THE NEEDS AND EXPERIENCES OF FAMILY MEMBERS AND FRIENDS OF SOMEONE WITH BORDERLINE PERSONALITY DISORDER

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Abstract

While the past twenty years has witnessed a surge in studies of caregiving, the experiences and needs of family members and friends caring for someone with Borderline Personality Disorder (BPD) has received limited attention. The aim of this thesis was to fill this gap. It provides an in-depth examination of family members’ and friends’ caregiving experiences, coping styles, psychological consequences, and interactions with health care systems when caring for someone with BPD.

Two studies were conducted. Study one was largely exploratory and focussed on the lived experience of the thirteen family members who participated. Using semi-structured interviews and a phenomenological approach in the qualitative analysis, four distinct coping groups were identified. The Loving-Active coping group and In-Flux participant used high levels of problem coping in combination with emotion-focused coping strategies and low levels of avoidant coping strategies. The Bound and Powerless, and the Distanced Managers groups used higher levels of avoidant coping, with the Bound and Powerless also using high levels of drugs and alcohol to cope.

Challenging behaviours demonstrated by their BPD family members in this study were associated with the coping styles and explanations given for the trauma symptoms experienced by all caregivers. Despite these challenges, most participants talked about experiencing turning-points and positive outcomes in the longer term. Many more negative than positive experiences were recalled by family members in their experience of services and in their contacts with professionals that contributed to caregivers’ feelings of isolation.

The aim of Study Two was to examine whether findings of Study One could be generalized to a larger and more varied sample of carers. The sample comprised 175 family members and friends, who completed a paper or internet survey on experience of caregiving, quality of life, coping strategies, distress levels, possible trauma, experiences of services for their BPD relative, and possible personal growth as a result of their experiences. Five distinct groups were identified based on their differing use of coping strategies. The Calmer Positive, Reactive Positive, and the Mixed Extreme groups used high levels of a combination of emotion and problem focused coping strategies, with the first two groups also low on avoidant coping.
The Mixed Extremes, however, resorted to high levels of avoidant coping as did the Mixed Coping group. The Mixed Coping group however, showed lower levels of effective coping strategies overall. The Less Challenged group tended to use lower levels of all coping strategies. Differences in the coping groups translated into differences in a number of areas of impact for family members/friends.

Across all groups carers reported experiencing six or more crisis times in a year wherein they experienced severe levels of depression, anxiety and stress and subsequent clinical levels of PTSD symptoms. Despite overall high levels of negative caregiving experiences and low levels of positive caregiving experiences, well-being levels for most groups were in the average range. But there was variation. The Mixed Copers had considerably lower well-being and posttraumatic growth than the Calmer Positive and Reactive Copers, most likely due to their lower use of effective problem-solving coping.

The Mixed Extreme Coping group presented the most complex picture. This group, more likely to be in a spousal relationship with their person with BPD, reported their person as experiencing more periods of crises and fewer periods of calm, and displaying higher levels of difficult behaviours including uncontrolled anger, which had a higher impact on the family. The Mixed Extremes themselves, experienced unmatched levels of PTSD symptoms and although this group demonstrated comparable levels of posttraumatic growth, and levels of well-being in some areas as the better functioning groups, they felt that their environment was beyond their control more often, and felt more personally challenged and self-doubting.

Common across all groups was the high dissatisfaction of professionals and services, both in the care they provided for their family/friend with BPD and in the support they provided to carers. Dissatisfaction levels were not related to whether the mental health sector was private or public. General practitioners were reported to be involved in the care of the BPD person more often than other professional and marginally higher satisfaction levels with GPs were conveyed. Lowest satisfaction was reported for Crisis Assessment Teams (CAT Teams).

In conclusion, this research offers some insight into what it is to be a carer of someone who displays BPD behaviours. Typically family members and friends bear immense responsibility in the care of their person with BPD, without being able to rely on the support of professionals and services. The caring role has costs on their
own mental health. However, turning points and posttraumatic growth was also experienced.
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Declaration of Originality

This thesis contains no material which has been accepted for the award of any other degree or diploma in any University, except where due reference is made in the text of the thesis. To the best of my knowledge, this thesis contains no material previously published or written by another person except where due reference is made in the text of the thesis. I further declare that the ethical principles of the Australian Psychological Society in relation to research have been observed.

Wenda McPherson

Date
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CHAPTER 1 : THE NEEDS AND EXPERIENCES OF FAMILY MEMBERS AND FRIENDS OF SOMEONE WITH BPD

1.1 Introduction

One in five Australians has a mental disorder with it being estimated that one in four families have a family member with a mental disorder (Wynaden, 2002). The movement from institution-based care to community-based care for individuals with a mental illness since the 1960s, and subsequent gaps in services for these individuals, has meant that many families have been required to assist in caring for their unwell relative. According to Camann (1996) “community care became, by default, care with little understanding of the implications for families” (p.481). Families became responsible for many of the physical, emotional, and social tasks associated with caring at home for a family member with a mental disorder (Reinhard, 1994). In this way families have come to assume a central role in the provision of community based mental health services (The Mental Health Council of Australia, 2000).

It is generally acknowledged that mental disorders create burdens for family caregivers (Rose, 1996), and that all aspects of family functioning, relationships, and roles are altered, sometimes permanently, through this burden (Marsh, 1992). Still, many families care for their unwell relative even when the personal cost of this care has been documented as considerable, and this care may last for many years (King, Collins, & Liken, 1995). Families have reported being expected to provide this care with limited support and resources from the health care system (Camann, 1996), and more often than not, with very little information and collaboration from health professionals, despite communicating their need for support (Chafetz & Barnes, 1989).

While the impact of caring for someone with a mental illness has been documented (Doornbos, 1997; Eakes 1990; Jones, 1996; Maurin & Boyd, 1990; Rose, 1996), the experience of caregiving from the carer’s perspective remains relatively unexplored (Falloon, McGill, Matthews, Keith, & Schooler, 1996). This is particularly so in the experience of caring for someone with Borderline Personality Disorder (BPD) where only a few, limited studies have been carried out. This thesis explores the caregiving experience of family members and friends of
someone with BPD. It was conducted to reveal how the carers experience this caregiving role, how these carers cope with the challenges the role brings, to begin to identify the positive and negative consequences of the caregiving role with this population, and to identify carers’ needs in order to support them in their role.

1.2 Overview of the Project

Chapter One of this thesis reviews the current literature on the experience of caregiving from varied perspectives, the experience of caregiver burden, the positive and negative psychological consequences of caregiver burden, and gives an overview of coping and coping strategies used by carers identified in previous research. Chapter Two presents the qualitative study conducted on the experience of carers of someone with BPD in Australia. It contains the methodology and results of the qualitative study, as well as an overview of phenomenological methodology used to analyse the interviews. Chapter Three builds on the qualitative study. It outlines the survey methodology and details the findings of the quantitative study conducted as part of this thesis. It incorporates a wider population of carers from within Australia and overseas and explores the experience, coping, and psychological consequences of caring for someone with BPD using quantitative survey methods. The fourth and final chapter of this thesis presents the integration of the qualitative and quantitative findings and discusses them in relation to pertinent theories, other research findings, and related literature. That chapter also considers the implications of the research findings and suggestions for further research.

1.3 Characteristics of BPD

Borderline Personality Disorder was recognized as a diagnostic entity in 1980, in the third Diagnostic Manual of the American Psychiatric Association (DSM-III) and was further refined in the revised version in 1987. Its distinguishing features are: a pattern of unstable and intense interpersonal relationships characterised by alternating between extremes of over-idealisation and devaluation of others; impulsiveness in self-damaging areas such as spending, substance abuse, and sexuality; affective instability, usually lasting a few hours and at the most a few days; inappropriate and intense anger or a lack of control of anger; recurrent suicidal threats, gestures, behaviour or self-mutilating behaviour; marked and
persistent identity disturbance with respect to areas such as self-image, sexual orientation, and preferred values; chronic feelings of emptiness and boredom; and frantic efforts to avoid real or imagined abandonment (American Psychiatric Association [DSM-IV-TR], 2000; Guttman, 2002).

### 1.3.1. Importance of Relationships to BPD

Koch and Ingram (1985) identify three criteria for BPD in the DSM IV that can be drawn on to understand the inseparability of the BPD psychopathology from relationship dynamics. They suggest first, that the constant physical presence of an “other” is required for the individual with BPD to fend off feelings of loss and abandonment, otherwise the individual with BPD will often engage in efforts to avoid abandonment such as declarations of love, and/or actual or threatened self-harm. Second, the relationships of a person with BPD are often described as unstable and intense. It has been observed that people with BPD desperately want closeness and intimacy but will often drive people away by the things they do to get it. And third, unstable mood with inappropriate and intense anger which the person with BPD has difficulty controlling is often directed at other family members and caregivers with resultant negative impact on these relationships. Other criteria, such as recurrent suicidal behaviour and self-harm also typically have interpersonal consequences (Mason & Kreger, 1998; Woodberry, Miller, Glinski, Indik, & Mitchell, 2002).

Individuals with BPD are also renowned for the significant impact their relationships have on their ability to function in their day-to-day lives. Some studies have found that individuals with BPD often experience people generally as deserving of fear and mistrust, which typically results in anxiety for the individual with BPD, and markedly affects the individual’s level of social functioning (Fallon, 2003). Moreover, it has been widely recognized that individuals with BPD are highly dependent on their relationships, with the clinical condition of borderline patients observed to fluctuate in tandem with their significant relationships (Links & Stockwell, 2001). This means that when important people in the lives of individuals with BPD are available and supportive, the individual does better. But the individual with BPD may regress substantially when important people are experienced as abandoning them so that the loss of a close relationship may even precipitate a relapse (Waugaman & Goldstein, 2003).
1.4 Caregivers and the Caregiving Experience

Since the 1980s the deinstitutionalization of the mentally ill has shifted the primary locus of care from psychiatric hospitals to community mental health centers. However the lack of resources has meant that the families of the mentally ill have needed to take increasing responsibility for practical help and emotional support for unwell relatives living in the community (Stengard, 2002). It is estimated that 35 to 40 percent of all discharged patients return to live with spouses, and 35 to 40 percent return to live with their parents and other relatives (Lefley, 1987). Subsequent studies of these families have fostered a recognition that families carry a tremendous burden in the care of a member with any psychiatric diagnosis. However the responsibility and care for the welfare of a mentally ill family member can become even more burdensome when the lack of care can mean the difference between life and death, as is the case for chronically suicidal patients such as those with Borderline Personality Disorder (BPD).

Although the experience of caregivers has been well studied across a range of both medical and mental illnesses, there have been only a few studies that have explored the experiences of the families and caregivers of individuals with BPD and no studies that have investigated caregiver burden for caregivers of individuals with BPD.

1.4.1 Caregivers: A Definition

According to Schofield and colleagues (1993; 1998) there is no universally accepted definition of a caregiver. A caregiver has been typically defined in either terms of the tasks they undertake, for example, carer of a child who has a disability, and/or by the amount of time they devote to the role of caregiving, such as in the definitions of primary or secondary caregiver. Formal and informal care is another way of defining a caregiver. Formal care is care provided by professionals and agencies either in the home and/or away from the home. In caring for an older person for example, in-home services could include, but are not limited to, visiting nurse services, homemaker services, respite care, and home health aide services. Formal care away from the home often involves services such as care provided in a physician's office, day care provided in a nursing facility, and nursing care provided in residential settings (Brubaker & Brubaker, 1993).
Informal care, sometimes referred to as family caregiving (Schofield, et al., 1998), is care that usually arises out of a relationship with the recipient in response to the need for support (Goodhead & McDonald, 2007). Informal care is typically provided by family members, but can also be provided by neighbours and friends and may precede, substitute for, or take place alongside the care provided by the formal care sector. Informal caregivers are usually people who are under a kind of obligation to care because of their close kinship or emotional bond with the care recipient (Schofield et al., 1998). It is precisely this relationship with the care recipient that makes it difficult to distinguish the role of a caregiver from ordinary parenting or support from family or friends (National Health Committee, 1998). In the literature, caregivers consistently viewed themselves as little more than a spouse, partner, or parent, yet their caregiving role within that relationship usually went well beyond that “of a wife, husband, mother, father, daughter, son, sibling, and friend” (Schofield et al., 1998).

Based on the findings of the Victorian Carers Program (VCP), a large scale, population-based longitudinal study conducted by Schofield et al. (1998), it was concluded that informal caring or family caregiving differs from other forms of care in our society in three key ways: responsibility, choice and customary expectations in relationships. It was proposed that the idea of being responsible for a person is central to the definition of an informal caregiver as it differentiated the caregiving role from the relationship with the care recipient by the level of responsibility that was required in the relationship, rather than just the tasks performed. In this way it allows the term to be relevant in other areas of care. For example, in a caregiving role with someone who has borderline personality disorder, it is unlikely that the care recipient would need help with the direct tasks of bathing, dressing and feeding themselves. But it is likely that the caregiver may feel responsible for the safety of the person they are caring for. Caregiving defined in terms of responsibility would seem to have much more potential to be appropriate and valuable in the area of mental illness.

The second defining feature of an informal (family) caregiver is that of choice. Schofield et al. (1998) argue that choice is a useful way of differentiating the informal (family) carer, from other carers, as it says something important about whether the caregiving role was freely chosen or imposed upon the person. For the
informal (family) caregiver there is often not such a clear choice to become a caregiver because of affecional ties or familial obligations. Braithwaite (1990) goes as far as saying that as a result of the way the formal care is structured in our society, informal (family) carers have very little choice about whether they provide the care that the care recipient needs. Moreover, Schofield and colleagues have said that rarely is the informal (family) carer able to choose the onset, intensity or duration of their caregiving as would a volunteer.

The third and final defining feature of informal (family) caregiving is that of customary expectations (Schofield et al., 1998). For example, it is customary and normal to expect that a parent will provide extensive care to their child when they are young and it is often not considered to be burdensome to do so. However it is not expected that this level of care would extend into that child’s adulthood. Somewhat akin to this is where a child assumes the role of a parent in times when the parent has episodes of being unwell. Schofield et al. (1998) suggest that the transgression of customary expectations could possibly be dependent on a number of factors including varying expectations in cultural, historical, class and other contexts, such as the life stage of the carer and the care-recipient (Schofield et al., 1998). For example, it might be expected that one partner may be caring for the other at some stage as the couple moves into old age, however younger couples may not be as well prepared for such a possibility.

Within the present thesis, the term carer or caregiver refers to informal caregiving unless otherwise specified, with the definition given by the National Health Committee (NZ; 1998) being adopted. Informal caregivers are those:

…caring for a friend, family member or neighbour who because of sickness, frailty or disability, can’t manage everyday living without help or support …[it] is not usually based on any formal agreement or services specifications. Informal caregiving is characterised by relationships and social expectations… (p. 9).

1.4.2 The Experience of Caregiving

There has been extensive investigation into the caregiving experience since the 1980s. In general when the experience of caregivers is examined it is in the context of caregiver burden experienced as the result of the caring experience.
Caregiver burden refers to the stress experienced by people who are caring for another person, usually with some kind of illness or disability (Maurin & Boyd, 1990). Burden is typically divided into objective and subjective burden aspects (Hoenig & Hamilton, 1966). Although some ambiguity still exists within the conceptual distinction between objective and subjective burden, in general objective burden refers to the concrete and observable costs for the caregiver such as time spent on caregiving, caregiving tasks, and financial commitments. Subjective burden refers to the psychological consequences to the caregiver which are often in response to the objective costs (Schofield et al., 1998). For example, a caregiver may experience psychological or emotional distress from having to perform unpleasant tasks, changing personal plans, or missing out on career opportunities (Van Exel, Brouwer, Van De Berg, Koopmanschap, & Van Den Bos, 2004).

1.4.2.1 The Experience of Caring for a Family Member with a Mental Illness.

The burden for assuming the care of a mentally ill family member is well covered within the literature, particularly in the area of schizophrenia. There is agreement that mental illness is stressful, not only for the mentally ill person but also for family members (Saunders, 2003), and that burden exists (Loukissa, 1995). The burden of people caring for a family member with a mental illness is regarded to be quite considerable, particularly if the mental illness is severe (Reinhard & Horwitz, 1995), and has been found to impact a caregiver’s experience in a variety of ways.

Objective burden, in the case of caring for someone with a mental illness, is often the result of the ill person’s disruptive symptoms, changes in household routines, strained social relations of both the caregiver and the unwell relative, diminished opportunities for leisure, and deteriorating finances (Knudson & Coyle, 2002; Stengard, 2002). Activities that were reported to be the most burdensome were providing transportation, help in money management, housework and cooking, need for constant supervision, restrictions in the caregivers’ personal activities, and providing financial help (Baronet, 1999).

Subjective burden is far ranging. These costs include feeling trapped, being confined to the house, becoming isolated from others, feeling responsible for others,
and emotional reactions toward others’ behaviours. Generally these felt emotional strains have included worrying, distress, stigma, shame and guilt (Knudson & Coyle, 2002; Sales, 2003; Stengard, 2002). It has been suggested that grief and loss, chronic strain, the emotional roller coaster of the course of the illness, and the empathic pain are additional sources of distress (Marsh & Johnson, 1997), as is the need caregivers often experience to conceal these feelings from the person they are caring for (Sales, 2003).

Studies have found that more subjective burden was experienced as a result of the disruptive behaviours of the ill relative than due to the tasks related to the caregiving situation (Baronet, 1999; Reinhard & Horwitz, 1995). The highest instances of subjective burden were found for issues of safety and possible violence of the ill individual toward the caregiver and others, excessive demands and high dependency toward the caregiver, night disturbances, embarrassing and symptomatic behaviours, worries about the future, and uncooperative attitudes of the ill relative leading to conflicts and family hardships (Baronet, 1999).

1.4.2.2 The Experience of Family Members and Carers of Someone with BPD.

Only a few studies have examined the experiences of family members and caregivers of someone with BPD. With the exception of Giffin (2002), these studies have not been empirical or systematic but have been limited to descriptive studies with small samples. Nevertheless, these studies can give some insight into the experiences of family members and carers of someone with BPD. A small anecdotal study by Single (1993) described the experiences of the children of mothers who had BPD and were appearing before the Children’s Court. He observed that these children, were not only overrepresented in the courts, but life with their mother was often frightening, chaotic, and full of confusing communications. He concluded that these children spent much of their energy avoiding, appeasing, or placating their chronically, angry borderline mother who was unpredictably violent not only toward them, but also toward their own partners.

A larger scale study that examined the entries of a web-based forum for family members of someone with BPD (Mason & Kreger, 1998) described the experiences of these family members as anxiety-provoking, intense and
unpredictable. Experiences of confusion and unpredictability when their person with BPD viewed them as either all-bad or all-good were described to be the norm, as was being the focus of sometimes rapid fluctuations between intense, violent, and irrational rages and periods when the person with BPD acted normally and was loving. These individuals reported avoiding the sharing of their thoughts and feelings for fear that they would be misinterpreted and used against them by their person with BPD. In addition to feeling manipulated, controlled, lied to, constantly being put down, and accused of things they never said or did by the person with the BPD that they cared about, planning ahead was reported to be difficult because the individual with BPD was often moody, impulsive, and/or unpredictable.

In spite of this, the family members felt that they could not leave the relationship because their person with BPD would try to prevent them, by declarations of love or threat of self-harm. When the individual with BPD was a blood relative, the family’s sense of obligation and guilt were likely to be much more intense, and leaving the relationship was even less likely to be an option. Nevertheless, the most anguished web-based postings were observed to come from partners, usually husbands, who were concerned about the emotional abuse of the children by their partner with BPD but who felt thwarted by the system, which had a tendency to side with the parent with BPD who had the ability to present well when needed (Mason & Kreger, 1998).

The only study that has empirically examined the experiences of carers of someone with BPD is that of Giffin (2002), who conducted a small indepth qualitative study on the experiences of four parents who had an adult daughter diagnosed with BPD. Giffin observed that, not unlike the parents and carers of individuals who have a mental illness in general, these parents reported experiences of chronic grief, family relationship strain, emotional distress, and self-blame. Parents also reported a sense of being disenfranchised in their caregiving role by health professionals who indicated to them that they needed to accept blame for their daughter’s diagnosis and their ongoing behaviours. It was the extent of the ongoing stress and trauma that Giffin considered to set the experiences of families and carers of individuals with BPD, apart from the families and carers of those who had other mental illnesses. Indicators of possible Stress Disorder were reported in the initial stages of their daughters’ illness, as these parents struggled to adapt to the
caring role of their daughter. Parents who were exposed to their daughters’ repeated acts of violence or self-harm and suicide attempts were more likely to display signs and symptoms of ongoing Post Traumatic Stress Disorder (PTSD).

1.4.2.3 The Experience of Professionals Caring for Someone with BPD.

As the literature offers little information on the impact people with BPD have on their families and thus informal caregiving experiences, it is useful to examine the experience of professionals who care for these individuals. Potentially, experiences of professional caregivers may mirror to some degree the experience of informal carers. A prevalence rate of BPD of between 11% to 20% in both hospital and community mental health settings ensures that mental health staff frequently care for clients with BPD (Gunderson, 2008; Swartz, Blazer, George, & Winfield, 1990). Individuals with BPD present mental health services with challenges unlike those of other clients found within this setting.

Self-destructive gestures and acting-out behaviours, which often occur with BPD, have been reported to leave staff feeling inadequate, helpless and professionally incompetent in providing care for this population (Cleary, Siegfried, & Walter, 2002). Reports of staff getting to the point of not knowing what to do with BPD clients and therefore feeling helpless and beside themselves, were not considered to be uncommon, as was the development of doubt about the appropriateness of standard interventions. Subsequently, this brought about feelings of helplessness and hopelessness in staff members, as well as being in conflict about their own feelings, and with other staff members regarding the BPD patient and their care. Staff reported struggling to make sense of clients’ experiences, particularly in relation to their self-harming behaviors, and reported feeling traumatized by the patients’ stories and their self-harming behaviours (O'Brien & Flote, 1997).

Ongoing feelings of continued threat to their professional effectiveness were found to contribute to staff experiencing a loss of self-esteem, loss of trust in themselves and their colleagues, and a loss of perceived control (Cleary et al., 2002). Moreover, negative experiences of staff in the care of someone with BPD were found to generate negative staff attitudes toward the diagnosis of BPD in
general, and clients with BPD in particular (Fallon, 2003; Waugaman & Golstein, 2003). This was found to leave staff feeling frustrated and angry towards people with BPD (Cleary et al., 2002), and less empathetic toward them as compared to people with schizophrenia (Gallop, Lancee, & Garfinkle, 1989). Providing care for clients with personality disorders has been related to tension, exhaustion, burn-out and a high staff turnover (O'Brien & Flote, 1997). The entire system has been described as vacillating between extreme care and rejection in response to the individuals with BPD behaviours (Dawson, 1993).

The literature clearly shows that caring for someone with BPD comes with its challenges even for professionals who have been trained to work with other mental illnesses. While it may be that the stress is different for professionals than for informal carers, there is evidence that professionals experience major stresses that include feelings of hopelessness, helplessness, trauma and a loss of confidence in their professional capabilities to care for the BPD person (e.g., Cleary et al., 2002). These findings may potentially reflect the experiences of the families and friend-carers of someone with BPD.

1.5 Psychological Consequences of Caregiver Burden

To date, research has consistently found that caregivers show poorer mental health than non-caregivers or the general population. An existing wealth of studies show that providing unpaid care for disabled and older people is associated with increased rates of anxiety, depression, and psychiatric illness compared with control groups or population norms (Schulz, O'Brien, Bookwala, & Fleissner, 1995; Singleton, et al., 2002). Awad and Voruganti (2008), in a recent review, conclude that available research clearly paints a picture of distressed caregivers who suffer significant psychological and emotional consequences, and who often experience impaired functioning and a compromised quality of life.

Studies have consistently provided evidence that caregiving has its psychological costs. For example, Saunders (2003) reported that as families have assumed more of the caregiver role for members with severe mental illness, high levels of psychological distress among caregivers have been documented. In a sample of caregivers for family members with severe mental illness, Oldridge and Hughes (1992) reported that psychological distress (anxiety, depression, and
insomnia) was twice as high as in the general population. Hirst (2003), in a review of research, found that carers presented with higher levels of distress than non-carers, and that the gap widened for those living with the person they care for, and for those devoting 20 hours or more per week to their caring activities. Furthermore, differences in distress rates between carers and non-carers were greater for women than for men (Zarit & Zarit, 2006). Mothers showed significantly more measurable emotional distress (anxiety, depression, fear and emotional drain) than did fathers (Cook, 1988), and spousal caregivers were particularly vulnerable to depressive symptoms (Baumgarten, et al., 1992). Caregivers were also found to use psychotropic drugs more often than the general population (Clipp & George, 1990).

Psychological distress was measured in caregiving studies in a variety of ways. Typically these studies either used some type of psychological instrument or an assortment of interviews. The psychological instruments were typically measures of psychopathology and covered a wide range of symptoms indicative of anxiety and depression, but also covered factors such as social dysfunction, loss of confidence and self-esteem (Hirst, 2005). Psychological distress assessed in interviews often included psychological instruments used to assess for symptoms of psychological distress and to produce an overall distress score (e.g., Canning, Dew, & Davidson, 1996). The focus of the interviews, however, was to obtain a rich qualitative understanding about the impact of the caregiving role on the caregivers’ own mental health (e.g., Ostman & Hansson, 2004). Significant caregiver distress, particularly stress, depression and anxiety were consistent findings in both types of data collection and analyses.

1.5.1 Depression in Caregivers

Psychological health is the area of the informal caregivers’ daily life that is most affected by providing care (Gray, 2003). Studies consistently report higher levels and more frequent occurrences of depressive and anxiety symptoms among caregivers than among their non-caregiving peers (Schulz, et al., 1995; Toseland & Smith, 2006; Zarit & Zarit, 2006). Although depression and anxiety are the most cited impairments within the caregiving literature (Grunfeld, et al., 2004), depression appears to be the most common disorder with 30% to 59% of caregivers reporting depressive disorders or symptoms (Family Caregiver Alliance, 2001; Cohen et al., 1990; Mittelman, et al., 1995). Recent studies have found that
between 32% and 50% of caregivers had depressive symptoms at a level suggesting clinical depression (Butler, Turner, Kaye, Ruffin, & Downey, 2005; Covinsky, et al., 2003).

Although the caregiver and depression literature is dominated by studies of caregivers of those with dementia, and other chronic or terminal illnesses, more recently researchers have begun to examine depressive symptomatology in the caregivers of someone with a mental illness. As with other caregivers, high rates of depression were found in caregivers of someone with a mental illness (Steele, Maruyama, & Galynker, 2010). No literature was found that examined the relationship between caring for someone with BPD and depression as a consequence of the caregiving. Since the literature offers little information on the relationship between caring for someone with BPD and depression, it was considered useful to examine the experiences of depression in the caregivers of other mental illnesses, such as Bipolar Disorder and Schizophrenia.

Even though the literature supports the relationship of depression as a consequence of caregiving, the jury is still out for the many physical, psychological, and social factors that may contribute to depression in caregivers. In the caregivers of someone with a mental illness and depression literature, a number of factors have begun to be identified.

Caregiver burden related to client behavioural problems and a lack of family support and agency support were considered to be significant contributors to depressive symptomatology in caregivers of someone with a mental illness (Song, Biegel, & Milligan, 1997). Depressive symptoms of caregivers have been found to increase as the number of psychiatric symptoms in the care recipient increase (Struening, et al., 1995). This was found to be particularly the case when the care recipient had depressive symptoms themselves or exhibited angry or aggressive behaviour, or other behavioural problems (Levine, 2003). Caring for a chronically mentally-ill patient, as opposed to those with severe, but brief symptoms has also been associated with depression in caregivers (Gonzalez, et al., 2007). However recent studies have indicated that caregivers’ perception of stigma may mediate the relationship between caregiver depression and patient symptoms, by decreasing a caregiver’s social network. It was found that caregivers may retreat from social support, a well established buffer for depression, to avoid anticipated rejection.
and/or embarrassment associated with having a family member with a mental illness (Perlick, et al., 2007).

Social support for the caregiver has been implicated in a number of studies, with lower social support significantly associated with increased caregiver depression (Chang, Brecht, & Carter, 2001; Grant, et al., 2006; Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Williams, 2005). The results of one study indicated that insufficiency of overall social support was the most powerful predictor of caregiver depressive symptomatology (Song, et al., 1997). The caregiving literature has documented that the social support of caregivers of those with a mental illness may diminish over time due to the societal stigma of mental illness, and/or the caregivers’ lack of skill, energy, or motivation to engage in social situations (Biegel & Tracy, 1993; Hatfield, 1978).

In a review of the literature relating to caregivers of someone with Bipolar Disorder, Steele, Maruyama, and Galymker (2010) identified four studies that indicated that non-biological caregivers were less likely to report depressive symptoms than biological relatives. Other studies have found more complex relationships. In one study, the caregivers of someone with a mental illness who exhibited increased suicidal ideation and depression over a period of time also reported more depressive symptoms themselves. This relationship was found to be mediated by the caregivers’ relationship to the patient, and the patient’s suicidal history. With parents experiencing higher levels of depressive symptoms than spouses if their adult child had a history of suicide attempts and current suicidal ideation, and spouses experiencing higher levels of depressive symptoms when their partner did not have a previous suicide attempt history but was currently reporting suicidal ideation (Chessick, et al., 2007).

The role of caregiver appraisal has also been shown to play an important role in whether a factor contributes to a caregiver’s risk of depression. Appraisal of burden, as an evaluation of the significance of what is happening in the person-environment relationship, or the significance of whether a particular factor is burdensome or not, has been found to contribute considerably to caregiver distress and depression (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Song, et al., 1997). An individual’s appraisal of a potential factor is influenced by the demands of caregiving, the impact of caregiving on their own lifestyle, and the sense of
burden they might feel (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989). Furthermore, the cognitive appraisal of a factor is proposed to be dynamic and can change as caregiving demands change or the resources available to the caregiver are altered (Carey, Oberst, McCubbin, & Hughes, 1991).

The factors that contribute to caregivers’ depression are likely to be part of a complex interaction of factors in a caregiver’s experience. That is, depression in caregivers is often the result of an interaction of independent factors. Stress proliferation (the tendency for stressors to create additional stressors) has been suggested to be an important contributor to depression among caregivers. Saunders (2003) reported that the actual task of providing care for someone with a severe mental illness can exert effects on the stressors of caregiving. As stressors increase and the conditions persist, the caregivers’ depressive symptomatology may worsen and in turn, the deterioration of the caregivers’ emotional health may impact on their ability to continue in their role.

1.5.2 Posttraumatic Stress Symptoms in Caregivers

Research considering posttraumatic stress symptoms arising from the care of someone with a mental illness has been limited. Posttraumatic Stress Disorder (PTSD) is an anxiety disorder that can develop after exposure to a terrifying event or ordeal in which grave physical harm occurred, or was threatened against the person themselves, was witnessed by the person happening to someone else, or where the person learnt about this happening to a family member or close friend. It is a condition characterized by intense fear, helplessness, or horror resulting from the exposure to extreme trauma. The characteristic symptoms of PTSD include intrusive worries or re-experiencing aspects of the traumatic event, avoidance of reminders of the event or a numbing of the emotions, and hypervigilance or increased physiologic arousal that was not present before the trauma (DSM-IV-TR, 2000).

Most research on PTSD symptoms in carers has been in the context of parents with children who have experienced a life-threatening illness (e.g., Alderfer, Cnaan, Annunziato, & Kazak, 2005; Manne, et al., 2004). A posttraumatic stress framework was used to explain the lingering distress of these parents. More recently, a small number of studies have emerged that have looked at PTSD
symptoms in the carers of someone with psychosis (Barton & Jackson, 2008; Ferriter & Husband, 2003; Loughland, et al., 2009; Vaddadi, Gillear, & Fryer, 2002). Similar to carers of children with health problems, these studies showed that between 35% to 51.5% of carers of someone with psychosis reported symptoms of traumatic stress.

In the small number of studies that have explored the relationship between posttraumatic stress symptoms and the care of someone with a mental illness, it would appear that PTSD symptoms were found to be associated with either aggressive behaviour directed toward the carer, and/or the witnessing of the actual, or aftermath of self-harm or suicidal behaviours of the care recipient. One particular study with carer-relatives of someone with psychosis in the community found that over half of the carer-respondents reported significant levels of PTSD as a result of aggressive behaviour directed toward them (Loughland et al., 2009). Many of these respondents reported that when the aggression occurred, they believed their life to be in danger. They were extremely concerned that the aggression would occur again in the future. In general, the levels of PTSD symptoms did not differ whether the aggression was verbal or physical.

Learning that a family member or close friend has been or is experiencing violent personal assault, serious accident, or serious injury, or learning that one’s child has a life threatening illness is considered a Criterion A event for posttraumatic stress disorder (DSM-IV-TR, 2000). While BPD may not be viewed as life threatening from a medical point of view, research has indicated that family members/friends can interpret the risk of suicide and self-harm as potentially life-threatening for their loved one with BPD (Ryan, 2002). Giffin (2002) reported that the parents of adult children with BPD indicated symptoms of acute traumatic stress following the first time their daughters seriously injured themselves. They indicated ongoing posttraumatic symptoms with their daughters’ ongoing self-harm and suicidal behaviours.

Since BPD behaviours characteristically include self-harm and suicidal behaviours which family members/friends may perceive to be life threatening, as well as intense anger and/or an inability to control this anger which may result in the person with BPD threatening, or causing the family members/friends, actual bodily harm, it is feasible to suggest that these BPD behaviours could qualify as
Criterion A events for trauma. Thus it would seem probable that many carers of those with BPD may experience PTSD symptoms.

1.6 Quality of Life of Caregivers

While the major focus of the caregiving literature has been on the negative impact of the caregiving role on mental health, there has been a growing awareness that the caregiving role can impact on the quality of life of those providing care. The last couple of decades have witnessed a proliferation of research on quality of life during which time the concept of well-being has evolved from a simple, unidimensional construct to a more complex concept that incorporates both objective and subjective components of well-being. Even so, the construct of well-being has been examined in studies of family caregiving in only a limited fashion (White, Lauzon, Yaffe, & Wood-Dauphinee, 2004).

It is now increasingly recognized that to assess quality of life, not only is objective data, such as level of income and standard of accommodation important (Land, 1999), but an assessment of an individual’s subjective well-being, or in other words, an individual’s perceptions of their objective conditions in life is necessary to yield a more accurate picture of their overall level of well-being (Best, Cummins, & Lo, 2000). Furthermore, it is now widely acknowledged that subjective well-being is impacted by the closely related components of affect and cognition (Cummins & Nistico, 2002; Shmotkin, 1998).

Watson and Tellegen (1985) suggested that individuals are inherently endowed with a tendency toward experiencing either negative or positive emotions that, in turn, influence feelings of satisfaction. The proposal that affect influences feelings of satisfaction has been demonstrated in a series of studies by Fogarty, Machin, Albion, Sutherland, Lalor, and Revitt (1999) that found that an orientation toward either positive or negative affect was able to predict levels of satisfaction. An orientation toward high negative affect was able to predict lower levels of satisfaction and higher levels of stress, whereas an orientation toward positive affect was predictive of higher satisfaction.

There is also a general agreement that a cognitive component to subjective well-being exists. This cognitive component involves an internalized comparative process between current experience and internalized standards (e.g., Alicke,
LoSchavio, Zerbst, & Zhang, 1997; Cummins & Nistico, 2002). For example, satisfaction may be a function of a person’s perceived discrepancies between their current life and their life of the past or future, and/or their life compared to that of others (Michalos, 1985).

### 1.6.1 Caregivers and Well-being

Research suggests that though there are positive and negative experiences associated with caregiving, it is the negative experiences that are more likely to impact on subjective quality of life (QOL). From a review of studies that examined the caregivers of stroke victims, White et al. (2004) proposed that QOL could provide a more comprehensive evaluation of the caregiving role as it is a reflection of the balance between the positive and negative outcomes of a situation from the individual’s perspective. Carers in general, including carers of someone with a mental illness, were found to experience significantly lower QOL compared with the general population, and this was especially in the domains of health and emotional well-being. In a review of the literature Glozman (2004) concluded that caregivers often suffer significant burden that threatens their physical and emotional well-being, which is detrimental to their health.

Explanations for the finding that caregivers are at risk for diminished quality of life have been thought to be the result of a complex interplay of variables within the caregiving situation, caregiver factors, and environmental factors (White et al., 2004). Within the caregiving situation, evidence was found to support a relationship between the functional status of the care recipient (physical, emotional, cognitive, and communication difficulties) and the caregiver’s QOL (Glozman, 2004). Carers of someone who is mentally ill often need to cope with difficult symptom behaviours. Moreover, the unpredictability of the episodic characteristics of mental illness and it’s relapsing and remitting nature, often place carers in a position where the needs and wishes of the person with the mental illness are constantly put before their own (Cousins, 2001).

Caregiver factors that negatively impacted on QOL included an increase in caregiving responsibilities. This allowed less time to socialize with friends and family, or engage in hobbies or other recreational activities, so that caregivers reported decreased enjoyment in life, and consequently diminished QOL (Bethoux,
Calmels, Gautheron, & Minaire, 1996); White, et al., 2004). Caregiver burden (e.g., Blake, & Lincoln, 2000; Bugge, Alexander, & Hagen, 1999), and caregiver depression (Grant, Bartolucci, Elliot, & Giger, 2000) have also been found to be negatively associated with caregiver QOL. In contrast, a caregiver’s sense of mastery, that is, their positive view of their ability and competence in their caregiving role, was positively associated with QOL (van den Heuvel, Witte, Schure, Sanderman, & Jong, 2001).

Social support was a significant component in the environmental factors found to impact a caregiver’s QOL (Grant, Elliott, Giger, & Bartolucci, 2001). Stress on carers’ social networks has been found to be a major contributor to predictions of quality of life (Love, Street, Harris, & Lowe, 2005). Loss of social support previously provided by the ill person, especially in the case of a spousal relationship, often resulted in a sense of loss of companionship (Bethoux et al., 1996; Coughlan & Humphrey, 1982) and was found to impact on the caregiver’s sense of well-being. Although caregivers who lived with their care recipient were more likely to report that they enjoyed life less, those who reported a very close relationship before the onset of the illness/disability were less likely to experience a decreased QOL (Andersen, 1992). Accelerated discharge from a formal care facility and financial concerns as a result of the caregiving role were other environmental factors found to negatively impact QOL by contributing to caregiver burden (Hackett, Vandal, Anderson, & Rubenach, 2002).

1.7 Posttraumatic Growth in Caregivers

While most research has centred on the negative outcomes of caregiving for caregivers, recent literature reflects a trend towards consideration of possible positive outcomes. This research instead focuses on how individuals are transformed and even how they thrive after a traumatic experience. Posttraumatic growth refers to the positive changes individuals may experience following a traumatic event.

The term *posttraumatic growth* was first formally applied to the concept of psychological growth after a distressing event or experience by Tedeschi and Calhoun (1996). Calhoun and Tedeschi’s (1998) model of posttraumatic growth has been described as the most comprehensive model and has been used widely to
describe and measure psychological growth (e.g., Berger & Weiss, 2002). According to Tedeschi and Calhoun (2004) the term posttraumatic growth refers to “positive psychological change experienced as a result of the struggle with highly challenging life circumstances” (p.1). Posttraumatic growth describes much more that just simply a return to a psychological baseline after trauma. Instead it describes the growth in an individual’s psychological development that surpasses what was present before the crisis occurred, in at least some areas of their life.

Within this model it is assumed that individuals develop and rely on a general set of beliefs and assumptions of the world that are shattered by the trauma (Tedeschi & Calhoun, 2004). This leaves the individual with the need to rebuild their beliefs and assumptions to incorporate the trauma, thus making them more shatterproof in the future (Janoff-Bulman, 2004; Tedeschi & Calhoun, 2004). In this way posttraumatic growth is not a direct result of the trauma but of the individual’s struggle with the new reality and their attempts to cope or survive the trauma (Janoff-Bulman, 2004). It is therefore assumed that the trauma must be challenging enough to an individual’s world to set in motion the cognitive processes necessary for growth (Calhoun & Tedeschi, 1998).

Tedeschi and Calhoun (1996) identified five major domains of posttraumatic growth in their posttraumatic model. The domains were born out of reviews of the literature and interviews from individuals who had experienced trauma. The first domain identified was an increased appreciation of life and a changed sense of what is important. The second domain was the experience of closer, more intimate, and more meaningful relationships with others. The third was a greater sense of personal strength or the recognition that one possesses personal strength. The fourth was an ability to identify new possibilities for life, or the possibility that one can take a new and different path in life. The fifth and final domain was in the individual’s spiritual development, either in a religious sense or engaging with the fundamental existential questions of life.

Experiencing posttraumatic growth, however, is not necessarily synonymous with better psychological outcomes. Posttraumatic growth and distress have been found to be separate dimensions, and growth experiences do not always put an end to distress in trauma victims (Calhoun & Tedeschi, 1998). In fact, continuing manageable levels of distress have been found to fuel sustained posttraumatic
growth (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Tedeschi & Calhoun, 2004). Moreover, few relations have been found between posttraumatic growth and variables such as well-being, optimism, depression, and neuroticism (Tedeschi & Calhoun, 2004).

Posttraumatic growth has received increasing attention in the psychological literature (Calhoun, Cann, Tedeschi & McMillan, 1998; Calhoun & Tedeschi, 1990; Tedeschi, 1999; Tedeschi & Calhoun, 1995; 1996; Tedeschi, Park, & Calhoun, 1998). Researchers have documented the occurrence of posttraumatic growth in a wide range of people facing a wide variety of traumatic circumstances. People have been found to develop psychologically following experiences as diverse as natural disasters (Thompson, 1985), war (Aldwin, Levenson, & Spiro, 1994), disability (Dunn, 1994), sexual assault and sexual abuse (Burt & Katz, 1987; McMillen, Zuravin, & Rideout, 1995), bereavement (Calhoun & Tedeschi, 1990), and refugee experiences (Berger & Weiss, 2002). Thirty to ninety percent of people who experience some form of traumatic event reported at least some positive changes following the trauma, with the figure dependent on the type of event and other factors (Calhoun & Tedeschi, 1999).

The research on posttraumatic growth and carers using this model has been limited to only a couple of areas, namely the carers of someone with HIV/AIDS (Cadell, 2003), and the husbands of breast cancer survivors (Weiss, 2002; 2004). Both the carers of someone with HIV/AIDS and the husbands of breast cancer survivors displayed evidence of growth related to their experiences despite the ongoing stressors involved with their roles. For both groups, the level of growth was closely related to the levels of social support available to them. The growth for husbands of cancer survivors was also closely related to the depth of support and commitment present in the marital relationship, as well as their wife’s own levels of posttraumatic growth (Weiss, 2004). Within the carers of someone with HIV/AIDS it was found that those who reported higher levels of posttraumatic stress symptoms during the caring phase, also reported the most growth after the death of the person they were caring for (Cadell, 2003).

In summary, although there are a number of ways to conceptualise personal growth after an individual experiences a distressing event/experience, Calhoun and Tedeschi’s (1998) model of posttraumatic growth appears to be upheld as the most
comprehensive and the most empirically researched. This model does not require that an individual look favourably on the traumatic event/experience, or to be free of distress symptoms. But it does require that the traumatic event/experience be “seismic” – it must be of sufficient magnitude to shake or shatter one’s basic assumptions about the world to trigger growth. Although there have been few studies exploring the experiences of carers and family members to date using this model, the carer/family member studies that have used the model have demonstrated that it is comprehensive enough to incorporate such populations and say something meaningful about their experience (e.g., Cadell, 2003; Weiss, 2004).

1.8 Coping

A new perspective on coping emerged in the 1960s. This major new development in coping theory and research occurred when the hierarchical view of coping, with its trait or style emphasis on coping, was abandoned in favour of an approach which treated coping as a process. In other words, this new approach emphasised processes more than structures or dispositions (Suls, David, & Harvey, 1996). Coping, according to this perspective, was conceptualised as a transactional process or exchange between person and environment with an emphasis on process rather than on personality traits (Folkman & Lazarus, 1985; Lazarus 1966; Lazarus & Folkman, 1984).

The process approach to coping comprises two broad types of coping, emotion-focused coping and problem-focused coping. Problem-focused coping refers to efforts to remove the threatening event or diminish its impact (Carver & Scheier, 1994), for example gathering information about a problem and formulating a plan of action in order to alter or eliminate the stressor (Suls, et al., 1996). Emotion-focused coping refers to efforts to reduce the negative feelings that arise in response to a threat (Carver & Scheier 1994), for example, processing and talking about feelings with others, or using alcohol and drugs to feel better (Suls et al., 1996). These two functions of coping have been recognised by numerous researchers (e.g., Baker & Berenbaum, 2007; Folkman, 1984; Magliano, et al., 1998) since its conception in the 1980s (Folkman & Lazarus, 1980).

Folkman & Lazarus (1980) proposed that the use of emotion or problem-focused coping strategies depends on one’s appraisal of the situation. There are two
kinds of appraisal decisions. Primary appraisal is a cognitive process whereby one assesses what is at stake in a given stressful situation, whereas secondary appraisal is where one evaluates what coping resources and options are available. In situations that were appraised to be changeable (improvable), problem-focused strategies would be employed, whereas emotion-focused strategies would be used in situations appraised as unchangeable. Confirming Lazarus and Folkman’s claims, the evidence is tipped toward the idea that stressful events perceived as changeable are less likely to be accepted (Schwartz & Stone, 1993), and more likely to result in the use of problem-focused strategies (Carver, Scheier, & Weintraub, 1989). Situations perceived to be relatively unchangeable have been associated with emotion-focused strategies (Folkman & Lazarus, 1980, 1985; Schwartz & Stone, 1993).

It is important to note that the process model of coping, unlike the trait approaches, does not view one coping strategy necessarily as more adaptive or maladaptive. In fact, even early research by Lazarus and his colleagues (Folkman & Lazarus, 1980; Lazarus, 1983) showed that individuals in highly stressful situations alternate between approaching and avoiding the problem, and both types of coping were used in over 80% of episodes. Lazarus himself (1993) was quick to emphasise that research has suggested that one strategy is not necessarily more adaptative than the other, but that both coping strategies can be beneficial depending on the characteristic of the stressor. Moreover Lazarus (2000) has suggested that both functions may interact to affect the same outcome. For example, successful problem solving may lower emotional distress and lowered distress due to emotional coping may affect the ability to problem solve.

1.8.1 Determinants of Coping

Studies have highlighted that men and women coping with a variety of real life issues were found to use both problem and emotion-focused coping in over 98% of issues. Most individuals were shown to use both forms of coping in stressful situations. The emphasis on one form or other however, varied according to the type of encounter, the way it was appraised, and the person themselves (Folkman & Lazarus, 1985).
A variety of factors were found that determined the ways in which people coped with any given issue. These included the type of situation one was facing (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Folkman & Lazarus, 1980); one’s perception of whether the situation could be changed (Lazarus & Folkman, 1984; Lazarus, 1993; McKee et al., 1997), perception of one’s ability to cope in the particular situation (McCrae & Costa, 1986; Pervin & John, 2001); one’s coping repertoire (Boekaerts, 1996); one’s ability to match a coping strategy with the requirements of the situation, and the stage of the coping encounter (Folkman & Moskowitz, 2004).

1.8.2 Meaning-Focused Coping

A third form of coping, meaning-focused coping, has also been conceptualised by Park and Folkman (1997). Meaning-focused coping does not attempt to change or alleviate the stressful event. Instead, this form of coping changes the appraisal of the situation to be more consistent with one’s goals and beliefs. Examples of meaning-focused coping involve making the meaning of a stressful event more benign, determining that an event is less important than originally perceived, or identifying opportunities for growth from the event (Park & Folkman, 1997). Park and Folkman suggest that meaning-focused coping is likely to be adaptive, regardless of the perceived controllability of the stressor.

Support for meaning-focused coping was initially established in a study of HIV positive men, wherein meaning-focussed coping was inversely related to depressed mood, regardless of the appraised controllability of the stressor (Park, Folkman, & Bostrom, 2001). The goodness-of-fit for problem-focused and emotion-focused coping to the respondent’s appraisal of controllability of the stressful situation in this study was not as clear-cut. The negative association between meaning-focused coping and depression and other mental health outcomes has since been replicated in various studies (e.g., Cadell, 2007; Kars, Duijnstee, Pool, van Delden, & Grypdonck, 2008).

1.8.3 Third Generation Approach to Coping

The idea that individuals who are able to adjust their coping strategies to meet the stressors at hand may experience better adjustment was discovered in a meta-analytic review of coping studies by Nes and Segerstrom (2006). Their
findings indicate that individuals who are able to be flexible in regard to the demands of the stressor, as well as being responsive to the possibility of modifying either the stressor itself or their responses to it, show better psychological adjustment to the stressor.

A third generation of coping theory and research that has brought together personality and situational factors has been proposed by Suls et al., (1996). This approach emerged from the reasoning that neither personality nor situational factors were adequate predictors of coping behaviour on their own. Despite its continuing evolution, this coping approach already has some discernable features. This approach acknowledges the importance of both situational and individual determinants of coping, and in agreement with the process model of coping, it makes no assumptions about the adaptiveness of particular coping strategies. Instead, this approach recognises the interplay between stressors, coping and personality by acknowledging that stressors influence aspects of one’s personality, either positively or negatively, so that encounters with earlier stressors can influence future coping efforts (Suls et al., 1996).

1.8.4 Coping and Carers

Adapting to the family stress and burden of living with a family member with a mental illness has provided the background for many studies of family caregiving (Schofield, et al., 1998). Not surprisingly, research has indicated that caring for someone with a mental illness can place high levels of stress and burden on carers (e.g., Saunders, 2003), and this experience, for some, may persist for long after their unwell relative’s symptoms have been managed (Barton & Jackson, 2008). However, comparatively fewer studies have examined the relationship between more specific coping styles and how they influence carer burden and psychological distress (Budd, Oles, & Hughes, 1998). These studies have focused mostly on those caring for someone with a diagnosis of schizophrenia, and to a lesser extent on the carers of individuals with depression and bipolar disorder (Perkins, Winn, Murray, Murphy, & Schmidt, 2004). There were no known studies that have examined the coping of family members and carers of someone with BPD at the time of this research. Hence this review of coping and carers will focus on findings of studies that were conducted with carers of those with other mental illnesses.
The onset of a mental illness within a family member usually triggers a major and often abrupt role-change in families that few families are prepared for, and which frequently continues for many years (Spaniol, Zipple, Marsh, & Finley, 2000). McCubbin and Figley (1983) described two categories of stressors that apply to families coping with stress. These are normative stressors, involving transitions throughout the life cycle as family relationships change and family members grow and develop; and catastrophic stressors, striking families suddenly and often overwhelming the family’s ability to cope. Severe mental illness was identified by McCubbin and Figley as an example of a catastrophic stressor for the family. A catastrophic stressor corresponds with the definition of an extreme traumatic stressor in PTSD. Consistent with an extreme traumatic stressor as defined in the DSM-IV-TR (2000), a catastrophic stressor is distinct from a normative stressor in its intensity and nature (McCubbin & Figley, 1983), and is usually outside the range of usual human experience.

As the serious mental illness of a relative is considered to be catastrophic stressor for families (Marsh, 1992; Spaniol & Zipple, 1994), comparisons of mental illness as a catastrophic event can be drawn with other catastrophic events. Marsh (1992) argues that, as in other catastrophic events, family members who have a relative with a mental illness are faced with extraordinary demands for coping and adaptation, often under crisis conditions. Moreover, the consequences for these families are often comparable to those of natural calamities, such as floods or tornadoes. For many individuals, the devastation compares with experiences of combat and imprisonment. There is also a qualitative break with life as it has been lived in the past.

Yet the familial experience of mental illness is also distinct from most other catastrophic events in terms of duration. Other time-limited events allow families and individuals to replenish their depleted resources and to reestablish normal patterns of living. In the case of serious and persistent mental illness, the catastrophic stressor is often present on an ongoing basis, with the potential for periodic emotional firestorms and recurrent crises (Marsh, 1992). For this reason, lifetime adaptations and ways of coping are often required when caring for someone with a mental illness.
Studies of coping in caregivers of someone with a mental illness have been mostly restricted to schizophrenia. Nonetheless several important findings have emerged from these investigations. Caregivers typically used a number of different coping strategies to deal with a person with mental illness (Birchwood & Cochrane, 1990; Hatfield, 1979; Zipple & Spaniol 1987). Similar to the coping patterns of caregivers of other disorders, two broad patterns of coping were identified in caregivers of someone with schizophrenia, problem-focused and emotion-focused coping strategies (Budd, Oles, & Hughes, 1998; Magliano, Fadden, Economou, et al., 1998; Magliano, Fadden, Madianos, et al., 1998).

Problem-focused coping strategies used by caregivers referred to efforts directed at solving or managing the problem that was causing the distress and were generally targeted at their mentally-ill person’s symptoms and/or behaviours and the resultant burden. They included measures such as seeking information, or learning to use positive methods of communication. Emotion-focused coping strategies were attempts at managing the emotional distress associated with the care of someone with a mental illness (Chakrabarti & Gill, 2002). The range of emotion-focused strategies used were quite broad and included strategies such as denial, focusing on and venting of emotions and positive reinterpretation of events (Baker & Berenbaum, 2007).

The choice of one or other pattern of coping for someone caring for someone with schizophrenia seems to be determined by a number of factors. Among them were demographic variables (Wilcox, O’Sullivan, & King, 2001; Wintersteen & Rasmussen, 1997), for example, problem-focused strategies were used more often by younger caregivers and caregivers of younger patients, whereas emotion-focused coping was more prevalent among older caregivers. Other factors influencing type of coping included appraisal of the stressful situation as being amenable to change and the caregiver’s own perceived ability to cope with the situation (e.g., Barrowclough & Parle, 1997). Consistent relationships across studies were found to relate to caregiver burden, social functioning of the patient, expressed emotions of caregivers, and the social support available for caregivers. High levels of burden, social dysfunction of the patient, and expressed emotion together with low levels of available support have been found to be associated with higher use of maladaptive, principally emotion-focused coping styles (Chakrabarti & Gill, 2002).
There is a view in the stress and coping literature that emotion-focused coping processes are maladaptive (Stanton, Danoff-Burg, Cameron & Ellis, 1994). Emotion-focused coping is often conceptualized as a weak alternative to problem-focused coping (Stanton et al., 1994). Although some studies seem to suggest that emotion-focused coping may be ineffective, Baker and Berenbaum (2008) caution us to be skeptical of the existing research for several reasons since emotion-focused coping incorporates a diverse range of coping strategies, including both adaptive and maladaptive strategies. The effectiveness of emotion-focused coping has been proposed to depend on the particular form of emotion-focused strategy employed rather than the broad category of coping under which it fits and the literature confirms this (Carver, et al., 1989; Stanton, Kirk, Cameron, & Danoff-Burg, 2000).

Moreover, a growing body of literature acknowledges that problem-focused coping strategies may not be effective in all situations (e.g., Baker & Berenbaum, 2007). For example, persisting in problem-focused coping strategies may be counter-productive if the situation is not amenable to change and requires a level of acceptance, such as trying to change the residual symptoms sometimes associated with the diagnosis of a mental illness. The success of the coping strategy according to this view is not related to whether the coping strategy is problem-focused or emotion-focused but rather to the match between the situation and the person’s ability to use the strategy (Lazarus & Folkman, 1984).

Numerous studies have identified that caregivers of someone with schizophrenia or bipolar disorder need to use a wide variety of problem-focused and emotion-focused coping strategies to cope with the stressors of caring for someone with a mental illness, and the resulting burden and grief (e.g., Chakrabarti & Gill, 2002; Solomon & Draine, 1995). Although there is little indication in these studies of the effectiveness of particular coping strategies, it was acknowledged that some of the coping strategies used may have been considered adaptive only if used in the short-term to reduce immediate stress (Solomon & Draine, 1995). For example, the short-term use of the emotion-focused coping strategies of self-distraction and behavioural disengagement in the care of someone with a mental illness may be necessary for self-care, and the avoidance of burnout, but used in the long-term this strategy may reflect avoidance of the situation and is likely to be associated with higher caregiver burden.
There is some evidence that the combination of problem-focused and emotion-focused coping strategies is beginning to be viewed as adaptive (Baker & Berenbaum, 2007). For example, the content of publications distributed by caregiver support organisations has been found to encourage caregivers to not only use the practical, skill-based solutions for the multitude of problems encountered by them providing care, but also to attend to their own psychological distress that often accompanies the caring for someone with a mental illness (e.g., Carers Victoria, 2010). This is indicative of the growing awareness that effective coping has a contextual component, in that it is dependent on the situation at the time. Wisdom, in this sense, may be in knowing what coping strategy to use in what situation.

1.9 Experiences of Caregivers with Services and Professionals

There is an increasing recognition that the family is often the primary source of support for people with a mental illness and serves as a safety net when other sources of help fail to respond (Greenberg, Greenley, & Brown, 1997). A comprehensive system of services for people with a mental illness should take into account the needs of families who are supporting a family member with a mental illness (Spiegel & Wissler, 1986). More recently carers, alongside service users, have been encouraged to be more involved in developing plans for care and treatment in the community for people with a mental illness (Mitchell, Ralston, McInnes, Crilly, & Anderson, 2009). For many carers, however, this is not the case, with many expressing dissatisfaction with mental health services and professionals.

Although a caregiver may have the practical responsibility for the care of their mentally-ill family member, it is often the case that the legal system, mental health providers, and the mentally-ill person themselves do not recognize that the caregiver is entitled to any rights (Wynaden & Orb, 2005). Consequently, the caregivers’ experience of the system, as a whole, is that they are allowed very little input into decisions regarding the care of their adult relative whom the caregivers view as being unable to adequately care for themselves or make decisions in their own interest (Wynaden, 2002). Yet these mentally unwell individuals are also often not being cared for anywhere else.

Overwhelmingly, research supports family and carer engagement with mental health services (Chambers, Ryan, & Connor, 2001), promotes inclusion of
carers in decision-making (Reid, Lloyd, & de Groot, 2005), and encourages information exchange and active partnerships in care (Lloyd & Carson, 2005; Rapaport, Bellringer, Pinfold, & Huxley, 2006). In Australia, the importance of carer participation in mental health services has been recognized in the National Mental Health Strategy (adopted in April 1992 and implemented in January 1993) and the Third National Mental Health Plan (2003), which recognise the role of informal care for someone with a mental illness and encourages carer participation. As a result, some Australian states have made a number of significant policy changes that have brought about more information and referral services for carers, and assisted in greater participation of families in treatment and service provision in parts of the public system (McAuliffe, et al., 2009). However, it is acknowledged that the vision for carer participation in the National Health Plans is still far from realized (Crowley, 2005).

What carers want from mental health professionals has been well documented by researchers and summarized by Bernheim (1994). Family carers expressed a need and desire for information and education about the illness, for specific suggestions for coping with the patient’s behaviour, for emotional support in their role as carers, for access to people who face similar problems, for timely crisis intervention, for respite services including times for alternate living options, for meaningful involvement in treatment, discharge, and rehabilitation planning, and for information and education about the mental health system which was reported to be complex and confusing (Bernheim, 1994; McAuliffe et al., 2009; McNamara, 2001; Noble & Douglas, 2004). Also well acknowledged was the significant discrepancy between what the carer perceived as being needed and what the mentally-ill care recipient reported they needed, particularly during acute episodes of mental illness (Goodwin & Happell, 2006; Lammers, Happell, & Ed, 2004).

There is overwhelming agreement in the literature that, worldwide, caregivers are expressing dissatisfaction with professionals and services in their care of someone with a mental illness ((Chafetz & Barnes, 1989; Fadden, Bebbington, & Kuipers, 1987; Grosser & Vine, 1991; Lefley, 1987; Ruggeri, Dall'agnola, Agostini, & Bisoffi, 1994; Stengard, Honkonen, Koivisto, & Salokangas, 2000; Winefield & Harvey, 1993). Comments concerning professional helpers were four times more frequently negative than positive (Winefield & Harvey, 1993). Caregivers were
dissatisfied with the lack of aftercare services, lack of emotional resources available to them as carers, lack of response to their requests for information, low level of carer involvement in treatment decision making (Biegel, Song, Milligan, 1995; Hanson & Rapp, 1992; Ruggeri, 1994), and lack of practical support in times of emergency, including times when caring for someone who was self-harming and/or suicidal (Beautrais, 2004; Giffin, 2008). A small qualitative study by Giffin (2008) who studied the experience of BPD carers observed that these carers criticized mental health services in unison for their lack of sensitivity to the carers’ needs and concerns, and their failure to recognize the value of the caregiver’s role (Giffin, 2008).

Caregiver satisfaction was found to vary significantly for the different categories of mental health professionals with whom the carer had contact. Carers reported greater satisfaction with psychologists, followed by nurses, then case managers, then social workers and finally psychiatrists (Tessler, Gamacho, & Fisher, 1991). Satisfaction with emergency services were generally found to be low, for the reason that emergency services were particularly difficult to get hold of in times of crisis (Morgan, 1989), and were often not found to be helpful when accessed (Giffin, 2008).

A perceived lack of support from the health and mental health systems was found to have consequences for caregivers. Higher levels of caregiver burden and psychological distress, and feelings of isolation and alienation, were consistently associated with lower levels of satisfaction with professionals and services for caregivers of someone with a mental illness (Loukissa, 1995; Marsh, 1992; Song, et al., 1997; Winefield, 2000). Moreover, higher levels of burden and distress impacted the entire family system by creating a more negative family atmosphere (Madianos, et al., 2004). In contrast, lower levels of psychological distress were found in caregivers who experienced a more collaborative relationship with health care providers (Greenberg, et al., 1997).

1.10 Summary

Informal caregivers play a vital role in supporting family members and friends in the community who experience a mental illness. In fact, informal caregivers, and particularly family members, often bear the responsibility of such
care. The objective and subjective burden is well documented and found to be considerable for these caregivers. Research has consistently found that caregivers show poorer mental health than non-caregivers and often this is in the form of increased levels of anxiety, depression, and other forms of mental illness. Caregivers have also been found to experience posttraumatic stress in situations where the individual they are caring for displays more extreme behaviours such as aggression, and self-harm and suicidal behaviours. The few studies that have studied the impact of caring for someone with BPD describe caregiver experiences of intense anger and violence directed toward them, as well as emotional distress, grief and self-blame.

Coping with the demands of caring for someone with a mental illness has been compared with coping with a catastrophic event, and yet distinct from other catastrophic events in that a mental illness is often present on an ongoing basis, therefore requiring lifetime adaptation and coping. The concepts of problem and emotion-focused coping were often used to describe the coping efforts of caregivers of someone with a mental illness. Adaptive coping of those caring for someone with BPD are likely to draw on both forms of coping and to be contextualized.

Although research overwhelmingly supports caregiver engagement with mental health services, the experience of caregivers on this matter for those caring for someone with BPD has not been examined in detail. Family members and caregivers of those with other mental illness in general describe experiences of feeling “disenfranchised”, left in the dark and unsupported by mental health services despite an expectation that the caregiver take responsibility that they care for their loved one. Lack of support from the health and mental health systems were found to have consequences for caregivers. Higher levels of distress and feelings of isolation were associated with less support from professionals and services adding to the burden of the caregiver.

1.11 Rationale and Objectives

Borderline personality disorder has become the most researched of the axis II disorders in the last ten years (Hooley, Phil, & Hoffman, 1999). However the main emphasis of this research has been on the aetiology of BPD in the context of the family and how the family may have contributed to the development of the
disorder. Only recently has the focus expanded to include how families can help the BPD person in the context of family therapy. Despite the abundance of literature on the caregiving experience of families e.g. (Mavundla, Toth, & Mphelane, 2009; Nankervis, Bloch, Murphy, & Herman, 1997; Tennakoon, et al., 2000; Twigg, 1992; Yates, et al., 2004; Zarit, 1989), there is a noticeable absence of research exploring the experiences of the family members and caregivers of people with BPD. The few studies that are available, although valuable in their contribution to knowledge in this area, are limited by being based on anecdotal information (e.g., Single, 1993), or are secondary descriptive analysis of a web-based forum so that the empirical validity is unclear (e.g., Mason & Kreger, 1998), or are hampered by extremely small numbers (e.g., Giffin, 2002).

The aim of the present investigation was to empirically examine the experiences of family members and informal care-givers of individuals with BPD within a coping framework. It was designed to contribute to knowledge and inform health care providers, policy makers, carers, and mental health clients in Australia and internationally. A major purpose of this study was to contribute to building the understanding of policy makers and health professionals of the experiences and needs of the carers of someone with BPD, so that they may therefore make more informed decisions about supporting carers in their challenging role. Finally, it was hoped that an understanding of the experiences and needs of carers of someone with BPD would encourage more effective collaboration between carers, mental health clients, and health professionals.

In order to achieve the above purposes, the objectives of this study were to:

1. Explore and describe the experiences and needs involved in caring for a person with BPD.
2. Explore and describe the psychological consequences of caring for a person with BPD.
3. To examine the coping styles of those caring for someone with BPD.
4. To examine the experiences of caregivers with the health care systems and professionals, and their reflections about these systems.
To meet these objectives two studies were performed. First a qualitative study was conducted to gain an initial in-depth understanding of the experiences and needs of family members of someone with BPD. The qualitative method of semi-structured interviews allowed the participants to respond in their own words and with greater spontaneity, which resulted in a richer and deeper understanding of their experiences and needs. This was considered to be valuable in a study that was explorative in nature and intent. The purpose of the second, quantitative study was to examine whether the needs and experiences relayed by the participants in the semi-structured interviews were typical of other family members and caregivers of someone with BPD. The quantitative study allowed accurate and more reliable measurements of the needs and experiences identified in the qualitative study with a greater number of participants from a wider geographical area. Integrating the quantitative and qualitative research methods lent depth and clarity to the objectives of this research.
CHAPTER 2: STUDY ONE - A QUALITATIVE STUDY

2.1 Overview

The purpose of this qualitative study was to explore the nature of the experiences and needs of informal caregivers who are in relationship with someone with Borderline Personality Disorder. The study involved interviews with family members of someone with BPD. It was largely exploratory and sought to shed light on the experiences and needs of the family members. The aspects of family members’ and friends’ experiences were partly informed by Giffin’s (2002) study, however the current study sought to expand upon her findings. This section of the thesis describes the outcomes of the interviews and how these findings relate to the family members’ overall functioning.

Qualitative research methods are considered an appropriate methodology for exploring the experiences and needs of a relatively unknown population such as the family members of someone with BPD. Qualitative research methods do not impose an external order upon the research, allowing respondents to clarify their understanding of processes, issues, and feelings. By allowing respondent’s voices to be heard, researchers seek to uncover the process shaping the phenomena (Smith, 2004).

The qualitative data in the current study explored: (a) family members’ descriptions of their relationship with their BPD relative, (b) the impact the relationship has had on their own lives and the lives of others around them, (c) the coping strategies they used to cope with the extreme behaviour of their BPD relative, and (d) their encounters with professionals and services in the care of their BPD relative.

2.2 Method

2.2.1 Participants

Thirteen family members volunteered to participate in Study One. The criterion for inclusion for the interviews was that they were in a relationship with someone who has Borderline Personality Disorder (BPD). The BPD diagnosis was confirmed with a set of screening questions which were asked prior to the commencement of the interviews. The participants were all female between the ages of mid-twenties to early seventies. Of the thirteen participants eight were currently
married, three were in a long term relationship, and two were single. The relationships of the participants to their BPD relative comprised two partners, nine mothers, one daughter, and one sister. Eight of the thirteen participants were living with their BPD relative at the time of the interview, with three participants residing in country Victoria, one participant residing on the outskirts of Melbourne, and nine of the participants residing in the Melbourne metropolitan area. Ten of the twelve BPD relatives of the participants were female and two male, with ages ranging from early twenties to early seventies. Length of association between the participants and their BPD relative ranged from about 10 years to just over fifty years in the case of the daughter of the mother with BPD.

2.2.2 Recruitment Method

Ethics approval was obtained from Swinburne University and the two participating Melbourne based BPD Carer Support Groups prior to any recruitment being undertaken. All participants were associated with one of the two BPD specific carer support groups that currently operate in Melbourne at the time. Several recruitment methods were used in this study. The participants were recruited directly through the groups’ monthly meetings where the facilitators distributed the recruitment information to the group members in attendance, or alerted the group members in attendance to the study and where they could access further information. The facilitator of one of the groups organised for the recruitment information to be sent out to all of the registered members of their group, while the other group facilitator sent the information out to only those registered members that had not attended the meetings. A notice alerting readers to the study was placed in the newsletter of an organisation that supports the family members and carers of someone who is mentally ill. Three of the thirteen participants were informed of the study by another participant.

The recruitment information contained a Plain Language Statement describing the study and the expected role of the participant in the study, and a Consent Form which asked for contact details (see Appendix A). Those interested in participating in the interviews were instructed to return the consent form, containing their contact details, in the stamped return-addressed envelope provided. The researcher then contacted them to set up a time to conduct the interview.
2.2.3 An Overview of Interpretive Phenomenological Analysis

This study used the Interpretive Phenomenological Analysis (IPA) approach. IPA is only one qualitative approach, however it is a distinctive approach which is being used with increasing frequency in published studies. Smith (2004), who developed IPA, described it as part of a stable of closely connected qualitative approaches which share a commitment to the exploration of personal lived experience, but which have different emphases or suggested techniques. IPA aims to explore participants’ experience of a specific event, process or relationship in great detail as in ‘pure’ phenomenology. It also aims to develop a more in-depth interpretive analysis by speculating about what it means for the participant to have expressed specific feelings and concerns in their particular situation (Smith, 2004).

When Smith (2004) talks about an indepth approach, he is talking about the detailed examination of one case until some degree of “gestalt or closure” has been achieved and then moving onto the second case and so on. Only when this has been achieved does the IPA approach suggest an attempt be made to conduct a cross-case analysis. Larkin, Watts, and Clifton (2006) characterise IPA methodology as a highly intensive and detailed analysis of the accounts produced by a comparatively small number of participants. IPA methodology guidelines recommend a sample size of between five and 15, a number small enough to enable the researcher to retain a picture of each individual case, and to enable placement of this case in relation to the group as a whole (Smith, 1996; Smith, Jarman, & Osborn, 1999).

The IPA qualitative method has been used in a variety of settings with a wide range of populations. A large number of IPA studies have been conducted in healthcare settings such as exploring the meaning of satisfaction of health care for people with dermatological problems (Collins & Nicolson, 2002), adolescents’ experience of inpatient treatment for anorexia nervosa (Colton & Pistrang, 2004), and men’s experience of chronic lower urinary tract symptoms (Gannon, Glover, O’Neill, & Emberton, 2004). An increasing number of IPA studies have examined the experiences of carers, for example, the experience of carers of stroke survivors (Hunt & Smith, 2004), and the parental responses to adult children with schizophrenia (Osborne & Coyle, 2002).
Most commonly, as described by Smith (2004), IPA methods have been used with individual semi-structured interviews. In a critical evaluation of the use of IPA in health psychology, Brocki and Wearden, (2006) identified 52 studies that used the IPA method, of which 50 were interviews of some kind. Smith (2004) thought that semi-structured interviews were ideal for IPA analysis as they allow the researcher to follow up on interesting and important issues that occur during the interview around a particular experience of the participant.

2.2.4 Interview Method

The interviews were semi-structured (see Appendix A) and aimed to identify the key issues shaping the participants’ experience in their relationship with, and often their care of, their BPD relative. The interviews also sought to identify the family members needs in these roles, and the barriers to having these needs met. Participants were given ample opportunity to answer the questions as freely as possible. The interviews were mostly conducted on a one-on-one basis with only the participant and the researcher present. However one interview was conducted with both the mother and sister of the BPD person simultaneously because of time limits. The interviews were conducted either at the participant’s home or in a convenient location that afforded privacy such as a counselling room. The duration of the interviews ranged between 1.5 hours to 3.5 hours.

2.2.5 Recording, Transcription, and Coding of Interviews

With the participants’ permission all interviews were audio-taped and then transcribed verbatim into Word documents for analysis. These transcripts formed the basis from which data was extracted to accord with the major themes of the study. The data was analysed using manual and N-Vivo coding which allowed full transcripts of interviews to be coded in multiple ways and themes developed from searches. A detailed coding frame was developed according to the study’s conceptual concerns.

Moreover, the data was coded on a number of different levels. Consistent with the Interpretative Phenomenological Analysis approach the content of the interviews was considered in relation to themes, issues and experiences with a number of different aims in mind. The first was to try and understand the participant’s world and their experience of the relationship with their BPD person.
and the impact this has had on their lives. The second was a more interpretive approach which allowed the researcher to speculate about what it means for the participants to have made the claims they made and to have expressed the feelings and concerns in their particular situation. Each interview was examined in detail before moving onto to the next interview to allow the development of emerging themes to be explored as each interview was analysed. That is, the themes and issues were analysed from the first interview and taken into the second interview to be further refined and explored. In subsequent interviews new themes and issues arose which were then explored in subsequent interviews and so on. Themes and issues identified in later transcripts were also taken back to earlier transcripts to be explored.

Anonymity of all respondents is essential to protect their identity. Therefore, all quotes in this section are attributed to the role of the family member in relation to their BPD person, for example, mother, daughter, partner or sibling. It was thought that using the role description would still allow for making meaningful comparisons and inferences of the data.

2.3 Results

2.3.1 Coping

In order to simplify the patterns of coping strategies used by the family members in the study, sub-groups of family members who reported similar types of coping were formed. Participants were grouped using a cluster procedure (Gordon, 1999; Sharma, 1996). This procedure grouped participants on the basis of the types of coping strategies they reported using. Four distinct groups were identified, the Bound and Powerless, the Loving Active Copers, and the Distanced Managers groups, and the In-Flux participant. The groups differed in the coping strategies they employed to cope with the demands of being in relationship with, and often caring for their relative with BPD, see Table 1. Coping strategies were identified using an abridged version of the brief COPE (Carver, 1997).

2.3.1.1 Group 1: The Bound and Powerless.

Group 1 could be characterised as the powerless, isolated, and least functional copers. This group contained two of the thirteen participants. As indicated in Table 1, the members of this small group when compared with the
Loving Active Copers were less inclined to use active coping in relation to their BPD relative and more likely to resort to substance use. But what distinguished this group most of all from all other groups was their turning to religion and their failure to seek instrumental social support for themselves. The general powerlessness of this group and their failure to use active coping strategies in relation to their BPD relative was most fully represented by their accounts of why they continue to live with their BPD person.

The members of this group indicated they continued to live with their BPD person, not because they chose to, but because they felt powerless to make any changes. This sense of powerlessness was, in one case for personal safety reasons. This participant felt that she was safer remaining in the family home with her BPD husband because she felt she was better able to manage him and his behaviours from a closer proximity.

Once I did start packing up stuff (to leave), and he absolutely fell apart. I was sticking to my guns and he became very vicious, and I realised that it was too unsafe to move, so then I had to be rather manipulative to turn around. I won’t be leaving because I don’t believe that it is safe enough - for both of us. Because I think he would have me killed, and he always says that he will suicide, he has been suiciding for 25 years........I am quite afraid that it would be a murder suicide – that he wouldn’t just let me go........I know it sounds bizarre but I am safer there.

In the other case the mother felt that because her BPD daughter did not have anywhere else to go she could not make any changes.

……...financially she couldn’t manage so she asked me could she move back home and I let her and that was the biggest mistake that I ever made...........it’s (our relationship) getting worse now – she just needs her space and I need mine....... they are trying to get her into supported accommodation again and I’m hoping that they do.......to relieve the pressure off me.

Both participants in this group gave the researcher the impression that, although they cared about the well-being of their BPD person, they were not emotionally engaged in the relationship. One participant’s description of her relationship with her BPD partner encapsulated this point.

My relationship with my husband is fragile, difficult, and complicated. I guess it has been a sham. Intimacy is very difficult, it’s occasional but it’s destructive, there’s always destructiveness. It’s very difficult, it becomes a
very limited relationship because of that. It’s been such a farce. You need to learn to detach.

Table 1

Percentage of Participants in Groups Employing Coping Strategies

<table>
<thead>
<tr>
<th>Coping Strategies</th>
<th>Bound and Powerless</th>
<th>Loving, Active Copers</th>
<th>Distanced Managers</th>
<th>In Flux</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n=2)</td>
<td>(n=7)</td>
<td>(n=3)</td>
<td>(n=1)</td>
</tr>
<tr>
<td>Self-Distraction</td>
<td>50%</td>
<td>86%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Active Coping:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Self BPD Person</td>
<td>50%</td>
<td>86%</td>
<td>100%</td>
<td>-</td>
</tr>
<tr>
<td>Instrumental Social Support</td>
<td></td>
<td>86%</td>
<td>100%</td>
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<td>Self Blame</td>
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This group was distinguishable from the other groups in the ways they coped in several ways. First, as indicated in Table 1, this group was the only group (apart from one participant in Group 2) that indicated that they found comfort in their
religion and regularly prayed and/or meditated to cope with the stress of living with their BPD person. In fact one participant reported that she spent so much time engaged in prayer and/or meditation after a stressful episode with her BPD partner that it affected other areas of her life, such as work, and that she felt resentful of the amount of time that it took from her daily life.

*I am a practising Catholic and that is very important to me. I do meditation and I love nature. I’ve designed my garden so it’s beautiful to look at and it’s very calming - spirituality in the wider sense. When I have had a bad episode (with BPD partner) I’ll just have to sit and read, stare out at my garden and do my meditation trying to get myself and my mind together. Sometimes this has meant getting to work late which is embarrassing but its no use trying to deal with my type of work when your mind’s scattered all over the place. I am very resentful that I lose time, because I am a bit of a time person and I like to do many things in my life. (It is not uncommon) for me to have wasted half a day here, a day there, or feel that I have not been very productive today. There’s a lot of resentment.*

Second, as demonstrated in Table 1, members of this group were the only ones (apart from one participant in Group 2) who did not seek instrumental support. They did not actively seek information, advice or assistance from others anywhere close to the amount other groups did to help them cope with their BPD person. This is not surprising, as both these participants reported isolation, up until the time of the interviews, from BPD carer-specific services. This was reported to be either as a result of lack of knowledge or geographical distance from these services. One participant had only just commenced involvement in a BPD specific support group at the time of the interview,

*It has only been since I have been coming here (support group for carers of someone with BPD) that I’ve been given some written bits and pieces. I’ve only just started coming because I didn’t know that it existed – nobody told me about it.*

The other lived in a country town that did not offer such services.

*When you live in a country town you don’t have access to a lot of things, so I’ve had to resort to reading .......... I haven’t been able to get to a meeting of the BPD Carer Support Group (in Melbourne) .......but I am still hoping to get there.*

Third, both members of this group reported regular use of alcohol or drugs as a way of coping with the stress of living with someone with extreme behaviours. One participant in this group reported that using drugs was a way of life for her and
that it assisted in the suppression of angry and anxious feelings concerning her BPD daughter, as well as calming her down after a stressful episode with her.

\[I\ \text{suppose I sit and smoke a bit of marijuana to help me cope with my daughter ........and to keep me calm ........I don't want to fight with the girl........if I start fighting with her you never know where it will finish – she's capable of killing.}\]

The other participant in this group used anti-depressants for a time but regularly uses alcohol in times of acute stress.

\[Yes\ I\ do\ use\ alcohol\ (to\ make\ myself\ feel\ better)........but\ fortunately\ I haven't\ become\ an\ alcoholic.\ I\ will\ open\ a\ bottle\ of\ wine\ on\ my\ own\ for\ that purpose,\ to\ try\ and\ calm\ down........and\ it\ works.\ If\ he\ (her\ BPD\ partner) sees\ me\ having\ that\ third\ glass\ he\ will\ know\ why\ I\ am\ having\ it\ and\ he\ will quite\ often\ back\ down.\]

Although one member of this group indicated that they used active coping in the relationship with their BPD person, it became clear that this participant uses this strategy very differently when compared with the other groups. This participant reported taking steps to actively set boundaries or use problem-solving to avoid triggers for their BPD person, as did the other groups, but for the reasons of their own self-protection or personal safety, as opposed to the protection and safety of their BPD person.

\[Well\ you\ work\ it\ out\ as\ you\ go.\ Very\ careful\ not\ to\ stress,\ not\ to\ upset,\ and then\ when\ they\ come\ home\ stressed\ to\ calm (them)\ down.\ Be\ sensitive\ and be\ aware\ of\ the\ triggers.\ Even\ an\ offer\ to\ help\ is\ a\ hair\ trigger\ for\ criticism and\ can\ bring\ on\ a\ rage............find\ a\ place\ between\ him\ and\ the\ door\ and don't\ give\ him\ eye contact – even\ that\ seems\ to\ make\ a\ bit\ of\ a\ difference – it's fuel\ to\ the\ fire.\]

While the two participants in the Bound and Powerless group were in different relationships, one a mother and the other a wife, and they lived in different circumstances, one in the country and one in the city, there were similar enough to form a group. One of the most prominent and distinguishing characteristics of this group was their reported feelings of concern about the potential danger that their BPD person is not only to themselves, but also potentially to the participant. This fear was coupled with the participants’ reported feelings of being forced to live with their BPD person due to circumstances that they were unable to change, as indicated by the dominant descriptive at the beginning of the profile of this group.
2.3.1.2 Group 2: The Loving Active Copers.

The second group could be described as the involved, strong, loving, active copers. This group was by far the largest of the groups with seven of the thirteen participants and consisted of six mothers and one partner. As indicated in Table 1, the members of this group when compared with all the other groups were the least likely to vent their emotions or resort to substance use to cope with their BPD person. But what distinguished this group the most from all the other groups was that they were the least likely to behaviourally disengage with their BPD person in order to cope. The general tendency of this group to strive to be continuously loving, understanding and involved with their BPD relative is most fully represented by their accounts of the roles and responsibilities they undertake in their BPD relative’s life and the sacrifices they make in their own lives to achieve it.

All the members of this group were actively involved in the care of their BPD person. This always involved keeping their BPD person safe, often being there as a confidante for their BPD person, and sometimes being involved in the treatment of their BPD person, including meeting with mental health professionals and dispensing their medication. The most distinctive factor of this group was their level of emotional engagement with their BPD person. This was most clearly displayed in the way these participants described their relationship with their BPD person as close and caring, although sometimes difficult.

She loves me and I love her, and I’m there to help her and she’s beautiful…..it’s hard though.

I would say that our relationship is very close….she confides in me and tells me a lot of things..........but she has also been very volatile.............she was never easy.

As mentioned previously, this group’s continuing devoted involvement in the care of their BPD person is demonstrated by them showing the least tendency to behaviourally disengage despite caring for their BPD person for a number of years (see Table 1). However, when this group did speak about periods where they had disengaged from their BPD relative, it was usually used as a temporary means or strategy used for the well-being of their relative and/or self-care for themselves. This is different to Group 1 and 3 who used disengagement as a long-term coping strategy.
……I walk most days that really helps me, having my own (time) in like I play golf so things like that take away the stress especially something like golf cause you get out there and you hit the ball and you don’t even think about anything else you just chat a way to the people your with you know so that’s really good um and you need that I need that to break up that stuff that all happens……

Similarly, this group coped with their BPD person’s periods of extreme, and sometimes, dangerous behaviours by suppressing many, and in some cases all, of their own activities to attend to their BPD person (see Table 1). For some members of this group however, they only suppressed their own activities during periods when their BPD person was displaying acute suicidal behaviours, when their BPD person was experiencing a period of crisis.

It appeared that, in this way, the participants felt that they had done all they could to keep their BPD person safe from harming themselves, as well as managing their own sense of anxiety of the risk and unpredictability of their BPD person’s behaviours. It was not uncommon for the members of this group to talk about limiting their outside home activities to be available for their BPD person. One mother gave up her employment for a number of months, two years running, to be able to be home full-time for her BPD daughter so as to help her get back on track with her treatment. Another mother chose to give up all her outside-the-home activities to be home for her daughter when her daughter was at her most suicidal. This mother even chose to go out to do her grocery shopping before her daughter woke up so that she did not need to leave her daughter home alone.

In the past, to cope with caring for my daughter with BPD I switched off anything that didn’t centre around doing really basic stuff of looking after yourself and your family........not having to do anything for anybody outside that tight-knit circle.......while things were bad we felt that we had to have constantly one of us at home.......I pulled out of everything..........I really wasn’t seeing anyone.

Apart from limiting their activities, as mentioned above, it was also not uncommon to hear that this group of participants ensured that they either always carried a mobile phone or organised it so that they could be contacted while at work so that their BPD person could always reach them when they were at a point of crisis.
I always try to be contactable for her and so carry my mobile phone whenever I go out. My husband would be around if I wasn’t or would certainly be contactable.

I have told her that she can ring me at work whenever she needs – I have spoken to my boss so that she is aware of it and understands how important it is for them to call me so that my daughter can speak to me if she needs me. Anytime and I’ll be there. I am lucky that I have a job that I can do that.

Active coping for this group was mainly focused around support and care for the well-being of their BPD person. This was achieved by hands-on caring, such as attempting to meet their BPD person’s physical needs, particularly by administering their medication, monitoring their treatment and relationship with mental health professionals and hospital staff, and tending to them when they have self-harmed. The members of this group also strove to meet their BPD loved one’s emotional needs by acting in the role of a support person, counsellor and/or advisor. This group of participants were also more likely to be more actively involved in the treatment of their BPD person in a hands-on way.

I take care of her. I administer her medicine because she forgets to take it. I go with her if she wants me to go anywhere to counsellors, case workers, to hospitals. I am the one who goes with her to the hospital and sits with her and helps her through throwing up after taking the charcoal. I am the one who can get her to come around sometimes which is so good.

I am her counsellor 24/7. Just constantly giving her advice, helping her with decision making. We play a huge role as far as her therapists and what have you – keeping in contact with them and stuff like that.

Active coping for this group was also evident in the way the group members expressed their need to problem solve and learn ways of understanding and managing their BPD person’s extreme behaviours. It was not uncommon for the members of this group to report that they were continually problem-solving and looking for ways to become more educated about the disorder and about ways to manage their BPD family member’s extreme behaviours. Although problem-solving and the need for education did not differentiate this group from Groups 1 and 3, the motivation for using these strategies, of keeping their BPD person safe did (see Table 1).

I read and try to become more knowledgeable with the actual illness you know. I don’t know how many books I’ve purchased and read, just trying to become more knowledgeable. A risk management course, carer.
groups......whatever you learn you try......sometimes it works, sometimes it doesn’t.

I’ve done that course with the Mental Illness Fellowship and I’ve tried to learn as much as I can......I try to get lots of information to try and improve the way I communicate with her.

Despite the fact that this group assumed more responsibility than any other group for the well-being of their BPD person, as Table 1 indicates, only a couple of participants indicated that they used any form of substances to cope with their BPD person. In these cases it was usually an anti-depressant and an occasional sleeping tablet in times of extreme crisis. Less than half of the group reported blaming themselves for what was happening to their BPD person. Not one participant indicated that they would blame themselves if their BPD person was to successfully suicide as they felt that they had done everything that they could have done.

I mean I know she can kill herself........and I’m more accepting of death probably than the rest of them (the family)..........and you start preparing yourself...........but she needs to take responsibility for herself and if it does happen I will know in my heart that I try and I can’t do anymore........I have become more accepting that I can’t possibly do any more.

This group were also the most likely to be assuming the responsibilities of the caring not only for their BPD person, but also ensuring that the remaining family members were coping with the BPD person’s destructive behaviours. This sometimes entailed shielding the other members of their family from their BPD family member’s distressing behaviours, and/or managing their family member’s distressed reactions. This fostered expectations that they needed to be strong and could not afford to “drop their own load”, take extended time out or, in some cases, even become ill.

I go home (from the carer group) and whatever I learn I say.......... if I see a behaviour in my husband that’s gunna flip her out or he’s having a really bad day I say “you having a bad day”? And I said well I think you better stay clear of her (our BPD daughter) then, ‘cos she’s having a bad day. I said why don’t you go up and watch telly or something........I said I can handle that. You need to step aside because our daughter’s upset so you go. I never told my husband because I didn’t want him to know and I don’t think he needs to know things that were so bad that um ‘cos he doesn’t handle it too good.

This loving, active, coping group came from a wide variety of backgrounds, culture groups and socio-economic environments. Yet as a group, these women
have often put their lives on hold to care for their BPD relative. In fact many of these women have provided so much of themselves to the relationships with their BPD person and other family members that they have often neglected to look after themselves. This is a defining characteristic of the group, the tendency of these women to strive to give such optimal care to their BPD person that they often neglect their own self care, as indicated in giving many, and in some cases all of their own activities, particularly when their BPD relative is experiencing extreme crisis and displaying parasuicidal behaviours. Their striving to provide the best possible care for their BPD loved one however, may be putting them at risk of potential burnout.

2.3.1.3 Group 3: The Distanced Managers.

Group 3 consisted of three of the thirteen participants in the sample and members of this group could be described as seasoned but distanced managers. As indicated in Table 1, the members of this group when compared with the Active Copers were more likely to vent their emotions and behaviourally disengage to cope with their BPD relative. But what distinguished this group from all the other groups was the length of time that they had lived with their BPD person, and the decision that they all had made to not suppress their own activities to cope with or manage their BPD person’s sometimes extreme behaviours. The general sense of distancing of this group from their BPD person and their use of active coping almost exclusively to protect themselves from the threat of their own sense of physical or emotional well-being, is most fully represented by their accounts of their attempts to set boundaries.

By and large, the members of this group had lived with their BPD person’s behaviours for the longest length of time when compared with the other groups, with the shortest duration in this group being 15 years, and with one member, now 52 years-old, growing up as the child of a mother with BPD and continuing to be involved with her to some extent.

She (BPD daughter) is forty-four years-old now and she has been presenting with BPD behaviours since puberty – it (the BPD behaviours) has been becoming far more dominant as time went on.

I've been living with it all my life.............even as a child growing up I can remember her rages and her hurting herself........she would lie on the floor
and throw tantrums and pull out her hair, and that because of something that I did. But I didn’t know what I did. I never knew what I’d done.

All the members of this group reported having been fully engaged with their BPD person at one time, but found the need to “step back” from the relationship for their own sense of well-being.

She would call me seven or eight times a day………she was totally controlling……..would be totally angry if I didn’t see her as often as possible……..be available for her as often as possible.........there’s no middle of the road – it’s all or nothing..........so it’s taken me ‘til the last two years to actually dissociate (from her).......to have a life of my own.

I used to go and stay with her during the week at her house and then come home to my husband for the weekends........this went on for a year...........I said ‘look I can’t take it anymore..........tomorrow I am driving her back to her house and I’m going to leave her there and she’s all yours (outreach mental health workers).

The need to step back was reported to be for reasons such as violent or aggressive behaviour on the part of their BPD person, and/or the inability of the BPD person to accept the participant’s boundaries and limits.

(Because she had previously violently attacked the participant ) I wouldn’t let her into the house, and all I, I did was I had to ring the police. I got my son to come over, um, so she didn’t actually see me at all. But the police came and they took her back to the place.

I haven’t had her stay here for about two or three years, because her behaviour’s so bad......... I can’t get through to her really…it’s a block. Because she’s very wilful, and she won’t let me - she’s been like this most of her life- she won’t let me set my own dignified limits, so I, I can’t do any kind of a deal with her.......... it’s a dilemma because you don’t ever want to put those...you don’t want to have to lay that on the line with your family, but there’s been no choice.

The participants in this group described their relationship with their BPD person as better with distance, and this distance was either physical such as geographical location, or relational, as in choosing not to relate to the person for a period of time. The latter was usually for the reason of setting boundaries, something this group spoke a lot about.

My relationship with my (BPD) mother is definitely not close......there’s no connection..........it’s very stressful..........whenever it gets too much for me, no matter what happens, even if she puts herself in hospital, I have to separate. I have to be physically totally away from her.......I can’t be in her energy at all.......her energy destroys me.........no contact whatsoever.
I don’t live with my (BPD) daughter. I couldn’t cope………….it’s much better now that she lives away in a country town……….I don’t see much of her now. When she lived in Melbourne in the later years it was like having this pull there…………this little black thing lodged in me.

Active coping for this group was used more often to preserve their own sense of well-being, which is different to the Active, Loving Copers who engaged in active coping more often to ensure the well-being of their BPD person and their families (see Table 1). Distanced managers actively coped by setting boundaries and limits for their BPD relative to ensure that they themselves were able to assume a life with some independence and “normal activities”, at least a life which was not entirely overshadowed by their BPD person. The Distanced Managers’ effort to live a “somewhat” independent life with normal activities was further demonstrated in the way this group used behavioural disengagement for the purpose of setting boundaries with their BPD person and in the way this group did not suppress other normal activities for their BPD person (see Table 1).

I won’t tolerate it anymore and if it’s (anger and rage) sustained after a couple of hours I say, ‘I was hoping tomorrow would be the day for you to go home, but I want you to go now’…………I’ve learned to do that with a little bit of concern……..but you can’t stop your own life.

In fact, members of this group frankly talked about how they had learned to live a life despite their BPD person’s sometimes constant and unrealistic demands of them by setting stringent boundaries. This not only ensured that the BPD person respected them, but that they themselves also maintained the control and protected their own life, something they spoke about as being very difficult to do. After being violently attacked by her BPD daughter one mother talked about the difficulty of taking out a restraining order on her own daughter,

I didn’t really want to be doing what I was doing, but we had to do it for our safety…………when she has just turned up at our door and we have had to send her back home she passed the comment ‘it’s terrible when your parents don’t love you’. And you know making us feel absolutely terrible.

There’s no boundaries as far as she’s concerned……… it’s the only time I feel alive, when I don’t have contact with her, but my conscience gets the better of me.

Although there was some variability within the Distanced Manager group in being able to vent their emotions, two of the three participants in this group indicated that they felt comfortable about venting their negative emotions as did the
member of the final group (see Table 1). This proportion was still higher than found in the Bound and Powerless, and the Loving, Active Coper groups. The venting of emotions in this group was mostly in the context of allowing themselves to feel and express sadness about things that were happening, or had occurred in their lives and was usually done when they were on their own.

\[\text{I had quite a few tearful lots} \ldots \ldots \text{sometimes I just let it} \ldots \ldots \text{when it sort of hit me at times} \ldots \ldots \text{try and get it our of my system, I didn’t fight it} \ldots \ldots \text{only there was possibly nobody around} \ldots \ldots \text{my husband finds it hard to cope with those kind of things (emotions).}\]

One participant also expressed anger quite openly at times and acknowledged that occasionally it spilled out towards others.

\[\text{But one of the things that I was doing, and it took me a long time to realise it, was when I’d had a bad session with her (BPD daughter) or when over anxious, I’d get angry with him (partner)} \ldots \ldots \text{he didn’t ever deal with it well.}\]

The one member of the Distanced Manager group who did not vent her emotions thought that this was disadvantageous to her well-being.

\[\text{I probably don’t (express my negative emotions), but that’s definitely to my disadvantage……. I wouldn’t like to be exposed, because I, it’s again that risk of someone not liking me, or…….the unacceptability of anything negative, and……. No, I always give that, if anybody, you know, give that persona of being the most confident, together, having everything person…….it takes a lot of energy.}\]

As Table 1 highlights, each member of this group indicated that they were taking, or had taken anti-depressants at some time in their lives to cope with their BPD person, but did not indicate any other form of substance use.

\[\text{But, um, anyway, he, um, she…um, he put me onto the anti-depressants} \ldots \ldots \text{I went on to a high dose, but it had helped me, it helped me tremendously with things that I’ve had to put up, with my (BPD) daughter} \ldots \ldots \text{it definitely helped me cope} \ldots \ldots \text{I was very happy that I had tablets.}\]

\[\text{I take anti-depressants, which could be genetic. Um, and I’ve only ever taken, the last few years, and I, I wish I’d sort of…the last, in, in my, you know, thirty years ago there wasn’t the choices now……. I’ve never abused, I’ve never abused drugs} \ldots \ldots \ldots \text{but when I’m really bad I would, you know, take a valium or a sleeping tablet whatever.}\]

Only one member of this group indicated that they blame themselves for what was happening to their BPD person (See Table 1). Yet this person was still
placing the responsibility of the BPD person’s difficulties with the reality that this person had a mental illness as did the other two members of this group.

_It’s very hard not to (blame yourself), yes over the years and you have to fight that one. And of course you make mistakes, as the years have gone on you make big ones……..when I can see it as an illness I can do better._

_It took me ’til I was about thirty to realise that there’s something wrong with her (BPD mother)............before I realised that she had a mental illness........before that, I actually full-on believed that it was all my fault._

The participants in the Distanced Managers group had by far, been living with their BPD relative the longest. Although fully engaged with their BPD relative at one time, the participants’ decision to take permanently a less active role in their relationship with their BPD person for their own sense of well-being is what set this group apart from the others. This decision was usually made after years of attempting to set boundaries with their BPD person to no avail. Sometimes this decision was initially forced upon them and they learned to live with it, as with the mother who was forced to take out an intervention order against her violent daughter, and at other times it was a decision the participant made in consultation with a professional person in their lives. But in all cases it was for the purpose of self-preservation, whether it be physical or emotional.

### 2.3.1.4 Group 4: In Flux: Close then Distant.

The final distinct profile identified was represented by only one person, and was the only sibling in the study. As indicated in Table 1 the member of this group, when compared with all the other groups, had difficulty accepting her BPD sibling’s behaviour as a mental illness and was not able to positively reframe her sibling’s extreme behaviours into something that she could understand.

Furthermore, this person did not seek emotional support to help her cope with her sibling’s behaviours. Although this participant demonstrated some similarities to the members of the distanced managers group, particularly in her tendency to distance herself from her BPD sibling to cope, this participant’s distancing was not a way of life as with the Distanced Managers. This participant also had periods of time when she was fully engaged with her BPD sibling and thus was more similar to the Loving, Active Coping group. A defining characteristic of this participant was her tendency to oscillate between being interested and close, and then to distance in her
relationship with her sibling. Her tendency to oscillate was fully represented by her accounts of her relationship with her sister and then her decision to step back.

Similar to many of the participants in the Active, Loving, Coping group this participant described her relationship with her sibling as close.

_We’re really close now again…….which is really nice…….and we used to be really close (as children growing up)…….we’ve always probably understood each other pretty well._

Also similar to the Active, Loving Copers, and the Distanced Managers at one time, this participant recalled a period when she was very engaged with her sibling and would run to her sibling’s side whenever she expressed a need, whether that need be physical such as requiring money for groceries, or emotional.

_There was a time when I wasn’t spending time with my husband and daughter because I was running to her every minute…….she was so needy you know…….just everything seemed to fade away, pale into insignificance._

Like the Distanced Managers, it was not until the participant’s own level of distress about what was happening to her sister began to affect her ability to function at work, and her partner and child began to communicate distress at her frequent absence when she went off to attend to her sister, that this participant made the decision to “back-off”.

_My husband, he tried really hard……..he was pretty patient and tolerant I reckon and very supportive of me……..but still you know he said ‘where are we going to end up’……..so that’s when I had to pull back a bit from her…… ’cause I wasn’t functioning at work either, I’d be teary at work……I would have become very ill if I hadn’t pulled back_

However, unlike the Distanced Managers, this participant did not behaviourally disengage from her BPD sibling permanently but continued to engage with her sibling on a regular basis, although not as often. Another factor that differentiated this participant from the Distanced Managers was the level that this participant continued to be engaged with her sibling emotionally, despite reporting many times that her sibling’s erratic behaviour has caused her grief.

_She’s interfered in some big times….she wrecked my hen’s night….the night of my wedding she nicked off and I didn’t see her until the next morning about 10 o’clock…..I didn’t sleep at all the night before my wedding , I was a mess ………when I look at her now I don’t think of those things at all…..and I would never want her to apologise for that behaviour because_
she wouldn’t even know that she did something wrong…..I’m just relieved to have my sister back.

The most noticeable area of difference highlighted in Table 1 for this participant as compared to the other groups is that, although she has learnt to accept some of her sister’s challenging behaviours, such as her need to self-harm, she has difficulty accepting that her sister’s behaviours are a result of a mental illness. This person described it as a difficulty separating the illness from the person. Although the other groups also reported difficulty in gauging what behaviours could be attributed to the illness or simply bad behaviour on the part of their BPD person, it was evident that this participant was ambivalent about accepting that her sister’s behaviours were the result of a mental illness at all.

I have never learned to live with it, I have accepted some of the behaviours…… yeah I rejected that a bit (being able to separate the illness from the person)……..I still don’t separate it well……..it’s confusing when you’ve been manipulated and you can’t tell what is real.

Yet on the other hand, the participant talked about the need to accept her sibling’s behaviours.

I reckon you have to accept it…….. you can’t, you can’t change it……..although it’s frustrating and upsetting and all of those things, you’re only tormenting yourself if you can’t accept it.

Another factor that sets this person apart from the other groups is that she does not actively seek emotional support for herself. Sometimes this person receives emotional support from her partner, but emotional support is not intentionally sought or asked for.

I didn’t talk to people about it (to cope)……..I found that I couldn’t talk about it...........by not talking about it was like finding some normality........because all my relationships we had within the family were all about her........I found it almost refreshing I guess, not to say anything about it.

This does not mean, however that this participant does not express her sadness and feelings of feeling overwhelmed by the state of affairs of her BPD sibling. In fact, as shown in Table 1, this participant reports the ability to vent her emotions, often in the need to cry and “just let it all out sometimes”.

I always cry…..I always let it all out......you feel heaps better......I probably just cry to my husband, that’s probably what I do.
Similar to the Distanced Managers, this participant expressed a need to be able to keep the part of her life that includes her sister who has BPD very separate from the other parts of their life to be able to cope and experience some “normality”.

*I needed to remember that there was a world that existed outside of my (BPD) sister........I like to get together with friends but not talk about it at all, talk about other stuff........I go for a walk with a friend but I don’t talk about it.*

Like the Distanced Managers and the Bound and Powerless groups, but unlike the Loving, Active Copers, this participant reported a need to take anti-depressants because the state of her BPD sister affected her level of distress to the point where she felt that she was unable to control her negative emotions and her ability to function normally in life. This was especially the case in her ability to work.

*I’ve had to, sort of, go on antidepressants myself to cope........and I’ll have some wine.*

All in all, the participant in the In Flux group did not fit neatly into either the Active, Loving Copers group or the Distanced Managers group but displayed characteristics of both. This was particularly the case in her tendency to oscillate between being fully engaged and present in the relationship with her BPD sibling as in the Active, Loving Copers group, and stepping back for periods of time to regain some sense of normality and tend to the other relationships in her life as with the Distanced Managers. Although it was clear that this participant often coped by keeping the part of her life that includes her BPD sibling separate from the other parts of her life, unlike the Distanced Managers group, she continued to feel connected with her BPD sibling emotionally.

### 2.3.2 Trauma

When analyzing the four identified groups for trauma indicators (see Table 2), the groups did not differ meaningfully in the classic trauma symptoms such as indicators of re-experiencing, avoidance and hyperarousal, with all reporting the majority of symptoms. However, upon closer inspection variation was evident between participants in both extremity of trauma and factors contributing to their experience of trauma.
Table 2
Percentage of Participants in Groups Experiencing Trauma Symptoms

<table>
<thead>
<tr>
<th></th>
<th>Bound and Powerless (n=2)</th>
<th>Loving, Active Copers (n=7)</th>
<th>Distanced Managers (n=3)</th>
<th>In Flux (n=1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being on guard watchful all the time</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Feeling of being on edge</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Difficulty concentrating</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Difficulty falling or staying asleep</td>
<td>100%</td>
<td>100%</td>
<td>67%</td>
<td>100%</td>
</tr>
<tr>
<td>Recurring images, thoughts or dreams</td>
<td>50%</td>
<td>57%</td>
<td>67%</td>
<td>100%</td>
</tr>
</tbody>
</table>

2.3.2.1 Group 1: The Bound and Powerless

Both members of the Bound and Powerless group reported experiencing trauma symptoms as a direct result of the behaviour of their BPD family member. While all groups experienced trauma symptoms it was only when specific contexts were considered that it became clear that the events that initially produced the trauma symptoms in the Bound and Powerless group were similar to those for the Distanced Managers, in that they were events perpetrated against the participants.

As with the Distanced Managers, the two members of the Bound and Powerless group were more inclined to report experiencing symptoms of trauma in relation to the fear of, or actual physical harm to themselves.

I only weighed 29.9 kg and I can remember her pushing me over in the passage at home and then kicking me and I just looked up and said “what are you doing” and she stopped........sometimes I tread on eggshells........I don’t want to fight with the girl. If I start fighting you never know where it would finish, she’s capable of killing........she has those (homicidal) thoughts..............the smallest (things) spark her off.

There have been times when I have felt very intimidated because he has said, on at least eight occasions, ‘I will shoot you’, and he insisted that guns were kept in the bedroom........
Unlike the other groups, one member of this group had actually been diagnosed with Post Traumatic Stress Disorder. This participant reported that although her husband had threatened her and been violent over many years, the most severe and ongoing trauma that she experienced was when her husband openly flaunted his lover in the family home in the presence of his wife and children.

_The worst experience, and the biggest shock (which) set me off into post traumatic stress was when we lived in England a year. He used to invite this nurse to our home for meals sometimes, and then we came back (to Australia) and she arrived here a couple of weeks after we came back, and he wanted her to stay at our house........he made (it) very obvious to me and the kids......that she was the focus of his attention, and of course the kids hated it, and I hated it........The sadism was so enormous because he could see we were all suffering......... I did not cope at all, and I could not cope with my children’s pain. And that’s the worst guilt for me ........when that is triggered, which continued to be triggered by flirting, by ridiculous attention to people (women).... the worst thing, is (the memory of) my children’s faces of shock and horror, and looking at me ‘mum, do something’._

This member of the group also spoke about the trauma experienced by her children as a result of her BPD husband’s violent and unpredictable behaviours toward them.

_I believe that both my kids have suffered post traumatic stress, particularly my daughter. ........she was very sick with severe anxiety, PTS, and depression, and she was on second level tablets for depression, and they weren’t always working. And that was for years..........My daughter told me just a few years ago that he had belted my son when I would go out for monthly meetings.... They slept in the same room, he didn’t belt her, but she thought he was going to kill her brother, and she thought she was going to be killed, and she thinks it happened several times._

The type of trauma symptoms experienced by the members of this group, were not that different to the symptoms experienced by other groups. Similar to the Distanced Managers group, the members of the Bound and Powerless group reported themes of fear and anxiety in relation to their BPD family member’s unpredictable and sometimes violent behaviour toward them and other family members. However it would appear that the trauma symptoms experienced in this group were more severe than in the Distanced Managers group.

_........... you are just coasting along, you are actually relaxed, for a second, ‘isn’t this nice, feeling relaxed’, and then suddenly you’ve got to gear up all your strength, emotional strength and strategies and put it all into action again. And you think, ‘oh, I should never have relaxed’. You get caught out, because it is so often. You can’t relax very much. I’m always_
tense...... And the anxiety is enormous, and there is anticipation anxiety because you are always planning ahead...... so much restraint.

I do behave like a hostage, you are just always watching, you are always wary, you are always ready to change with the mood or whatever...... you can’t even sleep properly without being ready to be quick to spring...... hyper vigilant, 24/7.

One Bound and Powerless Group member reported the cost of experiencing chronic trauma symptoms such as anxiety and hypervigilance over a period of decades was a succession of painful and sometimes debilitating physical illnesses.

There’s all the psychosomatic illnesses, the spastic colon, the stomach ulcer, the shingles..........

Overall, however, trauma symptoms seemed more severe for this group with their fear for themselves or other family members being seriously harmed or killed at the hands of their BPD relative being frequently present and real.

2.3.2.2 Group 2: The Loving, Active Copers.

All members of the Loving, Active Copers group reported experiencing at least some of the trauma symptoms, some of the time. The periods during which the Loving, Active Copers reported experiencing the symptoms most acutely were when their BPD person was in a period of crisis, which was usually when their self-harming was at its most severe and their behaviour was at its most unpredictable. It was during these periods that the members of this group experienced high levels of being on guard and watchful, had difficulty concentrating, and difficulty sleeping. Moreover all members of this group reported feeling a level of chronic anxiety, namely hypervigilance or being on guard, at other times even when their BPD person’s behaviours and distress had returned to a more normal level, and even after a long period of relative wellness.

What distinguished this group from all other groups were the reasons they gave for their experiences of trauma. Unlike the Bound and Powerless group, the Loving, Active Copers reported that their experience of trauma was more directly related to the emotional state of their BPD person. For example, themes of trauma emerged in situations when the participants feared for their BPD person’s life, the first time they had witnessed the consequences of their BPD person’s self-harm, or when they were most concerned for their BPD person’s dignity and well-being.
......she had cut herself everywhere.........and she was being very abusive up at the hospital....she was abusive and telling me to go away, and, “I don’t want you here,” and, “leave me alone,”........and that was the very first time that I have seen...the reality hit me that, you know, what she’d done: she was cut..........that was probably one of the very first times where I had to go to the hospital....

The worst experience we experienced is when she self-harmed to a horrific extreme and then disappeared........not knowing if we’re gonna find her or not, and if we find her, is she alive or not........and it has happened more than once......

Similar to the Bound and Powerless group, only one mother in this group reported that apart from her son’s flagrant self-harm, her son’s anger outbursts and risky and dangerous behaviour is what frightens her the most.

......I am in constant fear of him dying by either his own hand or misadventure........When he goes off his whole body is tensed up, he’s just about jumping out of his skin with rage. I mean he even went through a stage where he would almost froth at the mouth and look like a mad animal..... He really gets so angry it’s really scary and if there’s a lot of alcohol involved it’s even scarier.........

While the trauma symptoms experienced by the Loving, Active Copers on the surface seem not unlike the symptoms experienced by the Bound and Powerless group, they were more related to this worry that they have for their BPD person’s physical and psychological safety rather than their own safety.

......She doesn’t self harm in front of us but you see it seeping through her clothes.......It’s literally beyond words I can’t begin to tell you what it’s like to have to sop up your own child’s blood off the floor, on carpets, and in bathrooms........

I’m always on my guard when there’s alcohol around, that maybe she’s gunna go over the edge ..........I do, I guess, I’m on my guard all the time.

......There would be no sleep....constantly being on edge for me....... you’re always waiting for the phone call.....So I would do things quickly, rushedly, not think about stuff, not give myself any time, um, because I just had to be available for her.

......even when things are pretty kind of like steady at the moment you’re still always worried about the next time, about the rest......

The impact of the chronic experienced trauma on this group ranged from being constantly vigilant to what may happen to the physical inability to function in everyday life.
Just get your confidence back in her, and then she does something that sets you back again.........you become too afraid to expect that she might become well.......... 

......I just can’t function you know, I’m just wiped out. It really affects my stress levels and I find it hard to breath sometimes. Through anxiety I get chest pain, yeah I get very stressed from it........ it’s extreme and stressful and you’re tired.........

Overall, the trauma symptoms experienced by this group were related to their fear of their BPD loved one being seriously harmed or killed by their own hands, or by accident as a result of risky behaviours. This group also reported residual trauma symptoms such as hyperarousal in times when their BPD loved one was not displaying these behaviours.

2.3.2.3 Group 3: The Distanced Managers.

As with the Bound and Powerless group and Loving, Active Coping group, all the Distanced Managers reported having experienced periods when they felt like they were on guard and watchful all the time, feeling on edge, and having some difficulty concentrating. Two of the three members of this group also experienced difficulty getting to or staying asleep as a direct result of their BPD person’s behaviours, as well as experiencing recurring thoughts.

Similar to the Bound and Powerless group, two of the three Distanced Managers were more inclined to report trauma related to events that involved either physical violence or the potential for physical violence by their BPD person toward them. However, the Distanced Managers were more inclined to report events that took place in the past, whereas the Bound and Powerless members’ were more inclined to report events that were ongoing and still occurring at the time of the interview.

The worst and most frightening experience I’ve had with her was the night she attacked me.........yes that definitely was........I wouldn’t like to meet that again...........it really did frighten me.........

I’ve had cause to be concerned for my safety when she’s been around.......I frequently get a dose of verbal abuse which is very threatening and confusing.......she is verbally violent ........and she has attacked me, but only twice in all those years.........

The remaining group member’s trauma was more related to her BPD mother’s relentless, narcissistic blaming of the group member for her mother’s own tantrums
and unhappiness all through her life. These experiences of blaming would often include her BPD mother telling her graphic stories about what was going to happen to her as a result of some her daughter’s “supposedly” bad behaviour. To add to the confusion for this group member, her father could not be counted on for support as he oscillated between being quietly supportive of the group member and loyal to her BPD mother at other times in order to “keep the peace”.

_I was not concerned about my personal safety with her as she never laid a hand on me, she got my dad to belt me up......You wouldn’t know what triggered her......It was pretty horrific watching your mother lie on the floor, throw tantrums and pull out her hair ......I have not slept properly since I was 8 years old directly because of what my mother told me......My father would have to lie down next to me and I would fall asleep as I listened to his heartbeat.......Even now I have nightmares about it._

The trauma symptoms experienced by the Distanced Managers, while similar to the Bound and Powerless group, in that they related more to a fear and concern for their own physical and psychological safety, did not appear to be as severe for two members of this group. Possibly this is because these two members had more control over their contact with their BPD person as they did not live with them. Both women indicated a need for maintaining this physical distance from their daughters. For example, after her daughter violently attacked her, one mother reported:

_......I got to the stage of being scared of her ...... I always try to make sure that I if I’m sitting down and I’m with her, that I can get out in a hurry...... (since that time there have been times when) I have been worried that she might do a lolly, and break the window down, or something........She doesn’t have keys but she has got in the house during the night without keys before ......I make sure that I am not alone with her now if I can._

After a number of years of being verbally abused another mother reported:

_........I don’t quite trust her......When she picks up knives and things I get a bit nervous........there’s definitely apprehension........I think it has affected my mental health a bit, I get a bit down and feel a bit defeated........It has also affected my relationships with my other children as she (BPD daughter) has lodged distortion campaigns against me over the years......I have learnt to say ‘I want you to go (home) now’........_

Although the daughter with the BPD mother was never physically harmed by her mother, and despite the fact that she has not lived with her mother for over
30 years, the rejection and confusion experienced by the daughter her entire life has resulted in the daughter reporting the most severe trauma symptoms of this group,

\[ \text{......I've never relaxed in her (mother's) presence......it is stressful all the time......I can never do anything right ......and you never know when she’s going to pounce......There’s no sense of restraint in what she says to me and she seems to have no idea of the impact of what she says has on me......I have suffered severe depression ever since I can remember, even as a child.......I haven’t really slept since I was 8 years old.......I have terrible nightmares about things she has said to me.......the only way I can survive is to dissociate from her.......I will not answer the phone or open the door in case it’s her.........} \]

Overall, trauma symptoms for this group, although similar to the Bound and Powerless group for two of the members in that they had feared for themselves or other family members being seriously harmed at the hands of their BPD relative, did not appear to be as severe and had been more extreme in the past. For one member of this group however, the symptoms had a huge ongoing affect on her ability to function in her everyday life. This was despite her mother not having directly physically harmed her, and despite this member having very little ongoing contact with her BPD mother currently.

**2.3.2.4 Group 4: In Flux: Close then Distant.**

The In Flux participant reported having experienced all five trauma symptoms at some time in her relationship with her sister (see Table 2). The In Flux participant is most similar to the Loving, Active Copers in that she reports experiencing trauma in times when she felt most concerned for her sister’s physical and emotional well-being. This occurred mainly in the period when she was both living with her sister, a time when she was the one who frequently took her to the hospital because her sister had self-harmed, and later at times when her sister was displaying her most distressed and dangerous behaviours. The In Flux participant reported being on guard, watchful, and on-edge with her sister as an ongoing experience during these times her sister was at her worst.

Even at the time of the interview, when her BPD sister’s behaviours had somewhat stabilised, the In Flux participant still reported feelings of being on edge, and being on guard and watchful a great deal of the time. These feelings were
described as a chronic anxiety about the possibility that it would not take much to trigger a relapse.

When I started working at the college and I lived with her, I was in and out of the Emergency........A lot of it’s a blur, because it was so traumatic.............

I’m just relieved to have her back (laughs)........that’s how I feel at the moment........But then, I mean, it could change........so you just wait.

More similar to the Loving, Active Copers than the other two groups, the In Flux participant reported experiencing symptoms of trauma mainly in the context of concern for her BPD sister’s physical and psychological well-being. The experiences that the In Flux participant reported to be the most trauma-provoking included the first time she witnessed her BPD sister self-harm by cutting, as she was convinced that her sister was attempting to kill herself.

(One of the worst experiences for me) was when she was at my house ........and it was probably the first time I had seen her do it...........We had to bash the bathroom door in........ She’s just on the floor, and there’s just blood all over the bathroom..........I honestly thought that she was trying to kill herself..........I now know that that wasn’t the case but I didn’t know that at the time........

She also emphasized the constant fear for her sister’s safety, particularly at times when her sister would let it be known that she was potentially going to harm herself and then become un-contactable. This fear later generalized to times where no threats were made, but when she was unable to contact her sister when prior arrangements had been made and broken, and her BPD sister did not answer her door or phone.

You’d make an arrangement (with her and) she wouldn’t show up....she wouldn’t contact you........You’d try and ring her and her phone would be switched off........or you’d go round there, she wouldn’t answer the door........then you’re starting to panic, thinking, “Oh, what’s (she done), she’s OD’d.....she’s in there, she’s on the floor..... I’ve got to get her. I’ve got to get (to her).....”

The In Flux participant also reported instances where her sense of powerlessness was distressing and traumatic for her. One such time occurred when she had to watch her BPD sister being taken by the Crisis Assessment Team to a secure psychiatric unit involuntarily as they were concerned about the risk she was to herself.
They were putting her into the psych unit involuntary……..that was one of the worst things I’ve seen………

The participant also reported feeling powerless to help her sister alleviate the intense psychological pain she was experiencing which led her to harm herself for some relief.

……….So hard to understand how someone can be in so much pain that they actually hurt themselves…… I still don’t get it really…. It doesn’t make sense…… I got to the point one night where I just didn’t know what to do. I remember picking up a knife one night, and saying, “Ok, if you’re going to cut yourself, here’s the knife just do it and I’ll take you to the hospital.

She spoke of her sense of powerlessness arising from her felt inability to help her sister elevate her low sense of self-worth which the participant believed may be paramount to her BPD sister’s parasuicidal behaviours and her compromising relationships with undesirable others.

I would think the most challenging thing for me has been trying to get her to accept she’s worthwhile…… that’s still a massive challenge…… She still, I don’t think, accepts that she’s a valuable person……. yeah that I reckon that….is the biggest thing for me.

The In Flux participant reported that her experience of trauma in her relationship with her BPD sister has left its mark on her. It has left her feeling like she needs to walk on eggshells, particularly in the things she says and discusses in the company of her sister so that she is not responsible for bringing about a relapse in her sister.

There’s days where you can sense that you have to be really careful……. I still think about what I’d say to her a lot more than I do with anyone else…………

There was also a continuous struggle for this participant between combating her “terrible fear” that something could happen to her sister if she was not available for her when she needed her, and her need for time and space for herself and her own family.

We dread switching on the mobile……..because sometimes we’d turn it off overnight (to get some rest)…….Some mornings, like, you’d get, you’d get up, and you’d think, “Oh my god turn the mobile on”……. One morning there was twenty-four or twenty-five messages, you know?……. (We would worry) if she really did do something to herself (after hearing the messages she left threatening to self-harm or kill herself)…….
On the whole, the trauma symptoms experienced by this participant was related to their fear of their BPD loved one being seriously harmed or killed by their own hands, as did the members of the Loving Active Copers. Furthermore this participant also reported residual trauma symptoms such as hyperarousal in times when her BPD loved one was not displaying these behaviours but was displaying behaviour that had been signs of risk in the past, such as not being contactable

Overall, all interviewees reported experiencing the majority of trauma symptoms, particularly in acute times of stress. In general, for the Bound and Powerless, and Distanced Managers the contributing factor to their symptoms was fear of harm either to themselves or other family members at the hands of their BPD relative. For the Loving, Active Copers and the In-Flux group member, the main contributing factor was their fear of harm for their BPD relative. Members across the groups reported ongoing trauma symptoms even after the crises had passed. This was typically reported to be either feelings of being on edge, or/and being on guard for telling signs that something was amiss with their BPD relative. For one interviewee, the only adult child of someone with BPD in the sample, the trauma symptoms appeared to be chronically more severe than the remainder of the sample, despite now being in her fifties and having very little contact with her mother.

2.3.3 Turning Points and Positive Outcomes

Upon analysing the four groups for both identified turning points in their relationship with their BPD relative, and positive outcomes as the result of being in relationship with someone with BPD, the results were varied both within and between the groups. Initially a turning-point was defined as a “defining moment” or a “decision-point” at which time the participant chose either to do things differently in their relationship with their BPD person or think about things differently. However, it became evident that for some participants this turning-point evolved over time rather then occurring at some definite point.

2.3.3.1 Turning Points.

One member of the Bound and Powerless group, six of the seven Loving, Active Copers, all of the Distanced Managers and the In-Flux group member identified a turning-point in their relationship with their BPD person. The themes
for the turning-point varied and ranged from accepting that their BPD relative had a mental illness, and may always have a mental illness, to coming close to breaking-point for them to realise that they could not live the way they had any longer. A couple of participants talked about coming to the realisation that self harm does not necessarily mean death but was a way of coping for their BPD relative. This realisation helped them to manage their own anxieties and fears, and for one participant this meant a decision not to rush home in a panic each time her BPD partner rang her at work to inform her that she had self-harmed.

...in the beginning it was like obviously I was worried ... one cut, or the wrong cut, or one extra tablet, and that would be the end of it......I’ve noticed through the support group, the more those people have learnt and understood, and had experience by other people, the easier it is for them. And I mean, it just means you are not going through that same roller coaster. In the sense of the emotion. You’re just dealing with it. You have an understanding of what you need to do, to survive basically, so that you don’t go into a bit of a spiral case yourself......as time went on, when I got the call I just dealt with it in the sense of well, she’s done it. I didn’t pack my bags. I just took my time, and by the time I got to the hospital, or by the time you go home, you would just pace yourself, you just put things more into perspective instead of panicking.

While this Loving, Active partner in the sample spoke about her concern that the relationship was showing signs of developing a carer/caree relationship rather than a partner relationship, a few parents talked about accepting the possibility that their child may never be as independent as a parent might envision for their children to be once they had grown up. These participants discovered a need to relearn to live their lives with a BPD adult partner/child.

......you raise your kids. You hope they’re going to be independent and they go off and have their own lives and hopefully you keep a strong connection as family, that is important to me. But with my (BPD) son I gunna have to have a lot more to do with him than I’d wanted to, if you get my drift. I don’t mean that nasty, but he’s gunna need that constant support. It’s like having a long term child that never grows up in some respects ......I’ve accepted it now that life will be different but it took me a long time.....

The theme of accepting that their BPD person was suffering from a mental illness was something the majority of participants raised. In fact one of the two Bound and Powerless members, five of the seven Loving, Active Copers, two of the three Distanced Managers, and the In-Flux member reported that the discovery that their relative’s behaviour and emotional difficulties were able to be categorized and
labelling as a mental illness was illuminating and the beginning of a turning-point for them. One mother talked about how thinking about her daughter’s behaviours as a mental illness helped her to think differently about her daughter and in turn, assisted her in her caring role.

"..It’s almost like a relief to know that (that her daughter’s behaviours could be defined as a mental illness) because I think that you take on a lot of the blame as a parent for your child and when you sort of see that it’s that, well you can put it into that basket and say well hang on, it wasn’t all me it wasn’t all my fault. Because especially with a borderline they will be telling you it’s all your fault all the time. Very much my fault or your family’s fault."

For those participants who did not state that the discovery that their relative had a mental illness was a turning point, they did, however, refer to the BPD diagnosis as a plausible explanation for their relative’s extreme behaviours. All participants, however, spoke about continuing difficulties in being able to differentiate between just bad behaviour on their BPD relative’s part and the mental illness.

Not all participants considered learning that their BPD person had a mental illness as a positive turning point in their lives. Two members of the Active, Loving Copers did not agree that the labelling of their partner/daughter’s behaviour as BPD had been helpful for them personally, but said that in the longer term it had been helpful in securing treatment and services.

"...I honestly don’t think that by giving it a name it made that much difference to me, other than what we had to tell other people. So if someone was asking me about my partner, I guess it was easy to say that she had an illness of borderline. And did that help me? I don’t think it did. I don’t think a name helped it......having a diagnosis of BPD has helped my BPD partner get a case worker and get into Spectrum."

These group members spoke about how unwelcome the news was to them, particularly given the negative stigma a BPD diagnosis was given in the mental health services.

"......our counselor kinda like thought ‘Oh I think she is borderline’ and I felt so sorry for her. She rang me one day and I think she was going to put it to me and I kinda, like, bit her throat before she even mentioned it...... I don’t even think that it was that I felt that she was labelling it..maybe I was a bit in denial. I didn’t want it to be that. Because I had read so may negative things about it."
A number of participants reported getting to the point where they were forced to make the decision to balance their lives by looking after themselves and attending to the other relationships in their lives.

...,It was impacting) especially my relationship with my husband..... I had to go you know, whenever she called me, I had to...... just drop everything, give them (husband and child) a kiss and run out the door..... that wore really thin ....They needed me too...... I wasn’t spending time with them, and I was, you know, going, running over to her every minute.......And I wasn’t functioning at work, either.....like, I’d be teary at work.... I was depressed and on anti-depressants.... That’s when I got to the point where I had to sort of just pull back a bit from her....... because it was just too much........ I just couldn’t, yeah, couldn’t function.......just (needed to) get things in perspective again......in balance...

2.3.3.2 Positive Outcomes.

One of the Bound and Powerless group, six of the seven Loving, Active Copers, two of the three Distanced Managers, and the In-Flux group member were able to identify that something positive had come about as a result of being in relationship with their BPD person. The major themes of perceived positive outcomes for these participants included a better understanding of mental illness, an appreciation of the toll that mental illness has on individuals and their families, the reality or possibility that their knowledge and experience could be of help to someone else in a similar situation, more realistic expectations of their BPD relative given their condition, a greater appreciation of their BPD person, and a closer and deeper relationship with their BPD person.

......It has been positive in that it’s opened all of our eyes...to mental health problems....a better...understanding, appreciation, concern for anybody, really, with any kind of disability...And I think we’ve met through this, um, a number of fantastic people. I think it’s, it’s made us better people because of it.......I don’t think we ever realised, um, how severe and how totally consuming any, any family with problems....

I guess I’ve got (a) more positive thingy. I guess (what) has come out of it is an understanding of mental illness...That, perhaps, you know....maybe in the future, I can help someone else who is going through a similar situation.

I think there is a lot of positives.....There’s a huge sort of appreciation of how (she is) when she’s well and how precious she is and all that stuff and perhaps I might not have thought of, or might not have looked at all the good points that she has as well as I do now .....There’s been a whole awareness of mental illness and you know the people around us who are suffering it and doing some work on the help line (which has) all come out of
her being ill….. and the people I’ve met and learning a whole lot of things about it. So yeah, there’s lots of positives about it.

When learning that the behaviours their relative with BPD were displaying could be clustered together and labelled as a particular mental illness, a number of participants spoke about coming to a more realistic awareness. Often after many years of blaming themselves for their relative’s condition they learnt that it was not necessarily all their fault. This awareness, more often than not, led them to adjust their expectations of their relative to something that was more realistic given their condition.

*The change has been that I was always blaming myself ‘What have I done wrong, I must try harder’ …..it has helped things because my expectations are so much better, more realistic. It’s no use expecting the impossible, something a person can not give because now you understand why they can’t possibly, and in this situation they can never behave like that. So altering the expectations, it’s made things a lot better.*

One group member talked about learning to be more loving as a positive outcome in her relationship with her BPD partner.

*I’ve learnt to be a lot more loving definitely for my BPD partner. Because our family is not a loving family, in the sense of cuddling and all that sort of ... we’ve never been. You know you just sort of sit with your mum and tell her about what you did for the day. It’s always been ... you know, both my brother and I we’ve always had to be very structured. So my BPD partner, has definitely taught me that.*

The daughter of a mother with BPD thought that her ability to be an exceptionally good mother was influenced by her own relationship with her BPD mother and the conscious decision to be different. This member also felt that the longstanding and deep friendships she had with her two best friends was probably the result of her own neediness for relationship and may not have evolved if these needs had been met by her mother.

*...I just think I’m probably an exceptionally, ah, good mother, or, ah, have a good relationship with my children. .... I think it’s, I’ve got it, I’ve sort of got it together because of that (experiences of own mother)...... whereas if there was probably just a average level of dysfunction, I would have carried it on. I believe that’s what the people do....... But this (own experience of mother) was so extreme, and I, went so the other way, and…I, I know what’s so important not to do to a child........ maybe had it not been for that (experiences and rejection of mother), and I would never have been as needy, or maybe got to that point of such close and loyal friendships.....*
While, these participants could identify positive outcomes, they all indicated that it had been a tough road to achieving them, and as one group member put it, “not one you would wish on anyone”.

*I guess it is a learning experience, I mean whatever knowledge you gain from whatever is a learning experience. It’s been a tough one at that but ummm….but probably one that we could have done without……..

*I think it’s, it’s made us better people because of it….it’s an awful way to get there though……*

The Loving, Active Coper and the Distanced Manager who did not consider that anything positive had come out of their relationships with their BPD daughters, reported similar learning experience about the illness, but failed to see any positive outcomes from these experiences.

*I suppose it’s a learning experience….. I suppose we’ve learnt a lot about mental health……ummm I don’t see it as a positive I guess..*

It is not clear why these group members could not identify any positive outcomes in their relationship with their relative with BPD. However it would appear that the Loving, Active Coper may have been at a different stage in her caregiving journey, as well as indicating that she was feeling resentful of the impact that her daughter’s condition was having on her own life and relationships. The Distanced Manager reported that her relationship with her daughter had changed significantly since a time when her daughter had become extremely violent toward her and the participant no longer had any real contact with her daughter. It may be that, as a result, the participant no longer has the opportunity to receive any positive reinforcement from the relationship.

### 2.3.4 Experience of Services and Professionals

Analysis of the four coping groups revealed that the use of private or public systems was not influenced by group membership. Many more negative than positive experiences were recalled with services and professionals from both systems for the care given to the family member with BPD, and of the support available to the participants in their caring role. The negative experiences ranged from difficulties in gaining support and/or accessing services in times of crises, to experiencing a lack of desire or ability of professionals to care for someone with BPD, or deal with the relative’s involvement. Although many of the participants
described similar negative experiences in their dealings with the services and professionals caring for their BPD person, the different groups put a different meaning on these experiences.

**2.3.4.1 Difficulty Accessing Treatment.**

Somewhat different difficulties in accessing services were reported for the two systems. The participants whose family member had used the public system talked about the difficulty they often experienced securing even the most basic services for their BPD relative such as consultation with a psychiatrist in the public system which, in their experience, required at least a hospitalisation to attain.

....*We, you just couldn’t get the help she needed.....getting her into a psychiatrist or getting the right medication.....There’s been times when I’ve been worried about my daughter, and I’ve rung.....but cause she’s got out of the system, because she’s been ok, she’s had a stint of, you know, six months of being ok, so she no longer has a case worker....They just drop them.....and they tell us ‘oh, no, I’m sorry, there’s really no help available unless she’s in crisis’.....*

....*In the beginning for us, where we couldn’t get anywhere really to contain my partner in her self harm.....we went to a private hospital which is in X and twenty thousand dollars later ...We had no private cover, but I had to contain it.....I couldn’t even get into the public ... I couldn’t ring the public hospital and ask for help and say my partner needs to be contained or she will self harm, and they would go... We can’t take her, we have no beds.....I had no choice..... I had no choice at all....*

The participants whose family member had used the private system found it much easier to secure the services of a psychiatrist, but reported an ineligibility to access case-managers as a private client, and therefore felt even more uninformed of the services available for their BPD person. Moreover, they particularly observed that as private clients, their BPD person was not eligible for the Spectrum program which to date was the only intensive live-in treatment program available for BPD individuals.

.....*We don’t have a case manager, as such, because we’re in the private system.....So there wasn’t someone who could give us (that)advice.....There’s a huge hole.....we floundered for four or five years horrifically.........*

Many of the participants of this sample spoke about their dilemma in deciding whether to transfer to the other system in an attempt to secure services that they were unable to access in the system they were currently engaged with.
There’s a huge conflict in the system between private and public....If you’re a private patient, you’re not necessarily entitled to some things that you are if you’re a public patient....And yet, do you want to throw away the...psychiatrist you’ve got, or whatever, and swap over, and then go on a waiting list for a couple of years before things start happening, or something. So it’s a real catch-22.....

The clients of both systems however, reported inadequate access to professionals and services when their BPD relative was experiencing a crisis, and/or their emotions and behaviours were out of control, and they were at risk to themselves. For the Loving, Active Copers and the In-Flux participant, a reoccurring theme was the feeling that there was nowhere to go to get the help that their BPD relative obviously needed in these times, or for that matter that they needed to care for their BPD relative during these times.

The most challenging and ongoing experience with my daughter has been being on my own....not having training, not knowing and not getting help when I need help....no one to support me....I rang the CAT Team once when my BPD daughter was in crisis.....and I said, ‘I don’t know what to do’.... And they said, ‘You have to go back and manage it’....and I said, ‘I don’t know how to manage it....she is in major stress’....And they said, ‘Well, there are no beds available’....they were quite cold.....and I thought, ‘Oh, my God. I can’t do this’.....

The Bound and Powerless group members, reported being totally unaware of services that might have been able to help them when their BPD daughter or husband was being physically or emotionally violent toward them or others.

No one’s ever bothered to sit down and then try and explain to me (about BPD) until the support group but it was going on a long time before that........Sometimes I tread on eggshells because of her temper........She’s had fantasies about hurting children........she’s attacked me........she’s often verbally aggressive......

The inability to access services, or in the case of the Bound and Powerless group members, a total lack of knowledge of what was available to them, left many of the participants feeling alone and unsupported by the systems in the challenging role of caring for their BPD person.

2.3.4.2 Lack of Information.

All participants, apart from the Distanced Managers felt that they had not been adequately informed about the diagnosis of BPD, what they could expect and how they could best manage the symptoms and behaviours. For the Bound and
Powerless group, the issue was more about how they could keep themselves safe. A Bound and Powerless mother felt that not only did she have insufficient information to help her daughter adequately, but she also did not have enough information to keep herself safe when her daughter went off on a tirade.

... Yeah I got no explanations ..... no information of how I should treat her when she’s like this.... I need more information from her medical people..... as to how I can help her.... But also, how I can be safe and all that kind of stuff too .... It’s been a bad experience, ‘cos they tell me bloody nothing....

For the Active, Loving Copers and the In-Flux participant, the issue of not having adequate information was more about not being able to provide the best possible care and support for their BPD loved one.

... You do need to know things for her protection.... for her care, her protection, her life..... They don’t help you, professionals ...They make you feel like you, it’s none of your business..... I think the laws - I don’t know privacy laws, and all that should be changed for people like the main carer.... Stop all this rot and tell people what they need to know....

Apart from the Distanced Managers, who had information available to them at their fingertips through the family organisations they were involved in, and the Bound and Powerless group who did not actively seek out information on BPD, all other participants reported that their search for available information and services was a challenging experience. This was the case for finding resources for both the BPD person and for the carer themselves.

...... Look I guess they have been (informed of the services available for her son and herself as the carer) but only because really, ’cos I made it happen....I think if you didn’t really persevere, it’s really, really hard to know where to get help and it’s taken a long, long, long time for me to find the right places.... While you’re trying to find them you’re also going through a horrific life and family changes ‘cos your son’s gone out of control and you’re stressed....It’s just amazingly hard.... ‘cos nothings up to date and you’re passed around from one person to the other, to the other, to the other....very frustrating and in the mean time you’ve got your son trying to commit suicide jumping off a building and slashing himself and you’ll try to get help and it’s really hard......

The lack of information was considered to be a fundamental shortcoming for these group members and such information was considered to be essential to all carers and family members of someone with BPD, especially given the challenges of the role and the impact it has on others.
They don’t give you any information….They don’t offer extra things for her….They’ve never offered anything for you (the carer)…They need to diagnose more efficiently and effectively, and then tell the family what to expect, or at least what could happen…..you know, what behaviours, or what, whatever’s going to happen, and the places for you to go….Here are the places for her to go…..you know, what behaviours, or whatever’s going to happen….We muddled our way through for years…..and surely someone else has had this happen to them before, so surely there is someone who knows something about it, and can tell people that….We didn’t know what was going to happen….

For most participants, even mental health professionals were not able to help them find support in their role.

.....I don’t know how often I asked my daughter’s psychiatrist about a carers group, a support group….I actually found it myself through the internet, and kind of like surfing the internet and looking through all different mental health groups and like just clicking on different things - support groups and this group and that group and then actually ringing certain places .... It’s the desperation of wanting help....(There were times when) I swear by the time I had reached seven numbers I thought ‘This is ridiculous forget about it, just get on with your day’……..

Sometimes a problem with leaving carers to find their own information on what they think is going on for their BPD person is that the information can be out of date. Such was the case for one mother who read outdated literature from a time when BPD was still considered to be untreatable.

.....(I) think that was probably the first few things that I read....that eventually they do commit suicide....I’m thinking ‘my God Oh my God you know, we’ve got nothing to look forward to’ you know.... I guess I did read a lot of the negative stuff and yeah I guess I didn’t want it to be that.... I guess I was in denial, I guess deep inside my heart I knew that she kinda like was, and she was portraying all the signs and everything...... I didn’t deal with it too well....

2.3.4.3 Lack in Quality and Efficacy of Care.

The perceived lack of quality of care within both the private and public systems was not just the problem of accessing care but was often the way in which the care was delivered. The participants were especially critical of services and professionals in times of crises when their BPD relative had already self-harmed or was threatening to self-harm or suicide.

.....I mean services aren’t very good. OK hospitals are pathetic sometimes, most of the time.... We found that she’s being released too early, you know they look at her she’s OD and as long as she’s fit medically, and
they claim medically, as she’s got the right pulse and her heart is beating properly - that’s medical........I’ve found myself, in you know, big disputes with the medical staff, with the psych nurses trying to convince them that she’s not well enough to go home......And then having to deal with her out of control behaviour such as jumping out of the car while it was still moving on the way home......

....They cut back on her impulses and stuff, and only because they heavily medicated her, which became a huge problem when she came home...Of course she’s lost all impulses, she’s doped up to the eyeballs.....The medication, they put her on was the medication that she OD’d on....Her doctor didn’t like that, the mental health team didn’t like that in our area......

The respondents across the groups, apart from the Bound and Powerless group members and, the one member of the Distanced managers group whose relative was not receiving treatment for her BPD, strongly criticised professionals and services. They were of the opinion that crisis professionals were not as equipped to deal with someone who has BPD, as they were for clients who had psychotic episodes.

....I don’t know....I reckon most of the professions have been absolutely inadequate.....Their training needs to be more...broad, I think....whether they’re used to dealing with people having psychotic episodes more than a person who can rationally.... talk back to them intelligently....She’s an intelligent person.....you can’t mess with her....and they weren’t equipped to deal with her..... She can outsmart them in a way.... She talked them out of admitting her and all that stuff..... She would quite easily manipulate them, as well....And they should be experienced, or at least trained to deal with that......

This was particularly a problem for these relatives as they were the ones left to carry the burden of care when their BPD relative were not treated effectively, when they were sent home before they were ready and as a consequence still feeling suicidal, or were told that there was nothing to be concerned about.

I know at one stage, my brother-in-law took our BPD niece to the doors of the clinic one morning and would not let her have a shower or anything because she had blood all over her and had been throwing things around, smashing up things all night and drinking.... He said ‘I’m just going to take you as you are and show you to them before you have a shower and make yourself look fine.... And then let them say there’s nothing wrong’..........  

### 2.3.4.4 Lack of Respect and Communication.

A lack of communication between the professionals working with their BPD person and the carers themselves was another area with which the members of this
sample commonly felt dissatisfied. This lack of communication was reported to be upsetting as it often left the carers in a powerless position of not knowing how to best care for their BPD person, particularly as they were the ones left to carry the burden of care in times of crisis and extreme behaviours. This also added to their feelings of being unsupported and alone in what one mother described as a “horrific” time.

I find it really difficult that the psychiatrist doesn’t speak with us as well, to let us know more..... She’s their client and we’re not.....especially as we are the ones caring for her..... thinking that surely this is the person who can tell us if we are going about this (the caring) the right way or not..... not getting those answers.... We were ready to help them do the right thing, and didn’t know if what we were doing was right or wrong......

There were many reports from this group about the lack of respect that was shown for both the individuals with BPD and the carers themselves. When the group members spoke about the lack of respect that was shown to their BPD person, this typically occurred whilst their BPD person was in the middle of a crisis and was perpetrated either by the staff in the emergency department of hospitals or by members of the CAT Team.

...That was probably the worst, and with that, just probably the way you do get treated at the hospital.... Like I know they don’t know too much about borderline, but boy, they still don’t need to treat them the way they do. I mean one doctor was reported by the police not by us, at (a major public hospital).... The police actually did because of the way they treated my BPD partner....I mean I was just horrified, and I was so upset that the police took the doctor aside and actually reported him to the superintendent......It is that whole process of people just not understanding.... I can understand they are trying to save lives and when they’re seeing people who are trying to end their life ... But in saying that, there needs to be more understanding ....

Becoming involved in the care of their BPD relative did not come without its costs for many of the respondents who actively cared for their BPD relative. Carers were not immune to the lack of respect shown by professionals and this lack of respect was shown for a variety of reasons and by a wide variety of professionals. Most of the Loving, Active Copers and the In-Flux participant reported that it had not been unusual for them or other family members to have experienced a disrespectful attitude from professionals both in the general health and mental health systems in their role as carer of their BPD relative. This was generally reported to be in the form of being treated dismissively and/or with indifference by
professionals. However it also included expressions of judgement and criticism, being made to feel like an inadequate parent, not having their extreme experience or their caring efforts with their BPD person understood or acknowledged, and at times feeling that the professional was annoyed with them when they pursued an issue, particularly if the issue had to do with their BPD person’s care.

….I just felt like (I was) constantly being judged and labelled….by professionals........I was confronted by this mental health manager who said like that I was trying to...umm...what was the word he used....umm I was a power freak. And I was just like....I was just devastated.....And it played on my mind for months and months....you know and I was thinking ‘how dare you.... you don’t know.... You have no idea what goes on in my family....How dare you say such...how dare you’....It was like my whole world had caved in when they said that to me....

....I just I don’t think you’re taken seriously and as a mother....you’re so concerned about your son and I almost feel like they think well why are you so concerned.... They just don’t seem to get what’s going on and you’re going through absolute horrid stuff and (it’s) oh not again, or not you....

For the Distanced Managers, and one member of the Bound and Powerless group the issue of lack of respect and lack of communication was demonstrated in feeling that professionals were actively ignoring them by not responding to expressions of concern for their daughters with BPD, even when the expression of concern was in person. For the Bound and Powerless group it was in relation to being totally ignored on the regular visits to her home by the CAT Team to care for her daughter who lived with her. She described it as if she did not exist.

2.3.4.5 Support.

Support for this sample, came in a variety of ways. For some it was in the form of a good friend or group of friends. For many of the Loving, Active Copers it was in their participation in a support group. For two of the three Distanced Managers it was through their involvement in an organisation for families who have someone with a mental illness. For a number of participants it was in the form of a professional they were engaged with for their own needs. For a handful of participants support was found in the chance encounter of a particularly helpful professional. For the In-Flux participant it was through particular family members.
2.3.4.5.1 Support Groups.

Five of the seven members of the Loving, Active Copers had attended one of the two BPD Carers Support Groups available in Melbourne, and the other two members had attended either a more generalised support group in their country town or several psycho-educational groups offered by mental health organisations in Melbourne. All members of this group stated that they had found the input from these groups helpful in their role as carers of their BPD person. The members who attended the BPD specific group found the input was invaluable and a number indicated that the support group had been a key factor in their ability to survive to date.

...There is nothing for us....very little at all....the only support I’ve had is the support group....I’ve had no guidelines on how to care for my BPD daughter....I’ve found it all out by myself and through the support group.... I don’t know what I’d do (if it was no longer available).....The support group is the only place my needs are met as a carer....

....I am more informed of the services this year, because of coming into contact with, um, a support group, for borderline....

....It’s just the comfort of being able to talk to other people who have been through the same thing....it’s that sort of comfort.... You might get one small thing that someone has tried or done, .... Sometimes you’re not always able to help your own BPD person, but you can (help) another person in the support group....so you feel some sort of worthiness I guess in that respect.....

The two members of the Active, Loving Copers group that did not attend BPD specific groups felt that a BPD specific group may have offered more help than the general support group they attended.

....My husband I both went to a carers support group here in our country town.....I have never been involved in anything (BPD) specific....There is nothing specific available here......which makes it difficult.......

....I went to the Well Ways course....part of that is coping skills .... and how to communicate with someone that has a mental illness....A lot of it you can use across the board....but it’s not necessarily for BPD....It would be absolutely fantastic if there could be, um, a BPD specific skills type thing.....

For many, however, finding the support group was no easy feat.

....The people that come to support group, not one of them were told where to go.....We’ve all gone through the same thing....not one of them would know about these things......
2.3.4.5.2 Participation in a Family Organisation

Two members of the Distanced Managers group agreed that they have been fortunate enough to have found support for themselves as carers of someone with BPD through an organisation for family members of someone with a mental illness. It was through these organisations that they had come to understand the BPD diagnosis, be informed of services, and found the support and encouragement they needed as carers.

.... Ah...I think at times it’s what has saved me... has been the contact with a professional in for example, AREFMI (the Association for Relatives and Friends of the Mentally Ill).....you know...sometimes I’m down there (doing volunteer work), and I just say, “Oh, could you give me this information?”, or something.... it’s great....it’s a great comfort to me.....

2.3.4.5.3 Helpful Professionals.

It was observed that when individuals described services and professionals as “good”, it was usually in the form of a particularly helpful professional caring for their BPD person or a professional taking the time to ensure that the carer was coping and able to manage the situation. Apart from a handful of participants, who were receiving treatment for themselves in the form of counselling or psychiatric care, a helpful professional could not however be relied upon to be there, and was seen as an exception rather than the rule, and a bonus when found.

....I have had the reverse, as well....had someone actually sit me down, get me a cup of tea........you know, tissues, talking about the behaviours....and, you know, I have had a good person, once, but....

....The psychologist assigned to my son in CAMHS went above and beyond the call and she spent her own personal time looking up things.... She was wonderfully kind yeah....she was one of the gems I found....her and my counsellor (accessed and funded through a carers organisation) were the two gems I found in this whole (long) process......

A chance encounter with a supportive medical nursing staff member when her mother was in hospital was also reported as supportive, as it assisted to normalise her feelings of awkwardness as the estranged daughter.

...... There’s a wonderful nurse there (in the hospital)....’cos she said, ‘I’ve seen this before, you’re not the only person who has strange relationships with parents. Go with your heart’ she said to me..... ‘Go with your heart’..... I looked at her, I thought, ‘God bless you’....Because I just thought, ‘my heart says nothing....what, am I gonna go there and wail over the bed....because it’s expected.....
2.3.5 Suggestions for Improvements

The themes for suggestions made by participants for professionals and services to be better able to meet their needs and support them in their role as carers and supporters of their BPD person were consistent across the groups. The major points included the call for professionals to consider the needs of those who are directly involved with the person with BPD, to recognize that families and carers are doing their best, to make information and resources more available to family members and carers, and to re-examine the current privacy laws in the light of carers’ needs.

2.3.5.1 Consider Needs of Family Members/Carers.

The call for professionals to consider the needs of those directly involved with the BPD person was a theme that typically emerged from participants across the groups. This theme incorporated acknowledging the difficulties that other family members faced in families with someone with BPD, particularly with managing the BPD family member’s extreme and sometimes dangerous behaviours. As well as the negative impact that the BPD person’s behaviour and the resultant stress had on relationships within the family, the marriage relationship was quite often mentioned as the relationship that carried the most strain.

.....It has taken a huge role in my relationship with my husband.... because you have different ideas on things, on how things should have been handled, or shouldn’t have been handled....Like ‘You should have done this’ and ‘you should have done that’. ‘Why did you say that?’.....My daughter rejected me and attached herself to her dad (my husband)....so that was particularly divisive..... She would manipulate what I had said to him..... We almost couldn’t live with one another..... because she was dividing us..... And we both had different senses of what was happening... and how to handle it.....

2.3.5.2 Need for Respect and Acknowledgement.

Under the theme of professionals appreciating the important role that family members play in the life of a BPD person, participants were asking for professionals not only to understand and respect their experience, but also to acknowledge the role they played in their BPD person’s life and illness, where self-harm and suicidal behaviours were not unusual.

......How we were treated as carers was mixed.....It depended on who turned up......There has been a couple who have totally dismissed our
feelings........There have been times when I was absolutely frantic....They’ve got to acknowledge the role that you play........

A number of participants called for professionals to recognise and acknowledge that family members who care for their BPD person, are doing the best they can usually under very extreme circumstances.

....The way we do things, they (professionals) don’t realize that this is something that’s just hit you....You’re learning, you’re feeling your way through it....I guess there are no right ways, there are no wrong ways....you do your best....you’re feeling your way through....you do what you feel works and you learn as you go along....

2.3.5.3 More Readily Accessible Information.

There were a number of suggestions for services that participants felt would support their role as family members and carers of someone with BPD but were currently not available, at least in Australia. These were resources that would make information about the disorder and how to manage it more accessible for families. This included information about the disorder itself, what families can expect and be aware of, the learning of new skills that would help them with the day-to-day caring of their BPD family member, courses for carers that teach carers skills in managing BPD behaviours, particularly suicidal behaviours, and a referral service that has up-to-date information available for carers when they need it.

.... Well immediately, just put information out there in the hospitals....like bulletins on the board about what is available.... Up until that time, until you get to the hospital, you don’t know you are in a caring situation..... The first point of call is obviously that first experience in going to that hospital.....So an information pack from the hospital.... including something like the fact sheets.....

....My husband even suggested like a library.... in mental health places where you know, whatever the need may be.... It comforted me to go home and read a book..... you know what I mean, just to find something different....

....Someone (or something) that is able to say ‘These are what you’re going to go through, these are the things that you are going to go through’..... Someone maybe to say well, you do need to take care of yourself, to be a good carer.... As a carer you go into that negative and someone who could help you get past that.....

....There needs to be specific training for carers.... for coping with borderline..... ....have a sort of training session on issues such as self-harming....And say well, how much risk is there and all that....which would put it into perspective....
I would love to have been able to go, to go to some kind of a class session. Put out by the hospitals by professionals. You can read a lot about the traits and whatever, but to actually have coping skills specific to borderline. How to manage, how to talk to a person. How to recognise when things are getting bad. I suppose recognise triggers.

A referral service, you know. Like they have at Legal Aid. Where people can ring up and they have a whole folder full of this problem and that problem you know. Maybe they could have something (similar). It’s just like, I just can’t believe that they don’t have a referral service for people, like carers. And they must come across it day in and day out. Probably 50 or more times a day. Carers, you know just ringing in and wanting comfort or something. Just different places they can refer to them to whether it be counselling, debriefing, whatever would make them feel better.

Many participants considered that information about their BPD person currently protected by privacy laws should be made available to them to some extent so that they did not feel like they were trying to keep their BPD person safe or alive with their hands tied behind their backs, so to speak.

I think the laws - I don’t know privacy laws, and all that... I think they should be changed for people like the main carer. Stop all this rot, and tell people what they need to know. My daughter could be classed as just not capable. Knowing what’s good for her. Like a child I have to protect. I don’t need to know everything but enough to protect her and keep her safe.

2.3.5.4 Need for Support Services.

Another major resource that the participants thought would be helpful in their caring role and to their own well-being, and which was consistent across the groups was the ability to access support either regularly or when needed. A few participants suggested that a helpline specifically for carers of someone with BPD, and manned by someone who is trained and has hands-on experience in BPD would be enormously helpful for them. It was thought that the helpline would be able to help carers locate and access up-to-date information, resources and services, navigate the complex health and mental health systems, and most importantly be available when their BPD person is in the middle of an “episode” and give them on-the-spot suggestions and strategies to try. All agreed that this would be a way to decrease the aloneness they often felt, particularly when their BPD person was engaging in self-destructive and uncontrollable behaviours.
.... Maybe a lifeline type of crisis telephone information specific to borderline.... for carers.... You've got to help the carer, perhaps guide them, or what can you do. Or what's the next stage if you do need to go and get a psychiatrist, or you do need to go and get a case manager.... those sorts of things.... Helping the carer to care.... helping the carer to know what to do, where to go and what direction to go in to help.... If she has self harmed.... for them to say something like 'ring the ambulance'.... just to hear someone say, just ring the ambulance, get her to the hospital.... just to talk to someone..... and maybe help you work out what the next steps are....

..... Someone (in the UK) got on the phone and chatted to me about it (daughter and diagnosis of BPD).... It was a help line for mental illness but they had someone who could specifically talk to us about borderline so that was great....

A number of participants also mentioned that it would also give them a sense of support and therefore feel less alone if they were able to access affordable counselling for themselves and others, usually other family members, who had direct contact with the BPD person and were affected by their behaviours.

..... Counselling for carers..... someone that had an understanding of BPD..... Talking amongst a support group is good, don't get me wrong, but sometimes you need someone professional.... If you could get for a carer someone to talk to, and just a counsellor..... it could be once a fortnight or something like that, just have somewhere to go .... and it needs to be affordable....

..... I would like home visits..... I think whoever is going to be the main carer needs to have someone to talk to them... about scenarios that might happen and how you can assist them.... I would love someone to come round once a week, where I can talk to someone... "How's it going this week?" "Well, this. Well, that.".... Someone that can come and you can... you can bounce ideas off them, and, and talk to about how you're going.... I want someone trained... someone who's had hands-on experience (with BPD).... and maybe give some counselling to the others (other family members in household).... counsels and support the family....

2.4 Conclusion for the Qualitative Study

This exploratory study had two aims – to conduct an in-depth exploration into the needs and experiences of family members and friends of someone with BPD and to establish whether the findings were comparable to the findings of Giffin’s (2002) study.

An Interpretive Phenomenological Analysis (IPA) approach was used to explore the themes within the interviews of the thirteen family members. Four distinct coping clusters were identified, the Bound and Powerless group, The
Active, Loving group, The Distanced Manager group, and an In-Flux individual. Within these groups a variety of domains were explored, namely, the coping strategies used by the participants to survive their relationship with their BPD family member, trauma symptoms experienced by the participants as a result of their family member’s BPD behaviours, experiences of turning points and positive outcomes, and the participant’s experience of services and professionals in their care of their BPD family member. Also explored were suggestions made by the participants themselves as to what they thought would be helpful in their roles as family members and carers of someone with BPD. Although comparisons can be made with Giffin’s (2002) study for the themes of becoming a carer of someone with BPD, trauma experienced by these family members, and the family members’ experience of professional and services, the remaining themes were additional themes observed in the current study.

One major finding of the present study was that family members of someone with BPD were typically thrust into the role of caring for their family member and often assumed the role of counsellor, keeping their daughters with BPD safe and taking responsibility for their care in the community. This finding was consistent with Giffin’s (2002) study that found that parents became caregivers for their daughters with BPD involuntarily and out of necessity. Largely to protect their daughters and keep them safe from their suicidal and self-harming behaviours, to get them or keep them connected to community mental health services, and fill the gaps of care that community mental health services were unable to fulfill. Similar for many participants in the current study, the parents in Giffin’s study felt that if they did not care for their daughters and keep them safe, then no-one else would.

All participants across the groups in the current study reported experiencing some symptoms of trauma some of the time. Trauma symptoms were reported to be the most acute at times when their BPD person was in crisis and either displaying suicidal and self-harming behaviours, or angry and aggressive behaviours. Many participants, however, reported ongoing symptoms even when the crisis had passed. One participant had been diagnosed with Post Traumatic Stress Disorder, and at least one other reported sufficient and ongoing symptoms to satisfy the diagnosis. The groups did not differ greatly in the types of trauma symptoms experienced. The Active, Loving Copers and the In-Flux participant, however, gave accounts of
extreme and chronic worry and concern for the physical and psychological safety of their BPD family member as the reason for their trauma symptoms. On the other hand, the Bound and Powerless group members and the Distanced Managers were more inclined to report hostility and either the threat of, or actual acts of violent behaviour committed against them by their BPD family member as the source of their traumatic symptoms. Giffin (2002) focused on the self-harming and suicidal behaviours of the daughters with BPD in her study and the issue of violent behaviour toward the carer and other family members was not a theme explored. Nevertheless, consistent with the current study, Giffin found that the parents in her study displayed indicators of stress disorder when they initially became aware of their daughter’s suicidal and self-harming behaviours, which became symptoms of ongoing Posttraumatic Stress Disorder (PTSD) if exposed to repeated and ongoing acts of self-harm behaviours and suicide attempts.

Turning points and positive outcomes were identified as a result of the relationship with their BPD family member and were varied. Out of the thirteen participants in the sample, eleven were able to identify a turning point in their lives. This was most often the case when they discovered that their family member’s BPD behaviours could be explained as a mental illness, or they realised that the way they were living out their caring role was not sustainable in the long-term. The turning point for a couple of family members in the study was the discovery of ways to keep themselves safe from the violent or controlling behaviour of their BPD family member.

Eleven of the thirteen family members reported positive outcomes from being in relationship with their BPD relative. The reasons given were varied but included a better understanding of mental illness, a greater appreciation of other families’ struggle, a closer and deeper relationship with their BPD family member and other members of their families, and friendships that have been made in course of their journeys.

Many more negative than positive experiences were recalled by family members in their experience of services and professionals within both the public and private health and mental health sectors. The most common negative experiences across the groups were a lack of information about BPD, the accessibility and efficacy of care provided for their BPD family member, and the
lack of support offered to the participants in the caring role. This left participants feeling like they were on their own to work out how to relate to and care for their BPD family member. The result was that the majority of the participants felt alone and unsupported in their challenging role. A seeming lack of desire by professionals within the health fields to work with BPD family members, particularly when the client with BPD was in crisis was also noted. Many family members reported experiences of professionals blaming the participants for either the diagnosis of BPD of their family member, or the current mental state that they were presenting with at the time. This was reported to occur both directly and indirectly by looks and attitudes of the professionals toward them. There were, however, a few reports of positive experiences of professionals and organizations, although these were the exception.

The health and mental health systems as experienced by family members in this study concurs with earlier research conducted by Giffin (2002). Reported feelings that they are excluded from treatment processes, objectified as interfering, overanxious and often the cause of the problem by professionals was common in both studies. Similarly, family members in Giffin’s study also indicated the distress and aloneness they often felt when they were unable to access professional services or received insufficient assistance when they did access these services, particularly at times of frequent suicidal and self-harming behaviours. Also consistent with Giffin’s study were the reported concerns that professionals and services did not appear to know how to care for someone with BPD, and that they perceived this as a risk factor for their BPD family member.

Care must be taken not to assume causality in the relationship between coping and levels of support from services and professionals as this study had a number of limitations. The qualitative nature of the study did not allow for the measurement of levels and frequency of coping strategies used, and levels of dis/satisfaction with services and professionals, and therefore was not able to accurately draw conclusions about the possible relationships between levels of professional support and choice of coping strategies as did Magliano, Fadden, Economou, et al. (1998). Still this study achieved its aims of providing some insight into the experiences of family members of someone with BPD. It provided some understanding into the coping strategies used by family members, their experience
of trauma symptoms, their experience of services and professionals, and possible turning points and positive outcomes as a result of being in relationship with their BPD family member. Further research examining the relationships between the choice of coping strategies, socio-demographic characteristics, attitudes toward the BPD relative, and levels of social support received by the family members from services and professionals would allow a more accurate understanding of family members’ experiences and needs. This would also enable professionals to understand more fully their role in assisting relatives struggling to remain in a caring relationship with their BPD family member. The second study aimed to extend the current findings to a larger and more diverse sample by using a quantitative approach. Within this second study a better understanding was attained about the representativeness of the experiences of family members who are in relationships with someone who has BPD.
CHAPTER 3: STUDY TWO - A QUANTITATIVE STUDY

3.1 Overview

The research conducted in this thesis explored the experiences and needs of family members and carers of someone with Borderline Personality Disorder (BPD). As there has been meagre research in this area, Study 1 was largely exploratory and aimed to investigate these experiences and needs in great detail and depth. This was achieved by conducting semi-structured interviews with family members of someone with BPD and analysing the interview data using Interpretive Phenomenological Analysis. This allowed for an in-depth analysis of what it means for the family to have a relative with BPD, of how their lives are affected, what their needs and concerns are both for their relative with BPD and for themselves, and how they cope with the demands placed upon them.

The aim of Study 2 was to further explore the needs and experiences of family members and others in relationship with someone with BPD and to gain a sense of whether the findings in Study One could be generalized to a larger and more varied sample. Study 2 accomplished this aim through a questionnaire that was developed on the basis of responses to the qualitative interviews and the literature review. The questionnaire collected information on the participants’ demographics, experience of caregiving, quality of life, coping strategies, distress levels, possible trauma, their experiences of services for their BPD relative, and possible personal growth as a result of their experiences.

3.2 Method

3.2.1 Survey Participants

The final sample consisted of 175 respondents, 137 of whom were female (78%), and 37 whom were male (21%). One respondent did not specify their gender. Age of respondents varied with most being middle-aged. Two women and one man stated that they belonged in the 18 to 25 year-old age group, eight women and four men in the 26 to 35 year-old age group, 44 women and 18 men in the 36 to 45 age group, 54 women and eight men in the 46 to 55 year-old age group, 27 women and four men in the 56 to 65 year-old age group, and two women and two men in the over 66 year-old age group. One respondent did not specify their age-group.
Of the 175 survey respondents, the largest group of respondents were from the USA. This group consisted of 53.7% of the total sample ($n=76$; 58 women, 18 men). The next largest group of respondents were from Australia making up 26.9% of the sample, ($n=47$; 36 women, 10 men, plus 1 who did not specify gender). Other groups were smaller: 6.8% from the UK ($n=12$; 11 women, 1 man); 5.7% from Canada ($n=10$; 9 women, 1 man); 1.7% from Europe ($n=3$; 2 women, 1 man); 1% from New Zealand ($n=2$; 1 woman, 1 man), 1% from the Middle East (two women); 1% from Asia (two men); and 0.6% from South America (one man). Eleven of the Australian respondents (6.28%) completed a paper-and-pencil copy and the remainder completed the survey online.

### 3.2.2 Content of the Research Questionnaire

The self-report questionnaire completed by respondents consisted of an empirical section containing nine separate measures, interspersed with two open-ended questions, and a section of demographic questions. The cover page introducing the study, and explaining confidentiality and consent, is included in Appendix B, along with the other questionnaire instruments.

#### 3.2.2.1 The Personality Diagnostic Questionnaire – 4th Edition (PDQ-4)

The Personality Diagnostic Questionnaire (PDQ-4; Hyler, 1994) was used for screening to ensure that the respondents were caring for someone with BPD and not some other personality or mental disorder. The PDQ-4 is a 99-item self-administered true/false questionnaire that is capable of personality diagnosis consistent with the DSM-IV diagnostic criteria. Each PDQ-4 item corresponds to a single DSM-IV diagnostic criterion for a personality disorder (Bagby & Farvolden, 2004). This questionnaire is widely used in clinical practice and in research alike, and has been translated into several different languages. Though its principal use has been for screening personality diagnoses, the newest version includes a Clinical Significance Scale to make accurate diagnosis more possible.

In this study, only eight of the nine Borderline Personality items of the PDQ-4 were used as the item asking respondents about their family member/friend’s impulsive behaviours was missed. However analyses indicated that this item was not needed to assess whether the family members or friends of the respondents were
likely to fit the criteria for BPD as all respondents endorsed five BPD criteria items or more, which is the minimum number of items required to be highly suggestive of BPD.

Each item in the BPD scale directly assesses one of the DSM-IV criteria for BPD. The items on the PDQ-4 were modified in two ways for this study. First the items were modified so the family member/friend was asked to answer the questions with reference to the individual they were in relationship with who had BPD (Davison, Leese, & Taylor, 2001). Second, the PDQ-4 was modified such that respondents used a 5-point Likert-type scale to assess the extent the family member/friend were displaying these BPD behaviours (Lewis, Griffin, Winstead, Morrow, & Schubert, 2003). This meant that the items could not only be used to identify whether the respondent’s relative/friend displayed the symptom/behaviour but also the level to which they displayed the symptom/behaviour.

The PDQ respondents rated their relative/friend with BPD on a 5-point scale for each of the items, ranging from 0 (Never) to 4 (Nearly always). Individual items indicated to the researchers the types of symptoms that the relative/friend was displaying and whether this corresponded with the diagnosis of BPD. All endorsements of the items are considered to be pathological and scores of 5 endorsed items or higher are highly suggestive of BPD (Sansone, Chu, & Weiderman, 2006). Items were summed so that scores could range from 0 to 32 (with the one item missing), with higher scores representing greater demonstration of BPD behaviours.

There have been relatively few published studies on the PDQ-4 to date. Most of the studies on the psychometric properties of the PDQ were conducted with the previous versions of the PDQ (the PDQ and the PDQ-R) that differ in their content and number of items from the PDQ-4 (Bagby & Farvolden, 2004). Previous versions of the PDQ have been found to be useful screening tools for BPD in both clinical (Dubro, Wetzler, & Kahn, 1988; Hyler, et al., 1990) and non-clinical settings (Johnson & Bornstein, 1992), including the freestanding BPD subscale (Patrick, Links, Van Reekum, & Mitton, 1995). The PDQ has demonstrated adequate test-retest reliability and good concordance with other measures of personality disorders (Hyler, Skodol, Kellman, Oldham, & Rosnick, 1990). The alpha coefficient for the modified PDQ-4 in Lewis et. al.’s (1993) study was .79. In the current study, the Cronbach alpha was .68 demonstrating acceptable internal reliability (see Table 3).
Table 3

Number of Items, Theoretical Range of Scores and Reliability of Scales Used in the Current Study

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<tr>
<th>Scale</th>
<th>Number of Items</th>
<th>Range</th>
<th>Reliability</th>
</tr>
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### Posttraumatic Growth

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**Satisfaction with Professionals and Services**

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<th>Reliability</th>
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### 3.2.2.2 The COPE

Coping responses used by family members and friends to manage their stress in relationship to their BPD person were measured using the brief version of The COPE Inventory (Carver, 1997). The COPE Inventory was developed to take account of the diverse ways people respond to stress, and is a multi-dimensional measure of coping. Consistent with the goal to develop a coping inventory that was theoretically driven, the COPE was the product of a considerable body of research generated from pre-existing measures of coping.

The original version of the COPE included 53 items with four items on each of the 13 scales with one additional item. The COPE was expanded to 60 items with four items on each of 15 scales (Miyazaki, Bodenhorn, Zalaquett, & Kok-Mun, 2008). To minimise the time demand on participants, the Brief COPE was used in this study (Carver, 1997). The Brief COPE is the abridged version of the COPE inventory, with 2 items on each of fourteen scales, all assessing different coping dimensions. The scales, which include both adaptive and maladaptive coping skills are: active coping, planning, positive reframing, acceptance, humour, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioural disengagement, and self-blame (Carver, 1997). The Brief COPE retained the 4-point Likert scale format of the Full COPE, with respondents rating themselves on each item from 1 (Not used) to 4 (used a great deal). Total scores for each for the 14 scales were calculated by summing scores on the 2-items within each dimension, with a high score (maximum 8) indicating that this coping tendency was used to a great extent. Consistent with authors of The COPE, this study did not use an overall
score on this measure but looked at each scale separately to see what its relation was to other variables.

Although the Full COPE or Brief COPE has not been used in populations of carers or family members/friends dealing with a family member who has a mental illness, the Brief COPE has been used to examine the way patients cope with severe mental illness (Meyer, 2001), and the coping strategies of staff in mental retardation services working with people who display challenging and aggressive behaviours (Mitchell & Hastings, 2001). Psychometric analysis of the Full COPE demonstrated that convergent and discriminant validity was reported between the COPE scales and selected measures of optimism, control, self-esteem, internality, hardiness, Type A personality, monitoring, blunting, anxiety, and social desirability (Carver, et al., 1989). Cronbach alpha reliabilities for the Full COPE ranged between .62 and .92, with good test-retest reliability (Carver, et al., 1989). The Brief COPE, despite each coping strategy being measured by only two items, has been shown to demonstrate acceptable internal consistency with Cronbach alpha reliabilities for the different coping strategies ranging from 0.50 to 0.90 (Carver, 1997). Largely consistent with Carver’s (1997) findings, the Cronbach alpha reliabilities in the current study ranged from .46 to .94 with eleven of the 14 scales demonstrating acceptable to good internal reliability (see Table 3).

3.2.2.3 The Experience of Caregiving Inventory (ECI).

The Experience of Caregiving Inventory (Szmukler, et al., 1996) was used to measure the experience of caring for a relative or friend with Borderline Personality Disorder (BPD). The Experience of Caregiving Inventory is a 66-item self-report questionnaire which was specifically designed to measure caregivers’ appraisal of the experience of caring for someone with a serious mental illness. The ECI is unique in that it not only measures negative aspects of caregiving (caregiver distress), but also positive aspects of the caregiving experience (caregiver rewards). It identifies ten independent dimensions in the family members’/friends’ appraisal of caregiving including eight negative dimensions namely difficult behaviours, negative symptoms, stigma, problems with services, effects on family, need for back-up, dependency, and loss; and two positive dimensions, positive personal experiences, and good aspects of the relationship. Respondents rated themselves on each item according to a 5-point
scale ranging from 0 (never) to 4 (nearly always). Sub-scale scores were obtained by summing the items for each scale. Scores for the dimensions of caring were obtained by summing the scores for each of the eight negative scales to obtain a total negative score (ECI-neg), which ranged between 0 and 208, and summing the scores for the two positive scales to obtain a total positive score (ECI-pos), which ranged between 0 and 56. Ranges for the individual sub-scales are shown in Table 3 with higher scores in all cases indicating greater experiences of that type.

Szmukler et al. (1996) reported that each scale had a satisfactory Cronbach alpha coefficient, ranging from .74 to .91. In the current study, the Cronbach alpha coefficients ranged from .64 to .90 (see Table 3). The ECI has demonstrated strong face validity and the ECI’s construct validity was found to be credible when examined in relation to measures of coping and carer morbidity, particularly in a stress-coping model (Joyce, Leese, & Szmukler, 2000; Szmukler et al., 1996).

3.2.2.4 Crisis and Calm Times.

In order to assess the family member/friend’s experience of times of crises and relative calm in relation to their person with BPD, five items were developed by the author. Two items asked the respondents how many periods during the last year they had experienced crisis and calm times. Two items asked the respondents how long both the crisis times and calm times generally lasted, and the final item asked respondents to rate the severity of the crises times, on average, on a scale of one to 10, with one = mild, and ten = most severe (see Appendix B).

3.2.2.5 The Depression Anxiety Stress Scales (DASS).

The level of depression, anxiety, and stress experienced by family members and friends was measured using the DASS (Lovibond & Lovibond, 1995). The DASS contains three subscales to measure the negative emotional states of depression, anxiety, and stress. It diverges from other validated instruments that measure depression and anxiety in that it differentiates between anxiety as symptoms of physical arousal, not unlike panic attacks, and symptoms of generalised anxiety, for example, tension and agitation, known in this measurement as mental stress. This differentiation was thought to be important for the sample of family members and friends of someone with BPD, who had reported, in the interviews, ongoing symptoms of anxiety even when crises had passed. To minimise the problem of
participant response burden the 21-item version of the DASS (DASS-21), a short form of Lovibond and Lovibond’s (1995) 42-item DASS was used.

Several studies have demonstrated that both the 42-item and 21-item versions of the DASS items can reliably be grouped into the three scales originally proposed by Lovibond and Lovibond (1995; Antony, Bieling, Cox, Enns, & Swinson, 1998; Brown, Chorpita, Korotitsch, & Barlow, 1997; Henry & Crawford, 2005). The Depression scale assesses low positive affectivity, more specifically dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest/involvement, anhedonia, and inertia. The Anxiety scale assesses physical hyperarousal and fear symptomatology, namely autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious affect. The Stress scale assesses difficulty relaxing, nervous arousal, and being easily upset/agitated. Henry and Crawford (2005) proposed that although depression, anxiety, and stress are legitimate constructs in their own right, in combination there is considerable validity that they measure general psychological distress. As with the 42-item version of the DASS, respondents of the 21-item version rate themselves on each item according to a 4-point severity/frequency scale ranging from 0 (Does not apply to me at all) to 3 (Applied to me a considerable degree, or most of the time). Total scores for each of the three scales were calculated by summing the scores on the 7-items within each scale, with a high score (maximum 21) indicating high levels of depression, anxiety and stress experienced by the respondent. As recommended by Lovibond and Lovibond, the DASS 21 scores were multiplied by two (maximum 42) so as to compare the scores to other DASS normative data and other published data - as well as to interpret scores in the context of DASS cut off severity scores.

Although the DASS has not been used in samples of carers or family members with someone with BPD, the DASS has been used successfully with carers of home dialysis patients (Piira, Chow, & Suranyi, 2002), and with mothers of young children who experienced post-natal depression (Armstrong & Edwards, 2003). Psychometric analysis of the 42-item version of the DASS has shown that the DASS has demonstrated adequate convergent and discriminate validity. The Anxiety scale of the DASS correlates .81 with the Beck Anxiety Inventory (BAI), and the DASS Depression scale correlates .74 with the Beck Depression Scale (BDI) (Lovibond & Lovibond, 1995). Good convergent and discriminant validity of the DASS-21 was
also found when compared with other validated measures of depression and anxiety (Henry & Crawford, 2005). The DASS-21 demonstrated good internal consistencies with Cronbach’s alphas ranging from .87 -.89 for the Depression scale, .80 - .83 for the Anxiety scale, and .93 - .94 for the Stress scale (Henry & Crawford, 2005). The current study measured the family members/friends level of distress both in times when their BPD person was in crisis, as well as in relatively calmer times by asking respondents to answer the DASS 21 twice, once reflecting on a time of crisis and once reflecting on a time of relative calm. Cronbach alpha reliabilities in the current study also indicated very good internal consistency at both times, for Depression .90/.90; Anxiety .87/.85; and Stress .87/.88 (see Table 3).

3.2.2.6 PTSD Scale

Posttraumatic Stress symptoms experienced by family members and friends were measured using the PTSD Checklist – Civilian Version (PCL-C) (Weathers, Litz, Herman, Huska, & Keane, 1993). The PCL-C was developed to be a brief self-report scale to assess for the nine symptoms of Posttraumatic Stress Disorder (PTSD) in the general population, as opposed to the Military version that assesses PTSD symptoms specifically for military experiences. The authors suggest that the PCL-C can be used to derive a diagnosis, but can also be used as a continuous measure of PTSD symptom severity by summing across the 17-items to gauge the intensity of the PTSD symptoms being experienced. This was thought to be particularly helpful with family members/friends of someone with BPD as the interviews indicated that although every participant may not fit the criteria for a PTSD diagnosis, most had indicated a level of PTSD symptoms at some time.

The 17-items of the PCL-C were designed to correspond to the 17 symptoms of the DSM-III-R which is still in keeping with those of the more recent DSM-IV-TR. Respondents were asked to indicate how much they have been bothered by each symptom using a 5-point scale ranging from 1 (Not at all) to 5 (Extremely). Total scores can then be summed across the 17-items to assess symptom severity. Although an initial cut-off score of 50 was recommended to fit the criteria for a diagnosis of PTSD with the PCL-C, later studies have shown that a cut-off score of 44 received much higher sensitivity even with non-clinical participants (Blanchard, Jones-Alexander, Buckley, & Forneris, 1996; Ventureyra, Yao, Cottraux, Note, & De Mey-
Guillard, 2002). For this reason this study used the cut-off score of 44 when making overall generalisations of the diagnosis of PTSD. The PCL-C can also be divided into three subscores to assess the severity of symptoms in the three main syndromes of PTSD. These are Reexperiencing (items 1-5), Avoidance (items 6-12), and Hyperarousal (items 13-17) so that scores in these subscales when totalled range from 5-25, 7-35, and 5-25 respectively (Ventureyra, et al., 2002).

No studies were found where the PCL-C was used to assess PTSD in carers or family members of someone who has a mental illness. However, a number of studies have used the PCL-C successfully to assess for PTSD in family members where children have experienced childhood cancer (Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005; Manne, Du Hamel, Gallelli, Sorgen, & Redd, 1998), and Type 1 Diabetes (Landolt, et al., 2002).

Psychometric analysis found the PCL to have excellent test-retest reliability over a 2-3 day period and high internal consistency for each of the three symptom groups of Re-experiencing, Avoidance, and Hyperarousal, as well as for the full 17-item scale. The PCL was also found to correlate strongly with other measures of PTSD, such as the Mississippi Scale, the PK scale of the MMPI-2, and the Impact of Event Scale (Weathers, et al., 1993). Other studies found that, as a whole, the PCL correlated with the Clinician Administered PTSD Scale (CAPS) at a rate of .90, with a diagnostic efficiency of .90 versus the CAPS. Weathers et al. (1993) reported internal consistency (alpha coefficients) values that ranged from 0.89 to 0.92 for the 3 symptom clusters indicating very good internal consistency reliability for the instrument. Cronbach alpha reliabilities in the current study ranged from .81 to .88 (see Table 3).

3.2.2.7 The Scales of Psychological Well-Being.

The carer’s experience of psychological well-being was measured using a shortened version of the Scales of Psychological Well-Being (Ryff, 1989; 1995). The Scales of Psychological Well-Being was the result of the convergence of multiple frameworks of positive functioning found within the well-being literature and, as a result, it is a multidimensional measure of well-being. It is based on the notion that to be well psychologically is more than just to be free of distress or other mental problems, and is more than happiness or life satisfaction. It includes several
dimensions of wellness and accordingly, the Scales of Psychological Well-Being is comprised of six distinct dimensions of wellness namely, self-acceptance, autonomy, environmental mastery, purpose in life, positive relations with others, and personal growth. The original full scale version of the Scales of Psychological Well-Being (Ryff, 1989) consists of 120 items, but because of the time to complete such a lengthy instrument, the shorter 18-item version was included in this survey (Ryff, 1995). Respondents rated themselves on each item according to a 6-point scale ranging from 1 (strongly agree) to 6 (strongly disagree). Total scores for each of the six dimensions were calculated by summing scores on the 3-items within each dimension. Subscale scores range from 3 to 18, with a high score indicating greater well-being.

While the Scales of Psychological Well-Being have not been validated specifically with family members and friends of someone who has BPD, they have been used in several carer studies including studies of carers of someone with intellectual disabilities (Walden, Pistrang, & Joyce, 2000), and spousal carers (Marks, 1998).

Psychometric analysis of the shortened 18-item version indicated that it performs similarly to the 120-item version of the measure (Ryff & Keyes, 1995). Each item correlates strongly and positively with its own scale, and scale intercorrelations are generally low (ranging from 0.13 to 0.46) indicating that the six dimensions do not demonstrate excessive construct overlap. However, while the internal consistency reliability of the larger 120-item version is high (Ryff, 1989) ($\alpha$ coefficients ranging from 0.86 to 0.93), estimates of internal consistency reliability in the shorter 18-item version are low to modest ($\alpha$ coefficients ranging from 0.33 to 0.56). This is thought to be due to the small number of indicators per scale (Clarke, Marshall, Ryff, & Rosenthal, 2000; Clarke, Marshall, Ryff, & Wheaton, 2001). The current study found similar internal consistency reliabilities that ranged from .43 to .60 (see Table 3).

3.2.2.8 The Post Traumatic Growth Index (PTGI).

Possible posttraumatic growth was measured using the Posttraumatic Growth Index (PTGI; Tedeschi & Calhoun, 1996). The PTGI was developed to be a general measure of the perceptions of trauma-related positive changes that was applicable to a wide array of traumatic events. It is a 21-item scale that measures the degree of reported positive changes on five factors: New Possibilities (5 items), Relating to
Others (7 items), Personal Strength (4 items), Appreciation of Life (3 items), and Spiritual Change (2 items). Respondents rated themselves on each item according to a 6-point Likert scale ranging from 0 (I have not experienced this change) to 5 (I have experienced this change to a very great degree). An overall posttraumatic growth score was obtained by summing the scores for all the items. Possible overall scores ranged from 0 to 105. Total scores for each of the five factors were calculated by summing the scores for the items belonging to that factor. Subscale scores range from 0 to 35 for the Relating to Others factor, 0 to 25 for the New Possibilities factor, 0 to 20 for the Personal Strength factor, 0 to 15 for the Appreciation of Life factor, and 0 to 10 on the Spirituality Change factor. Higher scores for both the overall posttraumatic growth and for each of the factors indicated greater posttraumatic growth.

Although the PTGI has not been used specifically in samples of family members or friends of someone with BPD, it has been used effectively for HIV/AIDS carers (Cadell, 2003), and for the partners of cancer survivors (Thornton & Perez, 2006). Psychometric analysis of the PTGI demonstrated good internal consistency with the full 21-item scale $\alpha = .90$, and the individual factors ranging from $\alpha = .67$ to $\alpha = .85$, with New Possibilities ($\alpha = .84$), Relating to Others ($\alpha = .85$), Personal Strength ($\alpha = .72$), Spiritual Change ($\alpha = .85$), and Appreciation of Life ($\alpha = .67$). Acceptable test-retest reliability over a 2-month interval was also obtained with $r = .71$ (Tedeschi & Calhoun, 1996). In the current study Cronbach alpha reliabilities was indicative of good internal consistency (see Table 3). Test-retest reliabilities for the factors ranged from $r = .65$ to $r = .74$, except for Personal Strength ($r = .37$), and Appreciation for Life ($r = .47$) (Tedeschi & Calhoun, 1996). Convergent and discriminate validity of the PTGI was demonstrated with a number of validated measures including the NEO Personality Inventory, and Index of Religious Participation (Tedeschi & Calhoun, 1996).

3.2.2.9 The Use of Other Means to Cope.

In order to assess whether family members or friends of someone with BPD had used other means to cope with the challenges of being in relationship with someone with BPD, three items were developed by the author. Two items examined whether the family member or friend had used prescribed medication or engaged with
a mental health professional to cope, and one item asked the family member/friend whether they had experienced a turning-point in their relationship with their person with BPD wherein they developed a philosophy or stance that had helped them to manage better and live a more satisfying life (see Appendix B).

3.2.2.10 Overall Satisfaction of Professionals and Experiences.

To assess the family and friend’s overall satisfaction levels of professionals and services in their caring role of someone with BPD, a 10-point Likert scale was developed by the author. Ranging from 1 (completely dissatisfied), to 10 (completely satisfied), respondents were informed that choosing 5 on this scale would indicate mixed feelings about their experience of satisfaction (see Appendix B).

3.2.2.11 The Verona Services Satisfaction Scale-European Version (VSSS-EU).

Family members’ and friends’ experience of professionals and services in their care of the BPD person was established using the Verona Services Satisfaction Scale – European Version (Ruggeri, et al., 2000). The VSSS-EU is an adapted version of the Verona Services Satisfaction Scale (Ruggeri & Dall'agnola, 1993). The VSSS-EU assesses separately the skills of a range of professionals and has been translated in various languages to allow for international collaborative studies (Ruggeri, et al., 2000). The VSSS (Ruggeri & Dall'agnola, 1993) was developed as a multidimensional instrument that measured satisfaction with community-based psychiatric services in Italy and could be used to assess the satisfaction of patients, relatives, and professionals (Ruggeri, et al., 1994). It was designed to fill a gap in standardised instruments so that it not only measured satisfaction with psychiatric services but also the reasons for any dissatisfaction. Conceptually, the items in the VSSS-EU cover seven dimensions: Overall Satisfaction, Professional’s Skills and Behaviour, Information, Access, Efficacy, Types of Intervention and Relative’s Involvement.

A subset of questions from the VSSS-EU was selected for the current study that was considered to be relevant for the experiences of family members and friends of someone with BPD. Items assessing a relative’s/friend’s feelings of satisfaction toward a particular service or professional, and items related to a relative’s involvement in the care of their BPD person were targeted. Participants were asked to
rate services and professionals in the care of their BPD person on a 5-point Likert scale ranging from 0 (Not applicable to me) to 5 (Excellent). However, unlike the VSSS-EU, participants were also given the option to indicate if their BPD person did not use the particular service or professional.

Although the VSSS or VSSS-EU questionnaire has not been used specifically in the area of BPD, it has been widely used to measure patients’ and relatives’ satisfaction with a range of psychiatric services particularly in the area of schizophrenia (Ruggeri, et al., 1994; Ruggeri, et al., 2000). It has demonstrated a higher sensitivity than unstructured interviews in measuring service satisfaction, with relatives of mentally-ill people reporting the content validity of the questionnaire to be very good (Ruggeri, et al., 1994).

According to Ruggeri and Dall’agnola (1993), the initial VSSS test-re-test study provided encouraging results ranging from .41 on the dimension of Types of Intervention to .74 on Overall Satisfaction. A study reporting the development and reliability of the VSSS-EU conducted across a number of countries, demonstrated very good internal consistency and test-retest reliability. The alpha coefficient for the VSSS-EU total score in the pooled sample was 0.96, with alpha coefficients that ranged between 0.92 to 0.96, and test-retest reliability ranging from 0.73 to 0.93 (Ruggeri et al., 2000). In the current study Cronbach alpha reliability was .92, so was indicative of good internal reliability.

3.2.2.12 Involvement Evaluation Questionnaire (IEQ-EU).

Demographic data was obtained about the BPD person and their relative/friend by the use of the Sociodemographic module of the European version of the Involvement Evaluation Questionnaire (IEQ-EU; Schene, van Wijngaarden, & Koeter, 1998). The IEQ-EU was developed to measure the consequences of psychiatric disorders for relatives of patients, friends, or others involved. It is an 81-item questionnaire, which consists of seven modules. This study only used one of the modules that consisted of 15 items which was designed to gather socio-demographic information specifically for carers of someone with a psychiatric disorder. Socio-demographic information collected included age, gender of both the family member/friend and the person with BPD, education level and marital status relationship of the family member/friend, relationship to the person with BPD, living
arrangements and average weekly contact with the person with BPD, diagnosis, and time since mental health problems BPD family member/friend commenced.

3.2.3 Procedure

Ethics approval was obtained from Swinburne University. Upon receiving ethics approval, participants were recruited in a number of ways. Advertisements were placed in the newsletter of an organisation that targeted the family members and friends of someone with a mental illness, as well as being posted on the websites of general search engines such as Google and Infoxchange, and the websites of organisations that were either particularly relevant to the family members and carers of someone with a mental illness or targeted toward family members and friends of someone with BPD, such as Borderline Central and the BPD Google Group. Bookmarks advertising the study and paper-and-pencil versions of the questionnaires were also made available at support groups, forums and workshops organised for either family members and carers of someone with a mental illness in general, or BPD around Australia, but particularly in Melbourne. Participants were also accessed through snow-ball sampling through people who either knew about the study, or had participated in the study.

Participants had the choice to complete the questionnaire in one of two ways. The first was an electronic on-line version of the questionnaire that could be accessed via the internet. The second way was to request a paper-and-pencil version directly from the researcher either by emailing or phoning through a forwarding address. Either way, each interested participant received a Plain Language Statement that invited the interested person to participate, informed participants of the nature of the study, emphasised the voluntary nature of their participation, and indicated that their consent to participate was assumed if they completed the questionnaire.

Upon completion of the survey, the respondents who completed the paper-and-pencil version of the questionnaire returned them through the mail in the reply paid envelope provided in the pack that were either sent or given. For the respondents who completed the online version of the questionnaire, their data was automatically sent back to the Swinburne Server when they exited from the questionnaire. Although there were 192 family members or friends of who commenced the questionnaire
online, 17 did not complete enough of the questionnaire to be included in the final sample.

3.3 Results

3.3.1 Descriptive Characteristics of the Sample as a Whole

Table 4 shows the descriptive characteristics of the sample as a whole. Almost four times more women than men responded to the survey. The majority of respondents had university level education (61%), were either married or in a long-term relationship (63%), and were related to their person with BPD as either partners or parents (83%). Only a third of the respondents had not lived with their person with BPD for at least some of the time in the last twelve months, with almost half of the respondents living with them at the time they completed the survey. The average contact the respondents had with their relative or friend was widely varied. Larger percentages of respondents indicated that they either had almost no contact with their BPD person or they had more than 32 hours a week contact.

Although the number of years the respondents indicated that mental health problems had been manifest in their BPD person was scattered across the time-frames, very few individuals who responded to the survey had observed problems for less than two years. Over half of the respondents reported that their relative/friend had received a diagnosis of BPD, with the other half either not receiving a diagnosis or unsure as to whether they had received a diagnosis. Some of the respondents who had indicated that their friend or relative had not received a diagnosis reported that they had been informally advised by mental health professionals that their relative or friend was likely to receive the diagnosis if formally assessed. Those in the “not sure” category often indicated that this was the case because their person with BPD did not share their diagnosis with them. For this reason, it was important to include The Personality Diagnostic Questionnaire to avoid including respondents in the study who did not have a relative or friend with BPD.

3.3.2 Datascreening

Prior to analysis, all variables were examined for accuracy of data entry, missing values, and fit between their distributions and assumptions of univariate and multivariate analysis. Missing values were observed to be missing more or less in a
random pattern and were replaced by the SPSS programme using the multiple imputation method. (Tabachnick & Fidell, 2001), so as not to lose respondents who only had minor aspects of data missing (less than 10% of data missing).

Table 4
Demographic Profile of Survey Participants

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<tr>
<td>Skew/standard error</td>
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</table>

Normality was assessed using the criteria skew/standard error <3. Some evidence of skewness was detected, particularly for the variables Denial, Substance-
use, and Humour all from the COPE instrument, and Anxiety in crisis time, and Depression and Total Score in the non-crisis times from the DASS instrument. Inspection of the minimum and maximum values of these variables revealed, however, that all values were within the response options on their respective measure and as transformations are not recommended for data that are naturally skewed (Tabachnick & Fiddell, 2001), these variables were not transformed. Although it was noted that statistical results can be profoundly affected by outliers and a number of outliers were identified within the variables of the DASS, COPE, and ECI, these cases were not deleted in the present research. A case was made for the inclusion of these outliers for the reason that this study was considered to be an exploratory study and extreme scores on the distress, coping, and caring experience scales were not unexpected and therefore were real life examples of a family member or friend’s experience. Furthermore, leaving the outliers in the data set meant that possible relationships between the extreme scorers and others remained an option. There were no multivariate outliers using the Mahalanobis distance criterion of $p>.001$ ($\chi^2(50) = 86.661$). One hundred and seventy-five cases were retained for analysis (137 females, 37 males and one who did not specify their gender).

### 3.3.3 Division of Carers into Groups based on Coping Profile

Cluster analysis was performed on the fourteen COPE scales, to establish whether groups with divergent coping approaches could be identified within the sample. Cluster analysis is a method used to group respondents in clusters on the basis of similar response patterns. Grouping of cases was done using a two-step procedure (Hair, Black, Babin, Anderson, & Tatham, 2006). First a hierarchical clustering procedure using Ward’s Method and the Squared Euclidean Distances measure was used to find the most appropriate number of clusters and to define cluster centres. Using this technique maximises the within-cluster homogeneity while maximising the distance between clusters (Sharma, 1996). A second K-Means Quick Clustering procedure, which allows reassignment of cases around these cluster centres, was then used to refine the groups formed. This two-step procedure gives stable solutions, with Ward’s method giving the highest validity and recovery of known structure in methodological examinations of this technique (Milligan, 1981; Morey, Blashfield, Skinner, 1983).
After clustering the data using the hierarchical procedure, examination of the percentage change in proximity coefficients associated with moving to cluster solutions of increasingly less refinement (i.e., fewer clusters) suggested a five cluster solution was optimal (see Hair et al., 2006). Six and four cluster solutions were also considered. The five cluster solution was chosen because it resulted in conceptually meaningful groups that were distinct enough to enable further analysis of differences between the coping groups. The final five groups were labelled the Less Challenged Copers, the Mixed Copers, the Calmer Positive Copers, the Reactive Positive Copers, and the Mixed Extreme Copers.

### 3.3.3.1 Group Differences in Coping.

In order to examine group differences in coping strategies of the five groups defined, a one-way between groups multivariate analysis of variance was conducted. The dependent variables were the final fourteen scales of the COPE instrument, with the independent variable being the five coping groups identified. Preliminary assumption testing was conducted to check for normality, linearity, univariate and multivariate outliers, homogeneity of variance and covariance and multicollinearity. No serious violations were noted, apart from a violation of assumption of equality of variance for six of the fourteen coping dependent variables, namely denial, substance use, planning, humour, and emotional support. As recommended by Tabachnick and Fidell (2001) in such occurrences, a more conservative significance level was used to determine the significance levels between the groups.

A Pillai’s Trace criterion was used for statistical inference in the MANOVA as it has the advantage of being more robust to violated assumptions, such as small and unequal cell sizes, than the other tests. With a significance level of $p<.001$, there was a statistically significant difference between the coping groups on the combined dependent variables, Pillai’s Trace $= 1.79$, $F(14,157) = 9.31$, $p < .001$; partial eta squared $= .45$, suggesting a large effect. Furthermore, Table 5 shows that when the results for the dependent variables were considered separately, statistically significant differences were found between the groups on all the coping strategies within The COPE.

The first cluster contained 35 respondents (23 women and 12 men) comprising 20% of the sample. This group was referred to as the “Less Challenged Copers” as
they were characterised by low scores within all three categories of coping responses, disengagement, emotional-focused, and problem-focused coping, suggesting that this group was either not using the coping strategies to cope with their situation, or that they did not need to use the coping strategies to the same degree as there were fewer demands on them. Further investigation (described in later sections) revealed that the demands on this group were not as challenging when compared with the other groups.

The Less Challenged Copers scored the lowest on all of the scales in the disengagement and problem-focused categories, and in the lower end of scores in the emotion-focused category. They were less likely to behaviourally disengage than all the other groups, save for the Calmer Positives. However, unlike the Calmer Positive copers, they were significantly less likely to engage in problem-focused coping than other groups, save for the Mixed copers. Of note was the significantly lower level of instrumental support employed by the Less Challenged copers in comparison to all other groups. While generally showing relatively low use of emotion-focused coping, they were similar to the Calmer Positives in using low levels of denial and self-blame compared to other groups. However they also showed relatively low use of positive emotion-focused coping strategies such as positive reframing and seeking emotional support, so were similar to the Mixed copers on these aspects of coping, whereas other groups generally made greater use of these positive emotion-focused strategies.

The second cluster contained 42 (24%) of the respondents (33 women, 8 men, and one that did not specify their gender). This group, termed the “Mixed Copers”, reported a tendency to use a mixture of both positive and negative coping strategies at moderate levels from all of the three categories, emotion-focused, problem-focused, and disengagement. This group reported that they used moderate levels of self-distraction and behavioural disengagement from the disengagement group of strategies, moderate levels of self-blame, religious activities, and moderate levels of acceptance of their situation from the emotion-focused group of coping strategies, and moderate levels of active coping and planning from the problem-focused group of coping strategies.

The Mixed Copers were characterised by relatively low scores on problem-focused coping, yet reported using more behavioural disengagement than the Less Challenged Copers. They were relatively lower in their positive reframing while being
near the top in their use of self-blame and substance use, second only to the Mixed Extreme Copers who were the highest users of these strategies.

Table 5
Coping Profile of Each Coping Group

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<tr>
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<tbody>
<tr>
<td>Behavioural Disengagement</td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Self-distraction</td>
<td>M 4.57a</td>
<td>5.95b</td>
<td>5.04bc</td>
<td>6.26bd</td>
<td>6.54bd 9.58*** .18</td>
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<td>SD 1.66</td>
<td>1.30</td>
<td>1.60</td>
<td>1.28</td>
<td>1.63</td>
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<td>Substance use</td>
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<td>4.02b</td>
<td>2.34ac</td>
<td>3.58bd</td>
<td>4.36bd 9.59*** .18</td>
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<td>Behavioural disengagement</td>
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<td>4.64b</td>
<td>2.76bc</td>
<td>3.91ab</td>
<td>5.91b 14.13*** .24</td>
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<tr>
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<td>1.62</td>
<td>1.13</td>
<td>1.77</td>
<td>1.51</td>
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</tr>
<tr>
<td>Venting</td>
<td>M 3.77a</td>
<td>4.70b</td>
<td>4.35bc</td>
<td>5.53c</td>
<td>7.63a 21.14*** .33</td>
</tr>
<tr>
<td>SD 1.28</td>
<td>1.20</td>
<td>1.53</td>
<td>1.51</td>
<td>0.50</td>
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<tr>
<td>Emotion-focused coping</td>
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<td>Denial</td>
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<td>2.36ac</td>
<td>3.75b</td>
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<td>0.79</td>
<td>1.65</td>
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<td>5.20b</td>
<td>3.45bc</td>
<td>4.19c</td>
<td>6.81d 22.81*** .34</td>
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<td>1.53</td>
<td>1.37</td>
<td>1.58</td>
<td>1.72</td>
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<tr>
<td>Religion</td>
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<td>4.71a</td>
<td>5.86b</td>
<td>5.21b</td>
<td>6.63b 8.04*** .15</td>
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<td>2.41</td>
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<td>Positive reframing</td>
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<td>5.56b</td>
<td>6.09b</td>
<td>6.45b 20.34*** .32</td>
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<td>1.00</td>
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<td>3.11a</td>
<td>2.65a</td>
<td>4.60b</td>
<td>3.81ab 10.09*** .19</td>
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<td>1.41</td>
<td>0.84</td>
<td>1.89</td>
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<td>Emotional Support</td>
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<td>4.18a</td>
<td>5.58b</td>
<td>6.26b</td>
<td>6.04b 18.07*** .29</td>
</tr>
<tr>
<td>SD 1.38</td>
<td>1.29</td>
<td>1.80</td>
<td>1.62</td>
<td>1.82</td>
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<tr>
<td>Problem-focused coping</td>
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</tr>
<tr>
<td>Active coping</td>
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<td>5.47a</td>
<td>6.86b</td>
<td>6.82b</td>
<td>7.72b 30.65*** .41</td>
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<td>0.95</td>
<td>1.20</td>
<td>0.46</td>
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<tr>
<td>Planning</td>
<td>M 5.51a</td>
<td>5.96a</td>
<td>7.41b</td>
<td>7.52b</td>
<td>7.91b 27.86*** .39</td>
</tr>
<tr>
<td>SD 1.37</td>
<td>1.52</td>
<td>0.80</td>
<td>0.74</td>
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<td>6.30c</td>
<td>6.95c</td>
<td>6.63bc 29.25*** .40</td>
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<tr>
<td>SD 1.09</td>
<td>1.64</td>
<td>1.64</td>
<td>1.35</td>
<td>1.43</td>
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</table>

Note: Means that do not have a common subscript significantly differ according to Tukey’s HSD post-hoc contrast tests.***p<.001
The third cluster contained 46 (26%) of the respondents (41 women and 5 men). This group, termed the “Calmer Positive Copers”, were characterised by high levels of problem-focused coping, mostly high to moderate levels of positive emotion-focused coping, but low levels of negative emotion coping such as denial and self-blame. While they reported moderate levels of venting and self-distraction, they reported using very low levels of substance use and behavioural disengagement. These Calmer Positives reported using high to moderate levels of helpful coping strategies and yet were one of the groups, apart from the Less Challenged Copers, that were least likely to use verbally expressive strategies such as ventilating, or negative strategies such as substance use. The positive strategies they used more often were instrumental support, planning, and active coping, while also showing high levels of acceptance and seeking of emotional support. They also were the second highest group to use religion to cope.

The fourth cluster contained 41 (23%) of the respondents (31 women and 10 men). This group, termed the “Reactive Positives”, were characterised by high levels of problem-focused coping, as well as mostly moderate to high levels of emotion-focused coping. Their use of the disengagement coping strategies were mixed, using high levels of self-distraction, moderate levels of venting, and low levels of substance use and behavioural disengagement. Their coping profile suggested that they remained behaviourally engaged with their BPD person being relatively low, although not quite as low as the Calmer Positives, on behavioural disengagement. They also used the highest levels of accepting their situation, emotional and instrumental support, and humour to cope. They were also one of the highest groups, with the exception of the Mixed Extremes, in their use of self-distraction and venting their emotions. This group reported using many of the positive coping strategies a lot of the time, and yet also self-distracted, vented their emotions, and used humour more than the other groups.

Finally, the fifth and smallest cluster contained 11 (6%) of the respondents (9 women and 2 men). This cluster was originally incorporated into the fourth cluster when only a four cluster solution was chosen. But it became apparent that this small group of respondents were much more extreme in their reported use of the coping strategies, especially behavioural disengagement strategies, so that inclusion of this group within the fourth group, masked the true profiles of both groups. The
respondents within this group where characterised by the most extreme levels of coping on a range of coping strategies. Within the disengagement strategies they reported the highest use of self-distraction, substance use, behavioural disengagement, and venting their emotions. Within the emotion-focused strategies they reported the highest on four of the seven scales, namely the use of denial, self-blame, religious activities, and positive reframing, and had the second highest mean on another two scales within this category behind the Reactive Positives, in using humour and emotional support. Within the problem-focused strategies they reported the highest scores on two of the three scales active coping and planning, and were only just behind the Reactive Positives in the use of instrumental support. Accordingly, this group of respondents was referred to as the Mixed Extreme Copers.

In summary, there appears to be an overall trend for the Calmer Positive Copers, the Reactive Positive Copers, and the Mixed Extreme Copers to use higher levels of what is typically considered to be the more adaptive coping strategies. These coping strategies include active coping, planning, positive reframing, acceptance, humour, emotional support, and instrumental support. On the other hand, the Mixed Copers and also the Mixed Extreme Copers were the groups that tended to use the highest levels of what has been described as the maladaptive coping strategies, self-distraction, denial, substance use, behavioural disengagement, venting, and self-blame. The Mixed Copers only scored moderate to moderately high on these strategies, whilst the Mixed Extreme Copers reported using these strategies at high to very high levels. The other groups, including the Calmer Positives and Less Challenged Copers typically scored low on these strategies. They made relatively little use of what is considered to be the maladaptive coping strategies of denial, substance use, and behavioural-disengagement. These same groups however, used the self-distraction and venting strategies, also considered to be maladaptive, at moderate to high levels. The Less Challenged Copers generally used lower levels of the whole range of coping strategies, both adaptive and maladaptive, as compared to the other groups.

To understand how these different coping profiles might relate to various background characteristics, differences between the distinct coping groups were considered on a number of variables. Initially groups were compared regarding the general demographic characteristics of the caregivers, the frequency and extent of
crisis times compared to calmer times, demographic characteristics of the BPD care recipient, and other characteristics of the households. To encapsulate how the caregiving experience differed for these groups who had distinctive coping styles, their responses on the ‘Experience of Caregiving Scale’ (Szmukler, et al., 1996) were compared.

3.3.3.2 Demographic - Characteristics of the Coping Groups.

3.3.3.2.1 The Carer.

The demographic profile for the coping groups is presented in Table 6. It is clear from the Chi Square analyses that there was no tendency for the respondents of a particular age to occur in one of the coping groups more than another. When gender was considered, although no significant gender differences in the percentage of males and females across the groups were found, males were relatively more common in the Less Challenged Group and less likely in the Reactive Positive Group.

In the case of education, again no significant differences were apparent across the groups, although the Mixed Extremes tended to include more people with postgraduate university qualifications than the other groups.

The marital status of the respondents was also reasonably consistent across the groups, with no significant differences in status across the groups. The Mixed Extreme Copers were a slight anomaly in this demographic category as there were no single respondents but slightly more who were divorced, widowed, or married/in a long-term relationship. There were no significant differences between the groups in the geographic region they came from, although the Less Challenged Copers had the least number of respondents living in rural areas.

While, overall the groups did not significantly vary in the pattern of relationships to the person with BPD, the Calmer Positives tended to be parents rather than partners of the person with BPD, whereas the Mixed Extremes were more likely to be spouses/partners rather than parents.
Table 6

Distribution of Demographic Variables of the Respondents Across the Coping Groups

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<td>72.7</td>
</tr>
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<td>56 yrs and over</td>
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<td>23.8</td>
<td>19.6</td>
<td>17.1</td>
<td>18.2</td>
</tr>
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<td>(\chi^2(8) = 2.54, p = 0.959)</td>
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<td>Gender:</td>
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<td></td>
</tr>
<tr>
<td>Female</td>
<td>65.7</td>
<td>78.6</td>
<td>89.1</td>
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<td>81.8</td>
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<td>Male</td>
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<td>21.0</td>
<td>10.9</td>
<td>24.4</td>
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<td>(\chi^2(4) = 6.89, p = 0.142)</td>
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<td>Year 12 or less</td>
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<td>45.6</td>
<td>31.7</td>
<td>9.1</td>
</tr>
<tr>
<td>Postgraduate</td>
<td>17.1</td>
<td>21.4</td>
<td>17.4</td>
<td>22.0</td>
<td>36.3</td>
</tr>
<tr>
<td>(\chi^2(6) = 9.32, p = 0.675)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Marital status:</td>
<td></td>
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</tr>
<tr>
<td>Single</td>
<td>14.3</td>
<td>14.3</td>
<td>13.0</td>
<td>12.2</td>
<td>0.0</td>
</tr>
<tr>
<td>Married/ long-term</td>
<td>65.7</td>
<td>69.0</td>
<td>69.0</td>
<td>58.5</td>
<td>54.5</td>
</tr>
<tr>
<td>Divorced/separated/ widowed</td>
<td>17.1</td>
<td>14.3</td>
<td>26.1</td>
<td>29.3</td>
<td>45.5</td>
</tr>
<tr>
<td>(\chi^2(8) = 7.20, p = 0.515)</td>
<td></td>
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<tr>
<td>Geographic region:</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>Metropolitan</td>
<td>40.0</td>
<td>45.2</td>
<td>37.0</td>
<td>36.6</td>
<td>36.4</td>
</tr>
<tr>
<td>Outer metro</td>
<td>51.4</td>
<td>31.0</td>
<td>37.0</td>
<td>31.7</td>
<td>36.4</td>
</tr>
<tr>
<td>Rural</td>
<td>8.6</td>
<td>19.0</td>
<td>26.1</td>
<td>31.7</td>
<td>27.3</td>
</tr>
<tr>
<td>(\chi^2(8) = 14.76, p=0.254)</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Relationship to caree:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/ partner</td>
<td>51.4</td>
<td>47.6</td>
<td>37.0</td>
<td>51.2</td>
<td>72.7</td>
</tr>
<tr>
<td>Parent</td>
<td>25.7</td>
<td>31.0</td>
<td>45.7</td>
<td>34.1</td>
<td>9.1</td>
</tr>
<tr>
<td>Daughter/ son</td>
<td>0.0</td>
<td>2.4</td>
<td>4.3</td>
<td>4.9</td>
<td>18.2</td>
</tr>
<tr>
<td>Sibling</td>
<td>5.7</td>
<td>7.1</td>
<td>0.0</td>
<td>4.9</td>
<td>0.0</td>
</tr>
<tr>
<td>Other/ friend/ neighbour/colleague</td>
<td>17.1</td>
<td>9.5</td>
<td>13.0</td>
<td>4.9</td>
<td>0.0</td>
</tr>
<tr>
<td>(\chi^{2}(28) = 35.08, p=0.167)</td>
<td></td>
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</tr>
</tbody>
</table>

3.3.3.2.2 The Care Recipient.

Although not significantly differing between the groups, the majority of the relatives/friends with BPD across the groups were females and had received a diagnosis of BPD. The majority of BPD care recipients had received their diagnosis in the last five years. However mental health problems had been evident for much longer. About half of the care recipients in most groups, and 80% in the Mixed Extreme coping group, had displayed mental health problems for over 15 years. This indicates that the respondents may have been coping with their relative/friend’s
behaviours for a much greater period than their diagnosis, with this being more likely for the Mixed Copers.

The only demographic variable that was found to be significantly different between the groups however, was the age group of the BPD person (see Table 7). The proportion of BPD relatives/friends in the younger age group of 18 to 35 years was found to be significantly higher in the Calmer Positive Coping group than in the Mixed Extreme Coping Group. This younger age of care recipients within the Calmer Positive group likely reflects parents caring for their children. Conversely, the proportion of relatives/friends with BPD in the 36 to 55 years age group appeared to be significantly higher in the Mixed Extreme group. Again, this likely reflects the greater proportion of spouses/partners in this group.

**Table 7**

*Distribution of Demographic Variables of the BPD Relative/Friend Across the Coping Groups*

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>The caree:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>% 74.3</td>
<td>57.1</td>
<td>69.6</td>
<td>70.7</td>
<td>63.6</td>
</tr>
<tr>
<td>Male</td>
<td>% 25.7</td>
<td>40.5</td>
<td>30.4</td>
<td>29.3</td>
<td>36.4</td>
</tr>
<tr>
<td>Age:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18 – 35yrs</td>
<td>% 34.3</td>
<td>33.3</td>
<td>60.9</td>
<td>53.7</td>
<td>18.2</td>
</tr>
<tr>
<td>36 – 55yrs</td>
<td>% 51.4</td>
<td>50.0</td>
<td>23.9</td>
<td>34.1</td>
<td>63.6</td>
</tr>
<tr>
<td>56yrs and over</td>
<td>% 14.3</td>
<td>14.3</td>
<td>6.5</td>
<td>12.2</td>
<td>18.2</td>
</tr>
<tr>
<td>When did MH problems start:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Up to 5yrs ago</td>
<td>% 20.0</td>
<td>23.8</td>
<td>17.4</td>
<td>22.0</td>
<td>18.2</td>
</tr>
<tr>
<td>6 to 15 years</td>
<td>% 31.4</td>
<td>19.0</td>
<td>37.0</td>
<td>29.3</td>
<td>0.0</td>
</tr>
<tr>
<td>16 years or more</td>
<td>% 42.9</td>
<td>54.8</td>
<td>45.7</td>
<td>48.8</td>
<td>81.8</td>
</tr>
<tr>
<td>Have received a diagnosis:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>% 57.1</td>
<td>45.2</td>
<td>58.7</td>
<td>53.7</td>
<td>45.5</td>
</tr>
<tr>
<td>No</td>
<td>% 31.4</td>
<td>31.0</td>
<td>28.3</td>
<td>24.4</td>
<td>27.3</td>
</tr>
<tr>
<td>Not sure</td>
<td>% 11.4</td>
<td>21.4</td>
<td>13.0</td>
<td>22.0</td>
<td>27.3</td>
</tr>
<tr>
<td>How long since diagnosis:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Up to 5yrs</td>
<td>% 31.4</td>
<td>40.5</td>
<td>39.1</td>
<td>34.1</td>
<td>27.3</td>
</tr>
<tr>
<td>6yrs and over</td>
<td>% 25.7</td>
<td>28.6</td>
<td>28.3</td>
<td>24.4</td>
<td>27.3</td>
</tr>
<tr>
<td>Unsure</td>
<td>% 14.3</td>
<td>21.4</td>
<td>15.2</td>
<td>24.4</td>
<td>36.4</td>
</tr>
</tbody>
</table>

\[\chi^2 (4) = 2.60, p = 0.627\]

\[\chi^2 (8) = 16.02, p = 0.042\]

\[\chi^2 (8) = 9.14, p = 0.330\]

\[\chi^2 (8) = 4.07, p = 0.851\]

\[\chi^2 (8) = 2.99, p = 0.935\]
3.3.3.2.3 **The Households.**

Differences between the Coping groups were also considered at the household levels: who lived in the household, how long the BPD relative/friend had been in the household, and the amount of weekly contact between the respondents and the BPD care recipient (see Table 8). No significant differences were found between the groups in relation to household components. A much larger percentage of the respondents lived in households of 2 to 5 people, that consisted more often than not, of their spouses/partners and/or children.

Although there was a wide variation in both the length of time the relative/friend with BPD lived in the household in the previous twelve months, and the amount of weekly contact between the carer and the care recipient for all the groups, it was somewhat more likely that the BPD care recipient was part of their household at least some of the time. For around half of the respondents this was between 6 to 12 months of the last year. Weekly contact for the majority of the respondents was over 17 hours per week, and this was even more likely for the Mixed and Mixed Extreme coping groups.

3.3.4 **Carers’ Experiences of Borderline Personality Disorder Behaviours**

In order to examine possible differences between the groups in the type and number of BPD criteria the family members/friends were encountering, a series of Chi-square tests were performed on the properties of participants for each group who exhibited each specific symptom, in addition to a series of ANOVA analyses which compared the extremity of the symptoms exhibited. Chi Square tests confirmed that there was no tendency for any one BPD behaviour to be encountered in one coping group more than another. There were also no differences found between the groups in the number of BPD criteria endorsed. Respondents across the groups endorsed high numbers of BPD behaviours (7.62 to 7.81 out of a possible 8 items). All respondents endorsed five BPD criteria items or more, despite one BPD criteria item being missing (the item asking about impulsive behaviours). The endorsement of five items is the minimum number of items required to be highly suggestive of BPD. This indicates that the respondents from all the coping groups were, not only dealing with a
wide range of BPD behaviours, but also a sufficient number of behaviours to be indicative of a BPD diagnosis.

**Table 8**

*Distribution of Household Composition Across the Coping Groups*

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>How many live in household:</td>
<td>% 14.3 16.7 10.9 24.4 18.2</td>
<td>% 80.0 73.8 78.3 70.7 81.8</td>
<td>% 2.9 7.1 10.9 4.9 0.0</td>
<td>χ² (8) = 5.86, p = 0.663</td>
<td></td>
</tr>
<tr>
<td>Who lives in household:</td>
<td>% 17.1 16.7 17.4 26.8 27.3</td>
<td>% 71.4 76.2 78.3 65.9 54.5</td>
<td>% 11.4 4.8 4.3 7.3 18.2</td>
<td>χ² (8) = 6.23, p = 0.621</td>
<td></td>
</tr>
<tr>
<td>Is caree part of household:</td>
<td>% 51.4 42.9 45.7 34.1 54.5</td>
<td>% 31.4 33.3 28.3 41.5 45.5</td>
<td>% 17.1 21.4 26.1 24.4 0.0</td>
<td>χ² (8) = 6.53, p = 0.588</td>
<td></td>
</tr>
<tr>
<td>How long has carer lived with caree in past 12 months:</td>
<td>% 22.9 28.6 13.0 29.3 18.2</td>
<td>% 28.6 28.6 32.6 24.4 36.4</td>
<td>% 48.6 40.5 52.2 46.3 45.5</td>
<td>χ² (8) = 4.76, p = 0.783</td>
<td></td>
</tr>
<tr>
<td>Weekly contact:</td>
<td>% 20.0 21.4 19.6 36.6 36.4</td>
<td>% 40.0 23.8 37.0 26.8 9.1</td>
<td>% 40.0 50.0 41.3 36.6 54.5</td>
<td>χ² (8) = 9.18, p = 0.327</td>
<td></td>
</tr>
</tbody>
</table>

The results of a one-way between groups MANOVA analysis showed that the degree of severity of the BPD behaviours were significantly different between the groups, Pillai’s Trace .317, F(32, 664) = 1.78, p = .005, indicating a moderate and statistically significant difference between the groups on the combined dependent variables. As shown in Table 9 subsequent univariate analyses of the dependent variables, indicated significant differences on the items, “Total BPD Items”, “either loves someone or hates them with nothing in between”, “often wonders who they
really are”, “has difficulty controlling their anger or temper”, and “gets paranoid or blacks out when stressed”. Post hoc contrasts revealed differences between the groups.

In general, respondents frequently reported high levels of BPD behaviours, with scores in the top third of possible severity scores for all groups. The scores indicate that the Calmer Positive Copers, Reactive Positive Copers, and Mixed Extreme Copers were all dealing with extremely challenging BPD behaviours that were generally rated as significantly higher in severity than the Less Challenged Copers, and to a lesser degree higher in severity than the Mixed Copers rated the behaviours of their BPD person. This suggests that the BPD relative/friend of the Less Challenged Copers was less demanding to care for. On an item by item basis, there was some indication that the Mixed Extreme Copers, who scored in the top end of possible scores on most items, were in relationship with someone who was more demanding in more areas when compared with the remaining groups.

3.3.5 Carers’ Experiences of Crises and Calm Times

To determine whether there were any differences between the groups in the number of crises and calm times they experienced in the span of a year, Chi-square tests were performed. No significant differences were found between the groups in the frequency of periods of crisis they experienced in a year. The overall trend for the groups was to experience six or more periods of crises in a year. Over 70% of the members across the groups, and over 80% of the Mixed Extreme Copers reported that they experienced six or more crisis periods in a year.

The severity of the most extreme crises was rated highly across the groups ranging from 7.38 for the Less Challenged Copers to 8.73 for the Reactive Positive Copers out of a possible 10 (see Table 10 below for more details). The results of a one-way between groups ANOVA analysis however, showed that the severity of the crises times were found to be statistically significantly different between the groups $F(4, 168) = 3.19, p = .015$. Post-hoc tests indicated only a significant difference between the Less Challenged Copers who reported a significantly lower severity of crises when compared to the Reactive Positive Copers.
<table>
<thead>
<tr>
<th>No Items endorsed</th>
<th>Coping Groups</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>F</th>
<th>$\eta^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total BPD Items</td>
<td>Endorsed</td>
<td>7.62</td>
<td>7.78</td>
<td>7.86</td>
<td>7.70</td>
<td>7.81</td>
<td>3.88*</td>
<td>.08</td>
<td></td>
</tr>
<tr>
<td></td>
<td>M</td>
<td>21.45</td>
<td>23.88</td>
<td>24.74</td>
<td>24.79</td>
<td>24.72</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>.072</td>
<td>.066</td>
<td>.063</td>
<td>1.29</td>
<td>.67</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prevent those they love from leaving them</td>
<td>Endorsed</td>
<td>94%</td>
<td>93%</td>
<td>100%</td>
<td>95%</td>
<td>100%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>M</td>
<td>2.65</td>
<td>2.71</td>
<td>2.91</td>
<td>2.95</td>
<td>3.36</td>
<td>1.05</td>
<td>.02</td>
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</tr>
<tr>
<td></td>
<td>SD</td>
<td>1.18</td>
<td>1.34</td>
<td>.98</td>
<td>1.07</td>
<td>1.12</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Either love or hate others</td>
<td>Endorsed</td>
<td>97%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>M</td>
<td>2.85</td>
<td>3.14</td>
<td>3.34</td>
<td>3.43</td>
<td>3.72</td>
<td>3.83*</td>
<td>.08</td>
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</tr>
<tr>
<td></td>
<td>SD</td>
<td>.97</td>
<td>.84</td>
<td>.82</td>
<td>.70</td>
<td>.46</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wonders who they really are</td>
<td>Endorsed</td>
<td>100%</td>
<td>97%</td>
<td>98%</td>
<td>95%</td>
<td>100%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>M</td>
<td>2.60</td>
<td>2.66</td>
<td>3.30</td>
<td>2.75</td>
<td>2.74</td>
<td>3.66*</td>
<td>.08</td>
<td></td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>.84</td>
<td>1.09</td>
<td>.75</td>
<td>.99</td>
<td>1.34</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Have tried to hurt or kill themselves</td>
<td>Endorsed</td>
<td>80%</td>
<td>93%</td>
<td>91%</td>
<td>88%</td>
<td>82%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>M</td>
<td>1.88</td>
<td>2.23</td>
<td>2.47</td>
<td>2.19</td>
<td>2.09</td>
<td>1.15</td>
<td>.02</td>
<td></td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>1.30</td>
<td>1.22</td>
<td>1.20</td>
<td>1.24</td>
<td>1.37</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is a very moody person</td>
<td>Endorsed</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>M</td>
<td>3.25</td>
<td>3.57</td>
<td>3.50</td>
<td>3.58</td>
<td>3.54</td>
<td>1.42</td>
<td>.03</td>
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</tr>
<tr>
<td></td>
<td>SD</td>
<td>.81</td>
<td>.54</td>
<td>.72</td>
<td>.59</td>
<td>.68</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feels that life is dull or meaningless</td>
<td>Endorsed</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>97%</td>
<td>100%</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>M</td>
<td>3.11</td>
<td>3.02</td>
<td>3.04</td>
<td>3.02</td>
<td>2.86</td>
<td>2.66</td>
<td>.16</td>
<td>.00</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>.79</td>
<td>.84</td>
<td>.81</td>
<td>1.03</td>
<td>1.22</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has difficulty controlling their anger</td>
<td>Endorsed</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>M</td>
<td>3.00</td>
<td>3.30</td>
<td>3.28</td>
<td>3.63</td>
<td>3.81</td>
<td>3.66*</td>
<td>.08</td>
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<tr>
<td></td>
<td>SD</td>
<td>1.08</td>
<td>.84</td>
<td>.86</td>
<td>.62</td>
<td>.40</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gets paranoid or 'blacks out ' when stressed</td>
<td>Endorsed</td>
<td>91%</td>
<td>95%</td>
<td>98%</td>
<td>95%</td>
<td>100%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>M</td>
<td>2.07</td>
<td>2.71</td>
<td>2.86</td>
<td>3.14</td>
<td>2.63</td>
<td>4.92*</td>
<td>.10</td>
<td></td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>1.16</td>
<td>1.08</td>
<td>.95</td>
<td>1.13</td>
<td>1.12</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Means that do not have a common subscript significantly differ according to Tukey’s HSD post-hoc contrast tests. *p<.05
No significant differences were found between the groups in the frequency of periods of relative calm they experienced in a year. The trend for the number of calm periods across the year were somewhat more evenly distributed, the trend across the groups, with the exception of the Mixed Extremes, was for the respondents to experience six or more periods of calm.

The figures indicate that the Mixed Extreme Copers were more likely to experience more frequent periods of crises and fewer periods of calm, than members of the other groups, with the trend being that the groups that tended to have less involvement with their BPD family member/friend also tended to experience less severe crisis and more periods of calm.

Table 10

*Differences Across the Groups on their Experience of Crises and Calm Times*

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How many periods of crisis:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 or less times %</td>
<td>5.7</td>
<td>2.4</td>
<td>2.2</td>
<td>4.9</td>
<td>9.1</td>
</tr>
<tr>
<td>2 to 5 times %</td>
<td>17.1</td>
<td>23.8</td>
<td>21.7</td>
<td>17.1</td>
<td>9.1</td>
</tr>
<tr>
<td>6 or more times %</td>
<td>77.1</td>
<td>73.8</td>
<td>76.1</td>
<td>75.6</td>
<td>81.8</td>
</tr>
<tr>
<td><strong>Severity of crisis:</strong></td>
<td>M</td>
<td>7.38&lt;sub&gt;a&lt;/sub&gt;</td>
<td>8.07&lt;sub&gt;ab&lt;/sub&gt;</td>
<td>8.24&lt;sub&gt;ab&lt;/sub&gt;</td>
<td>8.73&lt;sub&gt;b&lt;/sub&gt;</td>
</tr>
<tr>
<td>SD</td>
<td>1.83</td>
<td>1.70</td>
<td>1.43</td>
<td>1.10</td>
<td>2.94</td>
</tr>
<tr>
<td><strong>How many periods of calm:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 or less times %</td>
<td>2.9</td>
<td>19.0</td>
<td>6.5</td>
<td>7.3</td>
<td>18.2</td>
</tr>
<tr>
<td>2 to 5 times %</td>
<td>25.7</td>
<td>16.7</td>
<td>41.3</td>
<td>31.7</td>
<td>36.4</td>
</tr>
<tr>
<td>6 or more times %</td>
<td>68.6</td>
<td>61.9</td>
<td>52.2</td>
<td>58.5</td>
<td>36.4</td>
</tr>
</tbody>
</table>

\[\chi^2(12) = 6.41, p = 0.894\]

\[F(4,168) = 3.19, p=0.015\]

\[\chi^2(12) = 17.15, p=0.144\]

3.3.6 *Differences between Coping Groups on their Experience of Caregiving*

In order to examine differences between the coping groups on the Experience of Caregiving measure a one-way between groups MANOVA analysis was performed. Twelve dependent variables were used: difficult behaviours, negative symptoms, stigma, problems with services, illness effects on the family, need for back-up, dependency, loss, positive personal experiences, good aspects of the caregiving relationship, the total negative score comprising the eight negative subscales, and the total positive score comprising the two positive subscales. Again,
using Pillai’s Trace criterion this analysis showed a significant multivariate effect, Pillai’s Trace \( .471, F(40, 656) = 2.18, p < .001; \) partial eta squared = .118, indicating a large and statistically significant difference between the groups on the combined dependent variables. When follow-up univariate tests were undertaken, ten of the twelve dependent variables were found to reach statistical significance. Means and Standard Deviations and results of these MANOVA analyses, and results of Tukey’s post-hoc contrast tests are shown in Table 11.

In general, apart from the Less Challenged Copers, the carers and friends within this study reported high levels of negative experiences in their relationship with someone with BPD. Table 11 presents the mean scores on each of the dimensions of the Experience of Caregiving measure. For the participants from all other groups, apart from the Less Challenged copers, the scores were generally high, with mean scores on most dimensions falling within the top third of possible scores for the total negative score (possible range between 0 and 208). Moreover the participants in this study, and this time including the Less Challenged Copers, scored only around the mid point on the overall positive scale (possible range of scores of 0 to 56). This suggests that the majority of this sample of carers encountered high levels of negative caregiving experiences and relatively low levels of positive experiences in their caregiving role with their BPD relative/friend.

While the Less Challenged Copers appraised their caregiving experience as significantly less negative overall compared with the other groups, particularly in the areas of the impact the BPD person had on the family, their need to deal with difficult behaviours, the level of stigma experienced, and the level of reliance their BPD person had on them, this group was not that different from the other groups in their experience of the positive aspects of the caregiving experience. This indicates that although this group encountered significantly less negative experiences in their care of their BPD person this did not equate to more positive experiences.

The Calmer Positive Copers reported the highest levels of positive experiences in their relationship with their relative/friend with BPD. They reported significantly higher positive experiences when compared with the Less Challenged Copers and Mixed Copers and slightly higher levels of positive experiences when compared with the Reactive Copers and Mixed Extreme Copers. However, they did not report
significantly lower levels of negative experiences overall than the other groups. In fact, there were notable areas where the trend was for this group to score highest on three of the specific negative experiences. These were problems with services, the need to back-up their BPD relative/friend, and a sense of loss.

Table 11

Means and Standard Deviations of Coping Groups on Experience of Caregiving Measures

<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total negative score</td>
<td>M 117.89, SD 24.27</td>
<td>M 135.83, SD 25.87</td>
<td>M 139.46, SD 20.18</td>
<td>M 140.84, SD 22.21</td>
<td>M 147.86, SD 16.94</td>
<td>6.92*</td>
<td>.14</td>
</tr>
<tr>
<td>Difficult behaviours</td>
<td>M 21.22, SD 5.53</td>
<td>M 24.42, SD 4.39</td>
<td>M 23.61, SD 4.05</td>
<td>M 24.78, SD 4.23</td>
<td>M 26.00, SD 3.31</td>
<td>4.27*</td>
<td>.09</td>
</tr>
<tr>
<td>Negative symptoms</td>
<td>M 14.81, SD 4.37</td>
<td>M 16.45, SD 4.71</td>
<td>M 16.41, SD 4.04</td>
<td>M 16.26, SD 4.54</td>
<td>M 19.22, SD 4.24</td>
<td>2.21</td>
<td>.05</td>
</tr>
<tr>
<td>Stigma</td>
<td>M 9.88, SD 4.07</td>
<td>M 11.89, SD 4.08</td>
<td>M 11.53, SD 3.24</td>
<td>M 12.17, SD 4.04</td>
<td>M 15.27, SD 4.24</td>
<td>4.99*</td>
<td>.10</td>
</tr>
<tr>
<td>Problems with services</td>
<td>M 14.19, SD 5.90</td>
<td>M 14.26, SD 6.20</td>
<td>M 17.83, SD 5.50</td>
<td>M 17.70, SD 6.28</td>
<td>M 14.82, SD 5.40</td>
<td>3.75*</td>
<td>.08</td>
</tr>
<tr>
<td>Effects on family</td>
<td>M 15.82, SD 5.11</td>
<td>M 20.33, SD 5.16</td>
<td>M 18.95, SD 4.84</td>
<td>M 20.78, SD 4.84</td>
<td>M 23.00, SD 4.87</td>
<td>8.05*</td>
<td>.15</td>
</tr>
<tr>
<td>Need to back-up</td>
<td>M 12.87, SD 4.60</td>
<td>M 15.39, SD 5.21</td>
<td>M 16.28, SD 4.39</td>
<td>M 14.96, SD 5.20</td>
<td>M 16.18, SD 5.60</td>
<td>2.57*</td>
<td>.05</td>
</tr>
<tr>
<td>Dependency</td>
<td>M 12.84, SD 2.70</td>
<td>M 14.07, SD 3.18</td>
<td>M 14.90, SD 2.94</td>
<td>M 14.85, SD 3.14</td>
<td>M 15.81, SD 2.13</td>
<td>3.71*</td>
<td>.08</td>
</tr>
<tr>
<td>Sense of loss</td>
<td>M 16.22, SD 5.15</td>
<td>M 19.00, SD 4.42</td>
<td>M 19.91, SD 4.37</td>
<td>M 19.31, SD 4.87</td>
<td>M 17.54, SD 4.56</td>
<td>3.59*</td>
<td>.07</td>
</tr>
<tr>
<td>Total positive score</td>
<td>M 30.27, SD 7.59</td>
<td>M 27.97, SD 6.30</td>
<td>M 33.43, SD 5.57</td>
<td>M 32.83, SD 6.29</td>
<td>M 30.40, SD 6.83</td>
<td>4.91*</td>
<td>.10</td>
</tr>
<tr>
<td>Positive experiences</td>
<td>M 17.21, SD 5.94</td>
<td>M 15.80, SD 4.48</td>
<td>M 20.00, SD 4.25</td>
<td>M 19.71, SD 4.80</td>
<td>M 18.68, SD 5.14</td>
<td>5.47*</td>
<td>.11</td>
</tr>
<tr>
<td>Good aspects of relationship</td>
<td>M 13.05, SD 3.27</td>
<td>M 12.16, SD 3.20</td>
<td>M 13.43, SD 3.33</td>
<td>M 13.12, SD 3.81</td>
<td>M 11.72, SD 3.10</td>
<td>1.16</td>
<td>.02</td>
</tr>
</tbody>
</table>

Note: Means that do not have a common subscript significantly differ according to Tukey’s HSD post-hoc contrast tests.
*p<.05

While the Calmer Positive Copers reported the highest positive experiences of all the groups, the Mixed Extreme Copers reported the highest negative experiences.
This was especially the case in the areas of needing to deal with difficult behaviours, negative symptoms, levels of dependency of the BPD person on them, experiences of stigma attached to the diagnosis, and the effects on the family. Moreover this group did not report levels of positive experiences that were dissimilar to the other groups. As the positive experiences of caregivers overall in this study were considered to be below average, this indicates a noteworthy bias toward the negative experience for this group.

### 3.3.7 Differences between Groups in the Psychological Functioning of the Caregivers.

This section considers how the demands of caregiving for a family member or friend who has BPD impacts on the mental health of the carer. Differences are considered first in terms of depression, anxiety, and stress, and then in terms of posttraumatic symptoms, psychological well-being, and posttraumatic growth.

#### 3.3.7.1 Differences between Groups on their Levels of Depression, Anxiety and Stress.

In general, the carers and friends within this study reported scores in the extremely severe range in times of crisis relative to the general population. It is important to note that these scores may have been reported to be so extreme due to being asked to reflect on their most extreme period of crisis. Still, this indicates that, in those times when their person with BPD was in severe crisis, the family members and friends’ of this person were experiencing their own symptoms of depression, anxiety, and stress at very severe levels. In times of relative calm, although the family members’ and friends levels of stress and anxiety returned to normal levels, they continued to generally experience depressive symptoms above the population mean. This means that their experience of distress continued to be above the population mean even in times when their BPD relative’s/friend’s behaviour was relatively calm. Table 12 presents the mean scores on each of the three dimensions of the DASS measure of distress in times of crisis and times of relative calm.

A mixed between-within subjects analysis of variance was conducted to assess whether the five groups differed on their depression, anxiety, and stress scores in times of crisis and in times of relative calm. There was no significant main effect of differences between the groups on the dependent measures, and no significant
interaction effects between group and time. That is, there was no differences between the groups on their levels of depression, anxiety, or stress either in the crisis times or relatively calmer times. The non-significant result may, however, be more of a reflection of asking about family members’/friends’ perceptions of their distress in their most extreme crisis, or when they are experiencing calm periods. Possibly differences between the groups may have been found if they had been asked to generally indicate their levels of distress.

However there was a significant main effect for time indicating a significant reduction in caregivers’ levels of stress, anxiety, depression and overall DASS score between the severe crisis times and the calm times for all the groups. All groups reported similar significantly lower levels of depression, anxiety, and stress in their calm times as compared to their severe crisis times.

### 3.3.7.2 Differences between Groups on their Posttraumatic Stress Symptoms

In order to examine differences between the cluster groups on the posttraumatic stress measure, a one-way between groups MANOVA analysis was performed. Four dependent variables were used: re-experiencing symptoms, avoidance symptoms, hyper-arousal symptoms, and a total PTSD score. Using Pillai’s Trace criterion for this analysis showed a significant multivariate effect, Pillai’s Trace .224, $F(12, 510) = 3.43, p < .001$; partial eta squared = .075, indicating a moderate and statistically significant difference between the groups on the combined dependent variables. When the results of the dependent variables were considered separately, all the variables reached statistical significance. Table 13 shows the means and standard deviations and post-hoc comparisons.

Using the recommended cut-off score of 44 or more for the PTSD total score, all the groups apart from the Less Challenged Copers fit the condition for a diagnosis of posttraumatic stress. The Less Challenged Copers only just missed out on meeting the criteria for PTSD.
Table 12

Means and Standard Deviations of Coping Groups on Depression, Anxiety and Stress Measures

<table>
<thead>
<tr>
<th>Coping Groups</th>
<th>1. Less Challenged (n=35)</th>
<th>2. Mixed (n=42)</th>
<th>3. Calmer Positives (n=46)</th>
<th>4. Reactive Positives (n=41)</th>
<th>5. Mixed Extremes (n=11)</th>
<th>F</th>
<th>$\eta^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Crisis times</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>$M$</td>
<td>26.27</td>
<td>25.94</td>
<td>29.06</td>
<td>25.85</td>
<td>22.54</td>
<td>1.25</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>11.21</td>
<td>9.34</td>
<td>8.83</td>
<td>11.08</td>
<td>8.85</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>$M$</td>
<td>17.25</td>
<td>16.68</td>
<td>17.91</td>
<td>18.78</td>
<td>17.45</td>
<td>.177</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>11.42</td>
<td>11.31</td>
<td>11.39</td>
<td>13.81</td>
<td>9.71</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>$M$</td>
<td>24.51</td>
<td>21.90</td>
<td>25.69</td>
<td>22.52</td>
<td>22.54</td>
<td>.736</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>12.08</td>
<td>10.59</td>
<td>11.84</td>
<td>13.01</td>
<td>10.24</td>
<td></td>
</tr>
<tr>
<td>Total DASS score</td>
<td>$M$</td>
<td>68.04</td>
<td>64.53</td>
<td>72.66</td>
<td>67.16</td>
<td>62.54</td>
<td>.489</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>32.64</td>
<td>28.22</td>
<td>28.39</td>
<td>35.33</td>
<td>25.41</td>
<td></td>
</tr>
<tr>
<td>Calm times</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>$M$</td>
<td>10.97</td>
<td>10.00</td>
<td>12.39</td>
<td>9.26</td>
<td>11.63</td>
<td>.726</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>10.93</td>
<td>9.30</td>
<td>9.16</td>
<td>7.46</td>
<td>9.41</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>$M$</td>
<td>5.97</td>
<td>4.19</td>
<td>6.26</td>
<td>4.48</td>
<td>5.42</td>
<td>.727</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>8.08</td>
<td>6.48</td>
<td>7.21</td>
<td>5.84</td>
<td>5.81</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>$M$</td>
<td>10.01</td>
<td>6.47</td>
<td>10.73</td>
<td>7.41</td>
<td>9.63</td>
<td>1.59</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>10.60</td>
<td>7.82</td>
<td>10.22</td>
<td>7.20</td>
<td>10.94</td>
<td></td>
</tr>
<tr>
<td>Total DASS score</td>
<td>$M$</td>
<td>26.96</td>
<td>20.66</td>
<td>29.39</td>
<td>21.17</td>
<td>26.69</td>
<td>1.13</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>27.63</td>
<td>21.65</td>
<td>24.23</td>
<td>18.08</td>
<td>24.72</td>
<td></td>
</tr>
</tbody>
</table>

Note: Means that do not have a common subscript significantly differ according to Tukey’s HSD post-hoc contrast tests.

*p<.05

Note: DASS 21 scores were multiplied by two to allow meaningful comparisons with DASS normative data and other published data, and to interpret scores in the context of severity cut-off scores.

Although the greatest group differences occurred between the Less Challenged Copers and the remainder of the groups in all domains, the Less Challenged Copers scored consistently lower than the other groups, and the Mixed Extreme Copers tended to report the highest levels of posttraumatic stress symptoms consistently across the domains. This group, more so than the others, would have encountered the symptoms of PTSD such upsetting thoughts, memories, nightmares, and flashbacks about their experiences in either caring for or being in relationship with someone with BPD. They would also have experienced feelings of being constantly on guard or jumpy about their BPD relative’s/friend’s distressing behaviour re-occurring, and engaged in avoidance of thoughts, feelings, and conversations about the distressing behaviour, and have feelings...
of foreboding, and distance from others, as well as difficulties experiencing positive feelings. While this group may be the most extreme, what is common across the groups, save for the Less Challenged Copers, is that the posttraumatic symptoms are experienced at clinical levels by the majority of carers/friends of those with BPD.

### 3.3.7.3 Differences between Groups on their Experience of a Turning-point

A Chi-square test for independence was performed to explore whether there were differences between the cluster groups in their experience of a time when they realised that they had developed a stance or a philosophy in their lives, and in their relationships with their person with BPD, that has helped them to manage better and live more satisfying lives. There were no significant differences found between the groups (see Table 14). However, over 70% of the Positive Reactive Copers and Mixed Extreme Copers reported having had this experience, whilst just over 50% of the Mixed Copers reported that they had experienced a turning-point. The Less Challenged Copers and the Calmer Positive Copers fell somewhere in between these with 57.1% and 60.9% members of these groups reporting such an experience in their relationship with their BPD person.

---

**Table 13**

**Means and Standard Deviations of Coping Groups on Posttraumatic Stress Symptom Measures**

<table>
<thead>
<tr>
<th>Coping Groups</th>
<th>1. Less Challenged (n=35)</th>
<th>2. Mixed (n=42)</th>
<th>3. Calmer Positives (n=46)</th>
<th>4. Reactive Positives (n=41)</th>
<th>5. Mixed Extremes (n=11)</th>
<th>F</th>
<th>$\eta^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Re-experiencing M</td>
<td>13.22a</td>
<td>17.19b</td>
<td>15.00ab</td>
<td>17.56b</td>
<td>20.81b</td>
<td>7.02*</td>
<td>.14</td>
</tr>
<tr>
<td>SD</td>
<td>5.23</td>
<td>4.71</td>
<td>5.21</td>
<td>5.01</td>
<td>5.70</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoidance M</td>
<td>16.10a</td>
<td>22.79b</td>
<td>19.04c</td>
<td>21.36bc</td>
<td>23.54bc</td>
<td>6.88*</td>
<td>.14</td>
</tr>
<tr>
<td>SD</td>
<td>5.48</td>
<td>5.49</td>
<td>7.29</td>
<td>5.87</td>
<td>8.45</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hyperarousal M</td>
<td>13.71a</td>
<td>18.28b</td>
<td>15.60ab</td>
<td>18.08b</td>
<td>20.45bc</td>
<td>8.40*</td>
<td>.16</td>
</tr>
<tr>
<td>SD</td>
<td>5.28</td>
<td>4.20</td>
<td>4.70</td>
<td>4.13</td>
<td>4.63</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PTSD Total Score M</td>
<td>43.33a</td>
<td>58.27b</td>
<td>49.65c</td>
<td>57.01bc</td>
<td>64.81b</td>
<td>9.85*</td>
<td>.19</td>
</tr>
<tr>
<td>SD</td>
<td>13.04</td>
<td>11.86</td>
<td>14.87</td>
<td>12.78</td>
<td>15.25</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note: Means that do not have a common subscript significantly differ according to Tukey’s HSD post-hoc contrast tests.

$^*p<.05$
### Table 14

**Percentage of Respondents in Each Coping Group who Experienced a Turning Point**

<table>
<thead>
<tr>
<th></th>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Did carer experience a turning-point:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>57.1</td>
<td>52.4</td>
<td>60.9</td>
<td>73.2</td>
<td>72.7</td>
<td></td>
</tr>
<tr>
<td>31.4</td>
<td>45.2</td>
<td>32.6</td>
<td>24.4</td>
<td>27.3</td>
<td></td>
</tr>
</tbody>
</table>

\( \chi^2 (4) = 4.37, p = 0.358 \)

#### 3.3.7.4 Differences between Groups on their Psychological Well-being

To examine the differences between the groups on the psychological well-being measure, a one-way between groups MANOVA analysis was performed. Six dependent variables were used: self-acceptance, positive relations with others, environmental mastery, personal growth, purpose in life, and autonomy. This analysis showed a significant multivariate effect, Pillai’s Trace .345, \( F(24, 672) = 2.64, p < .001; \) partial eta squared = .086, indicating a moderate and statistically significant difference between the groups on the combined dependent variables. When the results of the dependent variables were considered separately, the differences that reached statistical significance were self-acceptance, environmental mastery, and personal growth. Positive relations with others, purpose and autonomy did not differ significantly between the groups (see Table 15).

In general, the carers and friends within this study reported a moderate to moderately high level of well-being with mean scores, by and large, falling above the midpoint (Table 15). There was a trend across the groups to score higher in the personal growth, autonomy, sense of purpose, and positive relations with others, and lower in their sense of environmental mastery and self-acceptance compared with the other subscales. This suggests that this sample generally experienced higher levels of continued personal growth, a sense of determination and independence, satisfying relations with others, and a belief that their life has meaning when compared with their attitude toward themselves and their sense of their ability to manage their life and their surroundings.
Table 15
Means and Standard Deviations of Coping Groups on Quality of Life Measures

<table>
<thead>
<tr>
<th>Coping Groups</th>
<th>1. Less Challenged (n=35)</th>
<th>2. Mixed (n=42)</th>
<th>3. Calmer Positives (n=46)</th>
<th>4. Reactive Positives (n=41)</th>
<th>5. Mixed Extremes (n=11)</th>
<th>F</th>
<th>( \eta^2 )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-acceptance</td>
<td>M</td>
<td>11.86a</td>
<td>10.75a</td>
<td>13.15b</td>
<td>12.53ab</td>
<td>10.09a</td>
<td>4.39* 0.09</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>3.03</td>
<td>3.84</td>
<td>3.05</td>
<td>2.45</td>
<td>3.93</td>
<td></td>
</tr>
<tr>
<td>Positive relations</td>
<td>M</td>
<td>12.65</td>
<td>11.67</td>
<td>13.38</td>
<td>13.04</td>
<td>14.00</td>
<td>2.15 0.04</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>3.28</td>
<td>3.23</td>
<td>3.11</td>
<td>3.08</td>
<td>3.34</td>
<td></td>
</tr>
<tr>
<td>Environmental mastery</td>
<td>M</td>
<td>12.59a</td>
<td>10.00b</td>
<td>11.45ab</td>
<td>12.08a</td>
<td>10.45ab</td>
<td>4.53* 0.09</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>3.19</td>
<td>2.75</td>
<td>2.42</td>
<td>3.23</td>
<td>4.03</td>
<td></td>
</tr>
<tr>
<td>Personal growth</td>
<td>M</td>
<td>14.71a</td>
<td>12.94b</td>
<td>15.10c</td>
<td>14.67ac</td>
<td>16.00ac</td>
<td>6.62* 0.13</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>2.40</td>
<td>2.51</td>
<td>2.44</td>
<td>2.13</td>
<td>1.78</td>
<td></td>
</tr>
<tr>
<td>Purpose</td>
<td>M</td>
<td>13.68</td>
<td>12.13</td>
<td>13.73</td>
<td>13.26</td>
<td>12.90</td>
<td>1.70 0.03</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>2.71</td>
<td>3.40</td>
<td>3.23</td>
<td>3.22</td>
<td>3.91</td>
<td></td>
</tr>
<tr>
<td>Autonomy</td>
<td>M</td>
<td>14.42</td>
<td>12.78</td>
<td>14.41</td>
<td>13.85</td>
<td>14.18</td>
<td>2.25 0.05</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>2.36</td>
<td>2.99</td>
<td>2.83</td>
<td>3.11</td>
<td>3.18</td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>M</td>
<td>79.94a</td>
<td>70.28b</td>
<td>81.25a</td>
<td>79.46a</td>
<td>77.71ab</td>
<td>5.25* 0.11</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>12.68</td>
<td>13.19</td>
<td>11.58</td>
<td>11.88</td>
<td>12.89</td>
<td></td>
</tr>
</tbody>
</table>

Note: Means that do not have a common subscript significantly differ according to Tukey’s HSD post-hoc contrast tests.
*p<.05

The Calmer Positive Copers, the Reactive Positive Copers, and the Less Challenged Copers tended to consistently score higher across the majority of the well-being scales when compared with the other groups, indicating that these groups experienced slightly healthier levels of well-being in most areas of their lives. The Mixed Copers, on the other hand, tended toward the lower levels of well-being consistently across the well-being domains when compared with the other coping groups. The Mixed Extreme Copers, fluctuated in their level of well-being across the well-being subscales. This group fell in the lower end of the self-acceptance, environmental mastery, and purpose subscales, and yet the higher end of the positive relations with others and personal growth subscales.
3.3.7.5 Differences between Groups on their Experiences of Posttraumatic Growth

In order to examine differences between the coping groups on the posttraumatic growth measure, a one-way between groups MANOVA analysis was performed. Five dependent variables were used for this analysis: relating to others, new possibilities, personal strength, spiritual change, appreciation for life and the total PTGI score. Using Pillai’s Trace criterion, this analysis showed a significant multivariate effect, Pillai’s Trace $0.187, F(20, 676) = 1.66, p = .035$; partial eta squared $= 0.047$, indicating a small but statistically significant difference between the groups on the combined dependent variables. When the results of the dependent variables were considered separately, all the variables, apart from spiritual change, reached statistical significance. Table 16 shows the means, standard deviations, and results of the post-hoc comparisons on each of the five dimensions of the PTGI measure.

The PTGI total scores for the relatives and friends across the groups were all above the minimum score indicative of posttraumatic growth (minimum score is 42; Polatinsky & Esprey, 2000). This suggests that all the groups have experienced some positive outcomes from their experiences and relationship with someone with BPD. Nevertheless, the Mixed Copers tended to report the least posttraumatic growth in five of the six domains, namely, overall posttraumatic growth, relating to others, new possibilities, personal strength, and appreciation of life. This was particularly so in comparison to Calmer Positive Copers and the Reactive Positive Copers who, between them, tended to be the highest scorers in all the domains. While the Reactive Positive Copers tended to report the highest levels of relating to others, personal strength, and appreciation for life, the Calmer Positive Copers tended to report higher levels of new possibilities, and spiritual change, although the latter was still considered low.

3.3.7.6 Differences between Groups on their use of Professional Help and Medication to Cope

Table 17 shows the percentage of relatives/friends who have used professional help and/or medication to cope. To gauge whether there were differences between the cluster groups in their use of professional help for themselves and/or medication to cope in the situation with their BPD person, Chi-square tests were performed. A
statistically significant difference was found between the groups in their use of professional help to cope, $\chi^2(8, N = 175) = 20.04, p = 0.01$. An inspection of the scores indicated that the Less Challenged Copers reported the least use of professional help to cope (42.9%) with this percentage well below the other groups.

Table 16

<table>
<thead>
<tr>
<th>Coping Groups</th>
<th>1. Less Challenged (n=35)</th>
<th>2. Mixed (n=42)</th>
<th>3. Calmer Positives (n=46)</th>
<th>4. Reactive Positives (n=41)</th>
<th>5. Mixed Extremes (n=11)</th>
<th>$F$</th>
<th>$\eta^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relating to others</td>
<td>$M$ 15.90</td>
<td>13.82</td>
<td>19.49</td>
<td>20.60</td>
<td>19.00</td>
<td>4.09*</td>
<td>.08</td>
</tr>
<tr>
<td></td>
<td>$SD$ 10.63</td>
<td>8.21</td>
<td>7.79</td>
<td>8.04</td>
<td>10.43</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New possibilities</td>
<td>$M$ 10.17</td>
<td>9.17</td>
<td>13.19</td>
<td>12.72</td>
<td>11.36</td>
<td>2.54*</td>
<td>.05</td>
</tr>
<tr>
<td></td>
<td>$SD$ 8.20</td>
<td>6.03</td>
<td>6.61</td>
<td>6.54</td>
<td>7.56</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal strength</td>
<td>$M$ 11.17</td>
<td>8.98</td>
<td>12.59</td>
<td>13.63</td>
<td>11.63</td>
<td>4.73*</td>
<td>.10</td>
</tr>
<tr>
<td></td>
<td>$SD$ 6.24</td>
<td>5.37</td>
<td>4.41</td>
<td>4.61</td>
<td>5.71</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spiritual change</td>
<td>$M$ 3.52</td>
<td>4.41</td>
<td>5.78</td>
<td>4.82</td>
<td>5.09</td>
<td>1.89</td>
<td>.04</td>
</tr>
<tr>
<td></td>
<td>$SD$ 3.90</td>
<td>3.77</td>
<td>3.73</td>
<td>3.83</td>
<td>2.87</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appreciation of life</td>
<td>$M$ 8.07</td>
<td>7.15</td>
<td>8.82</td>
<td>9.87</td>
<td>8.63</td>
<td>2.43*</td>
<td>.05</td>
</tr>
<tr>
<td></td>
<td>$SD$ 3.91</td>
<td>4.25</td>
<td>4.35</td>
<td>3.65</td>
<td>4.84</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PTGI total score</td>
<td>$M$ 48.85</td>
<td>43.56</td>
<td>59.89</td>
<td>61.67</td>
<td>55.72</td>
<td>3.99*</td>
<td>.08</td>
</tr>
<tr>
<td></td>
<td>$SD$ 30.86</td>
<td>22.73</td>
<td>22.42</td>
<td>21.89</td>
<td>24.88</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Score</td>
<td>74%</td>
<td>65%</td>
<td>75%</td>
<td>73%</td>
<td>71%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note: Means that do not have a common subscript significantly differ according to Tukey’s HSD post-hoc contrast tests.

As for the remaining groups, at least two-thirds of the group members (65.2% to 90.9%) reported having used professional help to cope with their situation. The Mixed Extreme Copers however, were the highest users of professional help, with 90.9% of the members having used professional help to cope with their BPD person at some time.

There were also differences between the groups in their use of medication to cope with their BPD person. The differences just missed out on being statistically significant, $\chi^2(8, N = 175) = 14.93, p = 0.06$. An inspection of the scores indicated that again the Less Challenged Copers, as well as the Calmer Positive Copers reported the lowest use of medication to cope with their BPD person. Within the remaining
groups, more than half of the members indicated that they had used medication to cope.

**Table 17**

*Percentage of Each Coping Group Using Professional Help and Medication to Cope*

<table>
<thead>
<tr>
<th>Coping Groups</th>
<th>The carer’s experience</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n=35)</td>
<td>(n=42)</td>
<td>(n=46)</td>
<td>(n=41)</td>
<td>(n=11)</td>
</tr>
<tr>
<td>Used professional help to cope:</td>
<td>%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>42.9</td>
<td>78.6</td>
<td>65.2</td>
<td>78.0</td>
<td>90.9</td>
</tr>
<tr>
<td>No</td>
<td>57.1</td>
<td>21.4</td>
<td>32.6</td>
<td>22.0</td>
<td>9.1</td>
</tr>
<tr>
<td>$\chi^2(4) = 20.04, p = 0.010$</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Used prescribed meds to cope:</td>
<td>%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>37.1</td>
<td>59.5</td>
<td>37.0</td>
<td>61.0</td>
<td>54.5</td>
</tr>
<tr>
<td>No</td>
<td>60.0</td>
<td>40.5</td>
<td>63.0</td>
<td>36.6</td>
<td>36.4</td>
</tr>
<tr>
<td>$\chi^2(4) = 14.93, p = 0.060$</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 3.3.8 Professionals and Services

#### 3.3.8.1 Professionals and Services Used by the Groups.

Table 18 shows the variations between the coping groups in the types of services and mental health professionals used by the respondents’ BPD relative/friend within the mental health sector. A Chi-square test indicated that an association between group membership and the sector of mental health used by the BPD relative/friend just failed to reach significance, $\chi^2 (16, N = 175) = 25.04, p = 0.07$. An examination of percentages suggested that the Mixed Extreme Copers had, by far, the largest percentage of members (36.4%) whose BPD person had not used mental health services at all and the lowest percentage of members (9.1%) that used the public mental health sector. Over half (51.4%) of the Less Challenged Copers reported that their BPD person had been involved with both the public and private mental health sectors and reported the lowest use of the private mental health sector (8.6%). Almost one-third of the Calmer Positive Copers reported using the public sector (32.6%) and this was noticeably higher than the other groups. And although the Reactive Positive Copers reported the highest use of the private mental health sector (29.3%), this was only slightly higher than the Mixed Extreme Copers (27.3%) (see Table 18).
The results of another series of Chi-square tests indicated no significant association between group membership and the type of professional or service used.

Table 18
Distribution of the Use of Services and Professionals Across the Coping Groups (shown as percentages)

<table>
<thead>
<tr>
<th>Services and Professionals</th>
<th>Coping Groups</th>
<th>Overall (N=175)</th>
<th>1. Less Challenged (n=35)</th>
<th>2. Mixed (n=42)</th>
<th>3. Calmer Positives (n=46)</th>
<th>4. Reactive Positives (n=41)</th>
<th>5. Extremes (n=11)</th>
</tr>
</thead>
<tbody>
<tr>
<td>What sector of MH used:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td></td>
<td>16.0</td>
<td>11.4</td>
<td>26.2</td>
<td>6.5</td>
<td>14.6</td>
<td>36.4</td>
</tr>
<tr>
<td>Public</td>
<td></td>
<td>22.9</td>
<td>25.7</td>
<td>23.8</td>
<td>32.6</td>
<td>12.2</td>
<td>9.1</td>
</tr>
<tr>
<td>Private</td>
<td></td>
<td>20.6</td>
<td>8.6</td>
<td>21.4</td>
<td>19.6</td>
<td>29.3</td>
<td>27.3</td>
</tr>
<tr>
<td>Both</td>
<td></td>
<td>40.0</td>
<td>51.4</td>
<td>28.6</td>
<td>41.3</td>
<td>43.9</td>
<td>27.3</td>
</tr>
<tr>
<td>( \chi^2 ) (16) = 25.04, p = 0.069</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| GP's                      |               |                |                           |                |                             |                           |                   |
| Not used                  |               | 23.4           | 11.4                      | 26.2           | 17.4                        | 31.7                      | 45.5              |
| Used somewhat             |               | 37.7           | 40.0                      | 38.1           | 50.0                        | 26.8                      | 18.2              |
| Used quite a bit          |               | 15.4           | 22.9                      | 9.5            | 8.7                         | 22.0                      | 18.2              |
| Used a great deal         |               | 13.7           | 20.0                      | 11.9           | 17.4                        | 7.3                       | 9.1               |
| Don't know                |               | 7.4            | 5.7                       | 11.9           | 4.3                         | 7.3                       | 9.1               |
| \( \chi^2 \) (8) = 8.62, p = 0.375 |

| Social worker             |               |                |                           |                |                             |                           |                   |
| Not used                  |               | 47.4           | 45.7                      | 50.0           | 41.3                        | 46.3                      | 72.7              |
| Used somewhat             |               | 22.9           | 37.1                      | 14.3           | 23.9                        | 22.0                      | 9.1               |
| Used quite a bit          |               | 9.1            | 8.6                       | 4.8            | 15.2                        | 9.8                       | 0.0               |
| Used a great deal         |               | 6.9            | 0.0                       | 4.8            | 13.0                        | 9.8                       | 0.0               |
| Don't know                |               | 10.9           | 5.7                       | 23.8           | 4.3                         | 9.8                       | 9.1               |
| \( \chi^2 \) (8) = 7.31, p = 0.503 |

| Occupational therapist    |               |                |                           |                |                             |                           |                   |
| Not used                  |               | 61.1           | 51.4                      | 64.3           | 60.9                        | 63.4                      | 72.7              |
| Used somewhat             |               | 14.3           | 20.0                      | 2.4            | 17.4                        | 19.5                      | 9.1               |
| Used quite a bit          |               | 3.4            | 5.7                       | 2.4            | 6.5                         | 0.0                       | 0.0               |
| Used a great deal         |               | 3.4            | 5.7                       | 2.4            | 2.2                         | 4.9                       | 0.0               |
| Don't know                |               | 14.9           | 14.3                      | 23.8           | 10.9                        | 12.2                      | 9.1               |
| \( \chi^2 \) (8) = 5.13, p = 0.743 |

| Psychologist or CBT therapist |               |                |                           |                |                             |                           |                   |
| Not used                    |               | 25.1           | 20.0                      | 21.4           | 32.6                        | 22.0                      | 36.4              |
| Used somewhat               |               | 26.9           | 31.4                      | 38.1           | 17.4                        | 24.4                      | 18.2              |
| Used quite a bit            |               | 17.7           | 11.4                      | 7.1            | 21.7                        | 29.3                      | 18.2              |
| Used a great deal           |               | 21.7           | 28.6                      | 21.4           | 21.7                        | 17.1                      | 18.2              |
| Don't know                  |               | 6.9            | 5.7                       | 11.9           | 2.2                         | 7.3                       | 9.1               |
| \( \chi^2 \) (8) = 11.48, p = 0.176 |

<p>| Outpatient at a psychiatric hospital or dept |               |                |                           |                |                             |                           |                   |
| Not used                       |               | 38.5           | 37.1                      | 38.1           | 34.8                        | 36.6                      | 63.6              |
| Used somewhat                  |               | 26.4           | 25.7                      | 26.2           | 32.6                        | 22.0                      | 18.2              |
| Used quite a bit               |               | 10.9           | 11.4                      | 7.1            | 15.2                        | 9.8                       | 9.1               |
| Used a great deal              |               | 12.6           | 11.4                      | 11.9           | 15.2                        | 14.6                      | 0.0               |
| Don't know                     |               | 9.2            | 11.4                      | 16.7           | 0.0                         | 12.2                      | 0.0               |
| ( \chi^2 ) (8) = 2.01, p = 0.981 |</p>
<table>
<thead>
<tr>
<th>Services and Professionals</th>
<th>Overall (N=175)</th>
<th>1. Less Challenged (n=35)</th>
<th>2. Mixed (n=42)</th>
<th>3. Calmer Positives (n=46)</th>
<th>4. Reactive Positives (n=41)</th>
<th>5. Mixed Extremes (n=11)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not used</td>
<td>57.5</td>
<td>48.6</td>
<td>57.1</td>
<td>60.9</td>
<td>53.7</td>
<td>81.8</td>
</tr>
<tr>
<td>Used somewhat</td>
<td>13.8</td>
<td>17.1</td>
<td>14.3</td>
<td>15.2</td>
<td>12.2</td>
<td>0.0</td>
</tr>
<tr>
<td>Used quite a bit</td>
<td>7.5</td>
<td>17.1</td>
<td>2.4</td>
<td>4.3</td>
<td>9.8</td>
<td>0.0</td>
</tr>
<tr>
<td>Used a great deal</td>
<td>6.9</td>
<td>2.9</td>
<td>7.1</td>
<td>10.9</td>
<td>7.3</td>
<td>0.0</td>
</tr>
<tr>
<td>Don’t know</td>
<td>11.5</td>
<td>8.6</td>
<td>16.7</td>
<td>6.5</td>
<td>14.6</td>
<td>9.1</td>
</tr>
</tbody>
</table>

**Note:** Means that do not have a common subscript significantly differ according to Tukey’s HSD post-hoc contrast tests.

However an examination of the levels of use of the particular professionals/services within the groups indicated again that a larger percentage of the BPD persons of the Mixed Extreme Copers consistently either did not use or used less often a range of professionals and services (see Table 18). The most common services used by the coping groups were general practitioners (GPs), with about three-quarters of the friends and family members with BPD using GPs, followed by psychologists or CBT therapists, and then with about two thirds of the patients with BPD using the outpatient services of psychiatric hospitals or departments.

### 3.3.8.2 Differences between Groups on their Satisfaction Levels of Professionals and Services in their Care of the BPD Relative/Friend.

A one-way ANOVA was conducted to explore whether there were differences between the groups on their reported levels of overall satisfaction with professionals and services involved in the care of their BPD relative/friend. The initial question of how satisfied the family members/friends felt overall about the helpfulness of
professionals and services in the care of their BPD person was measured on a continuum of one to 10, with higher scores indicating greater satisfaction. Overall satisfaction with services and professionals did not vary between the groups, $F(4,170) = 1.02, p = 0.39$. The levels of satisfaction across the groups were very low with a mean range between 2.27 and 3.65 out of a possible 10. This indicates that, in general, this sample of family members and friends were dissatisfied with the helpfulness of professionals and services in the care they provided their BPD person, with the Mixed Extreme Copers having the lowest scores in their level of overall satisfaction (See Table 19).

### Table 19

**Means and Standard Deviations of Coping Groups on Levels of Satisfaction with Professionals and Services in Care of BPD Relative/Friend**

<table>
<thead>
<tr>
<th>Coping Groups</th>
<th>Overall satisfaction</th>
<th>Overall experience with:</th>
<th>Overall experience with:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$M$</td>
<td>$SD$</td>
<td>$M$</td>
</tr>
<tr>
<td>Overall</td>
<td>$3.65$, $SD = 2.74$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less Challenged</td>
<td>$(n=35)$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mixed</td>
<td>$3.42$, $SD = 2.87$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Calmer Positives</td>
<td>$(n=46)$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reactive Positives</td>
<td>$(n=41)$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mixed Extremes</td>
<td>$(n=11)$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall</td>
<td>$SD$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$(N=175)$</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Overall experience with:**

- **GP’s**
  - $M = 2.45_a$, $SD = 1.61$  
  - $M = 1.78_a$, $SD = 1.49$  
  - $M = 1.93_a$, $SD = 1.51$  
  - $M = 1.63_a$, $SD = 1.52$  
  - $M = 1.00_b$, $SD = 1.41$  
  - $M = 1.88$, $SD = 1.56$

- **Community mental health**
  - $M = 1.68$, $SD = 1.60$  
  - $M = 0.95$, $SD = 1.32$  
  - $M = 1.46$, $SD = 1.40$  
  - $M = 0.97$, $SD = 1.42$  
  - $M = 0.90$, $SD = 1.70$  
  - $M = 1.25$, $SD = 1.47$

- **Emergency depts of general hospitals**
  - $M = 1.57$, $SD = 1.63$  
  - $M = 0.97$, $SD = 1.33$  
  - $M = 1.46$, $SD = 1.56$  
  - $M = 1.19$, $SD = 1.48$  
  - $M = 0.54$, $SD = 0.82$  
  - $M = 1.23$, $SD = 1.48$

- **Inpatient units of general hospitals**
  - $M = 1.28$, $SD = 1.67$  
  - $M = 0.92$, $SD = 1.31$  
  - $M = 1.06$, $SD = 1.55$  
  - $M = 1.04$, $SD = 1.51$  
  - $M = 0.18$, $SD = 0.60$  
  - $M = 1.00$, $SD = 1.47$

- **Psychiatric units of general hospitals**
  - $M = 1.25$, $SD = 1.59$  
  - $M = 0.92$, $SD = 1.38$  
  - $M = 0.88$, $SD = 1.26$  
  - $M = 1.29$, $SD = 1.45$  
  - $M = 0.72$, $SD = 1.34$  
  - $M = 1.04$, $SD = 1.41$

- **Psychiatric hospitals**
  - $M = 1.37$, $SD = 1.51$  
  - $M = 0.90$, $SD = 1.44$  
  - $M = 1.00$, $SD = 1.49$  
  - $M = 1.09$, $SD = 1.54$  
  - $M = 0.36$, $SD = 0.80$  
  - $M = 1.02$, $SD = 1.46$

- **CAT Teams**
  - $M = 0.97$, $SD = 1.56$  
  - $M = 0.85$, $SD = 1.50$  
  - $M = 0.88$, $SD = 1.43$  
  - $M = 0.87$, $SD = 1.51$  
  - $M = 0.36$, $SD = 0.80$  
  - $M = 0.85$, $SD = 1.45$

- **Case managers**
  - $M = 1.17$, $SD = 1.44$  
  - $M = 0.73$, $SD = 1.37$  
  - $M = 0.86$, $SD = 1.27$  
  - $M = 1.09$, $SD = 1.64$  
  - $M = 0.45$, $SD = 1.03$  
  - $M = 0.91$, $SD = 1.41$

- **Support groups**
  - $M = 1.80$, $SD = 1.79$  
  - $M = 1.00$, $SD = 1.70$  
  - $M = 1.48$, $SD = 1.70$  
  - $M = 1.90$, $SD = 1.98$  
  - $M = 0.63$, $SD = 1.56$  
  - $M = 1.48$, $SD = 1.81$

*Note: Means that do not have a common subscript significantly differ according to Tukey’s HSD post-hoc contrast tests.

*p<.05
In order to examine differences between the coping groups on their levels of satisfaction with nine specific professionals and services, a one-way between groups MANOVA analysis was performed. This analysis did not show significant differences in the level of satisfaction between the coping groups on the nine specific services and professionals. However, follow-up univariate analysis and post-hoc contrast tests showed that for GPs, the Mixed Extreme Copers were significantly less satisfied. This reflected a noticeable trend for the Mixed Extreme Copers to be consistently the least satisfied with all professionals and services. The Less Challenged Copers, on the other hand, reported the highest levels of satisfaction when compared with the other groups. However, across all groups satisfaction with psychiatric services for their relative/friend with BPD was extremely low. Satisfaction was the highest for GPs (see Table 19).

### 3.3.8.3 Differences between Groups on their Satisfaction Levels with Professionals and Services in Supporting them in their Caring Role.

In order to examine differences between the coping groups on their levels of satisfaction with professionals and services in supporting them in their caring role, a one-way between groups MANOVA analysis was performed. Seven dependent variables were used for these analyses, namely the overall satisfaction with the ability of psychiatrist, psychologists, and other mental health professionals to listen and understand the concerns and opinions of the relative/friend; their satisfaction with the recommendations about how they could help their relative/friend with BPD; their satisfaction with information given to them about the diagnosis and prognosis of their BPD person; their satisfaction with the effectiveness of services in helping the relative/friend deal better with their BPD person’s problems, and their assessment of the effectiveness of services in helping the relative/friend improve their understanding of their BPD person’s problems. The analysis showed no differences between the groups on their satisfaction levels of these elements of professionals / services (see Table 20 for the means and standard deviations).

The satisfaction levels of the support the relatives/friends received in their caring role from professionals and services were generally low. Out of a possible score of 5, the highest satisfaction mean for this population was 2.45, with the majority of scores in the 1 to 2 range.
Table 20

Means and Standard Deviations of Coping Groups on Levels of Satisfaction with Professionals and Services in Caring Role

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Ability of psychiatrists to listen and understand</td>
<td>$M$</td>
<td>1.65</td>
<td>1.43</td>
<td>1.91</td>
<td>1.97</td>
<td>2.45</td>
</tr>
<tr>
<td></td>
<td>$SD$</td>
<td>1.43</td>
<td>1.45</td>
<td>1.34</td>
<td>1.50</td>
<td>2.33</td>
</tr>
<tr>
<td>Ability of psychologists to listen and understand</td>
<td>$M$</td>
<td>1.62</td>
<td>1.59</td>
<td>1.91</td>
<td>2.02</td>
<td>1.54</td>
</tr>
<tr>
<td></td>
<td>$SD$</td>
<td>1.59</td>
<td>1.59</td>
<td>1.60</td>
<td>1.55</td>
<td>1.96</td>
</tr>
<tr>
<td>Ability of other MH proffs to listen and understand</td>
<td>$M$</td>
<td>1.62</td>
<td>1.37</td>
<td>1.86</td>
<td>1.85</td>
<td>1.18</td>
</tr>
<tr>
<td></td>
<td>$SD$</td>
<td>1.37</td>
<td>1.53</td>
<td>1.42</td>
<td>1.31</td>
<td>1.77</td>
</tr>
<tr>
<td>With the recommendations of how to help your BPD person</td>
<td>$M$</td>
<td>1.77</td>
<td>1.37</td>
<td>1.95</td>
<td>1.56</td>
<td>0.81</td>
</tr>
<tr>
<td></td>
<td>$SD$</td>
<td>1.37</td>
<td>1.30</td>
<td>1.49</td>
<td>1.32</td>
<td>1.07</td>
</tr>
<tr>
<td>With the info about diagnosis and prognosis</td>
<td>$M$</td>
<td>1.54</td>
<td>1.35</td>
<td>1.77</td>
<td>1.75</td>
<td>1.81</td>
</tr>
<tr>
<td></td>
<td>$SD$</td>
<td>1.17</td>
<td>1.18</td>
<td>1.47</td>
<td>1.39</td>
<td>1.88</td>
</tr>
<tr>
<td>With the effectiveness of services in helping you deal better with BPD</td>
<td>$M$</td>
<td>1.31</td>
<td>1.27</td>
<td>1.44</td>
<td>1.31</td>
<td>1.36</td>
</tr>
<tr>
<td></td>
<td>$SD$</td>
<td>1.19</td>
<td>1.22</td>
<td>1.34</td>
<td>1.19</td>
<td>1.50</td>
</tr>
<tr>
<td>With the effectiveness of services in improving your understanding of BPD</td>
<td>$M$</td>
<td>1.51</td>
<td>1.29</td>
<td>1.71</td>
<td>1.63</td>
<td>1.18</td>
</tr>
<tr>
<td></td>
<td>$SD$</td>
<td>1.36</td>
<td>1.24</td>
<td>1.54</td>
<td>1.42</td>
<td>1.47</td>
</tr>
</tbody>
</table>

Note: Means that do not have a common subscript significantly differ according to Tukey’s HSD post-hoc contrast tests.

This indicates that, across the groups, there was extremely low satisfaction with the helpfulness of professionals and services in their ability to support and counsel relatives/friends in the caring role of someone with BPD (See Table 20).

Although extremely low satisfaction levels was reported across most measures by all the groups, there was a trend for the Mixed Copers and the Mixed Extreme Copers to report the most dissatisfaction with professionals and services to support
them in their caring role, and for the Calmer Positive Copers and the Reactive Positive Copers to report the greatest satisfaction.

3.4 Summary of Quantitative Findings

In summary, five distinct groups based on their differing use of coping strategies as measured by The COPE were defined using cluster analysis. These were the Less Challenged Copers, the Mixed Copers, the Calmer Positive Copers, the Reactive Positive Copers, and the Mixed Extreme Copers. These groups not only differed on the type and level of coping strategies used but also on demographic variables and several psychological measures.

The results showed that the only significant difference in the demographics of this sample was the age of the person with BPD that the participants were in relationship with. The Calmer Positive Copers had a greater percentage of relatives/friends between the ages of 18 to 25 years and tended to be parents, whereas for the Mixed Extremes their relative/friend with BPD were more likely to be 36 to 55 years and they tended to be spouses/partners. In general, the majority of relatives/friends lived with the participants in this study, and although the amount of contact between them was varied, in general, the most frequently selection option for contact was the over 17 hours per week option.

By and large, the participants reported high levels of negative experiences and lower than average level of positive experiences in their caring role of their BPD person. The Mixed Extreme Copers reported the highest level of negative experiences, the Mixed Copers reported the lowest level of positive experiences, with the Less Challenged Copers reporting significantly lower negative experiences when compared with the other groups, although they were on par with the other groups in positive experiences.

In general, the majority of each group reported experiencing six or more crisis periods, and six or more calm periods in the year prior to their involvement in this study. This is consistent with the labile nature of BPD. However the results indicated that the Mixed Extreme Copers were the most likely to experience more frequent periods of crisis and fewer periods of calm, whereas the Less Challenged Copers tended to have the most periods of calm. Moreover, the coping groups on the whole reported that they considered the periods of crises to be severe with scores ranging
from 7.38 to 8.73, out of a possible 10. Distress levels for the relatives/friends in these times of crises fell into the extremely severe range for members of all groups when compared with the general population indicating that in those times when their BPD person was in crisis, the family members and friends of this person were also struggling with their own symptoms of depression, anxiety, and stress at very severe levels. Even in times of relative calm, the participants in this sample continued to generally experience depressive symptoms at above the population mean.

The results of the PTSD Inventory showed that four of the five groups met the criteria for PTSD at one time, with the Less Challenged Copers just failing to do so. The highest levels of symptoms were shown by the Mixed Extreme Copers. The striking aspect of these results was that the severity of the PTSD symptoms was at a level that could be considered as extremely severe for those in the general population. In keeping with the severity of their distress, the participants in this study consistently reported very low satisfaction levels with both the care their BPD person received, and the support they themselves received in their caring role from services and professionals.

On a more positive note, a large percentage of the participants in this sample reported having experienced a turning point in their lives that has enabled them to better manage their life and live a more satisfying life, often in the midst of continuing to care and be concerned for their BPD person. Furthermore, the results of the posttraumatic growth measure indicated that an experience of posttraumatic growth was experienced across the groups. Generally the groups reported average levels of well-being save for the Mixed Copers who tended to report comparatively lower levels of well-being across the domains, and the Mixed Extreme Copers who demonstrated average levels of well-being in some domains and low levels in others.
CHAPTER 4 : DISCUSSION

In this chapter, the results of both the qualitative and quantitative studies undertaken in this research are discussed. The first part of this chapter summarises the results in relation to the aims of the study. The relationship of the current findings to other research in this area is then explored, followed by the clinical, social, and educational implications. Finally, methodological issues are addressed and proposals are made for further research.

4.1 The Research Findings

The purpose of this study was to explore the experiences and needs of those in relationship with someone with BPD. The analysis of the qualitative data provided an in-depth preliminary account of the respondents’ coping strategies used in relation to extreme behaviours exhibited by their BPD person. The nature of their relationship with their BPD relative was examined, as well as the impact the relationship had on their own lives and the lives of others around them. Finally, their encounters with professionals and services in their caring role with their BPD relative were considered. The purpose of the quantitative data was to gain a greater understanding of the issues for those in relationship with someone with BPD, and validate the results of Study 1 by examining a larger and more varied sample.

4.1.1 The Coping Strategies used to Cope with their BPD Person

The coping data collected from the participants of both the qualitative and quantitative studies suggested that groups were able to be created based on the coping responses. In the qualitative study four groups were formed, the Bound and Powerless Copers, the Loving, Active Copers, the Distanced Managers, and the In-Flux participant. In the quantitative study five groups were formed, the Less Challenged Copers, the Mixed Copers, the Calmer Positive Copers, the Reactive Positive Copers, and the Mixed Extreme Copers. The discrete collection of coping strategies used and the level to which they were used is what differentiated the coping groups in each of the studies. Both studies consisted of groups that predominantly used emotion-focused coping strategies to cope and others that used a combination of both problem-focused and emotion-focused strategies to cope with the challenges and distress of caring with someone with BPD.
The groups differed in their choice of, and the degree to which they used the coping strategies.

4.1.1.1 Maladaptive versus Adaptive Coping

The manner in which individuals react to or cope with stressful situations influences the long-term impact of those stressors, and differences in coping are important contributors to psychological adjustment (Min, Farkas, Minnes, & Singer, 2007). Adaptive coping has been described to both buffer the impact of the immediate stress and ensure a sense of self-worth. Within the context of the coping literature, adaptive coping refers to “the effectiveness of coping improving the adaptional outcome” (Lazarus, 1999, p.237). Adaptive coping then, is the application of behavioural strategies to effectively reduce actual or potential stress (Solomon & Draine, 1995). Both problem-focused, actively dealing with the problem, and emotion-focused coping approaches, reducing the negative emotions associated with the problem, have the potential to be adaptive (Park, Folkman, & Bostrom, 2001).

Maladaptive coping, on the other hand, has been described as a response to challenge or stress that works neither to reduce anxiety nor to resolve the situation in the long-term and often results in more problems for the person. Maladaptive coping strategies may reduce the level of stress in the short-term, but can affect physical and psychological health in the long term (Bartram & Gardner, 2008).

Examples of maladaptive coping strategies include drug or alcohol misuse, compulsive use of displacement activities such as playing computer games or exercising, wishful thinking, isolation, detachment, and taking frustration and aggression out on others.

4.1.1.1.1 Maladaptive Coping.

Maladaptive coping, defined as avoidant coping, was a theme in both the quantitative and qualitative studies. Although avoidant coping strategies were found to be used by all the groups in both studies to some extent, the Bound and Powerless group and the Distanced Managers in the qualitative study, and the Mixed and Mixed Extreme groups in the quantitative study reported higher levels of avoidant coping than the other groups. All these groups reported higher levels of emotional, cognitive and behavioural disengagement from their person with BPD to cope. The
Bound and Powerless group in the quantitative study, and both the Mixed and Mixed Extreme groups in the quantitative study, also reported high levels of drug and alcohol use.

Behavioural disengagement was a major theme in the Distanced Managers group of the qualitative study and Mixed and Mixed Copers in the quantitative study. The Distanced Managers reported high levels of long-term behavioural disengagement, achieved by limiting contact with their person with BPD, giving over the care of their BPD person to professionals in the community, and setting boundaries with their person with BPD about what was considered to be acceptable behaviour in relation to them. The Distanced Managers’ decision to behaviourally disengage from their BPD person was usually after many years of tolerating the demanding behaviour of their BPD person and in response to an awareness that this behaviour was unlikely to change. Although the Distanced Managers demonstrated that these ways of coping may be necessary for their own feelings of well-being, it was also evident that these family members were now resentful of any contact they needed to have with their person with BPD, indicating possible burn-out in the relationship and resulting in a need to avoid the relationship. By contrast, in the quantitative study it was not those who seemed most distanced who used the highest level of behavioural disengagement but those who were very much involved with their BPD person. In the quantitative study, the members of the Mixed and Extreme Mixed Coping groups, who reported the highest levels of weekly contact with their BPD person were also the most likely to use behavioural disengagement to cope. This was the case regardless of whether they were living with their relative/friend with BPD or not. The members of both of these groups, despite using high levels of behavioural disengagement, also used a variety of strategies to cope with their person with BPD, who was frequently a spouse/partner or adult child.

Use of drugs and alcohol to cope, another avoidant and maladaptive strategy, was also common for the Mixed and Mixed Extreme Copers in the quantitative study, and the Bound and Powerless group in the qualitative study. The Bound and Powerless group reported that their use of alcohol and drugs was a way to regulate their anxiety and fear in their relationship with someone who was unpredictably aggressive and violent toward them. Alcohol and drugs helped them to mentally disengage from their BPD person in circumstances when physically
removing themselves was not a long-term option. It was not as clear as to why the Mixed and Mixed Extreme Copers were the groups that reported the highest use of drugs and alcohol to cope. A few characteristics of these groups may go some way in explaining their high use of drugs and alcohol. The majority of the Mixed Extreme Copers, and almost half of the Mixed Copers were more likely to be in spouse/partner relationships and reported a greater number of contact hours with their person with BPD. This may make it more difficult for these members to easily remove themselves from the relationship with their person with BPD. The Mixed Extreme and Mixed Copers were also caring for someone who tended to be older, and had displayed mental health problems for a longer period of time. This indicates that these groups had been negotiating BPD behaviours for a long time, perhaps long enough to believe that these behaviours may not change.

The Mixed group did not report the highest number of occurrences of BPD behaviours overall, as the Mixed Extreme group did, but this group did report the highest occurrences of suicidal and self-harm behaviours. It is therefore possible that a combination of the more distressing BPD behaviours, such as aggressiveness and violence and/or suicidal and self-harm behaviours, or in the case of the Mixed Extremes, high levels of a greater number of the BPD behaviours, less ability to remove themselves from the relationship, greater number of contact hours, and the belief that these behaviours are unlikely to change, may be associated with higher levels of avoidant coping.

Avoidant coping has been generally regarded as maladaptive for the reason that it has been found to be a good predictor of poor psychological health (e.g., Blalock & Joiner, 2000; Mullins et al., 1991; Ottenbreit & Dobson, 2004). People who use this method of coping often show more signs of psychological disturbance (Patterson, Smith, & Grant 1990). In previous studies, the use of avoidant coping has been associated with higher distress scores (Fortune, Smith, & Garvey, 2005), negative well-being (Stevens, 2007), and higher levels of compassion fatigue and burnout (Prati, Palestini, & Pietrantoni, 2009). It has also been found to be ineffective for eliciting social support or engaging in problem solving activities (Min et al., 2007), as the avoidant individual avoids the problem and the associated cognitions and emotions.
Nevertheless the use of avoidance coping strategies may be helpful in reducing distress in the short-term and by giving an individual some temporary relief. As Carver, Scheier, & Pozo (1992) put it, avoidant coping strategies, used short-term, give individuals a psychological breather and an opportunity to escape from the constant pressures of the stressful situation which, in turn, can help them use more active and adaptive coping strategies in the longer term.

Avoidant coping strategies were also used by the remaining groups in both studies, but less regularly and used in conjunction with other more active coping styles. The Active, Loving Copers and the In-Flux participant may give us some insight into the use of avoidant coping for these groups. They reported using predominantly the avoidant coping strategy of self-distraction for short periods of time to create some temporary mental distance from their BPD person for self-care and “re-grouping” purposes. Self-distraction strategies frequently reported were activities such as playing computer games, surfing the net, watching TV or movies, work and playing a sport. These coping strategies were reported to be valuable diversions to help these family members remain in a caring relationship with their person with BPD over the longer term.

Some coping strategies however were considered to be inherently maladaptive in managing stress even for short periods (Zeidner & Saklofske, 1996). One major example of this is the use of alcohol and drugs to cope. Using alcohol and drugs to cope is considered to be maladaptive because the harm or risk of harm associated with the substance use outweighs the benefits. For example, an individual may need increasing amounts of the substance to cope with everyday life or particular experiences. The use of alcohol and drugs to cope and regulate emotions has been associated with a lack of alternative coping behaviours (Maisto, Carey, & Bradizza, 1999). Given that the Bound and Powerless Group in the qualitative study, and the Mixed Copers and the Mixed Extreme Copers in the quantitative one reported the least support in managing their BPD person’s behaviours up to the time of the interview, it is possible that they had not had the same opportunities to learn ways of coping with behaviours that would be considered to be exceptional. Furthermore, using substances to cope with stress has also been shown to hinder the development of more adaptive stress-coping repertoires even if given the opportunities to learn them (Wills & Hirky, 1996).
4.1.1.2 Adaptive Coping

Coping is considered to be adaptive when behavioural strategies are used to reduce actual or potential stress (Solomon & Draine, 1995). Both problem-focused and emotion-focused coping approaches have the potential to be adaptive (Lazarus, 1993; Park, Folkman, & Bostrom, 2001) when they promote long-term benefits for the individual. It has been proposed that adaptive coping is the use of an appropriate combination of strategies for the situation, a blend of problem-focused strategies and emotion-focused strategies dependent on the changeability of the situation and the degree of distress (Bartram & Gardner, 2008).

There were groups in both the qualitative and quantitative studies that demonstrated the use of a mix of problem-focused and emotion-focused strategies. The Loving, Active Coping group and the In-Flux respondent from the qualitative study, and the Calmer Positive Coping group, the Reactive Coping group and the Mixed Extreme Coping group of the quantitative study reported using high levels of most coping strategies. With the exception of the Mixed Extremes, none of these other groups resorted to high levels of avoidant coping strategies such as drugs and alcohol to cope.

The way the groups combined problem and emotion-focused coping to be adaptive could not be drawn out from the quantitative study. However, the qualitative study was rich with this information. A typical example of the way the Loving, Active Copers and the In-Flux group participant combined the coping strategies to be adaptive was to initially engage in emotion-focused strategies to acknowledge, process and then accept that their loved-one was experiencing a mental illness, and then after emotional equilibrium returned, to engage in more problem-focused coping to deal with the overall care of their loved-one.

What the qualitative study was also able to demonstrate was that the Loving, Active Copers and the In-Flux participant generally reported using problem-focused coping strategies with the goal of being able to take better care of their loved-one, whereas for the other groups in the qualitative study, when they did use problem-focused coping, they did so in the context of setting boundaries with their BPD person and keeping themselves physically and/or emotionally safe.
What sets these groups apart from the others was that both the Calmer Positive and Reactive Positive quantitative groups, and the Loving Active Copers and the In-Flux participant from the qualitative study were caring for younger individuals with BPD. Within these groups in the quantitative study a greater percentage of individuals with BPD were between the ages of the 18 years to 35 years. In the qualitative study the individuals with BPD for the Loving Active Coping group and the In-Flux were also significantly younger than those associated with the Bound and Powerless and Distanced Managers groups. It appears that, at least for this study, the age of the individual receiving care may be a factor influencing the coping style of the person giving the care. No previous studies were found that looked at the relationship between coping style of the carer and the age of the person with a psychiatric illness receiving care.

There were, however, previous studies that have found that the age of the carer can impact on their coping style. Kartalova-O’Doherty and Doherty’s (2008) finding that the higher proportion of carers of someone with a mental illness reporting the use of avoidant coping strategies were significantly younger than those who did not report the use of such strategies was not consistent with the findings of this research. In fact, the carers in the current qualitative study who were more likely to use avoidant coping were generally older than in the groups who used a more active coping style, and the division of ages within the groups in the quantitative study were remarkably similar.

In summary, the results of this study supported an association between coping styles and the more distressing BPD behaviours, the nature of the relationship between the carer and the person with BPD, and the time-span of the BPD behaviours. Aggressiveness, violence, suicidal and self-harm behaviours, and high levels of a greater number of BPD behaviours were found to be related to higher levels of avoidant coping and lower levels of active coping for the participants of this study. This is consistent with studies that have found that patient problem behaviours (Mausbach, et al., 2006) and psychological distress (Manne & Glassman, 2000) were positively correlated with escape-avoidance coping. Being a spouse/partner and the length of time the BPD behaviours have been present were also associated with greater avoidant coping.
Differences in the coping groups translated into differences in a number of areas of impact for the family members/friends of someone with BPD. The following sections discusses the findings that family members/friend's experience of the relationship and the impact that being in relationship with someone with BPD had on the respondents.

4.1.2 Turning Point

Over 70% of the qualitative respondents and between 50% and 70% of the quantitative respondents identified a turning-point in their relationship with their BPD person which impacted on their ability to cope with the challenges inherent in the relationship. The qualitative respondents reported that this turning-point was not always a point in time but was often experienced over a period of time and was often experienced in the form of a change of perspective either of the relationship, their role, or the BPD relative/friend themself.

Turning-points, as an event or a slow dawning about the relationship with their BPD person, in both the qualitative study and the qualitative component of the quantitative study were not unlike those found by Karp and Tanarugachock (2000). Karp and Tanarugachock, although identifying four distinct stages in the experience of a family caregiver of someone with a mental illness over time, identified two definite pivotal stages. One occurs generally at diagnosis, with the other occurring much later. The first stage culminated in the diagnosis of a mental illness which was identified by many, in both the Karp and Tanarugachock study and the current studies, as pivotal. A diagnosis was reported to be pivotal as it enabled family members/friends to make sense of the bewildering behaviours and resultant confusion (Karp & Tanarugachock, 2000).

For quite a number of the respondents across the groups in the qualitative and quantitative studies, the discovery that their relative’s struggles and behaviours could be explained as a mental illness was experienced as a critical turning point for them. In the qualitative study the respondents reported that this discovery gave them an ability to see and appreciate their family member/friend separately from their challenging behaviours. For many this discovery also meant that they may not be entirely to blame for their relative’s condition. Pakenham (2008) suggests that it is important for caregivers to make sense of the realities of their situation so as to be
able to adjust to traumatic life events. One way to restore meaning is to find reasons or an explanation for what is happening, with Pakenham arguing that the achievement of this has been associated with better adjustment. Such was the case with the respondents who experienced a turning-point in the qualitative study. They generally indicated a positive change in the way they viewed their BPD relative and also in the way they viewed themselves in the relationship.

The second pivotal stage identified by Karp & Tanarugachock (2000) often happens much later and occurs around the period when the family member/friend accepts that the illness is outside of their control. It is a time when the family member/friend begins to set boundaries and limits and to decrease their involvement with the view to help themselves manage better and live a more satisfying life. This is consistent with some of those family members/friends in the qualitative study who had been living with their person with BPD mental health problems for the longest period of time. The Distanced Managers had got to a point after many years of negotiating the difficult and, at times, aggressive behaviour of their family member with BPD, of the need to set boundaries and limits which for some of them, helped them remain involved in their family members’/friends’ life in the longer term.

In the quantitative study it was the Reactive Positive Copers and the Mixed Extreme Copers who had the largest percentage of family members/friends who reported experiencing a turning-point. Although, as with the Distanced Managers in the qualitative study, the Mixed Extreme Copers had been living with the mental health problems of their family/friend for the greater number of years by far, the Reactive Positive Copers were not that different, in that respect, to the other groups. However, similar to the Distanced Managers, these quantitative group members reported high incidences of angry behaviour demonstrated by their person with BPD. These groups coped with their person with BPD with high levels of behavioural disengagement, in combination with high levels of a range of adaptive coping responses. This is in contrast to the Mixed Copers who had the lowest percentage of members who reported experienced a turning-point. This group also used high levels of behavioural disengagement, but without the use of the more adaptive coping responses. This suggests a possible relationship between coping styles and turning points. It may be that turning points allow sufficient perspective for family members/friends to balance disengagement with support and practical
help. The experience of a turning point by family members/friends in their caregiving role of someone with BPD could be an interesting topic for further research.

All in all, it seems evident that a turning point experienced either as a point in time or one encountered over time, was an important and valuable coping mechanism for these respondents. It allowed them to manage the turmoil of caring for someone with BPD and in some cases this was to survive it and in other cases to remain engaged with their BPD loved one. It was interesting that for two of the three respondents in the qualitative study who were not able to accept this realisation, they were also not able to observe any positive outcomes from the relationship.

4.1.3 Experience of Caregiving and Relationship with their BPD Person

The presence of caregiver burden was evident in the samples of both studies. Consistent with previous findings that looked at the burden of carers of someone with a mental illness (Reinhard & Horwitz, 1995), all respondents reported some level of objective and subjective burden in response to their caregiving role. Family members/friends of both studies generally reported high levels of negative and low levels of positive caregiving experiences in their role. In the quantitative study, with the exception of the Less Challenged Copers, the family members/friends reported scores within the top third of possible scores for negative caregiving experiences, and including the Less Challenged Copers, scores around the mid-point of possible positive caregiving experiences. All the family members in the qualitative study reported high levels of negative experiences in their caregiving role, but for all the members of the Bound and Powerless, and Distanced Managers groups, and for one member of the Active, Loving Copers, few, if any, positive experiences were recalled.

Despite overall high levels of negative caregiving experiences, and low levels of positive caregiving experiences for the family members/friends in the quantitative study, differences in these levels between the groups were evident. There was a trend for the Mixed Extreme Coping group to report the highest level of negative care-giving experiences in the quantitative sample and the Less
Challenged Coping group to report significantly lower levels of negative caregiving experiences. The Mixed Extremes tended to report higher levels of difficult behaviours, negative symptoms, experience of stigma, and the effect of the illness on the family.

Higher negative caregiving experiences for the Mixed Extreme Copers may be explained by the display of higher levels of difficult behaviours and negative symptoms in their person with BPD. Previous research has found that the severity of psychiatric symptoms, and in particular threatening, violent, and suicidal behaviour was associated with greater care-giver burden (Greenberg, Hea, & Greenley, 1997; Lowyck, et al., 2004; Winefield, 2000). Although there was no indication that the Mixed Extreme Copers were experiencing higher levels of self-harming or suicidal behaviour than the other groups, their family member with BPD, together with the family members/friends of the Reactive Positive Copers, were displaying higher levels of uncontrolled anger.

The higher levels of negative caregiving experiences may also be explained by the role the Mixed Extreme Copers had in the relationship with their person with BPD. The family members of the Mixed Extreme Coping group were more likely to be spouses/partners, and given the typical age-group and household composition of this group, very possibly with children present in the relationship. Previous research has suggested that spouses report the highest level of stress in caregiving (Pearlin, 1994; Schulz & Williamson, 1994; Silverstone, 1993), for the reason that spouses are likely to assume caregiving responsibilities if at all possible, and need to balance the difficult and demanding role of spouse and carer (Sales, 2003). Spouses were also found to experience lower positive affect and more resentment in the caregiving relationship often due to experiences of overload from balancing their employment and caregiving roles (Schofield et al., 1997). The most anguished postings on a web-based forum were found to be from spouses/partners who were concerned about the impact their partner with BPD may have on the children in the family (Mason & Kreger, 1998).

Higher levels of positive caregiving experiences in the caregiving role were reported by the Calmer Positive and Reactive Positive Coping groups which had a more equal distribution of parents and partners. Previous literature has found that parents reported more satisfaction with the caregiving role than did spouses or adult
children (Schofield, Herrman, Bloch, Howe, & Singh, 1997). Parents of adult children with a mental illness were generally found to be older, working less or even retired, less likely to report adverse effects on their financial situation, and able to draw support from their spouse/partner relationship. Younger care-givers, such as spouses/partners, typically reported higher overload as they struggled to balance their employment and caregiving role, adverse financial effects as they had difficulty meeting living costs, and a loss of the support they once found in their spouse/partner (Schofield, et al., 1997).

The experience of caregiving in the qualitative study was also found to differ between the groups. The participants who continued to have a loving and involved relationship with their BPD person, namely the Loving, Active Copers and In-Flux participant reported feelings of powerlessness and great worry over what they could offer their BPD loved one, especially in a time of great distress and when there was a threat of their loved–one harming themselves or someone else. In the words of one such caregiver in the qualitative study, it haunted her to have to stand back and watch the child that she has loved, cared for and protected her whole life, now want to take her own life and hurt herself the way she does. This sense of helplessness and anguish was not limited only to parents, but was also identified in a partner and sibling of a BPD person in the qualitative study.

For the Bound and Powerless Copers and Distanced Managers, the family members who experienced a more abusive relationship with their family member with BPD, the source of burden was what their BPD person was doing to them which often included unpredictable rages, violence and threats of violence, as well as accusations and blame. These experiences often placed these group members in the dilemma of needing to protect themselves yet still caring for their BPD family member in some form. Consistent with previous studies, the qualitative findings suggest that the experience of the caregiving relationship may also be associated with the quality of the relationship. Negative caregiving experiences in the qualitative study, were found to be clearly linked to the “closeness of the kinship bond” (Murphy, et al., 1997), and the nature of the relationship between the care-giver and the person with BPD.
4.1.4 The Impact the Relationship had on the Respondents’ Lives

The impact that the relationship had on the respondents in the quantitative study was assessed within a number of themes that were initially observed in the qualitative study. The impact of the relationship/role was assessed under the headings of the experience of distress, experience of posttraumatic symptoms, psychological well-being, and the experience of posttraumatic growth. Within these domains there were clear differences found between the groups in the level of impact that the relationship/role had on the respondents of this study. This was particularly the case in some areas of psychological well-being, posttraumatic symptoms, and posttraumatic growth. Surprisingly, there were no differences found between the groups in their experience of distress in regard to levels of depression, anxiety and stress.

4.1.4.1 Experience of Distress.

The relatives/carers within both studies reported extremely high levels of distress in times when their BPD relative/friend was experiencing a crisis. In the quantitative study, the family members/friends across all the groups reported severe levels of depression, anxiety and stress symptoms when their person with BPD was experiencing a crisis. Although these family members’/friends’ levels of symptoms reduced in times when things were relatively calm in the caregiving role, many family members/ friends continued to experience levels of residual depression symptoms.

The qualitative respondents indicated that during the periods when they were required to manage their BPD relative/friend’s unpredictable, suicidal and often angry behaviours, many of them were experiencing extremely high levels of depression, anxiety, and stress themselves which they felt they needed to inhibit or keep under control so that they could either continue to care for their BPD person or keep themselves safe. Moreover, many of the qualitative respondents also spoke of being too wary to relax in the calm times as past experiences had shown them that the period of calm that their BPD family member was experiencing was unlikely to last.

The high rate of anxiety, depression and stress experienced by the family members and friends in the current study is consistent with previous studies of
carers of individuals with a wide range of illnesses (Australian Bureau of Statistics, ABS: 1998). Research into the impact of caregiving for someone with a mental disorder showed that one-third to one-half of carers suffered significant psychological distress (Shah, Wadoo, & Latoo, 2010), and depressive symptoms were twice as common in caregivers than in non-caregivers (Canadian Study of Health and Aging Working Group, 1994). There is also some evidence to suggest that depressive symptoms can be causally related to the caregiving situation. Dura, Stukenberg, & Kiecolt-Glaser (1991) found that nearly one quarter of caregivers met the criteria for depression whilst in the caregiving role, although they had never been diagnosed with depression prior to their assumption of this role. It has been demonstrated that if the problem behaviours and the functional impairment in the care recipients was greater, the strain score is higher and the carer is more likely to be depressed. Angry and suicidal behaviours, characteristic of BPD was found to be one of the most common distressing symptoms for family members and caregivers in previous studies (Gopinath & Chaturvedi, 1992).

Although there were significant differences found between the groups in how they coped, there were no real differences found in their level of distress, namely depression, anxiety and stress. This is surprising given the wide variations in the mix of coping styles between the groups, as demonstrated in the quantitative study between the Less Challenged Copers and Mixed Extreme Copers. It is unclear why this may be the case, particularly given that significant differences were found in the level of severity of the crises experienced between two of the groups, namely the Less Challenged Copers and the Reactive Positive Copers who reported the lowest and highest level of severity respectively. It is possible that the Reactive Copers, the group which reported the highest level of severity of crises, may have kept their distress levels on a more even keel with the other groups by using higher levels of problem-focused coping and acceptance, as well as high levels of emotional and instrumental support, and humour which have been found in previous studies to lower distress e.g., (Southwick, Vythilingham, & Charney, 2005).

However, it is also possible that no differences were found between the groups in their levels of depression, anxiety and stress because when assessed for distress respondents were asked to think back to difficult times and relative calmer times. It is possible that a measurement bias occurred when the respondents’ were
asked to recall their distress times in this way and respondents recall of their experiences during these times were correspondingly high.

4.1.4.2 Experience of Posttraumatic Symptoms.

Respondents of both studies reported symptoms of posttraumatic stress. In the quantitative study all of the groups were found to have high levels of posttraumatic symptoms at one time. In fact, four of the five groups met the criterion for levels of symptoms that would be sufficient enough to be considered posttraumatic stress disorder (PTSD), and the remaining group of Less Challenged Copers only just missed out on this criterion. This group, however, reported fewer negative aspects of caregiving than other groups, especially in relation to difficult behaviours and the effect that their relative with BPD had on the family. For them it seems caregiving did not give rise to so many traumatic symptoms. The Mixed Extremes, on the other hand, reported the highest level of PTSD symptoms. This was also the group that reported higher levels of negative caregiving experiences, especially in relation to difficult and angry behaviours, and fewer positive caregiving experiences than the other groups. As with the Less Challenged Copers, it seems that the Mixed Extreme Copers’ experience of caregiving may have been a factor in their traumatic symptoms. Even so, it may also be that coping style and relationship to the person with BPD may also have some effect on the experience of traumatic symptoms. The Calmer Positive Copers, who were still reporting clinical levels of PTSD symptoms but at a lower level than the Mixed Extreme Copers, used the fewest maladaptive coping strategies in general, but also had a higher rate of parental carers.

Themes of posttraumatic symptoms were also found for respondents in the qualitative study. However in the qualitative study it was evident that, although the symptoms such as being on guard and difficulty sleeping, and persistent feelings of being on edge were reported by all groups, they were present for very different reasons for each of the groups. For the groups that reported physical and emotional violence in the relationship, the symptoms were in relation to their anxiety and fear of harm to themselves. For the groups where the aggression was more directed at the BPD person themselves, the symptoms were more related to fear and anxiety as to what their person with BPD might do to themselves.
The substantial endorsement of posttraumatic symptoms in this sample of family members/friends of someone with BPD should not be surprising. The qualitative participants were able to identify and often describe vividly the self-harming, suicidal and impulsive behaviours that their BPD person engaged in, as well as articulate the resultant expectation that their family member/friend could die. Even when the current crises had passed, ongoing surveillance of their loved one was reported to be essential as one could never be sure when the next life threatening crisis or violent reaction could be triggered. Exposure to potentially traumatic events therefore continued.

4.1.4.3 Caregiver Well-being.

Well-being in the current study was complex. Themes of fluctuating well-being affected by the caregiving role were found in the qualitative study. Levels of well-being in the quantitative study generally fell into the average range when compared with a large-scale population study (Marks & Lambert, 1999), suggesting that the well-being for these respondents was not necessarily as grim as has been found in previous caregiver well-being studies (e.g., Cummins, et al., 2007). There was a trend across the groups to experience higher levels of continued growth and development as a person, a higher sense of autonomy, a higher level of the pursuit of goals and a sense of purpose in life, and a higher ability to establish quality ties to others, when compared with their levels of self acceptance and their feelings of being in charge of the situation in which they live. The latter two domains of well-being were also lower than found in Marks and Lambert’s (1999) study suggesting that these two well-being domains may have been the greatest affected for the family and friends.

Generally, these findings are not entirely in agreement with previous research that has consistently found that carers of someone with a mental illness experience lower levels of psychological well-being than comparable samples in the population (e.g., Awad & Voruganti, 2008; Cummins et al., 2007; Glozman, 2004). It is possible that, as in the findings of a smaller number of studies, normal levels of well-being are sometimes experienced despite high levels of caregiver burden. In these studies where a family member was the caregiver, where duty was experienced, and where a feeling of becoming a better person as a result of the
caring role was present, the carers’ level of psychological well-being levels were buoyed (e.g., Silverstone, 1993). Potentially, these family and friends caring for someone with BPD also experience similar affects, given their attribution of generally average sense of well-being on Ryff’s (1989) scales of continued growth as a person and sense of purpose in life.

Not all groups, however, fared so well. When looking across the groups, it became evident that the Mixed Coping group reported the lowest levels of well-being, and the Mixed Extreme Coping group clearly showed areas of vulnerability in their well-being. The Mixed Copers tended to experience the lowest levels of well-being across all the domains. This group however did not report higher levels of negative caregiving experiences, or distress and PTSD symptoms than the Calmer Positives and the Reactive Positives who experienced significantly higher well-being levels. But the Mixed Copers differed in that they used significantly less problem-solving coping strategies and experienced significantly lower positive caregiving experiences than these other groups.

It seems as if a maladaptive coping style and a lack of positive experiences in the caregiving relationship may explain the difference. This suggests a possible association between coping styles and positive caregiving experiences and levels of well-being. The finding that coping style can impact levels of well-being is consistent with previous studies that found that the use of problem-focused coping styles buffered the impact of caregiving stress on the psychological well-being of caregivers (Essex, Seltzer, & Krauss, 1999). The finding in the current study that positive caregiving experiences may have impacted on the respondents’ level of well-being for the Calmer Positives and Reactive Positives is not consistent with previous studies that have found that negative caregiving experiences tend to have more of an impact on well-being (e.g., Cousins, 2001).

The Mixed Extreme Coping group presented the most complex picture. Although overall, they demonstrated comparable well-being levels to the Calmer Positives and Reactive Positives, they also demonstrated clear areas of vulnerability in their psychological well-being. The Mixed Extreme Copers had comparably high levels of positive relations with others and personal growth, yet their levels of self-acceptance and environmental mastery tended to be comparably lower than the other groups, apart from the Mixed Copers who were low on all well-being
domains. This suggests that although the Mixed Extreme Copers were open to new experiences and were enjoying high quality, satisfying relationships with others, they did not necessarily feel positive toward themselves and/or their past life, nor do they feel able to manage or control their own life and surroundings.

Possible explanations for the Mixed Extremes low levels of well-being in areas of self-acceptance and environmental mastery may potentially be explained by their person with BPD more likely to be their partner/spouse. In the case of the Calmer Positives and Reactive Positives, the person with BPD was more likely to be the son or daughter or parent of the respondent. This finding of lower levels of well-being for the Mixed Extreme group in the self acceptance and environmental mastery domains, together with the trend for them to experience somewhat higher PTSD symptoms is in keeping with other studies that have found spousal caregivers to experience more negative effects from caregiving (Biegel, Sales, & Schulz, 1991). One longitudinal population study has also demonstrated that caregivers of a spouse experienced greater decline in well-being in the dimensions of environmental mastery and self-acceptance and other well-being domains (Marks & Lambert, 1999). It seems that for the Mixed Extremes, as has been found for other caregiving spouses (Marks, 1998), the role of a caregiving spouse brings with it issues different to those of a caregiving parent or adult child caring for a parent.

As Marks (1998) indicates spouses/partners who are carers face numerous difficulties. They may feel socially isolated and find it a struggle to combine the caregiving role with other responsibilities such as looking after the family. Caregiving can have great financial implications, especially for low income families as one or both partners may be forced to give up work (Rees, O'Boyle, & MacDonagh, 2001), or if separated the remaining parent would need to provide for the family. Partners of individuals with BPD may face special challenges, particularly if there are children in the relationship. They may feel afraid to leave their spouse/partner alone with the children for fear the parent with BPD may not be able to cope with the children or because of the children being exposed to uncontrollable anger outbursts (Mason & Kreger, 1998).

It may also be that the extreme challenges that the Mixed Extremes face in their relationship with their person with BPD impact more on areas of well-being related to how they feel about themselves and their life, and their ability to be in
charge of the situation in which they live. The Mixed Extremes were the most challenged group, in that they tended to experience the highest level of negative caregiving experiences and angry episodes, the most frequent periods of crises and less periods of calm, and the highest level of PTSD symptoms. Given this constellation of factors, and that previous studies have found that caregivers’ well-being is affected by difficult symptom behaviours (Glozman, 2004), it is not surprising that the Mixed Extremes also reported feeling that their environment was beyond their control at times, and that they felt more personally challenged and self doubting.

This last aspect of being beset by more self doubts may also be attributable to being the spouse/partner of someone with BPD since social support from the partner is lost. Loss of social support previously provided by the ill person, especially in the case of a spousal relationship, often results in a sense of loss of companionship (Bethoux et al., 1996; Coughlan & Humphrey, 1982) and has been found to impact on the caregiver’s sense of well-being. In previous studies, caregivers who reported an ability to rely on support from their spouse enjoyed greater rewards from the relationship (Raschick & Ingersoll-Dayton, 2004) and fared better in their well-being (Brody, Litvin, Hoffman, & Kleban, 1992).

Quality of relationships with others and social support from others were also found to contribute to carers’ well-being in the qualitative study. Family members who reported that their levels of well-being were satisfactory, also reported experiencing warm, satisfying, and trusting relationships with others in general, and with the care recipient in particular. In contrast, those in the qualitative study, who indicated lower levels of well-being also tended to be in difficult and abusive relationships with their person with BPD. The Bound and Powerless group, who indicated that their well-being levels had been impacted the most severely, consisted of the family members who lived with chronic feelings of fear and anxiety in regard to their abusive BPD family member who they lived with. In contrast to the Distanced Managers, who were also in relationship with an abusive family member, they received very little external support.

Consistent with previous studies, positive relationships and social support in a care-giver’s life are known resilience factors for those caring for someone with a mental illness (Fraser & Pakenham, 2009; Jonker & Greeff, 2009), and are factors
often found to influence well-being in population of carers in other studies (Webb, et al., 1998).

It appears that the family and friends in the current study who were well supported or who were not spouses were using higher levels of adaptive coping strategies and were reporting higher levels of well-being. The Mixed Copers, as a group, generally tended to be less inclined to use adaptive coping strategies and reported the lowest levels of well-being across the domains. The Mixed Extremes, who as a group, used a mixture of a wide range of adaptive coping strategies at high levels, but possibly because they were so challenged, also used the other less adaptive coping strategies, had a mixed picture of well-being.

Overall, the main carer well-being findings were that levels of well-being were not necessarily directly influenced by negative caregiving experiences or levels of PTSD symptoms. However, those care-givers who did report lower levels of well-being also experienced less positive caregiving aspects in their relationship, less warm and satisfying relationships in their life, less support, and in some instances, less control over their risk of exposure to their person with BPD’s abusive behaviour. Lower levels of well-being were also related to less use of the problem-coping strategies.

4.1.5 Experience of Posttraumatic Growth

Despite the enormous stressors involved in caring for someone with BPD, the majority of respondents in this study reported that something positive had come from their experiences. In the qualitative study 11 out of 13 respondents identified some sort of positive outcome consistent with the themes that emerge from the posttraumatic growth literature (e.g., Linley & Joseph, 2003). These positive outcomes included changes such as a greater belief in oneself and one’s own abilities, a desire to give to others in similar situations, increased knowledge and greater appreciation for families who are struggling with mental illness, a greater appreciation for the experience of the relative that is struggling with BPD, personal growth, and for some an enhanced relationship with their BPD person.

Posttraumatic growth was reported by all the groups of relatives/friends in the quantitative study. However the Less Challenged Copers and the Mixed Copers consistently experienced significantly lower levels of posttraumatic growth in
comparison with the other groups, with the Mixed Copers only minimally exceeding the criterion for post traumatic growth. Both these groups experienced significantly lower growth in all the posttraumatic growth domains apart from spiritual change, which was low for all the groups.

A relationship between lower levels of posttraumatic growth and lower levels of PTSD symptoms has been suggested in the literature (e.g., Hagenaars & van Minnen, 2010), as posttraumatic growth requires the condition of a trauma experience severe enough to challenge an individual’s beliefs and assumptions about their world (Janoff-Bulman, 2004). Lower levels of trauma may have been a factor for lower levels of posttraumatic growth for the Less Challenged Copers as these family members/friends experienced significantly lower levels of PTSD symptoms and negative caregiving experiences.

The Mixed Copers, however, were among the groups that reported the highest levels of PTSD symptoms, and yet unlike the Mixed Extremes, who reported the highest level of PTSD symptoms, this did not translate into higher levels of posttraumatic growth. This finding indicates that although experiences of trauma may be able to predict posttraumatic growth, on its own, it can not account for the level of posttraumatic growth. Although factors such as greater social support and stronger connection to spiritual beliefs have been found to be associated with higher levels of posttraumatic growth (Cadell, Regehr, & Hemsworth, 2003), these were not considered in this study. However consistent with the previous finding that problem-solving coping style contributes to posttraumatic growth (Ozlu, Yildiz, & Aker, 2010), the Mixed Coping group used significantly lower levels of problem-solving strategies as compared to the other groups in the quantitative study who reported comparable levels of posttraumatic symptoms and negative experiences. Setting achievable goals and following problem solving coping to reach those goals have been shown to lead to a feeling of control and mastery (Hastings & Taunt, 2002), and better psychological outcomes such as psychological well-being and posttraumatic growth (Elci, 2004), domains in which the Mixed Copers experienced significantly lower levels.

An additional explanation for the varying levels of posttraumatic growth between the groups is that those respondents who report higher levels of posttraumatic growth may also be experiencing ongoing trauma, which may, in fact,
be fuelling their ongoing posttraumatic growth (Tedeschi & Calhoun, 2004). It was beyond the scope of this study to confirm this possibility but would make valuable future research.

4.1.6 Encounters with Professionals and Services

The respondents of both the quantitative and qualitative studies reported low levels of satisfaction in their encounters with services and professionals. The qualitative respondents reported many negative experiences in various forms and their discontent included the way professionals and services responded to and cared for their BPD loved one, as well as the way the professionals and services interacted with the respondents themselves. The groups that were more involved with their person with BPD’s care in the qualitative study were also more vocal about their dissatisfaction.

Comparable to the qualitative respondents, the quantitative respondents reported very low satisfaction levels across the groups. Low satisfaction was reported, not only in how helpful professionals and services were in caring for their family member/friend with BPD, but also in the support the carers themselves received from the professionals and services in their caring role.

Low levels of satisfaction were not related to whether the mental health sector was private or public, or the type of professional used as there were no real differences of use between the groups that was linked to differences in satisfaction. The relatives/friends reported that their person with BPD was more likely to present to general practitioners than any other professional, with smaller numbers reporting that their person with BPD used psychologists and cognitive behavioural therapists, with an even smaller number using a range of other services and professionals including psychiatric hospitals/departments.

Satisfaction levels of the carers for all the services/professionals were very low. When asked on a scale of 1 to 10 how satisfied overall they were with professionals/services in the care of their family member/friend with BPD, the responses fell between 2 to 3 for all participants. Although still extremely low, these family members/friends indicated that they felt the greatest satisfaction with GPs in their care of their person with BPD. Low satisfaction levels were reported for inpatient units and emergency departments of both private and public hospitals, but
lowest of all satisfaction was with Crisis Assessment Teams (CAT Teams). This indicates that when the relatives/friends with BPD of the respondents were experiencing a crisis, typically displaying high levels of distress and/or suicidal and self-harming intentions or acts, and possibly intense levels of anger, the emergency departments of hospitals and CAT Teams were not found to be helpful.

The literature reflects that, although there has been some positive shifts in the satisfaction levels of caregivers with professionals and services since the 1980s (Stengard et al., 2000), particularly in the areas of the outcome of contacts with some mental health professionals (Biegel, 1995; Tessler, Gamacho, & Fisher, 1991), there continues to be a general lack of satisfaction in caregivers across the world (e.g., Grosser & Vine, 1991; Ruggeri et al., 1994; Stengard et al., 2000). In fact, Winefield & Harvey (1993) reported that negative comments were four times more frequent than positive about professional helpers in their sample of family caregivers of someone with schizophrenia. In the current quantitative study, satisfaction was consistently below the 20% mark, with satisfaction of CAT Teams below the 10% mark.

There were also differences found between the quantitative family members and friends in their tendency to use professionals themselves to cope. The Mixed Extreme Coping group tended to use professionals themselves to cope with their person with BPD far more often than the other groups, with over 90% of this group reporting having engaged with a professional. The Less Challenged Copers were the least likely to use professionals for themselves to cope with just above 40% of these family and friends having used a professional to cope. This considerable difference is conceivably because the Less Challenged Copers have not had to cope with the same level of difficult behaviours and negative caregiving experiences as did the Mixed Extreme Copers. In fact, the groups of family members/friends who reported higher levels of PTSD symptoms and higher use of the more maladaptive coping strategies also reported higher use of professional help to cope.

Although satisfaction levels of the carers experience of their own use of professionals to cope was not assessed, differences in the use of a professional for family members/friends to cope did not translate into higher levels of satisfaction with professionals and services in their support of them as carers. Neither did it translate into higher levels of posttraumatic growth or well-being. Satisfaction
levels for professionals and services of the family members/friends who engaged in professional help themselves to cope was found to be just as extremely low as those who were less inclined to engage with a professional. This indicates that family members/friends either did not factor in the experience with their own professional, possibly because the work they did with their professional was not seen to be directly related to their role as a carer. Or they felt that they could not rely on professionals or services to support them in the caring role, regardless of whether they themselves were engaged with a professional outside the care of their BPD person.

Areas of dissatisfaction for both the care provided by services and professionals, and the support offered to them as care-givers in both studies were consistent with the findings of previous studies. Both the quantitative and qualitative respondents reported insufficient levels of information and practical advice from professional helpers, with the qualitative respondents emphasising that they had little information to deal with future crises (Ruggeri et al., 1994). Respondents of both studies also reported low satisfaction levels with the ability of mental health professionals across the board to hear and understand their concerns, and with the support offered to them in their caring role (Ruggeri et al., 2003). Difficulty accessing useful professional help in the event of a crisis (Morgan, 1989), and inadequate secure aftercare services (Biegel et al., 1995; Hanson & Rapp, 1992; Ruggeri et al., 1994) were areas of dissatisfaction expressed by the caregivers in the qualitative study. There were also numerous references in the qualitative study to sending the BPD person home from hospital “too early”, for example when they were still feeling actively suicidal and/or self-destructive which meant that the caregiver was responsible for keeping them safe. Respondents of both studies indicated that even professional staff appeared unsure of how to adequately care for their BPD person at times.

Themes of dismissive attitudes by staff and strained relationships with the health and mental heath systems were consistent with previous studies (e.g., Giffin, 2008) and were not uncommon in the qualitative study. As was the experience that the respondents’ caregiving contributions were either undervalued or criticised by health professionals (Beautrais, 2004). Similar to the descriptions in Corrigan and Miller (2004) a number of qualitative respondents had been blamed openly for their
relative’s/friend’s condition. Negative experiences with professionals and services such as these were reported to leave the caregiver feeling even more cut-off and alone than they already did in managing the situation and their role.

The literature points out that a lack of support from health and mental health systems have negative consequences for caregivers. High levels of psychological distress (Winefield, 2000), caregiver burden and depressive symptomatology, such as that reported by the family members and friends in this study, have all been associated with dissatisfaction with mental health care providers (Song et al., 1997).

There is a strong consensus among the respondents of this study that they would benefit from enhanced knowledge about the diagnosis, its management, and the services available to them as caregivers. Stengard (2002) adds that once the informational need has been met, the caregiver may additionally benefit from interventions that train the caregiver in general problem-solving skills as well as more specific skills in areas such as managing the patient’s behaviours or their own affect.

4.2 Methodological Considerations

It has been said that the overall purpose of research in any profession is to discover the truth of the discipline (Carr, 1994). In the case of the current research it was to extend understanding of the experiences and responses of those in relationship with someone with BPD. To achieve this end the researcher utilised a combination of qualitative and quantitative approaches to reinforce and validate findings. Qualitative and quantitative approaches complement each other, so that the inadequacies of each method may be offset (e.g. Carr, 1994; Morse 1991). In the case of the current research, a qualitative approach was invaluable for the exploration of the subjective experiences and responses of the family and friends. The semi-structured interviews provided a rich source of information about the respondents’ experiences of being in relationship with, and caring for someone with BPD, whilst the quantitative component of the research facilitated the development of quantifiable information that allowed us to measure and analyse possible relationships between the different variables within the study in a larger and more diverse sample. It also allowed examination of whether similar ways of coping and
perceptions of the impact of caring for someone with BPD were evident in the larger sample.

However some caution is warranted. A significant factor is the lack of opportunity for independent verification of the events and responses reported. This problem is not unique to qualitative methods, as responses to the quantitative questionnaires were self-report and therefore also cannot be verified. Both the qualitative and quantitative data were based upon the participants’ recollection of how they responded to events that occurred in the past. In some cases, the event/s occurred a long time ago, and this increases the possibility that aspects have been forgotten or that the memory of the event/s have been distorted over time. This is however a common problem to all retrospective studies. Asking people what they did only days ago can elicit distorted recollections (Bernard, Killworth, Kronenfeld, & Sailer, 1984). Nevertheless, often an examination into the experiences and responses of someone who is very likely disoriented and even traumatised by the onset of what is often perceived as life threatening behaviours to someone they have cared about, can often only be recognised and reflected upon in retrospect. Some evidence of the validity of family members'/friends’ recollection of their experiences and responses can be found in the congruence between their responses to the research questions and those reported in the literature, as well as in the congruence between results determined by qualitative compared to quantitative methods.

Sample bias is a further issue warranting consideration. Participants in both studies volunteered. There is a possibility that family/friends who were more confident or considered themselves to be coping more effectively may have self-selected, and those who were less confident in their abilities or who were experiencing high levels of distress at the time of the study may have avoided participation. In fact, one mother who participated in the qualitative study identified that if her daughter had been experiencing a crisis episode at the time of the interview, then she would not have participated as she did not think that she would be capable of coping with the high levels of trauma and stress associated with the episode, and reliving it again by talking about it. The refusal to participate by potentially eligible participants has yet to be studied in PTSD outcome research (Spinazzola, Blaustein, & van der Kolk, 2005). However, efficacy research on Axis
disorders has revealed self-selection patterns that may limit generalization of study findings (Hofmann et al., 1998).

A further limitation is that the sample in the qualitative study was small and consisted totally of female participants and numbers of male relatives/friends in the quantitative study were insufficient to examine gender differences. Therefore male relatives/friends were not adequately represented and differences related to gender were not able to be assessed. The literature informs us that the caring experience of men and women may be different despite seemingly identical circumstances (e.g., Bedard et al., 2005).

Furthermore, the participants in the qualitative study were recruited mainly from two BPD Carer Support Groups operating in one capital city in Australia. At the time of recruitment for the qualitative study, the researcher was unable to locate any other support groups or programs specifically developed for the relatives and friends of BPD in Australia apart from these two, which made it difficult to access relatives and friends. Ideally, a sample taken from a variety of settings, and including those relatives and friends who have severed their ties with their BPD person may have given a fuller perspective on the experiences and needs of a wider-range of relatives/friends. Nevertheless, the respondents of the quantitative study came from all over the Western world which, although having its own limitations, provided a much larger capacity to generalise the results.

4.3 Implications

With the expansion of community mental health care, many more families/friends will be required to make a commitment to care for an ill family member. The experience of being a carer goes far beyond that of any professional caregiving experience (Jeon & Madjar, 1998). The findings of this study show that caring for a person with BPD has social, physical, and psychological costs, as well as compromising the family member’s/friend’s ability to work in some cases. The psychological costs, in particular, appear to be present for a lot longer than the BPD person’s extreme behaviours. The psychological costs are significantly increased by feelings of “being unable to cope” or manage during difficult periods, as well as the unpredictability and uncertainty of their BPD’s destructive and sometimes violent behaviours, and lack of informed strategies in times of emergencies. These factors
were exacerbated by feelings of isolation and aloneness created, in part, by a lack of professional support during these times.

The findings of this study suggest that the role of caring for someone with BPD is often unexpected and unplanned for, and therefore the family members/friends typically do not have the skills or resources to deal with behaviours that even professional carers find difficult and challenging to deal with. As a result these family members/friends experience high levels of distress, high levels of posttraumatic stress symptoms and caregiver burden both in times when their BPD person is experiencing periods of crisis and in times of relative calm. Insufficient practical and emotional support from professionals and services in their caregiving role, coupled with the sense that most health professionals do not understand the human experience of carers of someone with BPD, served to increase their feelings of confusion and isolation, and gave the message that they should manage on their own.

4.3.1 Initiatives Needed to Help Carers of People with BPD

The findings of this study demonstrated that family members and friends who find themselves in a caring role with someone with BPD could benefit from initiatives to better support and prepare them for their caregiving experience. These initiatives should aim to provide the family members and friends with knowledge, understanding, and information about the BPD diagnosis, as well as provide ongoing support.

As shown in this study, the family members and/or friends of someone with BPD often found themselves in the position of needing to care for their BPD person, particularly in a crisis situation without any formal training, and typically without having had any strategies to deal with the crisis. This was especially so at the onset of the difficult and self-harming behaviours. Participants’ feelings of not coping and being overwhelmed during these times were increased by their lack of knowledge, understanding, and information about BPD. The literature repeatedly demonstrates the benefits of providing educational programmes for new carers and ongoing support for more experienced carers of someone with a mental health issue, yet satisfaction with such services was extremely low indicating that they are inadequate (Dixon et al., 2004; Hayman, 2005).
The literature identifies that there are already existing resources for carers for a variety of disorders that have been found to be helpful. For example, family education programs exist that acknowledge the strengths and capacity of families to deal with problems (Atkinson & Coia, 1995; Solomon, 1996). Family education programs often aim to bolster the family’s sense of mastery and identify skills the family may be already implementing. These programs recognise the enormous burden that these families encounter (Solomon & Draine, 1995), and assume that, with assistance, families can develop successful coping strategies to live with their relative’s illness and reduce the burden and stress to themselves (Solomon & Draine, 1996). Family education programs specific to BPD, although still seriously lacking, have been slowly developing. Examples are the Family Connections Program (Hoffman et al., 2005), and psycho-educational programs (e.g., Gunderson, Berkowitz, & Ruiz-Sanchero, 1997), and multi-family groups (e.g., Gunderson & Berkowitz, 2006) developed specifically for BPD family members.

Family support groups run by both professional workers and peers have also been found to be valuable in providing information and support to carers. In the family literature self-help groups are more frequently referred to as support groups where dialogue, self-disclosure and encouragement amongst members of the groups is promoted (e.g., Mitchell, 1996). These groups are recognized as being a service targeted directly at meeting the needs of informal carers (Mitchell, 1996). Benefits to carers from attending support groups are well documented in the literature (Health Canada, 2002). For example, family support groups have been found to provide direct emotional support and relieve isolation (Kuipers, McCarthy, Hurry, & Harper, 1989), and assist with the objective and subjective burdens of caring for someone with a mental illness by providing education and information, increasing knowledge of services available and enhancing the problem solving capacity of carers (Reay-Young, 2001).

For the family members/friends in this study, information, education and support were found to be seriously lacking. As far as the researcher was aware there were only two support groups in Australia for carers of someone with BPD at the time of recruiting for this study, which met their educational and support needs most of the time. Although the bulk of the qualitative sample were attending or had been
attending one of these support groups, participants reported that it has been a challenge to find these groups, and was only achieved through unrelenting persistence on their part. Quantitative respondents also reported very low satisfaction levels with the resources available to them and with the ability of these resources to meet their needs for information and for their concerns to be heard.

The family members and friends in this study clearly indicated a need for education and training to ensure they have the skills and strategies to deal with potentially dangerous behaviours in their own home. Having some strategies to fall back on when their BPD person presents in crisis and are at risk of self-destructive or violent behaviours would also be helpful. This should not be surprising given that carers of someone with BPD are regularly exposed to self-harming, suicidal, and risky behaviours that could be potentially dangerous to either BPD family member or even to the carer themselves. Research has shown that overall, carers who received information on assessment and suicide prevention strategies felt more confident and at ease about dealing with these potential behaviours than those who did not receive this information (Sun & Long, 2008).

One of the few programs of this type that has been validated was a joint program of the Calgary Health Region and the Alberta Mental Health Board in Canada. The Calgary Psychosis Program demonstrated that a family intervention in the first two years after a family member has experienced an episode of psychosis, consisting primarily of frequent contact with workers offering high levels of practical and emotional support, education, discussion about coping strategies, and problem-solving skills, could result in a considerable reduction in distress and impact of the illness when the family program is an integrated part of treatment (Addington, Collins, McCleery, & Addington, 2005).

Mental health and health professionals are in the best position to routinely provide the family and friends of the presenting BPD individual with information about the BPD diagnosis, and to direct the affected carers to further resources, organisations and education/support groups. Health professionals could routinely provide carers with information about the diagnosis of BPD, the treatments available for their BPD family member/friend, and the details of organisations that could be of further support to the carers. Contrary to this practice, carers in the qualitative component of this study reported that health professionals that they came
into contact with in the care of their BPD person did not know of any BPD specific support resources for carers despite two support groups being in existence in the same city.

There is also a need for health professionals to promote structured and ongoing emotional support for carers. Current research is clear that carers who receive emotional support while caregiving fare far better and provide care longer than those who do not (e.g., Falloon, 2003). Some of this research also suggests that the uniqueness of each carer, their caregiving situation, and their assets must be acknowledged by health professionals and emotional support should focus on facilitating carers’ strengths rather than only educating the carer about their family member’s mental illness and related pathology (Doornbos, 1996).

The provision of emotional support is especially important during emergency situations given that the current treatment approach following self-harm is brief hospital admissions. After medical clearance by the emergency department, discharge to the care of family or significant others is often standard procedure (Giffin, 2002; Wynaden, 2002). As a result the carer is required to care for someone who is likely still distressed and possibly still feeling suicidal. A psychiatric emergency service that meets both the needs of BPD clients and carers could be made available to carers. Many qualitative respondents identified that as emergency situations arise after hours, this service needs to be available for carers 24 hours a day, and preferably manned by professionals who specialize in BPD and who may be able to offer practical advice and emotional support in times of emergency. The participants considered that this type of service would ease their feelings of isolation, decrease the trauma of feeling like they did not have the skills to cope with the situation and be a source of up-to-date information of other resources available for BPD carers. This type of specialized service could act as an emergency service for carers and support them at a time where many mental health professionals in emergency outpatient departments seem to lack the skills and resources to do so.

Other possible support for carers may develop via the internet, where support for carers is becoming more commonplace. Increasingly, carers are turning to the internet for quick and private accessing of information and emotional support (Blair, 2002). Although the internet can be a valuable tool that provides easy access
for carers to information and support, it also has it shortcomings. For example, it is
possible that the breadth of information available on the internet can be confusing
for the carer, and/or that the information may be inaccurate or out-of-date. This
occurred for one mother in the qualitative study who became despondent and felt
hopeless for a time because the information she read from the internet incorrectly
stated that BPD was practically untreatable and most BPD sufferers do end up
killing themselves. Support in the form of chat rooms and discussion forums have
often been reported by those who use them as validating and valuable. But again,
users need to be aware that not all posts on all forums are monitored which means
that the content of the posts would need to be treated with some caution. For these
reasons it is essential that professionals take some responsibility to increase
awareness of the potential value and pitfalls of using the web for information and
support. While they may encourage carers to seek out information and support on
the web, professionals need to warn carers to approach this information in a critical
manner, and to discuss their internet findings with a professional.

A model of a helpline for carers can be found in the Cancer Helplines
available in a number of countries. In Australia such a service is provided through a
national toll-free number assumed to overcome barriers to access such as
geography, ill-health, and cost. Cancer helplines provide potential assessment and
are a referral point for patients and family members. They are staffed by nurses and
allied health professionals who have experience and/or qualifications in oncology
and decision support. Such helplines provide brief cancer information, emotional
support, and up-to-date and extensive information of community and hospital based
services. Although there are a number of telephone helplines available for carers of
someone with a mental illness in Australia, for example Carers Australia which is
available in all states, and the helpline at Sane Australia, these Helplines are only
available in business hours and one is not guaranteed that the call will be received
by someone experienced with BPD.

4.3.2 The Enhanced Delivery of Formal Mental Health and Health
Services

Initiatives directed towards health professionals could also significantly
impact the family member’s/friend’s experience in caring for someone with BPD.
Carers in this study expressed the need to be acknowledged and valued by health professionals and to be seen as partners in the caring experience. Although the “partnership model”, as outlined in the Australian Second Mental Health Plan (Australian Health Ministers, 1998) encouraged the collaboration between carers, primary clients, and health professionals, a subsequent evaluation of the plan (Australian Health Ministers, 2003) stated that although progress had been made toward carer participation, it appears that this model has not been applied to BPD clients and their carers. Wynaden (2002) found that the collaborative model has not been routinely implemented at service level. In her study, as in this current study, many professionals continued to demonstrate an unwillingness to communicate with carers, as well as showing uncaring attitudes and responses toward carers. As Wynaden points out, these attitudes and responses on the part of professionals are in direct contradiction to the Australian National Mental Health Strategy. Moreover, the level of caregiver involvement was found to be dependent upon health professionals’ perception of how and when caregivers should be involved (Casey, 2000). Consequently, if the health professional at point of contact deems it unnecessary or inappropriate for the carer to be involved then it is extremely difficult for the family member/carer to get past this barrier due to the unequal distribution of power in the professional/family carer relationship.

Some of the possible obstacles for health professionals in allowing successful and meaningful participation of family/friends in the care of their BPD person may be a lack of knowledge, skill, and resources to enable health professionals to more effectively involve carers. Health professionals have been found to be often constrained in their ability to involve caregivers for a number of reasons. High acuity of illness and low staffing levels in many health settings have resulted in staff barely having enough time to care for the primary client (Wynaden et al., 2001). In addition, health services have failed to provide clinicians with best practice standards for the involvement of carers. Therefore carers’ involvement has been subject to the individual clinicians’ perception of how and when they should be involved (Casey, 1995). Furthermore, clinicians’ previous negative interactions with carers, such as carers directing their anger and frustration toward health professionals, have resulted in clinicians being defensive in further encounters with carers (Walker & Dewar, 2001). Not the least barrier to carer participation in the
care of their mentally unwell family member/friend is the continued confusion over the issue of a service’s primary client and confidentiality, and how this relates to the involvement of a carer.

In order to provide quality mental health care, health professionals require urgent education on patient confidentiality laws in relation to those who take part in the care of someone with BPD. Fitch (1994) maintains that, while health professionals have a requirement to maintain a client’s confidentiality, in practice this is not a straightforward issue. Marshall and Solomon (2000) found that carers were often deprived of all information regarding their family member’s illness as a result of health professionals’ confusion concerning what constitutes confidential information. This is a real issue given that carers are often the frontline carers for their BPD person and are repeatedly used as safety nets by mental health professionals when the BPD client is in crisis and/or at risk to themselves. Yet they are expected to accomplish this without being provided with an appropriate level of information. Education in the complexities of confidentiality both at a general service level and for all professionals is sorely needed. Ongoing education of professionals and ongoing support from management in the model of family sensitive practice is essential if a collaborative model of care is to be realised.

Education and training in family sensitive practice will need to target the individual clinician, as well as organisations as often the organisational culture may dictate that the client is only “the presenting patient”. Such training already exists in Victoria, Australia, where The Bouverie Centre promotes Family Sensitive Practice as a values-based framework for promoting constructive family involvement at all levels in the delivery of mental health care. Their program, FaST (Family Sensitive Training), promotes training to increase the sensitivity of mental health services to families, with details of the program provided on their website. This training also incorporates the understanding of the subjective experiences of families/carers, and the development of a sense of partnership between family members/carers and service providers.

**4.4 Further Research**

The findings of this study reveal the complexity and diversity of experiences of the family members and friends who care for a person with borderline personality
disorder. While this research adds to the existing literature on this topic, further research is needed. Such research needs to focus on the complex relationships between factors such as coping, quality of life, distress and experience of trauma, and posttraumatic growth, as well as social and emotional support. This research should focus on how health professionals and policy makers can better support these family/members and friends in their care of someone with BPD so as to help to reduce these individuals’ physical, social, economic, but in particular, the psychological costs of caring. Research needs to be completed in a variety of social, geographical, and cultural contexts to ensure all affected persons are taken into account, for as we know, BPD is not confined to any one specific culture or socioeconomic group (DSM-IV-TR, 2000).

It is recommended that further research be completed to evaluate the efficacy of mental health professionals’ ability to interpret and implement the concept of confidentiality in the context of family sensitive practice. This is particularly important as confusion about what information can be shared with carers has been shown to be a major contributor to little or no information being shared with carers in other studies (e.g., Marshall & Solomon, 2000). Too little or no information regarding their BPD person’s state has resulted in the family members/friends of the current study “floundering in the dark” in their caring role of someone who often displays risky behaviours. As a result of this lack of information, feelings of not being able to cope and ensuing distress are compounded for these members/friends caring for someone with BPD.

It would also be important for further research to assess the barriers to family sensitive practices both at an individual professional level, but also at an organizational level. It has been shown that an individual professional’s stance on family sensitive practice is not enough to make a difference if the organization they work for does not consider it to be an important issue. Some research has already been conducted in community mental health settings (e.g., Boots & Beasley, 1999; McNamara, 2006) where barriers in these organizations have been well studied and identified.

Finally, when the present study was conducted there were many references made to the costs of the other relationships in the life of the person primarily taking the caring role of the BPD person. The literature supports this view that there are
relationship costs for carers. For example, carers often report a tendency to withdraw from their social network for reasons such as lack of energy as a result of the demands of caring, and a perception that their social network would not understand the behaviours of the mentally unwell family member/friend (Magliano et al., 2006). Carers also reported having disagreements with other family members about caring even when they were well supported. Compared to carers of someone with a physical disability, carers of someone with a psychiatric disability have been found be the most likely to report two or more problems in family functioning, have higher rates of separation or divorce (Edwards, Higgins, Gray, Zmijewski, & Kingston, 2008), and have a negative impact on non-disabled siblings, perhaps because of the reduction in attention they receive (Higgins, Bailey, & Pearce, 2005). Although these issues were outside the scope of this study, they are important issues and important areas of future study.

4.5 Conclusion

The purpose of this thesis was to explore the experiences and needs of family members and friends caring for someone with BPD. This research offers some insight into what it is to be a carer of someone who displays behaviours that even professional carers find difficult to work with, and yet family members/friends do so without training. Using both qualitative and quantitative data, this study has highlighted that those caring for someone with BPD are typically thrust into this role without any preparation or resources to cope with the immense challenges that come with caring for someone with BPD, and that these resources and skills go far beyond what is usually required in ordinary living.

This research has also offered some understanding into the immense responsibility that the family members/friends of someone with BPD must typically undertake. Taking responsibility for keeping their BPD person safe from their own destructive behaviours was one responsibility commonly reported. As one respondent declared “what choice does one have when confronted with a someone (often a loved one) who is at risk of killing themselves either on purpose or by accident”. This responsibility ranged from taking their BPD person to the emergency department for medical treatment for their self-harm or suicide attempt, to guarding them in their own home, sometimes all day and all night.
The caring role for these respondents was not without its costs, and it appeared that the greatest cost for the respondents was their own mental health. High levels of negative caregiving experiences, frequent crisis periods, extremely severe distress levels during these crisis periods, and higher depression levels than the population norm even outside these crisis periods were standard for this population, as were posttraumatic symptoms that were high enough to meet posttraumatic stress disorder levels. Despite all of this, however, this sample also reported experiences of posttraumatic growth. Some participants in the study explained how their experience of caring for someone with BPD had changed them and forced them to reflect on other important areas in their lives. Several participants felt that, although they would never “wish such experiences on anyone”, they had grown from the experience and felt that they had become more compassionate, accepting, and tolerant of other people.

This detailed exploration into the experiences and needs of family members/friends of someone with BPD has been undertaken with the view that it be of value to other family members of someone with BPD, mental health professionals, family oriented organizations, health and government and policy planners. The findings can be used in a variety of ways to facilitate a carers’ movement from feeling overwhelmed, and alone and isolated in their caregiving experience to feeling supported in their demanding role. It is anticipated that the findings can be used to help health/mental health professionals become aware of the high cost of caring for someone with BPD and assist carers to access the support they need for themselves. Nevertheless, although this research has contributed to the knowledge about the experiences and needs of those caring for someone with BPD, there is much that is still unknown. It is the desire of the author of this study that the findings of this thesis inspire further research into this area.
References


Biegel, D., & Tracy, E. (1993). *Natural Supports Project: Final Report to the Ohio Department of Mental Health.* Cleveland: Case Western Reserve University.


Giffin, J. (2002). *The Experience of Parents Who have an Adult Daughter with a Diagnosis of Borderline Personality Disorder* (Unpublished master’s thesis). Latrobe University, Bundoora, VIC.


Ruggeri, M., & Dall'agnola, R. (1993). The development and use of the Verona Expectations for Care Scale (VECS) and the Verona Service Satisfaction Scale (VSSS) for measuring expectations and satisfaction with community-based psychiatric services in patients, relatives and professionals. *Psychological Medicine, 23*(2), 511-522.


The Mental Health Council of Australia, in partnership with the Carers Association of Australia. (2000). Carers of people with mental illness project.


My name is Wenda McPherson. I am currently completing my Professional Doctorate in Psychology at Swinburne University. My research examines the experiences and needs of family members and carers of someone who has Borderline Personality Disorder. This research is important because to date very little is known about the experiences and needs of individuals the Borderline Personality Disordered person is in relationship with. It is expected that this study will help others, including professionals gain a better understanding of that experience and begin to identify some of the gaps in the services for the families and carers of those with Borderline Personality Disorder. I would like to invite you to participate in this important research study to be conducted under the supervision of Dr Roslyn Galligan.

As the purpose of this study is to find out more about how the presence of someone with Borderline Personality Disorder affects the lives of the people around them, we will require participants to answer a series of questions that relate to this issue. This means that participants will take part in an interview in which personal questions will be asked about their lives, and how having to care for someone or be a family member of someone with BPD has affected different areas of their life. An example of the questions I will ask is “Has your BPD family member affected your social life” and “if so, then how has your social life been affected?” All in all, participation in the study will take around 90 minutes of your time.

For convenience I would like to use an audio-tape recorder to record your responses. While the information collected will be personal in nature, we will not be recording any of your personal identifying details with the interview information. You will, however, be asked to complete and sign an informed consent form to confirm that you are participating voluntarily, and understand what the study is about. Any documents that contain identifying information will be kept separate from the recorded interview at all times in a secure place. Where direct quotes are used for illustrative purposes in reports and publications they will be used in such a way that no individual may be identified.

Participation is voluntary, and participants are free to withdraw from the study at any time without adverse consequences. Any information gathered up until the time
any participant withdraws would then be destroyed. At the completion of the study a summary of the findings will be available to participants.

Should you decide to participate, please complete and sign the consent form and return it in the reply paid envelop provided (please note that a stamp is not necessary) or hand it back to the facilitator of your support group. The researcher will then contact you to set up a time and place that is convenient for you.

At the completion of the interview you will be given the option to participate in the second phase of this study which will involve filling out a questionnaire within about 6 months of the interview. This is absolutely optional and taking part in the interview does not oblige you to take part in the questionnaire phase.

This research conforms to the principles set out in the Swinburne University of Technology Policy on Research Ethics and the NHRMC guidelines as specified in the National Statement on Ethical Conduct on Research Involving Humans.

If you have any concerns during or after completing the interview you are encouraged to discuss these with the researchers, Ms. Wenda McPherson on 9214-8653 or Dr. Roslyn Galligan on 9214-5345.
CONSENT FORM

Project Title: The Experience and Needs of Family Members and Carers of Someone Who Has Borderline Personality Disorder

I, .......................................... of, ..............................................................
(Name) ................................................................. (Address)

Contact Phone No: ............................................

agree to take part in the above Swinburne University research study. I have had the study explained to me, and I have read the Plain Language Statement, which I may keep for my records. Any questions I have asked have been answered to my satisfaction.

I understand that my participation is voluntary, that I can choose not to participate in part or all of the study, and that I can withdraw at any stage of the study without being penalised or disadvantaged in any way.

I understand that agreeing to take part in this study means that I am willing to be interviewed by the researcher and that the interview will be recorded on audio-tape.

I agree that research data collected for the study may be published on the condition that any information I provide is confidential, and that no information that can lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable information personal data will be published. The identifiable data will not be shared with any other organisation. Where direct quotes are used to help illustrate the experiences and points of view of the family members and carers of someone who has Borderline Personality Disorder, I understand that they will be anonymous and used in such a way that no individual may be identified.

NAME OF PARTICIPANT:

SIGNATURE: ........................................ DATE: ........................................

PRINCIPLE INVESTIGATOR/S:

NAME: ........................................ SIGNATURE: ........................................ DATE: ........................................

Ms. Wenda McPherson

Dr. Roslyn Galligan

DATE: ........................................
SEMI-STRUCTURED INTERVIEW QUESTIONS

BPD Screening Questions

Do you think that your BPD person:
- Will go to extremes to prevent those that they love ever leaving them.
- Either loves someone or hates them with nothing in between.
- Often wonder who they really are.
- Have tried to hurt or kill themselves.
- Is a very moody person.
- Feels that life is dull or meaningless.
- Have difficulty in controlling their anger or temper.
- When they get stressed, things happen like they get paranoid or just black-out.

1. The nature of the relationship

Identifying information:
When were you born?
What is your current marital status?

Has ________________ received a diagnosis of BPD?
How long ago?
Has ________________ ever needed to be hospitalized with BPD?
If yes how many times? And for how long?
And for what?

What is your relationship to ________________?
Do you live in the same house as ________________?
How much contact do you have with ________________?
How many people in total live in your household?

How would you describe your relationship with ________________?

What role/s do you play in the life of ________________?
Caregiving?
Protector?
Confidante?

What behaviours and/or actions does ________________ demonstrate that you find difficult to deal with?
Unpredictable?
Impulsive?
Acting-out behaviours?
Risky behaviours?
Sexual behaviours?
Self harming behaviours?

How often would these behaviours been apparent?
On a scale of 1 to 100 how severe would these behaviours be?
What is the most challenging and ongoing experience you have as a relative or carer of ______________?

What is the worst experience you have ever had as a relative or carer of ______________?

2. The impact of the relationship

What impact is being in relationship with or caring for ________________ having on your own life?
   How would you rate the impact on a scale of 1 to 100?
   ▪ In your own mental health? (Had you experienced any mental health concerns prior to this yourself?)
   ▪ In your relationship with other members of the family?
   ▪ In your other relationships and friendships?
   ▪ In your social life in general?
   ▪ In your capacity to work?
   ▪ On your finances in general?
   ▪ On your physical health?
   ▪ On your overall sense of well-being?

Have you ever experienced?
   How often would you say you experience this?
   ▪ being on-guard (watchful) all the time
   ▪ feeling of being on edge
   ▪ difficulty concentrating
   ▪ difficulty falling or staying asleep
   ▪ recurring images, thoughts or dreams in relation to ____________’s behaviours?

Have you ever had reason to fear for your own or others safety because of ____________’s behaviours?

Has anything positive emerged as a result of being in relationship with or caring for ________________?

3. Coping behaviours used

What have you done in the past to cope with the stress of being in relationship with / or caring for ________________?
Examples:
Been turning to work to take my mind off things?
Been turning to other activities such as sport, hobbies, or other leisure pursuits?
Been taking action to try and make your situation better?
Been using alcohol and other drugs to make myself feel better?
Been getting comfort and understanding from others?
Been getting help and advice from others?
Been giving up the attempt to cope?
Been expressing my negative feelings?
Been trying to see it in different light?
Been learning to live with it?
Been trying to find comfort in my religious or spiritual beliefs?
Been blaming myself for what is happening with ______________?  

Are there times when you just have not been able to cope?  
If yes, on average how often have you had this experience?  

Can you recall a time when you have not been able to cope, for example an experience of extreme despair in your relationship with ____________?  
What did you do to cope during this time?  

Do you have any self-care behaviours in place to help you cope?  
Example:  
Take time out to do things that you enjoy doing?  
Spend time with others whose company you enjoy?  
Reward yourself with something you have wanted?  

When you are upset how do you calm down?  

What are the things you do to relax?  

4. Needs and services  

From your own experiences do you feel that your needs as a person are being adequately met by those around you?  
From professionals?  
From others?  

Do you feel that your needs are met as a relative or carer of ______________ who has BPD?  
From professionals?  
From others?  

Do you feel that you are adequately informed of the services that are available to individuals who have BPD?  

What has your experience been, as a relative or carer of ________________, with the mental health services in general?  
From general practitioners?  
Community mental health centres?  
Hospitals?  
CAT Teams?  
Case managers?  
Support groups?  

And professionals within these organisations in particular?  

From your experiences with mental health services and agencies, what suggestions would you make to improve the experiences of those, such as yourself, that have a relationship with/ or take care of someone with BPD?  

Is there anything that you would like to add to what we have talked about today?
Research Ethics Committee
School of Social and Behavioural Sciences
RECOMMENDATION FOR ETHICS APPROVAL

Project ID Number: 05/04
Project Title: The experience of families and carers who care for someone with borderline personality disorder
Project Duration: to 31/12/04
Principal Investigators: Roslyn Galligan, Wendle McPherson, Bruce Findlay

Office use only

Recommendation of the SBS Research Ethics Committee:

☐ Project Not Approved [Revise and Resubmit]
☐ Project Approved:
☐ Project Approved: Hawthorn & Lilydale campuses
☐ Project Approved Subject to:
  (i) Consider making reference to "borderline personality disorder" ??
  (ii) keep all ethical addresses on plain language statement
  (iii) remove "phone number =
  (iv) Consider Royal Centre phone no on pl.

You must supply any requested documentation to: Secretary, SBS Ethics Committee, Room BA317, before commencement of data collection

Chair: [Signature]
Date: [Date]

ETH/001 Issue Date: 14/06/2004
12th August 2004

To Wenda McPherson

Re: Change to Ethics application 98504

Dear Wenda,

Thank you for the revised plain language statement for your study “The experiences and needs of family members and carers of someone who has Borderline Personality Disorder” as requested by this committee. The Ethics Committee has considered the revisions, and approved them.

All the very best for your study.

[Signature]

Bruce Findlay, PHD
Chair
SBS Ethics Committee

Co: Dr. Roslyn Gallagher, Supervisor
Dear Wenda,

I confirm that the following projects were put to the former Human Ethics Sub-Committee – Social and Behavioural Sciences (HESC-SBS) and approved:

HESC-SBS Project 56/04 The Experiences and Needs of Family Members and Caregivers of Someone Who Has Borderline Personality Disorder [Qualitative Study]
Dr. R. Galligan, Ms. Wenda McPherson, Dr. B. Findlay, FLSS

HESC-SBS Project 62/05 The Experiences and Needs of Family Members and Caregivers of Someone Who Has Borderline Personality Disorder [Quantitative Study]
Dr. R. Galligan, Ms. Wenda McPherson, Dr. B. Findlay, FLSS

HESC-SBS functioned as a subcommittee of Swinburne's Human Research Ethics Committee (SUHREC).

I also acknowledge receipt today of final reports accounting for the human research activity conducted in the projects in line with approval conditions.

Best wishes for your thesis submission and examination.

Yours sincerely,

Keith

*******************************************************************************
Keith Wilkins
Secretary, SUHREC & Research Ethics Officer
Swinburne Research (SSR)
Swinburne University of Technology
P O Box 218
HAWTHORN VIC 3122
Tel +61 3 9214 5218
Fax +61 3 9214 5267

25/01/2012
APPENDIX B

THE QUANTITATIVE STUDY
Hi! My name is Wenda McPherson. I am currently completing my Professional Doctorate in Psychology at Swinburne University, Melbourne, Australia. My research examines the experiences and needs of family members and carers of someone who has Borderline Personality Disorder. This research is important because to date very little is known about the experiences and needs of those people who are in relationship with someone who has Borderline Personality Disorder. It is expected that this study will help others, including professionals, gain a better understanding of that experience and begin to identify some of the gaps in the services for these families, carers, and friends. I would like to invite you to participate in this important research study to be conducted under the supervision of Dr Roslyn Galligan.

If you agree to participate in this study you will be asked to complete the following questionnaire which asks you to answer questions about your caregiving experience, your quality of life, your coping style, possible distress levels, and your experiences of services and professionals in your care of your BPD person. All in all, participation in the study will take around 60 minutes of your time.

All aspects of the study, including results, will be strictly confidential. This is why it is important not to mark the questionnaire in any way with personal details such as your name. Data from this study will initially be published as a doctoral thesis and later submitted for publication in specialist journal articles. In all these reports individual participants will not be identifiable, and where direct quotes are used for illustrative purposes they will be used in such a way that no individual may be identified.

It is possible that some of the questions may be distressing, given your experience with your BPD person. If this is the case for you then we encourage you to either contact someone from the organisation that linked you to this study or alternatively you talk to someone on one of the following phone numbers.

Australia – Lifeline 131 114
UK – Supportline 020 8554 9004
USA – Help Line 1 561 659 6900
Or go to the Lifeline International Website for a counselling organisation in your country: www.lifeline.web.za/help.htm

Participation in this study is entirely voluntary and you are not obliged to participate, however if you do choose to participate you can withdraw at any time. Whatever your decision, it will not affect your relationship with the investigators or the organisation that linked you to this study. Return of this questionnaire will be taken as your consent to participate in this study.
A summary of the findings will be available to participants at the completion of the study.

If you have any concerns during or after completing the interview you are encouraged to discuss these with the researchers:
Ms. Wenda McPherson on 9214- 8653 or 4081250@swin.edu.au.
Or Dr. Roslyn Galligan on 9214-5345 or rgalligan@swin.edu.au.

If you have any queries or concerns that Dr. Roslyn Galligan was unable to satisfy, then contact:
The Chair, SBS Research Ethics Committee
School of Behavioural Sciences, Mail H24, PO Box 218,
Swinburne University if Technology,
Hawthorn, Victoria 3122, Australia.

If you have a complaint about the way that you were treated during this study, please write to:
The Chair, Human Research Ethics Committee
PO Box 218, Swinburne University of Technology
Hawthorn, Victoria, 3122, Australia.
Please read the following statements and circle the response that best applies to your BPD relative/friend:

0  Never  
1  Rarely  
2  Sometimes  
3  Often  
4  Nearly always  

My BPD relative/friend:
1. Will go to extremes to prevent those they love from leaving them.

   0  1  2  3  4
2. Either loves someone or hates them with nothing in between.

   0  1  2  3  4
3. Often wonders who they really are.

   0  1  2  3  4
4. Has tried to hurt or kill themselves.

   0  1  2  3  4
5. Is a very moody person.

   0  1  2  3  4
6. Feels that life is dull or meaningless.

   0  1  2  3  4
7. Has difficulty in controlling their anger or temper.

   0  1  2  3  4
8. When they get stressed, things happen like they get paranoid or just black-out.

   0  1  2  3  4

SECTION B: EXPERIENCE OF CAREGIVING

The following section contains a number of statements that commonly apply to persons who care for relatives or friends with a serious mental illness. We would like you to read each one and decide how often it has applied to you.

It is important to note that there are no right or wrong answers. It is best not to spend too long on any one item as often your first reaction will usually provide the best answer. While there may seem to be a lot of statements, you will find that it won’t take more than a moment or so to answer each one.

0  Never  
1  Rarely  
2  Sometimes  
3  Often  
4  Nearly always

How often have the following applied to you in relation to your person with BPD:

1. You have covered up their illness.

   0  1  2  3  4
2. You have felt unable to tell anyone of the illness.

   0  1  2  3  4
3. You have noticed that your BPD person

   0  1  2  3  4
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<td>4. You have had to support your BPD person.</td>
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<td>5. You have thought about what sort of life your BPD person might have had</td>
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<td>6. You have thought about your BPD person’s risk of suicide.</td>
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<td>7. You have learnt more about yourself.</td>
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<td>8. You have contributed to others understanding of BPD.</td>
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<td>9. You have been unable to do the things you want to do.</td>
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<td>10. You have experienced that health professionals do not take you seriously</td>
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<td>11. You have thought about your BPD’s person dependence on you.</td>
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<td>12. You have helped to fill in your BPD person’s day.</td>
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<td>13. You have contributed to your BPD person’s wellbeing.</td>
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<td>14. You have thought that your BPD person is making a valuable contribution to the household.</td>
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*How often have the following applied to you in relation to your person with BPD:*

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<td>15. You have thought about the effect on your finances if your BPD person becomes more seriously ill.</td>
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<td>16. You have had to deal with psychiatrists.</td>
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<td>17. You have noticed that your BPD person is always at the back of your mind.</td>
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<td>18. You have thought about whether you have done something to make them ill.</td>
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<td>19. You have thought that your BPD person has shown some strengths in coping with their illness.</td>
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<td>20. You have become more confident in dealing with others.</td>
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<td>21. You have thought that family members do not understand your situation.</td>
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<td>22. You have thought that your BPD person is good company.</td>
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<td>23. You have thought that you have become more</td>
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understanding of others with problems.

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<td>24. You have noticed that your BPD person thinks a lot about death.</td>
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<td>25. You have thought about your BPD person's lost opportunities.</td>
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<td>26. You have had to deal with mental health professionals.</td>
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<td>27. You have felt unable to have visitors at home.</td>
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<td>28. You have had thoughts about how your BPD person gets on with other family members.</td>
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<td>29. You have backed up your BPD person if they run out of money.</td>
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<td>30. You have thought that family members do not understand the illness.</td>
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<td>31. You have noticed that your BPD person deliberately attempts to harm themselves.</td>
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**How often have the following applied to you as a result of being in relationship with your person with BPD:**

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<td>32. You have become closer to some of your family.</td>
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<td>33. You have become closer to friends.</td>
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<td>34. You have shared some of your BPD person's interests.</td>
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<td>35. You have felt useful in your relationship with your BPD person.</td>
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<td>36. You have experienced that health professionals do not understand your situation.</td>
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<td>37. You have wondered whether your BPD person will ever get well.</td>
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<td>38. You have felt the stigma of having a mentally ill relative/friend.</td>
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<td>39. You have had to explain your BPD person's illness to others.</td>
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<td>40. You have had others leaving home because of the effect of the illness.</td>
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<td>41. You have setup your BPD person in accommodation.</td>
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<td>42. You have had to make complaints about your BPD person's care.</td>
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<td>43. You have met helpful people.</td>
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<td>44. You have discovered strengths in yourself.</td>
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<td>45. You have felt unable to leave your BPD person.</td>
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<td>home alone.</td>
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<td>46. You have thought about the effect of the illness on children in the</td>
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<td>family.</td>
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<td>47. You have thought about the illness causing a family break-up.</td>
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<td>48. You have thought about your BPD person keeping bad company.</td>
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<td>How often have the following applied to you as a result of being in</td>
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<td>relationship with your person with BPD:</td>
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<td>49. Have noticed how your BPD person’s illness affects special family</td>
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<td>events.</td>
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<td>50. You have found out how hospitals or mental health services work.</td>
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<td>51. You have been happy with doctors knowledge of the services available</td>
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<td>to families.</td>
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<td>52. You have found it difficult to get information about BPD.</td>
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<td>How often have you thought about your BPD person as being:</td>
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<td>53. moody</td>
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<td>54. unpredictable</td>
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<td>55. withdrawn</td>
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<td>56. uncommunicative</td>
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<td>57. not interested</td>
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<td>58. slow at doing things</td>
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<td>60. indecisive</td>
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<td>61. irritable</td>
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<td>62. inconsiderate</td>
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<td>63. behaving in a reckless way</td>
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</table>
64. suspicious
65. embarrassing in appearance
66. behaving in a strange way

SECTION C: EXPERIENCE OF LIFE
This following section contains 15 statements that people have used to describe their experience of life in general. Please read each statement carefully and circle the number that best reflects your experience.

The rating scale is as follows:
1. Strongly disagree
2. Moderately disagree
3. Slightly disagree
4. Slightly agree
5. Moderately agree
6. Strongly agree

1. When I look at the story of my life, I am pleased with how things turned out.
2. Maintaining close relationships has been difficult and frustrating for me.
3. In general, I feel I am in charge of the situation in which I live.
4. I think it is important to have new experiences that challenge how you think about yourself and the world.
5. I live one day at a time and don’t really think about the future.
6. I tend to be influenced by people with strong opinions.
7. I like most aspects of my personality.
8. People would describe me as a giving person, willing to share my time with others.
9. The demands of everyday life get me down.
10. For me, life has been a continuous process of learning, changing, and growth.
11. Some people wander aimlessly through life, but I am not one of them.
12. I have confidence in my opinions, even if they are contrary to the general consensus.
13. In many ways, I feel disappointed about my achievements in life.

14. I have not experienced many warm and trusting relationships with others.

15. I am quite good at managing the many responsibilities of my daily life.

16. I gave up trying to make big improvements or changes in my life a long time ago.

17. I sometimes feel as if I’ve done all there is to do in life.

18. I judge myself by what I think is important, not by the values of what others think is important.

19. On a scale of 1 to 10 how satisfied would you say you are with your life overall. 1 means you feel completely dissatisfied, 10 means you feel completely satisfied. And the middle of the scale is 5, which means you feel neutral.

SECTION D: COPING

This section deals with how people cope with stressful events in their lives and will help us to understand the ways in which relatives and carers of BPD persons are coping in the stressful situations they are faced with.

*In your relationship and care of your BPD person:*

1. Could you please briefly describe a time that you feel you coped most effectively

2. Briefly describe a time when you felt you did not cope well

3. Was there a point in your life when you realised that you had developed a philosophy or stance in your life and your relationship with your BPD person that has helped you to manage better and live a more satisfying life? Could you briefly describe this and the circumstances surrounding it.
SECTION D: COPING Continued

The next section continues to explore the ways in which you have been coping with the stress in your life living with and caring for someone who has BPD. There are many ways to try to deal with problems and different people deal with things in different ways. We’re interested in how you’ve tried to deal with the stresses in your life. The following 19 items say something about a particular way of coping and we would like to know to what extent you’ve been doing what the item says. How much or how frequently. Don’t answer on the basis of whether it seems to be working or not—just whether or not you’re doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

The rating scale is as follows:

1. I haven’t been doing this at all
2. I’ve been doing this a bit
3. I’ve been doing this a medium amount
4. I’ve been doing this a lot

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<td>11.</td>
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<td>15.</td>
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<td>17.</td>
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<td>18.</td>
<td></td>
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</tbody>
</table>
19. I've been giving up the attempt to cope.  
20. I've been looking for something good in what is happening.  
21. I've been making jokes about it.  
22. I've been doing something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping or shopping.  
23. I've been accepting the reality of the fact that it is happening.  
24. I've been expressing my negative feelings.  
25. I've been trying to find comfort in my religion or spiritual beliefs.  
26. I've been trying to get advice or help from other people about what to do.  
27. I've been learning to live with it.  
28. I've been thinking hard about what steps to take.  
29. I've been blaming myself for things that have happened.  
30. I've been praying or meditating.  
31. I've been making fun of the situation.  

32. Are you currently, or have you in the past, received professional help for yourself to help cope with your situation?  
   □ Yes  
   □ No  

Please briefly explain  

33. Are you currently, or have you in the past, needed to take prescribed medication (e.g. antidepressants, or medication to help you sleep) to help you cope in the situation?  
   □ Yes  
   □ No  

Please briefly explain  


34. Please briefly indicate what you think you need as an individual that would help you to cope better with being in relationship with, and caring for someone that has BPD?

SECTION E: IMPACT OF RELATIONSHIP

In this section we would like to get an idea of the pattern of crises your BPD person experiences. As well as, the impact that these crises have on you as relatives and friends of your BPD person.

1. Please circle, on average, how many periods of crises you would say your BPD person encounters in a year?
   - None
   - 1
   - 2 to 3
   - 4 to 5
   - 6 to 7
   - 8 to 9
   - 10 or more

2. How long do they generally last?

3. And how severe are they on a scale of 1 to 10? (With 1 being mild and 10 being the most severe)

4. How many calm times would you say your BPD person experiences in a year?
   - None
   - 1
   - 2 to 3
   - 4 to 5
   - 6 to 7
   - 8 to 9
   - 10 or more

5. How long do these generally last?
To gauge how the changeability in your BPD impacts on you, you will be asked the following 21 items twice. Once in a time of crises, and once in a time of calm.

If you could now think of time when your BPD person was in crises. It would be helpful if you could consider a period that you experienced as the MOST SEVERE and indicate how much the following statements applied to you DURING THAT TIME.

The rating scale is as follows:
0  Does not apply to me at all  
1  Applied to me to some degree, or some of the time  
2  Applied to me a considerable degree, or a good part of the time  
3  Applied to me a considerable degree, or most of the time

<p>| | | | | |</p>
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<th></th>
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<tbody>
<tr>
<td>6. I found it hard to wind down.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. I was aware of dryness of my mouth.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>8. I couldn’t seem to experience any positive feeling at all.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9. I experienced breathing difficulty, (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10. I found it difficult to work up the initiative to do things.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11. I tended to overreact to situations.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12. I experienced trembling.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13. I felt that I was using a lot of nervous energy.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14. I was worried about situations in which I might panic and make a fool of myself.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15. I felt that I had nothing to look forward to.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>16. I found myself getting agitated.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>17. I found it difficult to relax.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>18. I felt down-hearted and blue.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>19. I was intolerant of anything that kept me from getting on with what I was doing.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>20. I felt I was close to panic.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>21. I was unable to become enthusiastic about anything.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>22. I felt I wasn’t worth much as a person.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>23. I felt that I was rather touchy.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>24. I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase),</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Item</td>
<td>Rating</td>
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<td>2</td>
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<td>----------------------------------------------------------------------</td>
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<tr>
<td>25. I felt scared without any good reason.</td>
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<tr>
<td>26. I felt that life was meaningless</td>
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</table>

If you could now think of time when your BPD person experienced a period of RELATIVE CALM and indicate how much the statement applied to you DURING THAT TIME.

The rating scale is as follows:

0  Do not apply to me at all
1  Applied to me to some degree, or some of the time
2  Applied to me a considerable degree, or a good part of the time
3  Applied to me a considerable degree, or most of the time

27. I found it hard to wind down.                                     |        |   |   |   |   |
28. I was aware of dryness of my mouth.                               |        |   |   |   |   |
29. I couldn’t seem to experience any positive feeling at all.        |        |   |   |   |   |
30. I experienced breathing difficulty                               |        |   |   |   |   |
   (e.g., excessively rapid breathing, breathlessness in the absence of physical exertion)
31. I found it difficult to work up the initiative to do things.      |        |   |   |   |   |
32. I tended to overreact to situations.                              |        |   |   |   |   |
33. I experienced trembling                                          |        |   |   |   |   |
34. I felt that I was using a lot of nervous energy.                  |        |   |   |   |   |
35. I was worried about situations in which I might panic and make a fool of myself. |        |   |   |   |   |
36. I felt that I had nothing to look forward to.                    |        |   |   |   |   |
37. I found myself getting agitated.                                 |        |   |   |   |   |
38. I found it difficult to relax.                                   |        |   |   |   |   |
39. I felt down-hearted and blue.                                    |        |   |   |   |   |
40. I was intolerant of anything that kept me from getting on with what I was doing. |        |   |   |   |   |
41. I felt I was close to panic.                                     |        |   |   |   |   |
42. I was unable to become enthusiastic about anything.              |        |   |   |   |   |
43. I felt I wasn’t worth much as a person.                          |        |   |   |   |   |
44. I felt that I was rather touchy.                                 |        |   |   |   |   |
SECTION F: IMPACT OF STRESSFUL EXPERIENCES

1. The following items asks you to recall the most stressful experience that you have had in your relationship with your BPD person. You may like to describe the event/s in a few words below:

___________________________________________________________________________________________

2. On a scale of 1 to 10 how stressful did you find these event/s? 1 means that you did not find it very stressful and 10 means you found it extremely stressful. Please circle a number:

   1  2  3  4  5  6  7  8  9  10

   not very                      extremely

Below is a list of 17 problems and complaints that people have sometimes reported in response to stressful life experiences. Please read each one carefully, and then circle the response that describes how much you have been bothered by that problem in relation to your stressful experiences with your BPD person.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
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<tbody>
<tr>
<td>3. Having upsetting thoughts, or images about the stressful experiences that came into your head when you didn’t want them to.</td>
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<td>4. Having bad dreams or nightmares about the stressful experience/s.</td>
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<tr>
<td>5. Reliving the stressful experience/s, act of feeling as if it were happening again.</td>
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<tr>
<td>6. Feeling emotionally upset when you were reminded of the stressful experience/s (e.g., feeling scared, angry, sad, guilty etc.).</td>
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<tr>
<td>7. Experiencing any physical reactions when you were reminded of the stressful experience/s (e.g., heart</td>
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</table>
beating faster, trouble breathing, breaking out in a sweat).

<table>
<thead>
<tr>
<th></th>
<th>Avoiding thinking about or talking about the stressful experiences or avoiding having feelings related to it.</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>Avoiding activities or situations because they remind you of the stressful experiences.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10</td>
<td>Trouble remembering important parts of the stressful experiences.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11</td>
<td>Loss of interest in activities that you used to enjoy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12</td>
<td>Feeling distant or cut off from people around you.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13</td>
<td>Feeling emotionally numb (e.g., being unable to cry or unable to have loving feelings).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<tr>
<td>14</td>
<td>Feeling as if your future plans of hope will not come true (e.g., you will not have a career, or a long life).</td>
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<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15</td>
<td>Having trouble falling or staying asleep.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<td>16</td>
<td>Feeling irritable or having angry outbursts.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<tr>
<td>17</td>
<td>Having difficulty concentrating (e.g., drifting in and out of conversations, losing track of a story on television, forgetting what you read).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<td>18</td>
<td>Being overly alert or watchful or on guard.</td>
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<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19</td>
<td>Feeling jumpy or easily startled?</td>
<td>1</td>
<td>2</td>
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<td>4</td>
<td>5</td>
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</table>
SECTION G: EXPERIENCE OF PROFESSIONALS AND SERVICES

This section looks at your experiences with health and/or mental health services and professionals in your care of your relative/friend with BPD.

1. Please indicate what sector of the mental health services has your BPD relative/friend been involved with
   - □ Public mental health services
   - □ Private mental health services
   - □ Both of the above
   - □ None of the above

For the following section please indicate on a scale of 0 to 3 whether your relative or friend HAS received help for his/her mental health problems from any of the services or professionals below. MORE THAN ONE ANSWER IS POSSIBLE.

The rating scale is as follows:

<table>
<thead>
<tr>
<th>Rating</th>
<th>Description</th>
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<tbody>
<tr>
<td>0</td>
<td>Does not apply / not used</td>
</tr>
<tr>
<td>1</td>
<td>Used somewhat</td>
</tr>
<tr>
<td>2</td>
<td>Used quite a bit</td>
</tr>
<tr>
<td>3</td>
<td>Used a great deal</td>
</tr>
</tbody>
</table>

2. I do not know
   - 0 1 2 3

3. No professional help
   - 0 1 2 3

4. Yes, from G.P. / family doctor
   - 0 1 2 3

5. Yes, from a social worker
   - 0 1 2 3

6. Yes, from an occupational therapist
   - 0 1 2 3

7. Yes, at the Community Mental Health Centre
   - 0 1 2 3

8. Yes, from a psychologist or cognitive/behavioural therapist
   - 0 1 2 3

9. Yes, as an outpatient at a psychiatric hospital or the psychiatric department of a general hospital
   - 0 1 2 3

10. Yes, in a psychiatric day hospital
    - 0 1 2 3

11. Yes, as an inpatient in a psychiatric hospital or the psychiatric department of a general hospital
    - 0 1 2 3

12. Yes, living in supported housing
    - 0 1 2 3

13. Yes, other (please specify)

______________________________
______________________________

14
SECTION G: EXPERIENCE OF PROFESSIONALS AND SERVICES Continued

14. On a scale of 1 to 10 how helpful have you found services and professionals in your caring role of your BPD relative/friend.

1 means you feel completely dissatisfied. 10 means you feel completely satisfied. And the middle of the scale is 5, which means you have mixed feelings.

<table>
<thead>
<tr>
<th>Completely Dissatisfied</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>Mixed</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>Completely Satisfied</th>
</tr>
</thead>
</table>

More specifically, how have you felt overall about your experience with the following health and mental health services in your care of your BPD relative/friend:

The rating scale is as follows:

0  Don't know
1  Terrible
2  Mostly dissatisfied
3  Mixed
4  Mostly satisfactory
5  Excellent

15. With general practitioners
16. With community mental health centre
17. With general hospitals emergency departments
18. With inpatient units of general hospitals
19. With psychiatric units of general hospitals
20. With psychiatric hospitals
21. With CAT Teams (also known as Mobile Crisis Assessment Teams or Mobile Crisis Outreach Teams)
22. With case managers
23. With support groups
What has your experience been with the following health and mental health professionals and services in the care of your BPD relative/friend:

The rating scale is as follows:

0  Not applicable to me
1  Terrible
2  Mostly dissatisfactory
3  Mixed
4  Mostly satisfactory
5  Excellent

<table>
<thead>
<tr>
<th>Question</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>With the ability of psychiatrists to listen and understand the concerns and the opinions you may have about the BPD person.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>With the ability of psychologists to listen and understand the concerns and the opinions you may have about the BPD person.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>With the ability of other mental health professionals to listen and understand the concerns and the you may have about the BPD person.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>With the recommendations about how you can help your BPD person.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>With the information given about the diagnosis and prognosis of the BPD person.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>With the effectiveness of services in helping you to deal better with the BPD person’s problems.</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>With the effectiveness of services in helping you improve your understanding of the your BPD person’s problems.</td>
<td>0 1 2 3 4 5</td>
</tr>
</tbody>
</table>

31. What do you need from health and mental health professionals and services that would help you in your caring role of your BPD relative/friend.

---------------------------------------------------------------
| Response 1                                                                 |
|---------------------------------------------------------------
| Response 2                                                                 |
|---------------------------------------------------------------
| Response 3                                                                 |
|---------------------------------------------------------------
| Response 4                                                                 |
|---------------------------------------------------------------
| Response 5                                                                 |
|---------------------------------------------------------------
| Response 6                                                                 |
|---------------------------------------------------------------
| Response 7                                                                 |
|---------------------------------------------------------------
| Response 8                                                                 |
|---------------------------------------------------------------
| Response 9                                                                 |
|---------------------------------------------------------------
| Response 10                                                                  |
SECTION H: CHANGES

Some (not all) people have indicated that negative events and crises that they have experienced in their lives have influenced them in a positive way. It is of interest to us to know whether this has been your experience in your particular situation.

Please read each statement below and indicate the degree to which this change occurred in your life as a result of dealing with the negative experiences in your relationship with your BPD relative/friend.

The rating scale is as follows:

- 0 | I have not experienced this change
- 1 | I have experienced this change to a very small degree
- 2 | I have experienced this change to a small degree
- 3 | I have experienced this change to a moderate degree
- 4 | I have experienced this change to a great degree
- 5 | I have experienced this change to a very great degree

1. My priorities about what is important in life.  
2. An appreciation for the value of my own life.  
3. I developed new interests.  
5. A better understanding of spiritual matters.  
6. Knowing that I can count on people in times of trouble.  
7. I established a new path for my life.  
8. A sense of closeness with others.  
9. A willingness to express my emotions.  
10. Knowing I can handle difficulties.  
11. I'm able to do better things with my life.  
12. Being able to accept the way things work out.  
13. Appreciating every day.  
14. New opportunities are available which wouldn't have been otherwise.  
15. Having compassion for others.  
16. Putting effort into my relationships.
17. I'm more likely to try to change things which need changing.  
   0 1 2 3 4 5

18. I have a stronger religious faith.  
   0 1 2 3 4 5

19. I discovered that I'm stronger than I thought I was.  
   0 1 2 3 4 5

20. I learned a great deal about how wonderful people are.  
   0 1 2 3 4 5

21. I accept needing others.  
   0 1 2 3 4 5

SECTION I: ABOUT YOU AND YOUR BPD PERSON

In this (and final) section we would like to ask you some general information about you and the BPD relative/friend you are in relationship with.

1. Can we ask you to indicate (by marking the box) which age group you belong to?
   - 18-25 years
   - 26-35 years
   - 36-45 years
   - 46-55 years
   - 56-65 years
   - 66 years and over

2. What is your gender?
   - Female
   - Male
   - Other

3. What best describes where you live?
   - Metropolitan
   - Outer Metropolitan
   - Rural

4. What is the highest level of education you have completed?
   - Less than Year 12 Secondary School
   - Year 12 Secondary School
   - TAFE diploma or certificate
   - University degree or diploma
   - Postgraduate degree
   - Unsure

4. What is your marital status?
   - Single
   - Married/In a long-term relationship
   - Separated
5. Do you live alone or with others?
- I live alone (PROCEED TO QUESTION 7)
- I live with my spouse/partner
- I live with my spouse/partner and children
- I live with my parents and/or sisters/brothers
- I live with other relatives
- I live with friends
- Other (please indicate)

6. How many people, including yourself, are there in your household?
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9 or more

7. What is your relative/friend's age?
- 18-25 years
- 26-35 years
- 36-45 years
- 46-55 years
- 56-65 years
- 66 years and over

8. My relative/friend's sex is:
- Female
- Male
- Other

9. When did your relative/friend's mental health problems start?
- 0 to 1 year ago
- 1 to 2 years ago
- 2 to 3 years ago
- 3 to 4 years ago
- 4 to 5 years ago
- 5 to 10 years ago
- 10 to 15 years ago
- 15 to 20 years ago
- Over 20 years ago
10. Has your relative/friend received a diagnosis of Borderline Personality Disorder (BPD)?  
☐ Yes  
☐ No  
☐ Not sure  

11. What is your precise relationship with your relative/friend?  
☐ I am horhiest  
☐ mother/father (step, foster and adoptive parents included)  
☐ daughter/son  
☐ sister/brother  
☐ other relative  
☐ wife/husband, partner or girlfriendfriend  
☐ friend  
☐ neighbour  
☐ colleague/fellow student  
☐ other (please indicate)……………………………………..  

12. Is your relative/friend part of your household?  
☐ Yes  
☐ No  
☐ Sometimes  

13. Which of the selections below best describes the total length of time you and your BPD relative/friend have lived together at the same address during the past YEAR?  
☐ None  
☐ Less than 1 week  
☐ About 2 to 4 weeks  
☐ About 4 to 8 weeks  
☐ 2 to 3 months  
☐ 4 to 6 months  
☐ 6 to 9 months  
☐ 9 to 12 months  
☐ the whole 12 months  

14. What has been your average WEEKLY telephone or personal contact with your relative/friend, over the past FOUR WEEKS?  
☐ Less than 1 hour per week  
☐ 1 to 4 hours per week  
☐ 5 to 8 hours per week  
☐ 9 to 16 hours per week  
☐ 17 to 32 hours per week  
☐ More than 32 hours per week  

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15. Finally, we are interested in the reasons why relatives and friends continue in their care and relationship with someone who experiences BPD, given the challenges and difficulties one often faces in such a relationship.

If you continue to be in relationship with your BPD person, it would be really helpful to us if you could briefly indicate why you have chosen to persevere in the relationship.

________________________________________________________________________

16. Please feel free to say anything else (or not) here that you may wish to say that you have not had the opportunity to say about your experience as a relative or friend of someone with BPD, and/or regarding this study, and/or your experience of the survey.

________________________________________________________________________

________________________________________________________________________

17. To help us target as many family members and friends of someone with BPD as we can, could you please indicate where you found this and accessed this survey?

________________________________________________________________________

Thank you for taking the time to participate in this research project. Your participation is valuable and will contribute to our understanding of the needs and experiences of the individuals that are in relationship with someone who has Borderline Personality Disorder.

It is expected that a summary of this survey will be available to you, as a participant, in the first half of next year. If you are interested in receiving this summary it can be accessed in a number of ways.

If you accessed this survey through the website of a BPD or mental health organisation it is expected that the summary can be accessed from their website. If you completed the survey on the Swinburne University website or filled out a pencil-and-paper version of the survey, or if you would simply like a copy of the summary sent directly to you, (either electronically or standard mail) please email Wenda McPherson with your personal details at 4081250@swin.edu.au.

Thank you again,

Kind regards,

Wenda McPherson
Dear Wenda,

I confirm that the following projects were put to the former Human Ethics Sub-Committee - Social and Behavioural Sciences (HESC-SBS) and approved:

HESC-SBS Project 56/04 The Experiences and Needs of Family Members and Carers of Someone Who has Borderline Personality Disorder [Qualitative Study]
Dr Roslyn Giglione/ Ms Wenda McPherson/ Dr Bruce Findlay, FLSS

HESC-SBS Project 62/05 The Experiences and Needs of Family Members and Carers of Someone Who has Borderline Personality Disorder [Quantitative Study]
Dr Roslyn Giglione/ Ms Wenda McPherson/ Dr Bruce Findlay, FLSS

HESC-SBS functioned as a subcommittee of Swinburne's Human Research Ethics Committee (SUHREC).

I also acknowledge receipt today of final reports accounting for the human research activity conducted in the projects in line with approval conditions.

Best wishes for your thesis submission and examination.

Yours sincerely,

Keith

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