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A "fireball of emotion": a qualitative case study exploring the experiences of crisis and crisis intervention for people diagnosed with "borderline personality disorder", their family and friends, and professionals who work with them.

WARRENDER, D.R.

2024

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A “fireball of emotion”: a qualitative case study exploring the experiences of crisis and crisis intervention for people diagnosed with ‘borderline personality disorder’, their family and friends, and professionals who work with them.

Daniel Ross Warrender

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Abstract

Author: Daniel Ross Warrender

Submission Degree: Doctor of Philosophy

Title: A fireball of emotion: a qualitative case study exploring the experiences of crisis and crisis intervention for people diagnosed with 'borderline personality disorder' (BPD), their family and friends, and professionals who work with them

Aim: To explore the perspectives of people diagnosed with 'BPD' and relevant stakeholders regarding experiences of crisis and subsequent crisis intervention.

Background: Crisis and the use of crisis intervention is described as frequent for people diagnosed with 'BPD', though as yet the quality of evidence is described as poor, and often people are offered standard care with no clear model of intervention. 'Borderline personality disorder' is recognised as a stigmatised diagnosis and experiences of poor care during crisis are not uncommon. This study sought to capture a depth of experience, and to begin to chart a path towards improved care.

Design and Methodology: The study was of qualitative design, adopting a case study approach to explore crisis intervention from the perspective of service users, family and friends, and professionals. Data was collected through interviews with people diagnosed with 'BPD', their family and friends, and professionals who work with them. Semi-structured interviews utilised a topic guide to remain consistent with study objectives. A thematic analysis was constructed using constant comparison.

Main Findings: Six cases included six people diagnosed with 'BPD', four family and friends, and six professionals. Data analysis saw the construction of five themes; crisis as a multidimensional experience, entering a confused and anxious system, acts and omissions which lead to harm, the complex simplicity of helping people in crisis, and building a better service. The 'BPD' label contributed to stigma and discrimination and often negatively impacted on the care people received. A concept map was developed to capture the possible journey through crisis and crisis intervention and its complex influences.

Conclusions: This study offers a depth of understanding the crisis and crisis intervention experiences of people diagnosed with 'BPD', their families, and professionals who work with them. Crisis is a multidimensional experience with unique triggers, manifestation and coping mechanisms. Access to care is a challenge and people diagnosed with 'BPD' often enter a confused and anxious system where there is no clear model of intervention and

poor interagency working. Where there were good experiences, these centered around quality relationships where people diagnosed with 'BPD' are treated as people, and the professionals working with them are authentic. Recommendations are offered which may influence future service design.

Keywords and Phrases:

Borderline personality disorder, emotionally unstable personality disorder, personality disorder, crisis intervention, risk, self-harm, suicide, therapeutic relationship, stigma, iatrogenic harm.

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Abbreviations:

BPD	Borderline personality Disorder
CMHN	Community Mental Health Nurse
DSM	Diagnostic and Statistical Manual
EoSRES	East of Scotland Research Ethics Service
EUPD	Emotionally Unstable personality Disorder
ICD	International Classification of Disease
MBT	Mentalization Based Treatment
NICE	National Institute of Clinical Excellence
PdxBPD	<i>Interchangeably this is:</i> <ul style="list-style-type: none"> • People diagnosed with ‘borderline personality disorder’ • Person diagnosed with ‘borderline personality disorder’
RITB	Recovery in the Bin
SERP	School Ethics Review panel
WHO	World Health Organisation

1. Chapter 1: Introduction

1.1. Introduction to the introduction

Welcome to my thesis. Whilst perhaps a little informal for an introductory sentence, it nonetheless feels important to write. For so long it had felt as if I was constructing a thesis, not *my* thesis. Yet, on the home stretch, I found the confidence to bring myself into my writing in a much more honest and explicit way. It is for better or for worse, unashamedly mine.

This introductory chapter does its best to give a very brief account of ‘borderline personality disorder’ and crisis intervention prior to a detailed literature review in chapter 2, and provide some justification for why I chose to research this topic. Then, the bulk of the chapter acknowledges who I am and my place in the study, given that I am a key part of this research, and I cannot escape myself. Finally, there is a summary of chapters which form the thesis.

1.2. ‘Borderline personality disorder’ and crisis intervention

1.2.1. Personality and ‘personality disorder’

‘Personality’ is a term used to describe a person’s enduring or stable character (Pilgrim 2020), with a person’s distinctive characteristics consistently manifesting themselves across different situations (McMartin 2017). These characteristics then impact on how people behave and experience life, and how they interpret themselves, others and encountered situations (World Health Organisation (WHO) 2024). The dominant understanding of personality is the five-factor model (Costa and Macrae 1992) which consists of five broad domains: neuroticism, extraversion, openness, agreeableness and conscientiousness. Individuals are argued to have a personality which consists of unique combinations of these traits. This model has general consensus within psychology (Pilgrim 2020), is supported by empirical evidence (McCrae and Costa 2008) and personality disorder symptoms are accounted for within it (Widiger and Costa 2012). Personality disorder is characterized by an extended period of difficulties within the self and in relationships with others, and manifests through patterns of cognition, emotion and behaviour which are associated with significant distress (WHO 2024).

1.2.2. ‘Borderline personality disorder’

‘Borderline personality disorder’ first appeared as a psychiatric diagnosis in 1980, in the third edition of the diagnostic and statistical manual for mental disorders (DSM) (American Psychiatric Association 1980). The term ‘borderline’ can mislead into thinking people

‘almost’ meet criteria for a full diagnosis, however this is not the case. Adolph Stern proposed the term ‘borderline personality’ in 1938 to describe people who did not fit neatly into categories of neurosis or psychosis, and the term ‘borderline’ relates to bordering on other conditions (NICE 2009). ‘Borderline personality’ was thus placed between neuroses and schizophrenic disorders (Leichsenring et al 2024), rather than symptoms bordering on the edge of a full ‘personality disorder’ diagnosis. The symptoms of ‘BPD’ include an instability in interpersonal relationships, emotional dysregulation, unstable sense of self, and an impulsivity which can result in self-damaging behaviour including self-harm and suicide (WHO 2024).

1.2.2.1. The shifting sands of ‘borderline’ and ‘personality disorder’

Over the last few years ‘BPD’ and ‘personality disorder’ have underwent significant discussion which have led to a degree of change in their conceptualization, and may contribute to some understandable confusion. Two separate sets of diagnostic criteria, the diagnostic and statistical manual for mental disorders (DSM) and the international classification of disease (ICD), each reference ‘BPD’ though have now competing philosophies, the DSM having categories of personality disorder, and the most recent ICD advocating for a spectrum of severity for ‘personality disorder’, with domain traits offered to aid description.

The DSM has utilized the ‘BPD’ term in all versions since 1980, and continues to use the categorical model of ten different ‘personality disorders’, which are distinct from one another. The ICD-10 (WHO 1992) used the term ‘emotionally unstable personality disorder’, which separated into two variants of ‘impulsive’ and ‘borderline’ types, though these two variants each shared the theme of impulsivity and a lack of self-control, and were captured within the DSM’s broader term of ‘BPD’ (NICE 2007). The NICE (2009) guidelines for ‘BPD’ acknowledged they would also cover ‘EUPD’.

As per the ICD-11 (WHO 2024), the term ‘emotionally unstable personality disorder’ no longer exists. Alongside a spectrum of mild, moderate and severe personality disorder, there are now trait qualifiers (negative affectivity / detachment / dissociality / disinhibition / anankastia). Along with ‘EUPD’, the term ‘BPD’ was no longer to exist, however last-minute lobbying led to the retention of ‘BPD’ as an additional trait qualifier (Watts 2024). Some have argued it is no longer necessary as symptoms would map onto ‘personality disorder’ with traits of negative affectivity, dissociality and disinhibition (Mulder, Horwood and Tyrer 2020) and that the inclusion of ‘BPD’ may lead to a variation in the approach to diagnosis (Tyrer 2022). The ICD-11 itself acknowledges ‘borderline pattern’ is not necessary for

description, though remains through pragmatism, in order to link individuals to particular psychotherapeutic treatments which are evidence based for 'BPD' (WHO 2024).

Whilst I have opted to use the term 'BPD' throughout this study, participants also use 'EUPD' given their interchangeable use in clinical practice. Appreciating how confusing these terms and changes can be, full details of the current DSM-5 and ICD-11 diagnostic criteria are presented in the appendix (Appendix 8.1).

1.2.3. Aetiology and epidemiology

There are indications of a genetic vulnerability for 'BPD' symptoms, though research has been described as limited and having significant discrepancies (Braga et al 2015).

Furthermore, it has been argued the importance of genes in developing 'BPD' symptoms is much less when people have been through significant life events (Distel et al 2011). People diagnosed with 'borderline personality disorder' (PdxBPD) have shown a higher incidence of childhood sexual abuse and adverse childhood experiences than other psychiatric diagnoses and non-clinical control groups (McFetridge et al 2015, Porter et al, 2019).

The prevalence of 'BPD' in western countries ranges from 0.7% to 5.9% (Warrender et al 2021), though it has been argued there are difficulties obtaining accurate personality assessments in national surveys for 'personality disorders' opposed to other diagnoses (Tyrer, Reed and Crawford 2015). Difficulties are described to have a typical onset during adolescence, from around 12 years of age (Bohus et al 2021), and difficulties are described as having a late onset if diagnosed after the age of 25 (ICD-11). Though the prognosis is that recovery can be difficult to attain, once attained it can remain stable (Zanarini et al 2010), however there is a paucity of literature related to older adults and arguments that new diagnostic instruments need to be developed (Beatson et al 2016) as symptoms may present differently in older populations (D'Agostino, Pepi and Starcevic 2022).

There are estimates that 75% people diagnosed with 'BPD' are women (Bateman and Krawitz 2013), with one psychiatric outpatient sample showing 72% women and 28% men having the diagnosis (Zimmerman and Becker 2023). However, there are questions whether figures are influenced by sampling bias or diagnostic bias, and that true prevalence by gender may be unknown (Skodol and Bender 2003). It is also argued that men may be more likely to be in the criminal justice system or engaged with substance use services, or even diagnosed with antisocial personality disorder (Bateman and Krawitz 2013). There is a gap in literature around ethnic diversity, though there are indications ethnic minorities may be under-represented by the diagnosis (Lamph et al 2023). Complex reasons for this may include alternative service use, under-detection through diagnosis, or

a truly lower prevalence of difficulties (Hossain et al 2018). People may also be disadvantaged socially compared to the general population, with PdxBPD describing poor social support, often having more conflict in relationships, and less connection with people important to them (Beeney et al 2018). It has been estimated that 60-70% of the prison population would meet criteria for ‘personality disorder’ (National Offender Management Service 2015), and these diagnoses are more common among people experiencing homelessness than they are in the general population (Dell et al 2023).

There are significant issues with comorbidities, with ‘BPD’ unlikely to be a person’s sole diagnosis (NICE 2009). Bateman and Krawitz (2013) cite an extensive list of several known comorbidities including avoidant personality disorder, dependent personality disorder, paranoid personality disorder, antisocial personality disorder, major depressive disorder, dysthymic disorder, generalized anxiety disorder, panic disorder, agoraphobia, social phobia, post-traumatic stress disorder, obsessive compulsive disorder, alcohol and other substance dependence or use, bulimia, eating disorders, dissociation and attention deficit hyperactivity disorder. Difficulties in emotional regulation, interpersonal relationships and understanding others has also seen a suggestion of overlap with autistic spectrum conditions (Dudas et al 2017, May et al 2021), and there are shared characteristics with complex post-traumatic stress disorder (CPTSD) (Hyland et al, 2019).

1.2.4. Hotly contested debates

Despite the ‘BPD’ diagnosis being given legitimacy through inclusion in diagnostic manuals, there have been long standing and widespread opposition to the diagnosis and calls for it to be abandoned (Lewis and Appelby 1988, Langley and Price 2022). In one example, the cover of a popular issue of *Asylum* from 2004 reframed the acronym of ‘BPD’ as Bullshit Psychiatric Diagnosis, dedicating the entire edition to critiques of its validity and the harm it causes to people (Asylum 2004). Even psychiatrists specialising in the field of ‘personality disorder’ have written articles on ‘BPD’ stating “it has no right to exist” (Tyrer 2022, p.254), describing it as “a spurious condition unsupported by science that should be abandoned” (Mulder and Tyrer 2023). I justify why I have continued to use the term later in this chapter (see 1.3.7 ‘critique of the ‘personality disorder’ diagnosis’).

Diagnostic criteria require behaviour to be different from the expectations of culture (APA, 2013), and this has led to a critique of ‘BPD’ as not necessarily clinical pathology but a cultural disapproval of behaviour (Nyquist Potter, 2009). Furthermore, given that most people diagnosed are female, it has been argued that female behaviour viewed as deviant and difficult is labelled with ‘BPD’, in the same way as women’s behaviour was historically

viewed as witchcraft or hysteria (Shaw and Proctor, 2005, Ussher, 2013). Kendell (2002) argued it was impossible to conclude with confidence whether ‘personality disorder’ should be defined as a mental illness.

‘Recovery in the Bin’ (RITB), a collective of critical theorists and activists, aim to be neutral on diagnosis and support people to self-define however they choose if that helps them live (RITB 2024). However, they make a special exception for ‘BPD’, and officially oppose the diagnosis based on the harms it can cause. In an updated position statement they argue the diagnosis is misogynistic in being used against women, transgender and non-binary people who have experienced trauma, punitive in being given to people who “fail to ‘recover’” or respond to medication, and exclusionary in being used as an excuse to discharge or exclude people from care (RITB 2024). As Harding (2020, p.e25) writes, “the voice of those who want the term personality disorder eradicated is loud; the voice of those insisting that their own personalities are disordered is inaudible”. Prince and Ellis (2020, p.108) acknowledge, “to work in the field of personality disorder is to be all too aware of the debates and hotly contested discussions about the diagnosis”.

1.2.5. A stigmatized label

‘Borderline personality disorder’ has been argued to be the worst diagnosis for professional stigma (RITB 2019) and research has shown people working in mental health settings have more negative attitudes towards ‘BPD’ than they do other diagnoses (McKenzie, Gregory and Hogg 2022). As far back as 1988, a seminal paper titled ‘Personality Disorder: the Patients Psychiatrists Dislike’ (Lewis and Appelby 1988, p.44) explored psychiatrist attitudes and found people with these diagnoses were seen as “more difficult and less deserving of care” than other patient groups, and mental health nurses have also been found to often have negative attitudes towards people with the diagnosis (Dickens, Schoultz and Hallett 2022). People have unhelpfully been labelled as troublemakers, attention seekers, difficult, manipulative, dangerous, annoying and even “pains in the ass” (Lewis and Appelby 1988, Potter 2009 p.4, Sulzer 2015, MWC 2018).

1.2.6. Crisis and crisis intervention

These hotly contested debates and stigmatized label form part of the context around what can happen during crisis and crisis intervention, and it is important to remember that inside this context are human beings experiencing significant distress trying to get help. Crisis for PdxBPD is a recurrent, unpredictable, subjective, multidimensional and overwhelming experience, which often involves emotional dysregulation and can result in self-harm and attempted suicide. The National Confidential Inquiry into Suicide and Safety in Mental

Health (2023), collecting data from 2010 to 2020, found that suicides for people diagnosed with personality disorder in the UK are increasing, particularly for young women. There are several public accounts of PdxBPD dying by suicide, with failures in care and missed opportunities to help them (De La Mare 2023, BBC News 2020, Shepka 2020, BBC News 2022, Dick 2022, Mullen and Hirst 2023, Inquest 2023, Cuddeford 2023).

The evidence base for any particular crisis intervention for PdxBPD is poor. Crisis intervention is often in response to attempted suicide, and defined as “an immediate response by one or more individuals to the acute distress experienced by another individual, which is designed to ensure safety and recovery and lasts no longer than one month” (Borschmann et al 2012 p.2). Cochrane reviews exploring crisis interventions for ‘BPD’ in both 2012 and 2022 each found that the evidence base was limited, with no clear difference between any crisis intervention and usual treatment (Borschmann et al. 2012, Monk-Cunliffe et al 2022). DeLeo et al’s (2022) review found a lack of psychosocial interventions in crisis settings. Furthermore crisis-focused psychosocial interventions have been found wanting in terms of evidence base, with no consensus on outcome measures, and insufficient data to recommend any specific crisis-focused psychosocial intervention (Wood and Newlove 2022).

The National Institute of Clinical Excellence (NICE) (2009) have guidelines for the care of PdxBPD, and state that crisis care should assess risk, explore reasons for distress, empathise, explore options and consider referral to crisis unit or inpatient admission. However, reports of poor care are not rare. UK wide, there has been widespread recognition that the needs of people with all ‘personality disorder’ diagnoses are often unmet; being rejected by services, not being understood in their contexts which often include past trauma, a lack of early intervention and variable access to evidence based treatments (Mind 2018). A consensus statement was endorsed by, amongst others, the Royal College of Nursing, the Royal College of General Practitioners, the British Association of Social Workers and the British Psychological Society (Mind 2018).

1.2.7. Summarising the issue

Attempting to briefly capture the above, if I was asked to outline the topic and why it is important to a lay person, I’d likely say:

“‘Borderline personality disorder’ is a really controversial diagnosis and there is a lot of disagreement about it, but ultimately it describes a group of people who have often experienced traumatic events and can struggle with overwhelming emotions. Sometimes they self-harm and try to kill themselves. Mental health interventions sometimes help, but

sometimes make it worse. We need to understand people's in-depth experiences so we can try and improve the care people receive".

1.3. "Doing a Dan Warrender": my undeniable position in the study

As I crafted my thesis, I felt it was important to see where I have come from, and to recognize the knowledge, experiences and networks which have shaped the lens I now look through. Thomas (2021, p.73) describes researchers as having an "undeniable position" which influences all observations and interpretations they make, and advocates for this to be clearly articulated in the introduction to any case study research, stating that readers need to know "who you are and where you stand". This has ultimately become the story of my mental health nursing career and relationship with the topic to date, and this narrative has felt like the most appropriate way of approaching it and organizing my thinking. It has also become a rather self-indulgent curation of my public outputs on the topic.

1.3.1. A very brief history of me

I had a great start in life. My parents loved me, provided for me and cared for me, and they still do. I recognize this reflects a privilege which many do not have, and I am very aware of how lucky I am when I have heard very different stories from others. I am a heterosexual white Scottish man, and whilst I don't wish to apologise for my existence (because I had no part in the decision!), I acknowledge I may be lucky in that living in the UK, my demographic may not find itself obviously marginalized or oppressed as others may be. Whilst we should never make sweeping generalisations based on group, and there is a huge nuance to this, I can confidently say that I have been very fortunate.

On top of a seemingly innate low self-esteem, I was bullied at school and felt the sting of ostracism, and had difficulties with self-confidence. Sometimes I fantasised about being dead, but I took no steps to actively end my life. Nonetheless I did have some good friendships and relationships during my school years, and along with love from my parents, I grew up having a sense of my own value. After an MA philosophy which I completed in 2004, and soul searching after a broken heart and the end of a first love, I spent 6 months in Luton, and Kudus, in Central Java in Indonesia with voluntary services overseas. It was my first foray into projects which directly supported people, and the first time I began to understand the value of human relationships. I came home spiritually moved, and desperate for a meaningful existence. I worked for 4 years as a support worker for people with learning disabilities and loved it, then my Mum, a dual registered mental health and general nurse herself, encouraged me to explore mental health nursing as a career option. My Dad, a joiner, had long before said I shouldn't do what he did.

1.3.2. My mental health nurse education and the mess of crisis

During my undergraduate training as a mental health nurse, I recall an hour of didactic power-point teaching on personality disorders, a term I'm not sure I'd ever heard before. Memory recalls the room, the lecturer, but little of the content. There were words on a screen, but at that point in time, I had little understanding of what they meant, or of what the topic would come to mean to me over time. I had placements in an acute mental health ward in each of the three years of my training. These placements were around 12 weeks duration, so not long in a way. However, as extremely intense and unpredictable environments, it was always long enough to get a sense of it all. These wards were akin to emergency departments for mental health problems, with a huge variety of people and issues to work with, and no telling what was coming next. I quickly realized that a large number of people being admitted, often following attempted suicide or self-harm, were diagnosed with 'borderline personality disorder'. These admissions were described as 'crisis admissions'.

Unfortunately, these crises did not end immediately upon admission to hospital. Crisis was something which would continue and recur, not immediately solved by the 'safety' of an acute ward. Often patients would continue to attempt suicide and self-harm, but were then met with frustration rather than empathy. I was told by experienced nurses responding to self-harm, to "tend to the physical care, but don't make a big deal about it because it'll just encourage them to do it more. It's just attention seeking". Was this just a 'bad' nurse, or just ritual, with them regurgitating what they'd been told by someone before them? The truth may lay somewhere in between. This approach never sat well with me, as someone cutting themselves always felt like a big deal, but it was hard to stand alone and be doing something different to the herd, especially when you are being assessed and on the weak end of a power dynamic. I felt a discord with my values, and struggled to understand why people's distress was met with dismissiveness and frustration rather than compassion. I wonder if this may have been influenced by what was my luxury as a student, to have a brief placement with an end in sight, rather than seemingly infinite employment in what can feel like healthcare trenches (Warrender 2015). This sense of feeling trapped may have influenced the feelings of the registered nurses around me.

I now understand that while mental health care should be aimed at helping, if we can't help as we would like, as human beings we can quickly become frustrated. Johnstone (1989) described the 'rescue game', where psychiatric systems try to help people in distress, though when rescuing does not work, the approach can shift to that of persecution and

punishment. This echoes what I saw on acute wards, as relationships were fractured, roles blurred, and 'care' was most definitely compromised. Staff who initially wanted to help, became frustrated at patients who did not seem to benefit from their expertise, and staff helplessness quickly turned into something sour. Instead of looking at what we as a team could perhaps do differently, the 'blame' was placed at the foot of the patient. Despite anything we did, they 'refused' to get better. Notions of patient un-treatability were more comforting than the idea that staff and systems may require to take alternative approaches. It is often easier to project blame outwards rather than looking in.

As crisis was often recurrent and ongoing, and not solved by admission alone, there were patients who were admitted frequently, and some who spent very lengthy spells in hospital. I recall a patient admitted for an initial crisis admission in my 2nd year placement, who was still in hospital two years after I had qualified. A definition of crisis intervention states it is "an immediate response by one or more individuals to the acute distress experienced by another individual, which is designed to ensure safety and recovery and lasts no longer than one month" (Borschmann et al., 2012, p. 2). This individual ended up in hospital for four years. I now understand this to be something different than a crisis intervention, and for want of a better word, I can think of it as nothing more than a mess. It was a mess for the person diagnosed with 'BPD' who often felt in crisis and was met with frustration and disdain, it was a mess for the staff team who felt in a parallel crisis, wanting to rescue the patient, but angry that they 'refused' to be rescued.

1.3.3. Registered mental health nurse and failing to care for a stigmatized group of patients

When I completed my training in 2011, I went with what I knew, and accepted a job in acute mental health. I began my post as staff nurse in another but entirely similar ward, next door in fact to where I had been a student, and similar circumstances were experiences with a difference in role. My first six months as a registered mental health nurse (RMN), I felt the sting of accountability, as I attempted to manage risk with people who seemingly wanted help, but also 'resisted'. I recall a young girl who would frequently threaten suicide and run away from the ward, as I spent many minutes on the phone to police reporting her missing, and many hours hoping she was not dead. I was terrified and out of my depth. I remember approaching her bedside, to see what looked like a corpse, motionless, unresponsive with a dressing gown cord around her neck, and the few eternal seconds where I was sure she had died by suicide. In the end she was physically unharmed, but was clearly communicating a level of psychological distress she otherwise struggled to articulate, and

we struggled to understand. I recall the stress, the worry, the feeling of inadequacy as despite my best intentions I could not rescue her.

I know that the more I felt inadequate, the easier it was to blame her for not getting better. These experiences, shared by colleagues and I, have led to a common stereotype of the diagnosis, which was one of a 'difficult, time wasting, attention seeking' person. I remember 7am starts and handovers which would describe a person diagnosed with 'BPD' having been admitted during the night, having taken an overdose. Where we should as a caring profession expect compassion, it was disappointing to routinely hear the entire room of staff release an audible collective sigh (Warrender 2018a). This was a person who had tried to kill themselves, whom none of us had even met yet, and there was not even a micro-dose of compassion or warmth in the air. The label had such power, and the words "I think they've got a personality disorder" at times seemed synonymous with "I don't like them". There is something wrong with this narrative, which still interests (and haunts) me today, 10 years since I left that environment.

1.3.4. MSc Nursing and Mentalization

In 2012, after a competitive process I gained a place on the early clinical careers fellowship, and began a funded MSc in nursing. I knew immediately that my thesis would be around 'BPD', and made networks with our local psychotherapy department, where the head at the time introduced me to mentalization based therapy (MBT). Partly driven by my interest, and partly very fortunate timing, the psychotherapy department offered MBT Skills Training (not a full therapy training, but a grounding in basic principles). This was a revelation for me, as a basic understanding of attachment theory, how childhood relationships impacted on later relationships, and how our mentalizing (our understanding of our own and other peoples mental states) could explain many of the symptoms of 'BPD' and also many of the difficulties experienced by staff. The mess as I described earlier, could often be put down to a series of misunderstandings. People's perspectives were not understood, and their needs were not met. Furthermore, staff teams can stop mentalizing and empathizing as much, if not more than patients do (Warrender 2019). The term "just behaviour" often uttered by staff teams is a ludicrous one, and one which causes me to feel some personal embarrassment, being part of a profession which loves to champion itself as a collection of 'highly educated and skilled professionals', yet so often fails to deliver. Once you understand that behaviour is all based on mental states, behaviour always means something, and it should never be dismissed or belittled.

Following a grounding in MBT, I worked on the ward with a woman diagnosed with 'BPD' who frequently self-harmed. This was the first time I remember very deliberately sharing my mental state with a patient, and telling her I felt overwhelmed, and that I was worried about doing the wrong thing for her. She felt overwhelmed too, and was struggling to control her emotions and impulses to harm herself. We shared a moment as humans, and began to form a genuine and trusting therapeutic relationship. Things did not immediately get easy, but each instance of self-harm or attempted suicide we approached with care, compassion and curiosity. She recovered to the point of discharge, and gave me a card as she left. Inside, words which stuck with me, and are to this day are the root of how I work with all people, and how I teach and support student nurses; "I always felt like you cared". Being curious, caring and sharing responsibility rather than having all the answers or being able to fix it, was the invaluable grounding the MBT skills gave me, pulling me from feeling like an 'inadequate expert', into a 'caring and trying human being'. More recently, I worked with someone for two years who ended with the feedback; "I always felt I was talking to you, not the NHS". I am now a devout believer in the value of humanism, and this road travelled began with MBT. My MSc topic, which I researched and then published, was also around staff nurse experiences of using MBT skills in acute mental health when working with people diagnosed with 'BPD' (Warrender, 2015). It didn't fix anything, but it did give staff a useful model through which they could empathise and respond to mental states, rather than simply 'manage behaviour'.

1.3.5. Becoming a lecturer in Mental Health Nursing and confronting the theory-practice gap

As I shared this research at conferences throughout 2014, and thought about publication, I became aware of an opportunity to become a lecturer in mental health nursing. Whilst I was reluctant to leave clinical practice after only three years, I was partly driven by a desire to 'fish upstream', and give students the knowledge and understanding I didn't have when I qualified. I took the job. I brought attachment theory, mentalization and trauma-informed care into our undergraduate programs, and co-developed and evaluated innovative teaching on 'personality disorders' (Warrender and Macpherson 2018). The topics of 'BPD', attachment and trauma have never been far from my lips as I have always sought opportunities to emphasise their importance. This has gained me a reputation with some within local NHS services as an idealist, with fellow mental health nurses (even some of the people I trained with) turning me into a pariah, arguing that I make their job harder by asking for high standards of care. One student was explicitly sat down by a staff nurse, and told he should "stop trying to do a Dan Warrender with every patient", an instance which I

subsequently explored in an editorial (Warrender 2022a). This incident emphasises a need for a genuine bridge between academia and clinical practice, with development of good clinical-academic roles a necessity. I'm still a mental health nurse, though there is clear evidence of an 'us and them' mentality between academia and practice. This dichotomy between theory and practice in no way helps people diagnosed with 'BPD', and despite what is taught in university, the same patterns of poor care seem to repeat in practice.

As a lecturer, I also maintained an honorary contract with the NHS and the psychotherapy department up until the end of 2022. Though my clinical practice was limited to one person at a time, working as a mentalization based therapist helping PdxBPD understand themselves and others, I collected stories of how people experienced crisis care. Also, as a clinical supervisor to some experienced and some newly qualified nurses across healthcare environments, as well as hearing from students who are my eyes and ears across the health service, I still often hear of stigma, misunderstanding and patients met with dismissive or punitive responses. Having a twitter profile and many connections who have the diagnosis, I hear echoes of poor care which are perhaps not the norm, but certainly far from rare. If I was to hazard a guess, I think the possibility of receiving quality care may be 50/50. Luck seems to be a factor.

1.3.6. Meeting and thinking about *people*

Developing an academic profile, I have published, blogged, presented and spoken, and connected with all stakeholders; people with the diagnosis, people who support them, and health and social care workers involved in all aspects of care. I have had communications from people all over the world based on my academic outputs, I have absorbed every conversation, and I am in no doubt that the academic role has expanded my thinking, exposed me to different ideas and made me a better nurse. When I connect with people diagnosed with 'BPD' as a lecturer, there isn't the same power imbalance, and we can meet for coffee rather than for 'treatment' or 'intervention'. As I remarked at an invited lecture for Abertay University in August 2022, working in the ward "there were people with BPD and often self-harm and suicidality". Working as an academic, "I met a person, and often there was coffee". Meeting people in a different way, and being immersed in the topic, I have met many people at conferences and events, and now count some people with the 'BPD' diagnosis as my friends. I need to acknowledge that this has brought me closer to poor care, and in a different way. I am not 'once removed' from it as I might have been, operating in a purely professional capacity.

However all stakeholders are human beings, and each has their own story. People with the diagnosis have often experienced adversity and desperately struggle to live inside their own skin, people who support them experience the distress of seeing a loved one suffer, the panic of wondering how safe their loved one is, and the defeated impotence of not knowing how they can help. Likewise, I know that health and social care workers are human. They too (as I did) feel the very real worry, anxiety, stress, anger and frustration that comes with working with distressed people, with complex stories and complex ways of managing their emotions and relationships. However, as health and social care staff are ‘workers’ and ‘professionals’, I always hold us to a higher standard. In paid roles supporting people, we need to reflect, learn, grow and be better. If we are feeling angry or dismissive of people in distress, we need to catch that, make sense of it, and not let it impact on care delivery. Otherwise, we have no right to call ourselves ‘highly skilled professionals’. Not only should we provide quality care based on key values, but it is also literally the job we are paid to do. To not offer what you say you will, is at best fraudulent.

1.3.7. Critique of the ‘personality disorder’ diagnosis

As well as my opinions on how care is delivered, I’m aware of the importance of my perspective on how we understand ‘BPD’ and the difficulties associated with it. I’ve actively used inverted commas around ‘borderline personality disorder’ since the British and Irish Group for the study of personality disorders (BIGSPD) conference in Inverness in 2018, where I watched clinical psychologist Lucy Johnstone robustly and convincingly challenge the legitimacy of the diagnosis. I’ve since learned about movements such as ‘PD’ in the bin (2016), A disorder for everyone (2019/2023), trauma informed care (Sweeney et al 2018), and the power threat meaning framework (Johnstone et al 2018), an alternative to all psychiatric diagnosis. I am now sceptical of any notions of ‘BPD’ as a medicalized disorder that someone *has*, and understand the associated symptoms and distress as a result of childhood adversity, trauma and neglect. I feel we should all be understanding people as having been hurt by the world and adapting to their environments and experiences, rather than people being ‘difficult’ due to disordered personalities. I have said as much to people I have worked with in therapy, and until recently I had maintained an honorary contract with the NHS holding a caseload of one person at a time, and now I do the same privately. I want to work in a person-centred way, yet I still inhabit a system and culture which requires and emphasises the need for diagnosis. When writing letters to GPs or other professionals, I have used the diagnosis, though I make sure the person I am working with knows that I see beyond the label. I see them as human beings. It may seem

bizarre to be doing research on 'BPD' when I have little faith in it as a valid social construct. My reasons for using the term in research is that people still have the label, and the label can influence the way they feel about themselves, and the care they receive. The diagnosis itself has a tangible power which needs to be understood, as it is a very real influence on people's access to and experience of care.

Despite being aware of these diagnostic debates, I still know people who are grateful for the diagnosis as they feel it has given them hope, connected them with other people with similar difficulties and allowed them to access appropriate long-term treatment. In my opinion, the value of the diagnosis is most simply that it affords access to psychological therapy which is otherwise out of reach (and we might argue that a different label could do the same thing equally well). However, I have never heard of anyone being grateful for the diagnosis in terms of their access and experiences of crisis care, and in fact quite the opposite. The literature review which underpins this PhD study found that in terms of crisis care, as people had such different experiences, the diagnosis was not particularly useful, and that the label could carry a degree of stigma which had negative impacts on care (Warrender et al 2021).

1.3.8. Using networks and trying to make a difference

As I have developed a local and national profile of expertise in this area of study, which whilst incredibly validating as a human being, also means that I can be a victim of my own success. I was contacted by NHS staff on 2nd April 2021, asking for input into training materials, who led their approach by describing me as "a local academic whose name is synonymous with good practice around personality disorders". Whilst this is unusually flattering, what is not unusual is a request for my input and perspective. It is often difficult to refuse, because I think the things I advocate are simple, yet often different to mainstream approaches. I strongly encourage empathy, curiosity and remembering what people have been through. These shifts in thinking could positively influence peoples care. My sharing knowledge is not based in ego, rather in altruism. Whilst refusing is difficult, I do recognize I need to manage my time appropriately, as I wonder if I might have progressed more swiftly with my PhD study. The mission to improve the care of people with the 'BPD' diagnosis may in some small way be forwarded by this study, though a lifetime of work remains, waiting for me on completion of this PhD.

Since 2012 I have worked with NHS Grampian, The Royal College of Psychiatrists Scotland, the Scottish Personality Disorders Network, the British and Irish Group for the Study of personality Disorders, as well as publishing research and discussion papers, and delivering

conference presentations on this topic. I was external examiner 2019-2023 for an MSc personality disorder for the University of Central Lancashire, and working privately I have facilitated training to several 3rd sector organisations on ‘personality disorder’. I have found there is a thirst for knowledge in this area, as feeling out of one’s depth is not rare.

1.3.9. The Action/Consequences Model: making a real-life impact?

My model for ethical decision making (Warrender 2018b), which I constructed based on observing iatrogenic harm through the lack of clarity and consistency in crisis care, was included in both NHS Grampian (2019) and Royal College of Psychiatrists Scotland’s (2018) documents on ‘personality disorder’. I have since learned of teams in both Greater Glasgow and Clyde, and Cornwall, using the model to aid complex case discussions. This suggests that people feel the benefit of thinking in this area, and I feel this is where I can contribute. Essentially the model prompts thinking, not being a ‘how to’, but a conceptual model of what might happen if you contain risk, and what might happen if you tolerate risk. I have since updated the model in a poster and book chapter in press, framing the model as encouraging thinking and aiding decision making in this ethical minefield, as decisions regarding risk are complex, and even with the best of intentions healthcare can harm.

The Action/Consequences Model (Warrender 2018b, Warrender 2023a, Warrender and Young 2024).

Actions	Potential consequences				
	<i>Benefits</i>	<i>Dangers</i>	<i>Short term</i>	<i>Long term</i>	<i>Interpretation of motive</i>
Containing risk	Service user safety	Retraumatisation Disempowerment	Service user safety MH Nurse comfort	MH Nurse Comfort Creating dependence Alienation Evolution of risk	Care and compassion Punitive control
Tolerating risk	Service user autonomy	Retraumatisation Invalidation MH Nurse complacency Significant and lasting harm	Short term risk MH Nurse anxiety	MH Nurse Anxiety Opportunity for service user to develop own coping mechanisms	Neglect Trust and freedom

In the most recent publication (Warrender and Young, In Press), I used an analogy to describe how containing risk does not eliminate risk, and can in fact make it worse, creating a ‘mess’. Risk is not extinguished by containment such as mental health acts, hospital admission and observation (though they may have a place), but may be better alleviated by more relational approaches, focusing on compassion and emotional distress rather than simply preventing behaviour:

“Using an analogy, if you hold a piece of jelly in your hand, close your hand and try to contain it more and more, no matter how hard you press, it will gradually flow outside your hand and through your fingers. In the same way, if a person is distressed and contained more and more, removal of means and method may simply force a person to reconsider means and method. Containing risk in of itself is not treatment, and therapeutic responses need to address underlying distress”. (Warrender and Young, In press)

I now feel that there is a need for a truly person-centred ‘goldilocks/just-right’ approach, holding the jelly delicately, not crushing it nor carelessly dropping it. People should not be refused access to hospitals, but also should not be kept in hospital in a risk-averse limbo which can last years. A hospital is ultimately just a building, and it is what we do inside it that matters. When we complain of people having “back-forth” frequent or lengthy admissions to hospital (Warrender 2015), we also need to ask ourselves; are there any accessible alternatives? Certainly in my geographical and rural area, often there are not, and without appropriate supports available it should come as no surprise that people return in distress again. Whilst this model was not deliberately used in this thesis, as I wanted data to speak for itself, I have often held it in mind. It is certainly something which relates to this piece of work, and I am using this data to inform the models further development.

1.3.10. ‘Mental Health Deserves Better’ (#MHDeservesBetter)

During my PhD journey, I also found myself leading dissent against the status quo of nurse education in the UK, and in particular the nursing regulator the Nursing and Midwifery Council (NMC). From 2020, nurse education saw an increase in shared learning of all nursing students resulting from the NMC’s future nurse standards (2018). I along with others have written, presented, and campaigned extensively around the resulting dilution of mental health nurse education (Colwell, Cromar-Hayes and Warrender 2023, Mental Health Deserves Better 2022, 2023, Royal College of Nursing Congress 2022, Warrender 2022a, 2022b, 2022c, 2022d, 2023b, Haslam, Warrender and Lamph 2023, Warrender, Ramsay and Hurley 2023, Warrender et al 2024).

The core of the argument rests around students studying mental health nursing learning less about mental health than they would have previously (and I would have argued that it needed to improve even at that point). Graduates enter the NMC's register as 'registered nurse (mental health)', yet their experience of education is often one of learning more physical health skills they are unlikely to use or will use very little, and not spending enough time on the relational and psychosocial skills essential to the effectiveness of their role, which they will use every single day. When I think about what has driven me to devote so much time and energy to 'mental health deserves better' (particularly when I have always felt I should be using every moment to further my PhD), it is my experience of not feeling well prepared as a graduate mental health nurse, particularly to meet the needs of people who may be diagnosed with 'personality disorder', and yet seeing the situation of undergraduate preparation get worse rather than better. It was 20 years ago that Bateman and Tyrer (2004) argued that mental health professional education did not do enough to prepare people for working with people diagnosed with 'personality disorder'. I feel moral injury when I see education going in the wrong direction.

My engagement with the topic of 'borderline personality disorder' and the associated distress as well as the label and their huge impact on people's lives has shown me a depth of complexity which needs to be understood, and I am resolute that a specialist training for mental health nurses is essential if we expect newly registered mental health nurses to meet their needs. This personal resolution led to me changing employer, moving to another university that solely teaches mental health nursing in January 2024, towards the end of completing this PhD thesis.

1.3.11. Summarising my undeniable position

Whilst Husserl (1962) argued that research should suspend all beliefs and preconceptions, I am more inclined to side with Heidegger (1962) and Gadamer (1976) who countered that we necessarily require our own experience as a foundation for making sense of phenomena. I do not believe I can separate myself from my experiences, as they are ultimately the reason I am doing what I am doing, and will always be the lens through which I make sense of them. Nonetheless, I do need to be transparent about how my experiences may influence this study. Hence this disclosure.

I've been part of care delivery, and of systems which haven't cared for people as they should, and this has led to my career in academia and this journey as a PhD student. I know these poor experiences of care still happen. I want things to be better for people with the diagnosis, so I need to generate evidence, share ideas, as well as continuing to do my

best for the people I work with directly. This is what has brought me to this point, and I know I will keep me going beyond the PhD journey. In asking people about their experiences, I hope I can hold the microphone to voices which are often not heard.

1.4. Summary of chapters

Chapter 1: Introduction

This introduction very briefly introduces the topic under exploration, but more importantly explicitly acknowledges who I am as a person, and my experiences which have shaped my interest in the study. This is important to set the tone for all writing which follows in the thesis.

Chapter 2: Literature review

A more robust introduction to the topic captures relevant research literature around crisis intervention, exploring existing contexts of crisis and crisis care for PdxBPD. This chapter includes a published literature review capturing data from the year 2000 to November 2017, and an update from November 2017 to September 2023 which ensures a contemporary awareness of relevant research.

Chapter 3: Research methods

This chapter describes the underpinning philosophical approaches to generating new knowledge, exploring abduction and qualitative research. Case study is defined and explored as the frame for this study. Data collection methods include interviews, and data analysis used constant comparison. These practices are described, with reflexivity and reflection on what actually happened during the process.

Chapter 4: Findings

Data analysis saw the construction of five themes; crisis as a multidimensional experience, entering a confused and anxious system, acts and omissions which lead to harm, the complex simplicity of helping people in crisis, and building a better service. Findings explores people experiences in depth, using quotes from transcripts as examples to illustrate the themes and sub-themes.

Chapter 5: Discussion

The discussion pulls together the findings as well as literature review, and other relevant theory and literature based on my unique lens. Building on the concept map developed during literature review, a further and more detailed map is offered as a frame for this discussion, exploring the potential journey for PdxBPD through crisis and crisis

intervention, identifying the potential for what may happen to some of the people some of the time.

Chapter 6: Conclusion and recommendations

The conclusion revisits the aims of the study to discuss whether they have been achieved, and offers personal reflections on the PhD journey. The 5th theme of findings was focused on building a better service; thus it informs some key recommendations, which are made based on literature, findings and experience. Dissemination of the study findings is discussed, and future research and policy objectives are identified.

2. Chapter 2: Literature review

2.1. Introduction to the chapter

Having acknowledged my own position in this study, introduced the topic and given an overview of the thesis, this chapter explores the contemporary literature around experiences of crisis and crisis intervention for PdxBPD. The following literature review was published in the Journal of Psychiatric and Mental Health Nursing (Warrender et al 2021), and went on to win the journals article of the year (Appendix 8.2). Two further awards came from the publisher Wiley, with the article receiving a certificate for being a ‘top downloaded article’ certificate (Appendix 8.3), being amongst the publishers ten most downloaded papers, and a ‘top cited article’ certificate (Appendix 8.4), being listed among the journals top cited papers between 1st Jan 2021 to 15th Dec 2022 and recognised as generating an immediate impact in the research community.

This chapter presents the literature review as published, though as the original search explored papers from January 2000 to November 2017, an update is included to capture papers from November 2017 to September 2023.

2.2. Perspectives of crisis intervention for people diagnosed with “borderline personality disorder”: An integrative review

Warrender, D, Bain, H, Murray, I, Kennedy, C. Perspectives of crisis intervention for people diagnosed with “borderline personality disorder”: An integrative review. J Psychiatr Ment Health Nurs. 2021; 28: 208–236. <https://doi.org/10.1111/jpm.12637>

2.2.1. Accessible Summary

What is known on the subject?

- People diagnosed with “BPD” often experience crisis and use services
- “BPD” is a controversial diagnosis, and the experience of crisis and crisis intervention is not well understood

What this paper adds to existing knowledge?

- People diagnosed with “BPD” have different experiences of crisis, and using the diagnosis alone as a basis for deciding care and treatment is not appropriate

- There are many human factors which can influence how professionals deliver care to people diagnosed with “BPD”

What are the implications for practice?

- The education of staff, views on responsibility, team conflicts and access to clinical supervision can have an impact on how care is delivered, and should be addressed by organizations providing crisis care.
- Access to care often occurs when a person is self-harming or suicidal, but does not address underlying distress. Crisis care should go beyond managing behaviour and address any underlying needs.

2.2.2. Abstract

Introduction

“Borderline personality disorder” (“BPD”) is associated with frequent use of crisis intervention services. However, no robust evidence base supports specific interventions, and people's experiences are not well understood.

Aim

To explore the experiences of stakeholders involved in the crisis care of people diagnosed with “BPD.”

Method

Integrative review with nine databases searched January 2000 to November 2017. The search filtered 3,169 titles and abstracts with 46 full-text articles appraised and included.

Results

Four themes were constructed from thematic analysis: crisis as a recurrent multidimensional cycle, variations and dynamics impacting on crisis intervention, impact of interpersonal dynamics and communication on crisis, and balancing decision-making and responsibility in managing crisis.

Discussion

Crisis is a multidimensional subjective experience, which also contributes to distress for family carers and professionals. Crisis interventions had limited and subjective benefit. They are influenced by accessibility of services, different understandings of “BPD” and human dynamics in complex decision-making, and can be experienced as helpful or harmful.

Implications for practice

Subjectivity of crisis experiences shows limitations of the diagnostic model of “BPD,” emphasizing that interventions should remain person-centred. While thresholds for intervention are often met after self-harm or suicidality, professionals should review approaches to care and support people with underlying distress.

2.2.3. Introduction

“Borderline personality disorder” (“BPD”) in the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association (APA), 2013) (synonymous with “emotionally unstable personality disorder” in the International Classification of Diseases (ICD) version 10 (World Health Organization (WHO), 1992)) is a diagnosis associated with frequent crisis (Borschmann, Henderson, Hogg, Phillips, & Moran, 2012). Meeting the DSM-5 diagnosis requires five or more of nine criteria to be present, and although there are no essential core features, experts generally agree on symptoms of severe emotional dysregulation, strong impulsivity and social–interpersonal dysfunction (Fonagy, Luyten, & Bateman, 2017).

Estimates see “BPD” affect 0.7% of the UK general population (Coid, Yang, Tyrer, Roberts, & Ullrich, 2006), with most international figures between 0.5% (USA: Samuels et al., 2002) and 1.4% (0.95%, Australia: Jackson & Burgess, 2000, 0.7%, Norway: Torgersen, Kringlen, & Cramer, 2001, 1.4%, USA: Lenzenweger, Lane, Loranger, & Kessler, 2007, 1.1%, Germany: Arens et al., 2013). However, some estimates reach 2.7% (USA: Tomko, Trull, Wood, & Sher, 2014) and 5.9% (USA: Grant et al., 2008). Differentiation may relate to difficulties obtaining accurate personality assessments in national surveys for personality disorders, opposed to other diagnoses (Tyrer, Reed, & Crawford, 2015).

The experience of people diagnosed with “BPD” (PdxBPD) in crisis is poorly understood, and treatment response is ill-defined. Onset of crisis in “BPD” is associated with a precipitating event, reduction in motivation and problem-solving ability, and an increase in help-seeking behaviour (Sansone, 2004). PdxBPD are associated with repeated crises (Borschmann et al., 2012), with crisis frequently related to suicidal threat (Borschmann & Moran, 2010) and impulsivity associated with suicide completion (McGirr et al., 2007).

Studies across the last 20 years indicate that between 70% (Gunderson & Ridolfi, 2001) and 84% of PdxBPD may attempt suicide, multiple times (Soloff, Lynch, Kelly, Malone, & Mann, 2000). Suicide completion rates range between 3.8% (Zanarini, Frankenburg, Hennen,

Bradford Reich, & Silk, 2005) and 10% (Paris, 2002). Crisis intervention is often in response to attempted suicide and defined as “an immediate response by one or more individuals to the acute distress experienced by another individual, which is designed to ensure safety and recovery and lasts no longer than one month” (Borschmann et al., 2012, p. 2). A Cochrane Review found no adequate randomized control trial (RCT) evidence to support the use of any specific crisis intervention for “BPD” (Borschmann et al., 2012). Clinical decisions are challenging without an established evidence base.

Improving understanding of crisis is necessary, with suicide among PdxBPD more frequent than the general population (Pompili, Girardi, Ruberto, & Tatarelli, 2005). This issue has international significance, with WHO member states having a global target of a 10% reduction in suicide by 2020 (WHO, 2014). Controversially “personality disorder” diagnoses also comprise more than half of requested and received assisted suicides, legal in some European countries (Kim, De Vries, & Peteet, 2016; Thienpont et al, 2015).

The most recent available figures show high service use with PdxBPD constituting 4%–6% of primary care attenders (Gross et al., 2002; Moran, Jenkins, Tylee, Blizard, & Mann, 2000), 9%–10% of psychiatric outpatients (Lieb, Zanarini, Schmahl, Linehan, & Bohus, 2004; Zimmerman, Rothschild, & Chelminski, 2005) and 20% of psychiatric inpatients (Zanarini, Frankenburg, Khera, & Bleichmar, 2001). People often require intervention from psychiatric and emergency services (Comtois & Carmel, 2014; NICE, 2009) with hospital admission patterns potentially frequent and lengthy (Dasgupta & Barber, 2004).

Psychological therapies have proved effective in reducing “BPD” symptoms (Choi-Kain, Finch, Masland, Jenkins, & Unruh, 2017; Stoffers-Winterling et al., 2012), though such therapies are distinguished from crisis intervention as they are often longer-term and delivered in specialist services. It has been argued that high-quality generalist treatments may be “good enough” to treat PdxBPD, but “high-quality” care requires modest adaptations to current treatments, which may be ineffective or harmful (Bateman & Krawitz, 2013). The National Institute of Clinical Excellence (NICE) (2009) has guidelines for the care of PdxBPD, though these are countered by the reactionary “not so NICE guidelines” (Recovery in the Bin, 2017a) indicating that services may not always deliver as they should. UK-wide, there has been widespread recognition that the needs of people with all “personality disorder” diagnoses are often unmet (Mind, 2018).

There is a vast critique of “BPD” as a construct, and complications around how the diagnosis is understood. It has no core features, is a highly heterogeneous diagnosis

(Oldham, 2015; Trull, Distel, & Carpenter, 2011) and is associated with multiple comorbidities (Coid et al., 2009; NICE, 2009). It is argued as a flawed, highly contentious and damaging label which carries significant stigma (Johnstone, 2014; Johnstone et al., 2018), particularly at the interface of mental health care (Ring & Lawn, 2019).

There is a high correlation between childhood sexual abuse and “BPD” (Herman, Perry, & Van Der Kolk, 1989; McFetridge, Milner, Gavin, & Levita, 2015) and PdxBPD are 13 times more likely to report adverse childhood experiences than non-clinical control groups (Porter et al., 2019). It is thus argued that symptoms can be understandable responses to trauma and that diagnosis can be invalidating, framing “what people feel and do” into “something they have or are” (Johnstone et al., 2018, p. 28). There are movements campaigning for “BPD” to be abolished, embraced by professionals and people with the diagnosis (A Disorder for Everyone, 2019; “Personality Disorder” in the Bin, 2016).

The ICD-11 removed “personality disorder” categories, updating to a dimensional model focusing on clinical utility (Tyrer, 2014, 2018; WHO, 2018). Classifications now move from personality difficulty, through to mild, moderate and severe “personality disorder,” with anankastic, detached, dissocial, negative affective and disinhibited domain traits present to aid description (Tyrer, 2018). However, “BPD” is the most researched “personality disorder” with links to evidence-based treatment, and recommendations were made for a “borderline pattern” qualifier to allow PdxBPD to maintain access to treatments (Reed, 2018). This was accepted, and “borderline pattern” appears in the ICD-11 (WHO, 2018). “BPD” is a complex phenomenon with unclear aetiology, epidemiology and diagnostic validity. However, despite debate, controversy and recent diagnostic changes, the “BPD” diagnosis will continue to be used for the time being and will influence care delivery. The experiences of crisis intervention for PdxBPD are valuable, to increase understanding of this complex area. The high use of services, and potential for suicide completion in particular, demands crisis intervention be further explored.

2.2.4. Method

2.2.4.1. Review protocol and registration

Papers from January 2000 to November 2017 were accessed through several databases, ensuring the search was comprehensive. The nine databases were Cochrane Library, CINAHL, MEDLINE, SocINDEX, PsycINFO, PsycARTICLES, Web of Science, Knowledge Network and ProQuest. To ensure completeness, further articles were identified through the reference lists of included papers (Aveyard, Payne, & Preston, 2016). The SPICE

(setting/perspective/intervention/comparison/evaluation) framework (Booth, 2004, 2006) was used to develop an effective search strategy and refine the questions being asked (see Table 1).

TABLE 1. SPICE framework (Booth, 2004, 2006)

Setting
All settings in the UK and Ireland, continental Europe, Europe, the United States, Canada, Australasia and New Zealand
Perspective
People with a diagnosis of “borderline personality disorder”/“emotionally unstable personality disorder,” their family carers and professionals involved in their care.
Intervention
Crisis intervention for people diagnosed with “borderline personality disorder”/“emotionally unstable personality disorder”
Comparison
Comparison may be drawn between: <ul style="list-style-type: none"> • The perceptions and experiences of people diagnosed with “borderline personality disorder”/“emotionally unstable personality disorder,” their family carers and professionals involved in their care. • Variations in people's experience of crisis and clinical outcomes from intervention.
Evaluation
Clinical outcomes, views and experiences of crisis intervention

Comprehensive search terms were developed (see Table 2) by identifying relevant terminology, identifying synonyms and using terms already found in relevant publications (Aveyard et al., 2016). The wildcard symbol “*” was used to capture variations of root words (Hewitt-Taylor, 2017).

TABLE 2. Literature search terms

Search 1: (“Borderline personality disorder” OR “emotionally unstable personality disorder” OR “BPD” OR “EUPD”)
AND
Search 2: (Cris* OR emergenc* OR urgent OR risk* OR acute* OR critical* OR intensive* OR respon* OR Self-Injurious Behav* OR self harm* OR self injur* OR self mutilat* OR self poison* OR overdos* OR self burn* OR self cut* OR suicid*)
AND

Search 3: (experien* OR prefer* OR belie* OR perce* OR attitud* OR opinion* OR view* OR judg* OR reaction* OR impression* OR feel* OR satisf*)

*Wildcard—utilized to capture variations of root word.

The question was: “What are the experiences and perceptions of PdxBPD, their family carers and professionals around crisis intervention for ‘BPD’?” Specific aims should be a logical continuation of the research question (Hewitt-Taylor, 2017), and the following sub-questions were explored (see Table 3).

TABLE 3. Literature review questions

1.	What do people* understand by “crisis”?
2.	What forms of crisis intervention are utilized and what do they do?
3.	In which contexts do these crisis interventions take place, and does the context impact on experience?
4.	What are the barriers and facilitators to people feeling a crisis intervention has been beneficial?
* “People” refers to the multiple perspectives of: (a) People diagnosed with “BPD” (PdxBPD); (b) Families and carers (family carers); (c) Health, social care and emergency services staff (professionals).	

Inclusion and exclusion criteria were developed with reference to the University of Melbourne Guidelines (2019) (see Table 4).

TABLE 4. Inclusion and exclusion criteria (University of Melbourne 2018)

TABLE 4: Inclusion and Exclusion Criteria (University of Melbourne 2018)			
Criteria	Inclusion	Exclusion	Rationale
Date range	Publications between 2000 and 2017;	All publications prior to year 2000	Last 20 years have seen an increase in understanding regarding personality disorders and improvement in available treatments. Landmark publication “no longer a diagnosis of exclusion” (NIMHE, 2003) set out guidance for appropriate care

			for people diagnosed with personality disorders
Exposure of interest	Primary research studies evaluating crisis intervention, or including experiences of crisis and/or crisis intervention	Interventions that go beyond 1 month	Crisis intervention defined as action to “ensure safety and recovery and lasts no longer than one month” (Borschmann et al 2012).
Geographic location	Primary research studies performed in UK and Ireland, Continental Europe, Europe, USA, Canada, Australasia and New Zealand	Primary research studies not performed in UK and Ireland, Continental Europe, Europe, USA, Canada, Australasia and New Zealand	Personality disorder diagnoses are culturally defined and have been critiqued as a cultural disapproval of behaviour (Nyquist Potter, 2009). Therefore, countries with similar culture would provide a more valid data set. Also diagnostic criteria are not used universally across the globe
Language	Literature written in English language only	Literature not written in the English language	Chosen countries publish in the English language. Review team unable to read other languages. Cost and time of translation not feasible within study timeframe.
Participants	People diagnosed with ‘BPD’ aged 18 and over, their	Studies where primary diagnosis is	To increase validity of findings, studies exclusively

	family carers and the professionals involved in their care (inclusive of comorbidities but only where the primary diagnosis is BPD)	eating disorder or substance use, and any study where 'BPD' is not the primary diagnosis or participants are aged below 18.	using 'BPD' as the primary diagnosis were necessary.
Peer Review	Peer reviewed studies only	Non-peer reviewed studies	Peer review is a sign of a study's quality assurance
Reported outcomes	All outcomes		All outcomes required to build a comprehensive picture of the study topic
Setting	All settings		Crisis intervention may take place in a variety of contexts
Study design	All study designs		Integrative review captures a diversity of primary research
Type of publication	Empirical studies (quantitative, qualitative and mixed-methods studies) will be included.	Systematic reviews, editorials, commentaries or letters, discussion papers, opinion papers and non-empirical studies.	Primary research required for integrative review

The protocol for this study was developed in collaboration between all authors and registered with the International Prospective Register of Systematic Reviews (PROSPERO) (Warrender, Bain, Murray, & Kennedy, 2017). The full protocol can be accessed at http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42017075123.

2.2.4.2. Data collection

The review captured papers January 2000 to November 2017, with details reported through the PRISMA flow diagram (Moher, Liberati, Tetzlaff, & Altman, 2009) (see Figure 1). To increase quality assurance, two reviewers from the team were involved at each stage of the process: reviewing titles and abstracts, agreeing inclusion of papers, data extraction, data analysis and synthesis.

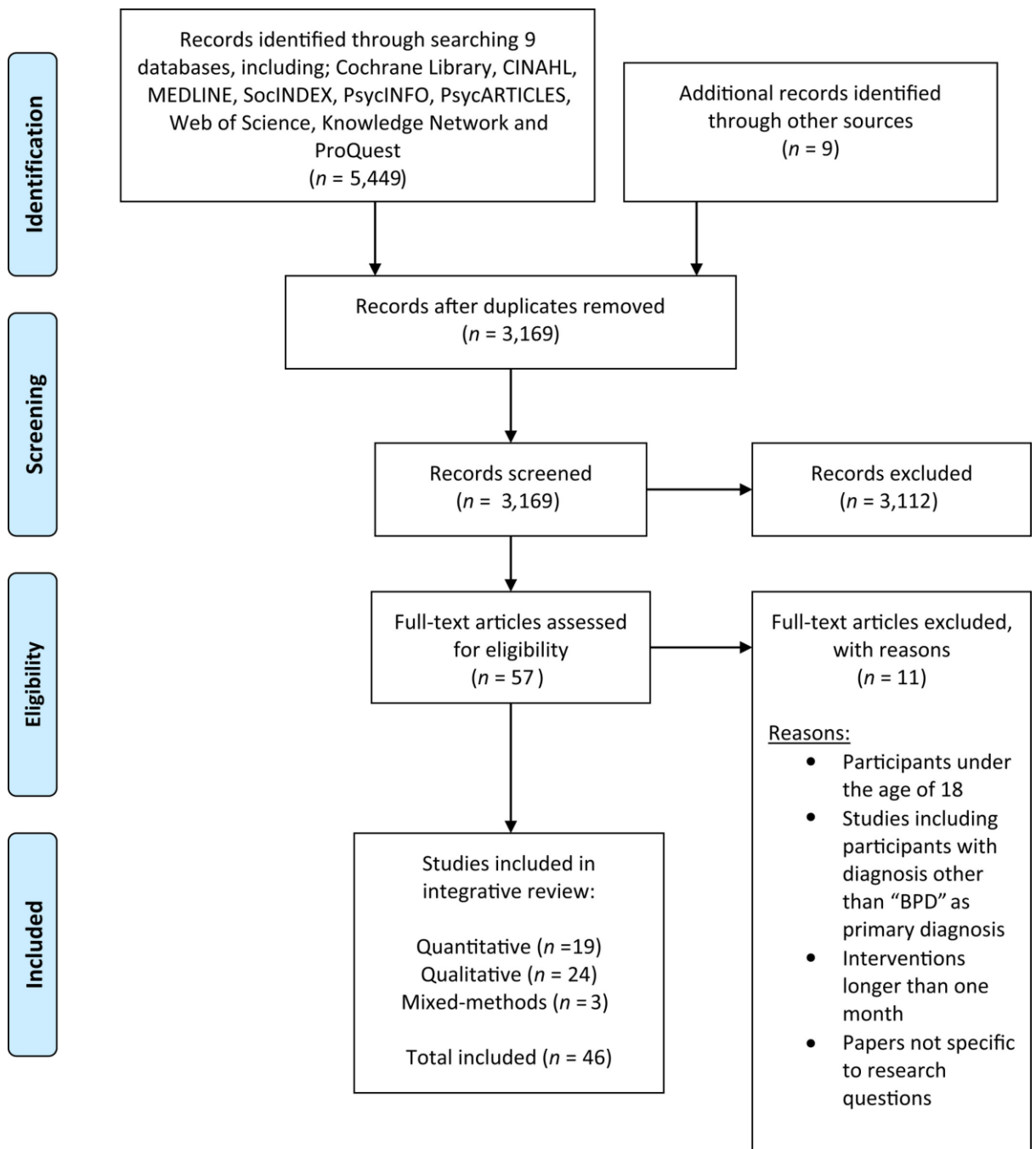


FIGURE 1: PRISMA 2009 flow diagram

2.2.4.3. Quality appraisal

Papers were appraised using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). This tool has specific questions for five categories of empirical study, qualitative research, randomized controlled trials, non-randomized studies, quantitative descriptive studies and mixed-methods studies. Each study was reviewed against relevant criteria. Scoring is discouraged (Crowe & Shepard, 2011; Higgins & Green, 2008), and excluding studies on the basis of quality is not recommended (Hong et al., 2018). The MMAT was therefore used to aid description. Percentages of affirmative MMAT responses were recorded, with negative responses requiring comment in the data extraction table (Appendix 8.5).

2.2.4.4. Thematic analysis

Braun and Clarke's (2006) thematic analysis framework guided analysis and organization of data. Data were analysed by all authors, identifying patterns within the data set which were relevant to the research questions. This was initially a theoretical thematic analysis, providing a detailed analysis of data set content relevant to research questions (Braun & Clarke, 2006). However, themes evolved through interpretation, identifying the significance of patterns in relation to not only research questions but relevant literature presented in the introduction to this paper. Themes were presented to provide a "concise, coherent, logical, nonrepetitive, and interesting account of the story the data tell" (Braun & Clarke, 2006, p. 23). These themes give readers an in-depth narrative of the human experiences, influences and variables associated with crisis and crisis intervention for PdxBPD.

2.2.5. Findings

Fifty-seven full-text papers were assessed with 46 included in the review (Appendix 8.5). This comprised 24 qualitative, 19 quantitative and three mixed-methods studies. Papers were from the UK (n = 16), Australia (n = 6), the United States (n = 4), Germany (n = 3), the Netherlands (n = 3), Sweden (n = 3), Switzerland (n = 3), New Zealand (n = 2), Belgium (n = 1), Ireland (n = 1), Norway (n = 1) and Spain (n = 1). Two studies took place across two locations, Australia and New Zealand (n = 1) and Germany and Switzerland (n = 1).

Twenty-nine papers collected data on PdxBPD, eleven on professionals, with family carers the least represented with six. Gender was overwhelmingly female in PdxBPD participants, who all met or had met DSM diagnostic criteria. Professionals included practitioners from mental health nursing, psychiatry, psychotherapy, psychology, counselling, case management, social work, art therapy, police and occupational therapy.

Many papers were qualitative with small sample size, though agreement about quality in qualitative research is elusive (Aveyard et al., 2016). It is argued that weaker studies would simply contribute less, rather than distort findings (Thomas & Harden, 2008).

Some papers were represented once and others across themes. Findings illuminate a variety of perspectives which may reflect the experience of “crisis” and intervention for PdxBPD. Four themes emerged; crisis as a recurrent multidimensional cycle, variations and dynamics impacting on crisis intervention, impact of interpersonal dynamics and communication on crisis, and balancing decision-making and responsibility in managing crisis.

2.2.5.1. Crisis as a recurrent multidimensional cycle

Twenty-eight papers characterized crisis as a recurrent, unpredictable, subjective, multidimensional and overwhelming experience. Internal or external triggers precipitated self-harm, which was a self-management or help-seeking strategy. Distress was paralleled in experiences of family carers and professionals. The word “crisis” did not feature in all papers, though all included experiences of feeling out of control. Two additional terms were identified: “aversive tension” (Stiglmayr et al., 2005, 2008) describing extreme emotional dysregulation which often precedes self-harm, and “agitation,” with measures including tension, uncooperativeness, hostility and poor impulse control (Damsa et al., 2007).

Crisis is complex with subjective precipitating factors. Brooke and Horn’s (2010) interviews (n = 4) identified distal and proximal factors, while Black, Murray, and Thornicroft’s (2014) (n = 9) described internal and external dynamics. Distal factors included histories of trauma (Brooke & Horn, 2010; Henderson, Wijewardena, Streimer, & Vandervord, 2013; Holm & Severinsson, 2011) and proximal factors/external dynamics related to interactions with others (Black et al., 2014; Brooke & Horn, 2010; Brown, Comtois, & Linehan, 2002; Henderson et al., 2013). Internal dynamics also saw crisis arise within the self (Black et al., 2014). Quantitative studies identified PdxBPD self-reporting triggers as feeling rejected, being alone, failure (39%, n = 63) (Stiglmayr et al., 2005) and inner helplessness (Stiglmayr et al., 2008). “BPD” was distinguished from other diagnoses in that tension arises from a negative view of the self (Stiglmayr et al., 2008).

PdxBPD felt crisis could arise suddenly, sometimes without warning and impact on emotional and perceptual states. Henderson et al.’s (2013) qualitative case series (n = 4) described crisis as having a quick onset, sometimes without warning signs (Helleman, Goossens, Kaasenbrood, & Achterberg, 2014). PdxBPD felt on edge, overwhelmed by

emotions (Perseius, Ekdahl, Asberg, & Samuelsson, 2005) as if they were going to explode (Brooke & Horn, 2010), with a desperate need to gain peace or escape (Holm & Severinsson, 2011). Perceptual changes included dissociative experiences (Black et al., 2014; Brooke & Horn, 2010; Henderson et al., 2013), while Slotema et al.'s (2017) quantitative study (n = 89) found PdxBPD with auditory verbal hallucinations correlated with a higher frequency of suicidal plans and attempts. Reasons for referral to emergency services included depression, anxiety, psychosis, drug abuse/dependence and disruptive behaviour (Pascual et al., 2007).

PdxBPD described difficulty articulating their experiences (Black et al., 2014; Helleman et al., 2014). This was confirmed by family carers (Dunne & Rogers, 2012). Some attempted to hide their experience of crisis (Holm & Severinsson, 2011; Perseius et al., 2005), at times to protect family (Black et al., 2014). Conversely, sometimes PdxBPD had difficulty thinking of others (Holm & Severinsson, 2011).

Professionals viewed crisis as an ongoing issue for PdxBPD (Commons Treloar, 2009; Nehls, 2000; Rizq, 2012; Rogers & Acton, 2012), and a quantitative study (n = 27) found a few PdxBPD comprising the majority of referrals (13 = 78%, 5 = 53%) to an intensive home treatment team (IHTT) (Turhan & Taylor, 2016). Through focus groups (n = 9), professionals described hospital admissions as recurrent “back, forth” admission cycles, adding that admission for one person lasted “3 or 4 years” (Warrender, 2015).

PdxBPD may have enduring negative emotional states which could impact experiences of crisis. A quantitative study of self-reported emotional responses found emotional reactivity similar whether PdxBPD were in crisis or not, indicating that negative thinking may be enduring (Staebler, Gebharda, Barnett, & Renneberg, 2009). Furthermore, hourly self-reporting over 48 hr saw aversive tension found to be more frequent, more intense and longer lasting in PdxBPD than in healthy controls (Stiglmayr et al., 2005). Unsuccessful suicide attempts could become a cycle of crisis, where feelings of failure reinforce suicidal thoughts (Black et al., 2014).

PdxBPD self-managed crisis through self-harm, or seeking help from professionals (Black et al., 2014). Self-harm, predominantly cutting and burning, was a self-managed personal crisis intervention. This was used as a response to dissociation (Black et al., 2014; Henderson et al., 2013) or emotional dysregulation (Brooke & Horn, 2010; Henderson et al., 2013), with people reporting subjective analgesia (Philipsen, Schmahl, & Lieb, 2004). Some people described progressive systems of coping, moving through self-harm to suicidality

(Brooke & Horn, 2010). Brown et al. (2002) found self-harm had a dual role, for reducing or expressing the feeling of crisis. Difficulties articulating distress could lead to self-harm as a means of communication (Brooke & Horn, 2010). A quantitative online survey found that feeling suicidal, feelings of self-harm and feeling unsafe were the most common reasons for PdxBPD seeking hospital admission (Lawn & McMahon, 2015a). Decisions to hospitalize were often associated with risk of suicide (Pascual et al., 2007).

Family carers could experience a parallel crisis to PdxBPD. Dunne and Rogers (2012) focus groups found family carers experiencing their own distress, with unstructured interviews finding distress related to PdxBPD self-harming and attempting suicide (Giffin, 2008). Free-text questionnaires and group interviews (n = 19) saw distress described as a permanent crisis and 24-hr duty of constant worry, which included powerlessness and frustration and mirrored the experience of PdxBPD (Ekdahl, Idvall, Samuelsson, & Perseius, 2011). Over one-third of family carers in a quantitative study (n = 32) knew little about “BPD” (Hoffman, Buteau, Hooley, Fruzzetti, & Bruce, 2004), while focus groups in a grounded theory retrospective study found family carers lacked skills for helping PdxBPD’s issues and wished for more information on how to handle situations (Dunne & Rogers, 2012; Lohman, Whiteman, Yeomans, Cherico, & Christ, 2017). However, greater knowledge about “BPD” was associated with higher levels of family burden, distress, depression and greater hostility towards PdxBPD (Hoffman et al., 2004). This may link to guilt felt by families due to preconceived ideas that parents are responsible for development of “BPD” (Ekdahl et al., 2011).

Furthermore, professionals experienced distress. Interviews (n = 29) identified a need for emotional support (Bergman & Eckerdal, 2000) with the threat of suicide considered the most distressing (Hughes, Bass, Bradley, & Hirst-Winthrop, 2017; McGrath & Dowling, 2012). Professionals further described feeling frustrated, inadequate, challenged (Commons Treloar, 2009), confused, uncertain, drained and personally distressed (Warrender, 2015).

In summary, crisis has multiple triggers, is subjective and people manage their distress in different ways. Crisis was recurrent and could have a quick onset, which may be linked to enduring negative thinking. The constant nature of crisis could contribute to distress in family carers and professionals, who may mirror PdxBPD’s crisis. The subjectivity of crisis experience may make it a challenge to treat, though threat of self-harm and suicide is often the reason for crisis intervention.

2.2.5.2. Variations and dynamics impacting on crisis intervention

Twenty-five papers explored access to care during crisis. The impact of professional interventions, resources available, treatment options and preferences and variables impacting on team approaches emerged.

PdxBPD experienced challenges accessing care. Self-referral could be difficult to arrange in the midst of crisis, and while PdxBPD could self-refer to a psychiatric emergency service, ambulance was the most common means of arrival (Pascual et al., 2007). Helleman et al.'s (2014) qualitative study (n = 17) found PdxBPD using preventative hospital admissions felt security and reassurance knowing admission was available. To the contrary, some PdxBPD and carers were refused hospital admission and reported significant distress (Lawn & McMahon, 2015a, 2015b). Morris, Smith, and Alwin's (2014) qualitative study (n = 9) saw PdxBPD describe services as reactive rather than proactive regarding risk, feeling thresholds for intervention were only met in immediate risk of suicide. Pascual et al.'s (2007) quantitative retrospective examination of patient records (n = 540) reported that though PdxBPD did self-refer, professionals' decisions to hospitalize were often based on suicide risk.

Access to and continuation of care can be influenced by the "BPD" diagnosis. PdxBPD in a qualitative study (n = 5) felt they were excluded from services or had care withdrawn based on their diagnosis (Horn, Johnstone, & Brooke, 2007), and professionals confirmed they had witnessed colleagues refusing to treat PdxBPD (Commons Treloar, 2009). In contrast, for mild-to-moderate suicidal ideation, PdxBPD were more likely to be discharged from toxicology services and admitted to psychiatric hospital than people diagnosed with depression (Carter, Lewin, Stoney, Whyte, & Bryant, 2005).

Professional interventions were often standard care, though took place in a variety of contexts including inpatient settings (Helleman et al., 2014; Koekoek, Van Der Snoek, Oosterwijk, & Van Meijel, 2010; Philipsen et al., 2004; Warrender, 2015), a crisis intervention unit (Berrino et al., 2011), emergency departments (Damsa et al., 2007; Pascual et al., 2007), toxicology service (Carter et al., 2005), a "BPD" resource centre (Lohman et al., 2017), intensive home treatment (Turhan & Taylor, 2016) and an intensive outpatient therapy (McQuillan et al., 2005). Professionally influenced interventions included joint crisis plans (Borshmann et al., 2013) and a smartphone application (Prada et al., 2017). PdxBPD accessed their general practitioners for support and referral to other services, and they were rated by family carers as the most responsive professionals (Lawn & McMahon, 2015b).

Hospitalization was common, though had subjective value. Preventative hospital admission saw a slight decrease in services used in terms of inpatient days recorded, and was evaluated positively by PdxBPD (n = 8) (Koekkoek et al, 2010). However, PdxBPD experiences of a 3-night hospital admission with support were both positive and negative (Helleman et al., 2014). Focus groups of inpatient mental health nurses (n = 9) using mentalization-based therapy (MBT) skills felt more empowered and able to facilitate positive changes for PdxBPD, though no patient outcomes were recorded (Warrender, 2015). Some professionals considered hospitals too busy and not conducive (Warrender, 2015), feeling that PdxBPD were best managed as outpatients without medication, receiving consistent support (Little, Trauer, Rouhan, & Haines, 2010).

There were positive impacts of services specifically purposed to manage crisis intervention. Admission to a crisis intervention unit (n = 100) saw reduced rates of self-harm (8%) and hospitalization (8%) compared to treatment as usual (TAU) (n = 100, 17% and 56%) (Berrino et al., 2011), and IHTT (n = 27) noted improvement in most PdxBPD (Turhan & Taylor, 2016). However, these interventions showed limited benefit for suicidality, with IHTT not enough to manage suicide risk in 34% of cases where PdxBPD were hospitalized (Turhan & Taylor, 2016). Although improved compared to TAU, the crisis intervention unit still recorded treatment failure through suicidal crisis (Berrino et al., 2011).

McQuillan et al.'s (2005) quantitative study on intensive outpatient dialectical behavioural therapy showed acceptability with high treatment completion and retention rates, and improvements on depression and hopelessness scales. A quantitative study on joint crisis plans co-developed by PdxBPD and mental health teams showed no reduction in instances of self-harm, though was used by 73.5% (n = 25/34) during a crisis, contributing to a greater feeling of control for 47.1% (n = 16/34) of participants followed up (Borschmann et al., 2013). A smartphone application using mindfulness-based exercises was evaluated as user friendly, and though mechanisms of change were unclear, it contributed to reduction in aversive tension (Prada et al., 2017).

Crisis intervention using specific medications was reported in two papers. Damsa et al. (2007) found intramuscular olanzapine (10 mg) reduced agitation; however, this was after refusal of oral medication and included 80% (n = 20/25) of participants being physically restrained. Naloxone (0.4 mg) administered intravenously showed improvement in dissociative symptoms, though was not better than placebo (Philipsen et al., 2004). Medications were often prescribed at a psychiatric emergency service (Pascual et al.,

2007), though PdxBPD in a qualitative study (n = 7) felt that medication was often used due to a lack of appropriate resources (Rogers & Acton, 2012).

Outcomes of crisis interventions are influenced by several factors. Resources available did not always meet demand (Lohman et al., 2017), and family carers (n = 121) described a lack of choice in services for PdxBPD (Lawn & McMahon, 2015b) and identified the need for an appropriate base and crisis accommodation (Dunne & Rogers, 2012). Commons Treloar's (2009) qualitative study (n = 140) saw professionals across emergency medicine and mental health services perceive current services as unsuitable for PdxBPD's needs. Once crisis and imminent risk of suicide were over, PdxBPD felt professionals were not interested in their underlying distress (Morris et al., 2014). Family carers further identified a lack of long-term consistent support as contributing to anxiety in PdxBPD (Lawn & McMahon, 2015b).

PdxBPD's preferences for care included therapeutic relationships giving emotional and practical support, while specific treatment refusals included particular medications and use of involuntary treatment (Borschmann et al., 2014). PdxBPD were mixed in perception of the usefulness of identifying early warning signs, developing crisis plans and hospital admission (Lawn & McMahon, 2015a). These were respectively found to be very unhelpful for around a quarter of carers in the study (25.4%, n = 18; 28.6%, n = 20; and 23.9%, n = 17).

Professionals identified conflict in teams regarding approaches to working with PdxBPD (Commons Treloar, 2009), describing lack of collaboration negatively impacting care (Bergman & Eckerdal, 2000). Family carers echoed this and at times heard contradictory advice (Giffin, 2008). An inter-agency quantitative study (n = 378) found that health and welfare, mental health and police responded to PdxBPD in different ways (Little et al., 2010).

Conflict could be due to different levels of education on "BPD" which varied between professionals (Bergman & Eckerdal, 2000). Family carers experienced staff with little knowledge (Ek Dahl et al., 2011), some telling them "it's just behaviour" (Dunne & Rogers, 2012). Professionals identified the need for specific education on "BPD" (Commons Treloar, 2009), and while they utilized clinical supervision (Berrino et al., 2011) and emphasized its importance (Commons Treloar, 2009), it was not always accessible (Warrender, 2015). Focus groups (n = 9) saw teams using MBT skills describe increased consistency in their approach (Warrender, 2015).

To summarize, PdxBPD had varying experiences of accessing care which could be influenced by diagnosis. Professional interventions took place in a variety of contexts but were most often non-specialist inpatient units and emergency departments, and showed limited or subjective benefit. Outcomes may be influenced by resources available, thresholds for intervention, conflict in teams, differing levels of professional education and access to clinical supervision.

2.2.5.3. Impact of Interpersonal dynamics and communication on crisis care

This theme was illuminated by 22 papers, highlighting interpersonal dynamics as a trigger to crisis and relationships holding contradictory roles in relieving or adding to suffering. Reputations for self-harm and the “BPD” diagnosis itself could contribute to discriminatory experiences.

Interpersonal issues could precipitate crisis (Black et al., 2014) and be a catalyst to self-harm (Henderson et al., 2013), with rejection self-reported as a precipitating factor to aversive tension (Stiglmayr et al., 2005). Brooke and Horn (2010) found PdxBPD used self-harm as a means of regaining self-control and inhibiting interpersonal behaviour which may be deemed inappropriate. A quantitative study (n = 75) using clinical history interviews recorded instances of parasuicide (suicide without supposed intent to die) and found 20% had an interpersonal influence (Brown et al., 2002). However, this study did not define parasuicide, and acknowledged limitations in that self-reporting of intent may not be known or remembered.

Social relationships had a subjective role, with PdxBPD’s preferences in crisis contrasting between connecting with others and the desire to be left alone (Borschmann et al., 2014). Black et al. (2014) found relationships with family could be protective against suicide, as a purposeful family role and responsibility engendered self-preservation. However, the same study found this responsibility to protect loved ones could lead PdxBPD to hide their distress.

PdxBPD (n = 17) valued contact with professionals (Helleman et al., 2014), and particularly those who invested in them and offered hope (n = 8) (Veysey, 2014). PdxBPD valued being treated like a person (Morris et al., 2014), shown dignity and respect, and receiving emotional and practical support (Borschmann et al., 2014). Collaboration was valued, as 47.1% (n = 16/34) of PdxBPD self-reported that developing joint crisis plans with professionals had improved their relationships (Borschmann et al., 2013). An aspect of crisis is a difficulty communicating and articulating experiences, and a qualitative study

interviewing professionals (n = 9) described their role as slowing things down and helping PdxBPD to think (Bowen, 2013).

Relationships with professionals had a dual role. Qualitative studies found they could relieve or add to suffering (Perseus et al., 2005) (n = 10) as PdxBPD experienced both helpful and discriminatory experiences (Veysey, 2014) (n = 8). Through interviews, professionals (n = 5) perceived that PdxBPD have high expectations of them and are sensitive to interpersonal disappointment due to adverse childhood experiences, further considering therapeutic relationships potentially re-traumatizing patients when ending (Rizq, 2012). Professionals perceived PdxBPD's difficulties with them as a parallel process and a repetition of experiences outside of care, though also valuable opportunities for learning (Bowen, 2013).

PdxBPD described "non-caring care," with some professionals perceived to be reluctant, unwilling or unable to work with them or dedicate time to therapeutic relationships (Morris et al., 2014), and lack of contact in an inpatient context contributing to negative emotions (Helleman et al., 2014). PdxBPD experienced professionals being dismissive of their distress (Rogers & Acton, 2012) (n = 7), describing being "dumped" or left in wards following frequent admissions (Rogers & Dunne, 2011) (n = 10). Dismissiveness was confirmed by family carers, with focus groups describing some professionals as unprofessional and unhelpful (Dunne & Rogers, 2012) (n = 8), and an online survey identifying the most challenging issue for PdxBPD as not being taken seriously (Lawn & McMahon, 2015b) (n = 121). Self-reporting emotional reactions of health and non-health-related agencies (n = 378) found the police as more likely to see PdxBPD as a nuisance, as in contrast to mental health professionals, police felt they needed to be available all the time (Little et al., 2010).

PdxBPD had perceived discrimination from professionals. An online survey found that 65.4% (n = 78/96) of PdxBPD who had accessed care for 10 years or more had experienced discrimination, particularly as inpatients (Lawn & McMahon, 2015a). Some PdxBPD felt they were not seen as a person (Holm & Severinsson, 2011; Walker, 2009), and Walker's (2009) narrative interviews (n = 4) found PdxBPD perceive their reputations as a "self-harmer" as overshadowing other issues. Veysey's (2014) qualitative study found through semi-structured interviews that PdxBPD (n = 8) with self-harm histories had increased experiences of discrimination, which impacted on self-image.

Stigma attached to the "BPD" diagnosis had a further impact. Interviews saw mental health nurses acknowledge the stigma attached to PdxBPD as they arrived at their service

(McGrath & Dowling, 2012) (n = 17) and a questionnaire found reduced sympathy for people with the diagnosis (Markham & Trower, 2003) (n = 48). PdxBPD felt their distress was often viewed in terms of “BPD,” and they could be misunderstood as being deliberately difficult (Morris et al., 2014). PdxBPD described professionals indicating they were selfish (Holm & Severinsson, 2011), and family carers acknowledged a stigma from professionals who described distress as “just behaviour” (Dunne & Rogers, 2012).

In summary, this theme showed the complex nature of social and professional relationships. Interpersonal issues were often a trigger to crisis, with social relationships of varying benefit. PdxBPD emphasized the value of the therapeutic relationship with professionals, though also described its double role through experiences of “non-caring care,” often experiencing discrimination which was sometimes related to diagnostic stigma.

2.2.5.4. Balancing decision-making and responsibility in managing crisis

Nineteen papers contributed to balancing decision-making and responsibility in managing crisis. Shared decision-making was identified as important, though experiences of this varied with complexity in power dynamics. There were often differing views on where responsibility lay for the management of crises, and this created difficulties for professionals and family carers.

PdxBPD welcomed choice and joint decision-making, though decisions were not always collaborative. PdxBPD (n = 17) with choice of hospital admission reported an improved sense of autonomy and responsibility (Helleman et al., 2014). Koekkoek et al (2010) (n = 8) identified that preventative hospital admission contributed to feelings of control over crisis, with PdxBPD feeling that having access to admission if needed and having control over their own treatment promoted their ability to self-manage their own difficulties. Focus groups of PdxBPD with experiences of inpatient settings identified good joint decision-making (Rogers & Dunne, 2011) and professionals also emphasized its importance (Bowen, 2013). Although noted in under half of the participants (47.1%, n = 16/34), using a joint crisis plan had contributed to greater feelings of control over problems (Borschmann et al., 2013). Professionals (n = 9) described their being placed in the expert role as unhelpful, shared decision-making encouraging shared responsibility, and that PdxBPD becoming disillusioned with them could lead to looking inward to their own resources (Bowen, 2013). The removal of responsibility and choice was not welcomed by PdxBPD. Holm and Severinsson’s (2011) qualitative interviews (n = 13) saw PdxBPD describe having

responsibility removed and lacking the power to make decisions as a barrier to effective intervention. Involuntary treatment was a specific treatment refusal in joint crisis plans (Borschmann et al., 2014), though this was used at times with 9/13 PdxBPD reporting difficulty accepting this and feeling violated (Holm & Severinsson, 2011). Particular psychotropic medications were a specific treatment refusal in some joint crisis plans (Borschmann et al., 2014), though PdxBPD described little choice regarding the use of medication in inpatient settings (Rogers & Acton, 2012). Furthermore, 80% of all participants (n = 20) in one study were physically restrained prior to medication administration (Damsa et al., 2007).

Power dynamics appeared to play a role in treatment, with the act of refusing the advice or guidance of professionals interpreted as pathology. “Uncooperativeness” was a measure of agitation (Damsa et al., 2007), while “noncompliance with treatment” was a reason for hospitalization (Pascual et al., 2007). The illusion of choice was noted by Rogers and Dunne (2011, p. 229) through de facto detention, with PdxBPD describing experiences as inpatients where professionals told them that they could be voluntary patients, “or we can section you” using mental health legislation. Some PdxBPD identified powerlessness and the paradox of being told to use their strengths, yet simultaneously having decisions made on their behalf (Holm & Severinsson, 2011).

Uncertainty emerged regarding who should hold responsibility for PdxBPD. Three qualitative studies using interviews found professionals felt responsibility for the safety of PdxBPD (Rizq, 2012) and sometimes felt this was transferred to them by patients (Hughes et al., 2017; Nehls, 2000). However, some PdxBPD countered that suicidality could actually be through their desire to take responsibility for themselves (Holm & Severinsson, 2011). Hughes’ (2017) interviews found some community mental health teams (n = 4) feared being blamed in the event of patient suicide. Furthermore, Krawitz and Batcheler’s (2006) quantitative self-report questionnaire found that decisions are sometimes made outwith PdxBPD’s best interests to protect professionals from legal repercussions. Defensive practice was influenced by the PdxBPD’s family and friends, though the biggest influence was cited as the media (Krawitz & Batcheler, 2006). Nonetheless, this was contradicted by a self-report questionnaire (n = 378) across professional agencies, which found that though the police felt they needed to be constantly available, there were no concerns in any group regarding damage to professional credibility nor legal consequences if suicide were to occur (Little et al., 2010).

Family carers described an all-or-nothing responsibility transaction between them and professionals. Qualitative studies using focus groups, interviews and questionnaires found family carers held full responsibility until their significant other was in hospital, then felt overlooked and had no responsibility (Dunne & Rogers, 2012) (n = 8), and were sometimes told by professionals that they were not needed (Ekdahl et al., 2011) (n = 19). Giffin's (2008) unstructured interviews (n = 4) saw family carers perceive that responsibility was often left with them, with their support used as a reason to avoid professional intervention. Family carers' involvement in care was often limited, though Lohman et al. (2017) randomly reviewed resource requests (n = 500) to find that they desired more communication with professionals. Family carers also had mixed experiences of care plans being shared (Dunne & Rogers, 2012) and felt there were no discharge plans (Giffin, 2008).

Professionals struggled with suicide risk and felt uncertain whether intervention was required or not (Rizq, 2012). Nehls' (2000) interviews with professionals (n = 17) described this as balancing over- and under-concern. Hughes et al. (2017) found professionals from community mental health teams (n = 4) describe balancing patient responsibility with professional responsibility, and found considerable variation in professional views regarding risk. This variation in views corresponds with carers being given contradictory advice by professionals (Giffin, 2008). Family carers' experience paralleled that of professionals, describing the challenge of balancing support and enablement between themselves and PdxBPD (Dunne & Rogers, 2012).

Mental health professionals appeared the most comfortable with handing responsibility back to PdxBPD and were more understanding than police or health and welfare of why a person may be discharged or not admitted to hospital for ongoing suicidality (Little et al., 2010). PdxBPD felt that they were compared to people with other diagnoses and seen as having more control than patients diagnosed with schizophrenia (Rogers & Dunne, 2011). This was confirmed in a study of mental health nurse attitudes, which viewed PdxBPD as being in control of their behaviour (Markham & Trower, 2003).

This theme saw PdxBPD welcome choice and joint decision-making. However, decisions were not always collaborative, and the removal of responsibility was perceived as a barrier to effective intervention, particularly recognizing power dynamics between PdxBPD and professionals. There was uncertainty between professionals, family carers and PdxBPD as to who held responsibility, with family carers describing their responsibility as all-or-nothing. Both professionals and family carers described difficulty in balancing the level of

responsibility they shared with PdxBPD for their safety. Mental health professionals appear to be the most comfortable in handing responsibility back to PdxBPD.

2.2.6. Discussion

This integrative review will inform evidence-based practice around crisis intervention for PdxBPD with RCTs lacking (Borschmann et al., 2012). Crisis is a subjective term and crisis intervention is not well understood. This justified an integrative review, including a broad and diverse range of literature (Aveyard et al., 2016). This approach is appropriate to defining concepts and reviewing theories (Whittemore & Knafl, 2005) and can provide foundations for future knowledge and research.

The contribution of this review to existing knowledge comes through the synthesis of 46 papers which highlight key themes on this complex topic. The overall quality of research was good, with affirmative MMAT responses ranging between 60% and 100%. The vast majority (29/46) achieved all affirmative responses, while negative responses often related to a lack of clarity rather than poor research practice. Some studies did not acknowledge the variables which may influence their outcomes, and this review contributes to the understanding of these factors.

A conceptual map of the potential journey from crisis to crisis intervention (see Figure 2) provides a visual representation of themes discussed.

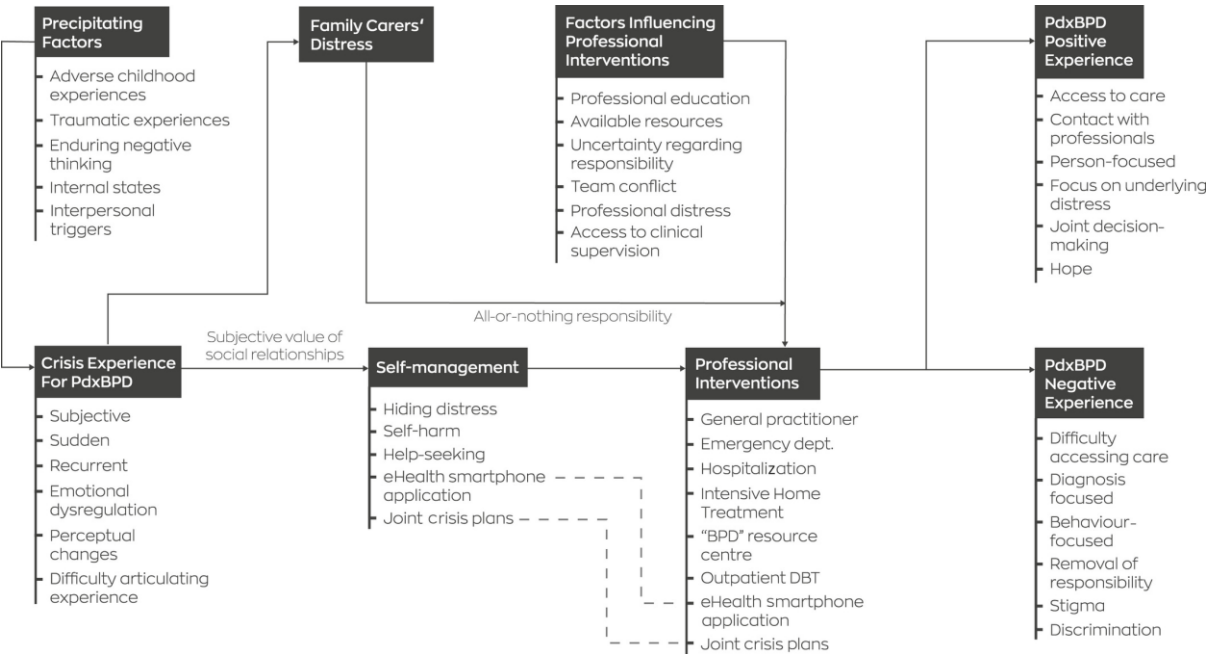


FIGURE 2: A conceptual map showing the potential experiences of people diagnosed with “borderline personality disorder,” their families and carers and professionals involved in their care, relating to crisis and crisis intervention. This captures the

potential journey from precipitating factors of crisis, to the crisis experience and crisis intervention, identifying experiences, influential factors and culminating in what was experienced as helpful and unhelpful for people with the diagnosis.

Sansone (2004) described crisis as being precipitated by an event, and this review identified events as internal or external, triggered from within the self or interpersonally. The influence of both self and others may be understood through the concept of mentalization. Mentalizing is “the process by which we make sense of each other and ourselves, implicitly and explicitly, in terms of subjective states and mental processes” (Bateman & Fonagy, 2010, p. 11). Difficulties mentalizing are influenced by childhood trauma or neglect and can lead to difficulties in the experience of oneself, and a vulnerability to interpersonal interactions (Bateman & Fonagy, 2010). It would however be unfair to suggest that all difficulties for PdxBPD in interpersonal relationships were due to their failure to mentalize, given family carers’ and professionals’ descriptions of stigma and discrimination.

PdxBPD experienced crisis in different ways, not surprising given the heterogeneous diagnosis. Sudden and recurrent onsets may relate to the consistent availability of triggers which could come from self or others, and recurrent crises may relate to enduring negative thinking. Emotional dysregulation and perceptual changes were features of crisis, and these would further impact mentalizing ability. The experience of feeling overwhelmed was consistent with general definitions of crisis (James & Gilligand, 2005), though the subjectivity of experiences indicates the need for sufficient flexibility in any intervention, remaining person-centred rather than diagnosis-centred.

A prominent self-management strategy for PdxBPD was self-harm. Felitti et al.’s (1998) study on adverse childhood experiences (ACEs) proposed that health risk behaviours such as smoking and obesity are viewed as societal problems, yet are solutions from the perspective of individuals. There is a high prevalence of ACEs in the histories of PdxBPD (Herman et al., 1989; McFetridge et al., 2015) and people who self-harm in general (Everett & Gallop, 2000; Vivekananda, 2000). This review found the “problem” of self-harm was often a solution for PdxBPD. Professional responses sometimes did not see beyond self-harm, treating personal solutions as problems, and not exploring the underlying distress. Self-management also contrasted between hiding distress and help-seeking, with hiding distress emphasizing the subjective value of social relationships and complex relationships with family carers.

Family carers experience distress, which paralleled crisis for PdxBPD, yet often had limited involvement with care and all-or-nothing responsibility. This emphasizes the importance of the “triangle of care” (Carers Trust, 2016) with carers involved in care planning and treatment, in true partnership working between people experiencing mental distress, family carers and professionals. However, this experience may not be unique to crisis intervention for PdxBPD, with a literature review across diagnoses finding that collaborative decision-making was not a regular experience and that there was an “us and them” divide between family carers and professionals (Doody, Butler, Lyons, & Newman, 2017).

Though some interventions contributed to reduced self-harm and hospitalization, improvement on depression and hopelessness scales and improvement in dissociative symptoms, largely interventions were of subjective and limited benefit. This review identified factors which may influence the quality of any crisis intervention. Professionals described deficits in resources and knowledge, and their own need for support. Targeted education on “BPD” can impact staff attitudes (Commons Treloar & Lewis, 2008; Miller & Davenport, 1996; Shanks, Pfohl, Blum, & Black, 2011), and it may be prudent to target professionals’ basic training (Warrender & Macpherson, 2018) and have education co-produced with experts by experience (Dickens, Lamont, Mullen, MacArthur, & Stirling, 2019). Given the prevalence of trauma histories in PdxBPD, trauma-informed care should also inform therapeutic relationships (Sweeney, Filson, Kennedy, Collinson, & Gillard, 2018). Clinical supervision has been specifically recommended to professionals working with PdxBPD (Bland & Rossen, 2005) and may be particularly valuable given complexities in decision-making and potential for team conflicts. Professional decision-making regarding risk has been described as an ethical dilemma, with well-intended decisions having the potential for iatrogenic consequences (Warrender, 2018).

PdxBPD had positive and negative experiences of care. These were polarized between feeling professionals were person-centred or diagnosis-centred, having access to care or finding it difficult, being included in joint decision-making or having responsibility removed, and feeling a therapeutic relationship had been established or experiencing stigma and discrimination. Regardless of any interventions design, these factors influence the experience. Furthermore, given interpersonal relationships as a potential trigger to crisis, professional stigma and discrimination can have an iatrogenic and counterproductive impact, as PdxBPD may be triggered back into crisis and feel worse in care (see Figure 3). The lack of hope has been described as a self-fulfilling prophecy, where the attitudes of professionals contribute to poor outcomes (Warrender & Macpherson, 2018).

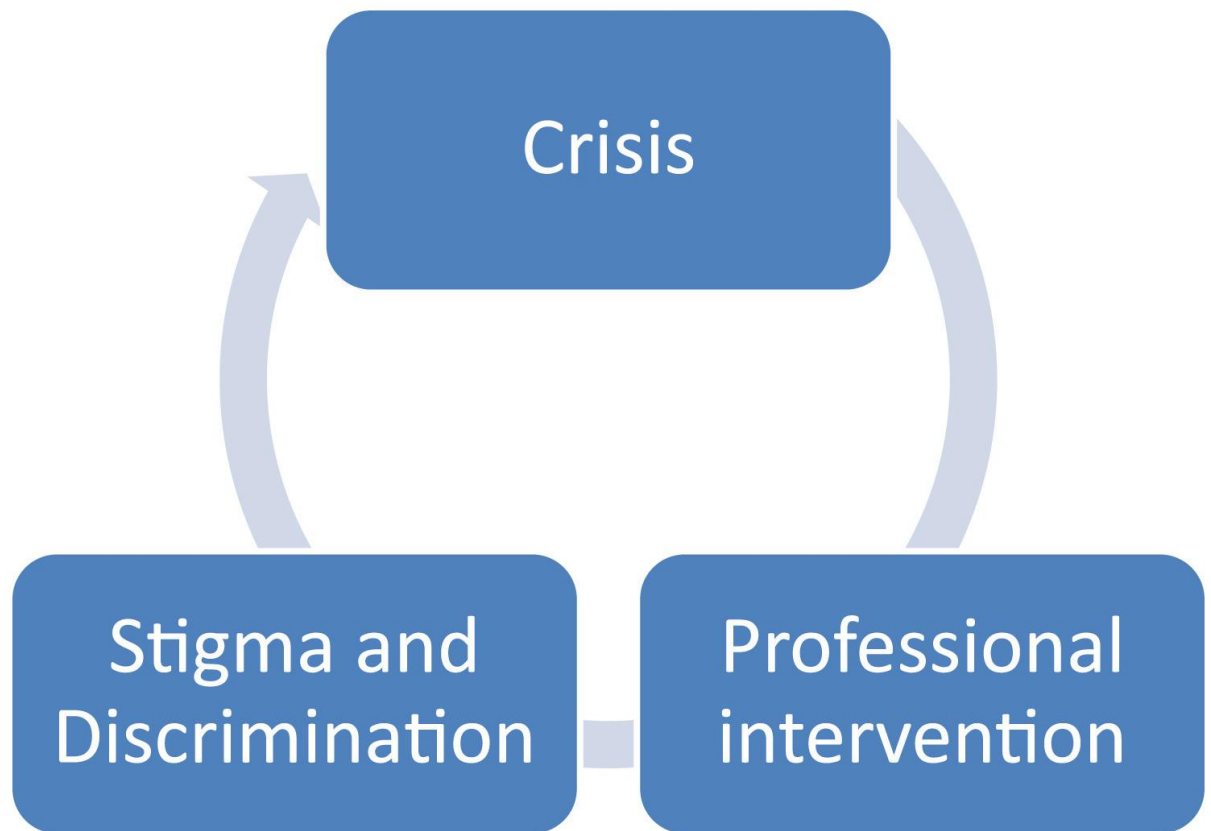


FIGURE 3: The crisis intervention interpersonal cycle of crisis

2.2.6.1. Implications for practice

The subjectivity of crisis experience shows the limitations of diagnosis, emphasizing that any intervention should remain person-centred. While thresholds for intervention were often met after self-harm or suicidal behaviour, professionals should review the ease of access to their services and ensure care goes beyond behaviour management and supports PdxBPD with underlying distress. PdxBPD preferences for care were not surprising or unrealistic in having access to care, joint decision-making and valuing therapeutic relationships. These findings highlight that PdxBPD may have poor experiences of care and that limited resources, deficits in knowledge, uncertainty, team conflict, distress and a lack of clinical supervision are potential factors which influence how professionals respond. Family carers should have access to appropriate support to manage their own distress, and the opportunity to be involved in care planning as per the triangle of care.

2.2.6.2. Limitations

Limitations of this review include the exclusion of groups including under-18s, and people with comorbid “BPD” though not as their primary diagnosis. Furthermore, the exclusion of other personality disorders was necessary to aim for validity around a common experience,

and thus, the difficulties and complexity of all personality disorder diagnoses have not been captured.

2.2.7. Conclusion

The experience of crisis for PdxBPD is complex, with subjectivity in precipitating factors, experience and ways of coping. Family carers experience their own distress and require support, and should be given more opportunities for involvement by professionals. Interventions are available, though often standard care, and despite showing some benefit to PdxBPD, there is inconsistency in that people have positive and negative experiences of care. Several factors influence professional interventions, and implications for practice suggest a review is required of crisis intervention services. This review will inform future research by highlighting the complexity and array of human factors in the delivery of crisis intervention, which may have an influence on recorded outcomes. Future research may be wise to focus on perspectives within single cases, comparing PdxBPD, family carer and professional perspectives on shared experiences, to provide in-depth exploration of interpersonal factors.

2.2.7.1. Relevance Statement

People diagnosed with “BPD” frequently present to healthcare services in times of crisis and are often cared for by mental health nurses. This review captures the experience of people with the diagnosis, family carers and professionals involved in their care. “BPD” is a controversial and complex diagnosis with crisis intervention common but not supported by a robust evidence base. Therefore, the collation of a broad range of literature is important to increase understanding of this area. The review highlights important themes for all professionals to consider when providing crisis care for people with the diagnosis.

2.2.7.2. Acknowledgement

Thanks to Rahul Oza, Online Learning Developer for the School of Nursing and Midwifery, Robert Gordon University, for his assistance in presenting the concept map.

This marks the end of the published literature review.

2.3. Literature review addendum: November 2017 to September 2023

To ensure contemporary understandings of the topic an exact repetition of literature review strategy and process, aside from timescale and databases utilised, was carried out in October 2023. Based on the value of particular databases on the last search, as well as the pragmatic limitation on time, the updated search used four databases (Cinahl, Medline,

Psych articles APA, Soc-index). A judgement was made that these databases were likely to be the most pertinent and there was not a high risk of missing key literature. In the original review, Cinahl and Medline had returned the most papers, whilst web of science, knowledge network and proquest had offered nothing in addition. The timescale searched was from November 2017 (the end search date in published review) to September 2023.

The search returned 1471 papers, with 1195 papers after the removal of duplicates. A review of titles and abstracts gathered 17 papers, 1 of which was removed as it didn't use the 'BPD' diagnosis to recruit patient participants to the study, with 16 papers making it to final review. This comprised 8 qualitative, 6 quantitative and 2 mixed method studies. The returned papers hailed from 8 countries, Australia (n = 4), Sweden (n = 3), United Kingdom (n = 3), Spain (n = 2), Netherlands (n = 1), USA (n = 1), Ireland (n = 1) and Canada (n = 1). Canada was the only country not represented in the original review. Nine papers collected data from PdxBPD, and seven papers collected data from a variety of professionals (with the vast majority being from mental health nurses). Once again families and carers were least represented with two papers. Papers were again quality appraised using the MMAT, with descriptions of all study findings and comments in an additional data extraction table (Appendix 8.6). Analysis of 16 papers revealed findings complementary to the original review, and are discussed here in relation to the existing themes.

2.3.1. Crisis as a recurrent multidimensional cycle: updated

In updated literature, papers explored triggers and experiences of crisis, and impacts on others. Interpersonal issues such as a perceived lack of warmth in others, chronic feelings of emptiness, loneliness and feelings of guilt and shame following attending services asking for help were all considered to be issues which could trigger and drive experiences of crisis. Crisis could often lead to suicidal ideation and behaviour, which could then result in contact with healthcare and emergency services. Crisis also impacts on families and professionals.

Precipitating factors to crisis were found with some consistency, and some in addition to or with more detail than the original review. A quantitative momentary assessment exploring experiences of 153 PdxBPD and 52 healthy controls found that interpersonal stressors could trigger crisis, with lower perceived interpersonal warmth in others linked to suicidal ideation (Kaurin et al 2022). This may too link to crisis whilst in professional care, as some PdxBPD interviewed by Ware, Preston and Taylor (2022) felt that poor interpersonal skills from professionals could increase the risk they may harm themselves. Kaurin et al's (2022) study also found that interpersonal triggers contributed to suicidal crisis, but indirectly,

with interpersonal triggers causing emotional dysregulation, which subsequently led to suicidal ideation. López-Villatoro et al (2023) too explored triggers for crisis using quantitative questionnaire with 103 PdxBPD and found that chronic feelings of emptiness, often arising through traumatic experiences, could be a predictor of suicidal behaviour. Vandyk et al (2019) qualitative interviews with PdxBPD (n = 6) found loneliness could be a trigger to crisis, and connecting with emergency services seen as a remedy for crisis as well as alleviating loneliness. The same study also found a cycle, where attending the emergency department during crisis could lead to feelings of guilt and shame, which could then fuel further crisis. Lundahl et al (2023) captured the views of nurses and psychiatric aides, and some felt PdxBPD in hospital could trigger one another, though no specific detail was offered.

Consistent with the previous review, crisis was overwhelming and recurrent with suicidality and self-harm common, and this often led to responses from healthcare and emergency services. Broadbear et al (2022) conducted a retrospective audit of emergency department attendances for 700 PdxBPD and found the most common reasons for attendance were suicidal ideation, self-harm or overdose, and 73% had attended more than once within a year, showing the recurrence of crisis. Campbell, Massey & Lakeman (2022) also saw mental health nurses in emergency departments and crisis settings describe working with PdxBPD several times in a month. Vandyk et al (2019) interviewed PdxBPD who struggled to employ coping mechanisms to deal with crisis, and would use self-harm, suicidal behaviour and substance use as self-management for crisis, with this leading to the emergency department either through their self-referral, or through police or ambulance. Ware, Preston & Draycott (2022) interviewed 9 PdxBPD and some felt they were more likely to receive help from services dependant on the severity of risk they posed to themselves. López-Villatoro et al (2023) also found that suicidal behaviour was more common in PdxBPD than it was with people diagnosed with eating disorders.

Crisis for PdxBPD was again found to have impacts on professionals and family carers. The impact of working with PdxBPD in crisis meant that nurses (n = 7) could feel powerless, frustrated, a sense of incompetence and poor job satisfaction, though none of these nurses had requested or received clinical supervision (McCarrick, Irving & Lakeman 2022). Relatives of PdxBPD (n = 12) were interviewed by Hultsjö et al (2023), who found that family carers can feel increased anxiety around PdxBPD being in crisis, and that they can benefit from respite when PdxBPD are offered brief admission to hospital.

2.3.2. Variations and dynamics impacting on crisis intervention: updated

Variations in care included access, model of care and team conflict, with many professionals acknowledging they could not offer quality care to PdxBPD. Difficulties accessing care was a prominent complaint in crisis care, and this may explain the prevalence of papers on the brief admission model which appeared to be more accessible. Consistent with challenges in the original review, Acres, Loughhead & Procter (2022) focus groups of carers saw them describe most often using the emergency department as they felt they had limited options when PdxBPD were in crisis.

Several papers had explored brief admission models of crisis care. Helleman et al (2018) used a Delphi study to review expert opinion on the core components of the brief admission model, and stated that the plan must be made in collaboration with the patient, that it should be mentioned in the care plan but that brief admission can only be offered together with treatment from a professional in the community. Enoksson et al (2022) interviewed PdxBPD using brief admission, and found this was rated favourably in terms of offering security through knowledge that PdxBPD could access care through self-referral. Views on a model of brief admission in Australia were collected through interviews from PdxBPD (n = 8) and nurses and nursing assistants (n = 10), with PdxBPD valuing being able to plan their own admissions and use it when they needed it, feeling they gained practical strategies for managing crisis which could be an alternative to self-harm, and some PdxBPD had reduced rates of self-harm as a result (Mortimer-Jones et al 2019). Hultsjö et al (2023) found family carers agreed that brief admission was a more accessible and predictable form of care. However, they also pointed out that even with brief admission places could be limited, and PdxBPD who were denied access may be less likely to apply for the service in future.

Difficulties in accessing care may justify the development of mobile apps, such as Frias et al's (2021) study which used quantitative measures to assess 25 PdxBPD's satisfaction with an app for self-managing crisis. PdxBPD considered the app to be user friendly, said it was soothing and gave them confidence, and they said it would be something they would use frequently when in crisis.

There was again conflict within teams. McCarrick, Irving & Lakeman (2022) found nurses experience disagreements around risk within the multidisciplinary team, and there were differing views on self-harm with some feeling it needs to be prohibited, others feeling if it is prohibited it makes it worse. Taylor, Stockton & Bowen (2023) also saw MH nurses acknowledge differences in the approach between individuals, and strong opinions on how care should be provided.

Mental health nurses were often dissatisfied with care provision. Campbell, Massey & Lakeman (2022) found from a survey of 54 MH nurses that 83% felt PdxBPD weren't adequately managed and 72% cited the reason as a lack of appropriate services. McCarrick, Irving & Lakeman (2022) interviewed 7 nurses in Ireland who said the kind of care they could offer PdxBPD in acute mental health wards did not meet their ideals, and they did not feel well prepared to work with people with the diagnosis through their undergraduate education. McCarrick, Irving & Lakeman (2022) found nurses felt their inpatient environments were not helpful in assisting recovery and that specialist services were needed. Lundahl et al (2023) found through questionnaires with 422 nurses and psychiatric aides that they felt improvements to services could include improved inpatient structure, use of 3-day voluntary admissions (akin to brief admission), and improved outpatient resources. Some MH nurses also felt that crisis care should be viewed as only one small part recovery-oriented care, given the short duration of crisis contact in their crisis resolution team (Taylor, Stockton & Bowen 2023). Vandyk et al (2019) found through interviews with PdxBPD that they felt services could not meet their needs due to the severity and persistence of their symptoms.

2.3.3. Impact of interpersonal dynamics and communication on crisis: updated

Interpersonal dynamics and communication could be influenced by different understandings of 'BPD', with some professionals describing PdxBPD as difficult to work with, and some stigmatising views impacting on care. Not having access to care was perceived as a communication of rejection and invalidation, whilst trust was identified as being difficult to establish between professionals and PdxBPD. Mental health nurses identified the importance of person-centred care, collaboration, validation and connectedness, but acknowledged PdxBPD may experience different approaches depending on the individual professional caring for them.

Acres, Loughhead & Procter (2022) carers saw PdxBPD rejected and invalidated by emergency department nurses, and that whilst physical health was attended to, mental health needs were often overlooked. Taylor, Stockton & Bowen (2023) acknowledged stigma around the 'BPD' label, with MH nurses (n = 7) acknowledging that it could invite suspicion and strong negative responses from professionals. Vandyk et al's (2019) interviews with PdxBPD supported this perspective, with PdxBPD feeling they were stigmatised and discriminated against as a result of their diagnosis.

Professionals could have varied understandings of PdxBPD and their behaviour. Campbell, Massey & Lakeman (2022) surveyed 54 MH nurses working in emergency dept and crisis

settings, and found 74% of MH nurses rating PdxBPD as moderately difficult to work with, however only 33% considered them to be more difficult to work with than people with other diagnoses. McCarrick, Irving & Lakeman (2022) found some nurses at times felt PdxBPD would self-harm to deliberately upset them. Campbell, Massey & Lakeman (2022) survey saw the most divided opinions through 61% feeling PdxBPD were manipulative, and 50% felt they split staff teams. Interpersonal interaction may be complicated through histories of trauma, as PdxBPD interviewed by Ware, Preston & Draycott (2022) shared that they struggled to trust professionals due to their traumatic experiences.

Taylor, Stockton & Bowen (2023) interviewed MH nurses (n = 7) working in a crisis resolution team, and they acknowledged the importance of person-centred care, collaboration, validation and connectedness, though they also recognised that there may not be consistent approaches to PdxBPD given individual differences in the approach of MH nurses. Ware, Preston & Draycott (2022) also found PdxBPD state they received inconsistent support from MH services.

2.3.4. Balancing decision-making and responsibility in managing crisis - updated

There continues to be dilemma and disagreement between how much responsibility PdxBPD feel able, and are perceived by others, to be able to take. Choice is important to PdxBPD accessing care, and there were consistent concerns that compulsory care was detrimental. Decision making around care is influenced by considerations around risk, and families and carers have continued to feel excluded from communication around these decisions.

Enoksson et al (2022) interviewed 16 PdxBPD using brief admission during crisis, and found that having the choice of how and when to use this had positive impacts on their sense of self-determination and responsibility. Ennoksson et al (2022) also found that choice shifted the balance of power for PdxBPD, with them feeling enabled to take more responsibility for their condition and be aware of any early deterioration. Furthermore, more control over being able to come and go as they please, and control over discharge, allowed PdxBPD to maintain work and family commitments. Hultsjö et al (2023) interviews with family carers found consistent opinion, with relatives feeling PdxBPD had increased personal responsibility and sought help in more time. However, Helleman et al's (2018) study agreed that despite having choice, not all behaviour from PdxBPD had to be accepted during a brief admission.

Though PdxBPD using brief admission valued using it whenever they needed it, nurses and nursing assistants were concerned that PdxBPD may become dependent on the service

(Mortimer-Jones et al 2019). Ware, Preston & Draycott (2022) found from PdxBPD that they could feel unsupported where a positive risk-taking approach was used, which encouraged them to take more responsibility for themselves. The complexity around a fluctuating ability to take responsibility seemed to be acknowledged by Campbell, Massey & Lakeman (2022), who surveyed 54 MH nurses working in emergency dept and crisis settings, finding majorities of 93% disagreeing that PdxBPD choose to behave the way they do, and 98% disagreeing that 'BPD' is a self-induced disorder.

Whilst having more choice was felt to have benefits to the care of PdxBPD, the consequences of compulsory treatment were also criticised. Lundahl et al (2023) used a mixed methods questionnaire to explore the views of nurses and psychiatric aides (n = 422) and found 68% felt a week's compulsory admission would increase self-harming, 69% felt compulsory admissions on their wards were too long and had detrimental impacts, and some felt the reasons PdxBPD got worse in hospital were due to letting go of their self-control and self-harming more, losing skills to cope with emotions, and becoming more anxious the closer they get to discharge. Some also felt PdxBPD demanded compulsory care as a way of transferring responsibility to others, to protect themselves from making bad decisions (Lundahl et al 2023). However, PdxBPD felt that both they and MH professionals could share a sense of powerlessness (Ware, Preston & Draycott 2022).

There was a feeling from nurses that they too wanted and felt the benefits of having more autonomy. Helleman et al's (2018) study saw a desire for responsibility to shift away from psychiatry and towards nursing, with contact with a nurse deemed necessary during brief admission, but disagreement that PdxBPD needed to be seen by a ward psychiatrist.

Nurses interviewed by McCarrick, Irving & Lakeman (2022) also felt frustration that the multidisciplinary team could impact on their autonomy, and interviews by Mortimer-Jones et al (2019) saw nurses and nursing assistants (n = 10) using a model of brief admission enjoy the ability to move away from the medical model with no doctors on site. The nurses felt the emotional impact of decision making, yet felt they had developed skills as a result, and improved their ability to set appropriate boundaries, actively listen to PdxBPD, awareness of effective strategies for working with PdxBPD, and also improved ability to support other staff.

Updated papers echoed a complexity of dilemmas and consequences around risk management. Questionnaires by Lundahl et al (2023) found 48% of nurses and psychiatric aides believing long hospital admissions were due to doctors fearing there may be self-harm by PdxBPD after discharge, and mental health nurses in a crisis resolution team also

acknowledged that anxiety around risk might influence their decision making (Taylor, Stockton & Bowen 2023). Families and carers may again experience the ‘all or nothing’ responsibility, with Acres, Loughhead & Procter (2022) finding that carers could feel excluded from communication with nursing staff, often on the grounds of confidentiality. Adding a layer of complication to this, some PdxBPD (n = 9) had inconsistent desires about including family in their care, particularly around risk management (Ware, Preston & Draycott 2022).

2.4. Conclusion

The timeline of completing my original literature review and then going on to collect data has meant that the additional papers since November 2017 onwards did not influence the study questions or design. However, the findings had echoed and supported rather than significantly contradicted or deviated from the original themes. It was interesting to note that one excluded study by Eckerström et al (2020) used the term ‘emotional instability’ rather than use the ‘BPD’ diagnosis, which may be evidence of a trend away from using the personality disorder label given its controversy.

Given the updated review captured similar data, the shape and content of the discussion concept map would have been similar, though additional detail may have been offered to precipitating factors through specific feelings of emptiness, loneliness, guilt and shame. There was consistency offered in terms of what PdxBPD found helpful and unhelpful, though complexities influencing how professionals deliver care also highlighted varied (and sometimes insufficient) education, and difficulties establishing trust with PdxBPD given their previous experiences of trauma. Again, some responses may not offer parity of esteem between physical health and mental health, with physical responses to self-harm offered, whilst mental health and the underlying distress can be overlooked.

The specific concepts further validated by the updated review were:

- Interpersonal issues can trigger crisis
- Internal states triggering crisis (specifically emptiness, loneliness, guilt and shame)
- Crisis was overwhelming and recurrent
- Crisis often leads to self-harm and attempted suicide
- PdxBPD experienced difficulties accessing care
- Crisis care was experienced as inconsistent
- The underlying distress of crisis may be overlooked by professionals
- PdxBPD valued choice and joint decision-making

- PdxBPD experience stigma and discrimination
- Families experienced anxiety when PdxBPD were in crisis
- Families and carers could feel excluded from PdxBPD's care
- Professionals experienced distress working with PdxBPD in crisis
- Professionals described varied access to clinical supervision
- Professionals experienced conflict within their teams
- Professionals experienced anxiety around risk and decision making
- People hold differing views around responsibility for managing crisis
- Professionals felt there were a lack of resources and appropriate services
- Professional education may have an impact on care delivery

The updated literature review allows the most contemporary literature to be synthesised with the original review and concept map. Following fresh data collected during this research, the updated review adds weight and currency to the discussion of the findings later in this thesis, and contributes to a more comprehensive concept map which precedes and accompanies the discussion chapter.

2.5. Chapter summary

This chapter has presented two separate literature reviews, one spanning January 2000 to November 2017, and the update spanning November 2017 to September 2023. In total, 62 (46 + 16) papers were included, and captured across four themes. The literature paints a picture of a crisis as a complex issue within and around a person, and crisis intervention as a complex phenomenon with many issues interconnected. There is no ultimate consistency to experiences and journeys given the heterogeneity of the 'BPD' diagnosis, the subjective nature of human behaviour, and the many influences on the experiences of PdxBPD, their family and friends, and professionals. This very point supports the use of case study research, discussed in the next chapter.

Through exploration of literature, the issue of crisis and crisis intervention for PdxBPD presents itself as a 'wicked problem'. Wicked problems are taken to be problems within social systems where there is confusing information, many decision makers who can have conflicting values, and proposed solutions can have worse impacts than the initial symptoms (Lönngren and Van Poeck 2021). People diagnosed with 'BPD' in crisis experience a range of thoughts and feelings, which influence their behaviour. They are often vulnerable to crisis through having experienced trauma and neglect. The mental states which come prior to behaviour can be both a part of the crisis experience, and also a

trigger to the crisis experience, with these complex human experiences never linear. Behaviour most often alerts professionals when PdxBPD engage in self-harm and attempted suicide, though their underlying distress can be overlooked. Professional response and access to care can be variable, and people present and receive support from a variety of services, though within these services there can inconsistency of service and individual approach, conflict in teams, disagreement around responsibility and an enormous anxiety around risk. Following receiving, or not receiving access to intervention, PdxBPD can feel they have been helped or harmed. In short, the review shows an incredibly complex crisis experience which sees all stakeholders experience a degree of powerlessness, and highlights crisis and crisis intervention as an incredibly complex phenomenon with multiple interconnected issues which cannot be easily understood. The next chapter explores the methodology for the study, utilising the literature review to justify specific research questions and design, and describing what I did and why.

3. Chapter 3: Research Methods

3.1. Chapter overview

This chapter builds upon the literature review to further define the research question, and to explore how I attempted to answer it. This includes a discussion on the philosophy underpinning the research methods, definitions and justifications for case study research, and detailing the methods of data collection and analysis. Throughout, I have attempted to be reflexive and not only state what I did and why I did it, but also reflect on how I think it went, and what might have been done differently. While undertaking this PhD, I have very much learned about the real world of conducting research through thinking, doing, then thinking about it some more.

3.2. Research questions arising from the literature

Before rushing towards a method, Thomas (2021) argues research should start with a purpose and question. I have outlined my interest in crisis intervention for PdxBPD and I have felt this purpose for several years, yet specific questions were necessary before moving forward. Literature reviews have been described as a means to an end, in refining sharper and more insightful questions on a topic (Yin 2018), and the review described in the previous chapter allowed this refinement.

However, not only do specific questions need to be considered, but also of who I am asking these questions. Whilst the broad aim of this thesis was to explore the experiences of PdxBPD regarding their being in crisis and subsequent crisis intervention, understanding is limited without the interconnected experiences of other stakeholders e.g. families, friends, carers, and paid professionals or health and social care workers. There has been critique of the term ‘carer’ as people may not identify with it, considering it to imply burden, with helping considered a normal part of their relationship with the person they support (Hughes, Locock and Ziebland 2013). Thus, the term ‘support person’ was adopted for this study. Furthermore, ‘professionals’ was replaced with the term ‘health and social care (HSC) worker’, to be inclusive of all health, social care and 3rd sector workers who may be in paid roles supporting PdxBPD. As the study only recruited professionals from mental health care, the term ‘professionals’ was retained through write up.

The integrative review found that crisis intervention can be hugely influenced by the resources, understandings and actions of family carers and professionals involved in the care of PdxBPD, with this triangle of human interaction having influences which flow in all directions, to and from each person. It is therefore necessary that research on PdxBPD’s crisis and crisis intervention experiences are understood within this dynamic social world

of human relationships. Whilst the broad overarching aim of the study was to explore in-depth the experiences of PdxBPD around crisis and crisis intervention, specific objectives were developed through engagement with the literature (Table 5).

Table 5: Study objectives arising from integrative literature review
*'People' refers to people diagnosed with BPD, people who support them, and health and social care workers who may be involved in their care
<ul style="list-style-type: none"> • How do people* understand the 'BPD' diagnosis?
<ul style="list-style-type: none"> • What precipitates crisis for PdxBPD?
<ul style="list-style-type: none"> • What is the experience of crisis like for PdxBPD?
<ul style="list-style-type: none"> • What are the experiences of support persons and HSC workers when with PdxBPD are in crisis?
<ul style="list-style-type: none"> • What self-management strategies are employed?
<ul style="list-style-type: none"> • Which HSC workers do PdxBPD access for support, and what is their experience of accessing care?
<ul style="list-style-type: none"> • What are the barriers and facilitators to a good crisis intervention experience for PdxBPD?
<ul style="list-style-type: none"> • What would help support persons and HSC workers provide support to PdxBPD?

Whilst these questions gave some edges to the conversations I had when conducting interviews, I was to later learn that spontaneity of conversation and semi-structured interviews would give me much more than I had asked for, with a real depth of human experience and emotion, some of which could only be articulated fully through metaphor.

3.3. Underpinning philosophy to generating new knowledge

Prior to discussing what I did, it is worth clarifying the philosophical underpinnings of my approach to generating new knowledge. Definitions are clarified and arguments are made for a relativist ontology, and interpretive and constructivist epistemological approach, and a qualitative approach.

3.3.1. Philosophy and being troubled by not-knowing

Philosophy is often viewed as both an intimidating word, and a complex undertaking (a view reinforced by years of teaching nursing students!). However, it is a very human activity, characterized by curiosity and wonder about ourselves and the world and universe in which we live. The word 'philosophy' derives from two Greek terms, philo, meaning 'love', and Sophia, meaning 'wisdom' (McKie 2014). This love of wisdom, driven by a deep curiosity, is

enacted through critical thinking and exploration of ideas and perspectives, and the willingness to change one's mind in the pursuit of understanding. McKie (2014) cites an excerpt from Jostein Gaardner's book 'Sophie's World', beautifully articulating the activity of philosophy:

"A philosopher knows that in reality he knows very little. That is why he constantly strives to achieve true insight. A philosopher is therefore someone who recognizes that there is a lot he does not understand, and is troubled by it. In that sense, he is still wiser than all those who brag about their knowledge of things they know nothing about" (Gaardner 1995, p.53)

Reflecting on my own position in this study, fuelled by my own experiences, I am troubled by the wickedness of this problem, the context of hotly contested debates which spill into service design and clinical decisions, the interconnected and dynamic human parts of the mental health care machine, and the fact that solutions to crisis can exacerbate rather than alleviate distress. This has driven my desire to understand. In being troubled and seeking a direction towards alleviation of this, I must ask two questions; what is the nature of that which I am troubled about, and how best to alleviate this troubled mind and increase understanding? Tomley and Weeks (2015, p.9) writing in a children's book of philosophy (showing that philosophy is for humans of all ages), define the activity as "trying to understand ourselves and our world by asking a lot of questions", with this accomplished through "a great deal of time thinking, wondering, talking and listening". Asking what I am trying to understand and how best to understand it relates to two branches of philosophy: ontology and epistemology.

3.3.2. Ontology: Relativism

'Ontology' is defined as the assumptions made about reality; what things are, and the nature of the world (Ormston et al 2014, McKie 2014, Silverman 2020). Zoë et al (2020) state that broad distinctions between ontological positions are those of realist and relativist. Realist ontology implies a single external reality which exists independently of people's experiences of it (Zoë et al 2020). In contrast, the philosopher Protagoras (490-420 BC), famous for the quote "man is the measure of all things", argued that belief is subjective and relative, and that what is true for one person may be false for another (Buckingham et al 2011). Relativist ontology assumes that there is no shared reality, only a series of different individual constructions which depend on those interpreting it (Guba & Lincoln, 1998; Ormston et al 2014, Lincoln, Lynham, & Guba, 2018).

In regard to mental health problems, it has been argued that ontological considerations such as types of reality or ways of being are crucial, as "mental disorders have more to do

with the human condition, with its social, cultural, and linguistic aspects, than with human nature understood in biological terms” (Pérez-Álvarez, Sass and García-Montes 2008). Indeed, whilst humans are biological creatures (and biology could be argued as having a single reality), the diagnosis ‘BPD’, which is applied to some, is a heterogeneous and contested social construct immersed in huge cultural influence. Furthermore, experiences of crisis are subjective, and crisis intervention takes place through interactions with other people, each with their own unique reality. Thus, it seems necessary to, and one may argue impossible not to, adopt a relativist ontology.

3.3.3. Epistemology: Interpretivism and Constructivism

‘Epistemology’ asks what we mean when we say we know something, and refers to the way we gain knowledge about things how we learn about the world (Ormston et al 2014, McKie 2014, Silverman 2020). One approach, positivism, is rooted in the scientific tradition and takes a realist view of the world, believing in the possibility of deducing universal laws to explain and predict all, including social, phenomena (Parahoo 2014). Whilst I find my natural inclination to reject the value in positivist approach to knowledge as regards to complex human experiences with a plethora of variables, I can accept this may be appropriate with more narrow research questions and a clear hypothesis. However, this study has broad aims and no fixed hypothesis, and thus interpretivist and specifically constructivist approaches are preferable.

Interpretivism arose as an alternative to positivism, the belief being that the social world is constructed by human beings as we interpret and give meaning to our social environments (Parahoo 2014), with this interpretation of events just as important as observation when it comes to understanding social worlds. Where constructivism distinguishes itself from pure interpretivism, is in the notion that there are not one but multiple realities, and different perceptions of what reality is (Parahoo 2014). Furthermore, these perceptions of reality are not passively received but actively constructed by human beings (Ormston et al 2014). The diagnosis of ‘BPD’ is itself a social construction, with a contested validity and usefulness, and different perspectives compete around risk, responsibility and effective care delivery. Thus, the inevitability of multiple realities, particularly when exploring the perspectives of different social positions (that of ‘patient’, support person and HSC worker) is undeniable. Finally, as researcher, my own “undeniable position” (Thomas 2021, p.73) (discussed in chapter 1) is taken into account, as I form a part of the research through developing the project, then undertaking data collection and interpreting the findings. My

own position I would argue is an asset in this study, so long as I am transparent about it, and its role in the generation and construction of knowledge.

3.3.4. Scientific reasoning: Abduction

In terms of scientific enquiry, three major types of inference and reasoning are deduction, induction and abduction. Deduction is a method which begins with a hypothesis which is then tested through observation, with results either confirming or contradicting the theory (Topping 2015). Whilst the study did begin with some theoretical propositions (Appendix 8.7), these were areas of curiosity rather than anything akin to a hypothesis. Yin (2018) describes theoretical propositions as directing attention to what should be examined within any given study and where the evidence should be sought. Douven (2021) distinguishes deduction, which has necessary inferences, from both induction and abduction which have non-necessary inferences. Deduction sees facts deduced from other facts (Silverman 2020), and if the initial facts, described as premises, are true, then the conclusion which follows is necessarily true (Douven 2021). Induction can be broadly described as building knowledge from the bottom up (Ormston et al 2014) and drawing implications from observation (Silverman 2020) by going from singular instances to universal generalisations (Bergdahl and Berterö 2014). Bergdahl and Berterö (2014) argue that there is a tendency to describe qualitative research as an inductive process, though question this assertion, actually arguing that it should use deductive reasoning.

Thomas (2021 p.75) insists that the scientific enquiry in case studies is that of abduction, where expectations of the ability to generalise through social studies are moderated, and accept a “looser generalisation” than may be facilitated through induction in the natural sciences. This looser generalization is fitting with the heterogenous diagnosis of ‘BPD’, and the unique and varied experiences of crisis shown through literature review. Thus, the study aims to explore in depth what can happen to some of the people some of the time, rather than achieve any more of a universal generalization. Abduction is described as arriving at the best explanation (Douven 2021) by drawing conclusions from partial knowledge (Silverman 2020). This method feels more modest, honest and appropriate for exploring the intangible and subjective experiences of a small sample of human beings.

3.4. Qualitative research and case study

The decision to undertake relativist, interpretive, constructivist and abductive research leans logically into qualitative research design. Qualitative research explores phenomena from the interior (Flick 2009), authentically capturing human experience by giving participants a voice (Silverman 2013) and there is a compelling argument for study which

explores the ‘how’ and the ‘why’ through an examination of the experiences of PdxBPD, support persons, and HSC workers involved in their care.

Whilst quantitative research designs are most suitable for numerical data which can be understood through statistical analysis (Lacey 2015), the subject matter under exploration in this study is not befitting to this approach. Given the relativist, interpretive and abductive underpinnings discussed, a qualitative approach is the best and perhaps only justifiable fit to a study of this nature. The basic characteristics of qualitative research are described by Silverman (2020) as having small samples often chosen through convenience, phenomena studied in its context, hypotheses generated through analysis rather than used as a starting point, and varying approaches to data analysis. Parahoo (2014, p.56) describes qualitative research as analogous to the discovery of new “lands, people or customs” learning about their perceptions and behaviour by exploring their perspectives in their own words and in the context in which they exist. Qualitative research also acknowledges that there may be different interpretations of the same phenomena (Parahoo 2014).

Crisis interventions for PdxBPD are complex and quantitative studies such as randomised control trials (RCTs) have not proven effectiveness (Borschmann et al 2012, Monk-Cunliffe et al 2022). This may be due to a lack of clarity around interventions and the specific mechanisms through which they operate. However, one could also argue that the RCT approach is severely limiting on this topic, with so many variables and context around care, and there is insufficient theoretical understanding of the dynamics of the human experience. The UK’s Medical Research Council (2000) argues that a good theoretical understanding is needed of how interventions cause change, and experts have prioritised building a knowledge base for health care systems to improve early intervention for ‘BPD’ (Chanen et al 2017). Exploratory qualitative research can be of significant value prior to RCTs, or as in this study, used as the most appropriate method in its own right. Moreover, it has been argued that case study research may provide insights which RCTs cannot (Yin 2018), and provide answers in ways that clinicians can transfer and apply more readily (Morgan 2014).

3.4.1. Case study

Based on the arguments presented above, I contend that exploring the social world of crisis intervention for PdxBPD requires a qualitative approach. Moreover, given the need to ensure multiple perspectives are explored in depth, I argue that the more specific and appropriate approach to undertake this exploration is through case study. Forester (1996) argued that a general approach to all research is not well reasoned, and that knowledge in

instances where there is significant individual variation, (evidenced in this study through a heterogeneous diagnosis with multidimensional experiences of crisis) could require 'thinking in cases'. The need for thinking in cases was echoed by Zanarini et al (2010), stating a need for more studies on PdxBPD in real life treatment situations. However, considering ethics, an observational study of seeing PdxBPD when they are actually in crisis may be hard to justify, given difficulties with informed consent when mental state is impaired, and concerns that research may interfere with the potential effectiveness of intervention. Thus 'real-life treatment situation' must be substituted for a reflection on the real-life treatment situation, facilitated at a later date when the person feels able to discuss their experience.

Case study has various definitions, though there is general agreement around key characteristics of exploring specific phenomena in depth. Thomas (2021) emphasises that case study is a focus rather than a method, and cites Stake (2005, p.443) who emphasises that "by whatever methods, we choose to study *the case*". Other scholars conceptualise case study research as an in-depth exploration, from multiple perspectives, of the complexity of a particular case, which is understood within its real-life context and unique set of circumstances (Stake 1995, Simons 2009, Yin 2018). Thomas (2021, p.12) considers various definitions, and offers his own which I have found useful:

"Case studies are analyses of... phenomena which are studied holistically by one or more methods to illuminate and explicate some analytical theme".

I feel I need to give a special 'shout out' to Gary Thomas (2021), and his work 'how to do your case study (third edition)', as prior to being recommended his book, I felt a little lost, and struggled to grasp 'case study' and what it meant. I mention this to defend my attachment and reliance on his writing in supporting much of what I have done, and to signal agreement with him that case study can be complex and confusing when so many authors use different terminology. Writing in language I found accessible and understandable, he suggests the need to select a subject, purpose, approach and process.

3.4.2. Defining the case and its context

Definitions of what constitutes a case are specific to individual studies (Clarke and Reed 2010), and the subject chosen here, and thus the 'case', is a person diagnosed with 'BPD' who has experienced crisis and crisis intervention. This is a 'local knowledge case' as I have been immersed in the topic of 'BPD' for several years (see 1.3 "Doing a Dan Warrender": my undeniable position in the study). Thus I 'know' (written with a tentative hesitancy!) much about the topic, and I want to understand it further.

The context which PdxBPD find themselves 'in' requires us to consider both the physical world, and the sociological world of ideas. Yin (2018, p.15) argues that case study is explored "in depth and within its real-world context, especially when the boundaries between phenomenon and context may not be clearly evident". Given PdxBPD are people and social beings, and they enter human systems, their experiences cannot be explored in isolation of this. In terms of the physical world, due to my geographical location, cases sat within one health board in the North-East of Scotland which at time of writing has a population of over 500,000 and no specific crisis intervention service for PdxBPD, with people treated through standard care. However, the context PdxBPD are 'in', and arguably that which may have more influence over their treatment, is that of ideas and cultures. The 'hotly contested' debates (discussed 1.2.4) are fused with frequent use of services by PdxBPD, 'BPD' being a stigmatized diagnosis, limited evidence bases for intervention, mixed experiences of support persons who are often overlooked, policy such as the mental health and suicide prevention strategies, and guidelines specific to 'BPD' which present good practice guidelines though which may not be followed. The literature review illuminated further context in the professional education of staff, conflict in teams, limited resources and professionals experiencing their own distress. As well as the physical space, this is the psychological and sociological space which PdxBPD find themselves 'in'.

3.4.3. Case study purpose, approach and process

In terms of purpose, the study is instrumental, with the aim to better understand crisis and crisis intervention so I might consider how people can be helped and improvements to care may be considered. To this end, there is more specifically an explanatory and exploratory purpose. Whilst explaining may be the most common reason for a case study, explanations are always limited. What case study does offer is an ability to look at the multifaceted nature of a case, relate one part to another and explore how issues are inter-related. In this Thomas (2021 p.131) says case studies are "the most powerful engine of potential explanations". However, I would also argue the purpose needs to be exploratory, as not everything is known, about what is not known. Whilst some things may be known enough to be explained, I believe that the dynamics of human subjects navigating complex systems and interacting with other human and their own dynamics, will always have an exploratory element. There may always be more to know.

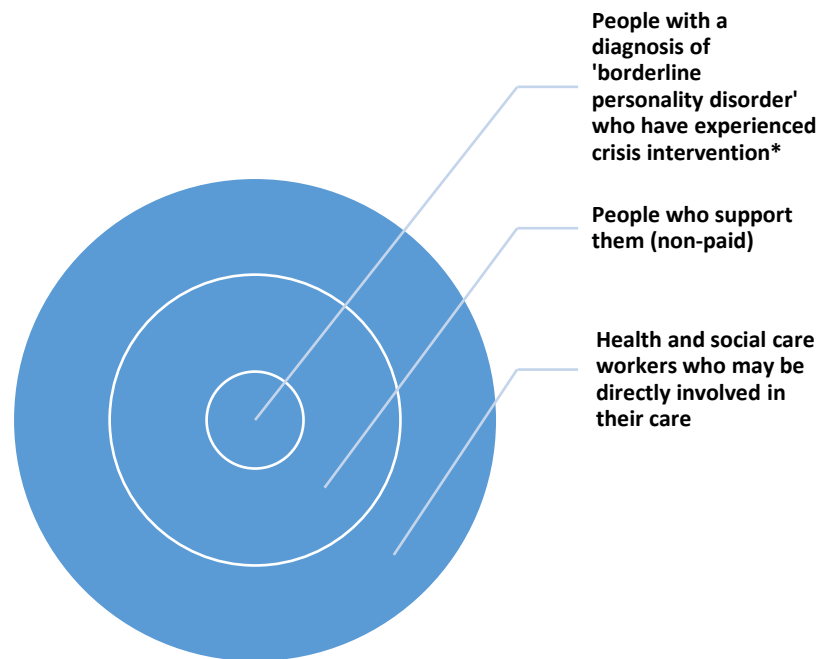
Thomas (2021) offers five types of approach, and whilst I can exclude two immediately and say I am not testing a theory or conducting an experiment, I am in some way adopting the others. The approaches of interpretation, building a theory and drawing a picture all felt

consistent with my aims. Interpretation acknowledges my role and undeniable position in the study, whilst building theory and drawing a picture are synchronous with my intent of explaining how and why things happen, and in doing this, illustrating this through building a conceptual framework, expanding on the literature review.

Thomas (2021) furthermore usefully sets the process of completing case studies, and this helped me decide to do a multiple, parallel, retrospective and nested case study. Given 'BPD' is a heterogenous diagnosis, having one person as a single case would not effectively represent 'BPD', and would also not offer illumination of any differences in care.

Furthermore, multiple cases have been described as providing more compelling and robust evidence, and also allowing comparison between cases (Yin 2018). It was decided to explore between 4 and 6 cases. There is no magic number specified in case study literature and this choice was primarily pragmatic, with 4-6 cases assumed to be enough to gain considerable depth, whilst being achievable for one person to collect and analyse data in a limited timeframe. These cases were to be parallel in having no relation to one another and not being studied in sequence, and they were retrospective in looking back at the previous experiences of PdxBPD in crisis. Finally, given PdxBPD were being explored in their context, the best way to do this was through including other people from their social world. It is further argued that cases should include multiple sources of evidence, as a single perspective is not enough to provide a full account or explanation of the research issue (Lewis and McNaughton Nicholls 2014). To this end, whilst PdxBPD are at the centre of a case, people who support them and professionals who work with them were also 'nested' in the case (see figure 4). As understanding cases involves their context, this relies on multiple sources of evidence and relativist perspectives with "multiple realities having multiple meanings" (Yin 2014, p.17).

Figure 4: The case



3.4.4. Summarising the characteristics of this case study

Thus, if asked 'what kind of case study?' I was doing, I would propose this rather lengthy, but hopefully clear, explanation: This is a case study where the subject is a person diagnosed with 'BPD' who has experienced crisis and crisis intervention. The purpose is instrumental, in aiming to explore and explain the person's experience in-depth. The approach is to interpret these experiences, attempt to build theory and draw a concept map to illustrate connections between circumstances. The process is to have multiple parallel case studies to explore different people's experiences, which are not sequential in any way and can be explored at the same time, retrospectively as PdxBPD are reflecting on previous experiences. The study also adopts a nested process, with case studies where PdxBPD are central but people who support them and professionals who work with them are 'nested' in the case able to provide additional perspectives. This is summarized in table 6.

Table 6: Characteristics of this case study

Subject	Purpose	Approach	Process
People diagnosed with 'BPD' who have experienced crisis and crisis intervention	Instrumental Explanatory Exploratory	Interpretive Building theory Illustrative	Multiple cases Parallel Retrospective Nested

3.5. Research methods

Following the underpinning philosophy and thinking behind what I did, this section on research methods explores what I actually did in the real world. In short, I spoke to people by interviewing them, analysed the data, then wrote it up into this thesis. Whilst the narrative of this section includes the sequence of ethics, data collection and then analysis, each of these things had been carefully considered prior to, yet also whilst they were being done. It is hard to organize this neatly into a story, as the reality has been me living in a melting pot of thinking and doing, all at once.

3.5.1. Ethical considerations

There are significant ethical implications of doing this study, given PdxBPD are a vulnerable population who have often experienced trauma, and continue to struggle with emotional distress. However, the World Medical Association (2013) helpfully highlight that it is unethical to omit vulnerable and underrepresented groups from research. I consider myself a thoughtful and philosophically minded individual who genuinely cares and considers the ethical implications of my actions in all aspects of the way I live and work (and find that rules and laws don't necessarily correspond to ethics much of the time), and I make a clear distinction between meaningfully considering ethics, and 'doing the forms'. Although ethical processes may prompt and safeguard people, if I do these things purely to get through the process, one might argue that is subservience rather than good ethics, obedience rather than moral virtue. I like to think that I would consider the experiences of PdxBPD because I feel it's the right thing to do, and not just because forms or processes tell me I must. Whilst I do not have space to fully detail my own personal ethics, I wish to emphasise that what I did, I did because I really care about people.

I carefully considered ethics through exploring the declaration of Helsinki ethical principles for medical research using human subjects (World Medical Association 2013), and I noted the necessity of beneficence, non-maleficence, fidelity, justice, veracity and confidentiality (International Council of Nurses 2003, Parahoo 2014). These six ethical principles have been synthesised into four rights of research participants (International Council of Nurses 2003, Parahoo 2014), and consideration of each of these is offered below (table 7), and threaded through the discussion which follows.

Table 7: Consideration of ethics and participant rights		
Participant rights (International Council of Nurses, 2003)	Potential conflicts with patient rights	Steps taken and how potential conflicts will be addressed
Right not to be harmed	Participants recruited to the study before they are well enough to do so	<p>Participants not to be offered recruitment flyer until crisis intervention is completed, or after assessment deems further intervention unnecessary</p> <p>The professional acting as recruitment agent to use clinical judgement and avoid any dissemination of flyers if they feel it would have adverse effects</p>
	Participants may be vulnerable and have ongoing mental health issues	Researcher has necessary skill to handle this effectively, being a registered mental health nurse, and currently practicing as a mentalization-based therapist, and working with people diagnosed with 'BPD'
	Participants may have a history of traumatic experiences	Study to follow trauma informed principles, including safety, collaboration, transparency, empowerment, choice and control (Sweeney et al 2018)
	Participants may find content of interview distressing	<p>Public involvement has informed how to safely conduct interviews with these groups (see appendix 8.8)</p> <p>Pre-empt difficult conversations by asking if there are any questions or</p>

		<p>content participants wish to avoid</p> <p>Offer participants to attend interview accompanied by a support person</p> <p>Remind participants of right to withdraw at any time</p> <p>Be flexible and able to stop interview at any time for any reason</p> <p>Offer participants information on relevant supportive resources following interview</p>
Right of full disclosure	Participants may not have time to read participant information sheet and ask questions	Ensure there is a minimum of 48 hours between dissemination information sheet to participant and data collection
	Participants may not understand information sheet or rights	<p>Ensure participant information sheet is in language and format which can be understood</p> <p>Confirm consent in writing prior to interview</p> <p>See informed consent as an ongoing process</p>
Right of self-determination	Participants could potentially have incapacity to consent to research	<p>Operate under the assumption that people have capacity to make decisions</p> <p>Having a mental health diagnosis is not an indication of incapacity</p> <p>If there are any doubts about capacity, do not proceed with data collection</p>
	Ensure informed consent	See above 'right of full disclosure'

	Participants may feel they do not have control or choice in how they participate	Offer participants: Choice to not participate Choice of date and time of interview Choice of location of interview (own home or university) Choice of method of interview (face to face or video call) Choice of who else is offered the opportunity to be part of their case study
	Participant views may be misrepresented by researcher	Offer all participants transcripts for verification and validation of their meanings
Right of privacy, anonymity and confidentiality	Participants may be identifiable within research	Anonymise names and take steps to minimise any identifiable features or content

3.5.2. Public involvement

Public involvement was also sought to inform the research process with respect to study aims, ethics and potential participant experience. The public are said to always offer unique, invaluable insights when designing, implementing and evaluating research (Staley 2009). These discussions can influence the participant experience in the research process, with feedback allowing refinement of appropriate and accessible information, and acceptable and sensitive methods (Involve 2018). Prior to including PdxBPD and relevant stakeholders in the study, public involvement was gathered through twitter for PdxBPD, email for professionals and attending a carers group meeting (Appendix 8.8). This informed the recruitment and data collection processes in particular, with emphasis on safety, choice, transparency which are explored later in this chapter (see 3.5.7: trauma informed interviewing).

3.5.3. Ethical Approval

Ethical approval was obtained from relevant bodies who reviewed the research proposal and all research instruments including participant information sheets (Appendix 8.9 - 8.11), consent form (Appendix 8.12) and interview topic guides (Appendix 8.13 – 8.15).

Completing a research ethics research student and supervisor assessment (RESSA), I sought approval from the Robert Gordon University Nursing, Midwifery and Paramedic Practice School Ethics Review Panel (SERP). An initial submission on 16th December 2020 received a response which sought clarification and amendments on 13th January 2021. Approval was granted by SERP on the 2nd February 2021 (Ref: 21-01, Appendix 8.16).

After completing project data through the integrated research application system (IRAS), ethical review was sought from the East of Scotland Research Ethics Service (EoSRES). I was invited to and attended a EoSRES research ethics committee (REC) on 16th July 2021, held online through zoom teleconference at 1.30pm. Following the meeting which had felt reasonably straightforward, I received an email 27th July 2021 which listed 12 items where either further information or amendments were required. The amendments and clarification requested included a clearer and more robust recruitment process, detail around the assessment of participants capacity, how participants at increased risk of harm would be supported, changes to the recruitment flyer, and detailing robust supervisory arrangements.

Following these changes, the REC reviewed the study protocol and documents, and granted a favourable ethical opinion on 10th September 2021 (REC Reference 21/ES/0074, IRAS ID 296337, Appendix 8.17). Due to the study taking place during the Covid-19 pandemic, a study exemption form was required to request face to face contact with participants for the following justification as stated in the application:

“This study is interviewing people about their experiences of crisis intervention. Sometimes, given this can be distressing, people would prefer to talk face to face rather than online or over the phone. This exemption request is to provide as much choice as feasible for potential participants”

On the 21st of October 2021 the project was registered with the NHS Grampian Research & Development Office, and as such gained Research and Development Management permission to proceed locally (Appendix 8.18). Permission and a ‘research passport’ were granted and a ‘letter of access for research’ was received, confirming my right of access to conduct research through NHS Grampian. One minor amendment following successful ethical review was to additionally offer Zoom as an online platform for interview, to

increase the options for those who may prefer this to Microsoft teams. Documents were updated to include this and submitted again through IRAS using the amendment tool. After being submitted on 29th October 2021, the amendment was approved and a letter from Research and Development dated 5th November 2021 stated this amendment did not alter existing permissions granted. There was also a routine research monitoring query sent and resolved on 21st April 2022.

Whilst this ends the section on ethics and ethical approval, ethical considerations are also threaded through the following sections in terms of what I did, with ethics connected to the real-world activity of research.

3.5.4. Sampling and recruitment

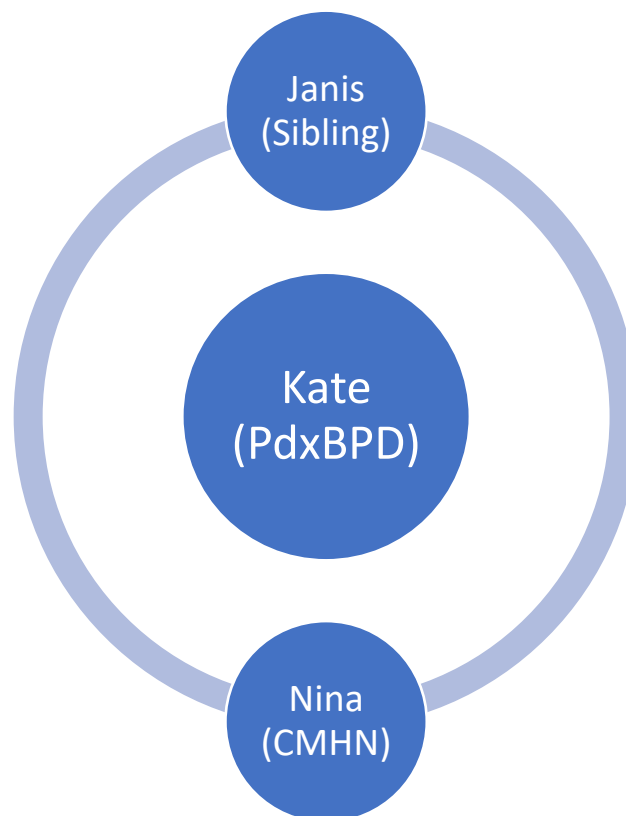
The study employed both purposive and snowball sampling. Purposive sampling is where potential participants are predefined, based on assumptions about which individuals would provide data of the most relevance and depth (Procter et al 2010, Hunt and Lathlean 2015). Potential participants were necessarily PdxBPD who had experienced crisis and crisis intervention. Exclusion criteria required that I ensured participants were aged over 18, and there were no participants who had been treated by me as a mental health nurse, to avoid role blurring between me as ‘nurse’ or ‘therapist’, and ‘researcher’. Snowball sampling was necessary to complete the nested cases. Snowball sampling is where participants refer people they know into the study (Parahoo 2014). To ensure autonomy of participants in the cases, PdxBPD had control over who they identified and recruited into their case.

Recruitment officially began 5th November 2021 when I circulated e-flyers (Appendix 8.19) online via social media, and through NHS gatekeepers. Using social media was important to give autonomy to PdxBPD, as without this, their involvement would rely on being given the opportunity by health and social care staff. This may have been unethical on two counts, one with perhaps over-protective paternalistic staff thinking they were protecting PdxBPD by withholding information about the study to them, and two, that given relationships between PdxBPD and professionals who work with them can be fractured and difficult, professionals may not want to give PdxBPD the opportunity to comment on care they had received. As it was, four of the six PdxBPD recruited came directly via social media, whereas two PdxBPD were informed of the study by professionals. Recruitment ‘snowballed’ with support persons and professionals by giving PdxBPD information about the study, and asking them to forward a flyer (Appendix 8.20) to anyone they wanted

included as part of their case. At each stage, recruitment ensured autonomy thorough requiring people to contact me via email if they wanted to be included.

All potential participants received an information sheet, consent form, and were offered the chance to ask any questions. There was a minimum of 48 hours between giving information and conducting interviews, ensuring time to review information and ask questions. In total I recruited 6 cases, and 16 people. Three other potential participants were in contact; one who declared interest then didn't respond, then a further two could not be included in the study due to the full sample quota being reached. I emailed these people apologising that I could not include them, but thanking them for their interest. Participants were made up of six PdxBPD, four support persons, and six professionals. The cases and nested participants are displayed below:

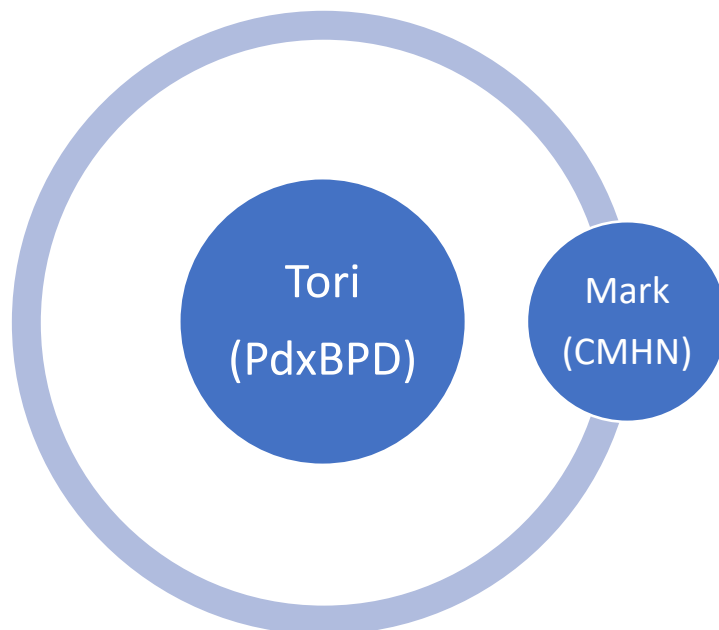
Case 1:



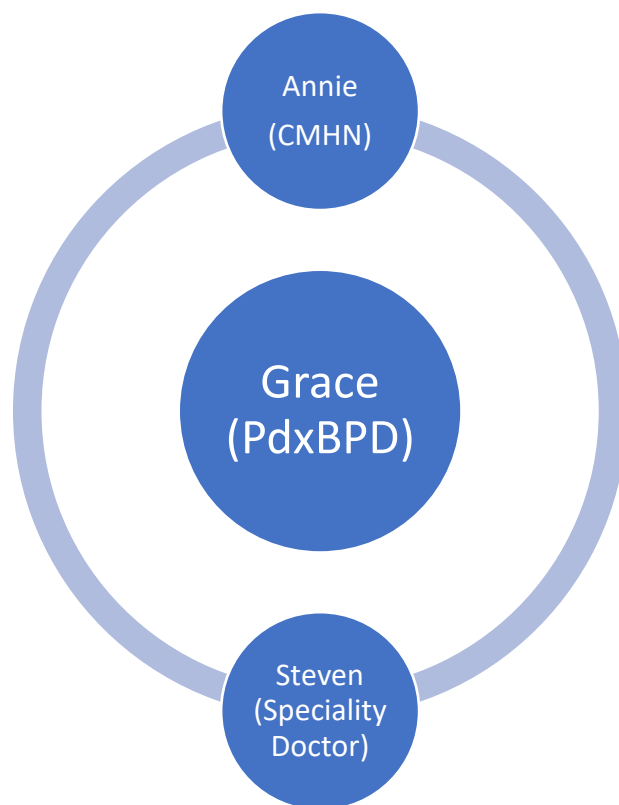
Case 2:



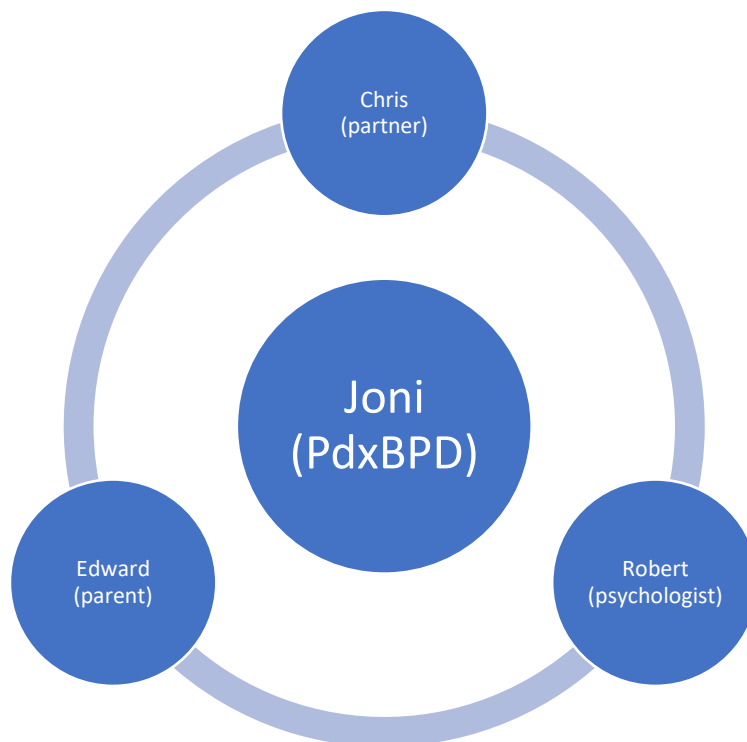
Case 3:



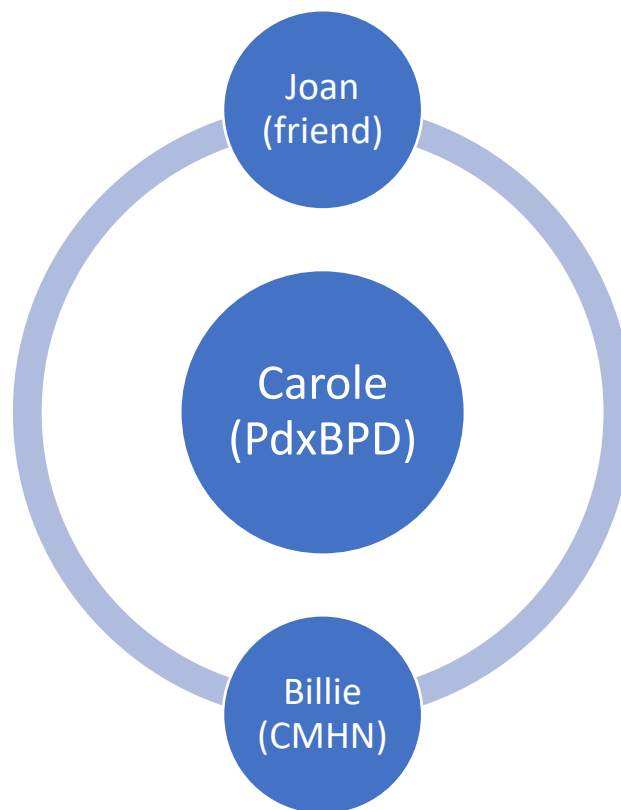
Case 4:



Case 5:



Case 6:



Parahoo (2014) cites a drawback of snowball sampling in that participants may recruit people with similar outlooks to themselves. I noted that all PdxBPD who had professionals nested in their case chose people who were part of long-term care rather than those who may have responded to them in crisis. Alison in case two however chose not to have anyone else included.

3.5.5. Ensuring informed consent

One of the biggest ethical issues prior to undertaking interviews was informed consent. NICE (2009) suggest that the nature of crisis for PdxBPD mean there can be considerable issues with consent. However, the British Medical Association (2009) suggest assessments of capacity should not be based on having a mental health diagnosis, and the adults with incapacity (Scotland) act (2000) suggests beginning with the assumption that people have capacity. Had there been doubts about a person's decision making or understanding, I would have made the decision to discontinue data collection. However, there were no concerns around capacity of any participants during the study.

Dew (2007) argues that due to impulsivity in PdxBPD, informed consent processes taking place over more than one visit may increase the validity of consent. Though there was not more than one visit, there were several instances of contact through emailing and arranging

interview, before consent was confirmed at interview, and a minimum of 48 hours in between the person receiving the participant information sheets and conducting the interview. Autonomy was considered through the onus being on participants to contact me, and informed consent was enacted as a “process rather than a one-off event” (Parahoo 2014, p.104).

Whilst participants could withdraw at any time, I intended to use professional judgement to assess whether there was any impact to informed consent during the data collection process. I am a registered mental health nurse and actively practicing mentalization-based treatment practitioner, and thus felt I had the necessary skills for this assessment.

3.5.6. Rationale and considerations for semi-structured interviews

Individual interviews were chosen as participants would be discussing emotional experiences, and being face to face is crucial to be sensitive to interviewee needs (Tod 2010). Although focus groups may have gathered some useful information, they have been described as unsuitable for the study of some sensitive issues (Parahoo 2014).

Interviewing 1-1 allows attention to focus on one person’s experience and mental state, and adapt according to their specific needs. Furthermore, interviews are a method which can be directly targeted towards case study topics and allow insightful explanations (Yin 2018).

Semi-structured interviews maintained focus on the specific topic and area of interest, though had the flexibility to explore additional participant experiences and unanticipated issues (Tod 2010, Parahoo 2014). To the end of giving some structure, a topic guide was developed based on the literature review. Topic guides (Appendix 8.13 – 8.15) had slight variations for interviewing PdxBPD, support persons and health and social care workers, with the same topics explored from different perspectives.

I deliberated over practical as well as ethical issues and compiled a list of considerations (see table 8).

Table 8: Interview Considerations	
Interview Considerations	Preparation, safeguards and rationale
Practical Considerations	
Recruitment	Recruitment process utilised social media as well as treating HSC who were asked to hand PdxBPD flyers following intervention when they are not in crisis. PdxBPD had the autonomy to contact the researcher and indicate their wish to be involved in the study.

	PdxBPD had autonomy over who else they include in their case, and could disseminate flyers to any support persons or HSC workers they choose.
Time	Planned for an hour and a half, but expected 45 mins and aimed for an hour maximum of actual interview. Maximum of two interviews in a day, to avoid interviewer fatigue and decrease quality of data.
Venue	<p>Needed comfort for participants (both physical and psychological), privacy and quiet (King and Horrocks 2010)</p> <p><u>Options explored were:</u></p> <ul style="list-style-type: none"> • Patients own home* • Support persons own home* • University premises • NHS premises • Microsoft teams or Zoom • Telephone <p>*For patients/families own home I considered interviewer safety and a safety protocol was developed which included giving time and location to 2 trusted colleagues, with checking in and checking out required.</p>
Who will be interviewed	One person at a time, however PdxBPD could be accompanied by a support person to increase their comfort.
Who will be the interviewer	<p>I was lead researcher and interviewer.</p> <p>Though public involvement indicated a choice of gender of interviewer as important to PdxBPD, the participant information sheet was clear that I was the interviewer, and a man. Potential participants who were uncomfortable with this could choose not to participate.</p>
Number of interviews	<p>To keep data manageable, there was a maximum of 4 different interviews per-case.</p> <p>Consideration of more interviews per-case would have been considered if recruiting less than 6 cases.</p>

Question Development	Questions for interview were based on study objectives, and amended following consultation with relevant stakeholders.
Data Recording	Recorded with Dictaphone with participant consent
Ethical and Emotional Needs	
Dress	<p>Interviewer attire could be important as it could give an impression which impacted the dynamics of interaction (King and Horrocks 2010)</p> <p>Dress was smart-casual to appear professional, yet less formal/intimidating.</p>
Consent	<p>Re-established consent at beginning of interview, reminding participant of the right to withdraw.</p> <p>Consent considered an ongoing process.</p> <p>Comfort of participants was monitored throughout.</p>
Role conflict	<p>I have roles as nurse and therapist, but in these interactions my main focus was being a researcher. I would have drawn boundaries within interview sessions if needed.</p> <p>Case participants who I had known in another role would have been excluded from the study for this reason.</p>
Discomfort with recording equipment	An audio recording could have made participants self-conscious. I began recording early to settle quickly while going over consent.
Accessible and sensitive interview questions and strategy	<p>Interview schedule/topic guide was reviewed by PdxBPD and support person groups to ensure accessible and sensitive language and questioning.</p> <p>I planned an interview strategy which eases participants in and establishes rapport, and eased them out, moving away from disclosing their experience and thus handing back as much control as possible (King and Horrocks 2010).</p>
Establishing trust and rapport	<p>Establishing rapport could have been challenging.</p> <p>Personal contact prior to interview was very important. I revisited the aims of study and what</p>

	would happen in interview, mentioning confidentiality and ensuring informed consent.
Managing distress	<p>I considered options for participants, should they become distressed in interview:</p> <ul style="list-style-type: none"> • I allowed PdxBPD and support persons to be accompanied by another person during interview • Offered participants the option to decline discussing any topics they wished to avoid • Would offer a short break • Could move to another topic • Could terminate interview and reschedule • Could withdraw from study
Exiting the interview safely	<p>Unethical to leave a person just after disclosing difficult content. Ended interviews by asking more general questions about improving care.</p> <p>Participants were left with an A4 sheet of signposting to helpful local and national resources (Appendix 8.21).</p> <p>I asked if there was anything else participants wanted to say/tell, or any questions about the research. Finished by asking people what they had planned for the rest of their day.</p>

3.5.7. Trauma informed interviewing

Given the literature suggests many PdxBPD may have experienced trauma, it was important to consider trauma-informed principles in guiding the conduct of the study, particularly when coming into direct contact with people. Sweeney et al (2018) outline ten trauma informed principles, some of which relate to services and systems, and some of which relate to conduct in interpersonal relationships.

Most relevant to my engaging with people in this study were those which related directly to interpersonal relationships; seeing through a trauma lens, sensitive discussions about trauma, trustworthiness and transparency, collaboration and mutuality, empowerment, choice and control, and safety. These are outlined alongside the approach taken to acknowledge and respect these principles (see table 9).

Table 9: Trauma informed interviewing

Trauma informed principle (Sweeney et al 2018)	How I attended to this in my approach to interviews
Seeing through a trauma lens	Seeing through a trauma lens requires understanding the prevalence, signs and impact of trauma, appreciating how this may influence the mental state and therefore behaviour of people affected. This was particularly important given the association of trauma with 'BPD'. I was aware of trauma and its impacts given my role as lecturer in mental health nursing where I taught students about trauma, and also in my role as nurse therapist, where I worked with people and had experience of recognizing and sensitively attending to impacts of trauma.
Sensitive discussions about trauma	Whilst participants were not being asked directly about traumatic experiences, there was huge potential that these could arise at some point, and they did. Discussions about trauma were respectful and sensitive, with people given a choice over whether they wanted to discuss them. Participants who disclosed trauma were responded to with empathy, reminded that they had complete choice over what they talked about, and offered the chance to stop the interview. Attention was paid to these moments and traumatic stories were not chased in any way, prioritizing the wellbeing of the person in the room.
Trustworthiness and transparency	People experiencing trauma have lived with secrecy, betrayal and powerlessness in relationships, thus positive relationships should be the reverse, emphasizing openness, transparency and respect. The main ethos behind being trustworthy was me doing what I said I would do, and not doing anything unexpected which I had not informed people about. This included basic things such as being on time, meeting people where and when they had agreed, and responding honestly and in a timely manner to all queries. Whilst participants all received information about the study, each were also given the opportunity to ask anything further about me or the study at the beginning and end of interviews.
Collaboration and mutuality	Given people who have experienced trauma may experience replications of power imbalances in interactions with others, and acknowledging I may be perceived as powerful being a mental health nurse, academic and researcher, I opted for smart casual dress for interviews. What interviewers wear has been described as important in influencing the dynamics of the interaction (King and Horrocks 2010). I also made a point of acknowledging, and appreciating, that people were sharing a lot of their personal

	<p>stories with me, and I offered the opportunity for them to ask anything about me. If they were curious about my opinions on any of the subject matter, this was ‘parked’ until the end of the interview so as not to cloud or bias their own unique perspectives.</p>
<p>Empowerment, choice and control</p>	<p>Trauma survivors may have experienced a lack of power and control. To ensure this was not re-enacted through interviews, participants were given as much choice as possible. They had the choice of participation, choice of time and venue for interview, and choice of having someone else support them throughout. Whilst consideration was given to the choice of gender and biological sex of interviewer, this was not possible due to me completing this as my PhD study and facilitating the interviews. However, the information sheet clearly specified that participants would be interviewed by me, a man, and people had the choice not to pursue participation at that point. The language I used throughout interview reflected attempts to empower interviewee’s and decrease any power imbalance.</p>
<p>Safety</p>	<p>Trauma is characterized by threats to physical and emotional safety, which can be re-enacted in subsequent relationships. During face-to-face interviews, personal space was respected both through common courtesy, but also mandated through covid-19 specific social distancing still in play at the time of interviews. Psychological safety was respected through attending to all aforementioned principles, attuning to the mental states of participants and looking out for any signs that people may not feel comfortable.</p>

3.5.8. Interviews and reflections

I conducted sixteen interviews, carried out between 13th December 2021 and 19th August 2022. Getting to the point of actually interviewing people was extremely gratifying after a long slog of a process which saw me come through two postgraduate research modules, a year’s temporary suspension of studies, the impact of covid-19, a transfer viva, university ethics then NHS ethics. Being aware Donald Trump had been elected as the next president of the united states as I had my first supervisory meeting in November 2016, it felt like the world had turned many times, and changed enormously, since the beginning of this journey. Following registering as a PhD student in March 2017 I finally did my first interview over five years later in December 2021. Having spent a large amount of time with documents and pieces of paper, the moment I sat down with a person to hear their story, I was reminded of the reasons I had interest in the subject and had started the PhD process;

I wanted to complete research to better understand and hopefully improve the future experiences of human beings. This was why it mattered.

I tried to set an appropriate tone at the start of each interview, emphasizing the persons choice and ability to control the situation. Taken from one of the transcriptions, I said to someone:

“I guess important to say again, that anything you don't feel comfortable sharing or anything that, you know what I mean, just feel free to say pass or no comment or whatever. And you're in total control of this. We'll probably kind of bounce around with a few questions. It's fine if we go off on tangents and stuff like that”

Whilst these were individual interviews, PdxBPD and support persons were offered the chance to be accompanied by someone they trusted if it would increase their comfort. Two PdxBPD had a partner present as they answered questions. Some participants knew who I was from my writing and presenting on the topic, and I speculated that this may have positively influenced their participation. Interviews ranged in length, though generally interviews with PdxBPD were quite long, and others with support persons and HSC workers shorter. Interviews with PdxBPD averaged 90 minutes, with support persons averaging 77 minutes and professionals averaging 82 minutes.

Most interviews were longer than the hour which was planned, and this may suggest that people have experienced not being heard nor understood, and relished the opportunity to share their story. One interview lasted two and a half hours, though I was fully engaged in the persons story, and did not notice the passage of time other than for my pleading bladder, which reminded me I may have been in this situation for some time. Rather than leave during their recounting of experiences I tolerated discomfort, respecting the person and valuing their story which was often emotive and deeply personal to them. These stories did not feel as if they could be interrupted with an intermission.

One participant had asked to see the questions prior to interview, and as many of these were prompts, in hindsight I may have given themes rather than my exact topic guide. Whilst this meant a great depth of information, it was less spontaneous, and driven by the participants pre-prepared responses which were read, and then discussed. This was still ethically the right thing to do given the person's personal preference, as too much spontaneity may not have felt safe. All other interviews were spontaneous from the participants point of view, and guided by a loose adherence to the topic guide.

As I went through the interviews, I gradually became a little more fluid and flexible with my approach. Early on I tended to cling to the structure and routine of my topic guide, perhaps anxious that I cover all bases. However, by the half way point in my interviews I had become much more trusting of the process, embracing the ‘semi-structured’ approach and seeing the value in simply letting people talk. Usually this more passive philosophy still covered all necessary themes, though whilst hardly required, prompts were offered when necessary. The more flexible I became, I feel I may have gained more unique and honest insights. As I did more research I perhaps became less of a researcher. I was Dan.

As my PhD study was being done part-time, it meant that during my schedule of interviews I was also preparing and delivering teaching, and marking assessments. This was just about manageable in terms of time, though hugely impacted the preparatory and post thinking space required to effectively process what I was about to do, or had just done. Some interviews were done immediately after teaching classes, with a five minute window of decompressing from teaching before going into interview. This was managed through a pragmatic ‘needs must’ approach, but certainly impacted on my ability to write reflective accounts, and revisit some interviews with PdxBPD central to cases, prior to speaking with the support persons and HSC workers who were ‘nested’ in those cases.

Reflecting on ‘who I am’ during interviews, I was brought back to the mental health nursing and nurse therapist roles which have also been a large part of my life. Whilst I was officially in the role of a researcher, these skillsets were very much with me. I was incredibly moved by stories of immense distress and suffering, and though I did not ‘nurse’ or provide therapy to people, I did utilize related skills of empathy, validation and understanding. In the same way that my “undeniable position” influences the study, it influences the kind of interviewer I am. Supervisors noted that the depth of data I received from participants was impressive, and this may be in part to my way of being with participants. (In a teasing nod to some of my upcoming findings, this may be my Dan-ness).

3.5.9. Transcription and ensuring confidentiality

Once interviews were complete, I transferred files to a contractor trusted by the university for transcription. This was done using funding from the university, and was done purely for pragmatic purposes, with part-time study affording little time for transcribing. I checked in with the wellbeing of the transcriber, as some content may have been distressing. This was appreciated as “considerate”, though they said they felt comfortable, being experienced hearing many stories through transcribing over many years.

Data was stored according to university and NHS research ethics policies. Paper copies were immediately scanned into digital format, then paper copies destroyed. All digital consent forms and recorded transcriptions were stored on the universities R drive which was password protected, with access restricted to myself and two supervisors.

3.6. Data analysis

Having collected the data, making sense of it was much harder than I had anticipated. Data analysis followed a process of ‘constant comparison’, defined as a simultaneous coding and analysis which develops concepts through continually comparing incidents in the data and refining them (Taylor and Bogdan 1984). The process of refinement firstly identifies the properties of these concepts, then explores their relationship with one another, and finally sees integration thorough the development of an explanatory model (Taylor and Bogdan 1984). Thomas (2021, p.225) argues that despite many different research terms constant comparison is the basic method of any interpretive inquiry, and explains plainly that this is constant, “going through data again and again” and comparative, “comparing each element – phrase, sentence or paragraph – with all the other elements”. For me, this ‘constant’ has felt near eternal, in analysing data one interview at a time, but then continuing to analyse through writing of the findings, and writing the discussion. Thinking, writing and re-writing. Every time I have approached the data, I have new thoughts and insights, and yet with a submission deadline I could not analyse data forever.

Data was analysed at the level of each individual interview, all interviews within each case, and across all cases. I aimed to complete a cross case synthesis, with each individual case analysed as its own whole, then compared and synthesised to seek any within-case patterns across the cases (Yin 2018). Consideration was given to using software such as NVivo, however it was personally preferable for me to physically ‘live’ in the data and feel more connected to it by adopting more ‘intellectually primal’ means, utilizing printed transcripts, pens, highlighters, markers and flipchart paper. This choice proved to be wise given the university’s struggles with NVivo software functionality during the years I was analysing data. Had I lost any of my work I may have died inside, such is the time I have spent with it! Moreover, having the ability to analyse data through paper and pens allowed a pragmatism which also suited family life, with my young children seeking attachment and connection if I was at a computer screen, though content to play around me if I was more available, and at times I would work on paper in the same room.

The general process utilized a step-by-step guide outlined by Thomas (2021), which was deemed a sensible, logical and straightforward means of exploring data. Thomas detailed ten steps which I used to guide my own specific activities, identifying adaptations made to suit my study. Polish-American mathematician Alfred Korzybski (1931) coined the phrase “a map is not the territory”, pointing to the complexity of the thing itself never being captured by the abstraction which represents it, and whilst a map can be similar, it can never be the same (Batty 2019). In this sense, the ten steps were a useful map, but the territory of analysing data was fraught with more complexity than I had perhaps bargained for. Whilst a step-by-step guide may give the illusion of data analysis being simple and straightforward, this was at times an excruciating and draining process, which took a lengthy period of time, and enormous cognitive effort to make sense of a substantial amount of data. Perseverance was derived from my continual interest in the topic, and perhaps more importantly feeling deeply moved by the lived stories of my participants, and knowing that these stories deserved to be told.

Data analysis began during the interviews, as I thought about people and their experiences considerably. However, it was during a period of study leave from January to April 2023 that I immersed myself in it and began to make significant progress. Analysis continued from this point until thesis submission, and these ten stages were not enacted in a strictly linear fashion. Sometimes it was one step forward, a couple of steps back. I bounced around these stages until I was complete.

3.6.1. Ten stage process of constant-comparison

1. **Read:** Data was initially examined through reading a transcript and listening to audio recordings, and reviewing any notes from reflective diaries (though these were limited due to often teaching and marking alongside my study). As the first interview was in December 2021 and last in August 2022, it was important to revisit and reconnect with all people interviewed. As I had facilitated interviews, these experiences quickly returned to me and emotionally reconnected me to the human beings I spoke to.
2. **Copy:** A copy of files was made. As I utilized a ‘hands on’ approach, one transcript was printed and utilized as a working document, whilst the raw file was kept as an untouched word document. This allowed a protection of initial transcript, and clear identification of the one which was active and open to additions such as highlights and notes which were made in the margins.
3. **Code:** As I read through my paper files, I developed initial codes by highlighting and underlining words, making notes in the margins, mapping connections between data on

separate flip chart paper, and identifying illustrative quotes and page numbers. I also completed a concept map for each interview, attempting to make connections between circumstances and concepts, and organise my thinking with a visual aid. This activity was completed for each interview in turn. Thomas (2021) argues that mapping is often the weakest part of students interpretation of data, and I was keen to explore how these issues related to each another during, rather than at the tail end of the process. During each interview transcript, I reviewed my initial codes and made a note of recurring themes. Thomas (2021, p. 225) describes these as “temporary constructs” which are then revisited and refined throughout this process.

Stages 1-3 were completed for each interview individually, and done in order of participant grouping. Being centre of the cases, each PdxBPD transcript was analysed first. Following these, support persons, and finally HSC workers.

- 4. Read again:** These temporary constructs were checked as I read through the data again. I found the most useful way for me to revisit the data and think deeply about how it fitted together, was to see my thinking on the page and start writing an early draft of my findings section. Through this process I sat with transcripts and photographs of flipchart maps, and attempted to organize temporary constructs into preliminary themes, and see that themes and constructs were evidenced by data. Whilst stages 1-3 were completed for each interview, it was at stage 4 that the cross-case synthesis began, with early writing informed by looking at each transcript and map in turn, and populating preliminary themes and temporary constructs with supporting data. Throughout this process, notes were made in italics on the draft of the findings, noting queries around the fit of data, and highlighting issues potentially relevant to the following discussion.
- 5. Sort and sift:** The process of sort and sift continued to utilize writing as a means of thinking, and then removing temporary constructs which were not fully supported by the data. Through writing, it became much easier to see where data felt inconsistent or out of place in the narrative of particular themes. Some data were absorbed into other constructs or themes, though nothing was deleted. Some data was ‘parked’ in a list at the end of the document, and then later considered as to whether it provided supporting or counter examples to any themes. The drive to sort and sift was aided by the need to give my supervisors some of the findings to read, and this pushed me to tidy up individual themes allow them to feed back. At this stage, it did feel a little like a swamp, and I was grateful to have fresh eyes looking at it.

6. **Re-code:** Following the second reading and sorting and sifting, temporary constructs are developed into “second order constructs” (Thomas 2021, p.226) which appear to fit the data and summarise the key ideas expressed. This was done through writing and considering supervisor feedback. There was also a pragmatic consideration of having a substantially growing document, which pushed me to not include everything, and seek the strongest themes which I could summarise in a limited document.
7. **Construct themes:** Whilst Thomas (2021 p.226) uses the phrase ‘emerge with themes’, Braun and Clarke (2020) have strongly argued that themes do not emerge, and require the researcher to take an active role in this process. Thomas (2021 p.226) himself acknowledges this, aware that emerging with themes does not mean that they will emerge like magic, and writes that meanings are “constructed by the participants (including you)”. In walking the interpretivist path and studying perceptions and experiences, researchers cannot act as “detached observers” (Parahoo 2014, p.37). I re-labelled this step as ‘construct themes’, ensuring it was explicitly articulated that I, being in my undeniable position, built the themes from the data.
8. **Think about the themes:** This process involved thinking about the themes, thinking they might not be quite right, rethinking them and eventually settling on those which I felt were an accurate and enlightening version of the stories and events shared by participants. Much of the thinking about themes came through the writing process, whereby I found I could see where content was a good fit, and where it may not be.
9. **Map:** Thomas (2021) suggests that constant comparison will do little to show the relationships between the themes, and one can better show inter-relationships through utilizing picture form through a map. The process of mapping was evident throughout the process, with maps completed for each participant (Appendix 8.22), and early intent to develop a cross-case map synthesising all data. I developed an overarching map, and with consideration of the concept map constructed as part of the underpinning literature review (Warrender et al 2021), pulled my findings and literature review into a new concept map. This map was used to guide the discussion chapter, with the concept map not a direct replication of themes, though with themes clearly within.
10. **Illustrate:** This requires selecting good quotations to clearly support and evidence the themes. This hardest part of this, was that I thought it was all good. There was a sense of loss with each quote which I abbreviated and cut out, though pragmatism and the

need for a thesis less than 200,000 words meant I needed to let a lot go. Choosing what to keep and what to cut was an ongoing process through writing and editing.

3.7. Credibility and trustworthiness of the study

The knowledge generated from this study, despite its small sample size, may still have a kind of generalizability. Firestone (1993) identified three categories of generalisation; statistical generalisation, analytic generalisation and transferability. Whilst statistical generalisation is the aim of many quantitative studies through extrapolating data from a sample to apply across a population (Polit and Beck 2010), the “looser generalisation” described by Thomas (2021, p.75) is not only achievable but also contains a distinct value rather than a deficit. Silverman (2020, p.75) states that “small samples can sometimes yield big insights”, and it could be argued that these are achieved through Firestone’s (1993) analytic generalisability and transferability. Analytic generalisability seeks to generalise from particular data to broader theory, concepts and constructs (Polit and Beck 2010), as Thorne et al (2009, p.1385) articulates; qualitative findings “can reflect valid descriptions of sufficient richness and depth that their products warrant a degree of generalizability in relation to a field of understanding”. Whilst Firestone (1993) originally termed his concept ‘case to case translation’, a more widely used term, and the one favoured here is ‘transferability’ (Lincoln and Guba 1985, Polit and Beck 2010).

Transferability is a generalization which takes place through the reading of a study’s findings, where the reader actively transfers the results to a different group of people and setting (Polit and Beck 2010). Obviously there will be considerations around how appropriate a transferability is, Lincoln and Guba (1985) describing this as ‘fittingness’, and the responsibility for this generalisation ultimately rests with the reader and their interpretation.

Thus, this study does not aim to, or consider it possible to, reach universal laws which apply to all people with the ‘BPD’ diagnosis. Human beings are unique, and their behaviour is incredibly dynamic and changeable. Yet, the study explores issues around ‘BPD’ and crisis intervention in fine detail, and human beings (to point out the obvious) are all human, and the settings and situations we find ourselves in often do have degrees of similarity. Analytic generalisability may give us a depth of things to think about uniquely within the field of ‘BPD’ and crisis intervention, with transferability a broader application of findings across many situations, most pertinently those involving human beings in distress who seek help from systems.

3.8. Chapter summary

This chapter has detailed what I did, and hopefully clarified why I did it, while humanizing some of the experience through offering reflections on the process. The following chapter presents the findings, on what may be the first reading for you dear reader, yet it is the summarized final product and evolution of several arduous edits for me.

4. Chapter 4: Findings

4.1. Introduction

The findings present content from 16 interviews, and though lengthy, after brutal edits this feels to me like an executive summary. Whilst I feel these are the key themes, there are nonetheless many unexplored alleys which were beyond the scope even of this thesis. This chapter begins by exploring the demographics of participants, before orienting readers to how they are represented in writing through pseudonyms. Five themes with subthemes are identified then explored in sequence. Themes are supported by direct quotes from participants.

4.1.1. Demographics

Demographics of PdxBPD included six people who were all women, five white British and one mixed race, aged between 23 and 46 (23, 29, 30, 30, 31, 46). ‘Borderline personality disorder’ has been considered a female-predominant disorder, though there may be sex differences in how men and women express their distress with current evidence inconclusive (Qian et al 2022), and longstanding questions as to whether differences are biological or sociocultural, or diagnostic bias (Skodol and Bender 2003). Sexual orientation varied with three heterosexual, two lesbian and one bisexual, and PdxBPD have higher rates of homosexual relationships than non-BPD individuals (Frías et al 2016). In terms of relationships, one person was married, three in long term relationships, one separated and one single, whilst two people had dependents. Living circumstances included one person living alone, one with a parent, two with partners and two with their dependents. Three people were employed, one was employed but on long-term sickness leave, one person in education and one unemployed. People had been given the ‘BPD’ diagnosis between one year ago and twenty years ago (1, 5, 5, 6, 9, 20), and the recency of crisis experiences ranged between being described as “permanent”, to one week, three months and up to a year when people considered their most severe experiences (1 week, 1 week, 3 weeks, 1 month, 3 months, permanent but serious crisis 1 year ago). The study recruited three complete cases, in having representation from PdxBPD, people who supported them and HSC workers. Two cases had PdxBPD and HSC workers, while one case had a sole individual diagnosed with ‘BPD’.

Support person demographics included one parent, one sibling, one partner and one friend, including two women and two men. Joan (P15 SP Friend C6), friend of Carole (P14 PdxBPD C6), offered the study a unique perspective as she had also experienced mental health care, and described herself “*as her friend with, probably like slightly different*

diagnostic labels, but actually quite similar experiences, similar stories, similar thoughts and feelings". This meant Joan could understand and validate Carole's experiences, as well as adding unique insights and experiences which were relevant to the study. Recruited professionals included four community mental health nurses (CMHN), a specialty doctor (specialising in psychiatry) and a psychologist. Of the professionals, there were three women and three men, and clinical experience ranged from 5 years to 40 years.

4.1.2. How participants are presented in the data

Participants have been kept anonymous. Having pseudonyms opposed to numbered identification was felt to be important for the readers to connect with the human experiences being explored. To orient readers to who is saying what during the findings, names are followed with brackets denoting the stakeholder group, participant number and case number (table 10). Names were chosen from the world of music; with singers and artists I admire selected and applied randomly to participants. For those interested in musical influences, these were: Kate Bush, Janis Joplin, Nina Simone, Alison Mosshart, Tori Amos, Mark Lanegan, Grace Slick, Annie Lennox, Steven Wilson, Joni Mitchell, Chris Cornell, Eddie Vedder, Robert Plant, Carole King, Joan Baez and Billie Holiday.

Table 10: Identification of participants in the data			
	Stakeholder group of participant and how they are identified in writing		
Case number	PdxBPD (n = 6)	Support persons (n = 4)	Professionals (n = 6)
Case 1	Kate (P1 PdxBPD C1)	Janis (P2 SP Sibling C1)	Nina (P3 CMHN C1)
Case 2	Alison (P4 PdxBPD C2)		
Case 3	Tori (P5 PdxBPD C3)		Mark (P6 CMHN C3)
Case 4	Grace (P7 PdxBPD C4)		Annie (P8 CMHN C4)

			Steven (P9 Specialty Doctor C4)
Case 5	Joni (P10 PdxBPD C5)	Chris (P11 SP Partner C5)	Robert (P13 Psychologist C5)
		Edward (P12 SP Parent C5)	
Case 6	Carole (P14 PdxBPD C6)	Joan (P15 SP Friend C6)	Billie (P16 CMHN C6)
Key			
P	Participant		
C	Case		
PdxBPD	Person diagnosed with borderline personality disorder		
SP	Support person		
CMHN	Community mental health nurse		

4.1.3. Themes and sub-themes

Data was constructed into five themes, some with sub-themes (table 11).

Table 11: Themes and subthemes					
Main theme	Understanding crisis: triggers, manifestations and personal strategies during crisis	A confused and anxious system	Acts and omissions which lead to harm	The complex simplicity of helping people in crisis	Building a better service
Subthemes	Vulnerability to crisis and the complexity of triggers	The dysfunctional relay	Wearing a stigmatized label and ceasing to be a person	Barriers to people being helpful	

	The experience of being in crisis	Anxiety around risk which influences decision making	Neglect revisited and the invalidation of a still-face	Helpful therapeutic skills and traits	
	Attempting to cope with crisis	Confusion around diagnosis	Chaotic and oppressive environments of 'care'		

Constructing themes was neither straightforward nor neat, as often a universal consistency could not be found across cases, and due to the dynamics of human beings, consistency may not be found within people themselves. People talked about their care generally as well as specific crisis situations, however this was still considered to be relevant and important data, capturing experiences which whilst not directly related to crisis, are important interconnected contextual factors which have a degree of influence over their experiences and perceptions. Not all sub-themes were supported by data from all participants, as due to the nature of semi-structured interviews, interviews had explored different tangents which were important to individual participants. People discussed events and experiences which were relatively recent, though some experiences included took place several years ago. The organization of the findings feels slightly chaotic, but this mirrors the reality of crisis, which was not linear, and an overwhelming multidimensional experience. Participants also use diagnostic terminology of 'borderline personality disorder' ('BPD') and 'emotionally unstable personality disorder' ('EUPD'), those these are conceptually consistent (see 1.2.2.1). As this is a long read sub-headings have been used, organising the narrative but more importantly acting as signposts, and lay-bys for tired eyes.

4.2. Theme 1: Understanding crisis: triggers, manifestations and personal strategies during crisis

This theme captured experiences and understandings of crisis, but firstly acknowledges the limitations of human language, with the mental states experienced during crisis as confusing, hard to recall and then subsequently articulate. Data was constructed to summarise crisis as a unique, subjective, multi-dimensional, unpredictable, and overwhelming experience, with a variety of subjective triggers sparking either a quick onset or slow build towards an experience of intense mental states of thinking and feeling, which were then expressed or managed through people's behaviour, and could become a vicious cycle. Rather than providing a single, robust and consistent definition of 'crisis', this theme explores a realm of possible experiences which are never linear, and can only ever be understood in the context of an individual person. Three subthemes explore 'Vulnerability to crisis and the complexity of triggers', 'The experience of being in crisis' and 'Attempting to cope with crisis'.

4.2.1. Subtheme 1: Vulnerability to crisis and the complexity of triggers:

4.2.1.1. "A bit of both": Influences on thresholds for crisis

People had particular sensitivities, noted by themselves and others, which may increase the risk to being triggered into experiencing crisis. Janis (P2 SP Sibling C1) queried the nature/nurture debate, and where Kate's (P1 PdxBPD C1) difficulties may have stemmed from:

"There's some backwards and forwards... is it like a hormonal thing, has it always been there... or is it... completely triggered by experiences... even when she was really young, she had like really big emotional reactions to things that most kids would've sort of gotten over, so... for Kate, I think it's maybe a bit of both. Some experiences, but there seems to be an imbalance there or... something that feels like it's organic and biological".

Mark (P6 CMHN C3) shared a biopsychosocial understanding of difficulties for PdxBPD, but highlighted the influence of experiencing adversity. He said *"It's... a combination of perhaps some predisposing factors in the person, whether that's biological or... psychological, I still probably... see... the trigger or the compounding events as being adversity and the learning to cope with adversity that's come from that"*.

Carole (P14 PdxBPD C6) described enduring negative patterns of thinking, including low self-esteem and low self-worth, which could make her vulnerable to crisis. She felt triggered by *"my own thoughts. I'm not a nice person to myself"*. As the findings move forward, it is important to see them through the lens of people who may have lower

thresholds for stress. This lower threshold may have a biological influence, but can more so be accounted for through adversity, trauma and neglect. Five of the six PdxBPD interviewed disclosed traumatic experiences in their lives.

4.2.1.2. Defining triggers

A trigger is defined as a movable part such as a lever which connects with something as a means of releasing or activating it (Merriam Webster 2023a). Triggers pushing PdxBPD into crisis were subjective, encompassing a variety of different potential ‘parts’; levers which were influenced by interactions both outside the person, but also within the person.

Triggers could be unpredictable, hard to recall, obvious or obscure, a single event or an accumulation of events, and were not always clear or consistent. Triggers could include change and transitions, sleep deprivation, interpersonal discord, emotional states, and thought processes. Triggers may also be rooted in specific experiences of trauma, and could be related to difficulties associated with other diagnoses.

Tori (P5 PdxBPD C3) considered triggers, thinking there *“doesn't seem to be a pattern... it can be like one little event... or... a buildup of things”*. Mark (P6 CMHN C3) agreed that Tori had *“hair trigger emotions”* and could be triggered easily. Tori stated after experiencing crisis she often *“can't ever remember what triggered it”*. Family and professionals acknowledged the difficulty in knowing what the trigger was. Steven (P9 Specialty Doctor C4) said Grace (P7 PdxBPD C4) *“can't identify its origins”* and she struggled with a *“failure to recognise what the trigger is”*. Chris (P11 SP Partner C5) thought Joni's (P10 PdxBPD C5) triggers could be so unique and subtle that *“there could be things that I would never in a million years think of”*. He was confused by the unpredictability of triggers, stating they *“could be anything”*, adding *“it can be a right minefield”*. Billie (P16 CMHN C6) understood that PdxBPD could seem to be triggered *“for no clear reason”* but stated *“usually when you pick away at it, there's always a reason”*.

4.2.1.3. Small triggers. Big consequences.

Many participants mentioned how small triggers could have big consequences. Nina (P3 CMHN C1) said Kate (P1 PdxBPD C1) could be triggered by *“quite a small event”*. Tori (P5 PdxBPD C3) acknowledged *“if something little goes wrong. It's like my whole life's falling apart. It's not worth living”*. She described feeling *“my whole life's a mess because the kitchen's a mess”*. Carole (P14 PdxBPD C6) felt her triggers could be *“anything”*, describing them sometimes being *“small things”* and *“everyday things”* which *“just tip it over the edge”*. Joan (P15 SP Friend C6), understood this fragility to being tipped over the edge as being due to the aforementioned vulnerability to crisis:

“There's a lot of stuff... consistent through her day-to-day life in terms of mood and like limited daily functioning... I think it's always sort of... buzzing away in the background... there's a lot of underlying stuff there. But it tends to be the kind of straw that broke the camel's back kind of situation”.

Allison (P4 PdxBPD C2) felt similarly about her own triggers to crisis, stating *“it feels like it builds up and builds up and builds up and just escalates... one thing will take me over the edge... I knocked my cup of tea over and that was just the thing that sent me...”*. Joni (P10 PdxBPD C5) echoed this, acknowledging subtle triggers and asking herself *“how has something so small led to me doing something so dramatic?”*. These small triggers could begin a chain reaction, and have big consequences, as Chris (P11 SP Partner C5) explained, *“it's like one thing just seems to lead into the other... if this, and this, and this, and this and then... then you've literally got police knocking at the door”*. Joni (P10 PdxBPD C5) agreed triggers could be so subtle and quick to escalate, and she constantly felt on the edge of crisis. She said, *“it sounds dramatic saying that but... when you have to like, manage every little thing you do... and if it goes wrong, then things can escalate so quickly... it's like an ongoing crisis”*.

4.2.1.4. Interpersonal triggers.

All PdxBPD identified interpersonal relationships as an arena full of potential triggers. Kate (P1 PdxBPD C1) identified fear resulting from sudden and dramatic issues like *“arguing and raised voices...physical violence, paranoia, loud noises”* and changes, interpersonal adjustments and transitions, *“big changes... for example, starting a new job, relationships ending... the starts and the ending of things”*.

Janis (P2 SP Sibling C1) acknowledged Kate's key triggers as *“any sort of relationship breakdown”* particularly feeling *“rejected”* and *“abandonment issues”*. This was common for PdxBPD. Allison (P4 PdxBPD C2) said *“I'll feel that like everyone hates me and like that will spiral and I get really overwhelmed”*. Grace (P7 PdxBPD C4) described being triggered by *“a relationship breakdown”* and professionals confirmed, Annie (P8 CMHN C4) offering *“it's mainly social stuff... around relationships”* and Steven (P9 Specialty Doctor C4) adding particularly experiences of *“criticism”*. Robert (P13 Psychologist C5) noted Joni (P10 PdxBPD C5) was sensitive to feeling *“judged”*. Given the digital age, interpersonal communication through social media could be a trigger. Nina (P3 CMHN C1) described Kate (P1 PdxBPD C1) being triggered by interpersonal uncertainty through WhatsApp messages, and Tori (P5 PdxBPD C3) also could experience issues through text, assuming rejection and struggling with not knowing others mental states. She shared *“if I... send a*

text... don't get a reply, or that reply doesn't sound like they're happy with me...I can get very upset... there's absolutely nothing wrong at all... they're busy... But things like that can set me off”.

Interpersonal triggers arose through interactions with family. Janis (P2 SP Sibling C1) felt triggers could be missed, as they weren't necessarily obvious in the moment. She recalled *“I've had conversations with Kate and went home and felt okay about it and then she's brought it up... months later, oh, you know, I felt quite upset after that conversation... it didn't register to me as something that would've been a big trigger point, so we definitely miss them, in terms of how she might experience things...”*. Nina (P3 CMHN C1) understood Kate's vulnerability, suggesting that someone might *“say something in a particular tone, so the actual comment itself is not significant”* however following interpretation concluded *“what it represents for Kate is significant”*. Edward (P12 SP Parent C5) echoed how assumed meaning could lead to crisis for Joni (P10 PdxBPD C5). He felt *“the signals which can cause her to go from being quite placid to very anxious, can be as little as she thinks, you've... looked at her, in a way that she suddenly goes, what was that look for?... And you're sort of... caught off guard and you sort of say, I didn't. Oh, yes, you did. Bang”*.

Interpersonal triggers also related to interactions with professionals. Janis (P2 SP Sibling C1) considered the impact of rejection from MH services, stating a trigger for Kate (P1 PdxBPD C1) was *“if she feels like she's trying to access support and getting not very far with it... in her eyes.”* Joan (P15 SP Friend C6) described Carole's (P14 PdxBPD C6) experiences, stating triggers were *“often relational stuff”*, citing that when she had a *“really horrendous encounter with another person”* that it had been *“unfortunately, quite often a professional, that pushed her buttons”*.

4.2.1.5. Triggers rooted in trauma

Some triggers were rooted in recent or historical experiences of trauma which were reactivated through reminders of this in the world. Grace (P7 PdxBPD C4) described an adverse experience and *“emotions that came with it”* were *“really difficult for me”*. Kate (P1 PdxBPD C1) felt *“situations that remind me of past trauma... past abuse... that's obviously going to be a trigger for crisis... I don't like it”*. Alluding to uncomfortable memories, Carole (P14 PdxBPD C6) described a trigger as *“an anniversary of something not great”* where a calendar date prompted her to revisit traumatic experiences. Joan (P15 SP Friend C6) also thought Carole could be triggered by *“physical health conditions... A lot of that... ties back to... historic stuff. So, there's... a lot of memories and emotions... being triggered”*. Billie

(P16 CMHN C6) shared that Carole's triggers could be sensory, recalling *"she smelled a smell... then it was stuck in her head... the way that it smells can kind of stick in your nose... I think Carole does... disassociate, and I think that a lot of her self-harm recently has been when she's been quite triggered by something, hasn't quite been able to get out of it"*.

Allison (P4 PdxBPD C2) had triggers which were actually rooted in her experiences of hospitalization which made returning for any reason a challenge. She said, *"the things that I experienced when in hospital... whenever I'm there, it kind of really brings things back"*.

4.2.1.6. Triggers relating to comorbidities

Co-occurring diagnoses and conditions were also relevant as regards to triggers. Joni (P10 PdxBPD C5) related much of her triggers to obsessive-compulsive disorder (OCD) and Robert (P13 Psychologist C5) agreed that whilst she was generally stable, that *"all goes out the window when the OCD takes over"*. This highlights the need for triggers to be explored in a holistic person-centred way, rather than explored in the context of any one particular diagnosis. Joni said:

"Something will happen...it's more connected to OCD ... I'll feel like something's got contaminated and I can't, unthink that... And then it gets bigger and bigger and bigger to the point that I feel like everything's contaminated and the only way I can feel like it will stop is if like, not necessarily kill myself, but like, even harm myself to the point that I need hospital treatment, then it takes me away from the thoughts".

4.2.1.7. Early warning signs of impending crisis

There could be early warning signs of impending crisis, though these were not always easy to notice, and may be noticed by others. Two participants mentioned the importance of sleep. Prior to one crisis, Grace (P7 PdxBPD C4) stated *"I was just shattered... didn't sleep for three or four days or something"*. Carole (P14 PdxBPD C6) also experienced a crisis where prior *"I'd not slept for four days"*. Kate (P1 PdxBPD C1) stated *"my family sort of notice mood and behaviour changes"*, adding that often her family *"notices it before I do"*. Kate noted impacts to daily functioning, saying she would become *"very withdrawn, very short fused, my eating stops... my hygiene stops... I go like more than a week without a shower... the rooms tipped upside down... everything's just messy"*. Her approach to relationships also changed and she would be *"avoiding seeing those who I would normally get enjoyment out of like friends and family and stuff"*. Similarly, Chris (P11 SP Partner C5) noticed Joni (P10 PdxBPD C5) becoming withdrawn, stating *"I sort of know she's working her way through something when she goes like really quiet"*. However, Edward (P12 SP Parent C5) paradoxically described Joni being happy and relaxed as a sign that she may be

on the verge of crisis, stating *“when she seems relaxed and happy, that's when (we) are really worried... because historically, that was when... she decided to kill herself... so (we) used to sort of go on hyper alert when that situation happened, because... something's going to happen, and 99 times out of 100 it did”*.

Alison (P4 PdxBPD C2) could notice a gradual build towards crisis, stating *“I'm trying to get help before things are absolutely at their extreme... I can feel them going that way”*. Other times there was a quick onset, where *“something can trigger it quite quickly and... I go from zero to 100”*. Edward (P12 SP Parent C5) noted similar routes to crisis for Joni (P10 PdxBPD C5), stating *“there's the sort of the two tracks now, there's the instantaneous response, and there's the build-up response”*. Carole (P14 PdxBPD C6) echoed this sudden or slow build: *“It can be either, it depends what the trigger is as well. Sometimes it's so strong that you can't think properly and there's no build up to it, it's really sudden. But the last few times, I suppose it has been like that sort of a slow build up. And then... you can make a decision sometimes to self-harm or not. But some of the worst occasions... there's no buildup, it's just sudden”*. Billie (P16 CMHN C6) confirmed Carole could *“go from nought to 100, what seems like instantly”*.

4.2.2. Subtheme 2: The experience of crisis

4.2.2.1. The limitations of language

A limitation of human language, and therefore this study (and any study for that matter), is that it can fail to effectively capture the complexity of the world and experiences of it. This was articulated by all PdxBPD who suggested that crisis may be defined and experienced differently at different times, that recollection of crisis could be poor particularly during dissociative episodes, and that it was often difficult to effectively articulate the experience. Not being able to articulate the experience could intensify distress, and make it more challenging for others to provide support. Joan (P15 SP Friend C6), when asked to describe the last time Carole (P14 PdxBPD C6) had been in crisis, offered that *“I don't really know... it depends on how intense you want it to be, to be a crisis”*. This raises an important point around the personal meanings of the word ‘crisis’, and how it may be a spectrum, yet there may be very different unique and subjective levels, intensities and types of experience which vary person to person, and we lack the language to adequately separate and categorise them.

4.2.2.2. The onset and spectrum of crisis

Once triggered, the way crisis could be activated or released also varied in terms of onset, longevity and how it was experienced and expressed. Nina (P3 CMHN C1) thought Kate (P1

PdxBPD C1) could “destabilise very, very quickly”, and Kate used metaphor to describe in detail how her crisis varied, sharing “someone can drown in a massive ocean, someone can drown in a puddle, it's still drowning, right?... It's not as simple as just saying... that was drowning. Crisis is like... you've got one massive end of crisis, which is like life-or-death crisis, that can happen within minutes. Then you've got your... lower-level crisis... not maybe onto the top scale, but leads you to feeling triggered and feeling... not enough to be at the top spectrum but... it's almost like... steppingstones. You're not at the top of the stairs, you're half-way, but you can feel yourself getting ready to take the next steps up”.

Alison (P4 PdxBPD C2) similarly identified with different levels of crisis, saying “I'll have different... types of crisis... sometimes it'll be my anxiety... having panic attacks that get quite extreme and my head kind of spirals and in that moment I act very impulsively and again... I guess it's more than a panic attack... And then there's also when I'm feeling extremely depressed, and will spend days really, really depressed in, in crisis in that sense that, but often I find that it's... my thoughts will spiral and get really negative thoughts in my head”.

4.2.2.3. Spiralling thoughts

The thoughts, feelings and behaviour experienced during and around crisis were tangled in a dynamic interaction, each influencing the other, yet never able to be neatly categorized or understood in a linear narrative. Carole (P14 PdxBPD C6) described crisis as so intense she has “no thought of anybody else”. Alison (P4 PdxBPD C2) described negative spiralling thoughts during crisis, sharing “my thoughts will spiral and get really negative thoughts in my head... I just lose absolute all rational thought”. Joni (P10 PdxBPD C5) felt isolated, not understanding her own thoughts, stating “I feel so alone and so like, scared because I don't understand what my thoughts are”. Carole (P14 PdxBPD C6) described negative thought cycles, saying “it just seems the worst, like catastrophizing, I think it's called, like, everything's worse, and not being able to mentalize... it just seems like inevitable that... everything bad is going to be happening to me”. Tori (P5 PdxBPD C3) similarly described catastrophising, stating “it's probably... over exaggerating what the actual situation is... an intense sort of overthinking, worrying about things all the time”.

Some PdxBPD also had violent intrusive thoughts. Annie (P8 CMHN C4), discussing Grace (P7 PdxBPD C4), stated “there was some intrusive type thoughts that were happening around... jumping in front of traffic”. Nina (P3 CMHN C1) described Kate (P1 PdxBPD C1) having suicidal fantasies, reporting “quite vivid” fantasies, where “she can see herself attempting to end her life... like a fantasy... she visualizes herself in her car, and she ties a

rope around a tree, and the other round her neck and drives off at speed... it's really quite violent".

4.2.2.4. A disconnection from self and the world

The experience of crisis could impact sense of self and connection to the world, particularly during dissociative experiences. Kate (P1 PdxBPD C1) said *"I no longer feel part of the earth"*, and Grace (P7 PdxBPD C4) described going into *"a world of my own"* with it then *"hard to get the memory again"*. There was a consistent feeling of crisis separating people from their sense of self, with Alison (P4 PdxBPD C2) stating *"I'm not myself... I lose control"*, Tori (P5 PdxBPD C3) claiming *"I don't feel like myself"* and Grace feeling *"not really yourself"* when in crisis. Kate (P1 PdxBPD C1) also linked experiences of crisis to past trauma, stating she felt like she had *"two brains"*:

"It's almost like you've got more than one... mind... my un-rational brain is my inner child's brain, my rational brain is my 29 year old brain and... it depends on the trigger... what brain is used... that's how I sum up my BPD is, you've got your two brains, you've got your rational, irrational, but I see my rational as the past traumas, triggers of abuse, and that's what makes the decision 90% of the time, and I'm trying to get it down to a ratio of, even if it was 50/50 I'd be happy".

Kate said during crisis *"it's too much to talk, even just to say yes or no to things, it's like an effort"*, and *"you don't remember a lot, you just remember feeling like you weren't worth living"*. Janis (P2 SP Sibling C1) felt Kate was *"so difficult to read when she's in crisis"*, and Nina (P3 CMHN C1) agreed that *"she can be quite mask like, her face doesn't give much away"*. Carole (P14 PdxBPD C6) said crisis was *"really hard to explain"*, and Tori (P5 PdxBPD C3) described not being able to communicate, saying *"I start crying cause I can't speak"*. Annie (P8 CMHN C4) perceived that Grace (P7 PdxBPD C4) *"doesn't have the words"* for crisis, and that this may increase the risk of her harming herself, stating *"things will more likely happen when she doesn't have the words to describe it"*.

4.2.2.5. Dissociation

Recollecting crisis may also be particularly challenging due to dissociative episodes. Kate described emotional dysregulation and *"becoming the emotion"*, reporting *"you've got your peak of just how much you can feel that emotion, that you check out, and that's when the dissociation hits in... that's when I dissociate and I have the outer body, like I can physically see myself and I'm distraught and day dreamy... that, to me is, crisis to me is frantic. Frantic but calm all at once and it's a very scary place to be and it's funny, this is saying scary from*

someone right now who's not in crisis, but at the time you don't see it as scary... you have tunnel vision”.

Janis (P2 SP Sibling C1) gave her perspective on Kate dissociating, recounting her as *“numb... it's almost like she gets so overwhelmed that she goes into neutral... incredibly quiet and disengaged... no attention span... she can appear really low... other times it's like... the lights are on, but nobody's home... she's just blank... that's a really big tell... when we know that she's stopped coping”*. Nina (P3 CMHN C1) had a similar experience of Kate, stating *“she was able to tell me how she was sort of physically feeling but unable to really sort of name and say what she was emotionally feeling. And she almost, when she's in crisis, she almost becomes robotic”*. Alison's (P4 PdxBPD C2) dissociation would impact her memory of events. She expressed *“I'm not thinking straight. I don't think about what I'm doing. I often will dissociate and black out and don't remember what I've done and people told me after”*.

Grace (P7 PdxBPD C4) described being triggered by traumatic memories, and considered dissociation to have a protective function. She said *“I think it's a protection thing for me?... I think if I was to remember everything I've been through, I think I'd be in a very, very dark place”*. Annie (P8 CMHN C4) described Grace's dissociative episodes, detailing *“she will, quite consistently, describe... feelings of numbness... not feeling anything at all... when it's like that she quite frequently doesn't sleep and then she has a need to do something, to feel something”*.

4.2.2.6. Overwhelming emotional states

All participants when asked to describe 'BPD' mentioned overwhelming emotional states. These were a consistent feature of crisis across cases, and could be uncontrollable, fluctuating rapidly. Joni (P10 PdxBPD C5) stated *“I can't control my emotions”* and Chris (P11 SP Partner C5) interpreted *“an uncontrollable like emotion”*. Kate (P1 PdxBPD C1) described *“tunnel vision... it's just that emotion... all you can feel, you live, breath, eat, sleep it... when you feel that emotion, you are that emotion”*. Alison (P4 PdxBPD C2) described feeling *“absolute mental pain”* where she could be *“screaming”* and *“suffering so badly”*. Carole (P14 PdxBPD C6) felt a similar intensity, stating *“you can only describe it as pain”* and *“it feels like your brain's on fire”*. Joan (P15 SP Friend C6) shared that that crisis for Carole was *“feeling things very intensely, and not necessarily having the coping skills to manage that in the moment”*. Tori (P5 PdxBPD C3) described *“extreme feelings of emotion”* which were *“so overwhelming”* and could fluctuate to extremes quite rapidly with *“such a massive... change in my emotion, in hours”*, and include *“intense moments of*

anger” and “lots of crying”. Similarly, Grace (P7 PdxBPD C4) described crisis as “intense emotions”, and Steven (P9 Specialty Doctor C4) added “she's not able to actually recognise the emotion itself... whatever it is, it's big, it's deep and it's bad, but she can't really label it. And... she can't work through the problem”.

Kate (P1 PdxBPD C1) also struggled with extreme positive emotions, which paradoxically led to negativity. She said, “I do struggle when I feel positive emotions... like it literally is just beaming out of you and your head spins... there's hyper and there's happy... you feel like you're on cloud nine... but it's overwhelming”. She said “every emotion I feel, even the happy ones, I always end up levelling off the emotion with anger... it's anger at feeling that much... Because I know I've to live with this and it's draining, so I get angry”. Tori (P5 PdxBPD C3) had emotions so overwhelming she said, “I want to escape, I want to run away, or I want to be dead”. Steven (P9 Specialty Doctor C4) spoke generally about PdxBPD being emotionally dysregulated, noting that during crisis people struggled to have a conversation about what they were experiencing and what may help. He shared “by the time they come to us in the in-patient service, the ability to do that piece of work at the front door is virtually absent”. He noted part of the crisis experience as an inability to effectively communicate it, detailing “they are currently offline ... people who are struggling with emotional dysregulation... someone's ability to... rationally have a discussion... it's not there right now, and that's part of the experience they're having”.

4.2.2.7. The sense of permanence and hopelessness of crisis

Whilst crisis wasn't a permanent state, it could be hard to see an end. Kate (P1 PdxBPD C1) stated “it is really hard to tell yourself, this shall pass”. Chris (P11 SP Partner C5) added for Joni (P10 PdxBPD C5) “it could take... days before... she's sort of like... levelled herself back out”. Thoughts of hopelessness were thus an issue. Nina (P3 CMHN C1) described Kate (P1 PdxBPD C1) “feeling completely unsafe, emotionally dysregulating and dissociating and feeling really, really hopeless... that her future, that this is her, this is what's her life is... there's no hope that it'll be different”. Carole (P14 PdxBPD C6) also shared her own hopelessness due to recurring crises, which could lead to suicidal thinking. She said, “lack of hope in the world, and myself... is a big one for me at the moment... my big thing... has been, I'm always going to be like this, so why would I live any longer?”

4.2.3. Subtheme 3: Attempting to cope with crisis

People would attempt to cope with crisis in various ways, with behaviour distinguished from their underlying mental states. People attempted to manage crisis through preventing it in the first place, and attending to experiences as they arose. People would try to prevent

and manage their crises through lifestyle choices, distraction, grounding techniques, relaxation, sedation, expression, reflection, tactile methods and finally exercise and activity. Coping mechanisms could also include self-destructive acts of self-harm and attempting suicide.

4.2.3.1. Trying to prevent crisis

Alison (P4 PdxBPD C2) described the irony of trying to prevent crisis, yet simultaneously making herself more vulnerable to it. As she noticed *“negative feelings, emotions... things I'm struggling with... build up”*, she employed an imperfect strategy of *“going 100 miles an hour and then crashing... it really is an all or nothing”*. She recounted *“I'll keep busy... to ignore... pretend... and distract myself... I'm also quite scared of going into that very depressive state where I don't get out of bed for days... if I don't stop, I'm functioning... in my head... I'm doing well... then I go... overdo it... and then it takes one tiny thing to send me over the edge... the last thing and that's it”*. Tori (P5 PdxBPD C3) described how she prevented crisis through lifestyle choices, saying *“I think if I had a drink... my inhibition would... go, and I would be likely to harm myself”*. She described learning to cope as a lengthy process, with strategies not consistently effective. She had a list of *“things I've learned over 20 years, but it's putting them into practice isn't always easy”*.

4.2.3.2. Distraction and expression

Grace (P7 PdxBPD C4) diverted her attention from crisis through grounding, stating she was *“counting the cars... I just like use grounding techniques like that”*. Tori (P5 PdxBPD C3) tried but was unable to relax, stating *“I run a really nice bath, and I put my candles on, but I can't seem to stay in it long... I don't know how to relax. I'm either... quite wound up or I'm asleep, I can't find a balance”*. Relaxation was thus acquired through medication with sedative effects, and escaping crisis through escaping consciousness. Tori said *“sometimes I will just go to my bed. I might pop an extra few diazepam or a sleeping tablet just to get away from it”*.

Some PdxBPD wrote to express themselves. Tori shared *“I write exactly how I'm feeling... I will write pages and pages... and I'll just have a big scribble or I'll just doodle... I do find that can be... a distractive technique that I use that tends to work for me I think”*. Kate (P1 PdxBPD C1) also described writing as a means of understanding herself. She said *“I'm learning... I do a reflection on my week. That's something new that I've found that I feel helps me”*. Sometimes the expression of crisis could be made public through social media, through writing or video. Edward (P12 SP Parent C5) described Joni (P10 PdxBPD C5) in crisis, recalling *“she'll go into social media... write this long diatribe... she'll film herself...”*

she'll be in floods of tears... she's... trying to cope with it... to try and say, look, this is what happens... I need to get my message out... she's seen on there... she's trying to use that as a coping mechanism”.

Tori (P5 PdxBPD C3) utilized tactile means of managing crisis, using *“ice packs for my neck... Or, I dig my nails in, but don't actually break the skin... I'll scratch and scratch sometimes til I bleed... I've tried sort of the elastic band type thing...”*. Grace (P7 PdxBPD C4) also used an elastic band, specifically for shifting from dissociative states. She said *“you get an elastic band and you just snap on yourself. It's kind of like a thing of self-harm. But it's like, not... severe, it's just like kind of putting you back in that moment... helps to stop the dissociation, I think”*. Nina (P3 CMHN C1) CMHN described how Kate (P1 PdxBPD C1) *“missed the physical contact from a hug... So she improvised with a weighted blanket, and... it was really effective”*.

Alison (P4 PdxBPD C2) emphasised the importance of exercise, stating she was helped by doing *“things that I enjoy. Currently ice skating... I did trampolining... and then gymnastics... pretty much every day I was doing most sport, which definitely... if I was struggling that day, and then went (to an activity) that night... all that would kind of almost disappear”*. Carole (P14 PdxBPD C6) recounted *“I used to go walking in the middle of the night... that was helping me”*. Tori (P5 PdxBPD C3), in tandem, agreed *“I actually do get more pleasure walking in the dark... I was away out walking at half four in the morning... it's the interaction with other people I find difficult”*.

4.2.3.3. Overwhelmed and hiding distress

However, there may be a limit to how much people could cope with or self-manage their experiences, and perhaps the description of crisis as an ‘overwhelming’ experience gives a clue. If people were always able to self-manage and take responsibility for themselves, perhaps this would not be referred to as crisis. Self-management could become impossible in crisis due to emotional overwhelm, as Carole (P14 PdxBPD C6) described: *“You forget all your distraction crap, it's not crap, but... you can't think of it in the moment.”* Edward (P12 SP Parent C5) understood that for Joni (P10 PdxBPD C5), *“there's very little she can do that doesn't ultimately lead to the crisis”*.

During crisis, PdxBPD hid their distress from others, often due to low self-worth. Kate (P1 PdxBPD C1) said *“I think I'm hiding it really well... I don't want to worry other people... and it's also that fear... from past trauma, when I've been in that mental state in relationships... they would leave me because they didn't know how to look after me... so I was left by*

myself, so I tend to suffer quietly now". Alison (P4 PdxBPD C2) said "I try to hide my mental health from (my parents) in the best way possible... they are aware and they try to be helpful, but I just don't find that they often are". However she would also hide her distress from those she felt would be helpful. She said "I'm quite bad for... not using the people that would help me... when I'm crisis, I feel like I'm a burden... It's almost like a mental block... I feel like I would be burdening them or inconveniencing them... which they have specifically said... would not be the case. But in that moment, my head cannot turn that switch off".

Steven (P9 Specialty Doctor C4) recounted conversations with Grace (P7 PdxBPD C4) recalling *"I've heard her describe before... as much as coming into hospital... is a respite... for her and from some of the responsibilities outside, she's acknowledged that it's actually somewhat of a respite for other people".*

4.2.3.4. Self-harm and suicide

Self-harm and attempting suicide were common across all cases. There were different methods of harm, and these served different functions which could be unclear, even contradictory, and may not help their predicament. Janis (P2 SP Sibling C1) reflected on Kate (P1 PdxBPD C1), stating *"some of her behaviours... exacerbate the problem... it's almost like, instead of trying to remove herself from that situation... she tries to grapple with it even more".* Alison (P4 PdxBPD C2) said she could *"act very impulsively... lose just all sense of control... I'm not thinking straight. I don't think about what I'm doing".*

Self-harm and attempting suicide could be conscious or automatic, and have dual purposes or meanings which could rapidly fluctuate. Nina (P3 CMHN C1) described Kate having carefully considered suicidal intent, stating *"she had started to research other ways of ending her life... she'd researched a kind of poison cocktail".* Alison (P4 PdxBPD C2) described self-harm as either conscious or automatic, stating *"sometimes... a conscious decision and sometimes it just happens without even my brain processing it".*

Carole (P14 PdxBPD C6) described self-harm as an effective release from crisis, stating *"once it hits you hard... sometimes self-harm's an easier way out... you know that it works".* Alison (P4 PdxBPD C2) listed forms of self-harm where she would *"cut myself and burn myself"* and at times start *"banging my head"*. Joni (P10 PdxBPD C5) shared *"I've cut my wrists or... burnt myself"*. Tori (P5 PdxBPD C3) had cut herself in the past, and now used scratching and elastic bands as an alternative. She described how she would *"scratch and scratch sometimes till I bleed, but I'm trying not to do that now. I've tried sort of the elastic band type thing to avoid all this actually cutting myself"*. Carole (P14 PdxBPD C6) had been asked to limit and control her self-harm, but needed a particular level of self-harm to reach

an effective dose. She recalled *"I've been told... if you want to self-harm, just try and stick to cutting your arms... But... it's like try and tell a heroin addict just to take weed"*. Due to needing a high dose, Carole (P14 PdxBPD C6) described serious and lasting harm, reflecting that *"I'm still dealing with the consequences today because of what I've done to myself"*.

Consuming or avoiding food was described by Kate (P1 PdxBPD C1) as a means of self-harm which was fuelled by suicidal ideation, as she shared *"I often feel unworthy of food"*. She said *"I also self-harm with food... I'll either binge eat, it's all or nothing... or, I will feel suicidal and think, I don't deserve this food and, this sounds really weird, but even to the point where I've thought of, I don't want to hurt my family by them finding me hanging or, having taken an overdose, so maybe if I starve myself something might happen"*.

Suicidality was also a common experience associated with crisis. People had put themselves in extremely risky and life-threatening situations. Kate, Grace, Joni and Carole had all taken overdoses, whilst Kate also *"walked down the middle of the train track"* and Tori (P5 PdxBPD C3) had a fear of her impulsivity, stating *"I haven't drank nearly a year now... because I don't trust myself, because I know I'd be in front of a train and I'd be off"*. Joni (P10 PdxBPD C5) and Grace (P7 PdxBPD C4) had both been in high places with risk of death from a fall. Grace shared *"I've jumped off bridges before, I've took overdoses"*.

4.2.3.5. Multiple functions of self-harm and suicidality

Self-harm and suicide might serve a communicative function. Alison (P4 PdxBPD C2) said self-harm was *"the only way I could get my words out to say I am in crisis"*. Carole (P14 PdxBPD C6) shared *"if your needs aren't met as a child... that's where I think communication comes in with the self-harm and stuff... maybe trying to get my needs met"*. Steven (P9 Specialty Doctor C4) described Grace's (P7 PdxBPD C4) behaviour as parasuicide, a term which has in the past been used to describe forms of self-harm which resemble attempted suicide though have no genuine intent to die (Bateman and Krawitz 2013). He stated, *"things escalate to the point of parasuicidal behaviour... she'll typically either go to the roof of a carpark or she'll take an overdose, or there'll be...sort of threats and communications that she's planning to self-harm that will raise the alarm"*. Annie (P8 CMHN C4) recalled *"she has jumped off the bridge... she's gone up on top of multi-story carparks and climbed the barrier, she's taken overdoses, including a really substantial one quite recently... these are her ways of marking her distress"*. However, whether marking distress without intent to die, or a genuine attempt at suicide, there could be life-

threatening consequences, as Annie described of Grace *“she actually landed up in ICU, she took such a bad overdose and she was intubated”*.

Comparably, prescription medication could be for either sedation or overdosing, and treading this line could be a dangerous one. Tori (P5 PdxBPD C3) sedated herself with diazepam in crisis, whilst Carole (P14 PdxBPD C6) described overdosing, with the purpose of sedation, but knowing it may carry more significant risks. She said *“there's times that I've taken overdoses... just to shut off... I'll take an overdose of like promethazine or something and that will put you in a little mini coma cause... it's pretty sedating... just shut off for a night or two, but it can go wrong”*.

Self-harm through cutting had multiple functions for Carole, as she listed release, grounding and control. She said *“the cutting and stuff on my arms were just releases... watching yourself lose blood is almost grounding... it's like watching your life sort of go away, and you can control, do you either let it go and let it go and let it go until you bleed to death, or you let it stop and you've gotten over it by them, but yeah, it's just a release”*. Alison (P4 PdxBPD C2) described self-harm as a means of preventing suicide attempts, though it could have the opposite effect. She said *“if I've made that conscious decision (to self-harm)... often that can prevent me from feeling suicidal... but then sometimes... when it's more impulsive, and I've not thought it through... when I kind of come back to reality... I then feel worse, because I'm like... look what I've done. I feel quite out of control and feel like... I'm not getting better... like it's a step backwards”*. Carole correspondingly echoed the delicate balance in gaining or losing control. She shared *“the only thing that I can control is (self-harm and attempting suicide), but sometimes... it can also be out of control as well, which is the scary part”*.

Joni (P10 PdxBPD C5) described a complex and contradictory thought process, seeing suicidality as not wanting to die, but also being aware of the risk of death, and fantasizing about the escape which death would bring. She said *“when I do things it's not to take my life, it's because I can't control my emotions. At that point... on the cliff... all I could see is just being under the water and not having to think about anything anymore”*. Carole (P14 PdxBPD C6) shared this confusion, and when asked about intent to self-harm or die by suicide said, *“sometimes I don't even know myself”*. She shared that the outcome didn't always match her intent, stating *“I have nearly killed myself when I haven't meant to, and then I've not died when I've meant to”*. Grace (P7 PdxBPD C4) echoed this, detailing *“it's always kind of in between, like you want to live and then you want to die kind of thing...”*

you're always kind of in turmoil with that. If that makes sense?... I want to live, but it's too like, hard”.

4.2.3.6. A “fireball of emotion”: the descriptive power of imagery

Whilst all PdxBPD would use the word crisis, Alison (P4 PdxBPD C2) also used “breakdown” and “meltdown” to label her experience. Given the limitations of human language, some of the most powerful recollections and accounts of crisis came through metaphor. Joni (P10 PdxBPD C5) felt *“like there was like a huge bubble around me and I couldn't burst out of it.”* Kate (P1 PdxBPD C1) described becoming a “fireball of emotion” stating *“I'd felt so much emotion that it was almost like I'd combusted”*. Carole (P14 PdxBPD C6) recounted, through powerful imagery, her experience of emotional dysregulation, inability to cope, and desperate and impulsive decision making to alleviate intolerable distress:

“Imagine that you are on top of a cliff, and you're just by yourself, and for some reason, you burst into flames. So below you is water... that would help you but you are falling 100 feet down. So you're going to potentially break all your bones. Now you also know how to roll around... but that doesn't work, so you're trying to roll around, you're trying to call for help, and nothing's working so your choice is to either burn to death, or fall 100 feet. So it's like, you're just so on fire that you just don't know, like it's such a quick decision. You can't just stand there forever. Or you'll feel like you're literally going to die if you don't act. Your emotions are so big... you forget all your coping mechanisms”

4.2.4. Theme summary

This theme explored crisis as a unique experience which is different for every individual, with a variety of different triggers which were not always understood and could be incredibly subtle. Interpersonal issues, traumatic memories and issues from co-occurring diagnoses were the most pronounced triggers. These triggers activated a slow build or sudden onset into crisis. Crisis involved intense mental states of thinking and feeling which people may hide from others, yet could also lead people to self-harm and attempt suicide, with these behaviours carried out for a variety of different purposes. This theme presented a chaos of thoughts, feelings and behaviour, with chaos defined as “a state of utter confusion” with “the inherent unpredictability in the behaviour of a complex natural system” (Merriam Webster 2023). The use of metaphor may provide the most compelling and moving description of crisis, as the limitations of human language may fail to effectively articulate the intensity of the experience.

4.3. Theme 2: A confused and anxious system

The confused and anxious system captures experiences with systems (made up of collections of people and processes), exposing confusions, tensions, and inconsistencies. These systems surround the experience of PdxBPD, in the context of both ongoing and crisis care.

4.3.1. Subtheme 1: The dysfunctional relay

The dysfunctional relay begins where PdxBPD in crisis try to seek appropriate help. This could result in contact with the general public, as well as a variety of services including telephone and online supports, mental health services, inpatient units, paramedics and ambulance, the coastguard, the police, custody suite and courts which each appeared to have different beliefs around who held responsibility for PdxBPD when they are in distress and how to respond to them. Access to care and transitions between services were often dysfunctional and unhelpful for PdxBPD. Alison (P4 PdxBPD C2) said *“if I don't get help in that moment, things will get worse and I'm trying to get help before things are absolutely at their extreme... then I don't get the help when I try to access it... then things get to the extreme... then I still don't get the help”*.

4.3.1.1. Helplines and apps

Kate (P1 PdxBPD C1) didn't find helplines helpful. She said, *“I would never phone the crisis helpline because I know they don't specialise in personality disorders”*. Janis (P2 SP Sibling C1) acknowledged *“generic helplines... her confidence in those sort of things is just not there”*. Joni (P10 PdxBPD C5) didn't feel helplines would be helpful without an established relationship. She described how *“the team... gave me the numbers... and it's like, you're phoning some random that you don't know, and they don't know you and they will try their best to help, but... it's not the same”*. Grace (P7 PdxBPD C4) was more positive about helplines, saying *“that kind of works sometimes... phone lines, but it depends what mood I'm in... I can reach out, other times I find it a bit more difficult”*. She also expressed preference for texting app 'shout', a free and confidential 24/7 text messaging service for anyone struggling to cope (Shout 2024). Grace preferred 'Shout' *“because you can text, that's the main thing... it's easier for me to like write things down”*.

Allison (P4 PdxBPD C2) described her experience of ringing 111, an emergency NHS service with an option for mental health help (NHS 111 Online 2024), saying *“you wait like half an hour to an hour on hold... then you get through to someone... then they pass you on to someone else. And they ask you just like all the questions... what's your date of birth, what, age, and that's not what you need when you're in crisis... then someone rings you back.”*

Tori (P5 PdxBPD C3) had phoned “breathing space” stating “sometimes there’s a bit of a wait” but operators had been “helpful”. Breathing space (2024) is a free, confidential, phone and webchat service for people in Scotland over the age of 16, who may be experiencing low mood, depression or anxiety. Tori continued, stating that sometimes, waiting any time at all could be too much, as she explained “I have suicidal thoughts a lot, and that’s when I reach out... I start crying cause I can’t speak. That’s when I panic a bit and want to phone 111 and sometimes I have to wait. So I just end up hanging up”.

Two PdxBPD also highlighted that whilst using apps and helplines, variable thresholds for risk could see the baton of responsibility passed to other services. Tori (P5 PdxBPD C3) said “I’ve used the Samaritans app... and every time I was doing it, it said call 999” yet she thought “I can’t do that” indicating disparity between her perception of her safety and that of the app. She described the approach taken by breathing space, saying “they basically sort of ask... do you feel unsafe, that sort of thing, and I normally say, yeah, I do but I know I won’t do it, cause they obviously would have to intervene... I think if you ask them to intervene they do I think”. This indicated she could control whether her call led to intervention or not. Grace (P7 PdxBPD C4) called 111 and said they “will call the police a lot, which I don’t really like, that’s why I normally... text Shout. You normally have that kind of conversation and don’t really do that unless you’ve said you’ve done something to yourself”.

4.3.1.2. A labyrinth of help seeking

It could be difficult to reach people’s usual care team. Janis (P2 SP Sibling C1) described Kate (P1 PdxBPD C1) and a labyrinth of help seeking, sharing that “she’d tried to contact the psychiatrist, who’d then given her phone numbers for places that were then shut, or their voicemails were giving you phone numbers to other places, and then she got told, once she did get hold of someone, that this particular place didn’t deal with BPD... rejection’s just such a big thing for her”. Tori (P5 PdxBPD C3) was happy with her current CMHN, saying “I’ll always get a response from him”, but remembered “in the past, trying to get hold of people who are meant to be there to help me isn’t always easy”. Alison (P4 PdxBPD C2) agreed, stating if contacting her CMHN “you have to leave a voicemail and someone gets back to you... I hang up before leaving a voicemail because I don’t want to”.

Grace (P7 PdxBPD C4) was passed back and fore between services, leaving her unsure where to turn. She said “I’ve tried to use my CPN, recently... she was busy one time... I texted her... and she never got back to me. So then I called the NHS one and then they said... keep trying your CPN, and when I kept on doing that... I just never got anything back

from her". Reaching out to her CMHN, who doesn't operate as a specific crisis service, had caused some tension between them. She said "we had a bit of an argument about it... she said that it was irresponsible or inappropriate... that I texted her so many times and called her. I only called her like three or four times... So when I was feeling like shit I didn't feel like I could actually go to her".

4.3.1.3. Attempts to pass the baton of responsibility

Where PdxBPD did manage to make contact with services, crisis care most resembled a dysfunctional relay between the police, the emergency department and mental health services. Responsibility could transition (or attempt to transition), back and fore between the person, the public, and from one agency to another. However, responsibility was not always accepted, roles were not always fulfilled to everyone's satisfaction, and PdxBPD and their families could feel unsupported. Alison (P4 PdxBPD C2) had contact with police which then led to an unfruitful experience at the emergency department. She recalled *"I'd had quite a bad (suicide) attempt... I was taken by police and ambulance there... then for them to just be like... just go home".* She'd proactively contacted MH services and *"reached out for help on the Friday",* though couldn't access support. Then on *"Tuesday... things got so bad... I ended up in A&E and then they... just sent me home again... it's never ending and then was back in A&E probably like six weeks later... after that... eventually got put on (hospital) enhanced access list. So I'd rang them probably like again a week later... but... whenever I do reach out for help, nothing's done. And I feel like I'm not taken seriously".*

The relay could be passed through the public, to 111, to paramedics, yet be passed back to PdxBPD. Alison said *"I once was... pulled off a bridge by some strangers... they called an ambulance, and the ambulance controller said... there's nothing physically wrong with her so we're not sending out an ambulance. That was it... there was nothing more done than that... what do I even do in that situation if I'm not getting help?"* Joni (P10 PdxBPD C5) similarly recounted an experience which resulted in activity from the coastguard, police, MH services and the Emergency Department, with the police the constant throughout, and ultimately responsibility then being diffused to her family:

"I couldn't cope and I'd went to the cliff... there was... people walking past with our dogs and they'd phoned the police... they got the coast guard out... I'd also overdosed as well... when... they got me off the cliff... they took me to the (MH Hospital)... and I said to the duty doctor, it wasn't a case of me wanting to end my life... I just couldn't cope with the feelings. I couldn't cope with not understanding what was going on in my head and the duty doctor like

was like, oh, well, I think you've got a good understanding of your mental health. I don't think we need to do anything, you can go home”.

4.3.1.4. Police as a frustrated de-facto mental health service

The police disagreed with that assessment. Joni (P10 PdxBPD C5) recalled *“the police were like... we don't think she can go home because... we were on the cliffs with her, we saw the distress she was in, we're also concerned about the amount of medication that she's taken... we don't think she can go home... the doctor was like, oh no, she can go home... it's all frustrating... doctors and that will say, oh, you seem to have a good understanding of your mental health, you seem to be able to communicate how you're feeling well, and it's like, just because someone can communicate how they're feeling... doesn't mean that what's going on in my head isn't any less real than someone who isn't verbally able to explain it... they almost think... she's appearing fine, so she must be fine... this is a duty doctor, who doesn't know me, doesn't know how I'm feeling, doesn't know anything”.*

The police were still concerned and took responsibility themselves. Joni (P10 PdxBPD C5) remembered that *“the police... spoke to... their sergeant and he was like... I'm not happy for her to go home either but the hospital are refusing to take her in so we'll have to put her into cells”.* The police also took responsibility for her physical health, with Joni recounting *“the police were like... she's overdosed... she needs checked over... the police... took me to like the, (physical health) hospital to get like my bloods and that checked for like the, like overdose that I'd taken”.*

Joni (P10 PdxBPD C5) summarized her dissatisfaction, saying *“the one place... the hospital, where it's meant to help... were like... we think she's fine... the alternative was to put me in a cell... the police were like, we don't want to put you in a cell but we can't send you home”.* Her father, Edward (P12 SP Parent C5), acknowledged that *“the police and the emergency services... did a phenomenal job”* though felt let down by the hospital saying *“they should've then be able to move along the chain, that just failed 100%”.* He continued, saying *“my view is that... police, fire and ambulance, cause she's been involved with all of them, are excellent. (the mental health hospital), you might as well put a match to it, for all the use it's been... the medical side is not nearly as able as the out of hospital side.”*

Carole (P14 PdxBPD C6) echoed this, stating *“the police will see the crisis... the nurses and doctors won't... They don't seem to care”.* She recalled *“I've been arrested... I was in crisis, I saw (MH services) during the day... go away home. I continue to be in crisis, so picked up again by police and I was taken back to be assessed... there's nothing we can do for her... I*

tried to hang myself in public... I just wanted to die right there... So (the police) took me to A&E... phoned back to the enhanced access, and they were like... we're not going to see her again. So the sergeant was like, well, if she goes home, she's going to die. So we're going have to take her and arrest her". Carole (P14 PdxBPD C6) added "because of self-harm, you have to be strip searched and stuff like that... I spent the rest of the night in cells, and I had to go to court in the morning". Despite Carole (P14 PdxBPD C6) going through criminal justice processes, she was eventually back at the hospital, though this time was accepted. As Carole remembered, "my psychiatrist was eventually phoned the next day, and she was like... well just take her to the ward. Why couldn't that have been done firstly? Obviously, the ward is not a great environment, but... that over being a cell".

Grace (P7 PdxBPD C4) again shared similar, understanding the frustration felt by police, as she was continually sent away from MH services only to have a circular journey. She said *"(MH services) just normally send you off and that's it until the next time... So I can understand (the police) probably see like nothing getting done nothing really changing... until the next time... and it's just a circle".* Grace (P7 PdxBPD C4) therefore witnessed the police feeling frustrated with MH services. She said *"I think they feel frustrated with like (the hospital) as well. A few police officers have said that to me, cause they don't understand it they don't really know how they best can help".* Perhaps one of the startling aspects of the dysfunctional relay and evidence of a confused system, was that the police were often first to respond to mental health crises, and yet are not mental health professionals. Grace (P7 PdxBPD C4) thought *"they're really busy... and they don't really know much about mental health".* Carole (P14 PdxBPD C6) agreed that *"they're not qualified, and they can get frustrated at you... they're really pissed off at the system".*

4.3.1.5. Family as an 'all or nothing' mental health service

Family and friends could become a MH service. Kate (P1 PdxBPD C1) emphasized family and their importance in her very survival. She felt *"the only reason I am here is because of my mum and my sister since moving up here... there needs to be something for people... because I rely on my mum and my sister so much, and there will be people out there who don't have that".* Nina (P3 CMHN C1) acknowledged during crisis that Kate's family had *"taken responsibility for her medication" and "removed the sharps from the kitchen".* Janis (P2 SP Sibling C1) described this responsibility for Kate's wellbeing during crisis akin to a job, saying *"we almost feel like someone has to be on shift with Kate... if that's the right term to use... someone's like just checking in with her quite frequently... you were on high alert and at times that got really exhausting".* Alison's (P4 PdxBPD C2) partner and parents

had looked after her, saying her partner *“made me go to my friends cause she knew that I couldn't be safe on my own”*. She also described them as performing the role of MH services, saying *“(my partner) and my parents are the one's picking up the pieces... they're the ones keeping me safe because mental health services effectively aren't”*.

Family could be deliberately used by other services, tasked with fulfilling the role of a MH service. In Joni's (P10 PdxBPD C5) case of a dysfunctional relay, the police felt obligated to offer continuing assistance, and after hospital refusal, utilized family who were essentially asked to become a secure unit and MH service. Joni explained, *“my mum and dad were willing to have me at their house, but the police had said it was horrible... my mum and dad said it was horrible as well... my mum and dad had been told to lock all the doors, not to let me out of the house... the police were scared if I go into the garden, I would run off... my dad was sleeping with the keys under his pillow... because he was so scared that I'd run off, and... the police were coming round, like every, like few hours to check that I was okay... the police themselves were saying, this isn't our job, we shouldn't have to be doing this. But we, we feel like you need help and we don't want to put you in a cell, but that was our only option. So this is another option. So it's like, all this is happening and where's the help from (the hospital)? there isn't any”*.

Whilst family could be used as a MH service, during previous years when Joni (P10 PdxBPD C5) was in hospital, Edward (P12 SP Parent C5) had felt sidelined, with all responsibility taken by the MH service and communication forbidden. This was akin to the ‘all or nothing’ responsibility experienced by families in the literature review (Warrender et al 2021). He felt *“nobody listened, other than one nurse in (the) ward. And she got it, and she really got it. And she started to engage with us and was warned off by the nurse manager, you do not speak to parents... that was very much the case, you do not speak to the parents, you do not tell the parents anything”*.

4.3.1.6. Criminalised for mental distress

There was confusion between systems regarding whether people should be treated as distressed, in need of support, or criminal, in need of justice. Whilst four of six cases described contact with the police, only one had contact which led to criminal charges. Grace (P7 PdxBPD C4) described jumping from a bridge, then being arrested and charged. She thought the reason for her caution was *“I think causing distress... to other people or something... I really didn't understand”*. Annie (P8 CMHN C4) offered her perspective, recalling *“I remember I was at a... multi-agency meeting, they were discussing... charging her, and it was because of the fact that... having to cordon things off, including roads and*

creating mass amounts of disruption in the city centre". Annie (P8 CMHN C4) continued "I'd seen her one day after she'd been charged, and she was really quite angry, which isn't an emotion she often expresses. So, I went through why that was happening. It was because of the disruption caused... rather than any other reason, it's not because of what you were doing, but by what it's caused beyond that... it was interesting to see what her response to that would be, and her immediate response was like quite ambivalent, but then when we spoke about it another time she was, you know, like, more, well, I can understand why that would happen. Whereas, I think, when I first spoke to her about she was pretty much, oh, fuck them, I don't care". Grace (P7 PdxBPD C4) recalled that she had been told by MH services to "take responsibility for it... But it's easier said than done kind of thing".

Annie (P8 CMHN C4) described the perceptions of some in MH services which agreed with criminalization, with attitudes suggesting Grace (P7 PdxBPD C4) caused a lot of disruption and "shouldn't be allowed to get away with that". However, Annie (P8 CMHN C4) described the dilemma as "a difficult one", and offered her understanding of Grace (P7 PdxBPD C4). She thought "there's a part of it... she knows the disruption she's causing, but because she's not managing to vocalize it... she's not sure... where to go with it and she can't name it... it's a response to distress and it's how it's managed... it's not to be punished". However, for Grace (P7 PdxBPD C4), being charged did feel punitive and led to her feeling worse. Grace (P7 PdxBPD C4) described feeling "angry", and said "I was a bit confused about it. I suppose it just felt a bit like, oh, nobody cares and I just felt even more suicidal".

4.3.2. Subtheme 2: Anxiety around risk and a fear of litigation which influences decision making

An aspect of the confused and anxious system was professional anxiety around how to best manage risk, particularly around suicide, and concerns professionals may be held to account and unsupported by their employing organisation if there were any adverse events such as PdxBPD dying by suicide. Professionals noted that stigma around 'BPD' may reflect staff helplessness, and responsibility could be put back to PdxBPD as a means of psychological self-defence. Nina (P3 CMHN C1) felt stigma was due to "clinicians that can't just say what they really mean, which is, I feel out my depth with people with EUPD".

4.3.2.1. High expectations, and anxiety around the 'gamble' and unpredictability of risk

There were concerns regarding society's high expectations of mental health care. Robert (P13 Psychologist C5) stated "there's that societal kind of feeling that we must kind of rescue people all the time and... how do we as a service deal with that when our patients die?". This fear manifested in both concern for the wellbeing of a PdxBPD, but also concern

around self-preservation from potential blame for negative outcomes. Steven (P9 Specialty Doctor C4) gave his perspective on the complexity and uncertainty of working with risk, saying *“these patients that I see... it feels like no matter what my intervention, I feel like I can... leave a room (having) done a very good piece of work with someone who's very thankful, and they can go and cut themselves or tie a ligature the next day... even that afternoon... it can still happen. I've found with all that unpredictability, the only thing that kind of tends to soothe it is, how many people across the board have I got on board who understand the situation? How well documented is their understanding that this risk is variable and chronic”*.

Robert (P13 Psychologist C5) agreed *“there is inherent risk in working with these folk... you're not a magic... treatment, you can't save everyone... but you have to offer the best possible care”*, and Nina (P3 CMHN C1) stated *“I think managing and holding risk, high risk cases, is a frightening thing”*. Annie (P8 CMHN C4) described her thoughts following Grace's (P7 PdxBPD C4) attempted suicide, saying *“I kept on reminding myself... I did everything I could. There's nothing more I can do, but then I was thinking this is more about litigation... rather than thinking about the personal side... the personal side was still there... there's still that, you know, is she okay”*. Billie (P16 CMHN C6) agreed, but also shared how fear of blame and litigation could impact on a professionals risk-threshold:

“I understand why people don't have a risk threshold, because... I know someone who's under investigation at the moment because one of their patients died, and they didn't die from mental health causes... so you do feel really vulnerable... and it's horrible... we're in such a vulnerable position, and I do understand that people reach a point in their careers, whether they've got a mortgage, you've got kids, it's not worth putting your reg on the line... I sometimes have flickerings of that feeling... is it worth putting my reg on the line to take this gamble, cause it is a gamble always. Because you don't have that confidence that your managers will have your back if things go wrong... that makes it really difficult to have a risk threshold and then that causes harm to the patient... that, to me, is a huge part of it... we live in a blame culture, and we are sitting ducks”.

Mark (P6 CMHN C3) agreed, sharing his own experiences of investigation. He said *“it's a litigious age, and organizations don't want any of the blame to hang on them... so I don't think it's entirely unreasonable to assume they'll hang it on you... if they feel like defending themselves... And certainly, when I look back to other experiences I've had vicariously of... bad things going wrong. And listened to what my colleagues... have to say about them... the organization does not love you... The organization loves itself... and will do everything to*

protect itself". He shared his perception of other professionals experiences, recalling "I can think of events... other suicides and things like that have happened... where some of my colleagues have come out of it really badly hurt... not only by the fact that we're there and some awful thing's happened, but by the fact that... they felt really like dragged through a hedge backwards by the organization... it's not 'what do I think could happen', it's what have I seen happen". Mark (P6 CMHN C3) described his personal experiences of investigations as 'reasonable', but said "I wouldn't have liked to have been there with my notes badly done". Steven (P9 Specialty Doctor C4) agreed "if something horrible is to happen with your patient, and you haven't documented very thoroughly, that there is this very high risk... you can end up in really serious bother".

4.3.2.2. Isolated decision-making and the need for a 'just right' response to risk

Steven (P9 Specialty Doctor C4) detailed how feeling responsible for risk could be an isolating experience, stating *"as I've sort of climbed up in seniority... there's less people to actually share the stress with"*. Robert (P13 Psychologist C5) agreed that *"there was a real kind of feeling that the risk just sat on the consultants, which wasn't fair"*. He argued that this isolation of responsibility *"wasn't helpful"* and could influence decision making. He said *"I think (psychiatrists) could often make kind of reactive decisions to either kind of admit someone when it wasn't helpful or to reject someone when it wasn't helpful... it's a really hard kind of position for them to be in"*. In agreement, PdxBPD described intervention not always matching what they felt they needed. Joni (P10 PdxBPD C5) said *"I hate hospitals... I hate going into them... that time last (year) was the first time in years that I'd been like, take me into hospital. Whereas... other times they take you in and you think that's not what I need"*.

Whilst some people had discussed difficulties accessing hospital when in crisis, Robert (P13 Psychologist C5) noted a sharp contrast as he worked with people *"coming into my service where it'd had gone too much the other way, where I was like having to rehabilitate people who have, diagnosed BPD, but have been living in a hospital for four years because people are so risk averse... and so afraid of kind of what they would do to themselves"*.

Mark (P6 CMHN C3) worried that this degree of containing risk could be harmful, by reinforcing PdxBPD's beliefs that they could not cope on their own. He thought *"the more they learn that it's unmanageable... the more... they learn helplessness... in the face of it, and the more desperately they will seek reassurance or try to get help in sometimes increasingly extreme ways... Whether that's... desperately seeking reassurance or being angry or you know, anesthetizing themselves with substances legal or otherwise"*. Robert

(P13 Psychologist C5) noted the need to get it 'just right', rather than any decision or another becoming standard practice. He said *"it can go too far the other way and become... oh no, we don't admit anyone"* or discharge people *"after two weeks and kick them out"*. *"That was never the idea"* he said. *"The idea was, you're constantly reviewing"*.

4.3.2.3. Inconsistent relationships due to anxiety around risk

Nina (P3 CMHN C1) described how anxiety around risk saw PdxBPD passed within MH services, with a negative impact on continuity of care and consistent relationships. She said PdxBPD could *"go into crisis and psychologist panics and wants a community mental health nurse to come on board to manage safety and stabilisation. But"*, she imagined replying, *"you're the one with the relationship with a patient... let's not add another person. Because... what does that feel like for the patient?"* Mark (P6 CMHN C3) also felt frustrated where PdxBPD were in crisis whilst engaged with psychology, with their response perceived as *"they're too unstable, so let's give them to the nurses"*, noting the contradiction that more specialised clinicians may not feel able to work with crisis. He felt PdxBPD were paradoxically *"too unstable for the really highly trained people... that's cynical, but it's sometimes feels like that."* Billie (P16 CMHN C6) had worked in a crisis service in another geographical area, and shared the phenomena of PdxBPD being passed around within a MH service, with responsibility being passed to 'cover themselves'. She described how crisis services *"just get used, by CPN's... and I understand why... someone comes in on a Friday and says, I'm suicidal, so they refer to crisis to cover themselves. A lot of it is covering themselves. But then... who does the crisis team go to, to cover themselves? The only avenue is hospital. That's the only next level from crisis to cover yourself... just pass it, pass it, pass it"*. Thus not only could there be a relay between services, but there could be an anxiety fuelled relay within services.

Billie (P16 CMHN C6) petitioned that the purpose of the MH nursing role may at times be gatekeeping, not necessarily about providing a therapeutic response. Billie recalled *"every time you're seeing a patient in crisis... in your mind... you're assessing risk, it's all about risk. So, you're not doing much other than assessing risk and calling it when they need to go in (to hospital)... I think that the initial intention of crisis services is very, very lost"*. Carole (P14 PdxBPD C6), attuned to what might have been the original intention of crisis services, just wanted to be listened to, and didn't always necessarily want or need to be passed on to another service. She acknowledged a culture of gatekeeping, but said when she was being assessed for admission, a therapeutic response from a professional may have been enough. She recalled *"someone told me that one of the nurses said to her, people with*

EUPD don't like me, because they don't get put into hospital, and that's only thing that they're there for. Where, 90% of that is actually just wanting to be listened to and talk through it... then go home and then see the community in the morning”.

4.3.3. Subtheme 3: Confusion around diagnoses

4.3.3.1. Unsupportive experiences of receiving the diagnosis

The ‘BPD’ diagnosis itself caused confusion for all stakeholders, and could impact care. The diagnostic process itself could confuse people, with PdxBPD not always understanding diagnosis or feeling supported during the diagnostic process, leading to confusion around what diagnosis meant for them. Kate (P1 PdxBPD C1) described being given the ‘BPD’ diagnosis with no explanation, directed by a psychiatrist to *“go home, read up about it”* and discuss with family and friends. Joni (P10 PdxBPD C5) described the diagnosis as *“something I’ve always been told that I’ve got, but I don’t necessarily understand it”*. Grace (P7 PdxBPD C4) got her understanding from peers and her own reading rather than psychiatry or the diagnostic process. This was echoed by Carole (P14 PdxBPD C6) who said *“I learned about it myself”*. Tori (P5 PdxBPD C3) mentioned the separate terminology used in the DSM-5 and ICD-10, and found she identified more with the ‘EUPD’ label than the ‘BPD’ label, due to it being more descriptively accurate. She said *“I just am emotionally unstable”*, but asked, expressing confusion around ‘BPD’, *“borderline personality is borderline of what?”*.

4.3.3.2. The subjectivity of diagnostic practice

A further issue is that diagnostic practice can be subjective, giving individual professional opinion enormous power. Steven (P9 Specialty Doctor C4) described that *“someone's borderline is someone else's bipolar in this line of work. And... right across clinicians and what they would call a symptom, there's often quite a bit of disagreement”*. He acknowledged that the diagnostic process could be rushed and inconsistent, disclosing *“I actually, use the phrase badly diagnosed... I certainly worry that anyone with a bit of emotional dysregulation, at the point of crisis, will be labelled as having a borderline personality, which I think is a very unfair thing to do”*. Acknowledging subjectivity he said, *“I think there is a lot of difference in what people... will call BPD”*. Alison (P4 PdxBPD C2) felt she was ‘badly diagnosed’ whilst in crisis in a private inpatient unit, where she went through an abrupt medication change, and was diagnosed after three meetings with a psychiatrist in a restrictive environment where she said she *“wasn’t myself”*. Despite being heterogenous with people very unique, Steven (P9 Specialty Doctor C4) agreed PdxBPD could be stereotyped because of the diagnosis. He postulated *“if you have two people, one*

has symptoms, one through five, and the other one has symptoms six through 10. They both get the diagnosis, but both clearly have a very different experience of being alive... I think for that reason... it's not a diagnosis that I find often has... consistency, but it's treated as if every single person with BPD is the same".

4.3.3.3. Becoming the diagnosis and losing the self

Whilst the 'BPD' diagnosis is heterogenous, meaning people with the same diagnosis can be very different and even have different symptoms, the label could also confuse people's sense of personhood and individuality. This shaped the way PdxBPD saw themselves, looking through the lens of a diagnosis. Kate (P1 PdxBPD C1) assumed if many people could have the same label, that they each must share symptoms, and as she spoke to others with the same diagnosis and heard about their difficulties, she thought *"well, I must have that because we're all in this one category"*. She thus believed any listed symptoms she had not yet experienced, she would come to experience. She lost hope, feeling *"doomed"* when reading about 'BPD' and its association with suicide, describing feeling *"like I was handed a death sentence"* and thinking *"well, I'm just going to be a statistic"*. Alison (P4 PdxBPD C2) too acknowledged the power of diagnosis on self-concept, stating she had been *"subconsciously trying to make myself fit the boxes"*. Billie (P16 CMHN C6) recounted her conversations with Carole (P14 PdxBPD C6) who she said *"describes kind of mimicking that... she felt, this is the diagnosis you've given me, so I'm going to live up to it"*. Thus people may become the diagnosis, and perhaps in the process lose themselves.

4.3.3.4. The confusion of comorbidities

Adding potential for confusion around personal identity and appropriate crisis response, all PdxBPD across cases were currently, previously, or had professionals query additional or alternative mental illness/disorder and neurodivergent diagnoses including anxiety, depression, autism, attention-deficit hyperactivity disorder, post-traumatic stress disorder, bi-polar disorder, panic disorder, eating disorders and obsessive-compulsive disorder. No one had a sole 'BPD' diagnosis. People found some symptoms overlapped between different diagnoses, and confusion at how their experiences were separated into different diagnostic categories. However, once 'BPD' was diagnosed, Alison (P4 PdxBPD C2) felt it was a powerful label which outranked other comorbid diagnoses, stating professionals *"don't even consider my ADHD, or even like my depression or anxiety"*.

Kate (P1 PdxBPD C1) was aware of her diagnoses having similar traits, finding it difficult to separate PTSD and 'BPD' which she felt went *"hand in hand"*. Joni (P10 PdxBPD C5) found diagnoses difficult to comprehend as she saw her behaviour *"to me as quite normal"* yet

felt separated into distinct categories with professionals communicating “*well that’s down to your autism, or that’s down to your BPD*”. Edward (P12 SP Parent C5) described his comprehension of Joni’s three competing diagnoses, stating a holistic rather than categorical view. He said “*I just see it as a plate of spaghetti, trying to unravel it is... are they two absolutely distinct or are they... perhaps more sort of Venn diagramish, where you’ve got bits that are very distinct, but there’s overlap... I think... what I’ve tried to do more is to see Joni as Joni*”.

4.3.3.5. Not ill and too ill: the spaghettification of distress

PdxBPD highlighted paradoxical views of ‘BPD’ within the mental health care system through professional attitudes as well as organizational structures and processes. During crisis in an inpatient setting, Alison (P4 PdxBPD C2) was told by a MH nurse to “*calm down*” because “*there’s ill people here*”, indicating she was not as ill or as deserving of care as other patients. Grace (P7 PdxBPD C4) thought that “*other disorders are taken more seriously*”, and Carole (P14 PdxBPD C6) heard professionals state “*it’s not even a mental illness*” and indicate she was “*taking time away from people that are actually unwell*”. Nonetheless, a contrasting message was conveyed where despite being on the waiting list for therapy, Alison (P4 PdxBPD C2) was told due to experiencing crisis, that she was too unstable to receive therapy. She recalled “*they were just like... you’re too unstable for therapy right now. I’m like, well, if I’d had therapy before I probably wouldn’t have got that unstable... my CPNS like... you just need like three months of stability, and then we can re-refer you... but how do I get stable for three months without any help... that makes no sense to me because... the whole time with my team, they’ve been like... it sounds like you need therapy*”. This was also experienced by Carole (P14 PdxBPD C6) who described it as a “*weird, vicious cycle*” where therapy may prevent crisis, however experiencing crisis meant you would not be offered therapy. She felt the message from MH services was one of requiring to get better before having access to long term support, “*the only thing that’s gonna work for you is therapy, but we’re not gonna give you therapy because you can’t stop self-harming*”.

Thus a fitting metaphor for this experience comes from the study of black holes, “spaghettification”, the theoretical phenomenon where immense forces pull at either side of an object and stretch it like spaghetti (Pinochet 2022). PdxBPD are spaghettified, stretched between opposing poles on a spectrum, with ideological forces from both professional attitudes and service organization simultaneously communicating that people are *not ill enough* and also *too ill*. Alison (P4 PdxBPD C2) asked herself “*well, am I not ill?*”,

while Carole (P14 PdxBPD C6) said *“you've got a diagnosis that isn't really helpable, other than therapy, and you're not stabilized for therapy, so... the door's just continuously closed on you”*.

4.3.4. Theme summary

The confused and anxious system, comprised of interconnected people and agencies, sees a dysfunctional relay where accessing support is not straightforward, and PdxBPD can experience poor or non-existent transitions through care. This may in part be because high risk causes anxiety in professionals and can influence their decision making. The diagnosis itself, significant in how people see themselves and are seen by others, can also hinder quality care through stigma, and organizational structures which penalize people for being in crisis, and denying them long-term support.

4.4. Theme 3: Acts and omissions which lead to harm

Crisis intervention through various agencies across healthcare and emergency services could also add to distress, both through omissions of helpful and empathetic responses, and harm through restriction and coercion. It seemed that two recoveries could be required of PdxBPD as they needed to both recover from crisis, as well as the intervention which could add to, rather than alleviate, distress.

4.4.1. Subtheme 1: Wearing a stigmatized label and ceasing to be a person

The 'BPD' label caused self-stigma as well as stigma from others. The terminology of 'personality disorder' led Kate (P1 PdxBPD C1) to feel like a *"wild, hated monster"*, and she read descriptions online discuss *"someone with BPD as if they weren't even human"*. Tori (P5 PdxBPD C3) saw herself in the symptoms of the diagnosis, but shared discomfort with the label, feeling it disconnected her from humanity and was insulting. She said *"it makes me sound like I'm on another planet... I like to think I have a nice personality"*.

4.4.1.1. Diagnosis overshadowing experiences of trauma

The diagnostic stereotype could also negatively impact sense of self through overshadowing the lived experiences which may have caused the distress they experience. Carole (P14 PdxBPD C6) described a journey with her understanding of the diagnosis. She remembered *"I struggled with (the diagnosis) for years, I didn't understand it... I looked it up and thought... that sounds right. But more that I learned... I found it's a trauma diagnosis, and a lot of people... come from like childhood sort of issues"*. Five of six cases saw PdxBPD mention past trauma. Carole (P14 PdxBPD C6) disclosed childhood trauma, yet was disappointed this was not acknowledged or linked to her difficulties when initially receiving the diagnosis, remembering *"they were sort of presenting it, this is all it is... your experience is almost invalid"*.

Not only did people feel that trauma may be overlooked, but they also felt that the diagnosis led to blame rather than compassion, and people were seen as fabricating their distress and being intentionally difficult. Alison (P4 PdxBPD C2) said *"you're not intentionally acting this way... my mental illness is what is causing me to be like this"*. However, Carole (P14 PdxBPD C6) felt the narrative from MH services was *"she knows what she's doing... she's doing it deliberately for attention"*. Carole (P14 PdxBPD C6) described her self-harm as a response to trauma, yet felt this was overlooked by MH services due to the 'BPD' diagnosis, with her behaviour seen as a conscious choice which she should be responsible for. She said *"they see it as made up... not based on 30 years worth of"*

trauma... they don't see that part of it. They just see... you've done this to yourself... Yes, I did. But, did I? This was just my hand."

4.4.1.2. Stigma and discrimination as a result of the 'BPD' label

The 'BPD' label was also powerful in shaping the views of others. The degree of stigma associated with the diagnosis created an unfavourable stereotype which was felt to influence personhood, with Alison (P4 PdxBPD C2) stating *"I feel like I'm not seen as a person... I'm just seen as this BPD label"*, and *"I feel like I'm prejudged before anybody even remotely gets to know me... That's what they see first"*. Nina (P3 CMHN C1) acknowledged a culture of stigma, and described feeling embarrassed of colleagues attitudes. *"Listening to the language"* she said, *"the way that patients are spoken about... it's shocking... it's not smart, it's not funny... quite frankly, I'm embarrassed"*. Steven (P9 Specialty Doctor C4) agreed, emphasising the weight that the label carries. He claimed *"it's a label that currently carries a lot of weight... for a person... for clinicians... not just in psychiatry, that's every other walk of life... if you've come through medical school, and you have encountered some BPD in each area, then whenever you see a patient, who's turned up in A&E, and they've got some other complaint, and they happen to have BPD... in their list of diagnoses, chances of you being sceptical are far higher than they are elsewhere"*.

This weight was felt by PdxBPD. Alison (P4 PdxBPD C2) felt the discrimination she experienced could be directly attributed to the BPD label, and reflected on the way she had been treated pre and post BPD diagnosis. She thought *"this label's damaging to many people... I very much notice that by how I was treated before and how I've been treated after... I have lost like that humanity and being treated like a person"*. Carole (P14 PdxBPD C6) agreed that experiences of poor care were rooted in the label itself. She said *"I think that diagnosis has ruined my life. Completely ruined my life... And I think that the attitude has come from the diagnosis alone, compared to other sort of diagnoses."*. Carole (P14 PdxBPD C6) described the impact of negative attitudes on her, and understood that stigma around 'BPD' was not just a local issue. She stated *"I don't know if they've gone into this job wanting to make people feel like the worst people alive, not even human, but that's what they've ended up doing with people like me, because I've heard it before, lots of times... in (the city), but I've heard it all the way across the country. So it's an attitude problem that is so contagious"*. Three PdxBPD felt they were treated as 'less than' other human beings, Alison (P4 PdxBPD C2) feeling like a *"second class citizen"*, Carole (P14 PdxBPD C6) feeling *"not even human"* through contact with mental health services, and Grace (P7 PdxBPD C4) stated the police *"treated me like I was a criminal"* and *"don't think they really treat me like*

a human being”. Kate (P1 PdxBPD C1), reflecting on inpatient care, said *“I felt like a number... just to go, yep, they’re breathing, yep, they’re taking their meds”*.

4.4.1.3. Seeing the stereotype rather than the person

Joan (P15 SP Friend C6) described the ‘BPD’ construct as a *“load of garbage”*. She felt it was too broad coming with *“too many component parts”*, as it could capture people who could be very different and categorizing them all under one label. Once categorized, she felt stereotypical symptoms and behaviours were *“assumed of you once you have given that label”*. She continued, stating *“there’s just an awful lot of assumption that comes with the label... and the diagnostic manuals probably don’t actually say that... they say that it can be a whole spectrum of things, but I think people just kind of get lumped together. If you have this label, you will behave in this way and we will treat you in this fashion”*. Nina (P3 CMHN C1) acknowledged within MH professionals there was an *“unspoken language”* where although *“everyone is different, everyone is individual”* there was a strong ‘BPD’ stereotype which overshadowed individuality, and professionals would *“lump under this sort of group of symptoms or traits or behaviours.”*

4.4.2. Subtheme 2: Neglect revisited and the invalidation of a still-face

This stigma could have a real-world impact, leading to exclusion, neglect and invalidation, and PdxBPD not feeling accepted, excluded from services, and also excluded within services. Grace (P7 PdxBPD C4) described experiencing the frustration of police officers. She recalled *“I’ve had a few recent experiences. I’ve went missing before and like one police officer said... wish you’d just like just drove past... when they found me. I’ve had a lot of shit from police... it was very loud. He was angry, you could see it”*. Grace reflected that *“the first time I felt that police were really helpful”* acknowledging *“they’ve probably... saved my life on a few occasions”*. However, after more experiences of crisis with risk of suicidality, she said *“now I just think they’re just fed up... nothing’ll happen or she won’t do it... I don’t think they take it seriously either anymore.”*

4.4.2.1. A diagnosis of exclusion and discrimination

An impact of the confused and anxious system was feeling invalidated when PdxBPD were not accepted by services. Joni (P10 PdxBPD C5) described desperation after being escorted to hospital by the police due to risk of suicide. She said *“I was like begging them to keep me and they wouldn’t keep me”* and describing the experience as *“scary”*. Carole (P14 PdxBPD C6) felt not admitting PdxBPD was due to a culture of stigma, postulating *“I get the sense that the people who are frontline sort of they’re the mental health nurses and doctors, they would rather chop their own arm off than admit a person with EUPD in the*

middle of the night". Mark (P6 CMHN C3) agreed that accessing hospital was a challenge, saying *"you end up with almost like a siege mentality in the hospital, because they're trying to pick out the people who fit the service they deliver, and not engage those who don't"*.

Alison (P4 PdxBPD C2) felt invalidated by a doctor in the emergency department. She shared *"I've been in for self-harm and he was like, what were you hoping to achieve by this?... he was like... I can see by looking at your arms this isn't new to you. And was very negative... almost undermining how I felt"*. Carole (P14 PdxBPD C6) recounted an unsavoury interaction with a security guard from the emergency department *"who said to me, you're the worst type of people because you're on benefits, and you're still abusing the system. I'm paying you to live. You're a waste to society"*.

4.4.2.2. Neglected and pushed away

Invalidation and neglect was also felt when PdxBPD spent time as inpatients. Kate (P1 PdxBPD C1), cited a fear of abandonment as a key difficulty, yet described being an inpatient and feeling ignored for 5 days. She recalled *"the only time... that the staff ever... came up and spoke to me, was actually cause they were noticing I wasn't going through at mealtimes... it was on my like fifth day or something, somebody had come through and said... you need to eat something... That's the only time I ever felt noticed... there was no other communication... I never actually had a relationship with any of the staff... I was a bit paranoid because I didn't know if I was being a hassle and it was a checklist they had to do... we better check on her cause she's not eating... I just didn't how sincere it was"*. She felt neglected during crisis, saying *"I personally felt I was drugged up and held to a room to ride it out in my most darkest crisis point as an in-patient. No one tried to take the time to talk to the quieter patients. I feel I was not heard or helped other than chemically sedated and isolated... I suffered in silence"*. She felt *"more support from the patients... we supported one another... comforted each other"*.

Kate's perspective was validated by Nina (P3 CMHN C1) who shared the professional experience of seeking out inpatient staff. She detailed *"you go into the ward, and as a clinician... I've got a uniform on, I've got a badge, and I'm knocking at a glass door, and not a single person will lift their head to acknowledge they've even heard the knock. I can't imagine what that must be like for a patient. If you've sat in your bed space thinking... I think I really need to go and speak to someone. Right, I'm going to go and speak to someone, to pluck up the courage to knock on that glass door to be ignored."* Not only did staff not make themselves available, Nina (P3 CMHN C1) felt a lack of warmth and sensitivity when responding. She said *"the other thing that I've seen that worries me more than anything is,*

you know that the MH nurse can't be more experienced than a couple of years, because of their age... but they have that resting bitch face... but it's to push you away... like, don't ask me, because I don't know, but they can't say that. So they'll do the attitude... that's how we're treating each other. So can you imagine what that's like for a patient if they get a resting bitch face?"

4.4.2.3. The 'still-face'

Nina (P3 CMHN C1) synchronised her understanding of this with attachment theory and the still face experiment (Tronick et al 1978), discussing the negative impact of caregiver neglect. She said *"all it is, is still face... there's so many times that you see it happen in psychiatry, with patients that have a diagnosis with EUPD, they're given the still face, I think how triggering... And genuinely, I think there's times where staff don't know they're doing it. Sadly, I think that are times where they do know they're doing it and it's deliberate"*. Joan (P15 SP Friend C6) had her own experiences of inpatient care, and shared the impact of feeling alienated and disliked in the ward environment. She said *"I felt like they couldn't stand me... all the other staff in the ward, I felt like they genuinely hate me. It's just a horrible feeling to have from people that are supposed to be helping you... that sense that everybody hates you all the time that you get from too many people in services is just counterproductive"*.

Alison (P4 PdxBPD C2) also described 'still face' responses to self-harm, as staff addressed her physical health needs, but overlooked the underlying distress which had led to it. She said staff would *"deal with my wounds, but they wouldn't even ask me how I was or what was going on, or sit and speak to me... I felt like I was like patched up and left on my own... then it would happen again."* Where the underlying distress was not responded to, patterns of self-harm could repeat. This neglect could be particularly damaging if it re-traumatised PdxBPD who had experienced this in childhood. Billie (P16 CMHN C6) recounted her understanding of Carole (P14 PdxBPD C6), reflecting that *"her background is primarily neglect... from how she describes it, her feelings about it. There's a lot of times where she would be crying, and she would just be put in a room and the door would be closed, and she would be left to cry"*. Carole used analogy to further describe the impact of her childhood experiences, stating if *"you kick a dog enough, it'll start thinking it's done something wrong"*.

4.4.2.4. Rejection, invalidation and revisiting neglect

As well as harm through omission of care there were instances where people sought help and were actively rejected, which PdxBPD often felt was due to their diagnosis. Carole (P14

PdxBPD C6) sought help from an inpatient staff nurse, saying *“I just want to talk”* but recounted being told *“well, that isn't my job”* as the nurse *“walked away and just left me there when I just asked to be talked to.”* Grace (P7 PdxBPD C4) thought the ethos may be *“to make sure you're safe rather than treating you”*. Alison (P4 PdxBPD C2) felt belittled and invalidated, remembering *“I started like having panic attack and breakdown, and one of the nurses was like, go to your room, and I was like, if I go to a room, I'm gonna hurt myself... the only way I could get my words out to say I am in crisis... I was actually asking for help, which is quite rare for me, and I got told by a nurse... I don't care, that's on you, stop having a tantrum... I wasn't having a tantrum. I'm not a toddler”*.

Alison (P4 PdxBPD C2) felt that not feeling accepted by MH nurses added to low self-worth, and would discourage her from seeking help from friends. She said *“I think that's where a lot of things like not wanting to burden my friends (come from)... if mental health professionals that have chosen to go into that field are going to have that perception of me, then why wouldn't anyone else?”*. Carole (P14 PdxBPD C6) too indicated that life experiences, replicated in healthcare, could reinforce low self-esteem and self-blame. She said *“it's just that repeatedly in life and then... when you get poor care... you think, am I wrong? Is it me?”*. Joan (P15 SP Friend C6) also understood that interactions with professionals sometimes *“brought up... memories, old relational experiences”* for Carole. She continued *“I think that it's almost sort of re-traumatized her in the moment”*. Billie (P16 CMHN C6) confirmed that mental health care may have helped *“had the response been healing, had it been the opposite of her childhood... but unfortunately, it was the same. It was still a little girl crying in a room and banging her head... and it just being annoying”*.

A lack of sensitivity could also be evidenced in MH nurses interactions with family. Edward (P12 SP Parent C5) described receiving unsettling news about Joni (P10 PdxBPD C5) in a blasé manner, remembering *“the nurses stopped me and said, oh, I just thought I'd let you know, so you don't seem too surprised, but she's cut up her face... whoa, you're just telling me she's taken a razor blade to her face and it's... just thought we'd tell you”*. There were overall multiple experiences of invalidation, with PdxBPD and families not feeling like professionals cared about them or their distress.

4.4.3. Subtheme 3: Chaotic and oppressive environments of care

Crisis intervention often included environments which were chaotic, and could feel oppressive through restriction and coercion. Hospitalisation was a common crisis intervention, and PdxBPD could feel powerlessness through uncomfortable restrictions put on them by the inpatient environment, which were not well communicated between staff

teams, not well communicated to patients, and added to their distress. Kate (P1 PdxBPD C1) described how the inpatient environment was 'hectic', noting the internal chaos of crisis could be outranked by that of the environment: *"To start off with, my head was more hectic than my environment, after a week, maybe ten days... the environment became more hectic than my head"*. Alison (P4 PdxBPD C2) added that she also felt scared, saying *"the atmosphere... was terrifying, to say the least"*.

4.4.3.1. Catch-22 and two recoveries following hospitalisation

Kate (P1 PdxBPD C1) described inpatient care as adding to her distress, and requiring a second recovery. She described *"you're triggered by the loud noises, the alarms... men shouting... it just all became too much, to the point where I actually wanted to escape... I know it's not supposed to be enjoyable but... it's not been helpful... it took me quite some time to get over what I'd been through in there, let alone going over why you were in there... it was sort of two recoveries at once."* Grace (P7 PdxBPD C4) felt the ward was simultaneously both helpful and unhelpful. She said *"I felt it quite therapeutic, to be honest... I think it's like a caring environment, and you're safe, and nothing's gonna happen to you. But it can also be quite triggering as well, because you've got a lot of other patients around you... It's like a sort of Catch 22 kind of thing. It's like good in a way, but not so great in others."*

However, hospital was not always considered a reliable means of ensuring safety. Kate (P1 PdxBPD C1) recalled alerting staff nurses, stating another patient *"was on his bed with a carrier bag over his head... there was maybe another four or five mental nurses in the glass room, the office, not doing checks, and I had to chap the door and say, he's got a carrier bag over his head"*. Witnessing suicidal acts could also have an element of contagion, as she added *"I knew I had carrier bags in my room and I thought, okay, that's something I could do"*. Edward (P12 SP Parent C5) also recalled how Joni had left the ward without nursing staff noticing. He remembered at *"one point she was under constant observation, and she phoned us up and said... I'm in (the) park. I said, okay, should you be there? No, she said. So we phoned (the ward) and said, do you know where Joni is?"*. A nurse who answered said *"Oh, she's here. She's under constant observation, isn't she?"*. She wasn't, indicating in the chaotic environment a patient's whereabouts may not always be accounted for.

4.4.3.2. The limitations of hospitalization and hesitancy around admissions

Professionals too recognize the chaos and limitations of inpatient care. Robert (P13 Psychologist C5) noted a limitation of hospitalization in that PdxBPD could still be *"doing awful, terrible self-harm to themselves"*, and that *"people still die in hospital"*. Mark (P6

CMHN C3) hesitated to see much therapeutic value in admission, asking himself “*what are they going to get in hospital, you know?*”, and Nina (P3 CMHN C1) acknowledged it was “*not a calm, soothing environment*”. After Kate (P1 PdxBPD C1) was admitted to hospital due to a high risk of suicide, Nina (P3 CMHN C1) felt relief, but also apprehension about the experience she may have, so much so that she visited her whilst in hospital:

“There was that, that sense of, okay, she’ll be safe. But what very quickly kicked in after that was, this could go really wrong. This could be really badly handled... quality contact that she gets from nursing staff will be dependent on clinical activity. Kate is... not somebody who beats her chest with her fists to get time with someone. She’s very subtle. So the rejection and the abandonment can be triggered, but it doesn’t look like that... so my relief was then very quickly, accompanied with fear again. So, to manage that I said I will continue to visit you as an in-patient. So I did, I came down to the ward and met with her once a week... I saw her I think three times, all in all, and I was worried about how that was viewed, but I felt I could justify the risk... cause back then it was about managing COVID risk first. And I felt I could justify... coming onto the ward wearing PPE. And actually what I did was, I took Kate off the ward and we just went for a walk... just to give her a bit of time off the ward, and we sat on the benches, and we just talked... there were things happening on the ward that were quite triggering for her. So it was helping manage that”.

However, the hospital grounds were also considered chaotic, with Kate (P1 PdxBPD C1) describing conflict between patients and drug dealing. She said “*I smoke an e-cig, and that was my escape from the ward when it was hectic... going down to the garden, which was also hectic. There’s nobody monitoring patients, there was arguments... conflicts in the garden between patients, it was very chaotic down there too... With no one... controlling that and the fence that’s at the very back of the smoking area, every single time, guarantee you... drugs get handed over that fence... Drugs and money... coming into (the hospital)”.*

Billie (P16 CMHN C6) heard from Carole (P14 PdxBPD C6) about how unhelpful hospital had been for her, and was reluctant to have any of her other patients admitted. She said “*we’ve talked about how damaging it was, that it wasn’t good... there is no reason to admit you, and that’s not because you’re not unwell enough to be admitted, it’s because it’s not going to help you... I’m the person who’s going to help you... I’ve never admitted someone with a personality disorder, never when I was working in crisis... I don’t think I’ve admitted anyone since I’ve been a CPN, cause I don’t really like hospital... I think if I had more faith in it, it’s something I would maybe utilize more readily, but I don’t, I don’t want my patients in there because... I don’t want that for them”.* Two participants (Kate and Joan) described

experiences of their friends who had worked as mental health nurses in the hospital. Kate (P1 PdxBPD C1) said her friend *“agrees with me a lot about how bad the in-patient was, which was why she doesn't work there anymore”*.

4.4.3.3. Harm resulting from restriction and coercion

Where there was intervention it often constituted emotional neglect, being restrictive and coercive rather than therapeutic, physical rather than psychological, overlooking the underlying distress and not responding sensitively to mental states. Whilst Kate (P1 PdxBPD C1) welcomed restriction in so far as being *“somewhere that I didn't have chances”* to die by suicide, this wasn't enough to improve how people felt. Alison (P4 PdxBPD C2) described emergency department staff reduce risk by adjusting the environment, but not addressing safety through therapeutic engagement. She said *“in A&E... I've had them come in to like the bay and remove anything, like the sharps bins and wires but just left me. Or sometimes they'll take in a security guard to stand and watch you... as nice guys as they are, they're not mental health trained... they're not even healthcare professionals in any shape or form... you feel a prisoner... you're taking risks away from me and... I'm being watched... but no one's sitting speaking to me or trying to de-escalate me, so I can be safe that way”*. Carole (P14 PdxBPD C6) shared a similar experience in an inpatient unit. She said *“they decided to take all my stuff away as well from me and there was no communication there... they just decided that I'm a risk, so I'll take all your stuff away... no communication... then the night shift will be on, like, well, we didn't make that decision, so we can't talk to you about it. You're just left alone in your bed space just to deal with it”*.

Alison (P4 PdxBPD C2) described the impact of restrictive practice including detention under the mental health act. She said *“being sectioned... I lost all control over my life. I had no control over any situation or any of my choices or anything I did. I just felt like I kind of lost... my human rights in a way”*. She hid her distress as a means of gaining discharge from hospital, stating *“I was very aware that (the hospital) was making me 10 times worse and I just... pretended I was fine, and like tried to stop... doing anything dangerous, impulsive that would keep me in there longer cause I was so desperate to get out of there and just was trying to prove that I was fine, didn't need to be there... it wasn't beneficial for me to be there because it wasn't, it was the absolute opposite, especially for the way staff treat me. It just absolutely was hell”*.

Harm could also occur through PdxBPD having personal coping mechanisms eliminated by hospital restrictions. Alison (P4 PdxBPD C2) described when her means of self-managing

crisis were removed, it could have the opposite effect and increase risk of harm. She said *“one thing for me is fresh air, walking, exercise. With my ADHD being cooped up all the time actually sends me the other way...this frustration... violence towards myself... aggression and stuff... it builds up because I have no way of like expelling my energy”*. Joan (P15 SP Friend C6) agreed, saying *“there's something about just being in hospital and being cut off from your usual coping strategies and things... in the sense that if someone's locked the door and said, I'm not allowed out, then I can't go for a walk, and actually, going for a walk's really good for me to regulate my mood and stuff. But also in more negative coping strategies, in terms of self-harm and things, it's very much, come into hospital and you're not allowed to hurt yourself anymore. But we didn't actually mind if you were hurting yourself at home, like that was fine”*.

4.4.3.4. Over-reactive restraint and failures to be ‘least-restrictive’

Whilst psychological distress could manifest in physical behaviour, PdxBPD felt that whilst a physical response could be warranted at times, it was often too extreme, not least restrictive, and neglected a psychological and therapeutic philosophy. Alison (P4 PdxBPD C2) described experiences in private and NHS inpatient units, feeling like she was an object rather than a person. She said *“I had a self-harm incident ... everyone came running... they didn't even speak to me or address me, or speak to me, like I was human... I'd be like grabbed and manhandled by multiple people... being restrained and bound is traumatizing... people pinning you down”*. Alison (P4 PdxBPD C2) described trauma experienced as a result of being restrained, which she felt was more harmful than helpful, saying *“often I'd be restrained by like six people, and I'm tiny. And then to be literally like have someone pile in and then... a weighted beanbag shoved on top of me and people laying on top of me, and literally being physically pinned down when all I was doing was having panic attacks and banging my head”*. She thought staff were justified in intervening, yet felt the way they responded was not least restrictive, and out of proportion to her needs. She said *“I think that there is some level of having my control taken away, especially cause... I wasn't rational, I wasn't in my right mindset. But there was times where... it was definitely... going too far... it seems very extreme... I think's caused more trauma than was helpful at the time even... didn't need to be that extreme, because I wasn't running, I'd never hurt anyone else”*.

Carole (P14 PdxBPD C6) similarly understood the need for physical intervention, but again felt this lacked a psychological focus. She recalled *“the door was open, so I went... and they caught me and they restrained me to the floor, lots of them, actually, which is, that's*

kind of normal, I can sort of see that... I know I got myself into that, but they could have just sort of communicated to me, let's just sort of talk one to one". This incident also failed to take account Carole's (P14 PdxBPD C6) advanced statement and personal wishes. Carole said *"I have in my advanced statement, I don't need a crowd of people, don't do that. It's going to make it so much worse. So my communication, I will shut down, but they don't care... they just dragged me through the corridor to my bed space to get me away. And I would have got up by myself if they just... got their hands off of me."* Joan (P15 SP Friend C6) wondered if there was a mindset of *"It's quicker just to restrain you than it is to listen to you"*.

4.4.3.5. Epistemic and narrative powerlessness

The oppressive nature of 'care' also included the oppression of narrative. As storytelling meaning-making animals, narratives about ourselves and the world are crucial to our sense of self. Experiences of mental health care could lead PdxBPD to feel powerless over their own stories, where professionals had power over the narratives of PdxBPD, interpreting their intent, minimizing the seriousness of events, and even documenting their experiences when writing clinical notes. Carole (P14 PdxBPD C6) shared frustration that her thoughts were often assumed, and her perspective not valued. She said *"I used to go walking in the middle of the night and I got told... you're just doing this for like attention and you'll get picked up by the police. But that was helping me... The times that I've nearly died... it's just been self-harm, but they take it as suicide and then they'll tell me, oh, well, you didn't really want to die because you've got help, but they're mishearing everything I'm saying"*. Edward (P12 SP Parent C5) similarly described how Joni's (P10 PdxBPD C5) intent around suicide was assumed, being belittled and invalidated by a nurse. He said *"we went into (the) ward after she'd cut her throat and one of the nurses said, auch, dinna worry, she said, if she really wanted to kill herself, she would have done because she had plenty of time... you suddenly realise, do you realise what you've just said to me? You just said to me that my daughter, if she'd really wanted to kill herself, would have done, so it was only a, what was it, what you telling me, you think it's a joke, that she's cut her throat?"*

Kate (P1 PdxBPD C1) described seeing nurses in discussion and writing notes without her involvement. She described *"it's quite intimidating to have quite a few people speaking about your care and they must do paperwork inside the little glass room, but you're not involved in that paperwork... they don't talk to you... there should be more involvement... you should also be part of your care"*. Kate (P1 PdxBPD C1) added, as she had very little

contact with nursing staff during her admission, that she was “...not really sure of what they would've said”.

Carole (P14 PdxBPD C6) described dissatisfaction with the way she was restrained, yet being told her subsequent complaint, and thus her perspective, was not valid. She remembered “*they were dragging me through the corridor and I had bruises all over my hand, that's not normal... I was told after I complained, can you take that complaint back, that's normal... it is normal, you caused that, take your complaint back cause you're just moaning... complaints are useless anyway cause they don't care*”. She felt her experiences were not accurately recorded in her notes, and would never represent her reality as they would always be biased in favour of the mental health professionals writing them. She thought “*notes will reflect they've had time with you... there's no accountability on their part because their notes are going to reflect they're great*”.

Carole (P14 PdxBPD C6) recalled being assessed for hospital admission and being told “*you're not psychotic, you're overreacting, and you can kill yourself if you want to*”. She described her perception that capacity was misunderstood, and weaponized into an excuse not to intervene. She stated “*if I had gone home to kill myself, he wouldn't have put that in the notes... all it would be is... she had capacity to make decisions, but in that moment did I really, like you know? So there's no accountability there cause it's used as, capacity she can do whatever she wants to because of her diagnosis and that's what he's told me. But he'll never put that in his notes, so that's why I feel like it's a weapon... an excuse not to do anything at all. And he could have done the bare minimum but he chose not to, he just closed the door on me instead.*”. Mark (P6 CMHN C3) acknowledged how anxiety regarding risk could influence the way notes are written, shaping the narrative around engagement with PdxBPD as an act of self-preservation against any possible litigation. He said “*you can see that in the language that's used often in the way people write things up... when we write down no plan and intention... no expressed suicidality, no blah, blah, blah, are we actually writing down a magic formula there... magic arse covering formula.*”

4.4.4. Theme summary

The ‘BPD’ label may overshadow lived experiences of trauma, and create a stereotype which obscures the person and leads to stigma and discrimination. People experienced emotional neglect and invalidation, with these omissions akin to experiences of a ‘still-face’ caregiver which could re-enact childhood neglect. Where there was intervention, this could add to distress through being over-reactive and not least-restrictive, including

examples of unwarranted restraint. The hospital environment could be chaotic with MH nurses reluctant to admit PdxBPD due to potential iatrogenic harm. Following these experiences, PdxBPD would be powerless over their own narrative, with professionals able to make sense of their experiences and record them in clinical notes.

In summarizing, Joan (P15 SP Friend C6) highlighted an own goal, commenting that in MH services quest to help, they “often increase the risk by the atmosphere of the hospital and the reactions that people get”. This theme has explored how interventions can in fact add to rather than alleviate distress, and that PdxBPD may need to not only recover from their initial crisis, but also recover from the negative impacts of crisis intervention.

4.5. Theme 4: The complex simplicity of helping people in crisis

Exploring what helps PdxBPD in crisis uncovered a startling simplicity in what may help, and yet a significant complexity in terms of the contextual factors and variables which could act as barriers. Barriers included emotional dysregulation getting in the way of human connection, the influence of the helpers' own experience, as well as pressures from the organisation and the working environment. In this context, professionals needed help to think, tolerate uncertainty and resist the urge to fix or give unsolicited advice.

Understanding was considered by professionals to be a valuable intervention, and a useful activity could be mapping the journey through crisis. Mutuality and being experienced as an authentic human being was important to PdxBPD, yet there were barriers to professionals remaining themselves inside the healthcare system. Remaining human may influence professionals' ability to apologise, and their ability to advocate for patients, and even break rules to provide good care. Finally, given issues for PdxBPD were never able to be offered a quick fix, perseverance was highly valued. This theme in essence captured a paradox; that helping people is simple, yet for many reasons, it isn't.

4.5.1. Subtheme 1: Barriers to people being helpful

4.5.1.1. Connecting with the disconnected

Connecting with PdxBPD in crisis could be challenging, given the experience of crisis can be one of disconnection. Kate (P1 PdxBPD C1), emphasizing emotional overwhelm she feels during crisis, thought help should be *"...just trying to tone down the emotion a bit"*. Steven (P9 Specialty Doctor C4) agreed, describing his experiences of assessing PdxBPD in crisis. He thought *"for a lot of people who are struggling with emotional dysregulation that's effectively... offline, someone's ability to... rationally have a discussion and things in their history, it's not there right now, and that's part of the experience they're having. So... that first meeting is really, rather than a medical assessment... especially the risk assessment's got to be a factor... strictly in the sort of BPD crisis situation, it's about taking the edge off the experience, and dealing with the dysregulated mood"*. Janis (P2 SP Sibling C1) noted that it could be particularly challenging to support Kate (P1 PdxBPD C1) if she was 'numb' and experiencing dissociation. She said *"it feels like a cycle. Like you don't want to be contributing to how she's feeling... she's feeling numb, we're not sure what to do, so she feels more numb and we still don't know what to do, so frustrating... we get lost as well"*.

4.5.1.2. Considering multiple experiences

Janis (P2 SP Sibling C1) identified a huge issue relevant in all human interactions, in that when supporting another person, we are always having a unique experience ourselves.

Given people see the world differently, managing personal experiences as well as that of others could be more challenging when there was high distress, risk and sometimes competing interpretations of events. Janis (P2 SP Sibling C1) described when trying to help Kate (P1 PdxBPD C1) *“that can be really difficult to do... if you are sort of not seeing things in the way that she's seeing them, and one of the difficulties, I think, with offering support at times, is that the two versions of what we see are so different”*. This could be further complicated if there were additional people to consider. Janis (P2 SP Sibling C1) also contended with not only mentalizing Kate (P1 PdxBPD C1) and herself, but also other family members. She said *“my worry sort of splits because I'm worried about Kate and also worried about my mum worrying about Kate. So, it's a dual, there's two sort of prongs to it”*. She also shared that when Kate is in crisis, *“I'm dealing with the emotional burden... the issue... that's going on as well, and it can sometimes feel slightly like you're having to drop all of your stuff and fully accommodate another person, which is easier to do if you're not involved in the situation, but if it's involving more than just Kate or if... I'm invested in more parties to the situation than just Kate it can be tricky to sort of navigate”*.

4.5.1.3. Stretched professional resources

Barriers to professionals being helpful included the above, but were complicated by inadequate time, lack of resources, lack of support, workplace stress and burnout. Annie (P8 CMHN C4) identified a barrier to giving people the time they needed was that *“my caseload's too big for me. It's fearsome”*. Billie (P16 CMHN C6) agreed, and thought if she had less patients on her caseload, she could be more effective in her role as CMHN. She said *“If you took 10 patients off my caseload, the amount I could do with people would be immense... I shouldn't have to pick and choose where I focus my attentions... if you capped my caseload at 20, I don't think any of them would ever be in crisis”*. Grace (P7 PdxBPD C4) shared her view of MH nurses from her time as an inpatient. She said *“I just don't think they've got enough time for you... always busy doing paperwork or sorting out other things... I've hardly ever had any like one to ones with nurses when I've been in hospital”*.

4.5.1.4. The relational distance, yet dominance of psychiatry

Relationships with psychiatrists were distant, yet they were considered to have a lot of authority over care. This could lead to PdxBPD feeling powerless, and confused as to who could make decisions for them. Kate (P1 PdxBPD C1) said *“the psychiatrist who... signs off my meds... I've never, ever, ever met her... for three years”*. Alison (P4 PdxBPD C2) said *“I've never seen a psychiatrist's face, it's always over the phone”*, and Joni (P10 PdxBPD C5) recalled *“I've maybe spoke to him twice over the phone in the whole time I've known him”*.

Meanwhile, relationships with CMHN's were closer, but they were limited in decision making power. Alison (P4 PdxBPD C2) recalled she was *"absolutely in crisis. So rang (MH nurse) but... she will admit... she doesn't have the control and power to do much... I do have quite a good relationship with her. I do feel she listens to me, but also... she feels that there's only so much she can do"*. Kate (P1 PdxBPD C1) described her nurse as a *"middleman"* between her and psychiatrist, which could impact on her trust in them. She recalled *"as soon as I want to come off (a medication) it's like, you'll have to give me a chance to get this approved... your trust in (the CMHN) kind of lowers down because you don't know whether the issue's coming from the psychiatrist or whether it's coming from your CPN"*. Chris (P11 SP Partner C5) reflected on Joni's care and asked *"how can someone with that much control... have that like, much little sort of input... You know, he doesn't know her"*.

4.5.1.5. **"Another problem, another pill": over-reliance on medication and side effects**

Medication had variable impacts which may prevent or exacerbate crisis. Tori (P5 PdxBPD C3) said *"I can't not be medicated"*, believing she was more likely to be in crisis without this, and medication helped Alison (P4 PdxBPD C2) feel *"somewhat stable"*. However, Grace (P7 PdxBPD C4) said *"medication hasn't really helped me"* and Kate (P1 PdxBPD C1) added her psychiatrist *"told me that these meds were going to be good for me, when actually all I got was side effects"*. Joni (P10 PdxBPD C5) felt similarly, stating *"you've got all this medication... that someone's telling you will make you feel better... it's not... it just makes things worse"*. Kate (P1 PdxBPD C1) felt an overemphasis on medication in her care, claiming *"I'm not... anti-meds but they're not the answer to everything"*. She described the approach of MH services as *"yet again, it's pill, pill"* and she could be *"literally rattling cause you've took so much meds"*. Alison (P4 PdxBPD C2) echoed this, stating *"nothing is ever done about the emotional side... what is causing it?"*, with the approach *"here's another pill, here's another tablet, oh, it's clearly not working, oh, we'll try another one"*. Kate (P1 PdxBPD C1) described her views of a medical reductionism as *"another problem, another pill."*

Side effects of medication included oversedation and weight gain, and these could impede therapeutic work done by MH nurses, and make PdxBPD feel worse and potentially more likely to experience crisis. Nina (P3 CMHN C1) said *"a brain that is sedated with benzodiazepines can't learn... so it's that balance, making sure that they're not over-sedated... not overmedicated"*. She continued saying that psychiatrists *"will see the patient and increase their anti-psychotic or add in a mood stabilizer when we're trying to*

move away from the medical model... it can undo all the good work that you've done". Kate (P1 PdxBPD C1) described weight gain as "a kick in the teeth" which "didn't do good things for my mental health either". Edward (P12 SP Parent C5) felt the impact weight gain may have on Joni's mental state was not recognized or taken seriously by mental health services. He said "how she looks impacts on her mental wellbeing... why the system doesn't appear to recognise that as being integral to her mental health and mental wellbeing and all the rest of it, is beyond me. Because, you know... she's very, very conscious of her size".

4.5.1.6. Traumatized and distressed mental health nurses

Whilst PdxBPD described poor experiences of inpatient care, no professional participants in the study were currently working as MH nurses in inpatient settings. Billie (P16 CMHN C6) however offered valuable insight as she stated of PdxBPD in her CMHN role *"I love working with them"*. However whilst reflecting on inpatient experience she gave a striking counter experience, stating *"in (the ward), I hated EUPD... I hated all the patients... I had no compassion for any of them... they were my problem"*. She clarified that working in MH inpatient settings was traumatizing for staff, yet with a culture of hiding emotional experiences. She proclaimed *"what happens to a person when they go into work terrified every day, but can't admit it... just the resentment, the anger, the bitterness... all of that, and I think that that's a lot of in-patient settings for people, is staff go to their work... scared of being assaulted, scared of a situation happening where... you walk into a room and somebody's cut themselves open, that's fucking traumatizing... somebody's blue with a neck ligature around their neck, it's traumatizing. But we can't admit that... if I was walking on the street, and someone grabbed me by the hair and tried to gouge my eye out, everyone would be like, oh, my God, that's awful... and it would be taken really seriously, but that happens to you in (hospital), and then you cry in the toilet, and then you go back to work"*. Billie (P16 CMHN C6) didn't think quality care was possible in the inpatient environment she had worked in, defending *"I don't think I blame myself for that, because it was an awful time... for a lot of staff, and I don't think I could have felt any differently in that environment. I don't think that anybody could, unless they were like Mother Teresa... you only have so many resources, and when it becomes about, I don't want my staff to be battered and almost killed in front of me, or I don't want to be assaulted again... I'm trying to cope with being assaulted the other day, and do my work and manage a shift, you don't have the resources to give to those people"*.

Steven (P9 Specialty Doctor C4) agreed that *“the role (MH nurses) can take on is really defined by how busy the ward is”* and how they could be *“stuck”* in *“difficult situations”* of competing priorities, being *“halfway through a conversation and the alarm goes”*. He saw the MH nursing role as reactive, flitting between *“this eight-person restraint in this other room... they cannot literally walk away from that, or several nurses are going to get battered here”*, to then a person *“going straight to take an overdose”*. Steven (P9 Specialty Doctor C4) commented there was also an *“unbelievable amount of admin they have to do”*, and acknowledging strained resources within current systems, stated that for an effective crisis response *“you’re talking about a situation where nurses have time, and doctors have time”*. Nina (P3 CMHN C1) suggested to provide quality inpatient care for PdxBPD in crisis, *“that team would have to be really well supported... and unfortunately... in the climate that nursing is at the moment, it just doesn’t happen. And what then spills out when you’ve got frustrated, unsupported staff, they don’t deliver good care... they get pissed off and do the bare minimum.”* Despite acknowledging difficulties faced by nursing staff and the distress they may be in, Carole (P14 PdxBPD C6) argued this was not her responsibility to solve, or a reason for her to accept poor care. She said *“they’ve had their experiences as well, but that isn’t my problem. No offence, but it’s not”*.

4.5.1.7. Socialisation and the disappearing ‘self’ of mental health nurses

The things which PdxBPD experienced as unique, genuine and human about their MH nurses were at risk of disappearing through their socialization into stigmatising cultures, which could mould a MH nurse into a professional stereotype with negative attitudes. The infancy of a career was considered a particularly vulnerable time. Alison (P4 PdxBPD C2) celebrated student nurses, saying they were *“amazing, they were the ones that would actually speak to us, get to know us, have any time for us or even take an interest of us and show they cared... I felt like they treated us like humans”*. Steven (P9 Specialty Doctor C4) described student nurses having the right values and intentions as they gain their registration, however, on entering a confused and poorly resourced system, he said *“they meet the reality of it, it just becomes impossible”*. Stigmatising cultures may have an indoctrinating function, and be reinforced through peer pressure, socialization and group norms which could ridicule genuine therapeutic relationships. Joan (P15 SP Friend C6) described this in action, recounting how *“one of my friends... she qualified (as a mental health nurse) a few years ago... when she was on placement, I think a patient had come to her, and she’d had really good conversations with them and felt like she’d done a really good job... and the patient wrote a card... for her, when they left, and the rest of the staff*

team laughed at her and said, ha, ha, you've just got a BPD card... you were being manipulated all this time". Billie (P16 CMHN C6) reflected on this cultural taboo of close relationships with PdxBPD, and said "nursing... has this big slant of you shouldn't have a kind of attachment with patients... Whereas obviously, psychotherapy and mentalization is all about attachment and how can you help someone if there's no attachment? And so, Carole was told over and over that she couldn't have attachments to people, she couldn't have attachments to her nurses... I know that Juliet was made to feel quite bad during that time as well".

Carole (P14 PdxBPD C6) witnessed student nurses become MH nurses and change as they became part of the system, rejecting their education to fit in with an ethos of *"comply with what we're doing, not what you're taught"*. She said *"the ward destroys people"* and felt for a nurse she had valued. She said *"I'm glad Juliet left. I don't know why she left. I can maybe... guess, but I wouldn't want Juliet to lose her Juliet-ness. Why am I away to cry? Because that's a terrible thing to realise and witness, but the ward is destroying nurses. And once they've complied... it's almost like a high school clique... You've kind of lost yourself. Even if you've got good intentions, I see them lose themselves"*. Joan (P15 SP Friend C6) saw how nursing students on placement had *"soaked up those ward attitudes"*, and Steven (P9 Specialty Doctor C4) thought *"people... they lose themselves and become nurses, if you know what I mean. I don't mean that as an insult, you know... it's a shame"*. Billie (P16 CMHN C6) confirmed that despite intentions to *"help people... connect with people"* and *"understand them"*, the stress of working as staff nurse in the inpatient environment changed who she was as a person, and resulted in compassion fatigue. She said *"I just became this really hostile, bitter, clinician, you know, I really lost all of my compassion... I was genuinely, like, nursing's ruined my life... It's ruined who I am as a person"*.

4.5.1.8. When professionals can't or don't think critically about their work

Given the aforementioned barriers and complex system, there was a need for professionals to receive support and think critically about their work. Billie (P16 CMHN C6) acknowledged the need to be self-aware as professionals are also human beings with stories, stating *"we are people as well... we have our own bags that we come with"*. Mark (P6 CMHN C3) agreed, saying *"we aren't bulletproof... the reason a lot of us do this kind of work is cause we know why it's needed"*. Robert (P13 Psychologist C5) acknowledged *"our staff stop mentalizing"*, with the stress involved in working with PdxBPD leading to *"judgement"* where *"people do go back on that kind of more paternal critical kind of way of viewing people when they're feeling attacked, or when they're feeling helpless"*. Billie (P16

CMHN C6) agreed from a MH nursing perspective that *“whenever we, as clinicians, feel like we're not managing to help somebody we become resentful to them. I think that's the natural response... they must be the problem”*. Billie added that *“I don't think that, as nurses... we do enough in terms of supervision about our feelings about the people we work with”*.

Strengthening the argument for routine spaces to help professionals think, Steven (P9 Specialty Doctor C4) described a proportion of MH staff as lacking in self-awareness and empathy, and perhaps not psychologically minded. He considered *“for a lot of our staff nowadays, I don't get the sense that they're sitting there thinking like, god, I felt really bad, I had to hold that guy down today... I don't necessarily know if it's... about preventing anxiety and preventing a trauma response. There are certainly nurses out there who are... rough and tumble folk... so it's all a big laugh in the rammy, and it's all a bit nuts in (the hospital)... that's part of that identity, and they are shielded from that harm. But I don't know if that's the majority or the minority, I don't know what's going on there. But I guess, it's not the same for any two people”*. However, acknowledging people do need support to think, Steven (P9 Specialty Doctor C4) conceded that *“the ward environment is so busy that it's very hard to get the available nursing staff to think about the problem”* and that even if they were thinking, *“truly it is the ward environment that prevents healthy engagement with a lot of these patients”*.

4.5.2. Subtheme 2: Helpful therapeutic skills and traits

Helpful therapeutic skills started with having a reflective space to consider how you worked with people, then avoiding unsolicited advice, empathy, understanding, and being genuine. People appreciated mapping how crisis had occurred. Important traits of staff were the ability to admit mistakes and apologise, the courage to stand up and advocate for PdxBPD in a system which could harm them, and perseverance where there were no simple solutions.

4.5.2.1. Professionals need support and reflective spaces

People were more helpful when they had a space to think about their interactions. Clinical supervision is a process where one professional helps another think about themselves, their patients, their relationships and wider systemic context, with a view to improving practice (Hawkins and Shohet 2012). All MH professionals mentioned utilizing clinical supervision and finding it helpful, and Steven (P9 Specialty Doctor C4) said *“you really need... that peer support”*. Within a team, Nina (P3 CMHN C1) shared *“I use clinical supervision as much as I can... we talk all the time, and our patients are at the centre of all*

our discussions”. Billie (P16 CMHN C6) valued clinical supervision, with the benefit being *“the next time you see (the person diagnosed with ‘BPD’)... you’re once again, able to actually be, hopefully, a decent nurse for them rather than an irritated person”*. Steven (P9 Specialty Doctor C4) and Robert (P13 Psychologist C5) saw part of their roles as providing an intervention for staff teams, to help them think. Steven said *“the very first step to doing anything therapeutic for patients with BPD, in an in-patient environment, is trying to do something therapeutic for staff”* and had facilitated a *“mini group intervention”* which he thought could *“really change the therapeutic atmosphere and the experience someone has in hospital”*. He described these changes as *“situations where nurses remember what they were into”*, perhaps returning them to humanity, being more than a ‘nurse in the system’ and restoring curiosity and compassion. Robert aimed to *“add a little bit more about my understanding of Joni from a psychology point of view and help people be a bit more empathic and understanding”* to help the staff team *“sort of stay with her and work with her”*. Kate (P1 PdxBPD C1) highlighted that to avoid her triggers, others needed to think, and *“put the work in too”*. She said *“I certainly do not have the anger outbursts that I did down the road, and that’s purely down to the people that I have relationships with doing their part as well as me”*.

4.5.2.2. Uncertain solutions and avoiding unsolicited advice

A challenge during crisis is that PdxBPD may not know what will help, neither did they expect others to have answers, though being helpful started with avoiding unsolicited advice. Kate (P1 PdxBPD C1) stated, *“I don’t know how to help myself when I’m in crisis... let alone expect someone else to know”*. Carole (P14 PdxBPD C6) understood the challenges for others in finding a solution to her crisis, but stated *“I don’t go in with the expectations... (of) a cure”*. Alison (P4 PdxBPD C2) thought her partner was helpful, but acknowledged *“there’s like only so much she can do”*. Many participants discussed receiving advice as unhelpful. Kate (P1 PdxBPD C1) recalled she had *“phoned the crisis line”* and a professional *“told me to put my hand on my heart and feel my heart beating. That was a kick in the teeth... when you’re telling somebody you’re suicidal... you could laugh at it, it was just not the help you needed at the time”*. Tori (P5 PdxBPD C3) described similar, being told to *“put one hand on one shoulder and one on the other and give yourself a hug. Put a P in one corner of your mirror and V in the other and everyday say how precious and valuable you are. That’s okay, but I was losing my mind... And that was very unhelpful and got me very wound up. I found it very patronizing actually, to be honest. I’m not a stupid woman”*. Nina (P3 CMHN C1) acknowledged she had colleagues in local services who

patronized patients, and empathized if she had heard what patients did, *“I would probably want to throw my phone against the wall”*. Family also learned that advice was not helpful. Janis (P2 SP Sibling C1) learned to *“avoid unsolicited advice”* for Kate, saying *“a lot of the advice that you try and give or, objectivity that you try and give... I've found that to actually not be helpful. I think that just makes her feel further sort of on her own and isolated and... shuts down a bit more”*. Billie (P16 CMHN C6) described that *“hearing all their problems and trying to fix them... is what we often feel we should do”*. However, she felt through giving advice *“we end up... undermining them and invalidating them... I know how I feel when someone gives me advice, and often I find it really annoying... if it's that simple, I would have done it”*.

4.5.2.3. Empathy, understanding and mapping the crisis

Whilst giving advice was not helpful, hearing people's experiences, empathising and trying to understand felt important to PdxBPD, and in the absence of a 'fix', understanding could be an intervention in itself. Joni (P10 PdxBPD C5) described *“just wanting people to... understand how you can't make sense of your head”*. Tori (P5 PdxBPD C3) wanted people to *“just understand, don't patronize how I'm feeling or underestimate the intensity of it”*, while Grace (P7 PdxBPD C4) prioritised someone *“being there”* and *“caring”*, who would *“empathise”* and *“understand”*. Kate (P1 PdxBPD C1) stated *“all you need is for someone to understand just how intense that you are feeling... even if they can't... at least try and understand”*. Nina (P3 CMHN C1) thought *“when they're in crisis, if they feel like you understand, you've heard, you've listened, you've remembered... that's really validating, and sometimes that can take the sting out of the crisis, it can allow that person to sort of feel emotions, appropriately, of sadness and upset without feeling like they shouldn't be that way”*. She added it was *“not just being heard, but being believed”*. Billie (P16 CMHN C6) described not knowing how to help Carole (P14 PdxBPD C6), and stumbling on *‘understanding as an intervention’*, and the power of *“just trying to get it”*. She shared that *“I genuinely came in not knowing what to do with her, so I just wanted to understand... and the more I've tried to get it, the more she's been able to get stuff out and make connections to things and also feel safe”*. Billie considered *“I think that that's what she needed... it's been about trying to shift from... I need to have a solution to your problems to... let's try and understand your problems... if I don't get you, then that's my job to try and get it a bit more”*. Carole (P14 PdxBPD C6) thought conversations around crisis should help *“understand why you've gotten there”* and Steven (P9 Specialty Doctor C4) saw value in helping people learn *“things to do and things to avoid”*. Kate (P1 PdxBPD C1) wanted *“to know how you went*

from A, B, C to Z”, to “*piece together the puzzle to try and problem solve why I was triggered, there's not always an answer*”. Joni (P10 PdxBPD C5) could only understand triggers and map events if she was in the right state of mind, ideally post-crisis. She said “*focusing on it and going through it at that time... never really works for me... What works quite well for me is... go away for a few hours, sleep for a couple of hours, and then get up and then sit down and speak through it with someone and... write down the sequence of events so I can see it*”.

4.5.2.4. ‘Being a person’ and ‘seeing a person’

Being genuine was valued by PdxBPD. Janis (P2 SP Sibling C1) considered Kate (P1 PdxBPD C1) thankful when professionals simply did what they said, “*if appointments are made, that they're honoured... promises to do things that they're upheld*”. Tori (P5 PdxBPD C3) described Mark (P6 CMHN C3) as “*great*”, saying “*I've got a lot of trust and a lot of respect for him*”. She also valued his sense of humour “*I've been in floods of tears, and by the time he's leaving, he's made me laugh*”. As a result of the connection she felt she was more willing to trust and respect what he would say, stating “*I listen to him and I've taken on board what he's telling me... whereas some people in the past I've had experiences where I just want to say, are you fucking joking? Do you know how I'm feeling?*”. Asked what she appreciated most, she said “*I think his manner... he doesn't make me feel like anything I tell him is right or wrong... doesn't push anything on me... sometimes we'll maybe have a plan for that day... But if I've had a really bad day... it's cool*”. Exploring what contributed to his approach, Mark (P6 CMHN C3) described mutuality in seeing the humanity in people he worked with, stating “*I don't think I'm different... the only thing that separates the two of us here is I've got the professional hat on today*”.

Whilst mutuality was rooted in seeing people as human beings and treating them as equals, this also required professionals to be experienced as people themselves. Whilst Tori (P5 PdxBPD C3) described valuing Mark’s (P6 CMHN C3) “*manner*”, ‘Name-ness’ was a concept used by Carole (P14 PdxBPD C6) to describe the quality of a MH nurse who was praised as “*a saving grace*” who “*made me trust again. I've gotten where I am because of her*”. The staff nurse from an inpatient unit was given the pseudonym ‘Juliet’. Carole (P14 PdxBPD C6) appreciated “*her Juliet-ness*” indicating authenticity and congruence are highly valued. It could be argued ‘manner’ or ‘name-ness’ are terms which equate to essence. Essence is defined as the “*ultimate nature of a thing*” and “*the most significant element, quality, or aspect of a thing or person*” (Merriam Webster 2024c). The essence of individual humans can be pragmatically described as ‘Name-ness’ e.g. for you the reader,

your 'You-ness', me the writer, my 'Dan-ness'. These essences are unique and cannot be quantified or replicated.

4.5.2.5. Advocacy and a willingness to dissent

A further quality of professionals which was valued by PdxBPD was advocating for them in dissenting against workplace culture or the organization in order to be more helpful. Alison (P4 PdxBPD C2) valued a nurse *"fighting"* for her, and arguing her case for receiving ongoing care. She recalled that *"she was like, nobody is paying attention... she was one that quite good at like... I'll get that sorted and like fighting for me and that, in terms of getting ongoing care"*. Carole (P14 PdxBPD C6) celebrated Juliet who *"kept still supporting me despite being told not to"*. Joan (P15 SP Friend C6) described a doctor who *"really listened and... really fought my corner... genuinely got angry when other people like didn't stick to the plan that we've made together... that, I think, just helped me feel a little, like I had a little bit more value... someone thinks I'm worth fighting for"*. Annie (P8 CMHN C4) shared how she would advocate for PdxBPD and challenge colleagues, though this could have varying responses. She said *"some people are quite taken aback if you... challenge them about their attitudes... occasionally, you'll get somebody who has a wee 'ah ha' moment"*.

4.5.2.6. Honesty and candour

Honesty, candour, and the ability to say sorry was appreciated by PdxBPD, yet nurses could be conflicted between their allegiance to their patient or their organisation. Nina (P3 CMHN C1) felt *"unfaithful"* as if she was *"cheating on the service"* when connecting with patients and validating their experiences of poor care, indicating there may be an allegiance to the organization which can create discomfort and be a barrier to genuine connection. Billie (P16 CMHN C6) described that a large part of Carole's (P14 PdxBPD C6) recovery was addressing her experiences of poor care, saying *"a lot of what we're doing is kind of trying to address what's happened to her in services, and that it's okay for her to have revolted against that and feel negatively about that"*. Billie (P16 CMHN C6) confessed how she had developed as a nurse, and could now acknowledge her mistakes. She said *"I think that a lot of staff would find these patients a lot easier to work with, if they could feel sorry and mean it"*. She owned that *"the bulk of my career, I've mismanaged people with personality disorders, and we genuinely are sorry... I wish that I could take a lot of those things back, cause I've been that person that Carole had negative experiences with... for many other people... it's not an easy thing... to genuinely go... that wasn't good... I wasn't right"*. Joan (P15 SP Friend C6) prized a professional who is able to *"acknowledge when you've got it wrong"*, and Mark (P6 CMHN C3) agreed that professionals should be willing to look at

themselves, considering *“if your... patients aren’t recovering, that possibly says something about you, not them”*.

4.5.2.7. Perseverance and mattering

Being helpful wasn’t easy and required perseverance. Annie (P8 CMHN C4) described interactions with PdxBPD as *“walking a bit of a tightrope”*, and Mark (P6 CMHN C3) noted he was working with *“people who are at considerable risk, and who are fragile and sensitive”* acknowledging that *“it’s easy to get it wrong”*. Carole (P14 PdxBPD C6) valued professionals being *“patient and kind”*. Nina (P3 CMHN C1) described a good therapeutic relationship with Kate (P1 PdxBPD C1) which hadn’t started that way. She described their initial meeting where Kate *“was... quite brittle, untrusting, irritated, emotional and felt unsupported”*, yet persevering and building trust over time. Counter to this, Alison (P4 PdxBPD C2) described an interaction in an inpatient unit, where she felt staff were not willing to persevere. She recalled *“I’d been caught self-harming... hidden the sharp thing I’d used and... had it in my hand or something. And they were... trying to get me to give it to them. And I wouldn’t and instead of... persisting they just... left me with it, and... I don’t feel very safe, and I just felt they gave up”*.

Finally, it may be most important for PdxBPD to feel like they matter. Billie (P16 CMHN C6) shared that Carole (P14 PdxBPD C6) mattered to her, and how she had allowed their relationship to change her and improve her as a nurse. Billie stated: *“Carole, for me, has changed the way I approach most of my patients... she’s quite an important patient to me, because most of my patients, I think, now have a better experience as a result of what I’ve learned from working with her...”*

4.5.3. Theme summary (and the role of luck)

Barriers to people receiving effective care included the challenges in making emotional connections with PdxBPD when their experience is one of disconnection, and considering multiple experiences in thinking about oneself, and any others in any given situation.

Professionals resources were often inadequate, and service design and culture often saw psychiatry as having a huge authority over care yet relational distance from people, with medication over-relied upon. The stress of mental health nursing may mean PdxBPD are supported by nurses who have been traumatized, though some may be socialized into stigmatizing attitudes. To help effectively, professionals needed a space to think and reflect. There are no simple solutions thus comfort working with uncertainty was an asset, unsolicited advice was best avoided, and empathy and understanding were valued.

Humanity and genuineness was prized by PdxBPD, whilst further key traits of professionals

which were valued included a willingness to advocate for them, be honest with them, an ability to apologise, and the commitment to persevere in attempting to help them.

Whilst things which PdxBPD found helpful were relatively simple, there were genuinely complex factors which could act as barriers to this occurring. Thus, the concept of luck becomes important, in wondering why some people receive poor care. Chris (P11 SP Partner C5) described his understanding of Joni's care, stating that though there was helpful input from CMHN and Psychologist, these were like the *"shiny penny in the muck pile"* and outweighed by negative experiences of services. Tori (P5 PdxBPD C3) also shared her delight at her new psychiatrist compared to previous experiences. She said *"when I spoke to that new psychiatrist the other day, I almost had that little bit of a lift, cause I thought, god, this man's actually read my notes. And he's obviously spoken to Mark, it was a totally different experience as to what I've had for the last couple of years"*. Carole (P14 PdxBPD C6) emphasised luck, with her experiences of professionals *"a mixed bag"* and *"hit or miss"*, stating *"maybe once in a while you'll get someone kind"*. After she had several poor experiences of professionals, she was very grateful for three nurses, saying *"I've been really lucky to have three people, consecutively, be nice to me. Which is so basic, but not everybody's been nice to me... it was just potluck that I've fallen into the right hands"*.

4.6. Theme 5: Building a better service

The theme of 'building a better service' emerged through conversation which encouraged participants to imagine how things might be different. In the aforementioned themes there were many instances of a dysfunctional system with instances of poor care, and Nina (P3 CMHN C1) stated *"I feel frustration, because there's a massive gap in the services"*. The earlier themes, through experiences of poor care and acknowledgement of the complexity of helping, identified important requirements for quality care delivery. However this theme aims to look forward to specific improvements regarding structure, design and philosophy, and all participants offered thoughts and ideas which are captured here.

4.6.1.1. A need for new models of crisis intervention

Whilst there was no specific crisis service for the area, Joan (P15 SP Friend C6) mentioned that developing something should be imaginative rather than replicate existing models. She said *"we don't have... a crisis service. But then any... area that has a crisis service, everyone says it's like shit anyway"*. Whilst any development of services can be met with a sense of pessimism and defeatism at a lack of resources and other significant barriers, as Mark (P6 CMHN C3) stated *"it can happen if you do it"*. Whilst building a better service should obviously address the failings of dysfunctional systems, aim to avoid harms caused and emphasise doing more of what helps PdxBPD, specific desires were for a coproduced service which is readily accessible, offering stepped and flexible personalized care, with a safe and welcoming environment and staff who attend to relationships and aim to provide holistic care. A focus of crisis care could be regulating emotions when in crisis, and developing plans for relapse prevention.

4.6.1.2. Co-production

Building a better service required the input and partnership of people who would use any said service, both in design and delivery. Carole (P14 PdxBPD C6) said *"I would start again... ask people who have used the service... find out what works for them"*. She felt this approach had been lacking in the past, stating *"no one that I know, has felt that their opinion's ever been asked to shape a service"*. Professionals wanted lived experience involvement in designing any future service. Mark (P6 CMHN C3) thought it was *"a real interesting idea to get into a kind of co-production thing of coming up with... a BPD service that was designed with the client group, not for the client group"*, and Annie (P8 CMHN C4) said there should be *"collaboration with the patient group as to how it was like decorated and furnished"*.

4.6.1.3. An accessible and responsive service which ensures safety

Given crisis can be unpredictable and spontaneous, PdxBPD require a service which is accessible and responsive to their needs. Edward (P12 SP Parent C5) said *“it’s got to be instant”* and Tori (P5 PdxBPD C3) needed someone *“there to talk to in an instant when you are in that moment”*. Joni (P10 PdxBPD C5) felt *“it needs to be somewhere that’s local”*. Janis (P2 SP Sibling C1) shared the family perspective of timely intervention, sharing it could prevent Kate (P1 PdxBPD C1) becoming numb and difficult to engage, preventing her from *“just going inwards and shutting the door”*, stating without early intervention *“it becomes really difficult to sort of get in”*.

All participants desired a 24-hour service. Janis (P2 SP Sibling C1) wanted *“somewhere that was maybe just manned and if you were feeling really low and you don’t have... round to the clock access to your family, there’s maybe somewhere that you can go... and it sort of stops that, or it minimises that”*. This indicated that their family may act as a 24 hour service at times. Edward (P12 SP Parent C5) said *“it has to operate as an emergency service”*, and Steven (P9 Specialty Doctor C4) and Joni (P10 PdxBPD C5) described a *“24-hour facility”*. The accessibility of emergency departments was desirable, but the ethos needed to be different. Joni (P10 PdxBPD C5) shared that *“you can always go to A&E... but if you turn up at A&E and you’re crying, and there’s nothing physically wrong with you... they will shrug you off, and they won’t understand it... they can’t do overly much for you there... you can be like safe there but they can’t offer you the support you need”*.

Safety was important. Joni (P10 PdxBPD C5) described a *“safety zone that you can go to”*, which others echoed, describing a *“haven”* (Tori - P5 PdxBPD C3) or *“a centre”* (Grace - P7 PdxBPD C4) that could offer *“drop-in”* accessibility (Janis - P2 SP Sibling C1). Tori (P5 PdxBPD C3) similarly described wanting *“a little safety net of some kind”*. Joni (P10 PdxBPD C5) suggested the value of knowing there was help available, stating *“that person then knows that if it gets to a point where they’re burning their arm with straighteners or like they’re pouring bleach over themselves... they know, I don’t have to do that, I can go to this place”*.

4.6.1.4. Multiple levels of support according to need

Participants felt there should be multiple levels of support offered according to need, including telephone, face-to-face support, the options to drop-in, and overnight stay if necessary. Outreach was also considered important, and how a service would go to people rather than always requiring people to come to it. Kate (P1 PdxBPD C1) felt *“there should be a helpline for personality disorders”* offering help as well as signposting and

connection to other services. She said *“there should be a helpline for, for every region... and there should be people on the other end of the phone who are clued up to the nines about personality disorders and know exactly what to do, what to say, where to go”*. Grace (P7 PdxBPD C4) agreed that she would like a service with *“someone that could help or just be on the other end of the phone if you need something if you feel suicidal”*. Edward (P12 SP Parent C5) suggested a stepped care model which might initially offer telephone support, but emphasised *“it has to be a system where there can... quite quickly be face to face input”*. Grace (P7 PdxBPD C4) thought *“out-patient would be the best”*, but acknowledged whilst some people may want one thing, *“other people are like, no”*. Steven (P9 Specialty Doctor C4) considered options, advocating for *“the kind of place where you could stay”* with *“a day hospital variant... Where they've got options of being day patients if... we're building to crisis time, or... they've got a bed there, if needs be”*.

It was also considered necessary that a service was able to go to people directly. Robert (P13 Psychologist C5) thought the service should ask *“is this something we can deal with over the phone or... should we dispatch the, the specialist mental health people to that address?”*. Steven (P9 Specialty Doctor C4) suggested a service with *“its own separate minibus”* and Edward (P12 SP Parent C5) proposed a crisis service with *“either mental health paramedics, or mental health nurses on a paramedic car...”*. Grace (P7 PdxBPD C4) wanted *“someone going out with the police that understands mental health. If there's like a crisis... like a mental health nurse”*. Nina (P3 CMHN C1) considered an ideal outreach service as *“an intensive treatment team”* as an alternative to hospitalisation. She described the model as *“two nurses going into that person's home... short term intensive... two, three appointments per week. But it only lasts a couple of weeks. It's to get that person out of that current crisis”*.

4.6.1.5. A therapeutic physical and psychological environment

The environment of a crisis centre was considered. Annie (P8 CMHN C4) suggested *“a comfortable quiet space”*, whilst Steven (P9 Specialty Doctor C4) argued that effective crisis responses need to take people *“away from the bluster”* and *“truly out of wherever the crisis is”*. Tori (P5 PdxBPD C3) echoed this, valuing *“sometimes just being brought out of... that place even physically”*. Steven (P9 Specialty Doctor C4) expanded, citing *“an environment that does not encourage people to become more agitated and feel more trapped than they already are... one that is... truly therapeutic”*. He advocated for green spaces, suggesting a *“natural environment... away from the sort of bluster of the city”*. The psychological environment was also important. Annie (P8 CMHN C4) imagined *“a*

welcoming place... a safe space”, and this was supported by PdxBPD. Grace (P7 PdxBPD C4) alluded to a community spirit, and “*caring environment that everyone's kind of like a family kind of thing*”, whilst Joni (P10 PdxBPD C5) valued feeling accepted and not-judged, imagining “*if there was this service... and you could turn up and not be like looked at as... this freak... that's just wanting attention*”. Steven (P9 Specialty Doctor C4) alluded to the visible and othering power dynamic, suggesting an environment where “*nursing staff are not in uniform*”. Kate (P1 PdxBPD C1) also felt that the gender and biological sex of professionals was important. She recalled “*my first CPN... because he was a male, I found it really difficult to open up to him...*”. Given that ‘BPD’ is a diagnosis predominantly applied to women, with a prevalence of trauma in the population, and much trauma is perpetrated by men towards women, the presence of men is an important part of the environment to consider.

4.6.1.6. Staff highly skilled in human relationships

Participants desired staff who worked there to have excellent relational competence, though there was disagreement about specific roles and level of specialism. Carole (P14 PdxBPD C6) felt the majority of her experiences with the NHS were poor, and said “*I would start again with the NHS... I wouldn't trust them as far as I could throw them*”, and when considering building a new service stated “*I wouldn't hire most of them*”. Grace (P7 PdxBPD C4) imagined a service with “*nurses and stuff, or a psychiatrist*”. Robert (P13 Psychologist C5) felt with quality relational practice “*you can start to make admission so much more therapeutic*” but also make “*keeping people out of hospital more therapeutic as well*”. Specialist practitioners were important to Kate (P1 PdxBPD C1), who offered an analogy that “*you wouldn't go to a GP about something to do with dermatology, they would refer you to the dermatologist*”. Mark (P6 CMHN C3) agreed, saying “*a specialist service is missing*”, and similarly used analogy to emphasise specific needs required a specialist service. He stated “*if you needed brain surgery, and you went off to (general hospital), and they said... we don't have any brain surgeons, but some of those general surgeons'll have a go, would you want a general surgeon pottering about with a scalpel inside your head?*”.

Kate (P1 PdxBPD C1) proposed new roles, saying “*there's just something missing that needs to be a mixture between a psychiatrist and a CPN... someone you can keep in contact with... a new role or something... they should have... training in medication to be able to prescribe and make those decisions rather than waiting for a Thursday meeting*”. This reflected a psychiatrist having power over prescribing, yet a relational distance and inaccessibility compared to CMHNs. Joni (P10 PdxBPD C5) felt specialism was less

important than an ability to relate to PdxBPD as people. She felt *“it wouldn't even have to be like, necessarily like trained nurses... or qualified people... it could just be people that care and people that understand... they don't have to have experience in every, like little bit of mental health... Just like normal people that care”*. Joan (P15 SP Friend C6) agreed stating *“I think a lot of it is just attitude... it's just the right people, at the right time, rather than any specific big, wonderful service... just... the right people thinking in the right way”*.

Steven (P9 Specialty Doctor C4) pointed out an important attribute, and felt any service needed *“people who have actually got the interest”* in working with PdxBPD. Annie (P8 CMHN C4) positioned that considerate, skilled and enthusiastic practitioners were necessary, wanting *“folk that were open, and had the skills to work with people with BPD falling into crisis. Folk that aren't burnt out and jaded”*. Mark (P6 CMHN C3) alluded to a trauma-informed, relationally competent, self-aware practitioner who would not be risk averse, offering that *“these are really damaged people. They need a huge amount of sensitivity, and they need people who are skilful and mentally robust, and risk takers”*. He advocated for staff with a broad range of skillsets, but each a specialist in relationships. He imagined *“you've got a range of people in there who can pull the necessary social work, nursing, OT, skills out the bag if needed. But actually, you've also got a range of people that can engage people”*. One might picture this as an integrated service with multiple professional disciplines, but each person is a specialist in human relationships. Kate (P1 PdxBPD C1) thought that therapeutic relationships were essential, and should be given the same esteem as medication: *“I can't emphasise enough how much people with BPD need someone ... an ongoing relationship with someone of a professional background in personality disorders... that should be prescribed as fast as the pills are prescribed to you”*.

4.6.1.7. Peer support

Participants thought service delivery should also include peer support. Grace (P7 PdxBPD C4) said *“I think it's important that... people that have had their own experiences with mental health would be there”* and Carole (P14 PdxBPD C6) agreed the service should *“work with people who are peer support”*. Grace (P7 PdxBPD C4) considered peer support to bring something different than paid professionals, offering their *“experiences and what's worked for them”*, saying *“that's really helped me a lot”*. She also considered peer support as giving hope, as she could see people had *“been through it and then came out the other side kind of thing, so you kind of like see that as like, you know, recovery”*.

4.6.1.8. Flexible and holistic person-centered interventions

Participants also described the need for any service to be flexible in having a variety of interventions and activity offered. Grace (P7 PdxBPD C4) acknowledged heterogeneity, saying *“it's so different for everyone with BPD”* and felt care should be *“tailored to the person”*. Participants imagined a service with a variety of functions and offerings, with a holistic approach which would pay attention to a person's entire needs ranging from social determinants, various psychological models, through to spirituality and meaning in life. Grace (P7 PdxBPD C4) suggested evidence-based therapies such as *“DBT”* (dialectical behavioural therapy) would be valuable. Nina (P3 CMHN C1) championed a variety of therapeutic models and approaches, stating *“the decider skill pack... if somebody's a visual learner, decider skills is great... but it's not for everybody... CBT... it's not for everybody”*. Whilst acknowledging the need for a range of approaches, one of the models used locally was mentalization based treatment (MBT), and this was singled out by professionals as being their favoured model. Mentalization-based treatment is an evidence-based psychotherapy developed specifically for ‘BPD’, which emphasizes encouraging staff and patients to consider mental states, to empathise and gain a deeper understanding of themselves and others. Two professionals felt it to be consistently useful, encouraging self-awareness as well as allowing delicate relational conversations. Steven (P9 Specialty Doctor C4) said *“I'm definitely an MBT fanboy... I found that absolutely just transformative in the way that I practice medicine”*. Nina (P3 CMHN C1) praised the MBT approach, stating *“I haven't found a single patient that I've not been able to use MBT skills with... it helps me think... quite challenging stuff about myself... it allows me to have really, really difficult conversations and maintain my therapeutic alliance”*.

Steven (P9 Specialty Doctor C4) felt any service should offer *“not just therapy... physical exercise and relaxation... creative working”*. Alison (P4 PdxBPD C2) earlier emphasised the value of exercise for her. Janis (P2 SP Sibling C1) agreed, saying *“it doesn't even need to be like therapy... Kate's quite creative, so sometimes just painting or like that sort of thing is really helpful for her”*. Carole (P14 PdxBPD C6) imagined as well as the option *“to talk”*, attending a service with staff who might suggest *“let's go and cook in the middle of the night, that's a distraction”*, or *“do you want to colour in with someone”*. Joni (P10 PdxBPD C5) would reject being pushed into talking before she felt ready, and wanted somewhere where you *“don't even necessarily have to sit and go over things with people”* and could *“just sit and chill... watch Coronation Street for half an hour... It makes like a huge difference having that place that you can just go and switch off”*. Steven (P9 Specialty

Doctor C4) considered a holistic view of how crisis impacts on mind and body. He said *“there's a physiological angle and a psychological angle people should take... that sort of drill capacity to have specific breathing techniques and patterns to use, is a helpful thing... to... bring physiology down”*. He continued, stating *“the physiological end is going to be about doing what you can to decrease heart rate... take someone's respiratory rate down, just really take the edge off the adrenaline... breathing patterns... is something we could look at”*. Grace (P7 PdxBPD C4) also considered there should be flexibility in whether people worked in groups or 1-1, saying *“maybe some people would like one on ones and other people would like a group”*.

Steven (P9 Specialty Doctor C4) felt care should not be focused on diagnosis. He imagined *“the training and the interest people have is very genuinely holistic... we're not just talking about, here's BPD, and here's what we do, and our pathway while you're here”*. Carole (P14 PdxBPD C6) wanted attention paid to the social determinants of health, giving an example of wanting staff to ask *“are you homeless?... Have you got money problems”*. Edward (P12 SP Parent C5) identified more spiritual aspects of mental health as hugely important, asking *“meaning... fulfilment... purpose.... can we help it to happen?”*. He felt every person had potential, considering that *“there is something, which if we could just find out what it is, and help them to be there, it would make their lives fulfilled... and to my mind, that's the, that's the type of thing that the hospitals, the experts, should do”*.

4.6.1.9. Relapse prevention and preparing for crisis

There was emphasis placed on preparing PdxBPD to attend to future crisis through relapse prevention, what Steven (P9 Specialty Doctor C4) defined as ‘drilling’ and learning coping skills. Mapping crisis and understanding triggers was a part of relapse prevention and avoiding, mitigating or minimising future crises, however people needed skills to cope with crisis on top of understanding how they had occurred. Nina (P3 CMHN C1) felt part of her role was to *“help teach emotional regulation”* whilst Mark (P6 CMHN C3) used a metaphor to state his role was to *“inflate your metaphorical life jacket with skills that will help you recover from this”*. Steven (P9 Specialty Doctor C4) thought mapping triggers allowed the drilling of responses, thus becoming more automatic. He said *“it may be during... a time like this, we are avoiding conversations with x, we are doing what we can to stay from the following triggers that we've identified...and here's a couple of go to phrases that we have drilled and that we will use in conversation during these times”*. He continued *“it's the remembering to do it and having that sort of automatic sense that this is a helpful thing that I should do right now, that I think we miss... It's just not well drilled in people like it would*

have to be... I guess what I'm talking about is during peacetime... when actually things are well, it's just saying... I appreciate things are really good right now, so let's have a think about when things... go off in future... here's what you're going to do in that situation. And just having this... plan A routine, going sort of over and over and over as a sort of constant reminder".

4.6.1.10. Consistent relationships and approaches

Community mental health nurses echoed the importance of consistent relationships. Nina (P3 CMHN C1) bemoaned passing PdxBPD between different professionals. She recounted *"what I see more often than not is... perhaps somebody is getting seen by psychology, and they go into crisis and psychologist panics and wants a community mental health nurse to come on board... But you're the one with the relationship with a patient"*. Mark (P6 CMHN C3) thought *"there's a lot to be said for having an eclectic range of people with an eclectic range of skills who can engage with people on the basis of the level of relationship they have with them, rather than... I'm an OT, so I'll do this or I'm a social worker, so I'll do this or I'm a nurse, so I'll do this"*. Billie (P16 CMHN C6) said *"I don't think that having a separate crisis team would solve the problem"*. She expanded that *"in (another location in Scotland)... there were teams with crisis teams, but there were a couple of kind of areas where it was just an integrated thing, they did evenings and weekends as well. And, genuinely, it seemed to work"*. She continued, stating *"relationship being key, if it's part of the service then... someone sees... someone that they really know, but at the very worst... somebody that knows of them, somebody that's in that team, somebody that understands a little bit of what's going on for them... it just means that when they do make contact, it gets dealt with... appropriately, because otherwise, you're expecting a clinician, who doesn't know the person to just come up with the right response, magically, and that's not as easy as with someone you've been working with for months, or, potentially, years"*. Edward (P12 SP Parent C5) spoke about Joni (P10 PdxBPD C5) and echoed the sentiment that *"consistency is absolutely fundamental"*, and wanted a consistent team of people, given potential for absence. He knew *"people go off sick, people have holidays, but the other aspect of this consistency is that if A goes off sick, well actually, B is there. Currently, there's no B. A goes off sick, A is off sick... and you might get anybody"*.

As well as consistent staff members, it was important that a team responded in a consistent manner. Robert (P13 Psychologist C5) re-emphasised *"regular supervision for inpatient staff... making sure you've got... training... or like a... therapeutic model, from which they can make sense of people. And they can also kind of contain their relationships,*

experiences with people". Nina (P3 CMHN C1) felt there should be a robust induction for new team members, stating the need to be *"educating people as they come in"*.

4.6.1.11. Perseverance and follow-up

Edward (P12 SP Parent C5) considered the act of finding out what works and doesn't as an ongoing uncertain process which required perseverance. He argued *"the whole reason we have the specialist is because their experience is of Joni... and then many, many others.... Plus they read research... So, they compile a vast knowledge of what worked here and what worked there and all the rest of it. So, they should then say, okay, today, I'm seeing x, so this is situation. So, what should we be able to try here? Because that worked here and there's similarities here... draw a mind map or whatever they want to do... And it might work, it might not work.... that is why we have the expertise... people... who study that and that because it could be soul destroying at times cause... we'll try that and it's a huge disaster, but it worked so well for this person, and it worked so well for that person, so why hasn't it worked for this person?"*.

Beyond crisis there should be follow up. Kate (P1 PdxBPD C1) wanted an ongoing relationship with *"a CPN or personality disorder specialist at least minimum once a month"*. Carole (P14 PdxBPD C6) wanted to *"start up a service that's not just a once off, oh, you're in crisis, we'll talk to you for 10 minutes, and then you'll go home"*. She wanted a service who would respond to crisis but also have an ethos of *"continuously working with people"* imagining *"I was able to go to a place, for longer than an hour"* with *"continuous support and then follow up in the morning"*. Joan (P15 SP Friend C6) agreed wishing for a service which would *"listen to you... bring you back down, and then follow up with you"*.

4.6.1.12. Connections to other services

Connections between existing services and efficient information sharing would be crucial. Carole (P14 PdxBPD C6) wanted the service to *"collaborate with what's already there"* including third sector as well as NHS services. Joni (P10 PdxBPD C5) advocated sharing a crisis plan, which she felt would have *"the highlights of what that person struggles with... I'm not asking them to understand it all, but... this is Joni... this is what she's got"*. Joan (P15 SP Friend C6) suggested improvement in lines of communication between services, stating *"another thing that's missing... you're assessed by someone... they write a letter that doesn't get to your care team for a week. There's no... familiar person that follows up with you and checks in with you"*. Robert (P13 Psychologist C5) added that he wanted to see *"much more joined up relapse prevention"*, gesturing that consistency and connection between various services was necessary to facilitate this.

4.6.1.13. Connections to and support for families

Connections should also extend to families and support persons, valuing their experience and offering them support. Kate (P1 PdxBPD C1) felt *“having loved ones be part of your treatment”* would be helpful, adding there should be *“more classes/groups for partners, friends and family”*. Kate (P1 PdxBPD C1) stated that her family also encouraged her relationship with mental health professionals, saying *“it's my mum that encourages me to be open and honest with my CPN”*. However, conversely Edward (P12 SP Parent C5) had not felt included in Joni's (P10 PdxBPD C5) care, and perceived MH services having an ethos of *“you do not speak to parents”*. He felt strongly that family expertise should be valued and also inform care, stating *“the family, those around her, we're with her 24/7, and we see things... we know things... you naturally put in place processes, and you don't realise always that you're doing it... And actually, I think... experts... should be able to say... almost as you're doing (meaning me as researcher asking questions), well, what did you do when this happened? What did you do? Ah, and what reaction did you get? Oh right, okay. So, because over the time... I can remember the last review meeting we had... (what was suggested to the family by mental health services)... that's what we were doing with her 15 years ago”*. He simply wanted to have the family perspective and input considered, stating *“what we're saying is not gospel... but at least put it into the mix, take it on board, think about it”*.

Any service should also consider how it helps those people who are often supporting PdxBPD, supporting them emotionally as well as with guidance on how to help. Kate (P1 PdxBPD C1) thought that *“having your mum, who gave birth to you, sit there and beg you to stay alive... must've been traumatic for her”*. Alison (P4 PdxBPD C2) understood her attempted suicide and subsequent intervention as being *“really traumatic”* for her partner. Janis (P2 SP Sibling C1) worried about suicide, saying *“there was always this big anxiety about, what were you going to find when you opened the door to go and in check on her”*. She continued, adding *“we all felt lost... just the worry that she going to do something to herself, and we couldn't prevent it cause we didn't know what we were doing... I'm not saying that it always needs to be hospitalisation, but if you could get a bit of reassurance from someone about what to do, I think that would've been really helpful, and it might help avert future crises”*. Chris (P11 SP Partner C5) also wanted guidance, imagining *“if this happens, make sure you don't sort of mention that... if Joni's doing this... make sure you do this... just some sort of reference... I can like look at”*. Janis (P2 SP Sibling C1) stated that whilst a carers support group was helpful *“we really had to dig around... to get access to*

the support for... us supporting her". However, the benefit was that "we got a better understanding of how Kate might feel in certain situations and it sort of helped to hear other people's experiences as well, what worked for them, because it meant we could start trying it". However, Chris (P11 SP Partner C5) noted an issue with providing guidance for families based on the 'BPD' diagnosis, stating "everyone's sort of situation's sort of a bit unique anyway. So... how would you get like a video that's sort of explains everyone's like circumstance, you know?". This raises an important point in the limitations of diagnosis when requiring truly person-centered understandings, and the need to personalize any attempt at providing help and support.

4.6.2. Theme summary

Participants considered the need for new models of crisis intervention which may be co-produced between professionals and people with lived experience of 'BPD' and associated distress. Any service was desired to be accessible and responsive, with multiple levels of support offered according to need, and flexible and person centred interventions tailored to individuals. Consideration should be given to a safe and welcoming physical and psychological environment, and it should be staffed by people who have expertise in relational based care, alongside peer support offered by people with lived experience of mental health problems. Participants considered that relapse prevention should be a core aim of the service, and that it should facilitate consistent relationships, continuity of care and connections with other services. Valuing and supporting families and friends of PdxBPD was important, and would have the dual role of supporting the family member whilst also benefiting PdxBPD receiving care. This may seem like a reasonable wish-list, regardless, change is often seen pessimistically as difficult if not impossible. Nonetheless, as Mark (P6 CMHN C3) stated, "it can happen if you do it", adding if you "get the imagination and the sponsorship of some senior people... the project takes on a life of its own after that".

4.7. Summary of findings and introduction to concept map

The findings have taken us on a journey through the multidimensional experience of crisis for PdxBPD, to the confused and anxious system where accessing help can be challenging, where anxious staff and confusion around the 'BPD' diagnosis can negatively impact on care. Data showed harm occurring through the absence of warmth and empathy, as well as through restriction, coercion, stigma and discrimination. Participant narratives from all stakeholders indicated that the things which ultimately do help people are relatively simple, yet the reasons they may not occur comes down to the complexity of human

factors and variables which act as barriers. Whilst much of the findings focused on ‘what not to do’ and things which were experienced as unhelpful, there was an emerging clarity around what people wanted of future services, particularly that of being accessible, flexible, with staff skilled in human relationships.

4.7.1. How the findings are embodied in the concept map

Each of the five themes, along with literature review, have been synthesised into a concept map which acts as a bridge between the findings and discussion chapters. Each theme is present, though these are interconnected and not necessarily linear. The concept map begins through theme 1 and ‘understanding crisis’, identifying what makes people vulnerable to these experiences, and listing potential triggers. Crisis itself is conceptualised based on features described by PdxBPD, and the way people cope with this are segregated to highlight the distinction between the underlying distress of crisis, and the behaviours used to cope with it. Following crisis, as people seek help, they are ‘wearing a label’ acknowledging that across themes, experiences of care are hugely influenced by the ‘BPD’ label, and the stigma which results. Themes 2 and 3, ‘a confused and anxious system’ and ‘acts and omissions which lead to harm’ are presented in listing the variety of services and agencies which are utilised when seeking support, and identifying harm which can occur during interaction with them. Theme 4, ‘the complex simplicity of helping people in crisis’, sees listed a series of variables which can influence care, before offering the counter to what harms, and identifying things that PdxBPD found helpful. Given so many human and organisational factors influence care, luck is placed in the concept map as a useful concept explaining why care received may be helpful or unhelpful. Family and friends lay in-between crisis and the confused and anxious system, acknowledging their role as an ‘all or nothing’ mental health service which can be providing all care, or on the periphery of professional interventions. Theme 5 of ‘building a better future’ is presented standing alone at the far end of the concept map, as a possible future.

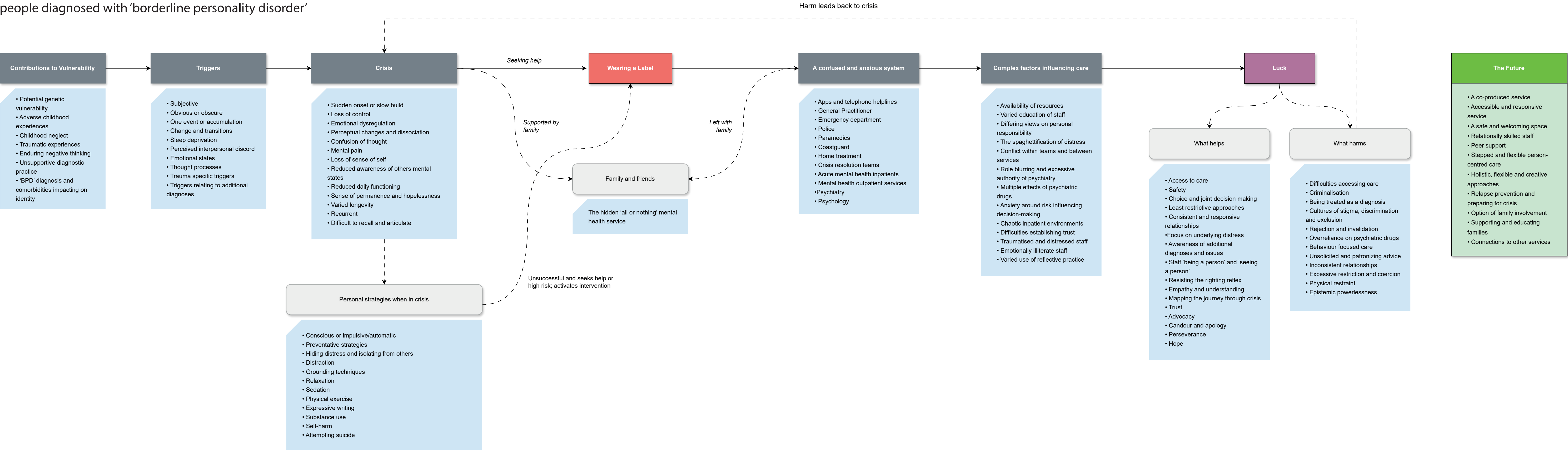
4.7.1.1. Figure 5: Crisis Intervention Concept Map: Potential journey through crisis and crisis intervention for people diagnosed with ‘borderline personality disorder’

The following page presents the concept map, a model presenting possibilities which may happen for some of the people some of the time. Chapter 5 utilises this concept map as a guide, creating a narrative through which literature review and research findings can be explored along the potential journey through crisis and crisis intervention for PdxBPD. Chapter 5 also returns to the idea of the ‘wicked problem’ (Ritell and Weber 1973), where

there is evidence that some of the solutions for crisis may in-fact exacerbate the issues and have waves of interconnected consequences.

Crisis Intervention Concept Map

Potential journey through crisis and crisis intervention for people diagnosed with 'borderline personality disorder'



5. Chapter 5: Discussion

5.1.1.1. Utility of the concept map throughout this chapter

The concept map immediately previous to this chapter provides a narrative through which the literature review and research findings will be explored. Given the small sample in this study, as well as issues such as heterogeneity of diagnosis and the enormous variables involved in human experience, this is deemed to be a model presenting possibilities which may happen for some of the people some of the time.

5.2. The ‘wicked problem’ of crisis and crisis intervention

The issues of crisis and crisis intervention for PdxBPD are consistent with definitions of a wicked problem (Rittel and Webber 1973), as problems and solutions are inextricably linked, with subjective criteria for where a problem is resolved, where every problem can be described as ‘one of a kind’ and every solution a ‘one shot operation’. Wicked problems have been pitched as an appropriate lens for understanding mental health, described as “a particularly untamed field” (Hannigan and Coffey 2011, p.222).

The theory of wicked problems thus offers a frame through which to explore the complexity of crisis and crisis intervention, where nothing is neat and tidy, and everything is subjective, chaotic and unpredictable. Dare I say, perhaps not surprisingly, the writing of the findings and this discussion chapter has been a challenge given the lack of a straightforward and linear narrative. Nonetheless, the potential journey through crisis and crisis intervention captured in the concept map offers a loose narrative and valuable insight into possible experiences, and a journey through concepts and the relationship between them. It thus offers avenues through which there may be clinical consideration of decision making, emphasis in education, policy development and further research. Despite being a wicked problem, there are still opportunities to improve the experiences of human beings, and the value yet limitations of the concept map can be summed up in an oft cited point from Box and Draper (1987 p.424) who state that “models are approximations”, acknowledging utility and pragmatism with the quote “all models are wrong, but some are useful”. The following discussion takes in sequence the elements of the concept map (figure 5).

5.3. Vulnerability to crisis

5.3.1. “A bit of both”: biological vulnerability or vulnerability through experience?

The vulnerability of PdxBPD being prone to experiencing crisis may link to genetics, though perhaps more so trauma, neglect and adverse childhood experiences. Supporting the consideration of genes, Janis (P2 SP Sibling C1) thought Kate (P1 PdxBPD C1) had big emotional reactions which were different than expected as a child, and thought her

difficulties were due to “a bit of both” biological vulnerability and responses to experience. Genes are implicated in experiences related to ‘BPD’, though research is described as limited (Braga et al 2015). Rather than a susceptibility gene, there are arguments that vulnerability comes from a genetic plasticity with an increased sensitivity to the environment, and where the balance leans towards negative events it contributes to ‘BPD’ symptoms (Amad et al 2014). Current theory is moving towards this ‘Gene x Environment’ model of ‘BPD’, and significant findings have shown that genes can be influenced by childhood maltreatment (Wilson et al 2021). Recent evidence shows that every person is on a spectrum of genetic risk to each psychiatric disorder, through the influence of thousands of genes acting together (Andreassen et al 2023). However, with so much complexity involved in living in the world and factors which may reverse the influence of genes, it has been argued that genes should never be viewed as an irrevocable determination of behaviour, as while they may begin to offer some statistical generalization, they offer nothing you would ever bet on (Dawkins 2016). Thus, genetics can never be ignored, yet it is not yet fully understood as to how it specifically relates to ‘BPD’ and crisis, a quandary which is certainly beyond the scope and focus of this study.

5.3.2. ‘What happened’ to lead to vulnerability?

Trauma was common amongst PdxBPD in the study. Whilst the question was not specifically asked, five of the six PdxBPD interviewed in the study identified as having experienced trauma, a trend which is consistent with research. A meta-analysis of 97 studies showed PdxBPD as 13 times more likely to report adverse childhood experiences than non-clinical control groups, and three times more likely than people with other psychiatric diagnoses (Porter et al, 2019). Furthermore, an umbrella review found a significantly higher association between trauma and ‘BPD’ compared with other diagnoses, with early adverse experiences linked to ‘BPD’ features of affect instability, emotional dysregulation and self-destructive behaviour (Hogg et al 2023). The one person who did not identify as having experienced trauma is a reminder of the heterogeneity of the diagnosis, as well as multiple potential pathways towards developing difficulties.

5.3.3. Vulnerable due to being “badly diagnosed”

People had experienced receiving the ‘BPD’ diagnosis as an unsupportive process, and may not be fully (or at all) informed around what it actually means. Steven (P9 Speciality Doctor C4) acknowledged some people were “badly diagnosed” and a systematic review of service user experiences found a significant difference between a well-delivered or poorly-delivered diagnosis (Lester et al 2020). People have shown elsewhere they feel

uninformed, not being told about their diagnosis directly by a professional, but sometimes finding out by reading their own notes, and being left with inaccurate understandings, for example one person believing “it’s borderline personality disorder, because it’s similar, but not quite as bad as other personality disorders.” (Motala and Price 2022, p.5). Lester et al (2020) found that a lack of information and unsupportive diagnostic practice could lead PdxBPD to feel confused, angry and dismissed, however countered that those positive experiences of diagnosis where time and care was taken to explain it, could give people a clearer understanding of themselves, help them connect with others, and offer a sense of relief. Further potential confusion, in addition to diagnostic practice, comes with the fact that pure ‘BPD’ is rare (NICE 2009), and consistent with this, PdxBPD in this study each had additional diagnoses of mental health conditions. Having these additional comorbidities added a degree of confusion for PdxBPD and this needs to be considered, though the experiences and understandings of service users with competing diagnoses may as yet be underexplored.

5.3.4. The cruel irony of identity disturbance

In conjunction with unsupportive diagnostic processes and the existence of comorbidities which may compound confusion, the subsequent personal meaning ascribed to diagnosis may also influence crisis through contributing to the symptom of “identity disturbance, manifested in markedly and persistently unstable self-image or sense of self” (WHO 2024). Using a study where people were assessed as to whether they intentionally sat in front of a mirror or avoided it, Winter, Koplin and Lis (2015) found that PdxBPD would avoid self-awareness cues (90% deliberately avoiding the mirror) and proposed possible explanations as a negative body related shame-prone self-concept, and a heightened sensitivity to self-awareness cues. However, while it may be argued PdxBPD have a baseline identity disturbance, following the potential personal meanings given to the diagnosis there is a cruel irony in a symptom of ‘BPD’ being unstable sense of self. Alongside the confusion of multiple diagnoses where Joni (P10 PdxBPD C5) had her distress separated, being told “*that’s down to your autism*” and “*that’s down to your BPD*”, the dehumanising terminology of personality disorder led Kate (P1 PdxBPD C1) to feel like a “*wild, hated monster*” and have Tori (P5 PdxBPD C3) uncomfortably reply “*I like to think I have a nice personality*”.

5.3.5. Self-stigma contributing to crisis

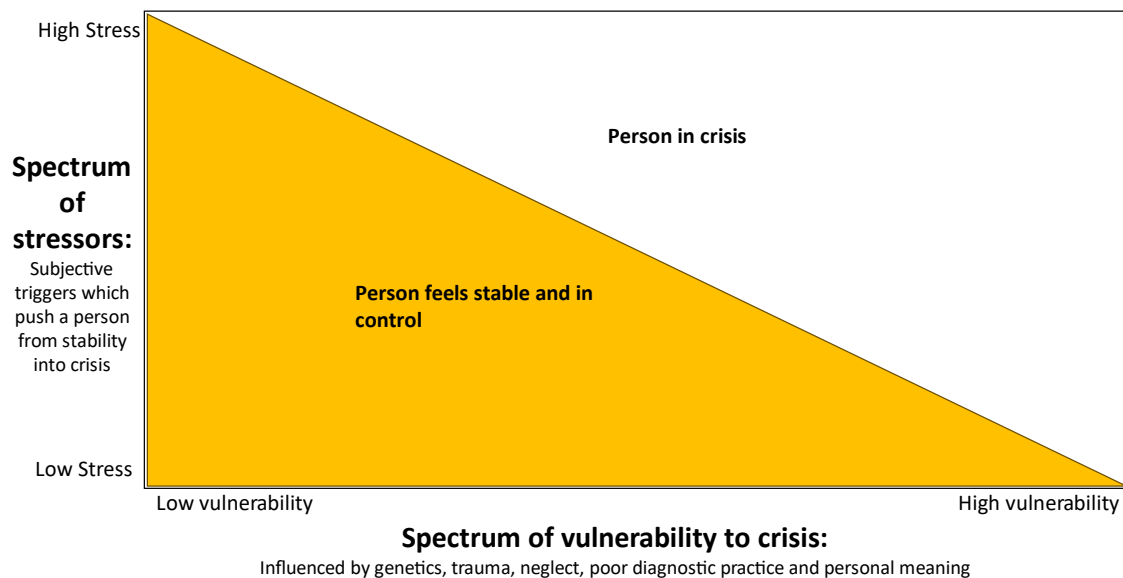
The ‘BPD’ label has also led others to describe themselves as ‘awful’ and ‘rotten’ (Motala and Price 2022), or see the diagnosis as an insult, feeling treated like “*a naughty, dirty person*” and “*not part of humanity*” (Bonnington and Rose 2014, p.11). It has been

acknowledged by experts that giving a personality disorder diagnosis can feel as if you are “*attacking the very ‘soul’ of the individual*” (Bateman and Fonagy 2016, p.149). Therefore, an issue which has perhaps been criminally underexplored, is that receiving and giving meaning to the diagnosis may impact sense of self and in fact create, or at least exacerbate, a symptom of the diagnosis. In a cross-sectional comparison Grambal et al (2016) found that ‘BPD’ was associated with higher levels of self-stigma than other diagnoses, while a qualitative study saw PdxBPD (n = 10) described the impact of the diagnosis on self-concept as broadly negative, with this arising through researching the diagnosis online, the way people felt treated by professionals and services, and concern around the possible responses of families, friends and local communities (Motala and Price 2022). In terms of how this may relate to crisis, self-stigma in other diagnoses has shown to have a correlation with suicidality and a history of suicide attempts (Latalova et al 2013, 2014). One can assume that PdxBPD may feel similarly.

5.3.6. High vulnerability and low thresholds for entering crisis

In terms of how each of these issues may relate to crisis, the stress vulnerability model (Zubin and Spring 1977) can offer an explanation. The model, which continues to be useful for understanding relapsing and recurrent distress (Goh and Agius 2010), was originally applied to the development of schizophrenia, proposing that a genetic predisposition to schizophrenia itself was not enough for a person to develop symptoms, arguing it was interaction with the environment which would see symptoms manifest. In the case of crisis for PdxBPD, I propose that the vulnerability to crisis for PdxBPD may in part be influenced by genetics, but more obviously shaped by trauma, adversity and neglect, and possibly exacerbated by poor diagnostic practice and negative personal meanings given to the ‘BPD’ label. Consistent with the model, the higher the vulnerability, the less stress it requires someone to experience before they cross the threshold from stability to distress. The frequency of crisis for some PdxBPD may in part be explained by this high vulnerability, and low tolerance to stress and sensitivity to personal triggers (figure 6). Consistent with Rittel and Weber (1973, p.165), ‘every wicked problem can be considered to be a symptom of another problem’, and being triggered and experiencing crisis can be a symptom of an underlying vulnerability with its various causes.

Figure 6 : Spectrum of vulnerability to crisis (adapted from Zubin and Spring 1977)



5.4. Triggers to crisis

Bohus et al (2021) describe the identification and understanding of triggers and contributing factors to crisis for PdxBPD as fundamental to effective crisis management. The triggers identified from PdxBPD in the study were consistent with literature, yet offered further depth of conceptualisation, with triggers always subjective, either obvious or obscure (in terms of not being obvious to the person themselves or others around them), and either arise from one single instance or event or an accumulation. Specific categories of trigger were identified, with change and transitions, lack of sleep, perceived interpersonal discord, emotional states, thought processes, trauma specific triggers and triggers relating to additional diagnoses each offered as possibilities.

5.4.1. The butterfly effect and the subtlety of triggers

The subjectivity and obscurity of triggers, and how seemingly small everyday instances can have huge and life-threatening consequences, might encourage us to view triggers for PdxBPD as a kind of butterfly effect. The butterfly effect is a metaphorical example relating to weather science, where Lorenz (1972, p.1) asked “*if a single flap of a butterfly’s wing can be instrumental in generating a tornado*”. This powerful metaphor offers a lens through which we may understand how seemingly benign insignificant events (a butterfly flapping its wings) may create a chain reaction and evolve into a crisis (the tornado). A high vulnerability means a low level of stress can be tolerated. The journey towards crisis is

dependent on the subjective perception and significance of each ‘butterfly flap’ to each individual. As Rittel and Weber (1973, p.164) argue, “*every wicked problem is essentially unique*”.

Though PdxBPD described a spectrum of crisis ranging from “low-level” up to extremes, no level should be taken lightly or overlooked, as these were seen as stepping-stones which if left unaddressed, would spiral into further distress. As Jacques (2014, p.9) writes, when discussing organizational crisis management, “*there is a maxim that ‘a crisis is an issue that wasn’t managed’*”. This may be similarly applied to crisis with PdxBPD, where paying attention to the butterfly’s wings may be an opportunity to prevent a person descending into crisis.

5.4.2. Categories of triggers

5.4.2.1. Change and transition

Change and transitions were a key influence on crisis, and this was consistent with psychotherapists views on change being a common trigger for all psychological disturbance (Riachi, Holma and Laitila 2022), with this identified as an area where PdxBPD specifically need support (NICE 2009). Whilst human beings are understood as creatures generally capable of adapting to high degrees of change, there exists a subjectivity based on variables explored in the vulnerability to crisis.

5.4.2.2. Sleep disturbance

Sleep deprivation too may be something most people can relate to, yet understandably for PdxBPD who may already be vulnerable, there may be a lower threshold for tolerating this without experiencing a crisis. Some of the short-term consequences of sleep deprivation include increased activity in the nervous system, a vulnerability to stress, emotional distress and disruption in mood (Medic, Wille and Hemels 2017). These issues feature not only in triggers to crisis, but in the conceptualization of crisis itself. Again, in sync with a wicked problem of which there is no definitive formulation (Rittel and Weber 1973), sleep deprivation could be both a trigger to and manifestation of crisis.

5.4.2.3. Interpersonal issues

Interpersonal issues were an unsurprising trigger given difficulties in relationships as a key and agreed upon feature of ‘BPD’ diagnostic criteria (WHO 2024). Triggers often centred around perceived rejection from others, or discord in relationships. Relevant research has seen PdxBPD with a larger preference for personal space (Fineberg et al 2017), and also to expect and perceive social rejection stronger than healthy controls (Winter, Koplin and Lis

2015). Furthermore, interpersonal issues can now manifest through interacting with social media, where smartphones offer a pocket sized 24/7 availability of trigger. Social comparison through social media is argued to be a significant factor which can influence poor mental health (Warrender and Milne 2020), and PdxBPD have shown increased social media posting, regret after doing so, while noting the importance of social media as an influence on their social behaviour (Ooi et al 2020).

5.4.2.4. Internal states of thought and feeling

Emotional states were a similarly expected trigger given the place of ‘emotional instability’ in diagnostic criteria (WHO 2024). Diagnostic criteria describe how ‘fluctuations in mood’ can be triggered by internal states, and this study found that internal emotional states can be viewed as leading to more intense feelings of crisis. This certainly raises questions around ‘chicken and egg’ and which comes first, though it may be argued given crisis is a multidimensional subjective experience, this can only be understood within an individual’s experience. Whilst this study noted fear, particularly in relation to trauma, as a key emotional state, the literature review additionally found emptiness, loneliness, guilt and shame to be important emotional triggers. Emotional states may also arise from poor experiences of receiving the diagnosis, with Lester et al (2020) finding communication of diagnosis and subsequent understanding leading to emotional states such as being confused and angry, and people could feel the diagnosis suggested they were “*bad*” or “*wrong*”.

Thoughts too could trigger crisis. Whilst enduring negative thinking was identified in the literature review and may form part of some people’s baseline vulnerability to crisis, negative thoughts were described by Alison (P4 PdxBPD C2) as spiralling, leading her towards crisis. Carole (P14 PdxBPD C6) described being triggered by “*my own thoughts*”, and particularly those around low self-worth. Tori (P5 PdxBPD C3) described catastrophizing and exaggerating potential negative outcomes of situations.

5.4.2.5. Trauma specific triggers

Any trigger may be rooted in a person’s experience of trauma. Research has indicated that neurodevelopment is significantly impacted in those who have experienced childhood trauma in particular, with the result being people who are easily triggered, and a compromised ability to self-soothe (Van Der Kolk 2003). Sweeney et al (2018, p.320) describe how “*trauma survivors are ‘primed’ to respond to situations and relationships that embody characteristics of past traumatic events or in which there is a perceived threat*”. The specific situations from PdxBPD in this study which embodied characteristics of past

traumatic experiences included a calendar date, physical health issues and a smell, with reminiscent situations rooted in relationships linked to fear of harm or rejection. This highlights the importance of helping a person understand their own trauma experiences and story, in terms of how they understand their experience of crisis.

5.4.2.6. Triggers relating to comorbid issues

Not only is 'BPD' already a heterogeneous diagnosis, but the addition of comorbid diagnoses also adds a layer of unique complexity to crisis and individual sensitivities which may trigger it. It is acknowledged that it is rare for PdxBPD to have solely that diagnosis (NICE 2009), and consistent with this PdxBPD in the study each had additional diagnoses. Given this fact, triggers should not be viewed through the lens of 'BPD', but through the lens of a unique individual, where subjectivity should be acknowledged and consideration given to the influence of other issues which may relate to additional diagnoses. Two striking examples within the study were related to people with comorbid diagnoses of attention deficit hyperactivity disorder, autism and obsessive-compulsive disorder. These issues are of huge significance in their own right, though people felt they were overshadowed by the 'BPD' diagnosis. It could be argued that viewing triggers only through the 'BPD' lens may be both negligent and unfruitful.

5.5. Crisis

Consistent with the literature review and the idea of a wicked problem, the experience of crisis was a multi-dimensional, unique and subjective experience. Further detail offered through the study identified additional features of a slow build or sudden onset, experience of losing control and losing the self, emotional dysregulation, perceptual changes including dissociation, and confusion of thought. During these times, there could be a reduced awareness of others mental states, reduced daily functioning, and a sense of permanence and hopelessness. Crisis could have varied longevity and could be a recurrent experience. 'Mental pain' was a broad but useful term for an experience which was difficult to recall and articulate. Readers will note that features of crisis are also described as triggers, exemplifying the cyclical and difficult to articulate experience. Perhaps where the experience can be so sudden, trigger and crisis experience may become indistinguishable from one another, or be quickly lost in a labyrinth of distress. The wicked problem is difficult to formulate, and each individual's experience is unique.

5.5.1. The slow build to crisis

Whilst the literature review found crisis described as a sudden experience, this study learned more about how there could also be a slow build with PdxBPD's accounts of

triggers both acute but also accumulative. This build towards crisis was something people could notice themselves, or family members may notice early warning signs. Whether acute or accumulative, the feeling of losing control is consistent with the precipitating literature review. This loss of control in particular relates to thoughts, feelings and perceptions. Whilst the loss of control can also extend to behaviour, behaviour and the things that people do are defined and explored separately as personal strategies for coping with crisis.

5.5.2. A confusion of thought

A confusion of thought was felt by PdxBPD, with people describing spiralling negative thoughts, losing rational thought, and not even being able to understand their own thoughts. Linking into potential impulsivity and personal strategies for alleviating crisis, some thoughts were intrusive and pertaining to suicide, including vivid violent fantasies of dying. Emotional dysregulation was a consistent feature of crisis identified by all PdxBPD and confirmed by support persons and professionals. People described their emotions during crisis as extreme, intense, overwhelming, uncontrollable and rapidly fluctuating.

5.5.3. Emotional dysregulation

Emotional instability features in diagnostic criteria (WHO 2024) and is one of experts agreed symptoms of 'BPD' (Fonagy, Luyten and Bateman 2017). Such is the centrality of emotions in people's distress, it has been argued by some experts in the field of 'personality disorder' that 'BPD' should not be included as a category of personality disorder at all, and could be better described as an "emotional dysregulation syndrome" (Tyrer 2018, p.83). Contemporary research is now trending to use the term 'complex emotional needs' alongside 'personality disorder' (e.g. Maconick et al 2023).

5.5.4. Dissociation and the loss of 'self'

The overwhelming experience of feeling intense emotions led Kate (P1 PdxBPD C1) to describe "*becoming the emotion*". This may relate to how people can feel they lose themselves and sense of self, with Grace (P7 PdxBPD C4) and Tori (P5 PdxBPD C3) stating you did not feel like yourself when in crisis. One might argue that if you 'become' an emotion, you cannot simultaneously be yourself. In this sense, the experience of mental pain may also contribute to continued identity disturbance. Another key factor relating to a loss of sense of self was perceptual changes and dissociation. Dissociation is a broad construct and often linked to trauma, and can be understood as a defensive strategy where people disconnect from the experience or memory of events, to make situations momentarily bearable (Clark et al 2015). Whilst it could be argued a coping mechanism, it

is automatic with no degree of control and may fit best as part of crisis. This study saw PdxBPD experience dissociation, feeling disconnected from the world, seeing themselves from the outside, and being described by others as appearing ‘numb’, ‘mask-like’ or ‘robotic’. The memory of these events was difficult to recall. Grace (P7 PdxBPD C4) shared the understanding of it being a defensive strategy, saying *“I think it’s a protection thing... if I was to remember everything I’ve been through, I think I’d be in a very, very dark place”*. Al-Shamali et al’s (2022) review found that dissociation is associated with increased severity of ‘BPD’ symptoms including self-harm, and is associated with deficits in working memory and cognition, decreased pain perceptions, altered body ownership and altered stress responses. Dissociation is such a disconnecting experience that identity disturbance might seem an inevitable tandem feature.

5.5.5. Impaired empathy and reduced daily functioning

Understandably, given the intensity of distress related to thoughts, feelings and perceptions, the ability of PdxBPD to be aware of others mental states can be impaired. Where crisis interferes with empathy and an ability to take the perspectives of others, it will further perpetuate the “pattern of unstable and intense interpersonal relationships” which features in diagnostic criteria (WHO 2023). Crisis is so overwhelming, that PdxBPD quite literally cannot mentalize and empathise during these times. Moreover, given the intensity and chaotic nature of the crisis experience, daily functioning may be impaired. Participants noted poor sleep, impacts to their eating routines, reduced attention to personal hygiene and difficulty communicating with others. Whilst PdxBPD often achieve improvements in many symptoms, research has suggested that some may achieve only a slight improvement in functioning over time (Álvarez-Tomás et al 2019).

5.5.6. The varied longevity but sense of eternity in crisis

Crisis had a varied longevity. The ICD-11 diagnostic criteria states emotional instability will “typically last for a few hours but may last for up to several days” (WHO 2024). Chris (P11 SP Partner C5) said *“it could take... days”*. Although the crisis experience would end, there could be a sense of permanence and hopelessness. Kate (P1 PdxBPD C1) felt it was *“hard to tell yourself, this shall pass”*, and though it would be over at some point, there was a sense of eternal distress. Furthermore it has been found that PdxBPD experience repeated crises (Borschmann et al 2012), and participants in this study confirmed crisis as a recurrent experience, with Joni (P10 PdxBPD C5) feeling constantly on the edge of crisis as an “ongoing crisis”. The fact crisis is also difficult to recall is testament to its emotional

intensity, and it overwhelms the person and their working memory. Memory impairment may however be a defensive strategy, and link to dissociation.

5.5.7. The impossibility of describing crisis and value in metaphor

The challenge in understanding crisis (and writing about it), is that people acknowledged it was hard to remember and articulate. Furthermore, whilst many of these experiences such as ‘emotional dysregulation’ are widely known as symptoms, I do wonder if professional and scientific terminology can act as a barrier to truly appreciating how distressing these experiences can be. Alison (P4 PdxBPD C2) described crisis as “*absolute mental pain*”, while two PdxBPD used metaphor to describe their experience. Kate (P1 PdxBPD C1) described a “*fireball of emotion... almost like I'd combusted*”, whilst Carole (P14 PdxBPD C6) said “*it feels like your brain's on fire*”. Fire is a highly visual and visceral metaphor for the experience of crisis, and may capture the breadth and chaos of “*absolute mental pain*”, and begin to capture the experience of crisis which all PdxBPD acknowledged is difficult to articulate. Using artistic metaphor may be of significant value in understanding the intensity of these experiences, and puts me in the mind of the heavily memed quote “when words fail, art speaks” (original quote from Hans Christian Anderson “when words fail, music speaks”).

5.6. Personal strategies when in crisis

Distinguished from crisis itself are the personal strategies utilized by PdxBPD to cope with the experience. This is a deliberate segregation and attempt to define separately the internal experience of crisis itself, from behaviour and the things that people do to cope with it. This choice was taken given the literature review had found people describe the underlying distress beneath their behaviour was overlooked. The wicked problem is such that understandings of what the crisis is may vary, for PdxBPD the crisis is the mental experience, whilst for professionals they may see only what people are doing to cope and try to address that. Thus, professional crisis intervention may intervene and address the personal strategy utilized by PdxBPD, but not actually get near the crisis. Sweeney et al (2018) describe people who have experienced trauma behaving in ways with three functions, to cope and manage experiences, to connect with others and try to have needs met, and to communicate where distress cannot be effectively conveyed through language. Whilst not all PdxBPD may identify with traumatic experiences, these functions are nonetheless a useful lens for understanding behaviour, particularly with the high prevalence of trauma in the diagnostic population.

5.6.1. Tactical lifestyles and the subjective value of social relationships

As with many things, the best way to address crisis is to prevent it in the first place. People described lifestyle choices such as regular exercise and abstaining from alcohol, or keeping busy as a means of constant distraction. However, Alison (P4 PdxBPD C2) felt getting the balance of being busy enough, but not so busy that she was pushed into crisis, as a challenge. Once crisis did arise, people used a variety of strategies, though noted these could be either conscious and thought out, or quite impulsive and automatic. Impulsivity features in diagnostic criteria for 'BPD' (WHO 2024), and some of these strategies may be impulsive due to the desperation of alleviating crisis and a need to escape oneself. Consistent with the literature review, there was a subjective value on social relationships. People would sometimes seek help, but other times also hide their distress and avoid contact with others. Perhaps related to enduring negative thinking and low self-worth, PdxBPD often felt like they would be a burden and at times deliberately did not use their support networks, suffering in silence.

5.6.2. Distraction and shifting attention

Distraction also features as a key personal crisis intervention in dialectical behavioural therapy, which is evidence based for the treatment of PdxBPD. Linehan (2015) offers three prompts for distraction, shifting attention away from what may be causing distress, focusing the mind on something else, or leaving the situation completely. These activities of distraction seemed consistent with PdxBPD in this study who tried to keep busy, used grounding techniques, and though trying to relax, could find this difficult. Further distraction could be sought through tactile means such as using ice packs, snapping an elastic band against the skin, and self-harm. Whilst Linehan (2015) also suggests leaving the situation completely, this can be impossible when the 'situation' is feeling an intense discomfort within your own skin. Thus, leaving the situation may involve leaving consciousness. Unlike some data from literature review, no PdxBPD within this study described illegal substance use, nonetheless sedation through prescription drugs was utilized. Tori (P5 PdxBPD C3) stated "*I want to escape*", and utilized prescription medication to sedate herself through crisis.

5.6.3. Expression and exercise

During crisis, PdxBPD may also need to use a more expressive means of coping. Expressive writing of thoughts and feelings was used as a distraction which expressed an internal experience onto a blank page. Writing is only one form of art, and many others have been shown to have psychological and physiological benefits including visual arts, dance and

movement, drama and music (Karkou et al 2022). However the use of the arts for PdxBPD during crisis may be underexplored. Some writing too may not be artistic, but rather a means of explicitly communicating distress through social media. Research has found PdxBPD may be more prone to posting on social media (Ooi et al 2020).

Exercise too was a means of coping. It has been argued that exercise is often an overlooked intervention for mental health problems, and has been proven to have both physical and mental health benefits (Sharma, Madaan and Petty 2006). In particular, physical activity has been shown to lower cortisol, an adrenal hormone which is released in response to stress (De Nys et al 2022). There are suggestions that some 'BPD' symptoms may be linked to atypical cortisol levels (Dyson et al 2023), which in turn may suggest a key role in exercise as an intervention.

5.6.4. Self-harm and attempting suicide

Despite being aware of coping mechanisms, the intensity of crisis experience could lead people towards self-harm and attempting suicide. Carole (P14 PdxBPD C6) said *"your emotions are so big... you forget all your coping mechanisms"*, and said of self-harm, *"you know that it works"*. Recurrent episodes of self-harm feature in diagnostic criteria, and all PdxBPD in the study had self-harmed in the past. People described means of self-harm including cutting, burning, scratching, and binge eating or self-starvation. Self-harm is not synonymous with 'BPD', yet it is something that professionals explicitly notice, and it is argued that there may be people who may meet criteria for 'BPD', yet remain 'hidden' where they do not self-harm (Zimmerman and Becker 2023). Self-harm could be planned or impulsive, and have varied functions including an emotional release, grounding, regaining control, and a means of communication. This was consistent with literature which understands self-harm as varying in nature and intent, with self-harm often to reduce painful inner emotional states (Paris 2019).

The line between acts of self-harm and those aimed towards dying by suicide can be a grey area, as intended self-harm could still put people at risk of dying, where death was not intended. The ambivalence of both wanting to live and wanting die was evidenced, with people saying they wanted both, Grace (P7 PdxBPD C4) saying *"I want to live, but it's too like, hard"*. People had considered and attempted suicide through walking along train tracks, jumping from buildings, overdosing, poisoning and cutting. Whilst it has been argued that people who recurrently attempt suicide and people who die by suicide are separate and distinct populations with different characteristics (Beautrais 2001), it may be difficult to ascertain intent. Whilst we cannot ask the people who die whether they fully

intended to die or not, PdxBPD in this study did not always fully know their own intent when they harmed themselves. As Carole (P14 PdxBPD C6)'s comment shows; *"I have nearly killed myself when I haven't meant to, and then I've not died when I've meant to"*.

Regardless of whether people die very intentionally or through self-harm which spirals out of control, worrying statistics remain, in that up to 10% of PdxBPD may die by suicide (Paris 2019).

The wickedness of self-harm and attempted suicide is that not only do people harm themselves in order to help themselves, but following these experiences, PdxBPD could feel worse, leading to further difficult feelings. Thus whilst self-harm and attempting suicide can be a personal strategy for coping with crisis, the resulting feelings can themselves become a trigger, creating a tragic cycle between trigger, crisis, and personal strategies which could continue ad infinitum.

5.7. Wearing a label

One final personal strategy for coping with crisis may be for a person to seek help from others. However, the person diagnosed with 'BPD' who seeks help or is deemed to need emergency intervention, may not be seen as a person at all. The diagnosis of 'BPD' is a powerful label which not only influences personal meaning, but also influences how a person is viewed by others, and this is consistent with the concept of 'othering' where people may be considered 'different'. Being seen as the 'other' has been argued to be important in mental health contexts where it may result in stigma and discrimination (Bhugra et al 2023). Ross and Goldner's (2009) review of stigma and discrimination in relation to mental illness found the 'BPD' label (and PdxBPD as a result) to be viewed negatively, with 'BPD' a pejorative term for patients' mental health nurses didn't like, and PdxBPD seen as 'bad' rather than 'ill'. More recently, Ring and Lawn (2019) also noted stigma around 'BPD' due to a perceived un-treatability of the condition, it not being seen as a real mental illness, staff feelings of powerlessness, and low health literacy around 'BPD' including preconceptions that PdxBPD would be manipulative.

In tandem with above research, this study found PdxBPD feeling they were treated differently and often more negatively than people with other diagnoses. Professionals too confirmed that there was a culture of stigma around 'BPD'. One of the most powerful testimonies of the impact of the label came from Carole (P14 PdxBPD C6) who felt her experiences of poor care were rooted in the label, saying *"I think that diagnosis has ruined my life"*. The label creates a powerful stereotype in terms of what others see and expect, and then can influence the way people are treated. A qualitative study which explored

mental health nurses perspectives, powerfully articulates the experience of staff faced with PdxBPD. The MH nurse states *“they arrive at the service... they have a diagnosis of BPD... it is like they have a red light flashing.. on them... and I suppose.. whatever that brings up for the health professional in question and I suppose, it always brings up your association with previous clients that you have had with BPD”* (McGrath and Dowling 2012).

Thus the following journey into trying to access care needs to be seen through the lens of a person wearing a stigmatized label, which Harding (2020) describes as leading to *“closed minds rather than open arms”*. Over twenty years ago, the National Institute for Mental Health for England (2003) published the landmark document ‘personality disorder: no longer a diagnosis of exclusion’. The document described the difficulty of people diagnosed with ‘personality disorder’ to access the care they needed. Snowden and Kane (2003) noted at the time while there was interest in improving care, there was also scepticism that little would change. Writing 21 years later, this study may provide evidence that their scepticism was warranted.

5.8. A confused and anxious system

Seeking help, yet wearing a label with a powerful stereotype, PdxBPD can enter a confused and anxious system as they try to access care, and I would argue that this system is more confused and anxious precisely because of the label. ‘System’ can seem like an abstract term which protects all individuals from any responsibility and accountability, leaving the status quo impervious to change. However, ‘system’ is defined as a group of items which interact and are interdependent in the performing of vital functions (Merriam-Webster 2024d), and the ‘items’ are each professional across every single service who are involved in the crisis care of PdxBPD. I would argue that every professional needs to identify as part of the confused and anxious system, as if they do not, it shifts responsibility and the possibility of change to the greater power of the ‘system’, an abstract idea which may be akin to seeking change by praying to a god or gods, and feel as controllable as the weather. The system is simply lots of individual people working together, following processes and procedures developed by people, and though certainly not easy, change is possible.

5.8.1. A variety of services and agencies

The confused and anxious system included the variety of services which PdxBPD may engage with during crisis. They ranged from the accessible self-directed apps and telephone helplines to primary care such as General Practitioner and the emergency department, and emergency services such as police, ambulance and coastguard. During crisis people could be referred or transition to different services, including mental health

inpatient and outpatient services, and though evident across the literature, home treatment and specific crisis resolution teams were not services available in the geographical area. Psychiatrists could be part of assessment and overall care, and whilst psychology wasn't specifically a crisis service, people could experience crisis whilst working with a psychologist and then be referred elsewhere. Mental health nurses were part of care across the system, though didn't always feel they had authority to make decisions.

5.8.2. Hard to access care and being passed around the system

Consistent with literature review and more recent research (Barr et al 2020, Klein, Fairweather and Lawn 2022a), PdxBPD could find it a challenge to access care. Where they did make contact with one service, their transitions to other services could be haphazard and feel unhelpful. Whilst apps and helplines were helpful and accessible, they could quickly escalate situations through contacting emergency services if there were any concerns regarding suicidal ideation. Even within mental health services, there were often not consistent relationships with professionals where there was risk of suicide. Mark (P6 CMHN C3) noted how psychology could refer PdxBPD elsewhere when they entered crisis, feeling there was a culture of *"they're too unstable, so let's give them to the nurses"*. Billie (P16 CMHN C6) felt there was a constant moving of PdxBPD between services due to services and clinicians feeling anxious and wanting to outsource risk, feeling decisions were taken to *"just pass it, pass it, pass it"*.

5.8.3. Police and the 'bystanders' of Mental Health Services

The most ineffective inter-agency working appeared to be between the police and mental health services. I utilized the term 'dysfunctional relay' to analogise the specific scenario where the police would attempt to transfer the baton of responsibility for a person's care to mental health services, and yet see the baton refused. The logic of the relay, certainly from the police and PdxBPD perspectives, appeared to be entirely dysfunctional. The police have been described as often the first, and sometimes only response available, given their legal obligation to respond 24 hours a day 7 days a week (Thomas et al 2022). Participants in this study described how the police would respond where mental health services would not, as Carole (P14 PdxBPD C6) stated, *"the police will see the crisis... the nurses and doctors won't"*. This phenomenon sees some patients described as the 'missing middle', where a conflict exists between the police trying to keep people out of the criminal justice system, but healthcare trying to keep people out of hospital to avoid medicalization and iatrogenic harm coming from hospitalization (Thomas et al 2022).

Nonetheless, despite this conflict existing, it may be the police who feel more burdened as a service, and recent reports have seen concerns for the NHS as the police plan to reduce their presence at mental health call outs (Devereux 2023). Edward (P12 SP Parent C5) felt during his daughter's crisis care "*the police and the emergency services... did a phenomenal job*". However, he felt that the mental health hospital was ineffective, saying "*you might as well put a match to it, for all the use it's been...*". Whilst CMHN's acknowledged hospital having a "*siege mentality*" and the role of services being "*gatekeeping*", this has been identified as a widespread and systemic issue, with NHS mental health services focused on how to deny people access to care rather than helping them to access it (Beale 2021). Moreover, mental health services may find it easier to deny people care where the police are already in contact with people. Darley and Latané's (1968) seminal research work described bystander apathy, whereby one bystander would help a person in distress, however where there were larger groups, responsibility was 'diffused' and people were less likely to help. I propose that at times a similar 'bystander effect' may occur where mental health services act as bystander to the police, not based on the number of individual officers in attendance, but due to PdxBPD being seen as the entire police service responsibility. Fischer et al's (2011) meta-analysis found that the more dangerous the situation, the higher arousal in those present and therefore more likelihood of helping behaviour. It may be possible that as police are first on the scene, they see and experience the danger as acute, whereas by virtue of PdxBPD being accompanied by police, mental health services have less concern.

5.8.4. The criminalization of suicidality and mental distress

The issue of criminalization was complex. Given PdxBPD could be refused admission to hospital and left with the police, they could be taken into the criminal justice system simply because there are continued concerns for safety, yet there is nowhere else to go. However, one instance in this study saw a person be criminally charged for recurrent suicidal behaviour. A high-profile example of this complexity was highlighted by a coalition of mental health service users and allies called 'Stop SIM', who campaigned against the 'high intensity network's 'serenity integrated mentoring' (SIM) which was rolled out across many areas in England (Stop SIM Coalition 2021). The serenity integrated mentoring intervention was specifically aimed at people who would present with frequent crisis which led to attempted suicide and self-harm (and thus many of these people may have also attracted a diagnosis of 'BPD'), who were described as 'high intensity users'. The intervention aimed to reduce the demand on emergency services by allocating a police officer mentor to people,

who if having recurrent instances of requiring emergency call outs, according to the SIM operational manual could be charged with criminal sanctions (Thomson et al 2022).

The SIM intervention was described as behavioural in nature, using the police as an intervention whilst there was a co-ordinated withholding of care from other agencies (Stop SIM Coalition 2021). The justification for criminalising mental distress may be rooted in behaviour modification theories such as operant conditioning, with assumptions that suicidal behaviour may be reinforced by emergency service response, but may be conversely extinguished by withholding compassion or applying criminal sanctions (Thomson et al 2022). Stop SIM challenged the evidence base, legality, human rights and ethics of this initiative, was supported by the Royal College of Nursing (2021) and the Royal College of Psychiatrists (2021), and was ultimately successful in stopping the initiative. Thomson et al (2022, p.653) claimed that this approach is *“not supported by research... not recommended in 21st Century good practice guidance, and contrary to international recommendations on decriminalising suicide”*.

Wu et al (2022) conducted a review of 171 countries and found a slight increase in the associated suicide rates in countries where it was treated as a criminal offence. Whilst the approach of police in this study was not explored from their perspective, and the laws in the UK are not explicitly to criminalise suicide, it is interesting to note that legislation is not a deterrent for emotional distress which may lead to suicide. Consistent with Grace’s (P7 PdxBPD C4) experience of being given criminal charges following suicidal behaviour, and then describing feeling more suicidal, the Lancet (2023, p1241) has described criminalizing suicide as *“punishing the tortured”* and an approach which will *“do little to alleviate pain or suffering”*.

5.8.5. Interagency confusion, ‘pinball syndrome’, and no clear model of intervention

There are clearly huge issues in terms of inter-agency working, as well as a lack of clarity around a model for intervention. Clibbens et al’s (2023) evidence synthesis on crisis care found that though inter agency working can complicate a person’s access to help, that crisis care works most effectively through inter agency working where there is information sharing and effective working across different services. The result of the dysfunctional relay, using a term which may more comprehensively capture the inadequate pathways between all services, may be that of ‘pinball syndrome’. Braillon (2018) argues for using the term ‘pinball syndrome’ to describe uncoordinated care pathways, suggesting the term may highlight that system functioning can hit rock bottom, and may change the mindsets

which allow it. Perhaps if professionals were aware just how much a person can ‘bounce around’ the system, and how harmful it can be, more effort may be put into organizing an effective pathway of response. Furthermore, the array of services perhaps remains a confused and anxious system due to the lack of a clear model of care, and no clear plan for what is done, and who does it. Recent reviews have continued to find sparse and low-quality evidence to support any particular intervention (Monk-Cunliffe et al 2022, Maconick et al 2023).

5.9. Family and friends

I’m acutely aware of the brevity of this section on family and friends, though this reflected them often feeling on the periphery of the systems providing crisis intervention, yet sometimes acting as a replacement for them. The support of family and friends was important to PdxBPD, both as a first port of call, but moreover as a de-facto intervention where the confused and anxious system failed. Consistent with literature review there was a stark example of the ‘all or nothing’ responsibility of families, where a father slept with house keys under his pillow, turning his home into a locked unit to safeguard his daughter from attempting suicide after she was refused hospital admission from mental health services. Support persons in the study did not feel well connected to mental health services, and certainly not during crisis care. DeLeo et al’s (2022) review also found carers describing feeling rejected, with their support needs not being adequately considered, decisions poorly communicated to them and professionals reluctant to involve them in their loved one’s treatment.

5.10. Complex factors influencing care

The complex factors influencing care further evidence the ‘wickedness’ of the problem of crisis care, with the problem of PdxBPD in crisis meeting the ‘solution’ of intervention, and yet the solutions are riddled with their own problems which influence care and can at times lead to a self-defeating exacerbation of crisis. The first stark example of ‘wickedness’, is that there may not be adequate solutions available, and there may be a postcode lottery in terms of resources. No-one in the study felt there were adequate resources to effectively meet the needs of PdxBPD in crisis, and the study took place in an area without a dedicated ‘personality disorder’ service. A national survey in England found a substantial increase in service provision for people diagnosed with ‘personality disorder’, though acknowledged a continued variability on the availability of these services and a lack of clarity around whether quality of care was improving (Dale et al 2017).

5.10.1. Varied and sometimes inadequate professional educations

The amount and content of education professionals receive is of importance in terms of how care is delivered to PdxBPD. Twenty years ago, Bateman and Tyrer (2004) argued professional educations did not prepare people to work effectively with people diagnosed with ‘personality disorder’, and the literature review identified varied education as a factor which may impact care delivery and contribute to conflict in teams (Warrender et al 2021). In a qualitative study, Sharda, Baker and Cahill (2023) found that general hospital clinicians would accept poor care delivery as they did not consider themselves mental health trained, though poor education is also a concern for mental health specific disciplines.

In my own MSc study, mental health staff nurses described needing to *“hit the ground running”*, yet feeling the topic of ‘personality disorder’ was neglected by their educational institution. One MH nurse stated *“I don’t think we did anything about personality disorder”*, while another suggested the input on BPD was *“very little”* (Warrender 2014, p.29).

Worryingly, these perspectives were captured 10 years ago, with recent arguments that education has been further diluted since that point. Moreover, in a more contemporary example, a study of Irish mental health nurses (where there is a different regulator and thus different standards for education to the UK) also saw concern around an insufficient education to prepare people to work with PdxBPD. McCarrick, Irving & Lakeman (2022, p.87) interviewed a MH nurse who said *“we are not sufficiently trained... they (MH nurses) feel unsupported and they get burnt out because they are not trained properly to deal with situations and they blame themselves”*.

In contemporary mental health nursing, concerns have been raised publicly about the quality of pre-registration education (Mental Health Deserves Better 2023), and specifically in terms of how education prepares people to work with complex emotional needs such as PdxBPD (Haslam, Warrender and Lamph 2023). My own experience saw a specific teaching session on ‘personality disorder’, which was studied and published (Warrender and Macpherson 2018), disappear from our curriculum following introduction of the NMC’s updated education standards. Stacey et al (2018) found specific training could improve student attitudes around ‘personality disorder’, though acknowledged limitation in having no follow up to see if these attitudes were maintained beyond pre-registration education. I share this concern, having re-connected with a former MH nursing student, 2 years after she qualified, for a conversation around ‘BPD’. Afterwards she commented, *“thank you for reminding me to have empathy”*.

Education may have a positive impact on care delivery, though most studies on this explore the education undertaken post-registration. Consistent with my own previous study (Warrender 2015), professionals identified mentalization based treatment skills trainings as helpful to their practice, and a recent review by Klein, Fairweather and Lawn (2022b) has suggested that educational interventions which inform professionals about ‘BPD’ may improve both attitudes as well as clinical practice. Ring and Lawn’s (2019) review found that stigma could be influenced by professionals not being adequately educated on ‘BPD’, and suggested the need for an education strategy which equips all mental health practitioners with empathy, tools, skills and attitudes to work with PdxBPD effectively.

5.10.2. Whose responsibility is a crisis?

Variations in education may influence differences in the views which people have about personal responsibility, contribute to conflict in teams, and also impact on the ability of professionals to establish trust. Taking responsibility for personal behaviour is described as central to treatment, though the complexity lays in encouraging agency and accountability for actions, without causing detrimental impacts through blame (Pickard 2011). Pickard (2011) also argues that attention to the past histories of people diagnosed with ‘personality disorder’ can encourage understanding, and create the conditions through which people can be asked to take responsibility for their actions without being blamed for them. Conflict within teams may be due to competing understandings of ‘BPD’, but also high stress situations. Haslam, Ellis, and Plumridge (2022) argue that whilst conflict in teams can be blamed on people diagnosed with ‘personality disorder’, conflict may in fact be due to systemic organizational issues and the psychological defence mechanisms of staff teams. Helping teams to think had been identified as a key role of specialty doctor and psychologist in this study.

5.10.3. Difficulties establishing trust

Difficulties establishing trust between professionals and PdxBPD is a relational challenge, and I would argue the relationship is the glue which can either hold all care together, or where it is lacking, see it fall apart. Professionals noted working hard to build trust and describing it as a tightrope. Building trust is important in any relationship, however, can be paramount given many trauma survivors have experienced secrecy and betrayal in their lives (Sweeney et al 2018). Fonagy et al (2017) propose that epistemic mistrust may be entrenched for PdxBPD, which may lead them to be described as ‘hard to reach’. Where the beginning of every relationship commences with an implicit mistrust, care provision will be more complex.

5.10.4. The dominance of psychiatry

There were complications around role blurring and what PdxBPD often felt was the excessive authority of psychiatry, who were described as often being the most distant in their care, yet having the most power with nursing often acting as *'middleman'*. A person who has experienced mental health care has written *"I think the psychiatrist is the invisible third person in every relationship between a nurse and patient"* (Stenhouse and Muirhead 2017, p.33). This has also been felt by MH nurses, who have described psychiatrists being in control of decision-making processes, and where there is nurse-led care, this has been at the psychiatrists discretion (Felton and Stacey 2018). If MH nurses have relational closeness, yet cannot make decisions, this may negatively impact their relationships with patients, and Kate had described at times mistrusting her CMHN as a go-between her and psychiatrist for changes relating to medication. McCarrick, Irving & Lakeman (2022) found that MH nurses perceived the problems they faced were not acknowledged by other disciplines.

5.10.5. The complications of psychiatric drugs

Care was also complicated by the multiple effects of psychiatric drugs. All PdxBPD were prescribed psychiatric medication, though there were multiple effects of these which were not always positive. Whilst some people found medication helpful, others felt they experienced side effects but little relief from symptoms. Kate (P1 PdxBPD C1) felt due to weight gain her mood was negatively impacted, thus something which is intended as a solution is linked to further problems. Polypharmacy is common for PdxBPD, and this has been described as concerning given the lack of evidence base for efficacy (Tennant et al 2023).

This study saw not only PdxBPD describe some benefit yet some harms and side effects from medication, but CMHN's felt that when overmedicated, PdxBPD could not fully engage with them in the therapeutic process. Ironically, some psychiatrists have acknowledged prescribing medication as a means of building their relationship with patients (Gunderson and Choi-Kain 2018). This may be a teleological gesture, where a modification in the physical world is utilized as a communication of care (Bateman and Fonagy 2016). Thus, the drug may not be as important as the act of giving the drug. Strikingly, this may see drugs used to strengthen the relationship between psychiatrist and PdxBPD, whilst simultaneously making it harder for mental health nurses to have meaningful conversations with them. Yet again, solutions create more problems. As each

individual is unique, there may be no single answer, and Sharda, Baker and Cahill (2022) found people in general hospital both under and overmedicated.

5.10.6. Anxiety around the risk of harm, and risk of litigation

Given the high risk of self-harm and suicide, there was a sense of anxiety from families as well as mental health professionals. Whilst family and friends worried about the safety of PdxBPD, professionals had a dual worry, both for the person's safety, and for their reputation were a person to die by suicide whilst under their care. Bateman and Krawitz (2013) suggest that a clinician can feel accountable for keeping PdxBPD alive, and while NICE (2009) advocate for risk to be shared with the entire multidisciplinary team, Steven (P9 Specialty Doctor C4) noted that as he had climbed in seniority, he had felt more isolated in terms of risk and decision making. Felton and Stacey (2018) describe how Stein's (1967) doctor-nurse game plays out, with nurses reinforcing the hierarchical position of doctors by not taking responsibility for risk management, whilst nurses feel as if they lack autonomy and simply act as enforcers of the more powerful doctors decisions. One of the biggest anxieties around risk, however, may be that which comes from the organization. Mental health nurses felt they were "*sitting ducks*" in a blame culture, and that they were at risk of being blamed as a scapegoat for the organization were any PdxBPD to die by suicide. Thus, whilst anxiety around potential death through suicide is understandable, this anxiety is so strong it can also influence clinical decision making, and I have argued before it can lead to low thresholds for risk and excessive restriction (Warrender 2018b, Warrender and Young, in press). Krawitz and Batcheler (2006) found 85% of clinicians had made decisions around the care of PdxBPD based on fear of litigation, and this study years later saw professionals acknowledge the same thing. The anxiety around risk which can lead to excessive restriction seems to contrast with some experiences of people struggling to access care, and being rejected from admission to the mental health hospital.

5.10.7. Spaghettification of distress

In a similar contradiction, spaghettification was a term borrowed from the science of black holes, and used to discuss the scenario where a person is stretched between two poles of immense gravity. In this study, PdxBPD described being stretched between the two poles of being 'not mentally ill', but also 'too ill for therapy', with their care being compromised as a result. Ring and Lawn (2019) identified that 'BPD' not being seen as a 'real' mental illness was an idea which perpetuates stigma, yet this idea also exists within legislation, with the Mental Health (Care and Treatment) (Scotland) Act 2003 identifying mental disorder as

mental illness, learning disability or personality disorder. Motala and Price (2022, p.5) qualitative study of PdxBPD experiences stated *“typical participant experience of mental health services was of being commanded to be ill, then accused of being well”*. This related to participant experiences of feeling their distress was not valid, with Alison (P4 PdxBPD C2) being told *“there’s ill people here”*, consistent with accusations of being well. Motala and Price’s (2022, p.4) ‘commanded to be ill’ related to an experience of distress being pathologised through the ‘personality disorder’ lens and overshadowing understandable responses to trauma, with people asked to *“accept a conceptualisation of their mental health problems that they did not always agree with”*. Similar to Carole (P14 PdxBPD C6), who said her trauma was overlooked with ‘BPD’ presented as *“all it is”*, Berrighan (2021, p.8) recounts *“my trauma and experiences are why my behaviour makes sense, yet they have been the first things to be denied and minimised by professionals”*. Furthermore, given Alison’s experience of being deemed too unstable for therapy, we might add to these themes by stating people are accused of being well, and commanded to be ill, but then further penalized for being too ill and denied psychotherapy. If people in need can be denied access to therapies, it certainly questions the validity of the evidence base for such therapies. As Benefield and Haigh (2020 p.41) state, *“if a service cannot engage those most in need of help, often in chaotic personal circumstances, any number of randomized control trials showing positive results are not relevant”*.

5.10.8. “Hellish” inpatient environments with traumatized staff

Some people admitted to acute mental health inpatient wards have been found to experience environments with serious shortcomings, which can be described as traumatizing and abusive (Waters and Repper 2023), and one poll showed 35% of British adults said they didn’t have confidence that a loved one would be safe if they needed hospital mental health care (Mind 2023). Whilst staff nurses have acknowledged that inpatient environments are not conducive to therapeutic care for PdxBPD (Warrender 2015), people spending time as inpatients have rightly questioned why this is, and why the response is to avoid admission rather than improve circumstances. Olive (2023), writing about time in a ward states, *“I have to wonder why the response to this harm is to say, ‘we shouldn’t admit these people’ instead of ‘how can we make wards less hellish for them?’”*. The study found PdxBPD describing a chaotic inpatient ward environment, yet a limitation was having no inpatient mental health nurses recruited to the study. However, Billie (P16 CMHN C6) offered her previous experience in ward settings, and spoke powerfully and honestly about an environment where she felt powerless and was left traumatized, with

this impacting on her ability to care for patients. While Billie described crying in the toilet and returning to work, a MH nurse in Ireland also described vicarious trauma, and how her and colleagues would experience serious incidents and *“go home crying more than once”* (McCarrick, Irving & Lakeman 2022, p.85). This confirmed my existing belief as shared in a lecture in 2022, that acute mental health environments may include *“traumatized people treating traumatized people”* (Warrender 2022c).

5.10.9. Emotionally illiterate staff

However, some staff may not necessarily be traumatized. As Steven (P9 Specialty Doctor C4) said *“there are certainly nurses out there who are... rough and tumble folk... so it's all a big laugh in the rammy, and it's all a bit nuts in (the hospital)... that's part of that identity”*. Whilst my immediate and unfiltered emotional reaction is to consider these people ignorant and perhaps stupid, an academic term fitting with this scenario is that of emotional illiteracy, where staff may not understand, be able to regulate, or communicate emotions relating to social contexts (Alemdar and Anılan 2020). There is certainly an emotional illiteracy involved in pinning another human to the ground, and thinking it's a laugh. However, emotional illiteracy may not even go far enough, as Gadsby (2018, p.16) believes there are mental health nurses *“who seek out violent roles and situations... that they find energizing and enjoyable in some way”*. A recent investigation uncovered a scandal of sexual assault of mental health patients within the NHS, some of which are perpetrated by staff (Thomas and Mulhern 2024).

5.10.10. The need for thinking spaces such as clinical supervision

Particularly given the stress of the job, this study found that professionals working with PdxBPD needed help to think, and one of the formal spaces and mechanisms for thinking and reflection is clinical supervision. This has been specifically recommended for staff working with PdxBPD (Bland and Rossen 2005, NICE 2009). All professionals in the study said they utilized and appreciated the role of clinical supervision, with Steven (P9 Specialty Doctor P4) and Robert P13 Psychologist C5) both seeing their roles as helping others, particularly nurses, think. Whilst all professionals in the study worked as nurses in the community, doctor or psychologist, these roles can offer more autonomy than a nurse working in a ward, and ward based mental health nurses have described challenges accessing clinical supervision (Warrender 2015). However, beyond struggling to access clinical supervision, there may be pressure to maintain the impression of resilience which sees professionals avoid these thinking spaces. Resilience is seen as a desirable trait for nurses, though has been critiqued as an unhelpful term which can unduly burden mental

health nurses with developing resilience, without taking into account the incredibly difficult contexts which they are in (Fisher and Jones 2023). Consistent with this was Billie (P16 CMHN C6) who said of her distress when working in an inpatient unit *“I don't think I could have felt any differently in that environment”*, though felt professionals *“can't admit”* how much distress they are in. Protecting this image of resilience and not admitting distress can see nurses not wanting to engage in clinical supervision for fear of how this may look to others. A mental health nurse described that she could, but didn't use clinical supervision, saying *“I know it's there... we should have clinical supervision... so if I really wanted it, I could go for it... because a lot of staff don't want to come forward and participate because they might think it will look like I'm not coping”* (McCarrick, Irving & Lakeman 2022, p.87).

5.11. Luck

Given the nature of the wicked problem, with multiple complexities interacting to influence the response PdxBPD receive, it might be argued that the only single factor a person might see is that of luck. Random luck is defined by Teigen (2014) as being associated with randomness and chance, and is viewed as an external factor which limits a person's possibility of self-determining an outcome. The randomness and chance are whether a PdxBPD meets the right person at the right time, as part of the right service with the right service model, with staff who have the right education and way of thinking, and then they do the right things. Whilst 'right' might have a degree of consistency were we to list the following ingredients of 'what helps' for best practice, due to the variables of human beings and their preferences, 'right' also has a degree of subjectivity. Thus, though luck might seem too insufficient a concept in a study which although imbued with subjectivity should still attempt to get close to tangible science where possible, luck is fitting given PdxBPD's position of powerlessness as they enter and try to navigate these complex systems of care. Carole (P14 PdxBPD C6) described her experiences of care as *“hit or miss”*, and receiving good care as *“potluck”*.

Luck is a feature of other research and discussion in the topic area. Lundahl, Helgesson and Juth (2018) interviewed psychiatrists and found decisions around care of PdxBPD were often made based on their own judgements and values rather than clinical or legal guidelines. Thus, they conclude that there can be vast differences in the mental healthcare offered depending on the individual psychiatrist charged with their care, and we can see an instance where the fixed rules which may offer some consistency may be less important than the hugely variable and subjective judgements. Taylor, Stockton & Bowen's (2023, p.562) interviews of mental health nurses also saw them acknowledge that every

practitioner works differently, some working “*better than others*” with PdxBPD, thus patients may experience “*consistently inconsistent care provision*”. Inconsistency in care and luck was also mentioned by PdxBPD as some said they needed to fight for support, whereas one person said “*if you hit it lucky, and you got [a care coordinator] who was great, you got a great response*” (Ware, Preston & Draycott 2022, p.338). Pritchard and Smith (2004) argue that outcomes are labelled lucky when they occur in the real world, but not in nearby possible worlds where things could have been different, and they are significant to the person. Given many experiences of poor care, and some experiences of good care, there is an understandable contrast between the actual and possible which can lead to things being understood as luck. The treatment people receive is undeniably significant to them, and when it is helpful, it may feel like winning the human lottery.

5.12. What helps vs what harms

The response of both professionals and support persons to PdxBPD in crisis can be either helpful or harmful and this can be understood, as Rittel and Webber (1973) describe, as good or bad, not true or false. Whilst Rittel and Webber (1973) state that there are no criteria to determine whether or not an outcome is correct and that outcomes are contingent based on subjective interests, I would argue in this case that the best ‘measure’ (if there is such a measure) of a person’s experience is their subjective account of that experience. Thus, there are no objective criteria for determining whether an intervention has been helpful, in sync with Rittel and Weber’s (1973) ‘no stopping rule’, which sees no clear end to the problem. Therefore, if people feel they have been helped or harmed we should believe them, then seek to understand why. What helps and what harms are discussed together given their contradictory nature, in that sometimes ‘help’ is a positive and helpful experience, as well as the absence of bad, while ‘harm’ is seen as negative experience, as well as the absence of good. Whilst much of these findings were consistent with existing literature, what this study has added is a degree of specificity and depth of understanding.

5.12.1. Timely intervention vs stigma and exclusion

Timely support and intervention was deemed important by all participants and is supported by wider literature related to crisis care (Clibbens et al 2023), yet this was often not achieved. Cultures of stigma, discrimination and exclusion may be one of the most significant harms related to this, given they can influence all interactions and decision making which impacts PdxBPD. Cultures of exclusion were also felt to impact support persons, and whilst PdxBPD were ambivalent about including family in their care, this

should be considered as an option where it is the patient's preference. Professionals in the study acknowledged there was a culture of stigma around the diagnosis, and PdxBPD had felt this during their care. The label itself and subsequent stigma may influence this, with service users feeling it could be a diagnosis of rejection and exclusion, with services withdrawn or their distress dismissed (Lester et al 2020). Given the diagnostic criteria features 'frantic efforts to avoid real or imagined abandonment' (WHO 2024), being told there is 'no room at the inn' might be a further trigger, constituting perceived interpersonal discord. This is why I have argued that not only is it important that decisions are well considered, but also that decisions are well communicated. Moreover, where people not only fail to access care, but are criminalized through the police and custody system, this goes beyond rejection and invalidation. The antithesis of trauma informed care is to have a trauma survivor in distress who has tried to kill themselves, strip-searched and locked up.

5.12.2. Choice and collaboration vs restriction

Consistent between the literature review and the findings of this study, care was complicated where there was a risk of suicide and differing views on personal responsibility. This study found PdxBPD wanted choice, joint decision making and least restrictive approaches to their care, but found criminalization, excessive restriction and coercion including physical restraint harmful. There is complexity and wickedness about where PdxBPD want to feel safe, yet sometimes in the name of safety there are overly restrictive practices which harm them, often taking place in the inpatient setting. I have noted before that whether risk is contained or tolerated, there may be beneficent intent yet maleficent outcomes (Warrender 2018b). This dilemma fuels anxiety around risk, as people given autonomy can kill themselves, whereas removing their ability to kill themselves can harm them through removing freedoms.

Opportunities to maintain autonomy when in crisis were valued by PdxBPD, but they have often experienced the opposite (DeLeo et al 2022). In this study Alison (P4 PdxBPD C2) felt she understood the need for restriction, but felt the approach was 'most restrictive' rather than 'least restrictive', not well communicated, and was standard care rather than a last resort with no therapeutic intervention offered. Nina (P3 PdxBPD C1) had been concerned about the quality of care Kate would receive as an inpatient, and Mooney and Kanyeredzi (2021, p.7) study of MH nurses found an acknowledgment that whilst some restrictive practice was justified, there were instances of "*unjustified use, disproportionate to risk*". Sweeney et al (2018) cites safety, empowerment choice and control, and collaboration as essential to the care of people who have experienced trauma, and the cruciality of

preventing further trauma in the MH system. Trauma could occur through physical restraint, having belongings removed, and not being allowed to leave the ward. The World Health Organisation (2023, p.14) question the legality, ethics and clinical value of any coercive practice, describing legal frameworks as “*a vehicle for the violation of rights*”. Furthermore, where PdxBPD were confined to locked wards, this could counterproductively remove usual coping mechanisms. Where Alison (P4 PdxBPD C2) felt frustrated as an inpatient not being able to exercise, evidence suggests that sedentary lifestyles and withdrawal of exercise can increase depressive symptoms and anxiety (Weinstein, Hoehmstedt and Kop 2017). Thus, a focus on safety and removal of human rights may exacerbate symptoms.

5.12.3. The place for but overreliance on psychiatric drugs

Whilst guidelines suggest medication can have a place in crisis care (NICE 2009), this study as well as wider literature suggest it is not always helpful, is not well supported by evidence for the treatment of PdxBPD, with mental health services described as having an over-reliance on medication as the intervention. During this study, PdxBPD participating all took medication, yet there was a feeling of an over-reliance on this, and an unhelpful philosophy of “*another problem another pill*”. The evidence base points to long term therapy as helpful, and medication with unclear efficacy, yet medication seems to be the default treatment option for some people. It has been argued that the biomedical approach which seeks to rectify symptoms through medication and short-term interventions rather than longer term therapy is not well suited to treatment of PdxBPD (Sulzer, Jackson and Yang 2016, Millar, Gillanders and Saleem 2012).

An apparent overreliance on medication has been consistent with other literature, with Ware, Preston and Draycott (2022, p.339) capturing PdxBPD who stated “*I was telling [psychiatrist] I was struggling, and her immediate response was, ‘you need these drugs’*”. There was an understanding that the problem of overmedication may relate to the lack of resources, as the same person continued; “*things are just so stretched, and there are few answers that don’t revolve around a prescription pad*”. Whilst resources are undoubtedly a pragmatic factor, there was clear feeling around what may be best for PdxBPD. As Kate (P1 PdxBPD C1) powerfully articulated, “*I can’t emphasise enough how much people with BPD need someone ... an ongoing relationship with someone of a professional background in personality disorders... that should be prescribed as fast as the pills are prescribed to you*”.

5.12.4. The need for consistent relationships yet barriers of risk anxiety

Quality relationships are paramount in helping PdxBPD, given the trigger of perceived interpersonal discord, and a vulnerability which could be born through difficult relational experiences in the past. Desirable qualities and circumstances relating to relationships with professionals included consistency, therapeutic skills such as empathy, understanding, trust, advocacy and candour, while the absence or opposite of these was unhelpful. In terms of valuing consistent relationships, it was interesting to note that of the six PdxBPD recruited, the professionals they consented to be included in the study were not the people who provided crisis care, they were instead the professionals involved in part of a longer-term treatment plan. This is both a finding and limitation of the study, as PdxBPD had trust in people who they worked with regularly, yet either did not have an ongoing relationship with those who had treated them in crisis, or did not want them included.

While inconsistent relationships may be harmful, they may also be rooted in anxiety around risk of suicide and self-harm. Returning to the metaphor of ‘fireball of emotion’, this may be experienced as too hot to hold, and thus passed on, akin to the term ‘hot potato’ which describes a controversial issue with unpleasant consequences for the person dealing with it (Merriam-Webster 2024e). Whilst professionals in the study noted the eagerness of some to refer PdxBPD elsewhere, with a culture of “*pass it, pass it, pass it*” (Billie, P16 CMHN C6) consistent with other literature. Taylor, Stockton and Bowen (2022) found MH nurses describing an eagerness to refer on and the impetus to move people through services quickly, in part due to professionals not wanting to have “*ownership*” of events associated with risk. This was acknowledged as not necessarily being in the patient’s best interests, and professionals in this study noted the importance of them trying to maintain their relationship with PdxBPD. A recent evidence synthesis found that continuity of care is an important feature of good crisis care (Clibbens et al 2023), and continuity might be important to consider in terms of specific agencies within the confused and anxious system, as well as a specific person or people.

5.12.5. Humanity, mutuality and caring

Working with PdxBPD requires a high level of interpersonal skills (Sharda, Baker and Cahill 2023), and clinician characteristics have been found to have a huge influence on the quality of crisis care (DeLeo et al 2022). This study found that professionals both ‘being a person’ and ‘seeing a person’ may be the underpinning outlook which precedes ‘what is done’ in the relationship. Consistent with my review, DeLeo et al (2022) found service users wanting

to be treated like a person and not a patient. Mark (P6 CMHN C3) felt it was important that he didn't feel he was different to PdxBPD, an ethos in tandem with Yalom's (2017, p.8) emphasis on seeing professional and patient not as us and them, but as "*fellow travellers*". Having this ethos may allow professionals to see beyond the powerful 'BPD' label and stereotype, and thus be able to treat PdxBPD as people rather than a diagnosis, and as a result also have interest in their underlying distress rather than being focused on their behaviour. Seeing a person rather than a label may also open professionals minds to other issues beyond 'BPD', such as other diagnoses and issues which PdxBPD in this study felt was important to their care. Furthermore, seeing beyond 'BPD' may facilitate a 'trauma lens', through which professionals can see the signs and effects of trauma, and understand how trauma influences emotions and behaviour (Sweeney et al 2018).

Professionals able and willing to 'be a person' were sought after, with Carole (P14 PdxBPD C6) valuing a particular MH nurse given the pseudonym 'Juliet', describing her 'Juliet-ness'. I would argue this 'name-ness' is the essence of a person, consistent with Rogers (1957) core condition of the therapeutic relationship of congruence and being your genuine self. People who have experienced mental health care have written that "*the most powerful 'interventions' occurred where the professional mask dropped and, even momentarily, there was authentic human-to-human connection*" (Collier-Sewell & Melino, 2023, p. 3). Consistent with this study, qualitative research has seen PdxBPD describe valuing the 'humanity' of their nurses, including availability and a sense of humour (Romeu-Labayen et al 2022). This is consistent with my own clinical experience, where the value of our true selves was highlighted through feedback I received from someone I had worked with, who said "*I feel like I've been talking to you, not the NHS*". This may be what it means to care, and to feel cared for, though it defies robust definition. David Graeber (2019, p. 262) in his theory of work describes the value of caring as "*precisely that element in labour that cannot be quantified*".

5.12.6. Therapeutic skills and traits

Key therapeutic activities of professionals appreciated by PdxBPD were empathy, understanding, resisting the righting reflex, establishing trust, advocacy, candour, and the ability to offer an apology where necessary. None of these are groundbreaking revelations, yet they add to a body of literature and guidance which suggests their importance (NICE 2009, Sweeney et al 2018, Romeu-Labayen et al 2022, Miller and Rollnick 2013, Rogers 1957). It is only through understanding the confused and anxious system and complex factors which influence care, that their absence can ever be understood. What this study

did add was that ‘understanding’ itself can be considered an intervention, and I would argue this cannot be done without empathy. Moreover, empathy and understanding follow from ‘resisting the righting reflex’, where the person helping resists the urge to ‘fix’ through offering advice or solutions (Miller and Rollnick 2013). Where there is time given to empathise and understand a person’s distress, this also allows the mapping of the journey through crisis. The study found PdxBPD and professionals feeling it was important to identify triggers and understand how a person had come to be in crisis. Mapping the journey involved helping a person identify their journey through crisis, from triggers, to the internal experience, to resulting behaviour, and may increase a person’s understanding of themselves as well as facilitate potential coping mechanisms. Mapping might also benefit from a model such as the concept map (see 4.7.1.1), offering a template and prompts whereby an individual’s unique needs and preferences may be understood by all stakeholders, improving abilities to pre-empt and navigate crisis, whilst exploring effective or ineffective intervention.

Where therapeutic skills and traits were valued, logically, the inverse was unhelpful, with rejection and invalidation felt to be hurtful, and unsolicited and patronizing advice unhelpful. However, patronizing advice, perhaps through the ‘righting reflex’, was experienced by PdxBPD in this study, and appears to be an anecdote I hear time and time again through professional networks and the testimony of PdxBPD across social media. These unhelpful responses were lampooned by Recovery in the Bin (2017b), who retort that the only time it may be appropriate to suggest a bath and a cup of tea (perceived as some of the most patronizing advice), is not when a person is in crisis, but only when the person is “stinky” or “thirsty”.

5.12.7. Advocacy and candour

Given PdxBPD enter a confused and anxious system which can harm them, advocacy was important. Genuine advocacy in mental health nursing, as argued by Connell et al (2022), relates to navigating conflicts of values, particularly the conflict between mental health service paternalism and that of service user autonomy. The acts of genuine advocacy in this study demonstrate “*advocation of the service user’s world*” (Connell et al 2022, p.477), and involved professionals supporting PdxBPD even if it meant a compassion-based dissent of breaking the rules of their own service, or helping people have their voices heard within complex systems of care. Candour and apology was also important, and where professionals could have improved their practice, that they acknowledged this and owned it.

Professionals owning their own errors or below-par care may be particularly important given the epistemic powerlessness of PdxBPD in the mental health care system, and the epistemic dominion of the professionals who work in it. ‘Epistemic’ relates to knowledge and knowing (Merriam-Webster 2024f), and put simply, whatever happens to PdxBPD in the confused and anxious system, the professionals will write the notes, and their perspective will become the legal record of events. Thus what is ‘known’ comes from a single perspective. Fricker (2007) argued that epistemic injustice is a form of social power which wrongs someone in their capacity as a knower, and can invalidate a person’s knowing of their own experience and can lead to their silencing. It has been argued that due to systemic prejudice, PdxBPD are subject to this (Kyratsous and Sanati 2017).

5.12.8. Perseverance

Perseverance was valued by PdxBPD, and this a quality which chimes with my own experience and understanding, reminding me of one of my favourite anecdotes which I have used in teaching mental health nurses. One of my psychotherapy supervisors said to me years ago *“people think we in psychotherapy are the absolute experts of personality disorder. We’re not. We just keep trying”*. In relation and of similar import, in order that professionals and support persons persevere, there must also be hope. Some PdxBPD have felt that professionals having a hope and confidence in their ability to recover could motivate them, especially where they do not have that hope themselves (Romeu-Labayan et al 2022).

5.12.9. Facilitating the simple things in a complex system

Whilst the inventory of what helps offers an idealistic frame through which care should be delivered, it is nonetheless very achievable, with little extravagance beyond what one could expect of any professional. However, the simple things are perhaps harder to accommodate given the complex factors influencing care delivery. When Lorenz (1972. p.1) proposed that a butterfly flapping its wings may cause a tornado, his logic was *“if the flap of a butterfly’s wings can be instrumental in generating a tornado, it can equally well be instrumental in preventing a tornado”*. Thus if small events may build towards or trigger crisis, similarly small events with a positive significance, whether personal strategies or interventions from others, may have a huge impact. Whilst there are simple things which may help, there are complex reasons as to why they may not happen. Nonetheless, the self-defeating nature of ‘care’ which harms is that when a person feels they have been treated poorly and harmed in some way, this further fuels and contributes to crisis. In a mental welfare commission for Scotland report (2018), PdxBPD reported stigma as the

most common trigger for crisis. Consistent again with the wicked problem, if the intended solution is not experienced as helpful, harm leads back to crisis, and the cycle recommences. The recurrence of crisis may at times be due to the harmful experiences resulting from healthcare.

5.13. Future service design

Having explored the potential journey for some of the people some of the time, there is a clear need for improvement. Beginning a plan, the simple needs stated, in that improvement can first consider all the harmful and ineffective systems and practices of care already discussed, and explore means and methods to *not* do that. Further, there were specific suggestions worthy of consideration, which have also contributed to the recommendations towards the end of this thesis.

Ultimately, the future direction of services needs to be directed by PdxBPD who will use them, and co-production is described as an important avenue for developing services for people with the diagnosis (Friesen et al 2022, Health Improvement Scotland 2023). Given the difficulties of PdxBPD accessing care, a future service needs to ensure it is accessible and responsive, and also safe and welcoming. This means rejecting any notions of ‘BPD’ being a diagnosis of exclusion, and ensuring that stigma and prejudice do not infect the helping environment. Steven (Speciality Doctor) mentioned the physical environment, suggesting green spaces which have been linked to improvements in levels of depression, anxiety and stress (Park et al 2010).

5.13.1. Stepped, flexible, person-centered care

Stepped and flexible, person centred care is essential given ‘crisis’ is not any one thing, and seems to be different for all PdxBPD, being incredibly dynamic and unpredictable. A one size fits all is impossible, and even were a model to be shaped around one person, the breadth of possibility of crisis could see that person themselves in a different shape to what they had been previously. Being flexible is important to be preventative and have somewhere for PdxBPD to go before crisis gets worse, and also needs to be able to step-up and cope with an intensity where crisis is sudden and life threatening. A recent report from Health Improvement Scotland (2023, p.45) argues for a stepped model of care which *“matches severity with appropriate treatment, interventions and support”*.

5.13.2. Involving and supporting families

The option of family involvement and support was important, and so too was offering support to families. Whilst PdxBPD can have different views on how much to include family in their care, and this should be an option rather than a standard, something likely to help

everyone is educating family and support persons around their difficulties and how they may help. Psychoeducational groups for close relatives of PdxBPD have been rated positively, with the highest ratings relating to developing communication skills and coping with crises (Pitschel-Walz, Spatzl and Rentrop 2022). Providing help to families and support persons could be invaluable given their ever-present role in a person's life.

5.13.3. Relationally skilled staff and peer support

Given the importance of therapeutic relationships, PdxBPD wanted staff who were relationally skilled, able to do 'what helps' from the conceptual framework. There was no preference for any particular model of care, though most professionals in the study favoured MBT skills. I own my bias in being trained in this and also finding it very useful for thinking about and working in relationships. However, PdxBPD also valued peers with the 'BPD' diagnosis, and had been helped by others informally in their lives or whilst in hospital. Barr, Townsend and Grenyer (2022) explored the impact of peer support, and found PdxBPD felt understood, less isolated and hopeful, with peer workers themselves seen as role models of a meaningful life. There was no model for peer support in the area of the study, however there is growing movement in this area with career pathways being considered (Ball and Skinner 2021).

5.13.4. Holistic and creative approaches

In terms of 'what is done' as a crisis intervention, PdxBPD and support persons wanted holistic, flexible and creative approaches, which considered the entirety of their lives and difficulties, and offered intervention based on the persons preferences. This study found PdxBPD and support persons describe a variety of useful interventions, including sitting with others in company watching TV, to talking and psychological therapies, and including artistic approaches such as writing or painting. Whilst not routine in many NHS services, art therapies have proved beneficial for people diagnosed with 'personality disorder' (Haeyen, Chakhssi and Van Hoore 2020), and this might be considered as an option for people when in crisis.

5.13.5. Mapping crisis, relapse prevention and connecting to other services

Whilst crisis for PdxBPD can be an intense suffering, intervention has been described as an opportunity to understand and work towards meaningful change (Fagin 2004). This may include a mapping of the journey to crisis, and a plan for relapse prevention which could include 'drilling' and practicing responses when not in crisis. Akin to the Latin proverb "*Si Vis Pacem, Para Bellum*", meaning "*if you want peace, prepare for war*", preparing for crisis may lessen the likelihood of it occurring, or minimize the impact and avoid spiralling

towards self-harm and suicide. Finally, it was felt that any service should have robust and clear connections with other services. As an antidote for a confused and anxious system, clear referral pathways and agreed ways of working between services and disciplines would be of benefit to avoid 'pinball syndrome'.

5.14. Summary

The 'story' of this discussion is a non-linear tale of vulnerable people overwhelmed by their mental states, yet when seeking help have variable experiences as they encounter multiple different professionals across various agencies. Findings from the study were consistent with wider literature, though offered more depth in places. A biopsychosocial understanding of 'BPD' was consistent with research, with emphasis placed on the impact of adversity, trauma and neglect. This study added insights that the experience of receiving a diagnosis itself, and the meaning given to that diagnosis, may also add to a vulnerability to crisis. Crisis was triggered by a variety of things always unique to the person, and the 'butterfly effect' was a useful concept for understanding how subtle these can be. Crisis was understood as a unique multidimensional experience consistent with literature, though alongside additional depth, the use of metaphor offered a visceral connection to the experience which was certainly new to me. Personal strategies used in crisis were highlighted, and included was the use of self-harm and attempted suicide. Emphasising the wicked nature of this problem, self-harm and attempting suicide could be a temporary solution which leads to waves of consequences including possible death, significant harm, and a cycle of complex negative emotions. Consistent with literature, these issues were the focus of intervention, and the underlying distress precursing these acts were often overlooked.

Seeking help cannot be understood without acknowledging the power of the 'BPD' label, which consistent with literature this study found to have a huge impact on the way people are treated. Entering the confused and anxious system, consistent with existing literature, people experienced a variety of services and agencies, none of which appear to have clear model for intervention. This can exacerbate distress as people struggle to access care, or are passed around agencies in an experience described as 'pinball syndrome'. The pinball could bounce back to family, as they offer the 'all or nothing' intervention which is always available.

The complex factors influencing care collect an enormity of variables proving the context around care, meaning that the concept of luck becomes a reasonable explanation for how some people can feel helped and some can feel harmed through intervention. The things

which help and harm are not surprising, and in writing this discussion I had wondered why the simple things which help, the positive flaps of the butterfly's wings, do not occur.

However, the immensity of variables, the complexity of human systems, and subjectivity of crisis experience can mean that these simple things are being performed against a tide of enormous complexity, making the simple harder to achieve. Suggestions for the future include not doing the things which harm people, yet also embracing coproduction, peer support, and more than anything else, emphasizing the importance of person-centered care by relationally skilled staff.

Whilst the discussion presents a concept map and this presents a useful guide for possible experiences and influences on that experience, the subjectivity of individual experience reminds me of the quote "a map is not the territory" (Korzybski 1931, p.750). In this regard, the model offers some provocation for further thought and potential outcomes, but owns its limitations in terms of neither being universal truth, nor a handy 'how to' guide for effective care. Being a wicked problem, this will never be easy, though there are opportunities for improvements which will be explored in the next chapter, conclusion and recommendations.

6. Chapter 6: Conclusion and recommendations

6.1. Chapter overview

This chapter attempts to summarise the personal, professional and academic journey through the 8 years since I started as a PhD student. I reflect on how the world, and my life has changed, and how this topic, and people diagnosed with ‘borderline personality disorder’ still matter to me. I reflect on the process of undertaking research and the methods used, revisit my aims and objectives and whether these were achieved, and offer some broad recommendations which if addressed, would likely improve crisis care for PdxBPD. I have noted ideas for further research, as I am not finished exploring this topic.

6.2. Appreciating the passage of time, and feeling this topic still matters

I have to appreciate the length of time this has taken me to complete, and the changes in my life and wider world which have accompanied me. Approximately 19% of my almost 42 years on the planet at time of writing, have been as an enrolled PhD student. Whilst I officially enrolled on the 6th of March 2017, I recall my first meeting with supervisory team on November 9th 2016, which sticks in my memory given Donald Trump surprised many by becoming the president elect for the United States of America the day before. How much has occurred in the world since then? After a lengthy negotiation process the United Kingdom left the European Union on 31st January 2020. The word ‘Brexit’ and its ramifications continue to populate political discourse in Britain and Europe. Covid-19 was declared a pandemic by the World Health Organisation on 12th March 2020, and I’m sure no-one needs a reminder of how this impacted every human being on the planet. May 25th 2020 saw the murder of black man George Floyd by a police officer, and widespread protests across the globe were linked to the Black Lives Matter movement. On the 24th February 2022 Russia launched a military invasion of Ukraine, and that conflict continues, with no end in sight at the time of writing. On the 7th of October 2023 terrorist group Hamas attacked civilians in Israel, and this led to an invasion of the Gaza Strip in Palestine by the Israeli military. Similar to Russia and Ukraine, and with the added complication of religious belief, there is no end in sight. Political instability in Britain has seen my PhD study span four Prime Ministers (May, Johnson, Truss, Sunak). My studies have also spanned two Monarchs, with the death of Queen Elizabeth on 8th September 2022, and subsequent coronation of King Charles. Whilst these events occur, there are concerns around climate change, a cost-of-living crisis, political populism, a fractured world order, and rising threat of global conflicts. Whilst wider world events may have little impact on my study, this is the

world in which we live, and looking at the planet and all its imperfections, I still feel the care of people diagnosed with ‘borderline personality disorder’ to be a significant issue. It may not get the attention of these global events, yet it feels to me as meaningful as all of them. It may be one area in which I might have a little impact on the world.

Personally, I have seen my 10th wedding anniversary in August 2023, and I am watching (and hopefully helping) my children grow up. My daughter Meadow has recently turned nine at the time of this thesis submission, where she was a little over two years old when I enrolled as a PhD student. My son Eli, who soon turns seven, is still younger than my tenure as PhD student. My long-suffering wife, who continues to jokingly ask “how’s that PhD coming along” knowing it is a constant source of strife, is progressing well in her own degree in social work. Professionally I have recently moved jobs, though what comes with me is the enthusiasm to stick with this area of research.

6.3. Reflections on the research process

Despite a plethora of fancy titles, terminology and jargon, I submit humbly that this process has been a case of having a vague idea of what I want to explore, thinking a lot, trying things to see if they work, changing my mind and learning from mistakes. I’d love to write that everything went according to plan, but that may overstate the plan I had to begin with. I knew I wanted to speak to PdxBPD about their experiences, and everything developed from that point. It is only through *doing* that I receive the gift of hindsight and consider things I may have done differently, though alternative ideas often require a change in research methods and a whole host of different ethical implications.

In seeking depth, I knew I had wanted to do qualitative research and interviews with people, though chose case study research after deciding I wanted multiple perspectives which were connected with one another. Whilst I could have alternatively been interviewing some PdxBPD, then some families and friends, then some professionals which may have not been connected in any way, there may still have been some useful insights gathered. However, bringing these multiple perspectives into single cases, where there was connection between participants, offered an intimacy, and thus a depth I would not have encountered otherwise.

Nonetheless there may be a limitation in what I defined as ‘the case’, or perhaps in the way I structured the topic guide for semi-structured interviews. Whilst the case was a person diagnosed with ‘BPD’ who had experienced crisis, and nested in these cases were family, friends and professionals of their choosing, what was discussed was not a single event of crisis but rather an experience of being, which sometimes included crisis, and led to

multiple reflections on multiple experiences. While the semi-structured interview was overall hugely valuable in getting more than I bargained for (in all the best possible ways), it meant that data was very broad, and data analysis a challenge. Had I tried to focus discussion on one event of crisis, and tried to push nested interviews in the same direction, what I may have received is a more coherent narrative and sharper data. However, I still feel that the semi-structured is more akin to my way of being (my Dan-ness), may feel more natural and conversational for participants when compared to a structured interview, and has also yielded insights I would not have been aware of had I been more rigid. Data analysis was a 'swamp', where I got lost and overwhelmed for a time. The honest and simple method of constant comparison saved me in being simple, described plainly by Gary Thomas (2021), and in line with my own logic. Looking at the data constantly. Comparing it to the other data. Trying to make sense of it. It wasn't until I fully committed to writing that the analysis turned a corner, and I shifted from not only how I make sense of it, but how I could make this make sense to other people reading it.

One of the biggest limitations of the study is not speaking to professionals who may have responded to PdxBPD in crisis. Whilst some of the professionals in the study had been part of, around or at least aware of the crisis care PdxBPD had experienced, there were many professionals spoken about in terms of how their interactions had impacted PdxBPD who were not included. There were no interviews with police officers, none with mental health nurses working in inpatient settings, and no professionals from emergency departments or urgent referrals services. Whilst ensuring autonomy and safety for PdxBPD by allowing them the option of who they included in their case was ethically the right thing to do, it nonetheless limits the perspectives captured. People have been spoken about, without being able to offer their perspective. However, through literature review, my own experience, and the reflections of all participants, there are glimmers of what might be happening in the minds and motivations of these people, and the concept map captures some of these possibilities.

6.3.1. Revisiting my research aims: What have I learned, and have I achieved what I set out to achieve?

As I have been so immersed in the topic, it may be hard to me to see what I have learned as this has been a gradual and accumulative process, and in the same way though I don't really see my kids grow, I do occasionally stop and notice, 'you're bigger than you were before'. If I deliberately stop and think; yes, I have changed, learned and grown through this process. Much of what I have found was consistent with my lived experiences and

expectations, however where I think the study offers something unique, and where I have taken most from it, is in its depth and through establishing some connections between the data. Whilst I have some answers I may have more questions, though even gathering more of the right questions to ask, I'd argue, is research progress.

In chapter 3 (3.2) I stated “the broad aim of this thesis was to explore the experiences of PdxBPD regarding their being in crisis and subsequent crisis intervention” and that “understanding is limited without the interconnected experiences of other stakeholders”. I have achieved depth in this regard, but further answered some of my more specific questions. The ‘BPD’ diagnosis itself can be understood in ways which impact self-concept and self-stigma, and actually further contribute to the likelihood of people experiencing crisis. I have achieved depth in understanding the triggers and precipitators to crisis for PdxBPD, and furthered my understanding of the experience of crisis. Understanding crisis included appreciating that the things that people do, including self-harm and suicide, can actually be, and should be, distinguished from crisis. Whilst they are issues in their own right, they are often the focus of intervention leaving the intensely painful mental states of thought and feeling overlooked. The experiences of family and friends are of feeling overwhelmed themselves, yet often on the periphery of crisis care, unless they are utilized as a de-facto mental health service themselves. The professionals PdxBPD would encounter when requiring support cross a variety of agencies which can vary depending on postcode, and across this study these agencies do not have clear and consistent ways of working with one another, or clear models of intervention. Professionals experience enormous stress, particularly around risk and fear of litigation, where they did not feel supported by their organisations or regulator. Simple things often help, yet achieving the simple is complicated by immense variables, including a lack of resources, role blurring, chaotic inpatient environment where some of the staff may themselves be traumatized. Professionals require support and dedicated thinking spaces to be able to perform their role well, though entirely improved and models of crisis care outwith the NHS may be a more prudent way forward.

I'm not sure if I was surprised by any of my data, though perhaps I was appreciative of the honesty and candour of the people I spoke to, and the unique ways they explained their experiences. When Billie (P16 CMHN C6) said there was a time she “fucking hated patients”, this was an honesty not often seen from a mental health nurse, though she explained this based on burnout, trauma and compassion fatigue. Where people with the ‘BPD’ diagnosis used metaphor to describe their distress, in particular that of being on fire,

it helped me understand this in a new and visceral way. The fire metaphor is one I think works on many levels, hence the title of my thesis.

6.4. Recommendations

I make recommendations acknowledging complexity and limitations on two counts. First, identifying crisis intervention for PdxBPD as a wicked problem and given the interwoven entanglement of the issues, making one recommendation necessarily links to other recommendations and some progress on one front cannot be made without a change in the conditions surrounding others. Thus, making one recommendation can spiral all the way from individual practice to policy and political decision making. Second, I hesitate a little as there are already plenty of recommendations and best practice for providing safe and effective care for PdxBPD. The problem, entangled with wickedness, is that many of these guidelines are not followed, and instead of creating new documents one wonders whether we should instead audit clinical practice to explore why these are not followed. The process of creating documentation which does not entail meaningful change has been described as ‘doing the document rather than doing the doing’ (Amhed 2007). It feels like I might be adding a little to the noise of ‘this needs to change, this should happen’ etc, whilst the real world does what has always been done, and the wickedness of the issue continues despite my little protests. This acknowledges the scale of the task and that there are no easy fixes. Still, this is not a reason not to try. What follows are four broad recommendations, which are neither straightforward nor impossible, which have implications for education, policy, practice and further research.

6.4.1. 1: Professional bodies should engage with service users to critique the use of the personality disorder label, discuss how to improve diagnostic support, and ensure professionals openly discuss personal meanings associated with any labels or diagnosis with all stakeholders

Crisis care is hugely influenced by the ‘BPD’ label, as this may add to the vulnerability of a person being in crisis, and furthermore be the first thing that professionals see, overshadowing the person in distress. There are few who like or enjoy the ‘personality disorder’ label, and often there is discomfort and acknowledgement it can feel like the label is “attacking the very ‘soul’ of the individual” (Bateman and Fonagy 2016, p.149). However, there is a distinction between those that feel as it is in diagnostic criteria we must continue to use it, and those who feel it should be abandoned entirely. Seeing the writing on the wall (and I share the belief that it is only a matter of time before this diagnostic label dies) there are examples of both research and service design now using the term ‘complex emotional needs’ rather than ‘personality disorder’ (Haslam et al 2024, NHS Leeds and York

Partnership 2024). Nonetheless, even ‘complex emotional needs’ has been criticized as no more than a euphemism (Recovery in the bin 2024). This conversation needs to continue, and be led by professional bodies with power e.g. the Nursing and Midwifery Council, the Royal College of Psychiatrists, and the World Health Organisation. Without naming specific organisations, we will fall into apathy, blaming ‘the system’, and knowing in our hearts that nothing will change.

Whilst this is a complex conversation which would require thought around agreeable alternative terminology and how this may rupture treatment pathways or access to services, it is a serious conversation which needs to be had. A question I often ask is, does the ‘personality disorder’ label help people in the real world? I’m not sure it does. There are surely ways of helping people which might use an alternative label to still direct care, and though I’m not a fan of labels at all, I do appreciate the need for a ticketing system which directs many people with relatively similar issues to care which may help. That said, the direction towards effective care may be most valuable when leading to long-term specialist therapies. Following this study and immersion in the literature, I am not convinced that as things stand, the label holds *any* value or benefit for people when accessing and receiving crisis care, as there is no consistency in this diagnosis, and no consistent evidence-based model of crisis care to offer.

Nonetheless, whilst the label exists and is used, the least we could do is acknowledge its power, improve diagnostic support and have open conversations with PdxBPD around how they make sense of and feel about the label, as it can make people feel worse, and even hopeless. I recall an experience where working with a person diagnosed with ‘BPD’, I had to use the label to communicate with a GP, and when showing the person the letter I had sent, acknowledged we had not spoken about the label. I appreciated their discomfort with it, and said out loud “it says you have the diagnosis of borderline personality disorder, but that’s not how I see you”. I let them know I saw and valued their name-ness. I saw them and not the label.

6.4.2. 2: Improving knowledge and understanding in all professionals and families

Whilst the best evidence base for treating PdxBPD comes from psychological therapies where people often have further specialist training, it is acknowledged that most PdxBPD, particularly when in crisis, will meet a generalist who has not done specialist training (Bateman and Krawitz 2013). Thus, it can be argued that as well as improving specialist therapies, it may perhaps be more of a priority to upskill people across the health service.

Given the ‘butterfly effect’ and how subtle interpersonal issues may lead to crisis, it can be argued that crisis care for PdxBPD is a weak-link endeavour. It can only take one stray stigmatizing and insulting comment, one rush to restraint before trying to talk, or one failure to explicitly empathise, to add to rather than alleviate crisis, and harm rather than help.

Weak-link philosophy has been explored in relation to football, where statisticians have discovered that poorer players can “undo all the good work” and describe that “success is determined not just by what you do well but what you don’t do badly” (Anderson and Sally 2014, p.199-200). Thus, as Malcolm Gladwell (a journalist and podcaster, from whom I first heard of this analogy) summarises, “upgrading the superstar doesn’t help as much as upgrading the worst player” (Pushkin 2016, Simon Says 2016). In terms of crisis care, we need to make our worst better. A way to do this may be through improved education, and quality mandatory clinical supervision or reflective spaces. This should apply to all people who have as a core component of their job, interpersonal communication with people who may be diagnosed with ‘BPD’. I appreciate that is broad, but without this approach, by the time PdxBPD reach the specialists, there is potential for enormous harm to have resulted at the hands of our worst players.

Whilst underexplored within the study and deserving of further inquiry, a strong argument could be made for strengthening education around ‘BPD’ and associated issues within pre-registration educations for all professions, as professionals will be working with PdxBPD in crisis often immediately upon graduating from respective programmes. As I have argued before, we should not be waiting until after people graduate to prepare them effectively for the job they will be doing (Warrender 2022). Furthermore, beyond a robust education, the stresses of the job mean that people will require help to think and see through the chaos, where due to emotional flames, everyone is burning. Whilst there may need to be different models of informing and supporting families, these are just as important for the same reasons.

6.4.3. 3: Improved coordination of crisis-care and communication between disciplines, agencies, services and families

The dysfunctional relay and the marginalization of family were some of the first data to really ‘pop out’ of this study. No-one seems to know where PdxBPD fit into these systems and they can end up being rejected from MH services, and even criminalized. The ‘all or nothing’ nature of family and friends involvement in crisis care was startling, and in fact their perspective felt marginal in this study as when it comes to crisis care, they often didn’t

have as much to say given they existed on the periphery of it, unless they were doing it themselves.

This sense of not knowing where to go, or even where you might be accepted, can exacerbate crisis further. There are key questions in terms of moving to improve this, but likely wickedness and complexity to the multiple answers which may return. These need to be asked, with all stakeholders around a table.

- What does each discipline, agency, service and family do when PdxBPD are in crisis?
- What do they think the others do, or should, or can do? Do we understand the consequences of these acts or omissions?
- How can we coordinate so disciplines, agencies, services and families complement rather than compete with one another, and each understand the other's role, purpose and limitations?
- How can we improve lines of communication between everyone, including the sharing of crisis plans?
- Is there adequate organization/resource to provide crisis care for PdxBPD? If not, what are these specific gaps, and what may need to change or develop to meet this need?

6.4.4. 4: Developing new models of crisis care

Given the experiences of PdxBPD in this study it is difficult to argue that current crisis-care, which often occurs in a complex interface between emergency and mental health services, is not at best seriously flawed. Following discussion on the above questions, discovering what everyone does or doesn't do, can or can't do, may lead us towards the development of new models of crisis care. Thankfully, these are already emerging, and perhaps finding that PdxBPD in crisis don't fit existing models of care, society is recognizing that new models are necessary. The theme of 'building a better service' explored points for improvement, and these can be used to inform the development of new and alternative services. At the end of March 2024, round the corner from my new workplace, I visited 'Hope Point' which opened in August 2023. This is a 24/7 self-referral crisis service which was co-produced with service users, which offers care not based on diagnosis, utilizes peer support, where people can be supported through text, phone or face to face, and will actively connect people with other services where appropriate (Dundee City Council 2023). It was wonderful to learn that their model, and what they do, is largely in sync with what people in this study wanted from a service (and not that I believe in fate, but I at least enjoy the happy coincidence that a new crisis service is around the corner from my new

workplace). This new model offers me hope, and connecting with them offers a new network and the potential to research how it works and why. This new service is an acknowledgement that others have seen what I've seen, and learned what I've learned. There needs to be change, and this appears to be a positive direction.

6.5. Some key questions which I may revisit in future research:

I am not done looking into this topic, and perhaps the fifth recommendation is that I, and others, keep on keeping on with research and critique. Whilst what follows may seem an extensive list, these are all connected issues which have sparked my interest. Given the semi-structured interviews, the data collected covered a breadth of content, all of which I find interesting, and where I started being troubled by this topic, I am still troubled, yet troubled with focus. Whether through my own research, or that of supporting others, I am interested in furthering understanding of each of these questions. Life is short and I may not get to them all, but it certainly gives me a mission and I will never be bored or idle.

- Availability of resources was a limiting factor noted by all participants. Nonetheless, there is a postcode lottery in terms of service design, crisis intervention offerings, and specialist personality disorder services. What influences these variations, and what impact do they have on people's care?
- What is best practice for assessment and giving a diagnosis, and what influences variation in the diagnostic support offered? How does this variation in approach impact on PdxBPD and how they understand themselves and their difficulties?
- Many PdxBPD have additional comorbidities. How do these comorbidities influence the experience of crisis? Are these comorbidities understood or appreciated by the person and with professionals providing crisis care? What are the impacts of comorbidities being understood or overlooked?
- What do all professionals who work with PdxBPD in crisis receive in their undergraduate educations around 'personality disorder' and associated difficulties? How does this impact on what they do, and how might this be improved?
- Professionals within services often have differing views around 'personality disorder', and there can be conflict within teams. What influences these differing views, and how are these conflicts resolved? On resolution (or not), what is the subsequent impact to care?
- Professionals, particularly mental health nurses, can find their roles and environments incredibly demanding, and they can become distressed and even traumatized as a

result. What are the specific circumstances which may lead to a person becoming distressed in their workplace, and what is the impact of traumatized people looking after traumatized people? What may better support mental health nurses so they can effectively care for others?

- Psychiatry is described as a profession with enormous power, yet often a relational distance to PdxBPD. Why does a psychiatrist have this power when they are often the most distant from a person's care? Might there be alternative models of nurse-led care which can include but not be dominated by psychiatry? How might alternate models influence care?
- Despite clinical supervision and reflective practice being advocated for years, why do some professionals not receive this? How does not having a dedicated thinking space impact on the care people can deliver. How might this be improved?
- Why are some PdxBPD labelled too unstable for therapy? What are the rationales and guidelines behind these decisions? How might the decisions to not offer someone therapy have an impact on people?
- Why, despite limited evidence of their benefit, are psychiatric drugs used so regularly to treat PdxBPD. What are the positive and negative effects of these drugs?
- There are alternative models of crisis care emerging. What are these and how effective are they? Might the NHS learn from these and what could it change to support people more effectively?

Priorities for the research community at large, from my perspective, should include how best to prepare and continue to support professionals to work relationally with a group of people who are prone to difficulties in relationships for an array of reasons, and do so well in a complex system of care. The need to improve the quality of relationships between professionals and PdxBPD is certainly a consistent theme from this study.

6.6. What I plan to do next:

On completing of this thesis, and after viva and making any amendments, I will contact participants to let them know of the study's conclusion and thesis completion, offering them the link to access the thesis as well as time to discuss the findings should they so wish. I will re-connect with leads at the health board, to ensure they are aware of the experiences of people who have used their services.

Given the depth of my findings, and the relative brevity of the findings section (which was originally double the length, and felt like it could have been added to), I am committed to returning to the data and pursuing academic publications, and perhaps a book. Having collected so much rich data, I felt a genuine loss at needing to significantly cut down on words and prioritise what I included, and even a sense of guilt for not including every word. However, through planning to write and publish across various avenues to various audiences, I hope to give these voices a space to be heard. Given I have 5 themes, I will approach journals to ask whether they might consider publishing a series of papers on the topic. I have also been asked to co-author with a friend with lived experience, a chapter on 'personality disorder' for the 4th edition of the mental health nursing book, the craft of caring, and whilst this will cover more than crisis care, many of the reflections and ideas within this thesis will make their way there. I am also interested in developing my writing in autoethnography, and have sought mentorship in this area as I write a chapter reflecting on my relationships with people with mental health problems in acute inpatient units, in psychotherapy, as a lecturer, and as a friend. Becoming interested in autoethnography as I wrote this thesis has certainly pulled out more of the 'auto' in my writing than I had perhaps anticipated.

A chance interaction on X (formerly twitter) with the Head of Mental Health Nursing for NHS England and NHS Improvement led to a conversation around the stressful experiences of MH nurses, with some of my data deemed valuable in showcasing the complexity and emotional labour of the work. I shared some of this 20th February 2024, in a presentation titled "you cry in the toilet, and then you go back to work: experiences of the mental health nursing workforce and impacts on wellbeing" at an online mental health nursing webinar for NHS England. Learning that there are increased suicide rates for nurses compared to the general population, and being aware that mental health nursing has unique complexities, I have submitted a proposal for funding to explore suicidal ideation in the mental health nursing workforce.

I am still involved in many of the projects I described in the opening chapter such as the Scottish Personality Disorder Network and the British and Irish Group for the Study of personality Disorder. I have used some of my data already in educating mental health nursing students at Abertay University, and I am starting an extra-curricular special interest group on 'personality disorder' after enthusiasm from students. I will be presenting my PhD findings at various conferences over the next year. There are professionals using my work to think about the care they provide, and I want to stay connected with them, and pursue

research and writing. I am bursting with ideas, but need to temper this with pragmatism. This topic has become a huge part of my life in many ways, and I still care enough about it to embrace this, and go with it.

6.7. Approaching the fireball

In ending this thesis, perhaps I should bring it back to the title, ‘a fireball of emotion’. These words were used by someone to describe their distress, and this stuck with me as I sometimes feel metaphor can powerfully articulate ideas in a way in which they can be more fully understood and connected with. If I can use what I have learned to develop this metaphor further, I’d summarise this thesis in the following way:

Fire has a reputation for destruction (stigma). The fire starts for many different reasons (how crisis is triggered), but once a person catches fire, they become a fireball and experience immense suffering. People who are paid to help may be afraid they get burned (professionals are scared of risk), so they keep their distance. Families try to help, and they too can catch fire (emotions are often contagious). Often professionals will turn the fireball away to try and avoid getting burned, or they will pick it up, but quickly pass it on to someone else (the dysfunctional relay). If they do intervene, it’s from a safe distance (emotional distance), using water from a hose (interventions which focus on behaviour but not the underlying distress). This can cause water damage (iatrogenic harm). However, what may be more effective in quelling the flames is for professionals to get close (meaningful relationships) and have a genuine closeness which can smother the flames and extinguish the fire (when people feel believed, validated and understood). This may mean that the professional also gets a little burned (emotional distress and/or trauma), but dealing with fire, it is impossible that people will not at least feel the heat.

I wrote this paragraph, then went for a run, and thought ‘but people actually really do know how to prevent and extinguish a fire’ in a way that mental health services just don’t with people in crisis. Thus, the metaphor runs out of steam when we look for the evidence base of what works and what doesn’t for helping PdxBPD in crisis, as there will always be subjectivity and uncertainty given the unique nature of human beings. That said, this is no reason to not at least try. I will keep trying.

7. References

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8. Appendix

8.1. Diagnostic criteria for ‘borderline personality disorder’

DSM-5 and ICD-11 Criteria	
DSM-5 ‘Borderline Personality Disorder’ (APA 2013).	ICD-11 ‘Borderline pattern’ (WHO 2024)
A pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:	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 many of the following:
1. Frantic efforts to avoid real or imagined abandonment. Note: Do not include suicidal or self-mutilating behavior covered in Criterion 5.	Frantic efforts to avoid real or imagined abandonment.
2. A pattern of unstable and intense interpersonal relationships characterized by alternating between extremes of idealization and devaluation.	A pattern of unstable and intense interpersonal relationships, which may be characterized by vacillations between idealization and devaluation, typically associated with both strong desire for and fear of closeness and intimacy.
3. Identity disturbance: markedly and persistently unstable self-image or sense of self.	Identity disturbance, manifested in 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	A tendency to act rashly in states of high negative affect, leading to potentially self-damaging behaviours

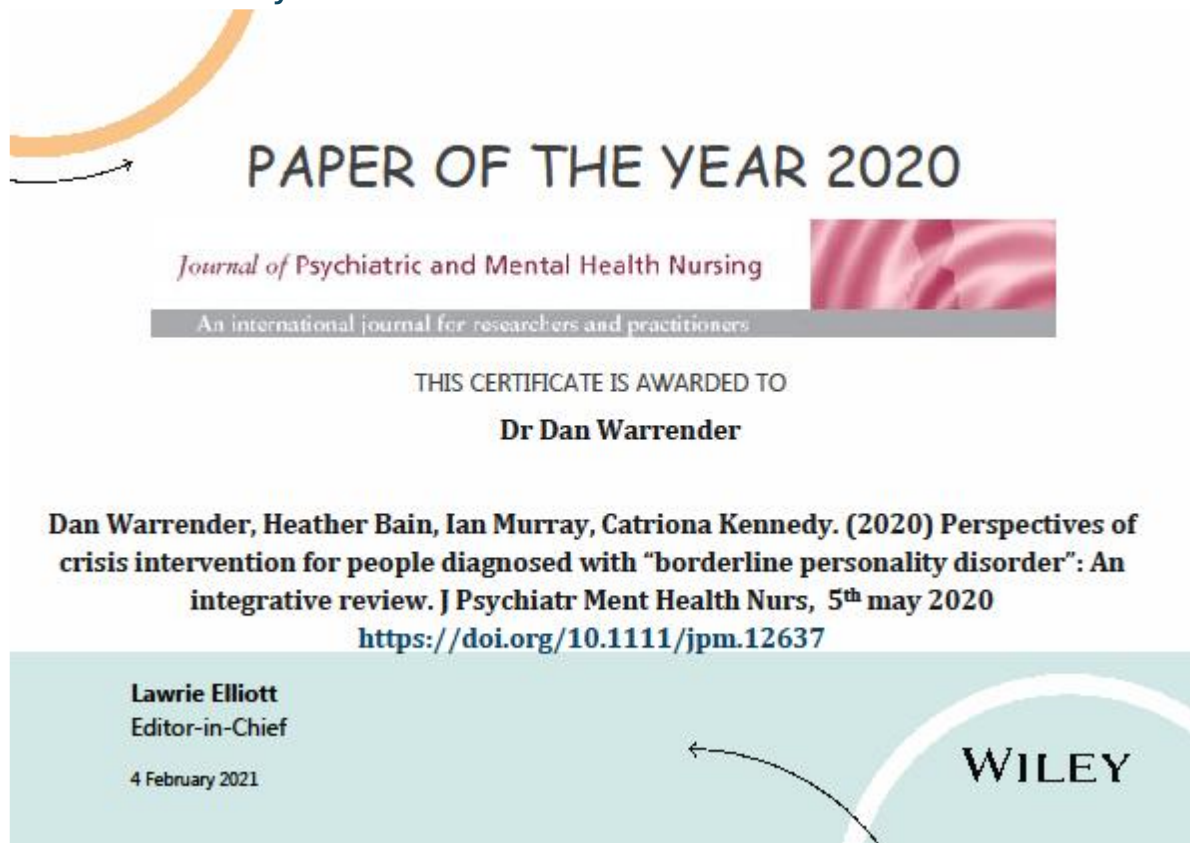
abuse, reckless driving, binge eating). Note: Do not include suicidal or self-mutilating behavior covered in Criterion 5.	(e.g., risky sexual behaviour, reckless driving, excessive alcohol or substance use, binge eating).
5. Recurrent suicidal behavior, gestures, or threats, or self-mutilating behavior.	Recurrent episodes of self-harm (e.g., suicide attempts or gestures, self-mutilation).
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).	Emotional instability due to marked reactivity of mood. Fluctuations of mood may be triggered either internally (e.g., by one's own thoughts) or by external events. As a consequence, the individual experiences intense dysphoric mood states, which typically last for a few hours but may last for up to several days.
7. Chronic feelings of emptiness.	Chronic feelings of emptiness.
8. Inappropriate, intense anger or difficulty controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights).	Inappropriate intense anger or difficulty controlling anger manifested in frequent displays of temper (e.g., yelling or screaming, throwing or breaking things, getting into physical fights).
9. Transient, stress-related paranoid ideation or severe dissociative symptoms.	Transient dissociative symptoms or psychotic-like features (e.g., brief hallucinations, paranoia) in situations of high affective arousal.
	<i>Other manifestations of Borderline pattern, not all of which may be present in a given individual at a given time, include the following:</i>

	<ul style="list-style-type: none"> • <i>A view of the self as inadequate, bad, guilty, disgusting, and contemptible.</i> • <i>An experience of the self as profoundly different and isolated from other people; a painful sense of alienation and pervasive loneliness.</i> • <i>Proneness to rejection hypersensitivity; problems in establishing and maintaining consistent and appropriate levels of trust in interpersonal relationships; frequent misinterpretation of social signals.</i>
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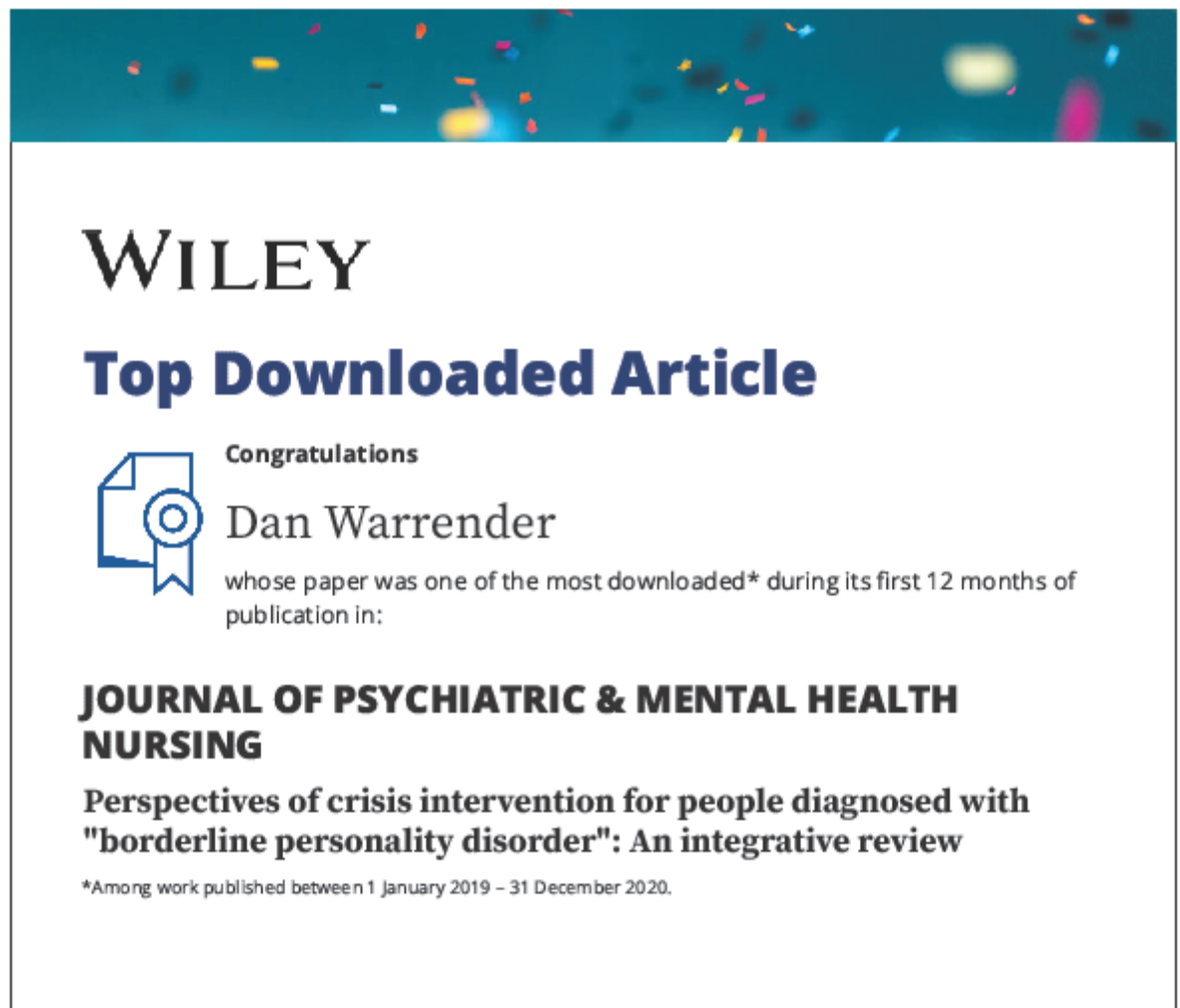
Note: The ICD-11 also states that ‘borderline pattern’ typically maps onto the following three trait specifiers (WHO 2024):

- Negative affectivity: the tendency to experience a broad range of negative emotions.
- Dissociality: disregard for the rights and feelings of others, encompassing both self-centeredness and lack of empathy.
- Disinhibition: the tendency to act rashly based on immediate external or internal stimuli, without consideration of potential negative consequences.

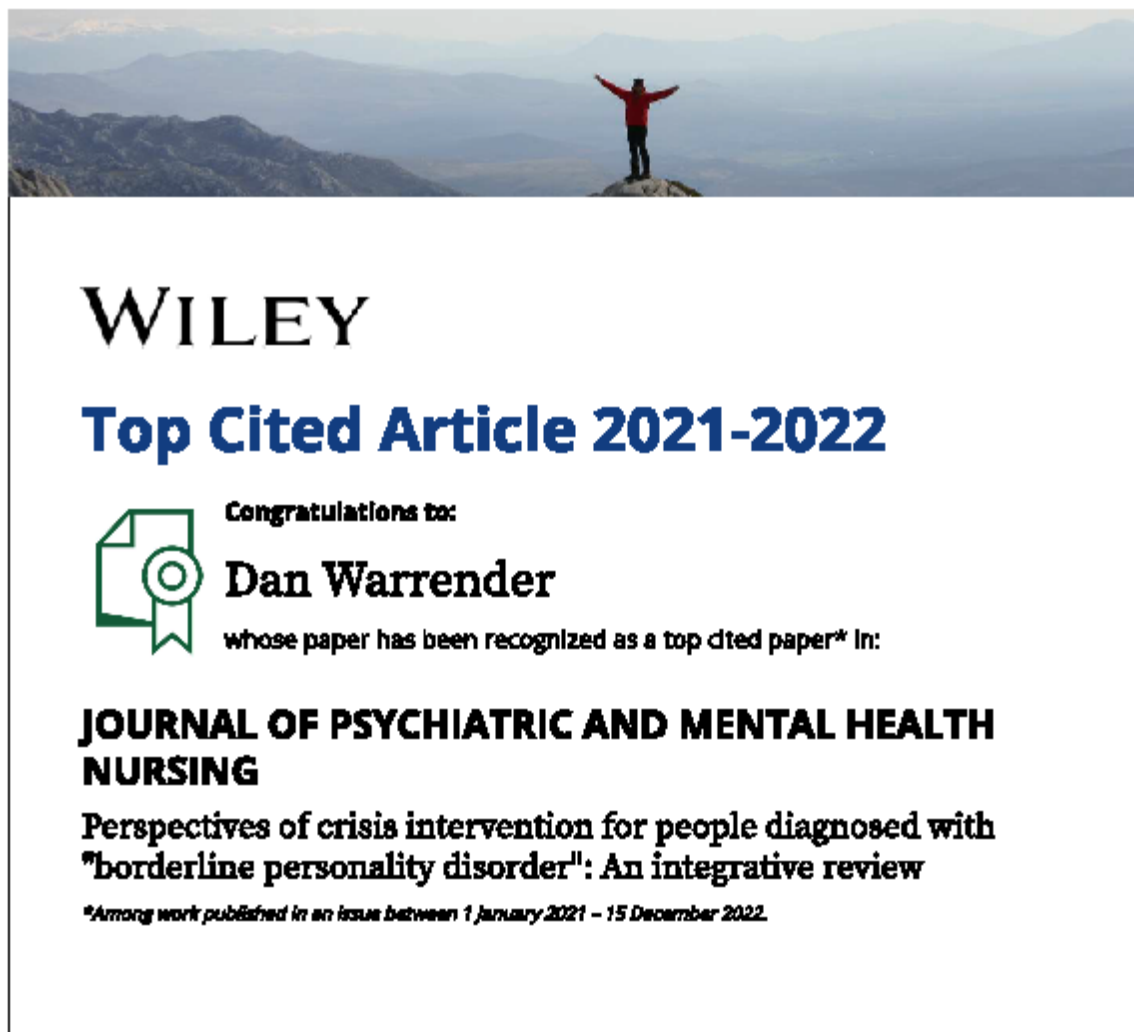
8.2. Article of the year certificate



8.3. Top downloaded article certificate



8.4. Top cited article certificate



8.5. Literature review data extraction table

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
Bergman and Eckerdal (2000)	To broaden understanding of what it means for professionals to manage PdxBPD	Inpatient and outpatient service 29 professionals (Sweden)	Qualitative Grounded theory Individual interviews	Need identified for emotional support and education on BPD. Differing levels of education on BPD and this influenced approaches to working with PdxBPD Organisations/teams that fail to work together and collaborate effectively perceived to have a negative impact on patient care.	100%
Berrino et al (2011)	To assess whether crisis intervention at a general hospital is a suitable management strategy for PdxBPD referred to the emergency room for self-harm.	Crisis intervention unit 200 PdxBPD 100 crisis intervention, 100 treatment as usual (Switzerland)	Quantitative Prospective 3 month follow up using patient records	Crisis intervention unit had 8 beds, max 5 night stay, intensive interdisciplinary care and daily clinical supervision After 3 months CI group had reduced rates of self-harm and hospitalization (8% + 8%) compared to TAU (17% + 56%) Treatment failure was defined as suicidal crisis with supplementary inpatient treatment, and was observed in both groups (CI=14 / TAU=56). CI was more cost effective than TAU	80% Crisis intervention group also received unplanned co-interventions

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
Black, Murray and Thornicroft (2014)	To understand the phenomenology of BPD from the patients perspective.	Dedicated personality disorder service 9 PdxBPD (UK)	Qualitative Interviews	<p>PdxBPD experienced dramatic perceptual and psychological changes, impacts on ability to communicate, experience of pain, memory loss and hallucinations.</p> <p>Responses to crisis were help seeking and self-harm.</p> <p>Families were perceived as either protective or burdensome.</p> <p>People felt a cycle as recovery from suicide attempt could generate new feelings and further suicidal thoughts.</p> <p>Crisis is multidimensional, with a complex relationship between internal and external factors in the experience of crisis.</p> <p>Crisis can rise from within the person (internal factors) as well as through experiences with others (external factors).</p>	<p>80%</p> <p>Unclear why interpretive and not descriptive phenomenology</p>
Borschmann et al (2013)	To examine the feasibility of recruiting and retaining adults with a diagnosis of BPD to a pilot RCT investigating the potential efficacy and cost	Community mental health team 88 PdxBPD 46 (TAU plus joint crisis plans) 42 TAU alone	Quantitative Pilot RCT, feasibility study Self-report questionnaires	<p>JCPs were acceptable to participants</p> <p>JCPs used both during and between crises</p> <p>Approximately half of</p>	<p>60%</p> <p>13 PdxBPD (14.7%) dropped out before follow up</p>

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
	effectiveness of using a joint crisis plan.	(UK)		<p>participants reported a greater sense of control over their problems and improved relationship with their mental health team</p> <p>No evidence that JCP's reduce instances of self-harm</p>	Treatment as usual for PdxBPD varied greatly
Borschmann et al (2014)	To investigate crisis treatment preferences	Community mental health 41 PdxBPD (UK)	Qualitative Open discussion (using crisis plan subheadings as a basis) on joint crisis plans created by participants.	<p>Variation in peoples preferences regarding crisis intervention, emphasising the importance of individually tailored crisis plans</p> <p>Being treated with dignity and respect and receiving emotional and practical support is important to PdxBPD</p> <p>Some PdxBPD identified the importance of connecting with others during crisis, but several indicated the desire to be left alone during a future crisis.</p> <p>Specific treatment refusals during crises included particular types of psychotropic medication and involuntary treatment</p>	100%
Bowen (2013)	To explore the experiences of good practice among mental health professionals working in a service that provided specialist treatment for PdxBPD	9 clinicians (4 nurses, 3 social therapists, 1 art therapist, 1 psychiatrist) (UK)	Qualitative, Semi-structure interviews	<p>Professional role felt to be to slow things down, to help PdxBPD to think</p> <p>Shared decision making and shared responsibility felt to be important</p>	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
				<p>Interpersonal issues between PdxBPD and professionals seen as a repetition of experiences outside their care, though this was seen as an opportunity for learning</p> <p>Professionals felt that when PdxBPD placed staff in the expert role it was unhelpful.</p> <p>Professional felt when PdxBPD become disillusioned with staff, they look to their own resources</p>	
Brooke and Horn (2010)	To explore the meanings of self-injury and overdosing and the relationship of each to the other for women who have fulfilled the diagnostic criteria for BPD	Psychotherapy service 4 PdxBPD (UK)	Qualitative Interpretive phenomenological analysis Interviews	<p>Both distal and proximal factors perceived as potential antecedents to crisis</p> <p>Crisis symptoms included feeling "like a pressure cooker", "about to burst" and dissociative experiences</p> <p>Self-harm identified as private form of self-help for regaining control of emotional dysregulation, or public form of communicating distress</p> <p>People have progressive systems of coping with distress, ranging from cutting to burning and overdosing.</p>	100%
Brown, Comtois and Linehan (2002)	To better understand reasons for suicide attempts and non-	75 PdxBPD (USA)	Quantitative, 'Parasuicide history interview'	People may feel that crisis is something to be reduced, or expressed.	80%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
	suicidal self-injury in women diagnosed with BPD		Recorded a comprehensive 47-item semi-structured interview measuring details of single parasuicide episodes.	Motives for suicidality are complex, and people may have multiple reasons. 20% of participants cited interpersonal triggers to suicidality.	PdxBPD confirmed reasons from a prepared list. New reasons not collected as data.
Carter et al (2005)	To compare the initial clinical management of hospital-treated deliberate self-poisoning patients with major depressive disorder (MDD) or borderline personality disorder (BPD)	Hunter Area Toxicology Service (HATS) 639 participants 484 dx MDD 116 PdxBPD 39 PdxBPD/MDD (Australia)	Quantitative, Data from HATS database	Diagnostic group had no effect on length of stay in the HATS unit, or psychiatric follow up. PdxBPD less likely to have a GP follow up arranged. For mild to moderate suicidal ideation, PdxBPD were more likely to be discharged to a psychiatric hospital than people dx MDD. Diagnostic label may have an impact on clinical management	100%
Commons Treloar (2009)	To explore experiences of clinicians across emergency medicine and mental health service settings in Australia and New Zealand in working with patients diagnosed with borderline personality disorder (BPD)	Mental health services and emergency medicine 140 registered health providers (Nurses, allied health and medical staff) 90 mental health service, 50 emergency medicine (Australia and New Zealand)	Qualitative Demographic questionnaire Open comment section asking for experience or interest in working with PdxBPD	Conflict in their teams regarding approach to working with PdxBPD Crisis perceived to be an ongoing issue for PdxBPD Professionals identified uncomfortable feelings in themselves, feeling frustrated, inadequate and challenged.	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
				<p>Professionals felt that current services were unsuitable for PdxBPD's needs</p> <p>Need identified for specific education on BPD and clinical supervision</p> <p>Professionals confirmed that some other professionals refuse to treat PdxBPD based on diagnosis</p>	
Damsa et al (2007)	To observe the safety and efficacy of Olanzapine 10mg IM medication in patients with acute agitation	25 PdxBPD who refused oral medication in an emergency room (Belgium)	Quantitative Prospective observational study	<p>Measures of psychomotor agitation included 'uncooperativeness', 'hostility', 'impulsivity' and 'excitement'.</p> <p>Reductions in psychomotor agitation after monotherapy with 10mg IM Olanzapine in patients with BPD</p> <p>Intervention used when PdxBPD refused oral medication, with physical restraint required in 20 patients (80% of sample)</p>	<p>80%</p> <p>Measures of agitation included being 'uncooperative' though unaccounted variable of physical restraint used in 80% of sample</p>
Dunne and Rogers (2012)	To explore carers' experiences of the caring role, and experiences of mental health and community services.	Community Personality Disorder Service 8 carers for PdxBPD (UK)	Qualitative Focus groups Thematic analysis	<p>Some professionals experienced as unprofessional and unhelpful e.g. stigma and being told it's 'just behaviour'</p> <p>Mixed experiences of care plans being shared</p>	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
				<p>Carers felt overlooked by MH services, with staff not realising the 24/7 role of carers</p> <p>Carers experience their own distress</p> <p>Carers feel unskilled and expressed wish for more information on how to handle situations</p> <p>Need identified for an appropriate 'crisis base'</p> <p>Carers said PdxBPD unable to articulate why they feel the way they do</p> <p>Challenge identified in 'the line between support and enablement'</p>	
Ekdahl et al (2011)	To describe significant others' experiences of living close to a person with borderline personality disorder and their experience of encounter with psychiatric care.	19 family carers to PdxBPD (Sweden)	Qualitative Free text questionnaire Group interviews	<p>Carers described a 24 hour duty of constant worry, calling it a 'permanent crisis'</p> <p>Carers wellbeing mirrored that of their loved one, with no line between. If PdxBPD are unwell carer is unwell.</p> <p>Carers felt powerless and frustrated that PdxBPD did not recover despite efforts of family and healthcare</p>	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
				<p>Guilt felt due to preconceived ideas that parents were responsible for development of BPD</p> <p>Professionals sometimes signalled that no help was needed from carers</p> <p>Responsibility was felt to be an all or nothing. Full responsibility with carer until the person was in hospital, then they had no responsibility</p> <p>Carers experienced professionals with little knowledge, who focused on some symptoms but not the big picture</p>	
Giffin (2008)	To hear the voice of a small sample who have a family member receiving treatment for severe personality disorder	Mental health services 4 family carers to PdxBPD (Australia)	Qualitative Informed by grounded theory Unstructured in-depth Interviews	<p>Families feel traumatic stress as they experience their child self-harming, attempting suicide and being near death.</p> <p>Families feel the burden of care was put onto them as professional would use family support as a reason to avoid clinical crisis intervention.</p> <p>Families did not feel supported by professionals, and heard contradictory advice regarding how much to support their loved one.</p> <p>Families felt there were no discharge plans.</p>	80% Approach to data analysis not clear

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
Helleman et al (2014)	To describe the lived experiences of PdxBPD with use of the brief admission intervention.	Inpatient wards 17 PdxBPD (Netherlands)	Qualitative Interviews Descriptive phenomenology	Results of brief admission can be positive or negative. PdxBPD described contact with a nurse as the most important part of brief admission. Lack of contact contributed to negative affect. PdxBPD reported greater autonomy and responsibility after having a choice of admission	100%
Henderson et al (2013)	To explore the characteristics of recurrent self-inflicted burn patients	Hospital burns unit 4 PdxBPD (Australia)	Qualitative Semi-structured interview Cases Retrospective study of admissions	PdxBPD who recurrently self-inflicted burns often had a history of trauma Precipitating factors to self-burning included proximal issues such as arguments with others PdxBPD had experienced their crisis as having a sudden onset PdxBPD had described dissociative experiences prior to self-inflicted burning	80% Approach to data analysis not clear
Hoffman et al (2004)	What is family members of PdxBPD level of knowledge about BPD? How does knowledge correlate with burden, depression, distress, and expressed emotion?	32 family members of PdxBPD (USA)	Quantitative In-person interviews Self-report instruments	More than a third of family members knew very little about BPD Greater knowledge about BPD was associated with higher levels of family burden, distress, depression and greater hostility towards PdxBPD	80% Rationale for quantitative rather than qualitative or mixed methods approach not clear

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
Holm and Severinsson (2011)	To explore how a recovery process facilitated changes in suicidal behaviour	13 PdxBPD (Norway)	Qualitative Exploratory design Interviews	<p>All participants identified distal factors of trauma and violation</p> <p>Crisis was described as a need to gain peace and escape</p> <p>Suicidality could be PdxBPD's desire to take responsibility for themselves</p> <p>PdxBPD had difficulty thinking of others in times of crisis, and how suicidality may impact on loved ones</p> <p>PdxBPD felt the need to hide their experiences of wanting to kill themselves</p> <p>PdxBPD saw barriers to feeling crisis intervention was beneficial were having responsibility removed, not having the power to make their own decisions, nurses indicating that they may be selfish and not being seen as a person.</p>	100%
Horn, Johnstone and Brooke (2007)	To explore user experiences and understandings of being given the diagnosis of BPD.	5 PdxBPD (UK)	Qualitative Semi structured interviews Interpretive phenomenological analysis	<p>PdxBPD felt they were rejected from services and had care withdrawn on the basis of their diagnosis</p> <p>Participant described being asked to leave inpatient ward and perceived this to be a result of receiving the diagnosis</p>	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
Hughes et al (2017)	To provide insight into the lived experience of clinicians working with PdxBPD who self-harm	Community mental health teams 4 professionals (UK)	Qualitative Phenomenology Unstructured interviews	<p>Participants felt that PdxBPD pushed responsibility towards the clinician</p> <p>Variation in views regarding the balance of clinical risk taking and avoiding undue risk.</p> <p>Difficulty described in balancing patient responsibility with professional responsibility and duty of care.</p> <p>Fear of being blamed in the event of a patient suicide and this contributed to anxiety</p>	100%
Koekkoek et al (2010)	To establish the preliminary effects of preventive psychiatric admission of patients with severe borderline personality disorder	Inpatient unit 11 PdxBPD (11 service data 8 consented to interview) (Netherlands)	Mixed methods Administrative records, cross-checked with individual patients' files. Individual semi-structured interviews.	<p>PdxBPD evaluated preventative admission positively</p> <p>PdxBPD using preventative admission felt more control over crisis and felt encouraged to self-manage symptoms until next admission</p> <p>Preventative admissions sees a slight decrease in services used in terms of inpatient days</p>	90% Quantitative measures of quality of therapeutic alliance only obtained from professional, not PdxBPD
Krawitz and Batcheler (2006)	To conduct a pilot survey about clinician views on defensive practice when working with adults with borderline personality disorder	Community mental health, acute inpatient and crisis teams 29 Professionals (New Zealand)	Quantitative Self-report survey questionnaire	Professionals admitted to making decisions which are not in PdxBPD's best interests but protect professional from legal repercussions.	60% Sampling strategy not clear. Inclusion and exclusion

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
				<p>PdxBPD's families/friends were cited as an influence on defensive practice</p> <p>Media cited as biggest influence on defensive practice</p>	<p>criteria not given.</p> <p>Approach to data analysis not clear</p>
Lawn and McMahon (2015a)	To explore experiences of care from the perspective of Australians dx with BPD.	153 PdxBPD (Australia)	Quantitative Online survey	<p>Feeling suicidal, feelings of self-harm and feeling unsafe most common reasons for PdxBPD when seeking hospital admission.</p> <p>PdxBPD had difficulty accessing services.</p> <p>PdxBPD reported high levels of distress when refused hospital admission.</p> <p>65.4% (n = 78) reported experiencing discrimination, particularly as inpatients</p> <p>Variation in preferences regarding care: Usefulness of identifying early warning signs, developing crisis plans and hospital admission was mixed, some finding these helpful and some unhelpful.</p>	100%
Lawn and McMahon (2015b)	To explore carers experiences of being carers, their attempts to seek help for PdxBPD, and their own needs	121 family carers of PdxBPD (Australia)	Quantitative Online survey	Carers perceived lack of choice of support services, difficulty accessing support when needed, and lack of long term consistent support all contributing to anxiety in PdxBPD	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
				<p>Carers perceived most challenging issue for the PdxBPD was not being taken seriously</p> <p>Carers had often asked for PdxBPD to be admitted to hospital but been refused.</p> <p>GPs were rated as the most responsive health professionals.</p> <p>Identifying early warning signs, developing a crisis plan and hospital admissions were perceived by carers as very unhelpful (25.4%, <i>n</i> = 18; 28.6%, <i>n</i> = 20; and 23.9%, <i>n</i> = 17, respectively).</p>	
Little et al (2010)	To explore the emotional reactions, concerns and beliefs related to working with PdxBPD by health and non-health related agencies	Police, health and welfare, and mental health services 378 Professionals (Australia)	Quantitative Self-report questionnaire	<p>Different agencies respond in different ways to PdxBPD</p> <p>Police saw PdxBPD as a nuisance</p> <p>Mental health staff believed PdxBPD were best managed out of hospital and without medication</p> <p>Mental health staff more likely to understand why a person either wasn't admitted or was being discharged despite ongoing suicidality than police or health and welfare professionals</p>	<p>80%</p> <p>Variation in sample sizes of professional groups. Police (<i>n</i> = 210) Health and welfare (<i>n</i> = 120) Mental health (<i>n</i> = 51)</p>

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
Lohman et al (2017)	To identify key resources for and barriers to obtaining supportive and treatment services for BPD from the perspective of individuals seeking information or services related to BPD ("BPD care seekers").	BPD resource centre 500 randomly selected subscribers from 6253 resource requests (USA)	Mixed methods Retrospective design Grounded theory Descriptive statistics Unstructured interviews regarding service needs and experiences Phone call requests	Available resources for crisis intervention did not meet current demand. Families indicated they lacked skills in dealing with PdxBPD's issues Families desired more communication with health services	100%
Markham and Trower (2003)	To investigate how the psychiatric label 'borderline personality disorder' (BPD) affected staff's perceptions and causal attributions about patients' behaviour.	Inpatient mental health 48 Professionals (UK)	Quantitative Questionnaire	Mental health nurses considered PdxBPD to be in control of their challenging behaviour This notion of control contributed to less sympathy for PdxBPD	100%
McGrath and Dowling (2012)	To explore registered psychiatric nurses' (RPNs') interactions and level of empathy towards service users with a diagnosis of borderline personality disorder (BPD)	Community mental health 17 professionals (Ireland)	Qualitative Descriptive Semi structured interviews, followed by scenarios and typical response to measure empathy	PdxBPD described as having stigma already attached to them as they arrive at the service Professionals indicated threat of suicide was the most distressing thing working with PdxBPD	80% Approach to data analysis not clear
McQuillan et al (2005)	To examine the effectiveness of an intensive version of dialectical behaviour therapy for patients in an outpatient setting who met criteria for borderline personality disorder and who were in crisis.	Outpatient dialectical behavioural therapy 127 PdxBPD (Switzerland)	Quantitative Depression Inventory, Hopelessness Scale, Social Adaptation Self-Evaluation Scale.	Treatment completion and retention rates were high, meaning this intervention is acceptable to PdxBPD PdxBPD showed improvements on depression and hopelessness scales	80% 18% participant drop out (16 of 87)
Morris, Smith and Alwin (2014)	To explore the experiences of individuals with a diagnosis of BPD in accessing adult mental	Adult mental health services 9 PdxBPD	Qualitative Semi-structured interviews	PdxBPD considered the relationship the most important thing for them,	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
	health services and to better understand which aspects of contact with services can be helpful or unhelpful.	(UK)		<p>being treated like a person and not a diagnosis or case number</p> <p>PdxBPD described non-caring care, perceiving staff reluctant, unable to work with them, unwilling or unable to dedicate time to their relationship</p> <p>PdxBPD described services as reactive not proactive regarding risk, and felt thresholds for intervention were only met in immediate risk of suicide – once crisis over service not interested in underlying distress</p> <p>PdxBPD felt that having the diagnosis meant that all difficulties were viewed in terms of BPD, distress seen as 'difficult'</p>	
Nehls (2000)	To study the day to day experiences of case managers working with PdxBPD	Community mental health 17 Professionals (USA)	Qualitative Interpretive phenomenology Unstructured interviews	<p>Crisis viewed as an ongoing and constant issue for PdxBPD</p> <p>Suicidality the biggest challenge for professionals, with difficulty in knowing how to balance over and under-concern with suicidal threat.</p> <p>Professionals felt responsibility for PdxBPD's safety was transferred from patient to professional</p>	100%
Pascual et al (2007)	This study aimed to determine factors associated with hospitalization and decisions to	Psychiatric emergency service	Quantitative Review of records including	PdxBPD accessed psychiatric emergency service through self-	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
	prescribe psychotropic medication for patients with borderline personality disorder seeking care at psychiatric emergency units.	Records of 540 PdxBPD, from 1032 visits (Spain)	sociodemographic, clinical, social, therapeutic information and Severity of Psychiatric Illness (SPI) score.	<p>referral, through ambulance and police. Ambulance most common.</p> <p>Reasons for referral included depression, anxiety, psychosis, drug abuse/dependence and disruptive behaviour.</p> <p>Most common reason for referral, outside 'other', was disruptive behaviour</p> <p>Decision to hospitalize was associated with risk of suicide, danger to others, severity of symptoms, difficulty with self-care, and noncompliance with treatment</p> <p>Psychiatrists often prescribe medications for PdxBPD in the psychiatric emergency service</p>	
Perseius et al (2005)	The aim of the study was to investigate life situations, suffering, and perceptions of encounter with psychiatric care among 10 patients with borderline personality disorder	Various psychiatric care settings 10 PdxBPD (Sweden)	Qualitative Narrative interviews	<p>PdxBPD perceive crisis as feeling on edge, being overwhelmed by emotions.</p> <p>PdxBPD may try to hide or 'mask' their distress.</p> <p>PdxBPD identified caregivers as having a double role which potentially relieves or adds to suffering.</p>	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
Philipsen, Schmahl and Lieb (2004)	To assess the impact of 0.4mg Naloxone administered intravenously compared to placebo	Inpatient and outpatient psychiatric care, recruited from Dialectical behavioural therapy programme 9 PdxBPD 5 given naloxone, 4 given placebo (Germany)	Quantitative Double blind crossover study Observer scales and self-report instruments	0.4mg Naloxone was tolerated well by all PdxBPD Naloxone showed best improvement in dissociate symptoms in those PdxBPD with the greatest number of DSM-IV BPD symptoms Naloxone not concluded to be more effective than placebo All reported subjective analgesia during self-mutilation	60% Method of participant allocation to treatment or placebo not clear PdxBPD reported subjective analgesia of self-mutilation, yet impact of injection not accounted for. PdxBPD also used personal anti-dissociative skills.
Prada et al (2017)	To assess the usability and efficiency of an App for monitoring and reduction of aversive tension in 16 PdxBPD over a 6-month period.	Recruited from dialectical behavioural therapy programme 16 PdxBPD 12 completed the self-report questionnaire (Switzerland)	Quantitative Self-report questionnaire	App was found to be user friendly and accessible Use of the app led to a reduction in aversive tension for PdxBPD (unclear the specific mechanism through which the app was successful in achieving this)	80% PdxBPD concurrently on a DBT programme which may have impacted experience
Rizq (2012)	This qualitative study explores the experiences of five primary care counsellors working in	NHS Primary Care 5 Professionals (UK)	Qualitative Interpretive phenomenology	PdxBPD were perceived as struggling to maintain boundaries, often	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
	the NHS with clients identified as diagnosable with borderline personality disorder (BPD).		Semi-structured interviews	<p>contacting professionals in crisis outwith expected contact</p> <p>Professionals often felt uncertain what do to, and whether action was needed.</p> <p>Professionals felt responsibility for the safety of PdxBPD</p> <p>Professionals felt that PdxBPD have high expectations of services and are sensitive to disappointment</p> <p>Professionals felt that therapeutic relationships were what was needed, but could re-traumatise when ending</p>	
Rogers and Acton (2012)	The aim of this study was to explore the experience of service users being treated with medication for the BPD diagnosis.	Recruited from specialist personality disorder service 7 PdxBPD (UK)	Qualitative Semi structured interviews	<p>PdxBPD felt they had little choice regarding the use of medication in an inpatient setting</p> <p>PdxBPD felt that medication was used due to a lack of resources</p> <p>PdxBPD felt that staff had been dismissive of their distress</p> <p>PdxBPD felt that staff believed that 'nothing worked for BPD' and that 'PdxBPD would be in repeated crises'</p>	100%
Rogers and Dunne (2011)	The purpose of the study was to explore the inpatient	Inpatient mental health care 10 PdxBPD	Qualitative Focus group	PdxBPD felt that staff compared them to other diagnoses, and saw	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
	experiences of service users with a personality disorder	(UK)		<p>them as having more control than patients with schizophrenia</p> <p>PdxBPD did identify some good joint decision making with professionals</p> <p>Following frequent admissions, PdxBPD felt they were just 'dumped' or left in the ward</p> <p>De facto detention described as PdxBPD were told they could be voluntary patients or they would have to be sectioned</p>	
Slotema et al (2017)	To investigate the relation between auditory verbal hallucinations (AVH) in BPD and suicidality.	Outpatient personality disorder service 89 PdxBPD 27 with auditory verbal hallucinations (AVH) 62 without AVH (Netherlands)	Quantitative Electronic medical records Psychotic symptom rating scales	<p>PdxBPD with AVH showed a higher frequency of suicidal plans and attempts in the month prior to the study</p> <p>The number of crisis service contacts and hospital admissions was higher among PdxBPD with AVH than those without</p> <p>Severity of AVH predicated presence of suicide plans</p> <p>Presence of AVH predicted shorter duration until hospitalisation</p>	100%
Staebler et al (2009)	To examine subjective emotional responses to films in borderline personality disorder at two assessment points, while	Recruited from psychiatric hospital 30 PdxBPD 27 dx with depression	Quantitative Beck depression inventory	Acute crisis defined as 'in hospital'	80% Incomplete outcome data at

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
	in acute crisis then 8 months later.	30 in non-clinical control group (Germany)	Symptom check list-90-revised (subjective experience of symptoms) Questionnaire of thoughts and feelings (QTF) Emotion Scale (self report inventory)	PdxBPD had a similar emotional reactivity to stimuli when in crisis or not in crisis When not in crisis scores on QTF (questionnaire on thoughts and feelings) PdxBPD were still in pathological range Negative thinking may be enduring in PdxBPD	2 nd assessment: 87% PdxBPD (26/30), 70% Depression (19/27)
Stiglmayr et al (2005)	This study was designed to examine the subjective appraisal of aversive tension under conditions of daily life in patients with borderline personality disorder (BPD).	Recruited from psychiatry and psychotherapy service 63 PdxBPD 40 healthy controls (Germany)	Quantitative Self-report through hand held PC	States of aversive tension occurred in PdxBPD more than in healthy controls 39% of PdxBPD described rejection, being alone, and failure as precipitating factors to aversive tension Supports view that PdxBPD experience more frequent, more intense and longer lasting aversive tension	100%
Stiglmayr et al (2008)	A systematic examination of different clinical groups' experience of inner tension.	Department of clinical psychology and psychotherapy 117 Participants 30 PdxBPD 30 dx depression 27 dx anxiety disorders 30 with no diagnosis	Mixed Methods Open questionnaire Qualitative Content Analysis	Inner tension was categorised as having cognitive, emotional, physical, and behavioural aspects of tension, action tendencies, and coping mechanisms. The experience of tension in PdxBPD is triggered by a sense of inner helplessness	90% Study did not measure the intensity of inner tension

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
		(Germany and Switzerland)		The experience of tension for PdxBPD was distinct from tension in other psychiatric disorders	
Turhan and Taylor (2016)	To assess the patterns of service use by PdxBPD taken on for crisis resolution and home treatment between 2010 and 2013.	Intensive home treatment team (IHTT) 27 PdxBPD (64 referrals) (UK)	Quantitative Demographic and clinical data collected Clinical global impression scale	<p>Majority of community referrals cited 'deterioration in mental state and increase in suicidal behaviour' as the reason for IHTT.</p> <p>A small number of patients were responsible for the majority of referrals, showing the ongoing nature of crisis for some PdxBPD.</p> <p>Improvement was noted in most PdxBPD after IHTT.</p> <p>In 34% of cases, IHTT was not enough to manage suicide risk and PdxBPD were hospitalised.</p>	100%
Veysey (2014)	To explore the experiences of eight people with a BPD diagnosis who self-identified as encountering discriminatory experiences from healthcare professionals.	8 PdxBPD (New Zealand)	Qualitative Semi structured interviews Interpretive phenomenological analysis	<p>PdxBPD experienced both helpful and discriminatory experiences with professionals</p> <p>PdxBPD with significant self-harm histories reported more discriminatory experiences</p> <p>Discriminatory experiences had an impact on PdxBPD's self-image</p>	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
				Individuals who offered PdxBPD hope through investing in them was seen to be helpful	
Walker (2009)	To examine and explore the subjective experiences of women who self-harm with a diagnosis of BPD.	4 PdxBPD (UK)	Qualitative Face to face in depth narrative interviews	<p>PdxBPD described their self-harm scars impacting on their self-hood, thinking people see the scars and not the person</p> <p>PdxBPD felt they received a reputation as a 'self-harmer' and accessing services saw professionals assume it was always the same issue</p>	100%
Warrender (2015)	This study aimed to capture staff perceptions of the impact of mentalization based therapy (MBT) skills training on their practice when working with people with a diagnosis of BPD in acute mental health.	Acute mental health unit 9 Professionals (UK)	Qualitative Focus groups Interpretive phenomenological analysis	<p>Professionals voiced confusion and uncertainty of approach, and saw the inpatient environment as not conducive to working with PdxBPD</p> <p>Hospital admissions described as recurrent and 'back, forth'</p> <p>Professionals described uncertainty in the purpose of hospital admissions for PdxBPD</p> <p>Professionals found MBT skills useful in increasing consistency of approach, ability to tolerate risk, empathy and empowerment when working with PdxBPD</p> <p>Professionals welcomed clinical supervision as a supportive measure</p>	100%

8.6. Literature review data extraction table (update)

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
Acres, Loughhead & Procter (2022)	To improve understandings of carers perspectives of emergency department nursing practice when PdxBPD are in crisis	Carer networks 13 carers of PdxBPD (Australia)	Qualitative Semi-structured focus groups	<p>Carers often use the emergency department when PdxBPD are in crisis as they have limited support options when there is threat of suicide</p> <p>Carers experienced PdxBPD being rejected and invalidated by emergency department nurses</p> <p>PdxBPD were seen to receive suitable and timely physical health care, though mental health needs were often overlooked</p> <p>Carers can feel excluded from communications with nursing staff, often on the grounds of confidentiality</p>	100%
Broadbear et al (2022)	To describe the prevalence, features and outcomes associated with emergency department presentations for PdxBPD	3 hospitals in Melbourne 700 unique BPD-related ED presentations between May 2015 and April 2016 (Australia)	Quantitative A retrospective electronic audit of 157 364 emergency department attendances	<p>Suicidal ideation, self-injury or overdose were the most common reasons for PdxBPD presenting to the emergency department</p> <p>73% of PdxBPD attended the emergency department more than once within a year</p>	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
				<p>PdxBPD were more likely to attend the emergency department via ambulance, be referred to mental health inpatients unit, and be referred to community mental health services when compared to people diagnosed with depression.</p> <p>PdxBPD accounted for only 1.8% of emergency department attendances despite reputation for high service utilisation</p>	
Campbell, Massey & Lakeman (2022)	To describe the attitudes of MHNs working in emergency departments and crisis services towards people who present with symptoms characteristic of BPD and to explore their knowledge of the diagnostic criteria of BPD.	Emergency departments and crisis settings 54 Mental health nurses (Australia)	Quantitative Descriptive survey	<p>All respondents reported having contact with PdxBPD at least several times a month</p> <p>83% believed PdxBPD were not adequately managed, 72% citing the reason as a lack of services</p> <p>The nurses role was felt to be assessment (98%), arriving at a diagnosis (81%), recommending management (96%) and providing education (93%).</p> <p>74% found working with PdxBPD to be moderately difficult, 33% stating they are more difficult to work with than people with other diagnoses</p>	<p>80%</p> <p>Convenience sample and non-response bias not addressed</p>

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
				<p>93% disagreed that PdxBPD choose to behave the way they do</p> <p>98% disagreed that 'BPD' is a self-induced disorder</p> <p>61% felt PdxBPD were manipulative and 50% felt they split staff teams</p>	
Enokksen et al (2022)	To explore how brief admission influences daily life functioning among PdxBPD and self-harming behaviour	3 psychiatric hospitals which offered brief admission 16 PdxBPD with self-harming behaviour (Sweden)	Qualitative Individual interviews	<p>Brief admission was experienced as having a positive impact on daily life functioning, and promoted self-determination and self-care.</p> <p>Brief admission shifted the power dynamic with the balance of power with the patient, enabling them to take responsibility for their condition and become aware of early deterioration</p> <p>Freedom and choice over when to use brief admission, an ability to come and go as they please, and control over discharge allowed PdxBPD to maintain employment and commitments</p> <p>Brief admission offered security through PdxBPD knowing they could access care through self-referral, and could offer respite as part of an established crisis plan</p>	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
Frías et al (2021)	To test the usability and satisfaction with a psychotherapeutic mobile app for self-managing crises in BPD	Adult mental health centre outpatients 25 PdxBPD (Spain)	Quantitative Difficulties in Emotion Regulation Scale Beck Depression Inventory The System Usability Scale	PdxBPD considered the app user friendly PdxBPD said they would use the app frequently when in crisis PdxBPD found the app soothing and felt it gave them confidence	100%
Grindey, Ottiwell & Lawrence (2023)	To evaluate a pilot service improvement which involved creating a 'managing distress' pathway, a crisis intervention for PdxBPD informed by structured clinical management	Home based treatment team 1 NHS mental health trust 8 PdxBPD 21 home based treatment team staff members (UK)	Mixed methods Service use data Semi-structured questionnaires	Significant reduction in the number of inpatient stays by PdxBPD 6 months after intervention (6) compared to 6 months before (572) Staff felt their skills and confidence in working with PdxBPD was improved PdxBPD were satisfied with their care	80% Service evaluation. No clear method of data analysis.
Helleman et al (2018)	To obtain consensus on the components of brief admission as a crisis intervention for PdxBPD	4 psychiatrists 5 advanced nurse practitioners 39 nurses 3 researchers (Netherlands)	Quantitative Modified Delphi study	100% consensus was reached on the following components of brief admission: <ul style="list-style-type: none"> Brief admission plan must be developed together with the patient The brief admission intervention should be mentioned in the care plan for the patient Not all behaviour on the part of the patient has to be accepted during a brief admission The brief admission can only be offered together with 	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
				<p>treatment by a community care professional</p> <p>There was disagreement that:</p> <ul style="list-style-type: none"> • Patient needed to be seen by ward psychiatrist when admitted for brief admission • Contact with a nurse would not be necessary during brief admission 	
Hultsjö et al (2023)	To describe experiences of brief admission of PdxBPD and self-harming behaviour, from the perspective of their relatives.	12 relatives of PdxBPD and self-harming behaviour who had access to brief admission (Sweden)	Qualitative Individual interviews	<p>The entire family can benefit from respite when PdxBPD are offered brief admission, with reduced anxiety and time to focus on other things</p> <p>Relatives felt PdxBPD had increased personal responsibility and sought help in more time, and thus maintained skills needed for daily functioning</p> <p>Brief admission was considered to be a more accessible and predictable form of care</p> <p>There were limited places for brief admission and if PdxBPD were denied access they might be more reluctant to apply in future</p>	100%
Kaurin et al (2022)	To examine how interpersonal stressors link to affect and impulsivity with suicidal ideation for PdxBPD, and how those links	Inpatient, outpatient and community settings 153 PdxBPD 52 healthy controls	Quantitative 21-day ecological momentary assessment protocol	Lower perceived warmth in others was associated with suicidal ideation.	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
	vary over time in people's daily lives	(USA)	Multilevel structural equation modelling	Interpersonal triggers impact on emotional dysregulation which leads to suicidal ideation. Suicidal crisis can unfold indirectly from interpersonal triggers	
López-Villatoro et al (2023) Point for discussion – medication may complicate data collection on emotional dysregulation	To investigate the feeling of emptiness in PdxBPD and patients diagnosed with eating disorder and its relationship with suicidal behaviour and childhood traumatic events.	Personality Disorders and Eating Disorders Day Hospitals 103 PdxBPD 107 people diagnosed with eating disorder (Spain)	Quantitative Questionnaires	PdxBPD and people diagnosed with eating disorders have similar levels of chronic feelings of emptiness, but the internal components of this feeling might be different. Suicidal behaviour was more common in PdxBPD Results may indicate that the feeling of emptiness acts as a mediator between traumatic events and suicidal behaviour in PdxBPD Feelings of emptiness could be a predictor of suicidal behaviour	100%
Lundahl et al (2023)	To explore how healthcare personnel perceive long hospital admissions for PdxBPD, and to what extent they think the use of compulsory care can be diminished.	21 psychiatric hospital wards 422 nurses and psychiatric aides (Sweden)	Mixed methods Questionnaire	68% participants felt a week's compulsory admission for PdxBPD would increase self-harming behaviour, 26% felt it had no effect. Some qualitative responses said it was 'sometimes helpful'. 69% felt compulsory admissions on their wards were too long and had detrimental impacts on PdxBPD	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
				<p>48% felt a reason for long admission was doctors fear that PdxBPD may self-harm after discharge</p> <p>Some felt that reasons PdxBPD get worse during admission could include letting go of their self-control and self-harming more, patients triggering each other, loss of skills to handle emotions, and an increase in anxiety close to discharge.</p> <p>Some felt PdxBPD demanded compulsory care to transfer responsibility to others to protect themselves from making bad decisions.</p> <p>Staff suggested improvements such as improved inpatient structure, 3-day voluntary admissions, and improved outpatient resources</p>	
McCarrick, Irving & Lakeman (2022)	To describe the experiences of psychiatric nurses working with PdxBPD in acute mental health in-patient settings	Acute mental health wards 7 nurses (Ireland)	Qualitative Individual interviews	<p>Nurses felt the kind of care they could offer to for PdxBPD did not meet their ideals, and they did not feel prepared by undergraduate training to care for PdxBPD</p> <p>Nurses expressed powerlessness, frustration, a sense of incompetence</p>	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
				<p>and poor job satisfaction when working with PdxBPD</p> <p>At times staff could consider PdxBPD's self-harm as an intentional way to upset them</p> <p>Nurses had differing views on self-harm, some saying prohibiting makes it worse, others saying it had to be absolutely prohibited</p> <p>Nurses felt inpatient care environments were not helpful in assisting recovery, and PdxBPD should be cared for by specialist services</p> <p>There could be problematic disagreements within the multi-disciplinary team around risk management of PdxBPD, and nurses felt the MDT impacted on their autonomy</p> <p>No nurses had requested or received clinical supervision</p>	
Mortimer-Jones et al (2019)	To explore perspectives of PdxBPD and staff of the Open Borders programme, a model of brief admission	Open Borders programme facility 8 PdxBPD 10 staff (nurses and nursing assistants) (Australia)	Qualitative Interviews	<p>No doctors on the site meant staff felt able to move away from the medical model</p> <p>PdxBPD valued being able to plan their own admissions and use it</p>	

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
				<p>whenever they needed it, but staff were worried about them becoming dependent on the service</p> <p>PdxBPD felt they had gained practical strategies for managing their own crises which could be an alternative to self-harm.</p> <p>Some PdxBPD had reduced incidents of self-harm.</p> <p>Staff described the emotional impact of decision making, but felt they had developed skills in setting boundaries, developing listening skills, strategies for working with PdxBPD, and supporting other staff.</p>	
Taylor, Stockton & Bowen (2023)	To understand the perceptions of crisis resolution home treatment team clinicians about their provision of recovery-orientated acute care, for PdxBPD	1 crisis resolution home treatment team 7 mental health nurses (UK)	Qualitative Individual interviews	<p>Participants recognised the importance of person-centred care through collaboration, validation and "connectedness"</p> <p>Mental health nurses felt crisis intervention was part of, but not synonymous with recovery-oriented care, given their interventions brief duration</p> <p>There may not be consistent approaches to PdxBPD given differences of individual mental</p>	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
				<p>health nurses which may be driven by strong opinion.</p> <p>Mental health nurses acknowledged anxiety around risk which can influence decision making.</p> <p>The 'BPD' label was acknowledged as powerful, and could invite suspicion and strong negative responses.</p>	
Vandyk et al (2019)	To explore frequent emergency department use by PdxBPD from their perspective	6 PdxBPD (Canada)	Qualitative Interviews	<p>PdxBPD struggled to consistently employ coping mechanisms to deal with crisis</p> <p>PdxBPD used self-management strategies such as substance use, self-harm or suicidal behaviour to manage crisis – these risky behaviours often led to emergency department via self-referral, or police or ambulance</p> <p>Loneliness could be a trigger for crisis and connecting with emergency services could alleviate this</p> <p>PdxBPD felt services struggled to meet their needs due to their severity and persistence</p>	100%

TABLE: Data Extraction					
Author (Year)	Aims	Setting and participants (Country)	Methods	Key findings	MMAT Appraisal (% of affirmative quality responses)
				<p>PdxBPD felt they were stigmatised and discriminated against as a result of their diagnosis</p> <p>Attending the emergency department can lead to feelings of guilt and shame for PdxBPD, which can fuel further crisis</p>	

8.7. Theoretical propositions

Yin (2018) suggests that bounding the case should strengthen connections between the case, research question and theoretical propositions. Theoretical propositions direct attention towards what should be examined within a study, and where to look for evidence (Yin 2018). Related to study objectives arising from integrative review, three theoretical propositions are displayed here. These were developed through integrating the findings from the integrative review with clinical experience.

Theoretical propositions
1. There may be different understandings of the ‘BPD’ diagnosis, which may impact on interactions between PdxBPD, people who support them, and HSC workers involved in their care. These may include different understandings of the diagnosis and causes, and different views of who holds responsibility for managing risk and ensuring safety and recovery.
2. There may be different motivations, perspectives and interpretations of a PdxBPD’s crisis and crisis intervention experience, these may not be communicated between or fully understood by those involved, and this may impact on experiences of care. When people do not understand each-other’s perspectives, PdxBPD’s needs may not be understood and this may lead to difficulties in interpersonal relationships and perceptions of ‘non-caring care’.
3. The interventions PdxBPD experience may focus on their behaviour, for example treating self-harm or suicidal behaviours, and may overlook what the behaviour is communicating, missing the underlying distress and impacting on the overall experience.

8.8. Public involvement

Carer support group: 30/07/2019

Literature review findings presented to carers. Attended by 2 carer advisers, and 10 individuals identifying as families and carers. Confirmed their experiences were synonymous with review findings. Following themes captured which influenced topic guide:

- Challenges communicating with the individual diagnosed with 'BPD'
- The impact on carers and families
- A lack of knowledge and skills
- Stigma around 'BPD'
- Challenges accessing care
- Difficulties in communication with professionals

Twitter/X post to people diagnosed with 'BPD': 10/01/2020



Dan Warrender
@dan_warrender



Later this year I'm hoping to do a study on experiences of crisis and crisis intervention for people diagnosed with [#borderlinepersonalitydisorder](#). I'm seeking the views of people with the diagnosis to inform how I carry out my study ethically. Please share. [#BPD](#) [#BPDChat](#)

Questions for people diagnosed with 'borderline personality disorder', regarding participation in a research study:

(please feel free to respond via social media, or email d.r.warrender2@rgu.ac.uk)

What should a researcher consider when:

- Recruiting you to the study?
- Asking questions in an interview about crisis and crisis intervention?
- Ensuring you feel safe throughout and following the process?

Do you have any additional thoughts or comments?

Many thanks for your input.

Dan Warrender

5:17 AM - 10 Jan 2020

93 Retweets 81 Likes

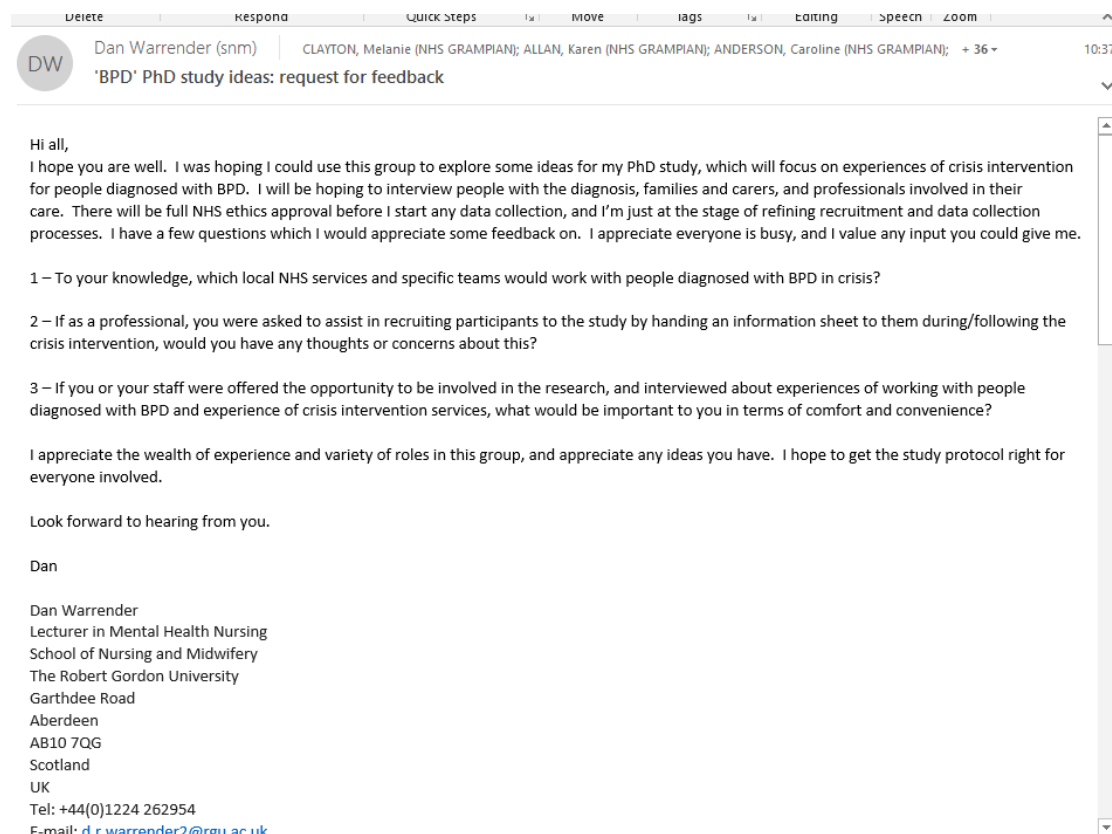


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Summary of key points (from 17 responses):

- Inform participants in detail what will happen during the study.
- Choice for participants over where interviews take place.
- Offer phone interviews for people who struggle with face to face.
- Trauma informed interviewing, including offering people choice of male or female interviewer.
- Ensure that experiences are validated.
- Support/resources offered following interview.
- Ensure anonymity and confidentiality.
- Safety.
- Support for the person after questioning.

Email sent to professionals from NHS Grampian BPD working group: 17/01/2020.



The screenshot shows an email client interface. At the top, there's a toolbar with icons for Delete, Respond, Quick Steps, Move, Tags, Editing, Speech, and Zoom. Below this is the email header: 'DW' (Dan Warrender) is the sender, and the recipients are 'CLAYTON, Melanie (NHS GRAMPIAN); ALLAN, Karen (NHS GRAMPIAN); ANDERSON, Caroline (NHS GRAMPIAN); + 36'. The subject is 'BPD' PhD study ideas: request for feedback'. The email body starts with 'Hi all,' followed by a paragraph explaining the PhD study on crisis intervention for BPD. It then lists three numbered questions for feedback. The email ends with 'I appreciate the wealth of experience and variety of roles in this group, and appreciate any ideas you have. I hope to get the study protocol right for everyone involved.' and 'Look forward to hearing from you.' The sender's full contact details are listed at the bottom.

Hi all,

I hope you are well. I was hoping I could use this group to explore some ideas for my PhD study, which will focus on experiences of crisis intervention for people diagnosed with BPD. I will be hoping to interview people with the diagnosis, families and carers, and professionals involved in their care. There will be full NHS ethics approval before I start any data collection, and I'm just at the stage of refining recruitment and data collection processes. I have a few questions which I would appreciate some feedback on. I appreciate everyone is busy, and I value any input you could give me.

1 – To your knowledge, which local NHS services and specific teams would work with people diagnosed with BPD in crisis?

2 – If as a professional, you were asked to assist in recruiting participants to the study by handing an information sheet to them during/following the crisis intervention, would you have any thoughts or concerns about this?

3 – If you or your staff were offered the opportunity to be involved in the research, and interviewed about experiences of working with people diagnosed with BPD and experience of crisis intervention services, what would be important to you in terms of comfort and convenience?

I appreciate the wealth of experience and variety of roles in this group, and appreciate any ideas you have. I hope to get the study protocol right for everyone involved.

Look forward to hearing from you.

Dan

Dan Warrender
Lecturer in Mental Health Nursing
School of Nursing and Midwifery
The Robert Gordon University
Garthdee Road
Aberdeen
AB10 7QG
Scotland
UK
Tel: +44(0)1224 262954
E-mail: d.r.warrender2@rgu.ac.uk

Responses: 4

Summary of responses:

- General practitioners, urgent referrals team, community mental health teams, Aberdeen City Enablement and Recovery Team (ACERT) and Liaison Psychiatry and some 3rd sector organisations were described as those who may see PdxBPD in crisis.
- Recruitment agents would need assurances that ethical approval had been granted
- Staff concerns at handing out a flyer or information sheet during crisis, but felt comfortable doing so at the end of intervention.
- Potential bias of staff in terms of who they offer flyers to.
- Flexible location and time would be important to ensure staff participation in the study

8.9. Participant information sheet for people diagnosed with 'borderline personality disorder'



A case study of people diagnosed with borderline personality disorder, support persons and health and social care workers experiences of crisis and crisis intervention

Participant Information Sheet Guide

People diagnosed with borderline personality disorder or emotionally unstable personality disorder

1. Study title, Investigators and Sponsor

A case study of people diagnosed with borderline personality disorder, support persons and health and social care workers experiences of crisis and crisis intervention

Chief Investigator: Professor Catriona Kennedy

Principle investigator: Dan Warrender

Sponsor: Robert Gordon University

2. Introduction

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part. I appreciate the time you are taking to read this.

3. What is the purpose of the study?

The purpose of this study is to learn from the experiences of people diagnosed with borderline personality disorder or emotionally unstable personality disorder, people who support them (which may include family, friends or other informal supports), and health and social care workers involved in their care. The study is interested in experiences of crisis, where a person feels distressed and overwhelmed, and crisis intervention, where others respond to this to aid safety and recovery. We know that this is not well understood, and understanding this from different perspectives would be valuable.

The study will take place over a few months, until there is enough information collected. You would be interviewed, and this would only be expected to take up around an hour of your time.

4. Why have I been chosen?

You have been chosen as you have a diagnosis of borderline personality disorder or emotionally unstable personality disorder, and have experienced crisis and crisis intervention within the last 12 months. Gaining an understanding of your experience is very important to this study.

5. Do I have to take part?

No. It is up to you. If you do decide to take part, you will be given this information sheet to keep, and you are free to discuss it with others and then ask any questions. You should have the information sheet for a minimum of 48 hours before agreeing to part, so you have enough time to read this carefully and ask any questions.

You would be asked to sign a consent form or give verbal consent before being interviewed. If you decide to take part, you can still change your mind and can withdraw at any time without giving a reason. A decision not to take part or to withdraw will not have any consequences for you.

6. What will happen to me if I take part?

It is important that you feel safe and in control throughout. Your interview will happen at a time and place of your choice, though the study will need to follow government guidance and research restrictions around face to face contact. If you would like to be face to face and this is permitted, it could be your home, or you are welcome to visit Robert Gordon University to meet the researcher there, and travel expenses are available. If you choose, or we are required to conduct interviews remotely, these may take place online over Microsoft teams or Zoom, or over the phone. You are also welcome to take someone along to support you if you wish.

The interviewer is male, and it would be important for you to consider whether you feel comfortable being interviewed by a man. If you want to know a little more about who will be interviewing you, Dan's staff profile is available online from this link: <https://rgu-repository.worktribe.com/person/123352/dan-warrender>

The study begins with the assumption that you have capacity, which the adults with incapacity (Scotland) act (2000) defines as being capable of acting, making decisions, communicating decisions, understanding decisions and retaining the memory of decisions. The researcher is an experienced mental health nurse and academic, and would pay close attention to your ability to make informed decisions. If there are any concerns about your capacity before or during interview, you would not be able to take part in the study and your data would not be used.

At the beginning of interview you would be asked some demographic questions, for example your age, biological sex, gender, sexual orientation and your living arrangements. During interview you would be asked questions about your experiences of crisis, when you have felt overwhelmed and struggled to cope, and your experiences of crisis intervention, when you have reached out to others and services for help. You do not have to answer any questions you are uncomfortable with. Questions are available in advance if you wish and can be obtained by contacting the researcher.

Interviews will be audio recorded using a Dictaphone or audio recording software, and then written down by the researcher and an external company who will transcribe the interview. Recording equipment and software will be password protected, and following interviews files will be uploaded to the universities secure hard drive, with original files deleted from Dictaphone or audio software. Any files shared with external transcribers would be done through a password protected file sharing site.

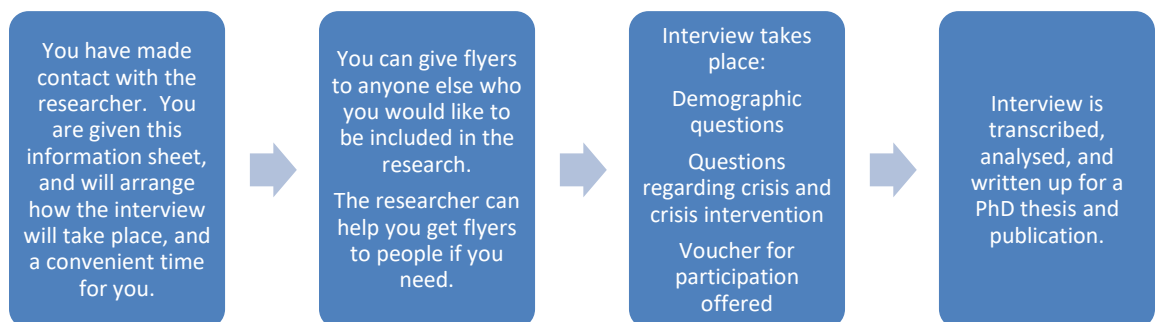
If at any point you become upset, the interviewer will offer a break, and you are still welcome to withdraw at any time. If there were concerns about your capacity, the researcher would make the decision to withdraw you from the study. If you choose to withdraw during the interview, or up until 48 hours after, your interview will not be used in the study. However, it is important you know that if you want to withdraw from the study after data analysis has started, anything recorded may still be used in the study. Things you say may be quoted in the research findings. Whilst the study will make every effort to ensure confidentiality by removing names and identifiable data, and writing in a broad manner, anonymity cannot be absolutely guaranteed.

As a small gesture of thanks for participating in the study, you would be offered a retail voucher to the value of £20.

The study also wants to learn from the experiences of people who support you, and health and social care workers involved in your care, but you will have choice over who else is included in the research. Anyone else you include in the study would be asked about their understandings of your diagnosis generally, and also specifically their experiences of supporting you. They would be asked about how they understand your experience, and also about their own experiences when you have been in crisis, including how you accessed care, their role in supporting you, and their thoughts and feelings on what is helpful or not. If you would like to see the questions they may be asked, the researcher can provide these for you.

You will be asked to give flyers to people who you would like to be included. If you need help getting a flyer to a health and social care worker, the researcher can assist with this. After getting the flyer, the people you identify would need to contact the researcher, and they could then be included. They would follow the same process you do, having an information sheet, then arranging a time to be interviewed. If you would like a joint interview with a person who supports you, this could be discussed.

A simple flowchart of what will happen is presented here:



7. What are the possible disadvantages and risks of taking part?

You will be asked to give up some time to be part of the study, though this shouldn't be any more than an hour. Questions will be around experiences of crisis and crisis intervention. As these may

have been difficult experiences for you, there is the potential that you may become upset during the interview. Remember that we want you to feel safe throughout, and you don't have to answer anything you don't want to, you are free to take a break whenever you like, and you are free to withdraw at any time. There is a prepared letter for your GP or people involved in your care, if you would like them to know that you are involved so they can appropriately support you following your involvement. You could pass this to them yourself, or the researcher would be happy to post it, but you would be under no obligation to let them know if you don't want to. You will also be given a sheet signposting to local mental health resources which may be helpful to you if you needed them, and the researcher will offer a follow up phone-call to consider how you are feeling a few days after interview.

Your safety and wellbeing is incredibly important, and if you were upset following interview or appeared to be at risk in any way, you would be encouraged to contact your GP or care team, or make use of other supports or resources you've been signposted to. While your interview will be held in confidence, there are limits to confidentiality. If there were concerns about any imminent risk of harm to yourself or anyone else, the interviewer would be obligated to pass this on to appropriate parties such as the emergency services. Nothing would be done without your knowledge.

8. What are the possible benefits of taking part?

We hope that by hearing and getting an understanding of your story, that this may give valuable information which could lead to improvements in how people diagnosed with borderline personality disorder or emotionally unstable personality disorder receive care in the future. If we involve people who support you, and health and social care workers involved in your care, we may learn how people may understand things in similar or different ways, and this may give us further suggestions as to how we could improve crisis care in the future.

As a small gesture of thanks for participating in the study, you would be offered a retail voucher to the value of £20.

9. What happens when the research study ends?

When the study ends, the interviews will be analysed and written up into a PhD thesis and articles for publication.

10. What if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions [Dan Warrender and Catriona Kennedy – Details below]. If you remain unhappy and wish to complain formally, you can do this by contacting the Robert Gordon University complaints team.

The Complaints Handling Procedure is available in different formats on request from complaints@rgu.ac.uk or telephone 01224 262195. Further information and guidance is available here: <https://www.rgu.ac.uk/complaints>.

11. How will we use information about you?

We will use the experiences you share through interview for this research project, and will also have your contact details. People who do not need to know who you are will not be able to see your name or contact details. We will keep information about you safe and secure.

All information which is collected about you during the course of the research will be kept strictly confidential. Any hard copies of any data will be stored securely and access limited to the supervisory team, with hard copies scanned and kept electronically as soon as possible. Paper copies will then be destroyed. Your contact details, consent forms and recorded interviews will be kept on the Robert Gordon University secure computer server.

Interviews will be transcribed using an external company trusted by Robert Gordon University to maintain confidentiality, and they have to follow our rules about keeping your information safe. When interviews are written up, these will have your name removed and be written in a way that no-one can work out that you took part in the study. You may choose a pseudonym for yourself if you wish.

You can stop being part of the study at any time, without giving a reason, but unless you withdraw within 48 hours of interview we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you. According to the Robert Gordon University research data management standard operating procedure, data from this project will be kept for 10 years post-study before being destroyed.

If you would like to find out more about how your information is being used, please contact the research team, or our data protection officer at the details here:

Data Protection Officer, Robert Gordon University, Garthdee, Aberdeen, AB10 7QB

Email: dp@rgu.ac.uk

Tel. +44 (0)1224 262076

12. What will happen to the results of the research study?

The results will be written up into a thesis as part of PhD study, and will also be written up for publication. This process may take up to three years following your interview. You will not be identified in any publication. If you would wish to be contacted when the results are published, the researcher will keep your contact details and get in touch.

13. Who is organising and funding the research?

The study is organised and funded by Robert Gordon University in Aberdeen. The researcher is completing this study as part of a PhD study.

14. Who has reviewed the study?

The study has been reviewed by the Robert Gordon University School of Nursing, Midwifery and Paramedic Practice ethics panel, and the East of Scotland Research Ethics Committee 1.

15. Contact for Further Information

For further information please contact Dan Warrender or Professor Catriona Kennedy at the details below.

Dan Warrender Email: d.r.warrender2@rgu.ac.uk
Professor Catriona Kennedy Email: c.m.kennedy1@rgu.ac.uk

Thank you for the time you have taken to read this and for considering to be a participant in this study.

8.10. Participant information sheet for support persons



**A case study of people diagnosed with borderline personality disorder,
support persons and health and social care workers experiences of crisis and
crisis intervention**

Participant Information Sheet Guide

Support Persons

16. Study title, Investigators and Sponsor

A case study of people diagnosed with borderline personality disorder, support persons and health and social care workers experiences of crisis and crisis intervention

Chief Investigator: Professor Catriona Kennedy

Principle investigator: Dan Warrender

Sponsor: Robert Gordon University

17. Introduction

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part. I appreciate the time you are taking to read this.

18. What is the purpose of the study?

The purpose of this study is to learn from the experiences of people diagnosed with borderline personality disorder or emotionally unstable personality disorder, people who support them (which may include family, friends or other informal supports), and health and social care workers involved in their care. The study is interested in experiences of crisis, where a person feels distressed and overwhelmed, and crisis intervention, where others respond to this to aid safety and recovery. We know that this is not well understood, and understanding this from different perspectives would be valuable.

The study will take place over a few months, until there is enough information collected. You would be interviewed, and this would only be expected to take up around an hour of your time.

19. Why have I been chosen?

You have been identified by a person diagnosed with borderline personality disorder or emotionally unstable personality disorder as someone who supports them. Gaining an understanding of your perspective is important to this study.

20. Do I have to take part?

No. It is up to you. If you do decide to take part, you will be given this information sheet to keep, and you are free to discuss it with others and then ask any questions. You should have the information sheet for a minimum of 48 hours before agreeing to part, so you have enough time to read this carefully and ask any questions.

You would be asked to sign a consent form or give verbal consent before being interviewed. If you decide to take part, you can still change your mind and can withdraw at any time without giving a reason. A decision not to take part or to withdraw will not have any consequences for you.

21. What will happen to me if I take part?

It is important that you feel safe and in control throughout. Your interview will happen at a time and place of your choice, though the study will need to follow government guidance and research restrictions around face to face contact. If you would like to be face to face and this is permitted, it could be your home, or you are welcome to visit Robert Gordon University to meet the researcher there, and travel expenses are available. If you choose, or we are required to conduct interviews remotely, these may take place online over Microsoft teams or Zoom, or over the phone. You are also welcome to take someone along to support you if you wish.

The interviewer is male, and it would be important for you to consider whether you feel comfortable being interviewed by a man. If you want to know a little more about who will be interviewing you, Dan's staff profile is available online from this link: <https://rgu-repository.worktribe.com/person/123352/dan-warrender>

The study begins with the assumption that you have capacity, which the adults with incapacity (Scotland) act (2000) defines as being capable of acting, making decisions, communicating decisions, understanding decisions and retaining the memory of decisions. The researcher is an experienced mental health nurse and academic, and would pay close attention to your ability to make informed decisions. If there are any concerns about your capacity before or during interview, you would not be able to take part in the study and your data would not be used.

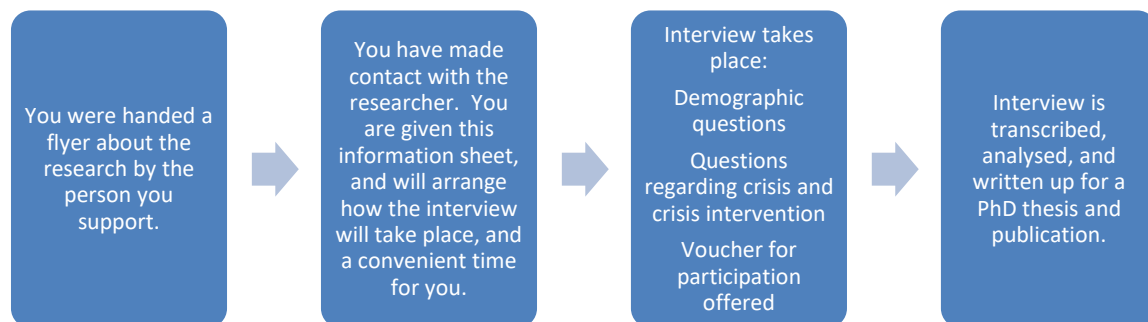
At the beginning of interview you would be asked some demographic questions, for example your age, biological sex, gender, sexual orientation and your living arrangements. During interview you would be asked questions about your experiences of the person you support feeling in crisis, when they have felt overwhelmed and struggled to cope, and your experiences of them accessing and receiving crisis intervention, when they have reached out to others and services for help. You do not have to answer any questions you are uncomfortable with. Questions are available in advance if you wish and can be obtained by contacting the researcher.

Interviews will be audio recorded using a Dictaphone or audio recording software, and then written down by the researcher and an external company who will transcribe the interview. Recording equipment and software will be password protected, and following interviews files will be uploaded to the universities secure hard drive, with original files deleted from Dictaphone or audio software. Any files shared with external transcribers would be done through a password protected file sharing site.

If at any point you become upset, the interviewer will offer a break, and you are still welcome to withdraw at any time. If there were concerns about your capacity, the researcher would make the decision to withdraw you from the study. If you choose to withdraw during the interview, or up until 48 hours after, your interview will not be used in the study. However, it is important you know that if you want to withdraw from the study after data analysis has started, anything recorded may still be used in the study. Things you say may be quoted in the research findings. Whilst the study will make every effort to ensure confidentiality by removing names and identifiable data, and writing in a broad manner, anonymity cannot be absolutely guaranteed.

As a small gesture of thanks for participating in the study, you would be offered a retail voucher to the value of £20.

A simple flowchart of what will happen is presented here:



22. What are the possible disadvantages and risks of taking part?

You will be asked to give up some time to be part of the study, though this shouldn't be any more than an hour. Questions will be around experiences of crisis and crisis intervention for the person you support who has a diagnosis of borderline personality disorder. As these may have been difficult experiences for you, there is the potential that you may become upset during the interview. Remember that we want you to feel safe throughout, and you don't have to answer anything you don't want to, you are free to take a break whenever you like, and you are free to withdraw at any time. You will also be given a sheet signposting to local mental health resources which may be helpful to you if you needed them, and the researcher will offer a follow up phone-call to consider how you are feeling a few days after interview.

While your interview will be held in confidence, there are limits to confidentiality. If there were concerns about any imminent risk of harm to anyone, the interviewer would be obligated to pass this on to appropriate parties.

23. What are the possible benefits of taking part?

We hope that by hearing and getting an understanding of your story, and your understanding of the experience of the person you support, that this may give valuable information which could lead to improvements in how people diagnosed with borderline personality disorder or emotionally unstable personality disorder receive care in the future. By hearing from people with the diagnosis, people who support them and health and social care workers involved in their care, we may learn how people may understand things in similar or different ways, and this may give us

further suggestions as to how we could improve crisis care in the future. Your perspective may also give us improved understandings of the needs of people who support people diagnosed with borderline personality disorder.

As a small gesture of thanks for participating in the study, you would be offered a retail voucher to the value of £20.

24. What happens when the research study ends?

When the study ends, the interviews will be analysed and written up into a PhD thesis and articles for publication.

25. What if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions [Dan Warrender and Catriona Kennedy – Details below]. If you remain unhappy and wish to complain formally, you can do this by contacting the Robert Gordon University complaints team.

The Complaints Handling Procedure is available in different formats on request from complaints@rgu.ac.uk or telephone 01224 262195. Further information and guidance is available here: <https://www.rgu.ac.uk/complaints>.

26. How will we use information about you?

We will use the experiences you share through interview for this research project, and will also have your contact details. People who do not need to know who you are will not be able to see your name or contact details. We will keep information about you safe and secure.

All information which is collected about you during the course of the research will be kept strictly confidential. Any hard copies of any data will be stored securely and access limited to the supervisory team, with hard copies scanned and kept electronically as soon as possible. Paper copies will then be destroyed. Your contact details, consent forms and recorded interviews will be kept on the Robert Gordon University secure computer server.

Interviews will be transcribed using an external company trusted by Robert Gordon University to maintain confidentiality, and they have to follow our rules about keeping your information safe. When interviews are written up, these will have your name removed and be written in a way that no-one can work out that you took part in the study. You may choose a pseudonym for yourself if you wish.

You can stop being part of the study at any time, without giving a reason, but unless you withdraw within 48 hours of interview we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you. According to the Robert Gordon University research data management standard operating procedure, data from this project will be kept for 10 years post-study before being destroyed.

If you would like to find out more about how your information is being used, please contact the research team, or our data protection officer at the details here:

Data Protection Officer, Robert Gordon University, Garthdee, Aberdeen, AB10 7QB

Email: dp@rgu.ac.uk

Tel. +44 (0)1224 262076

27. What will happen to the results of the research study?

The results will be written up into a thesis as part of PhD study, and will also be written up for publication. This process may take up to three years following your interview. You will not be identified in any publication. If you would wish to be contacted when the results are published, the researcher will keep your contact details and get in touch.

28. Who is organising and funding the research?

The study is organised and funded by Robert Gordon University in Aberdeen. The researcher is completing this study as part of a PhD study.

29. Who has reviewed the study?

The study has been reviewed by the Robert Gordon University School of Nursing, Midwifery and Paramedic Practice ethics panel, and the East of Scotland Research Ethics Committee 1.

30. Contact for Further Information

For further information please contact Dan Warrender or Professor Catriona Kennedy at the details below.

Dan Warrender Email: d.r.warrender2@rgu.ac.uk
Professor Catriona Kennedy Email: c.m.kennedy1@rgu.ac.uk

Thank you for the time you have taken to read this and for considering to be a participant in this study.

8.11. Participant information sheet for health and social care workers



**A case study of people diagnosed with borderline personality disorder,
support persons and health and social care workers experiences of crisis and
crisis intervention**

Participant Information Sheet Guide

Health and Social Care Workers

31. Study title, Investigators and Sponsor

A case study of people diagnosed with borderline personality disorder, support persons and health and social care workers experiences of crisis and crisis intervention

Chief Investigator: Professor Catriona Kennedy

Principle investigator: Dan Warrender

Sponsor: Robert Gordon University

32. Introduction

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part. I appreciate the time you are taking to read this.

33. What is the purpose of the study?

The purpose of this study is to learn from the experiences of people diagnosed with borderline personality disorder or emotionally unstable personality disorder, people who support them (which may include family, friends or other informal supports), and health and social care workers involved in their care. The study is interested in experiences of crisis, where a person feels distressed and overwhelmed, and crisis intervention, where others respond to this to aid safety and recovery. We know that this is not well understood, and understanding this from different perspectives would be valuable.

The study will take place over a few months, until there is enough information collected. You would be interviewed, and this would only be expected to take up around an hour of your time.

34. Why have I been chosen?

You have been identified by a person diagnosed with borderline personality disorder or emotionally unstable personality disorder as someone who was involved in their care during crisis intervention. Gaining an understanding of your perspective is important to this study.

35. Do I have to take part?

No. It is up to you. If you do decide to take part, you will be given this information sheet to keep, and you are free to discuss it with others and then ask any questions. You should have the information sheet for a minimum of 48 hours before agreeing to part, so you have enough time to read this carefully and ask any questions.

You would be asked to sign a consent form or give verbal consent before being interviewed. If you decide to take part, you can still change your mind and can withdraw at any time without giving a reason. A decision not to take part or to withdraw will not have any consequences for you.

36. What will happen to me if I take part?

It is important that you feel safe and in control throughout. Your interview will happen at a time and place of your choice, though the study will need to follow government guidance and research restrictions around face to face contact. If you would like to be face to face and this is permitted, it could be your home, or your place of work, or you are welcome to visit Robert Gordon University to meet the researcher there, and travel expenses are available. If you choose, or we are required to conduct interviews remotely, these may take place online over Microsoft teams or Zoom, or over the phone.

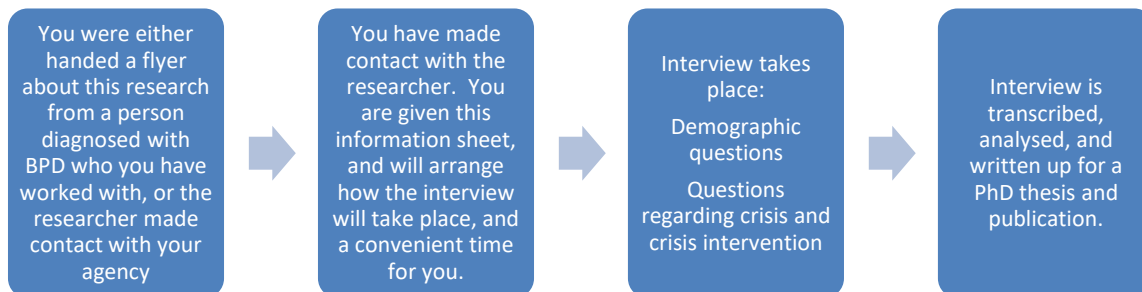
If you want to know a little more about who will be interviewing you, Dan's staff profile is available online from this link: <https://rgu-repository.worktribe.com/person/123352/dan-warrender>

At the beginning of interview you would be asked some demographic questions, for example your age, job title, role and years qualified in your profession. During interview you would be asked questions about your experiences of the person diagnosed with borderline personality disorder whom you worked with when they were feeling in crisis, and your experiences of them accessing and receiving crisis intervention, when they have reached out to health and social care workers for help. You would be asked questions on BPD/EUPD in general, as well as specifically about the person you cared for and your interactions with them. You do not have to answer any questions you are uncomfortable with. Questions are available in advance if you wish and can be obtained by contacting the researcher.

Interviews will be audio recorded using a Dictaphone or audio recording software, and then written down by the researcher and an external company who will transcribe the interview. Recording equipment and software will be password protected, and following interviews files will be uploaded to the universities secure hard drive, with original files deleted from Dictaphone or audio software. Any files shared with external transcribers would be done through a password protected file sharing site.

If at any point you become uncomfortable, the interviewer will offer a break, and you are still welcome to withdraw at any time. If you choose to withdraw during the interview, or up until 48 hours after, your interview will not be used in the study. However, it is important you know that if you want to withdraw from the study after data analysis has started, anything recorded may still be used in the study. Things you say may be quoted in the research findings. Whilst the study will make every effort to ensure confidentiality by removing names and identifiable data, and writing in a broad manner, anonymity cannot be absolutely guaranteed.

A simple flowchart of what will happen is presented here:



37. What are the possible disadvantages and risks of taking part?

You will be asked to give up some time to be part of the study, though this shouldn't be any more than an hour. Questions will be around experiences of crisis and crisis intervention for the person you worked with who has a diagnosis of borderline personality disorder. As these may have been difficult experiences for you, there is the potential that you may become upset during the interview. Remember that we want you to feel comfortable throughout, and you don't have to answer anything you don't want to, you are free to take a break whenever you like, and you are free to withdraw at any time. You will also be given a sheet signposting to local mental health resources which may be helpful to you if you needed them, a list of clinical supervisors should you wish professional support, and you will be given links to self-referral for the NHS Grampian Psychological Resilience Hub.

While your interview will be held in confidence, there are limits to confidentiality. If there were concerns about any imminent risk of harm to anyone, the interviewer would be obligated to pass this on to appropriate parties.

38. What are the possible benefits of taking part?

We hope that by hearing and getting an understanding of your story, and your understanding of the experience of the person diagnosed with borderline personality disorder or emotionally unstable personality disorder whom you worked with, that this may give valuable information which could lead to improvements in how people receive care in the future. By hearing from people with the diagnosis, people who support them and health and social care workers involved in their care, we may learn how people may understand things in similar or different ways, and this may give us further suggestions as to how we could improve crisis care in the future. Your perspective may also give us improved understandings of the training and support needs of people who work with people diagnosed with borderline personality disorder when they are in crisis.

39. What happens when the research study ends?

When the study ends, the interviews will be analysed and written up into a PhD thesis and articles for publication.

40. What if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions [Dan Warrender and Catriona Kennedy – details below]. If you remain unhappy and wish to complain formally, you can do this by contacting the Robert Gordon University complaints team.

The Complaints Handling Procedure is available in different formats on request from complaints@rgu.ac.uk or telephone 01224 262195. Further information and guidance is available here: <https://www.rgu.ac.uk/complaints>.

41. How will we use information about you?

We will use the experiences you share through interview for this research project, and will also have your contact details. People who do not need to know who you are will not be able to see your name or contact details. We will keep information about you safe and secure.

All information which is collected about you during the course of the research will be kept strictly confidential. Any hard copies of any data will be stored securely and access limited to the supervisory team, with hard copies scanned and kept electronically as soon as possible. Paper copies will then be destroyed. Your contact details, consent forms and recorded interviews will be kept on the Robert Gordon University secure computer server.

Interviews will be transcribed using an external company trusted by Robert Gordon University to maintain confidentiality, and they have to follow our rules about keeping your information safe. When interviews are written up, these will have your name removed and be written in a way that no-one can work out that you took part in the study. You may choose a pseudonym for yourself if you wish.

You can stop being part of the study at any time, without giving a reason, but unless you withdraw within 48 hours of interview we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you. According to the Robert Gordon University research data management standard operating procedure, data from this project will be kept for 10 years post-study before being destroyed.

If you would like to find out more about how your information is being used, please contact the research team, or our data protection officer at the details here:

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Email: dp@rgu.ac.uk

Tel. +44 (0)1224 262076

42. What will happen to the results of the research study?

The results will be written up into a thesis as part of PhD study, and will also be written up for publication. This process may take up to three years following your interview. You will not be identified in any publication. If you would wish to be contacted when the results are published, the researcher will keep your contact details and get in touch.

43. Who is organising and funding the research?

The study is organised and funded by Robert Gordon University in Aberdeen. The researcher is completing this study as part of a PhD study.

44. Who has reviewed the study?

The study has been reviewed by the Robert Gordon University School of Nursing, Midwifery and Paramedic Practice ethics panel, and the East of Scotland Research Ethics Committee 1

45. Contact for Further Information

For further information please contact Dan Warrender or Professor Catriona Kennedy at the details below.

Dan Warrender Email: d.r.warrender2@rgu.ac.uk
Professor Catriona Kennedy Email: c.m.kennedy1@rgu.ac.uk

Thank you for the time you have taken to read this and for considering to be a participant in this study.

8.12. Consent form



Consent form

Title of study: A case study of people diagnosed with borderline personality disorder, support persons and health and social care workers experiences of crisis and crisis intervention	
Participant ID Number:	
IRAS reference: 296337	
Name of CI: Prof. Catriona Kennedy	Name of PI: Dan Warrender
Consent:	Please initial
I confirm that I have read and understand the information sheet (Version No: 5 Date: 29/10/2021) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. Data collected up until the point of withdrawal may still be used in analysis.	
I understand that data collected during the study, may be looked at by individuals from Robert Gordon University. I give permission for these individuals to have access to my data.	
I agree to my interview being audio recorded. I understand that anonymised quotations from this interview may be used for presentations and publications.	
I agree that the supportive person and the health and social care worker I have identified may be included in the study, and that they may discuss my ongoing care and experiences.	
I agree that my interview may be transcribed by an external company contracted by Robert Gordon University	
I agree for my information to be stored in secure locations designated by Robert Gordon University.	
I consent to my GP or relevant care team receiving a letter informing them that I am taking part in the study	
I agree to take part in the above study.	

Name of participant

Date

Signature

Name of researcher

Date

Signature

One copy for participant, one copy for researcher

8.13. Topic guide for people diagnosed with ‘borderline personality disorder’



A case study of people diagnosed with borderline personality disorder, support persons and health and social care workers experiences of crisis and crisis intervention

**Topic Guide for
people diagnosed with borderline personality disorder**

Demographic Questions:

Inform participants they may choose not to answer any question

- Age
- Ethnicity
- Gender/sex
- Sexual orientation
- Marital status
- Family/dependents
- Employment
- Living alone/cohabiting/with parents?
- When were you given the BPD diagnosis?
- How recent was your last crisis and contact with health services?

Prompts for all questions

Many questions are broad and allow the freedom for participants to answer as they wish, but some questions may benefit from mentalizing prompts around thoughts, feelings and behaviour such as; “what did you think? What did you feel? What did you do?”.

How do you understand your BPD/EUPD diagnosis?
What does it mean to you?

The word ‘crisis’ is often used to describe when people feel overwhelmed and can’t cope. How do you describe this?

What kinds of things or triggers would you say lead you to feel overwhelmed and in crisis?

How do you make sense of these things and how they upset you?

How would you describe your experience of being in crisis and feeling overwhelmed?

What is it like for you?

When you feel overwhelmed and in crisis, what would you yourself do to try and get through it?

At what point would you need to seek help?

Who would you go to for help?

What is your experience of trying to get help from them?

How do you make contact and access care?

How easy is it? How challenging?

What do you think people are trying to do when they support you?

When you get support from HSC workers, what do you think they are trying to do?

What do you find helpful when people try and support you through crisis?

When support goes well, what happens? What does good support look like?

What do you find unhelpful when people try and support you through crisis?

What is missing from the support you are offered?

What do you think may help your support person and/or HSC workers better support you?

Thinking about the people that you get help from when you're in crisis, what do you think their experience is of trying to help you?

What do you think would make things better for people diagnosed with BPD?

Is there any one thing you feel is most important for improving crisis care for PdxBPD?

Do you have anything else you'd like to add?

8.14. Topic guide for support persons



A case study of people diagnosed with borderline personality disorder, support persons and health and social care workers experiences of crisis and crisis intervention

Topic Guide for Support Persons

Demographic Questions:

Inform participants they may choose not to answer any question

- Age
- Ethnicity
- Gender/sex
- Sexual orientation
- Marital status
- Family/dependents
- Employment
- Living alone/cohabiting
- When was the person you support given the BPD diagnosis?
- How recent was the person you support's last crisis and contact with health services?

Prompts for all questions

Many questions are broad and allow the freedom for participants to answer as they wish, but some questions may benefit from mentalizing prompts around thoughts, feelings and behaviour such as; "what did you think? What did you feel? What did you do?".

What is your understanding of BPD/EUPD?

What do you recognise as the triggers that lead the person into crisis?

What is your understanding of the triggers or things that lead the person to become overwhelmed?

How would you describe the persons experience of being in crisis and feeling overwhelmed? What is going on for them?

What is it like for you when they are in crisis?

How would you know the person needs support? Do they contact you, or do you notice?

Other than you, who would the person normally go to for help?

What has been your experience of them accessing crisis care?
How easy is it? How challenging?

What do you try and do to support the person? How do you support the person when they are in crisis?

What do you think is the purpose of professional support?

What do you think helps them or doesn't help them through crisis?

What do you think is unhelpful when they are in crisis?

Is there anything missing from the support you are able to offer to the person?

Is there anything missing from the support offered by HSC workers?
What would help you in providing support to the person?

When you are supporting the person, who supports you and what support do you receive?

What do you think would make things better for people diagnosed with BPD?

What may make things better for people supporting PdxBPD?
What is the most important thing from what you've mentioned?

Do you have anything else you'd like to add?

8.15. Topic guide for health and social care professionals



A case study of people diagnosed with borderline personality disorder, support persons and health and social care workers experiences of crisis and crisis intervention

Topic Guide for Health and Social Care Workers

Demographic Questions:

Inform participants they may choose not to answer any question

- Age
- Ethnicity
- Gender/sex
- Professional training or qualifications
- Current role/job title
- Length of time working with people diagnosed with BPD

Prompts for all questions

Many questions are broad and allow the freedom for participants to answer as they wish, but some questions may benefit from mentalizing prompts around thoughts, feelings and behaviour such as; "what did you think? What did you feel? What did you do?".

What is your understanding of BPD/EUPD?

What do you recognise as the triggers that led the person into crisis?

What is your understanding of things which might trigger or lead the person to experience crisis?

What is your understanding of the persons crisis experience? What is going on for them?

What is it like for you when they are in crisis?

What is your understanding of the pathway for the person to receive appropriate crisis care?

What has been your experience of them accessing crisis care?
How easy is it? How challenging?

Can you describe the crisis intervention you offer?

What is the purpose of the crisis intervention you deliver?

How do you support PdxBPD when they are in crisis?

What do you think is helpful for helping them through crisis?

What do you think is unhelpful when they are in crisis?

Is there anything missing from the support you can offer people?

What would help HSC workers provide support to PdxBPD?

When you are working with PdxBPD, what support do you receive as an HSC worker?

If there was one thing which you think would make things better for people diagnosed with BPD, what do you think it would be?

What may make things better for health and social care workers supporting PdxBPD? What is the most important thing from what you've mentioned?

Do you have anything else you'd like to add?

8.16. RGU School of Nursing, Midwifery and Paramedic Practice: internal ethical approval

Dan Warrender
PhD student
School of Nursing, Midwifery and Paramedic Practice
RGU

02 February 2021

SERP reference number: 21-01

Dear Dan,

A case study of people diagnosed with borderline personality disorder, support persons and health and social care workers experiences of crisis and crisis intervention


Thank you for submitting your application for ethical approval. The School of Nursing, Midwifery & Paramedic Practice Ethics Review panel has now reviewed the above research proposal. Your proposal has been approved. You may go ahead with your research unless the project requires further approval. Where the project involves NHS patients, approval through IRAS system must be obtained. Where the project involves NHS staff, approval through the NHS R&D office must be obtained and this is usually done through IRAS. <https://www.myresearchproject.org.uk/> Please email a copy of this approval letter along with your study protocol to Jill Johnston j.johnston4@rgu.ac.uk who tracks NHS IRAS applications on behalf of Sponsor Professor Cherry Wainwright.

SERP approval is valid for 1 year from the date of this letter. If your data collection period progresses beyond 1 year please notify the SERP convenor.

Please include your SERP reference number in a footer on all documents related to your study.

If you require further information please contact the committee by email at SNMP-SERP@rgu.ac.uk

Yours sincerely



Dr Aileen Grant
SNMP SERP Convenor on behalf of the committee.

8.17. Ethical approval from East of Scotland Research Ethics Service



East of Scotland Research Ethics Service (EoSRES)

Research Ethics Service

Tayside medical Science Centre
Residency Block Level 3
George Pirie Way
Ninewells Hospital and Medical School
Dundee DD1 9SY

Professor Catriona Kennedy
Queens Nursing Institute
School of Nursing, Midwifery & Paramedic Practice
Ishbel Gordon Building
Robert Gordon University
Aberdeen
AB10 7QE

Date: 10 September 2021
Your Ref:
Our Ref: LR/21/ES/0074
Enquiries to: Mrs Lorraine Reilly
Direct Line: 01382 383878
Email: tay.eosres@nhs.scot

Dear Professor Kennedy

Study title: A case study of people diagnosed with 'borderline personality disorder', support persons and health and social care workers: experiences of crisis and crisis intervention
REC reference: 21/ES/0074
Protocol number: NA
IRAS project ID: 296337

Thank you for your letter dated 25 August 2021, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and Scientific Officer.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The [UK Policy Framework for Health and Social Care Research](#) sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of [research transparency](#):

1. [registering research studies](#)
2. [reporting results](#)
3. [informing participants](#)
4. [sharing study data and tissue](#)



Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that all clinical trials are registered on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/>)

If you have not already included registration details in your IRAS application form, you should notify the REC of the registration details as soon as possible.

Further guidance on registration is available at: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/>

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: <https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/>

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: <https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/>



It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at <https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [RGU Ethical Approval]		02 February 2021
Copies of materials calling attention of potential participants to the research [Recruitment flyer 1]	3	21 August 2021
Copies of materials calling attention of potential participants to the research [Recruitment flyer 2]	2	21 August 2021
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity Insurance]		01 August 2020
GP/consultant information sheets or letters [Care team letter]	1	25 August 2021
Interview schedules or topic guides for participants [Topic Guide 1 (Participant)]	1	11 June 2021
Interview schedules or topic guides for participants [Topic Guide 2 (Support Persons)]	1	11 June 2021
Interview schedules or topic guides for participants [Topic Guide 3 (Health and Social Care Workers)]	1	11 June 2021
IRAS Application Form [IRAS_Form_24062021]		24 June 2021



Other [Lone Working Protocol]		
Other [Public Involvement Table]		
Other [Nick Fyfe (Sponsor Approval)]		
Other [Signposting participant to resources]	1	14 March 2021
Other [Study Exemption Form]	4	24 September 2020
Other [Evidence of peer review (SERP letter)]		13 January 2021
Other [Evidence of peer review (transfer VIVA feedback)]		29 January 2021
Other [Response to request for further information]		25 August 2021
Participant consent form [highlighted changes]	2	25 August 2021
Participant information sheet (PIS) [PIS 1 (Participant) - highlighted changes]	4	25 August 2021
Participant information sheet (PIS) [PIS 2 (Support Person) - highlighted changes]	4	25 August 2021
Participant information sheet (PIS) [PIS 3 (Health and Social Care Workers) - highlighted changes]	4	25 August 2021
Research protocol or project proposal [Research Proposal - highlighted changes]	4	25 August 2021
Summary CV for Chief Investigator (CI) [CI CV]		21 May 2021
Summary CV for student [Student CV]		21 May 2021
Summary CV for supervisor (student research) [Supervisor CV]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities— see details at: <https://www.hra.nhs.uk/planning-and-improving-research/learning/>



IRAS project ID: 296337 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



pp
Dr Bannin de Witt Jansen
Scientific Officer

Email: tay.eosres@nhs.scot

Enclosures: After ethical review – guidance for researchers

Copy to: Ms Jill Johnston

8.18. NHS Research and Development Approval

Research and Development Foresterhill House Annexe
Foresterhill
ABERDEEN
AB25 2ZB



Dan Warrender
RGU

Date 21/10/2021
Project No 2021RG003E

Enquiries to Linda Leith
Extension 53846
Direct Line 01224 553846
Email gram.randdpermissions@nhs.scot

Dear Warrender

Management Permission for Non-Commercial Research

STUDY TITLE: A case study of people diagnosed with 'borderline personality disorder', support persons and health and social careworkers: experiences of crisis and crisis intervention
PROTOCOL NO: V4, 25.8.21
REC REF: 21/ES/0074
IRAS REF: 296337

Thank you very much for sending all relevant documentation. I am pleased to confirm that the project is now registered with the NHS Grampian Research & Development Office. The project now has R & D Management Permission to proceed locally. This is based on the documents received from yourself and the relevant Approvals being in place.

All research with an NHS element is subject to the UK Policy Framework for Health and Social Care Research (2017 v3), and as Chief or Principal Investigator you should be fully committed to your responsibilities associated with this.

R&D Permission is granted on condition that:

- 1) The R&D Office will be notified and any relevant documents forwarded to us if any of the following occur:
 - Any Serious Breaches in Grampian (Please forward to pharmaco@abdn.ac.uk).
 - A change of Principal Investigator in Grampian or Chief Investigator.
 - Any change to funding or any additional funding
- 2) When the study ends, the R&D Office will be notified of the study end-date.
- 3) The Sponsor will notify all amendments to the relevant National Co-ordinating centre. For single centre studies, amendments should be notified to the R&D office directly.

We hope the project goes well, and if you need any help or advice relating to your R&D Management Permission, please do not hesitate to contact the office.

Yours sincerely



Susan Ridge
Non-Commercial Manager

cc: CI Professor Catriona Kennedy
Dr Flora Douglas
Jill Johnston
Research Monitor
Nicola Price
Rituka Richardson
Louise Milne

Sponsor: Robert Gordon University

8.19. Recruitment flyer

ROBERT GORDON
UNIVERSITY ABERDEEN

Version 3, 21/08/2021

Have you recently felt in **CRISIS**
and needed to **ACCESS HELP?**

Crisis is when we become overwhelmed, and feel like we don't have the ability to cope. During these times we may need help from others.

This study wants to learn from the experiences of people diagnosed with borderline personality disorder or emotionally unstable personality disorder, in how they experience crisis and what may help.

If you have either of these diagnoses, have felt in crisis and experienced crisis intervention any time over the last 12 months and would like to share your experiences, you are invited to take part in a research study.

For more information, please contact:
Dan Warrender
E: d.r.warrender2@rgu.ac.uk

8.20. Recruitment flyer for snowball sampling

The flyer has a geometric design with purple and blue diagonal stripes. At the top left is the Robert Gordon University Aberdeen logo. At the top right is the version number. The main title is centered in the upper half. The body text is in the middle, and the contact information is at the bottom right.

ROBERT GORDON
UNIVERSITY ABERDEEN

Version 2, 21/08/2021

Exploring the
experiences
of people who **support others**

You have been identified by a person
who would like you to be part of a research study
which they are involved in.

The research is focusing on people diagnosed
with borderline personality disorder or emotionally unstable
personality disorder, people who support them
and health and social care workers who work with them.
The study will interview people about their experiences
of supporting people with these diagnoses
when they are in crisis, and their experiences
of crisis intervention

For more information, please contact:
Dan Warrender
E: d.r.warrender2@rgu.ac.uk

8.21. Signposting to helpful resources

Version 1, 14/03/2021



Signposting to helpful resources

Thank you so much for taking the time to share your story with me. I appreciate this may not have been easy at times, and I have prepared a list of resources which may be helpful. You may have used some of these before, and some may be new to you, and I would encourage you to seek support should you need it. Remember if you have any immediate worries about your own or others mental health you could also contact your G.P.

I've selected a few of these local resources from the ACVO mental health directory, though there are more available at:

<https://acvo.org.uk/resources/mental-health/mental-health-directory/>

Aberdeen and Aberdeenshire 1st Response (Penumbra)

The 1st Response Service provides a first response and information service for people in Aberdeen aged 16 years and above with mental health problems. The service is for people who require immediate, short term support and those who may be in distress or in crisis. Support is provided by telephone, email, text or through face to face appointments. There is NO application form and NO waiting list. You can contact 1st Response Monday – Friday, 9am – 5pm.

Aberdeen:

Website: www.penumbra.org.uk/service-locations/north-area-services/aberdeen/aberdeen-1st-response/

T: 0800 234 3695 (Freephone)

E: aberdeen1stresponse@penumbra.org.uk

Aberdeenshire:

Website: www.penumbra.org.uk/service-locations/north-area-services/aberdeenshire/aberdeenshire-first-response/

T: 0800 1357950

E: aberdeenshire1stresponse@penumbra.org.uk

Aberdeen Counselling and Information Service (Mental Health Aberdeen):

Website: www.mha.uk.net/services/acis/index.php
T: 01224 573892
E: acis.office@mhaberdeen.org.uk

Aberdeen and Aberdeenshire Nova Service (Penumbra)

Penumbra's Aberdeen Nova Service provide flexible, person-centred, recovery-focused support. Nova Services provide 1:1 support, POWWOWS (Penumbra Workshops on Wellbeing) and Peer Support.

Aberdeen:

Website: <https://www.penumbra.org.uk/service-locations/north-area-services/aberdeen/aberdeen-nova-service/>

T: 01224 621 266

E: aberdeen.nova@penumbra.org.uk

Aberdeenshire:

T: 01261 833892

E: pauline.forbes@penumbra.org.uk
– Support Manager

E: emma.watson@penumbra.org.uk
– Assistant Support Manager

BPD Support Aberdeen:

A safe space to build a community of support for people diagnosed with BPD (Borderline Personality Disorder or similar emotional traits).

Facebook page: www.facebook.com/BPDtogether/

Facebook messenger: m.me/BPDtogether
E: bpdaberdeen@gmail.com

Breathing Space:

A free confidential phone service for anyone in Scotland experiencing low mood, depression or anxiety

Website: <http://breathingspace.scot/>
Helpline: 0800 838587

Cairns Counselling:

Cairns Counselling has been dedicated to providing counselling to the people of Aberdeen city and the surrounding area since 1994.

As a well-established service, we are trusted by many professionals and have a long history of enabling change.

Website: www.cairnscounselling.org.uk/
T: 01224 633131
E: info@cairnscounselling.org.uk

Harmless:

Harmless is a user led organisation that provides a range of services about self harm and suicide prevention including support, information, training and consultancy to people who self harm, their friends and families and professionals and those at risk of suicide.

Website: www.harmless.org.uk/

Rape Crisis Grampian:

An organisation providing support and advocacy to anyone who has experienced rape and sexual violence.

Website: www.rapecrisisgrampian.co.uk/
T: 01224 590932
E: info@rapecrisisgrampian.co.uk

Samaritans

Whatever you're going through, a Samaritan will face it with you. We're here 24 hours a day, 365 days a year.

Webpage with further links: www.samaritans.org/scotland/how-we-can-help/contact-samaritan/
T: 116 123

Email: jo@samaritans.org

Self-help app: <https://selfhelp.samaritans.org/>

Self Harm Project Aberdeen (Penumbra)

The Aberdeen Self Harm Service was opened in 2004 to provide a recovery focused, non-judgemental and user led support service to people who self-harm in Aberdeen City.

Website: www.penumbra.org.uk/service-locations/north-area-services/aberdeen/self-harm/
T: 01224 621 266
E: selfharm.aberdeen@penumbra.org.uk

Support Group for Partners and Families of those with Borderline Personality Disorder

Website: www.thirdlevelfoundation.co.uk/positive-parent-contact-centre/support-group-for-partners-of-those-with-borderline-personality-disorder

www.thirdlevelfoundation.co.uk/contact
T: 0800 021 7704
Text on: 07794 415410

Aberdeen City Carers Support Service

Mental Health Inforum Carers Group.
T: 01224 914036
E: aberdeencarers@quarriers.org.uk

Quarriers Aberdeenshire Carers Service

Wardes Road, Inverurie, AB51 3TT
T: 01467 538700
E: aberdeenshirecarers@quarriers.org.uk

