].

8.2.2 Difficult school relationships and experiences

The voices of loneliness, rejection, social exclusion and anxiety were dominant as many of the women relayed their stories of difficult relationships and experiences at school. In this section I include some brief examples that illustrate some of the women's experiences of being bullied at school, of experiencing anxiety, and of not coping at school.

The example presented here illustrates Pia's experience of being bullied in school. Adopting the voice of self-compassion, Pia described herself as having been a shy and anxious child whose was bullied in primary school. Pia described how a heightened level of anxiety later affected her secondary school experience where she struggled to the point of becoming physically overwhelmed:

"I really excelled in primary school. But [...] I was bullied in school and I think that had a huge impact on me, because I was always a very, very shy child. [...] when I got to secondary school 13, 14 things took a turn for the worse. Anxiety and depression, my mood was very low all through secondary school. At 16 I had to drop out of school, I couldn't sit in a classroom, I was just so unwell, I couldn't breathe with anxiety. And any day that I'd go into school I used to have to just run home, because I'd just be in hysteric of tears. [...] back then there was huge stigma associated with mental health ... of course there is now, but I don't think it's as much [...] so no one knew how to deal with it." [Pia]

Una's experience of being bullied resulted in significant feelings of loneliness and isolation. She further associated the cessation of the bullying with an even greater sense of abject loneliness. Adopting the voice of rejection, Una evocatively relayed defining memories of being bullied at school:

"Like I suppose my earliest memories of in school are like ... going back to like when, in the schoolyard, when I was really young, like from about the ages of five to about seven, just walking around the schoolyard ... on my own, and I'd be going from groups of children asking can I play with them and they'd be like no and I'd go round to the next group can I play with you, no, then I'd just be walking around on my own all lunchtime and just waiting for lunch to end and it'd be so lonely. And then like I was bullied a lot in primary school and bullied a lot in secondary school and then when the bullying stopped that was just ... then the girls just ignored me after the bullying stopped cos they'd be like 'awh, she'll tell on ya, her Mum will come in and talk to the teachers' so then it just got really lonely towards the end of secondary school." [Una].

In telling her story Mya also described the experience of being bullied at school over a long period. She recalled how she had embodied that experience to the point where her somatised distress manifested as physical illness including stomach ache. She described how awful it felt and how eventually she reacted aggressively with her peers to get attention. Adopting the voice of positivity, Mya happily described having eventually successfully moved to a new school midway through her second-level education:

"I was bullied a lot in school [...] right from the very get go. [...] I had never kind of spoken out from my perspective of like how my emotions felt and I had held in for so long and I was missing a lot of school and I was saying I have a stomach ache or whatever it was I just couldn't go to school [...] looking back now I know that it was emotions ... it wasn't a physical ailment ... sometimes even physical ailments were brought on probably by emotions [...]. I would literally sit in the school yard by myself in the corner and cry all day every day during break like it was awful and the other kids would be playing skipping and if I would go over, they would all just drop the skipping rope and walk away it was horrible so I would then push people to get attention and to lash out [...]. And then the secondary school I went to [...] was all the same people plus a few new people and the new

people learned pretty quickly that I was kind of not someone to hang around with [...] I stayed there until third year and moved schools then I [...] and it was amazing it was like a whole new world.” [Mya]

8.2.3 Psychological support needs in the early-life stage

Although each of the 14 women experienced significant challenges to their mental health in their childhood, or adolescent years, only four of them described receiving care and treatment under CAMHS. Five more of the women made reference to having either been referred for a CAMHS assessment, or having received a mental health diagnosis, under the age of eighteen. However, those five women had not had any further CAMHS involvement, or other follow-up, in terms of supporting their mental health and wellbeing.

Anna, for example, looking back on her adolescent years believed that she had probably experienced low mood since the onset of puberty. However, she was not diagnosed with depression, by her GP, until the age of 16:

“The first time I saw a doctor for depression was when I was 16 so I ... I was put on anti-depressants just after I turned 16 but I think I'd been depressed probably since puberty. [Anna]

Ava similarly experienced mental health problems from an early age and she recalled having made her first suicide attempt at the age of 12:

“My mental health took a really [...] bad turn when I was around twelve [...]. At twelve I had [Ava pauses] I had a first attempt to take my life and that's when I remember, that's the earliest that was my mental health was really bad.” [Ava]

When I asked Ava were her parents aware of her attempt to take her own life and of the onset and severity of her mental health difficulties at that early age Ava indicated that her parents became aware of the problem through her school

where it appears she may have made a disclosure of suicidality, or made a suicide attempt. Her parents were advised by the school to pursue a CAMHS assessment for their daughter. Ava recalled being duly brought to a mental health clinic which, in hindsight, she thought was actually the same clinic she currently attends which is an adult service. This may explain why Ava has no recollection of any follow-up care or treatment if perhaps her parents were redirected to another service and chose not to follow that up:

“My mam had meetings with the school and she’d actually brought me to the same place where I’m in now but I was a child [...] I don’t know why they brought me there, I’m pretty sure it’s an adult clinic but [...] that was the one time that I was brought there. [...] I don’t know why ... did anything ever happen of that ... Like the school literally told my mam that ‘you need to bring her and see what’s happening’ and that was the one time that I was brought to the doctor and that’s it. I do feel like if I was diagnosed earlier I could have had a better ... better chance and less trauma from ... not being diagnosed” [Ava]

Rose and Mya each described involvement with professionals in the field of psychology that appeared to be independent of any CAMHS multidisciplinary team involvement.

Rose talked about having had a psychology assessment which she perceived was aimed at identifying “*what was wrong with her.*” Rose stated that while the psychologist had identified attachment issues this did not lead to any therapeutic intervention or support and therefore she concluded that it was not in any way helpful:

“My mum [...] brought me to [...] a psychologist, I think when I was about seven, I don’t know whether somebody recommended her to do it. I had a few meetings with him ... and I think it was just to find out what was wrong with me ... I don’t remember it being an on-going thing where I got therapy or anything ... I think [...] he was just trying to find out [...] he told my mother there was an [...] attachment thing ... but I didn’t find that helpful at all.” [Rose]

Unlike Rose, Mya did undergo therapy during adolescence and she described having seen four or five different therapists during that time. Mya described how she would typically undertake a few months of psychotherapy with one therapist, before deciding to quit due to a perceived lack of progression. It appears it was challenging for Mya to engage in and try to build a therapeutic relationship. Mya concluded in hindsight that the nature of the psychotherapeutic sessions was not best suited to her needs and that a more active form of intervention may have been more appropriate at the time:

“I had been [...] seeing therapists in and out for a few years at this point, that was probably when I was about [...] 17. I think I had probably seen four or five different therapists at that point [...] I would stay a few months with one person and really just not find like I’m kind of moving in the right direction and finding another person and moving on but I just never found anything to be helpful. [...] it was really just psychotherapy you know, there was nothing in addition to that. They would sit there, I would speak and they would nod and I needed intervention. I needed practical ways to intervene and help and [...] actually go through what was happening with me.” [Mya]

The four women who did receive care under CAMHS teams indicated that they were initially given other diagnoses that included: anxiety, depression, bipolar affective disorder, and/or eating disorder. The supports and feelings of security provided within CAMHS appeared to have been valued by the women overall. They each described having “timed out” of CAMHS services meaning that they were discharged at the age of 18. Although CAMHS did not offer a panacea for their problems, as is evident in Brooke’s excerpt that follows.

Brooke described as very difficult her experience of being discharged from CAMHS and the impact of having to leave the service, having been under their care for more than three years. She struggled with this as she thought in a way it meant almost as if she wasn’t “*bad enough*” to continue being cared for in mental health services. She also argued that she had not been helped very much in her time in CAMHS:

“I guess because of the CAMHS rules I kind of just got essentially kicked out because I reached the end of their service age [...] and I remember being devastated because I was basically told I wasn’t bad enough to be referred to adult services and they kind of kept trying to say that they had helped me but I didn’t feel helped. [...] so then [...] for [...] over two years I wasn’t in any kind of service I had no kind of support.” [Brooke]

Two of the women, Pia and Jane, transitioned to adult mental health services where they were subsequently diagnosed with BPD. The two remaining women, Brooke and Leah, were deemed not to qualify for referral to adult services and were discharged from CAMHS with the result that they felt they had nowhere to turn for support at that time. For these two women the period between being discharged from CAMHS and later engaging with adult mental health services constituted a significant gap.

Leah’s frank description of her experience as a young adult trying to access mental health supports, having been discharged two years earlier from CAMHS, exemplifies this problem of a dangerous gap in mental health service provision. In this excerpt Leah told how she felt that she had to do something to get the support that she needed at the time, in terms of accessing adult services, framing her self-harm as a cry for help:

“I had taken an overdose of painkillers and it was the first time that I had done that ... but I was in the mental health services when I was a teenager with CAMHS. [...] I was just diagnosed with anxiety there but then [...] it was like a gap of ... I think I finished there when I was 17 and [...] when I was 19 ... I kind of reintroduced the mental health services through A&E. [...] I had only taken like twenty something painkillers [...] I knew I wasn't going to die but I felt like I just needed to do something big because I didn't know what else to do with what I was feeling [...] like I think it was for attention [...] like can someone help me please [Liv laughs wryly] or how do I ... make the doctors know that I'm not just being dramatic ... like I will do something eventually if you don't help me.” [Leah]

8.3 Supportive early-life relationships: Perceptions of social support

This subtheme focuses on the women's experiences of supportive early-life relationships and perceived social support. Despite certain challenges six of the women enjoyed a mostly positive relationship with one of their parents. Two of the women, Pia and Zoe, described having particularly good relationships with both parents, although those relationships were not without their everyday challenges. The women who lacked parental supports in their early lives, for whatever reason, typically developed an alternative support network.

Pia described both her parents as very loving and supportive. However, she also acknowledged that her mother carried a lot of guilt for allowing her to be subjected, twice, to medical examinations as a child that were traumatic. Those examinations pertained to a physical health condition for which Pia was required to take medication that could affect her physical development. In hindsight Pia's mother realised that those examinations were potentially unnecessary and could have been better managed to avoid traumatising Pia by coercing her to comply. As Pia talked about her mother, she adopted the voice of empathy demonstrating a level of understanding and forgiveness that speaks to the otherwise positive nature of their relationship:

"So I had very pleasant childhood, great upbringing really caring mammy and daddy was very loved. [...] I screamed and kicked and shouted and I didn't want to be seen by the doctor. But then my mum brought me back into her. And I think she bribed me with chocolate or something [...] I don't know what my mum was thinking. [...] But I suppose my mum, God love her, she thought she was doing the right thing. And she's very, very sorry about the whole thing and she blames herself. But she was trying to do what was best for me at the time." [Pia].

As she told her story Zoe made several references to being close to her family and expressed her appreciation of their support. She described having a very good

relationship with both of her parents. Adopting the voice of psychological safety Zoe emphasised how she felt particularly safe with her dad and that she could very much rely on him:

“My mum is like, she’s the best, like we have a really good relationship. I’m very close to all of my family [...]. When I was with my dad, I always felt safe and if something went wrong, he could take care of it [...]. You’d tell dad and dad would be able to help you.” [Zoe]

For many of these women, who had challenging parental relationships for various reasons, the development of alternative supportive relationships whether with other relatives, friends, colleagues or mentors appeared to be important. The support networks they had successfully developed included relationships with other relatives: siblings (especially sisters), aunts, cousins, and grandparents (especially grandmothers) played significant roles in the women’s lives through the provision of care and support. As adolescents and young adults most of the women’s support systems expanded naturally to include close friends and sometimes colleagues.

Leah, for example, identified her family supports included her sister and her aunt which was important to her particularly following the death of her mum. Using the voice of support, Leah summed up the significance of the supportive relationships in her life:

“I’d be close to ... my mam died when I was seventeen and my dad’s not around so ... it’s just my aunt and my older sister would kinda be ... my kinda mother figures almost ... or like they’d be my family like you know?”[Leah]

Brooke described how despite having had difficulties in the past she now enjoyed very good support from her mum and her sister:

“My mam and my sister are great now, I had really tough relationships with them in the past, but before I was diagnosed.” [Brooke]

Val described a close and very supportive relationship with her maternal grandparents, particularly her grandmother, as a child. She was further supported in terms of managing her mental health by one of her aunts and some new friends that she met as a young adult.

“My grandmother God love her she was brilliant ... loved her to bits, she was a real a mammy to me I was very, very lucky [...] she was absolutely brilliant [...] and my grandfather was excellent, d’you know, so I was very lucky that way . and my aunt ... my mother’s younger brothers [...] they were great as well [...] I had a good outside family.” [Val]

Jane adopted the voice of admiration as she spoke about a friend that she had met while living on campus at college, which she had found to be a very supportive environment overall. Jane described her friend in fond terms emphasising that she was non-judgemental, and she was pleased that they had stayed in touch. Jane seemed conscious that some people might see her through the lens of her diagnosis before getting to know her:

“There was a lot of support in that college and I lived on the campus [...] we’re still friends, she’s actually a lovely friend. She’s ten years older than me and ... maybe even a bit more and [...] like that, she had experience of working in mental health and she just never judged me [...] you know, she didn’t ... again, just didn’t view me through the diagnosis.” [Jane]

Kim adopted the voice of gratitude as she spoke about her two childhood sports coaches, whom she admired. As supportive and encouraging adults, their presence in her young life was very significant. Kim who appreciated their praise and that they showed her how proud they were of her recognised that they were very influential in her life:

“I had two coaches, and they are the first two people to ever tell me they were proud of me, so that was very, very important [...] they went out of their way to make sure I knew. Yeah and like shaped me [...] quite significantly.” [Kym]

Rose talked about how, as a young woman, she found that the support of kind and understanding female colleagues was hugely important and that it helped her a great deal in gaining confidence. She very much enjoyed working with the women, who were from a different socio-demographic group to her, for over 11 years and was grateful for their friendship. She also had the support of other female relatives and friends.

“I started working [...] and that helped me so much. I was so nervous and anxious and embarrassed and self-conscious [...] until I’d say the age of eighteen, nineteen, twenty, twenty-two and then when I started working in [XXXX organisation] it was full of women who were like really warm, down-to-earth [...] so it just seemed to be more ... open and honest and they had experienced suffering, most of them ... in their environment even if not in their personal life and they were so open about it, very different to where I came from.” [Rose]

8.4 Chapter summary

In this chapter I presented the findings that relate to the women’s early-life experiences. Family problems, difficult familial relationships and trauma were identified as defining features across the women’s narratives. Problems at school, difficult peer relationships, and bullying were discussed as problems commonly experienced among the women. The findings that reflect the women’s successful establishment of positive networks of support were also presented. Social support was recognised as important and highly valued in sustaining their mental health. In the next chapter I present the findings related to the diagnostic moment as the women narrate their diagnostic experiences.

Chapter 9: The diagnostic moment

9.1 Introduction

This chapter presents the findings from the second theme identified in the analysis that relates to the diagnostic moment and women's accounts of receiving the diagnosis of borderline personality disorder (BPD), see Table 9-1.

Table 9-1: Theme 2 in context

DYADIC RELATIONSHIPS: BEFORE ~ THE DIAGNOSTIC MOMENT ~ AFTER		
THEME 1	THEME 2	THEME 3
Life before being diagnosed as "borderline:" Women's early-life experiences	The diagnostic moment: Women's stories of being diagnosed with BPD/EUPD	Life after diagnosis: Women's stories of disclosure and living with the diagnosis of BPD/EUPD

This theme comprises two related subthemes that are discussed in the sections that follow: (i) women's diagnostic encounters, and; (ii) women's responses to their BPD/EUPD diagnosis, see Table 9-2.

Table 9-2: Theme 2 and subthemes

THEME 2: The diagnostic moment: Women's stories of being diagnosed with BPD	
Women's diagnostic encounters	Women's responses to their BPD/EUPD diagnosis

9.2 Women's diagnostic encounters

This subtheme focuses on the women's lived experiences of receiving the diagnosis of BPD. The stories the women told of their diagnostic encounters varied widely in terms of the level of discussion that took place regarding the diagnosis; how the diagnosis was articulated; whether they had anticipated the diagnosis, and; at what point the diagnosis was revealed. Of note, none of the women were provided

with any written information about the diagnosis, for example, service user information leaflets. Neither were they directed towards useful or reliable online sources for information and/or support, for example, mental health charities.

Only two of the women explicitly described quite positive experiences during which the consultant psychiatrist, who was giving the diagnosis, took the time to discuss its meaning, the rationale for giving it, and the treatment options. As outlined in her summary plot, Val was initially diagnosed with depression and later received a diagnosis of BPD and bipolar II. Her new consultant psychiatrist took the time to explain her diagnoses in detail and this was important to Val. Adopting the voice of gratitude, Val described a diagnostic moment that, overall, was very positive and meaningful for her as someone who knew nothing at that time about mental ill-health:

I had borderline personality disorder with bipolar II. [...] and like he explained it to me bit by bit. He was in the room with me and he was explaining to me everything [...] I'm very grateful to him. [...] he was explaining to me what bipolar disorder was and borderline personality disorder was [...] I didn't know what they were before I went in [...] I had no knowledge of mental illness." [Val]

Although her experience was perhaps not quite as positive as Val's, Leah also appeared to have been satisfied with her diagnostic encounter. Having presented in the ED following an overdose a couple of months previously, Leah had been referred for the first time to adult mental health services, as discussed in the previous chapter (8.2.3). Since she had been discharged from CAMHS more than two years earlier, at the age of 18, Leah had not had any clinical support for her mental health. She described how, as a result, she had looked forward to engaging with her adult mental health assessment as it meant she would have an opportunity to articulate her difficulties. She described, in a positive tone, having had a good conversation with the consultant psychiatrist during her assessment and how he had begun by asking her if she knew anything about the diagnosis of

EUPD. He then talked to her about the symptoms associated with it and what the diagnosis means suggesting it as a possible diagnosis for her while linking it to a probable referral for DBT:

“I was kind of looking forward to it in a way because I knew there was something ... I knew there was something going on that wasn't just anxiety, you know? [...] I was looking forward to kind of being able to express it to someone. [...] I just had an assessment with him and he was just asking had I ever heard of EUPD [...] he said [...] that was probably what I had and he kind of went through the symptoms and stuff with me and what it means to have it [...] he told me that [...] DBT would be [...] what we were going to go towards.” [Leah]

In comparison, Anna's experience of the diagnostic moment was less than satisfactory. She had entered the diagnostic encounter with some awareness of the stigma surrounding BPD. She explained that her ex-partner had that diagnosis and that she had also previously discussed it with friends who were diagnosed with BPD. Adopting the voice of incredulity, Anna quoted the consultant psychiatrist and the registrar, who had given her the diagnosis. Anna made it clear that she thought that the diagnosis had been very negatively framed as they warned her not to look the diagnosis up online, advising her instead to source some self-help books:

“‘So we think you have BPD or EUPD’ [...] They actually said ‘oh, you know if you want to find ... kind of self-help and stuff ... look at books don't look online, don't look it up online.’” [Anna]

For Kym, the diagnostic moment was devastating. Although she thought that she might have benefitted from mental health support during her childhood, Kym stated that she had not availed of CAMHS support. As an adult, Kym had previously been diagnosed with depression and anxiety. Using the voice of regret, Kym described having had a very good therapeutic relationship with her then consultant psychiatrist, who subsequently retired. Kym described then how she had disengaged from the service due to perceived inconsistency in the medical

team. Kym's mental health subsequently deteriorated, and she was referred back to mental health services at which point she was diagnosed with EUPD:

"I got a diagnosis a little over two years ago of BPD [...] prior to that I would have been availing of mental health services from the age of kinda 18 maybe ... probably could have done with CAMHS in my childhood but ... didn't avail of anything in my childhood. So prior to my diagnosis I would have been treated for depression and anxiety for a number of years. [...] I was in a service where [...] initially the Consultant I had was brilliant ... I worked really well with her and then [...] she left. [...] After that then I was seeing Regs every ... month and it was a new Reg every time, so then I just disengaged. [...] I became very overwhelmed so I [...] went to my GP and she referred me back to my mental health services. So after a few sessions with the consultant then he gave me the diagnosis of BPD. The only thing that stands out to me in the initial diagnosis, outside of pure anger and frustration, is "a personality disorder?" He didn't use BPD, borderline personality disorder, he uses the phrase EUPD ... even the phrase [...] to be just defined as emotionally unstable [...]" [Kym]

Ava's story in comparison to Kym's, in terms of the assessment process, revealed a very rapid assessment that resulted in her being diagnosed with BPD within two hours. As Ava told the story of how she came to be diagnosed with BPD she described how she had been struggling, as a college student and single parent. As a result, she had been planning to take her own life, but she decided instead to contact her GP. Ava was referred to mental health services and attended for her appointment during which it seems she wasn't made fully aware that her mental health was being formally assessed. Ava voiced surprise when she was diagnosed with BPD a couple of hours later:

"I got diagnosed somewhat by accident [...] I was in college and I was a single parent at the time and I was having a really, really bad time and I was planning my suicide and I had realised what I was doing and I went to my GP and my GP referred me to my local Community Health Centre and I went to the Mental Health Department there and the doctor, he was talking to me and then he just ... I didn't realise the questions were leading ... 'cos, yeah ... but then he just ... he told me, after about two hours of being there, he just told me that I had borderline personality disorder

and he'd give me, or ... prescribed medication to me [...] my GP previously had prescribed ... Sertraline? And that made me worse and then when I got diagnosed by the psychiatrist he actually told me that 'you don't need that medication, so you can start the reduction dose.' And he put me on a different medication which I don't remember what it was. And I'd come off the Sertraline and I'd started the new one and it didn't work out." [Ava]

In contrast to those who were surprised by their diagnosis, three of the women indicated in their stories that related to the diagnostic moment that they had actually, in different ways, anticipated the diagnosis and were therefore somewhat prepared for it.

Brooke, who had been discharged from CAMHS at the age of 18, without any link to further supports, as discussed in the previous chapter (8.2.3), told how she presented two years later at the ED with suicidal ideation. There she met with a duty psychiatrist, whose manner she found off-putting at first, as discussed in the next chapter (10.2.1). However, as they engaged in therapeutic communication, she found him to be understanding and empathetic. Having made an informal assessment he suggested that she might meet the criteria for a diagnosis of BPD. Brooke recalled feeling surprised at this:

"He said 'I don't think you have depression and I don't think you're suicidal, I think you have borderline personality disorder.' I was like what the hell like ... that's kinda weird. I knew vaguely what BPD was." [Brooke]

From the ED, Brooke was referred to adult mental health services and she described finding it worrying to have to wait for help and support as she was quite distressed at the time. Following a six-week wait, Brooke attended for her mental health assessment but described the diagnostic moment there as anticlimactic, it seemed to her as if it was just a formality. As she already knew about the diagnosis and believed it was a good fit for her problems. She was appreciative, however, of being back under the care of a mental health team:

“I knew kind of with Irish waiting times for services, I was like I don’t know how long I’m gonna be without help, ‘cos obviously I was still feeling distressed and in general I was in a very poor way with my wellbeing [...] So there was a few ... I think there was only about six weeks actually, which I suppose isn’t bad for Irish services. [...] I went in to see a psychiatrist there. And to be honest that interview, or the assessment, with her wasn’t very impactful ‘cos like I kind of, I know I didn’t have a formal diagnosis but I knew that it made sense. ‘Cos of course after he said it to me I had done a bit of research online and I kinda looked more into and I was like I know this is what I have without ... I didn’t say I had it but like without the formal diagnosis I knew it was right ... in me. So the assessment with the psychiatrist in my local service was more [...] like formally kind of getting the label from a professional to move things forward [...]

When I asked Brooke how it felt to have the diagnosis confirmed she replied positively to say that it felt exciting to potentially have a path to treatment and to have support for her mental health again:

“I think ... honestly, it was kind of exciting because I felt like I could maybe start like a proper ... like a treatment path. Yeah, I think I was excited to kind of see what they could do for me and right at the assessment she told me about DBT. I hadn’t heard of it before and ... well, obviously when I had been doing my research it came up like bits but I didn’t know much about it. So, yeah, she told me about DBT, she said there was a few months waiting list for it but until I started that I could see a psychologist there. So I kind of started talking to someone right away and I hadn’t had that sort of support for over two years at this point.” [Brooke]

Adopting the voice of relief, Rose described how good it felt to have someone to confide in within the diagnostic encounter, while at the same time recognising that by being very open and truthful in her assessment she was probably moving in the direction of being given the diagnosis of BPD. Rose chose to continue telling the truth about her experiences, which seems to speak to the power of therapeutic engagement and rapport. As Rose described her first encounter with her consultant psychiatrist it seems that the benefits of being able to off-load to her, in that moment, outweighed the risk of attracting the BPD diagnosis. For Rose, the diagnostic encounter opened up a space in which she felt heard for the first

time. She was also pleased to hear in the diagnostic moment that her consultant preferred not to use the formal diagnostic terminology:

“When I met the first psychiatrist ... it was such a relief to finally be able to tell somebody things that I’d never been able to share with anyone [...] about being upset as a teenager, about not having any friends [...] And I remember then, at one point [...] she said something and I said to myself ‘uh, oh here we go, am I going to go along with this?’ I had an [...] inclination that if I keep going and tell the truth, I’m going towards that diagnosis ... so I did [...]. I made that choice ... I didn’t have an awful lot of time. She said something about emotional dysregulation, don’t ask me how, I’ve only come across that term recently, but I said is that borderline personality disorder? [...] before that, yeah ... she said [...] ‘so tell me about your teenage years and your younger years’ and I had [...] all that drinking and impulsive behaviour and that’s when [...] my brain said ‘are you going to go there?’ [...] and I made the decision to [...] because it [...] felt so good to be able to tell someone ... so it was kind of a conscious choice but I’d say really I still didn’t think I would actually get the diagnosis. [...] ‘well, yes’ she said ‘but I prefer to call it emotional dysregulation’ which was very reassuring for me the way she said it out like that ... it kind of acknowledged for me ‘we know that’s not a great term, here’s the term I use.’” [Rose]

Mya also anticipated her diagnosis of BPD although, in contrast to the other women, she actively sought the diagnosis and was eventually diagnosed with BPD on three separate occasions, in three different mental health services. In brief, having experienced difficult-to-manage mood swings and episodes of explosive anger since adolescence Mya believed that the diagnosis of BPD was a good fit for her, but successive GPs did not agree and were not willing to refer her for specialist mental health assessment. Eventually, through persistently reporting the difficulties she was experiencing in terms of her mood and ongoing suicidal ideation Mya was referred by a new GP to public mental health services for assessment, and her diagnosis of BPD was confirmed. While she was awaiting treatment Mya moved to live in a new location and she was no longer in the catchment area for that service. While awaiting referral to her new local public mental health service Mya sought a private psychiatric diagnosis, with a view to availing of private treatment, and was relieved to have her BPD diagnosis

reconfirmed. However, DBT as her preferred option for treatment was not available in that service. Following the referral by her new GP, Mya attended her new local public mental health service where she was reassessed, and her diagnosis was confirmed for the third time. In this excerpt Mya described feeling vindicated when the diagnosis was first confirmed during her first ever mental health appointment:

“Right away at the first appointment he [her consultant psychiatrist] said ‘we usually would take a few appointments to get a diagnosis and it’s often misdiagnosed, usually it’s bipolar first maybe or something else,’ he said, ‘but everything you’ve said lines up 100%.’ He said ‘you have BPD and you were totally right’ so I felt an unbelievable sense of just satisfaction from that and just like a relief like wow I just felt a huge weight had been lifted just to know that. Okay it is a label, of course it is, but it’s a collection of symptoms that I’ve always experienced that I felt weren’t you know what falls into the norm for you know human experience.”

When I asked Mya what she meant when she talked about symptoms that didn’t “fall into the norm” she replied to say she felt that she was different than other people and it was good to know that there were other people had similar experiences, that she wasn’t alone. The diagnosis was also an important pathway to treatment and support:

“I think what I mean by normal is it’s not you know what’s in the wider population, it’s not the neurotypical experience of life and I felt just different, I just felt different and to know that there is a group of people that go through what I go through and have the same experience as me I was like ‘wow that’s such a relief.’ [...] Yeah so, I suppose the issue then was that I was asking ‘well okay, you know, what treatment is available for this?’ I mean that was very important because I wanted help, I wanted to try to manage and cope with this in a way that has been researched and found to work rather than just being stuck on antidepressants”

For three of the women, however, there was no true diagnostic moment in the sense that their original diagnosis of BPD was withheld from them in the first instance only to be revealed later, or otherwise found out. As outlined in their

plot summaries Stella, Jane, and Una, each told the story of how their diagnosis was not disclosed to them at the time that it was made.

Adopting the voice of dissatisfaction, Una described how she became aware of her diagnosis of EUPD during an encounter that she had with a psychiatric registrar while attending a routine mental health clinic appointment. In the course of this appointment her diagnosis was revealed to her for the first time despite her having been in the service for several years. Una came to the conclusion that she may have been labelled with EUPD several years earlier, while she remained under the impression that she was diagnosed with a depressive illness. Una appeared to be disappointed and somewhat frustrated that even when she was eventually told about her diagnosis it wasn't explained to her.

"[The registrar asked Una] 'do you know what your diagnosis is?' I was like, 'no, I haven't been told.' [...] I just thought it was under the umbrella like depression and she said 'it's emotional instability' and [Una laughs briefly] she didn't even explain it. [...] I don't know when they put that label on me [...] I'd say [...] it was like as long as I've been in the service maybe." [Una]

Jane similarly discovered, long after the fact, that she had been previously diagnosed with BPD. In Jane's case, having experienced a crisis in her mental health following the death of her father, she was referred to a mental health service in a different catchment area where she was diagnosed with BPD. In telling the story of her diagnosis Jane spoke with the voice of frustration as she revealed that while she was under the care of her new mental health team, she found out that she had been diagnosed with BPD in her previous mental health service. Jane describes as follows the circumstances under which her diagnosis was disclosed to her much to her consternation:

"I just remember being in crisis [...] and explaining the self-harm and the suicidal ideation and my dad dying and a couple of issues around my childhood [...] and how I'd been in different services and he [the

doctor/consultant psychiatrist] said 'borderline personality disorder' and [...] it turned out later, I found out that actually [...] when I was in [...] a different service [...] they did actually find out that it was written on my previous files and I was never told [...] about that diagnosis, I had never heard of it 'til this time." [Jane]

Stella narrated her experience of having discovered her diagnosis of EUPD by chance while in hospital for the treatment of her eating disorder. Adopting the voice of disapproval Stella spoke about the circumstances of that discovery and she appeared to think that her doctor's choice to withhold the diagnosis from her was indicative of them having a negative attitude towards it, or perhaps, towards the person with the diagnosis. Because the diagnosis wasn't discussed there was no opportunity for Stella to find out if that was true or if, perhaps, there was another reason why the diagnosis had been withheld. The manner in which she found out about her diagnosis led Stella to conclude, using the voice of resignation, that from the outset she was made to feel that the diagnosis wasn't open for discussion with her doctor. Overall, Stella perceived her diagnostic experience as unhelpful:

"I guess I'll start with how I found about it [...] 'cos that [...] says a lot about how the diagnosis is viewed [...] or how I felt my medical professional perceived it [...]. I only found out I had it when I was at a psychiatry review [...]. I was in treatment for an eating disorder at the time [...]. I saw both the diagnoses written down but it was just written down as EUPD and I didn't know what that was and I didn't say anything [...] I didn't think about it. So that's how I found out about it ... which from the get-go made me feel like this was something I couldn't even bring up with my doctor [...] that wasn't a very helpful experience." [Stella]

9.3 Women's responses to their BPD diagnosis

The ways in which the women initially responded to being given their diagnosis varied on a spectrum from very negative to very positive. The women who had an immediate negative response to the diagnosis were typically already aware of the

negative connotations of a “*borderline*” diagnosis. Some of the women knew little or nothing about the diagnosis and therefore had a more neutral initial reaction to it. The women who initially reacted very positively to the diagnosis believed it was a good “fit” for them and their experiences. For these women it was a relief in the first instance to be given the diagnosis of BPD which they believed would provide an explanation for the problems they were experiencing and a pathway to treatment that might help resolve their difficulties. Examples that illustrate this subtheme are drawn firstly from the women’s narratives that describe a positive initial reaction to the diagnosis, and secondly those that describe a negative reaction.

Fay, using the voice of wry amusement, described how her initial response to her diagnosis BPD was positive. Listening to her description it seemed almost euphoric. Fay described having gone through a period of intense distress immediately prior to being diagnosed with BPD, during which she questioned what was wrong with herself. She talked then about how receiving the diagnosis brought about an enormous sense of relief. Fay believed initially that since her experiences matched many of the criteria, that the diagnosis therefore offered a welcome explanation for the ongoing and intense distress that she experienced. Her initial relief gave way to feeling emotional and then she became content with the diagnosis for a time:

“There was just kind of this intense kind of build-up of like [...] what is wrong with me you know and so then when the psychiatrist [...] initially when she said the words [...] I’d heard of borderline personality disorder but I actually didn’t know what it was [Fay laughs] like I just didn’t know the characteristics or anything and [...] I remember when she said it I was just like ‘ok that’s something I can latch on to’ and then I came out and I remember just looking it up quickly on my phone and like looking down through all the criteria and being like ‘yeah, yeah, yeah’ [...] I don’t think there was anything on it that I hadn’t been doing or done or couldn’t identify with [...] then it was just this huge wave of [...] just the relief [...] ‘cos I didn’t really know what it was [...] I wasn’t really aware of you know all the challenges that would come after [...] I didn’t really think through even the word like ‘personality disorder’ what that meant [...] I was over

the moon, I swear to God I came out and I was like skipping around the place nearly I was [...] delighted with myself [...] and then I think the relief became a bit more emotional I remember I [...] was like very emotional then [...] not like out of upsetness, just [...] I think that kind of feeling lasted for [...] definitely I suppose a few days and just the general contentedness with the diagnosis ... this lasted ... maybe a couple of months I'd say." [Fay]

While Val described having been quite shocked and overwhelmed upon receiving her diagnosis, overall, her response to it was quite positive and she felt that the doctor was right and the diagnosis was correct:

"To be honest with you it was very overwhelming as well because I was in a little bit of shock. But he wanted me to know [...] what the situation was and how he came to this conclusion [...]. And he was very thorough [...] and he was right, everything he said was just right, after him interviewing my mother and everything." [Val]

Although her BPD diagnosis was also shocking at the time it appeared to make sense to Brooke. She described a sense of clarity that came with the diagnosis. It also gave her a sense of hope for a pathway to successful treatment and it was important to her that she felt, for once, as if she had been heard:

"It felt [...] it kinda felt like ... I don't know the emotion but it felt clear [...] things felt a bit clearer. It was kind of like an epiphany ... like hold on a minute like that makes sense. Maybe that could be ... I think that could be true [...]. But when he first said it ... it was like ... that makes sense ... that seems accurate ... and it kind of ... I guess it gave me like a bit of hope that maybe ... 'cos I ... like if I know what's wrong ... if you know what's wrong you can fix it ... I'm a big believer in that [...] like you need to know what's wrong. So anyway in that moment I was like ... wow ... like [...] it felt like things had cleared up a bit [...] and I felt like at least I kind of felt listened-to [...] for the first time, I think." [Brooke]

Brooke described how having left the ED to go home, following her conversation with the duty psychiatrist, the feeling of relief she had initially experienced left her and she felt quite shocked as she thought about the diagnosis. She also quickly

realised that without access to treatment a provisional diagnosis didn't help with her problems:

"And after leaving the hospital [...] I kinda felt relief I guess, after talking to him [the duty psychiatrist]. After leaving the hospital that kind of went away 'cos I was kind of left with ... I know there was nothing that could be done exactly ... but I kind of felt a like a bit of a bombshell 'cos even though it was a positive thing in a way it's still kind like it's shocking to hear you have something you didn't think you had. So I was kind of in a little bit of shock kind of like that was ... it just felt weird I guess. Yeah, it was kind of ... I don't know jarring really. [...] I came home and [...] I didn't really know how to feel. [...] the diagnosis didn't fix it ... not the diagnosis but him suggesting, it didn't fix it." [Brooke]

Listening back in the analysis to Kym's account of her diagnostic encounter, that was upsetting for her talk about, the contrapuntal voices of upset and anger were evident as she struggled to come to terms with the diagnosis. Although Kym became quite upset while telling the story of her diagnostic encounter she was determined to continue and to share her story that she believed was important. I noted in my reflective diary how Kym had fought back tears and obviously painful emotion as she gathered her strength and railed angrily against the diagnostic language that she perceived was used against her in a way that was unfair, aggressive, and frustrating:

"[...] I found frustrating and then just a 'personality disorder' as if like it was my core being was the problem. Prior to that ... having a diagnosis of depression anxiety was fine it was like ... oh you can say it's a chemical imbalance, it's so easy, you know, loads of people suffer from it, it's everywhere in the world but then to be told, well how I interpreted it initially, was that it was me specifically and I ... even when he said it, I knew I wasn't the first person to be diagnosed with it but it really felt like an attack on me as a person. So I did not leave that session in a great mood at all understandably and it took a while for me to come to terms with it and I'd say I probably still haven't come to terms with the diagnosis itself." [Kym]

When I asked Jane how it made her feel to know that her diagnosis was withheld, she adopted she voiced the contrapuntal voices of anger and regret in her reply as she described how for her the discovery of the withheld diagnosis triggered feelings of anger, regret, and abandonment. Jane thought that perhaps if she had known sooner about her diagnosis, she might not have had to endure such anguish and distress at the time of her father's death:

"At the time I was angry and I wanted to sue them [Jane laughs]. [...] I don't know if that's even possible but at the time that's how I just felt because I was just so angry and ... God if I had of known about this sooner, I maybe could have gotten to grips with it sooner and maybe it wouldn't have resurfaced the way it did when my dad died ... that just triggered off my abandonment stuff, really badly like, and I wanted to follow him basically, as ... I wanted to die with him [...] I wish I had of known about it because I didn't have the language to know that I had a really deep abandonment fear and stuff like that [...] yeah, so, I was angry." [Jane]

9.3.1 The impact of a lack of communication in diagnosis

As a direct result of the lack of discussion, or provision of information that most of the women encountered they were driven to seek information about their diagnosis online. Likewise, the women whose diagnosis had been withheld from them, also sought to find out more about BPD by researching online. All the women who did so described the content they found as predominantly negative and stigmatising.

Ava, for example, described how having suddenly and unexpectedly received the BPD diagnosis she returned home and began to research it online. Using the voice of disappointment, Ava revealed how the material that she read online, which was very negative and stigmatising, had negatively impacted her and how she felt about herself. Ava was upset to think that she had been labelled as a horrible person, she was particularly concerned since BPD was construed as a lifelong problem:

“But obviously after the diagnosis I went home and I done my research and by research I mean I didn’t realise there was a big stigma and I’d basically read all the stigma and I started feeling really crappy about myself because from what I got, you don’t ... you have it for life and here’s the internet telling me that I’m a horrible person for life.” [Ava]

Having opted not to ask her doctor about her diagnosis when she found out about it because it felt uncomfortable to do so, Stella described returning home and looking for information about the diagnosis online. Her shocked reaction to what she found online made her question why she hadn’t been made aware of the seemingly significant diagnosis she had been given:

“So then I went home and googled it and was like ... ‘what the hell?’ [Stella laughs wryly] ... ‘why haven’t I been told about this?’” [Stella]

Like Stella, Una didn’t ask anything about her diagnosis when she was given it. She talked about the fact that she “froze” and how she hadn’t known what to ask especially as she felt under time pressure in her appointment. She too resorted to looking online for information although she felt that wasn’t a good idea. Una thought the information she found online was very negative and stigmatising. In listing the issues that are negatively associated with the diagnosis Una appears to, perhaps subconsciously, identify with the diagnosis in her use of the word “we”.

“I went home [...] I froze, I didn’t know what to ask, I froze [...] ‘cos everything is just quick you only have your time [...]. So, I went home and I googled it and everything on Google, cos that’s the worst thing you can do, everything on Google is so like, negative. There’s so much stigma about it [...] ‘cos they call it ... manipulative and ... attention-seeking and especially when we [...] self-harm a lot or like attempt suicide a lot or whatever.” [Una]

Later in the interview when I asked Una how she felt when she read about the diagnosis online, she responded by describing the negative impact of what she had read and her embodied reaction of feeling sickened by the stigma:

“It gave me like a lump in my throat or a sick feeling in my stomach it made me feel real anxious, eh real upset [...] I felt like the doctor didn’t know what to give me, that I was too like complex or something or like he didn’t know me well enough. Or that [...] this was all he could come up with ‘cos he didn’t know me well enough. I wanted to hand it back ‘cos there was so much stigma online about it. [...] Yeah, hand it back to them and say, I want something else, yeah.” [Una]

9.4 Chapter summary

In this chapter I presented the inquiry findings that relate to the second theme that encompasses the diagnostic moment and tells the story of the women’s experiences of being diagnosed with BPD/EUPD. The exploration of the women’s diagnostic encounters revealed a diversity of experiences but also identified some striking points of convergence and the occasional point of divergence that are all key to answering the questions at the heart of this inquiry. In the next chapter I present the findings related to life after the diagnosis and women’s stories of disclosure and living with the diagnosis of BPD.

Chapter 10: Life after diagnosis

This chapter presents the findings from the third theme identified in the analysis that relates to life after diagnosis and women’s accounts of disclosure and living with the diagnosis of BPD, see Table 10-1.

Table 10-1: Theme 3 in context

DYADIC RELATIONSHIPS: BEFORE ~ THE DIAGNOSTIC MOMENT ~ AFTER		
THEME 1	THEME 2	THEME 3
Life before being diagnosed as “borderline:” Women’s early-life experiences	The diagnostic moment: Women’s stories of being diagnosed with BPD/EUPD	Life after diagnosis: Women’s stories of disclosure and living with the diagnosis of BPD/EUPD

The theme comprises two subthemes that are discussed in the sections that follow: (i) women’s BPD dilemmas: diagnosis and disclosure, and (ii) healthcare experiences of women labelled as “borderline,” see Table 10-2.

Table 10-2: Theme 3 and subthemes

THEME 3:	
Life after diagnosis: Women’s stories of disclosure and living with the diagnosis	
Women’s BPD dilemmas: Diagnosis and disclosure	Healthcare experiences of women labelled as “borderline”

10.1 Women’s BPD dilemmas: Diagnosis and disclosure

This first subtheme related to the women’s experiences of “life after diagnosis” focuses upon the dilemmas they faced in relation to receiving the diagnosis of BPD and of disclosing it to others. The findings are presented under the following headings: (i) women’s dilemmas related to the diagnosis of BPD, and; (ii) women’s dilemmas and experiences related to the self-disclosure of BPD.

10.1.1 Women's dilemmas related to the diagnosis of BPD

As discussed in the previous chapter (9.3.1) many of the women were compelled to learn what they could about the diagnosis online either because they were given the diagnosis with little or no discussion and no information provided, or because they found out about their diagnosis belatedly and even then it was not discussed, or they didn't feel comfortable to ask about it. As a result for many of the women their first impression of the diagnosis they had just been given is likely to have been formed on the basis of, or heavily influenced by, very negative, stigmatising, and wholly inaccurate *information* that circulates online pursuant to the damaging dominant "*borderline*" discourse. Even among the women whose diagnosis was explained and discussed with them in the diagnostic moment, they too inevitably also looked online to find out more and were similarly exposed to negative content. This may in turn have negatively impacted their understanding and internalisation of their diagnosis. The women therefore invariably described experiencing dilemmas as they engaged in dynamic sense-making process in their efforts to come to terms with their diagnosis. For some, that meant moving along a continuum from initially accepting the diagnosis to rejecting it, while for others it meant moving from initially rejecting the diagnosis more towards accepting it.

For many of the women the initial feelings of relief, or positivity, about the diagnosis were soon overshadowed as they encountered the stigma associated with it. Some of the women found in the longer term that the diagnosis was paradoxical. I interpreted this sense of paradox as the women feeling that in one way that they "fit" the BPD criteria to an extent and that the diagnosis therefore offered them an explanation for their mental health difficulties and, importantly for some of the women, a vital pathway to helpful treatment. However, when they thought about the trauma that they had endured it felt unfair that because of their responses to that trauma they had been labelled as having a "*disordered personality*" and that a stigmatised label had been attached to them "for life." The findings related to the dilemmas women faced as they lived with their diagnosis are represented in this section.

Ava described how reading very stigmatising material related to the BPD diagnosis had negatively impacted her in terms of how she felt about herself as a person and feeling that this was how she would be labelled for life. Ava felt that the material she read online led her to associate the diagnosis with being a horrible person. Ava adopted the voice of resistance when she stated that she therefore rejected the diagnosis as she did not want to be permanently labelled as a horrible person:

“After the diagnosis I went home and I done my research [...] I didn’t realise there was a big stigma and I’d basically read all the stigma and I started feeling really crappy about myself because from what I got [...] you have it for life and here’s the internet telling me that I’m a horrible person for life. And I really rejected the diagnosis because I don’t want that and I started looking for other things [...] but I just really rejected the borderline personality diagnosis because I just didn’t want to be a bad person for life basically.” [Ava]

Later in the interview Ava described conflicting feelings about her BPD diagnosis as she spoke of how in some ways it was beneficial to her:

“I would say it was really handy when I did get the diagnosis and I’d researched things. It was quite validating ... because I knew [...] that certain of my behaviours ... like the chronic feeling of emptiness, I finally know what that is. [...]. It just never made sense what it was [...] just a painful void and [...] I know now what it is.” [Ava]

I sought to explore Ava’s thoughts about the diagnosis a little further and asked her whether having read up on the diagnosis did she think it made sense to her why the doctor had given it to her. Ava adopted the voice of reflection as she replied to say that while some of the criteria in terms of instability and abandonment fit well with her childhood history, she still rejected the diagnosis on the grounds of stigma. She described feelings of disappointment when she realised she did not have a diagnosis of depression, and how she wanted a different diagnosis as she understood that BPD was untreatable. Ava’s dilemma was that while the diagnosis did make sense to her it was still difficult to accept

because of the associated stigma and her perception of BPD as a lifelong problem that was untreatable:

“It made perfect sense [...] and even thinking back to ehm ... my childhood or my teen years [...] there was a lot of instability [...] and abandonment, basically [...] in my childhood and it made perfect sense, I just still really did not want the diagnosis because there’s a lot of stigma around it. [...] I think the hardest part about getting the diagnosis was realising that ... because before I just thought I was a really depressed empath [...] and then to find out that that’s not the case, that I’m gonna live with this forever, for the rest of my life ... it was quite disappointing. And I think that’s why I just wanted a different diagnosis because I don’t want this ... I want something that I can actually ... do things and work on and [...] get better at it.” [Ava]

Towards the latter end of my interview with Leah, I asked her whether her perception of the diagnosis had changed, had the meaning of it changed for her as she lived with it. Leah adopted the voice of confidence as she replied to say that her perspective had changed as she matured and she no longer felt that the diagnosis defined her, that there’s much more to her than just the diagnosis. She described how she gives less attention now to the diagnosis and she can manage better as a result. Her response was indicative of her personal growth and having matured over the three years since she was diagnosed with EUPD at the age of 19:

“Yeah ... I think when I first had it I thought like this was everything like the diagnosis was all of me and I was always just going to be like kind of controlled by the things I do, because of what I have, but now it’s more like sometimes I react a certain way and it’s because of this but it’s not like, it’s not my whole personality either [...] like I don’t think about it as often it’s just it’s there. Like I would only think about it [...] ‘cos I have to go to see a psychiatrist or ‘cos I’m going to the doctor or ... something to do with medication really but [...] it’s not my whole existence anymore... [Leah laughs]. [...] I kinda just matured a bit [...] there’s lots of aspects to me rather than just this ... so I think it’s changed in that way. And because I give it less attention I feel I’m better able to manage myself as well.” [Leah].

I asked Anna a similar question about whether her feelings had changed about the diagnosis in the two years since she was given it and her response also indicated that although she accepts the diagnosis to a certain extent, she is not defined by it. She questioned whether the psychiatrists were right in their diagnosis, and she has adopted the attitude to disregard psychiatrists in the main rather than define herself by their way of thinking:

“I think so because at the beginning I was quite unhappy about it [...] Now I kind of accept it more [...] I kind of think well it doesn't really define me; it's just the label they've [doctors/psychiatrists] put onto what problems I'm having. [...] Who knows if they're even right I don't know [Anna laughs]. [...] I think if anything some of my acceptance has come from not really listening to psychiatrists as much [...] because if I believe everything they say and define myself by that then [...] that's not very nice. So it's kind of come from telling myself oh well it doesn't matter what they say.” [Anna]

Zoe described having initially welcomed her diagnosis of EUPD as a means of understanding and naming the difficulties that she was experiencing. She soon realised that the diagnosis was very stigmatising. She felt that mental healthcare professionals treated her differently once they knew of her diagnosis. Rather than helping her solve a problem, as anticipated, Zoe realised that to her the diagnosis was actually a hindrance:

“I suppose at the time I was glad to have something to put a name on it, because I didn't know what was going on with me. [...] then very quickly I started to see how stigmatising it was [...] People in the mental health services changed the way they acted around me when they knew my diagnosis. I realised that the diagnosis [...] which I thought was a good thing, so I could finally figure out how to tackle what was going on for me, that it was actually a weight around my neck.” [Zoe]

While explaining her dilemmas around the diagnosis Jane adopted a reflective voice as she related her mental health problems to her trauma history. She argued that the diagnosis was therefore unfair while listing the negative and stereotypical associations that are common including labelling people as “manipulative” or

“promiscuous.” She described BPD as something of a paradox since, while it was validating in some ways, it was also very stigmatising. Jane added that the diagnosis brought up a lot of shame for her. Jane certainly appeared to be conflicted about the diagnosis as while she rejected the BPD diagnosis in principle, she also had the thought that she wished she had known about it sooner:

“My issues were stemming from trauma and how I was treated [...] so I felt it was unfair to be diagnosed with something as if it was my fault. It felt like I was being [...] told [...] ‘you’re crazy basically [...] you drink too much, you take drugs, you’re promiscuous, you self-harm [...] it’s manipulative and you’re the bad guy’ so [...] it was hard to kind of swallow [...] in another sense it was kind of validating because I was like ... ‘wow it’s literally ... I [...] do those things’ [...] but it was like at the same time just bringing up so much shame. [...] As much as I didn’t want the diagnosis and [...] it’s kind of [...] a paradox as much as I didn’t want the diagnosis and I was like ‘no I’m just a nice, sensitive person, I was a victim, how dare you call me this whatever.’ The other side of it was like ‘God if I had of known like maybe I could of fixed it sooner.’ [Jane]

Stella uniquely voiced a counternarrative to the predominantly negative discourse that surrounds the BPD diagnosis by focusing on the positive aspects of how she experiences emotion. It is evident that thinking in a more positive way about how she experiences emotion as she came to terms with her BPD diagnosis was helpful for Stella:

“This is something I love about BPD [...] is that like I can be extremely passionate and when I feel good and excited about things I feel extremely good and excited about things and that is something I do love. [...] we can talk about how like terrible BPD is but also that passion is ... the depths of [...] I look at the whole paperchain [...] I feel like sadness really extremely, I feel anger really extremely, I feel happiness really extremely, I feel excitement, I feel love really [emphasis] extremely, I feel passion really extremely ... thank God! [Stella laughs]. So that’s kind of nice [...] yeah ... so that’s just a little positive. [...] I do think sometimes you can have ... be dysregulated in the right way. [...] Yeah, it’s not that often but it is [...] well I’m going to tell myself it’s related [to the diagnosis of BPD] even if it isn’t because ... it helps to know that, to think that.” [Stella]

Although the wider psychological issue of identity formation in BPD, as a phenomenon that is widely researched, is not the focus of this inquiry identity is naturally a cross-cutting issue as women assimilate their diagnosis. Some of the women made reference to having experienced a lack of a sense of identity, particularly in adolescence. Their struggles with identity appeared subsequently to be a significant factor in their acceptance of the diagnosis of BPD and feeling that it was a good fit for them in terms of matching the diagnostic criteria.

Stella's narrative offers a very clear articulation of how the diagnostic criteria fit for her in terms of the identity issues she experienced as an adolescent. Stella described looking inwards and finding no real sense of self and how this prompted her to in a way forge an identity for herself by adopting dance as a hobby and in essence becoming "the dancer." A fear of being rejected was significant in Stella's story and feeling the need to constantly change, to adopt a chameleon-like existence, to meet the expectations of others as is evident in this excerpt:

[...] out of like the diagnostic criteria for BPD I really resonate with ... is that like emptiness [...] I was given this form [at school] and being you know ... like 'what are your interests?' ... 'who are you?' basically [...]. And I was looking inwards and being like 'there's nothing here' [Stella laughs]. I remember really clearly [...] and I was like 'sh*t I have no' ... at the time I didn't know a sense of self ... 'I need to get a hobby.' That's actually when I took up dance [...] which then I totally made my whole personality about [...]. I had nothing ... I found this thing ... I became this entire thing [...]. I was like in fourth year ... I found dance I was like 'yeah, this can be my thing' ... totally used it as an identity 100%. [...] it's kind of a twofold thing of looking in and there being nothing there and then anything that I do feel I know about myself being too afraid to express because I'm so afraid of rejection. So, I think a result of that is that kind of like chameleon thing of like becoming who I think is wanted in every situation." [Stella]

The women richly narrated their experiences and the dilemmas they encountered as they learned to live with and attach meaning to their diagnosis of BPD. For some there was a paradox of meaning to the diagnosis which was perceived as both

helpful and unhelpful. It is apparent, overall, that although they have all been challenged to a greater or lesser extent by the “*borderline*” label, these women are not defined by their BPD diagnosis, rather they have survived the diagnostic moment and have moved on to “live with” the diagnosis whether or not they accept or reject it as relevant to them.

10.1.2 Women’s dilemmas and experiences related to self-disclosure of BPD

The section focuses on women’s dilemmas and experiences related to disclosure of their diagnosis of BPD. The findings reveal a diverse range of disclosure concerns, experiences, and responses and some significant points of convergence in the women’s stories. Trust emerged as an important facilitator of disclosure. For some of the women, their earlier disclosure experiences further influenced their decisions around future disclosure. For many of the women stigma and the fear of judgement or rejection resulted in significant dilemmas around disclosure.

Anna described how the diagnostic stigma associated with BPD impacted her in her relationships where she wanted to be open and honest but feared she would be judged:

I think the main kind of anxiety with me is when I get into relationships [...] and ... I feel like I want them to know but also it’s ... I don’t know what they’re going to think if they’ve heard bad things before, if they’re gonna see me differently [...]. And just yeah ... eh ... I tend to only tell people I’m very close to [...] because of the stigma. [Anna]

Fay expressed that while she had not yet embarked on any romantic relationships, if she were to do so in the future, she would not feel comfortable to share the BPD diagnosis with that person due to the associated stigma. Fay considered the diagnosis of eating disorder, and other mental health diagnoses, were less

stigmatised than BPD. Because she perceived BPD as having a surplus stigma, in comparison to other mental health problems, Fay had decided that she would not make any further disclosures:

“I definitely won’t ever tell anyone else. I often think like, like I’m not in a relationship now and I’ve never had a relationship but like I often think if I was to get into a some sort of a serious romantic relationship I don’t even think I’d be able to tell him like ... Nah, definitely not, happy enough to talk about eating disorder stuff but like [...] it’s just [...] it’s not the same as saying I have depression or anxiety or bipolar it’s not the same [...] it annoys me when people say that it is, ‘cos it’s not.” [Fay]

Stigma was also a significant factor in Leah’s decision to make a partial disclosure at work. Feeling that she needed some time off due to her mental health, Leah decided to disclose that she had a mental health difficulty. However, due to her perception of the level of stigma associated with the EUPD diagnosis, she chose to say that she had a diagnosis of bipolar affective disorder:

“I was just really burnt out and [...] I needed a week off and I felt it was easier to tell them ... I was like look I’m having mental health kind of problems. I told them I was bipolar I felt it was less of a ... they’d think ... it would be ... like it would be easier for them to accept and not judge. I felt if I said I was bipolar, rather than borderline, because there’s such as stigma that you’re like a crazy person, or you’re unstable you know, if you’re a borderline.” [Leah]

Zoe described conflicted feelings about her diagnosis rejecting it on one hand because most of the time she doesn’t believe it applies to her then, on the other hand, sometimes thinking maybe it does apply. She is adamant that she would never discuss it with family or friends believing that they would not understand. I reflected in my research diary that it is unclear whether Zoe thinks they would not understand the diagnosis or they would not understand how it applies to her. Zoe indicated also that she would prefer not to disclose her diagnosis if she was dealing with a new team of mental health professionals. She seemed to value the mental health team getting to know her and felt this would help avoid being judged by virtue of the “*borderline*” label:

“I would never talk about my diagnosis to family or friends simply because I don’t believe I have it most of the time. Then there is other times I’m like ‘f**k sake this is just me, like I definitely have it.’ They wouldn’t understand and even now if I had the chance to see a new mental health team I would purposely not disclose it. Because it carries that much stigma. I’d rather they got to know me first because they had this label that comes before me.” [Zoe]

The patterns of disclosure to parents that emerged in the women’s narratives were noteworthy in terms of the interpersonal relationship dynamics and the expressed fear of rejection that intersperse the findings of this inquiry. To synthesise, of the eleven women whose parents were both present in their lives, five chose not to disclose their diagnosis to either parent while four opted to disclose to both parents. Among the twelve women whose fathers were present in their lives, a further three women chose specifically not to disclose their diagnosis directly to their father. Leah also chose not to disclose her diagnosis directly to her stepfather, although she thought that her sister may have done so. Kym mentioned that her mother had disclosed her diagnosis to her father, whom Kym perceived as emotionally detached, and she added that he had simply ignored it. Fay, who was estranged from her mother, also chose not to disclose her BPD diagnosis to her father during the three-year period since she had been diagnosed, even though she described having a close and supportive relationship with him.

Una chose not to disclose her EUPD diagnosis to father, whom she described as a habitually heavy drinker, because she feared an angry and judgemental reaction from him based on her past experiences of his demonstrable annoyance that related to her having taken an overdose:

“I wouldn’t tell my Dad or anything cos he’s so old-fashioned I’d still feel judged or whatever ... ‘cos like he’d get ... he’d get so annoyed like if I ... if I overdose or whatever he gets so angry if I overdose.” [Una]

Mya talked about having disclosed her diagnosis to her mother, with whom she now had a good and supportive relationship, and explained that while she got on reasonably well with her father, he had a tendency not to engage on mental health topics and so she felt there was no point in directly disclosing her diagnosis to him or in seeking to discuss it with him:

“Obviously, I told my, I told my mam and I never, I don’t think I ever actually like had a conversation with my dad about ‘oh this is a diagnosis that I got’ but then we don’t really have that kind of relationship I suppose. I mean we kind of do but I think my mam told him. [...] certain things like, he’d be, you know we talk about politics [...] or we’d talk about you know different things but it’s kind of ... [...] I don’t know what he would say and I have talked to him about things before. I remember saying that I was really, really struggling and that you know I was finding things very difficult and he said ‘ah well look you’ll get over it,’ or whatever , and it was just ... there was no kind of point in telling him.” [Mya]

Ava chose not to disclose to either parent since she felt that her mother would use the diagnosis against her and that her father would not understand as he had grown up in another country where mental health was not a priority or even particularly recognised as an issue. Ava adopted the voice of regret as she described how she longed to discuss her mental health issues and ask him some questions, but that it would be futile such is his lack of understanding about it and he also doesn’t believe in it. Ava describes them as having an otherwise very good relationship:

“My family [...] they grew up [in a culture] where mental health was not ... was not a particular thing and [...] so I didn’t really want to share it and I know that my ... my mother would throw it in my face if I’d share it for her [...]. I have a much better relationship with my dad, like we actually have a good relationship now, but he still doesn’t understand mental health ... like, he just doesn’t believe in it, he’s never had mental health struggles and he doesn’t get it [...]. I want to ask him questions but I don’t even know what to ask him because he’s not going to understand my questions [...] he just doesn’t believe in it but we still ... we still manage to have a great relationship now even though ... it’s just a topic we don’t really discuss.” [Ava]

When I asked Stella if she planned on disclosing her BPD diagnosis to her parents, she replied tentatively to indicate that she doubted that she would because of their perceived tendency to invalidate Stella's experiences as discussed in Chapter 8 (8.2.1.) Stella, for financial reasons, was still living with her parents at the time of interview and so it was challenging:

"I don't think I will ... I think 'cos like I told them I have an eating disorder and she went 'well you're not anorexic or bulimic so you're fine' kind of thing and I was like 'you didn't even ask me if I was' [Stella laughs]. Actually I've had both those diagnoses in the past but I guess we're not having those conversations, you know? [...] it's eh very much a 'get on with it' culture I guess in my home." [Stella]

10.2 Healthcare experiences of women labelled as “borderline”

As the previous findings chapters have shown the women typically encountered early-life difficulties that had significant impact on their mental health. As a consequence, they developed mental health difficulties that ultimately led them to seek help from adult mental health services. As a tertiary-level service, public mental health services in Ireland can be accessed by the women in any one of a number of ways, either via: (i) direct referral from CAMHS for those deemed eligible for adult services; (ii) direct referral from their GP/primary care, or; (iii) onward referral from the ED. This subtheme focuses on the women's experiences as adults of accessing care related to their diagnosis of BPD in the following contexts: (i) care in the ED, and (ii) care in adult mental health services.

10.2.1 “I’m not an emergency case”: Care in the ED context

This subtheme centres upon the women's experiences of care in the ED setting related to their diagnosis of BPD. Seven of the women made some reference in their narratives to having attended the ED in the context of their BPD diagnosis.

Two of those women, Brooke and Kym, discussed their care experiences in the ED setting in some detail and from very different lived experience perspectives.

Brooke spoke about two attendances at the ED where she had negative experiences of healthcare in the ED setting. First, Brooke told the story of how she had been planning to take her own life and how at the last minute she chose to seek help from her mother who brought her to her GP. Her GP referred her to the ED seemingly in light of her suicidal intent. Brooke described having to wait many hours to be seen while she was experiencing what appears to have been an acute level distress. She described how her experience there was made significantly worse by the perceived discriminatory and prejudicial attitudes of the healthcare professionals she encountered and how at the time she lacked the communication skills to articulate her problems:

[...] my GP suggested that I went to the hospital so I went [...] that was an awful experience in and of itself [...] I was already in that really awful mindset. When I was there the nurses ... the triage nurse I think that I [saw] who kind of first just checked me in [...] sniggered when she said 'you're feeling suicidal?' and she kind of sniggered and she was like 'why?' [...] I didn't know what to say I was just like 'I don't know like I just am'... 'cos I didn't have the words at the time." [Brooke]

Brooke's experience on that night worsened as she was asked repeatedly to provide a urine sample, which she understood was to rule out substance misuse on account of her agitated state. She found it humiliating since this took place in the waiting room of the ED and she didn't feel the need to urinate so she could only produce a small sample which was deemed insufficient. Despite her needle-phobia, Brooke was coerced into having a cannula inserted in her arm all of which increased her agitation, her level of humiliation and her suicidal feelings, she regretted being there and felt stupid. When the duty psychiatrist first saw and asked why she was there his perceived off-hand manner was off-putting, which meant Brooke was made to feel small and she found it difficult to ask for help:

“I felt humiliated [...] I guess because of whatever state I was in, I think they assumed I was on drugs. [...] I was just very embarrassed ... very highly emotional state ... exhausted ‘cos it was [...] late at night at this point. [...] So I just felt extremely agitated, humiliated ... honestly, I felt worse I felt more suicidal [...] I felt stupid for being there. Finally, the psychiatrist came up to me and at first he had like a kind of [...] an off-putting like disposition [Brooke laughs a little] he seemed tired [...] he seemed like he’d had a long shift was kind of the vibe I got from him. [...] at first he was like ‘why are you here? and I kind of [...] after everything that had happened [...] I felt small [...]. I didn’t know how to ask for the help ‘cos I was like [...] I had gotten in my own head that I shouldn’t be there. [...] I kind of mumbled almost ... ‘I feel suicidal.’ [Brooke]

Brooke described a second attendance in an ED setting where she articulates very well the impact of poor healthcare practice that lacks empathy, compassion, or a trauma-informed approach. Brooke adopts the voice of disgust as she describes how the nature of her injuries was ignored and no effort was made to assess her wellbeing, level of distress, or level of risk for suicide or further self-harm during her treatment at the ED where she attended having cut herself. She described how her wounds were simply stitched and dressed as if they had occurred accidentally. Although Brooke states that she was not at further risk at the time she makes the important point that the healthcare professionals dealing with her did not know that and failed to ask. She described how the doctor didn’t speak to her all the while he was stitching her wounds which was dehumanising for her. She acknowledged that the staff were busy and, in the end, she felt as though she was wasting their time. Overall, the experience left her feeling humiliated and she left the hospital feeling worse about herself:

“I was a bit disgusted at how they treated it [...] like someone accidentally cut themselves cooking or something. I saw the triage nurse, she looked at it. [...] They didn’t ask me if I was ok [Brooke laughs wryly] they didn’t ask me if I was gonna do more. [...] I felt disgusted for the system because I just think it’s not [...] right that they did that. [...] I was okay [...] I wasn’t gonna hurt myself again [...] I wasn’t suicidal at this point, I was fine but they didn’t know that and I think that that’s not okay. [...] I just didn’t think it was right. [...] they seemed busy [...] they seemed too busy to ask. [...] I got brought into a bed to have the stitches done [...] I was lying there for

a while, the doctor flew in, done the stiches, said 'you're done' and left [Brooke laughs] like he didn't talk to me [...] I didn't feel like a person [...] I didn't feel like a patient that he was talking to [...] I coulda been a practice dummy [...]. He didn't talk to me like a person. I felt like I was wasting their time [...] like I shouldn't have been there. [...] it kinda just felt like a cattle-drive, like going in, getting the service and leaving [...] I just felt humiliated. [...] I went home feeling, like ... shit about myself [...] I felt really bad about myself." [Brooke]

Kym, who had professional knowledge and experience of healthcare systems, discussed how she perceived the ED as fundamentally unsuited to the care of people experiencing suicidal ideation. She described, from her own lived experience perspective, how difficult it is to navigate a system that is not designed for mental health and how, as a result, it can be very stigmatising trying to access support while experiencing crisis:

"I will get sent to a local ED [...] and I will be there for 12 hours, maybe 24 hours. They will leave me in the waiting room 'cos I'm not an emergency case ... I'm not there with Covid ... I'm not there with a car injury, I'm there in an attempt to prevent me from taking my own life. That is not viewed as a big deal I feel in ... general hospitals and then when you come in there is that stigma from staff that 'oh there's nothing we can do for you.' [...] the facilities that are in acute care and emergency care is not designed for [...] people with mental health disorders. [...] It's not designed for people with any kind of extra needs, you have to have a physical condition that you can see on a scan or a blood result to be treated in a hospital [...] if you have anything outside of that, you're screwed." [Kym].

10.2.2 Care in the context of adult mental health services

This subtheme focuses upon the women's experiences of care and treatment in relation to their diagnosis of BPD within the context of dedicated adult mental health services and settings. The women's overall experiences in mental health services were seldom framed as all positive, or all negative, and many of the women's experiences were mixed. Firstly, examples are presented that are

representative of some of the women's mainly positive mental healthcare experiences in terms of therapeutic relationships and beneficial treatments. Secondly, accounts of some of the women's more difficult or challenging clinical encounters and some of their more negative reactions to treatment are exemplified. Five of the women described their mental healthcare experiences in particularly positive terms while those of three of the women were predominantly negative. The six remaining women described a mix of positive and negative experiences.

Mya, Pia, Stella, Una, and Rose each described healthcare experiences within mental health services that overall were particularly positive.

For Mya, although her involvement with mental health services was brief, she felt the benefit of therapeutic engagement with her community mental health nurse (CMHN) and appreciated the skills she gained in a group based on the principles of DBT. Mya appeared to appreciate the individual therapeutic sessions that she had with her CMHN who worked closely with Mya from a strengths-based approach to practically address issues together so building Mya's confidence and problem-solving skills:

"So, the team there were great because they got me in pretty quickly to a mental health nurse led kind of DBT skills programme. [Prior to discharge] they said okay, 'we're going to do an extra,' I think it was three or six weeks, 'with the mental health nurse one on one' [...] I felt that was really good and she was very, very good because she was really practical and she actually, if I was saying I was having a problem with something, she would say [...] 'okay well let's have a look at this together' [...] it was really practical and it actually helped." [Mya]

Pia and Stella were both strongly of the opinion that DBT was life-changing for them.

Pia, who was very grateful to her psychologist attributed her mental health recovery to having participated in DBT, she also described having undertaken

acceptance and commitment therapy (ACT) which was very difficult but ultimately beneficial:

“I was really, really lucky to be tied in with a fantastic clinical psychologist who had me straight into DBT [...]. So that just saved my life. [...] DBT really helped me to learn coping skills, I think the distress tolerance skills were fantastic. [...] I was very anxious and I underwent ACT therapy, acceptance and commitment therapy for 10 weeks, really helpful. Horrifically difficult, so emotionally excruciatingly painful. But the after effects of the treatment was fantastic.” [Pia]

Stella, having undertaken several courses of DBT, also rated it very highly. She described the treatment as hugely beneficial for her in terms of managing her distress and learning to regulate her emotions. She also found that DBT was helpful to her in being able to enact the other therapies that she has undertaken including CFT. She added that her latest course of DBT was also helpful in relation to her eating disorder:

“The DBT programme was the best thing in the entire world. [...] it was brilliant. So I had done other treatments before [...] I got what they were going for but it wasn’t helping me in my life. [...] I had done CFT before, which would be a compassion focused therapy, and I was like I just couldn’t access it because I was too distressed [...] it was only after DBT that it was like ‘now I can access some of that’ [...] it was a huge game changer for me. I found it hugely validating. [...] I remember [...] the first time I did the course [...] at the end they got us to write like, on a card, something that we would like to know at the start. [...] and I remember writing like ‘I always felt like everyone else had a manual on how to be and I hadn’t got one and this was the manual.’ Oh my God, I love DBT. [...] they kinda brought the DBT skills into more of the food-related and that was really useful. It changed my life, it was brill. I loved it. I’m a firm believer in DBT.” [Stella]

Una and Rose each appeared to highly value their mental health treatment teams.

Una enjoyed very good support from her mental health team and described particularly good therapeutic relationships with the occupational therapist and the community mental health nurse on the team whom she felt she could trust to

Speak on her behalf when she felt unable to speak for herself because they each had demonstrated that they knew her and understood her very well. The perception that her mental health team knew her very well was highly valued by Una:

“I did see an OT in my mental health service [...] for a good few years [...] so she got to know me really well. [...] my key nurse [...] from the mental health team, she came to the team meeting [...] and one of the questions they asked me [...] I was like oh, I was thinking in my head ‘I don’t know how to answer this’ [...] and I kind of looked at her for the answer and she talked for me and when she answered the question I knew then, oh, she knows me as well as my OT knew me, so [...] I figure like that the mental health team know me inside out at this stage. It’s a good feeling [...] when I feel I have people on a mental health team that know me inside out.”
[Una]

Rose similarly described her planned two-week admission to hospital in very positive terms. Her experience of the care provided by the mental health service appears to have been excellent and she described the team as being very professional, reassuring, and helpful. She added that the team members were nice, understanding, and kind. She described her stay as very reassuring, and she enjoyed engaging with her psychologist who was kind as they worked on a formulation. Rose also praised the teams after-care service very highly:

“So I went into the hospital and I loved it. I spent two weeks there, the team were so nice, so understanding, so reassuring, so kind, so professional, so helpful. And it was very reassuring and I did a formulation up with the kindest psychiatrist ... or psychologist. [...] They [Rose’s mental health team] had such brilliant after-care it was amazing as well.” [Rose]

By contrast, Kym and Fay’s experiences of mental healthcare were quite negative overall. Central to their difficult experiences in mental health services were problematic relationships with their consultant psychiatrists.

Kym did not enjoy a good relationship with her psychiatrist, whom she perceived looked down on her, and with whom it appears she found it difficult to establish therapeutic communication or rapport. Her care experience was further negatively impacted by inconsistency in her treatment team with the registrars constantly changing rotation:

“I didn’t particularly like the Consultant either [...] he reminds me of kind of old-school mental health physicians who look down their noses at people and that was kind of the vibe I’d get off him which didn’t help in [...] the dynamics of try to talk ... and he’d often say I wasn’t listening to him when he talked to me and it just didn’t help. It’s like when you’re really stressed and people just tell you to calm down [...] I felt that was his method of communicating and then he had a new Reg. every month that I would see [...] I’m still under that mental health clinic and I still get the monthly sessions and it’s been a new Reg. every time since.” [Kym]

Fay, who had initially welcomed her diagnosis of BPD with a great sense of relief had come to strongly reject it. Her dissatisfaction appeared to be grounded in the fact that she disagreed fundamentally with the notion of a *disordered personality*. In relation to DBT she questioned how the recommendations contained in DBT could possibly address a problem with one’s personality. Fay described how she found it impossible to engage with DBT once she began to realise its primary focus was on developing better coping skills, as opposed to addressing the underlying issues. Although Fay thought the health professionals that she met were nice she felt as though she had somehow blocked herself on the grounds that she perceives personality traits as fixed and therefore could not engage in the therapeutic relationships on offer:

“In the DBT sessions [...] I remember just everything they were recommending just thinking ‘well how is that supposed to change my personality if there’s something wrong with my personality’ [...] all these kind of things that are supposed to help you get out of distress [...] ‘if there’s something wrong with my personality how were [...] any of those things going to change it?’ [...] I started to realise was that what they were

trying to teach us was ways to [...] cope with the personality disorder but [...] not actually as a treatment [...] for the disorder [...] we never actually made any progress because [...] every session with the guy I was with and he was lovely [...] I just couldn't grasp the ... I suppose it's so ingrained in me that I fundamentally can't change if this is a personality thing that [...] he spent most of the time trying to convince me to, to actually just work with him and give him, give it a shot whereas I just kept thinking [...] 'if this is a personality thing I'm not going to change' [...] I blocked myself [...] like 'if this is a personality thing what's the point you know?' [...] I've met some lovely people like counsellors and stuff but just never really clicked with ... with any of them." [Fay]

Ava's experience of mental health care and treatment is representative of the women's experiences that could be construed as quite mixed. Ava described her consultant psychiatrist in quite negative terms while she enjoyed an excellent therapeutic relationship with her psychologist. Ava described the DBT-based group skills sessions that she undertook as useful, however similarly to Fay, she described being frustrated at the idea of a treatment aimed at changing her behaviour rather than exploring more deep-seated issues. I was struck by Ava's incisive analysis of her both her lived experience and her treatment experiences. She described with great clarity how having learned how to behave well on the outside for others she had internalised her problems. Echoing Fay's perspective, she rejected the notion of focusing on external behaviours while not addressing anything internally. She likened the development of distress tolerance skills to learning better masking skills which she had also learned as a child:

"He's not a great doctor ... he was a little bit insensitive and he's still quite insensitive when I deal with him. [...] he's the kinda doctor that [...] he'd tell you just don't be anxious. [...] he does say quite insensitive things like [...] he doesn't even seem to try. [...] My psychologist, she's very nice and understanding and [...] not insensitive at all. [...] I am looking forward to having more time with my psychologist. [The skills group] was really helpful. [...] but I'm quite frustrated about this because [...] I found that a lot of it was my behaviour, so [...] I learned how to behave for other people while on the inside [...] I've basically internalised everything [...]. I behave really well [...]. But I basically learned to behave for other people while on the inside I'm still dying and [...] I just don't think it's a great approach. [...]"

going to classes and like support groups it's [...] all based about how you behave outwardly ... it's not [...] on the inside [...]. I did have to mask basically [...] as a kid and I think that now as an adult these classes are just teaching me better skills to mask and not really much on the inside" [Ava]

Anna described a very negative encounter with a mental health professional that occurred in the context of her assessment to participate in a DBT programme. Her perception of the health professional's negative attitude towards her led her to worry about how she might be treated in the future because of her diagnosis. Anna also makes clear her understanding of how a complaint might be perceived if she, as a woman with a diagnosis of BPD, were to complain about how she was treated by a mental health professional providing a good example of the issue of epistemic authority:

"[Anna's DBT assessment] that appointment was really, really awful and I refused to go back and see her. So I don't have any access to DBT 'cos she's the only person who does it in [Anna's area] and I think she has some not very nice ideas about people with BPD. [...] it was really upsetting and it made me worry for the future ... of other times I'd try and get help, are people going to be prejudiced against me and not believe me and make assumptions about me? [...] I feel kind of powerless because ... she gets to get away with treating people that way and [Anna make a small sigh] even if I complained you know she's the [healthcare professional] and I'm the person with a diagnosis of BPD so who are they going to believe? [Ava laughs briefly] ... they're going to believe her obviously ... so yeah it feels [...] quite disheartening [small sigh] to know that if I'm treated badly because of this diagnosis there's not really anything I can do about it." [Anna]

Leah's description of her consultant psychiatrist's behaviour was indicative of negative stereotyping where she perceived that he was attributing "*symptoms*" to her that she felt matched his image of a "*borderline*" woman:

"I felt like [...] because I'm a woman I think he was putting symptoms on me [...]. He said that I was very coquettish [...] and he was [...] pointing out the way that I dress and things like that [...] relating those things to being

a borderline ... like saying that the way I presenting [...] is because of my diagnosis. But [...] I was only like twenty and I was... [Leah laughs] wearing like black tights and I was wearing like a skirt [...] like I wasn't being revealing or anything and [...] I don't think I was flirting with him like I didn't intend to be flirting [...]. I felt like [...] there's like a stereotypical image of borderline women that he was putting on me ... or trying to pick things out of my personality to match what he thought a borderline woman was like.”[Leah]

Reflecting on how she felt looking back on how she was treated by her psychiatrist Leah recognised that her attachment issues, that she related to her father's absence throughout her life, and her perception that as a consultant psychiatrist this man's opinion of her must be correct, influenced her and led her to accept his behaviour and attitude and to doubt herself:

“I kind of felt [...] under pressure or on the spot or something [...]. He was much older than me too ... he was like 60 [...]. I continued to see him [...] but I always felt like [...] not so much anymore but when I was younger I would like get really attached to ... 'cos my dad wasn't around ... so I would get really attached to [...] older men and the fact that he said that and had given me attention in that way made me feel like well I better keep dressing really nice [...] it felt like [...] I had to play that character [...]. Even though it was in my head [...] I don't know [Leah laughs a little] like that's how he saw me so that must be how I am [...] I guess. I felt like I had to be a certain way to go in to him [...] it feels strange that he ... kind of pointed that out about me [...] like I don't want to say sexualising me but ... like I've never been to a doctor before where he tells me I'm flirting with him [Leah laughs wryly] like I genuinely wasn't like at all. [...] I think I was trying to act confident 'cos I'm naturally kind of shy and I guess maybe acting confident it came across like I was ... something else ... I don't know, I didn't mean to though [...]. Yeah, it was a bit weird (Leah laughs a little).

10.3 Chapter summary

This chapter presented a broad range of findings representing life after diagnosis and women's experience of living with the diagnosis. Women's dilemmas associated with diagnosis were identified. The relevance of how they felt about the diagnosis coupled with issues of trust and fear of judgement were examined as

they related to the women's disclosure dilemmas and experiences. The findings related to women's experiences of healthcare were also presented. In the next chapter the overall findings from the inquiry are discussed and contextualised in the literature.

Chapter 11: Discussion

11.1 Introduction

The aim of this inquiry was to explore women's lived experiences of diagnosis and disclosure of borderline personality disorder (BPD) in the Irish context. This was achieved through the narrative analysis of 14 women's individual narrative accounts of their lived experiences. The inquiry draws upon a broad range of existing literature, prioritising research undertaken from the lived experience perspective, critical perspectives on mental health, and feminist and sociological scholarship. The review of the literature reveals the majority of published empirical studies, that inform the ongoing development of aetiological theory, remains heavily gendered and dominated by the biomedical understanding of the BPD construct. Gaps were evident in the literature in relation to how women experience being given the diagnosis of BPD and their decision-making and experience around self-disclosure of the diagnosis to others. This inquiry values and privileges the perspective of women diagnosed with BPD as experts in their own lives and experience. The women's own voices are therefore prioritised over my voice as the researcher in this inquiry. In this way the inquiry contributes to the growing body of literature that challenges traditional biomedical conceptualisations of BPD and the dominant discourses that surround mental health and illness and the *borderline* construct.

The personal, intimate and very difficult stories the women narrated in this inquiry offer rich and meaningful insights into their lived experiences of the diagnosis and disclosure of (BPD) in the Irish context. The overarching finding of the inquiry, as identified in the horizontal RTA conducted across the women's individual narratives, was that dyadic relationships influenced the women's experiences during each of the conceptualised temporal stages that include: life before diagnosis, the diagnostic moment, and life after diagnosis. In an exploration of dyadic power theory Dunbar (2004) argues that relational power is an integral component of any relationship, particularly immediate family

relationships, since power determines decision-making in the family and influences how family members relate to each other. Power structures and imbalances, both within and without the dyadic relationships, emerged as an important consideration relevant to the findings of this inquiry. At the micro- and meso- levels of the individual stories dyadic power was evident in the women's experiences of early-life, of diagnosis, and of disclosure. At the macro-level the narrative power of dominant discourses is also evident in the women's stories across each conceptual stage, for example, the dominant biomedical psychiatric discourse and the *borderline* discourse. This chapter draws together and critically discusses the key empirical findings from the inquiry that were presented in the previous four chapters (7-10) and contextualises them within the existing theoretical and empirical literature. The chapter closes with a discussion of the significance of this inquiry as it contributes to new knowledge on women's lived experience of diagnosis and disclosure of BPD.

11.2 Choosing a framework for discussion

Given the richness and depth of the stories shared and the ethical responsibility I had to do the stories justice, it was difficult to decide how best to approach the critical discussion of the findings. Listening in the analysis to the women narrate their lived experiences amplified for me, what Domosh (1997, p. 83) described as the "*micro-scale impacts of the macro-scale politico-economic and socio-cultural processes*," that were at work in the lives of the women. Underpinned by my social constructionist epistemology, developing an understanding of the impact of those macro-level processes on the micro-level of the women's lived experiences through the application of my analytic strategy was key to achieving the aims and objectives of this inquiry, as discussed in Chapter 4. Within this discussion chapter, my challenge was to reflect from the micro- and meso- level the individual experiences of the women who were diagnosed and living with a highly stigmatised diagnosis but also to capture the powerful macro-level socio-cultural discourses that influenced their lives, their diagnosis, their disclosure, and their stories. Conscious of the pervasive feminist issues of medicalisation, biomedical

power, stigma and inequity that were unveiled through the in-depth analysis of the women's stories, it was crucial to make explicit in this discussion the role and influence of power in the women's lived experiences of diagnosis and disclosure. I chose therefore to adopt the principles of the Power Threat Meaning Framework (PTMF; Johnstone & Boyle, 2018) as a framework to guide and structure my discussion of the inquiry's findings.

11.2.1 Theoretical application of the PTMF

Given that I was applying the PTMF theoretically to the findings interpreted from the women's narratives, and not directing questions towards to the women themselves, I rephrased the core questions accordingly to structure my discussion, see Table 11-1. The theoretical application of these core questions, that underpin the PTMF, offers a suitable lens through which to view: (i) the various systems of power that operate in the women's lives; (ii) the kinds of threats posed to the women; (iii) the sense the women made of their experiences, and; (iv) how the women responded to those perceived threats. Accordingly, I frame the discussion of the findings to: (i) make explicit "what happened" in each of the three stages and how the women were impacted, and; (ii) consider how the women made sense of and survived their experiences.

Table 11-1: The PTMF questions adapted

The Power Threat Meaning Framework [adapted] (Johnstone & Boyle, 2018)	
1. What happened?	[How is power operating in the women's lives?]
2. How were the women affected?	[What was the impact on the women?]
3. What sense did the women make of it?	[What was the meaning derived from those experiences?]
4. What did the women do to survive?	[What kinds of threat responses did the women use?]

11.3 Life before being diagnosed with BPD

This section of the discussion focuses on the findings that were presented in Chapter 8 that relate to the women's experiences in their early-life stage, before being diagnosed with BPD. During this stage each of the women encountered difficult relationships and related adverse childhood experiences (ACEs) at home and/or at school and later as they sought help for their mental health difficulties as adolescents and young adult women. In the following sections I provide a discussion of the women's collective early-life experiences and explore the power influences at play. Before beginning my critical discussion of the findings related to the women's early-life experiences of dyadic relationships and ACEs it is important to clarify the concept of ACEs.

11.3.1 The concept of adverse childhood events

A seminal study by Felitti et al. (1998) found that ACEs were strongly associated with many leading causes of death including cardiovascular disease, diabetes and cancer. Many more studies ensued in which the range of health outcomes and the list of ACEs examined expanded (Cannon et al., 2010; Greenfield & Marks, 2009; Benedetti et al., 2011). Kalmakis & Chandler (2013) found that while ACEs have been associated with subsequent poor physical and mental health outcomes across the lifespan for many years (Chan & Young, 2009; Clark et al., 2010; Felitti & Anda, 2010; Pervanidou & Chrousos, 2007) the phenomenon had not been consistently operationalised and it lacked a clear operational definition despite widespread ongoing research. The need for conceptual clarity, upon which to build a body of high quality nursing research, led Kalmakis & Chandler (2013) to undertake a concept analysis that synthesised the data on adverse childhood experiences from 128 articles published from 1970-2013. They arrived at a clear and consistent operational definition of the concept that states "*adverse childhood experiences are childhood events, varying in severity and often chronic, occurring within a child's family or social environment that cause harm or distress, thereby disrupting the child's physical or psychological health and development*" (Kalmakis & Chandler, 2013, p.1495).

The conceptual model of ACEs is representative of both the family environment that surrounds the child and the social environment that surrounds the family. The concept therefore incorporates harm caused to the child by virtue of abuse or neglect, or exposure to family dysfunction. Issues in the social environment may also impact the family, for example poverty, racism, gender inequality, or violence in the community which can in turn impact the child. Events in the social environment that are external to the family including bullying or gang violence may also harm the child. In this model there is an interdependency between the child, the family, and the social environment which means that while the family or the social environment may function as a source of stress, equally they may function as a source of support that protects the child.

11.3.2 The association in the literature between ACEs and BPD

Given the volume of research published that associates ACEs with the diagnosis of BPD I have opted to support this section of the discussion with a synthesis of the findings from four contemporary systematic reviews (Bozzatello et al., 2021a; Bozzatello et al., 2021b; Porter et al., 2020; Yuan et al., 2023). It is important, for context, to make clear that many of the papers cited that examine the association between ACEs and the diagnosis of BPD demonstrate a biomedical understanding of the diagnosis of BPD as they explore the various risks for the *development* or *onset* of BPD as a *disorder*. They also examine, from a developmental aetiological perspective, not only the environmental risk factors that are of interest in this inquiry but also the *interplay* between *genetic*, *neurobiological* and *temperamental* risk factors that are not examined within the scope of this inquiry.

The first included systematic review conducted by Bozzatello et al. (2021a) synthesises studies that focus on BPD *symptoms* and *disorder* among adolescents up to the age of 20 years. The aim of the review was to examine the role of trauma in the lives of young people diagnosed with BPD and to publish an update on the different types of traumatic incidents including physical and sexual abuse, neglect, and bullying that when combined with temperamental, genetic, and

neurobiological risk factors might influence the *onset of symptoms* of BPD from an early age. The aim of the second included systematic review conducted by Bozzatello et al. (2021b) was to evaluate the evidence from the literature that explores *early detection* of BPD, to support the diagnostic process, with a particular emphasis on studies that address risk factors for BPD. In total 171 papers were included with the following study types: cross-sectional (67); longitudinal (61); reviews (33); commentaries/expert articles (7), controlled trials (2), and; case-report (1).

The third included review incorporates a meta-analysis by Porter et al. (2020) that sought to compare levels of exposure to ACEs among individuals diagnosed with BPD in comparison to clinical and non-clinical controls. In total 97 papers eligible for inclusion with the following study types: case-control (92); epidemiological (3), and; prospective (2). The final included systematic review conducted by Yuan et al., (2023) sought to identify studies that explore the role of trauma in the onset of BPD *symptomology*. In total 59 papers that included 89,438 participants in total, with a range of 35-34,653 participants. 72% of studies (n=43) included both male and female participants, 18.6% of studies (n=11) reported all-female samples, 1.7% of studies (n=1) reported all-male participants, and 6.8% of studies (n=4) did not reveal the sex of the participants in their studies. In terms of race and ethnicity 37.3% of the studies (n=22) reported the majority of their participants were White and 5.1% of studies (3) reported that all participants were White.

Overall, the findings from the systematic review by Bozzatello et al. (2021a, p.3) in relation to environmental risk factors for the early diagnosis of BPD indicate a strong association with numerous family-related factors that are described in the paper as “*childhood familial maltreatments*.” Similarly, a number of environmental factors categorised as family-related factors and trauma-related factors were implicated in the *onset* of BPD according to the findings of the systematic review by Bozzatello et al. (2021b). The principal findings from the meta-analysis by Porter et al. (2020) also indicate a strong association between the diagnosis of BPD

and ACEs. People diagnosed with BPD were shown in this review to be 13 times more likely to report ACEs when compared to non-clinical controls. This association is also consistently high when compared to people living with other mental health diagnoses. Overall, 71.1% of BPD participants in the review conducted by Porter et al. (2020) reported at least one ACE. Similarly the findings from Yuan et al. (2023) indicate that 88% of the studies (n=52) found that a minimum of one childhood trauma was significantly associated with the diagnosis of BPD; 12% of the studies (n=7) found no significant correlation between BPD and trauma. The synthesised findings from these reviews are drawn upon in the sections that follow to provide evidence in support of the discussion of ACEs and their association with the diagnosis of BPD.

11.3.3 What happened in the early-life stage and how were the women affected?

Here I will critically discuss the women's difficult early-life relationships and their exposure to ACEs. Although the women were not directly asked in the inquiry about their childhood history or relationships the findings reflect the ways in which each of the women similarly employed narrative construction as a means of making sense of their diagnosis. They did this by focusing on how their early-life relationships and associated experiences impacted their mental health and their ability to cope. In accordance with the PTMF I will focus upon "what happened" by exploring how dyadic power operated in the women's early-life stage and how the women were impacted in terms of their exposure to ACEs. I will explore the meaning they made of those relationships and experiences, and how they survived. Thinking first about the question of what happened to the women, and how dyadic relationships influenced their early-life stage, it is immediately apparent from the findings that difficult familial relationships were very significant, specifically parent-child dyadic relationships. The findings also clearly indicate that the early-life stage of each of the women was disrupted, to some extent, by at least one form of harm including abuse, neglect, bullying, bereavement, parental separation or conflict, or trauma over which they had no

control. The early-life experiences of the women in this inquiry were therefore reflective, to a greater or lesser extent, of the findings from the aetiological and empirical literature that suggests a strong association between the BPD diagnosis and the experience of childhood adversity (Borkum, 2017; Schulze et al., 2022; Zanarini & Wedig, 2014). Contemporary aetiological theories, as discussed in the literature review chapter (3.2), commonly identify ACEs as environmental risk factors for the *development* of BPD (Crowell et al., 2009; Linehan, 1993). It is important therefore to explore the influence of women's early-life relationships and their exposure to ACEs in terms of their impact on the women and consider the women's associated responses.

11.3.3.1 Difficult relationships and exposure to ACEs

For many, but not all, of the women the source of the ACEs they encountered were in the context of the familial relationship, specifically the parent-child dyadic relationship. Difficult mother-daughter and/or father-daughter dyadic relationships were common. It is evident from many of the women's stories, that they encountered numerous ACEs in their early-life years and that many of them may not have had adequate parental support in dealing with that adversity. This is significant since contemporary research shows that perceived low levels of social support increases the negative impact of ACEs (McCutchen et al., 2023; Webster et al., 2022). A study by Webster et al. (2022) indicates that children with secure (affectionate) parental attachment are less at risk of experiencing negative health outcomes, if exposed to ACEs, than children who do not have an affectionate parental relationship. This study also examined the prevalence and impact of ACEs and found that there is an increased likelihood of worse overall outcomes related to the number of ACEs children are exposed to and the duration of that exposure; a dose-dependent relationship is being explored.

11.3.3.1.1 Difficult mother-daughter dyadic relationships

Eleven of the women made reference to having encountered, at some point, a significant difficulty in their mother-daughter relationships. Where the

relationships were otherwise close, they managed to navigate the problem and resume a good relationship. However, for six of the women, there were ongoing challenges in the mother-daughter dyad. Three of the women described particularly difficult mother-daughter relationships that were characterised by their mothers' criticism, belittling, verbal and emotional abuse, invalidation and a deep sense of rejection. The dyadic power in those relationships impacted very negatively on the women's mental health in terms of their own self-concept, self-worth, and feelings of self-doubt. The women's experience of difficult and conflicted mother-daughter dyadic relationships align with the findings from numerous clinical studies conducted with young people diagnosed with BPD (Ball et al., 2018; Bezirganian et al., 1993; Schuppert et al., 2015; Williams et al., 2023). Those studies report problematic parenting practices among mothers that include emotional withdrawal, inconsistency, and invalidation of thoughts feelings and emotions. Further issues in the maternal relationship including low maternal satisfaction with the child, disrupted maternal communication, negatively-expressed maternal emotion, maternal over-involvement and maternal psychological control have also consistently been found to be problematic. A maternal diagnosis of BPD was also found to be a significant predictor for the *onset* of BPD (Bozzatello et al., 2021b). One of the women described a sense of embodied self-disgust in relation to a perceived physical resemblance to her mother, whom she had grown to despise as a result of her maltreatment. Such feelings of self-disgust, or self-loathing, are recognised in the literature as a common feature among people who have been diagnosed with BPD (Ket et al., 2023; Skodol et al., 2002).

11.3.3.1.2 Difficult father daughter dyadic relationship

In a similar pattern to the women's relationship with their mothers seven of the women made reference, as told in their stories, to problematic issues that related to their father-daughter relationship. Four of those relationships were physically and verbally abusive at one time, two were impacted by the father's substance misuse, one relationship was defined by rejection and neglect, and one was very

invalidating. In spite of these significant challenges some of the women described having established a reasonably good relationship with their father. However, for three of the women their father-daughter dyadic relationship remained very difficult with significant dyadic power imbalance. For one of the women her early-life father-daughter relationship indicates significant issues of emotional and financial neglect in terms of his failure to support the family, indifference, and a sense of role reversal where the father's needs were prioritised and where the burden of care was significant for the woman from the age of 11 years. Gendered role expectations and patriarchal power were evident in these findings.

11.3.3.2 Macro-level power influences

At the macro level the powerful influence of a patriarchal discourse that perpetuates male privilege, imbalances of power, gender-based violence and the oppression of women (Gupta et al., 2023; Rached et al., 2021) is also evident in the stories the women tell of the physical and emotional abuse and neglect and sexual abuse that so negatively impacted their lives. Coupled with this an individualist ideology that refuses to look beyond the individual who is distressed to address the wider issues meant that when the women did disclose their mental health struggles outside of the family setting, other than a perfunctory recommendation to the parents to get some help for their daughter, there was no follow-up, they were lost to the system that may have been able to help. The women's feelings of conflict in relation to maintaining a relationship with their mothers despite the inherent difficulties speaks to the traditional patriarchal conservative ideology of the family in Ireland described by Romero (2013, p. 82) who said: "[I]n Ireland the traditional family has too often been idealised as a site of peace and unconditional love, its members being united by unbreakable bonds of mutual affection." It was difficult for the women to prioritise self-preservation given the discourses that demand respect for parents and the unity of the family above all else and regardless of the circumstances.

11.3.4 ACEs that were evident in the women's stories

The narrative evidence of exposure to ACEs for each of the women in this inquiry is visible within each of their women's stories, within the summary plots, and within the empirical findings presented in Chapter 8.

11.3.4.1 Emotional abuse and neglect

Among the various ACEs described by the women in the inquiry emotional abuse was the most commonly occurring. For some of the women, emotional abuse and neglect were factors that negatively affected their relationships with both parents. This supports the findings of studies by Kanj et al. (2023) and Schulze et al. (2022) that suggest that the emotional abuse ACE was most closely associated with emotional dysregulation and the diagnosis of BPD. The reviews by Porter et al. (2020) and Yuan et al. (2023) both identify emotional abuse and emotional neglect as strong *predictors* of BPD.

11.3.4.2 Physical abuse and neglect

Physical abuse and issues that were indicative of physical neglect were also evident in the findings for some of the women. Bozzatello et al. (2021a) identify physical and emotional neglect as risk factors associated with early diagnosis of BPD in several of their included studies. Similarly, physical and emotional neglect were also ranked highly as risk factors for BPD by Yuan et al. (2023). Physical neglect was further identified as a significant risk factor for BPD by Bozzatello et al. (2021b) and by Porter et al. (2020) in their reviews.

11.3.4.3 Sexual abuse

For two of the women the effects of intergenerational inter-familial physical/sexual abuse and trauma were very significant. These women endured significant abusive maternal behaviour that included rejection, emotional and psychological abuse, emotional withdrawal, and inappropriate boundaries. Both of the women also considered that their mothers would meet the criteria for a diagnosis of BPD if assessed. This intergenerational cycle of parental childhood adversity and trauma that impacts parenting and influences child mental health is well recognised in the literature. In a systematic review by Rowell & Neal-Barnett (2021, p.174) the authors emphasise from the findings the significant need for a family-based approach to addressing the mental health needs of children and young people whose problems “*do not develop in a vacuum.*” They recommend a combination of individually-based and family-based therapeutic intervention where parents themselves have a history of ACEs. The findings from Bozzatello et al. (2021a) indicate that most of their included studies demonstrate a significant association between childhood sexual abuse and an early diagnosis of BPD. The authors further identify that several studies associated physical abuse with the *onset* of BPD. Bozzatello et al. (2021b) similarly indicate that sexual and physical abuse experiences are amongst the most consistently represented ACEs associated with the *onset* of BPD. Porter et al. (2020) also identified sexual and physical abuse as significantly associated with the BPD diagnosis while Yuan et al. (2023) found that sexual abuse was the most frequently reported type of trauma with 23 studies identifying a strong association with BPD. Physical abuse was also found to be a significant risk factor for BPD in this review.

11.3.4.4 Harsh or maladaptive parenting

Other issues that arose for some of the women in the context of their relationships with their parents included harsh parenting, a perceived lack of care, emotional withdrawal, inconsistent and conflicted relationships, and burden of care for siblings. These findings support a recent prospective study by Armour et al. (2023) that found a significant association between detrimental parenting practices,

defined as controlling, rejecting, and chaotic parenting practices, and the presence of symptoms of BPD in a non-clinical adolescent population. Bozzatello et al. (2021a) indicate that harsh parenting was associated in some studies with the early diagnosis of BPD. Bozzatello et al. (2021b) also indicate that difficult parent-child relationships are closely associated with the diagnosis of BPD. Specifically issues related to maladaptive parenting that included low levels of warmth, rejection, hostility, harsh parenting, inadequate parental boundaries, lower levels of care, and, conversely, parental over-control and intrusiveness were significantly associated with BPD.

11.3.4.5 Parental separation or conflict

The issue of parental absence due to separation, long-term residential care, or bereavement is evident in four of the women's early-life accounts. Six of the women lived in an environment of parental conflict, three of whom experienced parental separation. Yuan et al. (2023) also identified separation from parents as a risk associated with BPD.

11.3.4.6 Bullying victimisation

The findings from a number of studies on the effects of bullying victimization on mental health, emotional dysregulation, and the diagnosis of BPD reflect the experiences of five of the women in the inquiry (Haltigan & Vaillancourt 2016, 2018 ; Hong et al. 2018; Idsoe et al. 2021; Sansone et al. 2010; Winsper, 2018). They each identified in their stories significant patterns of bullying that had negatively impacted their peer-peer relationships at school. For two of the women the bullying was relentless and persisted through to secondary school. For one of the women her experience of bullying resulted in her having to change schools. Another of the women, who had been bullied in primary school, experienced anxiety in secondary school to the point that she dropped out because she could not bear to sit in the classroom. The association between bullying and the development difficulties related to self-regulation is well recognised in the literature (Haltigan & Vaillancourt, 2018; Sansone, 2010) The overall impact of

bullying victimisation on the women appeared very significant particularly in terms of feelings of loneliness, social isolation, and a sense of rejection. The review by Bozzatello (2021b) similarly found that victimisation in peer relationships related to school bullying was a significant predictor of BPD *symptomology*. Bullying at a young age (7-10 years) was found to be a significant risk for self-harm and the development of BPD *symptoms* in late adolescence. School-related negative experiences were also identified as significantly associated with the diagnosis of BPD by Yuan et al. (2023). That sense of rejection is an important consideration in terms of both the school (peer) relationships and the parental relationships that were problematic in many of the women's accounts in that both relationship types have been found to be vital in supporting personality development, as reported in the findings of a study by Skabeikyte-Norkiene et al. (2022). The experience of being bullied, specifically in the primary school setting, was identified by Bozzatello et al. (2021a) as a significant risk for the early diagnosis of BPD across a number of included studies. Those who were repeatedly bullied and victimised by peers were found in this review to be seven times more likely to experience *early onset* of BPD than those who had never been bullied.

11.3.4.7 The impact of ACEs on the women

Each of the 14 women was in some way deeply affected by one or more ACEs. As a result the women experienced, to a greater or lesser degree, significant distress related to what had happened to them. This had a negative impact on their mood, emotions, self-concept, mental health and, physical health. Some of the women felt overburdened, tired, unwanted, overwhelmed or, de-motivated. Most of the women experienced thoughts of suicide and many described a high level of suicidality. Emotional issues were particularly evident in adolescence in terms of mood and managing relationships and behaviour. Five of the women who experienced difficult relationships with one, or both, parents relayed strong feelings of perceived parental rejection and associated abandonment fears. This appeared to have a very significant negative effect upon them in terms of existential thinking. One of the women described a lonely and unhappy childhood, under the care of an authoritarian and physically abusive father, and a

cold and often absent mother. She believed that she was unwanted and told of how she perceived herself as a constant disappointment to her parents who had never given her any praise. Another of the women who had a very difficult relationship with her mother expressed, with resignation, her deeply-held belief that her mother had never wanted her and should have terminated her pregnancy and those of some of her siblings. Another of the women talked about how she sometimes felt so bad and despised her mother, who was abusive towards her, so much that she would fantasise about going back in time to ensure she did not survive as a foetus. Another of the woman described a very unstable childhood where she had experienced issues of separation and irresponsible parenting that resulted in her developing anxiety, nightmares, and a fear of abandonment. The fifth woman who experienced rejection in terms of her relationship with her mother described ongoing difficulties through her teenage years as she struggled with low mood. The problems experienced in that difficult mother-daughter dyadic relationship appeared to be grounded in complicated and unresolved issues around intergenerational abuse.

Five of the women also had a diagnosis of eating disorder, two of whom described ongoing issues in the home/family relating to food and diet where other family members also experienced eating disorder. Two of the women were significantly impacted by carer burden as they had significant care and household responsibilities in the family. There appeared to have been an expectation on them, as girls, that they would assume the carer role in the home as required. The three women who described particularly difficult mother-daughter dyads were significantly impacted by emotional or psychological abuse and a sense of rejection. Another of the women associated her parents habitual drug and alcohol abuse during her childhood with her own subsequent drug addiction as a young adult. Bullying at school was associated with a significant sense of loneliness, isolation, social exclusions and negative self-concept. Anxiety was a significant problem among the women in adolescence and for some it resulted in having difficulty at school. For some of the women who had experienced sadness,

loneliness, and feelings of rejection those feelings turned to anger. For some of the women they turned that anger inwards and began to self-harm.

11.3.4.8 How did the women make sense of and survive difficult early-life relationships and experiences?

Many of the stories shared with me in the course of this inquiry resonated with the embodiment of pain and suffering commonly associated with a diagnosis of BPD (Holm & Severinson, 2008). However, the women also demonstrate resilience and incredible strength in how they have survived the most difficult circumstances. Their determination overall not to be defined by their circumstances and experiences is palpable in the findings. Some described having developed coping strategies that included self-harm. It was unsurprising that the women variously struggled with very negative emotions, low self-esteem, negative self-concept, self-disgust and anger. Some of the women spoke about having attempted suicide at a young age, a number of the women referenced ongoing suicidal ideation. The women appeared to have struggled to survive in very difficult circumstances, many of them caught in very difficult, negative and overwhelming parent-child dyadic relationships. For some of the women their peer-peer dyadic relationships were problematic due to bullying that defined their school years. The difficulties described in the women's narratives, in terms of managing their distress, appeared to be building to a crescendo from the mid to late adolescence period. During their teenage years it appears that the impact of trauma and adversity on the women's mental health was further complicated with onset of puberty and its related significant physiological and hormonal changes.

11.3.4.9 Women's positive supports and seeking help

The women each demonstrated resourcefulness and they adopted a number of different strategies for dealing with the difficulties that they faced in their interpersonal relationships, particularly with their parent/s. Each of the women, for example, who for whatever reason, was lacking parental support had built up a network of supporters whom they could turn to for help, typically they turned

to other female members of their family. However, some of the women sought support and built relationships that were supportive and nurturing outside of the family circle. Establishing supportive relationships and building a strong support network in this way is important in terms of fostering recovery for individuals diagnosed with BPD (Grenyer et al., 2022; Ng et al., 2019)

While all of the women experienced significant challenges to their mental health in childhood/adolescence, only four of them availed of CAMHS. During their time in CAMHS each of the women was given a different diagnosis. For two of the four women, who attended CAMHS services, as adolescents, they found it difficult when they were discharged from the service and had to leave without any supports, because they were aged 18. One of the women described never having felt heard in CAMHS, she perceived her treatment there, overall, as unhelpful. She added that the mental health team in CAMHS did not understand her problems and how at the time she did not have the language to articulate her difficulties adequately. Another five of the women had brief involvement with mental health service providers, for example, two of the women were referred from school following disclosures. However, there was no follow-up in terms of support or treatment. One of the women was diagnosed with depression by her GP at age 16. Another of the women engaged in psychotherapy but ultimately found it unhelpful.

11.3.5 Summary: Life before being diagnosed with BPD

In this section that discussed the findings related to life before diagnosis the women's early-life experiences were contextualised in the literature. Difficulties relating to childhood adversity, difficult parental and school (peer) relationships were discussed and integrated in the literature. The complexity of the women's experiences in their early-life years within the family and at school was evident. Within the parent-child dyads there was also dyadic power at play and at the macro level the power of patriarchy and gendered discourse were evident. The

women's resourcefulness in terms of seeking help and forming supporting relationships strategies for coping were also discussed.

11.4 The diagnostic moment

11.4.1 What happened in the diagnostic moment and how were the women affected?

This section of the discussion focuses on the findings that were presented in Chapter 9 that relate to the women's lived experiences of the diagnostic moment and of receiving the diagnosis of BPD. Given the significance of the diagnostic encounter in relation to the research question and the aims and objectives of this inquiry it was important to have a framework to structure the analysis of the women's experience of diagnosis. The "diagnostic moment" framework, conceptualised by Heritage and McArthur (2019), proved useful for this purpose. The two stages of the diagnostic moment include:

- (i) the delivery of the diagnostic information, described as the "diagnostic utterance," in the diagnostic slot, and
- (ii) the patient's acknowledgement of that information

This deceptively simple framework worked well as a means of identifying the gaps in the diagnostic process that negatively impacted the women's experiences of being diagnosed with BPD. The stories surrounding the women's experiences of the diagnostic moment varied widely and are contextualised now in the literature.

Here I apply the core questions of the PTMF to the empirical findings that are central to answering the research question that seeks to understand from a critical perspective the women's lived experience of receiving the diagnosis of BPD. This use of the PTMF offers an alternative and holistic approach to understanding the women's diagnostic experiences that is removed from the dominant biomedical model. The two subthemes developed from the narrative analysis of the women's experiences of the diagnostic moment centre upon the diagnostic encounter and

women's responses to the diagnosis. The women's experiences of receiving the diagnosis crosses a spectrum from being devastated to perceiving the diagnostic processes in quite a positive way and to having had the diagnosis withheld. These findings are critically discussed and contextualised in the literature. The application of the first PTMF core question that asks what happened in the diagnostic moment and the women's experiences of receiving the diagnosis of BPD reveals that at times there was evidence of an asymmetric dyadic power in the doctor-patient relationship. The concept of biomedical power and epistemic power, or privilege, are also very much in evidence (Fricker, 2007, 2020).

11.4.1.1 Positive diagnostic encounters

The accounts of two of the women who perceived their diagnostic moment quite positively had three basic things in common that each relate to good diagnostic communication (Huynh, 2024):

- (i) the diagnosis was discussed with them and the rationale for giving it outlined
- (ii) they were given time to take in the information given and to ask questions, and
- (iii) an outline of treatment possibilities was explored

These findings align with the review findings of Lester et al. (2020) and the metasynthesis by Sheridan Rains et al. (2021) that identifies service user recommendations for what constitutes good quality mental health care for people diagnosed with personality disorder. In terms of what happened here these diagnostic encounters could be considered to be reflective of a well-balanced doctor-patient dyadic relationship. Where there is a good level of doctor-patient interpersonal communication there is more symmetry in the relationship and the power dynamic moves away from a traditional and outdated paternalistic model and more towards a more contemporary partnership or consumer model, certainly in terms of communication (Shutzberg, 2021). The power dynamic at the macro-level in this instance is likely to be influenced by the recovery discourse. The

women who experienced good quality communication in the diagnostic encounter appeared to be more satisfied with their diagnosis. Their experiences are reflective of the findings of the study by Milton and Mullan (2014) that explored patient preferences towards receiving a serious mental health diagnosis which included face to face communication and having time for discussion.

Three of the women had somewhat anticipated their diagnosis in different ways, one of whom had actively sought to be diagnosed. For all three women the diagnosis was important to them as it provided an explanation for them of their difficulties and an opportunity for therapeutic engagement and connecting with other people who had similar difficulties. This was important in terms of hope for recovery and as a means of reducing feelings of isolation. Four of the women, who described a huge sense of relief when they were given the diagnosis, appeared to feel in that moment that it explained a lot of things for them. It was also, at least initially, perceived by the women as validating of the difficulties they were experiencing. The literature shows that a sense of validation, of relief and the perception of gaining an explanation for the difficulties people encounter that led to their diagnosis of BPD is quite commonly reported (Lester et al., 2020; Sheridan Rains et al., 2024). The idea of forging connections through shared diagnosis speaks in ways to a recovery orientation.

11.4.1.2 Negative diagnostic encounters

Some of the women described being a little shocked by their diagnosis, during the diagnostic moment, which meant that they did not have the opportunity to ask any questions. There did not appear to be any follow up from their consultant psychiatrist in terms of confirming the patient response, in accordance with good practice in diagnostic communication. Although, upon reflection, it may simply not have been mentioned by the women if there was and I did not ask. Those who felt their diagnostic encounter itself was stigmatising felt angry and frustrated and a deep sense of injustice regarding the perceived labelling of their trauma-

responses. The women whose diagnosis was withheld from them expressed having felt angry, dissatisfied and unfairly treated when they found out about it. One of the women also regretted not having known about it sooner. For one of the women the fact that her diagnosis was withheld from her caused her to feel as though perhaps the doctor was biased in some way toward the diagnosis. I thought it significant in the findings from this inquiry that three of the women were essentially denied their diagnostic moment since their diagnosis was withheld at the time it was made only to be uncovered, or otherwise revealed, a long time later. The literature shows that people with lived experience of personality disorder diagnosis resent the notion of the diagnosis being withheld and consider that this adds to the stigma associated with the diagnosis (Sheridan Rains et al. 2020). This practice though often reportedly well-intentioned on the part of the clinician could be perceived of as very paternalistic and disempowering (Klein, 2022). Research shows that the majority of people diagnosed with BPD voiced a preference for open communication in terms of diagnosis (Sulzer et al., 2016). Yet, a meta-synthesis of 29 qualitative papers that explored the views of clinicians, from across all mental health disciplines, on good practice in community mental health related to the care of individuals experiencing complex needs indicated that many clinicians perspective on the use of personality disorder diagnosis was mixed (Troup et al., 2022). Some clinicians disliked the diagnosis and questioned its validity; they associated it with stigma, discrimination and a potential exclusion from services. They also felt that it would be difficult for patients to escape the label once it had been given. Some clinicians perceived the diagnosis as a means of medicalising distress and avoided using the label, opting instead for alternative diagnoses or the use of euphemisms such as “difficulty in managing emotions.” This review emphasises the complexity of the issues of personality disorder diagnosis and the often negative impact of those diagnoses that is very relevant to this inquiry and highlights the need for a new way forward in conceptualising complex needs associated with personality diagnosis in a more nuanced and trauma-informed way (Troup et al., 2022).

11.4.2 How did the women make sense of and survive the diagnostic moment?

The diagnosis could be conceived of as something of a “double-edged sword” as it appeared in one sense to have been comforting for the women, at least initially, in relation to alleviating feelings of blame related to their mental health problems and associated behaviours, as discussed in section 11.4. For a number of the women it also opened up a pathway to specialist treatment that otherwise was not available. This speaks to the argument posed by Tyrer et. al (2019) in relation to the utility of the diagnosis. However, for some of the women they perceived the diagnosis as labelling of their trauma-responses as BPD meant that the diagnosis was viewed as unfair, as discussed in section 11.4. Those women also resorted to researching their new-found diagnosis online and were also exposed to very stigmatising content that impacted them in a negative way in terms of self-concept. Even among those women whose diagnosis was explained and discussed with them in the diagnostic moment, they too inevitably also looked online to find out more and were similarly exposed to negative content. This may in turn have negatively impacted their understanding and internalisation of their diagnosis. The women appeared to take some time to think about and assimilate the diagnosis. They were proactive in seeking information about their newly-given diagnosis, albeit that that proved to be a mostly negative experience. The dilemmas they faced as they sought to come to terms with the diagnosis particularly in relation to their decision-making regarding disclosure are discussed in section 11.5 that explores “life after diagnosis.”

Similarly to the findings from Lovell and Hardy (2014), the women appeared grateful for a diagnosis that made sense to them. In my overall interpretation of the women’s diagnostic experiences I considered it significant that none of the women were provided with any information or guidance in relation to their diagnosis when it was given, many of the women indicated it would have been useful to be provided with some information. This reflects the findings of the systematic review by Lester (2020), that in nine of its included studies the

participants reported that they knew little about the diagnosis when they received it and they were provided with little or no information at the time of diagnosis.

The dominant discourses evident in the women's stories related to their diagnostic encounter and the experience of being given the "*borderline*" diagnosis include the discourse of biomedical psychiatry and biomedical authority that are evident in the inequitable doctor-patient dyadic relationships that resulted in poor diagnostic experiences and for some the denial of the diagnostic moment, however well-intentioned. The withholding of the diagnosis resulted in distress and feelings of being stigmatised and dismissed. In terms of dyadic power the doctor-patient dyad is challenging in terms of establishing equity which is highly dependent on the quality of the therapeutic relationship. This power differential is particularly true of the dyadic interaction in the context of the diagnostic moment where the women evidently had little power. Another issue that arose that has social significance and is significant also from a systems/organisational perspective, in healthcare, is the waiting time that was referenced by one of the women. She had a six-week wait for an outpatient mental health clinic appointment for assessment having presented at the ED with suicidal ideation and a plan to take her own life. It is indicative of the healthcare discourse that a six-week wait was considered "*not bad for Irish services.*"

11.4.3 Summary: The diagnostic moment

In this section the finding related to "the diagnostic moment" were discussed and the women's diagnostic encounters were integrated in the literature. The women's experiences of receiving the diagnosis and their initial responses to it were discussed and issues of power that arise in the doctor-patient dyadic relationship were also discussed in the wider context of the dominant Western biomedical discourse of psychiatry. The serious issue of the withholding of the diagnosis was

also discussed. The impact of the diagnostic moments that were lacking in terms of communication was discussed.

11.5 Life after diagnosis:

11.5.1 What happened in life after diagnosis?

In this section the discussion, framed using the PTMF questions, is focused on the findings that were presented in Chapter 10 that relate to “life after the diagnosis” of BPD. This final theme encapsulates the dilemmas the women faced in terms of their diagnosis and disclosure and their healthcare experiences in the context of their BPD diagnosis.

11.5.2 What happened about self-disclosure and how were the women affected?

The dilemmas that the women experienced in relation to their decision-making regarding disclosure appeared to centre upon their interpersonal dyadic relationships and issues in relation to trust and fear of judgment. In terms of future romantic relationships two of the women expressed concern and stated that they would be reluctant to disclose the diagnosis to a new partner due to stigma and fear of judgement. Where trust was established in the mother-daughter dyad the disclosure appeared to feel quite natural. These findings align with the findings of Lambert (2018) who reported in her study that the women diagnosed with BPD were cautious regarding disclosure and they chose only to disclose to friends whom they trusted would be non-judgemental and avoided disclosing to those who made insensitive remarks about mental health or who might not be trustworthy. A fear of judgement led one of the women to disclose an alternative diagnosis when she made a disclosure at work. This decision was indicative of the perceived surplus stigma that is associated with the BPD diagnosis (Rivera-Segarra et al. 2014). Stigma theory would suggest that the BPD label itself that is associated with negative stereotypes can lead to negative reactions and attitudes (Goffman,

1966; Masland & Null, 2022). Fear of judgement appeared to be an issue in the father-daughter dyadic relationships. This pattern in the narratives of women disclosing their diagnosis was interesting in terms of gender relations. The women were typically, although not all, more inclined to disclose their diagnosis to other women, whether a parent, another female relative, or female friends. I thought perhaps this might have related to the ideology of female solidarity, or the patriarchal notion of toxic masculinity that underpins the gender stereotype that men do not typically understand female emotion. I concluded that perhaps elements of both were subconsciously at play. That said in some of the narratives there appeared to be genuine reasons why the women chose not to disclose to their fathers.

11.5.3 What happened in healthcare and how were the women affected?

The challenging and stigmatising experiences described some of the women in terms of their attendance at the ED are reflective of findings of a recent systematic review by Miller et al. (2023) that sought to synthesise knowledge on consumer, clinician, and carer experiences of BPD in the ED. The review that included seven papers, five qualitative, one quantitative, one mixed methods, and two letters to the editor identified as a key theme discriminatory attitudes and practices that were understood to contribute to harmful outcomes and prompt repeat ED attendances. A key finding from a retrospective study of ED utilisations by patients with a diagnosis of BPD, by Broadbear et al. (2022), was that those patients were likely to reattend the ED which suggests a lack of access to effective BPD-specific treatment in the community. This suggestion of ED use being indicative of unmet mental health needs is supported by the findings of a study by Chen et al. (2024) that explored barriers to care for ED users with psychiatric diagnoses. These findings are reflective of the women's experiences in this inquiry whose episodes of acute distress necessitated attendance at the ED to seek help. The points made in relation to the unsuitability of the ED for individuals experiencing a crisis in their mental health is also supported by the findings from the study by Chen et al.

(2024). Closely related to issues of stigma Crichton et al. (2017) introduces the idea that epistemic injustice may be applicable in psychiatry. Pioneered by Fricker (2007) epistemic injustice is a philosophical theory that originally identified two distinct types of injustices related to knowledge and interpretation that are testimonial injustice and hermeneutical injustice. Fisher (2024) later discusses how the lived experience literature on epistemic injustice irrefutably demonstrates mental health service users experiences of being disregarded, silenced, or dismissed.

The nurse-patient dyadic relationships described by two of the women appeared to be grounded in mutual respect and rapport that are cornerstones of the therapeutic relationship and serve to flatten the power differential. The most common factor among the positive healthcare experiences described by the women appeared to be the therapeutic relationship which included those established with mental health nurses and other disciplines. Therapeutic engagement, trust, and practical support in the context of the therapeutic relationship was highly valued by the women. This supports the findings of a study by Romeu-Labayen et al. (2022) that explored the perspectives of people diagnosed with BPD on the attitudes of mental health nurses that support a therapeutic relationship which found that the following attitudes were important: a belief in the person's capacity for recovery, a non-judgemental attitude, a good sense of humour, availability and a humanistic approach. The women further valued multidisciplinary team input and feeling that the team knew them well and supported them was perceived as very important. For some their engagement with DBT treatment was described as life-changing through the development of skills. This supports the findings from studies that demonstrate the widely-accepted efficacy of DBT as a treatment for BPD (McMain et al., 2009; Storebø et al., 2020). The impact of positive relationships, personal and therapeutic, was significant in terms of decisions regarding disclosure and in terms of care and therapeutic relationship.

The women whose experience in the context of adult mental health services were quite negative experienced a number of challenges. For two of the women it appears poor communication and power struggles in the doctor-patient dyadic relationship led to a poorly perceived experience overall. The inconsistency in the treatment team for one of the women was very concerning in terms of iatrogenic harm, particularly in respect of providing trauma-informed care. Two of the women questioned the appropriateness of DBT as a behavioural treatment on the grounds of its behavioural basis and lack of trauma-informed approach. Serious issues were evident in the accounts of two of the women that related to stereotyping and testimonial injustice. These events had a significant impact on the women who were made to feel disrespected and “lesser than” in their clinician-patient dyadic relationships. This finding is consistent with the literature that indicates an ongoing risk of epistemic violence in relation to the diagnosis of BPD (Dorfman & Reynolds, 2023; Kyratsous & Sanati, 2017). Dorfman and Reynolds (2023) who explore the issue of epistemic injustice as it relates to people diagnosed with BPD argue that people living with the diagnosis are vulnerable to epistemic injustice, specifically testimonial injustice, as a result of the power imbalance that can lead to a person’s word or testimony being doubted or dismissed due to prejudice and deep rooted stereotypes and to higher value being attributed to the testimony of health professionals. They argue that in the case of personality disorder diagnoses there is often an assumption that service users are unaware of their behaviours and emotions which leads to the health professional framing aspects of their experience for them which means the testimony and expertise of the clinician is prioritised and the credibility of the service user is downgraded. This paternalistic approach changes the dynamic between patient and health professional from one of collaborative interpretation of experiences and meaning to favour only the interpretation of the health professions. Dorfman and Reynolds (2023, p.169) conclude that BPD locates the epistemically privileged health professional as the “true” knower of the service user’s personal experiences in a way that does not happen with many other diagnoses which can lead the service user to lose control of their narrative.

11.5.4 How did the women make sense of and survive life with a diagnosis of BPD?

Most of the women had engaged with treatment previously and a number of them had developed some DBT-based skills that they thought were helpful. The women had matured and developed since the time of their diagnosis and had developed their confidence in terms of challenging the dominant narrative. Many of the women mentioned following their interview that they were glad the topic was being researched and that they would have appreciated knowing more about the diagnosis at the time they received it.

11.5.5 Summary: Life after diagnosis

In this section the women's "life after diagnosis" was discussed and the findings that related to living with the diagnosis were discussed. First their dilemmas regarding diagnosis and disclosure were discussed. Next, the women's experiences within healthcare in the context the ED and tertiary adult mental health services were discussed including the positive impact of the therapeutic relationship and issues related to epistemic injustice.

11.6 Conclusion and chapter summary

The feedback that I received from each of the women from the initial point of engagement, at the recruitment stage, through to the completion of the face-to-face interviews was hugely positive and very encouraging. As one they expressed their gratitude that the study was being undertaken and their appreciation for being involved which is testament to the importance to these women of feeling heard and having an opportunity to speak openly and honestly about their experiences of diagnosis and disclosure of the highly stigmatised diagnosis of BPD. Many of the women reported a sense of satisfaction at having contributed to the body of research on BPD in a way that was meaningful and that would help educate others, this is not always the case among marginalised groups (Bhopal,

2010; Salway et al., 2015). Given that the stories the women told recounted very difficult and painful experiences it appears that their willingness to discuss sensitive topics openly and the way in which they welcomed the inquiry and my interest in their experiences very much aligns with the findings of the review by Alexander et al. (2018) as discussed in Chapter 5 (5.6.5).

11.6.1 Significance of this inquiry

As it is currently conceptualised borderline personality disorder is a contentious, feminised, and stigmatised psychiatric diagnosis (Klein et al., 2021, Warrender et al., 2020). Although BPD is frequently diagnosed and is the most-researched of all personality disorders (Leichsenring, 2024), there is a paucity of research that depicts the complex nature of what it is like to receive a diagnosis of BPD. There is less written still on what it means to self-disclose this problematic diagnosis. The significance of this inquiry, therefore, lies in its potential to promote a more nuanced and holistic understanding of women's lived experiences of diagnosis and self-disclosure of BPD. In line with feminist approaches to research and the principles of NI the women's voices are privileged in this inquiry. This was achieved via the methodology, the data generation, and the narrative analysis of the women's first-person narratives that critically examines the impact of receiving the diagnosis of BPD and disclosing it to others, a phenomenon that is under-explored.

11.6.2 Chapter summary

Within this chapter I draw together and critically discuss the empirical findings of the inquiry locating them in the contemporary BPD literature. The use of the PTMF, as a theoretical framework, allowed me to get behind the women's narratives to expose the influence of power at the micro- meso- and macro- level across each conceptual stage identified in the findings. By contextualising the findings in the literature I identified the intersections between what is "known", or claimed in the research, about BPD and my findings that relate to or contribute

to that knowledge. Some of the issues experienced by women diagnosed with BPD are more opaque and less-well researched including: their experiences of the diagnostic moment; the impact of stigma on women's decision-making regarding disclosure; the influence of dominant BPD narratives on healthcare practices and epistemic injustice. By focusing on the points of intersection identified in the discussion I identified points of potential intervention that inform my discussion of the implications and recommendations from the inquiry across the domains of nursing and healthcare practice, education, and research in accordance with the inquiry objectives. The strengths and limitations of the inquiry and its implications and recommendations form the mainstay of the next and final chapter (12) of the thesis that concludes this inquiry.

Chapter 12: Limitations, strengths and implications

This final chapter of the thesis first identifies the strengths and then the limitations of the inquiry. Next, I discuss the implications of the inquiry findings and make recommendations for healthcare practice, policy, education, and research. I close the chapter and the thesis with some concluding remarks.

12.1 Strengths and limitations of the inquiry

12.1.1 Strengths

- A major strength of this inquiry is that it privileges the voices of the women in the thesis so that the lived experience perspective and the women's narratives are foregrounded.
- Another strength of the inquiry is the novel contribution to the lived experience literature on self-disclosure of BPD.

12.1.2 Limitations

The following are the limitations that should be considered as they relate to this inquiry:

- Although the inquiry was open to adult women of all ages there was a notable absence of older women in the sample. The age range was relatively narrow spanning between 23 years and forty years old. It would have benefitted the inquiry, in terms of age diversity, to have some younger and older women participate. The point could be made that the lack of older women participating may have been influenced by the recruitment strategy that was conducted wholly online.

- There was a lack of diversity in the sample in terms of race and ethnicity. All of the women were White and only one of the women was born outside of Ireland to non-Irish parents. It would have benefitted the inquiry to also hear the stories of women from other cultural and ethnic backgrounds who are living in Ireland with a diagnosis of BPD.

- Although the sample size was sound in terms of NI, and I was not aiming for generalisability, the 14 women nonetheless represented only a very small number of the women living with a diagnosis of BPD in Ireland. The inclusion of other women in the inquiry who may have other stories to tell would have benefitted the inquiry.

- My status as a novice researcher while undertaking the interviews and conducting the analysis will have impacted my performance as a researcher which in turn may have impacted the findings. However, I was very well guided and supported in supervision to “learn as you go,” for which I’m grateful.

- The inquiry involved the women looking back at their diagnostic encounter, which for some had occurred a number of years previously. The diagnosis was also most likely to have occurred during a very difficult time in their life in terms of their mental health. This combination of factors may have meant that some important details may have been lost in terms of the women’s stories of diagnosis and/or disclosure.

- My position as a mental health nurse may have influenced the stories that the women told, or felt comfortable to tell, particularly in terms of healthcare experiences. I did make every effort to assure the women they should feel free to tell me whatever felt comfortable.

- The point could be made that due to the self-selecting nature of the sample it is possible that the women who chose to participate were particularly motivated to speak out, other women may have had different stories to tell.

12.2 Implications and recommendations

Overall, the findings from this inquiry reveal many important perspectives that relate to the women's lives in three conceptualised stages: life before the diagnosis, the diagnostic moment, and life after diagnosis. The findings therefore have a number of far-reaching implications for practice, policy, education, and research. The key findings from across each of the three life stages analysed and discussed in the inquiry are synopsised in this section followed by the recommendations for each sector that have been drawn from those findings.

Life before diagnosis stage: The findings from the inquiry that relate to the women's early-life experiences reveal significant:

- difficulties within the family that related to the cumulative effect of ACEs and difficult family dynamics, including intergenerational trauma, and/or
- difficult peer relationship at school due to bullying victimisation

Diagnostic moment stage: The findings that relate directly to the diagnostic encounter, or the "diagnostic moment" as it was conceptualised, reveal a mix of experiences some of which were positive, some less so, and some that the women described as very negative. The key to those experiences, good and bad, was diagnostic communication and the manner in which the diagnosis was delivered. The experiences of the women in receiving their diagnosis of BPD (or not) very much mirrored the findings in the literature in terms of diagnostic experience and best practice. The women's diagnostic responses are outlined below grouped together as follows:

- The diagnostic moment as a positive encounter – for those women the diagnosis was clearly communicated to them, the rationale for the diagnosis was given, some verbal information was given, there was an opportunity to ask questions, and treatment pathways/options were outlined.
- The diagnostic moment as a negative encounter – for those women the way in which the diagnosis was articulated, the “diagnostic utterance” in other words, and the language used was not helpful and the women found that difficult to manage.
- The lost opportunity to respond - for some of the women the diagnosis came as something of a shock which impacted their experience as they had little time to recover before their appointment ended which meant there was little opportunity for discussion.
- The diagnostic moment denied - for some of the women their diagnosis was withheld only to be revealed or uncovered some years later. The women described this experience as frustrating, upsetting and they found this practice to be stigmatising and unfair.
- The lack of information – the final major point is that none of the women received any information in terms of resources that might be useful to learn more about the diagnosis, neither were they directed towards any reliable and trustworthy sources of information.
- The outcome was that the women’s first exposure to information about their newly acquired diagnosis was online. The negative content they were exposed to had a detrimental effect at that vulnerable time.

Life after diagnosis stage: The findings from the women’s experiences of life after diagnosis, living with the diagnosis of BPD revealed:

- dilemmas in regards to their diagnosis in light of the stigma it attracts
- dilemmas regarding their decision-making around disclosure
- healthcare experiences that were positive and those that were stigmatising

12.2.1 Implications and recommendations for diagnosticians and managers

The findings suggest that a timely review of diagnostic policy and practice would support those who have the power to diagnose and managers of diagnostic settings to ensure that best practice is upheld in the care and treatment of people diagnosed with BPD. Importantly, the findings show in line with previous research that, whatever the reason and even if well-intentioned, the withholding of the diagnosis is not helpful. The women clearly indicated they would prefer to have known.

12.2.1.1 Recommendations for diagnosticians and managers of diagnostic settings

1. Review diagnostic practice, policies and protocols in accordance with relevant disciplinary best practice guidelines
2. Implement a protocol and an auditing tool to maintain the standard
3. Update colleagues as required, schedule required training
4. Review and reflect upon professional communication style and practice to ensure the principles of effective therapeutic communication are upheld
5. Develop consciousness in practice of the power of language and seek to adopt an affirmative approach
6. Investigate sourcing appropriate patient information resources and/or digital alternatives
7. Reflect upon the complex needs of the patient and the need for a trauma-informed and patient-centred approach

8. Develop policy and actions to tackle BPD stigma: discrimination, prejudice and stereotyping
9. Consider also the family and their needs for support
10. Maintain liaison with statutory bodies to promote wellbeing of the child/family

12.2.2 Implications and recommendations for mental health nurses and other healthcare professionals

The early-life findings suggest significant exposure to a high number of ACEs impacted the young lives of many of the women. This would imply the best practice trauma-informed and patient-centred approach that underpins our mental health services is an appropriate model of care. The women who described positive healthcare experiences valued highly the therapeutic relationship. However, for some stigma and issues of epistemic injustice were problematic at this stage. The findings from this stage indicate the women struggle with assimilating the diagnosis and disclosing it to others as a result of the stigma that is perpetuated in healthcare. To address the needs of those living with the diagnosis of BPD this must be addressed in practise where the problem primarily resides.

12.2.2.1 Recommendations for mental health nurses and other healthcare professionals

1. Reflect upon the complex needs of the patient and the need for a trauma-informed approach and person-centred care
2. Promote therapeutic engagement and the establishment of a therapeutic relationship that is recovery-focused
3. Develop policy and actions to tackle BPD stigma: discrimination, prejudice and stereotyping

4. Consider clinical supervision as an option to help manage any difficulties and avoid assigning blame for difficult or engaging in stigmatising language
5. Consider also the family and their needs for support
6. Be mindful of Children First Policy and mandatory reporting
7. Maintain liaison with statutory bodies to promote wellbeing of the child/family

12.2.3 Implications and opportunities for policy makers

The potentially high prevalence of ACEs implicated in the difficulties and difficult family dynamics that the women described, including intergenerational trauma, is significant in terms of unmet needs. Difficult peer relationship at school due to bullying victimisation also implies significant unmet needs. These needs extend beyond the realm of mental health services and the need for wraparound services to support children and families to mitigate problems and break the cycle of childhood adversity and trauma, including intergenerational trauma, is at once, obvious, significant, and urgent.

12.2.3.1 Recommendations for policymakers

Develop a policy and clinical care program for individuals with complex needs to incorporate the care of people diagnosed with personality disorder. Within the policy promote actions to tackle BPD stigma: discrimination, prejudice and stereotyping

1. Promote meanwhile the existing suite of child and family-centred policies and their equitable implementation through the resourcing of appropriate services at community level
2. Include as a priority category the care of individuals with complex needs / personality diagnosis in future revisions of mental health policy and health policies
3. Maintain a trauma-informed approach to underpin all social policies

12.2.4 Implications and recommendations for education and educators at all levels

As is evident in the findings the women encountered difficulties from a young age whether at home or at school or both. It is implied therefore that all three levels of education it is important to be trauma-aware in terms of difficult family dynamics and the impact of trauma on the child/adolescent/young adult. It is vital to be aware of bullying victimisations and to act to prevent and deal with issues of bullying so that patterns are not established. Educating children and adolescents on the topic of bullying is important.

In third level education, within the life/health sciences, it is important to consider the powerful use of language in teaching is important and modelling appropriate language to students regarding *personality disorders* and complex needs. It is important to educate students on the impact of the language that they use. It is important too to continue to develop curricula that promotes a critical approach and that takes consideration of the broader sociological context and its impact on health.

12.2.4.1 Recommendations for educators at all levels

1. Be trauma-aware when dealing with sensitive issues with students
2. Develop policy and actions to tackle BPD stigma: discrimination, prejudice and stereotyping
3. Model positive language and critical thinking in relation to mental health

12.2.5 Implications and opportunities for research and researchers

Here I will highlight my two main considerations in terms of research. First, the ethical responsibility we have in research to ensure the approach that we take and

the language that we use in researching, publishing, and disseminating our research is always respectful and represents the best interest of the researched person or identity. I have learned so much about this and the risk of causing harm, however inadvertent or unintentional, both from the women and through supervision on my PhD journey.

Second, there is a need for continued investment in co-produced and experiential research on BPD. If qualitative research was given some priority there is ample opportunity for research in each of the three significant areas of life addressed in the findings, life before diagnosis, the diagnostic moment, and life after diagnosis. While there is a large volume of research on stigma and BPD it seems the problem is perpetuated in healthcare and education programmes have limited effect in the medium-long term which as suggested by Seal et al.(2023) may be due to the power of the dominant BPD narratives that circulate. An interesting area for future research would be to examine the ways in which the perpetual stigma in healthcare services towards people with BPD contributes in a continuous negative feedback loop to that dominant BPD narrative that is so damaging particularly to young women. For me, the novel use of the PTMF framework and the LG method of analysis was a very positive experience. Adopting the PTMF for use in the study of stigma and dominate discourses in BPD would an interesting and novel approach.

12.2.5.1 Recommendations for researchers

1. Develop policy and actions to tackle BPD stigma: discrimination, prejudice and stereotyping
2. Consider ways of investigating how the dominant discourses that feed stigma in BPD can be changed: how, by whom, and why not?
3. Given the negative content available online that fuels the dominant narrative of BPD and the significance of that issue for the women in my inquiry, a co-produced creative study that incorporates digital storytelling

could be undertaken to continue the counterstories of women diagnosed with BPD.

12.3 Concluding remarks

This concluding chapter explored the strengths and limitations of the inquiry. The implications from the findings of the inquiry were discussed and the recommendations for healthcare practice, for policy, for education and for research were presented. To conclude, I will add that by adopting a social constructionist stance, the knowledge created through this inquiry drew upon the context and the unique interactions that ensued between me as the researcher and the individual women who participated in the inquiry. Together we explored, in-depth in the Irish context, women's experiences of receiving the diagnosis of BPD and of disclosing it to others, a phenomenon not commonly described in the literature. The use of a narrative methodology and a bespoke analytic strategy that combined the LG method and RTA ensured I maintained closeness to the data and enhanced the credibility of the findings presented. Contextual factors including childhood adversity, dyadic relationships, communication, stigma, epistemic injustice, and perceived supports were found to have significantly impacted the ways in which the women interpreted their diagnostic experiences and their decision-making regarding disclosure. The implications drawn from the inquiry findings in turn provided a solid grounding for the recommendations. Finally, it was healthcare practice concerns that brought me to this inquiry and I feel I have come full circle on my journey with the women to give something back to practice, to policy, to education, and to research from which we can all benefit.

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Appendices

Appendix 1: Recruitment Poster - Version 2

INVITATION TO PARTICIPATE

Are you a woman who has been
given a diagnosis of borderline personality disorder in Ireland?

Help us understand your experience
of diagnosis and disclosure of bpd

For further information:
Contact Tracey at: theeddstudy@gmail.com or
CALL, TEXT or WHATSAPP 087 656 4995

Follow us on Twitter @theeddstudy
#bpd #research #mentalhealth

"What happens if I change my mind?"
You have the right to withdraw from the study at any time

We are seeking to interview women aged 18+ who:

- ✓ have been given a diagnosis of BPD/ EUPD in the Republic of Ireland
- ✓ are fluent English speakers
- ✓ received their diagnosis more than 6 months ago

What does it involve?

- ✓ a one-to-one interview with the principal researcher
- ✓ at a time and location to suit you
- ✓ you may be invited to do a follow-up interview/s (optional)

EDD STUDY
experiences of diagnosis & disclosure of bpd

Appendix 2 - Participant characteristics form

Participant ID Number: _____

This optional short form is designed to gather personal information about you that is relevant to your participation in this study. This information will remain confidential.

1. Please indicate your gender:

Female ☐

Transgender Female ☐

Prefer not to state/not listed ☐

2. Please indicate your current age: years

3. Please indicate by ticking the box that best represents your sexual orientation

Attracted to the opposite sex ☐

Attracted to the same sex ☐

Attracted to men and women ☐

Attracted to neither men or women ☐

I prefer to use another way of describing my sexual orientation _____

4. Do you have any children? Yes ☐ No ☐

5. Please indicate by ticking the box that best represents your marital status

Married ☐

Separated / divorced ☐

Remarried ☐

Single ☐

6. If single please indicate by ticking the box that best represents your relationship status

Single and not dating ☐

Single and dating ☐

In a relationship ☐

Other ☐

7. Please indicate by ticking the box that best represents your highest level of educational achievement

Completed primary education ☐
Completed lower secondary education ☐
Completed upper secondary education ☐
Completed third level education ☐
Completed postgraduate education (PhD) ☐

8. Please indicate by ticking the box that best represents your current occupational status

Student ☐
Working in paid employment ☐
Working as a volunteer ☐
Looking after home/family ☐
Unemployed ☐
Unable to work due to illness/disability ☐
Retired ☐
Other ☐

9. Indicate the length of time since you received a diagnosis of BPD/EUPD:

Years Months

10. Do you currently attend or have you attended in the past a mental health service?

Yes ☐ No ☐

11. Are you currently prescribed any medication in respect of your mental health?

Yes ☐ No ☐

7. Please indicate by ticking the box that best represents your highest level of educational achievement

Completed primary education ☐
Completed lower secondary education ☐
Completed upper secondary education ☐
Completed third level education ☐
Completed postgraduate education (PhD) ☐

8. Please indicate by ticking the box that best represents your current occupational status

Student ☐
Working in paid employment ☐
Working as a volunteer ☐
Looking after home/family ☐
Unemployed ☐
Unable to work due to illness/disability ☐
Retired ☐
Other ☐

9. Indicate the length of time since you received a diagnosis of BPD/EUPD:

Years Months

10. Do you currently attend or have you attended in the past a mental health service?

Yes ☐ No ☐

11. Are you currently prescribed any medication in respect of your mental health?

Yes ☐ No ☐

Appendix 3 – Interview guide

Interview Guide

Introduction

- Introduction – introduce self and background
- Outline the inquiry with reference to the participant information leaflet
- Address any questions and/or make clarifications
- Seek informed consent (verbal and written) and discuss confidentiality

Interview

Researcher: Beginning wherever you wish can you tell me about being given the diagnosis of borderline personality disorder, or emotionally unstable personality disorder, and about telling others about that diagnosis? Please feel free to give me as much detail as you would like as everything you tell me about your story is important

Participant narration

Further questions /prompts can be used if required for clarification:

Would you tell me how the borderline personality disorder has affected your life?

- What kinds of issues do you face?
- How did you feel about the diagnosis and has that changed?

Can you tell me more about disclosing your diagnosis?

- How did you feel about telling others you had been given this diagnosis?
- How did you feel others reacted when you told them?

The researcher will discuss the context regarding disclosure to others that might include the following: partner, children, wider family, friend(s), colleague(s), employer(s), GP, other healthcare professionals, other service providers such as social welfare providers.

Conclusion

Researcher: Is there anything you would like to add to what you have told me today?

Researcher: Do you have any questions or concerns that you would like to discuss?

Conclusion with thanks and arrangement to check-in post interview as a courtesy.

Appendix 4– University ethical approval letter



Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin

Ollscoil Átha Cliath | The University of Dublin

Teresa McDonagh,
School of Nursing & Midwifery,
Trinity College Dublin,
24 D'Olier St.,
Dublin 2

7th December 2018

Ref: 181005

Title of Study: Experiences of Diagnosis and Disclosure of Borderline Personality Disorder (EDD Study)

Dear Teresa,

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in November 2018. We are pleased to inform you that the above project has ethical approval to proceed.

As a researcher you must ensure that you comply with other relevant regulations, including DATA PROTECTION and HEALTH AND SAFETY.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Prof. Brian O'Connell'.

Prof. Brian O'Connell
Chairperson
Faculty Research Ethics Committee

Appendix 5: Contact list for support services

Support Services for Mental Health

Organisation details	Website	Contact No.
Mental Health Ireland	http://www.mentalhealthireland.ie/	01 284 1166
GROW	https://grow.ie/	1890 474 474
Pieta House	http://www.pieta.ie/	1800 247 247
IACP	https://www.iacp.ie/	01 230 3536
Irish Advocacy Network	http://irishadvocacynetwork.com/wp/	01 872 8684
3Ts	http://www.3ts.ie/	01 213 9905
Mental Health Reform	http://www.mentalhealthreform.ie	01-874 9468

Appendix 6: Letter of Invitation to Participate



dd.mm.yy

Dear

Further to your enquiry yesterday I am writing to formally invite you to participate in the Experiences of Diagnosis and Disclosure of Borderline Personality Disorder (EDD) Study. As you are aware the study aims to build upon the knowledge and understanding of the lived experience of women given a borderline personality disorder (BPD) diagnosis and the disclosure of that diagnosis to others.

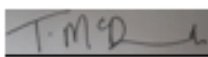
The objectives of the study are as follows:

- Elicit the stories of women who have been given a diagnosis of BPD/EUPD
- Explore the experiences of those women in disclosing their BPD/EUPD diagnosis to others

I would be grateful if you would take some time to consider your possible participation in this study. Participation in the study is entirely voluntary and I have enclosed a participant information leaflet that explains the study process in detail. Having read the information leaflet if you decide to participate in the study please express your interest in participating by emailing the enclosed Expression of Interest form to theeddstudy@gmail.com or by messaging to 087 656 4995. Once I have received your expression of interest I will contact you to arrange a time and location for our interview that is convenient for you.

I appreciate your interest in the study and appreciate you taking the time to read the material provided. Should you require any further information please do not hesitate to contact me by phone or email. I look forward to hearing from you.

Yours sincerely



Tracey McDonagh
School of Nursing and Midwifery
Trinity College Dublin

Appendix 7: Participant Information Leaflet



Participant Information Leaflet

Study Title: Experiences of Diagnosis and Disclosure of Borderline Personality Disorder (EDD) Study

Principle Researcher: Tracey McDonagh, School of Nursing and Midwifery, Trinity College Dublin. I am conducting this study, as part of my PhD, under the supervision of Dr Louise Doyle and Prof. Agnes Higgins.

Study Background: In mental health practice many clinicians persist in labelling complex human distress using the borderline personality disorder (BPD) diagnosis. BPD is widely recognized as a highly stigmatised diagnosis particularly from within the healthcare setting. Diagnosed in a ratio of 3:1 women to men the BPD label marginalizes women who appear not to conform to the norms of society.

Consideration of the issues around the BPD diagnosis, issues of gender imbalance, and continued stigma and discrimination leads the researcher to explore further the experiences of women in receiving a diagnosis of BPD, what that means to them and what it means to disclose that diagnosis to others.

Study Aim: The aim of this narrative study is to explore the experiences of women in receiving a diagnosis of borderline personality disorder and to gain an understanding of the meaning they attach to the diagnosis. The study also aims to explore the experiences of women in disclosing this diagnosis to others.

Study Participation:

You can participate in this study if you are female and:

- you are aged eighteen or over
- you have been given a formal diagnosis of borderline personality disorder / emotionally unstable personality disorder
- this diagnosis was received more than six months ago
- you are fluent in the English language

You are excluded from participating in this study if:

- you are aged under eighteen
- you have never been given a formal diagnosis of borderline personality disorder / emotionally unstable personality disorder
- this diagnosis was received less than six months ago
- you are not fluent in the English language

Study Process: The study will involve in-depth interviews with women who have been given a formal diagnosis of borderline personality disorder / emotionally unstable personality disorder. Interviews will take place at a private location at a time and date that suits you the participant. You will be asked to complete a written consent form prior to the interview. With your permission the interviews will be audio-recorded and later anonymised and transcribed to allow for analysis. A copy of the transcript will be made available to you for comment if you wish. The study findings will be published in academic journals and presented at conference and will also be written up as PhD thesis. You will also be asked following the interview if you would like to complete a short questionnaire that collects personal information (age, gender, sexual orientation, relationship status, educational achievement and occupational status) relevant to your participation in the study. Completing the questionnaire is optional and the information gathered will remain confidential.

Benefits: There are no direct benefits to participating in this study. You may however benefit indirectly in having the opportunity to share your story around being given the diagnosis of BPD and the experience of disclosing that diagnosis to others. You may also value making an important contribution to a research study that aims to represent the stories of women who have been given the BPD label.

Risks: The potential risk to you as a participant in this study is low, however there are some issues you should be aware of. You may find the process of telling your story emotionally stressful and upsetting and difficult memories may be triggered. If this happens you can stop the interview at any time without consequence. The interview

can be recommenced, rescheduled or cancelled according to your preference. You will be provided with contact details of support organisations should you require support following the interview.

Voluntary Participation: Participation in the study is voluntary and is subject to your informed consent as the participant. You maintain the right to withdraw from the study at any time.

Stopping the Study: Please be aware that the researcher may withdraw your participation in the study at any time without your consent. This is intended to ensure your safety and welfare.

Confidentiality: Your identity will remain confidential. Your name will not be published and will not be disclosed to anyone other than myself and my supervisors. A pseudonym will be assigned to each participant and will be used to ensure anonymity. No other identifying details will be published. The researcher will ensure that all documents, recordings, data and related information will be securely stored in a locked filing cabinet in a locked office. Material on computer will be stored securely using password protection / encryption. All data from this study will be handled and stored in accordance with the provisions of the General Data Protection Regulation (GDPR) (EU) 2016/679. The information you provide as a participant will be treated in the strictest of confidence. There are two possible exceptions to maintaining confidentiality:

- where you disclose during interview a risk of serious harm to yourself or others
- where previously undisclosed child abuse is disclosed during interview

In these circumstances the researcher is obliged to act including reporting to the relevant supports and authorities.

Compensation: This study is covered by standard institutional indemnity insurance. Nothing in this document curtails or restricts your rights as a participant. There is no payment for taking part in the study, neither will the study entail any cost to you as a participant.



Permission: This study has the approval of the Research Ethics Committee of the Faculty of Health Sciences at Trinity College Dublin.

Further information: If you require any further information, or clarification, on any matter related to this study, please contact me to discuss same. My contact details are as follows:

Tel. No.: 087 656 4995

Email: theeddstudy@gmail.com

Thank you for your time in reading this information and considering participating in this study. I hope to hear from you and also fully understand if you choose not to participate. If you do wish to proceed please follow the directions on the enclosed expression of interest form.

With thanks and kind regards

Tracey McDonagh

Appendix 8: Expression of Interest Form



EDD STUDY
experiences of diagnosis & disclosure of bpd

Expression of Interest Form

Expression of interest in study participation

Study Title: Experiences of Diagnosis and Disclosure of Borderline Personality Disorder (EDD) Study

In completing the details below you are confirming your interest in taking part in the above named study. Please scan/photograph this form and return by email. When this form is received you will be contacted by the researcher Tracey McDonagh to discuss arrangements for interview.

Name: _____

Address: _____

Tel. No.: _____

Email: _____

You can alternatively express your interest in participating by emailing the above details to me at theeddstudy@gmail.com or by text message, or WhatsApp, to 087 656 4995, once received I will be in touch to discuss arrangements for interview.

Appendix 9: Consent Form



Consent Form

Study Title: Experiences of Diagnosis and Disclosure of Borderline Personality Disorder (EDD) Study

Principle Researcher: Tracey McDonagh, School of Nursing and Midwifery, Trinity College Dublin.

Background: You have been invited to participate in an interview as part of this research study because you are a woman who has been given a formal diagnosis of borderline personality disorder / emotionally unstable personality disorder more than six months ago.

The purpose of the interview is to hear and record your story that relates to receiving that diagnosis and your experience of disclosing that diagnosis to others. I will invite you to tell your story around those experiences in as much detail as you wish to share. The interview will be one-to-one and will last no longer than two hours with an appropriate break. The interview will be audio-recorded and later transcribed and you will be offered a copy of that transcription with the opportunity for feedback. I may ask you to participate in more than one interview, however, this is voluntary and you can choose not to participate. Your identity will remain confidential and the information you provide will be treated in confidence, within the confines of Irish law. All data will be anonymised and published material will not contain any identifiable information. Should you require support following your interview the researcher will provide contact details for relevant support services.

Please read the following and confirm your consent by ticking the box if you agree:

I have read the participant information leaflet for this study	☐
I have had the opportunity to ask questions and have them answered	☐
I understand what is involved if I participate in the study	☐

I understand that I can withdraw at any time from the study without penalty ☐

I understand that the researcher can withdraw me from the study without my consent ☐

I understand that all information collected in this study will be treated as confidential and that my identity will remain confidential ☐

I consent to the use of anonymised quotations from the interviews in publications arising from the research ☐

I understand that data from the research will be stored for five years after the completion of the study and I consent to the publication of the results of this research ☐

I consent to the audio-recording of the interview ☐

I understand that I can have access to my interview transcript if I wish ☐

DECLARATION

I have read, or had read to me, the participant information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

Participant Name: _____

Contact Details: _____

Participant Signature: _____ **Date:** _____

Appendix 10: Indicators of quality narrative research (Andrews, 2021)

<i>Truthfulness</i>	Truth claims are often difficult to make in narrative research. While there are exceptions to this, eg the personal accounts of public figures describing their engagement in well-documented events, generally this is not the case. Nonetheless, the pursuit of truth must be a central driver of scholarship. What is meant here is captured in Bakhtin's description of the word truth: "Truth is not born, nor is it to found, inside the head of an individual person. It is born between people, collectively searching for truth, in the process of their dialogic interaction (Bakhtin 1984, 10). So in this sense, truth is not necessarily verifiable or objective, though it may be one or both of these. To distinguish what is meant here from a claim which can sustain factual scrutiny, I use the term 'truthfulness.'
<i>Trustworthiness</i>	The reader must have a sense that they are in trustworthy hands. Catherine Riessman has used the term 'persuasiveness' in a similar way, arguing that interpretations of data should be "plausible, reasonable, and convincing." This is not achieved by championing uncritical certainty. Rather, "persuasiveness is strengthened when the investigator's theoretical claims are supported with evidence from informants' accounts, negative cases are included, and alternative interpretations considered" (Riessman 2008, 191). This produces a "kind of objectivity suited to the narrative enterprise." (Riessman 2015, 229).
<i>Critical reflexivity</i>	In order for a guide to be considered trustworthy, it is important to know something about who they are. While it is important not to become overly engaged in a personal confessional, scholars should indicate the positioning of their own situated knowledge. This includes some discussion of who one is, and who one is not, in relation to the subject of the investigation. Riessman describes reflexivity as 'a hall of mirrors' and argues that it exposes "the inseparability of observer, observation, and interpretation." (2015, 221) Acknowledgment of situatedness of knowledge challenges some of the dogma of more traditional research methods such as the concepts of reliability and universalizability.
<i>Scholarship and Accessibility</i>	Research outputs should be both scholarly and accessible. This can be a difficult balance to strike. While it is important to demonstrate theoretical engagement, this should not be at the expense of being understandable. Part of this is a question of audience: who does one see oneself writing to? What is the purpose of the research? If, for instance, research participants are not able to understand what is being written about them, then at the very least this disjuncture needs to be acknowledged and addressed.
<i>Ethical sensitivity</i>	Although most scholarship proceeds only with the ethical clearance of universities, often the concerns which are identified are rather circumscribed, eg focusing on data storage, anonymisation, etc. Yet questions of the negotiation of power permeate all stages of the research, from research design to data gathering and analysis to publication.