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Caring for a person with personality disorder: A study of carer burden, support needs and interventions

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Caring for a person with personality disorder:
A study of carer burden, support needs and
interventions

A thesis submitted in fulfilment of the requirements for the award of the
degree

Doctor of Philosophy (Clinical Psychology)

From

University of Wollongong

By

Rachel Bailey, BA-Psych (Hons)

School of Psychology

2014

Certification

I, Rachel Bailey, declare that this thesis, submitted in fulfilment of the requirements for the award Doctor of Philosophy (Clinical Psychology), in the School of Psychology, University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged. The document has not been submitted for qualifications at any other academic institution.

Rachel Bailey

(August 2014)

Acknowledgements

This thesis is the product of many hours of procrastination and overwhelm – but mostly a labour of love. I have become deeply passionate about this area of research, however none of this would have been possible without the encouragement and guidance of my research and personal support team. The acknowledgements below are by no means an exhaustive list of those kind people who have supported me on this journey.

I would first like to acknowledge and thank the Project Air Strategy for Personality Disorders for partly funding this research and working tirelessly to improve psychotherapy treatments for carers and patients with personality disorders in New South Wales. Importantly, I would like to thank my supervisor, Professor Brin Grenyer, for his guidance, expertise, advice, faith and patience. I would also like to acknowledge my secondary supervisor, Associate Professor Peter Caputi, for his statistical expertise.

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Abstract

Personality disorders involve pervasive disturbances in self and interpersonal functioning as core criteria (American Psychiatric Association, 2013). As a consequence, the families and carers of people with a personality disorder can be challenged by the relationship. This work presents a sequential set of four studies aiming to advance our understanding of caregiving for a person with personality disorder. Study one was a systematic review of 6 studies meeting inclusion criteria with data on 465 carers of persons with borderline personality disorder. Study two evaluated new data on the experience of burden involving 287 carers. Taken together, the two studies showed that carers report significant levels of burden and grief compared to carers of persons with other mental disorders, and experience difficulties in wellbeing including symptoms consistent with depression, anxiety and post-traumatic stress. Study three explored the interpersonal environment reported by 280 carers. Findings revealed family environments characterised by elevated 'expressed emotion', representing a challenged interpersonal dynamic involving both conflict and emotional closeness. Study four evaluated a five session pilot intervention focused on modifying and enhancing the interpersonal environment with 32 carers of persons with personality disorder. Carers reported significant improvements in wellbeing, burden, quality of life and expressed emotion post-intervention. The four studies, taken together, demonstrate the interpersonal nature of personality disorder; both in terms of the interpersonal impact but also the opportunity to modify interpersonal patterns within the caregiving relationship to reduce burden and enhance carer wellbeing.

Publications Arising During the Candidature

Published Manuscripts

- Bailey, R. C., & Grenyer, B. F. S. (2013). Burden and support needs of carers of persons with borderline personality disorder: A systematic review. *Harvard Review of Psychiatry*, 21 (5), 248- 258. DOI: 10.1097/HRP.0b013e3182a75c2c.
- Bailey, R. C., Grenyer, B. F. S. (2014). Supporting a person with personality disorder: A study of carer burden and wellbeing. *Journal of Personality Disorders*, e-View Ahead of Print. DOI: 10.1521/pedi_2014_28_136
- Bailey, R. C., & Grenyer, B. F. S. (in press). The relationship between expressed emotion and wellbeing for families and carers of persons with Borderline Personality Disorder. *Personality and Mental Health*.

Conference Presentations

- Bailey, R. C. & Grenyer, F. S. (2013, October). *Burden and support needs of families and carers of persons with personality disorder and preliminary evaluations from Project Air Strategy workshops*. Paper presented at the ARAFMI 3rd National Borderline Personality Disorder Awareness Day Conference, Sydney, Australia.
- Bailey, R. C. & Grenyer, F. S. (2013, July). *Supporting a person with personality disorder: A study of burden and wellbeing*. Poster session presented at the 7th Annual Conference on the Treatment of Personality Disorders, Wollongong, Australia.
- Bailey, R. C. & Grenyer, F. S. (2012, November). *Burden and support needs of carers of persons with personality disorder: A systematic review*. Poster session

presented at the 6th Annual Conference on the Treatment of Personality Disorders, Wollongong, Australia.

Bailey, R. C. & Grenyer, F. S. (2012, November). *Staying connected: A study of family environment in Borderline Personality Disorder*. Paper presented at the meeting of the 6th Annual Conference on the Treatment of Personality Disorders, Wollongong, Australia.

Bailey, R. C. & Grenyer, F. S. (2012, December). *Staying connected: A study of family environment in Borderline Personality Disorder*. Paper presented at the meeting of the Society for Psychotherapy Research: Australian Regional Group Meeting, Melbourne, Australia.

Definition of Key Terms

CARER: for the purpose of this thesis, a carer was defined as any unpaid person in a close supportive relationship with a person with personality disorder. This included family members (such as parents, children or siblings), partners and spouses, friends, or significant others. We did not include paid professional or volunteer caregivers in the research.

CAREGIVING: for the purpose of this thesis, caregiving was defined as involving regular interactions with the person with personality disorder including tasks promoting wellbeing and recovery, which could simply involve being in a supportive relationship.

EXPRESSED EMOTION: refers to the affective attitudes and behaviours (including levels of criticism, hostility and emotional overinvolvement) of a significant other towards a psychiatric patient (Leff & Vaughn, 1985; Van Humbeeck, Van Audenhove, De Hert, Pieters, & Storms, 2002; Vaughn & Leff, 1976). Emotional overinvolvement is a component of expressed emotion “best characterised by excessive anxiety, overconcern, or overprotectiveness toward the patient” (Vaughn & Leff, 1976, p. 125).

PERSONALITY DISORDER: Personality disorders are defined by the Diagnostic and Statistical Manual for Mental Disorders (DSM-V) as “an enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual’s culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress or impairment” (American Psychiatric Association, 2013, p. 645). This pattern is required to manifest in at least

two of the following areas: cognition (ways of perceiving and interpreting the self, other people and events), affectivity (the range, intensity, lability, and appropriateness of emotional response), interpersonal functioning or impulse control (American Psychiatric Association, 2013).

RELATIVE: for the purpose of this thesis, a relative was defined as a person with personality disorder such as a biological family member (for instance parent, sibling, child) or non-biologically related significant other (for instance partner, spouse, close friend) to the carer.

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Chapter 1

Introduction and Aims

1.1 Introduction

1.1.1 Personality Disorders

Personality disorders are defined by the Diagnostic and Statistical Manual for Mental Disorders (DSM-V) as an enduring, pervasive and inflexible pattern of inner experience and behaviour (American Psychiatric Association, 2013). The DSM-V outlines ten personality disorder subtypes grouped into three distinct clusters based on descriptive similarities and presentations. Cluster A (described as *odd* or *eccentric* presentations) includes paranoid, schizoid and schizotypal personality disorders. Cluster B (*dramatic, emotional* or *erratic*) includes antisocial, borderline, histrionic and narcissistic personality disorders. Finally, Cluster C (*anxious* or *fearful*) includes avoidant, dependent and obsessive-compulsive personality disorders. However, all personality disorder subtypes involve a pervasive maladaptive relational style with many overlapping interpersonal symptoms. For instance, the most widely researched personality disorder, borderline personality disorder (BPD), is characterised by interpersonal disturbance involving mentalisation failure, rejection sensitivity, chronic feelings of emptiness, affective dysregulation and behavioural dyscontrol (Gunderson, 2007, 2010). These symptoms all represent and contribute to a disturbance in relating to the self and others. As such, previous research has suggested that BPD occurs in the context of relationships (Hoffman, Fruzzetti, & Buteau, 2007). However, this may be extended to include all personality disorder subtypes.

Previous research has identified a high comorbidity between personality disorder subtypes, implying that many patients may be diagnosable with more than one personality disorder at any given time (Grant et al., 2008; Zimmerman, Rothschild, & Chelminski, 2005). Research has reported the lifetime prevalence estimate of any personality disorder in the Australian adult population at 6.5%

(Jackson & Burgess, 2000). This is approximately nine times higher than the lifetime prevalence of schizophrenia at 0.3 to 0.7% (American Psychiatric Association, 2013; Saha, Chant, Welham, & McGrath, 2005). Thus, considering the high prevalence and interpersonal nature of personality disorders, it is surprising that very few studies have empirically researched the impact of supporting these patients on the families, partners and carers.

1.1.2 The Biopsychosocial Model of Personality Disorder Development

Historically, research on the development of personality disorders linked aetiology to early childhood abuse and neglectful parenting, which may account for the lack of research on the experience of carers of persons with personality disorder (Gunderson, Berkowitz, & Ruiz-Sancho, 1997; Herman, Perry, & van der Kolk, 1989; Masterson & Rinsley, 1975). Parents were often blamed for the personality disorder psychopathology by mental health professionals and the wider community (Gunderson et al., 1997). However, recent research has identified genetic (including biological and neurological; e.g. Gunderson et al., 2011; Torgersen et al., 2008), and environmental (including childhood and psychosocial; Zanarini et al., 2002) and psychological (including attachment, temperament and deficits in mentalisation; Bateman & Fonagy, 2003, 2010; Gunderson, 2007) factors that may contribute to the development of the affective and behavioural dysregulation and disturbed relatedness characteristic of personality disorders. This research has resulted in the biopsychosocial model of personality disorder development (Leichsenring, Leibing, Kruse, New, & Leweke, 2011). Thus, where it is possible that some carers may present with traits or symptoms (due to the genetic component and intergenerational transmission of attachment and trauma patterns; e.g. Benoit & Parker, 1994), many

other factors are also involved in the development of personality psychopathology. The biopsychosocial model has therefore allowed willing families and carers to be considered important collaborators in the treatment of persons with personality disorders in recent clinical guidelines (National Health and Medical Research Council, 2012; National Institute for Health and Clinical Excellence, 2009; Project Air Strategy, 2012c). This is particularly the case as families and carers assume the primary responsibility for the care and recovery of their relative due to recent trends for treatment to be based in community (rather than hospital) settings (Gunderson et al., 1997). Thus, it appears important to understand the experience of caring for a person with personality disorder and how best to support carers in this role.

1.1.3 The Experience of Carers of Persons with Personality Disorders

To date only two empirical studies have explored the impact of caring for a person with personality disorder, and these have been specific to persons with BPD. Goodman and colleagues (2011) conducted an online survey and found that parents with a daughter diagnosed with BPD experience significant burden within the caregiving role. This burden included strain on emotional and physical health, marital relationships and social supports. Further, Scheirs and Bok (2007) found that carers of persons with BPD report greater psychological distress on a standardized measure compared to the general Dutch population.

Qualitative research has also reported that carers of persons with BPD experience distressing emotions (such as grief, worry and guilt) and significant burden (including isolation, stigma and powerlessness) as a result of the caregiving role (Ekdahl, Idvall, Samuelsson, & Perseius, 2011; Giffin, 2008). Carers of persons with any personality disorder have qualitatively reported many interpersonal burdens

including uncertainty about interactions with their relative, doubt and dissatisfaction in the relationship and emotional estrangement (Bauer, Döring, Schmidt, & Spießl, 2012). Carers of persons with BPD also report significant difficulties in working with the mental health system, including stigma from professionals and exclusion from information, treatment and discharge planning (Dunne & Rogers, 2013; Ekdahl et al., 2011). Taken together, it appears that carers of persons with personality disorder experience significant burden which would likely impact on many areas of the carers life. However, this research has been limited in being mostly preliminary or qualitative in nature and focussing on carers or parents of persons with BPD. These limitations reduce the generalizability of the findings and fail to allow comparison of the experience of carers of persons with personality disorder with carers of persons with other mental illnesses.

1.1.4 Support Interventions for Carers of Persons with Personality Disorders

The current research evaluating support interventions for carers of persons with personality disorder is also minimal and limited. The most extensively researched intervention for carers of persons with personality disorder has been specific to carers of persons with BPD. A pilot and replication study of this intervention showed promising results in reducing carer burden, grief, depression and increasing empowerment over the 12 week program and 6 month post-baseline follow-up period (Family Connections; Hoffman et al., 2007; Hoffman et al., 2005). Further, a recent program designed for carers of persons with any personality disorder showed promising results in reducing isolation and carer burden (Sanders & Pearce, 2010). However, evaluation studies are yet to determine whether such interventions are

beneficial to the interpersonal environment for carers of persons with personality disorder.

1.1.5 The Interpersonal Environment and Personality Disorders

The interpersonal environment has been found to be of importance to the clinical outcome of patients with personality disorder, in particular BPD. Research has found that family environments elevated in expressed emotion (involving behaviours and attitudes of hostility, criticism and emotional overinvolvement) are associated to worse clinical outcomes for patients diagnosed with schizophrenia and mood disorders (Bebbington & Kuipers, 1994; Hooley, Orley, & Teasdale, 1986; Miklowitz, Goldstein, Nuechterlein, Snyder, & Mintz, 1988). However, family environments elevated in emotional overinvolvement have been associated with better clinical outcomes for patients with BPD. Hooley and Hoffman (1999) found that patients with BPD were less likely to be re-hospitalised over a one year period if their families expressed greater emotional overinvolvement. This finding was stable even when initial symptom severity was statistically controlled. Further, verbal comments expressing emotional overinvolvement have been found to activate areas of the brain associated with reward processing for patients with BPD compared to patients with dysthymia and healthy controls (Hooley et al., 2010). It has been speculated that the nature of emotional overinvolvement (the expression of anxious concern, overprotection and emotional closeness) may be experienced as validating and therefore potentially helpful towards recovery for the BPD patient (Hoffman & Hooley, 1998; Hooley & Hoffman, 1999). Thus, the interpersonal environment appears important in understanding personality disorders, the impact of caregiving, and in the evaluation of carer interventions.

1.2 Aims

The thesis aimed to empirically explore and describe the experience of caring for a person with personality disorder, including carer burden, support needs and interventions. The thesis aimed to achieve this sequentially by addressing the following:

1. Systematically review and consolidate the current empirical understanding of the burden and support needs of carers of persons with personality disorder and identify any limitations in the current literature (see Chapter 2).
2. Describe the unique experience (including burden, wellbeing and the caregiving relationship) of caring for a person with any personality disorder compared to carers of persons with other mental illnesses (see Chapter 3). It was aimed that this study would address some of the limitations identified in the systematic literature review conducted in Chapter 2.
3. Describe the interpersonal experience of caring for a person with BPD, in particular with regards to the relationship between emotional overinvolvement within the family environment and carer wellbeing (see Chapter 4).
4. Empirically pilot a psychoeducational support intervention for carers of persons with personality disorder in a pre-post analysis of carer burden, wellbeing and the caregiving relationship (see Chapter 5).

Chapter 2

Study 1

Burden and support needs of carers of persons with borderline personality disorder:

A systematic review

This is an identical version of the accepted manuscript published in full in the Harvard Review of Psychiatry.

Bailey, R. C., & Grenyer, B. F. S. (2013). Burden and support needs of carers of persons with borderline personality disorder: A systematic review. *Harvard Review of Psychiatry*, 21 (5), 248- 258. DOI: 10.1097/HRP.0b013e3182a75c2c.

2.1 Introduction

Personality disorders occur in the context of relationships (Hoffman et al., 2007) and may be characterized by chronically dysfunctional patterns in relating to others. For example, the most widely researched personality disorder, borderline personality disorder (BPD), is defined by the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) as involving a pervasive pattern of instability within interpersonal relationships, poor self-image, affect dysregulation, and marked impulsivity (American Psychiatric Association, 2000). BPD symptoms, such as impulsive anger and self-harm, and consequent burdens, such as therapy bills and a disharmonious household, would likely have adverse effects on relationship patterns, particularly with close relatives, partners, families, and carers. Likewise, the other personality disorders defined by DSM-IV all include problems in interpersonal relationships and maladaptive relational styles as essential criteria (American Psychiatric Association, 2000). It is therefore perhaps surprising that so little research has been directed at understanding the experience of families, partners, and carers of persons with personality disorders (Hoffman & Fruzzetti, 2007; Lefley, 2005).

The prevalence of personality disorders in community samples has varied from 4.4% (Coid, Yang, Tyrer, Roberts, & Ullrich, 2006) to as high as 20% (Grant et al., 2008; Grant et al., 2004), and a recent review found a prevalence of approximately 11% in community samples (Lenzenweger, 2008). Considering that each of these persons with a personality disorder likely has at least one partner, carer, or family member supporting him or her, these figures imply that a substantial number of persons in the broader community are affected by personality disorders.

Despite the high prevalence of personality disorders, carers of people with personality disorders have been stigmatized and not given adequate attention in the research literature. Early research regarding families of persons with BPD was dominated by findings of family trauma, abuse, neglect, and psychopathology (Herman et al., 1989; Masterson & Rinsley, 1975; Weaver & Clum, 1993). These findings resulted in the perception of carers of persons with BPD as toxic to the patient's recovery and as causing their difficulties (Gunderson, 2008; Gunderson et al., 1997). However, the ongoing trend toward community-based care and away from hospital-based care has resulted in families and carers taking on more and more responsibility for the care of those with mental illness, including personality disorders (Gunderson et al., 1997). Research on, and understanding of, carers of persons with mental illness has consequently increased, serving to modify negative attitudes about carers (Cuijpers, 1999). For instance, support groups for families and carers of people with schizophrenia have been found to reduce carer psychological distress, increase family functioning, and benefit the caregiving relationship (Cuijpers, 1999; Goldstein & Miklowitz, 1995; McFarlane et al., 1995). At present, however, the unique burden and support needs experienced by families, partners, and carers of persons with personality disorders have remained under-researched (Hoffman & Fruzzetti, 2007; Lefley, 2005).

The etiology of personality disorders is no longer considered to be the direct result of parental style, trauma, abuse, or neglect, but rather an interaction of many factors that define a biopsychosocial model of BPD development (Davis, 1997; Leichsenring et al., 2011; Paris, 1993, 1994; Zanarini et al., 2002). Although parental mental illness and harsh parental style may be associated with personality disorder development (Macfie, 2009), further research is needed to determine how these

experiences contribute to the development of adult psychopathology (Fossati, Madeddu, & Maffei, 1999; Leichsenring et al., 2011; Paris, 2007). The biopsychosocial model of personality disorder development recognizes that many factors, including biological (such as genetic heritability) and psychosocial experiences (such as adverse childhood experiences and temperament) may contribute to personality disorder development (Fossati et al., 1999; Paris, 1997). In view of this changed understanding, families and carers have come to be seen as important collaborators in the recovery effort for patients with personality disorders (Gunderson, 2008; Gunderson et al., 1997). The model also recognized that carers may experience negative effects from the maladaptive relational dynamics characteristic of those with personality disorders. Research has begun to focus on the unique experience of burden, support needs, and demands placed upon families, partners, and carers of those with personality disorders.

The present study aims to systematically review and synthesize the emerging literature on this topic, and to identify any gaps that need to be addressed in future research. For the purpose of the study, carer was defined as any person (biologically or nonbiologically related) who provides regular ongoing care, support, and assistance to persons with personality disorders.

2.2 Methods

2.2.1 Protocol and Registration

This review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) Statement for Reporting Systematic Reviews (Liberati et al., 2009) and additional guidelines for conducting and reporting systematic reviews (Sutton, Abrams, Jones, Sheldon, & Song, 1998). Methods of data collection and

inclusion criteria were predetermined and documented in a protocol (available at [http://www.crd.york.ac.uk/PROSPERO/Display_record.asp?ID = CRD42012001961](http://www.crd.york.ac.uk/PROSPERO/Display_record.asp?ID=CRD42012001961)). The protocol was registered by the International Prospective Register of Systematic Reviews (PROSPERO; registration number CRD42012001961).

2.2.2 Data Sources

Studies were identified in three phases: electronic databases were searched; reference lists were scanned; and experts were consulted. The three phases were completed from January to March 2012.

2.2.3 Searching Electronic Databases

Psychology and Behavioral Sciences Collection, PsycInfo, PubMed, Scopus, and Web of Science were searched for eligible studies. Search terms used for each database included the following: (Carer OR family) AND (personality disorder or borderline personality disorder or personality traits) AND (support OR intervention OR therapy OR treatment OR counselling OR service) AND (burden OR grief OR wellbeing OR guilt).

2.2.4 Scanning Reference Lists

The reference lists of studies included from the electronic database phase were scanned for further eligible studies.

2.2.5 Consultation with Experts

A list of the included studies was sent to experts in the area of research, inviting contribution of any further studies that may meet criteria. Experts were determined as having authored or co-authored three or more included studies from the initial search of electronic database phase.

2.2.6 Study Selection

One author reviewed the identified studies, which were then checked by an expert in personality disorders who was blind to prestige factors, including authors, institutions, journal titles, and publishers. No disagreements of inclusion were experienced. The inclusion criteria were as follows:

1. Carers or families of persons with personality disorders,
2. Intervention involving the carers or families (predominately for carer or family outcome),
3. Burden on carers or families (or related construct, such as grief or guilt),
4. Empirical studies (excluding anecdotal accounts, reviews, book chapters, and editorials),
5. Published during the last 15 years (1996 to 2011),
6. Published in English.

Inclusion required the study to meet criteria 1, either 2 or 3, and 4 through 6. In this way, the studies must have involved research into the burden experienced by families and carers of persons with personality disorders, or a study of a support intervention for carers of persons with personality disorders, and also be empirical in design, and published during the last 15 years in English.

2.2.7 Data Extraction and Risk of Bias

One reviewer extracted data from the included studies. The data-extraction form listed the source, design, aim, participants, findings, and limitations. Due to the small number of studies that met inclusion criteria, no validity assessment techniques were used. Risk of selection bias was minimized by using a blind rater and varied methods of study sourcing.

2.3 Results

2.3.1 Search Results

2.3.1.1 Search of Electronic Databases

The search of electronic databases resulted in the identification of 504 studies (437 with duplicates removed). Of these, 421 were excluded as their titles or abstracts clearly indicated that they did not meet the inclusion criteria. Of the remaining 16 studies, 11 were excluded because they were not specific to personality disorders (n=9) or because they mixed personality disorders with other diagnoses (n=2). This phase thus identified 5 studies for inclusion in the systematic review.

2.3.1.2 Scanning of Reference Lists

The scanning of reference lists identified a total of 145 citations from the 5 studies generated from the search of electronic databases (129 after duplicates and studies already included were removed). Of these, 123 studies were excluded as their titles or abstracts clearly indicated that they did not meet the inclusion criteria. Of the remaining 6 studies, 5 were excluded because the study was not specific to personality

disorders (n=3) or the study was not empirical (n=2). Therefore, this phase resulted in one further study included in the systematic review.

2.3.1.3 Consultation with Experts

Three experts were identified and contacted, however no additional studies were suggested or included in the study.

2.3.1.4 Total Studies Included

Based on the above process, 6 studies were included in the systematic review. Figure 2.1 depicts the flow of identified and eligible studies.

2.3.2 Study Characteristics

Since the included six studies were heterogeneous in both design and methodology, statistical aggregation in the form of a meta-analysis was not indicated. Three of the included studies met all six criteria, being pre/post evaluations of support interventions for carers of persons with personality disorders (Hoffman et al., 2007; Hoffman et al., 2005; Sanders & Pearce, 2010). These three studies were not randomized and included small sample sizes. Additionally, two of these studies included short follow-up periods when compared to studies evaluating interventions with carers of persons with Axis I disorders (Falloon & Pederson, 1985; Hogarty et al., 1991; Tarrier et al., 1989), and the same two studies were specific to carers of persons with BPD (Hoffman et al., 2007; Hoffman et al., 2005). The third of these

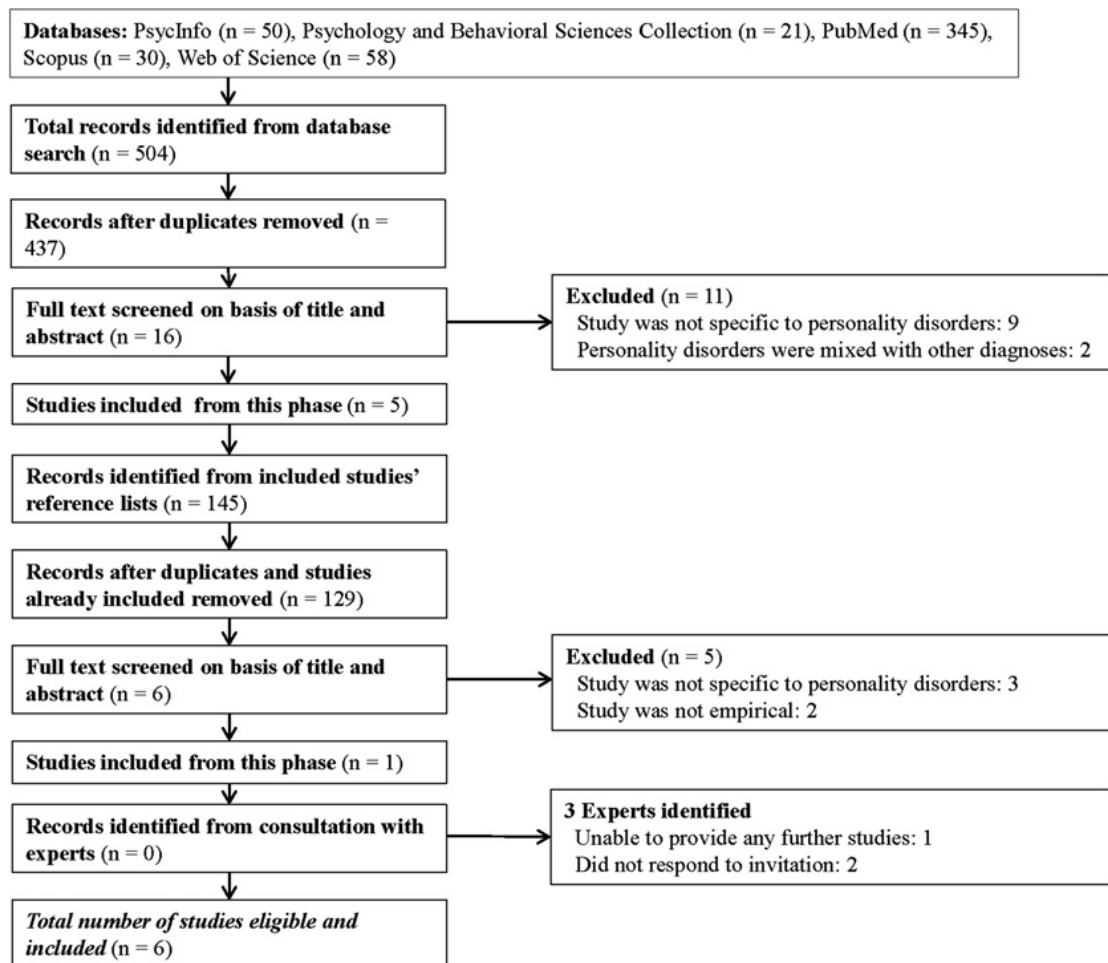


Figure 2.1: Flow diagram of information through the different phases of the systematic review.

three studies, while providing only minimal data, included carers of persons with any personality disorder (Sanders & Pearce, 2010).

The remaining three of the included studies met criteria 1 and 3 through 6; as such, they used constructs such as burden and wellbeing to assess the impact of caring for persons with personality disorders (Goodman et al., 2011; Hoffman, Buteau, Hooley, Fruzzetti, & Bruce, 2003; Scheirs & Bok, 2007). These three studies were specific to carers of persons with BPD.

It is worth noting that the included studies were published from 2003 to 2010, and that four of the six studies were published from 2007 to 2010. The characteristics

of the included studies are summarized in Table 2.1.

Finally, though the methodology was designed to capture relevant studies on carers of persons with any personality disorder, five of the six included studies specifically focused on carers of persons with BPD. Consequently, though the results and discussion will sometimes refer to personality disorders rather than BPD, it should be understood that the results are primarily focused on BPD.

2.3.3 Sample Characteristics

The six included studies reported on a total of 465 carers. However, demographic and empirical data that could be aggregated were available only for carers of persons with BPD. Table 2.2 outlines the available aggregated data on the characteristics of the carers, and Table 2.3 outlines the available aggregated data on the characteristics of the persons with BPD.

2.3.4 Main Findings

2.3.4.1 Burden

Carer burden was measured by five of the six included studies (see Table 2.1). Data from the Burden Assessment Scale (BAS; Reinhard, Gubman, Horwitz, & Minsky, 1994) was used by three included studies for carers of persons with BPD. The BAS is a 19-item measure of objective and subjective burden, in which higher scores indicate greater burden. Objective burden relates to the observable behavioural effects of caregiving (such as financial problems and household disruption), whereas

Table 2.1: Summary of the included studies.

Source	Design	Aims	Participants	Findings	Limitations
Hoffman et al. (2003)	Cross-sectional interviews	Explore the extent to which family members' knowledge of BPD is correlated with wellbeing	32 family members of persons with BPD (59% female; 69% parents; mean age 51 years)	Over a third of family members were unaware of the diagnosis; a further third could not accurately describe the symptomatology Greater knowledge was correlated with higher depression, burden, psychological symptom scores & hostility	Small sample size; causality cannot be inferred Family members' sources of information (e.g., Internet, books, professionals) were not indicated Limited to carers of persons with BPD
Hoffman et al. (2005)	Pre- & post-intervention	Pilot study evaluating the 12-week Family Connections intervention for carers of persons with BPD	44 carers representing 34 families of persons with BPD (88.6% parents, of which 61.4% were mothers; mean age 55.5 years)	Overall burden & grief decreased significantly from pre- to post-intervention; mastery significantly increased; depression & perceived burden did not change During the 6-month post-baseline follow-up, overall burden continued to significantly decrease; gains in mastery & grief were maintained	Included a short follow-up period compared to evaluations of Axis I carer-support interventions (Falloon & Pederson, 1985; Hogarty et al., 1991; Tarrier et al., 1989) HLM analysis indicated that a significant amount of variation in change over time could be explained by family variables (which was not explored) Limited to carers of persons with BPD

(table continues)

Table 2.1: Continued

Source	Design	Aims	Participants	Findings	Limitations
Hoffman et al. (2007)	Pre- & post-intervention	To replicate previous Family Connections findings & to evaluate whether pre- & post-intervention measures demonstrate gender differences	55 carers of persons with BPD (unclear how many unique families represented; 57% female; 77% parents; mean age 53.4 years)	<p>Findings of previous research were replicated:</p> <p>During the 6-month, post-baseline follow-up, grief continued to significantly decrease; all other improvements were maintained</p> <p>New findings:</p> <p>At pre-intervention, women endorsed significantly higher grief & subjective burden</p> <p>Controlling for baseline scores, no significant gender differences were identified at post-intervention</p> <p>Women showed significantly greater reductions in subjective burden & grief post-intervention</p>	<p>Includes a short follow-up period, with no measure of change in the caregiving relationship or patient symptom severity</p> <p>Initial & present study contained generally modest effect sizes for outcome variables</p> <p>Limited to carers of persons with BPD</p>
Scheirs & Bok (2007)	Cross-sectional survey	To investigate the influence of BPD on the psychological wellbeing of carers	64 Dutch carers of persons with BPD (44 female; mean age 44.8 years); 36 were biologically related (e.g., parents) & 28 unrelated (e.g., partners)	<p>Carers scored significantly higher than the general Dutch population on all SCL-90 symptom dimensions</p> <p>No significant difference between caregiver groups, except for somatization (those biologically related to patient scored higher) & hostility (those unrelated to patient scored higher). Older age & being female was associated with higher depression scores</p>	<p>Included no measure of the relationship's duration & therefore of potential exposure to the person with BPD</p> <p>Causality cannot be inferred</p> <p>Limited to carers of persons with BPD</p>

(table continues)

Table 2.1: Continued

Source	Design	Aims	Participants	Findings	Limitations
Sanders & Pearce (2010)	Pre- & post-intervention	Describe & evaluate a group intervention for carers of persons with personality disorders (OFAFE) & children of persons with personality disorders (YFAFE)	28 carers in OFAFE group, 9 in YFAFE group (10–17 years old); no demographic information was provided specific to these samples; carers were supporting a person with any personality disorder	OFAFE evaluation showed nonsignificant trends toward a reduction in isolation & burden No empirical data were provided regarding the evaluation of YFAFE	Pilot study with a small sample size Minimal empirical data provided for evaluating OFAFE; no data provided for evaluating YFAFE
Goodman et al. (2011)	Cross-sectional Internet survey	To measure the level of subjective burden experienced by parents of a daughter with BPD & determine correlates of parental burden	233 parents of daughters with BPD (95% female; mean age 51 years)	The majority endorsed emotional health as being most affected, followed by physical health & deleterious impact on marriage & social life Retrospective reports of adolescent acting-out behaviour, property destruction, delusional symptoms & hallucinatory symptoms were significantly correlated with intensity of parental burden The median out-of-pocket expense of caregiving was U.S.\$10,000	Limited to the United States (e.g., used US\$) Empirically validated measure of burden not used Results limited by self-selection & retrospective bias Limited to carers of persons with BPD

Note. BPD, borderline personality disorder; HLM, hierarchical linear modeling; OFAFE, Oxford Friends and Family Empowerment; SCL-90, Symptom Checklist-90, YFAFE, Young Friends and Family Empowerment.

subjective burden involves feelings, attitudes, and emotions expressed about the caregiving experience (such as embarrassment and guilt; Platt, 1985; Reinhard et al., 1994). The aggregated BAS data resulted in an average score of 43.91 ($n=131$; standard deviation [SD]=11.62) for carers of persons with BPD. By contrast, using the same measure of burden (the BAS), average scores have been reported as 38.54 ($n=135$; SD=13.27) for carers of psychiatric inpatients with mood, substance, neurotic, and psychotic disorders (Page, Hooke, O'Brien, & de Felice, 2006). These mean scores were significantly different, with a small to medium effect size: $t(264)=3.51$; $p<.01$; $r=0.21$. Therefore, the results indicate that carers of persons with BPD experience elevated objective and subjective burden approximately half a standard deviation above the mean compared to carers of inpatients with other serious mental illnesses, suggesting that this difference is likely of clinical significance.

In two of the included studies with carers of persons with BPD, grief was measured using the Grief Scale (Struening et al., 1995), which is a 15-item measure of current feelings of grief associated with the mental illness of a loved one. The carer data resulted in an average score of 54.01 ($n=99$; SD=11.14) on the Grief Scale, with potential scores ranging from 15 to 75. This average score approximates to a mean anchor rating of 3.60 (SD=0.74; between “Sometimes True” and “Often True”). Previous research with carers of inpatients with schizophrenia or major affective disorders have resulted in mean anchor ratings of 3.30 ($n=180$; SD=0.95; Struening et al., 1995). The mean anchor ratings were significantly different, with a small effect size: $t(277)=2.72$; $p<.01$; $r=0.16$. Therefore, the results suggest that carers of persons with BPD experience elevated grief compared to carers of persons with other serious mental illnesses.

Empowerment was measured by two of the included studies with carers of persons with BPD using the Family Empowerment Scale (FES; Koren, DeChillo, & Friesen, 1992) a 34-item scale based on two dimensions: the level of empowerment (family, service system, community/political) and the way that empowerment is expressed (attitudes, knowledge, behaviours). The measure was originally developed for use with families of children with emotional disabilities. The aggregated FES data for carers of persons with BPD resulted in an average score of 38.74 ($n=99$; $SD=13.09$). Previous research has reported average scores of 119.43 ($n=67$; $SD=14.49$) for a sample of carers for disabled children in the United States (Dempsey & Dunst, 2004). These mean scores were significantly different, with a large effect size: $t(164)=37.31$; $p<.0001$; $r=0.95$. This finding indicates not only that carers of persons with BPD are burdened and grieving, but that their sense of empowerment is seriously impaired. This lack of empowerment is likely of clinical significance since it is four standard deviations lower than the mean endorsed by carers of disabled children.

2.3.4.2 Carer Wellbeing

The carers' own mental health and wellbeing was measured in five of the six included studies (see Table 2.1). Two of the studies measured depression experienced by carers of persons with BPD with the Revised Center for Epidemiological Studies Depression Scale (Struening et al., 1995), yielding an average score of 27.10 ($SD=8.84$), with a potential range of 0 to 60. Previous research with carers of persons with schizophrenia or major affective disorder resulted in an average score of 15.84 (Struening et al., 1995). Unfortunately, the previous data with carers of persons with

Table 2.2: Available data on the characteristics of carers.

Studies	Sample size (n)	Characteristics of carers	n (percentage of sample)	Mean (standard deviation)
Hoffman et al. (2003); Scheirs & Bok (2007); Goodman et al. (2011)	329	Female	275 (83.6%)	
Hoffman et al. (2003); Hoffman et al. (2005); Hoffman et al. (2007); Scheirs & Bok (2007); Goodman et al. (2011)	428	Age		Mean=51.2 years
Hoffman et al. (2003); Hoffman et al. (2005); Hoffman et al. (2007); Goodman et al. (2011)	352	Parents	316 (89.8%)	
Hoffman et al. (2003); Hoffman et al. (2005); Hoffman et al. (2007)	131	Mothers	74 (56.5%)	
Hoffman et al. (2003); Hoffman et al. (2005); Hoffman et al. (2007)	131	Fathers	29 (22.1%)	
Hoffman et al. (2003); Hoffman et al. (2005); Hoffman et al. (2007)	131	Partner/spouse	20 (15.3%)	
Hoffman et al. (2003); Hoffman et al. (2005); Hoffman et al. (2007)	131	Sibling/children	8 (6.1%)	
Hoffman et al. (2003); Goodman et al. (2011)	256	College graduate or above	158 (61.7%)	
Hoffman et al. (2003); Hoffman et al. (2005); Goodman et al. (2011)	291	Income > U.S.\$50,000	213 (73.2%)	
Hoffman et al. (2003); Hoffman et al. (2007)	87	Living with the person with BPD	55 (63.2%)	

(table continues)

Table 2.2: Continued.

Studies	Sample size (n)	Characteristics of carers	n (percentage of sample)	Mean (standard deviation)
Hoffman et al. (2003); Hoffman et al. (2005); Hoffman et al. (2007)	131	Burden (Burden Assessment Scale)		Mean=43.9 (SD=11.62) ^{a,b}
Hoffman et al. (2005); Hoffman et al. (2007)	99	Depression (Revised Center for Epidemiologic Studies Depression Scale)		Mean=27.1 (SD=8.8) ^b
Hoffman et al. (2005); Hoffman et al. (2007)	99	Grief (Grief Scale)		Mean=54.0 (SD=11.1) ^b
Hoffman et al. (2005); Hoffman et al. (2007)	99	Mastery (Family Empowerment Scale)		Mean=38.7 (SD=13.1) ^b

^a Sanders and Pearce (2010) also measured burden with the Burden Assessment Scale but provided no descriptive statistics; that study is therefore not included in the calculation of this mean total.

^b Hoffman et al. (2005, 2007) provided descriptive statistics for multiple time points; only baseline measures were included in the calculation of this total data.

schizophrenia or major affective disorder did not report the standard deviation, which would have allowed statistical analysis of the difference in mean scores on carer wellbeing. However, the difference between the above means is clinically significant. Scores higher than 16 have been interpreted as indicating clinical depression (Radloff, 1977; Struening et al., 1995), which was exceeded by carers of persons with BPD (mean=27.10) yet not by previous research with carers of persons with schizophrenia or major affective disorders (mean=15.84). Therefore, carers of persons with BPD experience symptoms consistent with samples with clinical depression.

One study used the Symptom Checklist–90 and found that Dutch carers of persons with BPD were elevated on all subtests of anxiety, agoraphobia, depression,

Table 2.3: Available data on the characteristics of persons with BPD.

Studies	Sample size (n)	Characteristics of person with BPD	n (percentage)	Mean
Hoffman et al. (2003); Scheirs & Bok (2007); Goodman et al. (2011)	329	Female	315 (95.7%)	
Hoffman et al. (2003); Hoffman et al. (2005); Hoffman et al. (2007); Goodman et al. (2011)	354 ^a	Age		27.0 years
Hoffman et al. (2005); Hoffman et al. (2007)	89 ^a	Years since onset of disorder		10.8 years
Hoffman et al. (2003); Hoffman et al. (2007); Goodman et al. (2011)	320 ^a	Hospitalizations		3.7 times

^a Since Hoffman et al. (2007) did not specify the number of persons with BPD in their study, the number of persons with BPD was assumed to be equal to that of the sample size of carers (n=55).

somatization, insufficiency of thinking and acting, distrust, hostility, and sleeping problems compared to the general Dutch population (Scheirs & Bok, 2007).

Taken together, the included studies indicate that carers of persons with BPD experience objective and subjective burden, grief, impaired empowerment, and their own mental health problems, including depression and anxiety.

2.3.4.3 Generalizability

Five of the six included studies were specific to carers of persons with BPD, and as noted earlier, data that could be aggregated were available only for carers of persons with BPD. Further, the majority of reviewed research has focused on carers of

female patients (see Table 2.3), and the majority of identified carers are parents, particularly mothers (see Table 2.2). The search strategy and intention was to study all personality disorders and to study patients and their carers of both genders; the outcome of this strategy revealed large gaps in the literature about other personality disorders.

2.4 Discussion

The present study aimed to systematically review and synthesize the available demographic and empirical data on the burden and support needs of families, partners, and carers of persons with personality disorders. Although the study aimed to research the broad impact of caregiving for any personality disorder, data on the experience of carers of persons with personality disorders other than borderline are nonexistent. However, this study is the first to report demographic and empirical data on the largest aggregated sample size in the literature regarding carers of persons with BPD, resulting in important clinical and research implications. Six studies were eligible by the inclusion criteria.

As expected, research in the area has increased in recent years; indeed, the earliest study included here dates from 2003. The findings suggest that carers of persons with BPD experience elevated objective and subjective burden, grief, and impaired empowerment, and that they may also report suffering depression and anxiety. Interestingly, much of the available research has been specific to parents, often mothers, caring for persons with BPD. Further, the majority of research on the experience of carers has been limited to those supporting a female person with BPD. These limitations affect the generalizability of the findings. Moreover, the included studies did not share common methods or outcomes; meta-analysis was not feasible.

The included studies allow some empirical insight into the experience of supporting persons with BPD. Three of the included studies measured the experience of burden with carers of persons with BPD using the Burden Assessment Scale. Carers of persons with BPD endorsed elevated objective and subjective burden approximately half a standard deviation above the mean compared to carers of inpatients with other serious mental illnesses (Page et al., 2006). Items of objective burden include financial problems, limitations on carer activity, disruption of household routines and social functioning (including significant changes in work and in social and family life). The implication is that carers are significantly altering their lifestyles to take into account the needs of their relatives. In terms of subjective burdens, the attitudes and emotions expressed about the caregiving experience include shame, stigma, guilt, worry, and resentment (Reinhard et al., 1994). Therefore, not only are carers burdened in observable ways (e.g., financially or through disrupted routines), but they are also burdened in their internal experience (including conflicts around love and resentment). Previous qualitative research by Giffin (2008, p. 135) with parents of persons with BPD has documented the intense mother-daughter caregiving relationship as characterized by conflicting emotions of love and anger; as one mother noted, she “gave so much, but got nothing in return.” Further, carers of persons with BPD have been reported by Ekdahl and colleagues (2011, p. e71-72) to describe the experience as “I don’t dare to live my own life in the same way as before, I adjust all the time and I worry, worry every minute,” and as living life “on tiptoes.”

Grief and empowerment were also important themes. Carers of persons with BPD endorsed elevated grief compared to carers of inpatients with schizophrenia or major affective disorders (Struening et al., 1995). The experience of grief has been described in previous qualitative research by Ekdahl and colleagues (2011, p. e72) as

having two dimensions. One is the loss of the potential life that persons with BPD could have had—a grief described as “[p]owerlessness, not being able to help, to watch her youth go down the drain and know that my daughter also knows.” The other is *lifelong grief*, in which carers express concern for the future, especially about who will care for the person with personality disorder once the carers themselves are no longer able to do so. Therefore, carers of persons with BPD endorsed that they are burdened and grieving, including being concerned for the future. Ideally, burden and grief would be somewhat alleviated through effective interactions with mental health services, but carers also endorsed impaired empowerment, suggesting that this is currently not occurring.

The aggregated Family Empowerment Scale data indicated not only that carers of persons with BPD are burdened and grieving, but that they experience a sense of impaired empowerment. Carers have reported difficulties with the mental health system in previous qualitative research—including that the system has provided inconsistent or contradictory advice, lacked empathy, and failed to include carers in treatment and in discharge planning (Ek Dahl et al., 2011; Giffin, 2008). Further, carers have endorsed dissatisfaction with the clinical treatment of their daughters with BPD (Goodman et al., 2011). Therefore, carers of persons with BPD experience elevated objective and subjective burden, grief, and impaired empowerment—which, combined, would likely affect the carers’ own wellbeing.

The included studies also provided data specifically on the carers’ own mental health and wellbeing. Data from the Revised Center for Epidemiological Studies Depression Scale indicated that carers of persons with BPD experience their own mental health problems, including symptoms consistent with depression and anxiety. A further study reported that Dutch carers of persons with BPD endorsed elevated

anxiety and depression compared to the general Dutch population (Scheirs & Bok, 2007). Qualitatively, carers have described the ongoing “tension” involved in caring for BPD patients, with the consequence that “you don’t sleep some nights very much at all,” as reported by Giffin (2008, p. 134). Likewise, the rollercoaster milieu of parents is evident in the remark that “we live through our children, if they feel good we feel good,” as reported by Ekdahl and colleagues (2011, p. e72). It nevertheless remains unclear to what extent carers’ compromised sense of wellbeing preceded the caregiving relationship (and thus was a preexisting source of carer psychological distress contributing to the results) and to what extent it reflects the burden of the caregiving role itself. That said, previous research has reported the chronic and traumatic stress of families and carers who have witnessed self-harm, impulsive anger, and other destructive behaviours of their loved ones with BPD—events that would surely cause repeated distress, even trauma, and seriously affect carers’ wellbeing (Giffin, 2008). Therefore, notwithstanding some uncertainty as to cause and effect regarding carers’ sense of wellbeing, they experience elevated objective and subjective burden, grief, impairments in empowerment, and difficulties in their own mental health and wellbeing.

Interestingly, the majority of identified carers in the included studies have been parents (and specifically mothers) to female daughters with BPD. The mean age of the persons with BPD in the present aggregated sample was 27.02 years, and the average number of years since onset was 10.76 (see Table 2.3). The average age of symptom emergence was therefore approximately 16 years, which is consistent with previous research on the development of BPD (Stepp, 2012). From a psychosocial perspective, this age is crucial in developing both a sense of identity (often significantly impaired in persons with BPD) and intimacy with others outside of the immediate family—and

thus in separating from parents. Specifically, Erik Erikson's psychosocial theory of development described the adolescent and early adulthood stages as involving ego conflicts of identity versus role confusion and of intimacy versus isolation (Erikson, 1963). It is therefore possible that during the emergence of BPD symptoms in adolescence, which would presumably present difficulties in developing a sense of self and in transitioning into early adulthood (including forming intimate relationships), the parent-child (in particular, the mother-child) dyad may remain the patient's primary relationship. In qualitative research, for example, the mother-daughter relationship has been described as intensified when the daughter developed symptoms of BPD (Giffin, 2008). Further, an influential case study regarding a complex female client with BPD described the therapeutic importance of exploring the relationship with her mother and of creating separation in the recovery process—which facilitated the development of an intimate relationship with a suitable partner (Goodman, Hazlett, New, Koenigsberg, & Siever, 2009). Psychosocial development theory may also be relevant in understanding the high proportion of parents (particularly mothers) who identified as the primary carers.

The present review served to identify the existing limitations of research concerning carers of persons, of either gender, with personality disorders. The majority of research has focused on carers of persons with BPD in particular, and data on the experience of burden, grief, empowerment and wellbeing of carers of persons with other personality disorders is nonexistent. Since all personality disorders are characterized by maladaptive interpersonal styles, it is likely that carers of persons with other personality disorders (such as antisocial, histrionic, or narcissistic personality disorder) would experience similar burdens, grief, and interpersonal challenges in their supportive role. Further, the high comorbidity among the DSM-IV

personality disorders suggests that patients often suffer from more than one personality disorder (Grant et al., 2008; Zimmerman et al., 2005). Although these considerations suggest that the findings of studies specific to carers of persons with BPD could possibly be generalized to carers of persons with personality disorders, future research may benefit by comparing the burden and support needs of carers of persons with different personality disorders.

In the studies reviewed here, the carers of female persons with BPD are overrepresented. Although clinical samples have found a larger prevalence of females diagnosed with personality disorders in general (Skodol & Bender, 2003; Thomas, 1998; Zimmerman et al., 2005), epidemiological research with community samples has indicated that personality disorder diagnoses (in particular, of BPD) are balanced across gender (Grant et al., 2008; Lenzenweger, 2008). It has been hypothesized that this may be due to gender differences in clinical samples (and by the same token, the studies presented here), where females present as internalized and males as externalized in impulsivity and affective dysregulation (Grant et al., 2008; Johnson et al., 2003). However, carers in the community may be supporting more evenly divided populations of males and females with borderline or other personality disorders. It is a challenge for the field to identify and include males in future studies.

The present study is the first to systematically review previous research and to present the empirical data on a large, aggregated sample of carers of persons with BPD. The findings indicate that carers of a person with BPD are burdened (both objectively and subjectively), grieving, and impaired in their sense of empowerment, and that they may experience their own mental health problems. Importantly, it appears that objective and subjective burden and grief in the aggregated sample of carers of persons with BPD may be more elevated compared to carers of persons with

other serious mental illnesses. The research also suggests that support interventions may be beneficial to carer wellbeing, though the small sample sizes and short follow-up periods necessitate further research in order to reach firm conclusions. The present findings were limited due to five of the six included studies being specific to carers of persons with BPD. Further research is needed on other personality disorder diagnoses, and the carers of male patients with personality disorders need to be included. In the meantime, however, it is clear that carers of persons with BPD are seriously burdened. Developing effective means of support would obviously improve carer wellbeing and would also, most likely, benefit the patients themselves.

Chapter 3

Study 2

Supporting a person with personality disorder:

A study of carer burden and wellbeing

This is an identical version of the accepted manuscript published in full in the Journal of Personality Disorders.

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3.1 Introduction

The experience of caring for or supporting a person with personality disorder has been under-researched. Until recent years, carers of persons with personality disorder were considered causal of the consumers' mental health difficulties (Gunderson, 2008; Gunderson et al., 1997) and have reported experiencing "surplus stigma" from both the wider community and mental health professionals (Hoffman et al., 2005). However, the biopsychosocial model has suggested that personality disorder development is an interaction of many factors, rather than a direct result of parenting or caregiving (Leichsenring et al., 2011). Preliminary research involving carers of persons with personality disorder has begun to increase with qualitative and exploratory studies, yet further research with empirically validated measures is required to understand their experience compared to that of carers of persons with other mental illnesses and non-carers.

Personality disorders are highly prevalent in community samples. It has been estimated that 1 in 10 persons suffers from a diagnosable personality disorder (Lenzenweger, 2008). These persons would likely have at least one family member or significant other supporting them, implying that large numbers of the wider community are impacted by supporting a loved one with personality disorder. A qualitative study of four parents of a person with borderline personality disorder (BPD) reported themes of chronic and traumatic stress, grief, burden, interpersonal strain, difficulty navigating the mental health system and conflicting advice from mental health professionals (Giffin, 2008). A qualitative study with 10 parents and one adult child of a person with BPD resulted in themes of a life tiptoeing around the consumer, constant duty and worry, strained family relationships, shame and stigma, powerlessness, guilt and grief, and impaired trust toward the mental health system

(Ekdahl et al., 2011). Further, a recent qualitative study of 30 carers of a person with personality disorder identified 44 themes, highlighting the multidimensionality of burden experienced by carers (Bauer et al., 2012).

Quantitative studies have also explored the experience of caring for a person with BPD. An online questionnaire exploring the burden associated with caring for a daughter with BPD showed that the largest impact was on emotional health, physical strain, marital satisfaction and social life (Goodman et al., 2011). A further study found that both biologically related and unrelated Dutch carers of a person with BPD scored higher than the general Dutch population on the Symptom Checklist 90 (a measure of mental health problems; Scheirs & Bok, 2007). Thus, previous research suggests that being a carer of a person with BPD is associated with experiencing mental health problems above that of the general population.

Although previous research has made some progress towards understanding the experience of caring for a person with personality disorder, the literature remains sparse and limited. Most of the previous research has focused on carers of persons with BPD. BPD is the most widely researched personality disorder, but all personality disorders are characterised by impaired interpersonal functioning. For instance, many of the DSM-IV defined personality disorders (American Psychiatric Association, 2000) overlap in criteria that would likely impact the carer in similar ways. Additionally, the high comorbidity between personality disorders suggests that consumers are often diagnosable with more than one personality disorder (Grant et al., 2008; Zimmerman et al., 2005). Previous research has also been preliminary in nature, using qualitative and non-empirically validated measures that do not allow for comparisons with the experience of carers of persons with other mental illnesses. Thus, the present study aimed to compare the experience of caring for or supporting a

person with any personality disorder with published comparison groups using empirically validated measures of carer burden and wellbeing.

3.2 Methods

3.2.1 Recruitment and Inclusion

Participants gave explicit consent to participate following Institutional Board approval of the study. Carers were recruited to complete the survey either online or in print. Advertisements for the survey were located in local and international community forums including newsletters, carer events and educational presentations, blogs and websites including bpdfamily.com, bpdcentral.com, arafmi.org and projectairstrategy.org. The survey advertisement asked participants, *“Do you have a relative or significant other with Borderline Personality Disorder or another personality disorder? If so, you are invited to participate in a survey from researchers... interested in the unique experience of caring for a person with personality disorder on you, your life and relationships.”* Therefore, carers who participated in the research were actively engaged in seeking support, education and information from local and international forums, suggesting that they were aware of the issues involved in being a carer of a person with personality disorder.

For the purpose of the research, *relative* was defined as a person with personality disorder who may be a biological family member or significant other. *Carer/caregiving* was defined as regular interactions with the relative involving tasks promoting wellbeing and recovery, which could include simply being in a supportive relationship. To gain access to the survey, carers were required to endorse yes to *“Do you have a relative (including biological - such as parent or sibling, or non-biological - including significant other or friend) with a personality disorder?”* However,

previous research has reported that many carers are unaware of the diagnosis or unsure what a personality disorder means (Hoffman et al., 2003). Therefore, in a conservative effort to ensure that the included carers were appropriate to the research two criteria were applied. First, carers were required to state any personality disorder as their relative's mental illness. Second, carers who did not state any personality disorder as their relative's mental illness (did not meet criterion one) yet endorsed equal to or greater than seven items on the McLean Screening Instrument for BPD-Carer Version (MSI-BPD-C, described below; Zanarini et al., 2003) were included.

3.2.2 Participants

A total of 474 carers consented to the survey; 187 carers were excluded due to reporting that they do not have a relative with a personality disorder ($n=59$); not completing any questions ($n=108$); or not meeting the inclusion criteria ($n=20$). Therefore, 287 carers were included in the study. Responses with some missing data were not significantly different from surveys with full data on demographics including carer age, $t(284)=-1.70, p>0.05$, carer gender, $\chi^2(1)=0.05, p>0.05$, consumer age, $t(287)=-0.25, p>0.05$, consumer gender, $\chi^2(1)=0.76, p>0.05$ or the length of the caregiving relationship, $t(263)=-0.61, p>0.05$. Table 3.1 outlines the characteristics of the carer, and Table 3.2 those of the person with personality disorder.

Many carers identified more than one personality disorder as their relative's mental illness (see Table 3.2). Of those who did not identify the personality disorder subtype, 96% ($n=51$) scored greater than or equal to 7 on the MSI-BPD-C. Of those who identified BPD as the subtype, 86% ($n=202$) scored greater than or equal to 7 on the MSI-BPD-C (Zanarini et al., 2003). Therefore, the vast majority of carers

identified BPD as the diagnosis of their relative. We compared carers who identified BPD-only as the subtype (n=187) with carers who identified other subtypes on a measure of carer burden (Burden Assessment Scale, described below; Reinhard et al., 1994) and found no difference between the groups $t(270)=0.47$, $p>0.05$.

Table 3.1: Demographic characteristics of the carers of persons with personality disorder. Numbers in parentheses represent sample size.

Carer		
Age (286)	Mean (range)	47.2 years (16-75)
Length of caregiving relationship (265)	Mean (range)	12.90 years (0-61)
Gender	Male (93)	32.4%
	Female (194)	67.6%
Employment	Full-time (160)	55.7%
	Part-time (58)	20.2%
	Unemployed (64)	22.3%
	Did not state (5)	1.7%
Relationship to person with personality disorder	Mother (90)	31.4%
	Father (16)	5.6%
	Child (39)	13.6%
	Sibling (14)	4.9%
	Partner/Spouse (106)	36.9%
	Significant Other (22)	7.7%
Do you provide most of the care for your relative?	Yes (163)	56.8%
	No (122)	42.5%
Has a mental health professional explained the diagnosis to you?	Yes (179)	62.4%
	No (105)	36.6%

Table 3.2: Demographic characteristics of the person with personality disorder cared for in this study. Numbers in parentheses represent sample size.

Person with personality disorder		
Age (286)	Mean (range)	40.71 years (13-89)
Gender	Male (75)	26.1%
	Female (212)	73.9%
Employment	Full-time (64)	22.3%
	Part-time (41)	14.3%
	Unemployed (175)	61.0%
	Did not state (7)	2.4%
Personality disorder subtype	Borderline Personality Disorder (235)	
	Narcissistic Personality Disorder (33)	
	Obsessive Compulsive Personality Disorder (5)	
	Antisocial Personality Disorder (2)	
	Histrionic Personality Disorder (2)	
	Avoidant Personality Disorder (1)	
	Dependent Personality Disorder (1)	
	Paranoid Personality Disorder (1)	
	Schizotypal Personality Disorder (1)	
	Not otherwise specified (53)	
Hospitalisations (to carer's knowledge) in past year (284)	Mean (range)	1.06 (0-20)
Days of deliberate self-harm (to carer's knowledge) in past year (275)	Mean (range)	11.12 (0-365)
Days involving attempted suicide (to carer's knowledge) in past year (279)	Mean (range)	2.65 (0-365)
MSI-BPD-C items endorsed by carer (283)	Mean (range)	8.33 (2-10)

Note. MSI-BPD-C, McLean Screening Instrument for Borderline Personality Disorder-Carer Version.

3.2.3 Comparison Groups

A convenience comparison group for each measure was drawn from the published literature. As the measures have not been used consistently together, each measure corresponds to a different comparison group. Table 3.3 details the comparison groups, where diagnoses range from carers of persons with Axis I disorders to healthy controls. To our knowledge, the provided comparison groups represent the most relevant comparable published data available for each measure. The literature using the burden and grief measures addresses the specific question of carer burden (including grief and distress) in psychiatric hospital settings. In this context carers would be expected to inflate responses to communicate distress and invite service involvement and clinician support. However, carers in the present study were invited to respond honestly to an anonymous online survey where burden and wellbeing scores could not be expected to affect access to carer or consumer services.

3.2.4 Measures

McLean Screening Instrument for Borderline Personality Disorder-Carer Version (MSI-BPD-C). The MSI-BPD (Zanarini et al., 2003) is a 10 item screening instrument for BPD. A cut-off score of 7 or more items has shown good sensitivity and specificity for the DSM-IV diagnosis of BPD (Zanarini et al., 2003). The MSI-BPD has been adapted in previous research for carers to endorse observed symptoms of the person with personality disorder (Goodman et al., 2011). For the 283 participants with complete data on this measure, the MSI-BPD-C had weak internal consistency (Cronbach's $\alpha=0.46$). Closer examination of each item revealed that

dropping any one item would not substantially increase alpha, and thus all items were retained during analysis.

Burden Assessment Scale (BAS). The BAS (Reinhard et al., 1994) is a 19 item measure of objective and subjective burden, where higher scores indicate greater experiences of burden. The measure includes factors of disrupted activities, personal distress, time perspective (involving a negative temporal aspect of managing mental illness), guilt and basic social functioning (including significant changes in work, social and family life). The BAS showed strong internal consistency ($\alpha=0.88$, $N=272$).

Grief Scale (GS). The GS (Struening et al., 1995) is a 15 item measure of current feelings of grief associated with the mental illness of a loved one. Higher scores represent greater experiences of grief. The GS showed strong internal consistency ($\alpha=0.92$; $N=266$).

Mental Health Inventory-5 (MHI-5). The MHI-5 (Cuijpers, Smits, Donker, ten Have, & de Graaf, 2009) is a five item scale of depression and anxiety symptoms and psychological wellbeing from the Short Form-36 (SF-36; Ware et al., 1980), adapted from the original 38 item measure (Veit & Ware, 1983). The MHI-5 total score was linear transformed to a scale of 0 to 100, consistent with previous research (Cuijpers et al., 2009; Theunissen, Jansen, & van Gestel, 2011), where higher scores indicate better mental health. The MHI-5 showed strong internal consistency ($\alpha=0.85$, $N=244$).

Difficulties in Emotion Regulation Scale (DERS). The DERS (Gratz & Roemer, 2004) is a 36 item scale measuring nonacceptance of emotional responses, difficulties engaging in goal directed behaviour and impulse control, emotional awareness, access to emotion regulation strategies, and emotional clarity. Higher scores represent greater

difficulties in emotional regulation. The total score resulted in strong internal consistency ($\alpha=0.94$, $N=249$).

Leximancer. Qualitatively, 228 carers responded with free text to the question “*as a carer, what is your experience of caring for your relative (what impact has it had on you, your life and relationships)?*” Leximancer is a computer-assisted content analysis program that was used to identify and explore semantic relationships by providing a visual map of the relatedness of concepts from the qualitative text (Smith & Humphreys, 2006). Leximancer uses the qualitative text to identify lexical terms forming the basis of a bootstrapping thesaurus. The importance of the terms are ranked and weighted by how relevant they are to the concept. When weighted terms within sentence blocks (three sentences for longer text) accumulate and reach the required threshold a concept is formed (see Smith & Humphreys, 2006, for the statistical process of the program). The proximity of concept dots on the map represents their relatedness (often being mentioned together), and the prominence of the concept dot (i.e., size) represents the frequency of concepts present in the qualitative text. For example, the theme ‘family’ included concepts ‘family’, ‘issues’ and ‘friends’ and would translate as a broad theme of ‘family’ appearing frequently throughout the text with related specific concepts referring to ‘family’, ‘issues’ and ‘friends’. Word variants were merged (for example, ‘relationship’ and ‘relationships’) to simplify the findings.

3.3 Results

The variables were significantly skewed violating assumptions of normality. Therefore non-parametric correlations are reported. Table 3.3 provides the mean and standard deviation for each measure for the present sample and comparison groups.

3.3.1 Burden Assessment Scale

The mean BAS score was over one standard deviation higher than in previous research with carers of psychiatric inpatients with serious mental illness (Page et al., 2006). This difference was significant with a large effect size, $t(405)=13.59$, $p<0.0001$, $r=0.56$. The mean anchor rating was also significantly higher than that of parents of persons with schizophrenia (Foldemo, Gullberg, Ek, & Bogren, 2005), $t(308)=10.76$, $p<0.0001$, $r=0.65$ (large effect size). Kendall's tau-b two-tailed correlations indicated that higher scores on the BAS were correlated with lower consumer age, $\tau=-0.15$, $p<0.001$, $n=263$, greater frequency of deliberate self-harm, $\tau=0.18$, $p<0.001$, $n=262$ and suicide attempts, $\tau=0.15$, $p<0.01$, $n=266$. Further, higher scores on the BAS were correlated with higher scores on GS, $\tau=0.37$, $p<0.001$, $n=259$, and DERS, $\tau=0.20$, $p<0.001$, $n=244$, and lower scores on the MHI-5, $\tau=-0.27$, $p<0.001$, $n=238$. Qualitatively, a partner stated, *"Every step I take could have consequences, and so I had to learn to tiptoe around issues and give up things I liked whether I wanted to or not. I suddenly had to become more of a father figure than a lover, taking time off work to take her to doctor's appointments because she couldn't go alone, something I never thought I would be doing for another adult."*

3.3.2 Grief Scale

The mean anchor rating was significantly elevated compared to previous research with carers of inpatients with schizophrenia or major affective disorders (Struening et al., 1995), $t(444)=3.86$, $p<0.001$, $r=0.18$ (small effect size). Kendall's tau-b two-tailed correlations indicated that greater GS scores were correlated with

Table 3.3: Carers of persons with personality disorder and comparison groups scores on the measures.

Measure	Mean (SD) of carers of persons with personality disorder	Comparison group	Method of data collection for comparison group	Mean (SD) of comparison group
Burden Assessment Scale (BAS)	Total score: 55.36 (10.93) Anchor rating: 2.91 (0.58)	Carers of persons with severe mental illness participating in a community aftercare program or an intensive carer support service (Reinhard et al., 1994)	In-home face-to-face interview	Aftercare program: 55.3 (SD not provided) Support service: 32.1 (SD not provided)
		Carers of persons with mood, substance, neurotic and psychotic disorders (Page et al., 2006)	Face-to-face survey on admission to a psychiatric hospital	38.54 (13.27)
		Parents of persons with schizophrenia and randomly selected non-carers (Foldemo et al., 2005)	Face-to-face interview with carers of patients engaged in an outpatient clinic or non-carers drawn from population register	Parents: 1.8 (0.7) Non-carers: not provided
Grief Scale (GS)	Total score: 54.38 (12.60) Anchor rating: 3.63 (0.84)	Carers of persons with schizophrenia or a major affective disorder (Struening et al., 1995)	Face-to-face or phone interview on admission to a psychiatric hospital or ambulatory service	Anchor rating: 3.30 (0.95)
Mental Health Inventory-5 (MHI-5)	56.40 (20.96)	Random sample of resident registration office files in Germany (Rumpf, Meyer, Hapke, & John, 2001)	Face-to-face interview	Total scores less than 65 represent mood or anxiety disorders

(table continues)

Table 3.3: Continued

Measure	Mean (SD) of carers of persons with personality disorder	Comparison group	Method of data collection for comparison group	Mean (SD) of comparison group
		Random sample from postage registers in the Netherlands (Cuijpers et al., 2009)	Face-to-face or phone interview	Total scores less than 74 represent major depression or dysthymia
Difficulties in Emotion Regulation Scale (DERS)	83.31 (23.28)	Male and female university undergraduate students (Gratz & Roemer, 2004)	Questionnaire packets distributed to students	79.33 (19.76)
		Persons with PTSD and marijuana use in the last 30 days (Bonn-Miller, Vujanovic, Boden, & Gross, 2011)	Face-to-face interview and survey in response to community advertisement	84.77 (22.82)
		Females with Anorexia Nervosa and healthy controls (Harrison, Sullivan, Tchanturia, & Treasure, 2009)	Face-to-face interview and survey in response to community advertisement (healthy controls) or an eating disorder service and volunteer database	Anorexia: 108.8 (16.16) Healthy controls: 67.95 (14.46)

Note. SD, standard deviation; PTSD, post-traumatic stress disorder.

lower consumer age, $\tau=-0.15$, $p<0.01$, $n=265$, greater frequency of deliberate self-harm, $\tau=0.16$, $p<0.01$, $n=256$ and suicide attempts, $\tau=0.15$, $p<0.01$, $n=260$. Further, higher GS scores were correlated with higher scores on DERS, $\tau=0.25$, $p<0.001$, $n=247$, and lower scores on MHI-5, $\tau=-0.21$, $p<0.001$, $n=242$. A parent commented *“The biggest impact has been the grief of losing the person my daughter might have been, the heartache of seeing her suffer... my life has basically been 'on hold' hoping she will get better and become independent and now gradually realising this probably won't happen and starting to accept that I may have to care for a long time for someone with what I am starting to accept as a disability.”*

3.3.3. Mental Health Inventory-5

On average, carers of persons with personality disorder endorsed scores consistent with symptoms suggestive of clinical anxiety and mood disorders (see Table 3.3), where 64.3% of carers scored less than 65 (Rumpf et al., 2001), and 78.7% scored less than 74 (Cuijpers et al., 2009). Kendall's tau-b two-tailed correlation showed that lower scores on MHI-5, representing elevated mental health problems, were correlated with higher scores on DERS, $\tau=-0.39$, $p<0.001$, $n=234$. Qualitatively, a parent stated, *“When things are going well I am going well. When my daughter falls in a hole, so do I even though I feel I have been doing this caring for so long, I should be used to it.”*

3.3.4 Difficulties in Emotion Regulation Scale

The DERS resulted in a mean score consistent with a clinical sample of persons with post-traumatic stress disorder (Bonn-Miller et al., 2011), $t(326)=0.49$, $p>0.05$, *ns*. In contrast, the present mean was significantly higher than healthy controls (Harrison et al., 2009), $t(267)=2.90$, $p<0.001$, $r=0.17$ (small effect size) and undergraduate university students (Gratz & Roemer, 2004), $t(604)=2.27$, $p<0.05$, $r=0.09$ (small effect size). Kendall's tau-b two-tailed correlation indicated that higher DERS scores were correlated with shorter durations of the caregiving relationship, $\tau=-0.09$, $p<0.05$, $n=233$.

3.3.5 Leximancer

The concept map (Figure 3.1) visually depicts the relationship between identified concepts. The most prominent concept was 'family', which included references to various relationships such as son, daughter, husband, mother, and sister. Thus, carers identified that the biggest impact of caregiving was on their family relationships. 'Family' was also close in proximity to 'issues', 'work' and 'friends' indicating that they were often used in the text together. The following themes were identified within the map: family (including the concepts family, issues and friends), care (including care, emotional, marriage and accept), life, health (including health, mental and illness), relationship (including relationship and work), time (including time and depression), behaviour and home. For example, the response "*It has become a huge emotional weight and pressure on the family... All other family members are experiencing stress and anxiety due to [the person with personality disorder's] behaviour... Husband had to pass up job... Less social life, not having people over as*"

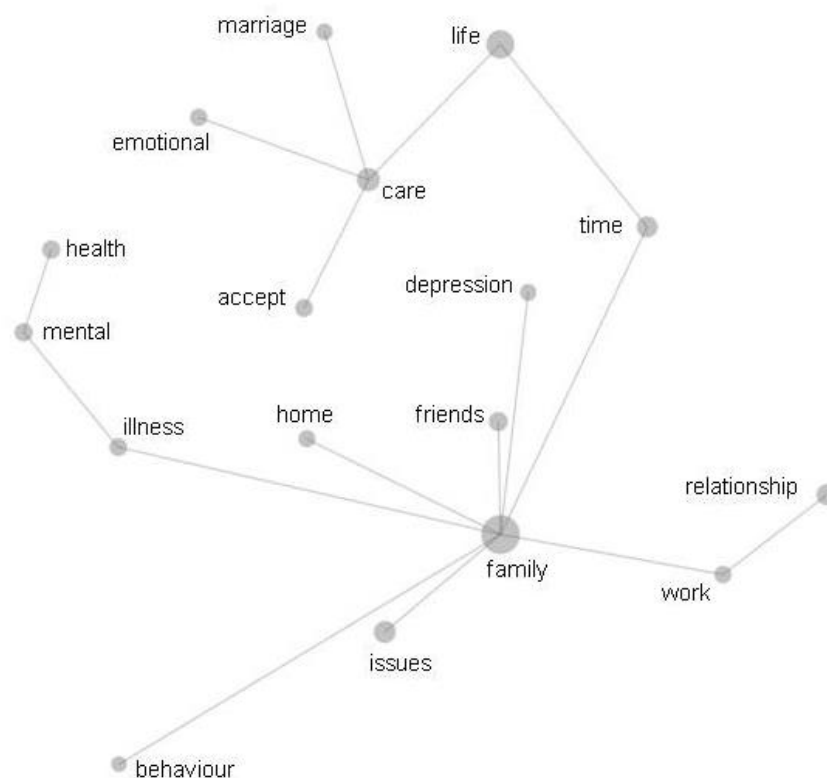


Figure 3.1: Leximancer concept map: Graphical representation of predominant themes in response to the question “*as a carer, what is your experience of caring for your relative (what impact has it had on you, your life and relationships)?*” (n=228).

it causes anxiety for relative and behaviour is erratic” qualitatively depicts the visual relationship illustrated in the concept map of the impact on family, work and friends.

3.4 Discussion

The present study aimed to compare the experience of caring for a person with any personality disorder with published comparison groups using empirically validated measures of carer burden and wellbeing. Carers of persons with personality disorder endorsed significantly elevated burden compared to carers of persons with other serious mental illnesses and report grieving the loss associated with the impact

of caring and change in their lives. Carers also reported impaired wellbeing including experiencing mental health problems and difficulties in emotion regulation similar to clinical samples diagnosed with anxiety, mood and post-traumatic stress disorder. Further, qualitative information highlighted the impact of caring for a person with personality disorder on other interpersonal relationships.

From the results, it appears that there are three predominant areas of impact when caring for a person with personality disorder: burden (including grief), impaired carer wellbeing (including mental health problems), and interpersonal strain. Qualitative information in the present study, visually represented in the concept map, suggest that caring for a person with personality disorder significantly affects relationships, including conflict and concern between family members and isolation from friends, consistent with findings from previous qualitative research (Ekdahl et al., 2011; Giffin, 2008; Goodman et al., 2011). Future research and the development of new guidelines may benefit from empirically exploring the interpersonal experience of caregiving to understand the relational dynamics potentially contributing to the experience of burden and mental health problems (Grenyer, 2013).

Carers of persons with personality disorder reported symptoms and difficulties in emotion regulation consistent with clinical anxiety, mood and post-traumatic stress disorders. Due to the cross-sectional nature of the present research, it is unclear whether such difficulties in wellbeing and emotion regulation were present prior to the caregiving relationship or developed as a result. However, previous qualitative research has documented the experience of carer trauma while witnessing behaviours such as deliberate self-harm and violence from a loved with BPD (Ekdahl et al., 2011; Giffin, 2008). In the present study carers qualitatively described the distressing experience of witnessing these behaviours: *“It makes your heart hurt and causes you*

to take a bit of a distance when you look at the suicide rates for this disorder and talk... about the real potential... to lose your son to suicide.” Further, carers reported experiencing significantly higher burden and grief than carers of persons with other serious mental illnesses. This elevated experience of burden may also reduce carers capacity to process and tolerate the consumers distressing behaviours, leading to further burden, interpersonal strain and impaired wellbeing including potential secondary trauma. However, few carers also commented on the potential for recovery and the benefits of persisting as a carer: *“During his childhood years it was very difficult and his behaviour disrupted our home and family... I thought his behaviour was my fault... he then got into counselling, and began to rebuild his life. He is making much better choices and I see improvement over the quality of his life... My children now have children of their own and they are mindful about mental health issues, they take parenting classes, take their children to counselling if needed, or go themselves. We look at mental health care the same as going to the dentist, it is just what you do to ensure everything is functioning with optimal energy... We support, nurture and lift each other up. My son is grateful for my support, tries and accomplishes tasks on his own, has a job and has purchased a home. He is a strong young person that handles his mental illness, it is unfair to see him struggle but I also know, life is never fair, we just have to deal with it.”*

Although the present study has increased understanding of the experience of caring for a person with personality disorder, it was limited in not including a control sample. Future research would benefit from including an additional sample of carers of persons with other mental illness to allow direct comparison. In addition, carers predominantly cared for people with BPD. Although there were no differences in burden with the non-BPD carer groups, the sample size of the latter was smaller.

Future research should aim to focus on larger samples of other personality disorder groups apart from BPD. The sample was recruited over the Internet, meaning samples came from multiple countries, but because of the research design we were not able to separate groups from different geographical locations, which may have had an unknown influence on the data. Further research into geographical and cultural differences is required.

The finding that carers of persons with personality disorder struggle with elevated burden, grief, mental health problems and interpersonal strain highlights the need for further clinical interventions and support options for carers. This is particularly salient since families and carers have the primary responsibility for the care and recovery of the consumer (Cuijpers, 1999), as most treatment occurs in the community and not in hospitals. Families and carers are often the most consistent resource for consumers; however if they are significantly burdened and experience impairment in wellbeing, it is possible that carers may be less effective in their role. Although preliminary research has begun to evaluate interventions for carers of persons with personality disorder (e.g. Hoffman et al., 2007; Hoffman et al., 2005; Sanders & Pearce, 2010), the research remains sparse and limited compared to those developed for carers of persons with other serious mental disorders, such as schizophrenia (Hoffman & Fruzzetti, 2007; Lefley, 2005). It is proposed that interventions tailored to the needs of carers of persons with personality disorders would likely decrease burden and grief, ease interpersonal strain, and increase wellbeing, allowing the carer to be the most effective resource to his or her loved one, which would likely also benefit clinical outcomes for the consumer.

Chapter 4

Study 3

The relationship between expressed emotion and wellbeing for families and carers of a relative with Borderline Personality Disorder

This is an identical version of the accepted manuscript in press in *Personality and Mental Health*.

Bailey, R. C., & Grenyer, B. F. S. (in press). The relationship between expressed emotion and wellbeing for families and carers of persons with Borderline Personality Disorder. *Personality and Mental Health*.

4.1 Introduction

The family environment has been a controversial and sensitive topic for people with Borderline Personality Disorder (BPD) and their carers. Early research identified associations of inadequate parenting and abuse with the development of BPD (e.g., Herman et al., 1989; Landecker, 1992; Masterson & Rinsley, 1975; Soloff & Millward, 1983; Zanarini, Gunderson, Marino, Schwartz, & Frankenburg, 1989). Early trauma has been suggested to be an important determinant in BPD development (Herman et al., 1989; Herman & van der Kolk, 1987). Recent findings now suggest that factors other than early childhood experience may also contribute to the development of BPD in a biopsychosocial model (Leichsenring et al., 2011). These include genetic (Distel et al., 2008), biological (Herpertz et al., 2001), and social-cognitive factors (King-Casas et al., 2008), and therefore that BPD is not simply complex Post Traumatic Stress Disorder (Lewis & Grenyer, 2009).

Current guidelines recommend that clinicians work with families and carers of people with BPD (National Health and Medical Research Council, 2012; National Institute for Health and Clinical Excellence, 2009; Project Air Strategy, 2012c) and research has begun to emerge on determining family environments that are most beneficial to the clinical outcome of the patient. The family environment has been found to have important implications for the clinical outcome of patients with a mental illness. In particular, there has been extensive research into the impact of expressed emotion (a measure of family environment involving behaviours and attitudes of hostility, criticism and emotional overinvolvement). Research has found that family environments with high expressed emotion are deleterious to the clinical outcome of patients with schizophrenia (Bebbington & Kuipers, 1994), depression (Hooley et al., 1986), bipolar (Miklowitz et al., 1988) and eating disorders (Butzlaff &

Hooley, 1998). Thus, family environments characterised by elevated expressed emotion have been found to be unhelpful to the recovery of patients with these disorders.

The impact of expressed emotion on the clinical outcome of patients with BPD has also been researched. Hooley and Hoffman (1999) explored the association between carer expressed emotion and patient relapse over one year. Contrary to research with other mental health disorders, criticism and hostility did not predict clinical outcome at follow-up for patients with BPD. However, emotional overinvolvement was associated with better clinical outcomes for patients with BPD, even when initial symptom severity was statistically controlled. The authors speculated that the nature of emotional overinvolvement (the expression of overprotection, anxious concern and extreme emotional closeness) might be experienced as validating and therefore potentially helpful towards recovery for the BPD patient (Hoffman & Hooley, 1998; Hooley & Hoffman, 1999).

Further research was then undertaken to explore neurological differences. Hooley and colleagues (2010) found that verbal comments expressing emotional overinvolvement cause neurological activation of the left superior frontal gyrus for patients with BPD compared to patients with dysthymia and healthy controls. This area of the brain has been associated with the processing of reward, approach-related or engaging stimuli (Pizzagalli, Sherwood, Henriques, & Davidson, 2005). Interestingly, the neurological difference between groups was not reflected in self-report findings; patients with BPD rated the valence of the comments as equally negative as the patients with dysthymia and healthy controls (Hooley et al., 2010). Therefore, family environments high in emotional overinvolvement might be experienced as rewarding and validating to people with BPD on a neurological level.

Previous research has established the unexpected benefits of family environments high in emotional overinvolvement on the outcome of patients with BPD. Although emotional overinvolvement is probably a reasonable response to the distress of a loved one with BPD, the impact of a family environment characterized by anxious concern, overprotection and extreme emotional closeness on the wellbeing of the carer remains unknown. Previous research has identified an association between elevated emotional overinvolvement, higher distress and reduced wellbeing for carers of persons with other disorders such as schizophrenia (Boye et al., 1998; Carrà, Cazzullo, & Clerici, 2012; Jeppesen et al., 2000) and intellectual disabilities (Dossetor, Nicol, Stretch, & Rajkhowa, 1994). Thus, the present study aimed to investigate the relationship between expressed emotion, burden and wellbeing in carers of persons with BPD.

4.2 Methods

4.2.1 Ethical Approval and Study Design

Participants gave explicit consent to participate following Institutional Board approval of the study. Carers were invited to complete the survey through calls in community forums including carer events, newsletters, blogs and websites. Therefore, carers who participated in the research were likely to be actively engaged in seeking support, education and information; suggesting that they were aware of the issues involved in being a carer of a relative with BPD.

For the purpose of the research, '*relative*' was defined as a person with BPD who could be biologically (e.g. parent, child, sibling) or non-biologically (e.g. partner, significant other) related to the carer. '*Carer/caregiving*' was defined as consisting of regular interactions with the relative involving tasks promoting wellbeing and

recovery, which could include simply being in a supportive relationship. To gain access to the survey carers were required to endorse the question “*Do you have a relative (including biological - such as parent or sibling, or non-biological - including significant other or friend) with a personality disorder?*” Previous research has reported that many carers are unaware of the specific diagnosis of BPD (Hoffman et al., 2003). Therefore, in a conservative effort to ensure that the carers were appropriate to the research they were also required to rate their relative on the McLean Screening Instrument for BPD – Carer Version and endorse at least 7 items to be included in the study (MSI-BPD-C, described below; Zanarini et al., 2003).

4.2.2 Participants

A total of 532 carers consented to the survey. 194 carers were excluded due to: immediately reporting that they do not have a relative with a personality disorder (n=65); not completing any questions (n=129); or scored less than 7 on the MSI-BPD-C (n=58). Therefore a total of 280 carers were included in the study. Table 4.1 outlines the characteristics of the carer, and Table 4.2 the characteristics of the relative with BPD.

4.2.3 Measures

McLean Screening Instrument for Borderline Personality Disorder – Carer Version (MSI-BPD-C). The MSI-BPD (Zanarini et al., 2003) is a 10 item measure of BPD symptoms, used as a screening instrument. The endorsement of 7 or more items has shown good sensitivity and specificity for the Diagnostic and Statistical Manual

Table 4.1: Demographic characteristics of the carers. Numbers in parentheses indicate sample size.

	Carer	
Age (279)	Mean (range)	47.00 years (16-75)
	Median	47.00 years
Length of caregiving relationship (260)	Mean (range)	12.40 years (0-59)
	Median	10.00 years
Gender	Male (81)	28.9%
	Female (199)	71.1%
Employment	Full-time (145)	51.8%
	Part-time (63)	22.5%
	Unemployed (68)	24.3%
	Did not state (4)	1.4%
Relationship to the relative with BPD	Mother (99)	35.4%
	Father (14)	5.0%
	Child (41)	14.6%
	Sibling (10)	3.6%
	Partner/Spouse (92)	32.9%
	Significant Other (24)	8.6%
Do you provide most of the care for your relative?	Yes (155)	55.4%
	No (124)	44.3%
	Did not state (1)	0.4%
Has a mental health professional explained the diagnosis to you?	Yes (175)	62.5%
	No (102)	36.4%
	Did not state (3)	1.1%
Have you ever sought any support options (support groups, long/short term therapy, internet support, education)?	Yes (251)	90.0%
	No (28)	10.0%
Have you been satisfied with the support options you have been offered?	Yes (126)	45.0%
	No (108)	38.6%
	N/A (36)	12.9%
	Did not state (10)	3.6%

Table 4.2: Demographic characteristics of the relative with BPD cared for in this study. Numbers in parentheses indicate sample size.

Relative with Borderline Personality Disorder		
Age (279)	Mean (range)	40.23 years (12-90)
	Median	36.00 years
Gender	Male (73)	26.1%
	Female (207)	73.9%
Employment	Full-time (60)	21.4%
	Part-time (41)	14.6%
	Unemployed (175)	62.5%
	Did not state (4)	1.4%
Hospitalisations (to carers knowledge) in past year (274)	Mean (range)	1.03 (0-20)
Days of deliberate self-harm (to carers knowledge) in past year (268)	Mean (range)	13.07 (0-365)
Days involving attempted suicide (to carers knowledge) in past year (272)	Mean (range)	2.69 (0-365)

of Mental Disorders (DSM-5; American Psychiatric Association, 2013) diagnosis of BPD (Zanarini et al., 2003). The present sample had a mean score of 8.70 (N=280, SD=1.04). The MSI-BPD has been adapted in previous research for carers to endorse observed symptoms of the relative with BPD (Goodman et al., 2011).

The Family Questionnaire (TFQ). The TFQ (Wiedemann, Rayki, Feinstein, & Hahlweg, 2002) is a 20 item measure of carer expressed emotion in the family environment. The TFQ includes 10 items for criticism and 10 items for emotional overinvolvement, where higher scores represent higher levels of criticism and emotional overinvolvement. TFQ has been shown to correlate well with the Camberwell Family Interview which has often been used in the measurement of

expressed emotion (Wiedemann et al., 2002). Both criticism ($\alpha=0.86$, $N=257$) and emotional overinvolvement ($\alpha=0.80$, $N=256$) subscales showed strong internal consistency.

Burden Assessment Scale (BAS). The BAS (Reinhard et al., 1994) is a 19 item measure of two domains of burden; objective and subjective. Objective burden relates to the self-reported behavioural effects of caregiving (such as changes in work, social and family life), whereas subjective burden involves feelings, attitudes and emotions expressed about the caregiving role (such as embarrassment and guilt; Platt, 1985; Reinhard et al., 1994). Higher scores on this measure represent greater experiences of objective and subjective burden. The BAS showed strong internal consistency ($\alpha=0.87$, $N=264$).

Mental Health Inventory - 5 (MHI-5). The MHI-5 (Cuijpers et al., 2009) is a 5 item scale with excellent validity for measuring symptoms consistent with depression and anxiety, and has a long history of use in large scale health studies. The MHI-5 total score was linear transformed to a scale of 0 to 100, consistent with previous research (e.g., Cuijpers et al., 2009; Rumpf et al., 2001; Theunissen et al., 2011), where higher scores represent better mental health. The MHI-5 showed strong internal consistency ($\alpha=0.85$, $N=240$).

Qualitative Data. 219 of the 280 included carers responded to the question “*as a carer, what is your experience of caring for your relative (what impact has it had on you, your life and relationships)?*” This additional qualitative information was sought to supplement the quantitative data and provide further insight.

Table 4.3: Scores of carers on included measures. N represents sample size that provided full data on the measure.

Measure	N	Mean	Standard Deviation	Median	Range
BAS	264	56.67	10.24	58	19-75
MHI-5	240	55.82	21.37	56	0-96
TFQ-Criticism	257	31.12	5.34	32	13-40
TFQ-Emotional Overinvolvement	256	30.32	5.13	31	16-40

Note. BAS, Burden Assessment Scale; MHI-5, Mental Health Inventory-5; TFQ-Criticism, The Family Questionnaire-Criticism Subscale; TFQ-Emotional Overinvolvement, The Family Questionnaire-Emotional Overinvolvement Subscale.

4.3 Results

201 (71.8%) carers returned complete surveys and 78 carers returned surveys with some missing data. Responses with missing data were not significantly different to participants with full data on demographics including carer gender, $\chi^2(1)=0.18$, $p=0.67$, relative with BPD age, $t(157.14)=-0.68$, $p=0.50$ (equal variances not assumed), relative gender, $\chi^2(1)=1.73$, $p=0.19$, the length of the caregiving relationship, $t(258)=-1.06$, $p=0.29$ or whether they were biologically or non-biologically related to the person with BPD, $\chi^2(1)=1.67$, $p=0.20$. Carer age was significantly older for those with some missing data ($M=49.49$, $SD=12.30$) compared to those with full data ($M=46.04$, $SD=11.15$), $t(277)=2.24$, $p=0.03$, however the effect size was small, $d=0.27$. All available data were included in analyses, meaning sample sizes were different depending on the missing data as shown in Table 4.3. Variables were significantly skewed violating assumptions of normality; therefore non-parametric tests of association are reported. Table 4.4 provides a Kendall tau-b two-tailed statistic correlation matrix of the variables.

Table 4.4: Kendall's tau-b correlation matrix of the variables.

	BAS	MHI-5	TFQ-Criticism	TFQ-Emotional Overinvolvement
BAS	1.00 ^a	-0.29** ^b	0.29** ^d	0.49** ^g
MHI-5		1.00 ^c	-0.15* ^e	-0.32** ^e
TFQ-Criticism			1.00 ^f	0.31** ^h
TFQ-Emotional Overinvolvement				1.00 ⁱ

* $p < 0.01$; ** $p < 0.001$

^a N=264; ^b N=233; ^c N=240; ^d N=251; ^e N=237; ^f N=257; ^g N=249; ^h N=253; ⁱ N=256

Note. BAS, Burden Assessment Scale; MHI-5, Mental Health Inventory-5; TFQ-Criticism, The Family Questionnaire-Criticism Subscale; TFQ-Emotional Overinvolvement, The Family Questionnaire-Emotional Overinvolvement Subscale.

4.3.1 Are scores on the variables different when considering heritability?

To investigate whether the findings were the result of heritability, the responses of biologically and non-biologically related carers were compared (see Table 4.5 for means). Biologically related carers were not significantly different to non-biologically related carers on TFQ criticism, $t(255) = -0.22$, $p = 0.83$, TFQ emotional overinvolvement, $t(254) = -1.50$, $p = 0.14$, and the MHI-5, $t(238) = 1.64$, $p = 0.10$. Non-biologically related carers scored significantly higher on the BAS than biologically related carers, $t(259.96) = 2.20$, $p = 0.03$ (equal variances not assumed), however the effect size was small, $d = 0.27$. Further, parents were not significantly different to partners or spouses on TFQ criticism, $t(187) = -1.00$, $p = 0.32$, TFQ emotional overinvolvement, $t(187) = -1.12$, $p = 0.26$, the MHI-5, $t(177) = 1.63$, $p = 0.11$ or the BAS, $t(193) = -1.56$, $p = 0.12$.

4.3.2 Severity of expressed emotion, burden and mental health symptoms

In relation to expressed emotion, carers reported a mean score of 31.12 on the TFQ subscale of criticism and 30.32 for emotional overinvolvement. Previous research has suggested that mean scores greater than 23 are considered elevated for criticism, and greater than 27 for emotional overinvolvement (Wiedemann et al., 2002). Therefore, on average carers reported elevated criticism and emotional overinvolvement within the family environment. TFQ emotional overinvolvement was not significantly correlated with carer age, $\tau=-0.02$, $p=0.62$, $n=255$ or length of the caregiving relationship, $\tau=-0.07$, $p=0.12$, $n=243$. However, TFQ emotional overinvolvement was negatively correlated with age of the relative with BPD, $\tau=-0.14$, $p=0.001$, $n=256$ using the Kendall tau-b two-tailed statistic. Further, TFQ criticism was negatively correlated with carer age, $\tau=-0.10$, $p=0.02$, $n=256$ and positively correlated with the length of the caregiving relationship $\tau=0.09$, $p=0.04$, $n=243$ and relative age, $\tau=0.10$, $p=0.03$, $n=256$ using the Kendall tau-b two-tailed statistic. Thus, emotional overinvolvement was higher for carers of a younger person with BPD. Higher levels of criticism were also associated to younger age of the carer, longer duration of the caregiving relationship and older age of the relative with BPD.

Carers reported an average of 56.67 on the BAS, where higher scores represent greater experiences of burden. Previous research with the same measure has reported a mean of 38.54 ($N=135$, $SD=13.27$) for carers of psychiatric inpatients with mood, substance, anxiety and psychotic disorders (Page et al., 2006). Therefore, carers of a relative with BPD endorsed levels of burden over one standard deviation higher than carers of patients with other mental illnesses. This difference was significant, $t(217.74)=13.90$, $p=0.00$ (equal variances not assumed), with a very large effect size, $d=1.88$. The BAS was not significantly correlated with carer age, $\tau=-0.06$, $p=0.18$,

n=264, or the length of the caregiving relationship, $\tau=-0.03$, $p=0.45$, $n=247$, using the Kendall tau-b two-tailed statistic. However, the BAS was negatively correlated with the age of the relative, $\tau=-0.14$, $p=0.001$, $n=263$. Therefore, burden was significantly higher for carers of a younger person with BPD.

Finally, carers reported an average score of 55.82 on the MHI-5, where higher scores represent better mental health. Previous research has suggested that scores less than 65 represent symptoms consistent with mood or anxiety disorders (Rumpf et al., 2001). 64.2% of participants scored 65 or less in the present sample. Therefore the majority of carers of people with BPD endorsed mental health problems consistent with clinical mood or anxiety disorders. The MHI-5 was not significantly correlated with carer age, $\tau=0.05$, $p=0.27$, $n=239$, relative age, $\tau=-0.02$, $p=0.64$, $n=239$, or the length of the caregiving relationship, $\tau=0.05$, $p=0.26$, $n=230$, using the Kendall tau-b two-tailed statistic. The mean, median, standard deviation and range of the TFQ, BAS and MHI-5 are reported in Table 4.3.

4.3.3 Is emotional overinvolvement related to carer burden and mental health?

TFQ emotional overinvolvement correlated positively with the BAS, $\tau=0.49$, $p=0.00$, $n=249$, and negatively correlated with the MHI-5 (where higher scores represent better mental health), $\tau=-0.32$, $p=0.00$, $n=237$ using the Kendall tau-b two-tailed statistic. Therefore, higher emotional overinvolvement was correlated with greater burden and reduced carer mental health. A mother provided a qualitative example of emotional overinvolvement, *“I will do anything to help her. I read, research and will fight to get her the best treatment. But I find that her issues become all I can think about sometimes. It's hard to find a good balance of my needs and*

Table 4.5: Scores on measures for biologically related and non-biologically related groups, and parents and partner or spouse groups. N represents sample size that provided full data on the measure.

Measure	Biologically related carers	Non-biologically related carers	Parents	Partners and spouses
TFQ – Criticism	N=151 M=31.06 SD=5.46	N=106 M=31.21 SD=5.18	N=103 M=30.42 SD=5.59	N=86 M=31.21 SD=5.22
TFQ – Emotional overinvolvement	N=152 M=29.92 SD=5.32	N=104 M=30.89 SD=4.81	N=105 M=30.26 SD=5.13	N=84 M=31.07 SD=4.72
BAS	N=155 M=55.56 SD=11.16	N=109 M=58.24 SD=8.57	N=106 M=56.32 SD=10.05	N=89 M=58.43 SD=8.61
MHI-5	N=142 M=57.69 SD=20.31	N=98 M=53.10 SD=22.65	N=99 M=58.10 SD=20.25	N=80 M=52.90 SD=22.34

Note. TFQ – Criticism, The Family Questionnaire – Criticism Subscale; TFQ – Emotional Overinvolvement, The Family Questionnaire – Emotional Overinvolvement Subscale; BAS, Burden Assessment Scale; MHI-5, Mental Health Inventory - 5.

helping her [to] navigate life.”

Previous research has suggested that TFQ scores greater than 27 are high and scores of 27 or less are low for emotional overinvolvement (Wiedemann et al., 2002). In the present sample, 61 participants (21.8%) endorsed low emotional overinvolvement. Carers who endorsed low emotional overinvolvement scored a mean of 46.43 (SD=10.50, median=45.5, range=19-66) on the BAS, which is within the same standard deviation as previous research with carers of psychiatric inpatients with mood, substance, anxiety and psychotic disorders (N=135, M=38.54, SD=13.27; Page et al., 2006). However, carers who reported high emotional overinvolvement (69.6%) scored a mean of 59.82 (SD=7.97, median=61, range=35-75) on the BAS, which is more than one standard deviation higher than previous research (Page et al.,

2006). The difference of BAS scores for low and high emotional overinvolvement groups was significant, $t(77.95)=-8.96$, $p=0.00$, with a very large effect size, $d=2.03$ (equal variances not assumed).

Carers who endorsed high emotional overinvolvement scored a mean of 51.60 (SD=20.43, median=52, range=0-92) on the MHI-5, where higher scores represent better mental health. Scores of less than 65 on the MHI-5 have been suggested to represent the experience of symptoms consistent with clinical mood and anxiety disorders (Rumpf et al., 2001), thus carers high in emotional overinvolvement report experiencing symptoms consistent with clinical anxiety and depression. In contrast, carers who scored low emotional overinvolvement reported a mean of 69.50 (SD=19.05, median=72, range=20-96) on the MHI-5, representing sub-clinical mental health difficulties (Rumpf et al., 2001). The difference between MHI-5 scores for high and low emotional overinvolvement groups was significant, $t(235)=-5.82$, $p=0.00$, with a large effect size, $d=0.76$. These results show that family environments high in emotional overinvolvement are correlated with increased experience of burden and mental health problems for the carer.

4.3.4 Is criticism related to carer burden and mental health?

In the present sample, 232 participants (82.9%) endorsed high levels of criticism on the TFQ (mean score greater than 23; Wiedemann et al., 2002). Kendall's tau-b two-tailed showed that TFQ criticism scores were positively correlated with BAS, $\tau=0.29$, $p=0.00$, $n=251$, TFQ emotional overinvolvement, $\tau=0.31$, $p=0.00$, $n=253$, and negatively correlated with MHI-5 (where higher scores represent better mental health), $\tau=-0.15$, $p=0.00$, $n=237$. Therefore, higher levels of criticism were associated

to greater burden and emotional overinvolvement, and reduced carer mental health scores. An adult daughter provided a qualitative example of criticism, stating that the most challenging aspect of caregiving was “*not having a mother, but a 62 year old child*”, whereas a partner stated “*dealing with the 180 degree mood swings. Sometimes she enjoys just keeping me on my toes I’m sure of it!*”

4.4 Discussion

Previous research has demonstrated that family environments high in expressed emotion, particularly emotional overinvolvement, are paradoxically beneficial to the clinical outcome of patients with BPD (Hooley & Hoffman, 1999). Further, comments expressing emotional overinvolvement have been shown to activate areas of the brain involved in reward processing for patients with BPD compared to healthy controls and patients with dysthymia (Hooley et al., 2010). However, the present study found that family environments characterised by high emotional overinvolvement are associated with impaired wellbeing and higher burden for carers of persons with BPD. This finding is consistent with previous research with carers of persons with other disorders (e.g., Boye et al., 1998; Dossetor et al., 1994; Jeppesen et al., 2000) and did not change when considering whether the carer was biologically or non-biologically related to the person with BPD.

BPD is a disorder of interpersonal functioning (Hoffman & Hooley, 1998) and is defined by the DSM-5 as involving pervasive instability in interpersonal relationships (American Psychiatric Association, 2013). Thus, the burden associated with caregiving for a relative with mental illness may be amplified by the interpersonal nature of BPD. For instance, previous research has identified a conflict between involvement and independence for patients with BPD when reflecting on the

relationship with their parents (Gunderson & Lyoo, 1997). The present findings also correspond to Hooley and Hoffman's suggestion that carers may "suffer along with the patient" (1999, p. 1561) and previous findings of interpersonal strain when caring for a person with personality disorder (Bailey & Grenyer, 2014b). The findings are also supported by previous qualitative research describing conflicting emotions of love and anger while caring for a daughter with BPD (Giffin, 2008). A wife qualitatively described the experience of closeness and conflict in the present study as follows *"I find myself crying on my own a lot and I feel anxious that, at 45, I am now facing deep regrets about my choice to stay with him after meeting him when I was 17... my husband has a lot of insight (when he's not 'on one') and strives to be a better person, he's charming, hilarious, very clever... So I love him and I hate him and that is very challenging for me."*

The challenging nature of the caregiving relationship, involving both emotional closeness and conflict, may also be paralleled in the therapeutic relationship. Clinicians express greater negative valence when discussing their responses to patients with BPD compared to Major Depressive Disorder (Bourke & Grenyer, 2010). The push-pull interpersonal dynamic may contribute to this experience (Bourke & Grenyer, 2013). Considering that this interpersonal strain may be challenging for trained clinicians to hold, it is likely that many carers are also struggling with a similar push-pull dynamic (characterised by both conflict and emotional closeness), as the data presented here suggests.

Interestingly, the present study found that biological versus non-biological relations did not influence the endorsement of criticism, emotional overinvolvement and mental health problems. This finding is of importance, as previous research has focussed primarily on parents of a person with BPD (Bailey & Grenyer, 2013;

Goodman et al., 2011). It has been suggested that people with BPD select non-biological carers or partners who will continue interpersonal patterns enacted by biological relatives (Hoffman & Hooley, 1998). However, this result could be conversely related to the experience of caregiving. For instance, the challenged interpersonal dynamic, impact on carer wellbeing and the witness of distressing and disturbing behaviours of a loved one with BPD may contribute to the development of secondary traumatisation regardless of biological relatedness. In the present study a wife described secondary traumatisation related to impulsive anger as a *“battle between love and fear. Loving too much to let go or let him down, while feeling scared in my own home for that same person I love so much and who should be the one I feel most safe with”*. A mother commented on the secondary traumatisation of self-harm, *“The most challenging aspects have been trying to look at the devastation my daughter [has] done to herself, e.g. cutting, overdoses, hanging, running out in front of a bus and a few cars, attempting to throw herself off a motorway bridge, setting herself on fire, her sisters cutting her from a rope.”*

The present findings raise the question of whether clinicians should intervene when presented with carers of a relative with BPD experiencing family environments elevated in emotional overinvolvement. People with BPD experience a disturbed sense of self including feelings of emptiness, rejection sensitivity and intense fears of abandonment (American Psychiatric Association, 2013). Therefore it is plausible that carer’s expressions of anxious concern, overprotection and extreme emotional closeness may be experienced as reassuring and validating to the person with BPD (Hoffman & Hooley, 1998; Hooley & Hoffman, 1999). However, the present study found that a family environment characterised by emotional overinvolvement is also associated with impaired carer wellbeing. Therefore, the present results suggest

important clinical implications; emotional overinvolvement has been demonstrated as beneficial to BPD patient outcome, yet also associated with impairment in carer wellbeing including increased experience of burden and carer mental health problems.

The clinical implications of these findings reinforce the importance of collaborative treatment for both the patient (to develop and integrate a stronger sense of self, diminish abandonment fears, increase rejection tolerance and emotion regulation capacity) and the carer (to balance healthy separation and facilitate care for self along with caring for the relative with BPD) where possible. However, if the person with BPD is not willing or unable to seek treatment, it is likely that carers may still benefit from support options to improve wellbeing and decrease burden and isolation. It is suggested that carers of a person with BPD might be receptive to the approach of effectively validating their loved one whilst maintaining healthy separation and boundaries. A mother commented; *“my husband and I have made mistakes but not with any bad intentions, yet we keep hearing that BPD is due to trauma and abuse caused in early childhood. This paints all carers of someone with BPD as being somehow ‘bad’ and yet the parents that I know love their daughters and are desperate for some sort of help and understanding of the illness. We want to know how to help yet at the same time keep our sanity by setting suitable boundaries.”*

The present study is important in increasing understanding of the issues involved in caring for a relative with BPD, however several limitations must also be considered when interpreting these results. This study was correlational in nature, therefore relationships between variables are difficult to interpret in terms of which were primary or secondary effects. Further, it is possible that a common variable may explain the association between expressed emotion and carer wellbeing. The study

was advertised on carer forums, thus involved carers who may have been more inclined to visit such forums and self-select to participate in the research. Further, although the study used a screening instrument in an attempt to ensure that the included carers were appropriate to the research, the study is limited in not confirming the diagnosis of BPD with a comprehensive assessment of the carer's relative. The study also did not invite participation from the relative with BPD, therefore all results are based on cross-sectional carer reports. The study did not include a sufficient sample size of siblings and children of people with BPD to allow statistical comparison of the experience of burden for these groups compared to parents and partners. We did not collect data on ethnicity so how this may moderate the findings reported here is unknown. Future research may benefit from addressing these issues. In sum, it is likely that a collaborative treatment approach, where possible, may be most beneficial to the outcome for both carer and relative with BPD. However, even where a collaborative treatment approach is not possible, it remains that carers of persons with BPD may benefit from intervention and support options considering the challenged interpersonal dynamic, burden and impaired carer wellbeing reported in this study.

Chapter 5

Study 4

A pilot study of a psychoeducational support
intervention for carers of persons with personality
disorder

5.1 Introduction

Personality disorders are defined as an enduring, pervasive and inflexible pattern of inner experience and behaviour, impacting areas of cognition (perception of self, others and the world), affective experience, interpersonal functioning and impulse control (American Psychiatric Association, 2013). Carers report strain within the caregiving relationship due to the mood fluctuations, self-harming, suicidal, impulsive and aggressive behaviours of their relative and stigma from the community and mental health system (Bauer et al., 2012; Ekdahl et al., 2011; Giffin, 2008; Goodman et al., 2011). Carers of persons with borderline personality disorder (BPD) also report experiencing difficulties in emotional health, physical strain, marital discord, feelings of guilt and grief, reduced social life and financial burden as a result of the caregiving role (Ekdahl et al., 2011; Giffin, 2008; Goodman et al., 2011). It is therefore unsurprising that families, partners and carers of persons with personality disorder are significantly burdened (both practically and interpersonally) and report experiencing problems in their own wellbeing and mental health (Bailey & Grenyer, 2013, 2014b; Scheirs & Bok, 2007). Taken together, carers of persons with personality disorder appear to be impacted in three key domains; burden (and grief), wellbeing (and mental health), and interpersonal strain (Bailey & Grenyer, 2014b).

Clinical guidelines now recommend the involvement of families, partners and carers of persons with personality disorders for both increased carer wellbeing and optimised patient outcome (National Health and Medical Research Council, 2012; National Institute for Health and Clinical Excellence, 2009; Project Air Strategy, 2012c). However, previous research aiming to evaluate interventions supporting carers of persons with personality disorders has been limited. A systematic review of the literature found that only two interventions designed to support carers of persons

with personality disorder have been empirically evaluated (Bailey & Grenyer, 2013). The most comprehensively evaluated intervention (Family Connections; with one pilot and replication study) found promising results in the reduction of burden, grief, depression and increased mastery at post-intervention and 6 months post-baseline. However, Family Connections was limited being specific to carers of persons with BPD (Hoffman et al., 2007; Hoffman et al., 2005). Preliminary analyses show that carers of persons with any personality disorder are not significantly different to carers of persons with BPD on a measure of burden (Bailey & Grenyer, 2014b). Thus, it is likely that carers of persons with any personality disorder may benefit from support interventions, rather than limiting this to only carers of persons with BPD.

Previous research evaluating support interventions for carers of persons with personality disorder have also been limited in failing to focus on and measure change within the caregiving relationship. The nature of personality disorder (involving pervasive disturbances in self and interpersonal functioning; American Psychiatric Association, 2013) likely amplifies the relational burden experienced by carers of persons with personality disorder. For instance, family environments for persons with BPD have been characterized by a conflict between independence and involvement (Gunderson & Lyoo, 1997), involving elevated levels of criticism (conflict) and emotional overinvolvement (overprotection and intense emotional closeness; Bailey & Grenyer, 2014a). Previous research has found that emotional overinvolvement may be experienced as validating and helpful to the recovery of patients with BPD (Hooley et al., 2010; Hooley & Hoffman, 1999). However, emotional overinvolvement has also been shown to correlate positively with carer burden and mental health problems (Bailey & Grenyer, 2014a). Thus, it is suggested that support interventions for carers of persons with personality disorder may be beneficial in improving the caregiving

relationship by decreasing levels of emotional overinvolvement and providing effective validation and interpersonal skills. Therefore, it appears important to assess whether support interventions for carers of persons with personality disorder improve the interpersonal environment.

The present study aimed to evaluate a pilot psychoeducational support intervention for carers of persons with personality disorders. The intervention was designed to focus on the interpersonal dynamic as a means to reduce relational strain and burden and improve carer wellbeing. The study aimed to evaluate the intervention considering the three domains that appear to be significantly impacted by the caregiving role; carer burden, wellbeing and the caregiving relationship.

5.2 Methods

5.2.1 Design and Ethical Approval

The present study is a pre-post analysis of a psychoeducational support intervention for carers of persons with personality disorder. The intervention (named Staying Connected when Emotions Run High) was the result of a partnership between New South Wales Health (public health system) and the Project Air Strategy for Personality Disorders. The Institutional Board approved this research program on carers and families.

5.2.2 Recruitment

Eligible participants were family members, significant others or unpaid carers of a person with any personality disorder. Previous research has identified that carers of persons with personality disorder often do not know the specific diagnosis or what

personality disorder diagnoses mean (Hoffman et al., 2003). Therefore, ‘personality disorder’ was described in advertisements as involving problems with managing strong emotions, self-destructive or self-harming behaviour, or problems with identity or sense of self. For inclusion carers were required to be over the age of 18 years (or accompanied by a parent or guardian if between the ages 16 and 17 years). The patient with personality disorder was required to be over 14 years of age. Carers were excluded (and referred to more suitable services) if the patient was diagnosed with schizophrenia or the main issue was substance addiction. Participants were recruited by flyers advertised through carer support services, newsletters, community mental health services, emergency departments and the Project Air Strategy for Personality Disorders website (www.projectairstrategy.org).

5.2.3 Intervention

The intervention was developed by family and carer clinicians within the public health service, and further developed in partnership with the Project Air Strategy for Personality Disorders. Personality disorders within this Strategy are understood from a relational model, both intrapersonal (how the person relates to themselves) and interpersonal perspective (how the patient relates to others; Grenyer, 2012). The intervention was based on the relational model, suggesting that if the carer is able to modify some of their responses, the relative with the disorder may also adapt their behaviour, improving symptoms and the relationship outcome (Grenyer, 2012; Project Air Strategy, 2012c).

The intervention involved a 14 hour group program over 5 sessions with an average of 6 to 12 group members. The intervention aimed to develop an

understanding of the carer's role within the relationship with the view to modify the interpersonal environment including promoting safety and enhancing carer wellbeing. In particular, carers were familiarised with four relational patterns (based on dimensions of warmth and control) and encouraged to reflect on their own caregiving and communication style; uninvolved (detached and unresponsive), authoritarian (rigid control and minimal warmth), permissive (indulgent and lenient) and authoritative (firm control, warmth and responsiveness; Maccoby & Martin, 1983). Short videotaped segments supplemented the group program's major components (Project Air Strategy, 2012b). Intervention topics included education on personality disorders and treatments, interpersonal issues involved with safety (including self-harm, suicide attempts and anger), self-care, further support options and mindfulness training. These topics were integrated into five simple core principles that were referred to throughout the intervention; the importance of self-care, keeping calm during distress, setting boundaries, non-directive counselling skills (listening and validating) and safety planning. The core clinical components are described in a fact sheet "Strategies for effective communication and health relationships" (available at www.projectairstrategy.org; Project Air Strategy, 2012a).

5.2.4 Evaluation of the Intervention

Participants completed self-report measures at pre-intervention and 2 weeks post-intervention. Participants were considered to have dropped-out of the intervention if they did not attend more than 2 of the 5 sessions. The present evaluation is preliminary pilot data from a larger trial reported elsewhere (Grenyer et al., 2014).

5.2.5 Measures

McLean Screening Instrument for Borderline Personality Disorder-Carer Version (MSI-BPD-C). The MSI-BPD (Zanarini et al., 2003) is a 10 item screening measure for BPD. Previous research has shown that the cut-off score of 7 or more has good sensitivity and specificity for the diagnosis of BPD (Zanarini et al., 2003). Previous research has adapted the MSI-BPD for carer populations (Goodman et al., 2011). The MSI-BPD-C was used as an indicator of psychopathology severity. The MSI-BPD-C resulted in a mean score of 7.88 (SD= 1.7, median=8, range 4-10).

Burden Assessment Scale (BAS). The BAS (Reinhard et al., 1994) is a 19 item measure of both objective and subjective burden. Higher scores represent greater burden experienced by the carer. Objective burden involves the observable impact of caregiving on daily life (such as changes in work). Subjective burden refers to the carers' attitudes towards the caregiving role (such as resentment). For the present sample, the BAS showed strong internal consistency (Cronbach's $\alpha=.86$).

Grief Scale (GS). The GS (Struening et al., 1995) is a 15 item measure of carer grief associated with the mental illness of the relative. Higher scores represent greater experiences of grief. The GS showed strong internal consistency (Cronbach's $\alpha=.91$).

Mental Health Inventory-5 (MHI-5). The MHI-5 (Cuijpers et al., 2009) is a 5 item scale measuring the experience of symptoms consistent with depression and anxiety disorders. The MHI-5 total score was linear transformed to a scale of 0 to 100 consistent with previous research (e.g. Cuijpers et al., 2009; Theunissen et al., 2011), where higher scores represent better mental health. Total scores of less than 65 on the MHI-5 have been shown to represent symptoms consistent with mood or anxiety

disorders (Rumpf et al., 2001). In the present sample, the MHI-5 showed good internal consistency (Cronbach's $\alpha=.86$).

Quality of Life (QOL). Overall quality of life was measured with the question “how would you rate your quality of life?” taken from the WHOQoL-BREF (Skevington, Lotfy, & O’Connell, 2004; World Health Organisation, 2004). To allow for greater flexibility in response, the original 0 to 5 scale was modified to a continuous measure from 0 (very bad) to 100 (very good), where higher scores represent better quality of life.

The Family Questionnaire (TFQ). TFQ (Wiedemann et al., 2002) is a 20 item measure of expressed emotion within the interpersonal environment. The scale includes 10 items measuring criticism and 10 items measuring emotional overinvolvement. Higher scores represent greater levels of expressed emotion. TFQ has been shown to correlate well with the Camberwell Family Interview which has often been used in the measurement of expressed emotion (Wiedemann et al., 2002). Total scores greater than 23 are considered elevated for criticism, and total scores greater than 27 are considered elevated for emotional overinvolvement (Wiedemann et al., 2002). For the present sample, both the emotional overinvolvement (Cronbach's $\alpha=.78$) and criticism (Cronbach's $\alpha=.78$) subscales of TFQ showed good internal consistency.

5.2.6 Design and Statistical Analysis

A one-way repeated measures ANOVA was used to determine whether scores changed significantly from pre-intervention to post-intervention time points. Carers

who dropped-out of the intervention were also followed up with post-intervention measures and thus included in the analysis.

5.3 Results

5.3.1 Participants

32 carers gave informed consent for the research. Demographic characteristics of the carer are represented in Table 5.1. Demographic characteristics of the person with personality disorder are represented in Table 5.2.

5.3.2 Drop-Out

25 carers completed the intervention and 7 dropped-out resulting in 21.9% attrition rate. Carers who completed the intervention were not significantly different to carers who dropped-out on demographics including carer age, $t(30)=0.01$, $p=0.99$, *ns*, carer gender, $\chi^2(1)=0.02$, $p=0.89$, *ns*, patient age, $t(30)=0.60$, $p=0.55$, *ns*, patient gender, $\chi^2(1)=0.001$, $p=0.98$, *ns*, the length of the caregiving relationship, $t(30)=0.35$, $p=0.73$, *ns*, pre-intervention patient symptom severity (MSI-BPD-C), $t(30)=-1.04$, $p=0.31$, *ns*, or pre-intervention carer burden (BAS), $t(30)=-0.20$, $p=0.85$, *ns*. For the 25 carers that completed the intervention, 98.75% of sessions were attended (2 carers missed 1 session each due to family commitments).

5.3.3 Measurement Means at Pre-Intervention

Descriptive statistics for the measures at pre and post-intervention are represented in Table 5.3. In regards to carer burden, mean scores on the BAS were

Table 5.1: Demographic characteristics of carers of persons with personality disorder (n=32). Numbers in parentheses indicate sample size.

Carer		
Age of carer	Mean (range)	53.25 years (34-74)
	Median	52 years
Length of caregiving relationship	Mean (range)	9.15 years (0.5-50)
	Median	5.25 years
Gender	Male (13)	40.6%
	Female (19)	59.4%
Employment	Full-time (13)	40.6%
	Part-time (7)	21.9%
	Unemployed (11)	34.4%
	Did not state (1)	3.1%
Nature of the relationship to person with personality disorder	Mother (14)	43.8%
	Father (7)	21.9%
	Child (1)	3.1%
	Sibling (1)	3.1%
	Partner/Spouse (9)	28.1%
Do you provide most of the care for your relative?	Yes (24)	75%
	No (8)	25%

similar in the present sample to scores previously reported by carers of persons with personality disorder ($M=55.36$, $SD=10.93$; Bailey & Grenyer, 2014b), $t(302)=0.19$, $p=0.85$, *ns*. Similarly, mean scores on the GS were not significantly different in the present study to those reported previously by carers of persons with personality disorder ($M=54.38$, $SD=12.60$; Bailey & Grenyer, 2014b), $t(296)=1.05$, $p=0.29$, *ns*. Thus carers of persons with personality disorder in the present study reported elevated levels of burden and grief, similar to previous research with this population.

Table 5.2: Demographic characteristics of the person with personality disorder cared for in this study (n=32). Numbers in parentheses indicate sample size.

Person with Personality Disorder		
Age	Mean (range)	33.18 years (17-68)
	Median	31.5 years
Gender	Male (9)	28.1%
	Female (23)	71.9%
Employment	Full-time (2)	6.3%
	Part-time (8)	25%
	Unemployed (21)	65.6%
	Did not state (1)	3.1%

For carer wellbeing, mean scores on the MHI-5 were also consistent with previous research with carers of persons with personality disorders ($M=56.40$, $SD=20.96$; Bailey & Grenyer, 2014b), $t(274)=0.12$, $p=0.90$, *ns*. Previous research has shown that total scores of less than 65 on the MHI-5 represent symptoms consistent with mood or anxiety disorders (Rumpf et al., 2001). In the present sample, 62.5% of carers scored less than 65 on the MHI-5 at pre-intervention. Thus, the majority of carers were experiencing symptoms consistent with anxiety and depression prior to the intervention.

In regards to the caregiving relationship, mean TFQ criticism scores were significantly lower in the present sample compared to previous research with carers of persons with BPD (mean=31.12, $SD=5.34$; Bailey & Grenyer, 2014a), $t(287)=2.48$, $p=0.01$, $d=0.29$ (small effect size). Whereas mean TFQ emotional overinvolvement scores were not significantly different from those previously reported (mean=30.32, $SD=5.13$; Bailey & Grenyer, 2014a), $t(286)=0.59$, $p=0.56$, *ns*. Previous research has

suggested that total scores greater than 23 are considered elevated for criticism, and greater than 27 for elevated emotional overinvolvement (Wiedemann et al., 2002). Thus, on average, carers of persons with personality disorder were elevated in criticism (mean=28.66) and emotional overinvolvement (mean=29.75) at pre-intervention (similar to previous findings; Bailey & Grenyer, 2014a). In the present sample 87.5% of carers endorsed high levels of criticism, and 62.5% endorsed high levels of emotional overinvolvement at pre-intervention.

5.3.4 Pre-Post Analysis (see Table 5.3)

5.3.4.1 Carer Burden

For carer burden, scores significantly reduced from pre to post-intervention for the BAS and GS with very large effect sizes (see Table 5.3 for pre-post analysis of each measure). Thus, scores of objective and subjective burden and grief significantly reduced after the intervention.

5.3.4.2 Carer Wellbeing

Scores significantly increased on the MHI-5 (where higher scores represent better mental health) with a large effect size post-intervention. Further, carers scored within the sub-clinical or normal range on the MHI-5 at post-intervention (cut-off at 65, where carers scored a mean of 65.88 at post-intervention; Rumpf et al., 2001). Scores also significantly increased on the QOL post-intervention with a very large effect size. Thus, symptoms of carer depression and anxiety significantly reduced and scores of carer quality of life significantly increased at post-intervention.

Table 5.3: Descriptive statistics and pre-post analysis (n=32).

Measure	Pre-Intervention		Post-Intervention		F-Statistic	P-Value	Cohen's <i>d</i>
	Mean	SD	Mean	SD			
BAS	55.75	9.17	48.78	11.11	18.94	0.00	1.56
GS	57.31	12.85	48.06	11.57	21.20	0.00	1.65
MHI-5	56.88	18.53	63.88	18.53	4.65	0.04	0.78
QOL	54.69	21.70	63.28	20.62	8.18	0.01	1.03
TFQ-Criticism	28.66	4.88	26.09	6.14	5.76	0.02	0.86
TFQ-Emotional Overinvolvement	29.75	5.42	26.22	5.22	13.39	0.00	1.31

Note. SD, standard deviation; BAS, Burden Assessment Scale; GS, Grief Scale; MHI-5, Mental Health Inventory-5; QOL, Quality of Life Scale; TFQ-Criticism, The Family Questionnaire-Criticism Subscale; TFQ-Emotional Overinvolvement, The Family Questionnaire-Emotional Overinvolvement Subscale.

5.3.4.3 Caregiving Relationship

Scores significantly reduced on the TFQ emotional overinvolvement subscale post-intervention with a very large effect size. Scores also significantly reduced on the TFQ criticism subscale with a large effect size. On average, carers remained slightly elevated in levels of criticism at post-intervention ($M=26.09$, where scores greater than 23 are considered elevated; Wiedemann et al., 2002), whereas carers reported below-threshold emotional overinvolvement at post-intervention ($M=26.22$, where scores greater than 27 are considered elevated). Thus, expressed emotion within the family environment reduced significantly from pre to post-intervention.

5.4 Discussion

The present study aimed to evaluate a pilot psychoeducational support intervention for carers of persons with personality disorder on domains of burden, wellbeing and the caregiving relationship. At two weeks post-intervention, carers reported significantly improved levels of burden, grief and wellbeing (including reductions in symptoms consistent with depression and anxiety and improved quality of life). Carers also reported significantly improved caregiving dynamics post-intervention (including reduced levels of criticism and emotional overinvolvement). Thus, it appears that an intervention focusing on the interpersonal dynamics of caregiving, providing psychoeducation, support and relational skills can be helpful in significantly reducing carer burden, increasing wellbeing and improving the caregiving environment for carers of persons with personality disorder.

The nature of the caregiving relationship within the present sample was predominantly mothers of a person with personality disorder. Research has compared the experience of parents and partners of persons with personality disorder and found

mixed results. Scheirs and Bok (2007) found that partners and parents of persons with BPD were not significantly different on a measure of mental health difficulties including anxiety, depression, and sleeping problems. Further, preliminary analyses found no significant difference between parents and partners of a person with BPD on measures of expressed emotion (criticism and emotional overinvolvement), burden and mental health (Bailey & Grenyer, 2014a). However, previous studies have found that partners or spouses experience significantly greater overall burden than other relatives (such as parents) of persons with personality disorders (Bauer et al., 2012). Therefore, it is possible that partners and spouses are similarly burdened (or more so) than mothers or parents of persons with personality disorder and thus further efforts need to be made to involve partners and spouses in support interventions.

Although the present study contributes to the literature by piloting a psychoeducational support intervention for carers of persons with personality disorder, several limitations must be acknowledged. First, the study was not randomised and did not contain a control condition. Second, the present study involved a pre-post analysis only. Thus, it is unknown if the reported benefits were maintained over time. Third, 21.9% of carers dropped-out of the intervention. Although this attrition rate is similar to that reported in previous research of an intervention for carers of persons with BPD (20%; Hoffman, Fruzzetti, & Swenson, 1999), it remains unclear how these carers impacted the results. Future studies may also benefit from measuring whether patient symptom severity is reduced over time as a result of carer interventions.

The present study aimed to pilot and evaluate a psychoeducational support intervention for carers of persons with personality disorder on domains of burden, wellbeing and the caregiving relationship. The intervention involved a focus on the

interpersonal environment and provided simple skills to strengthen and improve the caregiving relationship (including maintaining connection with the patient whilst also providing boundaries and healthy separation). The intervention also aimed to provide support, improve carer wellbeing and reduce the experience of burden. Carers reported significantly reduced levels of burden and grief and significantly improved wellbeing (including improved quality of life and reduced symptoms of depression and anxiety) at two weeks post-intervention. Carers also reported improvements within the caregiving relationship after the intervention, including reduced criticism and emotional overinvolvement within the family environment. Thus, the results suggest that carers of persons with personality disorder may benefit from psychoeducational support interventions focusing on the interpersonal nature of personality disorder (including increasing awareness of the carers own interpersonal patterns and enhancing the effectiveness of communication and boundaries). Although the study was limited, the results highlight the importance of offering support options to carers of persons with personality disorder. It is currently unclear whether such interventions also improve clinical outcomes for the patient with personality disorder. Specifically, future research may benefit from assessing whether reductions in carer emotional overinvolvement impacts the patient's psychopathology and course. However, it is possible that improvements in the carers own wellbeing, burden and interpersonal dynamics would provide the optimal foundation for effective treatment and recovery for the patient.

Chapter 6

Conclusions

6.1 Summary

The thesis aimed to empirically explore and describe the experience of caring for a person with personality disorder, including carer burden, support needs and interventions. The approach of this dissertation was to sequentially review previous research, evaluate new data, and pilot a psychoeducational support intervention for carers of persons with personality disorder. Thus, the thesis systematically reviewed and consolidated current understanding and identified limitations in the literature (Chapter 2) and described the experience of caring for a person with personality disorder compared to other mental illnesses with new data (Chapter 3). The thesis also described the relationship between family environment and wellbeing of carers of persons with borderline personality disorder with new data (Chapter 4) and evaluated a pilot psychoeducational support intervention for carers of persons with personality disorder (Chapter 5).

6.2 Clinical Implications

The findings of this thesis have important clinical implications. The significant burden, grief, interpersonal strain and difficulties in wellbeing reported by carers of persons with personality disorder in this thesis suggest that caregivers may be struggling within this role. Further, levels of expressed emotion were positively correlated with carer burden and mental health difficulties, suggesting that carers of persons with borderline personality disorder may experience a tension between caring for their relative and their own needs. Currently, it is unclear whether carers present with elevated burden, expressed emotion and difficulties in wellbeing due to experiencing personality traits or symptoms (due to the genetic component of the biopsychosocial model and intergenerational transmission of attachment and trauma

patterns; e.g. Benoit & Parker, 1994; Leichsenring et al., 2011), or whether this is a result of the caregiving relationship. Nonetheless, carers who are significantly burdened, experiencing impairments in wellbeing and difficulties within the relationship are less likely to be effective within the caregiving role. Taken together, the findings of this thesis suggest that a collaborative treatment approach (where possible) is likely to be most effective for both patient and carer outcome.

Considering this, the thesis then evaluated a pilot psychoeducational support intervention for carers of persons with personality disorder finding significant improvements in carer burden, wellbeing and the interpersonal environment. Thus, the findings of this thesis suggest that psychoeducational and supportive intervention options that focus on enhancing the caregiving relationship with simple skills in improving communication, boundaries and safety may assist carers of persons with personality disorder to be most effective within their role.

6.3 Limitations

The present thesis has made significant contributions to the literature by increasing understanding of the issues specific to caring for a person with personality disorder, however it is not without limitations. The aim of the thesis was to study personality disorders, however the majority of studies reviewed, and the majority of relatives and carers sampled, were concerned in particular with only one of the ten personality disorders - borderline. Thus the majority of the findings reported here are particularly salient for carers of persons with borderline personality disorder. This limits the findings as we are unable to make specific statements about the other personality disorders because of the low prevalence of carers volunteering for research, and the low volume of research studies published on the other diagnoses. In addition, the systematic review (Chapter 2) was limited in including studies only

written in English and those that have been published. It is possible that further empirical studies of carers of persons with personality disorders have been conducted that was not identified in the review. It is possible, for instance, that studies of the personality disorder 'C' cluster (avoidant, dependent and obsessive compulsive personality disorders) are hidden in papers focused on chronic anxiety and depressive disorders. Thus, the generalizability of the systematic review was limited.

Chapters 3 and 4 were limited in being unable to compare different relationship types on the experience of burden in caregiving due to insufficient sample sizes of siblings and children of persons with personality disorder. Anecdotal literature has suggested that siblings may feel pulled into a caregiving role, distance themselves from the family, experience guilt, fear, hate, loss of self-esteem or pressure to compensate for the behaviour of the sibling with personality disorder (Giffin, 2008; Kreger, 2008; Porr, 2010). Offspring of persons with personality disorder have been suggested to seek maladaptive adult relationships that mirror their childhood experience of rejection and feel pressured to remain within the caregiving role (Dunne & Rogers, 2013; Kreger, 2008). However, without empirical comparison of the experience of various relationship types these suggestions remain speculative. Therefore, future research may benefit from engaging larger samples of siblings and offspring of persons with personality disorder to determine potential similarities and differences in the experience of caregiving with other relationship types, such as parents and partners.

Chapter 5 was limited in being a pre-post analysis of the intervention rather than including a control group. Although the study included an intended design (where all participants were included in analysis regardless of drop-out), the small sample size and lack of follow-up data limit the findings. Future studies may benefit from

evaluating interventions for carers of persons with personality disorder in a randomised controlled trial. The study was also limited in including mostly mothers of a person with personality disorder. Thus, it was not possible to statistically compare the benefits of the intervention on the different relationship types. It is therefore suggested that future studies include follow-up analyses and engage more partners, siblings and children to determine whether such interventions are equally beneficial for all relationship types. Further, the study was limited in a lack of patient data. Previous research has shown improved patient psychopathology following carer intervention, for instance regarding disorders such as schizophrenia (e.g., McFarlane et al., 1995; Pitschel-Walz, Leucht, Bäuml, Kissling, & Engel, 2001) and alcohol use disorders (e.g., Smit, Verdurmen, Monshouwer, & Smit, 2008). Therefore future research may benefit from measuring change in functioning for people with personality disorders to determine whether carer intervention (or reductions in carer emotional overinvolvement) improves personality psychopathology over time.

6.4 Future Research

The research presented in this thesis has increased our understanding of the experience of caring for a person with personality disorder with a sequenced set of four studies reviewing previous literature, evaluating new data and preliminary evaluations of a pilot pre-post carer intervention. In this thesis carers of persons with personality disorder were found to experience significantly higher levels of burden and grief compared to carers of persons with other mental illnesses. Carers of persons with personality disorder also reported suffering from their own mental health problems, including symptoms consistent with depression, anxiety and post-traumatic stress. In addition, carers described interpersonal strain within the caregiving relationship, including elevated levels of criticism and emotional overinvolvement.

Further research is required to replicate these findings and understand these processes in more detail. For example, studies are required to further explore possible cross-generational influences on these results - whereby the burden on the carer has sources in both the relative with the disorder, but also the possible contribution of the carer's pre-existing personality traits and history as they interact in the current relationship. Future research is required to investigate further this intriguing possibility.

The results of this thesis highlight the complexity of relationships, in particular when caring for a person with personality disorder. Personality disorders are characterized by pervasive disturbances in self and interpersonal functioning (American Psychiatric Association, 2013) and thus occur in the context of relationships (Hoffman et al., 2007). Considering this, it is likely that further research and psychotherapy models involving families, partners and carers in the treatment of persons with personality disorder would assist to further understand and improve the interpersonal dynamic - from both the patient and carer perspectives. Future research would benefit from systematic evaluation of support interventions for carers with randomised controlled trials, longer follow-up periods and measuring the change in functioning or psychopathology of the person with personality disorder. Research on other mental illnesses, such as schizophrenia and alcohol use disorders, has shown improved patient functioning and psychopathology symptoms as a result of carer interventions (e.g., McFarlane et al., 1995; Pitschel-Walz et al., 2001; Smit et al., 2008). Thus, it is possible that psychoeducational support interventions for carers of persons with personality disorder that focus on improving the interpersonal dynamic would improve patient psychopathology and functioning by providing the optimal foundation for effective treatment and recovery. In sum, the thesis demonstrates the interpersonal nature of personality disorder; both in terms of the interpersonal impact

but also the opportunity to modify interpersonal patterns within the caregiving relationship to reduce burden and enhance carer wellbeing.

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