Designing an intervention to support carers of people diagnosed with Borderline Personality Disorder

Emma Lamont

University of Stirling

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Abstract

Background: Borderline personality disorder (BPD) is a highly disabling and enduring mental health condition, which is estimated to affect 1.6% of the general population. Family and carers often play a vital role in supporting a person with BPD. However, despite the United Kingdom (UK) carer support policies, evidence indicates there is a lack of services, support, and effective interventions for this population of carers. This study aims to explore the experiences and needs of carers supporting people with BPD and work with them to co-design an evidence-based supportive intervention tailored specifically for them.

Methods: This is a qualitative study utilising Facet Methodology. Semi-structured interviews were conducted with 20 carers and to co-design the intervention focus groups with 14 professional or carer stakeholders. Framework analysis was used to analyse the data, thereafter a socioecological model was developed to understand the social contexts in which carers' experiences occurred. The Six-Step Quality Intervention Development (6SQuID) framework guided the intervention design, involving carers and professional stakeholders throughout the process. Thereafter, the Template for Intervention Description and Replication (Tidier) supported the development of a comprehensive and accurate implementation plan.

Findings: Four overarching themes were identified from the analysis of carers' experiences and needs: i) Trauma by association; ii) Social and emotional isolation; ii) Beyond coping, and iii) Carers are people who need support too. The socioecological model showed the main focus for intervention should be social and emotional support and information and education about BPD. This informed the co-design of a multi-component intervention called Calm and Connected, consisting of an educational website, skills course, and peer support group.

In conclusion: This thesis makes a significant contribution to knowledge concerning the experiences and needs of carers of people with BPD. The studies generate an evidence base that has implications for policy and practice, presenting credible theories to support the future development of interventions for carers.

Acknowledgments

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Abbreviations

APA	American Psychiatric Association
BPD	Borderline Personality Disorder
CAU	Care as Usual
DBT	Dialectical Behaviour Therapy
DSM	Diagnostic Statistical Manual
FA	Framework Analysis
ICD	International Classification of Disease
JBI-QARI	Joanna Briggs institute qualitative assessment and review instrument
MRC	Medical Research Council
MWC	Mental Welfare Commission
NHS	National Health Service
NICE	National Institute for Health and Care Excellence Clinical Guideline
PD	Personality Disorder
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PTSD	Post-Traumatic Stress Disorder
PTM	Power Threat Meaning
RCP	Royal College of Psychiatrists
RCT	Randomised Controlled Trial
SMI	Severe Mental Illness
6SQUiD	Six Essential Steps for Quality Intervention Development (6SQuID)
TIDier	Template for Intervention Description and Replication
UK	United Kingdom
USA	United States of America
WHO: ICD	World Health Organisation [WHO]: International Classification of Disease

Chapter One: Introduction and context for the study

This thesis is about a poorly understood, and under-served population of carers, affected by a loved ones' mental health condition – the carers of people with a borderline personality disorder.

This thesis contains six chapters:

- Chapter One introduces the study by giving an overview of borderline personality disorder (BPD), and the current literature about carers' experiences, needs, and existing interventions. This culminated in presenting the rationale for the study, and the research questions underpinning this thesis.

- Chapter Two presents a review of the literature focusing on current evidence-based interventions to support carers of people with severe mental illness (SMI), inclusive of BPD.

- Chapter Three presents the methods and methodology undertaken for a qualitative study investigating carers of people with BPDs' experiences and needs, thereafter, co-designing a supportive intervention with key stakeholders.

- Chapter Four presents the findings of the qualitative study into the experiences and needs of carers of people with BPD.

- Chapter Five discusses how the intervention design process was actioned alongside the involvement of a stakeholder group, describing the key components and content of the supportive intervention for carers.

- Chapter Six provides a full discussion of the thesis findings, considering these in the context of existing literature and policy context. It also reflects upon the strengths and limitations of the research conducted and makes recommendations for policy, practice, and future research.

1.1   INTRODUCTION

The focus of this thesis was to explore the experiences and needs of carers supporting a person with borderline personality disorder BPD and design an evidence-based supportive intervention tailored to meet their needs.

According to the International Classification of Disease, 11th Revision [ICD-11]: World Health Organisation [WHO] (2018), BPD is a highly disabling and enduring mental health condition that becomes evident in adolescence or early adulthood and is associated with significant distress and impairments in personal, family, social, educational, and occupational functioning. BPD varies in severity and can be classified as mild, moderate, or severe (ICD:11 WHO 2018). The estimated prevalence of people with BPD in the general population is 1.6% (Ellison et al. 2018), and it is associated with multiple medical and psychiatric comorbidities (Chapman et al. 2021), as well as self-harm and suicide (Paris 2019).

BPD is a complex and often misunderstood diagnosis, even within healthcare (Warrander 2020). There is widespread stigma relating to the diagnosis, with both professional and public perceptions needing to be challenged and improved (Royal College of Psychiatrists [RCP] 2018). Recent developments in evidence-based treatments indicate renewed hope for recovery and remission (National Education Alliance for BPD 2021). Further, the National Institute for Health and Care Excellence (NICE) guidelines for the care and management of BPD emphasises the need to involve carers in assessment, diagnosis, care planning, and treatment (NICE 2009). Carers in this instance are defined by NICE (2009: P11) as:

> *"A person (such as a family member, or friend) who has regular close contact with the person with borderline personality disorder and is involved in their care."*

Carers have a vital support role, providing practical help, personal care, and emotional support (Lawn 2015). Clinical guidelines recommend that people with BPD receive community-based care instead of hospital admission unless the risk indicates differently (NICE 2009). This means carers have a significant role in supporting their relative, even when they are most unwell, and are often their primary caregivers providing support at home (Madigan et al. 2012). The physical, emotional, and psychological demands of caring, collectively known as the 'burden of care' have been widely researched (Duran-Gomez et al. 2020), showing caring is associated with reduced quality of life in terms of negative physical, mental health, employment, and financial impacts (Sanders 2020).

A recent Mental Welfare Commission Scotland (MWC 2018) report highlighted the emotional impact of caring for a person with BPD could leave carers feeling overwhelmed or powerless.

While NICE (2009) recognises the important role, carers play, especially if the family member is young, they also stress carers may need help and support themselves. However, their only recommendation is that healthcare professionals provide information about local carer support groups. This indicates a lack of guidance and supports Sander's (2020) argument that carer health remains an understudied area with a lack of robust evaluation of interventions and support services. Furthermore, a recent systematic literature review found few interventions specifically address the needs of carers supporting people with BPD internationally (Bailey and Grenyer 2013), and only one small study was conducted in the UK (Sanders and Pearce 2017). Evidence also indicates that the understanding of carers' experience is limited (Lamont and Dickens 2019), and only one small qualitative experiential study by Dunne and Rogers (2013) has been conducted in the UK.

1.1.1 A note on language

The discourse around mental health and mental ill-health is a source of debate within contemporary literature. Several terms are commonly used to describe mental illness, such as mental health problems, mental health issues, mental health conditions, severe mental illness (SMI), and mental disorders (Kent et al. 2020). There is also variation in terms used to describe BPD and personality disorder (PD) which will be explained in more detail in the next section. For simplicity and continuity, this thesis will describe the condition of interest as BPD, as this is the term most commonly referred to in the literature up until 2021. Likewise, SMI will be employed as an umbrella term used to describe conditions such as schizophrenia, bipolar, schizoaffective, BPD and PD as defined in the literature (NICE 2019).

1.1.2 Borderline personality disorder

To understand carers' experiences and needs it is important to understand the contemporary issues related to BPD. This includes a good comprehension of the prevalence, origins, and controversy of the diagnosis, difficulties, and risks for people with BPD, the stigma and discrimination experienced as well as care and treatment approaches.

It is estimated there is a point prevalence of between 1 and 2% of people diagnosed with BPD, and a lifetime prevalence of 5.9% in the general population, calculated by large, nationwide epidemiological studies in the United States of America (USA) (Grant et al. 2008). This is substantially higher in clinical settings representing around 22% of all in-patient mental health admissions, and 12% of outpatient mental health care (Ellison et al. 2018). Coid et al. (2009) conducted a cross-sectional survey of the UK household population. Results showed the

prevalence of BPD was 1.4%, and these individuals were more likely to seek treatment in the last twelve months than those with other Axis II disorders (e.g. schizophrenia, bipolar disorder). Studies carried out in the UK and USA (Coid et al. 2009; Dubovsky and Kiefer 2014; Skodol and Bender 2003) showed that BPD was diagnosed equally in men and women but higher in younger adults. Higher rates were also evident in those with low incomes and low educational attainment, and ethnic variations included being higher in native American men, and lower in Asian women and Hispanic populations.

In Scotland, no accurate source of overall diagnostic information is available however, the MWC (2018) estimates around one in 100 people (1%) in the general population are diagnosed with BPD, making an approximation of 54,540 people overall. Further, in 2018, 1,312 people with BPD were admitted to Scottish acute psychiatric in-patient care (NHS Scotland Information Services Division 2019). This figure has consistently risen over the last 10 years, but community figures are not recorded to understand how many people with BPD are receiving care in outpatient services, as recommended by clinical guidelines (NICE 2009; RCP 2018).

1.2   Origins and controversy of a BPD diagnosis

The origins of BPD stretch back to 1938 when the term 'borderline personality' was coined by the American psychiatrist, Adolph Stern. He used this to describe mental illness which was neither psychotic nor psychoneurotic because symptomatically it 'bordered' on both (NICE 2009). Over time psychiatrists began regularly using the term BPD which became an official diagnosis in 1980 when it entered the American Psychiatric Association (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM-III: APA 1980). This identified nine diagnostic criteria which were: i) frantic efforts to avoid abandonment, ii) unstable relationships, iii) identity disturbance, iv) impulsivity, v) recurrent suicidality or self-harm, vi) affective instability, vii) feelings of emptiness, viii) difficulty controlling anger, and ix) stress-related paranoia or dissociation. Individuals who met at least five of these criteria were considered to have BPD and given the diagnosis (DSM-III: APA 1980). The UK equivalent condition named, 'emotionally unstable, borderline type' [F 60.31] entered the WHO: ICD 10 in 1992, along with nine other PDs: paranoid, schizoid, schizotypal, antisocial, histrionic, narcissistic, avoidant, dependant, and anankastic.

Since that time the diagnostic criteria for BPD have remained unchanged, however, decades of debates about the utility of the diagnosis in clinical practice have led to international diagnostic frameworks revising their classifications to a multi-dimensional approach (DSM-V APA 2013; ICD 11: WHO 2018). As a result, in the ICD 11 (WHO 2018) psychiatrists now

consider personality as a spectrum of traits and PDs as maladaptive variants to the extent of mild, moderate, or severe. The ICD 11 (WHO 2018) criteria identify five personality trait domains that can be applied to individuals: i) negative affectivity, ii) detachment, iii) disinhibition, iv) dissociality, and v) anankastia. When diagnosing BPD, psychiatrists also distinguish a 'borderline pattern', where they consider an individual's difficulties to be characterised by a pervasive pattern of instability in interpersonal relationships, self-image, affect and marked impulsivity. A summary of the ICD 11 (WHO 2018) criteria for PD and borderline patterns is detailed in Appendix 1. Currently, there is limited evidence of the utility of the trait domains, however, psychiatrists hope that their use will mean a better understanding of PD and improved clinical care (Bach and First 2018; Mulder 2021).

Linehan's (1993) biosocial theory is one of the most commonly portrayed models to explain the aetiology of BPD. In this, the causes are said to be multifactorial, incorporating an interaction between genetic, and environmental interactions, adverse childhood experiences, and a vulnerable temperament (Linehan 1993; Paris 2013; Winsper 2018). Predisposing genetic and biological factors are suggested in twin studies (Porr 2010), and a 68% heritability rate (Torgerson et al. 2000). This theory proposes that genetically vulnerable people are already sensitive to experiencing ordinary interpersonal events as traumatic (Grenyer 2019). The impact of childhood trauma such as sexual abuse, psychological or physical neglect, parental violence, witnessing intimate partner violence, and other types of maltreatment are known to be associated with a wide range of psychological and relational issues in adult functioning (MacIntosh et al. 2015). Researchers consider this evident in BPD, supporting theories that a biological vulnerability is associated with environmental factors such as sexual abuse or neglect (Battle et al. 2004; Hermann 1992; Menon et al. 2016; Yen et al. 2002), attachment ruptures, overprotection, and invalidating environments (Bassir et al. 2018; Mosquera et al. 2014), and chronic peer bullying or victimization (Bozzatello et al. 2019).

The evidence further supporting these theories indicates that people with BPD have a far higher incidence of child abuse and neglect than any other PD (Battle et al. 2004; Hermann 1992; Porter et al. 2019; Yen et al. 2002). Treatment population prevalence studies report between 30% and 90% of people with BPD have this history (Battle et al. 2004; Borkum 2017). A similar study showed childhood neglect, and physical and sexual abuse histories exist in 70% of people with BPD and up to 90% in combined physical/sexual abuse compared to healthy comparisons (Hermann 1992). The length and intensity of childhood adversity are positively correlated with the severity of the disorder (Borkum 2017; Martino-Blanco 2014).

Linehan's (1993) biosocial theory also proposes that BPD symptoms are caused by a transactional relationship between pre-existing emotional vulnerability and an invalidating childhood environment. This theory argues that it provides a framework to understand why individuals develop BPD and can offer more accuracy than simply identifying an abusive

childhood (Scaramella and Leve 2004). According to Musser et al. (2008) invalidation is characterised as delegitimising a child's valid emotional experiences or expression of these. They posit that invalidating environments have four main features: communications of inaccuracy, misattribution, discouraging of negative emotional expression, and oversimplification of problem-solving. According to Linehan (1993), living in an invalidating environment combined with a genetic emotional vulnerability creates a conflict of fit between the child and their environment resulting in the emotional regulation difficulties characteristic of BPD in adulthood. These can originate from a child feeling their emotional responses are not correct, downplayed, or disregarded by caregivers (e.g. you are not sad, you are fine). Invalidating further occurs when caregivers highly discourage negative emotional expressions, and the child is encouraged to 'put on a brave face', or 'grin and bear it' in the face of adversity. According to Musser et al. (2018) these harmful invalidating environments can oversimplify and minimize for children how hard it is to solve or cope with problems (e.g. pull yourself together), and raises awareness of the potential family influences on the development of BPD.

Some associated theories further support diagnostic classification in an attempt to explain and medicalise people's problems. Fonagy and Batemen (2008) argue that for people with BPD persistent disorganised attachments prevent the development of mentalizing abilities and the building of a coherent self-image. Khoury et al. (2019) suggest that receiving disorganised emotional support from parents including verbal, physical, sexual abuse, or witnessing traumatising events can lead to individuals experiencing features consistent with BPD. Similarly, Fonagy et al. (2017) claim that vulnerability for BPD results from a lack of resilience and integrates theories on attachment, attending to mental states within ourselves and others, and inflexible thinking. They suggest that resilience development is then hampered by the inability to learn or gain benefit from the social environment.

However, the legitimacy and reliability of the diagnosis of BPD have regularly been questioned for several decades (Tyler 1997; Gunderson 2008), with criticisms of how the narrow diagnostic approach has failed professionals, people, and their families (Bach and First 2018). Given there is no laboratory test for this diagnosis or typical treatment responses, some even argue the diagnosis is logically flawed and empirically unsupportable, thereby supporting a drive toward a multi-disciplinary understanding of people and their difficulties more broadly instead of solely psychiatry (Gunderson 2008; Pilgrim 2001).

Some researchers argue that diagnosing individuals with complex post-traumatic stress disorder (PTSD) instead of BPD would be more accurate and appropriate (Timoclea and Taylor 2020). Complex PTSD applies to adults, adolescents, and children with prolonged, repeated, or multiple forms of traumatic exposure such as childhood abuse or torture (WHO 2018: ICD 11). Studies have indicated this is indistinguishable from BPD (Driessen et al. 2002; Ford and Courtois 2014, 2016; Gallop 2003; Herman 1992; Kulkarni 2017; McLean and

Pagura et al. 2010; Sara and Lappin 2017; Timoclea and Taylor 2020), and argued that not diagnosing the more accurate, complex PTSD only increases the stigma and discrimination for people with BPD and their families (MacIntosh and Godout 2015; Miller 2016).

Ford and Courtious (2021) investigated the relationship between BPD, PTSD, and complex PTSD, in a recent review. They found BPD and PTSD are distinct in terms of diagnostic features but have overlap in symptoms (e.g. pervasive negative changes in cognition, mood, and behaviour). In complex PTSD three disturbances of self-organisation domains (i.e. emotion dysregulation, negative self-perception, impaired relationships) mirror BPD features. However, Ford and Courtious argue there are marked differences in the specificity of the symptoms. For example, Keng et al's (2019) latent analysis found that in complex PTSD individuals have chronic difficulty in self-calming when distressed and chronic emotional numbing, but they do not experience emotional lability, extreme uncontrolled anger, and profound emotional dyscontrol that a person with BPD experiences.

Despite the debates over diagnosis, changing to complex PTSD is viewed as problematic when there are individuals with the same features who report no history of trauma (Lewis and Grenyer 2009). For some researchers giving complex PTSD as a diagnosis instead of BPD would be an ethical compromise, however, Grenyer (2019) deems this would be inaccurate. Similarly, others are concerned the current understanding of trauma and human distress is too narrow and requires development, not diagnosis (Timoclea and Taylor 2020).

In recent years, significant opposition to the use of medicalisation of BPD and associated psychiatric diagnosis has emerged from the British Psychological Society's Power Threat Meaning (PTM) Framework (Johnstone and Boyle 2018). Developed to fuel a paradigm shift, the PTM Framework has substantial importance for the diagnosis of BPD and argues that although medical diagnosis may be necessary to make sense of many bodily problems:

> *"Psychiatric diagnosis is inherently limited in its capacity to make*
> *sense of emotional/psychological distress. This is because it largely*
> *draws on theoretical models designed for understanding bodies rather*
> *than people's thoughts, feelings, and behaviour".*

(Johnstone and Boyle 2018: P5)

The British Psychological Society Division of Clinical Psychology (2013), in a position statement, affirmed that functional psychiatric diagnoses have considerable conceptual and empirical limitations. They emphasise the need to shift from the disease model toward conceptual theories that identify patterns and responses to distress (such as those experienced by people with BPD). Further, even within the psychiatric profession criticisms exist that diagnosis is unable to account for the full range of experiences of distress in the way

that a narrative formulation might (Critical Psychiatry Network 2013). Read and Harper (2020) have also argued that the PTM Framework is a more reliable response to understanding psychological distress and distress behaviour than the biomedical approach which dominates mental health services and minimises the influence of psychosocial adversities. According to the PTM Framework, a non-diagnostic view of emotional distress and troubling behaviour experienced by individuals is important, and rather than pathologising people, distress should be reintegrated back into normal universal human experiences. The Framework itself serves to support a non-medicalised approach to understanding distress as a response to adversity (Johnstone and Boyle 2018). Further, it reconceptualises previous limiting biosocial theories (e.g. Linehan 1993) which do acknowledge trauma and adverse childhood experiences but medicalise these into BPD.

To broaden understanding of distress behaviours, the PTM Framework (Johnstone and Boyle 2018) encompasses theories on social inequalities and networks of power. These emphasise that social/demographic characteristics such as sex and gender, race and ethnicity, and poverty or low socioeconomic status are all influential in an individual's and society's responses to adversity. Further, they argue that although biological factors do not sit entirely outside of cultural and social relations, they cannot be viewed as the primary cause of people's problems. Instead, biological processes are fundamental elements that are activated during distress, such as those which recall memories, enable dissociation to protect from overwhelming events, or allow fight, flight, and freeze responses. Therefore, individuals are not experiencing symptoms of illness but a reaction to a threat which is in effect a survival strategy. To fully understand this, individual narratives (i.e. a person's story) are elevated to be central in creating meaning and agency to further draw upon their strengths and resources (Johnstone and Boyle 2018).

This recent Framework signals a paradigm shift that has implications for public and mental health policy, service principles and design, therapeutic interventions, the legal system, and research (Johnstone and Boyle 2018). However, despite its' potential, and arguments on the damaging impact of diagnosis (Critical Psychiatry Network 2013), the literature suggests the disease model will remain dominant for some time. Some argue diagnosis is fundamental for receiving treatment and reducing harm, advocating a combination of this and psychological formulation (Campbell et al. 2020). Others consider diagnostic criteria to have meaning and purpose for different groups (Roy et al. 2019), or a turning point to allow individuals validation and recognition that they are not alone in their experience (Ng et al. 2019). These tensions also influence the socio-political context for families and carers.

1.2.2   Difficulties and risks for people with BPD

A central difficulty for people with BPD is an inability to manage emotions effectively within the context of relationships (National Education Alliance 2021). The ICD 11 (WHO 2018) criterion identifies core problems for individuals are associated with impulse control and emotion regulation which creates other difficulties such as intense mood shifts, angry outbursts, impulsivity, suicide and self-harm, fear of abandonment, identity disturbance, a profound sense of emptiness, and suicidality (See appendix 1 for more detail). The extent of recurrent self-harm including suicide attempts or gestures and self-mutilation are linked to the severity of BPD that individuals experience (Mosquera et al. 2014). As a result, individuals with this diagnosis are at high risk of self-harm and suicide. Approximately 69% to 80% of individuals with BPD self-harm or attempt suicide while in a distressed or crisis state of mind, and 10% of will die by suicide (Friedman et al. 2007; Oumaya et al. 2008; Pompili et al. 2005). Studies show the highest frequency of suicide attempts is in adolescents and young adults (Knafo et al. 2015; Sharp et al. 2012; Yen et al. 2015). This further stresses the importance of treatment and regular suicide risk assessment using standardised measures (Posner et al. 2011) of individual risk and protective factors (Guile et al. 2018).

Core difficulties for people with BPD also include experiencing intense emotions, which as a result means individuals often misunderstand the emotions of others, such as family members and those closest to them. Impulsive aggression can be triggered by perceived threats of abandonment, stemming from fears of being alone and neglected. Also problematic is rejection sensitivity which means individuals can be overly sensitive to rejection, anxiously awaiting it, see it when it does not exist, and overreact by harming themselves whether it is there or not (Kreger 2008).

There is a high prevalence of co-occurring health conditions and symptom overlap between BPD and other mental health conditions including PTSD, depression, anxiety, psychosis, or dissociative disorders (Johnson et al. 2010; Pagura et al. 2010; Sharp and Fonagy 2015; Slotema et al. 2018). This leaves it questionable if BPD can even be considered a stand-alone condition. Co-morbidity studies of clinical populations have reported that 75% also have depression, 60% have an anxiety disorder, 34% eating disorder, 19% have substance misuse, 29% have a panic disorder, and 35% have PTSD (Zanarini 2015). BPD has long been defined as bordering on psychosis, however, psychotic symptoms are often dismissed as not real, pseudo, or transient. A recent review by Calveti et al. (2021) reported auditory and verbal hallucinations as the most common form of psychosis, found in 29-50% of individuals. Further, a cross-sectional study by Slotema et al. (2018) of 84 female outpatients with BPD reported psychotic disorders were present in 38%, the most common subtype was a psychotic disorder not otherwise specified, evident in 20% and associated with a poorer recovery; the least

common was schizophrenia at 2%. Grant et al. (2008) found the co-occurrence of BPD and Bipolar 1 disorder was 35.9% and other PDs were 24%. Studies have shown people with BPD also have a greater lifetime disability and prevalence of co-occurring medical disorders, including cardiovascular disease, obesity, diabetes, back pain, chronic pain, urinary incontinence, hepatic and other gastrointestinal diseases, fibromyalgia, migraine, chronic fatigue, arthritis, and sexually transmitted infections (Dubovsky and Keifer 2014; El-Gabalawy et al. 2010; Frankenber and Zanarini 2004; Lubman et al. 2011; Sansone et al. 2001; Zanarini et al. 2004).

There is a dearth of literature relating to the co-occurrence of learning disabilities and BPD. However, Lindsay et al. (2018) reported that 10-13% of patients in a forensic learning disability service had a diagnosis of BPD, raising issues related to diagnostic overshadowing. Clinical samples have also shown that individuals with childhood attention deficit hyperactivity disorder are significantly more likely to be diagnosed with BPD than those without (13.5% versus 1.2%) (Weiner 2019). Consequently, co-occurring BPD with learning disabilities reveals an increased burden for individuals, carers, and services, requiring the development of treatment strategies to address multiple and complex needs (Feenstra et al. 2012).

1.2.3   Stigma and discrimination

Stigma and discrimination are widely known to exist toward individuals with mental illness, especially people with BPD (Grenyer et al. 2018). Many consider that the term 'borderline personality disorder' does not describe the condition well, is harmful, and is a source of prejudice and stigma itself (National Education Alliance for BPD 2021). BPD is often portrayed negatively on websites and media information which further propels hopelessness and stigma for those diagnosed and their carers (Hoffman 2005). For example, Dickens et al. (2016) reported that clinical professionals often have interpersonal, relational, and attitudinal difficulties with this group. This is exacerbated by the misconception that BPD is untreatable (Vesey 2014), or individuals being perceived as more culpable for their actions, and less deserving of care (Paris et al. 2013). Carers of people with BPD can also experience 'surplus stigma' (Hoffman et al. 2005) due to familial factors (including abuse, neglect) being linked to its development (Gunderson 2011), placing suspicion on parents as the cause, despite multifactorial biosocial factors being more accurate (Hoffman et al. 2005).

Stigma and discrimination are thought to be some of the reasons for problems with care and treatment such as poor access and in some cases exclusion and refusal of treatment by services (National Institute for Mental Health in England 2003). Not surprisingly, reports of suicide and self-harm have found it is common that people with BPD do not receive care in

line with evidence or guidance, and a reluctance to diagnose, or treat has ultimately led to service disengagement and death (National Confidential Inquiry in Suicide and Self-Harm 2018).

To counteract issues relating to professionals' stigma towards people with BPD, statutory organisations such as the RCP (2018) have published guidance stating professionals need attitudes of curiosity, compassion, and empathy, particularly because people with BPD regularly seek support from health services during an emotional crisis. Correspondingly, questions emerging around the diagnosis of PD are seeing a culture shift in the literature. Sometimes the term 'complex emotional needs' is used in an attempt to reduce the stigma or hopelessness around effective treatment and labelling (Sheridan et al. 2021; Troup et al. 2020; Trevillion et al. 2022). Trevillion et al. (2022) explored 30 service user experiences of community mental health services for people with complex emotional needs. Many reported extremely stigmatising interventions, lack of support, and fragmented services. The study found that long-term relational practice approaches were the best way to support individuals through non-stigmatising, individualised, compassionate and trauma-informed care. Clinicians' perspectives of good practice were investigated in a systematic review of 29 studies. This showed common issues were difficulties in identifying treatment, managing safety issues, and the need for supervision, joint working, and organisational support (Troup et al. 2020). A further review also found many professionals had poor health literacy which perpetuated stigma toward people with BPD and hampered engagement and treatment. Recommendations included targeted education, advocacy, and effective leadership (Ring and Lawn 2021). Klein et al. (2021) also reported structural stigma towards people with BPD is widespread and radical solutions are necessary, such as an overhaul of institutional policies, cultural norms, and organisational practices.

1.2.4 Care and treatment approaches for people with BPD

Recommendations for the care and treatment of people with BPD include assessment and management by primary and community mental health services, with specific interventions delivered by skilled, trained professionals. Inpatient care is only recommended for short periods when essential for patient safety (NICE 2009). However, difficulties occur with the diagnosis because people often do not report characteristic symptoms of BPD or underlying personality dysfunction (Irwin and Malhi 2019). As a result, referral to community mental health services for assessment is advised when individuals present in primary care with classic features such as repeated self-harm, suicidality, persistent risk-taking behaviour, or marked emotional instability (Guile et al. 2018; NICE 2009). This is recommended to avoid delay,

ensure accurate diagnosis, and initiate effective therapy, ultimately saving lives (Paris and Black 2015; Philip et al. 2010).

Guidelines recommend early diagnosis to enable the provision of the appropriate interventions (DSM-V: APA 2013; Guile et al. 2018; ICD-11: WHO 2018), reduce self-harm and prevent suicide (National Confidential Inquiry into Self Harm and Suicide 2018), and give an explanatory framework to those affected and their carers (RCP 2018). However, many professionals are reluctant to diagnose BPD due to difficulties separating it from co-existing conditions such as substance misuse and concerns over the links with trauma and the impact of the stigma this disorder holds (Boylan 2018). Despite reservations, evidence suggests the benefits of early detection, diagnosis, and intervention include improved wellbeing, reduced chronicity, and related adverse health outcomes (e.g. self-harm and suicide) (Chanen et al. 2013; Kaess et al. 2014).

Key messages for people with BPD, their families, carers, and health services are that remission and recovery are possible (Paris and Frank 2001). Studies suggest that when treated, symptoms can reduce substantially over time. For example, a large-scale retrospective study showed that 75% of patients who received treatment no longer met the diagnostic criteria for BPD at 15-year follow-up, increasing to 92% at 27-year follow-up (Paris and Frank 2001). Likewise, Zanarini et al. (2010) reported that 93% attained a sustained remission of symptoms lasting at least two years, while 50% of these sustained recoveries over 10 years following treatment. Ng et al. (2019) in a narrative study of 14 women reported that recovery occurred across four processes: hope, active engagement in the recovery journey, engagement with treatment services, meaningful activities, and relationships. This draws similarities with universal elements of mental health recovery including, connectedness, hope and optimism, meaning in life, and empowerment (Leamy et al. 2011). Ng et al. (2019) also emphasise that recovery needs to be measured not only in the absence of symptoms but in the engagement in treatment, meaningful vocation, and relationships.

At the heart of effective treatment are community-based services that promote recovery and are designed to meet the complex needs of individuals, involving carers in the process (NICE 2009; Ng et al. 2020). Services are advised to follow coherent theoretical frameworks and guidelines (NICE 2009), underpinned by principles of compassion, empathy, validation, hope, therapeutic alliances, well-structured treatment plans, and clinical supervision (RCP 2018). Crisis care is imperative to safeguard against risk and suicidality (Bateman and Krawitz 2013; Grenyer 2019).

Given that trauma is significant in the development of BPD, trauma-informed care and treatment are necessary to strengthen a sense of self, reduce emotional sensitivity and suffering, and improve interpersonal functioning (Lewis and Grenyer 2017). This can only

safely take place when sufficient self-esteem and trust are achieved (Grenyer et al. 2019). However, despite the risks of suicide and complex needs, many health services do not have dedicated services for people with BPD, and hospital admission or poor support following a crisis is common (MWC 2018; Ng et al. 2020; RCP 2018).

Structured psychological therapies are the recommended treatment for people with BPD (Cristea et al. 2017; NICE 2009; RCP 2018). Evidence from randomised controlled trials (RCT) supports the provision of Dialectical Behaviour Therapy (DBT), Schema Focussed Therapy, and psychodynamic approaches including Mentalisation Based Therapy, Transference-Focused Psychotherapy, Conversational Model therapy, and Cognitive Analytic Therapy. A recent systematic review and meta-analysis of RCTs into these psychotherapies found there was little difference reported between them in terms of efficacy (Cristea et al. 2017). However, despite psychological therapy for people with BPD being linked to preventing or reducing crisis events, poor access in Scotland has been reported as an issue by individuals and their families (MWC 2018). A dearth of trained professionals with skills to practice independently, lack of time, resources, funding, and long waiting times are all cited as barriers to delivering adequate psychological therapies (Toms et al. 2019). Furthermore, the UK Safer Care for Patients with PD report indicated that many individuals are only offered medication and monitoring as treatment (National Confidential Inquiry 2018). This was despite clinical guidelines recommending medication is only suitable to treat co-morbid symptoms of depression, anxiety, or psychosis in this population (NICE 2009; RCP 2018).

1.2.5 Family interventions and whole-system approaches

Given the relational issues encountered, several interventions tailored for people with BPD have a family/carer element, for example, DBT (Linehan 1993), or Systems Training for Emotional Predictability and Problem Solving (Black and Blum 2017) provide one or two sessions for carers (Linehan 1993; Black and Blum 2017). However, despite studies showing their efficacy for people with BPD, a recent systematic review by Sutherland et al. (2020) emphasised these have not been evaluated for their benefit to carers in their own right (e.g. Miller et al. 2007; Rathus et al. 2017; Uliaszek 2014). Future studies are recommended to include outcome measures for carers to understand their efficacy, as well as qualitatively clarifying carers' views of what they need and perceive as a meaningful outcome (Sutherland et al. 2020).

Family-based interventions aiming to improve the recovery of patients and family well-being are popular in the treatment of schizophrenia and recommended in clinical guidance (NICE 2015). In a systematic review, 53 studies into family interventions for schizophrenia suggested

that integrating carers into the therapeutic team, offering education in empathic engagement and communication skills, as well as clinical resources during a crisis, elicited positive outcomes in reduced relapse, carer burden, and improved family functioning (Pharoah et al. 2010). Similarly, the last two decades have seen a paradigm shift in America and Australia with the emergence of new strategies and specialist services for people with BPD and their families, indicating a rise in the prioritisation of BPD-related issues in these countries. These offer integrative relational stepped models of care for people with BPD, as seen in the Project Air Strategy 2016), the USA National Education Alliance for BPD (2022), Spectrum and the Australian BPD Foundation (2022), and the Australian Project Air Strategy (2016), These aim to raise awareness, reduce stigma, promote education, research, treatment and evidence-based care for people with BPD. Project Air Strategy (2016) and the National Education Alliance for BPD (2022) also include elements to support families and carers, providing free opportunities for training and support.

The Project Air Strategy (2016) supports recovery by taking a whole system approach underpinned by a relational model which centres on the intrapsychic difficulties and interpersonal conflicts the person with BPD experiences with treatment teams, families/carers, and the wider community (Grenyer et al. 2014). Studies evaluating the whole system approach to care for people with BPD have shown a reduced number of, and shortened hospital admissions (Grenyer et al. 2019). Likewise, Huxley et al. (2019) evaluated a brief psychological intervention within a stepped care model and found reduced symptom severity and suicide risk and improved quality of life. A further study related to the Project Air Strategy (2016) whole system approach was an RCT with 68 carers. This found that those participating in the Staying Connected psychoeducation programme compared to the waiting list group showed improvements in dyadic adjustment with their relative, greater family empowerment, and reduced carer expressed emotion, sustained after 12 months (Grenyer et al. 2019). Correspondingly, a qualitative study found staff knowledge, skills and positive attitudes gained through training and a psychological approach to care were necessary for the successful implementation of whole system approaches (Pigot et al. 2019).

However, it is important to highlight that the primary aim of including family members in family interventions and whole system approaches is to improve outcomes for the 'patient', with hopefully some indirect benefits for the family/carer (hence a lack of evidence on carer outcomes). These interventions do not aim to support the carer in their own right as this study intends to prioritise. As such they often do not include carer-focused interventions which aim to reduce or measure anxiety, depression, carer burden, and social support, irrespective of whether the 'patient' is involved with services (those studies that do are detailed in section 1.3.2). However, evidence indicates that many people with BPD are not attending services, or are in treatment programmes such as DBT even if they are (unlike the majority of people with

schizophrenia) (Lamont and Dickens 2019; National Institute for Mental Health in England 2003; National Confidential Inquiry in Suicide and Self-Harm 2018; Ring and Lawn 2021). Therefore, family-based interventions, such as those offered for schizophrenia, or the carer elements of the whole system approaches (as in the Project Air Strategy and National Education Alliance for BPD) are not necessarily applicable for carers of people with BPD within the current UK mental healthcare system. They are not even suggested in UK clinical guidance for people with BPD (NICE 2009).

1.3 The role and impact on family and carers

Unpaid carers provide invaluable support to family members, friends, and neighbours, making a huge contribution to care provision (Scottish Government 2021). It was estimated that in 2019/20 around 4.5 million people in the UK were providing informal care which represents around 7% of the population. (The Family Resources Survey 2021). Carers can be defined as:

> *"Anyone who cares unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support."*

(Carers Trust UK 2021: P1)

The number of carers living in Scotland is not known but it was estimated that there were around 7000,000 to 800,000 before the Covid-19 pandemic, and recent polling indicates this has grown to over a million (Scottish Government 2021). Figures indicate that in the UK, up to 1.5 million people are caring for someone with mental ill-health: 11% of those care for someone with dementia (Carers Trust 2019). Nationally and internationally there are no accurate estimates of how many individuals care for someone with BPD. Studies related to family members and carers of individuals with substance use have estimated that a cautious approximation would be to calculate that one person may be affected, or a carer for every person with substance use. They indicate this suggests a minimum of 91 million family/carers for people with substance use worldwide (Copello et al. 2010). Following this same model would suggest that every person with BPD [estimated by the MWC (2018) as 1% of the population] has approximately one carer, meaning in Scotland alone it can be estimated that 54,540 people are caring for a person with BPD at any given time.

Of all UK carers, 42% are men and 58% are women, with the economic value of the contribution being made at £132bn a year (Carers Trust 2019). A recent report on carers by the Scottish Government (2015) highlighted that support is aimed at reducing the negative

psychological, physical, and financial effects known to impact carers. They identified support to include information, advice and training, practical support, counselling, short breaks, and financial help. In recognition of the role of a carer, its demands, and the difficulties that exist in accessing support (Scottish Government 2015), several UK policy initiatives have been developed. This includes the Carers (Scotland) Act (2016) which supports carers' health and wellbeing to make caring more sustainable. Additionally, the Carer's Charter (2018) promotes carers' rights including accessing support, involvement in assessment, care planning, and hospital discharge. Further, the Department of Health (2018) states priorities for carers are support with employment and financial wellbeing; support for young carers; raising awareness of caring among the wider population; building carer-friendly communities, and innovative research and evidence to improve outcomes for carers.

Caregiving can be associated with positive aspects such as a source of happiness associated with giving a person's life meaning, or the opportunity to learn new skills and build strong relationships (Farina 2017; Future Care Capital 2019). Some carers relate to their role with a sense of pride in fulfilling family responsibilities, enhanced closeness, self-satisfaction with the role, and one's competence. This is enhanced when the carer receives support and regular time out from caring (Shah et al. 2010). However, for many, it can be extremely stressful and result in many adverse outcomes ranging from mild psychological stress to an increased risk of death (Duran-Gomez et al. 2020). Evidence suggests that carers of people with SMI, fulfil several roles including helping individuals engage with psychological and pharmacological interventions or programmes of care (Onwumere 2020). Carers are often the first to identify deterioration in a person's mental health, advocating for and organising service support (Onwumere 2018). Further, they are frequently on standby and offer support during crucial times of distress, such as when a person is hearing voices or experiencing suicidal thoughts (Onwumere 2020). A recent meta-analytical review into loneliness during psychosis showed that carers provide much-needed social contact and support, reducing stigma, isolation, and loneliness for their relative, with positive effects on their wellbeing (Michalska da Rocha et al. 2018).

The Carer's Trust UK (2019) survey of 2078 carers showed only 12% of carers said they received enough support from the social care system, and 64% were spending 50 hours or more per week caring. The UK State of Caring Report (2019) surveyed 7525 carers and found that a quarter had refused respite care due to concerns over the quality of care for their relative. Additionally, 27% rated their mental health as bad or very bad, and happiness an average of 4.7 out of 10, compared to the population average of 7.5 out of 10. Further evidence showed carers often experience depression, anxiety, or PTSD symptoms, and caring is associated with poorer physical and mental health, and reduced quality of life (Sanders 2020).

The more time a person spends caring was associated with increased incidences of smoking, physical inactivity, gaining weight, and eating unhealthily (Future Care Capital 2019). Forty-one percent of carers have reported a long-term condition, and poorer health associated with age and challenging carer situations (Carers Trust UK 2019). Further, most have reported issues such as back pain, tiredness, trouble sleeping, and reduced fitness (Cottagiri 2019). Over time, physical and psychological strain, high levels of unpredictability and uncontrollability, stress from work or relationships, and high levels of vigilance were reported as the main issues for carers (Cunningham 2019; Farina 2017).

Several key factors are known to improve carers' quality of life including a good level of social and family support; the ability to engage in social activities; access to respite and employment (Euro Carers 2018; Future Capital 2019). A recent review by Brimblecombe (2018) found multicomponent psychosocial, psychoeducational, and educational interventions reduced the level and burden of care. Further, the UK State of Caring Report (2019) recommended priorities for carers were: being identified early in their role; recognising and valuing their knowledge; treating them as partners; providing access to information, training, and equipment.

1.3.1   The experience of carers supporting a person with BPD

Current literature about carers' experience of supporting a person with BPD is limited. The author of this thesis recently conducted a systematic review of service users (people with BPD) and carers' experiences of care, support, and treatment provision published between 1999 and 2017 (Lamont and Dickens 2019). This included 37 studies, of which 33 focused on service users and the most relevant to this thesis were four studies that explored the carer's experience. These were conducted in the USA, Australia, and the UK. One study by Lawn and McMahon (2015) was a survey and the remaining three were qualitative studies (Buteau et al. 2008; Dunne and Rogers 2013; Giffin 2008) representing data from 24 carers in total. Lawn and McMahon's (2015) survey carried out in Australia examined 121 family carers of people with BPD. This aimed to elicit their experiences of being a carer and attempts to seek help and support for the person and themselves. This survey found carers experience significant exclusion when interacting with general and mental health services. The authors recommended education for health professionals to improve attitudes and skills, alongside specialist carer support to address their information, education, and support needs.

The only UK study by Dunne and Rogers (2013) used focus groups to explore the views of eight carers about their experience of the caring role and mental health and community services. Findings showed carers had many disappointing experiences around receiving information about BPD, accessing support for the person with BPD, and high-quality support for themselves. They knew little about what was available, involvement in care was regarded as tokenistic, and they received little communication from mental health services. Dunne and Roger's (2013) study also found carers had painful and stressful relationships with the person with BPD and very much wanted to understand their difficulties, however during overwhelming stress and crisis they found this difficult. They also reflected upon the life-changing nature being a carer had on their lifestyle, struggling when family and friends were judgemental, and perceiving public awareness or media portrayal as stigmatising and damaging. The review also included a study by Buteau et al. (2008) conducted in the USA involving semi-structured interviews with 12 family members to explore their personal experiences with BPD had similar findings. This found participants had difficulty accessing current evidence-based knowledge about BPD and treatments; a stigmatizing healthcare system; prolonged hopelessness; shrinking social networks; and financial burdens. The authors recommended professionals be educated about BPD, specific treatments, and information resources for families. A further qualitative study carried out in Australia by Giffin (2008) involved interviews of four family members who had daughters with BPD. This investigated their experiences of caring for and interacting with mental health services. The authors found family members experienced chronic and traumatic stress, relationships were strained, as were those between families and the mental health system. Findings indicated that treatment for BPD needs to adopt a systemic approach inclusive of individuals and their family relationships, as well as the treatment providers.

Overall, Lamont and Dicken's (2019) review found that carers perceived mental health professionals to have no understanding of their caring role and poor knowledge about BPD. Further, the mental health system offered little professional support to carers while depending heavily on them during treatment decisions. The authors recommended a cultural shift toward relational, person-centred, and recovery-focused care to improve individuals' and carers' experiences and outcomes. The review also identified that only one study (Lawn and McMahon 2015) had evidence of co-production, identified as valuable in research (Pinfold 2015). Therefore, this was recommended for future research to ensure support and interventions are guided by carers. Study quality in Lamont and Dicken's (2019) review was generally rated highly; all qualitative studies achieved two-thirds of the possible 15 quality checks *(Mdn*=11.25, range=10-13*)*, and the survey study met almost all quality checks achieving 15/16. However, only preliminary conclusions can be drawn as the findings were

limited due to only finding four studies focused on carers, with relatively small sample sizes in the qualitative studies.

A previous systematic review by Bailey and Grenyer (2013) examined the experiences, burden, support needs, and interventions for carers of people with BPD which included six studies published between 1996 and 2011. Of these, three specifically investigated their experiences, representing 329 carers. The first was by Hoffman et al., (2003) who conducted a qualitative study in the USA using cross-sectional interviews with 32 family members assessing for their level of knowledge about BPD. Knowledge level was correlated with family members' burden, depression, distress, and expressed emotion. Greater knowledge about BPD was associated with higher levels of family members' burden, distress, and depression. The authors determined that this raises questions concerning the quality and accuracy of the information given to carers. Secondly, Scheirs and Bok (2007) conducted a cross-sectional survey with 64 carers in Holland to investigate the influence caring for a person with BPD had on the psychological well-being of carers. Results showed higher incidences of depression, anxiety, somatisation, distrust, hostility, and sleeping problems than the general population. Thirdly, Goodman et al. (2011), carried out a cross-sectional internet survey in the USA on 233 parents of people with BPD to identify aspects of parental burden. Results showed the majority experienced negative impacts on their emotional health, physical health, marriage, finances, and social life. Three further studies in Bailey and Grenyer's (2013) review examined intervention efficacy and are discussed later in the chapter.

A further Australian survey study by Bailey (2014) also examined the burden and impact of caring on 287 carers using validated measures and a convenience comparison group drawn from published literature. Compared to carers of individuals with other mental illnesses (e.g. schizophrenia or bipolar) results showed that carers of people with BPD experienced significantly elevated burdens, including grieving the loss associated with the impact of caring and the changes it required in their lives. They also reported interpersonal strain and impaired wellbeing, including mental health problems and difficulties in emotion regulation similar to that of clinical samples diagnosed with anxiety, mood, and PTSD. More positively, the study highlighted that for some carers the potential for their relative's recovery motivated them to keep going, and recommended interventions to support carers of people with BPD. Limitations were considered to be the use of survey methods, and the researcher defined interests being explored.

Finally, the Scottish MWC (2018) reported findings of a survey that included six carers' experiences of supporting someone with BPD. Concurrent with other literature, results showed carers had difficulties gaining information or support for the person with BPD, and themselves,

particularly in times of crisis. However, the MWC (2018) recommended little in respect to carers, only suggesting health services direct to appropriate support.

In summary, in the UK there has only been one small qualitative study into carers of people with BPD experiences (Dunne and Rogers 2013), and only one intervention study by Sanders and Pearce (2010) which focused on PD rather than BPD. Therefore, more qualitative work is needed to underpin what an intervention should entail when addressing carers of people with BPD needs. Also, the potential intervention must be co-designed with prospective users to support its' acceptability and effectiveness.

1.3.2   Supportive interventions for carers

Scoping of the literature found few studies were focused on supportive interventions for carers of people with BPD, compared with other SMI (e.g. schizophrenia, bipolar disorder) (Bailey and Grenyer 2013; Yesufu-Udechuku et al. 2015).   Previous studies have found that supportive interventions for carers of people with SMI involving psychoeducation, support groups, supportive education, intensive behavioural family therapy, and problem-solving can be effective in reducing carer burden, improving physical and mental health, and overall quality of life (Chien et al. 2005; Gutierrez-Maldonado and Caqueo-Urizar 2007; MacLeod et al. 2011; Riebscheger et al. 2008; Yesufu-Udechuku et al. 2015).   A systematic review and meta-analysis (Yesufu-Udechuku et al. 2015) of twenty-one RCTs investigated the effectiveness of interventions designed to improve the experience of carers of people with SMI and reduce their burden. The review only included studies into carers of people with schizophrenia. Results showed that carers' experience was improved post-intervention compared to CAU or waiting list controls by psychoeducation, bibliotherapy, or support groups tackling psychological distress. Evidence for combining these or self-help / self-management was inconclusive. Studies were rated low and very low quality and although the review findings were limited, they indicate that supportive interventions should be considered as part of integrated care for people with SMI.

Supportive interventions for carers of people with BPD specifically, were appraised in the systematic review by Bailey and Grenyer (2013). This included three intervention studies, representing 136 carers. One intervention study was conducted in the UK. It used mixed methods to investigate the Oxford Family and Friends Empowerment psychoeducation group (Sanders and Pearce 2010) for carers of people with PD (as opposed to BPD). The intervention aimed to reduce the burden and improve empowerment, delivered in an 8-weekly course (or a weekend course) in collaboration with practitioners and a mental health charity.

The intervention focussed on PD specifically and aimed to provide information to help gain a better understanding of PD. Cognitive behaviour therapy and transactional analysis approaches were embedded into the course to change participants' behaviour and improve understanding (Sanders and Pearce 2010). The study was a pilot, which included a small sample of 28 carers and a further nine in a young family and friends' group. However, no empirical data was reported on the findings of the young carers aged 10-17 years. Results pre and post-intervention showed trends for an increased sense of empowerment, ability to access and identify services, manage violent incidents, and reduced isolation that would need to be tested in a fully powered empirical study.

A further two USA studies were by Hoffman et al. (2005; 2007). These examined pre/post evaluations of psychoeducation called the Family Connections Programme hosted by the National Education Alliance for BPD (2021). The programme aimed to improve carer wellbeing, empowerment, and reduce burden. It was developed by mental health professionals and delivered by trained family or friends weekly for 12 weeks. Content included education, skills training based on DBT, and the development of a support network. These studies included 32 and 44 carers respectively and found overall burden and grief decreased significantly post-intervention, and mastery significantly increased. During the six months post-intervention follow up the 'burden' of care continued to decrease and gains in mastery and grief management were maintained.

There were several limitations of the Bailey and Grenyer (2013) review, namely, there were only six articles and only three of these examined interventions. The studies were published between 2005 and 2010, meaning the interventions themselves were developed over 10 years ago. The heterogeneous design and methodology of included studies meant that a meta-analysis was not possible. Within the included studies there was no randomization or control group. Small sample sizes meant that by not collecting enough data to realise the real effects of the intervention some studies were underpowered. Additionally, there was a lack of long-term follow-up of interventions (the longest being six months) which meant longer-term effects were not assessed. Given these limitations, only preliminary conclusions can be drawn from this review which indicated supportive group interventions may reduce burden, and grief and improve health. There was not sufficient evidence to support the use of one intervention over another.

1.4 Co-production

The essence of this study is co-production. Co-production has become increasingly significant to researchers, policymakers, and practitioners in recent years as an approach to improving and evolving public involvement in research (National Institute for Health Research 2021; Power 2013). Co-production seeks to enable people with different expertise to collaboratively

work together, and provide policy or services that deliver outcomes that matter to people (Graham et al. 2019; Madden et al. 2020). The term co-production was coined by the political scientist Elinor Ostrom in the 1970s and defined as:

> *"A process through which inputs used to produce a good or service*
> *are contributed by individuals who are not "in" the same organisation"*
> (Ostrom 1996: P1073)

Later, Edgar Cahn, a civil rights lawyer powerfully proposed co-production can expand the limits on social change, empowering people to become change agents, shape their future and become the means to social justice (Cahn 2000). Subsequently, co-production has been used to describe the collaborative production of public services and is more than merely involving or engaging individuals (Heaton et al. 2016). According to Slay and Stephens (2013), citizens and professionals share the power to plan and deliver services using six principles: assets based, building on existing capabilities, reciprocity and mutuality, peer support networks, blurring distinctions, and public service agencies as facilitators, not main providers.

Evidence suggests that co-production has become an important influence in the development of health and social care services (Heaton 2015; Mind UK 2018; Social Care Institute for Excellence 2013; Walsh and Davies 2013). In literature, the terms engagement, participation, and involvement are often used interchangeably, proposing several methods to hear from people and communities including, surveys, citizen panels, focus groups, interviews, stories, and workshops (Kings Fund 2022). However, co-production occurs when people with lived experience are involved from the beginning before an agenda is set, with their expertise sought to frame problems and set priorities (Roper et al. 2018).

Co-production theories are important for this study. Using a co-production mindset will ensure that carers, stakeholders and researchers have equal importance and their involvement in the design and delivery of the intervention will hold equal value (Kings Fund 2022; Mind UK 2018). Roper et al. (2018) recently produced guidelines clarifying the significant elements of putting co-production into practice. They emphasised the need for consumers to be:

> *"Involved in, or leading, defining the problem, designing and delivering*
> *the solution and evaluating the outcomes either with professionals or*
> *independently."*

(Roper et al. 2018: P2)

Figure 1, adapted from Roper et al. (2018) displays how a co-produced initiative will typically involve the phases of co-planning, co-design, co-delivery, and co-evaluation.

Figure 1: What does co-production involve?

Co-planning
What are we looking to solve?
Who should be involved?

Co-evaluation
What should we measure?
How will we get the information?
Who will we ask?

Co-production

Co-design
Define the problem
Develop solutions together

Co-delivery
Delivering the solution
Who will do what?
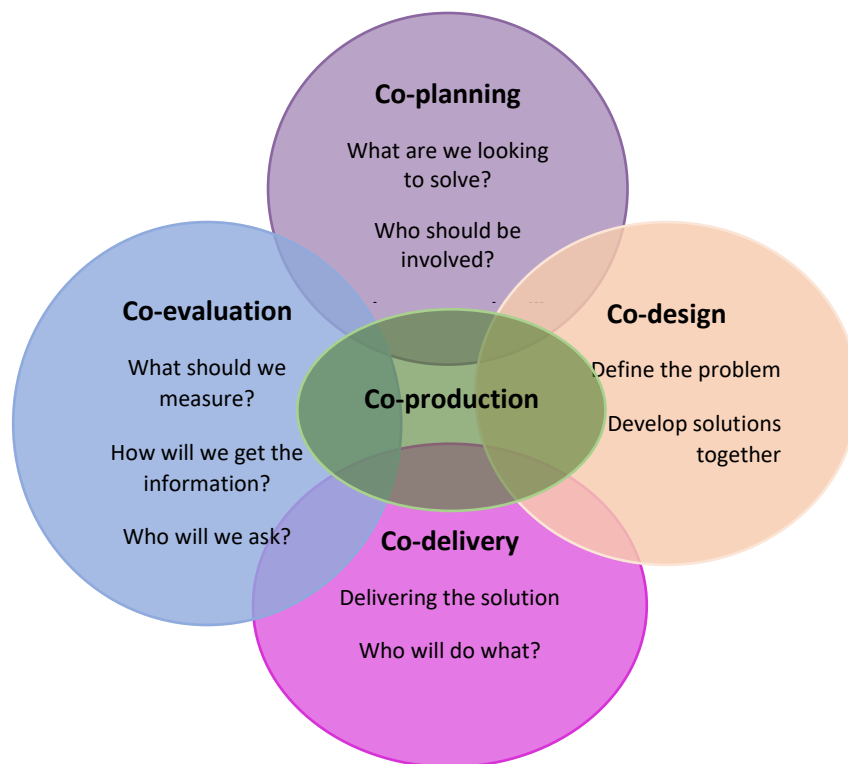
There are many good reasons to use a co-production approach when developing an intervention. According to Ward et al. (2018) interventions which are co-produced with key stakeholders are most likely to be acceptable, effective, and meet the needs of those who use them (Ward et al. 2018). Co-production principles can empower service users and family members to become active participants in the development of services they will use in the future (Green et al. 2020). Further, co-production enables building relationships, exchanging knowledge, and building capabilities that can continue beyond the initial purpose or project. Another fundamental principle is that the leadership and capacity of those with lived experience develops through the co-production process (Roper et al. 2018). Literature also indicates that the knowledge and expertise people with lived experience have, is essential for quality services, programmes, and policies (Slay and Stephens 2018).

Co-production in research, involving stakeholders in the way this study intended, helped to address inequalities in power and control, while also challenging traditional hierarchies (Pinfold et al. 2015). Similarly, with regards to the proposed intervention, those most affected by the intervention are in the best position to design and deliver it, having skills and knowledge of equal importance to professional experts/stakeholders (INVOLVE 2018). However, although co-production is an emerging theory for research and evaluation there is no consistent terminology to understand the diversity of participatory approaches being used worldwide (Slay and Stephens 2020). Concerns exist about considering that participation is

tokenistic, or simply replicates existing power imbalances between researchers and participants (Paylor and McKevitt, 2019). Many of the interventions for carers of people with BPD have shown little evidence of co-production with stakeholders and where they do this is often only in the delivery phase. For example, Hoffman et al's (2005; 2007) Family Connections programme is led by trained family members with support from professionals. Similarly, Sanders and Pearce's (2010) intervention was delivered in collaboration with current group members and involves service users' personal accounts of recovery and experiences.

Involving service users, carers, and health professionals in the design of services and interventions have become a regular discourse in policy and planning (Scottish Government 2013; Scottish Community Development Centre 2020). Co-design is becoming more popular, and instead of interventions designed with users in mind, they are designed together with end-users as equal partners and adopted into health care improvement practices (Ward et al. 2018). This enables staff, patients, and other service users to co-design services, interventions, and /or pathways, together in partnership (Point of Care Foundation 2021). A popular method of co-design found in healthcare literature is experience-based co-design (Bate and Robert 2007; Green et al. 2020) which encompasses participatory action research, user-centered design, learning theory, and narrative-based approaches to change (Donnetto et al. 2015). Experience-based co-design encourages eliciting the experiences of those affected through discussion, observation, and interviews. Although primarily used in quality improvement projects to enhance patient and staff involvement there is growing evidence of researchers using co-design within intervention projects with positive effects (Green 2018; Raynor et al. 2020). Therefore, co-production theory with the elements of co-planning, co-design, co-delivery, and co-evaluation was adopted for this study and is discussed further in Chapter Three (Methodology and Methods) and Chapter Five (Designing the Intervention).

1.5   My motivation for the study

My motivation for conducting this enquiry originated from my inherent interest in BPD, a desire to understand it better, and its impact on the person, and their carers. My own experience of BPD, working as a mental health nurse from 1990 to 2012, was that people with BPD had difficulty finding and engaging in supportive care and treatment from professionals. I observed anxiety about providing care and poor attitudes amongst colleagues and personally found supporting this group of individuals difficult and stressful with little resources or expertise available. The stigma experienced by both service users and their carers was profound even when professional support was offered. Very often it was their family and friends who carried most of the caring responsibility, with very little support or guidance for themselves.

Within my role as a nurse academic, I have undertaken several collaborative empirical research studies associated with BPD. Firstly, a systematic literature review by Dickens et al. (2016) investigated the attitudes, knowledge, and skills of nurses caring for people with BPD. This review highlighted that nurses find this a challenging population to care for, with many holding negative and discriminatory attitudes. There is a lack of coherent therapeutic frameworks to guide nursing practice, and the review found nurses would benefit from evidence-based education and training to improve their knowledge and skills. Second, a systematic literature review by Dickens et al. (2015) examined interventions available to improve nurses' skills, attitudes, and knowledge. This found a dearth of high-quality evidence and suggested further research was required to determine the most effective elements of nurse training programmes. Third, a mixed-methods study with Dickens et al. (2018) aimed to investigate and evaluate the effects of attending a screening of 'Ida's Diary', a first-person account of living with BPD, to determine if it had led to a change in student health professionals knowledge and attitudes. This study showed that student nurses found the film thought-provoking and increased their appetite for knowledge, improved attitudes but not knowing about the condition. It was suggested that the film would be more impactful if it was delivered in conjunction with more didactic information about BPD. We then conducted a mixed-methods evaluation of an educational intervention to change and improve mental health nurses' attitudes and knowledge (Dickens et al. 2019). This study showed the intervention had sustained benefits in some but not all areas: the qualitative findings highlighted some hostility from professionals towards the underpinning biosocial model relating to the origins and care for BPD. However, nurses reported a positive appreciation for the involvement of someone with lived experience in the intervention. Finally, I conducted a systematic literature review (Lamont and Dickens 2019) on service users diagnosed with BPD, and carer's perspectives of mental health services, care provision, and professional support. The findings of which have been presented in this thesis.

Whilst having focused most of our efforts on professional views and educational needs; then latterly service users and carers' experience, I became aware of the burden that carers also carry in caring for someone with BPD, and the lack of attention they have received both in research and professional support/resources. Therefore, I decided that my thesis would attempt to explore carers' experiences and needs with the aim of co-designing an evidence-based intervention to support them in their own right.

1.6   Chapter summary

This thesis was developed out of the recognition that people with BPD and their carers are a much-neglected research priority in Scotland, with poor service and support experiences.

Although there is recognition that caring for someone with BPD can be difficult and challenging, there is no recommendation in clinical excellence guidance of specific interventions available in the UK that services can adopt or offer to support carers (MWC 2018; NICE 2009; RCP 2018).

Given the limited literature available about carers of people with BPD, a broader investigation of evidence-based carer support interventions for people with SMI is justified to evaluate their efficacy and identify potential candidate interventions. To date, no Scottish studies have been undertaken to explore the experiences of carers of people with BPD to understand their challenges, support needs, and views about a future intervention. Therefore, this is necessary to progress work and co-design an evidence-informed intervention specifically for them.

1.7 Research objectives

This thesis has three linked objectives each one informing the development of the next which are as follows:

Objective One

- To identify, using a systematic literature review, current interventions available to support carers of people with SMI, inclusive of BPD, and evaluate their efficacy and suitability.

Objective Two

- To explore, using a qualitative study, the experiences of carers of people with BPD to understand their support needs and views about a future intervention.

Objective Three

- Drawing on existing evidence-based interventions and carers' experiences to work with carers to design an evidence-informed intervention specifically for them.

Chapter Two: Literature review

2.1   INTRODUCTION

The previous chapter discussed the current evidence for interventions to support carers of people with BPD. This was limited to the review by Bailey and Grenyer (2013) which identified only two interventions with outcomes specific to carers. These were the Family Connections programme reported in two USA studies (Hoffman et al. 2005; 2007), and the Oxford Family and Friends programme, examined in a small study conducted in the UK (Sanders and Pearce 2010). Results of these existing interventions showed promise, however, there were limitations in the quality of studies, and neither programme has been evaluated in comparison to a control or waiting list group in a controlled study. Further limitations were that Sanders and Pearce's (2010) intervention focused on carers of people with PD, potentially limiting the suitability of the content in supporting carers of people with BPD given the differences in presentation. Likewise, the Family Connections intervention by Hoffman et al. (2005; 2007) is only available and delivered in the USA and may not relate fully to UK carers. Additionally, an enquiry with the providers indicated it may also be difficult to access this programme for UK carers.

The preliminary conclusion is that these interventions are not suitable for a Scottish study. Further, since these studies are now 10 years old and older, the evidence needs updating to ascertain the current published literature. Initial scoping has ascertained that there are estimated to be 1.5 million people caring for someone with mental ill-health in the UK (Carers Trust 2019), and minimal literature is available for carers of people with BPD. Therefore, a broader investigation of evidence-based interventions for carers supporting individuals with SMI, inclusive of BPD was conducted. This would evaluate their efficacy and identify whether any of the current interventions were suitable or could inform a co-designed intervention specific to this group.

2.2   Aims of the review

This systematic literature review aimed to investigate current interventions to support carers of people with SMI, inclusive of BPD, the purpose of which was to find the best evidence for candidate interventions. Specific objectives were to scope study methods, intervention aims, models and theoretical frameworks, and outcome measures for testing the efficacy. Qualitative studies were examined for carers' experiences and perceived acceptability of interventions.

2.3 METHODS

A mixed-methods systematic review following the relevant sections of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines was conducted (Moher et al. 2009). This took an integrative approach to narratively synthesise the findings of any qualitative, quantitative, and mixed methods studies into a single review. The integrated design process followed these stages: formulating the research question; retrieval of empirical qualitative, quantitative, or primary mixed methods studies; mixed-methods analysis of findings and mixed research synthesis (assimilation) (Sandelowski et al. 2012).

2.3.1 Search strategy

The search was conducted between November 2018 and January 2019 by the first researcher (EL) using a population, intervention, comparison, outcome, timeframe (PICOT) approach to formulate and frame the question (Riva et al. 2012) (see figure 1 below). According to Pollock (2017), a range of frameworks can support the development of a good research question; PICOT is often used for studies into the effectiveness of interventions and can also be interpreted successfully for systematic integrative literature reviews which have a broader scope (e.g. Dickens et al. 2016).

Figure 2: PICOT framework

Population	Adult carers, family, friends of people with SMI (PD, BPD, schizophrenia, bipolar, psychosis, schizoaffective disorder)
Intervention	Psychoeducation, programme, support, support groups
Comparison	Quantitative: Treatment as usual, waiting list, alternative intervention(s) Qualitative: No comparison - experiences, views, perceptions
Outcome	Improve knowledge, reduce burden, improve mental health and wellbeing, the experience of caregiving
Timeframe	Articles published between January 2011 and November 2019

The question formulated was:

'What interventions are available to support carers of people diagnosed with SMI?

Time period limiters were set for articles published between January 2011 and November 2019 to include all studies published after Bailey and Grenyer's (2013) review and update the evidence. Only peer-reviewed, English-language journal articles were included. To search for the quantitative studies multiple computerised databases (CINAHL, PsycINFO, PsychArticles, Medline, Open Dissertations, Cochrane Library, (via EBSCOhost) were searched. The following combination of search terms and related words were used ('intervention' OR 'psychoeducation' OR 'program' OR 'support' OR 'groups' [abstract] AND 'carers' OR 'caregivers' OR 'family members' OR 'relatives' OR 'friends' [abstract] AND 'personality disorder' OR 'borderline personality disorder' OR 'emotionally unstable personality disorder' OR 'serious mental illness' OR 'severe mental illness' OR 'psychosis' OR 'schizophrenia' OR 'bipolar' [abstract]). To search for the qualitative studies multiple computerised databases (CINAHL, PsycINFO, PsychArticles, Medline, Open Dissertations (via EBSCOhost) were searched. Hand searching of unpublished Ph.D. / MPhil thesis and reference lists of included articles were conducted. The following combination of search terms and related words were used ('experience' OR 'perceptions' OR 'attitudes' OR 'views' OR 'feelings' AND 'intervention' [abstract] OR 'psychoeducation' OR 'program' OR 'support' OR 'groups' [abstract] AND 'carers' OR 'caregivers' OR 'family members' OR 'relatives' OR 'friends' [abstract] AND 'personality disorder' OR 'borderline personality disorder' OR 'emotionally unstable personality disorder' OR 'serious mental illness' OR 'severe mental illness' OR 'psychosis' OR 'schizophrenia' OR 'bipolar' [abstract]). The results of these were combined and presented in the PRISMA diagram below (Figure 2).

2.3.2   Inclusion and exclusion criteria

The inclusion and exclusion criteria covered four areas, study methodology, participants, type of intervention, type of outcomes, and measures. Inclusion at the title/abstract stage was conservative i.e., tending towards over, not under inclusion. Full-text versions of all potentially includable studies were sought, examined, and discussed by two reviewers (Emma Lamont [EL] and Emma King [EK]) before a final decision regarding inclusion.

2.3.2.1   Study methodology

Primary empirical research studies either qualitative, quantitative, or mixed methods were included. Quantitative designs included, but were not limited to, experimental designs (randomized controlled trials, controlled clinical trials, controlled before and after trials, and time-series studies) and observational designs (descriptive studies, cohort studies, cross-sectional studies, case studies, and case series studies). Qualitative designs included but

were not limited to, designs such as phenomenology, grounded theory, ethnography, and action research.

2.3.2.2   Types of participants

Studies were included if carers were aged 18 years or older and had taken part in interventions to support carers of individuals aged 15 years and older, diagnosed with an SMI inclusive of schizophrenia, psychosis, bipolar disorder, schizoaffective disorder, BPD, or PD. Carers were defined as any adult (inclusive of parents, children, partners, siblings, or friends) providing any level of informal care or support to the individual (Carers Trust 2019). Substance use, dementia, depression, and anxiety were excluded as these were not included in UK clinical guidance defining SMI (NICE 2019).

2.3.2.3   Intervention models and theoretical frameworks

Studies were included if the intervention consisted of any form of support psychoeducation, bibliotherapy, online or face to face, or a combination. Face-to-face interventions could be delivered in a one-to-one or group setting, or a combination of the two, in the individual's home or community setting. All duration and intensity types were included. Studies were included if the theoretical framework was described, even briefly.

2.3.2.4   Types of outcomes and measures

Outcomes that focused on (or were similar to) improving knowledge, reducing burden, improving mental health and wellbeing, the experience of caregiving, and the efficacy of interventions were all eligible. Studies, where the primary aim was to involve carers in the treatment of patients with SMI to improve patient outcomes, were excluded (see Tables 1 and 2). Validated and non-validated measures were included in the review, as were narratives of carer experiences, views, and perceptions as self-report measures.

2.3.3   Data extraction

Quantitative data were extracted using the standardized data extraction tool from the Joanna Briggs Institute Meta-Analysis of Statistics Assessment and Review Instrument (JBI-MAStARI 2014); similarly, qualitative data were extracted using the standardized data extraction tool

from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI 2014). Extracted data were entered into a summary table (see Table 1). This included author; year; intervention aims; participants' characteristics; patient diagnosis; intervention approach and delivery; control condition or comparator if applicable; core findings; and limitations. Information about intervention design, the content, and the theoretical framework was recorded. Synthesis of intervention aims and outcome measures used was also conducted (see Table 5).

2.3.4 Assessment of study quality

Following guidance for systematic reviews, studies were quality appraised and critiqued independently to assess the methodological quality and determine the extent to which the study addressed the possibility of bias in its design, conduct, and analysis (Tufanaru 2017). All papers selected for inclusion were quality assessed by the principal researcher, Emma Lamont [EL], and an independent researcher, Emma King [EK] using the Joanna Briggs Institute (2017) Tools for use in Systematic Reviews with the results contributing to the synthesis and interpretation of the review (Joanna Briggs Institute 2017). Given the variety of study designs we used three checklists: i) Checklist for Randomised Controlled Trials; ii) Checklist for Quasi-Experimental Studies (non-randomised experimental studies) and iii) Checklist for Qualitative Studies. The first asked the reviewers 13 questions relating to design, randomization, allocation, concealment, blind allocation, follow-up, analysis, outcomes, and measures. The second asked the reviewers nine questions relating to cause and effect, characteristics of participants, control group, measures, follow-up, outcomes, and analysis. The third asked the reviewers ten questions about the research, philosophical perspective, methodology, research question, methods, analysis, interpretation, culture and theory, the influence of the researcher, participant's voices, ethics, and conclusions from the study. Additionally, checklists asked for an overall appraisal, and if they should be included in the review. Each criterion was evaluated as 1= yes criterion met; or 0= no / unclear / not applicable, then collated and totalled (see Tables 2, 3 & 4).

Two questions were excluded from the RCT appraisal as they were impossible to achieve during intervention delivery. These related to 'blind to treatment assignment for participants' and 'blind to treatment assignment for those delivering treatment'. As a result, the final score for the RCT quality appraisal was a maximum of 11. Any discrepancies in the quality appraisal were discussed and resolved between the reviewers, with further opinions sought from PhD. supervisors if needed.

2.3.5 Data analysis

As the studies of interest were heterogeneous, a mixed-methods narrative synthesis was considered the best approach to synthesise the findings (Joanna Briggs Institute 2014). This entailed collecting, evaluating, and synthesising qualitative, quantitative, and mixed primary research studies and then applying techniques to integrate the studies into a review of the literature (Heyvaert et al. 2012). It was anticipated that a mixed methods research approach would give the advantage of combining data on the effectiveness with the data on lived experience, feasibility, and appropriateness to specific cultures or contexts, thus increasing their relevance for policy and practice (Pearson et al. 2015).

A three-step narrative approach suited for a range of designs was used for data analysis of the evidence and to report the study findings (Popay et al. 2006). This enabled key elements to be understood together, qualifying or converting quantitative findings into a qualitative form so that they could be combined with other qualitative data and then subjected to qualitative narrative analysis (Onwuegbuzie and Teddlie 2003; Sandelowski et al. 2013). As suggested by Popay et al. (2006) a preliminary synthesis was undertaken to develop an initial description of the results using thematic analysis. This was achieved by tabulating the data (e.g. SMI focus, interventions, evaluation methods, outcomes, measures), then grouping studies according to the mental health condition that the intervention focused its' support upon (e.g. schizophrenia, psychosis, bipolar, BPD), identifying the important themes and concepts across the studies within each, and giving textual descriptions. The next step meant exploring relationships within and between the studies through rigorous interrogation. Patterns began to emerge such as the context of the study (e.g. country, peer or professional-led), the method of study design (e.g. RCT, quasi-experimental, qualitative), the nature of the intervention (e.g. aims, theoretical components, social heterogeneity), variability of outcomes, efficacy, and experience. Finally, assessing the robustness of the synthesis produced was undertaken. This entailed assessing the trustworthiness of the primary studies included, reflecting critically on the synthesis process and limitations of the studies (e.g. quality, validity, generalisability, aspects that may influence implementation in real-world settings) (Popay et al. 2006). Overall, the narrative analysis took us towards improving the knowledge base (Torraco 2005).

2.4 RESULTS

2.4.1 Study characteristics

The search strategy yielded a total of 1429 articles (Figure 2), plus eight articles identified through other resources (hand search of references lists of included articles and for unpublished Ph.D. / MPhil thesis). After a stepwise process where titles and abstracts were assessed, 1407 did not meet the inclusion criteria leaving 30 full-text articles that were read and assessed for eligibility. Eleven articles were excluded for the following reasons: (*N=5*) the primary aim was to deliver patient care or support families to support patients' outcomes (Chien and Chan 2013; Chien and Thompson 2013; Friedman 2016; Glynn et al. 2010; Sono et al. 2008); (N=1) caregivers of chronic conditions but where mental illness was not specified (Hou et al., 2013); (N=1) one qualitative study of carers for older adults (not BPD) (Malley et al., 2018); and (N=4) RCT protocols where the study was underway but not complete (Betts et al. 2017; Katasuki et al. 2014; Lobban et al. 2017; Sin et al. 2015).

Nineteen primary studies were selected for inclusion. These covered 1147 carers, published between 2012 and 2018; conducted in Australia *(N=6)*; United Kingdom *(N=1)*; USA *(N=3)*; Iran *(N=2)*; China *(N=1)*; Spain *(N=1)*; Ireland *(N=2)*; Canada *(N=1)*; Turkey *(N=1)*. Study populations included carers of individuals with first-episode psychosis *(N=4),* (Chien et al. 2016; McCann et al. 2013; McCann et al. 2014; Whitehorn et al. 2017); psychosis *(N=2)*, (Deane et al. 2013; Roddy et al, 2015); schizophrenia *(N=4)*, (Bademli and Duman 2014; Fallahi Koshnab et al. 2014; Navidian et al. 2012; Weisman et al. 2015); bipolar disorder *(N=2)*, (Hubbard et al. 2016; Madigan et al. 2012); BPD *(N=6)*, (Bailey 2014; Bateman and Fonagy 2018; Flynn et al. 2017; Grenyer et al. 2018; Miller 2013; Pearce et al. 2017); and SMI *(N=1),* [comprising conditions above], (Polo-Lopez et al. 2015). See Table 1 for included studies.

Figure 2: PRISMA diagram

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┌─────────────────────────────────┐          ┌─────────────────────────────────┐
│ Number of records identified    │          │ Number of records identified    │
│ through database searching      │ ───────► │ through other sources           │
│                                 │          │                                 │
│ 1429                            │          │ 8                               │
└─────────────────────────────────┘          └─────────────────────────────────┘
                │                                              │
                ▼                                              ▼
┌─────────────────────────────────┐          ┌─────────────────────────────────┐
│ Number of records screened      │          │ Number of records/ duplicates   │
│ (titles / abstracts)            │ ───────► │ excluded at title / abstract    │
│                                 │          │ level                           │
│ 1437                            │          │ 1407                            │
└─────────────────────────────────┘          └─────────────────────────────────┘
                │
                ▼
┌─────────────────────────────────┐          ┌─────────────────────────────────────┐
│ Number of full text records     │          │ Number of full text records excluded│
│ assessed                        │          │ with reasons: 11                    │
│ 30                              │ ───────► │                                     │
│                                 │          │ Primary aim to deliver patient care/│
│                                 │          │ support families to support         │
│                                 │          │ patients: 5                         │
└─────────────────────────────────┘          │                                     │
                │                             │ Caregivers of chronic conditions but│
                ▼                             │ mental illness not specified: 1     │
┌─────────────────────────────────┐          │                                     │
│ Number of included studies      │          │ Qualitative study of older adult    │
│                                 │          │ caregivers: 1                       │
│ 19 primary studies              │ ───────► │                                     │
│                                 │          │ Randomised controlled trial protocol│
│                                 │          │ study underway but not complete: 4  │
└─────────────────────────────────┘          └─────────────────────────────────────┘
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Table 1: Summary of included papers

Study; country	Study design	Intervention aims	Sample size; characteristics	Intervention	Theoretical framework	Results	Limitations / weakness
Bademli & Duman (2014) Turkey	RCT	Improve mental health/ wellbeing, social support, self-confidence, optimism	46 Schizophrenia	8 weekly 2-hour sessions of Psychoeducational Family Support Group Control Group – TAU	Family to Family Support Programmes (Dixon et al., 2011). Health workers train volunteers/family members.	Significant improvement in 4 domains - self-confidence, optimistic approach, seeking social support & helpless approach low	Small sample size means underpowered; emotions not well documented; interaction between researchers and participants during the study.
Bateman & Fonagy (2018) USA	RCT	Improve mental health/wellbeing, empowerment; reduce burden/shame, depression; adverse incidents	56 BPD	Mentalization and Psychoeducation Group Five sessions lasting 1-1.5 hours Control Group - delayed treatment	Brief carers training and support programme based on the principles of Mentalizing, family interaction & relationships (Bateman & Fonagy 2016). Developed from family programmes (Hoffman et al., 2007; Pearce et al., 2017; Dixon et al., 2011). Families integral in the development	Significant decline in incidents, better functioning within the family, wellbeing increased. Overall burden and levels of anxiety and depression were reduced in both groups.	Small sample size / underpowered/ Bias where families receiving support may be more likely to report benefits. Reporting incidents may be reduced by attending support and feeling further burdened if they report incidents. Lack of long-term follow-up.
Bailey (2014) Australia	Quasi-Experimental	Improve carer burden, wellbeing, and caregiving relationship	32 BPD	Psychoeducation group of 14 hours / 5 sessions of 6-12 carers	Staying Connected - Project air strategy (2012a) – education on BPD and treatment, interpersonal issues, self-care, mindfulness, calm during distress, safety planning	Significant decline in carer burden, improved wellbeing, inc. depression and anxiety, quality of life, care relationship	Absence of control group No long term follow up 21.9% drop out so unknown their results
Chien et al. (2016) China	RCT	Improve caregiving experience; reduce burden /shame	116 First-episode psychosis	Problem-solving / self-help bibliotherapy. Two group sessions plus three review sessions & independently undertaking the module over five months.	Clinician supported bibliotherapy developed by McCann et al., 2013) translated into Chinese, validated by six experts on psychiatric rehabilitation	Can improve first-time carer experience and burden of care. Reduce patients' psychotic symptoms and improve functioning.	May not be representative of first-episode psychosis as 2 out of 18 outpatient clinics used. Carer participants were aged between 20 and 49 and literate with higher

				Control group- TAU			education and higher incomes, than the local average. Self-report measures might induce biased reporting of treatment effects.
Deane et al. (2013) Australia	RCT	Improve mental health/wellbeing, caregiving experience, optimism, knowledge; reduce psychological distress,	81 Psychosis	Family members received an information booklet and 12 recovery-focused newsletters. First-person stories from family members Control Group - Family members received a 96-page information booklet only	Family Connections for psychosis correspondence programme – no theoretical framework identified.	Analysis of participants who substantially completed allocated treatment showed significantly more improvements in wellbeing, positive experiences of caregiving, and distress.	The sample size per-protocol analysis was small. Assessors are not blinded but given mail follow-up and independently completing the questionnaires potential for bias is low. A longer follow-up would have determined if changes were sustained.
Flynn et al. 2017 Ireland	Quasi-experimental	Reduce burden, grief, depression, and increase mastery	80 BPD	Psychoeducation group manualised and shared with peers 12 weekly sessions Control group – Optimised treatment as usual – 3-week psychoeducation program	Family Connections based on DBT (Linehan 1993), developed by Hoffman et al., (2005;2007)	The treatment group showed significantly larger reductions in burden and grief. Groups did not differ on depression or mastery.	Non randomisation - difficult to determine if changes were wholly due to the intervention, or in part other factors such as time passing. No other evidence-based intervention available for the control group
Fallahi Koshnab et al. (2014) Iran	RCT	Reduce burden /shame / blame	71 Schizophrenia	Psychoeducation Group - Four weeks - 4 x two-hour sessions Control Group-TAU	Programme content is based on an educational programme of psychiatric nursing and psychiatric textbooks (Campbell 2009).	Significant reduction in family burden across all dimensions in the experimental group than in the control group.	40% of carers were illiterate which impairs the generalisability of results. A family burden was collected for just one family member, the primary caregiver – which may be higher than others in the family. Short follow-

							up limits understanding of long-term effects.
Grenyer et al. 2018 Australia	RCT	Improve relationship skills and interactional environment	68 BPD	Psychoeducation group of 10 weekly sessions of 6-12 carers in groups Control group – Waiting list	Staying Connected - Project air strategy (2012a) – education on BPD and treatment, interpersonal issues, self-care, mindfulness, calm during distress, safety planning	Significant improvement in family empowerment, relationship with a relative, reduction in expressed emotion, and improvements in carers' perception of playing an active role in interaction with service providers	Self-report diagnosis of BPD, programme efficacy reported through self-report questionnaires as opposed to interviews.
Hubbard et al. (2016) Australia	RCT	Reduce burden/shame, anxiety, depression, stress; improve knowledge	32 Bipolar disorder	Psychoeducation group using 'A guide for caregivers of people with bipolar' Two sessions of 150 minutes each Control Group- TAU	Adapted from the online bipolar disorder programme 'A Guide for Caregivers of People with Bipolar Disorder' (Berk et al., 2012) delivered by two clinical psychologists	The treatment group had significant reductions in carer burden and increases bipolar disorder knowledge and efficacy. No significant change on DASS-21.	Two validated measures were used for the study but also two newly developed. All outcomes are based on self-report which may mean socially desirable bias. Small sample size/ study underpowered: questions relating to whether this is representative of the target population.
McCann et al. (2013) Australia	RCT	Improve mental health and wellbeing, caregiving experience; reduce psychological distress	124 First-episode psychosis	Self-Directed Problem Solving Bibliotherapy Completed a self-help manual. Carers independently completed 5 modules over 5 weeks Control Group - TAU	Problem-solving bibliotherapy adapted from D'Zurilla (2010)	Recipients of PSBI had a more favourable experience of caring than those receiving TAU. Both groups demonstrated improvement by week 16 but the PSBI group improved earlier. PSBI group had a greater reduction in negative emotional evaluations and the need for more support for first-episode psychosis.	A self-help manual was only offered for 5 weeks which may explain why short-term benefits were not sustained at 16 weeks. 16 weeks follow-up period may be too brief to expect significant improvement.

						The level of psychological distress decreased faster in the PSBI group.	
McCann et al. (2014) Australia	Qualitative	Improve mental health and wellbeing, caregiving experience; reduce psychological distress	24 First-episode psychosis	Self-Directed Problem-solving Bibliotherapy Completed a self-help manual. Carers independently completed 5 modules over 5 weeks	As above	Three themes reflect carers' views about the usefulness of the manual: promoting the carer's well-being; increasing understanding of and support for a young person; accessibility and delivery modes of the programme. Highlights that guided self-help is useful in informing and supporting carers. Broadening delivery modes (including a CD, and more photographs) was suggested but the approach is easy to use and accessible and is an effective adjunct to standard support.	Generalisability is not achieved from sample representatives Telephone interviews may result in the loss of visual cues. Only carers with conversational English were included due to limited funding. One aspect of the intervention that was not evaluated was the weekly phone calls to carers to ask questions.
Madigan et al. (2012) Ireland	RCT	Improve knowledge; reduce burden, shame/blame	47 Bipolar disorder	Psychoeducation OR solution-focused therapy group Five two-hour sessions over 5 weeks Control Group – TAU.	Psychoeducation is based on Muessers et al., (1994) framework and adapted for bipolar according to Miklowitz's (2002) guidelines for carers. The solution-focused group followed Berg's (1994) family-based services – a solution-focused approach; also, Miller et al., (1996) handbook of solution-focused therapy	Carers in intervention groups demonstrated greater knowledge and reduction in burden than those in the TAU group. Improvement in carer psychological distress at both year one and two follow up, in both groups – none in TAU. Only a marginal improvement in global functioning in the intervention group over TAU.	Small sample size / underpowered. Only 26% of carers referred chose to take part, possibly due to hopelessness, shame, guilt, stigma, and refusal of involvement by the patient.
Miller (2013) USA	Quasi-experimental	Reduce burden, depression, hopelessness,	70 BPD	Psychoeducation group Eight manualised two-hour workshops plus eight	Family skills programme – based on DBT theory (Linehan 1993)	Significant decreases in measures of depression, hopelessness, and	Lack of a control group means changes cannot be determined solely due to

		mental well-being improvements		biweekly hourly sessions – cohorts of 6-12 carers		interpersonal sensitivity were reported post-intervention. No significant reduction in burden	the intervention. No, follow up
Navidian et al. (2012) Iran	RCT	Reduce burden, shame/blame	100 Schizophrenia and mood disorders	Group Psychoeducation Programme Groups consisting of four x 120-minute sessions over four weeks, one session per week. Groups were 8-9 carers and one nurse or psychiatrist.	Based on Anderson's (1980) Schizophrenia and family, a practitioner's guide to psychoeducation and management.	Zarit caregiver burden scores decreased significantly for the group who took part in the psychoeducation.	Follow up was 3 months so a fairly short time period.
Pearce et al. (2017) Australia	Quasi-experimental	Reduce psychological distress, burden, shame/blame	23 BPD	Psychoeducation: Making sense of BPD Group Three sessions of three hours developmentally tailored, the manualised psychoeducational group for family and friends.	The programme integrates psychologically informed clinical case management, individual cognitive analytic therapy (CAT) (Ryle and Kerr (2002), and general care.	Participants reported significantly decreased subjective burden and increased personality disorder knowledge. Objective burden and distress remained unchanged.	Small sample size: absence of control conditions means changes cannot be solely attributed to the intervention. No, follow-up time points. The diagnosis of the young person was taken from their referral form.
Polo-Lopez et al. (2015) Spain	RCT	Improve mental health and wellbeing	50 Mental disorders	Psychoeducation group of 10 weekly one-hour sessions using a handbook and homework	Cognitive behavioural approach (not referenced)	Significant improvements in the well-being of the intervention group persisted at the second assessment six months later compared to TAU.	The sample size would benefit from an increase and longer follow-up. No blind ratings of outcomes, all had university education so a broader sample was necessary.
Roddy et al. (2015) UK	Quasi-experimental	Reduce psychological distress, depression, acceptability, satisfaction	4 Psychosis	Individual sessions to identify their needs, specific goals, and problem-solving. A total of 2-3 hours was informed by models of	Family interventions in psychosis from Kuipers et al., (2002).	Post-intervention scores indicate reductions in levels of carer distress and depressive symptoms. High levels of acceptability and satisfaction were expressed.	Small sample size lack heterogeneity in sample characteristics, No comparison groups or blind assessment.

				structured family interventions in psychosis. Carers received Institute of Psychiatry resources, website information, and a discussion of an information pamphlet.			
Weisman et al. (2015) USA	RCT	Reduce burden shame / blame	113 Schizophrenia	Culturally informed treatment for schizophrenia (CIT-S) Group 5 modules, each lasting 3 hours incorporate therapeutic components on spirituality, family collectivism, psychoeducation, communication/problem-solving training, cognitive behavioural components drawn from family treatments. The Control group received a 3-hour Psychoeducation module/session only.	CIT-S was developed by Weisman and colleagues (2006), the theory is reviewed by Weisman de Mamani et al., (2010. Comparison programme: Psychoeducation based on intervention developed by Falloon et al., (1984) and Miklowitz & Goldstein (1997)	CIT-S outperformed Psychoeducation in reducing self-blame, guilt, and burden. Both groups demonstrated post-treatment reductions in shame; CIT-S did not outperform Psychoeducation in reducing levels of this construct.	May not generalise to a broader sample. Predominantly Hispanic and mothers. Short scales are used to measure guilt, shame/and blame. Length of comparison condition 12 weeks shorter, not comparing like with like. Treatment assessor not blinded to treatment condition unlikely systematic bias due to self-report.
Whitehorn et al. (2017) Canada	Qualitative	Improve caregiving experience	10 First-episode psychosis	Mindfulness Group Eight x ninety-minute meetings beginning with an introduction to the concept. Meetings took place over 12 months.	Theory adapted for clinical practice (Simkin & Black 2014).	Mindfulness practice was associated with 1) a greater sense of ease 2) increased awareness 3) less emotional reactivity 4) improved interpersonal relationships	Subjects were self-selected and may have had some interest in mindfulness before entering the group. Small sample size

2.4.2   Study methodology

The study methodology was categorised into three types, randomised controlled trials (RCT), quasi-experimental (including non RCTs), and qualitative studies (see Table 1).

i)   Twelve RCTs aimed to investigate intervention effectiveness for carer's outcomes, compared to usual care received or an active comparison such as psychoeducation (Bademli and Duman 2014; Bateman and Fonagy 2018; Chien et al. 2016; Deane et al. 2015; Fallahi Koshnab et al. 2014; Grenyer et al. 2018; Hubbard et al. 2016; Madigan et al. 2012; McCann et al. 2013; Navidian et al. 2012; Polo-Lopez et al. 2015; Weisman et al. 2015).

ii) There were five quasi-experimental studies, including uncontrolled or single group before and after studies which aimed to test intervention effectiveness for pre-specified carers' outcomes using a within-subject pre and post-intervention design (Bailey 2014; Flynn et al. 2017; Miller 2013; Pearce et al. 2017; Roddy et al. 2015).

iii) There were two qualitative studies, one using interviews and the other focus groups with analysis of narrative data. The study aims were to examine the benefits, appropriateness, and experience of the interventions offered (McCann et al. 2014; Whitehorn et al. 2017).

2.4.3   Overall study quality

Studies were assessed and charted in each of their categories (See Tables 2,3 & 4) which showed that study quality was rated generally high (Joanna Briggs 2017). Ten out of twelve RCT studies achieved more than half of the quality checks - (Mdn = 7.3, range between 4-11); the quasi-experimental studies achieved almost all quality checks (Mdn = 7.5, range between 7-8); both of the qualitative studies achieved six out of ten in quality checks. Studies were included in analyses irrespective of their quality; however, more robust studies were assigned a greater weight in integration and discussion (Atkins et al. 2008; Dixon-Woods et al. 2007). Full summaries of study quality are in Appendix 18.

Table 2: Randomised Controlled Trials

Author	1. Was true randomization used?			2. Was allocation concealed?			3. Were groups similar at baseline?			4. Were outcomes assessors blind?			5. Were groups treated identically?			6. Was follow-up complete?			7. Were participants analysed in groups randomized?			8. Were outcomes measured same way?			9. Were outcomes measured reliably?			10. Appropriate statistical analysis?		11. Design appropriate, deviations accounted?			Score: Max /11
	Yes	No	Uncl ear	Yes	No	Uncl ear	Yes	No	Uncl ear	Yes	No	Uncl ear	Yes	No	Uncl ear	Yes	No	Uncl ear	Yes	No	Uncl ear	Yes	No	Uncl ear	Yes	No	Uncl ear	Yes	No	Yes	No	Uncl ear	
Bademli 2014		X			X		X				X				X	X			X					X	X						X		6
Bateman 2018	X			X			X					X			X	X			X			X				X						X	7
Chien 2016	X			X			X			X			X			X			X			X			X					X			11
Deane 2015		X				X	X					X		X				X	X			X			X					X			6
Grenyer 2018	X			X			X				X		X			X			X			X			X			X		X			10
Hubbard 2016	X				X		X					X		X				X	X					X	X						X		5
Fallahi 2014		X		X			X					X	X					X	X			X			X					X			8
Polo Lopez 2015		X			X				X			X		X				X	X				X		X					X			4
Madigan 2012	X					X	X			X			X			X			X			X			X					X			10
McCann 2013	X			X				X		X			X			X			X			X			X					X			10
Navidian 2012	X					X	X					X			X	X			X			X			X						X		7
Weisman 2016			X			X		X			X		X			X			X			X			X					X			7

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Table 3: Quasi-experimental studies

Author	1. Is it clear in the study what cause and effect is (i.e. there is no confusion about which variable comes first)?			2. Were the participants included in any comparisons similar?			3. Were participants included in any comparisons receiving similar treatment/care, other than the intervention?			4. Was there a control group?			5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?			6. Was follow up complete, if not, were differences between groups in terms of their follow up described/analysed			7. Were the outcomes of participants included in any comparisons measured in the same way?			8. Were outcomes measured reliably?			9. Was appropriate statistical analysis used?			Score Max /9
	Yes	No	Unclear	Yes	No	Unclear	Yes	No	Unclear	Yes	No	Unclear	Yes	No	Unclear	Yes	No	Unclear	Yes	No	Unclear	Yes	No	Unclear	Yes	No	Unclear	
Bailey 2014	X			X			X				X		X				X		X			X			X			7
Flynn 2017	X			X			X			X			X			X			X			X			X			8
Miller 2013	X				X				X		X		X					X			X	X			X			4
Pearce 2017	X			X			X				X		X			X			X			X			X			8
Roddy 2015	X			X			X				X		X				X		X			X			X			7

Table 4: Qualitative studies

Author	1. Is there congruity between the stated philosophical perspective and the research methodology?			2. Is there congruity between the research methodology and the research question or objectives?			3. Is there congruity between the research methodology and the methods used to collect data?			4. Is there congruity between the research methodology and the representation and analysis of data?			5. Is there congruity between the research methodology and the interpretation of results?			6. Is there a statement locating the researcher culturally or theoretically?			7. Is the influence of the researcher on the research, and vice-versa, addressed?			8. Are participants, and their voices, adequately represented?			9. Is the research ethical according to current criteria, and is there evidence of ethical approval by an appropriate body?			10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?			Score Max /10
	Yes	No	Unclear	Yes	No	Unclear	Yes	No	Unclear	Yes	No	Unclear	Yes	No	Unclear	Yes	No	Unclear	Yes	No	Unclear	Yes	No	Unclear	Yes	No	Unclear	Yes	No	Unclear	
Whitethorn 2017	X			X			X				X			X		X				X			X		X			X			6
McCann 2018		X		X			X			x			x					X		X			X		X			X			6

2.5   Intervention features

A broad range of interventions were described within the studies. These were tailored specifically to the conditions that carers were supporting (e.g. schizophrenia, psychosis, BPD, bipolar), except for Polo-Lopez et al. (2015) which was a universal intervention for a range of SMI. Most intervention models were characterised as psychoeducational, aiming to reinforce personal strengths, resources, and coping skills, with educational and informative elements.

Three intervention delivery formats were found across studies: group, individual sessions, or guided learning. Most interventions were in group format and sometimes supported by one other mode such as a module, handbook, or newsletter. Some were delivered via manuals, within a module, providing information to connect carers to relevant resources, opportunities, or support. One exception was an eight-session mindfulness group for carers supporting people with first-episode psychosis and aiming to improve the caregiving experience (Whitehorn et al. 2017). Duration and intensity of sessions ranged from two to twelve, lasting between ninety minutes and three hours per session. The average module / manual learning was estimated as 160 minutes for each component over an average of 12 weeks. Three interventions adopted a lived experience carer approach which meant they were delivered by trained family carers (Bademli and Duman 2014; Bateman and Fonagy 2018; Flynn et al. 2017). The others were delivered by clinical professionals or a mix of both trained family carers and clinical professionals. Further details of intervention features and formats across studies are available in Table 1.

2.5.1   Intervention aims and outcome measures

Despite the diversity of SMI's (schizophrenia, psychosis, bipolar, BPD) the studies addressed, interventions held several commonalities including aims and outcomes, measures, and content. Across studies, interventions broadly aimed to improve carers' mental health and wellbeing, caregiver experience, knowledge, social support, self-confidence, optimism, and also reduce psychological distress, depression, anxiety, burden, shame, or blame. One study, with a BPD focus, also aimed to reduce adverse events and improve family functioning (Bateman and Fonagy 2018).

The studies employed a range of measures. Thirty-nine different measures were used in total across the quantitative studies, the most common being: the burden assessment scale

(Reinhard et al. 1994) which was used in seven studies. The experience of caregiving inventory (Szmukler et al. 1996), and Kessler psychological distress scale (Kessler et al. 2002) were both used in three studies.

The other measures were only used in one or two studies. These were: Becks depression inventory (Beck et al. 1961); Becks hopelessness inventory (1974); brief symptom inventory (Boulet and Bass 1991); care givers social problem-solving inventory (D'Zurilla et al. 2010); CORE (Connell and Barkham 2007); COPE inventory (Carver et al. 2009); depression anxiety stress scale (Lovibond and Lovibond 1995); dyadic adjustment scale (Sabourn et al. 2005); family empowerment scale (Koren et al. 1992); family burden interview scale (Pai et al. 1981); family burden questionnaire (Wiedemann et al. 2002); general health (Kilic 1996); general health questionnaire 12 (Miklowitz et al. 1988); grief scale (Struening et al. 1995); knowledge of bipolar and self-efficacy scale (Hubbard et al. 2016); knowledge of illness (Smith and Birchwood 1997); maladjustment scale (Echeburua et al. 2000); mental health inventory (Berwick et al. 1991); mental health inventory (Cuijpers et al. 2009); McLean screening for BPD – carers (Zanarini et al. 2003); patient health questionnaire (Kroenke et al. 2001); psychological wellbeing scale (Ryff and Keyes 1995); recovery knowledge inventory (Bedregal et al. 2006); revised centre for epidemiological studies depression scale (Radloff et al. 1977); Rosenberg self-esteem scale (Rosenberg 1965); score 15 family function scale (Stratton et al. 2010); short health survey (Ware et al. 1996); Spielberg state trait anxiety inventory (Spielberg et al. 1970); WHO QOL bref (1993); symptom checklist 90 revised (Derogatis (1992); symptom distress index (Derogatis and Unger 2010); stress coping questionnaire (Sandin and Chorot 2003); Warwick Edinburgh mental wellbeing scale (Tennant et al. 2007); ways of coping stress scale (Sarin and Durak 1995); and Zarit burden interview (Scott et al. 1985).

All quantitative measures were validated, except for one study by Hubbard et al. (2016) which used the Knowledge of Bipolar, and Bipolar Self-Efficacy Scales, developed by the authors. Qualitative measures included semi-structured interviews and focus groups. A summary of intervention aims and measures across studies is presented in Table 5.

Table 5: Summary of intervention aims and outcome measures

Study	Intervention aims and outcomes	Measures
Bademli & Duman (2014)	Improve mental health/ wellbeing, social support, self-confidence, optimism	Ways of coping stress scale (Sarin & Durak 1995); General Health (Kilic 1996)
Bailey (2014)	Improve carer burden, wellbeing, and caregiving relationship	McLean Screening for BPD – Carer (Zanarini et al. 2003) Burden assessment scale (Reinhard et al. 1994) Mental health Inventory (Cuijpers et al. 2009); Grief Scale (Struening et al. 1995); WHO QOL Bref (1993); Family Questionnaire (Wiedemann et al. 2002)
Bateman & Fonagy (2018)	Improve mental health/wellbeing, empowerment; reduce burden/shame, depression; adverse incidents	Becks depression inventory (Beck et al. 1961); Spielberg state-trait anxiety inventory (Spielberg et al. 1970); Burden assessment scale (Reinhard et al. 1994) Warwick Edinburgh mental wellbeing scale (Tennant et al. 2007); Score 15 family function scale (Stratton et al. 2010); Family empowerment scale (Koren et al. 1992); Diary
Chien et al. (2016)	Improve caregiving experience; reduce burden /shame	Family burden interview scale (Pai et al. 1981) Experience of caregiving inventory (Szmukler et al. 1996) Care givers social problem-solving; inventory (D'Zurilla et al. 2010)
Deane et al. (2015)	Improve mental health/wellbeing, caregiving experience, optimism, knowledge; reduce psychological distress	Experience of caregiving inventory (Szmukler et al. 1996); Kessler psychological distress scale (Kessler et al. 2002); Psychological wellbeing scale (Ryff & Keyes 1995) Recovery knowledge inventory (Bedregal et al. 2006)
Fallahi Koshknab et al. (2014)	Reduce burden /shame / blame	Family burden interview scale (Pai et al. 1981)
Flynn et al. (2017)	Reduce burden, grief, depression, and increase mastery	Burden assessment scale (Reinhard et al. 1994); Grief Scale (Struening et al. 1995); Revised Centre for Epidemiological Studies Depression Scale (Radloff et al. 1977)
Grenyer et al. (2018)	Improve relationship skills and interactional environment	McLean Screening for BPD – Carer (Zanarini et al. 2003) Burden assessment scale (Reinhard et al. 1994) Dyadic Adjustment Scale (Sabourn et al. 2005) Family Empowerment scale (Koren et al. 1992) Mental Health Inventory (Berwick et al. 1991)
Hubbard et al. (2016)	Reduce burden/shame, anxiety, depression, stress; improve knowledge	Burden assessment scale (Reinhard et al. 1994) Depression anxiety stress scale (Lovibond & Lovibond 1995) Knowledge of bipolar and self-efficacy scale (Hubbard et al. 2016)
Madigan et al. (2012)	Improve mental health and wellbeing, caregiving experience; reduce psychological distress	WHO QOL Bref (1993); Knowledge of illness (Smith & Birchwood 1997); General health questionnaire 12 (Miklowitz et al. 1988)
Miller (2013)	Reduce burden, depression, hopelessness, mental well-being improvements	Becks depression inventory (Beck et al. 1961); Becks Hopelessness inventory (1974); Brief Symptom Inventory (Boulet & Bass 1991); Burden assessment scale (Reinhard et al. 1994)
McCann et al. (2013)	Improve mental health and wellbeing, caregiving experience; reduce psychological distress and burden	Experience of caregiving inventory (Szmukler et al. 1996) Kessler psychological distress scale (Kessler et al. 2002) Family burden Questionnaire (Wiedemann et al. 2002 Short health survey (Ware et al. 1996)
McCann et al. (2014)	Improve mental health, caregiving experience; psychological distress	Semi-structured interviews
Navidian et al. (2012)	Reduce burden, shame/blame	Zarit burden interview (Scott et al. 1985)

Pearce et al. (2017)	Reduce psychological distress, burden, shame/blame	Burden assessment scale (Reinhard et al. 1994); Kessler psychological distress scale (Kessler et al. 2002); PD knowledge, attitudes, and skills Questionnaire (Bolton et al. 2010)
Polo-Lopez et al. (2015)	Improve mental health and wellbeing, knowledge, confidence; reduce anxiety, depression, stress	Becks depression inventory (Beck et al. 1961) Spielberg state-trait anxiety inventory (Spielberg et al. 1970) Symptom checklist 90 revised (Derogatis (1992) Symptom distress index (Derogatis & Unger 2010) Maladjustment scale (Echeburua et al., 2000) Rosenberg self-esteem scale (Rosenberg 1965) Stress coping questionnaire (Sandin & Chorot 2003)
Roddy et al. (2015)	Reduce psychological distress, depression, acceptability, satisfaction	CORE (Connell & Barkham 2007); COPE inventory (Carver et al., 2009); Patient health questionnaire (Kroenke et al. 2001)
Weisman et al. (2015)	Reduce burden shame/blame	Burden assessment scale (Reinhard et al. 1994)
Whitehorn et al. (2017)	Improve caregiving experience	Focus groups

2.6   Theoretical frameworks and content of interventions

The theoretical frameworks and content of interventions, along with the study findings were analysed and themed according to the SMI they supported carers with. These were: schizophrenia, psychosis, bipolar or universal interventions, and BPD. These are presented below and summarised in Table 1.

2.6.1   Schizophrenia carer support interventions

Four studies focused on psychoeducational group interventions for carers of people diagnosed with schizophrenia (Bademli and Duman 2014; Fallahi Koshknab et al. 2014; Navidian et al. 2012; Weisman et al. 2015). The first, conducted by Bademli and Duman (2014) in Turkey, was an RCT of 46 carers using the Family to Family Support Programme based on psychosocial theories proposed by Dixon et al. (2011). Healthcare workers trained volunteer carers with knowledge concerning self-help, emotional support, and skills to reduce the impact of caregiving. Results showed statistically significant improvements in self-confidence, optimistic approach, seeking social support, and reductions in helplessness following the intervention compared to CAU.

An RCT (Navidian et al. 2012) conducted in Iran, with 100 carers examined a psychoeducational group facilitated by a nurse or psychiatrist based on the family's needs. This used Anderson's (1980), Schizophrenia and Family: Practitioner's Guide to Psychoeducation and Management. Groups included: understanding the illness, recognising

effects of medication, compliance, warning signs of relapse, prevention, coping skills, communication and emotions, stress management, and relaxation for the family. Results found a significant decrease in burden for the group who took part in the psychoeducation programme compared to CAU. Fallahi Koshknab et al. (2014) conducted an RCT in Iran with 71 carers. This investigated an intervention based on psychiatric nurse education using Campbell's (2009) psychiatric textbook but gave little other description. A significant reduction in family burden was achieved from the intervention compared to CAU.

The most detail was provided in Weisman et al's (2015) RCT with 113 carers into Culturally Informed Therapy for Schizophrenia (Weisman et al. 2006) conducted in the USA. This was a manualized family treatment delivered by a therapist and comprised five modules with between sessions homework to practice skills taught during therapy. These incorporated therapeutic components informed by cross-cultural research and cognitive behavioural components from family treatments. The control group received a shortened version of CIT-S involving theories from Miklowitz and Goldstein (1997) and information about symptoms, exacerbating factors, environmental factors, and neurobiology. Results showed that the main intervention outperformed the shorter psychoeducation group in reducing caregiver burden, guilt, and self-blame for their relative's schizophrenia. Although carers in both treatment groups demonstrated significant post-treatment reductions in shame, compared to the control group receiving CAU, the main intervention was not found to outperform psychoeducation in reducing levels of shame.

2.6.2 Psychosis carer support interventions

Two studies investigated interventions for carers of people diagnosed with psychosis (Deane et al. 2015; Roddy et al. 2015), and a further four focused on first-episode psychosis (Chien et al. 2016; McCann et al. 2013; 2014; Whitehorn et al. 2017). The first, was an RCT conducted in Australia with 81 carers in an educational correspondence course, Family Connections by Deane et al. (2015). This consisted of an information booklet received by the control group; the intervention group additionally received 12 recovery-focused newsletters over 12 months. These were goal-directed, focusing on strengths, and core values, promoting growth and development, including first-person stories from family members. Journal-writing encouraged participants to document their journey, including thoughts and feelings about events. There was little detail given about the theory used, however, the authors advocated this course could have a wider reach given the distance learning nature. Results found statistically significant improvements across the whole sample with reductions in distress, negative caregiving

experience, and increased hope. Comparison of participants from the two groups who completed a substantial part of their allocated treatment showed superior gains in wellbeing, positive experiences of caregiving, and reduced distress from the full program than from the information programme alone. Roddy et al. (2015) conducted a quasi-experimental study in the UK with four carers, examining a problem-solving programme. This was provided on an individual basis with a psychologist, informed by structured family interventions in psychosis from Kuipers et al. (2002) and the Institute of Psychiatry resources. The content was based on individuals' needs, goals, crisis planning, sleep hygiene, problem-solving, information about psychosis, emotional processing, health problems, and support services. Results showed the post-intervention group scores had significant reductions in levels of carer distress and depressive symptoms.

First-episode psychosis carer support was the focus of an RCT involving 124 participants and a follow-up qualitative study with 24 carers by McCann et al. (2013; 2014) conducted in Australia. This examined an educational problem-solving bibliotherapy intervention adapted from D'Zurilla et al's (2010) self-help therapy book. The manual contained five modules to support carers with the following: strengthen well-being and coping skills, get the best from support services, promote the wellbeing of the person, deal with the effects of the illness such as social withdrawal, communication, risky and unrestrained behaviour, disturbed sleep, hallucinations, weight gain, reluctance to take medication, substance misuse, aggression, and suicide risk. CAU consisted of specialist support using a case management framework; the intervention group received CAU as well as the intervention. Results showed a reduction in negative emotional evaluations by week 16 across both the intervention and CAU groups. However, the intervention group responded earlier, concluding the intervention was a cost-effective adjunct to CAU. McCann et al. (2014) also used semi-structured interviews to evaluate carers' beliefs about the usefulness of the intervention. Carers perceived this was useful for informing and supporting their wellbeing, was easy to use and accessible, but also recommended broadening delivery modes (such as including a CD, and more photographs).

In a further RCT conducted in China by Chien et al. (2016) the same bibliotherapy course was offered (developed by McCann et al., 2013) to 116 carers by translating the manual into Chinese, validated by psychiatry experts. Chien et al's (2016) study showed improved experience and burden of care, a reduction in the patients' psychotic symptoms, and improved family functioning compared to CAU. A further qualitative study by Whitehorn et al. (2017) in Canada involved 10 carers in focus groups to explore the perceived impact of a mindfulness-based support group for parents of young people with first-episode psychosis. This was based on the theory by Simkin and Black (2014) and was adapted for clinical practice. They found

that consistent mindfulness practice led to an increased sense of ease and awareness, less emotional reactivity, improved relationships, and a greater ability to focus on their own needs.

2.6.3 Bipolar and universal carer support interventions

Psychoeducation tailored to carers of people diagnosed with bipolar disorder was examined in two studies (Hubbard et al. 2016; Madigan et al. 2012). Conducted in Australia, Hubbard et al's (2016) RCT with 32 carers investigated a group intervention adapted from an online bipolar disorder programme. This was called A Guide for Caregivers of People with Bipolar Disorder (Berk et al. 2012) and delivered by two clinical psychologists. Results showed large and significant reductions in carer burden and increases in bipolar disorder knowledge and efficacy but no significant change in depression and anxiety compared to the CAU / waiting list group. Similarly, conducted in the Republic of Ireland by Madigan et al. (2012), was an RCT with 47 carers of two group interventions. The first was the multifamily group based on the framework developed by Mueuser et al. (1994), and the second was an intervention adapted for bipolar disorder according to Miklowitz's (2002) guidelines for carers. Alternatively, solution-focused group therapy was guided by theories from Berg's (1994) Handbook of Solution-Focused Therapy (Miller et al. 1996). Both groups had joint facilitation by a psychiatric nurse and a social worker. Carers were allocated to either the multifamily psychoeducation or solution-focused therapy group, with the comparison group receiving CAU. Greater knowledge and reduction in burden were found for the multifamily psychoeducation and solution-focused therapy groups compared to CAU. There was an improvement in psychological distress at both one and two-year follow-ups for both groups, but none in CAU, and only a marginal improvement in global functioning in the multifamily psychoeducation over CAU.

One study conducted in Spain was a universal intervention, not specific to one mental health condition (Polo-Lopez et al. 2015). This was an RCT with 50 carers using a cognitive behavioural approach which provided one-to-one psychoeducational support for carers of people with SMI (psychosis; bipolar; severe depression; addictive disorders). The intervention aimed to improve mental health and wellbeing by teaching carers to cope with stressful life events using a handbook with sessional objectives and homework tailored to individual's needs. Specific theories were cognitive-behavioural approaches (not referenced), however, results showed significant improvements in the well-being of the intervention group which persisted at the second assessment six months later compared to CAU. The intervention was found to be effective as a treatment for relatives of people with mental health disorders.

2.6.4   BPD carer support interventions

Six studies reported on tailored interventions to support carers of people with BPD (Bailey 2014; Bateman and Fonagy 2018; Flynn et al. 2017; Grenyer et al. 2018; Miller 2013; Pearce et al. 2017). A quasi-experimental study conducted by Pearce et al. (2017) in Australia involved 23 carers receiving the intervention Making Sense of BPD, which was a manualised psychoeducational group personalised to individual needs for carers of young people with BPD (aged 15-25). This integrated concepts from the Helping Young People Early programme (Chanen and McCutcheon 2014), with emphasis on BPD being a relational disorder using psychologically informed clinical case management, and individual cognitive analytic therapy (Ryle and Kerr 2002). Topics included were features of BPD, diagnosis, causes, treatment, interpersonal skills, relationships, and self-care. Results from pre and post-intervention analysis showed carers had significantly decreased subjective burden and increased BPD knowledge, but objective burden and distress remained unchanged.

Similarly, Miller (2013) conducted a quasi-experimental study in the USA with 70 carers as part of a doctoral thesis. The Family Skills intervention aimed to reduce burden, depression, hopelessness, and improve mental wellbeing in a psychoeducational group. This consisted of eight manualised two-hour workshops plus eight biweekly hourly sessions with cohorts of 6-12 carers. Based on DBT theories (Linehan 1993) and delivered by a trained mental health professional, results showed significant decreases in measures of depression, hopelessness, and interpersonal sensitivity post-intervention. However, no significant reduction in burden was found.

Staying Connected was evaluated in two studies (Bailey 2014; Grenyer et al. 2018). Initially, Bailey (2014) conducted a quasi-experimental pilot study of this psychoeducational intervention in Australia as part of a doctoral thesis. This included 18 carers, with the intervention aiming to reduce burden and improve wellbeing and the caregiving relationship. Designed in partnership with families it consisted of 14 hours over five sessions with 6-12 participants in each group, delivered by service providers. This aimed to develop an understanding of the carer's role within the relationship and provided education on BPD, treatments, and interpersonal issues involving safety (e.g. self-harm, suicide, anger). Content also included self-care, keeping calm during distress, setting boundaries, nondirective counselling (listening, validating), and safety planning. The intervention was adapted from the work of Grenyer (2012) and the Project Air Strategy (2012). Results showed a statistically significant reduction in burden, grief, and increased wellbeing, including symptoms consistent with depression and anxiety, improved quality of life, and caregiving dynamics.

The same intervention was examined by Grenyer et al. (2018) in an RCT with 68 carers in Australia aiming to improve carers' relationship skills and interactional environment. The focus was on empowering carers with skills to change how they behave in their relationship with the person experiencing BPD, and gain knowledge about BPD and associated challenging behaviours (e.g., self-harm, suicide attempts, and impulsive anger). Delivered by health service providers this involved peer support, sharing experiences, and communication practice exercises to enhance skill development. Results showed improvements compared to the waiting list group for carers in dyadic adjustment with the person with BPD, greater family empowerment, and reduced expressed emotion, all sustained after 12 months. There were also improvements in carers' perceptions of playing a more active role in the care and interacting with service providers. Reduction in burden and improvement in mental health were found at 12 months follow up indicating this takes longer and reduces over time.

A further RCT, conducted in the USA by Bateman and Fonagy (2018) involved 56 carers of people with BPD in a group psychoeducation mentalization-based programme based on the theory of mentalizing (Bateman and Fonagy 2016), and several previous family intervention programmes (e.g. Hoffman et al. 2007; Pearce et al. 2017; Dixon et al. 2011). Families were involved in the development of the intervention (unspecified), which focused on skills for managing relationships and interactions. The intervention was delivered by family experts with experience who received training. The study found the intervention group had a significant decline in incidents, such as self-harm or aggression, and better functioning within the family compared to the control who was a waiting list control group. Self-reported wellbeing also increased alongside overall reduced burden and levels of anxiety and depression in both groups.

Finally, the Family Connections programme based on DBT (Linehan 1993), and building on the previous work of Hoffman et al. (2005;2007) was conducted in the Republic of Ireland by Flynn et al. (2017) using a quasi-experimental non-randomised controlled design. The study aimed to reduce burden, grief, depression, and increase mastery with 80 carers. Family Connections was a 12-weekly session, manualised psychoeducation group, with peer support and delivered by trained family members. Results showed the treatment group had statistically significantly larger reductions in burden and grief compared to the optimised CAU group who received a three-week psychoeducation programme containing DBT theories (Linehan 1993) and delivered by psychologists. Groups did not differ on outcomes for depression or mastery.

2.7   DISCUSSION

This review aimed to systematically synthesise the literature examining current interventions to support carers of people with SMI with a special focus on BPD. This updated and expanded on reviews conducted previously (i.e. Bailey and Grenyer 2013; Yesufu-Udechuku et al. 2015). Nineteen studies evaluating 15 different interventions published between 2012 and 2018 were included. As with previous research (Yesufu-Udechuku et al. 2015), carer support interventions for schizophrenia and psychosis were most commonly examined in 11 studies; BPD was the focus of six.

Important factors for interventions to address were found to be improving mental health, wellbeing, caregiving experiences, and knowledge. Interventions also aimed to reduce depression, burden, psychological distress, and increase social support. This reflected current evidence regarding the negative impact and high burden of caring that people experience (Carers Trust 2019); also resonating with current evidence about carers of people with BPD (Bailey and Grenyer 2013; Lamont and Dickens 2019). Burden within this context referred to the obvious and objective result of caring for a person with SMI, and the subjective distress or emotional consequences people report (Schene 1990). Examples included giving up social time, safety concerns (e.g. self-harm, suicide), or blaming themselves for the illness (Ostman et al. 2005). The burden for carers is said to increase for those who live with a person with SMI as opposed to those who do not.

Although psychoeducational, informative, and educational elements were popular, internet-based interventions such as websites or online courses were not described in any of the studies. Despite this, a recent review found internet-based resources were popular as interventions for carers of people with long-term illnesses (Sin et al. 2018). The review also found that often interventions were tailored to specific conditions, and adopted a theoretical framework specific to the SMI carers were supporting (e.g. schizophrenia, psychosis, bipolar, BPD), (except Polo-Lopez et al. 2015). This indicates that specificity may have been important to their acceptability and efficacy. Most studies were underpinned by a theoretical approach such as DBT, mindfulness, mentalization, problem-solving, or solution-focused, again indicating applying these theoretical approaches may be linked with positive outcomes. The wide range of interventions reviewed, further highlights the lack of established evidence-based interventions available for carers. Also, the preference for interventions that are tailored to specific conditions (e.g. BPD) but contain similar ingredients.

Significant to this thesis was that six studies evaluated interventions tailored for carers of people with BPD (Bateman and Fonagy 2018; Bailey 2014; Flynn et al., 2017; Grenyer et al. 2018; Miller 2013; Pearce et al. 2017). Results indicated that these interventions led to significant outcomes for participants and contained therapeutic evidence-based approaches already established as treatments for BPD itself (Cognitive Analytical, Mentalization, DBT, Project Air Strategy).

2.7.1 Study limitations

There were many limitations across the studies, including significant heterogeneity of populations, intervention design, delivery, and a wide range of outcome measures used at different time points (ranging from one week to two years). This meant meta-analysis was not appropriate or achievable. Five efficacy studies had an absence of control conditions (Bailey 2014; Flynn et al. 2017; Miller 2013; Pearce et al. 2017; Roddy et al. 2015) which meant it could not be concluded that changes were caused by the intervention alone and no other variables. Small sample sizes were reported in nine studies (Bailey 2014; Bademli and Duman 2014; Bateman and Fonagy 2018; Deane et al. 2015; Hubbard et al. 2016; McCann et al. 2013; Navidian et al. 2012; Polo-Lopez et al. 2015; Roddy et al. 2015). Short or no follow up periods were reported in eleven studies (Bailey 2014; Bateman and Fonagy 2018; Deane et al. 2015; Fallahi Koshknab et al. 2014; Miller 2013; Navidian et al. 2016; McCann 2013; McCann 2014; Pearce et al. 2017; Polo-Lopez et al. 2015; Roddy et al. 2015). It was therefore unknown if the improvements were maintained or if there were further improvements over time.

Generalisability may not be achievable as some studies reported that they might not fully represent the target group (Bailey 2014; Chien et al. 2016; McCann et al. 2014; Roddy et al. 2015; Weisman et al. 2015). Additionally, Bailey's (2014) study reported 21.9% of participants dropped out so it is unclear how these carers impacted the findings. Further limitations existed with regards to bias, where families receiving the interventions may be more likely to report benefits. This was highlighted by Batemen and Fonagy (2018) who found a reduction in incidents, however, they proposed this may have been because participants felt further burdened not to report due to attending the intervention. Two studies (Pearce et al. 2017; Grenyer et al. 2018) also highlighted that carers self-identified the BPD diagnosis; therefore, the diagnosis was not confirmed. Further, self-report questionnaires were conducted instead of researcher administered outcomes questionnaires.

The heterogeneity of the studies presented also meant there was limited evidence to support their overall generalisability for carers. However, review findings indicated that all interventions had positive effects on carers' outcomes in several domains including mental health and wellbeing, caregiving experiences, reducing the burden, and psychological distress alongside increasing social support. Studies to increase knowledge also had positive outcomes, however reducing anxiety, depression, and the burden was inconsistent across studies, indicating an additional intervention may be required for carers who have significant difficulties with these. Positive outcomes were found across the studies regardless of theoretical frameworks, delivery style and specific conditions they were designed to support carers with. However, there was little evidence of co-design or co-production with carers in most of the studies. Where there was, this was either in the delivery of the intervention only (Bailey 2014), or little information provided to fully assess (Bademli and Duman 2014; Bateman and Fonagy 2018). None clarified if they were developed based on the experiences and needs of care explored through a qualitative study.

The focus of this thesis is carers of people with BPD; therefore, it is important to highlight specifically the limitations of these studies with regards to how they relate to this thesis. In most studies burden was reduced following the intervention (Bateman and Fonagy 2018; Bailey 2014; Flynn et al. 2017; Grenyer et al. 2018; Pearce et al. 2017), except for Miller (2013) who reported no change but a reduction in measures of depression, hopelessness, and interpersonal sensitivity. Although a mentalization-based group (Bateman and Fonagy 2016) revealed a decline in incidents (e.g. self-harm, aggression), and overall better functioning within the family (Bateman and Fonagy 2018) it did not address elements evident in other interventions such as education or skills. Pearce et al. (2017) reported a statistically significant increase in knowledge and understanding of BPD, which carers in Lamont and Dicken's (2019) review identified as a need. However, this was focused on carers of 15-25-year olds only, therefore, it is unclear whether this would be generalisable to a broader age group.

There were limitations in Bailey's (2014) and Grenyer et al's (2018) interventions to consider also. Both studies evaluated the same intervention, Staying Connected When Emotions Run High which was part of an overall care programme within the Project Air Strategy (2012; 2016) offering a holistic approach to care for people with BPD and their families. Although the studies found the intervention effective it may be influenced by delivery within the context of the Project Air Strategy (2012; 2016) in its entirety and may not generalise well to healthcare systems that do not offer this.

One of the strengths of this review was overall study quality was generally high, and 12 of the 19 articles included were RCTs: the gold standard for evaluating effectiveness (Joanna Briggs 2017). The review included all studies regardless of their quality. Most studies were quantitative in design with only two being qualitative, exploring experience and acceptability of the intervention (McCann et al. 2014; Whitehorn et al. 2017). These both had a first-episode psychosis focus and highlight a gap in the literature of primary studies evaluating the lived experience, acceptability, and appropriateness of such interventions. Future research should address this as studies of this nature would increase the understanding of their acceptability to carers and strengthen their value for integration into policy and practice (Pearson et al., 2015). Although the findings of interventions to support carers of people with BPD are promising, only two of the interventions were RCTs (Bateman and Fonagy 2018; Grenyer et al. 2018), and the methodologies used in the studies did not clarify what the mechanisms of change were for participants.

Of nineteen studies in total, all but one originated from outside the UK (Roddy et al. 2015). Studies specifically focusing on carers of people with BPD were conducted in the USA, Australia, and the Republic of Ireland meaning access to the content and delivery of these interventions may be difficult for carers in the UK. Further, these may have limited application within the UK health and social care systems. The lack of interventions designed and delivered to carers living in the UK highlights a concerning gap in literature and provision in this country which future research should address.

2.7.2   Implications for future research

The purpose of this review was to help inform whether any of the current candidate interventions were suitable for meeting the needs of carers supporting people with BPD or could inform a co-designed intervention specific to this group. The review confirmed there is a dearth of high-quality literature, however, it has indicated potential ingredients of candidate interventions to support carers of people with SMI and to some degree people with BPD. It also identified a need for qualitative evidence identifying carers' lived experience of interventions, informing of its acceptability and feasibility. Across studies, the review found no conclusive evidence for the effectiveness of a single intervention type (e.g. knowledge acquisition, support, information, psychoeducation) in improving mental health, wellbeing, knowledge, and reducing negative carer outcomes compared to CAU. Further research is needed particularly in the UK with an emphasis on co-production and co-designing interventions with carers, for carers. Thereafter, evaluating their efficacy and suitability using a range of methods (quasi-experimental, RCT, qualitative).

For carers supporting a person with BPD, the best evidence currently pertains to the Family Connections programme (Hoffman 2005; 2007; Flynn 2017), and the Staying Connected When Emotions Run High intervention (Bailey 2014; Grenyer et al. 2018). However, there is insufficient evidence for determining which is most effective for these specific carers, and given these are from out with the UK they may not generalise fully, and be hard to access in Scotland.

The previous chapter identified only four studies have been published associated with carers' experiences of supporting a person with BPD (Lamont and Dickens 2019). This highlighted the stigma they experienced, however, no interventions reviewed discussed this at all. There are still many gaps in the literature, therefore an exploration of carers of people with BPD's experiences and needs is required to collect more detailed evidence. This should define or understand the problems they experience and need support for (such as emotional burden, stigma, and accessing information). This will in turn produce knowledge of what a supportive intervention might involve and include. It is important to examine this topic further in a new research study. The findings of this new study of carers' experiences would then be used alongside existing knowledge of evidence-based interventions to work with carers and other stakeholders, to co-design an evidence-informed intervention specifically for them. This would include underpinning the intervention with an appropriate theoretical framework and gaining an understanding of the mechanisms that may contribute to its' effectiveness or ineffectiveness.

2.8   Chapter summary

This chapter reported the findings of a systematic literature review examining current interventions to support carers of people with SMI. The results of the review have been helpful with preliminary findings indicating that interventions had positive effects on carers' outcomes including mental health and wellbeing, caregiving experiences, reducing the burden and psychological distress, alongside increasing social support. However, the evidence was limited particularly concerning carers of people with BPD. The input or level of co-production with carers of people with BPD could also not be fully assessed. Therefore, it was decided to proceed to a study that could identify carers' experiences of, and needs for, supporting a person with BPD; also, to work with carers to design an intervention to support these needs. The next chapter will present the methodology and methods for the qualitative study of carers' experiences.

Chapter Three: Methodology and methods

3.1   INTRODUCTION

This chapter describes the aims and objectives of this study. It will also examine the study design, philosophical underpinnings that guided the research, co-production elements, and the procedure for data collection and analysis. Thereafter the trustworthiness of the study, reflexivity, role of the researcher, and data management will be presented.

3.1.1   Aims of the study

This study aims to explore the needs and experiences of carers of people with BPD and to co-produce with them, and professional stakeholders a supportive intervention to meet their (carers) needs. The study was conducted in two corresponding phases, each with its objectives and research questions.

3.1.2   Specific objectives

3.1.3   Phase one

- To explore, the experiences of carers of people with BPD to understand their support needs and views about a future intervention.

3.1.4   Research questions

- What are the experiences of carers of people with BPD?
- What are their needs, either met or unmet?
- What is the impact of supporting family or friends diagnosed with BPD?
- What sources of support, both formal and informal, do carers receive or engage with, and to what extent does this support meet their needs?
- How might a supportive intervention be useful to carers?

3.1.5 Phase two

- Drawing upon existing evidence-based interventions and carers' experiences, to work with carers and professional stakeholders to co-produce an evidence-informed intervention specifically for them.

3.1.6 Research questions

- What would the key issues be for an intervention to address?
- What would be the first and most important to tackle?
- What should the individual components (content, theory stance) of the intervention be?
- How should the intervention be implemented (e.g. duration, frequency, and delivery of each component?)

3.2 Study design

The overarching design of this study is qualitative using Facet Methodology (Mason 2018), whereby individual interviews were the method of gathering data to elicit carers' experiences and needs. To enable co-production, focus groups were also conducted with carers and professional stakeholders to understand their views about intervention design. This enabled contextual factors from the interview data analysis to be clarified, needs to be prioritised, and co-design of the intervention, inclusive of scope, content, and delivery. Analysis was carried out using Framework Analysis (Ritchie and Spencer 1994; Ritchie et al. 2014) which enabled a theoretical foundation for the intervention. Thereafter, a structured intervention development framework (Wight et al. 2016) was selected to guide the process.

3.2.1 Philosophical underpinnings

A qualitative research approach was viewed as a good method for exploring this phenomenon as it has not been studied thoroughly from the perspective of carers before (Holloway and Galvin 2016). Qualitative research is broadly interpretivist and concerned with exploring the experiences and perspectives of people to understand the social reality of individuals, groups, and cultures (Grbich 2012). Qualitative principles adopted included: being systematic and rigorously conducted; strategic yet flexible and contextual; involving self-scrutiny and

reflexivity by the researcher; producing explanations to intellectual puzzles; constructing social explanations which are generalizable and researching an ethical practice (Mason 2018).

When considering the philosophical underpinnings for this study three major research paradigms: scientific, interpretive, and critical were considered (Scotland 2012), as were the ontological and epistemological positions of post-positive, interpretivist, and constructionist research paradigms (Merry-Jo 2013). Paradigms are a common set of beliefs that encompass different ontological assumptions and, epistemological traditions (Lincoln et al. 2011). They consist of the elements ontology, epistemology, methodology, and methods (Scotland 2012). As a branch of philosophy, ontology is concerned with the nature of being and assumptions about the nature of reality (Grbich 2012). Correspondingly, epistemology concerns the philosophical grounding for deciding what kinds of knowledge are possible and how to ensure they are both adequate and legitimate (Maynard and Purvis 1994). Combined, they provided the philosophical position to inform the study's methodology, a logical context, and criteria for the research process (Howell 2012). Importantly, Mason (2018) highlights that alternative ontological perspectives can tell radically different stories; therefore the decision was important to ensure it met the study aims. The ontological perspective for this study was examined early in the process before the topic was even clearly defined by asking the question:

> *"What is the nature of the phenomena, or entities, or social world that*
> *I wish to investigate?"* (Mason 2018: P4).

Social scientists have identified a broad range of ontological properties from which, for them, the 'social world' is made up. For example, people, lives, ecologies, minds, rationality, attitudes, identity, experiences, feelings, views, stories, actions, interactions, cultures, nature, rules, or institutions (Mason 2018). According to Merry-Jo (2013), these can be grouped into two ontological perspectives: the realist, where reality exists independent of the human mind not necessarily experienceable; and the relativist, with a belief that reality is a finite subjective experience, which does not exist outside the mind. The researcher's ontological perspective for this study was located within relativism, chosen as the study aimed to explore the carer's experiences, views, and perceptions to understand the impact, underlying mechanisms, support needs, intervention ideas, principles, and components. Howell (2012) suggests that these ontological positions relate well to researching experiences, interpretations, understandings, and social relations. They suit qualitative study designs and work well with the intellectual puzzle this study aimed to explore (Mason 2018).

Although there are three major epistemological research paradigms (scientific, critical, interpretive) that apply to how knowledge is derived, some are more suited to qualitative research and the ontological position selected by the researcher (Scotland 2018). Importantly, for this study, epistemology provided the principles and rules by which carers' social world could become known, be validated, and demonstrated through the study (Mason 2018). To identify the researcher's epistemological position initially the question was asked:

> *"What might represent knowledge or evidence of the entities or social world that I wish to investigate?"* (Mason 2018: P7).

The characteristics of scientific, critical, and interpretive paradigms were examined concerning their suitability to the intellectual puzzle and research questions (Mason 2018). The scientific paradigm became prominent during the Enlightenment era, characterised by positivism with the ontological perspective of realism applied to the study of the natural or social world (Scotland 2012). Commonly found within quantitative studies the scientific paradigm seeks to test the hypothesis and predict facts using mathematical logic (Grbich 2012). This paradigm was judged (by me) to be unsuitable because experimental or survey research designs used within quantitative research would not be effective to meet this study's aims. The critical paradigm is suited to qualitative research with an emphasis on identity and how this has been shaped (Felluga 2015). According to Scotland (2012), the ontological position of this paradigm is historical realism, which has a view that reality has been shaped by our social, political, cultural, economic, ethnic, and gender values. However, issues include stereotyping participants and labelling them as belonging to a particular marginalised group, and not acknowledging that participants enter research with different levels of reliability. Importantly, critical research focuses on power, inequality, and social change. It seeks to foster positive change in the systems being studied and should be conducted with this goal in mind. This raises questions about how realistic it is to expect researchers to promote social transformation (Grbich 2012).

The interpretive paradigm was selected as the researcher's epistemological position as it emphasizes the sense people make of their own lives and experiences (Grbich 2012). According to Scotland (2012), the ontological position of interpretivism is relativism, as such reality is subjective and something which differs from person to person. As with this study, interpretivism explores the social reality and lived experience of human beings along with how they interpret and make sense of these (Holloway & Wheeler 2016). An in-depth understanding of the problem, related issues, and potential solutions was necessary (Grbich 2012). The 'interpretive/constructive' theories originated in the nineteenth century from Dilthey's (1833-1911) philosophy, linking Weber's *'Verstehen'* approach. The *'Verstehen'*

concept considers interpreting the action of others, believing that social scientists should be concerned with the wider social environment and how this impacts the constructed understanding of how people interpret and make sense of their experiences. This includes the researcher's views and how they evolved (Grbich 2012). From this perspective, social researchers accept reality is viewed through a socially constructed lens and exists only in the mind. Therefore, it is highly likely there is no knowledge free of thinking and multiple realities are fluid, changing for each person (Scotland 2012).

By utilising interpretive paradigms, the study recognised that knowledge was subjective and based on shared signs which were recognised by members of the group studied (Mason 2018). Limitations to consider were subjectivity and lack of certainty that participants' minds were accessed. People do not recall events but the memory of these, and recall may have differed from time to time or person to person (Gilgun 2005). Further, participants' experience was unique in its form and only existed in their minds until shared. Once shared this version of their experience (or reality) can be interpreted differently by anyone who studies it (Grbich 2012). Therefore, the researcher was accountable for representing the carer's multiple perspectives, dominant features, and how they could be understood and viewed (Gilgun 2005). Although research paradigms are based on their own ontological and epistemological assumptions, they cannot be empirically proven, but their existence should be evident and reflected in the methodology, and methods throughout this study (Scotland 2012).

3.2.2   Methodology

The methodological approach was chosen on its ability to meet the aims and objectives of the study (Grbich 2012). While several qualitative approaches may have suited and are frequently used in health science research, such as narrative methodology of Grounded Theory (Holloway & Galvin 2016;) there were methodological conflicts to consider. For example, Grounded Theory is concerned with uncovering social processes to create a theory (Charmaz 2014). However according to Biggerstaff (2012), in psychological research due to the complexity of people's lived experiences, where participants are expressing their thoughts, feelings, and emotions, this approach may not be best suited. Therefore, narrative methodologies were also considered to allow the exploration of how people construct their reality through storytelling (Polkinghorne 1988). However, narratives can be ambiguous (Reissman 2008) making it difficult to code text descriptions systematically and reliably, with the risk of losing vital information which may be important to intervention development (Williamson et al., 2001).

This study aimed to explore shared signs and dominant features, casting and retracting light on the lived experiences and needs of carers (Mason 2018), then use these experiences to co-design an intervention. The methodology selected that was most suited to this was Facet Methodology.

3.2.3 Overview of Facet Methodology

Facet Methodology is a new approach to studying the multi-dimensionality of lived experience and offers a new way of thinking and undertaking social science research. With Facet Methodology:

> *"The gemstone is the research question and facets are conceived as different methodological- substantive planes and surfaces."*

> (Mason 2018: P28)

Developed by researchers led by Jennifer Mason at the Morgan Centre for Research into Everyday Lives, School of Social Sciences, at the University of Manchester, Facet Methodology is coined as an orientation rather than a set of rules. It was conceived from an interest in personal relationships, relationalities, and how these are lived. Facet Methodology assumes the world and what is understood from it is not only lived and experienced but also multi-dimensional, contingent, relationally implicated, and entwined. Due to what is known from the current evidence (Lamont and Dickens (2019) on the experiences of carers for people with BPD, a methodology that was sensitive and interested in the sociological and multi-dimensional aspects of relationships and lived experience was an important orientation for the current study. As such, Mason (2018) advocates that to understand lived experience we need to involve different lines of enquiry and different ways of seeing through creating a set of facets that related to the research questions and area of interest. Mason (2018) explains there are six enabling principles to Facet Methodology which are summarised below:

- Multi-dimensional, entangled, and connective ontology that assumes a broad ontological view attuned to and openly accepting complexities to explore them.

- Facets are artfully designed mini investigations which focus strategically on craftily created questions, not discrete topics, or sub-studies. Each facet represents a way of looking at and investigating something that is theoretically interesting to the overall puzzle. Facets can be different shapes and sizes; some may be very small.

- Facets produce flashes of insight rather than descriptive and comprehensive knowledge; they change what is seen by how it is looked at.

- Facets cast and refract light on the intellectual puzzle rather than illuminating it. With this in mind, what is seen is largely dependent on how light is cast upon it, creating constellations with some shining brighter than others.

- Facet Methodology involves some degree of risk-taking and experimentation, but with the aspiration to lift and overturn assumptions. This was crucial when deciding what the facets in this study would look like. Further, it was impossible to predict before designing the facets what assumptions the data generated would disrupt.

- Facet Methodology encourages engagement across epistemologies and creates critical contrasts. However, this can require a high degree of epistemological astuteness as well as a willingness to try these and see what they produce.

Facet Methodology has been used successfully in similar recent studies, for example, 'Critical Associations' study (Davies and Heaphy 2011). This explored personal associations/friendships critical to people's lives to ascertain the negative aspects as well as positive and supportive elements. In the study by Davies and Heaphy (2011), a series of small, linked facets explored the intellectual puzzle. These were: a mass observation directive of experiences with friends; era memory workshops and group sessions to elicit people's memories of friendships; exploration using interviews to access memories and ethnography using archived photos and Facebook; music and film to elicit memories of clubbing. Likewise, the 'Living Resemblances' study (Davies 2011) used linked facets, for example, an interview study of resemblances using ethnographic interviewing, biographical narratives, and visual methods of photos and video; website analysis of resemblances on the internet; metaphor led discourse analysis; a qualitative experiment using standardised visual audio and textual stimulant; an expert study to explore resemblance discourse. According to Davies and Heaphy (2011), Facet Methodology allowed them to research a complex blend of tangible and intangible aspects of relationships that can be difficult to grasp; while Davies (2011) emphasised that Facet Methodology enabled a range of methods and analytic approaches to explore different aspects. Mason (2018) also proposed that the rigour of Facet Methodology depends on the researcher's skill, inventiveness, imagination, and insight to create the facets and catch the light effectively.

It may seem that choosing a methodology with a sociological perspective is incongruent with a psychiatric condition such as BPD and intervention development which is a key aspect of

this study, however, careful consideration was given to this. The process for intervention development has been adopted by the medical professions and formalised within the UK's Medical Research Council framework for the development and evaluation of complex interventions (Craig et al. 2008). However, this study did not let medical model processes drive the intervention, especially given the debates already in existence around psychiatric diagnosis (Johnstone and Boyle 2018). The PTM framework by Johnstone and Boyle (2018) is arguably compatible with the sociological perspectives of Facet Methodology (Mason 2018), and the current evidence relating to carers' experience this study endeavours to build upon (Lamont and Dickens 2019).

The last decade has also seen criticism of the MRC (2008) framework with Moore et al. (2019) arguing that social interventions within families are complex due to the social systems that activities occur in, as well as the context and circumstances that they depend upon. Hawe et al. (2009) propose that public health interventions need to be viewed as 'events' within complex social systems and not decontextualised components requiring intervention. The updated MRC complex intervention framework by Skivington et al. (2021) further reflects a systems lens to understanding the socio-ecological contexts in which people experience life and upon which the effects of an intervention are reliant. Key dimensions include physical, organisational, social, cultural, political, or economic features of healthcare, health systems, and public health contexts. Further, Burgess et al. (2019) argue the importance of social interventions to improve global mental health, a factor indicated as an issue for carers of people with BPD (Dickens and Lamont 2019). Social interventions recognise the relationship between socio-structural difficulties and poor mental health. They are community-led, promote community empowerment, and prioritise service user knowledge for intervention design and delivery. They also call for joint action on social and health problems acknowledging the long-term relationship between interventions that address social determinants and mental health outcomes (Burgess et al. 2019). In this respect, the ontological and sociological elements of Facet Methodology led it to be considered compatible with the aims of this study.

3.2.4   Putting Facet Methodology into practice

When putting Facet Methodology into practice Mason's (2018: P47) recommended questions were addressed:

- *"What's fascinating, what is my intellectual puzzle?*
- *Are there assumptions to unsettle? which assumptions; what ideas might generate or facilitate insights?*

- *Can I design facets that will get me into a context from which insights might emerge; what ideas can I generate for facets?"*

3.2.4.1   Selecting the methods for data collection and co-design

When utilising theories in practice they need to translate in a way that facilitates a workable plan across settings (Hawkins et al. 2017). Several theories were adopted within this study including Facet Methodology, stakeholder consultation, and co-production which were symbiotic. Guided by Mason's (2018) Facet Methodology a series of linked facets were selected as methods to explore different aspects of carers' experiences, and needs, generate ideas, and co-design the supportive intervention. There were several elements to consider in developing the workable plan given the resources and time available for this study, as well as intellectual and practical concerns. Therefore, the most important priorities were identified, and affordable creative facets were chosen. These were:

- Stakeholder consultation, whereby the researcher engaged in a process of co-operative enquiry with stakeholders.
- Semi-structured interviews with carers (family members and friends), to bring a variety of perspectives on the experiences and needs of carers and collect their views on designing a supportive intervention.
- An intervention co-design process involves focus groups with a diverse group of stakeholders including family members, friends, professional experts, and carer support organisations. This created the stakeholder advisory group to co-design the intervention.
- Co-design also included email correspondence with the stakeholder advisory group to review and comment on drafts of the intervention design and content.

Recently published guidance has acknowledged the overlap between public and community involvement, engagement, and co-production. This emphasises that:

> *"There is no neat road map for coproduction, it does not have a clear procedure to follow and its nature is such that you cannot always anticipate the direction it will take."*

> (The National Institute of Health Research 2021: P7)

O'Caithin et al. (2019) suggest that stakeholders' views can be gained from qualitative interviews, surveys, or workshops and co-production involves stakeholders in the decision-making, whereas with consultation, decisions are made by the research team. Cautions are argued about claiming that patient and public involvement is co-production which has the potential for harnessing the lived experience of individuals and redistributing the power in decision making (Bevir et al. 2019). According to Petkovic (2020), stakeholder consultation and involvement are recommended to support the feasibility and acceptability of guideline development as well as the design, evaluation, and implementation of complex interventions (Hudson et al., 2020). This also supports closing the gap between research production and use in practice (Boaz 2018). Deverka et al. (2012) suggest stakeholders are individuals, organizations, or communities who have a direct interest in the process and outcomes of a project or research. As such, stakeholder involvement and consultation can comprise being members of committees or planning groups (Majid 2018); building and maintaining relationships, as well as gaining active support and commitment of people throughout a project (Hudson et al. (2020). Stakeholder surveys, meetings, and workshops are also useful approaches (Nitsch et al. 2021).

In-depth semi-structured interviews were chosen as they are a powerful and popular method of data gathering in qualitative research (Holloway and Wheeler 2016). According to Ritchie and Lewis (2008), the type of data required determines the method used. This can be naturally occurring, such as observation, documentary analysis, conversation, and discourse analysis, or generated data from interviews or focus groups. The ontological position of this study indicated that individuals' knowledge, views, interpretations, and experiences were valuable types of data for the social reality that the research questions intended to explore (Mason 2018). Interviews were considered an appropriate method to generate these and could be either structured, unstructured or semi-structured format (Holloway and Wheeler 2016; Grbch 2012; Mason 2018). Structured interviews can be quick to undertake however, the literature indicates these are more suited to quantitative research and have limited use for exploring views and experiences (Holloway and Wheeler 2016). Unstructured interviews start with a general question about the topic area and are accompanied by an aide memoir with further topics to explore. There are no set questions after the first one, as a result, an unstructured interview resembles a conversation angled towards the researcher's needs (Gray 2009). This was deemed unsuitable as the interviews were not only collecting experiences and needs but collecting views on the design of the intervention, therefore some structure was needed. Semi-structured interviews identify a series of questions within an interview guide that focuses on the topic areas. There is flexibility in the sequencing of questions depending on the responses of the participant, however, the structure enables similar data to be collected from each person

(Holloway and Wheeler 2016). Semi-structured interviews were selected as they allowed open-ended data to be collected which explored carers' thoughts, feelings, and beliefs about personal and sensitive issues which in turn would achieve the study aims (DeJonckheere and Vaughn 2019).

Given the co-production element of this study was to co-design the intervention, focus groups were selected as a good vehicle to work together and gain insight into complex topics where stakeholders' opinions and needs were multifaceted (Grbich 2012). Focus groups are frequently used in social science and health care research and are considered a useful strategy for evaluating services, interventions, and programmes (Holloway and Wheeler 2016). They are a type of in-depth interview that takes place in a group allowing rich, flexible collection of data that cannot be achieved when interviewing a person alone (Freitas 2022). Focus groups are also an important tool for programme and intervention development as they can generate contextual information that is required to meet the needs of the group in question (Knowles 2015). Literature indicates they are unique in the sense that they can enable the collection and analysis of data from individuals, groups, and through participant interaction, as well as allowing spontaneous discussion of topics (Avis et al. 2015).

Focus groups created an opportunity for individuals to share their thoughts, views, and expertise relating to the design of the intervention with others, responding not only to the researcher's questions but also to each other (Mason 2018). Focus groups do not rely on the ideas of the researcher only but allow members of the group to generate new thoughts, designs, and concepts, meaning their feelings, needs, and proposals were discovered by the researcher for intervention design (Holloway and Wheeler 2016). In this respect, the facilitator's role was to enable group interaction rather than lead the discussion (Denscombe 2014). Focus groups are also beneficial when designing programmes or interventions to address a specific issue and where researchers want to involve a specific community of people to identify their needs, assets, barriers, and facilitators of the potential intervention (Knowles 2015; Kruger 2018). In this respect, there was an overlap where focus groups were a method for data collection and co-design of the intervention. A power shift between the researcher and the participants took place wherein by sharing their ideas and preferences became co-designers.

Focus groups can be conducted online or in-person and Mason (2018) guides researchers to think through carefully what is to be explored. Narratives and biographies are not suited, however, opinions and views are compatible with focus groups. As this study aimed to gain these to co-design the intervention with key stakeholders this was deemed appropriate. Several studies into co-produced intervention development have utilised focus groups in the

co-design process. For example, Webber et al. (2015) developed a complex social intervention for people with mental health problems to improve their social networks using focus groups with workers and service users. Hawkins et al. (2017) developed a three-stage framework for the co-production and prototyping of public health interventions. This involved evidence review, stakeholder consultation with focus groups and interviews, co-production of the intervention through meetings, email exchanges, and prototyping using process data on fidelity and acceptability. The framework was tested with good effect in a peer-led intervention to prevent illicit drugs in school students.

Concerning running the focus groups there were several important considerations in terms of recruitment, facilitation, and analysis (Knowles 2015). Holloway and Wheeler (2016) suggest participants should be connected closely to the research topic, that complex topics benefit from small groups, and around three to four focus groups lasting between 1-2 hours are recommended, as are groups of six to eight people (Denscombe 2014). Mason (2018) suggests planning for setting ground rules, starting and ending the discussion, keeping the group on the topics of interest, encouraging shy people and curtailing dominant speakers, handling conflicts, sequencing, and flow. Likewise, Denscombe (2014) advises the success of a focus group depends on creating a climate of trust, with the facilitator putting participants at ease; importantly, explaining aspects of confidentiality so that they feel at ease to express their views and opinions. Hennink (2005) recommends developing a topic guide based on the research questions and aims of the focus group, as well as using previous literature on the topic and information received from informants. Open questions and additional probing questions or explanations of the topic are also guided as is avoiding too many questions to allow enough time for participants to talk about what matters to them. Holloway and Wheeler (2016) highlight that in focus groups as in other research, ethical issues are considered as well as analysis, which in this study was guided by Framework Analysis (Ritchie et al. 2014) for both the interviews and focus groups.

Following the focus groups, email correspondence with the stakeholder advisory group enabled feedback and comments on drafts of the intervention design which went through three iterations. Although not everyone commented many did which supported the valuable involvement of stakeholders throughout the process, was time-efficient, and overcame barriers of distance (Ratislavova and Ratislav 2014). Figure 2 below encapsulates the Facet Methodology gemstone and facets.

Co-planning
Stakeholder consultation

Co-design
Email correspondance with the stakeholder group re intervention design

Co-design
Semi structured interviews with family & friends

What are the experiences and needs of family / carers + the co-design of a supportive intervention

Co-design
Focus group with Carer support organisations

Co-design
Focus groups with family & friends

Co-design
Focus groups with expert professionals

3.3   METHODS

Following Facet Methodology, this study was a mixed qualitative methods design incorporating several facets. This involved procedures to guide the study and a process for participant selection, data collection, data management and analysis, data representation, ethical considerations, and trustworthiness and rigor (Mason 2018). Each procedure is defined, and a description of how it was applied follows.

3.3.1   Participant population

Two samples were included in the study, carers (previously defined as a person who has regular close contact with a person with BPD and is involved in their care), and health or social care professionals. These included staff from carer support and mental health organisations both statutory and non-statutory.

3.3.2   Inclusion criteria

Participants were eligible to be included in the study if they were:

- Aged 18 years or above and living in Scotland.
- Carers providing informal care and support to individuals aged 18 or over, who have/had a diagnosis of PD: borderline pattern, defined by the WHO ICD-11 (2018), or emotionally unstable personality disorder: borderline type (WHO ICD-10 1992), as stated by the carer.
- Capable of giving informed consent, reading, and speaking English sufficiently to be interviewed in-depth.
- Health and social care professionals from statutory and non-statutory carer support and mental health organisations in Scotland, with significant practice experience.

3.3.3   Exclusion criteria

Participants were excluded from the study if:

- The person receiving care/support had died more than five years ago

3.3.4   Sampling strategy and recruitment

Several factors were taken into consideration when deciding the sample size, for example, the inclusion criteria, the heterogeneity of the sample, and the resources available (Ritchie et al. 2014). This interview study aimed to recruit a heterogeneous sample of affected carers including parents, children, partners, spouses, siblings, grandparents, or friends. Carers were of individuals who were living or who had died in the last five years. Sometimes known as

maximum variation sampling, heterogeneous sampling seeks to explore variations in settings and individuals with different experiences (Holloway and Wheeler 2016) and supports the Facet Methodology principles adopted in the study (Mason 2018). A sampling matrix was created to list the variation; no one was rejected based on the sampling strategy. There was also an element of convenience in the participants selected because of their location and availability to the researcher (Ritchie and Spencer 1994).

Qualitative researchers are guided to continue to gather data until saturation is reached, where no new categories or codes are emerging from the data (Charmaz 2014). There is no set number of participants or interviews when theoretical saturation occurs (Strauss and Corbin 1998), however, too few participants can impact the overall quality of the study (Harper and Thompson 2011). Likewise, large sample sizes do not necessarily enhance a study and may harm meanings, uniqueness might be lost, or not respected (Holloway and Wheeler 2016). Holloway and Wheeler (2016) outline that a homogenous group needs six to eight participants, and a heterogeneous group 12 to 20. Therefore the study aimed to gather interview data from 20 participants when it was expected data saturation would be reached and further information collected repetitive and redundant (Bogdan and Biklen 2006). However, ambiguity exists on whether qualitative data can ever be truly saturated and how researchers can assess this accurately (O'Reilly and Parker 2012; Saunders 2018). Nevertheless attempting to achieve saturation is important to ensure adequate information has been gathered to accurately cast light on the experiences and needs of carers as well as co-design the intervention (Mason 2018).

When planning stakeholder consultation a range of individuals closely linked to the topic who could advise from several different perspectives were sought. When preparing for the recruitment for the interviews, the Good Practice Guidance for Involving Carers and Family Members of Service Users in Research was followed (NHS National Institute for Health Research 2014). Most of the recruitment was by the researcher directly accessing or trying to reach carers through several methods; NHS service users (or the person with BPD) were not required to act as gatekeepers which ensured the focus was on the needs of carers. Participants were recruited through specific arrangements made using the social media platform Twitter, via NHS Mental Health Services or Carer Support Organisations (such as Support in Mind Scotland or Cairn Fowk). For focus group recruitment, carers from the interview study were invited to join a stakeholder advisory group, as were representatives from NHS Mental Health Services and Carer Support Organisations with expertise in BPD or carer support.

3.3.5   Stakeholder consultation

The Scottish Personality Disorder Network was approached at the beginning of this study to explore their views and expertise in this area. The researcher was invited to hold a workshop at their annual meeting and presented an outline of the research idea for discussion and comment. In addition, a professional stakeholder from the NHS and a carer of a person with BPD were consulted on the project and shaped the initial idea and research questions. For example, the professional stakeholder advised of nurses' current role in carer support and what resources were available to them to offer carers. They also suggested options for carers to be referred into the study and what would be a practical process bearing in mind issues such as confidentiality. The questions were developed with a carer who suggested the topic areas and wording, we then did a practice run-through of questions and further amended these where we felt they were confusing or difficult to answer.

3.3.6   Recruitment to interviews

Methods of recruitment to the interviews were via *Three Options* to maximise reach and opportunity for identifying a diverse range of carers as detailed in the 'Recruitment Options' flowchart (Appendix 13).

3.3.6.1   Option One

Health professionals working in Community Mental Health Teams in contact with carers identified those who cared for a person with BPD. They informed the carer about the study giving them a Participant Information Poster (Appendix 7) and Participant Information Sheet (Appendix 2) to read. If the carer was interested the health professional (with their permission) gave the carer's name and contact details to the researcher and told them the researcher would be in contact in the next two weeks. The researcher contacted the carer to discuss the study in more detail and answer any questions. If the person wished to participate, a face-to-face meeting or Microsoft Teams /telephone meeting at an agreeable time and location was arranged to gain consent and do the interview.

3.3.6.2   Option Two

The social media platform Twitter was used to reach carers by posting the Participant Information Poster (Appendix 8) on the site via the researcher's personal Twitter account for work-related sharing. The poster asked interested persons to contact the researcher via telephone or email. Thereafter the researcher responded by giving information on the study and the Participant Information Sheet (See Appendix 2). They followed this up with a phone call or email to ascertain if the carer wished to progress and arrange a face-to-face or telephone / Microsoft Teams meeting at a convenient time and location.

3.3.6.3   Option Three

Carer support organisations such as Support in Mind Scotland, Cairn Fowk, Dundee, and the Scottish Personality Disorder Network were invited to support the study (Appendix 8). The study was also advertised via the University of Stirling website They were given a poster with brief information about the study and the researcher's contact details (Appendix 7). Where agreeable, they displayed these within their centres and shared them on social media sites such as Facebook and Twitter. The researcher was contactable via telephone and email for any potential participant to enquire and note their interest in the study. Thereafter, the researcher responded by giving information about the study and the Participant Information Sheet (See Appendix 2). This was followed up with a phone call or email to ascertain if the carer wished to progress and arranged a face-to-face or Microsoft Teams /telephone meeting at a convenient time and location.

Regardless of which option was selected for referral into the study, the researcher read through the Participant Information Sheet (see Appendix 2) and Consent Form (Appendix 3) when they met the carer. This was to aid understanding and overcome any literacy barriers. The researcher obtained written consent before the interview took place. The interview took place immediately after consent was gained.

At the outset, it was impossible to predict which recruitment method would be successful. Seven potential participants enquired but decided they did not wish to take part once they had read the Participant Information Sheet (Appendix 2), giving no reason. Option one elicited six participants, option two - ten participants, and option three derived four. This made up a total of 20.

3.3.7   Recruitment to the stakeholder advisory group

A stakeholder advisory group was formed by inviting all participants to take part in an intervention design stakeholder focus group which aimed to include a minimum of 14 people. The focus groups, to enable co-design of the intervention, were arranged following all interview data collection and analysis. The procedure for carers expressing interest to participate in the stakeholder advisory group was to tick the appropriate box on the interview Consent Form (Appendix 3) and provide a contact telephone number or email address. The researcher contacted the participants with an invitation and dates of the focus groups. The procedure for professional stakeholders to be involved was via email. An invitation letter was sent to Scottish Mental Health Services (NHS and third sector), and Carer Support Organisations (Appendix 9), this was passed on to potential professional experts who may be interested in taking part. They were asked to make contact if they wished more information about participation. These individuals were sent an email by the researcher with a Participant Information Sheet tailored for professional stakeholders (Appendix 10) with the dates/format of the stakeholder focus groups.

3.3.8   Consenting participants

The same procedure was followed for both carers, and professional stakeholders taking part in the study. All carers provided consent to take part in the interviews and those interested gave consent to participate in the focus groups, as did the professional stakeholders involved. Participation was voluntary and based on written informed consent. Participants were free to withdraw from the study at any time without consequence. However, data obtained to that point was retained as it was already pseudo-anonymized data likely to be coded and incorporated into the analysis. A Participant Information Sheet (Appendices 2 or 10) detailing key aspects of the study was sent / or given to the participants at least one week before the interview or focus groups. Participants had an opportunity to ask questions and discuss any concerns before the interview or focus group via email, telephone, or in person. At this time, informed consent forms were completed and signed (Appendices 3, 11, or 14). Consent forms included permission to audio record interviews and focus groups, details on confidentiality (including the limits of confidentiality), anonymization/anonymity, and data protection.

3.4   Data collection

Data gathering was an ongoing and iterative process collected through semi-structured interviews in phase one and then stakeholder focus groups in phase two. The principles of qualitative research and FM were followed for gathering data to ensure it was rich and gave flashes of insight into the intellectual puzzle being explored (Mason 2018).

3.4.1   Interviews

Interviews were in person face to face, over the telephone, or via Microsoft Teams, audio-recorded, and took place in a private room to ensure confidentiality and promote comfort (Mason 2018).   At the outset, carers were asked to complete a short demographic questionnaire (Appendix 6) to gather background information, and better understand or identify the population represented. Thereafter interviews were semi-structured at lasted up to 60 minutes which allowed key questions, concepts, and relationships to be explored (Fletcher 2016).

An interview topic guide (Appendix 5) was produced by the researcher/supervisors and a professional stakeholder from an NHS mental health service. Development involved several principles which included broad open questions linked with the study's aims and objectives. Topics covered were experiences and responsibilities of caregiving; the impact, challenges; needs; formal/informal support received; resolving issues; unmet/extra support needs; future hopes/plans; intervention design and content. Although the topic guide was quite detailed, it was not followed strictly and included some prompts along with focused questions. The sequence of questions varied but this method ensured that similar types of data were gathered from all participants in a way that put them at ease, and the interview resembled a social interaction (Mason 2018). The interview topic guide was adapted following the first three interviews because of initial coding and the response of participants (Spencer et al. 2014). The section 'Now and the Future' was removed as participants did not seem sure how to answer these questions. They did not link well to the previous and next sections which asked about their needs and preferences for supportive intervention.

The researcher, in the interviewing process, was aware of her pace and the tone of questions, as well as how a question was asked, or a point developed to elicit detail – such as 'what does that mean to you?' or how does that affect you?' (Hiller and Diluzio 2004). Interviews were audio-recorded and transcribed to enable the rich detail to be studied and analysed, while field notes offered supporting information, observations, and reflections (Mason 2018).

3.4.2 Stakeholder advisory focus groups

Central to the study was collaboration and involvement with key stakeholders. This was integral to the intervention design, which was guided firstly by the literature, then interviews, and thereafter a stakeholder advisory group (Wight et al. 2016). Originally ethical approval had been granted for in-person focus groups. However, to improve accessibility a minor amendment for virtual/online focus groups was applied for and granted via the University of Stirling Research Ethics Committee (Appendix 16). This changed the format to online focus groups and these met for 90 minutes via Microsoft Teams.

Four small focus groups were planned to include four participants each with a target of 14 - 16. All carers who took part in the phase one interview study were contacted and invited to be involved in the stakeholder groups. Also, professionals relevant to the focus of the study and known for their knowledge and expertise were approached via email to be involved. These included staff from carer support and mental health organisations. Even distribution of carer and professional stakeholders was sought by listing the category of each person who volunteered. Thereafter, focused recruitment to enable an equal balance of eight carers and eight professional stakeholders. As the number was relatively small all carers who volunteered were included regardless of their relationship (e.g. parent, child, sister, friend).

Time management was adhered to by the researcher, as was giving each participant a fair opportunity to speak. Groups were kept small to enable this as well as to enhance comfort and confidence given the online format and the sensitivity of the subject. Ground rules about confidentiality and respectful behaviour were addressed at the commencement of each meeting (Holloway and Galvin 2016). These followed Chatham House Rules where participants were asked not to identify or reveal the affiliation of any other participant (Chatham House 1927). Consent was collected from each person via email before each focus group. The focus groups were audio-recorded then transcribed and notes were taken to document ideas, decisions, and plans. Care was taken to manage the dynamics and comfort/confidence of each group and support different perspectives (Holloway and Wheeler 2016). This involved grouping carer participants and professional stakeholders in separate groups to focus on their different perspectives.

A focus group topic guide was developed and is detailed in Appendix 15. This included the researcher setting participants at ease and facilitating introductions, giving a short presentation informing them of the scope and purpose of the group, and the findings of the

qualitative carer study (Mason 2018). Following this, open questions were posed, and a discussion was encouraged on the key issues an intervention would address the priorities, content, and delivery model.

3.4.3 Study updates

Participants were in the study for a period of six to twelve months and given an update via email with a summary of the progress made, findings, and next steps – this took place six-twelve months after their interview depending on when it took place (Ratislavova and Ratislav 2014). They could also receive a copy of an accessible final summary of the findings if they wished.

3.5 Ethical considerations

The NHS, Invasive or Clinical Research Committee of the University of Stirling reviewed and approved the study [Reference: NICR/18/19-Paper 051; 11.07.19], as did the London-Surrey Borders NHS Research Ethics Committee [Reference: 19/LO/1452 on 05.11.19], via the Integrated Research Ethics Application system (2009). (See Appendix 16). The main ethical challenges and potential risks were detailed during this process and consideration was given as to how participants might be affected because of taking part in the study. Participating in the research was considered low risk and adverse events were not anticipated to cause participants physical harm or discomfort. Ethical considerations included handling sensitive topics, informed consent, confidentiality, child/adult protection, data protection, and researcher safety. These are summarised below.

3.5.1 Handling sensitive topics

This study involved the discussion of sensitive topics including relationships, parental roles, professional roles, ill health, adversities, experiences of services, and personal needs. Carers sometimes became upset or emotional during interviews. However, the researcher is an experienced registered mental health nurse and remained vigilant for signs of discomfort and distress to intervene and support where necessary. If participants became upset during the interviews or focus groups, the researcher paused and asked if they would like to continue or not. The researcher also made clear that the interview could be stopped/postponed, or they could leave if preferred. Given that the well-being of participants was important the researcher discussed this with the participant at the outset of interviews/focus groups and time was given within the structure to facilitate a short break where necessary. If further support was required,

the researcher planned to take the appropriate steps and guide them to phone a friend, relative, or supportive organisation, however, this was not necessary.

3.5.2 Debriefing

Some participants may have been experiencing adversity and difficulty, and this made it crucial that where possible interviews and focus groups ended on a positive note. At the end of each, the researcher turned off the voice recorder and had a brief conversation to thank the participants and to signpost them to ongoing advice and support should they require this before saying goodbye. A Debriefing Information Sheet (Appendix 4) was given to all participants at the end of each interview or focus group, this included contact details of the researcher and supportive organisations.

3.5.3 Informed consent

Participant Information Sheets (Appendix 2) were provided before the study and read to all potential participants to ensure they understood what was involved and had the opportunity to ask questions before providing written consent. Throughout the research, it was made clear to participants they had the right to withdraw from the study at any time, without any consequences but that any data collected could not be withdrawn as it had already been part of an iterative analysis process and anonymised. The researcher developed interview questions in line with the UK policy framework for health and social care research (NHS Health Research Authority 2017) when assessing capacity to consent. If at any point there had been any doubt that a participant could provide informed, written consent it would not be sought, and they would not have been included in the study. See Consent Form (Appendix 3).

3.5.4 Confidentiality and anonymity

Confidentiality was maintained wherever possible but could not be guaranteed. Participants may have disclosed adult protection issues while talking about the care and support they gave or any behaviour towards them. The researcher ensured this was explained to potential participants while going through the Participant Information Sheet and Consent Form and they understood the circumstances in which confidentiality could not be maintained and information shared. Examples were given which helped participants understand what is meant by the terms 'adult protection issues' and 'significant risk of harm'. Any actions in response to any adult protection concerns would have been discussed with the supervisor. If necessary, the researcher or supervisor would have involved the police/health/social services in cases where the immediate safety or wellbeing of a participant or other adult was at risk. The researcher

and supervisory team have clinical expertise and training in adult protection, mental health, and addictions and would have implemented the best course of action. As it was there were no concerns to action.

There was a risk of anonymity in the focus groups as they may have known each other. Participants were made aware of the risks before consenting to take part, provided with a Participant Information Sheet (Appendices 2 or 10), and allowed to talk through this with the researcher. Focus groups followed the Chatham House Rules where participants were free to use the information received, but not identify or reveal the affiliation of any other participant (Chatham House 1927). In writing up the study, each participant was assigned an identification code. Any distinctive identifying characteristics such as names or geographic location were omitted to hide participants' and others' identities. Interviews and focus groups took place from Monday - Friday, 9am - 5pm working hours, in local NHS Tayside Mental Health Services premises to limit the burden of travel, time, and suitability of the venue. Where interviews and focus groups took place via Microsoft Teams or telephone, this was done in a private room using headphones to ensure the participants' privacy (Mason 2018).

3.5.5 Researcher safety

The researcher adhered to the University fieldwork safety protocol whereby the address and location of the interview were given to a designated colleague whilst undertaking fieldwork. The researcher texted this colleague before and after each participant interview. If necessary, the colleague knew to contact the police should the researcher's safety and wellbeing be at risk. The researcher interviewed participants in NHS Tayside premises, or University venues where safety equipment and procedures are in place. She followed safety procedures in each venue. The researcher followed the Social Research Association's Code of Practice for the safety of social researchers (Social Research Association 2001). This included safety protocols for issues such as the assessment of risk, interview precautions, strategies for handling risk situations (e.g. people who are aggressive or intoxicated), as well as debriefing after fieldwork. The researcher was mindful that some interviews may be personally upsetting, and the supervisory team provided regular opportunities for supervision and support.

3.5.6 Data protection

This study complied with the Data Protection Act (2018), the University of Stirling's Data Protection Code of Practice, Research Data Management Policy, and followed the study's data management plan. A University of Stirling Data Protection Impact Assessment was carried out before commencing the study and informed the measures taken. Any email

correspondence was transmitted via the researcher's University email address which is password protected. All personally identifiable data (e.g. consent forms) were kept on paper copies only and stored in a locked cupboard in a locked room in the university accessible only to the researcher. A password-protected mobile phone was used to contact participants, for example to schedule or confirm interview times, and any text messages were deleted immediately afterward. This mobile phone was only used for the study and not the researcher's personal phone. The researcher worked on a computer that was encrypted, and password-protected, access to research data was through the University of Stirling's remote secure network. Dr Josie Evans was the custodian of the data, with overall responsibility for compliance with the data management plan.

Interviews and focus groups were audio-recorded on an encrypted digital voice recorder to ensure the security of data. Each time an interview/focus group was carried out this recording was downloaded onto a University computer using the secure network, the x-drive folder only accessible by the research team and the recording was deleted from the recorder straight after. All participants were given a unique identifier code at the start of the study which was applied to the recording and transcripts. All recordings were transcribed by a Faculty Approved Transcriber who followed and signed a Data Processing Agreement. Transcripts were password protected and on receipt fully anonymised with any names and data identifying participants or anyone else removed or changed. Others in the research team (Ph.D. supervisors) had access to the anonymised data as necessary, to assist in data analysis. Participant Names and addresses were only shared to carry out the fieldwork safety protocol.

3.6 DATA ANALYSIS AND MANAGEMENT

3.6.1 Overview of framework analysis

Framework Analysis was selected for this study to manage and analyse the data. This approach was chosen as it suited the study design, research aims, and is congruent to interpretive/relativism and Facet Methodology stances. Further, Framework Analysis would rigorously support data management, identification of themes, and the interpretation of carer and professional stakeholders' accounts (Gale et al. 2013). Framework Analysis is part of the broad family of thematic analysis which:

> *"Identifies commonalities and differences in qualitative data, before focusing on relationships between different parts of the data, thereby seeking to draw descriptive and/or explanatory conclusions clustered around themes"* (Gale et al. 2013: P3).

Framework Analysis was developed in the 1980s at the UK's National Centre for Social Research by social policy researchers (Ritchie and Spencer 1994). Defined as an approach to qualitative research, a more recent version was released by Ritchie et al. (2014). This method is increasingly used across social, nursing, and psychology research and provides a pragmatic, flexible and rigorous framework for data analysis (Parkinson et al. 2016). Framework Analysis is not a research paradigm but a method of data management and analysis that is not aligned with any epistemological, philosophical, or theoretical paradigm (Gale et al. 2013). Like thematic analysis, this gave freedom and flexibility for the best fit to explore the lived experience of carers (Braun and Clarke 2006; Mason 2018; Ritchie and Spencer 1994).

The five interconnected stages of Framework Analysis allowed for theme-based and case-based analysis by building up 'matrices' (Ward et al. 2013; Miles 2019). It provided clear guidance on data analysis, from data collection and management through to the development of summaries and explanatory accounts (Spencer et al. 2014). Key to this approach was the development of a thematic framework that allowed the researcher to label, classify, and organise data concerning main themes, concepts, and categories (Ritchie et al. 2014).

Ritchie and Spencer outline several advantages to using framework analysis:

- *"Grounded or generative: it is heavily based in, and driven by, the original accounts and observations of the people it is about*
- *Dynamic: it is open to change, addition, and amendment throughout the analytic process*
- *Comprehensive: it allows a full, and not partial or selective, review of the material collected*
- *Enables easy retrieval: it allows access to, and retrieval of, the original textual material*
- *Allows between and within-case analysis: it enables comparisons between, and associations within, cases to be made*
- *Accessible to others: the analytic process, and the interpretations derived from it, can be viewed and judged by people other than the primary analyst."*

(Ritchie and Spencer 1994: P176)

Framework Analysis was considered suitable for this study as the perspectives being explored were carers to gain an understanding of their experiences and needs (Ritchie and Spencer 1994). Analysis was both inductive and deductive where a priori theories were used to guide analysis (e.g. impact, difficulties, challenges, and problem-solving) while also recognising the absence or limited theory available (Ormerod 2010). The diagram below shows how one approach complements the other and would be combined to achieve the research aims.

Figure 4: Inductive and deductive approach

Induction

Observation → Hypothesis → Theory

Deduction
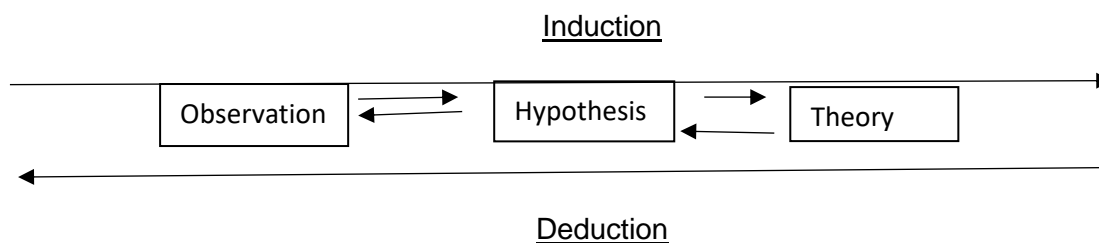
As a systematic and transparent approach, Framework Analysis was carried out both during and after data collection (Ritchie et al. 2014). Both the a priori issues and emergent data-driven themes guided the development of the interpretive analytic framework (Ritchie et al. 2014). This was important as there were areas identified in the literature reviews that the researcher wanted to explore as well as discover the unexpected (Grbich 2012). Framework Analysis also provided results and conclusions that could be related to the original data (Johnston et al. 2011); the steps involved ensured data analysis was grounded in data and as themes developed from descriptive to analytical, the essence was not lost (Ritchie et al. 2014). This method is also compatible with Nvivo qualitative data software program which was a useful tool for collaborating and managing the data. This also aided the involvement of the researcher's supervisors who had access to the Nvivo programme during the analysis process. Framework Analysis also allowed for direct comparison of data from different categories and participants through the development of charts and summary matrices. One of the study's aims was to identify needs and preferences for a supportive intervention therefore, this was useful to aid the process (Ritchie et al. 2014). Some authors have criticised Framework Analysis for being time-consuming and resource-intensive, therefore the time needed to be factored into the project. Other pitfalls that were highlighted included the necessity for training. Researchers may require to learn how to code, index, and chart data and think reflexively during the analysis process (Gale et al. 2013). The researcher had

previously used this method and two experienced supervisors helped to ensure the credibility and robustness of the process (Ritchie et al. 2014).

For this study, the five stages of Framework Analysis were followed, which incorporated data management through to abstraction and interpretation (Ritchie et al. 2014). These were: familiarisation, constructing an initial thematic framework, indexing, and sorting, reviewing data extracts, data summary, and display. Figure 4 shows this sequence and the process is discussed in detail below.

Figure 5: Five stages of framework analysis
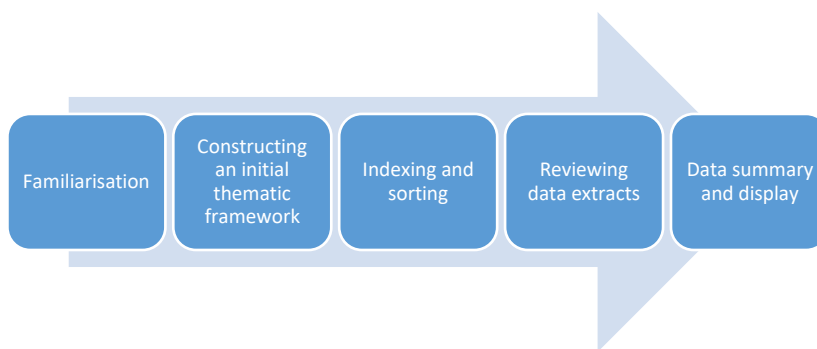
3.6.2   Stage one: Familiarisation

Stage one involved becoming familiar with the data beginning by reading the transcripts several times with the study's aims and objectives in mind. Bogdan and Biklen (2007) explain data analysis as a systematic process of sifting and arranging the information obtained from interview transcripts and field notes to increase the understanding of the data, and enable the presentation of what has been discovered. Familiarisation and organisation of the initial 10 transcripts were undertaken in the first instance (Ritchie and Spencer 1994). This phase was particularly reflexive and involved me constantly interrogating my early analytical decisions (Mason 2018). During this stage the researcher familiarised herself with the transcripts by reading them thoroughly, writing down ideas, and labelling data extracts with words that assigned meaning to them.   This allowed organisation and the establishment of group headings or index lists for initial enquiry within the text. Seven initial topics of enquiry and interest were identified in the index list and are shown in Table 6 below.

Table 6: Initial topics of enquiry/index list

• Experiences receiving the diagnosis
• Experiences of life and support provided
• Impact of living with / supporting someone with borderline PD
• Perceptions of health care and treatment
• Challenges and support needs
• Experience of family support received or not
• Views on a supportive intervention

3.6.3 Stage two: Constructing an initial thematic framework

Stage two involved constructing the initial thematic framework for organising the data using NVivo computer software methods. The main purpose was to help organise and manage the data set, particularly for the initial themes phase (Birks and Mills 2018). Each transcript was examined to identify underlying themes or ideas such as experiences, beliefs, views, impact, and behaviours.

The a priori issues relating to the study aims, interview topic guide, and regular topics discussed during data gathering guided the development of a thematic framework (Ritchie and Spencer 1994). During supervision meetings, initial themes and subthemes were identified, discussed, and agreed upon before applying to all transcripts. An excerpt of the initial thematic framework for the interview study is shown below in Table 7.

Table 7: Extract/example of the initial thematic framework

Experience of Diagnosis	Perception of care /treatment	Impact of living/supporting a person with BPD	Experience of life and support given	Challenges & support needs	Support	Views on supportive intervention
Belief and understanding	Positive and therapeutic	Feeling alone or isolated	Responsibility/care support given	Emotional support and counselling	For siblings	Self-care and emotional well-being tools
Diagnosis bringing understanding	Negative and hopeless	Feeling angry	Self-harm and suicide	Family support and education	Formal	Someone to talk to
Journey to diagnosis	Difficult getting information	Feeling battered and abused	Dread coming home	Good quality information	Informal	Peer support/talking to others

On completion of this stage, it was apparent that the sub-themes, *experience with self-harm and suicide*, and *experience of distress, anger, and violence*, featured highly in participants' accounts. Therefore, these were moved from the theme, *experience of life, and support provided*, and given their theme categories for closer examination. It was also at this stage that the theme named, *experiences receiving the diagnosis,* was merged into*, perceptions of healthcare and treatment*, due to overlap. Also merged were, *the experience of family support received, or not,* and, *challenges and support needed*, this created a new theme entitled, *views on carer suppor*t. This is further clarified in Stage 3.

3.6.4   Stage three: Indexing and sorting

Indexing was the process where the thematic framework was systematically applied to all data and involved multiple judgements as to the meaning and significance of the data (Ritchie et al. 2014). During this phase data from each transcript was given a descriptive label and assigned to a theme and subtheme using Nvivo software, (see Table 8 below for an example of indexing for each participant's data). In an iterative process, where data related to an existing label it was assigned to this. Where it did not a new label was created and added to the framework (Ritchie et al. 2014). Data collection continued throughout this stage until data saturation was achieved at 20 transcripts. At this point no new labels/ideas or insights were emerging, and saturation was considered as achieved. Participants were talking about similar topics and experiences and it was expected that conducting additional interviews would not provide any further insights (Francis et al. 2009). Making decisions on when to stop recruiting and interviewing was pragmatic, determined by using reflexive and subjective judgement that no new themes or ideas were emerging and in the knowledge that the study was time-bound (Maltby et al. 2010).

Table 8: Example of indexing for each participant's data

Theme 1: Experience with healthcare and treatment

Subtheme: Experience of diagnosis
Diagnosis making sense of behaviour: *"Before his diagnosis, it was hard because I just thought he was being grumpy or he was being argumentative, or he was just being detached. Since his diagnosis, I think it's almost in a way a little bit harder because now I know that there's no way of altering that and that is what we have to deal with." (Participant 2)*

Subtheme: Perception of care and treatment
Lost in the system: **"***the mental health nurse, basically said he has been lost in the system. So he kind of has been failed by the system, because if he had been diagnosed a lot earlier then I think he*

> *would have been a lot further down the line by now, but because it's still early days and a lot of the diagnosis was about accepting what was wrong with him, and accepting that he wasn't born this way and there was a lot of guilt…" (Participant 2)*
>
> **Theme 2: Experience of life and support provided**
>
> Subtheme: Interpersonal and relational aspects
> Learning coping strategies and techniques: *"If it was a bad week, I would have to ensure that I paid him attention, and make sure to check in with him. I'm very aware now of when starts to do the whole splitting thing, and I've done quite a lot of reading on it." (Participant 2)*
>
> Day-to-day support: *"Well I think it varies from week to week, to be honest. But probably in a typical 'good week', probably very little. It would just go, well we've got two young children so it would go from day-to-day…weekends can be a wee bit tricky, especially if it's his day off …we have to make that plan beforehand, then we end up doing very little because he doesn't like being off – it's out of his routine. So, he tends to not do very much, which tends to drive me a bit nuts, which ends in a lot of bickering." (Participant 2)*

After indexing was completed the data was sorted so that material with similar content or properties could be viewed all together. The purpose of sorting was to allow the researcher to focus on each topic in turn by using the thematic references to bring all participants' data indexed together and create thematic datasets (Ritchie et al. 2014). According to Ritchie and Spencer (1994), this hierarchical arrangement allows the researcher to hold the overall structure in their head. This was done by creating Microsoft Word tables to create matrices and transposing themed data from Nvivo for each participant into these. An example of sorting into thematic datasets is below in Table 9. Full details are in Appendix 18.

Table 9: Example of sorting using 'Initial theme three' (topic by topic)

Theme 3: Experience of self-harm and suicide
3.1 Coping with suicide thoughts/ attempts or self-harm
"So, she called me, and I said, 'what have you done?' 'nothing, fine', so that's not too good so I said 'I'll cancel my day, I'll come through so I came through, and only after we were talking for a long time and she'd begun to get drowsy and then came and she said 'I've taken this'…and that's when I realised how serious it was." (Participant 1)
"I tried to keep her connected to the real world and help pull her through when she was suicidal – I always tried to find the positives if she did something impulsive and harmful I would say yes but you contacted me – or you cut your hair off because you were feeling deep pain but you didn't hurt yourself or kill yourself." (Participant 4)
3.2 Coping with suicide thoughts/attempts

> *"I'm coming through things I think but one should never be deluded, you know, cause I'm grieving and going through that process. I think where I got to is, I've got a lot to do for my development as well and in a way to, I would say, honour my relationship with [X] appropriately, and to do all of that."(Participant 3)*

> *"Since her diagnosis, it's been as you say very stressful. For the first year, I think I didn't sleep because I was worried, I was going to get a phone call saying she was dead. I said with this last admission that, I've confided in close friends, but I don't think she's going to live to see her 30th birthday and that's very, very difficult to deal with."* (Participant 8)

> *"We were at a meeting between Dr [X], the social worker, myself, [X's] CPN at that time and the psychiatrist turned around and said 'well Mr [X] what you've got to do is brace yourself for the worst because I'm in no doubt that [X] will kill herself at some point."(Participant 11)*

3.6.5   Stage four: Reviewing data extracts

When indexing and sorting were complete, the data extracts, themes, and categories were re-examined to identify if there was overlap and ensure no additional themes/categories had been overlooked. Finally, in this stage, the indexed catalogue was reviewed theme by theme. Data was rechecked and where necessary similar categories of experiences, feelings, or views were grouped into the newly identified subthemes. At this stage, a revised descriptive thematic framework was developed with seven themes and 14 subthemes to work with for data summary, shown in Table 10 below.

Table 10: Revised thematic framework

Themes and subthemes
1.1 **Experience in healthcare and treatment**
1.2 Relating to receiving the diagnosis
1.3 Perception of care and treatment approaches
2. **Experience of support provided**
2.1 Interpersonal and relational aspects
2.2 Practical and emotional support given
3. **Experience of self-harm and suicide**
3.1 Coping with suicide or self-harm thoughts /attempts
3.2 Fears and reflections before and after suicide

4. Experience of distress, aggression, and violence
4.1 Experience of incidents
4.2 Dealing with / coping strategies
5. Impact of living with / supporting a person with BPD
5.1 Emotional (thoughts and feelings)
5.2 Family and relationships
6. Views on carer support
6.1 Challenges and needs
6.2 Support received or not
7. Views on a supportive intervention
7.1 Concept design / Content
7.2 Form of delivery (Inc. deliverers, materials, procedures)

3.6.6 Stage five: Data summary and display

The final stage of data management involved data summary and display. This involved reducing the amount of data to a more manageable level by summarising the original data using key phrases or quotes which ensured accuracy and context were not lost (Ritchie et al. 2014). Matrices generated in Nvivo were exported into Microsoft Word for greater manipulation and visibility. Ontologically and epistemologically the data summarised and presented were in the form of lived experiences, perspectives, views, and the impact of being a carer (Mason 2018). By taking a systematic approach to navigating the data set, all content was considered by giving each theme its matrix with each sub-theme allocated a column. Thereafter, all data relating to a theme was individually paraphrased and summarised before moving on to the next to retain the context and essence of the point without losing the language or voice of the participants (Ritchie et al. 2014).

In total there were seven matrices, one for each of the themes identified in the final thematic framework. Each matrix displayed the relevant subthemes along with data extracts from participants and paraphrased summaries for each data extract. Therefore, each matrix allowed the researcher to compare the responses across each theme. An example of one matrix relating to *the impact of living / supporting a person with BPD* is shown in Table 11 below with full examples in Appendix 18.

Table 11: Excerpt of matrix theme: Impact of living/ supporting a person with BPD

Emotional (thoughts and feelings)	Relational and behavioural
Feeling isolated or alone	Relationships with the person and family
"I suppose I feel isolated in terms of I don't believe people would understand her very well, and my partner he's like if something's broken he can fix it, you know but I need him to listen to me and acknowledge how I feel but he's not good at that….what I really want is person to person that I can actually get a feeling or a hug from." (P1 – Sister)	*"It's been huge. It's been huge for all of us really [gets upset]. It's difficult with the family, you know, our son's been… I mean, our son's amazing how he seems to have not been impacted by it, he's quite an easy-going chap but he's witnessed all kinds of, well, you know, not witnessed but heard lots of difficult times and seen me crying, you know, and it's been really hard." (P18 – Mother)*
Stigma, shame, and isolation	**Family and home destroyed**
"You've got the stigma and shame of it, it's made me isolate myself from my community, it's made me question my friends, I mean, I don't think I've got any, you know, it's just kind of you narrow yourself in to protect yourself and your family, and you don't know who to talk to." (P16 – Mother)	*"I would love to be, if I had a goal I would love just to be able to have a home I can call home for the whole family, you know, but you can't… it's just destroyed really our whole, everything that we've set up for our family has just been destroyed through all of this." (P13– Mother)*
Closed down	**Distanced, deteriorated and alienated**
"Oh yeah definitely, definitely. I mean, it's not even got beyond, it's kind of things were just closed down almost immediately, you just think 'oh right I won't go there with that person when clearly' you know, 'it's not something they can cope with'." (P16-Mother)	*"Yeah because everybody distanced themselves; I think it's (1) because probably maybe they don't understand, or (2) that they're worried and scared. Friends and that have sort of deteriorated quite a bit." (P11-Father)*
Not the life he hoped for	**Narrowed in to protect herself and family**
"We just stumble from one crisis to another. I always hope that's the last time it will get this bad but then it always does again. That said I still worry a lot and am anxious about the future. It can be very isolating and lonely too, it's not the life we hoped to have together, and we've talked about that briefly before." (P19-Husband)	*"It's made me isolate myself from my community, it's made me question my friends, I mean, I don't think I've got any, you know, it's just kind of you narrow yourself in to protect yourself and your family, and you don't know who to talk to." (P16-Mother)*
Emotionally dead	**No chance of honest relationship**
"For several years now, and this bit's much more about me rather than the situation, for several years now a combination of factors has combined to make me what I would describe as emotionally dead." (P14-Father)	*"I sometimes feel like saying it is not all about you – you could care about me for once – but I don't say anything I can't have an honest relationship I just have to smile at her all the time and be there for her."* (P7-Daughter)
Key	
Subtheme: Derived from the theme, in green box **Case name**: participant identifier and relationship e.g. (P19-husband) **Researcher comment:** headings in bold in grey box **Quotations:** short verbatim extracts, shown in "quote marks" in blue box	

Data summary and display enabled the construction of a theoretical model comprising four descriptive themes and related subthemes which provided insight into the core experiences and needs of carers. These were: Stress, the stressful or distressing experiences faced by carers; Impact, the emotional suffering, damage experienced, cost to their relationships and way of life due to stressful or distressing events and experiences; Resilience, the strategies, skills, and approaches carers used to cope, respond, manage, or move forward from problems; and Support, the social and emotional support received or needed by the carers both currently and in future intervention. These are summarised in the Stress, Impacts, Resilience, Support theoretical model which is shown in Figure 5 below.

Figure 6: Stress, impact, resilience, support theoretical model
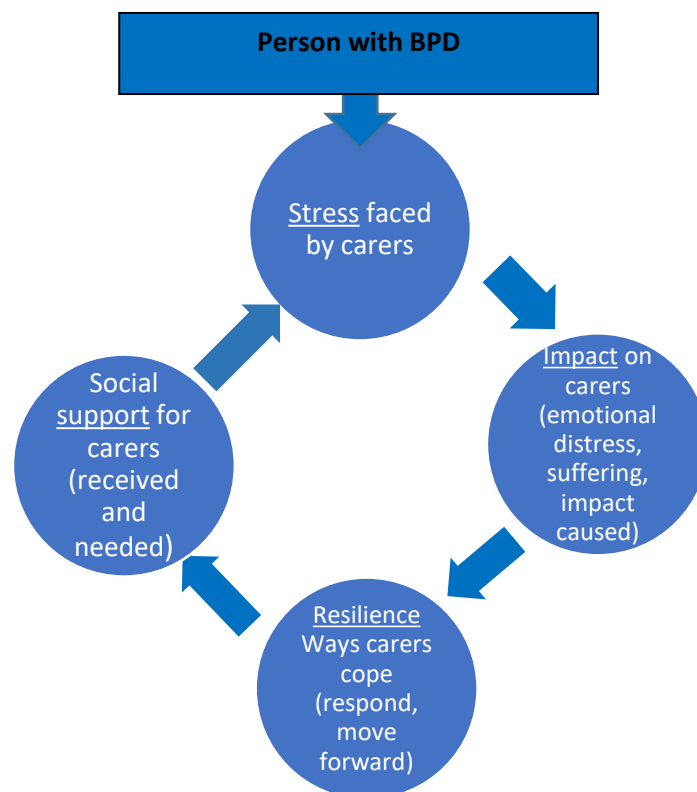
3.6.7 Abstraction and interpretation

The final stage of the Framework Analysis process was abstraction and interpretation (Ritchie et al. 2014). Creative aspects of Facet Methodology were used when interpreting and presenting data, for example thinking holistically, ecologically, narratively, and visualising using, quotations, tables, and diagrams (Mason 2018). Categories were developed by revisiting the intellectual puzzle being explored (Mason 2018) to identify the lived experience

and needs of carers. This was achieved by re-examining the interviews and studying the data extracts from each matrix then naming the detected elements that characterised and distinguished each summary or quotation and grouping them into subthemes and categories (Ritchie et al. 2014). An example is presented in Table 12 below.

Table 12: Example of detected elements

Descriptive themes	Subthemes	Detected elements / Categories
Stress	Emotional distress	• Suicide and self-harm thoughts expressed by the person with BPD • Sudden mood changes in people with BPD
	Experience in healthcare and treatment	• Delayed/ absent diagnosis • Poor or lacking care
	Chronic demands/behaviour	• Mood changes, • Violence and aggression • Financial/family issues

3.6.7.1   Discovering the analytical themes

Facet Methodology principles guided how to make sense of the data through a process of interpretive and reflexive readings. These involved reading beyond the data and constructing a version of '*what is going on?*' and *'what might this mean, represent or signify?'* At this stage, Facet Methodology suggested:

> "*Listen gently to your data rather than your first impulses being to try and force it into categories. Follow what is fascinating, intriguing, and puzzling in your data.*"

(Mason 2018: P213)

To further assist this, supervision allowed analytical ideas to be discussed, explored, and noted down. Keeping a journal also further expressed the researcher's reflections which were re-examined, enabling further interpretation and comparison (Mason 2018) with the interview data, themes, and categories. It was only then that the analytical themes were identified as detailed in Table 13 below and highlighted in green.

Table 13: Final thematic and analytical framework

Descriptive themes	Subthemes	Detected elements / categories	Analytical themes	Analytical subthemes
Stress	Emotional distress Chronic demands/behaviour Experience in healthcare and treatment	Suicide & self-harm Violence and aggression Sudden mood changes/behaviour Financial issues; Family aspects Diagnosis / Lacking care	Trauma by association	*"Living in a nightmare"* Traumatic stress and vicarious trauma *Being "failed by the system"*
Impact	Emotional distress	Finding out about sexual abuse Walking on eggshells Losing hope		
	Relationships/way of life Quality and nature of the relationship (with person with BPD)	Isolation, loneliness Living a double life, brave face Home, work, friends, social network	Socially and emotionally isolated	Change in quality and nature of the relationship Withdrawing from family, friends/communities
Resilience	Strategies / skills Supporting the person with BPD Reflecting / sense-making With family and friends	Doing what helps Accepting/ supporting distress Being there; Financial support Relative being supported /complaining Trying to make sense of the cause Help-seeking for self/work Memories / good times / reflection Aspects relating to family/friends	Beyond coping	Coping strategies for themselves Providing long term care and support
Support	Help-seeking Lack of Positive and helpful Unhelpful Future intervention	Emotional and social Peer support and self-care Information, education & skills Instrumental support Modes of delivery	Carers are people who need support too	Lived experience of carer's support What people need What people want in an intervention

3.7   Trustworthiness, validity, and reliability

Assessing and evaluating the quality and rigour of the research was essential for the findings to be utilised in practice (Mason 2018). Therefore, strategies to ensure trustworthiness, validity, and reliability were identified and evidenced (Nowell et al. 2017). These included ensuring the integrity of the data, a balance between reflexivity and subjectivity, and clear communication of findings (Williams and Morrow 2009). The integrity of the data was maintained by using Framework Analysis and developing thematic matrices which provided a structure and opportunity for the study to be led by the data, and analysis transparent (Shaw and Saltalkar 2018). Further, the adequacy or dependability of the data began with a clear articulation of the research question, methodology used, and an obvious systematic process.

Details regarding recruitment, interviewing, transcription, and data analysis presented in this chapter offered assurance and the opportunity for replication of the process (Williams and Morrow 2009). This chapter has also shown how the interpretation fitted with Framework Analysis, by using the five stages guided by Spencer et al. (2014), presenting extracts/examples of the thematic matrices developed, and direct quotes which represented the participants' views (Mason 2018; Spencer et al. 2014). Diversity of demographics and viewpoints were sought from different carers and professional stakeholders using Facet Methodology principles (Mason 2018). This supported eliciting rich data, sufficient quality and quantity of data were evidenced and analysed following Framework Analysis methods (Spencer et al. 2014).

Reflexivity is an important and essential concept within qualitative research and cultivates good habits, an awareness of self, and critically reflecting upon or being able to identify clearly what came from the participants and what came from the researcher (Mason 2018). As previously discussed, I am a nurse with many years of experience, and this has shaped my viewpoint concerning mental ill-health and BPD specifically. My experience as a researcher has now led me to question the validity and reliability of mental illness diagnoses and I have a rising concern about the stigmatisation of people diagnosed with BPD and its impact on both them and their families or carers. This influenced and motivated my choice of topics for investigation in a PhD study and it was important that the methods used in my research enabled the voices of families and carers to be heard and their experiences understood. Thereafter, using the knowledge learned from them, I was keen to use theories of co-production, such as those identified by Roper et al. (2018), to define the problems they have, and develop solutions together, with a view to further testing these.

Reflexivity and subjectivity were addressed by recognising that I, as the researcher was central and as such I reflected on my thoughts, feelings, actions, and conflicts throughout the study (Williams and Morrow 2009). I was conscious to examine my role within the research process rather than considering myself as a neutral data collector so that this could enhance the quality of findings (Mason 2018). Two methods of reflexivity that I adopted were writing about my experiences, thoughts, ideas, and decisions, in field notes and in a journal (Denscombe 2014; Holloway and Wheeler 2016). I kept notes from the stakeholder consultations, interviews, focus groups, supervision, and analysis as well as a critically reflective account of each interview held in the form of a reflexive journal (Tobin and Begley 2004). These were handwritten and then transferred to a secure word document folder with the source destroyed. These were discussed during supervision and influenced the study design, analysis and presentation of findings within this thesis.

This process allowed reflecting upon personal perspectives and recognising these as separate from the participants (Tobin and Begley 2004). I was also conscious of my identity being part nurse, part researcher, how this might be perceived by participants, and how they might view me as an authority figure or someone who has possibly supported or let them down in the past. Therefore, I considered myself an active participant and was also concerned they would think I could develop an intervention for them to use soon. I was conscious of telling participants at the end of each interview what would happen next on my Ph.D. journey. Participants in both the interviews and focus groups were very open with me, I was aware that I was using some of my therapeutic rapport skills learned as a nurse with them and also mindful not to mislead them into thinking I could help them with the issues they were struggling with when in reality my agenda was to collect data and co-design the intervention. Feeling their desperation in most of the interviews I did spend some time at the end of each being friendly, offering support, information about BPD, or guidance on how they might connect with currently available carer support organisations. This was individual to each participant. An overwhelming feeling I had during the interviews was empathy for carers, particularly parents of young people who were struggling with BPD. As a parent of teenagers and young people, I could not help but think about how I would cope with their situation. Holloway and Wheeler (2016) describe the importance of critically reflecting upon my preconceptions and monitoring the relationship between myself and participants as well as my reaction to their experiences. An example of this is in Figure 6 below.

Figure 6: Example of a journal entry following an interview

> **Reflection:** "*During the interview, she told me, 'I feel like a battered wife' and at that moment, I thought, 'you are…'. I nearly said this but decided to continue listening; I think she told me because she felt safe to, she perhaps thought I wouldn't judge her, or give my opinion or advice so I didn't. I wasn't there to do that and I think she knew this.*"
> (Researcher reflection upon an interview with a carer)

Reflexivity and maintaining a self-critical position, within social and political contexts continued throughout data collection, analysis, interpretation, and writing up the findings (Holloway and Wheeler 2016). Daily aspects of the research process, methodological decisions, personal reflections of values, insights, and interests were recorded in two large notebooks (Mason 2018). By using this approach, a reflexive stance towards the entire research process was taken, regularly considering how theories and themes evolved (Charmaz 2014). To support member checking, summarising, and clarifying my interpretation and participants' meaning a sample of the transcripts, data analysis including themes and analytical notes were checked by my supervisors and discussed during supervision (Grbch 2012). An example of notes from a supervision discussion is in Figure 7 below.

Figure 7: Example of notes from supervision

> **Reflection:** "*Carers described the trauma they felt by witnessing and being exposed to a traumatised person – in a sense, it was vicarious trauma. But they also experienced first-hand direct trauma and traumatic stress from these, such as suicide, self-harm, and aggression – it would be frightening to see someone you love hurt themselves so badly.*"
>
> (Notes from a supervision discussion with my supervisors when we were interpreting the data and developing the themes)

It was important to do justice to the findings of the study and communicate the experiences, problems, and needs of carers. This began with clearly defining the research question and thereafter evidencing that the research question was answered. This involved the interpretive task of drawing out carers' meaning within their social context in a way that was easily understood and supported by their quotes (Charmaz 2014). Moreover, I attempted to communicate what was discovered and why it was important, tying the results to existing literature and describing its relevance to the topic area (Mason 2018). During this process, I developed a working relationship with a core group of stakeholders including carers and professionals who can support the next stages of intervention development. The findings of

this study, therefore, identified strengths, and limitations, and developed ideas that could contribute to change and the development of an intervention (Noble and Smith 2015).

3.8 Chapter summary

In summary, Facet Methodology was utilised to design the study and be consistent with my ontological and epistemological approach. Facet Methodology also informed the subsequent data gathering and analysis. Additionally, I used Framework Analysis methods to facilitate an inductive and deductive approach to managing, and analysing the data which helped to support the development of concepts, themes, and analytic categories (Spencer et al. 2014). The reflexive journal and field notes assisted my critical reflection upon the experience, and multiple perspectives to explain the social phenomenon (Mason 2018). Creatively, a theoretical model was developed to understand and present the descriptive findings before abstraction and interpretation of the data into analytic themes. These were later used in the focus groups to guide the discussion and develop the supportive intervention. The study's findings will be presented in Chapters Four and Five.

Chapter Four: Findings

4.1 INTRODUCTION

The overall aim of this study was to examine the experiences and needs of carers who support a person with BPD and to develop an evidence-informed supportive intervention specifically for carers. This chapter presents the findings relating to their views and experiences, as well as the support they require and would find helpful from an intervention. The chapter will begin with a profile of the participants who took part in the study, and a general overview, followed by the analytic themes on carer experiences, concluding with a chapter summary.

4.2 Profile of participants

The 20 participants who took part in this study lived across Scotland. Sixteen were female and four were male. Three were 60 years or older, six were between 50 and 59 years, eight were between 40 and 49 years, one was between 30 and 39 years and two were between 20 and 29 years. Relationship status was mixed with 16 participants stating they were married or in a relationship, one widowed, two single, and one divorced. With education, one participant held a Ph.D., five a master's degree, nine a degree, and five a secondary/certificate education. Thirteen participants worked full-time, four part-time, two were retired and one undertook voluntary work. Sixteen participants identified the person with BPD that they supported as female, and four were male. Participants also declared their relationship with the person as a mother (9), father (2), wife (2), husband (1), partner (1), sister (2), daughter (1), aunt (1), friend (2). Of note, one participant supported two people with BPD (a husband and daughter).

The study included 18 family members and two friends. Eleven family members lived with the person with BPD and nine family/friends lived nearby. Full participant information is presented in Table 14 below. It is perhaps unsurprising that only two friends participated given the interpersonal and relational challenges of being in a relationship or friendship with a person with BPD. The interviews reflect this and there are significant differences in the experiences of friends versus family members, which will be highlighted within this chapter.

Table 14: Profile of participants

Participant ID	Participant gender	Age group	Relationship status	Education	Employment	Diagnosis of family/ friend	The person with BPD gender	Relationship to person	Proximity to the person with BPD
P1	Female	50-60	Married	Certificate	Full-time	BPD	Female	Sister	Lives nearby
P2	Female	40-49	Married	Masters	Full-time	BPD	Male	Wife	Lives with person
P3	Male	40-49	Widowed	Masters	Full-time	BPD	Female	Partner	Lived with person
P4	Female	40-49	Married	PhD	Full-time	BPD	Female	Friend	Lives nearby
P5	Female	21-29	Single	Secondary	Part-time	BPD	Female	Friend	Lives nearby
P6	Female	Over 60	Divorced	Secondary	Retired	BPD	Female/Male	Mother/Wife	Lives nearby
P7	Female	40-49	Married	Masters	Full-time	BPD	Female	Daughter	Lives nearby
P8	Female	40-49	Married	Masters	Full-time	BPD	Female	Mother	Lived with person
P9	Female	Over 60	Married	Degree	Full-time	BPD	Female	Mother	Lives nearby
P10	Female	Over 60	Partner	Masters	Full-time	BPD	Male	Mother	Lives with person
P11	Male	50-60	Single	Secondary	Full-time	BPD	Female	Father	Lives with person
P12	Female	40-49	Married	Degree	Part-time	BPD	Male	Mother	Lives with person
P13	Female	50-60	Married	Degree	Part-time	BPD	Female	Mother	Lives with person
P14	Male	50-60	Married	Degree	Retired	BPD	Female	Father	Lives with person
P15	Female	21-29	Married	Degree	Full time	BPD	Female	Sister	Lives nearby
P16	Female	50-60	Married	Secondary	Volunteer	BPD	Female	Mother	Lives with person
P17	Female	50-60	Married	Degree	Part-time	BPD	Female	Mother	Lives nearby
P18	Female	40-49	Married	Degree	Full time	BPD	Female	Mother	Lives with person
P19	Male	30-39	Married	Degree	Full time	BPD	Female	Husband	Lives with person
P20	Female	40-49	Married	Degree	Full time	BPD	Female	Aunt	Lives nearby

4.3　　　　General overview

Four overarching themes were identified in the analysis related to carers' experiences and needs in supporting a person with BPD. These were: i) Trauma by association; ii) Social and emotional isolation; ii) Beyond coping; iii) Carers are people who need support too.

Participants described their life coping with the emotional instability of the person with BPD as a stressful and distressing experience. This was influenced by the proximity of the relationship and their sympathetic participation in the suffering of the person. Family members experienced more difficulties and greater impact than friends. Trauma by association with the person with BPD was expressed by participants who exhibited emotions and behaviours consistent with traumatic stress and vicarious trauma. Correspondingly, participants described experiencing significant social and emotional isolation. They reported this as affecting their home, working life, health and wellbeing, friends, and social network, as well as the quality and nature of their relationship with their relatives and others.

 Although carers described the various ways they coped or moved forward with the multiple highly complex situations and problems in their daily life, many were 'beyond coping' and expressed endlessly trying every strategy they could think of to manage and improve their quality of life. Participants stressed that they needed support too. While some recalled receiving support many had not and described feeling socially isolated, uninformed about the condition itself, how to support the person with BPD, or support available for themselves. Finally, they discussed a potential and logical solution in terms of what would be helpful from a supportive intervention. The carers who participated in this study welcomed the proposal of an intervention. Their accounts and insights enabled their rich and unique perspective to be understood and will be presented in more detail throughout this chapter. A description of themes and subthemes is below in Table 15.

Table 15: Description of themes

Themes	Subthemes	Description
ONE		
Trauma by association	*"Living in a nightmare"*	This theme reveals participants lived experiences of life caring for a person with BPD. Key features of concern were coping with sudden mood changes; dealing with self-harm and suicidality; and living with aggression or violent behaviour.
	Traumatic stress and vicarious trauma	Participants detailed the impact of caregiving evident through signs of traumatic stress and vicarious trauma, including a negative perception of their life and the future.
	Being "failed by the system"	Underpinning participants' stress and trauma was a sense of being failed by the healthcare system. This was about diagnosis, access to treatment and support for the person with BPD, stigmatising and negative attitudes or advice from professionals, and receiving poor support and guidance for themselves.
TWO		
Social and emotional isolation	Change in quality and nature of their relationship	This theme explores factors influencing the social and emotional isolation carers experience. The burden and responsibilities of being a carer, coping with unpredictability and hostility in day-to-day life, and how carers try to hold onto the positive aspects of their relationship with the person with BPD.
	Withdrawing from family, friends, and communities	Carers described withdrawing from family, friends, and communities due to several issues. Stigma and shame were common barriers, linked to receiving negative and judgemental responses. They often concealed or withheld the truth about their life, isolated themselves, and avoided social contact.
THREE		
Beyond coping	Coping strategies for themselves	This theme describes how participants were proactively strategising about how they were going to live and cope with the complex demands and enduring crises. They described learning from experience, distancing themselves to take care of themselves, time away from caring responsibilities, and trying to make sense of the cause.
	Providing long term care and support	Participants moved into finding ways to live with their relative's difficulties long term offering as much support as they could and trying to practically enable the person with BPD. They often developed individualised strategies and skills.
FOUR		
Carers are people who need support too	Lived experience of carer's support	This theme discusses participants' lived experience of carer support both formally and informally. It describes a logical solution from carers in the form of components for a future intervention.
	What carers want from an intervention	

4.4 Theme One: Trauma by association

Participants were asked what their life was like living with or supporting a person with BPD, and to describe a typical day or week either presently or in recent years. They painted a picture of a life that was dominated by trauma by association with the person with BPD. They experienced symptoms of traumatic stress and vicarious trauma due to being in a close relationship with and caring for the person. There was also a sharp sense of stress when dealing with healthcare providers. Participants felt failed by the system with regards to support for the person with BPD and support for themselves.

4.4.1 *"Living in a nightmare"*

Participants described in detail experiences that depicted their lives as "*living in a nightmare*", coping with the person's BPD's emotional instability, distress, and crisis. These centred around three key issues for carers: coping with sudden mood changes; dealing with self-harm and suicidality; living with aggression and violent behaviour.

When discussing their day-to-day lives participants often reported being affected by the persistent burden of the person with BPD's sudden mood changes and impulsive behaviour. This concentrated on the person with BPD expressing enduring feelings of hopelessness, suicidality, and impulsivity. Often these were triggered by difficulties in relationships, financial issues, sensitivity to their environment (e.g. noise), or for no apparent reason at all:

> *"Her moods can change within seconds. I've seen me sitting having dinner with her, we'll both finish our dinner, put our dishes through, [X] will go upstairs, five minutes later come down the stairs covered in blood; slashing her stomach, slashing her legs… she's cut her throat, she's hung herself, she's overdosed on tablets."* (P14: Father)

> *"If there is noise in the house it puts her in a really bad place and she will come downstairs in a bad mood and we have to creep around, yeah, we tend to hold our breath until we see what kind of mood, she is in."* (P13: Mother)

Some participants reported having to *"creep around the house"* or *"stay out the way"* to prevent angry outbursts from the person with BPD, sacrificing their needs for them. There was also a

sharp sense of having to control their feelings for the sake of the person with BPD, and needing to "*bite your tongue",* and *"watch what you say":*

> "*You've got to choose what you want to say in front of her because it*
> *can become an issue later on whatever she's listening to or picking*
> *up on, so you have to be very mindful."* (F17: Mother)

Dealing with self-harm and suicidal thoughts or attempts by the person with BPD was expressed as one of the hardest and most stressful aspects of participants' lives. They described self-harm and suicidality as manifesting themselves quickly, and without warning. All carers worried about the person with BPD ending their life, and 18 out of 20 had experienced dealing with self-harm and attempted suicide on one or more occasions:

> *"The greatest challenge is to keep her alive at the moment because I*
> *do fear quite often, we are in danger of losing her."* (P14: Father)

Three participants had lost someone diagnosed with BPD to suicide (a mother, partner, and friend). Many recounted harrowing stories of coping with multiple violent self-harm and suicide attempts. They described having to be hypervigilant and *"walking on eggshells",* watching out for the next suicidal crisis or self-harm episode at home:

> *"My daughter was suicidal, self-harming, I was having to watch her all*
> *the time, every second, watch her when she got undressed so I knew*
> *what was going on because she was cutting her arms, her legs, cutting*
> *places I couldn't see. I was having to go through her washing and*
> *check for things in her pockets, you know, sharp stones and anything*
> *that could cut her. I was going in the bathroom in the middle of the*
> *night and sliding on blood on the floor because she'd been cutting*
> *herself."* (P6: Mother)

The fact that suicide attempts were sudden, life-threatening, frightening, and dramatic was particularly traumatic and challenging for participants, however, they valued the support from the emergency services (police or ambulance) who responded to their calls for help:

> *"We had a dreadful episode two weekends ago, ended up calling the*
> *Police out because she'd barricaded herself into her room and had tied*
> *a noose around her neck and I could hear her choking and I couldn't*
> *get into the room, so I phoned the Police and that seemed to de-*
> *escalate things eventually."*(P13: Mother)

Life before the diagnosis of BPD was also found to be stressful as this had often involved the shock of their relative self-harming or attempting suicide for the first time. One mother recalled arriving home from work and seeing an ambulance outside her house:

> *"I came home from work and there was an ambulance outside, my daughter had found him in his bedroom, he'd taken an overdose."*
> (P12: Mother)

Being the first to discover that person with BPD was attempting suicide was also a source of fear, stress, frightening memories, and worry for participants about *'what if?'*:

> *"So then when [X] was 22 and he had a serious, and I mean really serious suicide attempt, and he'd tried to hang himself and if I genuinely hadn't come in when I did, I came home early unexpectedly and found him."* (P10: Mother)

For many participants, they had been coping with years of recurring, impulsive, and risk-taking behaviour from person with BPD. For example, their child running away, jumping in front of cars, or threatening to jump from a bridge whilst in a distressed and suicidal state. Participants had an overwhelming sense of responsibility and burden meaning they often responded by searching for, or rescuing the person with BPD, worried that otherwise, they would end their life :

> *"We've had numerous episodes of her leaving the house and we don't know where she is, or she leaves the house and one of us will follow her on foot and she's walking into town cause she's going to jump off the bridge in [X], and it will result in us may be catching up with her…you know, one o'clock in the morning you're sitting in a field having a suicide chat and why do it/why not do it, just I suppose until it just wears off, that adrenaline from that particular episode has rung itself out, or you say something that dissolves the situation slightly. It's just trying to find that trigger that will help solve that situation."* (P14: Father)

Most reported being the one that the person with BPD called on to help them during a crisis or when they were in danger. This created tension between wanting to be there for them and the strain of always being the one they called on for support:

> *"I've had to help her in crisis many times, drive to England, give her money urgently to get her to safety – that was a nightmare, an absolute nightmare cause for some reason she just wasn't coming home and*

she would've been on the street, she never had any money… the decisions she makes make no sense…" (P6: Mother)

Experiencing aggression and violence at the hands of the person with BPD was prevalent, stressful, and fear evoking. This involved physical, or verbal aggression, threatening behaviour, and damage to their property. In total, thirteen out of 20 participants said that they were regularly on the receiving end of violence and aggression in one form or another. For 11 participants this was physical violence or the threat of, directed towards them, a loved one, or damage to property at home:

> *"For myself, it's been truly horrendous. [X] can be very, very aggressive, she can be very volatile. I woke up one night at three o'clock in the morning and she was sitting at the end of my bed with a baseball bat. I asked what she was doing, and she said, 'I'm going to smash your face in. Another time I woke up in the early hours of the morning and she was sitting on the edge of my bed with a knife and stating that she was going to stab me to death."* (P11: Father)

"Physically hurt her mum" was reported by a parent who also explained the violence and damage to their home and property from their daughter's rages and *"temper tantrums"*:

> *"Well, yeah she could run away, she could smash up her room, at least once but probably more physically hurt her mum, yeah bawling and shouting, screaming, yeah there was a glass went out the window, we've got a huge dent in the fridge; so temper tantrums can result in physical violence."* (P14: Father)

Participants also described coping with verbal aggression such as swearing, rants, insults, or criticism directed towards themselves and other members of the household, including parents and siblings:

> *"She can get verbally abusive to me and swearing and screaming and what seems like overreacting, but she has never been violent to me, I don't think she ever would – I think she would hurt herself more than anyone else."* (P19: Husband)

Participants often considered their relative's violence and verbal aggression to be related to the person being in distress or crisis:

> *"If she's in the midst of a crisis she'll be that bad and she'll just keep ranting on and shouting and getting angry and it's like everything that*

> *you say…she's like full-on and you can't calm her down."* (P17: Mother)

One parent likened her daughter's distress to the *"Tasmanian Devil"*:

> *"She can be verbally abusive, just out of control, God love her; we call her the Tasmanian Devil when she's like that… she assaulted her boyfriend….so bad… he was in intensive care with a head injury."*
> (P18: Mother)

In summary, the subtheme, *"Living in a nightmare"* revealed that coping with dangerous suicide attempts and self-harm were core to participants' lives which were dominated by the fear and trauma associated with such experiences. Sudden mood changes and aggressive behaviour were an everyday occurrence but also often viewed as a precursor to, or expression of the person with BPD becoming distressed (such as self-harm, suicide, aggression). Therefore, participants felt pressure to care for these to prevent them from escalating into a full crisis. Participants' accounts of recurrent shouting, rages of verbal abuse, and physical violence showed that these were a potential for many interactions with the person with BPD. This left participants living in a fearful, emotionally charged environment that could be ravaged at any moment.

4.4.2   Traumatic stress and vicarious trauma

Prolonged exposure to traumatic incidents and acute distress, described in theme one, strongly affected participants' emotional and psychological wellbeing. This was apparent in two key areas: expressing symptoms of traumatic stress and vicarious trauma, and a negative perception of their life and the future.

Participants, predominantly family members, experienced a substantial amount of emotional suffering consistent with traumatic stress and the longer-term impact of vicarious trauma (e.g. anxiety, worry, fear, panic, surreal), depression (e.g. hopelessness, sadness, numbness), and PTSD like symptoms (dissociation, visualisation, reliving, detached, memory issues). This was due to witnessing highly distressing events and repeated empathic engagement with the person with BPD. Highly evident was that participants had a sense of responsibility or commitment to help or rescue the person from frequent life-threatening or traumatic incidents such as suicidality or self-harm. As a result, many expressed being in constant worry and fear:

> *"I worry about her [cries] - she doesn't eat well – she is underweight, we can't leave her on her own and I don't know how much longer her body can cope with being so underweight. It's hopeless."* (P20: Aunt)

Some participants described fear, anxiety, and panic affecting them due to always having to be ready to face the worst-case scenario:

> *"When I see her name on my phone I panic as I never know what is going to come up, is it 'give me a lift from the bus stop' or is it 'this is [X] phone and she's taken an overdose. So, everybody's on tenterhooks all the time."* (P18: Mother)

> *"The second overdose was about ten days ago. That was very traumatic….I started to shake violently, and I shook for about 20 minutes, and weirdly I have a red mark under my eye… and I think I must have burst a blood vessel under my eye."* (P19: Husband)

Vicarious trauma features often mirrored those of PTSD, such as visualising their loved one's death, while others described poor recall and memory issues about traumatic events involving the person with BPD:

> *"For a while where every day I drove home, I was visualising seeing a Police car in the drive because [X] had hanged herself or she'd committed suicide in one way or another. So yeah, I visualise that constantly."* (P14: Father)

> *"It was probably all the violence, to be honest with you I probably deleted the tape [memory] from those years to be honest because I'm very hazy on a lot of it, but I was physically attacked a lot of the time."* (P18: Mother)

Accounts indicated that the more involved the relationship was the greater the intensity of anxiety and trauma symptoms (e.g. parent or partner living with the person with BPD). Others described becoming emotionally shut down and dissociating from their emotions to protect themselves from experiencing further unwanted traumatic experiences:

> *"For several years now a combination of factors has combined to make me what I would describe as emotionally dead."* (P14: Father)

> *"My husband and kids were bawling their eyes out and they were pretty, I mean, this was the worst one, we did suspect she wasn't going*

> *to pull through this time, and I was feeling nothing. Nothing."* (P18: Mother)

Many participants' accounts showed negative changes to their perception of self, others, and life. Fatigue, powerlessness, helplessness, and grief were highly evident as a result of caring for the person with BPD. Loss of hope was linked to *"no chance of a normal life"* and perceiving a lack of support or any clear treatment provided for the person with BPD from services. Some questioned if their *"nightmare"* would ever end, while others experienced caring as a *"rollercoaster":*

> *"When will this ever end as it is a nightmare sometimes, like I am living in a nightmare, and I feel responsible for her now."* (P19: Husband)

> *"It's a rollercoaster…we're okay as long as it's good but when it's bad it's bad it's awful and no chance of a normal life."* (P13: Mother)

They also felt that BPD had caused the breakdown and destruction of family life and the enduring nature of care contributed to their helplessness, often reported in terms such as *"soul-destroying":*

> *"I would love just to be able to have a home I can call home for the whole family, you know, but you can't [cries]…it's just destroyed our whole everything that we've set up for our family has just been destroyed through all of this."* (P16: Mother)

> *"For me, it's been soul-destroying to watch her doing what she does to herself. Just a bit of feeling of helplessness that there's nothing you can do, you know, if the medical health experts or mental health experts can't do anything it's like I'm a bit awash to do anything as well.* (P11: Father)

Carers also worried about the future of other family members (e.g. other children). Some reported seeing mental health issues, such as anxiety and depression in their other children. They attributed this to being exposed to self-harm, violence, and crisis in their homes. These worries further burdened participants:

> *"It's been huge. It's been huge for all of us really [gets upset]. It's difficult with the family, you know, our son's been… I mean, our son's amazing how he seems to have not been impacted by it, but he's witnessed and heard lots of difficult times and seen me crying, you know, and it's been hard."* (P18: Mother)

In summary, the participants' accounts reflected the significant impact the caregiving relationship with the person with BPD had on their emotional and psychological well-being characterised by features of traumatic stress, vicarious trauma, and PTSD-like symptoms.

4.4.3   Being "failed by the system"

Participants felt let down and failed by the health care system in several ways during the process of diagnosis; trying to access treatment and support for the person with BPD; experiencing stigmatising and negative attitudes from professionals; and receiving poor support, involvement, and guidance for themselves.

Many participants described delayed or absent diagnoses for the person with BPD as a source of stress for them. One described no formal diagnosis of any mental health condition for her son following years of self-harm, suicide attempts, and psychiatric medicine before his suicide at 25 years old. She recalled a *"throwaway"* diagnosis of BPD being given by a community mental health nurse and never followed up:

> *"It was mentioned that he had Borderline Personality Disorder by a*
> *nurse, but nothing was ever followed up…my son was on several*
> *different mental health medications but never had a diagnosis of any*
> *kind, and the comment almost seemed to be throwaway by the nurse."*
> (P10: Mother)

Some participants reported a lengthy process of diagnosis through child and adolescent mental health services. This was exacerbated by a perceived lack of understanding, belief, or compassion on the part of most professionals towards the person with BPD and carers:

> *"She would have been about 17 when she was diagnosed, but that*
> *was after five years of violent episodes and suicide attempts and she*
> *was attending child and adolescent services. She did have one doctor*
> *who understood, and he was the one who did the BPD diagnosis, and*
> *after that, they put her on the DBT programme."* (P18: Mother)

Others recalled years of multiple diagnoses such as depression, anxiety, and bipolar before BPD. Ultimately, this meant delayed or absent psychological therapy for the person with BPD, and increased self-harm, suicide attempts, or completed suicides:

> *"She was initially diagnosed with depression, so she immediately went*
> *on antidepressants and at the time….then later a psychiatrist said to*

> *her, 'you don't meet the criteria for bipolar'…it must be BPD… I'd never*
> *actually heard of BPD."* (F9: Mother)

Participants felt that a delayed diagnosis meant delayed treatment and recovery, impacting not only the person with BPD's recovery but the participants' well-being too:

> *"The mental health nurse he went to see said he has been lost in the*
> *system. So, he kind of has been failed by the system, because if he*
> *had been diagnosed a lot earlier then I think he would have been a lot*
> *further down the line by now."* (P2: Wife)

Strong feelings were also expressed about the poor or lacking care that the person with BPD received post-diagnosis and throughout their journey of care. Participants felt they were left trying to organise care and support or provide it where services were absent which added to their stress and worry. Terms such as: *"failed by the system"*, *"gaps in care", "never properly assessed" "no follow-up treatment", "nobody help*ed", and *"waited four hours to see a psychiatrist"*, were commonly used to describe the person with BPD's care experiences. Poor support or treatment for the person with BPD were frequent complaints as they heavily impacted the carers' role. For example, being discharged from hospital or crisis services without the appropriate treatment, or indeed any follow up:

> *"After the six months again, she got out with no CPN, no follow up*
> *treatment and she attempted suicide again and was back in within a*
> *week, and she was there for a couple of months again."* (P8: Mother)

Concerns were often raised about trying to get help for their relative during a suicide crisis. Participants expressed this was a stressful or even impossible endeavour. Even when professionals did see the person with BPD, participants believed their responses and interventions were inappropriate, uncompassionate, or even dangerous:

> *"They just went, 'oh well, the suicide attempt had been a really bad*
> *self-harm thing, I'd taken him to hospital, we waited for four hours then*
> *they said so I think you should just go home, and we'll write to your*
> *GP'. And, you know, nobody helped."* (P10: Mother)

Not only did participants feel the person with BPD was failed by the health care system, but they also believed they were failed as carers in the support, involvement, and guidance they received. They found professional's attitudes towards them were often negative, and unsupportive giving perceived stigmatising information, and dehumanising advice about the person with BPD condition:

> *"A few staff members said 'this is a revolving door condition, she's going to be in and out with us for the rest of her life, you better get used to that, and sometimes it's better just to walk away, some parents just can't deal with this so you should walk away from her'."* (P8: Mother)

> *"The thing I found alarming was that her psychiatrist had told me to put bolts on the inside of my bedroom door to keep myself safe."* (P11: Father)

Participants also often reported receiving a hopeless prognosis from professionals in an uncompassionate and flippant manner:

> *"Well Mr [X] what you've got to do is brace yourself for the worst because I'm in no doubt that [X] will kill herself at some point."* (P14: Father)

A perceived lack of compassionate, and judgemental attitudes from healthcare professionals also added to participant's emotional suffering, causing them to panic further about the outcome for their relatives:

> *"When you're dealing with the mental health system, I've found I shut down and not say anything I want to say as you're so judged……when we went to the crisis service at 4 in the morning we were just wandering around and no-one was there…we found a waiting room and sat for 40 minutes and I was kind of like panicking all the time thinking 'my daughter said she's going to kill herself if she goes home tonight and it was like a surreal film trying to get help but nobody caring."* (P16: Mother)

Participants also felt professionals lacked compassion or understanding (regarding sexual abuse), hid crisis events (such as physical restraint), and often used patient confidentiality as a reason to be obtrusive and not involve them in care planning:

> *"I was in shock and reeling, I'd just found out my daughter had been sexually abused by my ex-husband… they put me in a room off the ward for over an hour on my own…when the nurse finally came in she was accusing and said, 'what you mean you really didn't know? I couldn't believe it, no compassion or care for what was happening."* (P10: Mother)

"They greatly let everything fall back onto me, what they'll now say is 'because [X] is 19 we can't discuss that with you" (P8: Mother)

When considering *"being failed by the system"*, participants perceived both they and their relatives needed more care and support from health services. Although lacking care was revealed as an issue for the person with BPD, it was also a problem for carers who felt they were left providing the support they perceived should be given by professionals. Participants believed that experiencing stigmatising or negative attitudes, poor care, involvement, and guidance for themselves added to the negative impact that being a carer had on them.

4.4.4   Summary

In summary, this first theme revealed the harsh reality of life for carers. Analysis of interviews showed the stressful and challenging, nonlinear cycle of living with their relatives' self-harm and suicide attempts, the fear of aggression or violence, and difficulties in coping with sudden moods and behaviour. Prolonged exposure to traumatic incidents and engaging empathically had resulted in a sense of *"living in a nightmare"* with little hope for the future. Highly evident was the influence of traumatic stress and vicarious trauma on their emotional and psychological wellbeing. Adding to their burden of care was the perception that care for their relative was poor and they were persistently *"failed by the system"*. This was the experience primarily reported by family members and interviews with friends did not reflect the same level of stress, therefore did not feature in this theme.

4.5 Theme Two: Social and emotional isolation

Participants spoke about the negative impact BPD had on the quality and nature of the relationship they had with their relatives. Difficulties associated with supporting the person with BPD often led to participants withdrawing from family, friends, or communities and as a consequence becoming socially and emotionally isolated, both internally (through thoughts and feelings) and externally (through behaviour and actions).

4.5.1 Change in quality and nature of their relationship

From the onset of difficulties for the person with BPD, participants experienced a change in the quality and nature of their relationships and way of life. They often talked about the burden and responsibilities they held by taking on a supportive caring role; being obligated to maintain the relationship and resolve conflicts, and proactively trying to hold onto the positive aspects of their relationship.

Participants described how their carer role extended far beyond that of their previous relationship with the person. They felt responsible for managing the regular traumatic incidents the person with BPD experienced while coping with their own emotions resulting from the trauma. Participants described that the activities of being a carer ranged from safeguarding the person from themselves in a crisis to counselling, mediation, and dealing with practical matters. This often led to emotional and physical exhaustion:

> *"I've been everything from a counsellor, crisis therapist, mediating with*
> *services… and taking her to appointments or picking up medication."*
> (P3: Husband)

> *"Just being in the caring role, being with somebody 24/7 that you're*
> *caring for in one way or another, it's physically and mentally*
> *exhausting."* (P17: Mother)

The carer role had led to some participants feeling they needed to be hyper-vigilant with the person with BPD (a state of stress in itself), regularly checking up on them, avoiding or emotionally disconnecting to self-preserve:

> *"She's always at the back of my mind I'm always thinking I should*
> *check in on her, then there's the element of being scared of what I'll*
> *hear because I don't want to hear the bad stuff."* (P1: Sister)

They also found it hard to cope with the person with BPD's hostility towards them. Participants often felt blamed for their relative's problems and the butt of their frustration, disgruntled mood, and anger. This manifested itself in several ways, regularly they would be cruel and nasty towards them:

> "She was almost cruel, she's almost like being judgemental. I can never hoover properly, I can't hang up clothes properly, like, it is constant, and I feel either stupid, not good enough sort of thing." (P15: Sister)

There was tension and anxiety from some participants about maintaining a relationship with the person. For example, one recalled childhood experiences with her mother's hostility and mood swings as *"very difficult".* This resulted in needing counselling for anxiety and depression, but the memories lived on:

> "It's very difficult, when we were little, she would have hysterics, mostly when my dad was out at work – she would break down crying tell us we were evil, and she couldn't cope. She would tell us she wanted to kill herself because of us, lock us out of the house all day and say we were getting taken to a children's home when our dad came home."
> (P7: Daughter)

To a lesser degree friends were also cognisant of the person with BPD's mood changes impacting their relationship and had to consider the effect this had on what they did together:

> "I had to understand that [X] could change her mind on the day if she wasn't feeling up to a meeting or going out – she let me down a lot like that but I just had to get used to it – maybe 1 in 3 of our plans to meet up would go ahead." (P4: Friend)

It was important for participants to hold onto positive aspects of their relationship with the person with BPD. Although this was overshadowed by the weight of responsibility and effects of the carer relationship, most spoke lovingly, compassionately, and highly about the person and what they loved about them. This helped them to reflect and create a balance to cope with the more difficult aspects of the relationship. For those who had lost their relative by suicide these memories were treasured:

> "I think within the first year of our relationships we travelled throughout [X], we did a lot of travelling throughout [X]. We were both interested in the arts, we would go to the cinema, [X] worked in the film and television industry when she was well; we liked to dine out, you know,

> *part culture, part food. So those were the kind of things that we would*
> *do together."* (F3: Partner)

And friends remembered too:

> *"It could be really hard but at the same time we have had a lot of fun*
> *over the years…. She made me a better, more caring person than I*
> *ever would have been."* (F4: Friend)

Participants also mused over enjoying time with their child, enjoying fashion, a coffee, sharing clothes, and seeing *"a lot of myself in her".* They emphasised fun-loving aspects of their personality such as being sociable, their sense of humour, and laughing together:

> *"I see a lot of myself in her, we usually meet up and go round the shops*
> *together, she likes fashion and clothes and I quite like all that. We go*
> *to the cinema sometimes together and we just meet up and we have*
> *a laugh sometimes, you know, but like I say she's great and she's got*
> *a great sense of humour and she's really good company."* (F9: Mother)

In summary, the quality and nature of the participants' relationship with the person with BPD had changed and in many ways, deteriorated. In many respects participants believed they had been required to transgress into the caring role and forge a new relationship, accepting the person's illness and problems. It was evident that participants were at different stages of this. For some, this was peppered with the need for hypervigilance and the acceptance of unpredictability and hostility towards them. However, significantly many still managed to hold positive aspects of a relational experience.

4.5.2   Withdrawing from family, friends, and communities

Several features characterised participants withdrawing from family, friends, and communities. These centred around receiving negative or judgemental responses, concealing or withholding the truth about their lives from others, and isolating themselves to avoid social contact. Participants felt their family, friends, and communities did not understand the difficulties they were coping with and often gave advice that was unhelpful, negative, or judgemental towards the person they loved:

> *"Yeah, friends are supportive, but I don't suppose I tell them much and*
> *that's not through shame, I don't want anybody looking at [X] and*
> *judging her for something that's not her or judging me."* (P8: Mother)

> *"I don't want them to judge her badly…It's not her it's the BPD that causes her to be impulsive so when she has taken an overdose or cut herself, I only tell them if I really have to."* (P19: Husband)

Being open about their lives and what they were coping with (self-harm, suicide attempts, or aggression) was frequently met with upsetting and negative responses. Participants often felt rejected or judged which led to them distancing from sources of support, further reinforcing their isolation and need to keep their issues private:

> *I've emptied parties when I've been open with people talking about my daughter's sexuality and I may be mentioned self-harm, you know, you just can't talk about it, you start to question your whole community really."* (P16: Mother)

Participants frequently expressed that their isolation was compounded by concealing or withholding the truth of their situation and feeling they could not be honest with others about what was really happening. Some compared their lives to other families:

> *"I think that's the absolute worst thing is the isolation, sometimes it feels isolating to look at other people's families and everything's great in that family and my family is carnage."* (P9: Mother)

It was not unusual for participants to disclose they had no friends, felt very isolated, or concealed the diagnosis from family, friends, and employers:

> *"We haven't told anyone about [X] diagnosis, they know she has depression but nothing more, we don't want them to judge us or her."* (P13: Mother)

> *"You've got the stigma and shame of it, it's made me withdraw and isolate myself from my community, it's made me question my friends, I mean, I don't think I've got any, you know, it's just kind of you narrow yourself in to protect yourself and your family, and you don't know who to talk to."* (P14: Father)

Concealing the truth often meant putting on a *"brave face"* for anyone outside their home or avoiding seeing people. Many participants described almost living a double life; there was life at home with the person with BPD, then there was life at work, with friends or other family members and the two did not converge. However, this meant participants had to conceal crises when they occurred:

Participant: *"I'm in charge of a business so, you know, I've found myself ten minutes before going into a board meeting where I'm leading and chairing the discussion and you get a phone call saying, 'I'm out walking on the side of the motorway, I'm just thinking I might jump in front of a lorry' and I think oh my god, I mean, what do I do?"* (P14: Father)

Interviewer*: And what do you do?*

Participant*: I just have to carry on – or make an excuse and leave, it depends."* (P14: Father)

Participants said they often isolated themselves, avoided social contact, or people visiting their home to prevent having to explain how their life was:

"I have found myself not wanting to go out, to meet people because they're always asking 'how is everybody, how's [X]?' and when life's shite at home, you don't really want to tell people that and sometimes it's hard to keep a smiling face." (P17: Mother)

"You isolate yourself because you don't want people to come up and see that kind of behaviour, right, so you do tend to isolate yourself because they don't care who's here, they'll act out in front of anybody. If I bring somebody in my house for instance that if he doesn't like them…well he'll go round banging doors and everything in the house because he doesn't like the person that's in." (P6: Ex-Wife)

This even included other family members (such as other children) if the person with BPD did not want them there. This created difficult decisions and stress about who to prioritise and how to manage family dynamics. They also had to cope with the damage and loss this caused to those relationships:

"So we've now got the environment where [daughter A] cannot come home because [daughter B] will go and take herself off and be in her room for three days…….she is communicating that she's hanging herself or she's smashing things up or she's barricading the door down, or whatever, then actually well it does become everybody's problem." (P11: Father)

Often efforts to reduce loneliness or isolation and improve their social and emotional wellbeing were thwarted by having to cancel plans at the last minute, such as going out with friends for

dinner. Participants expressed stress from having to lie, make excuses or put a brave face on in these situations:

> *"On many, many, many occasions we've had to cancel things at the last minute, you know, we could be going out to friends for dinner, you go through a period where you make excuses and you say, [wife] has got a cold so she's not at the party tonight, but actually [wife] at home trying to talk [daughter] out of killing herself."* (P14: Father)

Overall, withdrawing from family, friends, and communities by concealing the truth, not talking about their problems, and being burdened by stigma or traumatic experiences fuelled participants' social and emotional isolation and only emphasised their experience of "*living in a nightmare*". There was a strong link between this and the negative emotional impact of life as a carer. The more isolated and lonelier, the greater the emotional toll and vice versa.

4.5.3   Summary

In summary, this second theme of social and emotional isolation for participants revealed a significant aspect of the impact that trauma by association with a person with BPD has on carers. A significant finding was the deterioration over time of the quality and nature of their relationship with the person with BPD, family, and friends. This added further stress, causing forced isolation and loneliness at a time when they were most in need of connection and support.

4.6   Theme Three: Beyond coping

Participants were asked about how they coped, responded, managed, or moved forward with everyday life. Initially 'resilience' was identified as a descriptive theme, however deeper analysis, and interpretation found that many carers were in a 'beyond coping' phase. This was where they were proactively strategising about how they were going to live and cope with the complex demands and enduring crises the BPD condition presented. This was to try and improve their emotional well-being and quality of life. They spoke about using an eclectic selection of coping strategies, both for themselves as well as to support and practically enable the person with BPD.

4.6.1   Coping strategies for themselves

For many participants, coping strategies focused on supporting the person with BPD. However, the analysis revealed that all participants employed a variety of strategies to help *them* cope with everyday life. Key features of these were learning from their own experiences, stepping back, or distancing themselves, time away from caring responsibilities, and trying to make sense of the cause.

Learning from experience meant participants employed an eclectic selection of strategies and skills which they had gained through *"trial and error"*. For example, at a rudimental level many described trying to separate the person from the illness:

> *"I just remind myself that it's not necessarily her that's being in that shit mood with me, you know what I mean, quite a lot of the time it's the illness, you can't be too angry at her."* (P16: Mother)

They emphasised a lack of direction from professionals on how to manage or support a person with BPD. However, they had themselves developed what they described as strategies, approaches, or coping tools:

> *"I would say all of those coping tools were built from my self-care insight and research into the disorder, none of… I was given no real direction insight in how best to respond and to manage."* (P3: Partner)

Likewise, participants expressed their frustration and exhaustion at having to cope with their own *"trial and error",* and making mistakes:

> *"I also think it is because I am finding out how to manage it through my trial and error so I may well be making mistakes in how I manage it so if I knew how to manage it if someone told me."* (P2: Wife)

Several spoke of doing their best for the person and one participant referred to this as just using her *"gut"*:

> *"I use my gut on how I can help but if I really knew how to support someone with BPD in distress or crisis then I would do that."* (P4: Friend)

Stepping back and distancing themselves from the person with BPD was an approach they discovered helpful for looking after themselves:

I've had to pull myself back and… years ago, I mean, I was right in the
middle of it all the time, but I think I have had to pull myself back and
start looking after me." (P16: Mother)

At different points on their journey, most participants described having to think about themselves, put themselves first, and take steps to cope with the long-term strain. One participant verbalised this saying:

"For a while it was somebody's going down and it's not me." (P16: Mother)

Friends interviewed, said they were happy they had set the parameter of what they could give:

"I think she sometimes wanted things from me but couldn't say what
they were, but I was clear to her what I could and couldn't give with my
kids and work life." (P4: Friend)

Whereas some participants had taken it to the extent of not living with the person, which for one meant divorcing her husband:

"I mean, he's got his own house so I don't have to feel bad about
saying to him he's not coming in here, you know what I mean, cause I
know that he's got, I mean, I helped him to get his house, he's got his
house nice and it's comfy." (P6: Ex-wife)

Participants described the benefits of having time away from caring responsibilities. This included working or volunteering which gave them ring-fenced time away from supporting the person with BPD and optimistically described as a *"miracle"* or a protective *"work bubble"*:

"My job is a miracle, so it's not just my livelihood it's also my passion
and I'm completely evangelistic about it… so you're completely
focused on the task at hand." (P18: Mother)

"When you're in work it's kind of all-consuming, you know, you're there
and you're in your work bubble so it is easy to put what's going on
outside aside for that time that you're at work….it is my sanity time."
(P13: Mother)

Participants were generally aware of the psychosocial causes attributed to BPD development therefore a core element, especially for family members was trying to understand what might have caused their relatives' BPD and come to terms with it. Childhood sexual abuse in several guises featured in the accounts of participants. For some finding out and acknowledging that

the person with BPD had been sexually abused in childhood helped make sense of their behaviour. This also aided in understanding what the person had been through. However, in some cases, it emphasised participant's feelings about a lack of child protection and missed opportunities by health professionals:

> *"It's helped us because we got to see in his medical records…from the age of two he was diagnosed with anxiety – he was being sick and having these strange attacks, and his family moved him around the countryside a great deal, and we couldn't understand why. There was a note on his records to suggest that this was child abuse, so they moved, and it was never followed up."* (P2: Wife)

For others when sexual abuse was disclosed it meant a range of emotions such as guilt, anger, and disbelief for family members, leaving them searching for answers:

> *"Finding out my ex-husband had abused my daughter was the worst, I was devastated and she blamed me, she thought I knew….he was violent towards me and that's why I left him, but I opened the door to him abusing her when I wasn't there, and I have to live with that."* (P12: Mother)

Other childhood adversities were considered as the cause, for example, parent divorce, moving to a new house, or losing a grandparent. Some parents recalled their child showing signs that something was wrong as early as four years old and remembered a *"sensitive child"* with emotional or behavioural problems:

> *"When he was about four years old, my husband and I divorced and he started having difficulties with behaviour and sleeping patterns were very difficult and controlling his emotions was very difficult, he was always a very sensitive child, you know, very loving but he would have these outbursts and I did approach my health visitor at the time for help."* (P12: Mother)

Adverse childhood experiences were not evident to all participants leading them to question the cause further:

> *"The concept that these behaviours presented in childhood or she was emotionally unsupported by her parents I don't see that, or even a tragic event – there was no tragic event – they moved house when she was 10 but kept her at the same school so sometimes we wonder if that was it but there is no trauma other than that."* (P20: Aunt)

Overall, participants described a wealth of experience in the way they were learning how to live with and cope with the problems they faced. Learning from experience, stepping back, distancing themselves, taking time away from caring responsibilities, and trying to make sense of the causes were all approaches they adopted but overarching this was the anguish and lack of guidance that they felt would benefit them.

4.6.2 Providing long term care and support

An aspect of the 'beyond coping' theme meant moving into providing long-term care and support for the person with BPD. The key elements of this were supporting and practically enabling the person with BPD, and using individualised strategies and skills.

When considering the practical support that participants provided, they spoke about "*being there*" for the person and trying to help them to live safely day-to-day. This was everything from housework and collecting prescriptions to enabling the person to engage in treatment, providing financial support, and importantly being ready for the next crisis:

> *"I do the housekeeping stuff too like the cleaning and pick up medicines…day-to-day everything can be ok for a while…then something will trigger her, and she emotionally is very low or anxious and having a crisis."*(P19: Husband)

On a practical level, several described caring to involve phoning the Police or Ambulance in an emergency when their relative was self-harming, or attempting suicide:

> *"Yeah, yeah in a crisis I would just phone the Police because, I mean, a lot of people say the Police are useless, but I find them good in an emergency…"* (P6: Mother)

There was a sharp sense of supporting the person with BPD to maintain social and vocational functioning in life. For those who were in work or education this meant participants supporting them with difficult situations as they arose:

> *"I fought really hard to get his job back because he'd been employed temporarily but for two years as a labourer."* (P10: Mother)

Similarly, attending work-related meetings when the person with BPD was having interpersonal difficulties with colleagues and work issues:

> *"I actually went along to meetings with her work and I could see that they were bending over backward, you know, to keep her going but [sigh] she just let it go."* (P9: Mother)

For some participants practically enabling the person with BPD meant doing things against their better judgement or personal values that they considered to be the *"lesser of two evils".* For example, one participant spoke about driving his daughter to buy *"weed"*; he felt the alternative would be violence and a suicidal crisis with *"no help available"* from services:

> *"We have found ourselves in the position where we will drive her… so that she can buy some more cannabis…because we are making a decision based on, we know what's coming when she runs out of weed, we know that we will be up all night, we will be repairing smashed things in the house, I may be following her down to a bridge in [X] at three in the morning which happened three weeks ago to try and prevent her jumping off, and I'm going to say, and this is an incredibly negative comment, I'm going to say because we know there is no help available it's better to drive through and pick up some weed then maybe we'll get some peace for a while…because I know what it is like being in the eye of the storm and that sadly the cannabis is the lesser of two evils."* (P14: Father)

For many participants, although not all, supporting their relatives financially was a cause of tension but also felt a necessity. Be it paying off debts, funding their accommodation and independent living costs, or giving advice on budgeting and managing money. This came down to a common element for many that the person with BPD was not good at managing money, would overspend on items such as expensive trainers, or vinyl records as an aspect of their illness:

> *"I bail her out financially because she's terrible with money…but the last time just a few weeks ago she came to me and said 'd'you think you could pay off my overdraft?' And I said, 'no I'm not doing it I said, 'what we will do is sit down and we'll work out a way'"* (P10: Mother)

When asked what they felt they managed well or did well, participants identified a wide range of individualised strategies and skills they had devised to regularly use, such as encouraging self-management and coping skills in the person with BPD. These were used to try and mitigate or relieve the person with BPD's distress, suicide, self-harm, or anger, and to support

them in everyday life. Setting boundaries or firm rules to try and reduce the likelihood of violence, self-harm, and suicide attempts were commonly tried with mixed results:

> *"I said 'listen, you use drugs and you have no support from me, you need to know that!' she said 'well I was drunk mum' I said 'so don't drink, if you're going to start using drugs just because you lose your sense of ability to make the right decisions then you can't drink!'"* (P18: Mother)

Meanwhile, others coped by devising self-management strategies, so they were not always the source of solutions:

> *"I think having strategies, 80% of the time defusing him, supporting him. He would be angry and the times that he couldn't express it he hurt himself, I would try to get him to devise strategies to manage himself … because I tried not to be his supply his solutions."* (P10: Mother)

Several strategies were used to diffuse situations or prevent a crisis from escalating. These included learning to recognise situations that may trigger distress or noticing for warning signs that the person with BPD may not be feeling themselves:

> *"I manage, well maybe not always but over time I understand, you know, things that will trigger her like making decisions I try not to offer choice, and distracting, you know, distracting away from something if you suddenly get a sense something's about to blow you think of other things and other ways of changing the subject."* (P16: Mother)

Trying to keep their relative calm was a coping strategy for many participants to manage their lives. They also tried to reassure and validate the person with BPD's feelings, using distraction techniques, or changing the subject. Just "*being there*" after a period of distress or angry outburst was commonly explained, but none of this was without difficulty and challenged participants:

> *"Probably when she is in crisis, self-harming and suicidal. I try hard to keep things calm by just being there to try and notice the warning signs when she isn't herself so I can manage it and try and validate how she is feeling – if she is upset or angry about something then I try and reassure her I think she needs but it's not easy and sometimes I make things worse and her mood explodes."* (P19: Husband)

When aggression escalated out of control some participants spoke about leaving the person with BPD alone or even getting out of the house themselves, this was as much to de-escalate as it was to keep themselves safe:

> *"I think when he gets angry, when he has anger outbursts I find that difficult because when he's you know, throwing things or he's kicking things it's difficult to reason and try and talk him round, I just feel like I have to leave him to almost, as long as he's safe, but leave him."* (P12: Mother)

> *"I phoned [Y] from the Carers group when he was being aggressive in the house and she said 'get out the house, just get out the house and go away in your car!'"* (P6: Ex-Wife)

Although not a prevalent theme one participant was positive about how their relationship had adapted to manage his partner's mood changes through support and validation:

> *"People can find it very difficult in relationship with people who suffer from BPD because of the mood swings and anger that can result from that and we had that managed exceptionally well so it would be mitigated so I knew when to validate or when to not to…was just part of the relationship."* (P3: Partner)

When it came to supporting skills, both friends expressed that they were good at calming in a crisis, listening, and being there:

> *"I think I was good at calming her and reasoning with her in crisis, she always contacted me so I think she must have thought I responded good – I let her say what she felt and scream her distress, I think people need that..."* (P4: Friend)

However, even where participants felt they were managing crisis well and had established a pattern of how they coped they still found this very difficult and stressful:

> *"The crisis management of suicide attempts was also very difficult as well, however, we got into a pattern of being able to manage that when it arose and again prevent it where we could, but that was difficult I would say."* (P3: Partner)

Overall, the interviews suggested that providing long-term care and support was a priority for participants. As such, in the absence of guidance or training from professionals, they had adopted an eclectic mix of mostly ad-hoc strategies, involving anything they thought might

work in the situation, or they could use to support themselves. These were with varying success and many participants expressed a constant sense of not knowing what they were doing.

4.6.3 Summary

In summary, 'beyond coping' meant proactively using a range of strategies to both support themselves as carers, and the person with BPD. Many tried to make sense as to why (especially parents) the person had developed BPD, reflecting upon the psychosocial causes that may be responsible and sometimes questioning their actions. Participants gave a lot of themselves, emotionally, practically, and often financially, and reported little in the way of support, education, or guidance from professionals or carer services.

4.7 Theme Four: Carers are people who need support too

The overall argument explored here is an accumulation of the previous three themes. Despite their stressful and challenging lives, participants described receiving very little in the way of support for themselves. It was evident from their accounts that carers need recognition of their role and as such require support. Participants made logical conclusions about their needs and transposed these into solutions or key ideas for the proposed supportive intervention.

4.7.1 Lived experience of carer's support

The overall perception from many participants was that although they often received little or no high-quality support, it was valued when they did and caused further stress when they did not. Areas highlighted by participants focused on their experiences of formal and informal practical or informative support, as well as social and emotional support.

Practical and informative support from statutory services was often perceived by participants as absent or poorly executed. One significant example was receiving a carer's assessment and support plan focusing on their individual needs, which is a directive of the Carers [Scotland] Act (2016). Some had received an assessment but were unimpressed by no follow-up or support being deployed, many had not. This emphasised a lack of coordination and provision of support, recognition, or understanding for their role:

> *"One of her CPNs put us in touch for a carers assessment and she came out and did a big, long interview and I don't mean to sound ungrateful, that's all it was. That wasn't the kind of support that we were looking for."* (P13: Mother)

Some participants said they knew nothing about what was available for them in terms of carer support. One participant recalled receiving *"a couple of fact sheets"* and was aware that the carer's assessments existed. He had been told he would receive one, however, this had not transpired:

> *"I don't receive any support, you know, the social workers were supposed to do a carer's plan but they have never done it, basically been given a couple of fact sheets and told to read them and just get on with it, like this is what's wrong with [X]."* (P11: Father)

Carers were disillusioned as they wanted and needed high-quality information about BPD itself, and had received little or none from the services treating the person with BPD:

> *"I haven't had any information on the condition – she was diagnosed with BPD after we were married, and no one talked me through or supported me through that and what to expect."* (P19: Husband)

In the absence of professional advice and information, many had sought knowledge from the internet or books. However, they were unsure how reliable this was, and some found it difficult to understand:

> *"There is so much information out there and it is hard to understand, and there's awful stigmatised and misinformation, it takes real effort to find good quality information, contemporary literature, and direction. There's a good book called 'Loving Someone with Borderline Personality Disorder'…and that's a really, really good book, I'd recommend it."* (P3: Partner)

Carer information groups hosted by professionals were also reported as unhelpful. Instead of being informative and supportive, these were expressed as feeling awkward and judging:

> *"We were invited to the Steps programme at the end as a group thing…they gave us the pamphlets about, you know, basic stuff about BPD and ran it through us, and it wasn't like it was a session for us, it*

was a session for them to tell us how to behave with people with BPD."
(P16: Mother)

Participants also highlighted their experiences of receiving social and emotional support. As previously discussed, informal support was significantly hampered as participants had a reduced social support network. What may have appeared strong was often superficial, or unhelpful for participants, therefore they were unable to use family or friends in the way they really needed:

> *"Family don't understand and think she just needs a bigfoot up the backside and if we try and challenge it on her behalf it doesn't go down well."* (P20: Aunt)

Conversely, several participants had been able to draw some support from family and friends. Where this was possible, they really valued their support and understanding:

> *"My husband, and thank god I've got him, I mean, he's got enough on his plate but it's like the two of us say, 'right, we'll get through this, it's a difficult time'."* (P10: Mother)

Where supportive counselling had been received this was also positively viewed. Participants said it helped them come to terms with the diagnosis, strong emotions such as guilt or sadness, deal with stress or anxiety, and develop coping mechanisms:

> *"I think that year of counselling helped me through the guilt, the sadness that I feel, I think I've got enough coping mechanisms now…, it's a free counselling service. I used them for a year and that was fantastic, really, really good."* (P8: Mother)

There was a mixed discussion about self-care activities. Despite participants looking for support and solutions, many struggled to describe any kind of regular programme of self-care for themselves. Those who did stress its' value:

> *"I go for a massage twice a month as part of my self-care, so without that, I would be severely struggling."* (P1: Sister)

> *...and having an outlet so I play rugby, see if I've had the most stressful day..."* (P5: Friend)

Some participants (less than half) reported being involved with carer support organisations which they highly praised and said offered invaluable help such as groups, respite care, advice about finances, or signposting to self-care activities:

> *"Carers support, they have been amazing, they put in place a community service, the financial plan for [sister] and that was the best thing ever because I was like 'right okay then I don't need to deal with that now."* (P15: Sister)

> *"So, I contacted Young [X] and explained the situation and how can I explain all this to my 11-year-old daughter, and they were fantastic, they were brilliant. I followed their advice and it's worked out really well."* (P8: Mother)

Significantly, carer support groups were only accessed by five participants most of whom found them very helpful and valued the support they received. These groups were for carers of people with SMI and none were specific to BPD. However, having someone to talk to who was understanding and non-judging led to friendships and social activities which reduced isolation:

> *"If I had problems with my daughter and if I'm all stressed out with it there's somebody in the group I can phone, and they'll listen, and they won't judge you and they understand what you're going through"* (P17: Mother)

> *"We have a great time at the groups, we go out for dinner or to the theatre…and we have these days trips, all of us on a bus and we go somewhere, and what a laugh we have, we act like kids… and forget about it all for a day."* (P6: Mother)

However, not all carers' groups were positive or what people felt they needed, emphasising the importance of the need to tailor interventions for people:

> *"So I did go to a couple of their meetings, it was a difficult one cause most of the people who went to that their family member had killed themselves, so although it was about self-harm it was mainly suicide survivors – for me, it is very little around."* (P15: Mother)

Overall, participants' experience of support for themselves highlighted an uncoordinated or standardised approach from statutory services, and although third sector carer support

organisations addressed the support needs of a few, most were not accessing these, and they were not available to give specific information about BPD.

4.7.2   What carers want from an intervention

Participants' experiences of support began to elicit where the most pressing gaps existed and as such, they identified two core areas that they would like an intervention to address, i) support for social and emotional self-care; and ii) information and education. This was vital information for the intervention design process and gave an early indication They also considered potential modes of delivery for an intervention. First and foremost, they wanted an intervention to bring hope and help them to see there is an end to the stress, the emotional toll on their lives, and a way forward for the future:

> *"The ability to feel that you are moving forward. Some hope that things aren't going to just stay the same."* (P20: Aunt)

Participants identified peer support as one of the best mechanisms to achieve self-care. They visualised this would mean being able to talk to, or learn from peers in a similar position and would help them receive necessary emotional and social support. They also believed connecting with other families would enable them to hear about shared experiences. All participants generally assumed that peer support would be delivered in a group forum and while some highlighted that everyone's experience is different, they felt they held a mutual understanding and could share problems and strategies for coping:

> *"Some of the best things you can learn are from peer support, and being in an environment with others who understand, being able to talk properly with people who understand because they've been through it, and okay their experience might be different but it's like anything if you can be with other people you can talk about the problems and the successes and you can think about things to try."* (P16: Mother)

Most participants reported they did not know anyone else in a similar position and this added to their isolation. Therefore, they perceived talking with others would reduce the stigma and isolation they often felt when they talked to people who had no understanding of their life:

> *"I'd hope just to be able to connect with others who understand so you're not feeling isolated and you're able to kind of share things you may not share with others without the shame."* (P12: Mother)

Another participant pertinently visualised an *"easy group"* for a meeting, talking, and sharing stories good and bad:

> *"I think if it was what I would call an easy group, where you could say, 'well I've experienced that, this is how we got past this' or 'this is what I think I might do in those circumstances, that I can see being helpful."*
> (P14: Father)

Points were also made with regards to the benefits of being able to talk with others who may be *"a wee bit further through it"* about how they cope and provide care:

> *"I think it would help to speak to other people who, are perhaps a wee bit further through it than we are and just to talk about their coping strategies. When they're in the middle of an episode, d'you know, how do they deal with it, how do they help their loved one to come out of it."* (P13: Mother)

> *"Strategies in how to deal with what we are dealing with, maybe a role-play situation I did this, that – that's where a support group would be useful someone to say oh, I'm having a crap day."* (P2: Wife)

As well as peer support participants suggested they could gain helpful insights by talking to someone with BPD themselves and hearing their experience. Most only knew their relative and had not met anyone else with the diagnosis:

> *"It would be good to find out what it is like to have BPD from the people who have it – so maybe some personal accounts of what it feels like to have BPD - everyone will be different but that's good too to hear how different they are."* (P4: Friend)

However, group peer support was not for everyone; two participants said they would not like this but would be happy to talk on a one to one with an *"advocate":*

> *" They offered me group support but I'm not the type of person that would go to a group, I don't want to sit and listen to other people's problems and I'd feel very vulnerable but I would want an advocate that I could maybe speak to say at the hospital."* (F8: Mother)

The second element participants expressed that would be essential to include in a future intervention was high-quality information and education. They believed this would enable them

to gain an understanding of BPD and learn how to support or take care of the person with BPD. Presently they perceived a lack of this which left them managing day-to-day life through trial and error. As a result, the emotional stress impacted their well-being and took a toll on their relationships more than they perceived necessary. At a fundamental level, they wanted to understand the prevalence and causes of BPD, recognise the range of difficulties that a person with BPD may have, and the treatment approaches available:

> *"Knowing what it is and what causes it, how it affects people and what treatments are there and what to expect if you have a BPD diagnosis – not the myths about it but the truth – how does it affect people."* (P4: Friend)

Several participants suggested a website (either new or recommended) tailored to families would help them understand BPD better:

> *"It would help to know why she behaves the way she did – I think it is because she has a lot of emotional pain, but we have never talked about it. It would be good if websites were recommended or information was tailored to families as this would help, perhaps a good website."* (P7: Daughter)

They also suggested peer-led digital resources (such as Apps, or podcasts) to hear from others in a similar position. This would enhance the opportunity to share their experiences of life:

> *"Podcasts with people with lived experience and hearing their stories – it's hoping that drives people at the end of the day. An app that could be built around taking people through the stages of how they might manage a situation."* (P20: Aunt)

Participants' suggestions for an intervention often focused on support for the person with BPD rather than themselves. They strategised that if they learned skills that would help the person with BPD then that would help them cope too. In this context they described receiving a form of vicarious help (something that helps carers to help the person with BPD) would reduce their stress:

> *"We want her to be the best she can be and have the best life. When she is upset and unstable, we all suffer and worry. Some education on*

> *coping strategies and how to help suicide thoughts and that kind of thing."* (P19: Partner)

Further strategies would include learning skills in how to set ground rules and adapt to their *"new normal":*

> *"We just feel our life isn't normal and I suppose finding ways of adapting to the new normal. I suppose it's just finding ways of accepting that this is how it's going to be and she might be with us for quite a few years more so that it's about, you know, putting down ground rules, we find ground rules are just kind of gone."* (P13: Mother)

Some participants (with this experience) suggested information should be age-appropriate, specifically for other family members, such as grandparents, siblings, and children, as well as the wider public:

> *"Different media for information for siblings because it was really difficult for [named children] I think …so I would say some sort of age-appropriate intervention for siblings would be really important and helpful. And maybe age-appropriate information for grannies. I think what I'm trying to say is that a range of interventions for a range of situations would be useful and something for schools, and workplace or something that people can understand."* (P10: Mother)

Several participants talked about the problems relating to stigma and wanted an intervention that would raise public awareness, improve understanding, and alleviate the stigma:

> *"I think a lot of the problems supporting someone with borderline is that there's a lot of misjudgements in the general public and having some form of knowledge can be good, but it depends on how it's portrayed and avoid stereotypes."* (P5: Friend)

Participants suggested the modes of delivery for these interventions would depend in part on individuals' preferences. Online, face to face, individual, or group work were all proposed, and the consensus was that "a bit of everything" would be suitable, with choices welcomed as the needs of carers varied from person to person and time to time:

> *"Probably a bit of everything so that you've got choices, sometimes you're just not in the mood to be talking with others when you've been struggling all day to have conversations, so it'd be nice even if there was something online or somebody that you could just talk to in similar positions."* (P17: Mother)

Some suggested an education course or study afternoon format:

> *"If we could find out more that would be great. We have said if something was being run that was like a course or a study information afternoon or anything like that, we would both come along to that."* (P13: Mother)

As indicated at the outset not all participants wanted or needed the same from a supportive intervention, and many recognised the difference in both individual and collective needs. Given their own experience, they knew that their support needs were dynamic and varied over time. Therefore, a *"menu"* of what was available and how it may help could offer participants comprehensive information when needed:

> *"Clear signposting to 'this is what's available and this is how it may help you because there might be things that some people do and don't need but, you know, almost like a menu."* (P3: Partner)

In summary, this theme presented one of the key findings of the study which was 'Carers are people who need support too'. The strength of this claim cannot be underestimated due to the extent of the carers' experiences presented in the earlier themes and their lived experience of current support provision. Key areas for intervention development were the need for a peer network for mutual support, self-care, and an opportunity for healing, also information and education about BPD, strategies, and guidance on how to support someone with BPD.

4.8   Chapter summary

This chapter presented the findings relating to the experiences of carers supporting a person with BPD, as well as the support they require and would find helpful from an intervention. Four overarching themes were identified: 'Trauma by association' revealed participants' lived experience of caring for a person with BPD which was expressed in terms such as *"living in a nightmare"*. Key aspects of concern were coping with sudden mood changes, dealing with self-harm or suicidality, and aggressive or violent behaviour. The impact of caregiving was

evident through participants' accounts of traumatic stress and vicarious trauma, including a negative perception of their life and the future. Underpinning their stress and trauma was a sense of being failed by the healthcare system. This was from diagnosis and poor access to care for the person with BPD, to stigmatising and negative attitudes from professionals, and receiving poor support or guidance for themselves.

The second finding showed multiple factors influencing the 'social and emotional isolation' carers experienced. These include changes in the quality and nature of their relationship with the person with BPD and withdrawing from family, friends, or communities due to issues such as overwhelming stress, stigma, and negative or judgemental responses. The third finding indicated that participants moved into a 'beyond coping' phase where they proactively strategised about how they were going to live and cope with the complex demands and enduring crises. Learning from experience; distancing themselves; taking time away from caring; and trying to make sense of the cause were common features of self-preservation. Participants also found ways to provide long-term care or support and often developed individualised strategies and skills with varying success. The fourth finding was that participants were heavily invested in supporting the person with BPD, emotionally and practically, but received very little in terms of support for themselves. Most had not received any support formally from services, and where they had, it had not met their needs in many cases.

An important finding of this study was participants felt they needed more support and welcomed the prospect of a supportive intervention tailored to their needs. They suggested the key elements for an intervention to focus on would include receiving social and emotional support and self-care through a support network of peers with similar lived experiences; education and information concerning BPD, strategies to support the person with BPD in crises; and raising public awareness of BPD to reduce the stigma. In particular, they wanted an intervention to signpost them to carer support opportunities. The next chapter will present the methods used to design the supportive intervention and will include details of the core components and underpinning theories adopted within the design.

Chapter Five: Designing the intervention

5.1 INTRODUCTION

The study aimed to design a theoretically informed and evidence-based public health intervention to reduce the negative impact on emotional wellbeing that carers experience supporting a person with BPD. This chapter describes the methods of how the intervention was co-designed, giving details of the intervention development frameworks chosen and how they were used. An overview of how a stakeholder group was involved and findings from focus groups will be presented, as well as a description of the resultant structure and design of the intervention, including core components, underpinning theories, and principles.

5.2 Methods and design

A public health intervention is a series of planned actions designed to prevent or reduce a health problem or the determinants of a defined problem in an identified population (Funnell and Rogers 2011). Stakeholders were central to this study. Evidence suggests that interventions are most likely to succeed when developed through collaborations with practitioners, researchers, policymakers, and the people who are affected (Croot 2019). This would maximise the fit of the intervention with the identified populations' perceived needs, increasing the acceptability and potential adoption by practitioners and policymakers (Wight et al. 2015). Given the complexity of carers' needs and experiences, a complex intervention was deemed appropriate. Therefore, relevant aspects of the Medical Research Council's [MRC] (2021) guidance for developing and evaluating complex interventions were followed. These included: identifying skills and behaviours required to deliver the intervention; identifying a range of possible outcomes; including flexibility in the design for tailoring; making use of the evidence base and appropriate theories; and having a good theoretical understanding of how the intervention causes change, to identify and strengthen any weakness in the causal chain (MRC 2021).

Several intervention design frameworks may have suited this study. For example, intervention mapping by Bartholomew et al. (2016) was used in similar recent studies (e.g. Louijmans 2011; Bryd 2012; Taylor 2013; Hall 2017). However, according to Mol et al. (2017), the disadvantages of this method are that it is detailed, time-consuming (Mole et al. 2017), and requires extensive training and knowledge of behaviour change theories (Hurley et al. 2016, McEachen et al. 2008). Others, such as the PROCEED/ PRECEDE model (Green and

Kreuter 1999; Phillips and Davidson 2012) take a socioecological approach, yet critics find it gives little practical information on how to design the intervention and very detailed technical instructions which may not be feasible or require great skill, time and money (Philips and Rolley 2012). The Six Essential Steps for Quality Intervention Development (6SQuID) has been used in several recent studies (Pringle et al. 2018; Hartley et al. 2018; Hubbard et al. 2020) and is considered a straightforward, practical approach to intervention development (Wight et al. 2015) with processes reflecting the MRC (2019) good practice guidance. This approach was considered achievable and useful; therefore it was adopted for this study.

The Six Essential Steps for Quality Intervention Development (6SQuID) developed by Wight et al. (2016) is a pragmatic and evidence-based six-step framework for intervention development to assist public health practitioners and researchers. The six crucial steps provide a useful guide to determining how best to develop interventions and maximise effectiveness. Each step can be applied within the process of development using an iterative process combining existing literature and evidence alongside new data collected to i) define and understand the problem and its causes; ii) identify which causal or contextual factors are modifiable: which have the greatest scope for change and who would benefit most; iii) identify how to bring about change: the change mechanism; iv) identify how to deliver the change mechanism; v) test and refine on a small scale; vi) collect sufficient evidence of effectiveness to proceed to a rigorous evaluation.

5.3   Designing the intervention

The first four steps of 6SQuID (Wight et al. 2016), were employed in the process of designing the proposed intervention. Steps five and six were not carried out as part of this thesis as these would require further funding to test on a small scale (step five) before proceeding to a more rigorous evaluation (step six), therefore these will take place as part of any subsequent work. Step one aimed to define and understand the problem and its causes; step two clarified which causal or contextual factors were malleable and had the greatest scope for change; step three identified how to bring about change: the change mechanism; and step four identified how to deliver the change mechanism. The framework and how it was applied in this study are summarised below in Table 17. Each step of the process is linked to and informed by the next step and often involved moving back and forth across all four.

Table 16: Summary of the 6SQuID framework

Six main steps in quality intervention development	Research methods that apply to each step
1. Define and understand the problem and its causes	Literature reviews, interviews with carers
2. Clarify which causal or contextual factors are malleable and have the greatest scope for change	
3. Identify how to bring about the change: change mechanism	Interviews, stakeholder focus groups, and consultations
4. Identify how to deliver the change mechanism	
5. Test and refine on a small scale	Steps five and six will be taken forward as part of subsequent work
6. Collect sufficient evidence of effectiveness to proceed to rigorous evaluation	

5.4   Step one: define and understand the problem and its causes

The first step was to understand and clarify the problems and their causes with stakeholders using existing research evidence. As discussed in Chapter One, a systematic literature review by Lamont and Dickens (2019) of carers' experiences indicated that carers encounter emotional stress, and financial burdens and face significant challenges in coping with their relative's difficulties. It also identified the life-changing nature of being a carer, the perceived absence of understanding about their role, with many carers not aware of any support available for themselves. Difficulties for carers included accessing information about BPD, navigating the mental health system, and locating treatment for their relatives. The review also revealed the negative attitudes and stigma experienced by families, as well guilt about feeling responsible for the person developing BPD (particularly in parents). One study (McMahon and Lawn 2011) suggested that specialist carer support with distinctive information and education was needed.

Although the review (Lamont and Dickens 2019) found several problem areas concerning carers, it was recognised that the evidence was limited. Therefore, a qualitative study using semi-structured interviews with 20 carers was conducted to explore their experiences,

alongside defining, and understanding the problems and their underlying causes. In addition, their needs, and preferences for the components of a supportive intervention were explored. This revealed four conceptual themes reflecting the core experiences and needs of carers: i) Trauma by association; ii) Social and emotional isolation; ii) Beyond coping, and iii) Carers are people who need support too. These are presented in detail in Chapter Four: Findings.

Wight et al. (2016) proposed that understanding what shapes and perpetuates the problem makes it possible to identify ways to intervene. Further, evidence indicates that successful interventions are associated with understanding health behaviours within the social contexts in which they occur (Glanz et al. 2002). The socioecological model was used to tailor individual carer health concerns and problems across multi-level influences on health behaviour. Five important elements classified by McLeroy et al. (1988) were considered. These were: individual, interpersonal, institutional, community, and policy levels. Four levels of the socioecological model were identified when compared with the study findings. These included:

- **Individual-level:** carers found living with their relatives' emotional distress, and frequent crisis events such as self-harm, suicidality, suicide attempts, violence, and aggression very stressful and distressing. Coupled with having little knowledge about BPD or skills to support their relative this contributed to a negative experience of the carer role and loss of hope that life would ever get better. Carers' mental health, such as depression and anxiety, as well as features of vicarious trauma were often affected by the unpredictable and difficult lives they lived.

- **Interpersonal-level:** The persistent emotional instability, distress, and impulsive behaviour expressed by the person with BPD negatively impacted the quality and nature of the relationship carers had with them, as well as family and friends. These were often strained relationships, and carers perceived others had a poor understanding of the problems they were facing within families and friendship groups. As a result, they were often socially and emotionally isolated having either distanced themselves or been distanced from others; therefore, they had poor informal support networks. Additionally, carers often had little or no formal support from health services and little awareness of what carer organisations offer.

- **Community-level:** Carers perceived poor public awareness of BPD reinforced by the problems raised at an interpersonal level and therefore the gravitas of their problems was unknown by most. The negative stigma about mental illness is well documented

but this seems to be particularly evident with BPD, resulting in carers feeling stigmatised, guilty, and shame by association.

- **Institutional-level:** The study highlighted that carers perceived flaws and failures in the healthcare systems with delayed diagnosis, poor or lacking care for their relative, and a lack of information on care/support for themselves.   There were limited partnerships between carer support organisations and statutory health services, and few protocols for carers to be guided to or referred for support by these services. Further, carers found there were limitations and barriers to their relatives receiving sufficient support or crisis responses from healthcare professionals or services. Often this left the burden of crisis support and the fear of death or responsibility for their life on them. Incongruent to this, the study found there were further barriers to carers being given information or involved in relatives' care. These are summarised graphically in Figure 6 below.

Figure 7: Socioecological model of carers' experiences
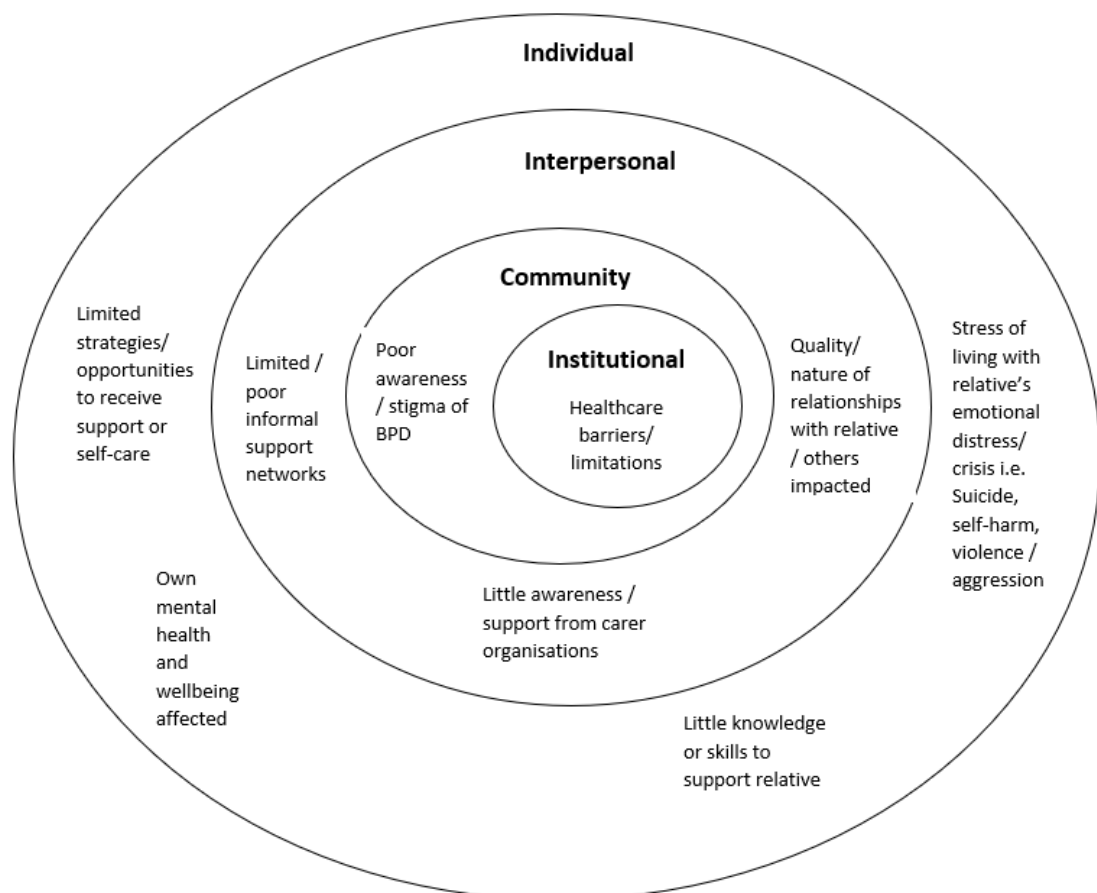
5.5   Step two: Clarify causal or contextual factors that are malleable and have greatest scope for change

The next step was to identify which of the causal or contextual factors that shaped the problems were malleable and had the greatest scope to be changed through intervention (Wight et al. 2016). Evidence suggests that interventions designed to help with individual or interpersonal factors are more malleable to change and can have a large population impact if applied broadly. Whereas structural factors, (community and institutional), require less individual effort and have the greatest population impact but can take longer to achieve requiring whole systems or policy change (Frieden 2010).

According to Wight et al. (2016) being aware of the relevant interventions that currently exist, their design, efficacy, and acceptability were important, alongside the justification for why a new intervention was needed. Recent literature reviews examining supportive interventions for carers of individuals with SMI have detailed a range of psychoeducation and ehealth approaches, which have benefits (Yusuf-Udechuku et al. 2015; Sin et al. 2017; Sin et al. 2018). However, only one small review (Bailey & Grenyer 2013) included carers of people with BPD. Therefore, a further review, presented in Chapter Two systematically appraised and synthesised the interventions available to support carers of people with SMI inclusive of BPD. This review included 19 studies published in the last seven years and found positive outcomes for carers post-intervention regardless of theoretical frameworks, delivery style, and specific conditions. All interventions were psychoeducational and targeted a range of areas such as improving mental health and wellbeing, caregiver experience, knowledge, social support, and also reducing psychological distress, depression, anxiety, and burden. A variety of theoretical and delivery modes were utilised with manualised group interventions most common. The evidence relating to BPD was limited to only six studies (Bailey 2014; Bateman and Fonagy 2018; Flynn et al. 2017; Grenyer et al. 2018; Miller 2013; Pearce et al. 2017). Therefore, the qualitative study with carers presented in Chapter Three was conducted to enhance and add to this evidence.

Using the findings from the qualitative study and the socioecological model, seven causal factors at 'individual' and 'interpersonal' levels were identified, considered to be modifiable, and with the greatest scope to change from an intervention. These were:

- Experiencing the stress of living with a person with BPD's distress, and crisis
- Mental health affected / traumatic stress and related vicarious trauma features
- Negatively impacted quality and nature of relationships

- Little knowledge or skills to support the person with BPD
- Limited or poor support networks
- Limited strategies/opportunities to receive support or self-care
- Little awareness of / or support from carer support organisations

The data also reflected problems at community and institutional levels relating to stigma, limited public awareness, as well as healthcare barriers and limitations. However, few solutions were identified concerning this during the study and would require wider community and institutional stakeholder support.

5.6   Step three: Identify how to bring about change; the change mechanism

With the most modifiable causal factors identified, the next step was to identify the desired outcomes and articulate the underpinning theories, active ingredients, or outputs that an intervention should contain. This in turn articulated the change mechanisms (the process or activities responsible for the therapeutic outcome) (Wight et al. 2016; Hubbard et al. 2020).

To enable this, four focus groups were held via Microsoft Teams to bring together stakeholders to advise on and co-design the intervention. These involved 14 participants, comprising three groups of four and one group of two as detailed in Table 18 below. Care was taken to create a balance between family and professionals, and manage the dynamics of the group to support different perspectives (Holloway and Wheeler 2016).

Table 17: Focus group participants

Stakeholders	Number participated
Statutory mental health and social care professionals	4
Third sector mental health and carer support practitioners	3
Family and friends from the interview study	7 (5 parents, 1 partner, 2 friends)

Each focus group received a short presentation by the researcher at the outset informing them of the scope and purpose of the group and the findings of the carers' qualitative study. This detailed the problems identified by carers and their initial suggestions for the content of a supportive intervention. Following this, using the Focus Group Topic Guide (Appendix 15) participants were asked to reflect upon the findings and discuss:

- What would a resource or intervention look like?
- What would be the key issues for the resource to address?
- What would it include? What would the format be? How would you like it delivered?
- What should the individual components (content, theory stance) of the intervention be?
- How should the intervention be implemented (e.g. duration, frequency, and delivery of each component?)

Group discussions and activities were noted using the online whiteboard tool and the discussion/chat area within Microsoft Teams. The researcher/facilitator encouraged discussions to remain focused on the study aims, and objectives and covered topics related to key findings from the carers' interview study. Thematic analysis of the focus group transcripts enabled themes to emerge (Spencer and Ritchie 1994). These related to potential intervention content and modes of delivery but also allowed for the identification of theoretical frameworks to underpin the proposed intervention (for example, DBT, peer support, eHealth). The focus groups were iterative, meaning that each one built on the previous, the ideas and views generated were collated thematically and added to the information presented at the start of the next focus group until all four were completed (Mason 2018). The findings from the interview study and the socioecological model presented previously (Figure 7) created the basis for thematic analysis (Spencer and Ritchie 2014) of the data gathered in the focus groups. As the intervention components emerged, drafts were sent by email to the stakeholder advisory group for further comment and redrafting (See Appendix 19 for an example of this process).

5.6.1 Findings from stakeholder advisory focus groups

The stakeholder advisory focus group data identified two key issues for an intervention to address. These were information and education, and social and emotional support. The outputs or active ingredients associated with achieving these were: an educational website; skills workshops; and peer support.

5.6.2 Educational website

Stakeholders suggested an educational website with several key features would support them to receive information and education about BPD, and ultimately cope better with the caregiving experience. This would include information about BPD, how to support a person with BPD, and guidance on the role of a carer:

> *"Guidance to recognise the roles and responsibilities of being a family member, what you can do and what you can't do."* (Focus Group 1)

> *"Education is the way forward and the more we know about it the better equipped we are to cope with it."* (Focus Group 3)

Stakeholders made suggestions of what a website should include. They suggested high-quality information about the causes, features, and care/treatment options. This would reduce the misinformation and ensure credible sources were used, as well creating an opportunity to gain a better understanding of the condition in a way that would be useful for families and friends:

> *"Providing information to families about BPD, what it means, how it is thought to arise and educational issues… high-quality information, or even signposting to credible sources of information is important."* (Focus Group 1)

Tips on how to minimise a crisis were also requested:

> *"I also think of what not to do – almost a prevention – how not to wind someone up who has BPD in your day-to-day."* (Focus Group 4)

Carers also suggested a website that could explain the pathway of care and what to expect for their loved ones. This would enable them, in turn, to understand better how they fitted into that with regards to giving day-to-day support:

> *"So, if you are at square one and we are trying to get to square 100 which is a happy healthy independent adult – is that realistic and if so, what does square five look like and how can we support it… I could be doing things that are negative and counterproductive because I don't know what I am doing."* (Focus Group 2)

Another popular educational proposal combined learning with peer-led resources, such as developing video case studies that could be populated onto the website:

> *"SAMH has good resources about young people talking about their mental health… something makes you think there is value in fighting this fight so whether it is a video resource but if we could get someone to put their face to it and say these are the challenges I am facing and here is how I cope. "* (Focus Group 3)

Using short film animations was also proposed to enhance the educational aspects of online learning and skills development for carers:

> *"I could visualise short animations/videos – in times of crisis-this is what you can do. A lot of content can be produced in an animation relatively easy and that would be a good starting point."* (Focus Group 4)

Two organisations offering carer support were keen to be involved in a future intervention and identified how carers might be identified and reached. They described this can be difficult and posed some solutions. These included linking the intervention with their hospital link worker, educating clinical professionals on the availability of support, signposting to the website via a leaflet, and using the new website to promote what is available for carers and how to access this:

> *"A lot of people don't self-identify as a carer and know they are entitled to support, so maybe we need to go back to basics with our hospital link worker and once the cared for is identified, giving the family a leaflet about carer support or the website and how they can access it. It's about educating the professionals that carer support is there, and they can access it – and give the leaflet/resource."* (Focus Group 3)

> *"An informative website dedicated to families of people with BPD would be good, from a carers support organisation perspective we could link into this and promote what is available for families across the country and how they might access this."* (Focus Group 2)

Stakeholders from carer support organisations also requested education and information relating to BPD, acknowledging it would support them in their role. They were keen to learn to provide the best support, and highlighted a lack of training opportunities:

> *"For us to give the best support we can to carers my team also needs to have that knowledge and awareness and I think that's something that's lacking and there is a lack of training opportunities for staff and lack of support for carers."* (Focus Group 2)

Carer support organisations also recognised that some support for carers may be too complex for them to provide, such as what to do in a crisis, but were happy to signpost onto specific resources or guidance such as an informative website:

> *"What to do when a person is in crisis - That might be the kind of thing as a carer service we might struggle with and need to signpost onto and rely on a resource or website and then we could use it."* (Focus Group 2)

5.6.3   Skills course

Carers were keen to learn skills and strategies in how to respond to their relatives'/ friends' distress or crises and learn how to minimise risk. The study found these were a regular occurrence and source of traumatic stress and vicarious trauma for carers. The preferred modes for learning these were via a tailored website or skills group/course. It was suggested there could be some overlap in what was offered via a website or skills course, and one could support the other in a blended learning format:

> *"Online website or a face to face course, it would be good for the website to correspond with what we've learned on the course so we can refresh ourselves at home when we need it and read a bit more about it after the course has finished."* (Focus Group 3)

Stakeholders (carers and professionals) in several focus groups proposed learning practical skills and tools for emotion regulation, calming, and validation. Some suggested these be drawn from the theories of DBT and would be useful for the carer's own self-regulation in crises, and for using to support the person's BPD. Two carers recommended a book by Shari Manning called 'Loving Someone with BPD', which is underpinned by DBT. Participants advocated that strategies from this could be summarised into a framework to be used by carers in times of stress and distress:

> *"A framework can also be really useful because when any of us are distressed our ability to think reduces and it can help us maintain a useful way of going about something when someone we care about is in a state of high distress. The book 'Loving Someone with BPD' provides a very useful synthesis of approaches for support.* (Focus Group 1)

Similarly, a professional stakeholder recognised it is distressing living with someone who is often distressed, and also proposed the intervention include skills to support developing carers' emotional resources and self-regulation for these difficult situations:

> *"It is distressing living with someone who is in distress all the time and I think to be a benefit to the person, the family member has to be as regulated themselves as possible. So, if you have got someone in a state of high distress it is distressing but before you can help that person it is important that you can lower your levels of distress and regulate yourself. So, it's important to provide skills to support families in these difficult situations to keep themselves regulated in these testing situations."* (Focus Group 1)

In support, one stakeholder highlighted the value of using these skills in stressful moments:

> *"I've learned to try and keep calm. I used to panic and think where this will all lead whereas now, I do think just talking and sharing and trying, to be honest, is best."* (Focus Group 4)

A professional stakeholder also suggested it would be useful for carers and the person with BPD to develop a crisis self-management plan so they could plan together in advance what the person would like in terms of support from the carer. This could include early warning signs of a crisis occurring, and strategies for both the person with BPD and the carer to employ during emotional distress or crisis:

> *"Helping people keep a crisis self-management plan, a plan they do in the cold light of day to support them when they are emotionally intense. So, plan, how do I know when I am entering a crisis? How do I know or become emotionally intense? What can I do that's helpful? What do I do that's not helpful, what do others do that's not helpful? Who can I call? what skills can I use?"* (Focus Group 1)

Carers also proposed something similar and agreed that a plan of what to do in a crisis would be helpful, as well as skills to defuse the person with BPD's anxiety and emotional distress which was referred to by one carer as a *"toolset of calm"*:

> *"A toolset of calm which can diffuse a crisis as it is rising, and the other side of what not to do. A plan – a structured approach for crises."* (Focus Group 4)

> *"For me, it's how to deal with a crisis and what the overall plan is – we know you will encounter these flash fires but we have a strategy for that but you also know what you're trying to do to make sure the fire doesn't ignite in the future. If that's done with us supporting another family."* (Focus Group 2)

5.6.4   Peer support

Concerning achieving social and emotional support carers identified that an intervention that enabled them to talk to or learn from peers in a similar position was a key priority. They considered this would reduce stress, and social and emotional isolation, improve emotional and social wellbeing, bringing a much-needed self-care element. Carers offered a range of possible mechanisms for receiving peer support such as a group, one to one connections, and digital resources via the website:

> *"It can be hard for people to share and empathise from a carers point of view but in a facilitated support group that would be very helpful."* (Focus Group 4)

Some already received peer support through a carers group and confirmed its value:

> *"Being able to get peer support is the thing that's done the most for me."* (Focus Group 2)

Others visualised the benefits of a support network of people in the same position as them who can understand and relate to exactly what they are experiencing:

> *"Some form of a support network of people who are in the same position as us – not necessarily professional carers but other parents of someone with BPD who can understand and relate to exactly what you are experiencing and going through."* (Focus Group 1)

It was expected that peer support would enable carers to share strategies and coping skills. They believed this would reduce their stress and improve emotional and social wellbeing by increasing their informal support networks, knowledge, and skills to support their relatives. Over time, they considered this would improve their overall mental health, as well as the quality and nature of their relationships:

> *"Shared experience - it becomes less stressful when someone says, 'Yes, I have been through that, I know what you mean'."* And being

> *able to talk together about strategies, as it can be hard to learn so I'd*
> *like to find out what other people find useful."* (Focus Group 3)

Connecting with peers would also enable carers to give and receive support and understanding by validating what they do. They believed this would build self-efficacy in their role as a carer and reduce the loneliness and isolation they feel:

> *"That would help people from the loneliness perspective because the*
> *loneliness aspect is very specific, it is 'who knows I've got this*
> *experience?'."* (Focus Group 4)

> *"We need to let family and friends know that they are doing a good job*
> *and that they are not on their own…because the person who has a*
> *diagnosis has the support from services."* (Focus Group 3)

Carers also suggested peer support would enable them to meet people whose relatives may have made progress (or even recovery) and therefore bring hope or useful advice:

> *"We don't know what is realistic to expect for our daughter's recovery*
> *so it would be good to hear from others who have not even necessarily*
> *recovered but have made progress."* (Focus Group 2)

The focus groups believed that a peer support intervention would encompass social self-care activities over and above giving and receiving emotional support. Carers acknowledged that they had limited opportunities for social self-care such as going on day trips, or out for meals due to withdrawing from other family and friends in their day-to-day life:

> *"Sharing self-care socialising activities that can nurture our wellbeing."*
> (Focus Group 1)

The name of the intervention emerged during the focus groups. Participants often used the words *"Calm"* and *"Connected"* or similar variations to describe what they wanted and needed. However, the name itself was finally derived from one carer who said:

> *"An intervention which can calm and connect people would be good."*
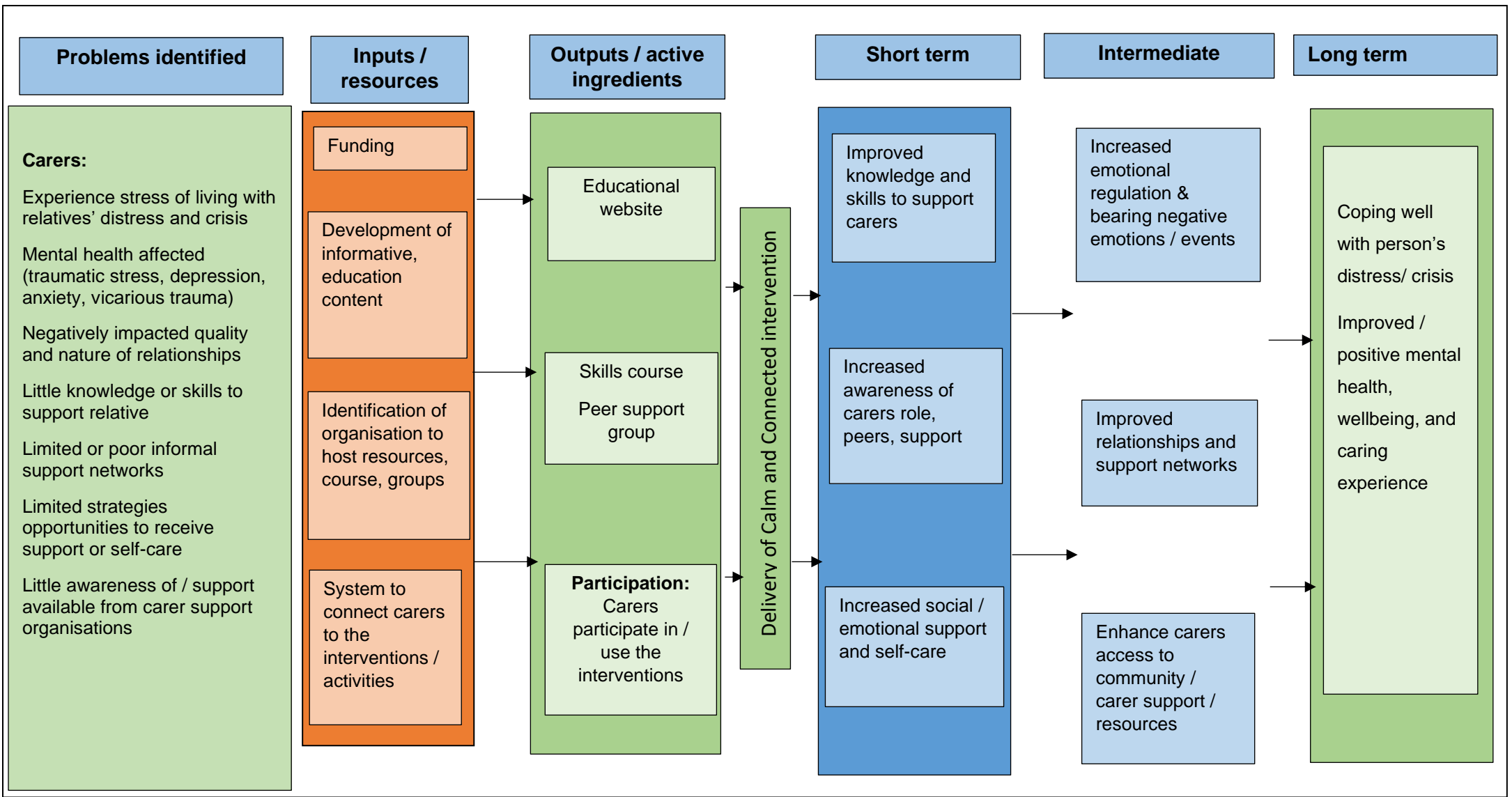> (Focus group 4)

In summary, analysis of the focus group data supported the identification of how to bring about the desired changes; this was the change mechanism. In turn, this assisted the next step of intervention design, which entailed identifying how to deliver the change mechanism (Wight et al. 2016).

5.7   Step four: Identify how to deliver the change mechanism

Having identified the change mechanisms, step four involved creating a Logic Model which is a graphic representing a Theory of Change about how the intervention will work to deliver the change in a real-world environment (MRC 2021). The design of logic models varies however, they commonly summarise an interventions' inputs or resources, implementation or outputs, outcomes, context, and the relationships between them (Funnell and Rogers 2011). In this study, the Logic Model used a forward mapping approach where the problems identified from the literature, qualitative study, and the socioecological framework (McLeroy et al. 1988) were discussed in the focus groups of stakeholders. This enabled the co-design of the inputs (resources) required, the outputs (active ingredients), and outcomes, therefore, creating the Theory of Change (Bartholomew Eldredge et al. 2016). This method showed step by step why the activities planned should achieve the aims, forming the basis for further refining, and evaluation of the intervention (De Silva et al. 2014; Breuer et al. 2016). The graphic illustration is detailed in Figure 7 below.

Figure 8: A Logic Model for an intervention to support carers of people with BPD

Problems identified	Inputs / resources	Outputs / active ingredients	Short term	Intermediate	Long term
Carers: Experience stress of living with relatives' distress and crisis; Mental health affected (traumatic stress, depression, anxiety, vicarious trauma); Negatively impacted quality and nature of relationships; Little knowledge or skills to support relative; Limited or poor informal support networks; Limited strategies opportunities to receive support or self-care; Little awareness of / support available from carer support organisations	Funding; Development of informative, education content; Identification of organisation to host resources, course, groups; System to connect carers to the interventions / activities	Educational website; Skills course; Peer support group; **Participation:** Carers participate in / use the interventions	Improved knowledge and skills to support carers; Increased awareness of carers role, peers, support; Increased social / emotional support and self-care	Increased emotional regulation & bearing negative emotions / events; Improved relationships and support networks; Enhance carers access to community / carer support / resources	Coping well with person's distress/ crisis; Improved / positive mental health, wellbeing, and caring experience

Delivery of Calm and Connected intervention

Assumptions: continued funding, effective referral system, staffing

External factors: Resources, changes in provision of carer support

Informed by Funnell & Rogers (2011), Socio-ecological framework, McLeroy et al., (1988)

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During the creation of the Logic Model, contextual factors malleable to change were mapped from the socioecological framework (McLeroy et al. 1988). From here the focus group data identified two important change mechanisms relating to the problems. These were i) social and emotional support; and ii) education and information. Several intervention components (outputs) could have delivered this however the stakeholder group advised their preference to be an educational website, skills course, and peer support, group. Carers also identified through the interview and focus groups data that issues they wanted to be addressed were the stress of coping with their relatives' distress and crises and improved mental health and caregiving experience. The table below presents a summary of the 6SQuID steps and identified change mechanisms relating to the proposed intervention.

Table 18: Summary mapping 6SQuID process of design and Theory of Change

Step 2 ⟶ Factors malleable to change	Step 3 ⟶ Change mechanism	Step 4 ⟶ Intervention identified	Outcomes
The stress of living with distress and crisis	Social and emotional support Education and information	Peer support group Skills course	Coping well with a person's distress/ crisis
Mental health affected, such as depression, anxiety, vicarious trauma	Social and emotional support	Peer support group Skills course	Improved / positive mental health, wellbeing, and caring experience
Negatively impacted quality and nature of relationships	Social and emotional support Education and information	Peer support Skills course	
Little knowledge or skills to support relative	Education and information	Educational website Skills course	
Limited or poor informal support networks	Social and emotional support	Peer support group	
Limited strategies/opportunities to receive support or self-care	Education and information Social and emotional support	Educational website Peer support group	
Little awareness of / support from carer support organisations	Education and information	Educational website	

5.7.1   Review of the first protocol for an intervention

Having identified the change mechanisms, and how to deliver them it was further necessary to involve the stakeholders with their relevant lived experience and expertise to co-develop the implementation plan. This was achieved by drafting a first protocol of the intervention based on their suggestions in the focus groups, using the TIDier framework to structure the implementation plan (Hoffman et al. 2014). Thereafter, draft protocols were circulated by email to focus group stakeholders who made further suggestions and provided clarity with regards to the content, design, and delivery as well as acceptability:

> *"The website is a good way of getting information out to people and I like that the model expands to cover some face-to-face peer support for carers. Would you consider a private chat room forum within the website for families to connect?"* (Participant from Focus Group 4)

> *"The peer support group and website information really appeal to me. The skills course would be useful for my family and I too and something we would use."* (Participant from Focus Group 3)

One carer participant added to the Control, Ask, Lower, Move forward (CALM) framework which was developed in response to suggestions from the focus groups (see Appendix 19 for excerpt). By using his lived experience, he was able to propose a cooling down period instead of forcing problem-solving during times of extreme pressure or intensity:

> *"The usefulness of a cooling down period is very valuable and I think would benefit from emphasis, i.e. sometimes leaving the person to cool down benefits the situation greatly, trying to force problem-solving and brainstorming when the carers feel distressed or under pressure can be counterproductive."* (Participant from Focus Group 4)

There were three drafts of the implementation plan until the final version was settled upon. Below will detail the finalised intervention implementation plan.

5.8 Intervention implementation plan

A widely used template for intervention description and replication (TIDier) was adapted to present the key components of the intervention and offer clarity to the conditions, resources, and expertise that would be necessary to include (Wight et al. 2016). TIDier is a 12-point checklist, however, for this study, the first seven points were relevant and used (Hoffman 2014) (see sections 5.8.1-5.8.7 below). Evidence suggests using this guideline is good practice for improving completeness in the development and reporting of health research (Hoffman 2014; Cotterill et al. 2016; National Institute for Health Research 2017). The implementation plan using the first seven steps of TIDier (Hoffman 2014) will now be described.

5.8.1 Intervention name: Calm and Connected

Calm and Connected is an intervention aimed to support carers of people with BPD, restoring calm, connecting people, educational resources, and support.

5.8.2 Rationale, theory, and goals of essential elements

This study has reaffirmed that supporting a person with BPD can be stressful and distressing, often having a significant impact on the social and emotional well-being and lives of carers. Evidence suggests supportive interventions such as education, information, peer support, and skills courses can help build knowledge and skills to cope, manage, and improve social and emotional support (Chapter Two). The qualitative carers study (Chapter Four) found that carers were keen to have access to interventions that would support their carer role. However, the availability of these is few and far between with nothing currently available in Scotland.

The Calm and Connected intervention aims to reduce the stress, burden, and negative impact carers experience, ultimately improving their quality of life. The carers and professional stakeholders identified the elements essential to the intervention were:

- BPD specific supportive resources
- Education and information, to build knowledge and skills on how to positively support their relatives and themselves

- Social and emotional support - connecting people to peers and a support network of people in a similar position
- Educational website resources with high-quality information, animations, and films
- Skills courses or workshops
- Leaflet with fundamental information and signposting to the intervention for referrers

Therefore, Calm and Connected comprises three components:

- An educational website
- Skills course
- Peer support group

The Calm and Connected Theory of Change was created using a forward mapping method of 'IF – THEN' statements which described the logical connections between the concepts identified (Funnell and Rogers 2011). These were:

- IF carers' traumatic stress and vicarious trauma, are caused by persistent traumatic crises, sudden changes in moods, and behaviour by the person with BPD; little knowledge, or skills to support them; negatively impacted relationships, social and emotional isolation, poor support networks; limited opportunities to receive support or self-care, and little awareness or support from carer support organisations.
- THEN gaining knowledge, skills, social and emotional support from peers, organisations, and evidence-based courses will help solve these problems.

This is on the basis that when carers learn new knowledge, skills, and receive support these will translate into reduced traumatic stress, burden, vicarious trauma, and increased emotional regulation, the ability to bear negative emotions or events, improved relationships, support networks, and increase carers access to community/carer support. In the long term, this will lead to enhanced resilience and coping, positive mental health, wellbeing, and caring experience. In summary, managing the traumatic stress and burden of caring using supportive, helpful approaches will lead to more positive social and emotional outcomes, and improved quality of life, shown in Figure 8 below.

Figure 9: Calm and Connected intervention process
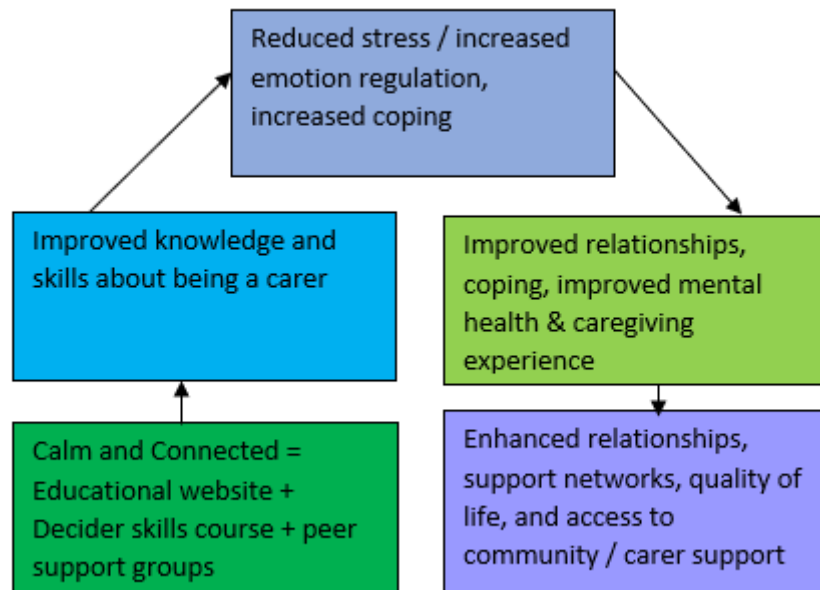
5.8.3 Intervention component one: The educational website

To deliver Calm and Connected, firstly a bespoke website will be designed based on the education and information components that stakeholders identified as necessary. These are summarised below:

- Information and education about BPD, causes, features, care options, treatment, and lived experience
- Education about the value of self-care, wellbeing, and information about resources available to access resilience opportunities
- Information about stress management and emotion regulation skills
- Educational tools for calming both self and person with BPD
- Guidance on how to validate self and distressed relative
- Educational skills and strategies in how to respond to mental health crises (suicide, self-harm, aggression) / develop crisis/ safety plans
- Strategies on how to minimise risk and reduce the likelihood of a mental health crisis
- Information about being a carer, carer support organisations available, carers legislation and rights
- Recommendations about how to navigate the healthcare system in Scotland, access support and treatment for the person when required

The website will be developed using current evidence-based DBT resources including Linehan's (2015), DBT Skills Training Manual, Sharri Manning's 'Loving Someone with Borderline Personality Disorder' (2011), and the Decider skills (Ayres and Vivyan 2019). Carer support information and resources will be sourced from the Carers Trust (2013); Carers Scotland Act (2018); Carers Charter (2018); NICE 2020; Scottish Government 2021). Additionally, the National Network of Carer Centres Managers, Scotland will provide details of organisations and resources which could be included on a website with support relevant to Scotland. A member of this network is part of the study stakeholder/advisory group and will support the sourcing of suitable information. The theoretical position and content of these resources align with the learning needs suggested by carers and professional stakeholders. The CALM model is shown in Figure 9 below details an example of how the website will offer carers education on how to respond to a mental health crisis, emotion regulation, and tools for calming.

Figure 10: CALM Model (Adapted from Manning 2011)

Control your response

It is distressing supporting someone in distress so regulating your own emotions is important. Pause, take a breath and notice your physical sensations, label them as the emotion you are experiencing; pay attention to your body posture, unclench your hands, relax the muscles on your face, relax other muscles; send calming messages to your brain; validate and soothe ('my emotions are understandable).

Ask/Assess the situation

Ask gently what has happened, how can you help, listen actively, don't judge, contradict, decide if you need to seek or give immediate support for safety or treatment (A&E, NHS 24, GP, Samaritans, Breathing Space).

Lower the emotional temperature and validate

Having BPD means that a person is regulated externally by things in their environment and this includes you. If the environment is calming, they will calm. Validation is essential for creating a meaningful connection. Soothe your loved one's current emotions by finding something to acknowledge (the emotion, the thoughts, the actions). For example: *'You sound really angry, it must be really painful for you what happened'.* By doing this you are letting the person know you understand that they feel out of control, in a frightening place.

Move forward

Communicate to the person your hope and belief in their ability to get in control again and move forward. Recall times when they felt like this before and got through while still validating how difficult it is right now. eg. *'I know it feels like you can't take anymore but you are very strong, I've seen you get through times....'*

Find out if they would like help in solving the problem that has caused their pain. When emotions are running high, fuelled by fear and anxiety it can be difficult to focus or problem solve. It also takes longer for emotions to settle. Suggest brainstorming the problem together but if this isn't working then a cooling down period can be valuable for both involved.

After the distress or crisis - Take time out to process and reflect on what has happened. After normalising from the stress response think about what you may do differently when distress reoccurs, both in how you respond in the situation as a carer, and what self-care did and did not work so well. Fear and anxiety caused by stressful crisis events can be exhausting and take their toll on your health and wellbeing. It is natural to worry but it is essential to soothe and calm yourself daily to counteract the effects of worry and anxiety. Take time every day to do something to de-stress and feel better. Use the five senses: e.g. touch – stroke your pet, relax in the bath, wrap up in a warm blanket. Remember what helps one person may not be another so do what works for you. Talk to a friend, family member, or peer about what has happened and how you feel.

5.8.4   Intervention component two: Skills course

The skills course offered will be the 'Decider' which is firmly grounded in cognitive behaviour therapy and DBT and has an impressive evidence base for their efficacy in supporting a wide range of mental health issues (David et al. 2018; Valentine et al. 2015; Bloom et al. 2012; Stoffers et al. 2012). Given that DBT is a recommended treatment for people with BPD (NICE 2009; RCP 2018), this corresponding course will support carers' understanding of treatment approaches that are often used to support the persons' recovery. The Decider was designed in 2010 by Ayres and Vivyan (2019) and can be used for a range of service settings and professionals, including mental health workers, educators, and organisations interested in promoting mental wellness. Further, they recommend its' use with carers to support both themselves and the person they care for.

According to guidance from Ayres and Vivyan (2019), the Decider is a manualised course with 32 therapeutic skills people can learn by attending a two-day workshop facilitated by local trainers. However, the duration of the course delivered within Calm and Connected could be flexible given it is part of a multicomponent intervention. For example, it could be delivered over more than the standard two days to further support carers with skills development and practice. Workshops within Decider Skills include group discussion and skills practice, online training is also available, and many resources are available via their website. These include skills guidance, handouts, and demonstration videos. Many of the Decider skills mirror cognitive behaviour therapy and DBT under four core skill sets of distress tolerance, mindfulness, emotion regulation, and interpersonal effectiveness, however, they differ by the style and intensity of teaching, making them user-friendly, accessible, fun to teach, and easy to learn. The main features of the course which make it appealing for this intervention are its focus on learning to regulate own emotions, and developing emotional resources and tools for calming and validation. These were identified by carers and professional stakeholders as important outcomes of an intervention due to the frequent, enduring stressful mental health crises that family members cope with. For example, central to the Decider (2019) is the life jacket metaphor:

> *"Each skill inflates the lifejacket and the client learns to use it if an emotional emergency occurs which enables the client to float rather than sink when it seems they are drowning in a sea of distressing emotions. The FIZZ represents the physical signs in our body when we are feeling emotion".*

> (Ayres and Vivyan 2019: P2 The Decider Skills Manual)

The Decider course reflects other skills training for families using a DBT approach (Ekdahl et al. 2014; Grenyer 2019; Linehan 2015; Manning 2011; Swales 2018; Sanders et al. 2010). In recent years several NHS and third sector organisations have adopted the Decider skills course into their practice for adult and children's mental health [e.g. NHS Fife, Lothian, Tayside, Forth Valley, Guernsey, and Barnardo's] (Decider 2021). Currently, there is very little published evidence relating to the use of Decider as an intervention. However, testimonies and quality improvement evaluations published on their website are promising. Similarly, Christopher et al. (2017) evaluated a pilot intervention conducted in a third sector organisation using Decider skills with young people experiencing mental health problems, and their families who met as a support group. A pre/post analysis found reductions in depression, anxiety, and improvement in mental health, self-care, living skills, and social networks for young people. The study quality however was weak, reported as service improvement rather than research, and several elements were not reported. Also, of note was the parent support group was not evaluated only the young people. Only preliminary conclusions can therefore be drawn and further research into Decider skills as an intervention is necessary.

5.8.5 Intervention component three: Peer support group

Given that participants attending the Decider group will all be supporting a person with BPD, peer support will be an element of this group. However, stakeholders were keen on an easy access, ongoing peer support group. The Mind UK (2017) resource called: Developing Peer Support in the Community, a Toolkit, plus peer support resources from the Scottish Recovery Network (SRN) will guide this aspect of the intervention (Scottish Recovery Network 2021). The group will meet monthly for a two-hour session with a specific focus on allowing participants to share their own experiences, and give and receive support. An optional private Facebook page for participants to continue to give or receive peer support during the sessions will be facilitated however there will be no ongoing input from the group facilitators.

5.8.6 Who the intervention will be provided by

A professional website designer will be required to develop the Calm and Connected educational website in collaboration with the researcher and stakeholders; funding will be sought to cover the costs. A charitable organisation called the Scottish Personality Disorder Network has expressed interest to host the website as an aspect of their main website which

is currently under development at https://www.scottishpersonalitydisorder.org/. Two members of this network are currently part of the study stakeholder group and further discussions can take place during the intervention development and implementation phase.

The Decider skills course and peer support elements of the intervention will be provided by trained wellbeing mentors with the relevant expertise in delivering psychoeducation, such as a counsellor, or practitioner for a third sector mental health organisation, mental health nurse, psychologist, dialectical behaviour trained practitioner. The Decider skills course authors provide accredited training and ongoing support which will be accessed. Important to the success of the intervention will be a referral pathway or signposting for carers. This will be achieved in collaboration with carer support organisations and NHS services providing care to people with BPD who may be in contact with carers. Several stakeholders are currently involved in the design of the intervention and are keen to remain involved in the proposed implementation phase. In addition, the website can support awareness of the skills course and peer support groups. Further, a leaflet summarising what is available and how to access will be developed and circulated to relevant parties.

5.8.7   Modes of delivery

The intervention will be delivered via the internet for the website; the Decider skills course and peer support group will be offered in face-to-face groups of up to twelve participants. There may be scope to offer a private Facebook page and an online version of the peer support group via the website. How often the course runs will depend on funding and demand.

5.8.8   Where the intervention will be delivered

The educational website will be hosted by the Scottish Personality Disorder Network and delivered online via the internet. The Decider skills course and peer support group will be hosted by a third sector mental health organisation with a remit to support carers and with the relevant expertise. Therefore, this will be held at their local premises.

5.9   Chapter summary

This chapter presented the methods of how the intervention was designed using 6SQuID (Wight et al. 2016) as the overarching theory for development, and underpinned by the socioecological model (McLeroy et al. 1988). Central to the design was the involvement of stakeholders who participated in focus groups and commented on protocol drafts, and whose views and perspectives have shaped this intervention. As a result, Calm and Connected has emerged as a co-designed intervention for carers of people with BPD containing three interlinked components. These are an educational website hosted by Scottish Personality Disorder Network; a skills course utilising the Decider skills, and a peer support group hosted and facilitated by a third sector mental health organisation working collaboratively with key stakeholders. The peer support group will have scope for both online and face-to-face interaction allowing carers to meet, share experiences, support, and learn with others in a similar position.

The next and final chapter will provide a full discussion of the thesis findings, considering them in the context of existing literature and policy context. It will also reflect upon the strengths and limitations of the research and make recommendations for policy, practice, and future research.

Chapter Six: Discussion

6.1   INTRODUCTION

This thesis was developed out of the recognition that people with BPD and their carers are a much-neglected research priority in Scotland with emerging reports of poor care and support experiences. The purpose of the study was to attempt to reduce the gap in published literature by exploring the experiences and needs of carers of people with BPD and to co-design a supportive intervention tailored for them.   The exploratory and co-designed approach taken was valuable for understanding carers' experiences, then working together with them, and professional stakeholders to find a logical solution. This chapter provides a full discussion of the thesis findings, considering these in the context of existing literature and policy. This chapter also reflects upon the strengths and limitations of the research conducted and makes recommendations for policy, practice, and future research.

6.2   Findings from the systematic literature review

To ensure a good understanding of recent developments and the provision of interventions for carers, a systematic literature review was conducted. This investigated supportive interventions for carers of people with SMI, inclusive of BPD, psychosis, schizophrenia, bipolar disorders, and updated previous reviews (Yesufu-Udechuku et al. 2015; Bailey and Grenyer 2013). Nineteen studies were included evaluating 15 different psychoeducational interventions published between 2012 and 2018. Of these, six studies conducted in the USA, Australia, and the Republic of Ireland examined tailored interventions to support carers of people with BPD (Bailey 2014; Bateman and Fonagy 2018; Flynn et al. 2017; Grenyer et al. 2018; Miller 2013; Pearce et al. 2017). Bateman and Fonagy (2018) used mentalization theories; Pearce et al. (2017) offered a cognitive analytical approach including education relating to BPD. Bailey (2014) and Grenyer et al. (2018) evaluated a BPD-focused intervention adopted from the Project Air Strategy (2012; 2016) encompassing the principles of enhancing carers' mood, identity, and relationships. Finally, Flynn et al. (2017) built on the earlier work of Hoffman et al., (2005; 2007) examining a DBT based group intervention.

The review provided helpful information about developing a new intervention for carers of people with BPD. The results across studies showed that psychoeducational interventions had a significant positive effect on carers' outcomes. These included improving their mental health and wellbeing, caregiving experiences, reducing burden, and psychological distress,

alongside providing increased social support. Studies aiming to reduce depression and anxiety were inconsistent in their findings. This may be significant when considering the intervention developed within this thesis and how it might or might not reduce the traumatic stress and vicarious trauma that carers described. Group-based interventions using manualized programmes and theoretical frameworks such as DBT, mentalization, cognitive analytic, problem-solving, or solution-focused approaches were popular and proved effective. Most interventions were tailored to the mental health conditions that carers were supporting their relative with (e.g. BPD, schizophrenia). This was indicated as important for carers to learn about the specific conditions and receive support from their peers within the group process.

No single intervention type was identified as most effective, and there were limited interventions directed at carers of people with BPD, therefore no single existing intervention could be recommended for adoption or implementation. Additionally, only preliminary conclusions about the type and efficacy of individual interventions could be drawn from this review. The input or level of co-production with carers of people with BPD could also not be assessed. Therefore, it was decided to proceed to a study that could identify carers' experiences of, and needs for, supporting a person with BPD; also, to work with carers to design an intervention to support these needs.

6.3   Findings from the qualitative study

The empirical study used the qualitative methods of Facet Methodology and Framework Analysis to explore the experiences of carers of people with BPD to understand their support needs and views about future intervention. Analysis of 20 semi-structured interviews with carers identified four overarching themes: trauma by association; social and emotional isolation; beyond coping; and carers need help too.

The first theme, 'trauma by association' described the causes and extent of traumatic stress and vicarious trauma carers' experienced within their everyday lives whilst coping with the person with BPD's sudden moods and behaviours. Giving a voice to their experiences further revealed how the trauma of witnessing recurring self-harm, suicide attempts, and their fear of aggression or violence affected them. Carers were in regular pursuit of care and treatment for the person they supported, which they perceived as lacking or absent, further burdening them with the responsibility and stress of caregiving. The second theme, 'social and emotional isolation' captured the toll on the emotional and social well-being of carers. The quality and nature of the relationship they had with the person with BPD were severely impacted, as were their relationships with others such as family or friends. This was considered due to the

emotional and practical burden of care, frequent crises, and stigma of BPD. The result was carers were left socially and emotionally isolated at a time when they arguably needed support the most. The third theme, 'beyond coping' showed how carers coped day-to-day by trying to use an eclectic selection of ad-hoc strategies such as counselling, calming, validation, or distancing. This was without any training, or guidance from mental health professionals, and with varying success.

Finally, the fourth theme found was that 'carers were people who needed support too' and that this support should be tailored for them. The findings identified a logical solution with key elements for an intervention to focus on. Some participants who had received support described being given advice, information, counselling, or attending support groups, as helpful. However, support was reported sporadically and inconsistently across carers; many believed what was offered did not meet their needs. Carers welcomed the proposal of a supportive intervention that focused on building a support network of peers with similar lived experiences; education, and information about BPD; strategies to prevent or use in crises; and in particular, an intervention signposting to carer support and self-care. Raising public awareness of BPD to reduce the stigma they and the person with BPD experienced was also identified but could not be addressed in this intervention.

6.4   Findings from stakeholder advisory focus groups and intervention design

The overarching theory used to design the intervention was 6SQuID (Wight et al. 2016) which supported collaboration with stakeholders to maximise efficacy by ensuring the design was a good fit, practical and acceptable. Four focus groups with stakeholders, represented by seven carers, four mental health or social care professionals, and three carer support professionals enabled the intervention co-design. This was supplemented by additional feedback on drafts via email (see Appendix 19). Topics discussed were the key issues and priorities an intervention should address, the content, delivery, format, and intervention name.

Following the steps of 6SQuID (Wight et al. 2016), the literature review had already identified psychoeducational interventions that can be effective to support carers and some potential ingredients. The qualitative study explored the carers' experiences and needs which defined the problems, causes, and which causal factors were most malleable to change. A socioecological model emphasised differing carer needs and confirmed the requirement for an intervention that targeted multiple levels (McLeroy et al. 1988). Integral themes from the

focus groups were mapped to the socioecological model and further identified factors with the greatest scope for change from an intervention. These were:

- The stress of living with the person's self-harm and suicide crises
- Impacted relationships
- Limited strategies to receive support or self-care
- Little knowledge or skills to support the person with BPD
- Limited support networks
- Little awareness of, or support from carer organisations

The stakeholder advisory focus groups advised several approaches to address these issues in a real-world environment, creating a Logic Model and Theory of Change (Bartholomew Eldredge et al. 2016) for the proposed intervention (Figure 7). The TIDieR framework (Hoffman et al. 2014) guided the implementation plan ensuring completeness in design. This supported creation of the intervention named Calm and Connected, and its' parts. These were: an educational website hosted by a charitable group called SPDN; the Decider skills course (Ayres and Vivyan 2019); and a peer support group guided by the Mind UK (2017) Toolkit for community peer groups. All are intended to be hosted by third-sector organisations.

6.5   Strengths and limitations of this research

This study is the first in the UK to explore the experiences and needs of carers of people with BPD and work with them to co-design an intervention. Methodologically this study was strengthened by using qualitative methods to explore the experiences and needs of carers to inform the intervention design. There is little evidence of co-design or co-production in previous intervention studies. For example, Bailey (2014) used a survey questionnaire before intervention development which would not enable a rich contextual understanding of difficulties. Further, where co-production was described there was little detail to assess the level of involvement (Bailey 2014; Bateman and Fonagy 2018). Given this is an under-researched area the methodology also enabled key issues to be explored and components tailored to areas that needed to be targeted.

The study design was also strengthened by using evidence-based intervention development and implementation science theories (e.g. 6SQuID; TIDier) and ensuring the involvement of stakeholders was at the heart of the process. Several carers and mental health professionals from the NHS and third sector organisations were consulted and contributed early to the study

design process to ensure the study was relevant and feasible. They also gave an early indication of encouragement and support for this study.

Participants were drawn from across Scotland, rather than a local geographic area which strengthened the study by offering a breadth to the findings. Initially, the study aimed to recruit in partnership with the NHS and more broadly social media, however, few carers came forward via the NHS, and more volunteered via social media. The permissions of ethics were adjusted to enable online interviews, therefore researcher access to participants who were not local was not an issue. Carers included friends as well as family members and although only two friends participated, this is the first study to consider their experiences and needs concerning supporting a person with BPD.

These factors were all highly influential in designing the Calm and Connected intervention, with its different intervention components addressing multiple socioecological factors. McLeroy et al's (1998) socio-ecological model was applied in several ways throughout this work and encouraged identifying behavioural and environmental factors which influenced carers' problems at individual and interpersonal levels. Using Framework Analysis meant a systematic, pragmatic, and rigorous approach to data management with the creation of seven matrices to further document, interpret, and analyse carers' lived experiences (Ritchie et al. 2014). An intervention development framework [6SQuID], guided the design of the intervention (Wight et al. 2016). This further ensured a stepped process of drawing upon the literature and qualitative data to understand the issues, those most malleable, to identify mechanisms and a Theory of Change (Bartholomew et al. 2016). This along with the TIDieR framework (Hoffman et al. 2014) enabled a realistic and tailored intervention design with sufficient detail for future pilot study development.

All research has limitations and there were several to highlight in this study. Firstly, the literature review in Chapter Two did not search for service-wide/system-based/integrated interventions, such as the Project Air Strategy or Spectrum Project developed in Australia. Instead, it focused on specific individualised interventions, such as group programmes. This was a decision taken to ensure that the intervention outcomes focused on carers rather than the person with BPD, however, may mean that some studies with joint outcomes (service user/carer) were not included. Despite this, the Project Air Strategy intervention for carers (Staying Connected) was evaluated in two studies included in the review (Bailey 2014; Grenyer et al. 2018), and offered valuable insight.

A further limitation to consider is that the Calm and Connected intervention may not address all the unmet needs and difficulties carers have identified. The intervention aims to provide social and emotional support, information, education, and skills development for carers. The Logic Model recognised that carers who participated in the Calm and Connected intervention may be able to cope better with the burden of care, traumatic stress, and vicarious trauma they experienced. However, previous studies examined in Chapter Two have shown that interventions may not be effective to resolve clinical depression and anxiety for carers, therefore Calm and Connected may not be able to address the effects of the trauma they experience. Further, research would be required to examine the mental health outcomes for carers participating in Calm and Connected.

The sample profile was also a limitation. Participants self-selected and may have had an interest in the topic before entering the study, they also self-identified as carers of people with BPD. There will always be those who decline to participate, and those who volunteer are likely to be interested in the study or topic area which can make for rich data. The depth of experiences carers described confirmed that the sample was constituted of people who had significant involvement in supporting a person with BPD, and were willing, or needed to tell their story. Professional stakeholders were selected by the roles they held and willingness to participate, therefore they may not have been experts in all aspects of this study, e.g. interventions, BPD, and carers. Convenience sampling had the following impact on the sample: only two friends took part; most participants were female, caring for people mostly female; there was a high level of educational attainment; carers were from Scotland only, and none were from a black or minority ethnic background. Therefore, they may not be representative of the population or generalise to a broader sample. However, the study aimed to explore the experiences of caring for a person with BPD and the consistency of findings across the sample indicated that these experiences are generalizable. Further, the analysis was presented to stakeholders to confirm the findings were representative of the key issues they faced. To ensure the anonymity of carers, the geographical areas were not presented, however, most were from the central area of Scotland. The subject was sensitive and participants may not have been comfortable in fully sharing their experiences, however, the explicit nature of some of the stories carers shared would indicate that we had developed a sufficient rapport for carers to feel comfortable, and Facet Methodology allowed for constructing the meaning of the experiences expressed by carers.

Some interviews and all focus groups were changed to online during the data collection phase due to Covid 19 pandemic lockdown. This may have hampered the interaction and depth of the interviews as it was harder to develop a rapport and recognise visual cues. Despite this, the online interviews took approximately the same length of time as in-person interviews. To

mitigate any problems with comfort during the online focus groups, these were organised to be smaller (in participant numbers) and shorter than previously planned, therefore an additional two took place to ensure the same level of involvement overall. Further limitations to holding focus groups were highlighted by Holloway and Wheeler (2016) who argued it can be difficult to manage debates in focus groups, the researcher has less control than in a one-to-one interview, and some individuals can dominate the discussion. This was evident in the first focus group which combined a psychiatrist, a mental health nurse manager, and two carers. The carers confronted the professionals on several areas they felt services fell short and had been highlighted in the interviews. This affected the dynamics of the group and it was difficult to keep the discussion on point (this being to generate ideas or views for intervention design). Future focus groups were held with carers only, or professionals only, to avoid conflict, keep to the intervention co-design agenda, and ensure all stakeholders had a fair opportunity to express their views.

There was also a financial limitation due to this being an unfunded study, which may have influenced the use of Facet Methodology and the co-design process. These encourage researchers to be creative and inventive in their approach, for example using memory workshops with archived photos, music, and films (Mason 2018; Roper et al. 2018). However, this would have required financial resources which were not available in this study.

The study also has potential for researcher bias, given this was a Ph.D. thesis most of the research was conducted by one sole researcher. This was overcome by regular supervision and discussions with supervisors which helped develop ideas and scrutinise theories. Additionally, the stakeholder advisory focus groups and email consultation helped shape the emerging theories for the intervention. An element of reflexivity was consistent throughout the research process which was also documented demonstrating transparency for decisions made. The positionality of the researcher as a nurse and professional may have affected how participants viewed me, and potentially how I viewed them. My background was explained at the start of each interview to introduce me and give participants a context for the study.

Despite the involvement of stakeholders, the generalisability of the proposed intervention to other geographical locations may be limited as most professional stakeholders were from the Tayside area and have expressed support to pilot the intervention. Therefore, some of the components may need consideration when developing this intervention in other settings. However, the findings were not solely based on professionals but more so on carers from across Scotland. Further, to successfully implement and pilot this intervention, a collaboration between carers, the NHS, third sector organisations, and funding will be necessary to realise its potential in practice.

6.6 The findings in relation to existing literature

6.6.1 Carers and trauma by association

It was evident there was a complex interplay of factors that created carers' experiences and impacted many aspects of their lives. The study found family members were most affected and experienced emotional stress related to trauma by association with the person with BPD. Participants were regularly exposed to direct trauma, where a traumatic event such as witnessing self-harm, suicide attempts, or being the victim of violence and aggression occurred (May and Wisco 2016). These crises events led to carers facing traumatic stress, including intense shock, confusion, fear, or numbness; these are normal responses that occur following a disturbing event and gradually fade over time (Brittany et al. 2014).

However, this study also found many carers experienced longer-term impacts consistent with vicarious trauma and referred to as secondary traumatic stress (Cohen and Collens 2013; Figley 1990). Vicarious trauma often affects professional helpers and is conceptually linked to compassion fatigue, empathy-based stress, and burnout (Newell and MacNeil 2010; Rauvola et al., 2019). According to Pearlmann and Caringi (2009, P202-203), vicarious trauma is:

> *"The negative transformation in the helper that results (across time)*
> *from empathic engagement with trauma survivors and their traumatic*
> *material, combined with a commitment or responsibility to help them."*

There is growing interest in the prevalence of trauma and the related negative psychological consequences (Pearlmann and McCann 1995; Tol et al. 2013). The greater the exposure to trauma the greater the risk to helpers of vicarious trauma, which can produce PTSD-like symptoms (McCann and Pearlmann 1990). PTSD suddenly manifests as a normal reaction to an abnormal event, whereas vicarious trauma builds more slowly as a normal reaction to exposure to multiple traumatic materials (Kliem et al. 2013). Carers experiencing vicarious trauma showed a range of psychosocial symptoms including anxiety, worry, fear, panic, or surrealism; and depression including hopelessness, sadness, or numbness (Tabor 2011). Further, consistent with PTSD, many carers also faced episodes of dissociation, visualisation, reliving trauma, detachment, and memory issues (Kim et al. 2021). Literature highlights that exposure to trauma can result in chronically impacting a person's social, cognitive, psychological, and biological development across the lifespan (D'Andrea et al. 2015; Spinazzola et al. 2005; Van der Kolk 2005).

This study extends what is known from previous research (Bailey and Grenyer 2013; Bailey 2014) about the significant impact on carers of psychological burden, grief, impaired empowerment, depression, and anxiety. A subsequent quantitative study of 280 carers of people with BPD by Bailey and Grenyer (2015) further showed that expressed emotion, burden, and wellbeing were all affected by witnessing the distress of a loved one and may contribute to secondary traumatization However, this is the first study to suggest persistent exposure to traumatic events and a traumatised individual leaves carers vulnerable to, and suffering from vicarious trauma (Kim et al. 2021).

Most of the research identifies those at risk of vicarious trauma are human service providers, such as social workers, nurses, therapists, or lawyers (Cohen and Collens 2013; Jenkins and Baird 2002; McCann and Pearlman 1990; Rauvola et al. 2019). However, research has previously recognised that family or friends in continued close contact with trauma survivors can also experience this (Figley 1990). A survey study of 180 foster carers revealed they experienced higher than average vicarious trauma and high levels of burnout. Findings highlighted that threats to themselves or their family and home-based caring created problems with boundaries and distancing when the carer role affected them (Bridger et al. 2019). Vicarious trauma features were also evident in 10 carers' experiences explored in a qualitative study by Meshinyazd et al. (2020). Participants described their life peppered with chaos, negative feelings, sorrow, unhappiness, and even a wish to die. Correspondingly, a review by Warrander (2020) indicated that carers experience distress that is parallel to people with BPD and need access to appropriate support to manage their suffering. A further quantitative comparison study (Seigerman et al. 2020) with 82 carers of young people with BPD also found significantly elevated levels of distress, negative caregiving experiences, expressed emotion, and maladaptive coping strategies compared to carers of people with SMI; raising the potential for this to also be considered as vicarious trauma. However, the lived experience of carers of people with BPD has been under-researched qualitatively. Therefore, this present study further expands on previous research by demonstrating the degree of the impact, detailing carers lived experiences and how core elements are linked to causes.

Findings from this thesis also add to existing research by demonstrating the extent to which carers experience aggression and violence from people with BPD, and how traumatic stress caused by this influences their development of vicarious trauma. Corresponding with this study, previous research has identified coping with self-harm, suicidality, financial issues, and accessing care and treatment as core difficulties for carers (Lamont and Dickens 2019). However, this study's findings indicated nearly two-thirds of participants also lived with the fear of physical or emotional aggression and violence. In particular, those who lived with a person with BPD described an unpredictable and emotionally charged home with recurrent

shouting, ranting, and rages of verbal or physical aggression directed towards them. Many were cautious of triggering these in the person and often felt a degree of responsibility to prevent this. Wider evidence supports that people with BPD may be physically violent towards partners and non-intimate acquaintances, damage property, and on rare occasions even murder family members or others (Sansone and Sansone 2012). There is a significant correlation between BPD symptomatology and externalised aggressive behaviours related to impulsivity and mood dysregulation. Researchers have attributed this violence to co-morbidity with substance use, anti-social PD, and anxiety (Gonzalez et al. 2016). Literature also suggests there may be a relationship between adverse childhood experiences and physical or emotional aggression due to the development of insecure attachment, anger, PTSD, or social processing deficits (Cascardi et al. 2017; Taft et al. 2008). The findings of this study extend the evidence concerning how carers experience violence and aggression from the person they care for. The biosocial theories linked to BPD development (Linehan 1993), and the prevalence of physical and emotional aggression indicated in this study show that carer support should be cognisant of this serious issue and its effects.

6.6.2   Stigma and negative attitudes affect care and carers

This study found that trauma by association was also exacerbated by several factors. Stigmatising or negative attitudes from healthcare professionals, difficulties accessing care for the person with BPD, little involvement of carers in care planning, and poor knowledge or understanding about BPD were consistent issues highlighted in the carers' accounts. This led to perceiving they and the person were being ignored or failed by the healthcare system, which communicated hopeless or uncompassionate messages, and poor prospects of recovery to carers. Previous research has also determined stigma, poor knowledge, and care provision as issues (Barr et al. 2020; Lamont and Dickens 2019; Seigermann 2020). Health guidelines and reports have attempted to address this yet stubbornly they persist (MWC 2018; NICE 2009; RCP 2018).

This study also found this extends to carers who experienced the phenomenon 'surplus stigma' (Seigermann et al. 2020) which places suspicion and blame on parents due to familial factors (neglect or abuse) that are linked to BPD development (Buteau et al. 2011; Hoffman et al. 2005). Seigermann et al. (2020) also indicated that surplus stigma could be a factor in carers' negative caregiving experience. This thesis adds to previous research by identifying how much these issues contributed to the traumatic stress and vicarious trauma that carers experienced. They perceived their stress was fuelled by surplus stigma, structural stigma,

discrimination, and a lack of compassion in terms of professionals' practice and pathways to care. Previous research has indicated that structural stigma is a widespread phenomenon in health systems used by people with BPD (Sheehan et al. 2017). Often associated with institutional policies, cultural norms, and organisational practices structural stigma is considered to limit access to services, quality care, and impacts recovery for people with BPD (Klein et al. 2021). According to Pugh (2015), structural stigma related to BPD has been found across many private and public organisations including the criminal justice system, and the media which often portray damaging beliefs related to individuals being dangerous, less competent, or required to be socially distanced from. Given the extent and impact of stigma, an overhaul of institutional policies, cultural norms, and organisational practices for people with BPD has been argued as the necessary solution (Klein et al. 2021).

The present study supports previous literature about poor access to recommended psychological therapies for the person with BPD (NCISH 2018; MWC 2018). However, it also emphasises the difficulties they have engaging in therapy despite carers trying to support this practice. A recent qualitative study with 22 people experiencing mental health issues and co-morbid PD found a need to adapt from prescriptive cognitive behavioural models towards flexible and personalised treatment with this group. This would entail time to offload, build therapeutic relationships, and link past experiences to current problems. The authors proposed the consideration of new ways of working which support the development of effective interventions via a stepped care approach and may make therapies more accessible for people with BPD (Lamph et al. 2020).

This study also found that professionals lacked empathy, knowledge, or understanding about the complex situations carers coped with and the dangers of suicidal crises they often sought support for. Acres et al. (2018) review of carers' experience of emergency services also reported professionals lacked understanding of the person with BPD's distress or the nature of BPD, creating a barrier to effective crisis management. For example, research indicates that 10% of people with BPD will die by suicide, and coping with multiple failed suicide attempts causes alarm in professionals and carers (Paris 2019). Clinical guidance and evidence advise a person with BPD who is suicidal should be treated on an outpatient basis using specialised psychotherapy and hospitalised only following a near-fatal suicide attempt for re-evaluation (NICE 2009; Paris 2019; RCP 2018). This study adds to previous research by carers identifying that refusal of hospital admission during a suicidal crisis was common, often accompanied by being offered little or nothing else, and leaving carers with the responsibility and stress of managing suicide risk.

However, hospital admission or care in itself is complicated, can be counter therapeutic, and not without risk. In a recent mixed methods study into mental and physical healthcare for people with PD in general acute wards, Sharda et al. (2021) found admission often led to individuals experiencing significant psychological and emotional distress and they perceived professionals' viewing them as difficult rather than in crisis. Results showed professionals showed little compassion and were unresponsive to the need for a trauma-informed approach to care. Although Sharda et al.'s (2021) study focuses on non-specialist services only, evidence from this present study and previous literature (Lamont and Dickens 2019) echoes poor care experienced by mental health services also. Further, carers questioned, if not hospital care then what? Carers in this study expressed a need for high-quality replacement or respite care during a crisis, supported by previous literature (Barr et al. 2020; Segermann 2020). The NICE (2020) guidance for carers also advises that local authorities should offer replacement or respite care on a planned or emergency basis, however, this study found this had never been offered to carers. Further, they were rarely involved in the care or discharge planning. This problem is, however, not isolated to carers of people with BPD. Evidence suggests that despite carer involvement in mental healthcare leading to better outcomes for patients and carers, implementation in practice remains poor (Dirik 2020; Kaselionyte 2019). A substantive theory identified from this study and the supporting literature was that stigma and negative attitudes about people with BPD detrimentally affected their care and carers.

6.6.3 *Social and emotional isolation*

This study found carers often expressed intense emotional involvement, going above or beyond, and investing both emotionally and timewise in caring. Previous carer studies have indicated the intensity of relationships and sometimes emotional over-involvement with the person as a negative (Lamont and Dickens 2019). Yet Bailey and Grenyer (2015) found that emotional over-involvement (overprotection, anxious concern, and extreme emotional closeness) can be validating to the person with BPD and support their recovery. However, this can also be associated with impaired well-being and a higher burden for carers necessitating enhanced carer support.

The present study adds to the existing literature as it also found many carers were able to identify positive aspects of caring; characteristics that they loved and admired in the person, as well as activities they enjoyed together. Friends in this study were less affected by traumatic stress and vicarious trauma than family members and emphasised that their relationship with the person with BPD enhanced their lives, and sense of self, and brought value to them. The

social and emotional impact on them, as described in their accounts was, therefore, more positive. No previous evidence exists about positive aspects of informal caring for a person with BPD. However, the Scottish Government Carers Report (2015) highlighted the importance of considering this more generally and understanding the factors that may contribute to a rewarding experience. A recent survey of 204 carers of people diagnosed with dementia conducted in Portugal found an association with caregiving enriching lives. This depended on several factors including carers' experiencing lower levels of psychological distress and burden, and the care recipients being older (Ribeiro and Martin 2011).

This study also found many family carers withdrew from social networks or concealed the extent of difficulties they were experiencing with the person with BPD, creating tension between their real life and the one they projected as less traumatic. This was for several reasons, but frequently stigma, shame, or blame were indicative factors. Where some had been more honest, they often experienced negative and judgemental responses or were even ostracised from friends and their community. Similar findings are reported in recent literature, emphasising the life-changing nature being a carer had on their lifestyle; and finding family, friends, and health professionals to be judgemental (Barr 2020; Lamont and Dickens 2019; Meshinyazd et al. 2020). This only added to the social and emotional isolation they felt with efforts to socialise and improve their mental well-being sometimes hampered by this, or the person with BPD needs to be cared for. Findings from this thesis strengthen the existing literature (Lamont and Dickens 2019; Meshinyazd et al. 2020) by demonstrating that this is a key feature of loss for carers and central to the impact of having to support a person with BPD. Meshinyazd et al. (2020) also found that social restrictions on the carer's daily life, an inability to pursue life activities, and neglecting other family members or friends had a detrimental impact on their emotional wellbeing. They also reported being rejected by relatives and acquaintances, others resorted to secrecy, hiding the diagnosis to prevent judgement and prejudice. These findings further resonated with this study which also found the combination of these factors led to forced isolation and loneliness at a time when carers were most in need of connection and support. This leads to the theory that additional support is required to meet the carer's social and emotional needs.

6.6.4   Long term strategies and needs

This study also found that carers (inclusive of friends) had to develop long-term strategies to manage day-to-day and were in a 'beyond coping' phase. This was where they were proactively strategising about how to adjust to life on a long-term basis and deal with the

complex difficulties the person with BPD presented. Carers supported the person with BPD on several levels to live safely day today. Little evidence exists with regards to the role of these carers, however, this study found support included housework, collecting prescriptions, taking them to hospital or therapy appointments, social contact, and being there to rescue them when they were suicidal or in a distressed state. Olasoji et al. (2017) found similar activities were undertaken by carers of people with SMI who spent considerable time negotiating between services (police and crisis assessment teams) and advocating for their relative's need for care. Likewise, Rowe (2012) highlighted that where carers are expected to fulfil some obligations, they should also have rights associated with the role actioned. For example, those identified in the Carers (Scotland) Act (2016), and Carers Charter, Scotland (2018).

This study found that some carers reported their employment, counselling, artwork, exercise, supporting others, and receiving support from good friends or family members as a refuge and break. A recent systematic review of 31 studies into effective components of interventions to support carers of people diagnosed with dementia found that multi-component interventions can help maintain psychological health. The authors reported that to be most effective interventions should have both educational and therapeutic elements, such as peer support, cognitive behavioural therapy, or befriending (Dickinson et al. 2017). Previous studies have not elicited specifics about the role of carers for a person with BPD or identified elements of their life they find supportive. Therefore, this study advances knowledge in this area as well as how carers cope, what helps or hinders and determining potential ways to further develop their coping strategies and skills.

Similarly, no previous research has been conducted about emotional and social adjustment or coping strategies for carers of a person with BPD. However, the 'beyond coping' phase identified in this study has similarities to adjustment and coping strategies found in wider carer literature. For example, a recent cross-sectional study (Kazemi et al. 2021) with 110 carers of individuals who previously had a stroke found coping strategies included a positive appraisal of and accepting responsibility for their current status. A significant correlation was found between carers' experiencing higher burdens and using emotion-focused strategies such as escaping and distancing. Likewise, a systematic review by Hawken et al. (2018), into carers' coping and adjustment responses found problem-focused coping was associated with less distress and more positive adjustment (e.g. reducing work hours, using paid carers, integrating care into the family culture, using social support, or education). Cognitive strategies (e.g. acceptance, appraisal, social support) were also positively related to adjustment, whereas emotion-focused coping was negatively associated with adjustment and linked to increased psychological and emotional distress. The authors recommended harnessing these factors

within coping skills and support networks; this supports the theories underpinning the Calm and Connected intervention.

The fourth theme found in this study emphasised that many carers were struggling with their role and urgently needed help and support. A recent survey study by Lawn et al. (2020) reflects some of the issues about poor support for carers. Conducted in Australia 58 carers of people with SMI and 94 clinicians were surveyed to collect their views of carer support against six service standards. Results found there was limited knowledge of a carer policy and training opportunities in carer awareness for clinicians. Some carers reported good support and others none at all. Also evident was a lack of understanding that carer engagement was part of a clinician's role, and improvement was needed concerning sharing information with carers. There was no evidence of staff designated to be a 'carer champion' which would support the development of best practices. Further, given the limited understanding of clinicians around carer support, referral of carers to local carer support and advocacy was rarely undertaken. The authors' recommendations correlate with areas for development found in this study including a significant focus on staff education, clinical discussion, and supervision to meet standards for carers.

This study also found no carers had a carer support plan in place as advised by the Carers (Scotland) Act (2016), extending the current evidence and highlighting gaps between policy and practice. Similar to this study existing research has argued that many carers want to access support, but little is available and offered either informally, or via health or social care providers (Lamont and Dickens 2019; Sutherland 2020). This study addresses weaknesses in previous literature as they have only highlighted the experiences and needs of carers (Lamont and Dickens 2019; Sutherland 2020). Whereas this study has harnessed these and co-designed a supportive intervention that may mitigate the harmful impact of caring.

6.7   Calm and Connected as an intervention for carers

The literature review (Chapter Two) found there was no one theory-based intervention available that was likely to be effective, adaptable, or accessible for this context. Therefore, stakeholders co-designed the multi-component psychoeducational intervention comprising an educational website, skills course, and peer support group which aimed to build strengths, resilience, and coping skills while increasing knowledge. Evidence from the literature review (Chapter Two) has suggested such interventions have positive results in key outcomes, including reductions in mental health outcomes and improving quality of life. Calm and Connected addresses weaknesses and gaps in other interventions in several ways including

being co-designed, trauma-informed, and multi-component to specifically address these carers' needs.

6.7.1   A co-designed and trauma-informed intervention

This study has extended the evidence base by involving carers and professional stakeholders from conception to design ensuring a robustly co-produced intervention that meets the needs of carers and the scope of service providers. There was little evidence of co-design or co-production in previous intervention studies for carers' of people with SMI examined in the literature review (Chapter Two). However, this study has upheld co-production principles by ensuring that researchers, practitioners, and the public worked together, sharing power and responsibility from start to finish, including the generation of knowledge (Madden et al. 2020). This was in the understanding that those most affected by the intervention were best placed to design and deliver it, with their skills and knowledge of equal importance. Using 6SQUiD (Wight et al. 2016) also guided the co-production process with stakeholder involvement. As did the socioecological model which identified causal factors of carers' issues, understanding these concerning the environment and social context they occurred (McLeroy et al. 1988). Similar methods have been used in recent studies of co-produced intervention development for stroke survivors using behaviour change wheel (Hall et al. 2020), peer-led drug prevention (Hawkins et al. 2017), and alcohol consumption with medication (Madden et al. 2020). Given the value of co-production, this will remain the main feature of the intervention going forward, inclusive of carers and professional stakeholders.

Given the frequent stressful or traumatic incidents carers experienced, causing vicarious trauma, and the links BPD has with trauma and adversity (Linehan 1993), Calm and Connected is underpinned by trauma-informed principles shifting the orientation from, "what's wrong with you? to "what's happened to you?" This way we can understand the carers' distress as a human response to overwhelming stress (NHS Education for Scotland 2021; Richmond Youth Service 2015). Calm and Connected is also underpinned by DBT, which aligns with the principles of being trauma-informed (Ayres and Vivyan 2019; Linehan 2015; Manning 2011). Important factors of trauma-informed approaches necessary for this intervention included four key assumptions: i) a programme that realises the widespread impact of trauma and the potential for recovery, ii) recognises the signs of trauma in carers and others involved in their lives, iii) responds by fully integrating knowledge about trauma into the programmes, iv) and actively seeks to resist re-traumatisation (Substance Abuse and Mental Health Services

Administration 2014). Similarly, elements of reassuring, restoring, and regulating (Forkey 2019) are core features.

6.7.2 A multi-component intervention

This study identified novel components for a psychoeducational intervention with potential benefits for carers when delivered together (website, peer support, skills course). Existing interventions have one component or two at most (Chapter Two). However, the Project Air Strategy (2012) intervention, Staying Connected (Bailey 2014; Grenyer et al. 2018), available in Australia has some commonalities and positive implications for Calm and Connected in as much as the peer support and skills development elements have parallels. Although this intervention reflects some of the principles of The Project Air Strategy (2016) for carers, differences are evident as they engage whole systems and family approaches to the care and treatment of people with BPD. However, the UK has yet to adopt such a strategy and develop services that align with this proactive ethos.

An informative and educational website specific to carers of people with BPD, identified as a component of Calm and Connected is a novel approach that no previous intervention studies reviewed had considered or designed (Chapter Two). EHealth interventions for carers of people with long-term conditions were found popular, and had high rates of satisfaction and acceptability in a recent review of 78 studies. Supplementary modes of communication, such as network support with professionals and peers were also recommended by the authors. However, efficacy required further examination to extend the evidence base (Sin et al. 2018).

The second component, involving the Decider skills, DBT based group course (Ayres and Vivyan 2019), extends the current evidence base as this has not previously been offered to carers or empirically studied in carer-focused interventions. DBT is an evidence-based therapy for people with BPD; a recent systematic review found this, as well as other therapies (e.g. eye movement desensitization, cognitive behaviour therapy), was effective for treating traumatic life events, including PTSD, anxiety, and depression (Hans et al. 2021). DBT courses for people with BPD generally only involve families on a limited basis, offering one session to inform them of the therapy and its' benefits (Linehan 2015). However, a recent systematic review by Sutherland et al. (2020) has found that several existing interventions using DBT based approaches for carers of people with BPD have shown positive outcomes in reducing the burden and improving carer wellbeing (Flynn et al. 2017; Hoffman et al. 2005; 2007; Miller and Skevern 2017; Uliaszek et al. 2008; Woodberry and Popenoe 2008).

Therefore, Decider skills as a component of Calm and Connected bring these resources and theories to carers, further extending knowledge and understanding of the carers' experience through a trauma lens (Substance Abuse and Mental Health Services Administration 2014).

The third component in Calm and Connected, importantly is peer support. This has increased in popularity in recent years (Mind UK 2017; Scottish Recovery Network 2020; Stratford et al. 2017) and when concerning carers, this involves receiving support from someone in the same or similar circumstances (Carter et al. 2020). Clinical guidelines for supporting carers have also highlighted the value of reducing isolation, providing empathy, and social or emotional support through individualised, groups or online networks delivered by third sector organisations (NICE 2020). Benefits are found to include opportunities to talk freely, putting their experiences to use (Greenwood et al.,2013), fostering hope, overcoming stigma, and enabling the development of social support networks (Worrall et al. 2018). Evidence from Yesufu-Udechuku et al's (2015) review suggests that peer support interventions can greatly improve the experience of caring but cease to be effective more than six months after groups have stopped, indicating this needs to be available on a long-term basis to maximise efficacy. Studies also suggest in-person or online peer support is popular, and tailored peer support interventions are recommended to ensure needs are met (Carter et al. 2019). However, little evidence exists for the use of peer support for carers of people with BPD. Therefore, this study extends the current evidence base by identifying peer support for carers of people with BPD and proposing its' place within a multi-component intervention.

6.8   Implications for policy and practice

Despite the limitations in current research, evidence supports providing psychoeducation and support to carers of people with BPD as good practice (MWC 2018; NICE 2009). This may reduce stress, burden, and shame, as well as improve knowledge, quality of life, and caregiving experiences (Bailey 2014; Grenyer et al. 2018). Recognising the contribution carers make to supporting individuals with long-term conditions has become a common discourse in UK government strategies and policies (Carer Scotland Act 2016; Carers Charter Scotland 2018; Department of Health 2018; NICE 2020; Scottish Government 2019). However, the evidence presented in this thesis indicates a disparity in what carer policies say and what happens in practice in Scotland. Previously in health policy documents, addressing carers' needs has been minimal, if at all considered (e.g. NICE 2009; RCP 2018; MWC 2018; Scottish Government 2017). The UK clinical guidelines for the management of PD (borderline and antisocial) only suggests carers be directed to information about local carer support groups

(NICE 2009) and omits guidance about psychoeducational support. Further, their quality standards do not discuss families or carers at all (NICE 2015). This suggests they disregard or are unaware of the complexities surrounding the carers' role for a person with BPD, the impact, and how they are perceived within healthcare and social environments. Further, they fail to provide any detail on how carers can be supported in the real world.

In contrast, clinical guidelines for psychosis and schizophrenia have a quality statement highlighting carer-focused support programmes to reduce burden, and psychological distress and improve carers' quality of life. Similar to the needs of carers of people with BPD identified in this thesis, these entail carer-focused education, such as groups providing information, mutual support, and open discussion for carers (NICE 2015). The Scottish Government Mental Health Strategy 2017-2027 (Scottish Government 2017) takes a broad perspective of mental health but only briefly mentions supporting young carers' mental health. Therefore, there is no provision for adult carers in the Scottish Government Mental Health Strategy (2017), neglecting the impact or contribution of carers. Arguably, future policies and strategies should include attention to carers, particularly in light of the development of the Carers (Scotland) Act 2016 and the findings of this thesis. The Carers Scotland Act (2018) has recognised that carers are entitled to support in their own right and should receive an assessment and be offered a support plan. However, this study found most carers were not recipients of this support, and professionals focused solely on the person with BPD. Professionals also made assumptions about the role carers would take and did not consider the long-term impact or carer' needs. This indicates there is no consistent approach or tailored provision to support these carers in line with guidance (Carers Trust 2013; Carer Scotland Act 2018). The priorities set out in the Carer's Charter (2018), such as accessing support, involvement in assessment, care planning, and hospital discharge; support with employment, financial wellbeing, and carer-friendly communities (Department of Health 2018) remain to be addressed for carers of people with BPD.

More recently NICE (2020) published guidelines for supporting adult carers in their own right, addressing several areas found to be problematic and highlighted in this study. Their priorities comprise that local authorities, health, and social care workers should take every opportunity to provide information for supporting carers in their role. The guidance includes actively seeking to identify carers; assisting carers to access social and community support such as carer support services, self-help groups, or self-care advice; acknowledging carers as partners in care, and sharing information carers need to care effectively and safely while respecting confidentiality. They propose psychological and emotional support with a range of psychosocial and psychoeducational opportunities and group-based options. Similarly, the

Scottish Governments' Carers Strategic Policy Statement (2019), currently in consultation, aims to maximise the benefits of national policies (Carers Trust 2013; Carers Scotland Act 2018; Carers Charter 2018; Scottish Government 2021). Their foundational principles profess to be preventative, offering support to help prevent problems from occurring, and providing a range of options to carers so that support can be personalised. These recent policies and carers guidelines demonstrate a shift in focus and create a new opportunity to realise carer support in practice. How this translates into practice for this neglected group of carers remains to be seen and the findings of this thesis provide evidence of the current state but also a way forward to implement and deliver on these policies.

The proposed intervention, Calm and Connected corresponds with recent health policy, best practice recommendations (MWC 2019; NICE; 2009; NICE 2020; RCP 2018), and current carer policies (Carers Trust 2013; Carers Scotland Act 2018; Carers Charter 2018; Scottish Government 2021). The need for this intervention is overdue, however, it is timely in terms of these recent policies and guideline developments. Co-designed by carers with lived experience, their needs require to be front and centre when implementing this intervention and transforming these recent policies into practice.

This thesis has implications for healthcare professionals and services also. The UK clinical guidelines for the management of PD (borderline and antisocial) are now 12 years old (NICE 2009). Despite the attempts to address multiple issues relating to health care for people with BPD including professionals' negative attitudes, stigma, discrimination, access to services, and disparity of care, these poor practices and issues are still evident in carers' accounts. Further, they indicate the presence of surplus stigma that carers experience and magnify the impact of negative attitudes on outcomes of care. This thesis also demonstrates the need for the education of professionals in therapeutic approaches, trauma-informed care for people with BPD, and a whole system approach to care involving carers as indicated in the Australian-based Project Air strategy (Project Air Strategy 2012; 2016; Grenyer 2019).

Important omissions at policy and guideline levels are likely to impact healthcare practice also. For example, the Scottish Government's Mental Health Strategy (2017) does not address PD specifically. Recent guidelines on the treatment of PD from the UK RCPs (2020) stress the need for high-quality care and treatment, and how this can be implemented. However, problematically, despite advocating a whole systems approach, they do not include service users or carers in the development of the guidelines, nor do they identify carers as partners in care, as recommended by the Carers Charter Scotland (2018). Nevertheless, the RCP's (2020) report outlines a robust and comprehensive four-tier system (depending on the severity

of PD) which could be effective if adopted into policy and implemented by health and social care partnerships in Scotland, in consultation with service users and carers. The RCP's (2020) tiered system proposes tiers one and two involve primary care, voluntary sector, mainstream mental health services, acute and crisis services, psychology, and therapy services. Tiers three and four are specialist and dedicated services with outpatient, day patient, partial hospitalisation interventions, and intensive multi-modal treatment programmes. For those most severely affected with BPD, they also specify the need for regional units with residential care, highly skilled professionals working together, NHS or independent sector provision, and attention to the impact and needs of staff.

To address the issues highlighted and gaps in policy, a dedicated Scottish Strategy for PD needs to be developed similar to other issues or conditions such as Every Life Matters, Suicide Prevention Strategy (Scottish Government 2018), the Scottish Strategy for Autism (Scottish Government 2018), and the Beating Cancer Update Strategy (Scottish Government 2020). This would specifically address actions, outcomes, and priorities, such as the educational and attitudinal development of health care professionals, and provide a roadmap for service delivery. A Scottish PD strategy would also address the wider community and societal level stigma that is evident in literature and further reinforced through carers' accounts in this thesis. The prevalence of people with BPD in care settings and the general population justifies a national strategy that incorporates challenging stigma, trauma-informed practices (NHS Scotland 2021), education for staff, and care standards. Importantly, this should incorporate carers and be informed by their experiences and needs, as well as the supportive intervention co-designed by them and presented in this thesis.

6.9   Recommendations for future research

This thesis has developed a roadmap for a possible intervention tailored to the specific needs of carers of people with BPD. Post-doctoral research is required to further progress the work presented. To complete stage five of intervention development funding will need to be secured to develop the intervention, test, adapt and refine it on a small scale (Wight et al., 2016). This can potentially be via an MRC intervention development grant (MRC 2021) and will include funding to enable carers, stakeholders, and researchers to co-produce, inclusive of co-design, co-delivery and co-evaluation (Roper et al. 2018). The development will be in line with the MRC intervention development and evaluation framework which advises modelling the intervention before full-scale evaluation. This may entail studies to further develop the intervention, identify suitable measures, and predict long-term outcomes (Craig et al. 2008).

The MRC guidance shows core elements at this stage include context, development, refining the intervention, testing the programme, engaging stakeholders, identifying uncertainties, and making economic considerations (Skivington et al. 2021).

This study has established a stakeholder advisory group that can support intervention development and join a working group that will be established for this stage. This group will clarify who will take responsibility for each element of its' development. The Calm and Connected pre-existing plan will be further developed into implementation resources co-designed by the working group which will consist of carers, practitioners, and researchers following co-production principles (Roper et al. 2018). These will include branded materials for the intervention and each of the components (educational website, skills course, and peer support group). Similar to other interventions, an Information Leaflet, Practice Guidance, and Implementation Manual will be co-designed clearly articulating the intervention and how it should be implemented (Bailey 2014; Guida et al. 2019; Mc Cusker et al. 2018; Webber 2019). The working group will work closely with a design company to ensure the materials and associated website reflect the aims and content required and are easy to use. Wight et al. (2016) highlight that testing the intervention will clarify important issues such as:

> *"acceptability to the target group, practitioners and delivery organisations, optimum content, structure, and duration, who should deliver it and where what training is required, and how to maximise population reach."*
>
> (Wight et al. 2016: P524)

It is expected there will be several iterations of the intervention materials which will be tested and refined with the working group through meetings, discussions, and workshops following the updated MRC guidance (BMJ 2021). At this stage, further partnership work will be done with carer support organisations, NHS mental health care providers, and other necessary pathways to ensure their involvement and expertise. Once into the research phase, the working group will become a stakeholder advisory group, but some will also be part of the delivery project team or may participate in the pilot study of the intervention for carers.

Stage six of intervention development will entail collecting sufficient evidence of effectiveness to justify rigorous evaluation and implementation (Wight et al. 2016). Refining and evaluating the proposed intervention is consistent with 6SQuID (Wight et al. 2016) and the MRC (2014) framework which recommends testing complex interventions using smaller-scale studies, before conducting a larger full-scale evaluation usually using an RCT (Craig et al. 2008).

However, third sector organisations often move to wide-scale implementation without conducting rigorous evaluation due to resource constraints (Wight et al. 2016). Stage six will enable the full-scale intervention to be developed and data collected to examine that it works as intended and there are no serious unintended effects (Pringle et al. 2018; Wight et al. 2016). It will also allow uncertainties to be addressed and prevent the evaluation and implementation phase from being weakened by difficulties with acceptability, compliance, delivery, recruitment, and retention (Craig et al. 2008). Following the guidance, a formative evaluation will be conducted to ensure the intervention is feasible, appropriate, and acceptable before fully implemented (BMJ 2021; Centres for Disease Control & Prevention 2014; MRC 2014). The primary purpose of both feasibility and pilot studies is to test the process, resources, management, and scientific basis of a future RCT (Tickle-Degnen 2013). Feasibility, pilot, and implementation studies are encouraged by the MRC (BMJ 2021). The NIHR (2021) suggests a pilot study is a subset of feasibility research; it asks the same questions but can also conduct a future evaluation study on a smaller scale using a randomised or non-randomised approach. Therefore a pilot study of the Calm and Connected intervention is proposed.

The pilot study will be a mixed-method pre-post analysis of the intervention conducted within one third sector organisation in Scotland. The proposed organisation was involved in co-designing the intervention and has expressed an interest in hosting this. They will form an integral part of the ongoing working group and advisory group. Similar pilot intervention studies have followed a pre-post intervention analysis format (e.g. Bailey 2014; Flynn et al. 2017; Miller 2013; Pearce et al. 2017) before undertaking a more rigorous RCT (e.g. Bailey et al. 2018).

The primary aim of this study would be to determine feasibility by measuring the number of carers interested in receiving the intervention, who participated in the intervention, their attendance and retention, completion of the pre-post study measures, and three-month follow-up. Acceptability would be assessed by the number of carers who completed the intervention, their characteristics (i.e. parents, gender, age, ethnicity), and staff and carers' satisfaction with the intervention. Appropriateness of the intervention will be assessed by outlining the needs carers expressed and comparing these to the intervention components used to meet these. A secondary aim of the study would be to evaluate the outcome benefits of the intervention in relation to carer identified unmet needs previously shown in the Logic Model (P167). Skivington et al. (2021) recommend an evaluability assessment wherein stakeholders agree together on the expected outcomes and options for designing the evaluation. Given the co-production endeavour of this intervention, this will be a key element of this stage, with valid and reliable outcome measures selected (Craig et al. 2008). The study will also include

qualitative methods involving semi-structured interviews to gather information on staff and carers' experiences of delivering and receiving the intervention and further explore the feasibility. This will further strengthen the evidence, balance out the limitations of each method and support further co-design (Regnault et al. 2018). The findings of this study will indicate if the intervention requires further development or is suitable to move to the evaluation and implementation phase in a larger study across several geographical areas to further build the evidence base.

Further research is also necessary to address the negative attitudes, knowledge, and skills of healthcare professionals, as well as the difficulties accessing care and treatment this study found. This requires exploration of professionals' views of their role in supporting people with BPD and carers. Further research is also required using interventions to improve their knowledge, skills, and attitudes alongside the service they provide; drawing on existing evidence (Dickens et al. 2015; 2016; 2018; 2019) and policy and guidelines (NICE 2009; NICE 2020; Carers Act 2016; Carers Charter 2018).

Future research should also focus on a wider demographic of participants, such as friends, broader gender groups, or eliciting the experience of carers from black and minority ethnic backgrounds. Also, evident from this study was the lack of evidence concerning experiences of violence and aggression towards carers, which is an issue and requires further examination. This study has also progressed the knowledge that there is a lack of respite or replacement care opportunities and how these carers' needs may differ from other carers. Further, from a carer's perspective, the study noted there was a lack of supported social and vocational opportunities for people with BPD. If more readily available, this could provide replacement care, create a respite for carers, as well as potentially improve the lives of people with BPD, and their carers. This requires further investigation.

6.9.1   Conclusion

This study explored the experiences and needs of carers of people with BPD, thereafter, co-designing a supportive intervention tailored for them. The research utilised the 6SQuID methodology for intervention development, underpinned by qualitative methods and a socioecological model to design an intervention that aimed to reduce the stress, burden, and negative impact carers' experience, ultimately improving their quality of life. Highlighted throughout, were the multiple and complex factors that can influence their experiences and needs. This thesis gives a rarely heard voice to carers of people with BPD which further

reveals the stressful, traumatic, and emotional toll of their day-to-day lives. The study identifies the eclectic strategies they use to care and cope illuminating that carers receive little support and need help too. Presented is a co-designed implementation plan for a new multi-component intervention called Calm and Connected. Carers and professional stakeholders were at the heart of the design and established the content to be an educational website, Decider skills course, and peer support group delivered by a third sector organisation. Despite policy ambitions, there is currently a lack of opportunities for carers of people with BPD to receive the support they need and deserve, and this intervention attempts to address this.

Further research continuing this work is required to develop and refine the intervention resources, assess, and plan what is required to deliver the proposed intervention and its' evaluation. Despite the limitations, this thesis presents an important contribution to extending the research around carers of people with BPD, supporting future policy direction, and carer support development which is necessary, important, and timely.

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Appendices

Appendix 1: Summary of personality disorder / borderline pattern

Dimension	Features
Mild	- Notable problems in many interpersonal relationships and the performance of expected occupational and social roles, some relationships are maintained / some roles carried out - Not associated with substantial harm to self or others
Moderate	- There are marked problems in most interpersonal relationships and in the performance of expected occupational and social roles across a wide range of situations that are sufficiently extensive that most are compromised to some degree - Often associated with a past history and future expectation of harm to self or others, but not to a degree that causes long-term damage or has endangered life
Severe	- There are severe problems in interpersonal functioning affecting all areas of life. The individual's general social dysfunction is profound and the ability and/or willingness to perform expected occupational and social roles is absent or severely compromised - Usually associated with a history and future expectation of severe harm to self or others that has caused long-term damage or has endangered life

Criterion
- Frantic efforts to avoid real or imagined abandonment   - A pattern of unstable and intense interpersonal relationships   - Identity disturbance, manifested in markedly and persistently unstable self-image or sense of self   - Impulsivity manifested in potentially self-damaging behaviours (e.g., risky sexual behaviour, reckless driving, excessive alcohol or substance use, binge eating)   - Recurrent episodes of self-harm (e.g., suicide attempts or gestures, self-mutilation)   - 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; typically lasts for a few hours but may last for up to several days   - Chronic feelings of emptiness; inappropriate intense anger, difficulty controlling anger manifested in frequent displays of temper (e.g., yelling or screaming, throwing, breaking things, fights)   - Transient dissociative symptoms or psychotic-like features (e.g., brief hallucinations, paranoia) in situations of high affective arousal   - Other manifestations of Borderline pattern, not all of which may be present in a given individual at a given time, include the following: a view of the self as inadequate, bad, guilty, disgusting, and contemptible; an experience of the self as profoundly different and isolated from other people   - Proneness to rejection hypersensitivity; problems in establishing and maintaining consistent and appropriate levels of trust in interpersonal relationships   - Frequent misinterpretation of social signals

Source: ICD 11 (WHO 2020) Diagnostic guideline for personality disorder

Appendix 2: Participant information sheet family/carers

Title: Family Intervention Research Study (FIRST): Supporting people who support individuals with Borderline Personality Disorder

You are being invited to take part in a research study. Before you decide you need to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us 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.

What is the purpose of the study?

To find out more about the needs of family members/carers of people diagnosed with Borderline Personality Disorder and to develop an intervention to support family members/carers. The study is designed to involve family members/carers as much as possible in the development of the intervention to ensure it is acceptable and helpful.

Why have I been invited?

You have indicated that you live with or support a person diagnosed with Borderline Personality Disorder, you live in Scotland, you are aged 18 years or older and you are willing to discuss your views and experiences with the researcher.

Do I have to take part?

No. Your participation in this study is entirely voluntary. It is up to you to decide whether to take part. We will describe the study and talk through this information sheet and answer any questions you have when we meet with you. If you do decide to take part, we will ask you to sign a consent form. You can withdraw from the study at any time without giving a reason, any support you are currently receiving will not be affected by participating in this study or if you decide to withdraw at any stage.

What will happen if I agree to take part?

The researcher will arrange a suitable time to meet for an individual interview in a private room / via telephone or Microsoft Teams. The interview will take approximately 1 hour and be audio recorded (with your permission) so that we have an accurate record of what we have talked about. The researcher will talk to you about topics such as your role in caring and supporting, challenges you have faced, what support you have received; how well your own needs are met; in situations where you have felt you required additional support, what has helped, or ideas about how you could be more effectively supported. We will also ask for some information such as gender, age, and how long you have been supporting/living with the person diagnosed with Borderline Personality Disorder.

You will also be invited to take part in two focus groups which will comprise 10-12 participants, who like yourself have experience of supporting individuals with this diagnosis. These are optional and you do not require to take part if you would prefer to be interviewed on a one-to-one basis only. The focus groups will last 3 hours, and you will be offered refreshments and a £10 shopping voucher for taking part in each one. They will involve discussing and planning the development of a supportive intervention for family members/carers. These will take place between 1 and 6 months after you complete your interview. They will take place in a private room in a convenient location.

Are there any benefits of taking part?

The interview /focus groups will allow you to talk about your views and experience which will assist us with developing an intervention programme for family members/carers. The study may not benefit you directly but the information you provide may help families and carers in the future.

Are there any potential risks in taking part?

We think the risk of harm from the research is very low. However, some people can get upset or emotional in interviews when they talk about things that are important to them. Your wellbeing is of primary importance and if you do feel emotional or upset, we can pause, take a break, or stop the interview if you prefer. We will also direct you to appropriate support if you need it after the interview or focus groups.

If you require any help and support, it may be helpful to contact your General Practitioner (GP) or contact the organisations below who provide support.

Organisation	Telephone / email
NHS 24	111
Samaritans	116 123 or jo@samaritans
Breathing Space	0800 838587
Mental Health Cairn Fowk – Carer support	07704514103 or info@dmhcairnfowk.org
Support in Mind Scotland	Scotland: 01316224359 supportinmindscotland.org.uk/contact Perth: 01738 580899 pandkinfo@supportinmind.org.uk Angus: 07734739667 or ismillie@supportinmindscotland.org

Confidentiality

Your involvement in the study will be kept strictly confidential unless you disclose details about a child or vulnerable adult at risk of harm, in this case, the researcher will need to share this information with the relevant professionals, following discussion with yourself. All the information you provide for the study will be anonymised so your identity cannot be revealed. Consent will be sought to use direct quotations with the understanding you, and anyone else you talk about, cannot be identified. Only the research team, who are bound by confidentiality will have access to your anonymised research data.

Legal basis for processing personal data

As part of the project, we will be recording personal data relating to you. This will be processed in accordance with the General Data Protection Regulation [GDPR] (2018). Under GDPR the legal basis for processing your personal data will be public interest / the official authority of the University.

What happens to the information I provide?

With your permission, your interview and focus groups will be audio-recorded on an encrypted digital voice recorder. This will be downloaded onto a University computer within 72 hours and the recording deleted. Audio files will be deleted as soon as they have been transcribed. Transcripts will be fully anonymised and stored securely. This study will comply with the Data Protection Act 2018, University of Stirling's Data Protection Code of Practice and Research Data Management Policy, and GDPR rules. Anonymised study data will be kept for 10 years on the University's secure research network. All personal identifiable data will be stored securely and destroyed within 12 months of the end of the study.

Will the research be published?

The study will be published as a Ph.D. thesis and in professional peer-reviewed journals. You will not be identifiable in any publication. A summary of the completed study will be available, and you can contact the researcher at any time if you would like an update on the study progress. In addition, it is anticipated that this research will be presented at conferences and educational workshops.

Who has reviewed this research project?

The University of Stirling NHS, Invasive or Clinical Research Ethics Committee, and NHS Research Ethics Committee [Ref: 265596] have been reviewed and approved this study.

The study is sponsored by the University of Stirling.

Who do I contact if I have any queries about this study or wish to complain?

If you would like to discuss the research with someone please text / the principal researcher: Emma Lamont; Text: (07745675820): or E: emma.lamont@stir.ac.uk).

Alternatively, you can contact an independent person, Professor Jayne Donaldson, Dean of Faculty, Health Sciences and Sport, Jayne.donaldson@stir.ac.uk, 01786 466343.

You will be given a copy of this information sheet to keep.

Thank you for your participation, Emma Lamont

Appendix 3: Carers consent form

Title: Family Intervention Research Study (FIRST): Supporting people who support individuals with Borderline Personality Disorder

Name of Researcher: Emma Lamont, Ph.D. research student, University of Stirling

	Participant: Unique ID [add] Please initial each box	
1	I confirm that I have read and understood the information sheet, dated_____, version_____, for the above project and I have had the opportunity to ask questions and I am satisfied with the answers.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without having to give a reason and without any consequences. I understand that once my data has been analysed and/or results published it will not be possible to remove my data from the study.	
3	I understand that participation in this study is confidential and my identity will not be revealed. However, I understand that if I disclose details about a child or vulnerable adult at risk of harm, the researcher will need to share this information.	
4	I agree to take part in an individual interview with the researcher.	
5	I consent to my interview being audio recorded.	
6	I agree to take part in this study.	
7	I am interested in being contacted to be invited to take part in the focus groups and provide my contact details below.	

Name of participant	**Date**	**Signature**
Name of person taking consent	**Date**	**Signature**

Contact details for focus group invitation (optional)

Appendix 4: Participant debriefing sheet

Title: Family Intervention Research Study (FIRST): Supporting people who support individuals with Borderline Personality Disorder

Thank you for taking part in this study.

 If you require any further help and support it may be helpful to contact your General Practitioner (GP) and there are a number of organisations listed below that can provide additional support.

Organisation	Telephone / email
NHS 24	111
Samaritans	116 123 or jo@samaritans
Breathing Space	0800 838587
Dundee Mental Health Cairn Fowk – Carer support	07704514103 or info@dmhcairnfowk.org
Support in Mind Scotland	Perth: 01738 580899 pandkinfo@supportinmind.org.uk Angus: 07734739667 or ismillie@supportinmindscotland.org https://www.supportinmindscotland.org.uk/

Once again, I would like to thank you for your participation, Emma Lamont

Appendix 5: Interview topic guide

Firstly, set the person at ease, tell them a little about myself, my job, professional background, and interest in this area. Make it clear they do not need to answer any questions that they feel uncomfortable about.

Example open questions

Opening questions

- What is it that interests you about this study?
- Could you tell me a little about yourself? (Who you live with, support or care for, how long for)

Life / responsibilities

- What is it like for you living with, or supporting your [insert relevant title – husband, wife, son, daughter, friend, or partner]?
- Can you tell me some of the things you do together, for [insert name]?
- Can you describe a typical day/week in relation to your life, or the support of your relative/ friend? (What do you do, how and why?)

Impact

- How would you define the impact [name] has on you, your life?
- Could you tell me how their condition affects you?
- Your home and working life? / Your health and wellbeing? Your friends and social network?
- What are your challenges and needs?
- Have things changed over time?
- What has helped/hindered this?

Problem-solving / resolving issues (including barriers/facilitators)

- What do you feel that you manage and cope with well?

Unmet needs / ongoing problems / issues (including barriers/ facilitators)

- What do you find particularly difficult to manage or cope with?
- Anything else?

What if any, formal/informal support do you receive?

(Suggestion: GP, Mental health service, carer support, friends, family)

- What has been offered / available?
- What do you think of this support?
- What, if any support do you receive from family and friends? (has this changed over time) How do you access this?
- How many people do you think to know about the caring role you play?
- How many people have you spoken to about some of the responsibilities and roles you have?
- Who do you share issues or concerns with?
- Do you use any existing support – online / carers groups?
- If you were involved in a supportive intervention how do you think they would feel?

What do you feel you could do with extra support?

- Health, social, emotional?

Now and Future (Omitted)

- What activities/events do you find meaningful, important/ enjoyable?
- If you had more time/headspace what sorts of things would you like to do?
- What are your hopes/plans for the future?
- Where do you see yourself in 6-12 months, in relation to your life, and your caring role?
- What do you feel your needs are?

Support, interventions, and design

- Do you think a supportive intervention would be something you would like?
- If yes - what would you hope to get out of it? If no - why not?
- If we were to design the ideal support intervention for you what would it include?
- What would the duration, location, mode of delivery be (group, online,–to one)?
- Who would provide this, what approaches might you like / need?

Appendix 6: Demographic questionnaire

Title: Family Intervention Research Study (FIRST): Supporting people who support individuals with Borderline Personality Disorder

Please take a few minutes to complete this questionnaire. You can leave any questions blank if you wish. If you have any questions please ask the researcher, Emma Lamont.

Which category below includes your age:	Please mark with X
18-20	40-49
21-29	50-59
30-39	60 or older
What is your gender:	
Female	Other (please specify)
Male	
What is your current relationship status:	
Married Cohabiting with a partner	Single
What is the highest level of formal education you have completed or the highest degree you have received:	
No formal education Primary school	Secondary school College or university: Bachelor's degree / Master's degree; Ph.D.; Doctorate
Which of the following categories best describes your employment status (answer more than one if applicable):	
Employed: full-time; part-time	Disabled, not able to work
Student	In receipt of welfare benefits
Retired	Receiving carers allowance
What do you understand to be your family member/friends mental health condition:	
Borderline Personality Disorder	Personality Disorder: borderline pattern
Emotionally unstable personality disorder	Other [please state]
What is their gender:	
Female	Other (please specify)
Male	
What is your relationship to the person you live with, support, or care for:	
Married / spouse	Parent
Partner	Grandparent

Sibling/brother sister	Other relatives e.g. niece/nephew
Son / daughter	N/A
Friend	
How long has this person been a part of your life / how long have you supported them:	
[ ] Years	N/A
Do you live with this person, nearby, or some distance away?	
Live with [ ] Nearby [ ] Distance away [ ]	

Many thanks for your time completing this questionnaire

Do you live with, or support someone diagnosed with Borderline Personality Disorder, in Scotland?

If yes, would you like to take part in a research study?

We would like to talk to you about your views and experiences

designed by freepik.com

This study involves an interview with the researcher and / or a focus group

For more information, please contact the researcher: Emma Lamont

Text: 07745675820; Twitter: @emmajcat73; email: emma.lamont@stir.ac.uk

This study is organised and sponsored by the University of Stirling and approved by The University of Stirling NHS, Invasive or Clinical Research Ethics Committee, and NHS Research Ethics Committee [Ref: 265596]. Looking for research participants from across Scotland.

Appendix 8: Email to professional stakeholders

Family Intervention Research Study (FIRST)

Supporting people who support individuals living with Borderline Personality Disorder

Dear colleagues,

 <u>We need your help with some exciting research into Borderline Personality Disorder</u>

Very little research exists into the support needs of people supporting individuals with borderline personality disorder (BPD), particularly in the UK where culture, health service design, and provision are unique. Recent studies suggest the negative impact and burden caring for someone with borderline PD can have and indicate that supportive intervention are beneficial for enhancing carers' knowledge, social/emotional support, and the caregiving experience. However, the current evidence is insufficient for determining which type of intervention is most effective for carers of individuals diagnosed with borderline PD. New research is warranted into the experiences of people supporting individuals with borderline PD to define and understand the problems they experience and design an intervention with them, for them.

To do this we are keen to <u>talk to any family members or carers of individuals who have borderline personality disorder.</u> I have attached further information about the study for you to read. If you know someone who may be eligible please give them this information and ask if they would be interested in talking to me, the researcher. If they say yes, please email me their contact details and I will contact them to answer any questions they may have. If they still wish to take part, I will arrange to meet them to talk.

Alternatively, if you are in contact only with the person with Borderline Personality Disorder, please give them the information attached, and ask if they can pass this to their family members/carers.

Additionally, can you please place a copy of the Information Leaflet/poster in your waiting room and share it on social media as you consider appropriate.

The information we collect from families and carers will be vital in the development of the intervention aimed at providing appropriate support to them.

Many thanks, if you have any queries please feel free to get in touch,

Emma Lamont, Ph.D. Researcher, University of Stirling

Appendix 9: Invitation to invite key stakeholders to focus groups

Title: Family Intervention Research Study (FIRST): Supporting people who support individuals with Borderline Personality Disorder

Dear [insert name]

Very little research exists into the support needs of people who are supporting individuals living with borderline personality disorder (PD), particularly in the UK where culture, health service design, and provision are unique. Recent studies suggest the negative impact and burden caring for someone with borderline PD can have; the stigma, discrimination, and dis-empowerment experienced, alongside difficulties carers have in accessing support and education for themselves (Lamont & Dickens 2019). Studies indicate that supportive psychoeducation is beneficial for enhancing carers' knowledge about mental health, the caregiving experience, social and emotional support, however, few are specific to borderline PD (Bailey & Grenyer 2013). The current evidence is insufficient for determining which type of intervention is most effective for supporting carers of individuals diagnosed with borderline PD. Furthermore, no studies reviewed used an evidence-based framework such as Intervention Mapping which has successfully provided a framework for developing health education programmes with similar aims (Bartholomew et al., 2013).

Additional research is warranted into the experiences of people supporting individuals living with borderline PD to define and understand the problems they experience and need support for. Thereafter using an Intervention Mapping approach, we will detail what an intervention co-produced by carers might involve and include combining this with a theoretical basis sufficient to gain an understanding of the mechanisms that contribute to their effectiveness or ineffectiveness (Bartholomew et al., 2013).

We would like to invite you to participate in a Stakeholder Focus Group as part of our Family Intervention Research Study (FIRST) which aims to develop an evidence-based intervention to support families /carers of individuals living with Borderline Personality Disorder or Emotionally Unstable Personality Disorder.

To date, we have talked to a number of families and carers to collate their perspectives, experiences, and potential needs from such an intervention. We now aim to create a Stakeholder Focus Group of ten family members, carers, and key informants who have expertise in this area.

This group will meet on two occasions for a half-day (3 hours) and with the help of myself, the researcher, will use the information gathered from carers to collaboratively develop an intervention aimed at providing appropriate support for families/carers.

I have attached further information about the study for you to read and would be delighted if you were interested in joining this group / or giving an interview.

I would appreciate it if you could clarify if you are in a position to help and be involved; or if you would like to meet / or talk on the phone to discuss further.

Hope to hear from you soon, many thanks,

Emma Lamont

Ph.D. Research Student, Faculty of Health Sciences and Sport, Pathfoot Building, University of Stirling, FK9 4LA.

Appendix 10: Participant information sheet for professionals

Title: Family Intervention Research Study (FIRST): Supporting people who support individuals with Borderline Personality Disorder

Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The study aims to develop an evidence-based intervention to support families /carers of individuals living with Borderline Personality Disorder. The study is designed to involve family members/carers and those with expertise, such as yourself as much as possible in the development of the intervention to ensure it is acceptable and helpful. To date, we have talked to a number of families and carers to collate their perspectives, experiences, and potential needs from such an intervention.

Why have I been invited?

You have been invited to take part in this study because you have experience and expertise in this field and may be willing to discuss your views and experiences in a focus group with the researcher.

Do I have to take part?

No. Your participation in this study is entirely voluntary and it is up to you to decide. We will describe the study and talk through this information sheet and answer any questions you have when we meet with you. If you do decide to take part, we will then ask you to sign a consent form to show you have agreed to take part. You can withdraw from the study at any time without giving a reason and without penalty by advising the researcher of this decision.

What will happen if I agree to take part?

You will be invited to take part in four focus groups which will comprise 10-12 family/carers and professionals who like yourself have experience of supporting individuals and families with Borderline Personality Disorder. The focus groups will last 3 hours, and you will be offered refreshments throughout. Groups will involve discussing and planning the development of the supportive intervention. These will take place in a private room, in an NHS Tayside Community Mental Health Team premises at a mutually agreeable time over 4- 6 months.

Are there any benefits of taking part?

The meetings will allow you to talk about your views and experience which will assist us with developing a carer intervention programme. The study may not benefit you directly but the information you provide may help families and carers in the future.

Are there any potential risks in taking part?

We think the risk of harm from the research is very low. However, some people can get upset or emotional when they talk about things that are important to them. Your wellbeing is of primary importance and if you do feel emotional or upset, we can pause, you can take a break,

or stop if you prefer. We will also direct you to appropriate support if you need it during or after the interview.

Confidentiality

Confidentiality and anonymity are assured with all information you provide for the study being anonymised; your name and any data that could identify you or any other person will be removed or changed to ensure identities cannot be revealed. Consent to use direct quotations is with the understanding that neither you nor any other person will be identifiable. Only the research team, who are bound by a confidentiality agreement, will have access to the research data.

Legal basis for processing personal data

As part of the project, we will be recording personal data relating to you. This will be processed in accordance with the General Data Protection Regulation [GDPR] (2018). Under GDPR the legal basis for processing your personal data will be public interest / the official authority of the University.

What will happen to the information I provide?

Focus groups will be facilitated by the researcher who is experienced in this area; notes will be taken to document ideas, decisions, and plans. These will be shared with the group before each focus group. As well as tabled discussions, group activities to illicit ideas and information will be noted by using flip charts and post-it notes. With your permission, the focus groups will be audio-recorded on an encrypted digital voice recorder. This will be downloaded onto a University computer within 72 hours and the recording deleted. Audio files will be deleted as soon as they have been transcribed. Transcripts will be fully anonymised and stored securely. This study will comply with the Data Protection Act 2018, University of Stirling's Data Protection Code of Practice and Research Data Management Policy, and GDPR rules. Anonymised study data will be kept for 10 years on the University's secure research network. All personal identifiable data will be stored securely and destroyed within 12 months of the end of the study.

Will the research be published?

The study will be published as a Ph.D. thesis and in professional peer-reviewed journals. You will not be identifiable in any publication. Participants will be provided with a summary of the completed study and can contact the researcher at any time if they would like an update on the study progress. In addition, it is anticipated that this research will be presented at conferences and educational workshops.

Who has reviewed this research project?

The University of Stirling NHS, Invasive or Clinical Research Ethics Committee and NHS Research Ethics Committee [Ref: 265596] have been reviewed and approved this study.

The study is sponsored by the University of Stirling.

Who do I contact if I have any queries about this study or wish to complain?

The study is sponsored by the University of Stirling. If you would like to discuss the research with someone please contact the principal researcher: Emma Lamont, T: 01786 466397; or E: emma.lamont@stir.ac.uk).

Alternatively, you can contact an independent person Professor Jayne Donaldson, Dean of Faculty, Health Sciences and Sport, Jayne.donaldson@stir.ac.uk, 01786 466343.

You will be given a copy of this information sheet to keep.

Thank you for your participation

Appendix 11: Consent form for professionals

Title: Family Intervention Research Study (FIRST): Supporting people who support individuals with Borderline Personality Disorder

Name of Researcher: Emma Lamont, Ph.D. research student, University of Stirling

Participant: Unique ID [add]

		Please initial each box
1	I confirm that I have read and understood the information sheet, dated_____, version_____, for the above project and the researcher has answered any questions to my satisfaction.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without having to give a reason and without any consequences. I understand that it will not be possible to remove my data from the focus groups from the study.	
3	I understand that my participation in this study is confidential and my identity will not be revealed.	
4	I consent to my ideas and views being documented in notes and on flipchart activities for the purposes of the project.	
5	I consent to the focus groups being audio recorded.	
6	I agree to take part in four focus groups with the researcher.	
7	I agree to take part in this study.	

Name of participant	Date	Signature
Name of person taking consent	**Date**	**Signature**

Appendix 12: Recruitment options flowchart

BPD Family intervention research study referral / recruitment options

*More than one can be used

Option 1

CMHT practitioners will identify service users they provide support to with a diagnosis of BPD and any carers who may be interested in taking part in study

Give the service user an information leaflet and participant information sheet and ask them to give to the carer

If carer interested they can contact the researcher who will give them more information about the study and answer any questions

Option 2

CMHT practitioners will identify carers who may be eligible, where they have the opportunity for direct contact with them

They will tell the carer about the study giving them an information leaflet and participant information sheet

If carer is interested the practitioner will ask them to sign an 'expression of interest consent form' adding their contact details which the practitioner will share with the researcher to contact

Option 3

Posters sent / shared via NHS Tayside's CMHT, Support in Mind Scotland, Cairn Fowk, Scottish Personality Disorder Network, Twitter, posters shared on social media and websites

They will display these within their centres and on social media sites such as Facebook and Twitter

If carer is interested they will contact the researcher who will give more details about the study and answer any questions - recruit

Family Intervention Research Study V3.0 - 19/11/19

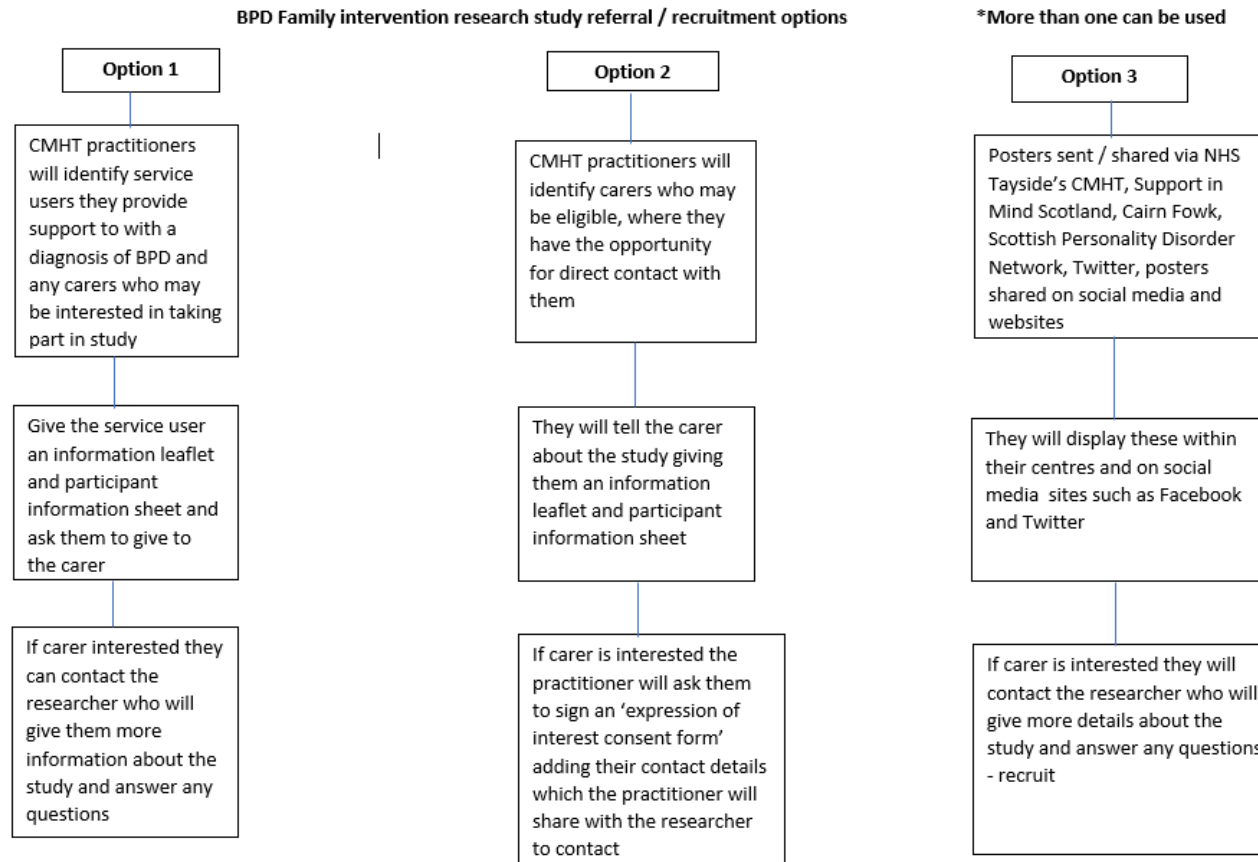## Appendix 13: Expression of interest/consent to contact (carers)

Title: Family Intervention Research Study (FIRST): Supporting people who support individuals with Borderline Personality Disorder

Name of Researcher: Emma Lamont, Ph.D. student, University of Stirling

I would like to express my interest in taking part and agree to [insert practitioner name] ……………… passing my contact details to Emma Lamont (the researcher) for the above study.		
Name: **Address:** **Telephone number:**	**Date**	**Signature**
Email address:		
Name of person taking consent to contact:	**Date**	**Signature**

Appendix 14: Consent form for family/carers focus groups

Title: Family Intervention Research Study (FIRST): Supporting people who support individuals with Borderline Personality Disorder

Name of Researcher: Emma Lamont, Ph.D. research student, University of Stirling

Participant: Unique ID [add]

		Please initial each box
1	I confirm that I have read and understood the information sheet, dated_____, version_____, for the above project and I have had the opportunity to ask questions and I am satisfied with the answers.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without having to give a reason and without any consequences. I understand that it will not be possible to remove any data that has been analysed as this will already be anonymised and unidentifiable.	
3	I understand that participation in this study is confidential and my identity will not be revealed. However, I understand that if I disclose details about a child or vulnerable adult at risk of harm, the researcher may need to share this information.	
4	I agree to take part in the focus groups.	
5	I consent to my ideas and views being documented in notes and on flipcharts for the purposes of the project.	
6	I consent to the focus groups being audio recorded.	
7	I agree to take part in this study.	

Name of participant	**Date**	**Signature**
Name of person taking consent	**Date**	**Signature**

Appendix 15: Focus group topic guide

At the start of each focus group– welcome and introduce the group, agree on ground rules/ways of working with the group following the Chatham House Rules (1927). This is where participants are free to use the information received, but neither the identity nor the affiliation of the speaker, nor any other participant, is revealed.

- Each focus group will receive a short ten-minute presentation by the researcher at the outset informing them of the scope and purpose of the group, and the findings of the carers qualitative study. Following this, a discussion will be encouraged in relation to the following questions:

- What would a resource or intervention look like?
- What would be the key issues for the resource to address?
- What would it include? What would the format be? How would you like it delivered?
- What should the individual components (content, theory stance) of the intervention be?
- How should the intervention be implemented (e.g. duration, frequency, and delivery of each component?)

Appendix 16: Ethics Approvals

UNIVERSITY of STIRLING

NHS, Invasive or Clinical Research (NICR) Committee

Emma Lamont
Faculty Health Sciences and Sport
University of Stirling
FK9 4LA

Research and Innovation Services
3B1 Cottrell Building
University of Stirling
Stirling   FK9 4LA

11 July 2019

Tel: +44 (0) 1786 466233
Email: nicr@stir.ac.uk

Dear Emma,

Project Title: Supporting people who support those living with Borderline Personality Disorder
NICR 18/19 – Paper No. 051

Thank you for your email in response to the NICR correspondence dated 4 July 2019.

I am happy to approve your study under Chair's Action for the NICR Panel and authorise its submission to NHS Research Ethics Committee.

May I remind you of the need to inform NICR (nicr@stir.ac.uk) prior to making any amendments to this protocol, or any changes to the duration of the project and provide notification of study completion.

Please bear in mind that your study could be audited for adherence to research governance and research ethics protocols.

NICR 18/19 – Paper No. 051
Please quote this number on all correspondence

Yours sincerely

Dr Josie Evans
(Depute Chair)

London - Surrey Borders Research Ethics Committee

05 November 2019

Ms Emma Lamont
University of Dundee
62 Fairies Road
Perth
PH1 1LX

Dear Ms Lamont,

Study title:	Family Intervention Research Study (FIRST): Supporting people who support individuals with Borderline Personality Disorder
REC reference:	19/LO/1452
Protocol number:	1
IRAS project ID:	265596

Thank you for your letter of 16 October 2019, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved on behalf of Chair.

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.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given

permission for the research to proceed (except where explicitly specified otherwise).

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.

<u>Registration of Clinical Trials</u>

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register 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/

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

You should notify the REC of the registration details. We routinely audit applications for compliance with these conditions.

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

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

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [University Ethics]		
Copies of advertisement materials for research participants [poster]	V2.0	02 July 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor insurance]	1	12 July 2019
Interview schedules or topic guides for participants [Interview]	V2.0	02 July 2019
IRAS Application Form [IRAS_Form_19082019]		19 August 2019
Letter from sponsor [Letter from sponsor]	1	12 July 2019
Letters of invitation to participant [Invitation]	V2.0	02 July 2019
Non-validated questionnaire [APPENDIX 6 Tracked changes]	V3.0	30 September 2019
Non-validated questionnaire [APPENDIX 6 New version]	V3.0	30 September 2019
Other [Consent form / Profs.]	V2.0	02 July 2019
Other [Consent form / focus group]	V2.0	02 July 2019
Other [Expression of interest]	V2.0	02 July 2019
Other [Debriefing]	V2.0	02 July 2019
Other [Minor amendments]	V2.0	04 July 2019
Other [CV - supervisor]		06 July 2019
Other [APPENDIX 10 Tracked changes]	V3.0	30 September 2019
Other [APPENDIX 10 New version]	V3.0	30 September 2019
Other [APPENDIX 8 Tracked changes]	V3.0	30 September 2019
Other [APPENDIX 8 New version]	V3.0	30 September 2019
Other [APPENDIX 5 Tracked Changes]	V3.0	30 September 2019
Other [APPENDIX 5 New version]	V3.0	30 September 2019
Other [APPENDIX 9 Tracked Changes]	V3.0	30 September 2019
Other [APPENDIX 9 New version]	V3.0	30 September 2019
Other [Response to ethical review]	V1.0	02 October 2019
Participant consent form [Consent]	V2.0	02 July 2019
Participant information sheet (PIS) [APPENDIX 1 New version]	V3.0	30 September 2019
Participant information sheet (PIS) [APPENDIX 1 Tracked Changes]	V3.0	30 September 2019
Research protocol or project proposal [Protocol]	V2.0	12 July 2019

Summary CV for Chief Investigator (CI) [CV CI]		12 July 2019
Summary CV for student [CV]		12 July 2019
Summary CV for supervisor (student research) [CV]		04 June 2019
Summary, synopsis or diagram (flowchart) of protocol in non technical language [referral options]	V2.0	02 July 2019

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/

19/LO/1452	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely,

Ms. Christine Braithwaite
Chair

Email: nrescommittee.london-surreyborders@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Ms Rachel Beaton

NHS Tayside

07 November 2019

Ms Emma Lamont
University of Dundee
City Campus
11 Airlie Place
Dundee
DD1 4HJ

Dear Ms Lamont,

R&D MANAGEMENT APPROVAL – TAYSIDE

Title: Family Intervention Research Study (FIRST): Supporting people who support individuals with Borderline Personality Disorder

Chief Investigator: Ms Emma Lamont

Principal Investigator/Local Collaborator: Ms Emma Lamont

Tayside Ref: 2019MH06   NRS Ref: n/a   IRAS ID: 265596

REC Ref: 19/LO/1452

Sponsor: University of Stirling

Funder: Unfunded Study

Many thanks for your application to carry out the above project here in NHS Tayside. I am pleased to confirm that the project documentation (as outlined below) has been reviewed, registered and Management Approval has been granted for the study to proceed locally in Tayside.

Approval is granted on the following conditions:-

- ALL Research must be carried out in compliance with the Research Governance Framework for Health & Community Care, Health & Safety Regulations, data protection principles, statutory legislation and in accordance with Good Clinical Practice (GCP).

- All amendments to be notified to TASC R&D Office via the correct amendment pathway. Either direct to the R&D Office or via the Lead Co-ordinating Centre depending on how the study is set up.

- All local researchers must hold either a Substantive Contract, Honorary Research Contract, Honorary Clinical Contract or Letter of Access with NHS Tayside where required (http://www.nihr.ac.uk/about-us/CCF/policy-and-standards/research-passports.htm).

- TASC R&D Office to be informed of change in Principal Investigator, Chief Investigator or any additional research personnel locally.

- Notification to TASC R&D Office of any change in funding or an extension to study timelines.

- As well as any obligations to your Sponsor, you are required to notify TASCgovernance@dundee.ac.uk of all serious breaches of GCP and Serious Unexpected Serious Adverse Reactions (SUSARs) for Hosted Clinical Trials of Investigational Medicinal Products (CTIMPs).

- As custodian of the information collated during this research project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT Security Policies, until destruction of this data.

- All eligible and adopted studies will be added to the Central Portfolio Management System (CPMS). Recruitment figures for eligible and adopted studies must be recorded onto the Portfolio every month. This is the responsibility of the lead UK site. If you are the lead, or only UK site, we can provide help or advice with this. For information, contact the local Portfolio team at tascportfolio.tayside@nhs.net.

- Annual reports are required to be submitted to TASC R&D Office with the first report due 12 months from date of issue of this management approval letter and at yearly intervals until completion of the study.

- Notification of early termination within 15 days or End of Trial within 90 days followed by End of Trial Report within 1 year to TASC R&D Office.

- You may be required to assist with and provide information in regard to audit and monitoring of study.

Please note you are required to adhere to the conditions, if not, NHS management approval may be withdrawn for the study.

Approved Documents

Document	Version	Date
IRAS - 265596/1359825/37/895		13/08/2019
Localised OID	1.0	18/09/2019
University Ethics		
Study Poster	2.0	02/07/2019
Sponsor insurance		12/07/2019
Interview schedule	2.0	02/07/2019
Letter from sponsor		12/07/2019
Letters of invitation to participant	2.0	02/07/2019
Questionnaire	3.0	30/09/2019
Participant Information Sheet - Professionals	3.0	30/09/2019
Participant information sheet	3.0	30/09/2019
Consent Form - Professionals	2.0	02/07/2019
Consent Form – Focus Group	2.0	02/07/2019
Participant consent form	2.0	02/07/2019
Expression of interest	2.0	02/07/2019
Invite to referrers	3.0	30/09/2019
Invite to Professionals	3.0	30/09/2019
Focus topic guide	3.0	30/09/2019
Debriefing	2.0	02/07/2019

Minor amendments		01/07/2019
Protocol	2.0	12/07/2019
Flowchart / Referral Options	2.0	02/07/2019
CV – E. Lamont (CI / PI / Student)		12/07/2019
CV – A. Whittaker (Supervisor)		04/06/2019
CV – M. Maxwell (Supervisor)		09/07/2019

May I take this opportunity to wish you every success with your project.

Please do not hesitate to contact TASC R&D Office should you require further assistance.

Yours sincerely

Elizabeth Coote
Head of Non-Commercial Research Services

TAyside medical **S**cience **C**entre (TASC)
Ninewells Hospital & Medical School
TASC Research & Development Office
Residency Block, Level 3
George Pirie Way
Dundee DD1 9SY
Email: liz.coote@nhs.net
Tel: 01382 383876   Fax: 01382 740122

C.c.   margaret.maxwell@stir.ac.uk
        anne.whittaker@stir.ac.uk
        Tascportfolio.tayside@nhs.net

26 November 2019

Miss Emma Lamont
University of Dundee
City Campus
11 Airlie Place
Dundee
DD1 4HJ

Dear Miss Lamont,

ACCEPTANCE OF AMENDMENT LETTER

Title: Family Intervention Research Study (FIRST): Supporting people who support individuals with Borderline Personality Disorder

Chief Investigator: Ms Emma Lamont

Principal Investigator/Local Collaborator: Ms Emma Lamont

Tayside Ref: 2019MH06   IRAS ID: 265596

REC Ref: 19/LO/1452

Amendment Number: NSA1   Amendment Date: 11 November 2019

Thank you for submitting the above amendment for review by the R&D Office here in NHS Tayside. Following my assessment of the proposed changes I am pleased to confirm that **subject to the following condition** NHS Tayside has no objection to these being implemented locally:

- **You may not implement this amendment until and unless you receive, and forward to the R&D Office, all required ethical and/or regulatory approvals (where applicable).**

Approved Documents

Document	Version	Date
Notification of Non-substantial Amendment		11 November 2019
Notification Email		19 November 2019
Appendix 1: Participant Information Sheet	4	14 November 2019
Appendix 12: Referral Options	3	14 November 2019

I thank you for keeping the R&D Office informed of the study progress.

Version 1.0 dated 28/01/19
Non-NRS Study Amendment Approval

- 1 -

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Yours Sincerely

Elizabeth Coote
Head of Non-Commercial Research Services

TAyside medical **S**cience Centre (TASC)
Ninewells Hospital & Medical School
TASC Research & Development Office
Residency Block, Level 3
George Pirie Way
Dundee DD1 9SY
Email: liz.coote@nhs.net
Tel: 01382 383876 Fax: 013812 740122

C.c.   Professor Margaret Maxwell – margaret.maxwell@stir.ac.uk
        Professor Anne Wittaker – anne.wittaker@stir.ac.uk
        Mrs Rachel Beaton – Rachel.beaton@stir.ac.uk

Appendix 17: Quality appraisal of included studies in the literature review

All papers selected for inclusion were assessed for methodological quality and risk of bias by the principal researcher and a second independent researcher using standardised critical appraisal instruments from the Joanna Briggs Institute (2017). Due to the variety of study designs we employed this approach using three critical appraisal checklists: Checklist for Randomised Controlled Trials; Checklist for Quasi-Experimental Studies (non-randomised experimental studies); Checklist for Qualitative Studies (Joanna Briggs 2017). These were summarised in each of their categories.

Checklist for Randomised Controlled Trials

This checklist asked 13 questions of the reviewers; two questions were excluded from the appraisal as the reviewers agreed these were impossible to achieve. These pertained to if participants were blind to treatment assignment, and if those delivering treatments were blind to treatment assignment. It was agreed that those receiving the intervention support knew they were, others knew they were receiving care as usual or on a waiting list; similarly, those delivering the intervention knew they were. As a result, they did not feature in the final score, 11 being the maximum.

Randomisation

Six of the twelve RCT studies were randomized for assignment of participants to treatment groups using computer-generated randomization lists and presented as low risk of bias (Bateman 2014; Chien et al., 2016; Grenyer et al., 2018; Hubbard et al., 2016; McCann et al., Madigan et al., 2012). Two studies (Navidan et al., 2012; Weissman et al., 2019), were unclear and a medium risk as they gave little information on recruitment or randomization but said that participants were randomised to either control or intervention group. Four were at high risk of bias as they did not use clear randomization methods, for example, Bademli et al., (2014) gave participants a piece of paper with A or B, which gave potential for bias or swapping numbers; Deane et al., (2017) used a random number generator but participants were assigned by block randomization based on the age of relatives; Koshnab et al., (2014) had various levels of cluster and multistage sampling before block randomization, and Lopez et al., (2015) used a convenience sample by the order that participants arrived.

Allocation concealment

For most studies, allocation concealment was not achieved (Bademli et al., 2014; Grenyer et al., 2018; Hubbard et al., 2016; Lopez et al., 2015), or there was insufficient information to

make an informed judgement (Deane et al., 2015; Madigan et al., 2012; Navidan et al., 2012; Weissman et al., 2016). Four studies reported procedures for allocation concealment that were deemed low risk (Bateman & Fonagy 2018; Chien et al., 2016; Koshnab 2014; McCann et al., 2013).

Treatment groups similar at the baseline

Nine studies were assigned low risk as they reported that treatment groups were similar at baseline (Bademli et al., 2014; Batemen & Fonagy 2018; Chien et al., 2016; Deane et al., 2015; Grenyer et al., 2018; Hubbard et al., 2016; Koshnab et al., 2014; Madigan et al., 2012; Navidan et al., 2012). Two were unclear, with Lopez et al., (2015) and Weissman et al., (2015) giving very little information about participants. McCann et al., (2013) was assigned high risk as they were not similar, demographics showed that there was a significantly longer time since diagnosis in the intervention group.

Blinding of outcome assessment

The outcomes assessors were described as blind to treatment assignment in three studies and considered low risk of bias (Madigan et al., 2012; McCann et al., 2013; Chien et al., 2016). In some studies, this was unclear, as data was self-reported or collected via computer (Bateman & Fonagy 2018; Grenyer et al., 2018; Koshnab et al., 2014; Lopez et al., 2015); others gave little detail to ascertain (Deane et al., 2015; Hubbard et al., 2016; Navidan et al., 2012; Weissman 2019). Bademli et al., (2014) did not blind assess as they gave questionnaires to different groups inferring they knew the groups.

Treatment groups treated identically

Six of the twelve studies were deemed low risk of bias as they detailed how treatment groups were treated identically to the intervention group (Chien et al., 2016; Grenyer et al., 2018; Koshnab et al., 2014; Madigan et al., 2012; McCann 2013; Weissman 2016). Three were unclear, for example, Bademli et al., (2014) gave little detail; Bateman and Fonagy (2018) offered delayed intervention therefore a longer time between baseline and follow up for the control group, and Navidan et al., (2012) gave little information however both groups received usual care plus or minus the intervention. In three studies groups were treated differently, Lopez et al., (2015) gave questionnaires at different times in the control and intervention groups and the intervention groups received three with the control group only two. With Hubbard et al., (2016) the waitlist group collected an extra data collection time point as well as having to wait during the control period before they received the intervention. While with Deane et al., (2015) the control group received an information booklet to read and the

intervention group received the information booklet plus 12 interactive newsletters over one year.

Incomplete outcome data

In seven studies the risk of bias was low as the follow up was reported as complete, or if not differences between groups in terms of their follow up was adequately described and analysed (Bademli et al., 2014; Bateman & Fonagy 2018; Chien et al., 2016; Grenyer et al., 2018; McCann et al., 2013; Navidan et al. 2012; Weissman et al., 2019;). Three studies were unclear and had a medium risk of bias giving little information or reasons about dropout rates (Lopez et al., 2015; Fallahi Koshnab et al., 2014), Hubbard et al., (2016) only gave illness/ work as reasons. While Deane et al., (2015) provided a detailed diagram of dropouts they did not give information about the difference between the two groups. In all studies participants were analysed in the groups they were randomised to.

Outcomes measured in the same and reliable way

Most studies were measured in the same way for both groups and assigned a low risk of bias (Bateman and Fonagy 2018; Chien et al., 2016; Deane et al., 2015; Fallahi Koshnab et al., 2014; Grenyer et al., 2018; Madigan et al., 2012; McCann et al., 2013; Navidan et al., 2012; Weissman et al., 2016). Three studies were high risk, Bademli et al., (2014) measured questionnaire instruments at more time. Hubbard et al., (2016) reported the baseline the same, but waitlist participants took part in an extra outcome data collection point; while Lopez et al., (2016), reported the intervention group collected data at baseline, end of the intervention, and then + 6 months, versus the control group who were at baseline and baseline + 6 months. Ten studies were assessed as having a reliable procedure for reporting outcomes and presented an as low risk of bias (Bademli et al., 2014; Chien et al., 2016; Deane et al., 2015; Hubbard et al., 2016; Koshnab et al., Lopez et al., 2016; Madigan et al., 2012; McCann et al., 2013; Navidan et al., 2012; Weissman et al., 2016). Two studies Bateman & Fonagy 2018; Grenyer et al., 2018) were assigned as unclear as they used self-reported questionnaires which were not necessarily reliable.

Appropriate design and statistical analysis

In nine studies the design was assessed as appropriate (Bademli et al., 2014; Chien et al., 2016; Deane et al., 2015; Grenyer et al., 2018; Koshnab et al., Lopez et al., 2016; Madigan et al., 2012; McCann et al., 2013; Weissman et al., 2016). Bateman and Fonagy (2018) conducted a step wedge (delayed intervention) trial, so control results were only available for 3 weeks; similarly, for Hubbard et al., (2016) a trial design was appropriate, but no information was given why a step wedge design was used rather than one group simply not receiving the

intervention. Navidan et al., (2012) gave very little information about the trial design so unclear. In all studies, appropriate statistical analysis was used.

Checklist for Quasi-Experimental Studies (non-randomised experimental studies)

This checklist asked nine questions of the reviewers, one question was not applicable as there were no comparison groups therefore removed. The total score that a study could achieve is eight.

Cause and effect

All four studies (Flynn et al., 2017; Miller 2013; Pearce et al., 2019; Roddy et al., 2019) were clear on the cause and effect, this being intervention studies that collected data pre and post-intervention. Likewise, all studies included similar participants who were carers and met the inclusion criteria.

Control group, comparisons receiving similar treatment

There were no comparison participants or control groups in two studies (Miller 2013; Roddy et al., 2015). Pearce et al., (2017) had no control group in their study however, those not taking part were offered an alternative intervention as care as usual, but no data was collected to compare. Flynn et al., (2017) had a control group receiving optimised treatment as usual which involved a short psycho education course with some similar components but not evidence-based.

Measurements and follow up

There were multiple measurements of the outcome both pre and post the intervention in all four studies (Flynn et al., 2017; Miller 2013; Pearce et al., 2017; Roddy et al., 2015). In Pearce et al., (2017) follow-up was not complete but differences were described and viewed as low risk of bias; Roddy et al., (2015) were not complete and the description identified that all were analysed the same, meaning a high risk of bias. Low risk of bias was assessed for outcomes as they were measured in a reliable way within the studies using standardised questionnaires and appropriate statistical analysis. Flynn et al., (2017) highlighted dropout rates were similar in both intervention and control groups, and most completed post-intervention measures with three months follow up for both groups but only 12-19 month follow up for the FC group limiting the comparison. These were analysed appropriately. Miller (2013) had no control group and there was no follow-up beyond the immediate post-intervention measure limiting the quality of findings.

Checklist for Qualitative Studies

This checklist asked ten questions of the reviewers, the total score that could be achieved was ten. There was little information about the philosophical perspective to judge if there was congruity in the McCann et al., (2014) study; Whitehorn et al., 2017 used interpretive phenomenology and was considered a low risk of bias. Both studies had congruity between the research methodology and the methods used to collect the data assessed as a low risk of bias. In McCann et al., (2014) there was congruity between the research methodology, the representation, analysis of data, and interpretation of results was considered to be a low risk of bias; this was unclear in Whitehorn et al.,(2017) as little detail given, therefore judged to be a medium risk. McCann et al., (2014) did not offer a statement locating the researcher culturally or theoretically or address the influence of the researcher on the research while Whitehorn et al., (2017) gave a statement regarding the researcher but did not consider their influence on the research. In both studies, participants, and their voices, were not adequately represented and assessed as high risk of bias. Both studies were ethical according to current criteria had evidence of ethical approval by an appropriate body. For both studies conclusions drawn in the research report flowed from the analysis, or interpretation, of the data as presented, however, given the risk of bias for representation of participants this was unclear and considered a medium risk of bias.

Summary

Study quality was rated generally high. Nine out of twelve RCT studies achieved more than half of the quality checks - (Mdn = 7.3, range between 4-11); the mixed methods studies achieved almost all quality checks (Mdn= 7.5, range between 7-8); both of the qualitative studies achieved six out of ten in quality checks. Studies were included in analyses irrespective of their quality; however, more robust studies were assigned a greater weight in integration and discussion (Atkins et al., 2008; Dixon-Woods et al., 2007).

Appendix 18: Examples of thematic datasets developed using Framework Analysis

1. **Experience of health care**

Experience of diagnosis	Perception of care and treatment approaches
FC2: Diagnosis making sense of behaviour FC2: "Before his diagnosis, it was hard because I just thought he was being grumpy or he was being argumentative, or he was just being really detached. Since his diagnosis, I think it's almost in a way a little bit harder because now I know that there's no way of altering that and that is what we have to deal with. It can go for months with it being absolutely fine, and then we have massive big flare ups and he goes either really high or really low most of the time, which is quite difficult to manage. So he has significant highs and significant lows. For example… and they become really, really exaggerate in social situations and really, really noticeable now that we know they've 'got a name' you know, now that we know it's a diagnosis". Whereas since our diagnosis, then as hard as it is to deal with the fact that there is something clinically wrong with him, it's easier to know that this is what it is, and it's not me necessarily." **FC2: Journey to diagnosis** "It's been an exceptionally long journey. We asked for his records from the doctors, so from the age of 2 he was diagnosed with anxiety – he was being sick and having these strange attacks; and his family moved him around the countryside a great deal, and we couldn't really understand why. There was a note on this to suggest that this was child abuse, so they moved and it was never followed up – his parents always said he had ADHD.. because if he had been diagnosed a lot earlier then I think he would have been a lot further down the line by now, but because it's still early days and a lot of the diagnosis was about accepting what was wrong with him, and accepting that he wasn't born this way and there was a lot of guilt." **FC6: BPD diagnosis mentioned as a throw away remark** "I think because it was mentioned that he had Borderline Personality Disorder, it was mentioned by a nurse but nothing was ever followed up. Very briefly, my son was on several different mental health medications but never had a diagnosis of any kind, and the comment almost seemed to be throwaway by the nurse."	**FC1: Unhappy about restraint and bruising** "Having to stand up, you know, things like 'why are you doing a face down restraint on someone with sexual abuse, why?' 'why are there bruises all up her arms?' 'why are you throwing her into the wall?' 'oh we didn't do that', so I went and asked her the next day, having spoken to the person who denied that that happened and gave me all this what we would want to hear talk." **FC1: Giving more than one diagnosis but no access to treatment, not recognising trauma** "Navigating the system as a person with a label, I don't want to even give it the word diagnosis, she's labelled and she's got more than one label now because they added, and when I asked them about it, I said 'well what does that mean, does that mean she's no longer considered to have Borderline anymore?' 'oh no this is a working diagnosis' 'so you're just giving a label to symptoms, you're not looking at the root cause which is trauma she experienced in childhood, when are you going to treat that?' 'when she's stable', and when's that going to be?" x months down the line no treatment." **FC1: Not receiving support to do what best suits her – so that being left to me**"CPN that she can get a support worker, well what does that mean, I said 'you need to ask what that means'; take her for a coffee or take her swimming or… she says 'I don't want to go swimming, I don't want to go for a coffee and make polite conversation with somebody that I don't know and don't want to go to the gym' she's overweight because of the medication, the cocktail of stuff she's on, so what would be good is if somebody could drive her to the kind of things that she'd want to do so that she's not having to spend an hour on a bus to go somewhere that would take half an hour in a car, so she could get to do something but I don't know if that's going to be the support that she can get from support workers, maybe not going to be what would best suit her, so it's going to be back down to me to do the kinda stuff that would best suit her" **FC2: Being lost in the system and failed by the system many times even now** "And a lot of it, the one he went to see from the mental health nurse, basically said he has been lost in the system. So he kind of has been failed by the system, because if he had been diagnosed a lot earlier then I think he would have been a lot further down the line by now, but because it's still early days and a lot of the diagnosis was about accepting what was wrong with him, and accepting that he wasn't born this way and there was a lot of guilt… So that has been a lot to deal with, and a long journey. epsy drugs. And they said they were going to take him off them after quite a lot of debate. So he then got referred to a psychologist at that point, basically told him how to manage his relationship with his parents as he was still in touch with them at that point, and then there was nothing! Discharged and absolutely nothing after that."

2. **Experience of life and support provided**

Interpersonal and relational aspects	Practical and emotional support given
Learning coping strategies and techniques: **FC2:** "I think making sure, if it was a bad week, I would have to ensure that I paid him attention, and make sure to check in with him. I'm very aware now of when starts to do the whole splitting thing, and I've done quite a lot of reading on it" **FC3:** "That is what I could cope with but I would say all of those coping tools were built from my own self-care insight and research into the disorder, none of… in fact, an important point, I was given no real direction insight in how best to respond and to manage" **FC9:** "Yes, yes and it did work but, I mean, as I say, I weighed out the pros and cons and thought this could either be really bad or really good, and it's worked and it really has worked. I think because he doesn't have to get any buses or anything like that, and it's okay people saying 'oh I wouldn't put up with that, don't let him in your house', not quite so simple as you think. So that seems to have worked a lot better, he's moved here and he's got his own space and it's just round the corner and it seems to be working. But I'll never say never" **FC9:** "Yes, yes and it did work but, I mean, as I say, I weighed out the pros and cons and thought this could either be really bad or really good, and it's worked and it really has worked. I think because he doesn't have to get any buses or anything like that, and it's okay people saying 'oh I wouldn't put up with that, don't let him in your house', not quite so simple as you think. So that seems to have worked a lot better, he's moved here and he's got his own space and it's just round the corner and it seems to be working. But I'll never say never" **FC3: Having to change plans** "The unpredict… I think becoming acquainted with unpredictability and being able to plan ahead to do something, so if you were going to definitely do something on this day that was very difficult to do, and sometimes having to change plans, that was difficult" **FC4:** "The older x got the harder it was for her – she didn't get better she was getting worse and finding it really hard to go out of the house or mix with other people – if we planned to do anything it had to be well planned to make sure it wasn't going to be too much for her – e.g. she could manage a trip to the cinema and then go for tea after if I picked her up and dropped her off but then if we tried to add something like meeting up with another friend too then it could become too much for her – and the next day she would be feeling really anxious and depressed – texting and phoning me a lot for reassurance – I also had to understand that x could change her mind on the day if she wasn't feeling up to meeting or going out – she let me down a lot like that but I just had to get used to it.	**Supporting through work and education issues** **FC6:** "Yes that I think. And when he did have all these difficulties at school and at work, and don't get me wrong I was never one of these mums that my child was faultless, but actually, certainly at work, it was completely unfair and my late husband, x stepdad, he worked in the Estates Department at x as well and I knew from what he was telling me that he was witnessing was that it was not fair on x, it wasn't me being the protective mama, and I supported him through two or three really difficult situations and they sacked him in the first three days of his apprenticeship because he had his hat on in class. It was a baseball cap and actually looking at things I've read and looking at other people and knowing x, his hat was his hiding cause sometimes he'd have his hoodie up and his hat and it was just he needed that, and to sack him for something like that was ridiculous. And I fought really hard to get his job back cause he'd been employed temporarily but for two years as a labourer, and now in hindsight maybe if I hadn't and he could've gone somewhere else life might have been easier. But the only thing you can do is do what you think's best at the time, and maybe if I hadn't maybe he'd of got started with somebody that understood him better, so yeah it's difficult" **FC10:** "She got a job in the schools as an assistant with a view to doing a course along those lines, and I remember at the time, you know, when she started saying the same stuff again like 'oh the teacher I'm with she sabotages everything that I… she doesn't like me' and all this, so you know, I would get up and I'd say 'well I'll walk you down to school' so I would go down to see her in the door kind of thing and then sometimes meet her after, you know, but then eventually that didn't really help. And I actually went along to meetings with the head teacher and the deputy head and I could see that they were bending over backwards, you know, to keep her going but [sigh] she just let it go. And then she was unemployed and she's been unemployed since then" **FC12:** "Outwardly he can cope better and he's managing to keep his job, he's had a job for over a year now, he works in a busy hotel and even when he's having a lot of… he's had a few episodes where he's stormed out, he's told them he's quitting several times but they've not accepted it and fortunately he's got a very supportive environment there, they do understand and he's always been able to come back and carried on". **FC16:** "Like, for example, I have a little shop in x and although she's had little jobs in x part time often what happens is she'll just flip out and run out and never go back and so, you know, to help her with that she's come and done a few, you know, she used to do weekends in the shop, she could do it with my support and she was getting to the point of managing to do it on her own for about half a day without me being there, but she's just completed her Honours Degree, she got a First for a x Degree in x Uni so, you know, the last year she's been really focusing on the studies more than working at the weekends and stuff.

3. **Experience of self-harm and suicide**

Coping with suicide or self-harm attempts / thoughts	Fears and reflections before and after suicide
Experience of suicide attempts **FC1:** **First experience of coping with a suicide attempt** "So she called me and I said 'what have you done?' 'nothing, fine', so that's not too good so I said 'I'll cancel my day, I'll come through' so I came through and only after we were talking for a long time and she'd began to get drowsy and then came and she said 'I've taken this'. I was trying to call all the numbers on her card, none of them were answering cause it's Friday afternoon and they're all home. Nobody's available. I eventually got through to something who said I 'need to call 999' 'so okay, so I'll do that' and that's when I realised how serious it was. So they took her away, I took her dog to my mum's and I followed her in to find her behind a curtain slumped in a wheelchair blocking her airway. 'Could somebody come and help me?' cause I said 'well where is she?' 'oh behind there', and I said 'well you can't see what she's doing' they could not have seen, so you're making assumptions thinking that she's a drug addict and even then you shouldn't be making assumptions about, you know, these are human beings. So that was the first real awakening I had to the difficulties she was dealing with. Up till then mum would deal with the kinda things, I didn't really talk about it that much to her so that was my real first awakening of." **Managing crisis** FC3: "The crisis management of suicide attempts was also very difficult as well, however, we got into a pattern of being able to manage that when it arose and again prevent it where we could do, but that was difficult I would say. **Multiple self-harm cutting and suicide attempts** FC9: "My daughter was actually harder in a different way cause she was, oh, she was suicidal, she was self-harming, I was having to watch her all the time, every second, watch her when she got undressed and just catched so I knew what was going on because she was cutting her arms, cutting her legs, cutting places that I couldn't see. I was having to go through her washing and check for things in her pockets, you know, sharp stones and anything that could cut her. I was going in the bathroom in the middle of the night and sliding on blood on the floor because she'd been cutting herself. She never got to sit in her room very long on her own because you didn't know what she was doing in there. She took tablets on the internet in front of everybody, luckily one of her friends phoned an ambulance and the first thing I knew was the door went and I went to the door and he said 'ambulance' and I… he said 'your daughter's just taken something' and I'm like, but her room was right opposite this room, you know what I mean, and she had…"	*Reflections after suicide* **FC3:** **Coming through my partners suicide** "I've got a strong, I'm coming through things I think but one should never be deluded in that respect and I think, you know, cause I'm grieving and going through that process. I think where I got to be I've got a lot to do for my own development as well and in a way to, I would say, honour my relationship with xxx appropriately, and to do all of that. So what's next for me is I'm thinking about my career quite a lot. I'm thinking about what I am doing, is it the right, you know, for example it was a case of I would say I was fortunate enough to be paid a bit above average and fortunate in the role that I'm in just now, however my financial drive was always based on the fact that, well xxx not going to be able to work and it was to give her opportunities, so I don't really have the same incentive there so I'm looking at a different career. I've got that at the back of my mind but I've also got quite an ambitious drive as well, so yeah physically and mentally looking after myself and just I'm weighing up what my options are. So that's one aspect of it but there's an aspect as well of going all the way to, you know, do I write a book, how do I write a book about my experience, how could people benefit from that, benefit from my recovery experience and benefit from, I think there's… I'm very careful how I use this vocabulary, just compassion for people who suffer from BPD and bringing my experience in some way. I think I've got a lot to give in all of that, I think it's just getting the right vision and taking the right steps to do that and seeing what arises. So again this is a bit of an opportunity to actually just kinda start providing some of that input and experience." **FC3: Views on cause of death** "I think it was in two parts and the services interventions, especially the medicalisation of xx in tandem with the trauma with her family circumstances culminated in her decline ultimately."

4. **Experience of distress, anger and violence**

Views of incidents	Dealing with / coping strategies
FC6: **Anger an expression of his distress** "So he would hold everything in at either school or work and when he came home we would have the absolute eruption usually in the kitchen and never once, and I want to make this really, really clear, never once did he ever physically threaten me or did I feel physically threatened, but his anger and distress was really, really obvious to all. And so sometimes it was about leaving him alone to calm down, other times it was actually sitting him down and talking him through, but every day that he was either working or at school that distress that manifested in anger I think, it wasn't that he was angry or he was angry, but the anger was the expression of distress and hurt and low self-esteem, so every single day there would be this, at least one, episode of having to respond to how he was feeling and what had happened to him, and that was constant over years and years and years and years and years; so probably from the age of eight when he was first diagnosed with LD until he died at 25 it was every day." **Shouting and swearing** **FC19:** She can get verbally abusive to me and swearing and screaming and what seems like overreacting but she has never been violent to me or x I really don't think she ever would – it think she would hurt herself more than anyone else. FC9: **Getting the police to stop the violence** "My husband was more, I used to have to get the Police in to get him out, you know, he was aggressive and violent and couldn't remember anything, and he tended to go and… alcohol, right, now alcohol and the symptoms they get do not go together, and the medication remember. So it got to the point that I just got the Police, I mean, there was no way, I just had to get the Police to move him because he refused point blank to go. And he would lift his hands if he got half a chance, yes definitely and he was scary, he was definitely scary. So I ended up he'd to get his own place, right, because I'm just not, I'm just not doing it, you know, he used to say to me 'oh you're leaving me sleeping on park benches'. Wellbeing quite honest, weigh that up against me getting murdered in my house and he can sleep on a park bench, you know what I mean. I'm not the type to just 'oh but he's ill' and 'oh but this' and 'oh but that' you know, I just… no I wasn't going to put up with it, he was my second husband, right, and there was no way I was, like, I came out of my first marriage a lot stronger if you know what I mean and it was my house, me and my kids lived there, nobody was going to change that, you know. So with a bit of help from the hospital and what not, you know, he got his own house but I still tended to have a lot of bother cause he still used to come to my house and refuse to go, so I still used to get the Police to move him, right. I mean, you just… where do you draw the line? Does he get to do what he wants	FC2: "I feel like a battered wife at times, only verbally, but then is that just an excuse? Should I be accepting that as something I'm okay with? But I think if it was happening all the time but it's not happening all the time its once every so often those really serious moments." **Maybe prevented something worse** FC6: "I think 80% of the time defusing him, supporting him and defusing him and knowing, and being able to. I think having strategies, so knowing that he was going to come in from work, and I can still see him in the kitchen, x was really tall, all my boys are really tall, but x was really tall, really broad so this kind of bear in the kitchen who was angry, distressed, upset but the fact that he could be like that with me, so he trusted me enough to expose all this, I think was a success. Because if he'd kept it in, and the times that he couldn't, those were the times that he self-harmed. So he would be really, really angry and the times that he couldn't express it, rather than hurting me or hurting his girlfriend or hurting the twins, he hurt himself, so that wasn't so successful, but all the times that I may be prevented that or, you know, talked him down and calmed him down so that he could cope for that day and get strategies for the next time I think." FC6: **Trying to help** "Sometimes I had to but other times it was 'well what are you going to do and what can I do to help?' because sometimes you'd offer suggestions but he'd be so angry and distressed that that was rubbish, and I knew it wasn't rubbish so you can't take it personally, but it was more to try to say 'right, you take responsibility, what are you going to do and how can I help?' rather than me taking control." And yet on the other hand, you know, he would come down the stairs after having rampaged up the stairs and [makes roaring sound] and he'd come down very quickly actually, very quickly and come down and there would be a cuddle and 'I'm sorry, this is how I'm feeling' so again it's learning do I leave him or do I, and I'd said that earlier as well, but he was always, it was never for a long time and there was always my son back at the end of it with a hug and a cup of coffee, d'you know, it was… he always was there underneath it all which made it easier to manage, if that makes any sense. FC9: **Get out of the house myself** "Drop everything for them but, I mean, I think I've kinda thought… I mean, one thing that I did have to do and it was carer support right, he was coming here and he was refusing to move and I was getting myself in a really, a state, you know, cause how dare he, this is my house…'

5. **Impact of living / support someone with BPD**

Emotional (thoughts and feelings)	Relational and behavioural
Feeling isolated or alone FC1:I suppose I feel a bit more isolated in terms of I don't believe people would understand her very well, and my partner he's like if something's broken he can fix it, you know, I don't even ask 'can you fix it?' I'll know he will be able to fix it, he'll find a way to fix it. If I need something, you know, when my sister was in hospital he took up the slack but he's not the person I can go to talk about how it feels, cause he'll want to fix it and he can't fix it and I need him to listen to me and acknowledge how I feel but he's not good at that. And then who else could I talk to because they're all busy with their own lives and… I didn't really feel there was anybody I could really talk to that I have close by, the kinda people that I thought that I could probably talk to, because we've got the internet they are further afield, they're not somebody I can speak to person to person and get a hug from, and I felt that what I really wanted was person to person that I can actually get a feeling or a hug from, is what I would've liked. FC13: We do feel quite alone in this, d'you know, we do feel that there isn't really much support and I'm probably not that great at going and speaking to people anyway, d'you know, in the past as I said I would perhaps have chosen not to have gone out and met friends for a coffee or a dog walk because I was feeling low that day and I just couldn't face going out and seeing anybody. I can quite easily see how people become depressed with things that are going on. FC16:you've got the shame of it, it's made me isolate myself from my community, it's made me question my friends, I mean, I don't think I've got any, you know, it's just kind of you narrow yourself in to protect yourself and your family, and you don't know who to talk to. Oh yeah definitely, definitely. I mean, it's not even got beyond, it's kind of things were just closed down almost immediately, you know, so you just think 'oh right I won't go there with that person then clearly' you know, 'it's not something they can cope with'. FC2: It can be really lonely dealing with this and sometimes people will say oh yeah my mums got schizophrenia and I am like – great what do you want me to do as its nots the same thing…	**Family and home life** FC12: It was difficult for my daughter as well cause she was really young at the time, it just sort of, you know, looking back now it feels like she just got, had to look after herself a lot at that time because I had to spend so much time, and I suppose that's really been the case throughout their childhood because my daughter was always very well behaved, very quiet, went to school, you know, and didn't have any problems with her mental health and you try to treat your children equally but then when one needs extra attention you can't do that, it's very difficult and I know she does have anxiety problems now and I know that that's probably as a result of everything that she's been through as well. FC13: it is my two days away from home, d'you know, my home, we moved to this house 10/11 years ago and it's really nice rural setting and I've always regarded my home as my sanctuary, you know, it's my place I go to at the end of the day and I can shut the door and it's just me and my family and, d'you know, it's just my place and it's not that anymore. It can be quite a miserable place. Yeah, no one of the things that J has discovered with her time with x is that a lot of how she feels comes from x. When J was younger S would say to her 'you can't do that, you're rubbish at that' and they're two very different children, you know, you couldn't ever say to S 'you can't do that' because the reverse psychology works a rare treat on her and more often than not to her detriment she'll go and prove you wrong. And J, if you tell x 'you can't do that, you're rubbish at that' she'd just go 'yeah you're right' and then she wouldn't even try and that's just always how they have been. I think part of y is she kind of just sort of shuts herself off from x, she doesn't go there, she'll maybe ask her one in six times how she is but she doesn't get too close with any of the mental stuff, the mental health, and x finds that hard and she thinks her sister isn't there for her. So, you know, Coronavirus has happened and it's been quite good for x's mental health in that we because y's not here and she's not coming home any time soon, so we've still got that one to address going forward. No, no, no but it's just difficult when x is here in the house and this dictating that she has to go and stay in her room when y's here, and we've said to her, d'you know, this is y's house as much as hers and we're not stopping y from coming back any time she wants to, but it's very difficult when she is. FC14: I'll have phone calls like this one, I'll be on and off my computer, I might load or unload the dishwasher; well I can't do that because it makes noise, and noise is a problem because x will still be sleeping till 12 o'clock and, you know, yeah, I'm constantly biting my tongue to avoid exploding, however over the course of a long period of time I have learnt to do that. So, I mean, the obvious thing, I am going to draw a breath in a second, the obvious thing here is the well what about the…

6. **Views on families and carer support**

Challenges and needs	Support received or not
Finding good quality information FC16: It's understanding it, even though I've read through the Steps programme it's so Americanised, I don't like the language, I don't like… I always think that everyone is individual as well and I just would love to know more because I know that there are some people who are high functioning Borderline Personality, some people are low but I don't know enough about it, I don't know anything that's been useful and helpful other than… I mean, I've read some books and things but you just don't know what's right really. <Files\\FC3:Yeah and there is so much information out there, I think there's a point there's awful stigmatised and misinformation but it takes real effort to find good quality information, contemporary literature and direction, albeit that's an ongoing phase of research but there's a lot of good stuff out there that can help. Yeah. There's a good, I would say an example of a good piece of literature was a book called Loving Someone with Borderline Personality Disorder. It was written by, I can't remember the author but there's an association with Marsha Linehan who developed DBT as I'm sure you know, and that's a really, really good book but I can't… <Files\\FC4: I didn't use any online or carers groups I don't think they are helpful – I have looked up information before but there is so much and they don't always talk about the really hard stuff about BPD - about how to support and calm someone who is in distress and suicidal for the fifth day in a row, and no-one professional can help or will help them <Files\\FC7: With the internet now I have looked it up a lot but often the information isn't clear enough or it is too hard to understand. **Family support and education** FC10: I would love to speak to some of the professionals and actually, I mean, I've never spoken to <Files\\FC15> More information I would never say no to. I think what as well we wanted, well what my sister I know that I think she would maybe appreciate is, like, the family sort of dynamic, like, more my mum getting involved as well. She's lovely, I love her to bits, like, we lived, like, I love my mum but she's not great at dealing with A and she's not great with mental health, not in a bad way…	**Little or no information /support** FC1: Have you been offered anything? RES: No. INT: Do you know what is there for you? No and if we don't know what there is how can we ask for it? Yeah. I don't remember having any specific 'this is what you're entitled to, this is what you could be having', maybe my mum might have been given that back then but it's never come up again since mum died, and I wouldn't know what to ask for. <Files\\FC11: Me I've always said, d'you know, I don't receive any support, you know, the social work were supposed to do a carer's plan but they never done it, they've still not got round to it yet. I just find that there's no support for a lot of people that are parents or siblings or family of people with mental health disorders. I think they're just expected a lot of them are expected just to be left and deal with it their-selves, you know, but as I've said already I'm not trained in mental health, you know, so I couldn't begin to think where to actually deal with it, but for years it was basically if she's released from hospital just send her back home, B will look after her, B her dad, I'm her dad, he'll deal with it. Well what happened was, I mean, I think about a year ago I was basically given a couple of fact sheets and told to read them and this is what's wrong with N. <Files\\FC12: Nothing. I haven't been offered anything at all. I talk to my parents but not much as they don't really understand. <Files\\FC13: One of her CPNs put us in touch for a carers assessment with them and she came out and did a big, long interview and I don't mean to sound ungrateful, that's all it was. That wasn't the kind of support that we were looking for. <Files\\FC15: like, the amount of times that I've taken my sister to MH hospital and she'd never once been given any letters or leaflets or nothing, like, I've been given nothing, and there was this one woman who then handed me the leaflet for Local carer support and then they helped me get in contact with the council. It was only that one person that decided, d'you know what I mean, why is it not more out there? , I can't… we're actually in the process of trying to pack up to move to a new house just now so I've got a lot of books about BPD. There's one about walking on eggshells and things, so there's a lot that made absolute sense to me as to why x was behaving the way she was behaving. Those books really helped me kinda step away from the drama…

7. **Views on supportive intervention design**

Concept design / Content	Mode of delivery (inc. deliverers, materials, procedures)
Tackling stigma and misconceptions FC2: "Also it to be wider known in the public that this is a thing" FC3: "I think that really needs to be tackled head on. I think especially with parents, the notion of, you know, the genesis of BPD and to look at that in a compassionate way and understand that." "I would say her BPD was manageable, it was the breakdown in the relationship with her family and I think this centres around where psychoeducation is really important and that's what precipitated, let's call it the beginning of the end, was a conversation with her family member where that family member had suffered from mental ill health as well and xxx was in dialogue with them and said 'I've been unwell' but the message that came back was, well, and she was trying to relate to that person and said 'well you were unwell at that time' and that person said 'well yeah, I've got an illness but you've got disorder', so there was an implicit and explicit message to xxx that her illness wasn't really an illness, it was her bad behaviour that she was in control of and that this bad behaviour had led, you know, again it was implicit and explicit that she had destroyed the family and led to their chronic degenerative illness, which was XX's trauma that she felt that she had killed her parents and that recursive trauma was which then required, some medication intervention and which on top of that ultimately led to her death. So I think there's an importance around, you know, getting over the old stigma I think is really important. So I don't think there's anything more." **Acknowledging differences** FC3: "And I think the other point to maybe make is again from my understanding, I think there's a kinda lumping of BPD, it's almost like a kind of, well a spectrum with different types of behaviours to different magnitudes across all of that, so I think sometimes if you are, you know, you could be comparing apples with oranges, you know, the sufferer may have the same label but they behave and suffer in very different ways." FC8: Yeah, I think that BPD's so complex and comes out because of so many things and not everyone's going to have BPD because they're abused and not everyone's going to have BPD because of something else, you know. So I just think as a parent it is very, very individual and although we know that other people have got BPD their stories are completely different.	**Online/ face to face, one to one** FC11: bit of all of these would be okay by me, I mean, I don't mind talking in a group, I don't mind talking one to one and I don't mind talking on the phone, email, you know, talking like I am to you or talking face to face one to one, I don't mind. I find any interaction like that would be beneficial to a lot of people, not just me. <u>\<Files\\FC12></u> - § 1 reference coded [1.38% Coverage] I think online resources and a support group, perhaps strategies in how to help him, and cope with crisis and distress, I only know what to do from very limited knowledge and it would be good to have some therapy style strategies recommended by experts. <u>\<Files\\FC14></u> - § 1 reference coded [0.32% Online no not really, I'm probably just too old for that, probably rather look someone in the eye. <u>\<Files\\FC16></u> - § 1 reference coded [1.90% I think it would be accessed on all mediums really so that all types of people can get their hands on the information, the links to things, but whatever I would say is that whatever is done so often the case is you'll spend hours trying to find things online, you'll click on the resource and then low and behold it's been changed, it's shutdown, it's this, it's that and, you know, what's really hard is coming across something that you think you've found the answer and then it's a non-existent thing and it's just making sure that whatever goes up stays up to date, you know, and I think using all mediums, social media and so on as well as real people, I think it needs to be a combination. You know, Zoom and stuff now at least there's that, at least if people are spread all over the place it won't matter in the future, you know, it's quite a positive move really. <u>\<Files\\FC17></u> - § 1 reference coded [1.90% Coverage] RES- Say there was something developed, would you like a group or would you like something one to one, would you want online, would you want a bit of everything? Yeah probably a bit of everything so that you've got choices, yeah, I mean, sometimes you're just not in the mood to be talking when you've been struggling all day to have conversations, so it'd be nice even if there was something online or somebody that you could just kinda in similar position.

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Appendix 19: Extract from Calm and Connected intervention draft with example of stakeholder comments

CALM Model (Adapted from Manning 2011)

Control your own response

It is distressing supporting someone in distress so regulating your own emotions is important. Pause, take a breath and notice your physical sensations, label them as the emotion you are experiencing; pay attention to your body posture, unclench your hands, relax the muscles on your face, relax other muscles; send calming messages to your brain; validate and soothe ('my emotions are understandable).

Ask/Assess the situation

Ask gently what has happened, how can you help, listen actively, don't judge, contradict, decide if you need to seek or give immediate support for safety or treatment (A&E, NHS 24, GP, Samaritans, Breathing Space).

Lower the emotional temperature and validate

Having BPD means that a person is regulated externally by things in their environment and this includes you. If the environment is calming, they will calm. Validation is essential for creating a meaningful connection. Soothe your loved one's current emotions by finding something to acknowledge (the emotion, the thoughts, the actions). For example: *'You sound really angry, it must be really painful for you what happened'.* By doing this you are letting the person know you understand that they feel out of control, a frightening place to be.

Move forward

Communicate to the person your hope and belief in their ability to get in control again and move forward. Recall times when they felt like this before and got through while still validating how difficult it is right now. E.g. *'I know it feels like you can't take anymore but you are very strong, I've seen you get through times….'*

Find out if they would like help in solving the problem that has caused their pain. When emotions are running high, fuelled by fear and anxiety it can be difficult to focus or problem solve. It also takes longer for emotions to settle. Suggest brainstorming the problem together but if this isn't working then leave it and return later. **Comments from carer participant** – The usefulness of a cooling down period is very valuable and I think would benefit from emphasis, i.e. sometimes leaving the person to cool down benefits the situation greatly, trying to force problem-solving and brainstorming when the carers feel distressed or under pressure can be counterproductive.

After the distress or crisis - Take time out to process and reflect on what has happened. Fear and anxiety caused by stressful crisis events can be exhausting and take their toll on your health and wellbeing. It is natural to worry but it is essential to soothe and calm yourself daily to counteract the effects of worry and anxiety. Take time every day to do something to de-stress and feel better. Use the five senses: e.g. touch – stroke your pet, relax in the bath, wrap up in a warm blanket. Remember what helps one person may not be another so do what works for you. Talk to a friend, family member, or peer about what has happened and how you feel. **Comments from carer participant:** On the reflection and processing, after normalising from the stress response think about what you may do differently when distress reoccurs, both in how you respond in the situation as a carer, and what self-care did and did not work so well.