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Coping Strategies, Distress and Well-being of Informal Caregivers of People with Borderline Personality Disorder

Thesis presented by

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Thesis submitted as part of the requirements for the Doctor of
Clinical Psychology

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Declaration

This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism.

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Glossary of Frequently Used Acronyms

APA	American Psychiatric Association
BPD	Borderline personality disorder
DSH	Deliberate self-harm
IC(s)	Informal caregiver(s)
NICE	National Institute of Care and Excellence
PwBPD	People with borderline personality disorder
TSC	Transactional Model of Stress and Coping (Lazarus and Folkman, 1984)
WHO	World Health Organisation

Chapter 1 Thesis Rationale and Layout

Borderline personality disorder (BPD) is characterised by persistent dysregulation in emotions, relationships, behavioural impulsivity and self-image. Many countries recommend that treatment for BPD is focussed in the community (National Health and Medical Research Council, 2012; National Institute for Care Excellence [NICE], 2009). As a result, family and significant others play an important role in supporting people with BPD (PwBPD). However, this support provided to PwBPD may occur at the expense of the informal carer (IC). Research has found that ICs of PwBPD experience levels of distress and burden greater than the general population and compared to ICs of people with other mental health disorders (Bailey & Grenyer, 2014, 2015; Kirtley et al., 2019; Scheirs & Bok, 2007). Qualitative research agrees with these findings. ICs of PwBPD experience trauma, stress and neglect of their own well-being due to their caring role (Dunne and Rogers, 2013; Giffin, 2008; Kay et al., 2018). Further, being an IC of a PwBPD can adversely impact many areas of the IC's life, including finances, work and social roles, social support, and family relationships (Dunne and Rogers, 2013; Ekdahl et al., 2011; Goodman et al., 2011; Lamborn and Cramer, 2020).

These findings suggest that ICs of PwBPD are a population in need of support. Interventions have been developed, informed by theoretical models of BPD. Positive effects of interventions have been observed post-intervention. However, in the few controlled trials that have been completed, results are less favourable when compared to treatment control (Sutherland et al., 2019), suggesting that interventions could benefit from improvement (Jørgensen et al., 2020). Empirical evidence of modifiable factors associated with differences in carer well-being may inform the development and adaptation of interventions to improve carer outcomes. To date, there remains a scarcity of empirical research identifying such factors in this specific carer population. As every mental health disorder is distinct, and the relationship dynamic between ICs and the care recipient differ, caution is required when translating findings from one carer population to another (Wasley & Eden, 2018). The factors associated with the well-being of ICs of PwBPD may differ from ICs of people with other

mental health disorders as characteristics of the disorder are significantly entwined with interpersonal relationships (Hoffman et al., 2003).

Lazarus and Folkman's (1984) Transactional Model of Stress and Coping (TSC) is a prominent theory explaining differential outcomes in response to a threat or stressor and highlights the important role of coping as a moderator of stress. Building on this, caregiver-specific theories, such as the stress-process model (Pearlin et al., 1990), explain variance in carer outcomes in response to caregiving stressors. Among other factors, the stress-process model hypothesises the important stress-buffering role of coping and social support on carer outcomes. Informed by the TSC and the stress-process model, the study presented in chapter 5 aimed to empirically investigate the relationship between IC social support and coping strategy use and IC outcomes of psychological distress and positive mental well-being in a population of ICs of PwBPD. The purpose of the study was to add to the existing empirical evidence on factors associated with IC outcomes. An empirical understanding of the relationship between modifiable factors and IC outcomes will support clinicians in designing, developing or adapting interventions targeted at this carer population so as to improve outcomes for the carers.

In populations of carers of people with schizophrenia, studies have investigated how coping strategies relate to psychological distress and well-being (e.g. Fortune et al., 2005; Szmukler, Burgess, Herrman, Benson, et al., 1996; Yu et al., 2019). However, findings have not been synthesised across studies, complicating the use of the results to inform interventions and supports for carers. In response, the systematic review presented in chapter 3 aimed to synthesise existing published research on the relationship between IC coping strategies and IC psychological distress and well-being in a different IC population, ICs of people with schizophrenia. It was also hoped that the systematic review results could be compared to the findings of the empirical study, enabling preliminary assessment of whether different coping strategies were effective for different populations of ICs of people with mental health difficulties.

This research was carried out in the shadow of the Covid-19 pandemic in 2020. Data collection had not yet commenced when countries worldwide were beset by lockdowns. In response, the research design was adapted to consider the influence of the Covid-19 pandemic.

Informed by the TSC and the stress-process model, this thesis aimed to answer the following three research questions in order of their presentation in the thesis:

1. What is the relationship between coping strategies and outcomes of psychological distress and well-being in a population of ICs of people with schizophrenia?
2. What is the relationship between perceived social support, coping strategies and outcomes of psychological distress and positive mental well-being in a population of ICs of PwBPD?
3. What is the relationship between the use of coping strategies and change in caregiving stress due to COVID-19 in a population of ICs of PwBPD?

A systematic review with a narrative synthesis was undertaken to answer the first question and a cross-sectional quantitative empirical study was conducted to answer the second and third research questions.

Thesis Overview

The systematic review and the cross-sectional quantitative study are presented in preparation for publication in two identified research journals in chapters three and five, respectively. Additional chapters provide information outside of the scope of a research publication. This section briefly describes each of the chapters.

Chapter two details the relevant literature relating to the ICs of PwBPD supplementary to the research paper presented in chapter five.

Chapter three presents the systematic narrative review of the relationship between coping strategies, psychological distress and well-being in ICs of people with schizophrenia. This paper has been prepared in accordance with an identified journal.

Chapter four provides additional methodological detail supplementary to the systematic review paper (chapter three).

Chapter five presents the empirical study responding to research questions two and three. This paper has been prepared in accordance with an identified journal.

Chapter six provides supplementary information about the empirical research detailed in chapter five, including methodology and analysis.

Chapter seven describes the research design adaptations considering the COVID-19 pandemic.

Chapter eight presents the research conclusions, including a summary of the thesis aims and results and implications for clinical practice and research.

Chapter 2 Literature Review

This chapter presents the literature which informed the empirical study presented in chapter 5, focussing on why informal carers (ICs) of people with BPD (PwBPD) are a population of interest; existing research on ICs of PwBPD; theoretical models that informed the research; and the COVID-19 pandemic.

Borderline Personality Disorder (BPD)

Definition and Prevalence

BPD is the term used by the Diagnostic Statistical Manual (American Psychiatric Association [APA], 2013). The International Statistical Classification of Diseases and Related Health Problems 10th edition (World Health Organisation [WHO], 2016) used the term Emotionally Unstable Personality Disorder (EUPD); nomenclature has been updated to Personality Disorder, Borderline Pattern in the 11th edition (World Health Organisation, 2018). BPD is the most commonly employed term in research. For consistency, throughout this thesis, BPD will refer to BPD, EUPD, and Personality Disorder, Borderline Pattern.

BPD is defined by persistent dysregulation in various domains and across contexts, including emotions, relationships with others, behavioural impulsivity, and self-image. BPD diagnosis is made when five of nine diagnostic criteria are present: (1) attempts to deter abandonment; (2) recurrent insecure relationships; (3) unstable self-identity; (4) impulsivity, including maladaptive behaviours such as careless spending, substance abuse, sexual activity, and dysregulated eating patterns; (5) acts or threats of self-injurious or suicidal behaviour; (6) emotional instability and reactivity; (7) enduring feelings of emptiness; (8) anger management difficulties or incongruent displays of anger; and (9) temporary experience of dissociation or paranoid ideation in response to stress (APA, 2013). BPD is associated with high suicide and self-harm rates (Kirtley et al., 2019; Paris & Zweig-Frank, 2001).

Reported prevalence ranges from 0.7% to 3.2% in the Netherlands (ten Have et al., 2016, p.141), Norway (Torgersen et al., 2001), the United Kingdom (Coid et al., 2006; Zanarini et al., 2011)

and the United States of America (USA) (Crawford et al., 2005; Lenzenweger et al., 2007).

Longitudinal studies are required to verify prevalence across the age range; cross-sectional studies suggest a decline in prevalence with age (Ellison et al., 2018). Diagnosis rates are higher in females (75%) (APA, 2013), but sex-related differences in diagnosis rates may be an artefact of differences in the presenting characteristics, comorbidities and treatment paths (Sansone & Sansone, 2011).

The prevalence of BPD in mental health care settings is higher than in the general population (Zimmerman et al., 2008). PwBPD are among the highest users of mental health services (Bender et al., 2001), with reported mean prevalence rates of approximately 22% in inpatient, 12% in outpatient (Ellison et al., 2018) and 6% in primary care settings (APA, 2013). In Ireland, BPD represents 11-20% of clinical presentations in mental health outpatient clinics (Government of Ireland, 2006).

Models of Borderline Personality Disorder

Past research on BPD aetiology focussed on the role of early childhood trauma (Herman et al., 1989; Masterson & Rinsley, 1975), with an emphasis on family abuse (Gunderson et al., 1997). Childhood trauma is indeed a risk factor for BPD (Battle et al., 2004; de Aquino Ferreira et al., 2018; Infurna et al., 2016; Widom et al., 2009). However, severe abuse does not determine the development of BPD (Musser et al., 2018); it is limited to a minority of PwBPD; and is also a risk factor for a wide range of psychiatric disorders (Winsper, 2018). Contemporary psychological models of BPD reflect the complex aetiology of the disorder (Winsper, 2018). No one factor can explain BPD development in isolation (Linehan, 1993). While more research is necessary to elucidate the aetiology of BPD (Cameron et al., 2018), theories have been proposed to explain BPD development and maintenance. This section describes several theories, emphasising those that have informed the development of interventions for ICs of PwBPD.

The Biosocial model (Linehan, 1993) hypothesises that the primary difficulty in BPD is emotion dysregulation, developing from a transaction between a person's biological, emotional vulnerability (increased sensitivity to emotions and heightened emotional reaction related to

temperament) and the experience of invalidating interactions with others. Emotion dysregulation leads to other characteristics, including disordered cognition, behaviour, interpersonal interactions and sense of self (Fruzzetti et al., 2005). The model allows for differential aetiological paths and proposes that emotional vulnerability may not be present at birth but evolves in response to environmental invalidation. Similarly, the invalidating environment may be present at birth or, in a reciprocal relationship, emotional dysregulation by the person who develops BPD can directly influence significant others' behaviour and coping responses, leading to invalidation. Over time, emotion dysregulation is shaped, maintained and reinforced through learned inaccurate expression by the PwBPD and significant others' invalidating responses (Fruzzetti et al., 2005). Invalidating responses may include sexual abuse at the extreme but can also be intentional and unintentional dismissal of emotions and misattribution of the person's experiences to internal defects (Linehan, 1993). Hence, the Biosocial model highlights the central role of relationship interactions in developing and maintaining BPD (Fitzpatrick et al., 2019).

The object relations model of BPD (Clarkin et al., 2007) was an early theory attempting to explain BPD aetiology. This model proposed that infants develop internalised representations of the self, the self in relation to others, and emotions through interactions with caregivers (object relation dyads), which provide a blueprint through which the self and future interactions with the world and others are viewed. According to the model, adverse early relationship experiences, across a continuum from inconsistent parenting to severe abuse, contribute to unintegrated positive and negative object relations for people who develop BPD. This impedes the development of mature defences and results in continued reliance on early primitive defences such as splitting. A black and white view of the self, relation to others, and the world cause difficulty regulating emotions, understanding others, and impulsive behaviour (Clarkin et al., 2007; Kring et al., 2010). Cognitive Analytic Therapy (CAT) theory integrates components of object relations and cognitive psychology theories. CAT emphasises the importance of social interactions in developing individual self-concept and ways of responding to the world (Ryle, 2004).

Informed by psychoanalytic theory, attachment and social cognition research, Fonagy and Bateman (2007) ascribe the development of BPD to the inability to mentalise during interpersonal interactions. This vulnerability arises from early experiences of unpredictable social communication, disrupting the development of mentalisation and recognition of social signals. The child may become hypervigilant or closed off to social communications, misattribute others' intentions, and have difficulty flexibly incorporating social information to adapt their actions to events. Social learning and interpersonal interactions are impacted, leading to diminished social networks, further obstructing social learning. These factors increase vulnerability to emotion dysregulation and unpredictable social communication from others.

Summary

In summary, BPD is a complex disorder associated with a high level of service use. Despite coming from different theoretical backgrounds, there is a striking commonality across theoretical models that relationships play a prominent role in BPD aetiology and maintenance. The relationship between care recipients and carers is proposed to be transactional and interdependent (Bidwell et al., 2017). It is, therefore, of interest to consider the experience and well-being of ICs of PwBPD, who may be negatively impacted by emotion dysregulation and the impulsive and sometimes lethal behaviours associated with BPD.

Informal Carers (ICs)

There is variance in how informal carers (ICs) are described across studies. ICs are frequently defined by their relationship with or whether they are cohabitating with the person receiving care or by the type of support afforded (WHO, 2015). Often ICs were seen as family members who offered unpaid regular instrumental assistance to enable independent living (Given et al., 2004; Roth et al., 2015). More recently, the characteristics that define an IC have been expanded to include other significant people such as friends or neighbours who may reside with or separate from the care recipient (WHO, Department for Work and Pensions, 2020; National Alliance for Caregiving & AARP,

2015). The IC's role can vary from performing instrumental tasks such as domestic or personal care to emotional support (Pakenham & Bursnall, 2006).

The deinstitutionalisation of psychiatric care to community-led care in Ireland and abroad has led to reduced patient admission and shorter inpatient stays for those with mental illness. Despite continual efforts to develop and improve services, there remain deficits in community support (Walsh, 2015), placing an informal demand for relatives and significant others to help people with mental illness (Saunders, 1999). The IC role is vital to provide effective care for those with mental ill-health (Treasure & Nazar, 2016). Caregiving tasks depend on care recipient needs and may include assisting with daily living activities and symptom management, liaising with health and other services, and dealing with problem behaviours (Lin et al., 2018; McEvoy et al., 2019). In the USA, 3.8% of the adult population report that they provide informal care to persons with emotional/mental health problems (National Alliance for Caregiving & AARP, 2015). Approximately 2.3% of the UK population say they care for a person with mental health problems (Worthington et al., 2013). The CSO (2017) figures in Ireland do not discriminate the type of care recipient. However, a proportion of the 4.1% of unpaid carers in Ireland likely support individuals with mental health difficulties. These statistics point to a hidden international workforce caring for individuals with mental ill-health (Herley, 2015).

The Impact of Being an Informal Carer (IC)

Caring is associated with uncertainty and lack of control. It impacts all areas of life, beyond the direct caregiving role, and so represents a chronic stressor (Schulz & Sherwood, 2008). Quantitative research shows that ICs of people with mental ill-health, including those who care for people diagnosed with bipolar affective disorder, eating disorders and schizophrenia, experience psychological distress, objective and subjective burden, and poor quality of life (Coomber & King, 2013; De La Rie et al., 2005; Lerner et al., 2018; Srivastava et al., 2010; Stanley et al., 2017; Steele et al., 2010; Treasure et al., 2001; Van Der Voort et al., 2007; Weimand et al., 2010). In a meta-synthesis of ten qualitative studies in sub-Saharan Africa, Ntsayagae et al. (2019) identified four

themes: caregivers' perceived responsibility; negative emotions; inadequate support; and the relationship between supports and coping strategies on caregiving perspective. They revealed that caring for the person with a mental health disorder was associated with a negative effect on other life roles due to the all-consuming nature of caregiving; feelings of shame, fear and hopelessness; negative effect on family relationships; perceived stigma; lack of knowledge and coping skills and feelings of powerlessness (Ntsayagae et al., 2019). Shiraishi and Reilly (2019) undertook a qualitative systematic review of the positive and negative effects of caring for a family member with schizophrenia. They included 23 qualitative studies from five continents. They also identified a lack of support, knowledge, stigma, a shift from other life roles and diminished focus on their own needs, feelings of uncertainty and family strain associated with being an IC of a person with mental illness. The correspondence between the qualitative reviews and findings of quantitative studies highlights that there are adverse psychosocial outcomes associated with being an IC of a person with mental ill-health. Haug (1994, p. 1) called attention to the negative impact of IC health by referring to ICs as the "hidden patient".

It seems, however, that negative caregiving effects are not inevitable (Schulz & Sherwood, 2008). For example, a study comparing mortality of spousal ICs (n=392) to controls (n=427) found higher four-year mortality in ICs who reported high, but not low, caregiving strain compared to non-caregivers (Schulz & Beach, 1999). Further, in an eight-year study, lower mortality risk was found in older adult ICs (n=375) (Fredman et al., 2010) with low compared to high stress. These outcomes suggest that the risk of mortality is not the same for all ICs and is dependent on IC's experience of stress and strain; ICs who experience low IC strain may not be at increased risk of mortality relative to non-caregivers. IC appraisals of caregiving may also moderate outcomes. For example, a systematic review of 53 studies on dementia caregivers reported that recognising positive aspects of caregiving correlated with greater IC well-being, mental health, quality of life and self-efficacy (Quinn & Toms, 2018). There is also some evidence of positive outcomes in ICs of people with mental health difficulties. Some ICs reveal positive feelings and experiences associated with the

caring role (Ntsayagae et al., 2019; Shiraishi & Reilly, 2019), and a cross-sectional study of ICs of people with first-episode psychosis (n=99) suggests IC caregiving appraisals impact caregiver outcomes (Jansen, Haahr, et al., 2015).

Summary

In summary, ICs may be related or non-related persons cohabitating, or not, with the care recipient. They undertake a range of activities depending on the care recipient's needs. Being an IC is associated with a range of adverse psychosocial outcomes, though these may not be inevitable. The next section will specifically discuss the experience of ICs of PwBPD.

The Experience of ICs of People with BPD (PwBPD)

In many countries, national guidelines recommend that PwBPD be supported in the community instead of inpatient units (National Health and Medical Research Council, 2012; National Institute for Health Care Excellence [NICE], 2009). Therefore, family and significant others of PwBPD are at the front line of treatment decisions, safety, and other difficulties associated with the disorder (Acres et al., 2019; Giffin, 2008; Hoffman et al., 2007). They play multiple roles, including “advocate, caregiver, coach and guardian” (Flynn et al., 2017, p. 2). However, the burden of being an IC may extend beyond these roles as the disorder's characteristics entwine with interpersonal relationships (Hoffman et al., 2003). Hoffman et al. (2003) suggest that BPD characteristics of fear of abandonment, recurrent insecure relationships, difficulty with sense of self, impulsivity, self-injurious behaviour, emotional instability, and difficulties with anger expression are directly related to relationships. They also suggest that the other possible characteristics, persistent feelings of emptiness and temporary experience of dissociation or paranoid ideation in response to stress, indirectly impact people close to them. More recent qualitative (e.g. Dunne and Rodgers, 2013; Meshkinyazd et al., 2020) and quantitative research (e.g. Lamborn and Cramer, 2020; Seigerman et al., 2020) further explores Hoffman et al.'s (2003) suggestion that people close to the PwBPD may be negatively impacted by the behaviours associated with BPD characteristics. The next section

summarises current knowledge of the experience of ICs of PwBPD, and the possible impact of the caring role, informed by the peer-reviewed research.

Qualitative Research

Qualitative research on informal carers of PwBPD has been conducted across different cultures, using different methodologies and samples. Existing studies will be introduced in the next three paragraphs, followed by a consideration of the results pertinent to the current thesis.

Giffin et al. (2008) undertook early qualitative research focusing on this population and, using a grounded theory approach, conducted unstructured interviews with four parents (three mothers of PwBPD) in Australia focusing on their experience and the family's experience of having a PwBPD in the family and their experience of the mental health system. Three themes relating to the caregiver and family experience of BPD were identified: stress due to both worry and in response to the behaviours associated with BPD, a dialectic between providing too much and too little support for the child with BPD, and a negative impact on other family relationships. Further themes relating to the engagement of the family with the mental health system and the wider system also emerged. Buteau et al. (2008) investigated the experience of 12 family members of PwBPD (ten females) who had been in contact with an organisation supporting ICs of PwBPD. Extending research beyond parent caregivers, Buteau et al. (2008) included one spouse and one sibling in their sample. They also used a different methodological approach to Giffin et al. (2008). Data was collected through in-depth semi-structured interviews with interview questions being informed by an iterative research method, a Delphi study, with clinicians and family members. Four main areas of interest were identified: having information and knowledge about BPD and interventions, how family members cope and areas of hope.

Ekdahl et al. (2011) collected data from family members attending a group for ICs of PwBPD in Sweden. Initially, 19 people, 14 females (17 parents, one spouse and one child), completed a questionnaire, whose results informed a follow-up narrative group interview with 11 of the original participants. Interviews focussed on their experience (1) of being near a PwBPD and (2) with health

services. Interview transcripts were analysed using content analysis. Themes relating to “a life spent tiptoeing” (Ekdahl et al., 2011, p. 71); negative feelings of lack of power, guilt and grief; being left out of services; and low confidence in services were identified. More recently, Kay et al. (2018) and Meschkinyazd et al. (2020) undertook phenomenological studies in South Africa and Iran, respectively, extending cross-cultural understanding of ICs’ experiences. Kay et al. (2018) conducted open-ended interviews with eight family members, aged 24 to 74, comprising three mothers, one father, two husbands, an uncle and a daughter. Participants were identified through purposive sampling. Four themes considered participants experience of BPD characteristics; intra- and interpersonal experience of the person with BPD; the process of adjustment; and a search for improved caregiving experience. Meshkinyazd et al. (2020) undertook semi-structured interviews with ten people specifically identified as carers of PwBPD attending a psychiatric hospital. Six ICs were female and ranged in age from 25 to 55. The interview focussed on caring and understanding of caring for a PwBPD. Meshkinyazd et al. (2020, p. 177) identified three themes relating to “life in hell”, “black shadow of stigma”, and “chain to the feet”. Dunne and Rogers (2013) undertook a thematic analysis of data collected from two focus group discussions, with eight ICs attending the first and five attending the second group. This was the only study to have a majority sample of male (five) participants and partners (four). Similar to Ekdahl et al. (2011), Dunne and Rogers (2013) had two areas of interest “the role of mental health services” and “experiences in the community” (Dunne & Rogers, 2013, p. 644). The focus groups also considered ICs experience of a local IC service. They identified the following themes: needs of the IC, the relationship between the person with the personality disorder and the IC, IC supports, the life-changing nature of being an IC; financial strains due to being an IC; difficulties accessing information about services; difficulties with professionals’ consideration of ICs and lack of understanding about personality disorders.

Most studies have focused on family members, parents, and female ICs. Only two studies specified that the participants were carers (Dunne & Rogers, 2013; Meshkinyazd et al., 2020). However, the content of the other four studies indicates that family members were likely providing a

supporting and caring role for the PwBPD, and therefore, the remainder of this section will describe both carers and family members as ICs. There was strong replication of themes across studies. The main findings pertinent to the current thesis are now described.

ICs experienced chronic stress elicited by the constant worry about the PwBPD; the pervasive nature of the caring role; a perceived need to be permanently available to the PwBPD; the management of life-threatening behaviours; the disruptive nature of some behaviour associated with BPD; and the lack of control the ICs have over the behaviour. BPD behaviours that contributed to caregiver stress included constant crises, suicide attempts and non-suicidal self-harm, impulsive, unpredictable, and aggressive behaviour (Dunne & Rogers, 2013; Ekdahl et al., 2011; Giffin, 2008; Meshkinyazd et al., 2020). This accords with Hoffman et al.'s (2003) suggestion that the characteristics of BPD directly impact interpersonal relationships.

This chronic and traumatic stress impacted IC well-being, for example, post-traumatic stress from witnessing life-threatening behaviours (Giffin, 2008). One IC expressed a passive death wish due to the lack of positive life experiences resulting from their caregiving role (Meshkinyazd et al., 2020). Others noted sleeplessness and exhaustion associated with the pervasiveness of the caregiving role (Giffin, 2008; Meshkinyazd et al., 2020). Negative feelings related to caregiving included despair, hopelessness, sadness, self-blame, guilt, grief, and shame were expressed by ICs (Buteau et al., 2008; Ekdahl et al., 2011; Giffin, 2008; Kay et al., 2018; Meshkinyazd et al., 2020). Self-blame and guilt related to a sense that the IC was causal in the development of BPD. ICs revealed neglect of their own health as they put the needs of the PwBPD first (Ekdahl et al., 2011; Meshkinyazd et al., 2020), suggesting that self-sacrificing may be linked to the development of their own health difficulties.

The research has also highlighted that there were wide-ranging secondary impacts on ICs' lives, potentially further magnifying their negative experience. ICs revealed an increased strain in other family relationships resulting from a focus on the PwBPD and the behaviour of the PwBPD (Ekdahl et al., 2011; Giffin, 2008; Kay et al., 2018). They also identified reduced time for other life

roles, such as work and social interests (Dunne & Rogers, 2013; Ekdahl et al., 2011; Meshkinyazd et al., 2020). Life changes, such as having to reduce work hours, may have partially contributed to the resultant financial strain and burden noted by ICs in several studies. Financial strain may also relate to a lack of publically funded service provision, which may increase financial pressures in addition to increasing the reliance on the IC to provide support (Buteau et al., 2008; Dunne & Rogers, 2013; Kay et al., 2018; Meshkinyazd et al., 2020). Several studies evidenced ICs' diminished social supports as ICs experienced shame, stigma and lack of understanding from friends, relatives and the community (Buteau et al., 2008; Dunne & Rogers, 2013; Ekdahl et al., 2011; Kay et al., 2018; Meshkinyazd et al., 2020). These findings suggest that secondary stressors (including family, financial and role stress) emerge from the primary caregiving stress. The role of primary and secondary stressors in explaining IC experience is supported by the wider caregiving literature and also by models of caregiving stress, discussed later in this chapter (Pearlin et al., 1990; Pearlin, 1999).

The research extended to ICs' experience of professional services. ICs described stigma and blame from professionals. A repeated theme across studies was that carers were expected to be highly involved in supporting the PwBPD in the community, yet mental health services excluded them from involvement in care within mental health services (Dunne & Rogers, 2013; Ekdahl et al., 2011; Giffin, 2008). For example, ICs were expected to support the PwBPD following discharge from hospital, but ICs were not included in discharge planning (Giffin et al., 2008). The lack of communication to support the caring role (Barr et al., 2020; Giffin et al., 2008; Dunne and Rogers, 2013; Kay et al., 2018) contributed to ICs experience of uncertainty, stress and a sense of disempowerment (Ekdahl et al., 2011). ICs noted that it was difficult to get information about BPD and how to support the person with BPD from professional services. The lack of available information from professional services may have contributed to ICs' lack of accurate knowledge about BPD, ways to cope with supporting the PwBPD, and how to respond to the PwBPD (Buteau et al., 2008; Giffin, 2008; Kay et al., 2018). The lack of knowledge may have contributed to ICs' sense of

powerlessness over the PwBPD's behaviour echoed across several studies (Kay et al., 2018; Meshkinyazd et al., 2020).

Further, as discussed in the previous paragraphs, ICs highlighted that the caregiving role negatively impacted them across several domains, including resultant mental and physical distress; reduced social support from family, friends and the wider community; broader family relationship difficulties; and ability to engage in leisure, social and work roles. Despite these stresses and the level of impact across the ICs' life, a recurrent finding across studies was ICs experience of a lack of adequate support services for caregivers (Buteau et al., 2008; Dunne & Rogers, 2013; Ekdahl et al., 2011; Giffin, 2008). Across studies, ICs identified a need for improved support and services for themselves (Buteau et al., 2008; Dunne & Rogers, 2013; Ekdahl et al., 2011; Giffin, 2008; Kay et al., 2018). Caregivers expressed a wish for improved recognition of ICs by professional mental health services; involvement with professional services throughout the PwBPD's mental health journey, including improved involvement at levels of BPD assessment, diagnosis, care and discharge planning; information about BPD and how to support a person with BPD from professionals; respite support within the community; peer support groups; and counselling and interventions targeted at ICs, their caregiving role and the impact of caregiving on the caregiver. Indeed there is qualitative evidence that ICs benefit from peer support as it reduced the isolation associated with being an IC for a PwBPD (Buteau et al., 2008). There is also growing evidence for some beneficial effects of interventions for this caregiver population on burden and well-being, though interventions may still benefit from improvement (see section "Interventions for Carers of PwBPD" for a summary of current evidence). Improved support and interventions for ICs may help empower ICs in coping with caregiving stress and in their support of and relationship with the PwBPD, thus reducing some of the adverse effects of caregiving on this IC population.

Despite difficulties engaging with services, ICs appeared to be motivated to get support, knowledge and to develop new skills to support the PwBPD and themselves (Kay et al., 2018). This motivation was supported by Giffin (2008) and Buteau et al. (2008), who noted that, in response to a

lack of information from professionals, ICs sought it themselves. However, the outcome of this informal research could elicit feelings of hopelessness (Buteau et al., 2008). It is possible that hopelessness may have resulted from accessing inaccurate information about BPD as, in the past, BPD was considered to have a poor prognosis. This again highlights the necessity of ICs to get better support and information from professionals.

The qualitative research described herein has advanced understanding of this carer population, verifying that caring is a 24-hour role that results in significant caregiving stress and has a broad impact on many areas of the IC's life, including their well-being and health, financial resources, engagement in work and social roles, wider interpersonal family relationships, social support and financial resources. The qualitative research suggests that ICs are motivated to obtain support to help them cope with the caregiving role. They have a desire for accurate knowledge about BPD and improved support for ICs. Studies have been conducted involving a range of cultures and research methods, supporting the validity of the findings. However, the generalizability of results is limited by a reliance on small sample sizes, self-selecting, purposeful sampling, and mainly female and parent ICs. In some cases, there was minimal description of the sample.

Quantitative Research

Quantitative studies have been undertaken using larger samples and provide evidence to support the qualitative findings. Scheirs and Bok (2007) investigated psychological distress in 64 ICs of PwBPD (44 female), approximately 50% recruited from support groups in the Netherlands and 50% from BPD websites and newspaper advertisements. More than half (n=36) were biologically related to the PwBPD. ICs of PwBPD scored higher on all scales of a measure of psychological distress, the Symptom Checklist (SCL-90) (Arrindell & Ettema, 2003), compared to general population norms. Studies by Bailey and Grenyer (2014; 2015) support these findings, using another self-report measure (Mental Health Inventory -5 (Cuijpers et al., 2009)) and larger sample sizes, increasing study power. Their samples were recruited through advertisements on BPD and IC websites and newspapers and at local Australian IC events. The first study recruited 287 ICs (194 female; 37%

parents; 37% partners) of people with a personality disorder (82% BPD); the second recruited 280 ICs of PwBPD (199 female; 40% parents; 33% partners). Nearly two-thirds of the sample experienced clinically evident anxiety and mood problems (Bailey & Grenyer, 2014, 2015). Another study supported these results. Seigerman et al. (2020) sampled ICs of adolescents and young adults with characteristics of BPD, whose diagnosis was confirmed clinically, extending the validity of the findings of earlier studies. ICs of young people with BPD characteristics (n=82) had higher psychological distress than published data on ICs of people with cancer and similar to ICs of people with first-episode psychosis (Seigerman et al., 2020).

Extending this research, self-reported grief was higher in ICs of people with a personality disorder (82% BPD) than previously published results of ICs of inpatients diagnosed with schizophrenia or major affective disorder (Bailey & Grenyer, 2014). The self-reported burden of ICs of PwBPD was significantly higher than the burden reported by ICs of inpatients with other mental health diagnoses in a previous study (Bailey & Grenyer, 2015). Using the same measure of burden, Kirtley et al. (2019) also reported higher levels of burden in a UK sample of ICs of PwBPD compared to ICs of people with other mental health diagnoses. Kirtley et al.'s (2009) findings strengthen the earlier results as they sampled both ICs of PwBPD (n=38) and ICs of people with other mental health diagnoses (n=60), including anxiety, depression, schizophrenia, PTSD, and OCD from a waitlist for IC intervention, rather than using previously published results for the comparison group. Their study comprised 60% parents (40% partners), though they did not differentiate relatedness within care groups. Using a non-standardised measure of burden and online recruitment of ICs, Goodman et al. (2011) assessed six domains in which 233 parents of females with BPD may experience burden. Emotional health was the most endorsed impact of caring followed by social life (59%); physical health (58%); negative impact on the marital relationship (56%); standard of living (44.2%); and career path (36%). ICs of young people with BPD characteristics reported higher negative caregiving experiences but similar positive caregiving experiences to previously published findings in ICs of young people with anorexia nervosa and first-episode psychosis (Seigerman et al., 2020). Details of

the negative caregiving experience subscales, as measured using the Experience of Caregiving Inventory (Szmukler et al., 1996), were not provided by Seigerman et al. (2020). It was, therefore, difficult to explore the reasons for the higher negative caregiving experience reported by ICs of young people with BPD characteristics.

Research illustrating high distress, burden and grief echo the qualitative findings that being an IC of PwBPD is associated with reduced well-being and NICE's (2009) suggestion that ICs may have needs in excess of other ICs of people with mental health difficulties. Goodman et al.'s (2011) study extends to a larger sample the qualitative findings that the IC role impacts many areas of life.

Emerging research explores the correlates of these negative outcomes. Informed by the stress-process model (Pearlin et al., 1990) and using partial least squares modelling, Lamborn and Cramer (2020) found preliminary evidence for primary and secondary stressors contributing to the psychological distress of 106 ICs of people with personality disorders (85% of which had a diagnosis of BPD). Important primary stressors included caregiver worry, the instrumental demands and interpersonal difficulties of the PwBPD. Important secondary stressors included family, health and schedule strain, and lower levels of perceived mastery and caregiver esteem. The results correspond with the qualitative findings that caregiving demands and BPD characteristics contribute to IC distress and that low self-efficacy relating to the caring role has adverse effects on IC well-being (Dunne and Rogers, 2013; Ekdahl et al., 2011; Giffin, 2008; Kay et al., 2018; Meshkinyazd et al., 2020). Further, the results agree with both the qualitative (Dunne and Rogers, 2013; Ekdahl et al., 2011; Giffin, 2008; Kay et al., 2018; Meshkinyazd et al., 2020) and existing quantitative (Goodman et al., 2011) evidence base that caregiving stress goes beyond primary stress and can impact on other life roles as well as family relationships and caregiver health, which then further contribute to IC distress.

Inconsistent results have been found for the age-effect on outcomes. Hoffman et al. (2003) was one of the pioneers of research in this area. They recruited 32 key family members (19 female, 69% parents, 31% partners) of PwBPD attending personality disorder clinics in the USA. Younger

family members reported higher burden and depression. Lamborn and Cramer (2020) also reported that younger compared to older ICs experienced higher psychological distress. In contrast, Scheirs and Bok (2007) reported that older caregiver age was associated with more significant depression and sleep problems, while no age-effect on mental health symptoms (Bailey & Grenyer, 2015) or burden (Bailey & Grenyer, 2015; Kirtley et al., 2019) were identified by others. It is difficult to explain differences in findings due to limited sample description in some studies; however, it may relate to sociodemographic differences across studies. Younger participants in Hoffman et al. (2003) may have comprised mainly partners of the PwBPD, whereas Bailey and Grenyer's (2015) study also included siblings (3.6%) and adult children (14.6%). Further, Lamborn and Cramer (2020) suggest that younger ICs may be more likely to live with the PwBPD and their study found that cohabitation was positively related to caregiving stress. Therefore cohabitation may partially explain higher distress in younger ICs reported in some studies and may explain differences in the age-effect on caregiver distress across studies.

Being a female IC was associated with higher depression (Scheirs & Bok, 2007) and burden (Kirtley et al., 2019). Caring for males correlated with greater hostility (Scheirs & Bok, 2007). Bailey and Grenyer (2014; 2015) did not report sex-effects on results, and so it is unclear whether they found no effect on outcomes or did not assess this possible confound. In contrast to other studies, Lamborn and Cramer (2020) found that male ICs experienced higher primary stressors compared to females. The authors suggested that the discrepancy between their findings and earlier studies may be due to the impact of other socio-demographic variables, such as cohabitation, as male ICs may have been more likely to reside with the PwBPD, increasing caregiving stress and psychological distress. Scheirs and Bok (2007) found that biologically related ICs (N=36) had higher somatisation scores, whereas non-biologically related ICs (N=28) had higher hostility scores. However, the effect of relatedness disappeared when controlling for IC age and sex and sex of the PwBPD (Scheirs & Bok, 2007). Consistent with this, relatedness (biological versus non-biological) was not an important background variable in the model of Lamborn and Cramer (2020), and Bailey and Grenyer (2015)

reported no effect of relatedness on measures of mental health. However, they did find higher burden for non-biologically- than biologically-related ICs, albeit with a small effect size. Kirtley et al. (2019) did not find an effect of relationship (parent versus partner) on burden, disagreeing with Bailey and Grenyer (2015). Smaller sample size may explain this as Bailey and Grenyer (2015) only found a small effect size and used a larger sample. However, Bailey and Grenyer (2015) did not consider age or sex confounds in their analysis, which Scheir and Bok (2007) had noted to be important controls. Therefore, their findings may relate to these other variables. Interestingly, Jørgensen et al. (2020) observed higher levels of burden in biological (n=65) compared to foster parents (n=6) in a sample of 75 ICs in Denmark. However, the foster parents' sample was small; therefore, the results must be considered with caution. Family member income and education were not related to IC burden in Hoffman et al.'s (2003) study, supported by Jørgensen et al. (2020)'s finding of no effect of employment or education on IC burden.

Regarding factors associated with the PwBPD, higher burden was associated with the PwBPD being younger in the study by Bailey and Grenyer (2014, 2015). In contrast, Hoffman et al. (2003) found no effect of PwBPD age on IC burden. Hoffman et al. (2003) had a much smaller sample size, and differences in results may be an artefact of study power or may be explained by differing sociodemographic characteristics across samples. None of these studies accounted for confounds in their analyses. Symptoms of BPD, measured using the frequency of deliberate self-harm and suicidal attempts, were positively related to IC burden (Bailey & Grenyer, 2014). In contrast, symptoms measured using the Brief Symptom Checklist (Derogatis & Melisaratos, 1983) and the Beck Depression Inventory (Beck et al., 1961) were not (Hoffman et al., 2003). Differences again may be due to differences in study designs or may indicate that it is the life-threatening behaviours that most impact IC burden.

High criticism and emotional overinvolvement were positively related to IC burden in two studies using correlations (Bailey & Grenyer, 2015; Kirtley et al., 2019). Interestingly, an earlier study reported that family member emotional overinvolvement correlated with improvements for the

PwBPD at one-year follow-up in a sample of 35 PwBPD and their relatives (74% parents) (Hooley & Hoffman, 1999). The different effect of emotional overinvolvement on outcomes in ICs and the PwBPD suggests that benefits to the PwBPD may be at the IC's expense. Difficulty in ICs' emotion regulation also positively correlated with IC mental health symptoms, burden and grief (Bailey & Grenyer, 2014).

Hoffman et al. (2003) observed that knowing more about BPD correlated with higher IC self-reported depression, burden, distress, criticism and hostility. This differs from schizophrenia, where higher knowledge about the disorder is associated with better IC outcomes. Hoffman et al. (2003) did not collect data on the sources, quality, or accuracy of participants' knowledge - variables that may have impacted results. Qualitative research (see previous section) has described how ICs faced with a lack of knowledge had to self-seeking informal sources of information, leading to feelings of hopelessness (Buteau et al., 2008). Inaccurate knowledge and information gathered through informal sources may have led to the positive association between knowledge and adverse ICs outcomes in Hoffman et al.'s (2003) study. Attitudes, knowledge about the development of and interventions for BPD, and availability of information have progressed since Hoffman et al.'s (2003) research. Notwithstanding this, their research, combined with the qualitative findings (see previous section), suggests that ICs' BPD knowledge is an important factor related to caregiver distress and burden. Lawn et al. (2015) recently found that, in a sample of 93 ICs, only a third reported that they had received and understood an explanation of BPD. Furthermore, reflecting qualitative research outcomes, dissatisfaction with professional clinicians correlated with parental burden (Goodman et al., 2011).

Seigerman et al. (2020) recently reported that ICs of young people with BPD characteristics reported lower use of avoidance and task-orientated coping and similar use of emotion-orientated coping compared to the general population as measured using the Coping Inventory for Stressful Situations (Endler and Parker, 1994). The authors did not report how these coping strategies were associated with IC distress. Task-oriented strategies predominantly involve attempts to problem

solve. Therefore, the findings suggest carers of young people with BPD symptoms have reduced use of coping strategies typically considered adaptive compared to the general population (Seigerman et al., 2020).

In summary, quantitative research shows that ICs experience high levels of distress, burden and grief and that knowledge of BPD, emotion dysregulation, emotional overinvolvement and criticism may relate to negative outcomes. Similar to the qualitative research, many studies relied upon self-selecting samples and majority female and parent participants, limiting generalizability of results. All studies were cross-sectional, limiting statements of causality, and the majority relied on correlation analysis without consideration of confounds.

Summary

Research on ICs of PwBPD includes qualitative and quantitative methodology with cross-sectional studies, focus groups, individual interviews, self-report questionnaires using standardised measures, non-standardised quantitative questionnaires and open-ended qualitative questionnaires. Qualitative studies have focused on small sample sizes to elucidate ICs' detailed experiences and have been undertaken across cultures, while quantitative studies have employed large samples, which allow some generalizability of findings. Despite the limitations described above, the evidence suggests that the caring role is associated with impaired mental health, quality of life and well-being. Quantitative and qualitative research converges to describe a population under stress and in need of support.

While there is now evidence that caring for a PwBPD is associated with adverse effects for the IC, there remains a paucity of research investigating potential moderators of outcomes.

Qualitative research has revealed that ICs report difficulty coping with the caregiving role and diminished social support, factors that may impact well-being. The relationship between these factors and IC outcomes has not been investigated quantitatively in a large sample. One way to counteract feelings of despair, disempowerment and lack of knowledge in ICs is by providing coping skills, support, and information to family members through interventions (Kay et al., 2017).

Interventions for Carers of PwBPD

National guidelines (National Health and Medical Research Council, 2012; NICE, 2009; 2013) recommend that ICs of PwBPD are informed about available support groups. ICs report difficulty accessing interventions (Lawn et al., 2015). However, there has been a recent growth in therapies for ICs of PwBPD. This section will briefly consider some interventions.

Family Connections (Hoffman, Fruzzetti, Buteau et al., 2005) comprises 12 weeks of group psycho-education and skills training to provide support and information to carers. Programme development was informed by (1) the Transactional Model of Stress and Coping (TSC) (Lazarus & Folkman, 1984), which proposes that coping strategies will help family members adaptively respond to the stress of supporting a PwBPD, and (2) Linehan's (1993) Dialectical Behaviour Therapy (Hoffman et al., 2007). The programme comprises six modules focused on psychoeducation about the characteristics and aetiology of BPD and DBT-informed intra- and inter-personal skills to improve emotion regulation, well-being and family relationships (Hoffman et al., 2005). Uncontrolled pilot studies observed a pre- to post-intervention reduction in burden and grief and increased mastery (Hoffman et al., 2007; Hoffman et al., 2005). These effects remained or improved after three months. Hoffman et al. (2007) also observed a post-treatment reduction in depression in 77 family members. Hoffman et al. (2005) reported no pre- to post-intervention change in depression scores in 44 family members. The difference may be due to the former's larger sample size providing increased study power. Extending these findings, Liljedahl et al. (2019) also observed improvements in family functioning post-treatment. Flynn et al. (2017) advanced the earlier work by comparing the treatment group to optimised treatment-as-usual. The results mirrored earlier findings, but a significant treatment effect was only found for burden and grief. No randomised control trials (RCTs) of Family Connections have been published to date; however, an RCT protocol for this programme has recently been published (Fernández-Felipe et al., 2020). Several other programmes have been developed based on adaptations of DBT (Guillén et al., 2020). For example, Family skills (Miller & Skerven, 2017) provide psychoeducation about emotion regulation disorders followed by teaching

adapted DBT-informed skills. The programme requires ICs to attend a full-day workshop followed by eight 2-hour sessions over four weeks. Improvements in depression and hopelessness, but not burden, were observed post-treatment (Miller & Skerven, 2017).

MBT-FACTS (Bateman & Fonagy, 2019) is a five-week group intervention for ICs, delivered by family members with experience and informed by Metabolisation Based Treatment (MBT) for BPD (Bateman & Fonagy, 2016). The first session provides psycho-education about the disorder. The remaining four sessions teach skills to respond to the PwBPD, including mindfulness and mentalising, empathic validation and problem-solving. A delayed-treatment RCT (n=56) found post-treatment improvements in adverse incidents with the PwBPD, carer anxiety, distress, burden, mastery and family functioning. However, compared to waitlist control, treatment effects were only found for reduction in adverse incidents, improvements in well-being and family functioning at post-treatment (Bateman & Fonagy, 2019).

Staying Connected (Project Air Strategy for Personality Disorders, 2016) was developed to meet the specific needs of ICs of PwBPD and reduce IC burden. It comprises a day-long group followed by four fortnightly two-hour sessions and is informed by a relational model of BPD (Project Air Strategy for Personality Disorders, 2015). The programme focuses on psychoeducation about BPD and skills to optimise relationships between ICs and the PwBPD. A RCT (n=68) compared the intervention to waitlist control in 68 PwBPD (Grenyer et al., 2019). No pre- to post-change in IC distress or burden was observed. Significant pre- to post-treatment improvements in measures of family interactions were found compared to waitlist, which remained 12 months post-treatment. There was also a 12-month improvement in IC distress and burden. However, the long-term results were not compared to the control group.

Making Sense of BPD (Pearce et al., 2017) is informed by CAT and targeted ICs of adolescents (13-18 years) with BPD characteristics. It comprises three two-hour group sessions providing psychoeducation on BPD, skills to respond to common relationship dynamics, and self-care. A pilot study (n=23) found reduced subjective burden and increased personality disorder knowledge, but no

difference in carer distress post-treatment. An RCT protocol for this programme has been published (Betts et al., 2018).

Summary of Interventions

The limited evidence provides preliminary support that programmes for ICs are associated with improvements for carers, albeit with mixed effects, and results are less promising when compared to controls. Family Connections currently has the most evidence supporting effectiveness (Guillén et al., 2020; Sutherland et al., 2019), though compared to non-randomised optimised treatment-as-usual, benefits were only observed for carer burden and grief. As interventions comprise multiple components, often combining psychoeducation, skills, and peer support, change mechanisms require clarification (Sutherland et al., 2019). RCTs, use of larger sample sizes, and replication studies are needed to investigate intervention efficacy across a range of clinical outcomes measures. Further research elucidating factors that may be associated with better IC outcomes may help inform the development and optimisation of interventions (Jørgensen et al., 2020; Sutherland et al., 2019).

Theoretical Framework for the Research

The current study was based on Lazarus and Folkman's (1984) TSC, which proposes that a stress response is elicited when the environmental stressor outmatches a person's coping resources. According to the model, in response to a stressor, the dynamic interaction between cognitive appraisal, coping responses, and the stressor mediates the individual's psychosocial outcome (Lazarus & Folkman, 1984).

The appraisal process comprises two parts. Primary appraisal involves cognitive assessment of how the event influences well-being. Events can be categorised as irrelevant, likely to enhance or to negatively impact well-being. Secondary appraisal is the cognitive assessment of the possible outcomes. During secondary appraisal, the person typically considers the available coping options and the likelihood of being able to effectively implement the coping method to achieve the desired effect (Lazarus and Folkman, 1984).

Lazarus and Folkman (1984, p. 141) define coping as the “cognitive and behavioural efforts to manage specific external and/ or internal demands that are appraised as taxing or exceeding the resources of the person.” The coping method employed is contingent on the context, the resources available to the person and personal characteristics. For example, middle-aged people responded to work stress with more problem-focused methods but employed emotion-focused responses to health stress (Moos et al., 1990). Different people may respond to the same stimulus using different strategies (Greenaway et al., 2014; Lazarus & Folkman, 1984).

Building on the TSC, Pearlin et al. (1990) developed the stress-process model to explain the development of caregiving stress. This model proposed that variation in IC outcomes occur as a result of a dynamic interaction between background variables and primary and secondary strains moderated by social support and coping. Background variables include socio-demographic variables and resources to help manage, such as access to formal support for ICs. Primary stressors included the severity of illness of the care recipient and the extent of work required by the IC to respond to the associated behaviours. Secondary stressors encompass aspects of life that are impacted by the caregiving role and which subsequently augment the IC stress, including difficulties with family relationships, jobs, and finances in addition to the impact on the person, such as loss of self.

The qualitative and quantitative research described earlier provides preliminary evidence for the applicability of this model to the ICs response to stress associated with caring for a PwBPD. For example, research has shown that female caregivers may be more vulnerable to distress (background variables). Self-harm and suicide by the PwBPD correlate with IC burden (primary stressors). ICs reveal reduced opportunity to engage in their non-caregiving roles such as work and leisure (secondary strains) and difficulty with moderating factors such as diminished social support and lack of knowledge about how to cope. Specifically, Lamborn and Cramer (2020) assessed the applicability of the stress-process model (Pearlin et al., 1990) to a population of ICs of people with personality disorders and found preliminary evidence for the model’s ability to explain the psychological distress in this caregiving population. Their results indicated a pathway from

relationship (cohabiting) and background variables (gender and age) to primary stressors (caregiver worry, the instrumental demands and interpersonal difficulties of the PwBPD) and secondary stressors (family, health and schedule strain and lower levels of perceived mastery and esteem) to psychological distress. They also investigated the impact of IC help-seeking behaviour, but this variable was not found to significantly contribute to any of the other variables. The impact of potential stress-buffering factors such as social support and coping on outcomes has not yet been investigated.

Coping

Coping is a complex construct and, as there are many different coping strategies that can be employed in response to a stressor, researchers have tried to create higher-order categories (Greenaway et al., 2014). Lazarus and Folkman (1984) classified coping by its function into problem-focused versus emotion-focused strategies. Problem-focussed methods are those that modify the stressor to mitigate stress, for example, problem-solving, whereas emotion-focused strategies focus on altering the emotional response, including responses such as denial, distraction, and reappraisal, among others (Lazarus & Folkman, 1984). Problem-focused methods are employed most frequently when the situation is appraised as controllable; otherwise, emotion-focused strategies are preferred and, at times, may be more adaptable. Many other systems have been advanced, including those related to orientation towards the stressor (e.g. approach versus avoidance; engagement versus disengagement). However, all of the above two-dimensional classification systems have been criticised as oversimplifying the coping construct (Skinner et al., 2003).

The use of these two-dimensional higher-order families of coping is unhelpful as they are not mutually exclusive (Skinner et al., 2003). Some coping strategies cannot easily be classified into one of the two dimensions (Folkman & Moskowitz, 2004). For example, positive reappraisal is categorised by some as problem-focused (Thunyadee et al., 2015) and others as emotion-focused (Anderson et al., 2015). Furthermore, some coping strategies do not sit in either category, such as seeking social support (Folkman & Moskowitz, 2004). In response to these limitations, additional

categories have been advanced alongside problem- and emotion-focused strategies, including meaning-making and social support (Folkman & Moskowitz, 2004).

Others propose that the above-mentioned coping families should not be used as they result in the loss of important information on other dimensions of coping. Higher-order classification systems need to describe coping families in relation to mental health outcomes and not what they do (Skinner et al., 2003).

The Relationship between Coping and IC Outcomes

Across caregiving populations, researchers have found support for coping as a predictor of caregiver outcomes. Despite the above limitations, many researchers reduce coping strategies into commonly used two-dimensional classification systems. Problem-focused coping correlates with better outcomes, including lower psychological distress (Hawken et al., 2018; Monteiro et al., 2018). Emotion-focused strategies are frequently associated with increased distress, for example, in ICs of individuals with severe traumatic brain injury (Sander et al., 2013), cancer caregivers (Teixeira et al., 2018), and older adults (del-Pino-Casado et al., 2011). However, results are inconsistent across studies. Emotion-focused strategies sometimes relate to better outcomes (Hawken et al., 2018). Avoidance coping is related to adverse carer outcomes across populations (del-Pino-Casado et al., 2011; Hawken et al., 2018; Morris et al., 2018); results for approach coping are less consistent (del-Pino-Casado et al., 2011).

Coping has also been investigated in populations of ICs of people with mental ill-health. Maladaptive (Coomber & King, 2012) and avoidant-oriented coping (Parks et al., 2018) are associated with adverse outcomes, while approach-orientated strategies relate to positive experiences in ICs of people with eating disorders (Parks et al., 2018). Similarly, in ICs of individuals with bipolar affective disorder, a positive correlation between avoidance coping and greater burden was found (Chadda et al., 2007). Most research has focused on ICs of people with schizophrenia, where maladaptive coping strategies have been found to correlate with higher levels of IC distress (Fortune et al., 2005; Lam et al., 2015; Ong et al., 2016; Szmukler, Burgess, Herrman, & Benson,

1996; Thunyadee et al., 2015), burden (Hanzawa et al., 2010; Kate et al., 2013), and reduced quality of life (Kate et al., 2014). A systematic review of the relationship between coping strategies and psychological distress and well-being of ICs of people with schizophrenia is detailed in chapter three.

The Covid-19 Pandemic

Increased societal psychological distress is recognised in the current COVID-19 pandemic, in individuals with and without previous history of mental illness (Mucci et al., 2020; Park et al., 2021; Skapinakis et al., 2020; Yao et al., 2020). There was a reported 43% increase in urgent and emergency cases to see psychiatrists in the UK and a 45% fall in outpatient appointments in the earlier stages of the pandemic (Torjesen, 2020). For those with mental health conditions, the professional supports and outpatient appointments usually available may have been restricted (Yao et al., 2020) or fear of contagion may have reduced attendance (Torjesen, 2020). COVID-19 restrictions on movement and social interactions increased societal distress, and changes in professional mental health supports may not only be impacting people with mental ill-health. There is a suggestion that they have also increased their reliance on ICs, magnifying IC social, interpersonal and financial strain (Eckardt, 2020). Increased interpersonal stress and reliance on ICs are particularly pertinent in ICs of PwBPD due to the associated role of interpersonal difficulty. It is therefore important that research elucidate the impact of COVID-19 on ICs of people with severe mental ill-health. To our knowledge, no study has to date investigated the effect of COVID-19 on ICs of PwBPD.

Preliminary research supports the importance of coping strategies in managing COVID-19 related distress. Coping strategies predicted COVID-19 related psychological distress and well-being in the general population in the USA (Park et al., 2021) and Greece (Skapinakis et al., 2020) and a population of people with disabilities and chronic illness (Umucu & Lee, 2020). Umucu and Lee (2020) found that active coping, emotional support, humour, religion, and denial predicted higher well-being. Self-blame predicted lower well-being. Park et al. (2021) reported that active coping, distraction and humour significantly negatively predicted measures of anxiety, depression and

peritraumatic distress in the general population, USA. In Greece, positive coping strategies (active coping, positive reframing, planning, humour and acceptance) were negatively associated, while supportive/ distractive coping strategies (distraction, emotional support, instrumental support and venting) were positively associated with depression (Skapinakis et al., 2020). Across studies, there were some differences in the coping strategies predicting outcomes, which may relate to variation in locally available environmental resources and COVID-19 restrictions. All studies were undertaken in April 2020. Park et al. (2021) suggest that reduced coping resources available due to COVID-19 restrictions may have impacted the results. Despite differences, the literature does provide preliminary support for the importance of coping strategies, particularly active, humour and distraction coping, as potential moderators of psychological distress and well-being related to COVID-19.

Summary

BPD is associated with life-threatening and impulsive behaviours, emotional dysregulation and interpersonal dysfunction. Characteristics and models of BPD show a strong association with interpersonal relationships, suggesting that those supporting PwBPD may be negatively impacted. Indeed, the extant literature indicates that ICs of PwBPD are a vulnerable population in need of support. However, negative caregiving effects may not be inevitable. ICs identify a need for improved supports and interventions for themselves. Existing interventions for ICs of PwBPD show promising results, though studies indicate that they could be further improved to optimise IC outcomes. Models of stress and of caregiving hypothesise that coping and social support moderate the adverse impact of caregiving stress on ICs. Qualitative research on ICs of PwBPD supports these models and suggests that social support and coping strategies may influence ICs' response to caregiving stress. Chapter 5 of this thesis presents an empirical study to investigate the relationship between outcomes and social support and coping strategies of ICs of PwBPD. The next chapter presents a systematic review of the relationship between coping strategies and psychological distress and well-being of a different IC population, ICs of people with Schizophrenia.

Chapter 3 The Relationship between Coping Strategies, Psychological Distress and Well-being of Carers of People with Schizophrenia: A Systematic Review

Abstract

This systematic review aimed to identify the relationship between coping strategies and psychological distress and well-being in carers of people with schizophrenia. Electronic searches were conducted in PsycINFO, Pubmed, Scopus and CINAHL Plus. Reference lists of included studies and related published reviews were subsequently manually searched. A total of 1984 papers were screened. Fourteen studies conducted between 1996 and 2020, comprising 1987 carers of people with schizophrenia, met the inclusion criteria. All studies identified had cross-sectional designs. The quality of the studies, variation in carer samples, and heterogeneity of questionnaires and scales used to measure coping, psychological distress and well-being limited the strength and clinical utility of conclusions. Based on cross-sectional designs, there is preliminary evidence that carer coping strategies are associated with carer psychological distress and well-being. Further research is required to identify whether coping strategies buffer the impact of caregiving stress on carer outcomes and which coping strategies are most useful. Recommendations are made to optimise the research and clinical utility of future studies.

Introduction

The prevalence of schizophrenia worldwide is almost 20 million (GBD 2017 Disease and Injury Incidence and Prevalence Collaborators, 2018). An estimated 80% of those treated for the disorder receive care in outpatient facilities (Lora et al., 2012). Informal caregivers, such as family members and significant others, play an essential role in supporting a person with schizophrenia (Cleary et al., 2020; Kuipers et al., 2010; Pharoah et al., 2010), hereon referred to as the care recipient. Inclusion of a family member in treatment is associated with improved outcomes for the care recipient, including better treatment adherence (Ashcroft et al., 2018; Glick et al., 2011), reduced hospital admissions and relapse rates (Ashcroft et al., 2018; Pharoah et al., 2010).

The positive impact of caregiving on care recipient outcomes may be achieved at the expense of carer well-being. Caregivers of people with schizophrenia experience high rates of psychological distress and poor quality of life (Lerner et al., 2018; Magaña et al., 2007; Stanley et al., 2017; Winefield & Harvey, 1993), significantly higher than controls (Chen et al., 2004; Gupta et al., 2015; Hayes et al., 2015; Mitsonis et al., 2012). Despite advances in carer research, caregiver experiences may not have improved in recent years (Hayes et al., 2015).

Evidence identifying possible correlates of carer outcomes remains inconclusive. Poorer outcomes may be associated with carers who are female, the parent of the care recipient, or of younger age (Hsiao et al., 2020; Mitsonis et al., 2012; Möller-Leimkühler, 2005; Rammohan et al., 2002; Stanley et al., 2017). Service user symptoms may also impact carer outcomes, though there is a lack of consensus. Some studies report a significant correlation (Hsiao et al., 2020; Mitsonis et al., 2012), while others observed no impact of symptom severity (Möller-Leimkühler, 2005). A significant relationship between distress and duration of illness has been revealed, but the direction of this relationship is uncertain. Lower levels of psychological distress have been associated with both longer duration (Gibbons et al., 1984; Martens & Addington, 2001) and a shorter duration of illness (Mitsonis et al., 2012). No significant relationship between duration of illness and carer outcomes have been reported by others (Li et al., 2007). Variation in study inclusion criteria may partially

explain the heterogeneity of results. For example, some but not all studies excluded carers of people with recent diagnoses of schizophrenia of less than two years (Mitsonis et al., 2012). One consistent finding is the link between social support and better carer outcomes (Dyck et al., 1999; Magliano et al., 2000; Möller-Leimkühler, 2005).

Importantly, adverse outcomes are not inevitable for caregivers (Oldridge & Hughes, 1992), and there are positive aspects of caregiving (Shiraishi & Reilly, 2019). International clinical practice guidelines recommend the inclusion of families in treatment and highlight the importance of identifying care needs and support for family members (American Psychiatric Association, 2020; Galletly et al., 2016; National Institute for Health and Care Excellence, 2014). In response, individual and group psychoeducation programmes have been developed with the aim of improving carer experiences. Positive effects of psychoeducation on carer knowledge, self-efficacy, coping, and social support have been observed. However, a systematic review of interventions did not reveal a definitive positive impact on carer psychological well-being or distress (Sin & Norman, 2013), signifying that programmes may benefit from adaptation and improvement.

Interventions need to be developed based on evidence of modifiable predictors of carer distress or well-being to optimise benefit to caregivers. The Transactional Model of Stress and Coping (TSC) (Lazarus & Folkman, 1984) hypothesises that appraisal and coping strategies mediate an individual's stress response to an event. It is one of the leading models explaining outcomes across carer populations (e.g. Anderson et al., 2015; del-Pino-Casado et al., 2011), including carers of people with mental disorders (Lau & Pang, 2007). Many higher-order categories have been advanced to provide a parsimonious explanation of this construct (Folkman & Moskowitz, 2004). The most commonly referenced classification systems are emotion-focused versus problem-focused coping strategies (Lazarus & Folkman, 1984) and avoidance versus approach coping (Moos et al., 1990; Roth & Cohen, 1986). Problem-focused strategies comprise methods to modify the stressor to reduce distress, whereas emotion-focused strategies involve efforts to directly reduce the distress triggered by the stressor without directly addressing the stressor (Lazarus & Folkman, 1984). Similar

to problem-focused methods, approach coping involves behavioural and cognitive strategies to solve the problem. In contrast, the person avoids the issue and indirectly attempts to reduce stress when using avoidance strategies (del-Pino-Casado et al., 2011). These overarching terms refer to the function or feature of coping rather than the effect of the strategy on outcome (Skinner et al., 2003). The terms have been criticised as over-simplifying the construct, resulting in loss of important information about the coping strategy and its moderating effect on the relationship between the stressor and outcomes such as mental health problems (Folkman & Moskowitz, 2004; Skinner et al., 2003). For example, emotion-focussed coping can include a broad range of strategies from self-soothing, to cognitive strategies such as a focus on negative thoughts or positive reappraisal, to methods to escape the situation (Carver & Connor-Smith, 2010). Despite these limitations, these higher-order categories remain in use.

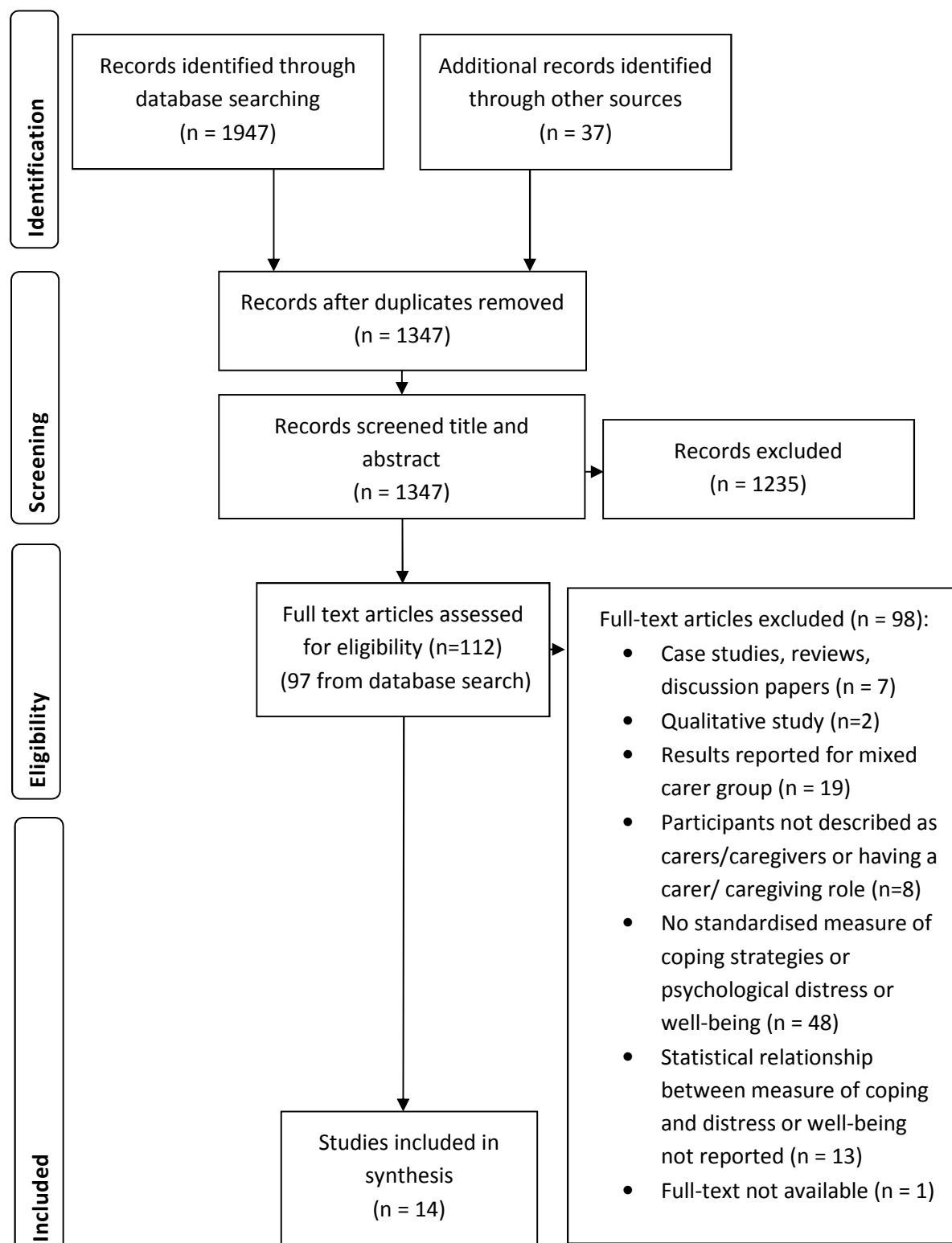
Problem-focused strategies have been associated with better outcomes, including lower psychological distress. Emotion-focused strategies are frequently associated with an increase in distress; however, results are not consistent with some emotion-focused methods relating to improved outcomes and some problem-focused strategies, such as confrontation, associated with adverse outcomes (Anderson et al., 2015; Hawken et al., 2018; Monteiro et al., 2018). Avoidance coping has also been related to adverse carer outcomes (del-Pino-Casado et al., 2011). There is some evidence of age (Chen et al., 2018) and gender effects (Khan & Panday, 2017; Lam et al., 2015) and an impact of duration of care recipient illness on coping strategies (Magliano et al., 1995). Further, culture and ethnicity may impact the appraisal of the caregiving role, the perception of caregiving stress, the choice of coping strategies and the relationship between coping strategies and psychological distress (Lam et al., 2015; Shaw et al., 1997). For example, there is some evidence that, compared to people from western cultures, people from eastern collectivist cultures employ more internally-targeted coping strategies (Tweed et al., 2004) and religious coping strategies (Chai et al., 2012).

A recent systematic review on the factors related to caregiver distress in early psychosis found support for the relationship between avoidance coping and carer psychological distress and burden (Jansen et al., 2015); however, these findings must be considered with caution as Jansen et al. (2015) identified methodological limitations in the studies included in their review and reliance on cross-sectional studies. Mui et al. (2019) undertook a qualitative systematic review of the experiences of carers of individuals with early psychosis. Of interest to the current study, they found that stigma influenced caregivers coping behaviours and expression of emotions and that the potential coping strategy of help-seeking behaviour was impacted by knowledge of mental health services. Of note, the reviews by Jansen et al. (2015) and Mui et al. (2019) were not specific to schizophrenia as they focused on the broader category of early psychosis and did not consider the longer-term impacts of caring for a person with chronic schizophrenia. Despite interest in coping strategies used by carers and the inclusion of coping as a component in support interventions for this population (Sin et al., 2013), the quantitative research findings on coping strategies have not been synthesised. Understanding the relationship between coping strategies and caregiver well-being and distress through a synthesis of the available research may assist informed use of coping strategies to improve effective interventions for this population.

It is vital to address both positive and adverse caregiving outcomes as "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organisation, n.d.). Positive and negative aspects of mental health are independent (Huppert & Whittington, 2003), and different factors can moderate their outcomes (Karademas, 2007). Positive aspects of well-being include life satisfaction, mood and energy; negative components include distress and negative mood (Karademas, 2007). Therefore, the relationship of coping strategies with both psychological distress and well-being are considered in this review.

Figure 3.1

Flow Diagram Summarises Study Selection, Guided by Moher et al. (2009)



This review aims to answer the following question: What is the relationship between carer coping strategies and carer outcomes of psychological distress and well-being in a population of carers of people with schizophrenia?

Materials and Method

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (Moher et al., 2009) guided this review. The methodology outlined below was predetermined and registered in the International Prospective Register of Systematic Reviews (registration number CRD42020213595).

Search Strategy

The following online databases were searched to identify studies published in peer-reviewed journals that met the inclusion and exclusion criteria: PsycINFO, PubMed, Scopus, and CINAHL Plus in July 2020, with an updated search in February 2021. The search strategy included these terms:

("care giver*" OR carer* OR supporter* OR famil* or caregiv* OR parent* OR sibling* OR spouse* OR partner*) AND (schizophrenia) AND (coping or adaptation or "adaptive behaviour" or "adaptive behavior" or Cope) AND (well-being OR wellbeing OR "well being" OR "quality of life" OR distress* OR depress* OR anxiety OR "mental health").

Inclusion and Exclusion Criteria

Search criteria were defined per the PICO framework. Studies that met the following criteria were included: 1) quantitative studies reported in peer-reviewed journals; 2) reports on adult carers, over 18 years, of people with schizophrenia; 3) reports the statistical relationship between caregiver coping strategies and psychological distress or well-being; 4) employed standardised questionnaires (Boynton & Greenhalgh, 2004) to measure coping strategies and the dependent variables; 5) reports results for carers of people with schizophrenia as a separate category; 6) text available in English; 7) full-text available. Qualitative studies, editorials, letters, commentaries, reviews, single case studies, and studies of relatives not otherwise described as caring for a person with schizophrenia were excluded. There were no restrictions on publication date or setting.

Definition of Constructs

This study adopted the following definitions of measured constructs. Coping was defined as "cognitive and behavioural efforts to manage specific external and/ or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). Psychological distress was defined as "a state of emotional suffering, characterised by symptoms of depression and anxiety" (Drapeau et al., 2012, p. 107). Studies that measured psychological distress using specifically constructed questionnaires or measures of anxiety or depression were included. Psychological well-being aimed to capture positive indicators of health and was defined as the person's perception of themselves and their quality of life (Ryff, 1989). Due to the overlap between psychological well-being and quality of life (Holley et al., 2011; Salvador-Carulla et al., 2014), quality of life was included as a measure of well-being.

Study Selection

Figure 3.1 summarises the study selection method. Searches were undertaken in July 2020 and February 2021, yielding 1984 papers; 637 duplicates were removed. The remaining studies were screened for the inclusion and exclusion criteria in two steps: (1) title and abstract review and (2) full-text review. Reviewer AH undertook step one using a conservative approach. 1217 papers that did not meet the inclusion criteria were excluded. AH reviewed all 97 papers in the second step, with the assistance of a pre-developed template of inclusion and exclusion criteria; MD reviewed a random sample of 40% of studies. The studies included and excluded by each reviewer were compared with no disagreements. Following the second step, 14 studies met the inclusion criteria. The reference lists of identified studies and relevant published reviews were then manually scanned to identify additional relevant studies. Thirty-seven articles were identified, 15 of which required full-text screen. No additional papers met the inclusion criteria.

Table 3.1*Summary of Study Characteristics*

Study	Location	N	Carer mean age (SD)	Carer sex, % female	Relationship to care recipient (% N)	Care recipient mean age (SD)	Carer recipient sex, % female	Care recipient mean duration of illness in years (SD)	Coping strategy measure	Outcome measure	Analysis
Budd et al. (1998) ¹	UK	59	NR ¹	NR ¹	NR ¹	NR ¹	NR ¹	NR ¹	CCSQ	GHQ-28	Correlations. Stepwise linear regression.
Fortune et al. (2005)	UK	42	57.3 (8.2)	64	Parent (93) Spouse/ Partner (7)	NR	NR	6.1 (3.2)	Brief COPE	HADS	Correlations. Hierarchical multiple regression. Mediation analysis.
Geriani et al. (2015)	India	110	43.8 (NR)	73	NR	NR	NR	NR	FCQ	WHOQOL-Bref	Chi-square

Study	Location	N	Carer mean age (SD)	Carer sex, % female	Relationship to care recipient (% N)	Care recipient mean age (SD)	Carer recipient sex, % female	Care recipient mean duration of illness in years (SD)	Coping strategy measure	Outcome measure	Analysis
Hsiao et al. (2020)	Taiwan	157	54.5 (12.2)	63.7	Parent (43.4) Spouse (8.3) Sibling (31.8) Adult Child/ Close relative or friend (16.6)	45.6 (9.3)	39.5	16.3 (7.3)	F-COPES	WHOQOL-Bref	Correlations; Step-wise multiple regression
Kate et al. (2014)	India	100	46.0 (11.5)	35	Parent (52) Spouse (22) Sibling (20) Other (6)	30.8 (9.8)	44	5.7 (3.0)	CC	WHOQOL-Bref	Correlations
Lam et al. (2015)	Hong Kong; China	109	64.1 (11.7)	67.9	Parent (81.7) Other (18.3)	38.9 (8.5)	45.9	16.9 (8.8)	WOCQ – R, Chinese	GHQ-12, Chinese	Correlations
Lohacheewa et al. (2016)	Thailand	210	NR	68.6	Parent (59.5) Spouse (11.4) Child (1) Other (28.1)	30 (NR)	<50	NR	WOCQ, Thai	GHQ-12, Thai	Path analysis
Nihayati et al. (2020)	Indonesia	222	NR	34.2	Parent (35.1) Couple (19.4) Child (12.2) Sibling (33.3)	NR	NR	NR	WOCQ	SCQLQ	Spearman correlation

Study	Location	N	Carer mean age (SD)	Carer sex, % female	Relationship to care recipient (% N)	Care recipient mean age (SD)	Carer recipient sex, % female	Care recipient mean duration of illness in years (SD)	Coping strategy measure	Outcome measure	Analysis
Ong et al. (2016)	Malaysia	200	NR	57	Parent/ child (60.5) Spouse (22) Sibling (13.5) Other (4)	43.36 (15.88)	NR	>3	Brief COPE	K10	Correlation Multiple-regression
Rammohan et al. (2002)	India	60	48.5 (9.9)	52	Parent (40) Spouse (40) Sibling (20)	36.3 (9.7)	55	10.1 (6.6)	CCL	PWQ	Correlation Stepwise multiple regression. Correlation
Rao et al. (2020)	India	100	43.5 (11.5)	45	Parent (29) Spouse (62) Others (9)	36.2 (11.6)	48	11.9 (8.3)	WOCQ, Hindi; Brief RCOPE	GHQ-12, Hindi	Correlation
Szmukler et al. (1996)	Australia	63	46 (15)	≥73	Parent (63.5) Spouse (14.3) Sibling (12.7) Child (9.5)	31 (12)	NR	8.4 (9.0)	WOCQ-28	GHQ-28	Multiple regression
Thunyadee et al. (2015)	Thailand	200	NR	76.5	Parent (63.5) Sibling (16.5) Other relative (20)	NR	35.5	NR	WOCQ, Thai	CES-D, Thai	Linear regression.

Study	Location	N	Carer mean age (SD)	Carer sex, % female	Relationship to care recipient (% N)	Care recipient mean age (SD)	Carer recipient sex, % female	Care recipient mean duration of illness in years (SD)	Coping strategy measure	Outcome measure	Analysis
Yu et al. (2019)	China	355	41.3 (13.6)	45.9	Parent (40.8) Spouse (25.9) Sibling (21.7) Child (11.5)	32.3 (11.7)	54.4	NR	SCSQ	SCL-90R	Correlation Structural equation modelling

Note: N = number; SD = standard deviation; NR = not reported or reported in ranges; 1 = not reported for sample of interest;; UK = United Kingdom; CCSQ = Carer Coping Style Questionnaire; GHQ-28 = General Health Questionnaire, 28 item version; HADS = Hospital Anxiety and Depression Scale; FCQ = Family Coping Questionnaire; F-COPES = Family Crisis Oriented Personal Evaluation Scales; CC = Coping Checklist, Hindi Version; WOCQ-R = Ways of Coping Questionnaire, revised 50 item version; GHQ-12 = General Health Questionnaire, 12 item version; WOCQ = Ways of Coping Questionnaire, 66 item version; WOCQ = Ways of Coping Questionnaire, 66 item version; SCQLQ = Schizophrenia Caregiver Quality of Life Questionnaire; K10 = Kessler Psychological Distress Scale; CCL = Coping Checklist; PWQ = Psychological Wellbeing Questionnaire; Brief RCOPE = Brief religious coping scale; WOCQ-28 = adapted Ways of Coping Checklist, 28 item version; CES-D = Centre for Epidemiological Studies Depression Scale; SCSQ = Simplified Coping Style Questionnaire; SCL-90R = Symptom Checklist-90-revised.

Table 3.2*Summary of Quality Assessment Results*

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Overall rating
Budd et al. (1998)	Yes	No	NR	Yes	No	NA	NA	CD	No	NA	NR	NA	NA	No	Poor
Fortune et al. (2005)	Yes	Yes	Yes	NR	No	NA	NA	Yes	NR	NA	NR	N/A	NA	NR	Fair
Geriani et al. (2015)	Yes	Yes	NR	NR	Yes	NA	NA	No	NR	NA	NR	NA	NA	No	Poor
Hsiao et al. (2020)	Yes	Yes	Yes	Yes	Yes	NA	NA	Yes	Yes	NA	Yes	NA	NA	NR	Fair
Kate et al. (2014)	Yes	Yes	Yes	Yes	No	NA	NA	Yes	NR	NA	NR	NA	NA	NR	Fair
Lam et al. (2015)	Yes	Yes	Yes	NR	No	NA	NA	Yes	NR	NA	NR	NA	NA	No	Fair
Lohacheewa et al. (2016)	Yes	Yes	Yes	Yes	Yes	NA	NA	Yes	Yes	NA	Yes	NA	NA	No	Fair
Nihayati et al. (2020)	Yes	Yes	Yes	Yes	No	NA	NA	CD	NR	NA	NR	NA	NA	No	Poor
Ong et al. (2016)	Yes	Yes	NR	Yes	No	NA	NA	Yes	Yes	NA	Yes	NA	NA	No	Fair
Rammohan et al. (2002)	Yes	Yes	Yes	Yes	No	NA	NA	No	NR	NA	Yes	NA	NA	No	Fair
Rao et al. (2020)	Yes	Yes	Yes	Yes	No	NA	NA	Yes	NR	NA	NR	NA	NA	No	Fair
Szmukler et al. (1996)	Yes	Yes	Yes	Yes	No	NA	NA	Yes	NR	NA	NR	NA	NA	No	Fair
Thunyadee et al. (2015)	Yes	Yes	NR	Yes	Yes	NA	NA	Yes	Yes	NA	Yes	NA	NA	No	Fair
Yu et al. (2019)	Yes	Yes	Yes	Yes	Yes	NA	NA	Yes	Yes	NA	Yes	NA	NA	Yes	Good

Note: NR = Not reported; NA = Not applicable; CD= Cannot determine.

Data Extraction and Quality Assessment

A data extraction template informed by PRISMA guidelines (Moher et al., 2009) and the Cochrane data extraction template (Ryan et al., 2016) was developed. Data extraction was undertaken by one reviewer (AH). Where queries arose regarding missing or ambiguous data or relating to the analyses, attempts were made to contact the relevant study authors. Quality was assessed using the National Institutes of Health (2014) Quality Assessment Tool for Observational Cohort and Cross-sectional Studies. The 14 item tool allows the study quality to be rated as "poor", "fair", or "good" based on the reviewers' qualitative assessment. Five questions did not apply due to the cross-sectional design of the included studies and the subjective nature of the exposures (coping strategies) and outcomes (psychological distress and well-being). Reviewer AH conducted the quality assessment for all 14 studies. Reviewer MD independently assessed two randomly selected studies (14%) for quality. Differences in ratings were discussed, and consensus was reached. Reviewers conferred about and reached an agreement on the quality rating of the remaining 12 studies. All 14 studies were included in the analysis regardless of quality to minimise the risk of study selection and reporting bias (Boutron et al., 2020).

Data Analysis

Meta-analytic synthesis of results was not undertaken due to the heterogeneity of the definition and measurement of variables across studies, see Table 3.1. The findings were therefore synthesised into a narrative summary.

Results

Study Characteristics

Following the steps outlined in Figure 3.1, a total of 14 studies undertaken between 1996 and 2020 were included in the review. Table 3.1 details the included studies. Recruitment occurred in a variety of settings, including psychiatric inpatient, rehabilitation units or hospitals (Geriani et al., 2015; Hsiao et al., 2020; Kate et al., 2014; Nihayati et al., 2020; Szmukler et al., 1996); psychiatric

outpatient and public mental health and community services (Kate et al., 2014; Lohacheewa et al., 2016; Ong et al., 2016; Rammohan et al., 2002; Rao et al., 2020; Thunyadee et al., 2015; Yu et al., 2019); home crisis departments (Szmukler et al., 1996); non-governmental services (Geriani et al., 2015; Lam et al., 2015); nursing homes (Geriani et al., 2015); family resource centres (Lam et al., 2015); and relative information and support groups (Budd et al., 1998; Fortune et al., 2005). Five studies recruited from more than one setting. Purposive or convenience sampling was described by all 14 studies. Five studies justified their sample size (Geriani et al., 2015; Hsiao et al., 2020; Lohacheewa et al., 2016; Thunyadee et al., 2015; Yu et al., 2019). Response rates were provided for ten studies (Fortune et al., 1995; Hsiao et al., 2020; Kate et al., 2014; Lam et al., 2015; Lohacheewa et al., 2016; Nihayati et al., 2020; Rammohan et al., 2002; Szmukler et al., 1996; Rao et al., 2020; Yu et al., 2019). No study reported characteristics of participants who did not participate. All studies used self-report measures for both the exposure and outcome variables. The most commonly used method to investigate the relationship between coping strategies and the outcome was correlations, employed by ten studies (Budd et al., 1998; Fortune et al., 2005; Hsiao et al., 2020; Kate et al., 2014; Lam et al., 2015; Nihayati et al., 2020; Ong et al., 2016; Rammohan et al., 2002; Rao et al., 2020; Yu et al., 2019). Two studies employed structural equation modelling (SEM) or path analysis (Lohacheewa et al., 2016; Yu et al., 2019); seven used regression analysis (Budd et al., 1998; Fortune et al., 2005; Hsiao et al., 2020; Ong et al., 2016; Rammohan et al., 2002; Szmukler et al., 1996; Thunyadee et al., 2015); and one included mediation analysis (Fortune et al., 2005). One study provided description of their consideration and use of control variables in their analysis (Yu et al., 2019). All other studies either did not report, did not provide sufficient details about the analysis, or did not adequately address confounds in their analysis.

Caregiver Characteristics

A total of 1987 caregivers participated in 14 studies. Definitions of caregivers varied across studies. Eleven studies specified a requirement to be a relative (Budd et al., 1998; Fortune et al.,

2005; Geriani et al., 2015; Hsiao et al., 2020; Lam et al., 2015; Lohacheewa et al., 2016; Nihayati et al., 2020; Rammohan et al., 2002; Szmukler et al., 1996; Thunyadee et al., 2015; Yu et al., 2019); seven identified caregivers as living with the care recipient (Geriani et al., 2015; Kate et al., 2014; Nihayati et al., 2020; Rammohan et al., 2002; Thunyadee et al., 2015; Rao et al., 2020; Yu et al., 2019); five defined caregivers as holding primary responsibility for the care recipient (Geriani et al., 2015; Hsiao et al., 2020; Kate et al., 2014; Lohacheewa et al., 2016; Szmukler et al., 1996); six specified involvement in care activities (Geriani et al., 2015; Kate et al., 2014; Ong et al., 2016; Rammohan et al., 2002; Rao et al., 2020; Yu et al., 2019); and the definition of caregivers in one study included a need to have close contact with the care recipient (Ong et al., 2016). Eight studies set minimum timeframes that caregivers either needed to be in their caring role or living with the care recipient (Geriani et al., 2015; Hsiao et al., 2020; Kate et al., 2014; Ong et al., 2016; Rammohan et al., 2002; Rao et al., 2020; Thunyadee et al., 2015; Yu et al., 2019). Three studies did not define a caregiver beyond being a relative of the care recipient (Budd et al., 1998; Fortune et al., 2005; Lam et al., 2015).

Cumulative caregiver characteristics are summarised here. Characteristics of one study (Budd et al., 1998) are not included as details were not reported for the subsample that completed measures of interest to this review. Across 12 studies, 55% of caregivers were female ($n=1042$) (Fortune et al., 2005; Geriani et al., 2015; Hsiao et al., 2020; Kate et al., 2014; Lam et al., 2015; Lohacheewa et al., 2016; Nihayati et al., 2020; Ong et al., 2016; Rammohan et al., 2002; Rao et al., 2020; Thunyadee et al., 2015; Yu et al., 2019); one study specified that at least 73% were female (Szmukler et al., 1996). Caregivers had a mean age of 47.7 years across nine studies ($n=1096$); four studies reported age ranges (Lohacheewa et al., 2016; Nihayati et al., 2020; Ong et al., 2016; Thunyadee et al., 2015). In 12 studies, all caregivers were relatives of the care recipient; one study also included friends (Hsiao et al., 2020), while one study did not note the relationship status of a minority of participants (Kate et al., 2014). Across 11 of the studies, 50.4% of caregivers were

parents (n=816); one study did not report the number of parents as a single category (Ong et al., 2016); and one study did not report the relationship to the care recipient (Geriani et al., 2015). Ten studies reported cohabitation (Geriani et al., 2015; Hsiao et al., 2020; Kate et al., 2014; Lam et al., 2015; Nihayati et al., 2020; Rammohan et al., 2002; Rao et al., 2020; Smukler et al., 1996; Thunyadee et al., 2015; Yu et al., 2019), with 86% of caregivers living with the care recipient (n=1269). All care recipients were living in inpatient units in one study (n=157) (Hsiao et al., 2020).

Care Recipient Characteristics

Details of reported care recipient characteristics varied across studies and are summarised in Table 3.1. As detailed above, the characteristics of care recipients provided by Budd et al. (1998) are not included in this summary. Across seven studies, 46% (n=501) of care recipients were male; more than half of care recipients were male in an eighth study (Lohacheewa et al., 2016); and five studies did not provide detail of care recipient gender (Fortune et al., 2005; Geriani et al., 2015; Nihayati et al., 2020; Ong et al. 2016; Smukler et al., 1996). Across nine studies (n=1354), the mean age of care recipients was 35.9 years (Hsiao et al., 2020; Kate et al., 2014; Lam et al., 2015; Lohacheewa et al., 2016; Ong et al., 2016; Rammohan et al., 2002; Rao et al., 2020; Smukler et al., 1996; Yu et al., 2019). Across seven studies (n=631), the mean duration of care recipient illness was 11.9 years (SD = 8.4). Two studies reported the duration in ranges (Nihayati et al., 2020; Thunyadee et al., 2015), and four studies did not report the duration of illness (Geriani et al., 2015; Lohacheewa et al., 2016; Ong et al., 2016; Yu et al., 2019).

All care recipients had a reported schizophrenia diagnosis as per the inclusion criteria for this review. Nine studies (64%) stated the care recipients were diagnosed in accordance with ICD-10, DSM-III, DSM-IV or DSM-V, verified either as part of the research or based on a review of case records. One study specified medical chart review but did not specify clinical criteria for diagnosis (Lohacheewa et al., 2016). Four studies did not report verification of care recipient diagnosis (Budd et al., 1998; Fortune et al., 2005; Lam et al., 2015; Nihayati et al., 2020).

Study Quality

The main quality issues were non-reporting of information, including a description of the sampled population, inclusion and exclusion criteria, sample size justification, validity and reliability of measures, methodology for identifying construct factors, and consideration or details of consideration of potential confounding variables. Table 3.2 shows the results of the quality appraisal. One study was rated as "good" as it met all the appraisal criteria. A "fair" rating was given to ten studies that did not report consideration of confounds, sample size justification and/ or reliability or validity of measures. Three studies were rated "poor" as they lacked detail across a number of important factors, including validity and reliability of both the independent and dependent variables, the determination of construct factors, confounding variables, sample size justification, or sample details.

Measurement of Constructs

Table 3.1 summarises the measures used. Ten different questionnaires were employed to assess coping strategies. Seven studies used variants of the Ways of Coping Questionnaire (WOCQ) (Lazarus & Folkman, 1984). Two studies used a Thai version of the WOCQ (Lambert et al., 2004); one study used a Hindi version of the WOCQ; one study used a Chinese translation of the 50-item revised version (WOCQ-R; Folkman et al., 1986); and one study used a 28-item revised version (WOCQ-28; MacCarthy & Brown, 1989). It is unclear from the paper of Nihayati et al. (2020) which version of the WOCQ was used. Of these studies, three reported coping using all eight subscales of the WOCQ (Lam et al., 2015; Rao et al., 2020; Thunyadee et al., 2015). Szmukler et al. (1996) classified coping into four categories; Lohacheewa et al. (2016) reported coping as a single construct by summing values across all scales in the WOCQ; while Nihayati et al. (2020) categorised participants into one of two dichotomous coping categories, emotion-focused or problem-focused, and did not provide details or validation of the methodology.

Two studies classified coping using the 14 scales of the Brief COPE (Carver, 1997). The remaining researchers selected heterogeneous measures and coping subscales to report coping strategies. Yu et al. (2019) used the Simplified Coping Style Questionnaire (SSCQ; Xie, 1998), which is based on the WOCQ and categorises coping as positive (proactive efforts) or negative (escape and avoidance strategies). Rammohan et al. (2002) used the Coping Checklist (CCL; Rao et al., 1989), comprising one problem-focused and five emotion-focused subscales. Kate et al. (2014) employed another measure, also called the Coping Checklist (CC; Nehra et al., 2005), which had five subscales. Hsiao et al. (2020) used the Family Crisis-Oriented Personal Evaluation Scale (F-COPES; McCubbin et al., 1981), comprising five coping categories. Rao et al. (2020) specifically assessed positive and negative religious coping strategies using the Brief Religious Coping Scale (Xie, 1998). Geriani et al. (2015) reported participants coping strategies as "fair" or "good" based on a cut-off on a total coping score of the Family Coping Questionnaire (FCQ; Magliano et al., 2000; Magliano et al., 1996). No details were provided to explain their categorisation method. Budd et al. (1998) developed their own Carer Coping Style Questionnaire (CCSQ) comprising nine subscales and did not include validation of the questionnaire.

To record outcomes, nine studies measured psychological distress, and five studies reported well-being. Five studies used variants of the General Health Questionnaire (GHQ; Goldberg, 1972). Two studies employed the 28-item version (GHQ-28; Goldberg & Hillier, 1979) and three used language translations of the 12-item version (GHQ-12; Goldberg & Williams, 1988). The WHOQOL-Bref was used in three studies (World Health Organisation, 1996). The remaining five studies used the Centre for Epidemiological Studies Depression Scale translated into Thai (CES-D; Boonpongmanee et al., 2003; Radloff, 1977); the Kessler K10 Psychological Distress Scale (K10; Kessler et al., 2002); the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983); the Chinese version of the Symptom Checklist-90-R (SCL-90-R; Tang et al., 1999); the Psychological Well-

being Questionnaire (PWB; Bhogle & Prakash, 1995); and the Schizophrenia Caregiver Quality of Life Questionnaire (S-CGQoL; Richieri et al., 2011).

Relationship between Coping and Psychological Distress and Well-being

Table 3.3 summarises the main relevant results from each study. All 14 studies reported a relationship between coping and carer psychological distress or well-being. The strategies associated with the outcomes differed across studies, and there was limited replication of results. The heterogeneity of measures, the lack of methodological detail to explain coping categories, and variations in the statistical approach and analysis complicated the synthesis of findings.

Path analysis indicated that coping strategies mediate social support's influence on psychological distress (Lohacheewa et al., 2016). However, the authors did not report the significance of the effects within the final model. This has prevented an interpretation of their model findings and, specifically, an understanding of the indirect and direct impact of coping on psychological distress. In another study, a SEM revealed that coping strategies indirectly influenced caregiver negative mental health, mediated by caregiver burden. There was a significant negative effect of positive (proactive) coping strategies and positive influence of negative (escape/ avoidance) coping strategies on caregiver burden (Yu et al., 2019).

Coping strategies accounted for between 7% and 40% of psychological distress and 57% of well-being in seven studies that used regression analysis (see Table 3.3). Analysis methods differed across these studies. Three studies (Fortune et al., 2005; Szmukler et al., 1996; Thunyadee et al., 2015) used theoretical models to inform the inclusion of coping strategies in the regression analyses. The factors included in the regression model were informed by the outcome of correlations in two studies (Hsiao et al., 2020; Ong et al., 2016). Three studies employed stepwise regression (Budd et al., 1998; Hsiao et al., 2020; Rammohan et al., 2002).

Table 3.3*Summary of Study Results*

Study	Relevant significant research findings
Budd et al. (1998)	Collusion, emotional over-involvement, criticism/ coercion and overprotectiveness were positively associated with an increase in psychological distress. Collusion and emotional over-involvement accounted for 21% of the variance in psychological distress.
Fortune et al. (2005)	More self-blame and lower amounts of positive reframing, religion/ spirituality, active and acceptance coping associated with higher psychological distress. Self-blame, acceptance and positive reframing accounted for 40% of the variance in psychological distress and mediated the relationship between illness identity and distress.
Geriani et al. (2015)	Good coping strategies related to better environmental domain of quality of life.
Hsiao et al. (2020)	Coping strategies of acquiring support, reframing, mobilising support and seeking spiritual support positively related to physical, psychological, social and environmental domains of quality of life. Passive appraisal was negatively associated with physical, psychological, social and environmental domains of quality of life. Psychological reframing and seeking spiritual support were predictors of all four domains of quality of life (environmental, psychological, physical, and social).
Kate et al. (2014)	Seeking social support was negatively associated with quality of life. Collusion was negatively associated with total quality of life. Coercion was negatively associated with general health and environmental domains of quality of life. Problem-focused and avoidance strategies were not associated with quality of life.
Lam et al. (2015)	Hong Kong sample: confrontational coping was positively related to psychological distress. Guangzhou sample: positive reappraisal was negatively associated with psychological distress. Total sample: No relationship between coping strategies and psychological distress
Lohacheewa et al. (2016)	Identified a model incorporating coping to explain 33% of the variance in psychological distress. However, significance levels were not reported. Further results could not be included in this review.
Nihayati et al. (2020)	Reported a significant relationship between coping and better quality of life, based on the categorisation of participants into problem-focused or emotion-focused coping groups.

Study	Relevant significant research findings
Ong et al. (2016)	Substance use, emotional support, behavioural disengagement, venting and self-blame were associated with increased psychological distress. Positive reframing was associated with lower psychological distress. Emotional support, behavioural disengagement, venting, positive reframing and self-blame accounted for 25.6% of the variance in psychological distress.
Rammohan et al. (2002)	Problem-solving and social support were related to higher well-being. Denial was related to lower well-being. Denial and problem-solving accounted for 57% of the variation in carer well-being.
Rao et al. (2020)	Negative relationship between psychological distress and seeking social support, accepting responsibility, planful problem solving and positive reappraisal and positive religious coping. Positive relationship between psychological distress and escape avoidance coping and negative religious coping.
Szmukler et al. (1996)	Practical, emotional and detachment strategies explained 7% of the variance in psychological distress. Only emotional coping was significantly associated with psychological distress.
Thunyadee et al. (2015)	Self-control was associated with depression.
Yu et al. (2019)	Negative and positive coping strategies correlated positively and negatively with mental health. A significant indirect effect of positive (IE=-0.16, $p<.001$) and negative coping (IE=0.11, $p<.001$) on psychological distress was found.

In two studies that used the Brief COPE, correlation analyses revealed that strategies frequently categorised as avoidant and approach coping (Eisenberg et al., 2012) were associated with higher and lower psychological distress, respectively. Both studies found that self-blame, a form of avoidant coping, and positive reframing, a form of approach coping, were positively and negatively associated with psychological distress, respectively (Fortune et al., 2005; Ong et al., 2016). Reframing, measured using the F-COPES, was also positively related to quality of life (Hsiao et al., 2020). Avoidant coping, measured using the Coping Checklist, did not correlate with quality of life (Kate et al., 2014).

The three studies that employed the same subscales of the WOCQ found different associations between coping and distress and well-being. WOCQ subscales are frequently categorised as emotion-focused and problem-focused strategies (Folkman & Moskowitz, 2004).

Using these over-arching terms, emotion-focused strategies of emotional coping (Szmukler et al., 1996), self-control (Thunyadee et al., 2015) and escape-avoidance (Rao et al., 2020) were associated with higher psychological distress. However, the emotion-focused strategies of accepting responsibility and positive reappraisal correlated with lower psychological distress in one study (Rao et al., 2020). Lam et al. (2015) also observed a negative relationship of psychological distress with positive reappraisal. The problem-focused strategy of planful problem-solving correlated with lower psychological distress in one study (Rao et al., 2020). However, confrontational coping (Hong Kong sample; Lam et al., 2015), another form of problem-focused coping, was associated with increased psychological distress. A relationship between problem- and emotion-focused strategies and caregiver outcomes was supported by Rammohan et al. (2002). They reported that problem-solving and the emotion-focused strategy of denial were related to higher and lower well-being, respectively.

Two studies defined collusion and criticism or coercion coping categories and observed an association with an increase in psychological distress (Budd et al., 1998) and a reduction across some domains of quality of life (Kate et al., 2014).

Social support coping is often independently categorised (Folkman & Moskowitz, 2004). Several studies included identified an association between social support and better caregiver outcomes. Social support was linked with higher well-being (Rammohan et al., 2002). Acquiring and mobilising social support was associated with better quality of life (Hsiao et al., 2020). Seeking social support correlated with lower psychological distress (Rao et al., 2020). In contrast, Ong et al. (2016) reported a positive relationship between emotional support and psychological distress, consistent with an inverse relationship between seeking social support and quality of life observed by Kate al. (2014).

Religious coping was assessed in six studies. Positive and negative religious coping strategies were associated with reduced and increased psychological distress, respectively (Rao et al., 2020). In

agreement, Hsiao et al. (2020) observed a positive relationship between seeking spiritual support and quality of life, and Fortune et al. (2005) reported an association between lower religion/ spiritual coping and increased psychological distress (Fortune et al., 2005). In contrast, others identified no relationship between religious coping and psychological distress (Ong et al., 2016) or well-being (Rammohan et al., 2002).

Discussion

This review aimed to synthesise the results of studies investigating the association between caregiver coping strategies and caregiver outcomes of psychological distress and well-being.

Relationship between Coping and Distress and Well-being

The quality of the studies and methodological variability across studies was such that there is insufficient evidence to make a firm conclusion on the relationship between coping strategies and psychological distress and well-being of carers of people with schizophrenia. One study was rated as 'good' using a quality assessment tool for cross-sectional and observational studies. This study still depended on a cross-sectional design, thus limiting conclusions about causality. The remaining studies were rated as 'fair' or 'poor' due to methodological limitations. Limitations of the studies that contributed to the 'fair' or 'poor' rating are further discussed in the section below.

Considering studies rated as 'good' and 'fair', the results provide preliminary support that coping strategies are related to distress and well-being in carers of people with schizophrenia, though no inference can be made on causality or which specific coping strategies have the strongest relationship with psychological distress or well-being. Similar to findings in other carer populations, strategies previously categorised as approach or problem-focused and emotion-focused were not found to be uniquely associated with either better or worse outcomes (e.g. Anderson et al., 2002; Hawken et al., 2018; Sander et al., 2013). While the specific coping strategies associated with outcomes varied across studies, there was some limited agreement. Self-blame, collusion, and

criticism correlated with poorer outcomes and the strategies of positive reappraisal, reframing, and religious coping were associated with better outcomes in more than one study.

Results were inconsistent in relation to the utility of social support as a coping strategy. This may have been due to differences in the carer populations. However, it is difficult to be clear due to a lack of detail in some studies and the limitations of the analysis methods used; most analyses did not include controls. Differences in the measurement of support coping may have contributed to variation in results. For example, Rammohan et al. (2002) used a questionnaire that specified that support was received from someone "who can do something about the problem". In contrast, the measures used by Kate et al. (2013) and Ong et al. (2016) did not specify the supporter's capabilities in relation to the problem. The quality of the assistance received and agreement between the support received and the carers' needs may have impacted the results (Ong et al., 2016).

Limitations of the Extant Research

One study received a 'good' quality rating, ten received a 'fair', and three received a 'poor' quality rating. Methodological issues across studies limited the outcomes and conclusions of this review. The studies typically employed small samples, with only five studies justifying sample size. No study provided information on caregivers who did not participate. Roick et al. (2006) found that non-participants were caring for individuals with more severe illness symptoms, potentially reducing the generalisability of results.

The studies included were all cross-sectional, and most relied on simple analysis methods such as correlations, limiting statements of causality. For example, a high level of psychological distress and low well-being may evoke the use of maladaptive coping or, indeed, there may be reciprocal causation (Hung et al., 2017; Weinstein, 2007), as suggested in the TSC (Lazarus & Folkman, 1984). Researchers that undertook regression, path analyses, and SEM followed different approaches to choosing variables to include in their analyses. Only five studies based their statistical calculations on a theoretical model. Several studies employed stepwise linear regression. Stepwise

methods are not recommended. The results are based on mathematical criteria and are unlikely to be replicated (Thompson, 1995), thus casting doubt on these studies findings. This casts doubt on the results. Only one study provided sufficient detail about the inclusion of confounds in their analysis (Yu et al., 2019). There is some evidence that psychological distress and well-being varies with care recipient illness severity, duration of illness, caregiver characteristics, kinship, and social support. Gender (Khan & Panday, 2017) and age-related (Chen et al., 2018) differences in coping strategies have been reported (Khan & Panday, 2017), while strategies may also alter with duration of caregiving (Magliano et al., 1995). Therefore, it is important that researchers consider potential confounds in their analysis and either design studies to mitigate the confounders' impact or address them in their analysis.

Synthesis of results was also limited because of the variation in the definition of caregivers used across studies. For example, in some studies, caregivers were convenience samples of individuals attending a support group for relatives of people with schizophrenia, while others required participants to endorse that they were the primary caregiver in regular contact with the care recipient and undertaking specific care activities. The variance in these definitions and level of care being provided by those sampled may have contributed to a difference in results across studies.

With regard to the measurement of coping strategies, ten different questionnaires or variants of questionnaires were used. In addition, studies that used the same questionnaire sometimes reported results using different subscales. Most studies used more than two categories to report coping strategies. In one respect, this is positive as the use of broader factors can result in loss of important information (Folkman and Moskowitz, 2004) and minimise clinical utility. However, comparing across a large number of different coping subscales has resulted in the need for item-by-item comparison of results across studies (Skinner et al., 2003). Some coping measures are not accessible or widely used. This can render the synthesis of results problematic, which again obstruct synthesis of results, as experienced in this review. Quality of reporting further impeded

understanding of the findings. Three studies did not provide details about how they defined categories of coping, while another study failed to report the significance of results. Studies included in this review were undertaken across different countries, highlighting that the experience of this specific population of carers is important cross-culturally. Research suggests that coping strategy use may vary across cultures (Tweed et al., 2004). However, due to the limitations already outlined, the impact of cultural context on the relationship between coping strategies and caregiver outcomes could not be assessed in this review.

Future Directions

Future research on the relationship between coping strategies and carer outcomes should include clearly defined inclusion and exclusion criteria and a detailed description of the caregiver population. Details such as carer sociodemographics, relationship definition, duration of caregiving, amount of contact, and social support, in addition to information about the care recipient, should be included. Researchers need to include confounds in their analyses and fully report consideration of potential confounds in their methodology.

Study designs should be informed by established theoretical models of coping and the use of controlled designs (Hung et al., 2017). Longitudinal studies should be undertaken to assess changes in the relationship between coping strategies and outcomes over time and as the course of schizophrenia progresses. There is some evidence that carer distress is highest at the earlier stages of diagnosis (Jansen et al., 2015). Carer needs may differ at earlier and later stages of the disorder. Studies need to explore if different coping strategies predict outcomes at different stages of the carer journey. Future studies should also investigate the influence of culture on the relationship between coping strategies and carer outcomes. Replication of existing studies should be undertaken to verify findings.

The heterogeneity of coping measures and classification systems employed across studies in this review is understandable as there remains no consensus on how best to capture this complex

construct (Carver et al., 1989; Skinner et al., 2003). However, a good starting point to develop a reliable research base in this area may be to replicate existing studies using the same measures. In parallel, similar to recommendations for burden measurement (Schene et al., 1994), it would be helpful if coping researchers agreed on a few standard coping measures that would be most beneficial both clinically and in research. Researchers coordinated efforts to develop any new coping measures, rather than creating measures independently, would also benefit this field of study.

Finally, researchers should report their methodology in detail to ensure transparency of findings. Guidelines are already available to aid best practice reporting, for example, the Strengthening the reporting of observational studies in epidemiology (STROBE) guidelines (von Elm et al., 2007). The recommendations in this review aim to maximise the utility of research findings to advance this research field and clinical application.

Strengths and Limitations of Review

This review followed a systematic approach following PRISMA guidelines. All studies that met the inclusion criteria were included to reduce reporting bias (Boutron et al., 2020). The exclusion of studies not available in English may have limited this review's findings. Where non-English studies were identified, attempts were made to contact authors and obtain an English-language copy to minimise potential cultural bias. The exclusion of relatives not described as carers or having a caring role may have led to the omission of some research on carers of people with schizophrenia. However, the inclusion of studies on relatives without mention of a caring role may have invalidated the relevance of findings to the caregiving population. The exclusion of grey literature to maximise the quality of research reviewed may have led to publication bias (Martin et al., 2005).

Conclusions

This review has found preliminary support for the relationship between coping strategies and carer outcomes of psychological distress and well-being, suggesting that coping strategies are a

useful component in interventions for carers. However, it is not possible to identify with confidence which coping strategies best predict psychological distress and well-being as the quality of the studies was such that there is insufficient evidence to make any conclusions. Further, there was a lack of consistency or limited replication of findings across studies and, due to the cross-sectional design employed by all studies, no inferences can be made about the direction of the relationship between coping strategies and carer outcomes.

This review highlights the need for greater clarity and transparency of reporting of research design and methodology and the use of more robust statistical analysis. Specifically, studies should clearly define the sample; select questionnaires that are valid and reliable; carry out analysis to confirm the questionnaires' reliability and factor structure in the specific study sample (Skinner et al., 2003); and use statistical methods that consider potential confounding variables. Study designs should also be informed by theoretical models and include controls or designs that can assist in understanding the direction of the relationship between variables (Weinstein, 2007). These improvements will require the use of larger samples. In addition, longitudinal analyses would advance understanding of how optimal carer coping strategies may change throughout the course of the disorder. The additional information garnered from such studies would inform the inclusion of coping strategies in interventions for carers, with the aim of optimising outcomes for both carers and the care recipient.

References

- American Psychiatric Association. (2020). *The American Psychiatric Association Practice Guideline for the Treatment of Patients With Schizophrenia* (3rd ed.). American Psychiatric Association Publishing. <https://doi.org/https://doi.org/10.1176/appi.ajp.2020.177901>
- Anderson, M. I., Parmenter, T. R., & Mok, M. (2002). The relationship between neurobehavioural problems of severe traumatic brain injury (TBI), family functioning and the psychological

well-being of the spouse/caregiver: path model analysis. *Brain Injury*, 16(9), 743-757.

<https://doi.org/10.1080/02699050210128906>

Anderson, M. I., Simpson, G. K., Daher, M., & Matheson, L. (2015). The relationship between coping and psychological adjustment in family caregivers of individuals with traumatic brain injury: A systematic review. In Y. P. Conley (Ed.), *Annual Review of Nursing Research*, Vol. 33, 2015: *Traumatic brain injury*. (pp. 219-247). Springer Publishing Company.

<https://ucc.idm.oclc.org/login?URL=http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2015-49596-007&site=ehost-live>

Ashcroft, K., Kim, E., Elefant, E., Benson, C., & Carter, J. A. (2018). Meta-analysis of caregiver-directed psychosocial interventions for schizophrenia. *Community Ment Health J*, 54(7), 983-991.

<https://doi.org/10.1007/s10597-018-0289-x>

Bhogle, S., & Prakash, I. J. (1995). Development of the Psychological Well-Being (PWB) questionnaire. *Journal of Personality and Clinical Studies*, 11(1-2), 5-9.

<https://ucc.idm.oclc.org/login?URL=http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=1996-02368-002&site=ehost-live>

Boonpongmanee, C., Zauszniewski, J. A., & Morris, D. L. (2003). Resourcefulness and self-care in pregnant women with HIV. *Western Journal of Nursing Research*, 25(1), 75-92.

<https://doi.org/10.1177/0193945902238837>

Boutron, I., Page, M. J., Higgins, J. P. T., Altman, D. G., Lundh, A., & Hróbjartsson, A. (2020). Chapter 7: Considering bias and conflicts of interest among the included studies. In H. J.P.T., T. J., C. J., C. M., L. T., P. M.J., & W. V.A. (Eds.), *Cochrane Handbook for Systematic Reviews of Interventions version 6.1 (updated September 2020)*. www.training.chochrane.org/handbook

Boynton, P. M., & Greenhalgh, T. (2004). Hands-on guide to questionnaire research: Selecting, designing, and developing your questionnaire. *BMJ: British Medical Journal*, 328(7451), 1312-1315. <https://doi.org/10.1136/bmj.328.7451.1312>

- Budd, R. J., Oles, G., & Hughes, I. C. (1998). The relationship between coping style and burden in the carers of relatives with schizophrenia. *Acta Psychiatr Scand*, 98(4), 304-309.
<https://doi.org/10.1111/j.1600-0447.1998.tb10088.x>
- Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine*, 4(1), 92-100.
https://doi.org/10.1207/s15327558ijbm0401_6
- Carver, C. S., & Connor-Smith, J. (2010). Personality and coping. *Annu Rev Psychol*, 61, 679-704.
<https://doi.org/10.1146/annurev.psych.093008.100352>
- Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*, 56(2), 267-283.
<https://doi.org/10.1037/0022-3514.56.2.267>
- Chai, P. P. M., Krägeloh, C. U., Shepherd, D., & Billington, R. (2012). Stress and quality of life in international and domestic university students: Cultural differences in the use of religious coping. *Mental Health, Religion & Culture*, 15(3), 265–277. <https://doi-org.ucc.idm.oclc.org/10.1080/13674676.2011.571665>
- Chen, P. S., Yang, Y. K., Liao, Y. C., Lee, Y. D., Yeh, T. L., & Chen, C. C. (2004). The psychological well-being and associated factors of caregivers of outpatients with schizophrenia in Taiwan. *Psychiatry and Clinical Neurosciences*, 58(6), 600-605. <https://doi.org/10.1111/j.1440-1819.2004.01309.x>
- Chen, Y., Peng, Y., Xu, H., & O'Brien, W. H. (2018). Age differences in stress and coping: Problem-focused strategies mediate the relationship between age and positive affect. *The International Journal of Aging & Human Development*, 86(4), 347-363.
<https://doi.org/10.1177/0091415017720890>

- Cleary, M., West, S., Hunt, G. E., McLean, L., & Kornhaber, R. (2020). A qualitative systematic review of caregivers' experiences of caring for family diagnosed with schizophrenia. *Issues in Mental Health Nursing*. <https://doi.org/10.1080/01612840.2019.1710012>
- del-Pino-Casado, R., Frías-Osuna, A., Palomino-Moral, P. A., & Pancorbo-Hidalgo, P. L. (2011). Coping and subjective burden in caregivers of older relatives: a quantitative systematic review. *Journal of Advanced Nursing*, 67(11), 2311-2322. <https://doi.org/10.1111/j.1365-2648.2011.05725.x>
- Drapeau, A., Marchand, A., & Beaulieu-Prévost, D. (2012). Epidemiology of psychological distress. In *Mental illnesses - Understanding, prediction and control*. <https://doi.org/10.5772/30872>
- Dyck, D. G., Short, R., & Vitaliano, P. P. (1999). Predictors of burden and infectious illness in schizophrenia caregivers. *Psychosomatic Medicine*, 61(4). https://journals.lww.com/psychosomaticmedicine/Fulltext/1999/07000/Predictors_of_Burden_and_Infectious_Illness_in.1.aspx
- Eisenberg, S. A., Shen, B.-J., Schwarz, E. R., & Mallon, S. (2012). Avoidant coping moderates the association between anxiety and patient-rated physical functioning in heart failure patients. *Journal of Behavioral Medicine*, 35(3), 253-261. <https://doi.org/10.1007/s10865-011-9358-0>
- Folkman, S., Lazarus, R. S., Dunkel-Schetter, C., DeLongis, A., & Gruen, R. J. (1986). Dynamics of a stressful encounter: Cognitive appraisal, coping, and encounter outcomes. *Journal of Personality and Social Psychology*, 50(5), 992-1003. <https://doi.org/10.1037/0022-3514.50.5.992>
- Folkman, S., & Moskowitz, J. T. (2004). Coping: Pitfalls and promise. *Annual Review of Psychology*, 55, 745-774. <https://doi.org/10.1146/annurev.psych.55.090902.141456>
- Fortune, D. G., Smith, J. V., & Garvey, K. (2005). Perceptions of psychosis, coping, appraisals, and psychological distress in the relatives of patients with schizophrenia: An exploration using

self-regulation theory. *British Journal of Clinical Psychology*, 44(3), 319-331.

<https://doi.org/10.1348/014466505X29198>

Galletly, C., Castle, D., Dark, F., Humberstone, V., Jablensky, A., Killackey, E., Kulkarni, J., McGorry, P.,

Nielssen, O., & Tran, N. (2016). Royal Australian and New Zealand College of Psychiatrists

clinical practice guidelines for the management of schizophrenia and related disorders.

Australian and New Zealand Journal of Psychiatry, 50(5), 410-472.

<https://doi.org/10.1177/0004867416641195>

GBD 2017 Disease and Injury Incidence and Prevalence Collaborators. (2018). Global, regional, and

national incidence, prevalence, and years lived with disability for 354 diseases and injuries

for 195 countries and territories, 1990-2017: A systematic analysis for the Global Burden of

Disease Study 2017. *Lancet*, 392(10159), 1789-1858. <https://doi.org/10.1016/s0140->

6736(18)32279-7

Geriani, D., Savithry, K. S., Shivakumar, S., & Kanchan, T. (2015). Burden of care on caregivers of

schizophrenia patients: a correlation to personality and coping. *J Clin Diagn Res*, 9(3), Vc01-

vc04. <https://doi.org/10.7860/jcdr/2015/11342.5654>

Gibbons, J. S., Horn, S. H., Powell, J. M., & Gibbons, J. L. (1984). Schizophrenic patients and their

families: A survey in a psychiatric service based on a DGH unit. *The British Journal of*

Psychiatry, 144, 70-77. <https://doi.org/10.1192/bjp.144.1.70>

Glick, I. D., Stekoll, A. H., & Hays, S. (2011). The role of the family and improvement in treatment

maintenance, adherence, and outcome for schizophrenia. *Journal of Clinical*

Psychopharmacology, 31(1), 82-85. <https://doi.org/10.1097/JCP.0b013e31820597fa>

Goldberg, D. (1972). *The detection of psychiatric illness by questionnaire*. Oxford University Press.

Goldberg, D., & Williams, P. (1988). *A user guide to the General Health Questionnaire*. NFER-Nelson.

Goldberg, D. P., & Hillier, V. F. (1979). A scaled version of the General Health Questionnaire.

Psychological Medicine, 9(1), 139-145. <https://doi.org/10.1017/S0033291700021644>

- Gupta, S., Isherwood, G., Jones, K., & Van Impe, K. (2015). Assessing health status in informal schizophrenia caregivers compared with health status in non-caregivers and caregivers of other conditions. *BMC Psychiatry*, 15. <https://doi.org/10.1186/s12888-015-0547-1>
- Hawken, T., Turner-Cobb, J., & Barnett, J. (2018). Coping and adjustment in caregivers: A systematic review. *Health Psychology Open*, 5(2), 2055102918810659. <https://doi.org/10.1177/2055102918810659>
- Hayes, L., Hawthorne, G., Farhall, J., O'Hanlon, B., & Harvey, C. (2015). Quality of life and social isolation among caregivers of adults with schizophrenia: Policy and outcomes. *Community Mental Health Journal*, 51(5), 591-597. <https://doi.org/10.1007/s10597-015-9848-6>
- Holley, J., Crone, D., Tyson, P., & Lovell, G. (2011). The effects of physical activity on psychological well-being for those with schizophrenia: A systematic review. *British Journal of Clinical Psychology*, 50(1), 84-105. <https://doi.org/10.1348/014466510X496220>
- Hsiao, C.-Y., Lu, H.-L., & Tsai, Y.-F. (2020). Caregiver burden and health-related quality of life among primary family caregivers of individuals with schizophrenia: A cross-sectional study. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*. <https://doi.org/10.1007/s11136-020-02518-1>
- Hung, M., Bounsanga, J., & Voss, M. W. (2017). Interpretation of correlations in clinical research. *Postgraduate Medicine*, 129(8), 902-906. <https://doi.org/10.1080/00325481.2017.1383820>
- Huppert, F. A., & Whittington, J. E. (2003). Evidence for the independence of positive and negative well-being: implications for quality of life assessment. *Br J Health Psychol*, 8(Pt 1), 107-122. <https://doi.org/10.1348/135910703762879246>
- Jansen, J. E., Gleeson, J., & Cotton, S. (2015). Towards a better understanding of caregiver distress in early psychosis: A systematic review of the psychological factors involved. *Clinical Psychology Review*, 35, 56-66. <https://doi.org/10.1016/j.cpr.2014.12.002>

- Karademas, E. C. (2007). Positive and negative aspects of well-being: Common and specific predictors. *Personality and Individual Differences*, 43(2), 277-287.
<https://doi.org/10.1016/j.paid.2006.11.031>
- Kate, N., Grover, S., Kulhara, P., & Nehra, R. (2014). Relationship of quality of life with coping and burden in primary caregivers of patients with schizophrenia. *International Journal of Social Psychiatry*, 60(2), 107-116. <https://doi.org/10.1177/0020764012467598>
- Kessler, R. C., Andrews, G., Colpe, L. J., Hiripi, E., Mroczek, D. K., Normand, S. L. T., Walters, E. E., & Zaslavsky, A. M. (2002). Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychological Medicine*, 32(6), 959-976.
<https://doi.org/10.1017/s0033291702006074>
- Khan, M. S., & Panday, R. (2017). Coping strategies of male and female care givers of individuals suffering from schizophrenia. *Journal of Psychosocial Research*, 12(2), 477-484.
- Kuipers, E., Onwumere, J., & Bebbington, P. (2010). Cognitive model of caregiving in psychosis. *The British Journal of Psychiatry*, 196(4), 259-265. <https://doi.org/10.1192/bjp.bp.109.070466>
- Lam, P. C. W., Ng, P., Pan, J., & Young, D. K. W. (2015). Ways of coping of Chinese caregivers for family members with schizophrenia in two metropolitan cities: Guangzhou and Hong Kong, China. *International Journal of Social Psychiatry*, 61(6), 591-599.
<https://doi.org/10.1177/0020764014565797>
- Lambert, V. A., Lambert, C. E., Itano, J., Inouye, J., Kim, S., Kuniviktikul, W., Sitthimongkol, Y., Pongthavornkamol, K., Gasemgitvattana, S., & Ito, M. (2004). Cross-cultural comparison of workplace stressors, ways of coping and demographic characteristics as predictors of physical and mental health among hospital nurses in Japan, Thailand, South Korea and the USA (Hawaii). *International Journal of Nursing Studies*, 41(6), 671-684.
<https://doi.org/https://doi.org/10.1016/j.ijnurstu.2004.02.003>

- Lau, D. Y. K., & Pang, A. H. T. (2007). Validation of the Chinese version of Experience of Caregiving Inventory in caregivers of persons suffering from severe mental disorders. *Hong Kong Journal of Psychiatry*, 17(1), 24-31.
<https://ucc.idm.oclc.org/login?URL=http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2007-15580-005&site=ehost-live>
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer Publishing Company, Inc.
- Lerner, D., Chang, H., Rogers, W. H., Benson, C., Lyson, M. C., & Dixon, L. B. (2018). Psychological distress among caregivers of individuals with a diagnosis of schizophrenia or schizoaffective disorder. *Psychiatric Services*, 69(2), 169-178. <https://doi.org/10.1176/appi.ps.201600422>
- Li, J., Lambert, C. E., & Lambert, V. A. (2007). Predictors of family caregivers' burden and quality of life when providing care for a family member with schizophrenia in the People's Republic of China. *Nursing & Health Sciences*, 9(3), 192-198. <https://doi.org/10.1111/j.1442-2018.2007.00327.x>
- Lohacheewa, S., Sitthimongkol, Y., Sirapo-ngam, Y., & Viwatwongkasem, C. (2016). Psychological distress of family members caring for a relative with first episode schizophrenia. *Pacific Rim International Journal of Nursing Research*, 20(3), 183-195.
<https://ucc.idm.oclc.org/login?URL=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=116406911&site=ehost-live>
- MacCarthy, B., & Brown, R. (1989). Psychosocial factors in Parkinson's disease. *British Journal of Clinical Psychology*, 28(1), 41-52. <https://doi.org/10.1111/j.2044-8260.1989.tb00810.x>
- Magaña, S. M., García, J. I. R., Hernández, M. G., & Cortez, R. (2007). Psychological distress among Latino family caregivers of adults with schizophrenia: The roles of burden and stigma. *Psychiatric Services*, 58(3), 378-384. <https://doi.org/10.1176/appi.ps.58.3.378>

- Magliano, L., Fadden, G., Economou, M., Held, T., Xavier, M., Guarneri, M., Malangone, C., Marasco, C., & Maj, M. (2000). Family burden and coping strategies in schizophrenia: 1-year follow-up data from the BIOMED I study. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*, 35(3), 109-115. <https://doi.org/10.1007/s001270050192>
- Magliano, L., Guarneri, M., Marasco, C., Tosini, P., Morosini, P. L., & Maj, M. (1996). A new questionnaire assessing coping strategies in relatives of patients with schizophrenia: Development and factor analysis. *Acta Psychiatrica Scandinavica*, 94(4), 224-228. <https://doi.org/10.1111/j.1600-0447.1996.tb09853.x>
- Magliano, L., Veltro, F., Guarneri, M., & Marasco, C. (1995). Clinical and socio-demographic correlates of coping strategies in relatives of schizophrenic patients. *European Psychiatry*, 10(3), 155-158. [https://doi.org/10.1016/0767-399X\(96\)80104-0](https://doi.org/10.1016/0767-399X(96)80104-0)
- Martens, L., & Addington, J. (2001). The psychological well-being of family members of individuals with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*, 36(3), 128-133. <https://doi.org/10.1007/s001270050301>
- Martin, J. L. R., Pérez, V., Sacristán, M., & Álvarez, E. (2005). Is grey literature essential for a better control of publication bias in psychiatry? An example from three meta-analyses of schizophrenia. *European Psychiatry*, 20(8), 550-553. <https://doi.org/10.1016/j.eurpsy.2005.03.011>
- McCubbin, H., Olson, D., & Larsen, A. (1981). Family Crisis Oriented Personal Evaluation Scales. In H. I. McCubbin, Thompson, A. I., McCubbin, M. A. (Ed.), *Family assessment: Resiliency, coping and adaptation: Inventories for research and practice* (pp. 455-508). University of Wisconsin-Madison Publishers.

- Mitsonis, C., Voussoura, E., Dimopoulos, N., Psarra, V., Kararizou, E., Latzouraki, E., Zervas, I., & Katsanou, M.-N. (2012). Factors associated with caregiver psychological distress in chronic schizophrenia. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*, 47(2), 331-337. <https://doi.org/10.1007/s00127-010-0325-9>
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *BMJ*, 339, b2535. <https://doi.org/10.1136/bmj.b2535>
- Möller-Leimkühler, A. M. (2005). Burden of relatives and predictors of burden Baseline results from the Munich 5-year-follow-up study on relatives of first hospitalized patients with schizophrenia or depression. *European Archives of Psychiatry and Clinical Neuroscience*, 255(4), 223-231. <https://doi.org/10.1007/s00406-004-0550-x>
- Monteiro, A. M. F., Santos, R. L., Kimura, N., Baptista, M. A. T., & Dourado, M. C. N. (2018). Coping strategies among caregivers of people with Alzheimer disease: A systematic review. *Trends in Psychiatry and Psychotherapy*, 40(3), 258-268. <https://doi.org/10.1590/2237-6089-2017-0065>
- Moos, R. H., Brennan, P. L., Fondacaro, M. R., & Moos, B. S. (1990). Approach and avoidance coping responses among older problem and nonproblem drinkers. *Psychology and Aging*, 5(1), 31-40. <https://doi.org/10.1037/0882-7974.5.1.31>
- Mui, E. Y. W., Chan, S. K. W., Chan, P. Y., Hui, C. L. M., Chang, W. C., Lee, E. H. M., & Chen, E. Y. H. (2019). Systematic review (meta-aggregation) of qualitative studies on the experiences of family members caring for individuals with early psychosis. *International Review of Psychiatry*. <https://doi-org.ucc.idm.oclc.org/10.1080/09540261.2019.1659236>

- National Institute for Health and Care Excellence. (2014). *Psychosis and schizophrenia in adults: prevention and management (CG178)*. Retrieved 1/10/2020 from <https://www.nice.org.uk/guidance/cg178/evidence/full-guideline-490503565>
- National Institutes of Health. (2014). *Quality Assessment tool for observational and cross-sectional studies*. Retrieved 24/08/2020 from <https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools>
- Nehra, R., Chakrabarti, S., Kulhara, P., & Sharma, R. (2005). Caregiver-coping in bipolar disorder and schizophrenia: A re-examination. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*, 40(4), 329-336. <https://doi.org/10.1007/s00127-005-0884-3>
- Nihayati, H., Nur Gunawan, D., Wahyuni, S., & Yunita, F. (2020). Is there a correlation between the coping strategy used and the quality of life of the caregivers of schizophrenic patients in a family unit? *International Journal of Psychosocial Rehabilitation*, 24, 9079-9087. <https://doi.org/10.37200/IJPR/V24I7/PR270899>
- Oldridge, M. L., & Hughes, I. C. T. (1992). Psychological well-being in families with a member suffering from schizophrenia: An investigation into long-standing problems. *The British Journal of Psychiatry*, 161(2), 249-251. <https://doi.org/http://dx.doi.org/10.1192/bjp.161.2.249>
- Ong, H. C., Ibrahim, N., & Wahab, S. (2016). Psychological distress, perceived stigma, and coping among caregivers of patients with schizophrenia. *Psychology Research and Behavior Management*, 9. <https://doi.org/10.2147/PRBM.S112129>
- Pharoah, F., Mari, J. J., Rathbone, J., & Wong, W. (2010). Family intervention for schizophrenia. *Cochrane Database of Systematic Reviews*(12). <https://doi.org/10.1002/14651858.CD000088.pub3>

- Radloff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*(3), 385-401.
<https://doi.org/10.1177/014662167700100306>
- Rammohan, A., Rao, K., & Subbakrishna, D. K. (2002). Religious coping and psychological wellbeing in carers of relatives with schizophrenia. *Acta Psychiatrica Scandinavica, 105*(5), 356-362.
<https://doi.org/10.1034/j.1600-0447.2002.1o149.x>
- Rao, K., Subbakrishna, D. K., & Prabhu, G. G. (1989). Development of a coping checklist: A preliminary report. *Indian Journal of Psychiatry, 31*(2), 128-133.
<https://ucc.idm.oclc.org/login?URL=http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=1991-17252-001&site=ehost-live>
- Rao, P., Grover, S., & Chakrabarti, S. (2020). Coping with caregiving stress among caregivers of patients with schizophrenia. *Asian Journal of Psychiatry, 54*, 102219.
<https://doi.org/10.1016/j.ajp.2020.102219>
- Richieri, R., Boyer, L., Reine, G., Loundou, A., Auquier, P., Lançon, C., & Simeoni, M. C. (2011). The Schizophrenia Caregiver Quality of Life questionnaire (S-CGQoL): Development and validation of an instrument to measure quality of life of caregivers of individuals with schizophrenia. *Schizophrenia Research, 126*(1-3), 192-201.
<https://doi.org/10.1016/j.schres.2010.08.037>
- Roick, C., Heider, D., Toumi, M., & Angermeyer, M. C. (2006). The impact of caregivers' characteristics, patients' conditions and regional differences on family burden in schizophrenia: a longitudinal analysis. *Acta Psychiatrica Scandinavica, 114*(5), 363-374.
<https://doi.org/https://doi.org/10.1111/j.1600-0447.2006.00797.x>
- Roth, S., & Cohen, L. J. (1986). Approach, avoidance, and coping with stress. *American Psychologist, 41*(7), 813-819. <https://doi.org/10.1037/0003-066X.41.7.813>

- Ryan, R., Synnot, A., Pictor, M., & Hill, S. (2016). *Cochrane consumers and communication group data extraction template for included studies*. CCCG. <http://cccr.org.cochrane.org/author-resources>
- Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, 57(6), 1069-1081.
<https://doi.org/10.1037/0022-3514.57.6.1069>
- Salvador-Carulla, L., Lucas, R., Ayuso-Mateos, J., & Miret, M. (2014). Use of the terms "Wellbeing" and "Quality of Life" in health sciences: A conceptual framework. *The European Journal of Psychiatry*, 28, 50-65. <https://doi.org/10.4321/S0213-61632014000100005>
- Sander, A. M., Maestas, K. L., Clark, A. N., & Havins, W. N. (2013). Predictors of emotional distress in family caregivers of persons with traumatic brain injury: A systematic review. *Brain Impairment*, 14(1), 113-129. <https://doi.org/10.1017/BrImp.2013.12>
- Shaw, W. S., Patterson, T. L., Semple, S. J., Grant, I., Yu, E. S. H., Zhang, M. y., He, Y., & Wu, W. y. (1997). A cross-cultural validation of coping strategies and their associations with caregiving distress. *The Gerontologist*, 37(4), 490-504. <https://doi-org.ucc.idm.oclc.org/10.1093/geront/37.4.490>
- Schene, A. H., Tessler, R. C., & Gamache, G. M. (1994). Instruments measuring family or caregiver burden in severe mental illness. *Social Psychiatry and Psychiatric Epidemiology*, 29(5), 228-240. <https://doi.org/10.1007/BF00796381>
- Shiraishi, N., & Reilly, J. (2019). Positive and negative impacts of schizophrenia on family caregivers: A systematic review and qualitative meta-summary. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*, 54(3), 277-290. <https://doi.org/10.1007/s00127-018-1617-8>

- Sin, J., & Norman, I. (2013). Psychoeducational interventions for family members of people with schizophrenia: A mixed-method systematic review. *The Journal of Clinical Psychiatry*, 74(12), e1145-e1162. <https://doi.org/10.4088/JCP.12r08308>
- Skinner, E. A., Edge, K., Altman, J., & Sherwood, H. (2003). Searching for the structure of coping: A review and critique of category systems for classifying ways of coping. *Psychological Bulletin*, 129(2), 216-269. <https://doi.org/10.1037/0033-2909.129.2.216>
- Stanley, S., Balakrishnan, S., & Ilangoan, S. (2017). Psychological distress, perceived burden and quality of life in caregivers of persons with schizophrenia. *J Ment Health*, 26(2), 134-141. <https://doi.org/10.1080/09638237.2016.1276537>
- Szmukler, G. I., Burgess, P., Herrman, H., & Benson, A. (1996). Caring for relatives with serious mental illness: The development of Experience of Caregiving Inventory. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*, 31(3-4), 137-148. <https://doi.org/10.1007/BF00785760>
- Tang, Q., Cheng, Z., Yan, A., & Den, Y. (1999). The use and reanalysis of the SCL-90 in China. *Chinese Journal of Clinical Psychology*, 7(1), 16-20. <https://ucc.idm.oclc.org/login?URL=http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=1999-13194-005&site=ehost-live>
- Thompson, B. (1995). Stepwise regression and stepwise discriminant analysis need not apply here: A guidelines editorial. *Educational and Psychological Measurement*, 55(4), 525-534. <https://doi.org/10.1177/0013164495055004001>
- Thunyadee, C., Sitthimongkol, Y., Sangon, S., Chai-Aroon, T., & Hegadoren, K. M. (2015). Predictors of depressive symptoms and physical health in caregivers of individuals with schizophrenia. *Nursing & Health Sciences*, 17(4), 412-419. <https://doi.org/10.1111/nhs.12205>

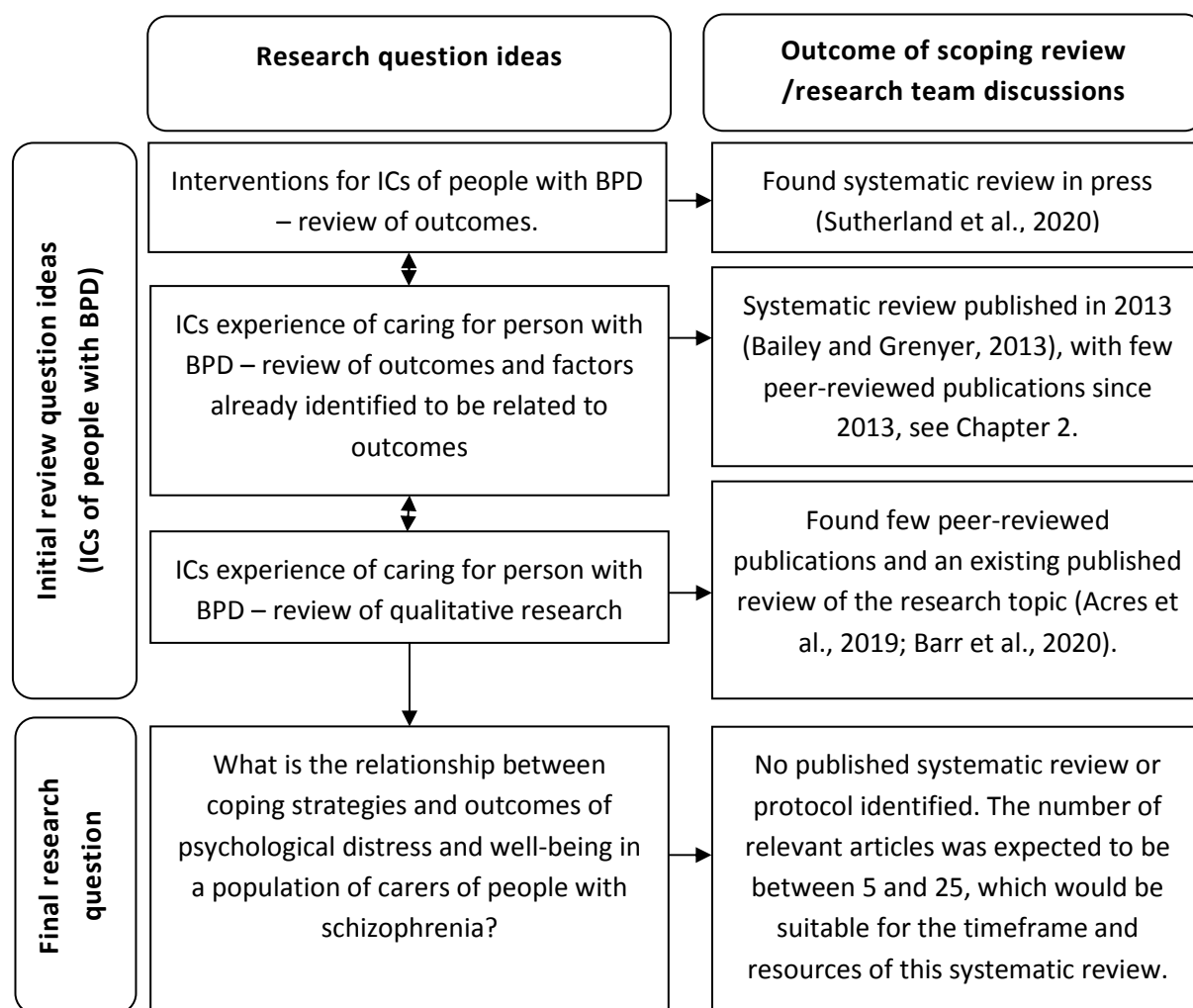
- Tweed, R. G., White, K., & Lehman, D. R. (2004). Culture, stress, and coping: Internally- and externally-targeted control strategies of European Canadians, East Asian Canadians, and Japanese. *Journal of Cross-Cultural Psychology*, 35(6), 652–668. <https://doi-org.ucc.idm.oclc.org/10.1177/0022022104270109>
- von Elm, E., Altman, D. G., Egger, M., Pocock, S. J., Gøtzsche, P. C., Vandenbroucke, J. P., & Initiative, S. (2007). Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *BMJ (Clinical research ed.)*, 335(7624), 806-808. <https://doi.org/10.1136/bmj.39335.541782.AD>
- Weinstein, N. D. (2007). Misleading tests of health behavior theories. *Ann Behav Med*, 33(1), 1-10. https://doi.org/10.1207/s15324796abm3301_1
- Winefield, H. R., & Harvey, E. J. (1993). Determinants of psychological distress in relatives of people with chronic schizophrenia. *Schizophr Bull*, 19(3), 619-625. <https://doi.org/10.1093/schbul/19.3.619>
- World Health Organisation. (n.d.). <https://www.who.int/about/who-we-are/constitution>
- World Health Organisation(1996). *WHOQOL-BREF : introduction, administration, scoring and generic version of the assessment : field trial version, December 1996*. World Health Organization. <https://apps.who.int/iris/handle/10665/63529>
- Xie, Y. N. (1998). Preliminary study to the reliability and validity of the Simplified Coping Style Questionnaire. *Chinese Journal of Clinical Psychology*, 6, 114-115.
- Yu, W., Chen, J., Hu, J., & Hu, J. (2019). Relationship between mental health and burden among primary caregivers of outpatients with schizophrenia. *Family Process*, 58(2), 370-383. <https://doi.org/10.1111/famp.12340>
- Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67(6), 361-370. <https://doi.org/10.1111/j.1600-0447.1983.tb09716.x>

Chapter 4: Systematic Review Supplementary Methods

The systematic review process was informed by Boland et al. (2017) and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher et al., 2009).

Figure 4.1

Summary of Steps Followed to Choose Systematic Review Topic



The Review Question

Figure 4.1 summarises the development of the research question, which evolved from an initial interest in the experience of ICs of people with BPD and a broader interest in ICs of people with mental health difficulties. The final research question was informed by scoping searches and discussion with the research team.

Scoping Searches

Published or ongoing systematic reviews were identified through searches in PsycINFO and PROSPERO. The overall aim of this thesis was to understand the relationship between coping and outcomes of well-being and distress in ICs of people with BPD. As shown in Figure 1, the initial questions of interest relating to the ICs of people with BPD were not suitable for a systematic review. Subsequently, it was determined that a systematic review of this relationship in another population of ICs of people with mental ill-health would further contribute to the extant literature on ICs. A decision was made to focus on ICs of people with schizophrenia as this population has been widely researched. Scoping searches in PsycINFO and PubMed indicated between five and 25 papers relevant to the topic, depending on the inclusion criteria and search strategy.

Inclusion and Exclusion Criteria

Only English-language publications in peer-reviewed journals were included. Abstracts of foreign language articles were screened for the inclusion criteria to minimise potential language bias (Boland et al., 2017). When abstract details pointed to the study's possible relevance, attempts were made to contact the authors and obtain an English translation for full-text screening. Four articles fell into this category. Attempts to contact three authors failed. The fourth author confirmed that their text was only available in the published language (French) and they did not measure coping in their research.

Grey literature was excluded from this systematic review, possibly leading to publication bias as peer-reviewed journals frequently exclude null findings (Adams et al., 2016). To aid transparency, the grey literature was only excluded following completion of database searches, see Figure 3.1. Only studies that used quantitative, standardised measures of the constructs of interest were included. In this thesis, a standardised questionnaire was one "that is written and administered so that all participants are asked precisely the same questions in an identical format and responses recorded in a uniform manner" (Boynton & Greenhalgh, 2004, p. 1313). Non-standardised questionnaires were excluded to increase the reliability of the outcome measured (Boynton &

Greenhalgh, 2004). To minimise bias, there were no limits on research publication dates or on research settings.

Search Strategy Rationale

A librarian was consulted to develop the search strategy to improve the review's quality.

Four databases were selected. Reasons for selections are as follows:

- PsycINFO focuses on the psychological discipline of interest in this review.
- PubMed extends its interest beyond the psychological field to the broader health sciences that may have researched this area.
- CINAHL is a database specific to nursing and allied professionals, who generate a significant amount of research in the area of both schizophrenia and caregiving.
- Scopus incorporates research carried out across disciplines beyond health sciences and was included to ensure a comprehensive search.

The following four steps informed terms employed in the search strategy:

1. A review of terms used in existing systematic reviews investigating caregivers, schizophrenia, and constructs of coping strategies, psychological distress and well-being;
2. A review of synonyms in the database thesaurus;
3. Discussion with the research team and the librarian; and
4. Pilot studies of the search terms.

Search Terms

Terms chosen aimed to maximise sensitivity while maintaining reasonable precision (Lefebvre et al., 2020). Terms were searched across title, abstract, and keywords (or database equivalent); see Appendix A. The following sections provide the rationale for the final search terms.

Schizophrenia

As the focus was specifically on ICs of people with schizophrenia, related terms, for example, "schizoaffective" or "psychosis", were deemed beyond the review inclusion criteria.

Informal Carer (IC)

ICs are referred to using variations of the term "carer" or by relationship status, for example, "parent" or "sibling". The final search terms excluded the term "relative" to improve search precision. Pilot searches in PsycINFO and PubMed assessed sensitivity when using the term "relative*", yielding an additional 28 and 34 hits, respectively. Only three of the PsycINFO articles and four PubMed articles used "relative" to describe relationship status. None of these articles met the inclusion criteria for this study, indicating that this term's inclusion would not increase search sensitivity. This approach is in line with previous systematic reviews of caregivers (Anderson et al., 2015; Jansen, Gleeson, et al., 2015).

Coping Strategies

In this review, the construct of coping strategies was measured using a quantitative and standardised measure of the cognitive, behavioural and emotional responses to a stressor (chapter three). Coping questionnaires typically have the term "cope" or "coping" in the title (see Kato, 2015). Previous systematic reviews have used variations of the term "cope" (e.g. Anderson et al., 2002; del-Pino-Casado et al., 2011; Hawken et al., 2018). Terms related to "adaptation" were included, informed by database thesauruses and MeSH databases. As a cautionary check, a pilot search in PsycINFO included the terms "adjust*" and "problem solv*" to assess whether these terms would improve the search effectiveness. Title and abstract screen resulted in no additional articles meeting the review criteria, indicating that inclusion of these search terms would not improve search sensitivity. Therefore "adjust*" and "problem solv*" were omitted from final searches.

Psychological Distress and Well-being

Terms such as life satisfaction or happiness, which are linked to well-being, were not included as they are only a component of well-being and therefore cannot be used to fully capture the construct (Camfield & Skevington, 2008; Salvador-Carulla et al., 2014).

Data Extraction

The data extraction template included the following information: aims of study; hypothesis; study design; ethics; time period; location; setting; details of missing data and selective reporting; inclusion and exclusion criteria; participant, index patient and relationship characteristics; assessment of index person diagnosis; data collection methods and measures used; analysis methods; and key relevant results. Single data extraction was undertaken due to resource limitations. Caution was applied to avoid errors per recommendations (Buscemi et al., 2006). The reviewer cross-checked all data extracted for errors of omission or inclusion.

Quality Assessment

Studies identified for inclusion in this systematic review were cross-sectional non-randomised studies (also referred to as observational studies). Sanderson et al. (2007) recommend that quality assessment tools specifically created for observational designs be used. However, a gold standard tool has not yet been identified (Jarde et al., 2012; Moskalewicz & Oremus, 2020; Sanderson et al., 2007). Previous systematic reviews do not include recently developed quality assessment tools for cross-sectional studies (Deeks et al., 2003; Jarde et al., 2012). Jarde et al. (2012) and Sanderson et al. (2007) recommend the following be addressed when assessing quality: participant sampling; methods of measurement; data collection; statistical methods; consideration of confounds; and conflict of interest. The three most important factors to be considered are participant selection, methods of measurements and inclusion of confounds (Sanderson et al., 2007).

For cross-sectional studies, Ma et al. (2020) recommend the National Institutes of Health (NIH, 2014) Quality Assessment Tool for Observational Cohort and Cross-sectional Studies; the Joanna Briggs Institute (JBI; 2017) critical appraisal checklist for analytical cross-sectional studies; and the Appraisal tool for Cross-Sectional Studies (AXIS; Downes et al., 2016). Adapted versions of the Newcastle-Ottawa Scale (NOS) have also been developed (Moskalewicz & Oremus, 2020). For this systematic review, the NIH (2014) assessment tool was selected. The questions covered the most important quality assessment factors (Jarde et al., 2012; Sanderson et al., 2007) and included

specific questions on the validity, reliability and standardisation of measurement of exposure and outcome variables and on confound variables. The tool also provided a transparent checklist for qualitative rather than numerical rating of studies. A numerical rating scale to assess quality is not recommended as they lack reliability and empirical support (Higgins & Green, 2011; Sanderson et al., 2007). Inclusion of studies irrespective of their quality is recommended to minimise the risk of biased study selection. However, quality assessment should be discussed when synthesising the results (Higgins & Green, 2011). Pilot use of the NIH (2004) quality assessment tool also indicated it to be user friendly.

Dissemination

The systematic review will be submitted to the journal, see Appendix B.

Chapter 5 The Relationship between Social Support, Coping Strategies and Psychological Distress and Positive Mental Well-being in Carers of People with Borderline Personality Disorder

Abstract

Background

Informal carers of people with BPD experience high levels of burden and psychological distress and may be facing even greater stress in the context of COVID-19. There is a scarcity of research evidencing the influence of modifiable factors on carer outcomes to inform interventions. This study aimed to investigate (i) the relationship between social support, coping strategies and psychological distress and positive mental well-being in carers of people with BPD and also (ii) the relationship between coping strategies and change in carer stress due to COVID-19.

Methods

1207 carers completed the McLean Screening Instrument for BPD-Carer Version, the Brief COPE, the Multidimensional Scale of Perceived Social Support, the Kessler Psychological Distress scale, the WHO-5 Well-being Index, the Coronavirus Anxiety Scale, and measures of change in use of coping strategies and change in caregiver stress due to COVID-19. Data for 863 participants who met the inclusion criteria were analysed.

Results

Carers reported low positive mental well-being, high psychological distress and a mean increase in caregiving stress due to COVID-19. Perceived social support and coping strategies were significant unique predictors of psychological distress and positive mental well-being. Perceived social support and the coping strategy of positive reframing were the strongest predictors of higher positive mental well-being and lower psychological distress. Self-blame, behavioural disengagement and substance use were the strongest predictors of adverse outcomes. Although coping strategies were a significant predictor of change in caregiving stress due to COVID-19, the importance of the relationship was small. Change in use of planning was the strongest predictor of change in caregiving stress due to COVID-19.

Conclusions

The findings suggest that interventions that assist informal carers to decrease the use of self-blame, behavioural disengagement and substance use and to develop quality social support and skills to positively reframe caregiving situations may support improved caregiver outcomes.

Introduction

Borderline Personality Disorder (BPD) is defined as persistent dysregulation in emotions, relationships with others, behavioural impulsivity and self-image (1-3). An estimated 75% of people with BPD have self-harmed (4), and an estimated 10% complete suicide (5). In many countries, community-based treatment is now recommended, with limited admission to non-specialist inpatient services (6, 7). As a result, family members and significant others, referred to here as informal carers, are at the frontline of informal support for individuals with BPD in the community (8-10).

Informal carers (ICs) of people with BPD reveal traumatic stress, exhaustion, feelings of hopelessness, worry, guilt, shame, sadness and despair (10-13). Being an IC alters their lives; limits engagement in their other life roles and access to social support (13-15); increases inter-family relationship strain (10-12); and causes neglect of their well-being and self-care (12, 14). Significantly higher levels of burden and grief are reported by ICs of people with BPD than people with other mental health diagnoses, and greater levels of psychological distress are found compared to population norms (4, 16-19). These IC experiences are unsurprising because characteristics of the disorder are entwined with interpersonal relationships (20) and are associated with long-term adverse outcomes (19).

National guidelines (6, 7) recognise the challenges faced by ICs of people with BPD and that they may require support. Interventions exist, informed by different models of BPD, for example, Family Connections (21); Mentalisation Based Therapy-Families and Carers Training and Support (22); Staying Connected (23) and Making Sense of BPD (24). The evidence (9, 21, 22, 24-27) shows some positive outcomes of interventions, but benefits are limited when compared to controls, suggesting that interventions may require improvement to optimise IC outcomes. Further studies to identify which ICs would benefit most from these interventions and modifiable factors associated

with better carer outcomes are required to inform interventions and potentially improve treatment efficacy (28, 29).

There remains a paucity of research on factors predicting outcomes for this carer population. Being a female IC (4, 18), difficulties with emotion regulation (16, 17), emotional overinvolvement, criticism (4, 16), and higher frequency of self-harm and suicide attempts by the person with BPD (16) correlate with higher carer burden and distress. The relationship between carer age and outcome is inconsistent (4, 16, 18). Parents and spouses/ partners do not differ in levels of reported burden or psychological distress (4, 16, 18), although there may be variations when considering other carer relationships (29).

Stress process models explain caregiver outcomes in response to caregiving stress (30). These models hypothesise that characteristics of the primary stressors (e.g. characteristics of the care recipient and care situation), secondary stressors (e.g. impact of primary stressor on leisure activities, work or family relationships), IC appraisals, sociodemographic characteristics of the IC and moderating factors (e.g. coping, knowledge about the disorder, social supports and other resources) influence IC psychosocial, physiological and general health outcomes (31). Among these, social support and coping strategies are proposed to be important moderators of IC adjustment across caregiver populations (32-37). Lamborn and Cramer (38) have found evidence for the applicability of the stress-process model to ICs of people with personality disorders but did not investigate the influence of perceived social support or coping strategies on IC outcomes.

Coping is the process of behaviourally and cognitively responding to a situation appraised as stressful (39). In IC populations, the use of coping strategies predicted carer burden and mental health (e.g. 36, 40). Maladaptive coping strategies predicted psychological distress in ICs of people with eating disorders (41) and affective disorders (37). Avoidance coping strategies correlated with burden in ICs of people with schizophrenia and bipolar affective disorder (42). In caregivers of people with schizophrenia, coping strategies of self-blame, collusion and criticism have been related to adverse outcomes. Strategies of positive reappraisal, reframing and religious coping correlated

with better well-being in more than one study (chapter 3). Qualitative research has highlighted that ICs of people with BPD feel powerless to help the person with BPD and that they struggle to cope with the stress of caring for a person with BPD (11, 12, 15).

Social support, such as seeking instrumental or emotional support, is considered an adaptive coping strategy and is measured in many coping inventories (43). However, the availability of social support differs from the use of social support coping and may ameliorate caregiver experiences. Higher levels of social support are associated with better outcomes across IC populations, including ICs of people with mental health diagnoses (38, 45). ICs can experience reduced social support and increased isolation (44). Qualitative research, with small samples of ICs of people with BPD, indicate that social support is important for IC well-being and that ICs perceive social support diminishes due to their caregiving role (12-15).

While research has provided some understanding of ICs experience, there has been a focus on the negative outcomes, such as grief, burden and psychological distress. Well-being, or good health, extends beyond minimising illness or distress and requires the presence of positive psychological well-being (45-49). Factors influencing positive well-being differ from those influencing distress (46, 47). Positive health outcomes, such as longevity, are predicted by positive rather than negative affect (51). Therefore it is important to examine the influence of moderators on both positive and negative well-being. Positive well-being includes life satisfaction, mood and energy; negative components include distress and negative mood (47).

The current research was undertaken during the international COVID-19 pandemic. Globally, people's movement, social behaviour, and employment were restricted, which may have evoked societal psychological distress (52, 53). For people with mental health diagnoses, restrictions affected access to or attendance at mental health services (54, 55). The role of ICs to support people with BPD in the community may have become even more important and may have magnified IC burden and distress (56). An understanding of the pandemic's impact on caregiving stress and on the coping response of ICs is necessary to inform the development of supports at this time.

The extant research has established that ICs of people with BPD experience significant burden and distress. There remains a scarcity of evidence for modifiable factors associated with adverse outcomes (4, 28). Theories of caregiving, research in other IC populations, and qualitative research suggest that social support and coping strategies influence outcomes. Exploration of these factors in a large sample of ICs of people with BPD will help to develop an empirical evidence base that clinicians and others can use to help optimise interventions. Therefore, this study aims to examine the relationship between social support, coping and outcomes of psychological distress and positive mental well-being in ICs of people with BPD. A second goal was to explore the relationship between the use of coping strategies and COVID-19 related changes in caregiver stress.

Method

Design and Procedure

A cross-sectional mixed-methods design was employed. ICs of people with BPD completed self-report questionnaires and qualitative questions. This empirical paper focuses on the quantitative results. A separate paper will detail the qualitative findings. The Clinical Psychology Research Ethics Committee, University College Cork, granted ethical approval for this study. The survey was advertised on a public mental health service website and an international community forum, sent via email to people registered with two international organisations supporting carers of people with BPD, and to registered past and current attendees of a local programme for ICs of people with BPD. The online survey comprised the following sections: (1) information about the study and request to consent to participate; (2) a sociodemographic questionnaire; (3) the measures described below; and (4) four open-ended qualitative questions related to COVID-19. Participants provided tick-box consent to participate. Participants could withdraw consent by not submitting the survey. A minimum sample of 250 participants was estimated to be required (57). Recruitment occurred between August and November 2020.

Participants

Participants were self-selecting individuals who identified as ICs of a person with BPD, provided tick-box consent and submitted the online questionnaire. For the current research, the term IC refers to a person who identified as the primary carer and could be a family member or significant other (e.g. friend) of a person with BPD. No limits were placed on the type of care provided, cohabitation or amount of contact. Inclusion criteria to participate were: (1) minimum 18 years of age; (2) English-speaker; (3) endorse a statement that the person they care for has BPD or Emotionally Unstable Personality Disorder¹; (4) a relative or significant other of a person with BPD; and (5) supporting or caring for a person with BPD. Participants were screened for inclusion criteria (1) to (5) at the beginning of the survey. Participants were included in the current analysis if they endorsed a minimum of seven items on the McLean Screening Instrument for Borderline Personality Disorder – Carer Version (MSI-BPD-C, adapted from Zanarini et al., 2003); were caring for a person with BPD who was minimum 12 years of age; and identified themselves as the primary caregiver.

Measures

A sociodemographic questionnaire comprised questions about the IC, the person with BPD and the caregiving relationship (see Table 5.1).

The MSI-BPD-C (17) is a 10-item screening instrument for BPD, adapted from the MSI-BPD (57). Endorsement of seven items or more is reported to have an acceptable diagnostic accuracy (AUC = 0.73-.83) and test-retest reliability (ICC=0.72-0.78) in adolescent and adult populations (57-59). The instrument was adapted to the MSI-BPD-C to allow ICs to report the symptoms of the person with BPD. The MSI-BPD-C has been used previously to validate the participants self-report that the person they are caring for has a BPD diagnosis (4, 13, 16, 17, 27, 62). A mean score of 8.6 (SD = 1.05) was found in the current sample, similar to scores previously reported (16).

¹ The International Statistical Classification of Diseases and Related Health Problems 10th edition used the term used the term Emotionally Unstable Personality Disorder (EUPD) (58).

The Brief COPE (63) was adapted from the Coping Orientation to Problems Experienced (COPE) Inventory (64). It comprises 28 statements about coping methods and exploring 14 subscales (listed in Table 5.2). The subscales have demonstrated reliability from 0.5 to 0.9 (63). Convergent and concurrent validity and test-retest reliability ($r=0.58-0.72$) are reported in IC populations (65). The developers recommend a study-specific assessment of the factor structure and that wording can be adapted to specify situational coping, particular to the focus of research (63). In this research, participants were asked what they were "doing to deal with the stress associated with caring for a person with Borderline Personality Disorder/ Emotionally Unstable Personality Disorder". The original 14 subscales were retained in the analysis, informed by factor analysis. Mean inter-item correlations between 0.27 and 0.93 indicated adequate internal consistency (66).

The Kessler Psychological Distress scale (K10) (67) measures generalised psychological distress. Participants respond to ten questions about how they've been feeling over the last 30 days on a Likert scale from 1 (none of the time) to 5 (all of the time). Total scores range from 10-50. Scores over 22 represent high levels of psychological distress (68, 69). The K10 has demonstrated moderate validity compared to the General Health Questionnaire (GHQ; $\rho=0.5$) and Short Form-12 ($\rho=-0.6$) (65) and good internal consistency (0.93) (67). It has been implemented in general population research and mental health ICs (19, 68, 70, 71). The K10 internal consistency in this study was 0.91.

The World Health Organisation – Five Well-being Index (WHO-5) measured positive mental well-being. It is one of the most established measures of subjective psychological well-being (72). Participants rate how frequently they had five positive experiences in the last two weeks on a six-point Likert scale from 0 (at no time) to 5 (all of the time). Responses are summed and transformed to give a total score range from 0 to 100. Higher scores show greater levels of positive mental well-being. An expert panel found the WHO-5 to have high content validity (73). It is a valid predictor of change in self-reported health (49). Comparison to measures of depression show construct validity (e.g. $r=-0.42$ compared to Beck's Depression Inventory, BDI-6 (74)). The WHO-5 has demonstrated

adequate reliability (internal consistency 0.8 to 0.9). A cut-off score of ≤ 50 is used to screen for depression (72). The internal consistency in this sample was 0.89.

The Multidimensional Scale of Perceived Social Support (MSPSS) (75) measures perceived social support across three scales (family, friends and significant others), which sum to a total score. Respondents answer 12 questions on a Likert scale from 1 (very strongly disagree) to 7 (very strongly agree). Internal reliability (0.90 to 0.95) and test-retest reliability (ICC=0.84-0.89) have been reported across scales. Factorial and construct validity have been demonstrated. The MSPSS score correlated with depression ($r=0.48$) and health-related quality of life ($r=0.32$) in the expected direction (76, 77). The internal consistency in the present study was 0.94.

The Coronavirus Anxiety Scale (CAS) (78) was used to measure participants' anxiety due to Covid-19. Participants respond to five statements about their experience in response to COVID-19 over the last two weeks on a Likert scale from 0 (not at all) to 4 (nearly every day). A higher score represents greater COVID-19 anxiety. The internal reliability is 0.92, with construct validity illustrated through correlation with measures of impairment, psychological distress and worry about coronavirus (2, 3). The internal consistency in this study was 0.85.

The Brief COPE-Change was developed to measure change in coping strategy use because of COVID-19. The 28 statements in the original Brief COPE (63) were used. The instructions were altered to measure change in use of coping strategies. The instructions read, "The Coronavirus (COVID-19) pandemic may have impacted on some of the things you do to cope with the stress associated with caring for a person with Borderline Personality Disorder. In responding to this questionnaire, please rate the extent to which COVID-19 has changed how much you've been doing what the item says". Participants responded to each statement on a Likert scale from -2 (since COVID-19, I do this a lot less) to +2 (since COVID-19, I do this a lot more). A score of 3 indicated no change in the use of the coping strategy. The structure of the 14 subscales of the Brief COPE was maintained. Mean inter-item correlations of 0.29 to 0.81 indicated adequate internal consistency (66).

A single question assessed the impact of COVID-19 on caregiving stress. Participants were asked, "Has COVID-19 changed the amount of stress you experience as a result of your caregiving role?" They responded on an 11 point scale from -5 (significant decrease in caregiving stress) to +5 (significant increase in caregiving stress); 0 corresponded to no change in caregiving stress.

Statistical Analysis

Data were analysed using IBM SPSS Statistics 26.0 for Windows (79). Missing data were observed for 6.6% of participants; 21 people (1.7%) had more than 40% missing data on any one measure. These participants were excluded from further analysis. Multiple imputation was employed to manage the remaining missing data, which exceeded 5% missingness (80). Five data sets were imputed. The average imputed value replaced each missing data point. Means and standard deviations were calculated for all self-report measures. Two outliers that were obvious errors on one variable, years of caregiving, were replaced with the next highest score (81). For the analysis, education categories were collapsed to less than graduate degree (n=239), graduate degree (n=314) and postgraduate degree (n=310). Employment categories were collapsed to working (n=586) and not working (n=277). Incongruity in the responses to the IC age, PwBPD age and relationship category for a minority of participants (n=85) who had selected either the parent or child relationship category was identified. Checks were carried out to understand the discrepancy, and it was deemed that it was due to confusion between the parent and child relationship response options. The relationship responses for these participants were recoded to either parent or child to correspond with the IC and PwBPD age difference. As a cautionary check, the analyses presented here were run excluding these participants, and no meaningful impact on the results or findings were identified, see chapter 6.

Preliminary analyses of the relationship between the sociodemographic variables and the three dependent variables were examined using correlations, one-way analysis of variance (ANOVAs) and independent sample t-tests. Where a variable was found to be non-normally distributed, non-parametric equivalents were conducted. Parametric test results are reported unless

there was a discrepancy with the nonparametric results. Psychological distress and positive mental well-being were compared to published data using one-sample t-tests.

A series of hierarchical multiple regression models investigated the relationship between perceived social support, coping and the dependent variables. Sociodemographic variables that showed a significant relationship with the dependent variables in preliminary analysis were included in the regression model as controls. COVID-19 anxiety was included as a control as data were collected during the pandemic. Where there was more than one level of a variable, the category with the strongest relationship was included in the final regression as a dummy variable. The estimated number of days of self-harm and estimated number of days of attempted suicide by the PwBPD were not included as controls in the regression analysis as the majority of ICs reported that they estimated rather than knew the number of days of self-harm and suicide of the PwBPD in the last year (see note 2, Table 5.1). Therefore inclusion of days of self-harm or suicide in the regression might reduce the validity of findings.

Step 1 of each hierarchical regression included the sociodemographic control variables, COVID-19 anxiety and perceived social support. The 14 coping strategies were introduced in step 2 of each model to identify (i) the percentage of the variance explained by the coping strategies combined and (ii) which coping strategies were the strongest predictors. Data were checked for the assumptions of multicollinearity, homoscedasticity and for bias. For each model, Cook's distance, standardised DFBeta, and DFFit were all less than 1, indicating cases are unlikely to be influencing the statistics (81). The squared semi-partial correlation coefficient was used to assess the percentage of variance uniquely explained by predictor variables.

Mediation analyses were undertaken using model 4 of Process version 3.5 (82), followed by a Sobel test (83). Effect sizes are reported as Hedges' g for independent sample t-tests, η^2 for ANOVAs, and Cohen's f^2 for the local effect size in multiple regressions. Small, medium and large effect sizes are interpreted as follows: small ($f^2 \geq .02$; $\eta^2 \geq .02$; $g \geq .2$); medium ($f^2 \geq .15$; $\eta^2 \geq .13$; $g \geq .50$); and large ($f^2 \geq .35$; $\eta^2 \geq .26$; $g \geq .80$).

Table 5.1*Characteristics of the Informal Carer and the Person with BPD*

Carer		
Age (n=856)	Mean (SD)	53.5 (10.7)
Gender (n=862)	Male	118 (13.7%)
	Female	739 (85.6%)
	Non-binary	3 (0.3%)
	Prefer not to say	2 (0.2%)
Education level (n=862)	Less than high school	4 (0.5%)
	High school graduate	39 (4.5%)
	Intermediate/ technical training	36 (4.2%)
	Some college, no degree	160 (18.5%)
	Bachelor's degree	314 (36.4%)
	Master's degree	241 (27.9%)
	Doctoral degree	27 (3.1%)
	Professional degree	41 (4.8%)
Employment	Working	586 (67.9%)
	Retired	124 (14.4%)
	Homemaker	65 (7.5%)
	Student	9 (1.0%)
	Not working	79 (9.2%)
Relationship to person with BPD	Parent	649 (75.2%)
	Child	32 (3.7%)
	Sibling	19 (2.2%)
	Spouse/ Partner	137 (15.9%)
	Significant other	26 (3.0%)
Living with the person with BPD	Yes	521 (60.4%)
Mean years caregiving ¹	Mean (SD)	12.7 (9.8)
Mean hours contact per week in last month	Mean (SD)	49.6 (54.5)
Received intervention	Yes	639 (74%)
Chronic illness	Yes	244 (28.3%)
Person with BPD		
Age (n=862)	Mean (SD)	29.8 (13.5)
Gender (n=861)	Male	191 (22.1%)
	Female	640 (74.2%)
	Non-binary	25 (2.9%)
	Prefer not to say	5 (0.6%)
Employment (n=862)	Working	265 (30.7%)
	Retired	18 (2.1%)
	Homemaker	21 (2.4%)
	Student	187 (21.7%)
	Not working	371 (42.9%)
Estimated no. days self-harm of the PwBPD in last year (n=615) ²	Mean (SD)	22.5 (59.8)
Estimated no. of days attempted suicide in last year (n=772) ²	Mean (SD)	1.0 (4.4)

Note: n= number of people who responded. 1 Two extreme outliers (100, 80) replaced with the highest value that is not an outlier (49 years). 2. These values were reported by the IC rather than the PwBPD. The survey asked IC participants if they knew or were estimating the number of days of reported self-harm and attempted suicide days of the PwBPD. 19.5% of ICs that responded to the question on days of self-harm reported that they knew the number of days of self-harm by the PwBPD in the last year; 80.5% of ICs reported that their response was an estimate. 50.5% of ICs that responded to the question on days of attempted suicide reported that they knew the number of days of attempted suicide by the PwBPD in the last year; 49.5% said their response was an estimate.

Results

1207 participants consented to participate and submitted completed surveys. 344 participants were excluded because the MSI-BPD-C score was less than seven (n=216), they were not primary caregivers (n=105), they were caring for a person with BPD under the age of 12 (2), or there was more than 40% missing data on any one measure (n=21). Data for 863 participants were analysed.

Descriptive Statistics

Tables 5.1 and 5.2 detail the descriptive statistics for the sociodemographic characteristics and the self-report measures. The majority of ICs resided in North America (n=774; 89.6%).

IC Psychological Distress and Positive Mental Well-Being

The mean psychological distress score (M=24.99, SD=7.74) was significantly higher than reported in a general adult population (M=14.5, SD=9.4) (69), $t(862)=39.82$, $p<.001$, $d=1.35$, with a large effect size, and compared to reported values for ICs of people with schizophrenia in China (M=19.54, SD=5.29) (70), $t(862)=20.70$, $p<.001$, $g=0.73$ and Malaysia (M=17.8, SD=7.08) (71), $t(862)=27.30$, $p<.001$, $g=0.94$, with a medium to large effect size. The score was similar to that reported for ICs of outpatient adolescents with borderline personality features (M=24.99, SD=8.83) (19), $t(862)=0.03$, $p=.98$, $g<.001$. 63% of the sample scored at or above the cut-off value of 22, indicating that they had high levels of psychological distress.

Table 5.2*Descriptive Statistics of Self-report Measures*

	Mean	SD
Psychological distress (K10)	24.99	7.74
Positive mental well-being (WHO-5)	42.01	20.89
Change in caregiving stress due to COVID-19	2.39	2.21
Coping strategies		
Self-distraction	5.79	1.51
Active coping	5.73	1.63
Denial	2.59	1.16
Substance use	3.22	1.77
Use emotional support	5.05	1.77
Use instrumental support	5.01	1.80
Behavioural disengagement	3.43	1.57
Venting	4.29	1.38
Positive reframing	4.72	1.64
Planning	6.09	1.64
Humour	3.16	1.46
Acceptance	6.37	1.46
Religion	4.50	2.17
Self-blame	4.62	1.89
Change in use of coping strategies due to COVID-19		
Change in Self-distraction	0.64	1.78
Change in Active coping	0.63	1.81
Change in Denial	-0.78	1.68
Change in Substance use	-0.28	2.08
Change in use of emotional support	0.05	1.73
Change in use of instrumental support	0.17	1.77
Change in Behavioural disengagement	-0.35	1.68
Change in Venting	0.07	1.48
Change in Positive reframing	0.23	1.56
Change in Planning	0.90	1.65
Change in Humour	-0.59	1.72
Change in Acceptance	0.63	1.38
Change in Religion	0.38	1.89
Change in Self-blame	-0.04	1.65
Perceived social support (MSPSS)	4.59	1.40
Coronavirus (COVID-19) anxiety	1.76	2.97

Positive mental well-being in the current sample ($M=42.01$, $SD=20.89$) was significantly lower, with a medium effect size, compared to the mean population score reported for Serbia, the country with the lowest average score on the WHO-5 in the European Quality of Life Survey (EQLS) 2015

($M=52$), $t(862)=-14.05$, $p<.001$, $d=.48$ (84). The well-being of the current sample was also significantly lower than people who identified as caregivers' in the EQLS ($M=60.84$, $SD=22.6$) (85), $t(862)=-26.47$, $p<.001$, $g=0.84$, with a large effect size, and ICs of people with traumatic brain injury (transformed $M=49.6$, $SD=24.4$), $t(862)=-10.67$, $p<.001$, $g=0.36$ (86), with a small effect size. Nearly two-thirds (62.6%) of the sample scored less than 50 on the WHO-5 well-being scale, the screening cut-off for depression (72).

Predictors of Psychological Distress

Table 5.3 details the relationship between psychological distress and the socio-demographic variables. Education level and relationship status had more than one level. Distress was significantly higher for ICs who had postgraduate than less than graduate-level education, $t(547)=3.18$, $p<.01$, $g=.28$. Parents, $t(861)=-2.64$, $p=.008$, $g=0.21$, had significantly lower and spouses/ partners, $t(861)=3.43$, $p=.001$, $g=.32$, had significantly higher distress than the other relationship categories combined, with small effect sizes. Linear regression of dummy variables for each category of relationship status and education showed that being a spouse/ partner and less than graduate-level education were the strongest predictors of distress. Step 1 of the regression included the following: IC age; whether the IC was a spouse/partner, had less than graduate education, was working, had received an intervention, had a chronic illness, or was living with the person with BPD; hours of contact per week with the person with BPD; COVID-19 anxiety; and perceived social support.

Table 5.3

Relationship between Sociodemographic Variables and Psychological Distress, Positive Mental Well-being, and Change in Caregiving Stress due to COVID-19

	Psychological Distress				Positive Mental well-being			Change in caregiving stress		
	Test	Statistic	p	Effect size ⁶	Statistic	p	Effect size ⁶	Statistic	p	Effect size ⁶
Carer variables										
Age ^{1,4}	r	-.21	<.001		0.14	<.001		-.08	.02	
Gender ²	F(3, 859)	1.60	.19	<.01	1.19	.31	<.01	1.02	.39	<.01
Education ²	F(2, 860)	5.03	<.01	.01	4.45	.01	.01	.12	.89	<.01
Employment ³	t(861)	2.22	.03	.16	-1.21	.23	.09	.76	.45	.05
Intervention ³	t(861)	6.34	<.001	.49	-4.46	<.001	.35	1.58	.12	.12
Chronic Illness ³	t(861)	-6.59	<.001	.50	6.55	<.001	.50	-1.33	.19	.10
Person with BPD variables										
Age ¹	r	-.02	.50		.07	.05		-.02	.59	
Gender ²	F(3, 859)	1.61	.19	<.01	1.41	.24	<.01	.69	.56	<.01
Employment ³	t(861)	-1.36	.17	.10	1.98	.05	.15	-1.30	.19	.09
Estimated no. of days of self-harm ⁴	r	.15	<.001		-.15	<.001		.06	.15	
Estimated no. of days of suicide attempts ⁴	r	.15	<.001		-.09	.01		.06	.08	
Relationship variables										
Relation to person with BPD ²	F(4,858)	3.12	.02	.01	2.52	.04	.01	1.58	.18	<.01
Living with person with BPD ²	t(861)	-4.06	<.001	.28	5.95	<.001	.41			
Living with person with BPD ⁵	Z							-2.54	.01	.11
Hours of contact ⁴	r	.17	<.001		-.23	<.001		.11	.001	
Years of caregiving ⁴	r	-.06	.05		.06	.09		-.03	.38	

Note: 1 Pearson correlation; 2 One-way ANOVA 3. T-test. 4 Spearman correlation; 5 Mann-Whitney test; 6 Effect sizes reflect Hedge's g for t-tests (small

(0.2), medium (0.5) and large (0.8)) and η^2 for one-way ANOVAs (small (0.02), medium (0.13) and large (0.26)).

Table 5.4*Hierarchical Regression Model of Predictors of Informal Carer Psychological Distress*

			B (95% CI)				
	B	SE B	Lower	Higher	β	t	p
Step 1							
(Constant)	38.15	1.69	34.84	41.46		22.60	<.001
Age	-0.11	0.02	-0.16	-0.06	-0.15	-4.66	<.001
Education (less than graduate)	0.67	0.51	-0.34	1.67	0.04	1.30	.19
Relationship (spouse/ partner)	-0.09	0.69	-1.43	1.26	0.00	-0.13	.90
Working	-0.67	0.51	-1.66	0.32	-0.04	-1.32	.19
Received intervention	-2.00	0.54	-3.06	-0.94	-0.11	-3.71	<.001
Chronic illness	2.38	0.51	1.37	3.39	0.14	4.64	<.001
Cohabitation	0.96	0.55	-0.13	2.04	0.06	1.72	.09
Hours of contact	0.00	0.01	-0.01	0.01	0.02	0.43	.67
COVID-19 anxiety	0.65	0.08	0.50	0.81	0.25	8.46	<.001
Perceived social support	-1.63	0.17	-1.96	-1.30	-0.29	-9.73	<.001
Step 2							
(Constant)	23.34	2.15	19.12	27.56		10.85	<.001
Age	-0.08	0.02	-0.12	-0.04	-0.11	-3.79	<.001
Education (less than graduate)	0.20	0.44	-0.67	1.06	0.01	0.45	.65
Relationship (spouse/ partner)	-0.29	0.61	-1.48	0.91	-0.01	-0.47	.64
Working	-0.58	0.43	-1.43	0.27	-0.04	-1.35	.18
Received intervention	-1.06	0.47	-1.99	-0.13	-0.06	-2.24	.03
Chronic illness	2.16	0.44	1.30	3.02	0.13	4.91	<.001
Cohabitation	0.38	0.47	-0.55	1.31	0.02	0.81	.42
Hours of contact	0.01	0.00	0.00	0.01	0.04	1.22	.22
COVID-19 anxiety	0.44	0.07	0.30	0.57	0.17	6.45	<.001
Perceived social support	-1.15	0.17	-1.48	-0.81	-0.21	-6.74	<.001
Self-distraction	0.20	0.13	-0.06	0.46	0.04	1.48	.14
Active coping	0.19	0.16	-0.12	0.50	0.04	1.22	.22
Denial	0.69	0.19	0.32	1.06	0.10	3.68	<.001
Substance use	0.50	0.11	0.28	0.73	0.12	4.45	<.001
Use emotional support	-0.08	0.17	-0.42	0.26	-0.02	-0.44	.66
Use instrumental support	0.26	0.16	-0.05	0.56	0.06	1.67	.10
Behavioural disengagement	0.68	0.15	0.40	0.97	0.14	4.66	<.001
Venting	0.10	0.15	-0.20	0.40	0.02	0.64	.52
Positive reframing	-0.67	0.13	-0.93	-0.41	-0.14	-5.08	<.001
Planning	0.27	0.15	-0.03	0.56	0.06	1.75	.08
Humour	-0.10	0.14	-0.37	0.17	-0.02	-0.73	.47
Acceptance	-0.21	0.15	-0.50	0.08	-0.04	-1.42	.16
Religion	-0.09	0.09	-0.27	0.10	-0.02	-0.93	.35
Self-blame	1.11	0.12	0.88	1.33	0.27	9.60	<.001

Note: Step 1 $R^2=.28$, $F(10, 852)=33.80$, $p<.001$; Step 2 $R^2=.50$, $F(24, 862)=34.34$, $p<.001$.

Table 5.5*Hierarchical Multiple Regression Model of Predictors of Informal Carer Positive Mental Well-being*

	B (95% CI)						
	B	SE B	Lower	Higher	β	t	p
Step 1							
Constant	18.76	4.63	9.68	27.84		4.06	<.001
Age	0.18	0.07	0.05	0.31	0.09	2.76	.01
Education (post-graduate)	0.81	1.36	-1.85	3.47	0.02	0.60	.55
Relationship (spouse/partner)	1.96	1.94	-1.85	5.78	0.03	1.01	.31
Received intervention	2.95	1.51	-0.02	5.92	0.06	1.95	.05
Chronic illness	-6.92	1.43	-9.72	-4.11	-0.15	-4.84	<.001
Cohabitation	-5.07	1.56	-8.14	-2.01	-0.12	-3.25	<.01
Hours of contact	-0.03	0.01	-0.05	0.00	-0.07	-1.86	0.06
COVID-19 anxiety	-1.16	0.22	-1.59	-0.73	-0.16	-5.31	<.001
Perceived social support	4.19	0.48	3.25	5.12	0.28	8.81	<.001
Step 2							
Constant	31.39	6.37	18.90	43.89		4.93	<.001
Age	0.16	0.06	0.04	0.28	0.08	2.57	.01
Education (post-graduate)	1.28	1.24	-1.16	3.72	0.03	1.03	.30
Relationship (spouse/partner)	3.83	1.84	0.22	7.45	0.07	2.08	.04
Received intervention	0.39	1.41	-2.38	3.16	0.01	0.27	.78
Chronic illness	-6.51	1.30	-9.07	-3.96	-0.14	-5.00	<.001
Cohabitation	-3.86	1.42	-6.65	-1.07	-0.09	-2.72	.01
Hours of contact	-0.03	0.01	-0.06	-0.01	-0.08	-2.45	.01
COVID-19 anxiety	-0.86	0.20	-1.25	-0.46	-0.12	-4.22	<.001
Perceived social support	2.70	0.51	1.70	3.70	0.18	5.29	<.001
Self-distraction	-0.55	0.40	-1.34	0.24	-0.04	-1.37	.17
Active coping	0.62	0.47	-0.31	1.54	0.05	1.31	.19
Denial	-0.83	0.56	-1.94	0.28	-0.05	-1.47	.14
Substance use	-0.90	0.34	-1.57	-0.24	-0.08	-2.68	.01
Use emotional support	0.59	0.52	-0.43	1.62	0.05	1.14	.25
Use instrumental support	-0.51	0.46	-1.42	0.41	-0.04	-1.09	.28
Behavioural disengagement	-1.56	0.44	-2.42	-0.70	-0.12	-3.55	<.001
Venting	-0.44	0.46	-1.35	0.47	-0.03	-0.95	.34
Positive reframing	2.50	0.40	1.73	3.28	0.20	6.31	<.001
Planning	-1.38	0.45	-2.27	-0.48	-0.11	-3.02	<.01
Humour	1.08	0.41	0.27	1.88	0.08	2.62	.01
Acceptance	0.93	0.44	0.07	1.80	0.07	2.12	.03
Religion	0.49	0.28	-0.07	1.05	0.05	1.73	.08
Self-blame	-1.68	0.34	-2.36	-1.00	-0.15	-4.87	<.001

Note: Step 1 $R^2=.22$, $F(9, 853)=26.56$, $p<.001$; Step 2 $R^2=.38$, $F(23, 839)=22.06$, $p<.001$.

Table 5.4 summarises the regression results. The overall model explained 49.6% of the variance in distress. The sociodemographic variables, COVID-19 anxiety, and perceived social support contributed significantly to the regression model, $R^2=0.28$, $F(10, 852)=33.80$, $p<.001$. The addition of coping strategies in step 2 uniquely explained an additional 21% of the variance. This change was significant with a large effect size when controlling for age, education, relationship category, working, receipt of intervention, chronic illness, hours of contact, coronavirus anxiety and perceived social support, $\Delta R^2=0.21$, $\Delta F(14,838)=25.14$, $p<.001$, $f^2=0.43$. In the regression model, age, receipt of intervention, and chronic illness were the only significant sociodemographic predictors of distress. COVID-19 anxiety also positively predicted distress. Social support and positive reframing were significant negative predictors of psychological distress. Self-blame, behavioural disengagement, substance use and denial were significant positive predictors of distress. Self-blame and social support were the strongest predictors of psychological distress, uniquely explaining 5.5% and 2.7% of the variance, respectively. Positive reframing, behavioural disengagement and substance use significantly explained 1.6%, 1.3% and 1.2% of the variance, respectively. Denial had minimal influence on psychological distress, explaining 0.8% of the variance in psychological distress.

Predictors of Positive Mental Well-being

Table 5.3 details the relationship between positive mental well-being and the socio-demographic variables. Positive mental well-being was significantly higher for ICs who had postgraduate compared to less than graduate-level education, $t(547)=-3.01$, $p<.01$, $g=.26$, with a small effect size. Spouses/ partners had significantly lower well-being than the other relationship categories, $t(861)=-2.57$, $p=.01$, $g=0.24$, with a small effect size. Linear regression of dummy variables for each category of relationship status and education showed that being a spouse/partner and postgraduate level education were the strongest predictors of positive mental well-being. The following were included in step 1 of the regression: IC age; whether the IC was a spouse/partner, had post-graduate education, had received an intervention, had a chronic illness, or

was living with the person with BPD; hours of contact per week with the person with BPD; COVID-19 anxiety; and perceived social support.

Table 5.5 summarises the regression results. The overall model explained 37.7% of the variance in positive mental well-being. The sociodemographic variables, COVID-19 anxiety, and perceived social support contributed significantly to the regression model, $R^2=0.22$, $F(9, 853)=26.56$, $p<.001$. Use of coping strategies uniquely explained 15.8% of the variance above step 1 with a medium to large effect size when controlling for age, education, receipt of intervention, chronic illness, relationship status, cohabitation, hours of contact, coronavirus anxiety, and perceived social support, $\Delta R^2=0.16$, $\Delta F(14,839)=15.20$, $p<.001$, $f^2=0.25$.

Age, relationship (being a spouse/partner), chronic illness, and cohabitation were the only significant sociodemographic predictors of well-being. COVID-19 anxiety also negatively predicted positive mental well-being. Perceived social support and coping strategies of positive reframing, humour, and acceptance were significant positive predictors of positive mental well-being. Self-blame, behavioural disengagement, planning, and substance use were significant negative predictors of positive mental well-being. Positive reframing, perceived social support, and self-blame were the strongest predictors. They uniquely explained 3.0%, 2.1% and 1.7% of the variance in positive mental well-being, respectively. Behavioural disengagement (0.9%), planning (0.7%), substance use (0.5%), humour (0.5%) and acceptance (0.3%) each uniquely explained a minimal amount of the variance in positive mental well-being.

Perceived Social Support as a Mediator of the Relationship Between Use of Emotional Support Coping and Mental Well-being

Emotional support coping became a significant predictor of distress when perceived social support was excluded from the two regression models described above, suggesting that the emotional support's influence is mediated by perceived social support. For this reason, a mediation analysis was conducted. Regression analysis showed that controlling for the mediator (perceived social support), emotional support coping had a non-significant direct effect on psychological

distress, $b=0.00$, $t(863)=0.17$, $p=.98$, and positive mental well-being, $b=0.19$, $t(863)=1.70$, $p=.09$.

Linear regression of use of emotional support on to the mediator, perceived social support, was significant, $b=0.42$, $t(863)=18.61$, $p<.001$. Regression of the mediator on to psychological distress, $b=-2.03$, $t(863)=-9.74$, $p<.001$, and well-being, $b=1.14$, $t(863)=8.02$, $p<.001$, controlling for the use of emotional coping, was significant. A Sobel test showed that perceived social support fully mediated the relationship between use of emotional support coping and psychological distress, $Z=8.57$, $p<.001$, and between use of emotional support coping and positive mental well-being, $Z=7.02$, $p<.001$.

Predictors of Change in Caregiving Stress due to COVID-19

The majority of ICs (80%) identified an increase in caregiving stress due to COVID-19. Table 5.3 details the relationship between the socio-demographic variables and change in caregiving stress due to COVID-19. The following were included in step 1 of the regression model: age, cohabitation, hours of contact, COVID-19 anxiety and perceived social support. Two regression models were conducted.

The first model investigated how coping strategies predicted change in caregiving stress due to COVID-19 (see Table 5.6). The overall model explained 8.2% of the variance in change in caregiving stress due to COVID-19. The sociodemographic variables, COVID-19 anxiety, and perceived social support contributed significantly to the regression model, $R^2=0.03$, $F(5, 857)=5.59$; $p<.001$. The addition of coping strategies explained an additional 5% variance above step 1 with a small effect size when controlling for age, cohabitation, hours of contact, COVID-19 anxiety, and perceived social support, $\Delta R^2=0.05$, $\Delta F(14,843)=3.29$, $p<.001$, $f^2=0.05$.

Sociodemographic variables and perceived social support were not predictors of change in caregiving stress due to COVID-19. Coronavirus anxiety was a significant unique predictor of change in stress, explaining 1.6% of the variance in change in stress. Higher use of acceptance coping negatively predicted a minimal amount of the variance in change in stress due to COVID-19 (0.8%), where a positive change in stress means an increase in stress. Higher use of religion and planning

coping positively predicted change in caregiving stress due to COVID-19 and explained a minimal amount of the variance, 0.45% and 0.44%, respectively.

Table 5.6

Regression of Use of Coping Strategies onto Change in Caregiver Stress due to COVID-19

	B (95% CI)				β	t	p
	B	SE B	Lower	Lower			
Step 1							
(Constant)	2.86	0.50	1.87	3.85		5.67	<.001
Age	-0.01	0.01	-0.02	0.01	-0.04	-1.09	.28
Cohabitation	0.32	0.18	-0.04	0.67	0.07	1.74	.08
COVID-19 anxiety	0.11	0.03	0.06	0.16	0.15	4.45	<.001
Perceived social support	-0.08	0.05	-0.19	0.03	-0.05	-1.48	.14
Hours of contact	0.00	0.00	0.00	0.00	-0.04	-0.87	.39
Step 2							
(Constant)	1.39	0.79	-0.17	2.94		1.75	.08
Age	0.00	0.01	-0.02	0.01	-0.02	-0.64	.52
Cohabitation	0.23	0.18	-0.13	0.58	0.05	1.26	.21
COVID-19 anxiety	0.10	0.03	0.05	0.15	0.13	3.87	<.001
Perceived social support	-0.06	0.06	-0.18	0.07	-0.04	-0.87	.39
Hours of contact	0.00	0.00	0.00	0.00	-0.03	-0.64	.52
Self-distraction	0.09	0.05	-0.01	0.19	0.06	1.68	.09
Active coping	0.02	0.06	-0.10	0.13	0.01	0.29	.77
Denial	0.00	0.07	-0.14	0.14	0.00	0.00	1.00
Substance use	0.08	0.04	0.00	0.17	0.07	1.94	.05
Use emotional support	-0.02	0.07	-0.15	0.11	-0.02	-0.35	.73
Use instrumental support	0.07	0.06	-0.05	0.19	0.06	1.18	.24
Behavioural disengagement	0.06	0.06	-0.05	0.17	0.04	1.01	.31
Venting	0.11	0.06	-0.01	0.22	0.07	1.80	.07
Positive reframing	-0.08	0.05	-0.18	0.02	-0.06	-1.61	.11
Planning	0.12	0.06	0.00	0.23	0.09	2.01	.04
Humour	-0.06	0.05	-0.16	0.04	-0.04	-1.12	.26
Acceptance	-0.15	0.06	-0.26	-0.04	-0.10	-2.66	.01
Religion	0.07	0.04	0.00	0.14	0.07	2.04	.04
Self-blame	-0.00	0.04	-0.09	-0.08	0.00	-0.06	.95

Note: Step 1 $R^2=.03$, $F(5, 857)=5.59$, $p<.001$; Step 2 $R^2=.08$, $F(19, 843)=3.96$, $p<.001$.

Table 5.7*Regression of Change in Use of Coping Strategies onto Change in Caregiver Stress due to COVID-19*

	B (95% CI)						
	B	SE B	Lower	Lower	β	t	p
Step 1							
(Constant)	2.86	0.50	1.87	3.85		5.67	<.001
Age	-0.01	0.01	-0.02	0.01	-0.04	-1.09	.28
Cohabitation	0.32	0.18	-0.04	0.67	0.07	1.74	.08
COVID-19 anxiety	0.11	0.03	0.06	0.16	0.15	4.45	<.001
Perceived social support	-0.08	0.05	-0.19	0.03	-0.05	-1.48	.14
Hours of contact	0.00	0.00	0.00	0.00	-0.04	-0.87	.39
Step 2							
(Constant)	2.10	0.50	1.11	3.09		4.17	<.001
Age	-0.01	0.01	-0.02	0.01	-0.03	-0.76	.45
Cohabitation	0.31	0.18	-0.03	0.65	0.07	1.77	.08
COVID-19 anxiety	0.09	0.02	0.04	0.14	0.12	3.61	<.001
Perceived social support	-0.02	0.05	-0.13	0.08	-0.02	-0.45	.65
Hours of contact	0.00	0.00	0.00	0.00	-0.04	-1.08	.28
Change in Self-distraction	0.11	0.04	0.03	0.19	0.09	2.62	.01
Change in Active coping	-0.05	0.06	-0.16	0.07	-0.04	-0.79	.43
Change in Denial	-0.15	0.06	-0.26	-0.03	-0.11	-2.55	.01
Change in Substance use	0.06	0.04	-0.01	0.14	0.06	1.63	.10
Change in Use emotional support	0.01	0.06	-0.11	0.13	0.01	0.18	.86
Change in Use instrumental support	-0.06	0.06	-0.19	0.06	-0.05	-0.99	.32
Change in Behavioural disengagement	-0.05	0.06	-0.16	0.06	-0.04	-0.89	.38
Change in Venting	0.05	0.06	-0.06	0.16	0.03	0.88	.38
Change in Positive reframing	-0.15	0.06	-0.26	-0.04	-0.11	-2.68	.01
Change in Planning	0.35	0.06	0.22	0.48	0.26	5.43	<.001
Change in Humour	-0.11	0.05	-0.21	-0.01	-0.09	-2.24	.03
Change in Acceptance	-0.16	0.06	-0.28	-0.03	-0.10	-2.44	.01
Change in Religion	0.12	0.04	0.04	0.20	0.10	2.96	<.001
Change in Self-blame	0.16	0.05	0.06	0.25	0.12	3.18	<.001

Note: Step 1 $R^2=.03$, $F(5, 857)=5.59$, $p<.001$; Step 2 $R^2=.14$, $F(19, 843)=7.30$, $p<.001$.

The second model considered how the change in the use of coping strategies in response to caregiving stress predicted change in caregiving stress due to COVID-19, see Table 5.7. The overall model explained 14.1% of the variance in change in caregiving stress due to COVID-19. The addition

of change in the use of coping strategies explained an additional 11% of the variance above step 1 with a small effect size when controlling for age, cohabitation, hours of contact, COVID-19 anxiety, and perceived social support, $\Delta R^2=0.11$, $F(14,843)=7.69$, $p<.001$, $f^2=.13$. COVID-19 anxiety was again a significant unique predictor of change in stress, explaining 1.3% of the variance, controlling for the other variables. Increase in the use of planning, self-blame, religion and self-distraction positively and significantly predicted increase in caregiving stress due to COVID-19. This indicated that an increase or decrease in use of these coping strategies due to the COVID-19 pandemic predicted a change in caregiving stress due to COVID-19 in the same direction. Change in use of positive reframing, denial, acceptance, and humour negatively and significantly predicted change in caregiving stress, indicating that an increase in the use of these coping strategies due to the COVID-19 pandemic predicted a change in caregiving stress due to COVID-19 in the opposite direction. Change in the use of planning was the strongest predictor, uniquely explaining 3.0% of the variance in change in caregiving stress; change in use of self-blame uniquely explained 1.0% of the variance. Change in use of religion (0.9%), self-distraction (0.7%), positive reframing (0.7%), denial (0.7%), acceptance (0.6%) and humour (0.5%) only explained minimal amounts of the variance in change in caregiving stress due to COVID-19.

Discussion

ICs endorsed levels of psychological distress greater than population norms, concordant with previous research (16-18). The results also show that ICs of people with BPD experience lower levels of positive mental well-being than population norms and other caregiving populations. This is an important contribution to the current understanding of the health of this population, as good mental health goes beyond the absence of distress (50) and requires the presence of positive psychological well-being (49). Furthermore, most of the respondents reported increased caregiving stress due to the COVID-19 pandemic, supporting Eckardt's (56) argument that ICs of people with mental ill-health may be experiencing increased stress and strain due to pandemic-related restrictions. This study, therefore, adds to evidence that this is a population in need of support.

This study aimed to investigate whether social support and coping strategies used in response to caregiving stress were predictors of psychological distress and positive mental well-being in ICs of people with BPD. Consistent with the stress-process model of caregiving (31), perceived social support and coping strategies predicted psychological distress and positive mental well-being when controlling for sociodemographic variables and COVID-19 anxiety. Perceived social support predicted higher positive mental well-being and lower psychological distress, echoing previous qualitative interviews that revealed a perceived loss of and need for social support by ICs of people with BPD (11, 13-15) and research showing that social support is an important moderator of adverse outcomes across caregiver populations (45, 87, 88). In this study, perceived social support mediated the relationship between use of emotional support and both positive mental well-being and psychological distress, indicating the importance of adequate social support to enable the beneficial use of emotional support coping. Carers attending group interventions and support programmes have previously noted the positive effect of received group peer support (13, 27, 89). Based on the evidence from this study, group interventions may benefit from a specific focus on helping ICs to develop their social supports both within and outside the group.

Among the coping strategies, positive reframing was the strongest predictor of better outcomes. Positive reframing involves seeking positives in the situation or trying to view the situation from an alternative positive perspective. Positive reframing predicted higher positive mental well-being and lower psychological distress, concordant with previous research on ICs of people with other mental health disorders (90, 91). In other IC populations, positive reframing has predicted lower IC distress at one-year follow-up, controlling for caregiver appraisals (92), and the ability to recognise positive caregiving features related to greater IC well-being and lower levels of distress (85, 93-95). In this study, humour and acceptance coping were also positively related to positive mental well-being. However, their predictive strength was less important, and these strategies were not significant predictors of psychological distress. Of interest, previous research has categorised humour and acceptance coping with positive reframing to form a coping family of

positive cognitive restructuring (96). Combined together, the results suggest that assisting ICs to cognitively reframe situations in a positive way may support better IC well-being. Previous research suggests that interventions may support this indirectly through psychoeducation about BPD. ICs attending a carer intervention have previously said that psychoeducation about BPD contributed to a more positive understanding of stressful caregiving situations (89). No research has yet been published identifying how positive appraisals of caring for a person with BPD influence IC well-being or coping strategies. Seigerman et al. (2020) (19) did measure caregiving appraisals of ICs of people with BPD but did not report the relationship between IC appraisals and outcomes. This study suggests that the inclusion of a component to assist positive reframing of typical caregiving stressors may improve the effectiveness of interventions.

Use of self-blame coping was the strongest coping predictor of higher psychological distress and lower positive mental well-being. Self-blame is also associated with adverse outcomes in ICs of people with other mental health disorders (71, 97). In qualitative interviews, ICs of people with BPD revealed perceived stigma and judgment from family, friends, and professionals. They also identified self-blame and blame from professionals for BPD (12-15, 21). This is not surprising as, although today BPD is understood to have a complex aetiology (98), historical literature emphasised the causal role of family abuse (99). The current study did not assess the quality of the self-blame statements. However, the results provide evidence that negative self-judgments in response to caring for a person with BPD are linked to poorer well-being and may be a risk factor for adverse outcomes in this population. Existing carer interventions provide up-to-date psychoeducation about the development of BPD (21-23). Qualitative research with small samples suggests that this knowledge helped reduce ICs' self-blame for the person's presentation (89) and that professional support helped alleviate self-blame (10). Inclusion of a component to directly identify and address self-critical thoughts in response to caregiving may further improve interventions to help ICs.

Behavioural disengagement from the stressor (giving up) and substance use predicted greater psychological distress and lower positive mental well-being, although the predictive strength

for the latter was less important. Denial also explained minimal variance in psychological distress but not positive mental well-being. These three strategies are frequently categorised as avoidant. The findings are consistent with a large body of evidence showing avoidance to be associated with increased adverse outcomes in response to stressful life events, including caregiving stress (42, 47, 64, 92, 95), and with qualitative research in which ICs of people with BPD reported a wish sometimes to give up (13, 15). The current study results suggest that interventions may improve carer outcomes by including a component that actively assists ICs to reduce the use of behavioural disengagement and substance use in response to caregiving stressors.

Use of disengagement coping is related to lower perceived control, which relates to lower well-being (100). ICs of people with BPD report feeling powerless and note a lack of knowledge about BPD and about how to respond to the person with BPD (11, 12, 14), suggesting a lack of perceived control over the caregiving situation. It is possible that assisting ICs to develop perceived control over their caregiving situation through psychoeducation to improve knowledge and understanding of BPD and teaching of adaptive skills to support both the person with BPD and themselves may help reduce avoidance of caregiving stress. This strategy is supported by qualitative reports that one intervention, Family Connections (21), helped ICs of people with BPD to clarify their role in supporting a person with BPD and increased their perceived control (89). Further research is required to investigate this hypothesis and the relationship between behavioural disengagement, knowledge of BPD, skills, perceived control and caregiver outcomes.

Interestingly, in this study, planning related to a reduction in positive mental well-being, though it only explained a minimal amount of variance, and active coping did not significantly predict carer outcomes. Furthermore, change in use of planning was the strongest predictor of change in caregiving stress due to COVID-19. Results indicated that caregiving stress increased with increased use of planning. Planning involves identifying strategies to respond to a stressor. Planning is a problem-focused strategy and, with active coping, is typically associated with better outcomes. Problem-focused strategies are optimal when coping with controllable stressors (96). The

unpredictability associated with BPD and with COVID-19 may obstruct the effectiveness of IC planning. This hypothesis is supported by IC qualitative reports that they cannot make plans due to the uncertainty associated with the caregiving role (12). In this context, interventions may benefit from assisting ICs to identify when planning is an effective coping response and when it may serve to augment distress in response to caregiving stressors.

The second aim of this study was to investigate whether coping strategy use predicted change in caregiving stress due to COVID-19. A change in caregiver stress was significantly predicted by the use of coping strategies and change in use of coping strategies due to COVID-19 when controlling for sociodemographic factors and COVID-19 anxiety. However, the small effect size indicated that use of coping strategies might not be important in explaining change in caregiving stress due to COVID-19. Despite this, the results largely support the relationships described above and further suggest that increased use of self-blame and planning may be maladaptive, while increased use of positive reframing, humour and acceptance may be adaptive coping strategies in response to the stress associated with caring for a person with BPD. However, change in use of denial coping predicted a change in stress in the opposite direction, though the relationship was weak. This contrasts with the earlier findings. Interestingly, social support did not predict change in caregiving stress due to COVID-19, suggesting that social support did not buffer against the additional caregiving stress resulting from the COVID-19 pandemic.

Several sociodemographic factors predicted mental well-being, helping identify which caregivers may be most in need to support. Being a younger caregiver predicted lower positive mental well-being, higher psychological distress, and increased caregiving stress due to COVID -19. Living with a person with BPD predicted lower positive mental well-being but not distress. These results suggest that younger ICs and those living with or in more contact with the person with BPD may be most in need of support. Higher levels of psychological distress (38), depression (20) and burden (16) in younger caregivers have previously been reported. However, other studies have reported greater depression in older caregivers (18) and no age-effect on mental health (16). The

differences may arise from variance in sample characteristics, including cohabitation (38), sample sizes, and measures. In this study, lower positive mental well-being and higher psychological distress were observed for spouses/ partners, and lower levels of distress were found in parents. However, relationship status was not a predictor when controlling for age and other sociodemographic variables, including gender, concordant with the findings of Scheirs and Bok (2007) (18). Consistent with Bailey and Grenyer (2015) (16), no relationship was observed between the length of caregiving relationship and outcomes. Receipt of intervention predicted lower psychological distress, but there was no relationship with positive mental well-being. This indicates some positive effects of extant interventions, but these may not extend to improving positive well-being. This analysis did not differentiate the type of intervention received, and so the finding should be considered with caution. Caregivers who endorsed a chronic illness or who had higher levels of COVID-19 anxiety had higher levels of psychological distress and lower well-being. In a study of people with chronic illness and disability, stress due to COVID-19 also predicted lower well-being (101).

Limitations

The current study has added to the literature elucidating tangible modifiable factors to improve outcomes for ICs of people with BPD. However, the findings must be considered in the following context. The study was cross-sectional, limiting statements of causality (102, 103). Indeed, Lazarus and Folkman's (39) model of stress and coping emphasised the transactional relationship of stress, appraisals, and coping. Participants comprised an online population who were likely support-seeking, as evidenced by a large proportion who had received an intervention (74%). However, this sample was matched on levels of psychological distress reported by ICs of outpatients with borderline personality features (19), suggesting that the sample is representative of the distress experienced by ICs of people attending mental health service interventions. This sample also comprised a high percentage of females (85.6%), which is higher than the percentage accessing treatment as reported in intervention studies for this population (19, 22, 25, 104). The majority of the study sample was North American. Therefore the findings presented here may not be

generalizable to populations from other cultures or geographical locations. Supplementary analysis presented in chapter 6 supports that the results may have been influenced by a high proportion of participants from the USA and Canada (89%). Different coping strategies may be more important predictors of IC outcomes in other geographical regions, for example, Europe. However, the number of participants from other geographical regions or cultures was not sufficient to draw firm conclusions on cultural influence. It is recommended that future research is undertaken to assess cultural influence on the relationship between coping strategy use and outcomes in ICs of PwBPD. The BPD diagnosis was assessed by IC self-report and verified using a screening instrument, the MSI-BPD-C. Although the carer adaptation of this instrument has been widely used, it has not been validated, and clinical assessment of the BPD diagnosis was not conducted. Further, while this study assessed carer-reported estimates of days of self-harm and suicide by the PwBPD, the personal nature of these experiences meant that a high proportion of ICs estimated these figures, and accuracy could not be verified. Therefore, this study did not control for BPD symptoms in the regression models. The relationship status of a minority of parent/ child participants (n=85) was recoded as outlined in the methodology. Additional analysis was undertaken excluding these participants, and no meaningful difference in results was identified.

Conclusions

Despite these limitations, this study shows that ICs of people with BPD experience low levels of positive mental well-being, in addition to the high levels of distress previously reported in the literature. These results also provide preliminary evidence that ICs of people with BPD have experienced increased caregiving stress due to COVID-19, adding to the evidence base that this is a vulnerable population in need of support. This study contributes to a shortage of existing empirical research exploring factors associated with outcomes in this population and identifies that social support and coping strategies are significant predictors of both IC psychological distress and positive mental well-being. Interventions may be improved by incorporating components that directly assist ICs to develop quality social supports; to reframe cognitions with a focus on developing positive

appraisals of typical caregiving situations and reducing self-critical judgments and self-blame in response to caregiving stress; to move away from coping strategies such as behavioural disengagement and self-blame; and to consider when planning coping may be effective and when it may be maladaptive in response to caregiving stressors. Similar to previous studies (38), these results suggest that younger caregivers and those living with or spending more time with the person with BPD may be most in need of support. Future research should further explore the role of ICs' knowledge of BPD; appraisals of BPD and caregiving, perceived control, and how these factors relate to the use of coping strategies. The current study results should also be verified in a sample of ICs in the community who may be more socio-demographically representative of the IC population and in a sample where BPD diagnosis has been assessed clinically.

References

1. American Psychiatric Association [APA]. Diagnostic and Statistical Manual of Mental Disorders: DSM 5. 5 ed. Washington DC: American Psychiatric Publishing; 2013.
2. Lee SA. Coronavirus Anxiety Scale: A brief mental health screener for COVID-19 related anxiety. *Death Studies*. 2020;44(7):393-401.
3. Lee SA, Mathis AA, Jobe MC, Pappalardo EA. Clinically significant fear and anxiety of COVID-19: A psychometric examination of the Coronavirus Anxiety Scale. *Psychiatry Research*. 2020;290.
4. Kirtley J, Chiocchi J, Cole J, Sampson M. Stigma, emotion appraisal, and the family environment as predictors of carer burden for relatives of individuals who meet the diagnostic criteria for Borderline Personality Disorder. *Journal of Personality Disorders*. 2019;33(4):497-514.
5. Paris J, Zweig-Frank H. The 27-year follow-up of patients with borderline personality disorder. *Comprehensive Psychiatry*. 2001;42(6):482-7.
6. National Health and Medical Research Council. Clinical Practice Guidelines for the Management of Borderline Personality Disorder. Melbourne: National Health and Medical Research Council; 2012. Available from: <https://www.nhmrc.gov.au/about-us/publications/clinical-practice-guideline-borderline-personality-disorder#block-views-block-file-attachments-content-block-1>.

7. National Institute for Health and Care Excellence. Borderline personality disorder: recognition and management (CG78). 2009.
8. Acres K, Loughhead M, Procter N. Carer perspectives of people diagnosed with borderline personality disorder: A scoping review of emergency care responses. *Australasian Emergency Care*. 2019;22(1):34-41.
9. Hoffman PD, Fruzzetti AE, Buteau E. Understanding and engaging families: An education, skills and support program for relatives impacted by borderline personality disorder. *Journal of Mental Health*. 2007;16(1):69-82.
10. Giffin J. Family experience of borderline personality disorder. *ANZJFT Australian and New Zealand Journal of Family Therapy*. 2008;29(3):133-8.
11. Kay ML, Poggenpoel M, Myburgh CP, Downing C. Experiences of family members who have a relative diagnosed with borderline personality disorder. *Curationis*. 2018;41(1):e1-e9.
12. Ekdahl S, Idvall E, Samuelsson M, Perseus K-I. A life tiptoeing: being a significant other to persons with borderline personality disorder. *Archives of Psychiatric Nursing*. 2011;25(6):e69-76.
13. Buteau E, Dawkins K, Hoffman P. In their own words: Improving services and hopefulness for families dealing with BPD. *Social Work in Mental Health*. 2008;6(1-2):203-14.
14. Meshkinyazd A, Heydari A, Fayyazi Bordbar M. Lived experiences of caregivers of patients with Borderline Personality Disorder: A phenomenological study. *Int J Community Based Nurs Midwifery*. 2020;8(2):177-88.
15. Dunne E, Rogers B. "It's us that have to deal with it seven days a week": carers and borderline personality disorder. *Community Mental Health Journal*. 2013;49(6):643-8.
16. Bailey RC, Grenyer BFS. The relationship between expressed emotion and wellbeing for families and carers of a relative with borderline personality disorder. *Personality and Mental Health*. 2015;9(1):21-32.
17. Bailey RC, Grenyer BFS. Supporting a person with personality disorder: A study of carer burden and well-being. *Journal of Personality Disorders*. 2014;28(6):796-809.

18. Scheirs JGM, Bok S. Psychological distress in caretakers or relatives of patients with borderline personality disorder. *International Journal of Social Psychiatry*. 2007;53(3):195-203.
19. Seigerman MR, Betts JK, Hulbert C, McKechnie B, Rayner VK, Jovev M, et al. A study comparing the experiences of family and friends of young people with borderline personality disorder features with family and friends of young people with other serious illnesses and general population adults. *Borderline Personal Disord Emot Dysregul*. 2020;7(1):17.
20. Hoffman PD, Buteau E, Hooley JM, Fruzzetti AE, Bruce ML. Family members' knowledge about borderline personality disorder: Correspondence with their levels of depression, burden, distress, and expressed emotion. *Family Process*. 2003;42(4):469-78.
21. Hoffman PD, Fruzzetti AE, Buteau E, Neiditch ER, Penney D, Bruce ML, et al. Family Connections: A program for relatives of persons with Borderline Personality Disorder. *Family Process*. 2005;44(2):217-25.
22. Bateman A, Fonagy P. A randomized controlled trial of a mentalization-based intervention (MBT-FACTS) for families of people with borderline personality disorder. *Personality Disorders: Theory, Research, and Treatment*. 2019;10(1):70-9.
23. Project Air Strategy for Personality Disorders. Family, Partner and Carer Intervention Manual for Personality Disorders. Wollongong: University of Wollongong, Illawarra Health and Medical Research Institute; 2016. Available from: <https://documents.uow.edu.au/content/groups/public/@web/@ihmri/documents/doc/uow212928.pdf>.
24. Pearce J, Jovev M, Hulbert C, McKechnie B, McCutcheon L, Betts J, et al. Evaluation of a psychoeducational group intervention for family and friends of youth with borderline personality disorder. *Borderline Personal Disord Emot Dysregul*. 2017;4:5-.
25. Flynn D, Kells M, Joyce M, Corcoran P, Herley S, Suarez C, et al. Family Connections versus optimised treatment-as-usual for family members of individuals with borderline personality disorder: non-randomised controlled study. *Borderline Personal Disord Emot Dysregul*. 2017;4:18-.

26. Liljedahl SI, Kleindienst N, Wångby-Lundh M, Lundh LG, Daukantaitė D, Fruzzetti AE, et al. Family Connections in different settings and intensities for underserved and geographically isolated families: a non-randomised comparison study. *Borderline Personal Disord Emot Dysregul.* 2019;6:14.
27. Grenyer BFS, Bailey RC, Lewis KL, Matthias M, Garretty T, Bickerton A. A randomized controlled trial of group psychoeducation for carers of persons with borderline personality disorder. *Journal of Personality Disorders.* 2019;33(2):214-28.
28. Sutherland R, Baker J, Prince S. Support, interventions and outcomes for families/carers of people with borderline personality disorder: A systematic review. *Personality and Mental Health.* 2019.
29. Jørgensen MS, Storebø OJ, Poulsen S, Simonsen E. Burden and treatment satisfaction among caregivers of adolescents with borderline personality disorder. *Family Process.* 2020.
30. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist.* 1990;30(5):583-94.
31. Sorensen S, Duberstein P, Gill D, Pinquart M. Dementia care: mental health effects, intervention strategies, and clinical implications. *Lancet Neurol.* 2006;5(11):961-73.
32. Calvete E, de Arroyabe EL. Depression and grief in Spanish family caregivers of people with traumatic brain injury: The roles of social support and coping. *Brain Injury [Internet].* 2012 Jun [cited 2021 Jul 17];26(6):834–43.
33. George ES, Kecmanovic M, Meade T, Kolt GS. Psychological distress among carers and the moderating effects of social support. *BMC Psychiatry.* 2020;20.
34. Sabella SA, Suchan CS. The contribution of social support, professional support, and financial hardship to family caregiver life satisfaction after traumatic brain injury. *The Journal of Head Trauma Rehabilitation.* 2019;34(4):233-40.
35. del-Pino-Casado R, Frías-Osuna A, Palomino-Moral PA, Pancorbo-Hidalgo PL. Coping and subjective burden in caregivers of older relatives: a quantitative systematic review. *Journal of Advanced Nursing.* 2011;67(11):2311-22.

36. Morris N, Moghaddam N, Tickle A, Biswas S. The relationship between coping style and psychological distress in people with head and neck cancer: A systematic review. *Psycho-Oncology* [Internet]. 2018 Mar [cited 2021 Jul 17];27(3):734–47.
37. Wasley D, Eden S. Predicting psychological distress of informal carers of individuals with major depression or bipolar disorder. *International Journal of Mental Health Nursing*. 2018;27(1):358-67.
38. Lamborn P, Cramer KM. Factors associated with distress in caregivers of people with personality disorders. *Community Mental Health Journal*. 2020; 56:1298-1310.
39. Lazarus RS, Folkman S. *Stress, Appraisal, and Coping*. New York: Springer Publishing Company, Inc.; 1984 1984.
40. Hawken T, Turner-Cobb J, Barnett J. Coping and adjustment in caregivers: A systematic review. *Health Psychology Open*. 2018;5(2):2055102918810659.
41. Coomber K, King RM. Coping strategies and social support as predictors and mediators of eating disorder carer burden and psychological distress. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*. 2012;47(5):789-96.
42. Chadda RK, Singh TB, Ganguly KK. Caregiver burden and coping: A prospective study of relationship between burden and coping in caregivers of patients with schizophrenia and bipolar affective disorder. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*. 2007;42(11):923-30.
43. Greenaway KH, Louis WR, Parker SL, Kalokerinos EK, Smith JR, Terry DJ. Chapter 12 Measures of Coping for Psychological Well-Being. 2014 [cited 12/06/2019]. In: *Measures of Personality and Social Psychological Constructs* [Internet]. San Diego, UNITED STATES: Elsevier Science & Technology, [cited 12/06/2019]. Available from: <http://ebookcentral.proquest.com/lib/uccie-ebooks/detail.action?docID=1781027>.

44. Greenwood N, Mezey G, Smith R. Social exclusion in adult informal carers: A systematic narrative review of the experiences of informal carers of people with dementia and mental illness. *Maturitas*. 2018;112:39-45.
45. Ribé JM, Salamero M, Pérez-Testor C, Mercadal J, Aguilera C, Cleris M. Quality of life in family caregivers of schizophrenia patients in Spain: Caregiver characteristics, caregiving burden, family functioning, and social and professional support. *International Journal of Psychiatry in Clinical Practice*. 2018;22(1):25-33.
46. Huppert FA. Psychological well-being: Evidence regarding its causes and consequences. *Applied Psychology: Health and Well-Being*. 2009;1(2):137-64.
47. Karademas EC. Positive and negative aspects of well-being: Common and specific predictors. *Personality and Individual Differences*. 2007;43(2):277-87.
48. Diener E. Subjective well-being: The science of happiness and a proposal for a national index. *American Psychologist*. 2000;55(1):34-43.
49. Bech P, Olsen LR, Kjoller M, Rasmussen NK. Measuring well-being rather than the absence of distress symptoms: A comparison of the SF-36 Mental Health subscale and the WHO-Five Well-Being Scale. *Int J Methods Psychiatr Res*. 2003;12(2):85-91.
50. World Health Organisation. 2020 [Available from: <https://www.who.int/about/who-we-are/constitution>].
51. Xu J, Roberts RE. The power of positive emotions: It's a matter of life or death—Subjective well-being and longevity over 28 years in a general population. *Health Psychology*. 2010;29(1):9-19.
52. Park CL, Finkelstein-Fox L, Russell BS, Fendrich M, Hutchison M, Becker J. Americans' distress early in the COVID-19 pandemic: Protective resources and coping strategies. *Psychological Trauma: Theory, Research, Practice, and Policy*. 2021.
53. Skapinakis P, Bellos S, Oikonomou A, Dimitriadis G, Gkikas P, Perdikari E, et al. Depression and its relationship with coping strategies and illness perceptions during the COVID-19 lockdown in Greece: A cross-sectional survey of the population. *Depression Research and Treatment*. 2020;2020.

54. Torjese I. Covid-19: Mental health services must be boosted to deal with “tsunami” of cases after lockdown. *BMJ*. 2020;369:m1994.
55. Yao H, Chen J-H, Xu Y-F. Patients with mental health disorders in the COVID-19 epidemic. *The Lancet Psychiatry*. 2020;7(4):e21-e.
56. Eckardt JP. Caregivers of people with severe mental illness in the COVID-19 pandemic. *The Lancet Psychiatry*. 2020;7(8):e53-e.
57. Green SB. How many subjects does it take to do a regression analysis. *Multivariate Behav Res*. 1991;26(3):499-510.
58. World Health Organisation [WHO]. International statistical classification of diseases and related health problems (10th ed.). 2016.
59. Zanarini MC, Vujanovic AA, Parachini EA, Boulanger JL, Frankenburg FR, Hennen J. A screening measure for BPD: the McLean Screening Instrument for Borderline Personality Disorder (MSI-BPD). *Journal of Personality Disorders*. 2003;17(6):568-73.
60. Chanen AM, Jovev MP, Djaja DB, McDougall EB, Yuen HPM, Rawlings DD, et al. Screening for Borderline Personality Disorder in outpatient youth. *Journal of Personality Disorders*. 2008;22(4):353-64.
61. Patel AB, Sharp C, Fonagy P. Criterion validity of the MSI-BPD in a community sample of women. *Journal of Psychopathology and Behavioral Assessment*. 2011;33(3):403-8.
62. Goodman M, Patil U, Triebwasser J, Hoffman P, Weinstein ZA, New A. Parental burden associated with borderline personality disorder in female offspring. *Journal of Personality Disorders*. 2011;25(1):59-74.
63. Carver CS. You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine*. 1997;4(1):92-100.
64. Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*. 1989;56(2):267-83.

65. Cooper C, Katona C, Livingston G. Validity and reliability of the Brief COPE in carers of people with dementia: the LASER-AD Study. *J Nerv Ment Dis.* 2008;196(11):838-43.
66. Briggs SR, Cheek JM. The role of factor analysis in the development and evaluation of personality scales. *Journal of Personality.* 1986;54(1):106-48.
67. Kessler RC, Andrews G, Colpe LJ, Hiripi E, Mroczek DK, Normand SLT, et al. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychological Medicine.* 2002;32(6):959-76.
68. Andrews G, Slade T. Interpreting scores on the Kessler Psychological Distress Scale (K10). *Australian and New Zealand Journal of Public Health.* 2001;25(6):494-7.
69. Slade T, Grove R, Burgess P. Kessler Psychological Distress Scale: Normative data from the 2007 Australian National Survey of Mental Health and Wellbeing. *Australian and New Zealand Journal of Psychiatry.* 2011;45(4):308-16.
70. Chen X, Mao Y, Kong L, Li G, Xin M, Lou F, et al. Resilience moderates the association between stigma and psychological distress among family caregivers of patients with schizophrenia. *Personality and Individual Differences.* 2016;96:78-82.
71. Ong HC, Ibrahim N, Wahab S. Psychological distress, perceived stigma, and coping among caregivers of patients with schizophrenia. *Psychology Research and Behavior Management.* 2016;9.
72. Topp CW, Østergaard SD, Søndergaard S, Bech P. The WHO-5 Well-Being Index: A systematic review of the literature. *Psychotherapy and Psychosomatics.* 2015;84(3):167-76.
73. Hall T, Krahn GL, Horner-Johnson W, Lamb G. Examining functional content in widely used Health-Related Quality of Life scales. *Rehabil Psychol.* 2011;56(2):94-9.
74. Blom EH, Bech P, Högberg G, Larsson JO, Serlachius E. Screening for depressed mood in an adolescent psychiatric context by brief self-assessment scales-testing psychometric validity of WHO-5 and BDI-6 indices by latent trait analyses. *Health Qual Life Outcomes.* 2012;10:149.

75. Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, 52(1), 30–41. https://doi-org.ucc.idm.oclc.org/10.1207/s15327752jpa5201_2
76. Dahlem NW, Zimet GD, Walker RR. The Multidimensional Scale of Perceived Social Support: A confirmation study. *Journal of Clinical Psychology*. 1991;47(6):756-61.
77. Cartwright AV, Pione RD, Stoner CR, Spector A. Validation of the Multidimensional Scale of Perceived Social Support (MSPSS) for family caregivers of people with dementia. *Aging & Mental Health*. 2020.
78. Lee SA. Coronavirus anxiety scale: A brief mental health screener for covid-19 related anxiety. *Death Studies*. 2020; 44(7): 393-401
79. IBM Corp. IBM SPSS Statistics for Windows, Version 26.0. Armonk, NY: IBM Corp; 2019.
80. Jakobsen JC, Gluud C, Wetterslev J, Winkel P. When and how should multiple imputation be used for handling missing data in randomised clinical trials – a practical guide with flowcharts. *BMC Medical Research Methodology*. 2017;17(1):162.
81. Field A. *Discovering Statistics Using IBM SPSS Statistics*. 4th ed. London: Sage Publications Ltd; 2018.
82. Hayes AF. *Introduction to Mediation, Moderation, and Conditional Process Analysis A Regression-Based Approach*. 2nd ed. New York: The Guilford Press; 2018.
83. Preacher KJ. Calculation for the Sobel Test An interactive calculation tool for mediation tests 2021 [Available from: <http://quantpsy.org/sobel/sobel.htm>].
84. Eurofound. European Quality of Life Survey 2016 [Available from: <https://www.eurofound.europa.eu/data/european-quality-of-life-survey>].
85. Maguire R, Hanly P, Maguire P. Beyond care burden: Associations between positive psychological appraisals and well-being among informal caregivers in europe. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*. 2019.

86. Vogler J, Klein A-M, Bender A. Long-term health-related quality-of-life in patients with acquired brain injury and their caregivers. *Brain Injury*. 2014;28(11):1381-8.
87. Sołtys A, Tyburski E. Predictors of mental health problems in formal and informal caregivers of patients with Alzheimer's disease. *BMC Psychiatry*. 2020;20.
88. Greenwell K, Gray WK, van Wersch A, van Schaik P, Walker R. Predictors of the psychosocial impact of being a carer of people living with Parkinson's disease: a systematic review. *Parkinsonism Relat Disord*. 2015;21(1):1-11.
89. Herley SM. Experiences of the 'Family Connections' Programme: A Group Intervention for Family Members of Individuals with Borderline Personality Disorder. Limerick: University of Limerick; 2015.
90. Lam PCW, Ng P, Pan J, Young DKW. Ways of coping of Chinese caregivers for family members with schizophrenia in two metropolitan cities: Guangzhou and Hong Kong, China. *International Journal of Social Psychiatry*. 2015;61(6):591-9.
91. Rao P, Grover S, Chakrabarti S. Coping with caregiving stress among caregivers of patients with schizophrenia. *Asian J Psychiatr*. 2020;54:102219.
92. del-Pino-Casado R, Serrano-Ortega N, López-Martínez C, Orgeta V. Coping strategies and psychological distress in family carers of frail older people: A longitudinal study. *Journal of Affective Disorders*. 2019;256:517-23.
93. Quinn C, Toms G. Influence of positive aspects of dementia caregiving on caregivers' well-being: A systematic review. *The Gerontologist*. 2018;59(5):e584-e96.
94. Szmukler GI, Burgess P, Herrman H, Benson A, Colusa S, Bloch S. Caring for relatives with serious mental illness: The development of the Experience of Caregiving Inventory. *Social Psychiatry and Psychiatric Epidemiology*. 1996;31(3-4):137-48.
95. Jansen JE, Haahr UH, Harder S, Trauelsen AM, Lyse H-G, Pedersen MB, et al. Caregiver distress in first-episode psychosis: The role of subjective appraisal, over-involvement and

symptomatology. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*. 2015;50(3):371-8.

96. Folkman S, Moskowitz JT. Coping: Pitfalls and promise. *Annual Review of Psychology*. 2004;55:745-74.

97. Fortune DG, Smith JV, Garvey K. Perceptions of psychosis, coping, appraisals, and psychological distress in the relatives of patients with schizophrenia: An exploration using self-regulation theory. *British Journal of Clinical Psychology*. 2005;44(3):319-31.

98. Winsper C. The aetiology of borderline personality disorder (BPD): contemporary theories and putative mechanisms. *Current Opinion in Psychology*. 2018;21:105-10.

99. Gunderson JG, Berkowitz C, Ruiz-Sancho A. Families of borderline patients: a psychoeducational approach. *Bull Menninger Clin*. 1997;61(4):446-57.

100. Dijkstra MTM, Homan AC. Engaging in Rather than Disengaging from Stress: Effective Coping and Perceived Control. *Frontiers in psychology*. 2016;7:1415-.

101. Umucu E, Lee B. Examining the impact of COVID-19 on stress and coping strategies in individuals with disabilities and chronic conditions. *Rehabilitation Psychology*. 2020.

102. Weinstein ND. Misleading tests of health behavior theories. *Ann Behav Med*. 2007;33(1):1-10.

103. Hung M, Bounsanga J, Voss MW. Interpretation of correlations in clinical research. *Postgrad Med*. 2017;129(8):902-6.

104. Miller ML, Skerven K. Family skills: A naturalistic pilot study of a family-oriented dialectical behavior therapy program. *Couple and Family Psychology: Research and Practice*. 2017;6(2):79-93.

Chapter 6 Empirical Paper Supplementary Information

Design Rationale

This study used a cross-sectional design to allow the collection of all variables at one time-point and a preliminary investigation of associations between the variables of interest in this population. The survey used mixed methods. Chapter five details the findings from the quantitative data. The emergence of the COVID-19 pandemic led to the redesign of the survey (chapter seven) and to the inclusion of open-ended qualitative questions to capture participants' perception of the coping strategies they use and their subjective experience of the impact of COVID-19 on their caregiving role and use of coping strategies. The qualitative data are beyond the scope of the current thesis (see the section on Open-Ended Questions below).

Methodology and Procedure

Ethical Approval

Appendix C includes the letters of ethical approval by the Clinical Psychology Research and Ethics Panel, University College Cork.

Choice of Online Survey

In Ireland, BPD is typically treated in community mental health services. Informal caregivers (ICs) of people with BPD (PwBPD) are not automatically part of the treatment. There is a barrier to directly accessing ICs of PwBPD through public mental health services. Consent from the PwBPD is required, and many clinicians would need to be involved in this process. It was not deemed possible to collect a sufficiently large sample within the timeframe of this thesis through public mental health services.

Online surveys allow access to a large and diverse sample (Shaughnessy et al., 2009) and to underrepresented groups through online support and special interest forums and organisations (Skitka & Sargis, 2006). There are several online forums and organisations that provide support to ICs of PwBPD. Feasibility analysis of previous studies using online recruitment indicated that the required sample size could be accessed online. Using online surveys, Goodman et al. (2011) and

Bailey and Grenyer (2015) recruited 566 and 280 carers of PwBPD, who met their inclusion criteria, respectively. Therefore, an online survey was chosen to maximise the opportunity to achieve the required sample size.

Online surveys can cause sample bias as the respondents are typically a convenience sample with internet access and literacy (Shaughnessy et al., 2009). Posting online surveys on special interest groups and organisations may promote bias as people in these groups are not representative of the whole population (Skitka & Sargis, 2006). These limitations have been considered when making conclusions and recommendations about this research study's results. Despite these disadvantages, people may experience an "online disinhibition effect" (Suler, 2004, p. 321). Online surveys are associated with less social desirability bias than telephone surveys. They produce similar quality data compared to paper or face-to-face survey methods (Skitka & Sargis, 2006).

Recruitment

Online Recruitment

A survey advertisement was posted on a public mental health service website, hse.ie, and an international community forum, bpdfamily.com, and emailed via listserv to people registered with two international organisations supporting ICs of PwBPD, the Sashbear Foundation and the National Education Alliance for Borderline Personality Disorder (NEA-BPD).

The advertisement posted on the online forum and via email provided details of the research objective, what was involved in participation, eligibility to participate, and a link to the survey. This information was drawn from the "Participation Information" section of the survey (see Appendix D), in line with the requirements of the respective organisations.

The advertisement posted on hse.ie stated: "Are you caring for or supporting a relative or loved with a diagnosis of Borderline Personality Disorder or Emotionally Unstable Personality Disorder? We invite you to participate in a research survey that will help us better understand the

experience and impact of supporting a person with Borderline Personality Disorder. More information and the survey can be found by clicking on this link: [Link to survey.](#)"

Community Mental Health Programmes

ICs of PwBPD attending Family Connections (Hoffman et al., 2005) in the local public mental health service in August 2020 were verbally informed of the research by clinicians facilitating the programme. Following receipt of verbal consent, a clinician emailed a link to the survey information. Family Connections graduates registered as interested in being contacted with information were sent a text message informing them about the research. The following message was sent to participants: "UCC is currently undertaking research to help better understand the experience of supporting a person with Borderline Personality Disorder. If you are interested in participating, more information and the survey can be found by clicking on this link: [Link to survey.](#) The treatment provided by the HSE to you or the person you are caring for will not be impacted by participation or non-participation in this research."

Details of the Online Survey

The online survey opened with a participant information sheet (Appendix D). In the next section, participants indicated yes or no if they wanted to voluntarily participate in the research. A separate question asked for confirmation that they met the inclusion criteria one to five listed in chapter five (Appendix D).

Tick-box consent was requested to ensure the anonymity of participants. Only participants who responded yes to both of these questions progressed to the next sections of the survey. The sociodemographic questionnaire, the seven measures, the change in caregiving stress due to COVID-19 question, and the four open-ended questions followed. Debriefing information was presented on completion of the survey (Appendix E).

Selection of questionnaires to assess the constructs of interest in this study was based on validity and reliability, accessibility, and brevity. Brevity was required to maximise survey completion rates and to minimise participant burden in a population already experiencing high levels of burden.

The survey comprised 115 questions. Long survey lengths are consistently associated with a decline in completion rates (Liu & Wronski, 2017). However, feasibility assessment showed that a similar length survey (109 questions; Goodman et al., 2011) had previously recruited the sample size estimated for the current research.

Sociodemographic Questions

The sociodemographic questionnaire included 21 questions. Questions were selected: (1) to ensure adequate description of the sample and (2) to provide information about potential confounding variables. Potential confounds were identified from the existing literature on BPD and on ICs of people with other mental health difficulties (see section Assessment of Sample Size below).

Ten questions asked personal information about the ICs of PwBPD, including age; gender; country of residence; education level; employment; chronic illness; whether they are the primary caregiver; received any intervention in relation to being a carer; and experience of leading or teaching a programme for carers. One follow-on question asked for the name of the intervention attended if applicable.

Four questions asked about the relationship with the person with BPD, including the relationship category, cohabitation, average hours of contact per week over the last month, and how many years they had been caring for the person with BPD since they became unwell.

Five questions asked about the person with BPD, including their age, employment status, estimate/known number of days of self-harm in the last year, and estimated/ known number of days of attempted suicide in the last year. Due to the personal and sensitive nature of the latter two questions, participants could select "I cannot estimate the number of days".

Response options for questions on gender, education level, employment and relationship category were chosen based on the following:

- Review of response options used in the existing literature on carers to maximise the opportunity for researchers to compare the current sample with samples in other published articles.

- Categorical response options were chosen for education rather than years of education in line with published articles of caregivers of people with mental ill-health.
- Consideration of inclusivity.
- Review of response options within the research team and adapted based on feedback from university research reviews.

Coping Strategy Measure

Coping questionnaires measure efforts, not outcomes, of coping responses (Greenaway et al., 2014). Coping can be conceptualised as a dispositional trait response (Carver et al., 1989) or a situational, dynamic state response to a specific stressful event (Lazarus & Folkman, 1984). Lazarus and Folkman (1984) criticise trait coping as minimising the complexity of coping. Instruments that measure state coping strategies rather than trait coping styles are suggested to be more valid predictors of outcomes in response to particular stress events (Greenaway et al., 2014). A measure of situational rather than dispositional coping was preferable as this study aimed to specifically measure coping response to caregiving stress. As outlined in chapter three, a second factor of importance was to choose a widely used coping measure to increase the chance of comparing results across studies.

There are many types of coping strategies. Measures can be lengthy, limiting their use in clinical populations due to participant burden (Greenaway et al., 2014). The Brief COPE (Carver, 1997) is one of the most frequently used questionnaires (Kato, 2015). It is a shortened version of the COPE (Carver et al., 1989), designed to reduce participant burden (Carver, 1997) and measures a large number of different coping responses (Greenaway et al., 2014). The Brief COPE comprises 14 theoretically-informed coping strategies based on the transactional model of stress and coping (Lazarus & Folkman, 1984) and the behavioural self-regulation model (Carver et al., 1989). The Brief COPE has been employed in research with ICs of people with mental ill-health (e.g. Coomber & King, 2012; Fortune et al., 2005; Ong et al., 2016; Wasley & Eden, 2018). While Carver (1997) originally

developed the Brief COPE to measure trait coping styles, he designed it to allow adaptation of the frame of reference, including situational or dispositional coping to a specific stressor. For these reasons, this study selected the Brief COPE.

Each coping subscale score is calculated from the sum of two items. Appendix F presents the alpha coefficients for each subscale in the current study. The values are similar to those reported by Carver (1997) and were all above 0.6 except for self-distraction and venting. For two-item subscales, Chronbach's alpha undervalues reliability (Eisinga et al., 2013), and the mean inter-item correlation is used as a better measure of internal consistency. A value of .3 or higher is considered acceptable (Briggs & Cheek, 1986; Mitchell & Jolley, 2010). For this reason, mean inter-item correlations are reported in chapter five and presented in Appendix F.

The mean inter-item correlations indicated that the reliability of the self-distraction scale is questionable. All 14 subscales were retained in the analyses. Interpretation of results considered the reliability of the subscales. Self-distraction was not a significant predictor of the IC outcomes in any of the models.

Measure of Psychological Distress

Psychological distress is "a set of painful mental and physical symptoms that are associated with normal fluctuations of mood in most people" (American Psychological Association, 2020) and is thought to relate to symptoms of anxiety and depression (Drapeau et al., 2012). Several measures of psychological distress have been developed; the three most widely used scales are the General Health Questionnaire (GHQ; Goldberg, 1972), the Kessler scales (Kessler et al., 2002), and the Hopkins Symptom Checklist (Derogatis et al., 1974).

The Kessler K10 (Kessler et al., 2002) was chosen as it is a brief, 10-item version of psychological distress that is freely accessible (Andrews & Slade, 2001). It has no significant gender, education or age bias (Baillie, 2005) and differentiates cases and non-cases of mood and anxiety disorders and serious mental illness in a community population (Kessler et al., 2002; Kessler et al., 2003). The K10 ranges of 22-29 and 30-50 have been used to indicate high and very high

psychological distress, respectively, in an Australian population (Australian Bureau of Statistics, 2012) (Byles et al., 2014). Andrews and Slade (2001) reported a sensitivity of 0.55 and a specificity of 0.95 for a cut-off score of 22 for identifying people with current anxiety or affective disorder. A lower cut-off of 20 increases the sensitivity to 0.66 and reduces the specificity to 0.92. Previous research has also used a cut-off score of 22 (Chen et al., 2016; Korda et al., 2014).

Measure of Positive Mental Well-being

Subjective well-being is defined as subjective affect and life quality. Psychological well-being is frequently linked with eudaimonic well-being, focusing on meaning and purpose in life (Diener et al., 2018). However, these two terms are frequently used interchangeably, and they are shown to highly correlate at the general level, though their specific dimensions differ (Chen et al., 2013). There is a wide range of measures available, with no gold standard (Linton et al., 2016). The WHO-5 was selected as it measures positive aspects of general mental well-being. It is an established measure of general subjective psychological well-being and is brief and freely accessible (Topp et al., 2015). The WHO-5 has been widely used in clinical populations in children, adults, the elderly, and general population studies (Maguire et al., 2019; Topp et al., 2015). A cut-off of 50 is used to screen for depressive symptoms. Lower cut-offs of 28 and 30 have been used to indicate depression, with a score of 20 indicating the need for treatment for major depression (Topp et al., 2015).

Change in Coping Questionnaire

Restrictions in movement and resources due to the COVID-19 pandemic may have impacted IC coping strategies at the time of data collection. As no validated scale of change in coping strategies existed that mirrored the Brief COPE, a measure of change in coping strategies due to COVID-19 was developed. The 28 statements of the Brief COPE were used to compare the change in coping strategies with the measure of currently used coping strategies. A new rating scale was developed to measure the increase and decrease in use of coping strategies.

The literature provides evidence for the number of response options below which a scales' psychometric properties reduce and above which there is no additional gain in reliability and

validity. Lozano et al. (2008) reported that between four and seven response options were optimal. Lee and Paek (2014) found minimal variation in the psychometric properties of scales with between four and six options. Simms et al. (2019) advise that a trade-off between simplicity of use for respondents and precision of measurement (with higher response options improving precision) is required. Some researchers advise against the inclusion of a middle option as it may introduce ambiguity; however, Simms et al. (2019) found no difference in the validity of scales with odd or even number of response options.

The original Brief COPE scale employed four response options. In the case of the change in coping questionnaire, a neutral option was required to allow the possibility of no change in use of the coping strategy. Therefore, the final questionnaire was designed with five response options based on evidence from the literature cited above and a preference for parsimony. Appendix F presents the alpha coefficients and mean inter-item correlations for the current study. All are above 0.6 except for self-distraction. As described above, mean inter-item correlations are reported in chapter five and in Appendix F as subscales only comprise two items. All subscales showed mean inter-item correlations greater than 0.3, which is considered acceptable (Briggs & Cheek, 1986; Mitchell & Jolley, 2010).

Measure of Change in Caregiving Stress due to COVID-19

A single question with an 11-point scale was designed to measure change in caregiving stress due to COVID-19. A single-item question was selected because (1) there was no existing measure of this specific construct, and (2) the survey was already of a length that might result in response attrition. In previous research, a single-item measure of stress symptoms with five response options demonstrated reliability and validity (Elo et al., 2003). A single-item measure for anxiety and for depression with two response options was found to have adequate sensitivity (anxiety = 0.78; depression = 0.63) and specificity (anxiety = 0.75; depression = 0.84) when compared to the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) (Turon et al., 2019). Single item measures of current stress (Karvounides et al., 2016) and pain intensity (von Baeyer et al.,

2009) with an 11-point response scale have also been reliable and valid. One of the most frequently used single-item measures is the Distress Thermometer (Roth et al., 1998), which monitors cancer-specific distress, anxiety and depression on an 11-point response scale (Chambers et al., 2014). Based on the literature, a single-item scale was designed to measure change in caregiving stress due to COVID-19 from -5 (significant decrease in caregiving stress due to COVID-19) to +5 (significant increase in stress due to COVID-19). There was a small, significant positive correlation between change in caregiving stress due to COVID-19 and COVID-19 anxiety, $r=0.17$ $p<.001$. This is in the expected direction, suggesting some construct validity in addition to face validity.

Open-ended questions

During the redesign of the research due to COVID-19 (chapter seven), four open-ended questions were included in the study to obtain information on ICs perception of how COVID-19 may have impacted what they do to cope with their caregiving role, see Appendix G. The questions were designed in consultation with the research supervisors; with consideration that this survey would be posted online; and that they may be completed in different countries with different levels of government COVID-19 restrictions. Due to the number of participants, amount of information, the time constraints of the thesis and a motivation to do ethical research in which appropriate resources and analytic techniques are used, the qualitative responses will be analysed separately and are outside of the scope of this research project.

Analysis

Assessment of Sample Size

A sample size of 250 was estimated (Green, 1991). This sample size was based on the inclusion of the 14 coping subscales, perceived social support, COVID-19 anxiety and a maximum of nine sociodemographic factors as control variables.

Choice of Potential Confounds

Stress process and appraisal models illustrate that many factors that can influence caregiver outcomes in response to a stressor. Confounding variables have only been considered in

one previous study with ICs of people with BPD. Confounds in this research were limited to IC and care recipient sociodemographic variables, anxiety due to COVID-19, which relates to distress (Lee, 2020), and chronic illness, which is associated with higher levels of depression and anxiety (Clarke & Currie, 2009; NICE, 2009). During the proposal stage, the following sociodemographic factors related to the IC were expected to be included as confounds: age, gender, whether they had received an intervention, relationship to the person with BPD, and whether they were living with a person with BPD. The following variables related to the person with BPD were expected to be included as confounds: age, gender, self-harm and suicide.

There remains a scarcity of information on potential confounding factors in this population. Relationship of IC outcomes with sociodemographic variables remains inconclusive in ICs, though there is evidence that mental well-being may vary with carer gender, age, cohabitation and relationship to the care recipient (Bailey & Grenyer, 2014, 2015; Lamborn & Cramer, 2020; Scheirs & Bok, 2007); symptoms of the person with BPD as measured by DSH and suicide attempts (Bailey & Grenyer, 2014, 2015); age (Bailey & Grenyer, 2014, 2015) and gender (Scheirs & Bok, 2007) of the person with BPD; and whether the IC had received an intervention as research shows that intervention has resulted in post-treatment improvements in distress and mental health (e.g. Bateman et al., 2018; Flynn et al., 2017). In caregivers of people with other mental health disorders, the relationship of IC outcomes with sociodemographic variables remains inconclusive. There is evidence that mental well-being varies with carer gender, age, and relationship to the care recipient (Hsiao et al., 2020; Mitsonis et al., 2012; Möller-Leimkühler, 2005; Rammohan et al., 2002; Scheirs & Bok, 2007; Stanley et al., 2017), education (Yusuf & Nuhu, 2011), duration of illness (Gibbons et al., 1984; Martens & Addington, 2001), cohabitation (Östman & Hansson, 2004), and care recipient gender (Winefield & Harvey, 1993; Yusuf & Nuhu, 2011).

Recoding of Data

When checking the validity of the data set, an inconsistency between the relationship category and participant/ person with BPD ages was observed for the "child" and "parent" relationship categories. Some participants who were substantially older than the PwBPD had indicated that the PwBPD was their parent, or participants who were substantially younger than the PwBPD had selected that the PwBPD was their child. Participants with this inconsistent response accounted for 9.8% of the sample included in the analysis presented in chapter 5.

In order to assess the possible reason for the inconsistency, the survey format and questions were first reviewed. The information about the carer and the PwBPD were located in different sections of the survey that were clearly labelled: "About you" and "About the person you care for". The questions on age were also very clear: "What age are you?" and "What age is the person with Borderline Personality Disorder?" This suggested that the inconsistency was unlikely due to an error inputting the IC age in response to the question about the PwBPD or inputting the age of the PwBPD in response to the IC. Therefore it was likely that there was an error in interpreting the question regarding the relationship to the PwBPD, leading to incorrect responses for the child and parent categories. To correct for this, the relationship status was corrected to correspond to the age difference between the IC and the PwBPD for the parent and child relationship categories. The association between relationship category and outcomes in this study agreed with previous research, supporting the validity of this correction.

In the original regression models presented in chapter 5, relationship was not a significant predictor of psychological distress (Table 5.4). Relationship was a significant predictor of positive mental well-being in step 2 of the regression of coping strategies onto positive mental well-being ($\beta=.07$, $p=.04$) (Table 5.5). Relationship only explained 0.3% of the variance of the model, suggesting that relationship to the PwBPD was not a meaningful predictor of positive mental well-being. For these reasons, it was not considered that the recoding of the relationship variable significantly impacted the results.

Additional analysis

As a cautionary check, the analysis presented in chapter 5 was rerun with 778 participants and excluding the participants with inconsistent age/ relationship responses.

Regression onto psychological distress. Table H.1 presents the results of the regression of social support and coping strategies onto psychological distress. The overall model results were similar to those presented in chapter 5, Table 5.4. Mirroring the results presented in chapter 5, relationship status was not a significant predictor of psychological distress ($\beta = -.01$, $p = .64$). Amongst the coping strategies, self-blame, positive reframing, behavioural disengagement, and substance use remained the strongest significant predictors of psychological distress, accounting for 5.4%, 1.1%, 1.5%, and 1.1% of the variance explained, respectively. Social support continued to be a significant predictor, explaining 2.8% of the variance in psychological distress. Denial was also a significant predictor of psychological distress but had minimal influence explaining only 0.5% of the variance in psychological distress. There was one difference between the present findings using the smaller sample and the larger sample presented in chapter 5. Acceptance coping became a significant predictor of psychological distress (Table H.1). However, acceptance coping had only minimal influence on psychological distress, accounting for only .4% of the variance in the current analysis. This represents an increase in variance explained by acceptance coping compared to the analysis presented in chapter 5 (.12%). However, across both samples, the percentage of variance explained by acceptance coping suggests that it had minimal influence and is not an important predictor of psychological distress in the study sample.

Regression onto positive mental well-being. Table H.2 presents the results of the regression of social support and coping strategies onto positive mental well-being. The overall model results were similar to those presented in chapter 5, Table 5.5. Mirroring the results presented in chapter 5, relationship to the PwBPD was a significant predictor of well-being in step 2 of the model ($\beta = .07$, $p = .02$), but explained only a minimal amount of the variance in positive mental

well-being (0.4%). The percentage of variance explained by relationship to the PwBPD was similar to the analysis with the total sample presented in chapter 5 (0.3%).

Amongst the coping strategies, positive reframing and self-blame remained the strongest significant predictors of positive mental well-being, accounting for 2.4% and 1.8% of the variance explained, respectively. Social support continued to be a significant predictor, explaining 2.3% of the variance in psychological distress. Behavioural disengagement (0.9%), planning (0.9%), substance use (0.6%), humour (0.6%) and acceptance (0.6%) each uniquely explained a significant but minimal amount of the variance in positive mental well-being. In a departure from the results presented in chapter 5, religious coping became a significant predictor of positive mental well-being (Table H.2). However, religious coping had only minimal influence on positive mental well-being, accounting for only .4% of the variance. This represents an increase in variance explained by religious coping compared to the analysis presented in chapter 5 (.2%). However, across both samples, the percentage of variance explained by religious coping suggests that it had minimal influence and is not an important predictor of positive mental well-being in the study sample.

Change in caregiving stress due to COVID-19. There was not a significant difference in change in caregiving stress due to COVID-19 across relationship categories in the reduced sample ($n=778$), $F(5, 772)=1.44$, $p=.21$, or the sample presented in chapter 5 (Table 5.3). As a result, relationship was not included as a control in the regression of social support and coping strategies on to change in caregiving stress due to COVID-19 (Table 5.6 and Table 5.7). As relationship was not an important control variable for change in caregiving stress due to COVID-19, regression of social support and coping strategies onto change in stress was not repeated for the smaller sample described in this section.

Summary of Impact of Recoding the Relationship items for 9.8% of Participants

In summary, the results of the smaller sample ($n=778$), excluding the participants with inconsistency in response to the age and relationship questions, were comparable to the results when all 863 participants were considered. One additional coping strategy became a significant

predictor of psychological distress (acceptance coping) and positive mental well-being (religious coping) when the analysis was undertaken with the smaller sample. However, the variance explained by each of these coping strategies is minimal and does not meaningfully affect the findings of the study. These minor differences do not alter the interpretation of results or conclusions presented in chapter 5. The additional analyses presented here supports the validity of the results and discussion presented in chapter 5.

Missing Data Analysis

Missing data is important as it can introduce bias into the analysis. Missing data is categorised as missing completely at random (MCAR), missing at random (MAR) and missing not at random (MNAR). MCAR means that the missing values will be similar to the observed values. In most data sets comprising psychological data, there is no way to verify the missing data and, therefore, no way to definitively categorise data as MCAR (Bhaskaran & Smeeth, 2014). This problem is augmented with anonymous survey data. Similarly, it can be challenging to differentiate MNAR from MAR data. MAR means that relationships with the observed data can explain the differences in the missing and observed data. MNAR means that the differences in the missing and observed data cannot be explained by relationships with the observed data and are related to the missing variable score (Hughes et al., 2019; Jakobsen et al., 2017).

Complete case analysis can be used when missing data are MCAR or when the proportion of missing data is below 5%. Otherwise, complete case analysis may cause biased results. Multiple imputation is a statistical method widely used to impute missing data. It can be used if the data is MAR and if there is not a large proportion of missing data (Jakobsen et al., 2017; Sterne et al., 2009). Multiple imputation uses linear and logistical regression for continuous and categorical variables, respectively.

Missingness in the current sample.

There was more than 5% missing data. Little's Chi-square test was undertaken with categorical predictors cross-tabulated with continuous predictors and dependent variables. Little's test confirmed that values were not MCAR, $X^2 (DF=5311) = 595.67, p < .001$.

There were more than 40% missing data on important measures for 21 of the participants. These cases were excluded from the analysis (Jakobsen et al., 2017), leaving 863 participants. Sociodemographic variables were not significantly different between participants with more than and less than 40% missing data on important measures, except for gender, $X^2(3)=9.12, p=.03$. For the remaining 863 participants, five imputed data sets were generated using a multiple imputation model. A Fully Conditional Specification Method with a maximum of 5000 iterations was employed. Constraints were applied to ensure that the imputed values could not exceed the possible range for each variable. Five imputations were conducted. The sociodemographic variables and the MSPSS, CAS, Brief COPE, Kessler K10, WHO-5 well-being, Brief COPE Change and the change in caregiving stress due to COVID-19 were included in the model. Each missing case was replaced with the average of the five imputed values.

Comparing the results of the imputed dataset with the exclusion of cases listwise.

In the case of MNAR, multiple imputation may bias results; complete case analysis may be more appropriate (Hughes et al., 2019). As I could not be sure if the data were MNAR or MAR (Jakobsen et al., 2017), a second analysis was undertaken with all cases included. For each multiple regression in SPSS, cases were excluded listwise. The results of the imputed and non-imputed data were similar. See Appendix I for results of the regression analysis with casewise deletion. This was possibly because percentage missingness in the current data set (6.6%) was just above the 5% threshold. The results for the imputed models are reported in the empirical paper as they have increased power.

Supplementary Results

Comparison of Outcomes to Population Norms

Chapter five reports the difference between psychological distress and positive mental well-being to population norms. The results were also categorised by gender and compared to male and female norms to account for the high percentage of females in the study sample. The female ICs ($M=25.05$, $SD=7.65$) had higher levels of psychological distress than the female population norms (Slade et al., 2011) ($M=15.8$), $t(739)=32.89$, $p<.001$. The male ICs ($M=24.64$, $SD=8.29$) had higher levels of psychological distress than the male population norms, $t(117)=13.3$, $p<.001$.

Female ICs of PwBPD ($M=41.82$, $SD=21.08$) had significantly lower positive mental well-being scores than the mean female population score reported for Serbia (Eurofound, 2016), $t(739)=-11.84$, $p<.001$. Male ICs of PwBPD ($M=43.25$, $SD=19.78$) had significantly lower positive mental well-being scores than the mean male population score reported for Serbia, $t(117)=-5.35$, $p<.001$.

Regression Analysis

The study used regression analysis. Control predictors for each of the regression models were informed by the theoretical model of caregiving stress as described in chapter five. COVID-19 anxiety was also included to account for the specific environmental conditions in which this research was being conducted. Exploratory analysis was undertaken to investigate which sociodemographic factors significantly related to outcome measures in this study's sample. Only factors that had a significant relationship were included in the final model for each regression model.

Selecting Dummy Variables

For categorical variables with more than two levels significantly associated with the dependent variable (education and relationship status), dummy variables were created for each level. Each dummy variable was linearly regressed onto the dependent variable; see Appendix J for results.

Assumptions and Casewise Diagnostics to Check for Bias

The assumptions of the multiple linear regression test were checked for each model. Scatterplots of the independent versus dependent variables investigated the assumption of linearity. Homoscedasticity was checked by observation of scatterplots of standardised residuals versus predicted values. Multivariate normality was assessed using a histogram of the residuals. Three checks were conducted to investigate multicollinearity following the criteria set by Field (2018):

- Predictor variable correlations in the correlation matrix were less than 0.8.
- Variance Inflation Factor (VIF) less than 10.
- Tolerance statistic >0.2.

In addition to the bias checks described in chapter five, the standardised residuals were checked for evidence of outliers that may bias the model. The following criteria were set (Field, 2018):

- Minimum 95% cases have standardised residuals within ± 2 and 99% within ± 2.5 .
- Standardised residuals have a maximum value of 3.29.

Table 6.1

Multicollinearity Checks

Model	Max predictor variable correlation	Max VIF	Min Tolerance
Psychological distress	0.65	2.62	0.38
Positive mental well-being	0.65	2.62	0.38
Coping strategies on to change in caregiver stress due to COVID-19	0.65	2.58	0.39
Change in coping strategies on to change in caregiver stress due to COVID-19	0.70	2.52	0.40

Regression on to Psychological Distress and Positive Mental Well-being

Plots confirmed that linearity and homoscedasticity assumptions were met. The criteria for the no multicollinearity assumption, see Table 6.1, and standardised residuals were achieved.

Therefore these regression models can be generalised (Field, 2018)

Regression of Coping Strategies on to Change in Caregiving Stress due to COVID-19

All non-categorical variables met the assumption of linearity. The assumption of no multicollinearity was achieved, see Table 6.1. The scatterplot indicated that the assumption of homoscedasticity might have been violated. However, regression analysis is robust in response to breaches of homoscedasticity for large samples once they are not extreme (Field, 2018; Statistics Solutions, 2021). 3% of standard residuals exceeded the limit of ± 2.58 . Six cases (0.7%) exceeded 3.29 (range -3.31 to -3.71). It is likely that these cases are not causing undue bias as Cook's distances were significantly less than 1 (range 0.01 to 0.02) (Field, 2018).

Regression of Change in Use of Coping Strategies on to Change in Caregiving Stress due to COVID-19

All non-categorical variables met the assumption of linearity. The assumption of no multicollinearity was achieved, see Table 6.1. Change in use of emotion support and instrumental support had the highest correlation at 0.70. The scatterplot indicated that the assumption of homoscedasticity might have been violated. However, regression analysis is robust in response to breaches of homoscedasticity for large samples once they are not extreme (Field, 2018; Statistics Solutions, 2021). 2.6% of standard residuals exceeded the limit of ± 2.58 . Four cases (0.5%) exceeded 3.29 (range -3.49 to -3.72). It is likely that these cases are not causing undue bias as cook's distances were significantly less than 1 (range 0.004 to 0.02) (Field, 2018).

Exclusion of Perceived Social Support from the Regression Models

Appendix K provides the results of the regression of coping strategies onto psychological distress and positive mental well-being with perceived social support excluded. As can be seen, use of emotional support becomes a significant predictor in both models when perceived social support is excluded. This result informed the mediation analysis described in chapter five.

The Interaction between Change in Use of Coping Strategies and Coping Strategies

As data collection was undertaken during the COVID-19 pandemic, it was possible that the coping strategies measured would depend on the change in use of those strategies due to the

COVID-19 pandemic. To assess this, interaction terms were created for coping strategies that had significantly predicted the dependent variables. The interaction terms were included in step 2 of the regression model. The results are presented in Appendix L. None of the interaction terms were significant predictors of positive mental well-being. Self-blame coping x change in coping was the only interaction term that significantly predicted psychological distress. The interaction term explained a small amount of the variance in psychological distress (<.5%), suggesting minimal effect.

The Relationship between Coping Strategies and Outcomes controlling for Geographical Residence of participants

The majority of the sample (n=770) were from the USA and Canada. The cultural environment of the participants may have influenced their coping responses (Tweed et al., 2004). Due to the dominance of participants from this geographical region, the findings of the study may not be generalizable to other areas.

The question of whether culture impacted the findings of the study in chapter 5 was not one of the research questions. Further, the sample sizes outside of the dominant USA/Canadian sample were below the required sample size for the final regression model included in chapter 5 (estimated required sample size 242). For this reason, a detailed analysis of the influence of culture was not assessed in the empirical paper in chapter 5. However, the potential limitation on the generalizability of results to geographical areas outside of North America is acknowledged. Supplementary analyses were undertaken to investigate the potential impact of culture on results.

Additional regression analyses were carried out with participants from Europe and the USA/ Canada only (n=820). Firstly, an additional control variable, geographical residence, was included in each regression model. The results are presented in Appendix M. As shown in the Appendix, the geographical residence was not a significant predictor of IC psychological distress (Table M.1), positive mental well-being (Table M.2) or change in stress due to COVID-19 (Table M.3). Further, reduction in the sample size and inclusion of geographical residence did not change the

relationship between coping strategies and IC psychological distress, positive mental well-being or caregiver stress due to COVID-19, respectively.

Geographical residence (USA/Canada) was a significant negative predictor of change in caregiving stress due to COVID-19 when change in coping strategies was regressed onto change in caregiving stress due to COVID-19, see Table M.4. This indicates that change in caregiving stress due to COVID-19 in the USA/Canada was less than in Europe. However, geographical residence only explained a minimal amount of the variance in change in caregiving stress (0.4%) and therefore was not an important predictor of change in caregiving stress due to COVID-19. Chapter 7 provides further discussion of possible reasons for ICs experience of an increase in caregiving stress due to COVID-19.

Compared to the analysis presented in chapter 5, change in use of humour no longer significantly predicted change in stress due to COVID-19 when geographical residence was included in the regression model. In the original analysis, change in use of humour only predicted a minimal amount of the variance (0.5%) in change in caregiving distress (Table 5.7), which reduced to 0.34% in the current analysis (Table M.4). These results suggest that one geographical region may have changed their use of humour coping a little more than the other. However, in both analyses, humour only explained a small amount of variance in change in caregiving stress and therefore, overall, was not an important coping strategy in the model.

Secondly, the analyses were rerun for the samples from the USA/ Canada and Europe separately. The results for the sample from the USA/ Canada are presented in Tables M.5 to M.8 in Appendix M. The results for the European sample are presented in Tables M.9 to M.12. The results for the USA/ Canadian sample are similar to the findings for the whole sample, chapter 5.

Comparing the results between the European and USA/ Canadian samples, social support was a significant negative predictor of psychological distress and positive predictor of positive mental well-being in both samples. However, there was no agreement in the coping strategies that predicted

psychological distress, positive mental well-being or change in caregiving stress across the two geographical areas (Europe compared to USA/ Canada).

In the European sample (Table M.9 to M.12), use of emotional support coping was a negative predictor of distress and a positive predictor of positive mental well-being. Use of instrumental support was a positive predictor of psychological distress and a negative predictor of positive mental well-being. Humour coping was a positive predictor of psychological distress. Acceptance coping was a positive predictor of positive mental well-being. Self-distraction was the only significant predictor of change in caregiving stress due to COVID-19 in the European sample. Self-distraction positively predicted change in caregiving stress, indicating that an increase in self-distraction coping was associated with an increase in caregiving stress due to COVID-19.

Regression of social support and change in coping strategies onto change in caregiving stress due to COVID-19 was not significant in the European sample. Regression of age, cohabitation, hours of contact, COVID-19 anxiety, and perceived social support did not significantly predict change in caregiving stress in step 1 of the regression model, $R^2=.06$, $F(5, 44)=.55$, $p=.74$. Further, addition of change in coping strategies due to COVID-19 did not significantly predict change in caregiving stress due to COVID-19 in step 2 of the model, $R^2=.30$, $F(19, 30)=.67$, $p=.82$.

While these preliminary results do suggest a geographical effect on the relationship between coping strategies used and caregiver outcomes, these results must be considered with caution as there were only fifty participants in the European sample, which is below the required sample size for regression models with between 19 and 24 variables run in this study (estimated required sample size of 202 for 19 variables and 242 for 24 variables (Green, 1991)). Further, participants were residents across 10 European countries that spanned Eastern and Western Europe and therefore may not correspond to a cohesive cultural region. Despite these limitations, the results do indicate that future research should be undertaken on cross-cultural differences in coping strategy use in populations of ICs of PwBPD.

It was not possible to compare results across other geographical areas due to the small number of respondents from countries located in the continents of North and South America (n=10), Asia (n=7), Africa (n=2) and Australasia (n=23). It was not possible to compare an Irish sample to the USA/ Canadian Sample due to the small number of respondents from Ireland (n=10).

Brief COPE Dimensions

The author of the Brief COPE recommends that any second-order components are developed based on study-specific data (Carver, 2021). Principal components analysis was used to reduce the 14 subscales on the Brief COPE to a smaller number of dimensions. Four components were extracted. However, it was decided that the results of the dimension reduction were not satisfactory because many of the subscales had many correlations less than 0.3, suggesting that they should be excluded; Kaiser-Meyer-Olkin (KMO) was 0.68, indicating mediocre sampling adequacy; and residuals between observed and reproduced correlations were high (61% nonredundant residuals with values more than .05) (Field, 2018).

Comparison of Brief COPE Results to Published Data

The Brief COPE subscale scores were compared to published scores for ICs of people with schizophrenia (Ong et al., 2016). The purpose of this was to help understand the results presented in Chapter five and inform the discussion. Table 6.2 presents a summary of the results and comparison to the published data. Comparison of means was undertaken using one-sample t-tests. Use of positive reframing and religion were significantly lower in ICs of PwBPD than ICs of people with schizophrenia with a large effect size. Use of self-blame coping was significantly higher in ICs of PwBPD than ICs of people with schizophrenia with a large effect size. Substance use and behavioural disengagement were also significantly higher in the IC of PwBPD, with a medium effect size. Use of instrumental support and venting did not significantly differ between groups. These results support the discussion in chapter five recommending that interventions focus on assisting ICs of people with BPD to develop positive reframing and reduce use of self-blame coping strategies.

Table 6.2*Mean Coping Scores Compared to Mean Scores Published by Ong et al. (2016)*

Subscale	t	p	g
Self-distract	13.33	<.001	0.43
Active	-12.37	<.001	0.43
Denial	-12.27	<.001	0.40
Substance use	15.58	<.001	0.57
Use of emotional support	6.46	<.001	0.22
Use of instrumental support	1.75	.08	0.06
Behavioural disengagement	15.93	<.001	0.56
Venting	-0.48	.63	0.01
Positive reframing	-27.03	<.001	0.91
Planning	-2.36	.02	0.08
Humour	-4.72	<.001	0.16
Acceptance	-6.69	<.001	0.23
Religion	-23.59	<.001	0.80
Self-blame	24.96	<.001	0.88

Dissemination

The empirical research presented in chapter five will be submitted to the journal specified in Appendix B. The empirical paper has been prepared in line with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist for cross-sectional studies (von Elm et al., 2007) and the reference format required for the identified journal.

Chapter 7 Impact of COVID-19 on Research

The research proposal and plan was developed in late 2019, prior to the global COVID-19 pandemic, and was adapted in June 2020 in response to the COVID-19 pandemic. The following sections outline modifications to the research plan.

Changes to Study Aims

Informed by the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984), the original research proposal aimed to assess both the relationship between caregiving appraisals, coping strategies and psychological distress and positive mental well-being of informal caregivers (ICs) of people with BPD (PwBPD). Therefore, the study originally included the additional component assessing how caregiving appraisals related to coping strategy use and caregiving outcomes. The original survey included a standardised measure of caregiving appraisals, the Experience of Caregiving Inventory (Szmukler, Burgess, Herrman, & Benson, 1996).

It became apparent in spring 2020 that COVID-19 evoked societal anxiety, and unprecedented restrictions were placed on people's lives globally. Therefore COVID-19 may impact the measurement of constructs of interest to this study. The research was modified as follows to allow measurement of the potential COVID-19 impact on constructs of interest:

- A standardised measure, the Coronavirus Anxiety Scale (Lee, 2020), was employed to control for the impact of COVID-19 anxiety on psychological distress and positive mental well-being.
- An adapted version of the Brief COPE was used to measure change in use of coping strategies as a result of the COVID-19 pandemic.
- A question was included to measure change in caregiving stress due to COVID-19.
- Four qualitative questions were included to explore people's experience of change to caregiving stress and coping strategies due to COVID-19.

The original survey had already been identified as lengthy by the research team and university reviews. Therefore, participant burden in an already burdened population may be too

great if all the original measures and the additional measures were included in the survey. Through discussion with the research team, it was decided to focus on the relationship between coping and caregiver outcomes and omit investigation of caregiver appraisals from the study at this time. The construct of social support was being investigated as a control variable in the original research design. During the design review, social support was identified as an important construct that had not yet been explored in a large sample in this population. Therefore, the research was adapted to include a focus on the relationship between social support and caregiver outcomes and include an assessment of the impact of COVID-19.

Access to IC Population

In the original research proposal, the recruitment of the majority of the participants was expected to be via online organisations and forums. Therefore the pandemic did not impact the main recruitment stream, with the exception of delays in recruitment due to modifications to the research design and the additional stress on organisation resources during the pandemic.

The original proposal also aimed to recruit participants attending in-person group programmes for ICs of PwBPD within a local public mental health service. These participants would be given a choice of either hard or soft-copy questionnaires. If numbers allowed, it was hoped that the sociodemographic profile of ICs attending the local service could be compared to the online group. This would allow some assessment of the generalizability of findings in the larger sample. Due to the research redesign, there were delays in the commencement of recruitment, which limited recruitment to attendees of only one IC programme. In addition, the COVID-19 pandemic resulted in a movement to an online rather than in-person programme. The ICs attending the online programme were informed of the research and sent a link to the research. However, the response rate was low, potentially impacted by the virtual setting. The small number of participants from this recruitment stream meant that the sociodemographic profile of the attendees of the local programme could not be compared to the wider sample recruited through online forums and organisations.

Impact of COVID-19 on Informal Caregiver Stress

The results presented in chapter 5 indicate that there was an increase in caregiving stress due to COVID-19. There may have been a number of reasons for the increase in caregiving stress. Eckardt (2020) suggests that people with mental health difficulties may have increased reliance on ICs during the COVID-19 restrictions, magnifying the social, interpersonal and financial strain of ICs. PwBPD may have experienced restricted access to professional mental health supports and outpatient appointments during the pandemic (Yao et al., 2020) or they may have reduced attendance at appointments for fear of COVID-19 (Torjesen, 2020). It is possible that a reduction in access to professional supports may have increased reliance on ICs. The study presented in chapter 5 found that cohabitation and hours of contact with the PwBPD negatively predicted IC positive mental well-being. These results are supported by the previous studies of ICs of people with personality disorders (Lamborn and Cramer, 2020). The COVID-19 restrictions on movement may have led to increased time spent at home, thus increasing contact between ICs and PwBPD who reside together and subsequent increase in caregiving stress. Interestingly, additional analyses conducted in chapter 6 indicated that change in caregiving stress due to COVID-19 was greater for participants from Europe than from the USA/ Canada. This may have been due to a number of reasons, including differences in COVID-19 restrictions across regions.

The study presented in chapter 5 focused on the quantitative results from a larger survey. The survey also included responses to open questions that, as previously discussed, will be analysed separately and are outside of the scope of this thesis. These open questions asked participants how COVID-19 impacted their role as a caregiver for a PwBPD and also about the local COVID-19 restrictions in place. This information may help further elucidate why the participants in the study presented in chapter 5 experienced an increase in caregiving stress due to COVID-19.

Chapter 8 Conclusion

Informed by the Transactional Model of Stress and Coping (TSC) (Lazarus and Folkman, 1984) and the stress-process model of caregiving (Pearlin, 1999), this thesis aimed to elucidate the relationship between modifiable factors and outcomes in informal caregivers (ICs) of people with schizophrenia and people with Borderline Personality Disorder (PwBPD). The research questions were:

1. What is the relationship between carer coping strategies and carer outcomes of psychological distress and well-being in ICs of people with schizophrenia?
2. What is the relationship between perceived social support, coping strategies and outcomes of psychological distress and positive mental well-being in ICs of PwBPD?
3. What is the relationship between the use of coping strategies and change in caregiving stress due to COVID-19 in ICs of PwBPD?

Summary of Research Findings

Research Question 1

There is published research investigating the relationship between coping strategies and psychological distress and well-being in ICs of people with schizophrenia, and so a systematic review was conducted. Searches identified 14 studies that met the inclusion criteria. The quality of the studies and methodological heterogeneity across studies was such that there is insufficient evidence to make a firm conclusion on the relationship between coping strategies and psychological distress and well-being of carers of people with schizophrenia. Considering these limitations, synthesis of the results across studies provided preliminary support that coping strategies are associated with IC psychological distress and well-being in this caregiving population. However, further research would be required to verify if coping strategies buffer the impact of caregiving stress on carer outcomes and to identify which coping strategies are associated with better IC outcomes.

Research Question 2

Both social support and coping strategies were observed to be significant predictors of psychological distress and positive mental well-being of ICs of PwBPD, controlling for sociodemographic factors and COVID-19 anxiety. In the models, the most important predictors of outcomes were perceived social support, positive reframing, self-blame, behavioural disengagement, and substance use. Perceived social support and positive reframing were each significant unique predictors of better IC outcomes, while self-blame was the strongest unique predictor of adverse outcomes. Behavioural disengagement and substance use also predicted higher psychological distress, though with less strength than self-blame, and explained a minimal amount of variance in positive mental well-being. Other coping strategies explained significant, though minimal, amounts of the variance in IC outcomes, indicating that they were less important: humour and acceptance positively predicted positive mental well-being; planning negatively predicted positive mental well-being; and denial positively predicted psychological distress.

Research Question 3

Use of coping strategies and change in their use as a result of COVID-19 significantly predicted change in caregiving stress due to COVID-19 when controlling for sociodemographic factors and COVID-19 anxiety. However, the small effect size associated with the findings indicated that coping strategies might not be important explanatory variables of change in caregiving stress due to COVID-19.

Despite this, the relationships largely corresponded with research question 2. Change in use of planning was the strongest predictor of change in caregiving stress and was associated with a change in caregiving stress in the same direction. For example, an increase in use of planning related to an increase in caregiving stress due to COVID-19. Notably, previous studies assessing coping response to stress during COVID-19 have not found this association (see chapter 2). Further, change in use of self-blame also related to change in caregiving stress in the same direction, though this was a less important predictor. Other coping strategies and changes in coping strategies due to COVID-19

explained only minimal amounts of variance in caregiving stress. Change in use of positive reframing, humour and acceptance predicted a change in caregiving stress in the opposite direction, indicating that increase in the use of these strategies related to a reduction in caregiving stress. These findings support the results of research question 2 and again indicate that planning and self-blame may be maladaptive, while positive reframing, humour and acceptance may be adaptive coping strategies in response to stress associated with caring for a PwBPD. Change in use of religion positively predicted, and change in use of denial negatively predicted change in caregiving stress due to COVID-19.

Additional Observations during the Research

There were several additional findings beyond the main research questions. The results add to the existing evidence base regarding high psychological distress in ICs of PwBPD and extend previous research by also showing that ICs of PwBPD experience lower levels of positive mental well-being than other ICs. Furthermore, this study found that ICs perceived a mean increase in caregiving stress due to the COVID-19 pandemic. Interestingly, while perceived social support was associated with better caregiver outcomes, perceived social support was not a significant predictor of change in caregiving stress due to COVID-19.

Of interest, the systematic review presented in chapter 3 found that more than one study has reported a significant association between coping strategies of self-blame and positive reframing and outcomes in ICs of people with schizophrenia. Together with the findings of the study presented in chapter 5, these results suggest that there are parallels across IC populations and that cognitive coping strategies may be important moderators of IC distress and well-being of ICs of people with mental ill-health. However, these results would have to be further assessed using other methods to assess the directionality of influence between coping strategies and IC distress and well-being.

The analyses presented in chapter five and chapter six also revealed information on sociodemographic factors associated with outcomes for ICs of PwBPD, which are of interest when considering which carers may benefit most from interventions. While many IC sociodemographic

variables correlated significantly with outcomes, there were few sociodemographic predictors when controlling for the other variables. Younger ICs and ICs living with or having more contact with the PwBPD may be at greater risk of adverse outcomes. Cohabitation and hours of contact were only associated with lower positive mental well-being and not higher psychological distress, suggesting that living with or having more contact with the PwBPD may reduce positive mental well-being but not increase negative symptoms. This hypothesis would need to be verified by further research as this study used a cross-sectional design. The only care recipient variables associated with outcomes were the estimated number of days of self-harm and suicide. This finding echoes previous quantitative and qualitative research and indicates that ICs of people who are frequently self-harming or attempting suicide may be at greater risk of adverse outcomes.

Strengths and Limitations

This thesis has addressed the paucity of empirical information on modifiable factors associated with outcomes for ICs of PwBPD by investigating the relationship between social support and coping strategies and IC outcomes. It has also provided a synthesis of the published results relating to coping strategies and outcomes for ICs of people with schizophrenia. These findings can be used by clinicians to inform the development of interventions for ICs of PwBPD and can also be used to identify future research directions. The studies presented used published practice guidelines. The systematic review followed PRISMA guidelines (Moher et al., 2009) and the research study considered STROBE guidelines (von Elm et al., 2007) to strengthen study quality and the utility of the results. The systematic review and the research study were also informed by theoretical models, which assisted the development of the research questions and the identification of limitations and future research directions.

The studies described in this thesis were limited by several factors discussed in chapters three and five. In summary, the systematic review results may have been biased by exclusion of studies not available in the English language, the grey literature and studies on relatives of people with schizophrenia who were not described as carers or having a caregiving role. However, these

exclusions also served to improve review quality, and attempts were made to obtain non-English language studies.

With regard to the empirical study presented in chapter 5, the cross-sectional design limits statements of causality. In fact, it is likely that coping strategies and social support do not unidirectionally predict carer outcomes but that there is a transactional interaction. The study used an online self-selecting sample, which may not represent the sociodemographic profile or range of experiences of ICs of PwBPD. The study did not formally confirm BPD diagnosis. Attempts were made to verify diagnosis through IC confirmation that the care recipient had BPD and also including a screening instrument in the survey. However, the results need to be verified in a community sample with access to the care recipient or confirmation of the care recipient's diagnosis. The results relating to change in caregiving stress due to COVID-19 must be considered preliminary as non-validated measures were used to assess this construct and to measure change in use of coping strategies. The study was undertaken during the COVID-19 pandemic, which may have influenced some findings. The majority of the sample resided in North America. Therefore, the results may not be generalizable outside of this geographical region.

Theoretical models describe the complexity of the stress process in ICs, and all factors were not considered in this research. This research limited its focus to the relationship between coping strategies, social support and outcomes, controlling for sociodemographic characteristics and COVID-19 anxiety. However, this study does provide preliminary support for the applicability of the TSC and stress-process model of caregiving to ICs of PwBPD and provides evidence that future research should be undertaken to further investigate the hypotheses of these models in this population.

Implications for Clinical Practice

This research underscores that ICs of PwBPD are a vulnerable population in need. It supports Haug's (1994, p.1) contention that ICs be described as "hidden patients". Furthermore, the research provides preliminary evidence that ICs of PwBPD experience a reduction in positive mental

well-being and an increase in caregiving stress as a result of COVID-19, in line with Eckardt's (2020) hypothesis. These results agree with previous qualitative and quantitative research to highlight that this population would benefit from intervention and support, even more so during a pandemic.

The systematic review findings provide preliminary support for a significant relationship between coping strategies and carer outcomes of ICs of people with schizophrenia. However, the quality and methodological variability across studies included in the review was such that there was insufficient evidence to make firm conclusions about the direction of the relationship or about specific coping strategies that had the strongest relationship with IC outcomes. Therefore the systematic review was not able to make any recommendations for clinical practice.

The empirical research study provides preliminary support for the inclusion of both social support and coping strategies in interventions for ICs of PwBPD, though further research is required to confirm the direction of the relationship between IC social support and coping strategies and IC outcomes and replicability of results. Specifically, for ICs of PwBPD, the results suggest that interventions directly address self-blame cognitions evoked in response to caregiving stressors and assist ICs to reduce the use of avoidant coping strategies such as behavioural disengagement and substance use. Interventions may also be optimised by supporting ICs to develop skills to improve social supports and to positively reframe cognitions about typical caregiving stressors. Furthermore, interventions may benefit from helping caregivers identify when planning is effective and when it may serve to augment caregiving stress. Considering the findings in the context of previous qualitative and quantitative research, reduction in self-blame and behavioural disengagement and increase in positive reframing may be supported by helping ICs increase their knowledge and understanding of BPD. This hypothesis requires further research.

For ICs of PwBPD, the research presented herein also identifies that those most at risk of adverse outcomes are younger ICs, ICs living or spending more time with the PwBPD, ICs with chronic illness, and ICs have who low perceived social support, who have difficulty generating

alternative positive thoughts about caregiving situations, and who use a lot of self-blame in response to caregiving stressors. These ICs should be targeted for priority intervention.

Implications for Research

Based on the findings of this thesis, it is recommended that researchers ensure transparency of their methodology and findings; follow best-practice guidelines for their research design; use statistical methods that consider potential confounds; employ validated measures of coping strategies, distress, and well-being; and undertake replication studies. This will assist comparison of findings across studies and maximise the generalizability and utility of results.

The research study has informed several avenues for future research. The use of coping strategies by ICs may be influenced by their appraisals of the caregiving situation, as suggested by the TSC (Lazarus, 1994), or by their beliefs about BPD, as suggested by the self-regulation model of illness (Leventhal et al., 1997). This hypothesis is supported by existing qualitative research. Future research should investigate the relationship between appraisals, coping use and outcomes, in addition to exploring how ICs knowledge of BPD and perceived control of caregiving situations influences coping strategies and IC outcomes. Such research would provide additional information to inform intervention design.

Future research designs should allow clinical verification of the BPD diagnosis and consider how symptoms and behaviours associated with BPD influence IC outcomes in line with the stress process model of caregiving (Pearlin, 1999). Finally, the findings of the current research should be verified in a community sample of ICs of PwBPD who may be more sociodemographically representative of the caregiving population, preferably employing a control group.

References

- Acres, K., Loughhead, M., & Procter, N. (2019). Carer perspectives of people diagnosed with borderline personality disorder: A scoping review of emergency care responses. *Australasian Emergency Care*, 22(1), 34-41. <https://doi.org/10.1016/j.auec.2018.12.001>
- Adams, J., Hillier-Brown, F. C., Moore, H. J., Lake, A. A., Araujo-Soares, V., White, M., & Summerbell, C. (2016). Searching and synthesising 'grey literature' and 'grey information' in public health: critical reflections on three case studies. *Systematic Reviews*, 5(1), 164. <https://doi.org/10.1186/s13643-016-0337-y>
- American Psychiatric Association [APA]. (2013). *Diagnostic and statistical manual of mental disorders: DSM 5* (5 ed.). American Psychiatric Publishing. <https://doi.org/10.1176/appi.books.9780890425596>
- American Psychological Association. (2020). *American Psychological Association (APA) Dictionary of psychology: Psychological distress*. Retrieved 12/11/2020 from <https://dictionary.apa.org/psychological-distress>.
- Anderson, M. I., Parmenter, T. R., & Mok, M. (2002). The relationship between neurobehavioural problems of severe traumatic brain injury (TBI), family functioning and the psychological well-being of the spouse/caregiver: path model analysis. *Brain Injury*, 16(9), 743-757. <https://doi.org/10.1080/02699050210128906>
- Anderson, M. I., Simpson, G. K., Daher, M., & Matheson, L. (2015). The relationship between coping and psychological adjustment in family caregivers of individuals with traumatic brain injury: A systematic review. In Y. P. Conley (Ed.), *Annual Review of Nursing Research, Vol. 33, 2015: Traumatic brain injury*. (pp. 219-247). Springer Publishing Company. <https://ucc.idm.oclc.org/login?URL=http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2015-49596-007&site=ehost-live>
- Andrews, G., & Slade, T. (2001). Interpreting scores on the Kessler Psychological Distress Scale (K10) [<https://doi.org/10.1111/j.1467-842X.2001.tb00310.x>]. *Australian and New Zealand Journal*

of Public Health, 25(6), 494-497. <https://doi.org/https://doi.org/10.1111/j.1467-842X.2001.tb00310.x>

Arrindell, W. A., & Ettema, J. H. M. (2003). *SCL-90. Handleiding bij een multidimensionele psychopathologie-indicator*. Swets & Zeitlinger.

Australian Bureau of Statistics. (2012). *Information paper: Use of the Kessler Psychological Distress Scale in ABS Health Surveys, Australia 2007-08*. . Retrieved 23 January 2021 from <https://www.abs.gov.au/ausstats/abs@.nsf/mf/4817.0.55.001>

Bailey, R. C., & Grenyer, B. F. S. (2014). Supporting a person with personality disorder: A study of carer burden and well-being. *Journal of Personality Disorders, 28*(6), 796-809. https://doi.org/10.1521/pedi_2014_28_136

Bailey, R. C., & Grenyer, B. F. S. (2015). The relationship between expressed emotion and wellbeing for families and carers of a relative with borderline personality disorder. *Personality and Mental Health, 9*(1), 21-32.

Baillie, A. J. (2005). Predictive gender and education bias in Kessler's Psychological Distress Scale (K10). *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services, 40*(9), 743-748. <https://doi.org/10.1007/s00127-005-0935-9>

Barr, K. R., Jewell, M., Townsend, M. L., & Grenyer, B. F. S. (2020). Living with personality disorder and seeking mental health treatment: patients and family members reflect on their experiences. *Borderline personality disorder and emotion dysregulation, 7*(1), 21. <https://doi.org/10.1186/s40479-020-00136-4>

Bateman, A., Campbell, C., Luyten, P., & Fonagy, P. (2018). A mentalization-based approach to common factors in the treatment of borderline personality disorder. *Current Opinion in Psychology, 21*, 44-49. <https://doi.org/https://doi.org/10.1016/j.copsyc.2017.09.005>

Bateman, A., & Fonagy, P. (2016). *Mentalization-Based Treatment for Personality Disorders: A practical guide*. Oxford University Press.

<https://doi.org/10.1093/med:psych/9780199680375.001.0001>

Bateman, A., & Fonagy, P. (2019). A randomized controlled trial of a mentalization-based intervention (MBT-FACTS) for families of people with borderline personality disorder. *Personality Disorders: Theory, Research, and Treatment*, 10(1), 70-79.

<https://doi.org/10.1037/per0000298>

Battle, C. L., Shea, M. T., Johnson, D. M., Yen, S., Zlotnick, C., Zanarini, M. C., Sanislow, C. A., Skodol, A. E., Gunderson, J. G., Grilo, C. M., McGlashan, T. H., & Morey, L. C. (2004). Childhood maltreatment associated with adult personality disorders: findings from the Collaborative Longitudinal Personality Disorders Study. *Journal of Personality Disorders*, 18(2), 193-211.

<https://doi.org/10.1521/pedi.18.2.193.32777>

Beck, A. T., Ward, C. H., Mendelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. *Arch Gen Psychiatry*, 4, 561-571.

<https://doi.org/10.1001/archpsyc.1961.01710120031004>

Bender, D. S., Dolan, R. T., Skodol, A. E., Sanislow, C. A., Dyck, I. R., McGlashan, T. H., Shea, M. T., Zanarini, M. C., Oldham, J. M., & Gunderson, J. G. (2001). Treatment utilization by patients with personality disorders. *The American journal of psychiatry*, 158(2), 295-302.

<https://doi.org/10.1176/appi.ajp.158.2.295>

Betts, J., Pearce, J., McKechnie, B., McCutcheon, L., Cotton, S. M., Jovev, M., Rayner, V., Seigerman, M., Hulbert, C., McNab, C., & Chanen, A. M. (2018). A psychoeducational group intervention for family and friends of youth with borderline personality disorder features: protocol for a randomised controlled trial. *Borderline Personality Disorder And Emotion Dysregulation*, 5, 13-13. <https://doi.org/10.1186/s40479-018-0090-z>

- Bhaskaran, K., & Smeeth, L. (2014). What is the difference between missing completely at random and missing at random? *International Journal Of Epidemiology*, 43(4), 1336-1339.
<https://doi.org/10.1093/ije/dyu080>
- Bidwell, J. T., Lyons, K. S., & Lee, C. S. (2017). Caregiver well-being and patient outcomes in heart failure: A meta-analysis. *Journal of Cardiovascular Nursing*, 32(4), 372-382.
<https://doi.org/10.1097/JCN.0000000000000350>
- Boland, A., Cherry, M. G., & Dickson, R. (Eds.). (2017). *Doing a systematic review: a student's guide* (2nd Edition ed.). SAGE.
- Boynton, P. M., & Greenhalgh, T. (2004). Hands-on guide to questionnaire research: Selecting, designing, and developing your questionnaire. *BMJ: British Medical Journal*, 328(7451), 1312-1315. <https://doi.org/10.1136/bmj.328.7451.1312>
- Briggs, S. R., & Cheek, J. M. (1986). The role of factor analysis in the development and evaluation of personality scales. *Journal of Personality*, 54(1), 106-148. <https://doi.org/10.1111/j.1467-6494.1986.tb00391.x> (Methodological developments in personality research)
- Buscemi, N., Hartling, L., Vandermeer, B., Tjosvold, L., & Klassen, T. P. (2006). Single data extraction generated more errors than double data extraction in systematic reviews. *J Clin Epidemiol*, 59(7), 697-703. <https://doi.org/10.1016/j.jclinepi.2005.11.010>
- Buteau, E., Dawkins, K., & Hoffman, P. (2008). In their own words: Improving services and hopefulness for families dealing with BPD. *Social Work in Mental Health*, 6(1-2), 203-214.
https://doi.org/10.1300/J200v06n01_16
- Bytes, J. E., Robinson, I., Banks, E., Gibson, R., Leigh, L., Rodgers, B., Curryer, C., & Jorm, L. (2014). Psychological distress and comorbid physical conditions: disease or disability? *Depression & Anxiety* (1091-4269), 31(6), 524-532. <https://doi.org/10.1002/da.22162>
- Cameron, A. A., Calderwood, K., & McMurphy, S. (2018). A systematic literature review of the etiology of borderline personality disorder from an ecological systems perspective. *Social Work in Mental Health*. <https://doi.org/10.1080/15332985.2018.1555104>

- Camfield, L., & Skevington, S. M. (2008). On subjective well-being and quality of life. *Journal of Health Psychology, 13*(6), 764-775. <https://doi.org/10.1177/1359105308093860>
- Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine, 4*(1), 92-100.
https://doi.org/10.1207/s15327558ijbm0401_6
- Carver, C. S. (2021). *Brief COPE*. Retrieved 10 April 2021 from
<https://local.psy.miami.edu/faculty/ccarver/sclBrCOPE.phtml>
- Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology, 56*(2), 267-283.
<https://doi.org/10.1037/0022-3514.56.2.267>
- Central Statistics Office [CSO]. (2017). *Census of Population 2016 - Profile 9 Health, Disability and Carers*. <https://www.cso.ie/en/releasesandpublications/ep/p-cp9hdc/p8hdc/>
- Chadda, R. K., Singh, T. B., & Ganguly, K. K. (2007). Caregiver burden and coping: A prospective study of relationship between burden and coping in caregivers of patients with schizophrenia and bipolar affective disorder. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services, 42*(11), 923-930. <https://doi.org/10.1007/s00127-007-0242-8>
- Chambers, S. K., Zajdlewicz, L., Youlden, D. R., Holland, J. C., & Dunn, J. (2014). The validity of the distress thermometer in prostate cancer populations. *Psycho-Oncology, 23*(2), 195-203.
<https://doi.org/https://doi.org/10.1002/pon.3391>
- Chen, F. F., Jing, Y., Hayes, A., & Lee, J. M. (2013). Two concepts or two approaches? A bifactor analysis of psychological and subjective well-being. *Journal of Happiness Studies: An Interdisciplinary Forum on Subjective Well-Being, 14*(3), 1033-1068.
<https://doi.org/10.1007/s10902-012-9367-x>
- Chen, X., Mao, Y., Kong, L., Li, G., Xin, M., Lou, F., & Li, P. (2016). Resilience moderates the association between stigma and psychological distress among family caregivers of patients

- with schizophrenia. *Personality and Individual Differences*, 96, 78-82.
<https://doi.org/https://doi.org/10.1016/j.paid.2016.02.062>
- Clarke, D. M., & Currie, K. C. (2009). Depression, anxiety and their relationship with chronic diseases: a review of the epidemiology, risk and treatment evidence. *Med J Aust*, 190(S7), S54-60.
<https://doi.org/10.5694/j.1326-5377.2009.tb02471.x>
- Clarkin, J. F. P., Lenzenweger, M. F. P., Yeomans, F. M. D., Levy, K. N. P., & Kernberg, O. F. M. D. (2007). An object relations model of borderline pathology. *Journal of Personality Disorders*, 21(5), 474-499. <https://doi.org/10.1521/pedi.2007.21.5.474>
- Coid, J., Yang, M., Tyrer, P., Roberts, A., & Ullrich, S. (2006). Prevalence and correlates of personality disorder in Great Britain. *The British Journal of Psychiatry*, 188(5), 423-431.
<https://doi.org/10.1192/bjp.188.5.423>
- Coomber, K., & King, R. M. (2012). Coping strategies and social support as predictors and mediators of eating disorder carer burden and psychological distress. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*, 47(5), 789-796. <https://doi.org/10.1007/s00127-011-0384-6>
- Coomber, K., & King, R. M. (2013). A longitudinal examination of burden and psychological distress in carers of people with an eating disorder. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*, 48(1), 163-171. <https://doi.org/10.1007/s00127-012-0524-7>
- Crawford, T. N., Cohen, P., Johnson, J. G., Kasen, S., First, M. B., Gordon, K., & Brook, J. S. (2005). Self-reported Personality disorder in the children in the community sample: Convergent and prospective validity in late adolescence and adulthood. *Journal of Personality Disorders*, 19(1), 30-52. <https://doi.org/10.1521/pedi.19.1.30.62179>
- Cuijpers, P., Smits, N., Donker, T., ten Have, M., & de Graaf, R. (2009). Screening for mood and anxiety disorders with the five-item, the three-item, and the two-item Mental Health

Inventory. *Psychiatry Research*, 168(3), 250-255.

<https://doi.org/https://doi.org/10.1016/j.psychres.2008.05.012>

de Aquino Ferreira, L. F., Queiroz Pereira, F. H., Neri Benevides, A. M. L., & Aguiar Melo, M. C. (2018).

Borderline personality disorder and sexual abuse: A systematic review. *Psychiatry Res*, 262, 70-77. <https://doi.org/10.1016/j.psychres.2018.01.043>

De La Rie, S. M., Van Furth, E. F., De Koning, A., Noordenbos, G., & Donker, M. C. H. (2005). The

Quality of life of family caregivers of eating disorder patients. *Eating Disorders: The Journal of Treatment & Prevention*, 13(4), 345-351. <https://doi.org/10.1080/10640260591005236>

Deeks, J. J., Dinnes, J., D'Amico, R., Sowden, A. J., Sakarovich, C., Song, F., Petticrew, M., & Altman,

D. G. (2003). Evaluating non-randomised intervention studies. *Health Technol Assess*, 7(27), iii-x, 1-173. <https://doi.org/10.3310/hta7270>

del-Pino-Casado, R., Frías-Osuna, A., Palomino-Moral, P. A., & Pancorbo-Hidalgo, P. L. (2011). Coping

and subjective burden in caregivers of older relatives: a quantitative systematic review.

Journal of Advanced Nursing, 67(11), 2311-2322. <https://doi.org/10.1111/j.1365-2648.2011.05725.x>

Department for Work and Pensions. (2020). *Family Resources Survey, United Kingdom, 2018/19*

Background Note and Methodology. Retrieved from

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/874514/family-resources-survey-2018-19-background-note-methodology.pdf

Derogatis, L. R., Lipman, R. S., Rickels, K., Uhlenhuth, E. H., & Covi, L. (1974). The Hopkins Symptom

Checklist (HSCL): a self-report symptom inventory. *Behav Sci*, 19(1), 1-15.

<https://doi.org/10.1002/bs.3830190102>

Derogatis, L. R., & Melisaratos, N. (1983). The Brief Symptom Inventory: an introductory report.

Psychological Medicine, 13(3), 595-605. <https://doi.org/10.1017/S0033291700048017>

Diener, E., Lucas, R. E., & Oishi, S. (2018). Advances and open questions in the science of subjective

well-being. *Collabra: Psychology*, 4(1). <https://doi.org/10.1525/collabra.115>

- Downes, M. J., Brennan, M. L., Williams, H. C., & Dean, R. S. (2016). Development of a critical appraisal tool to assess the quality of cross-sectional studies (AXIS). *BMJ Open*, 6(12), e011458. <https://doi.org/10.1136/bmjopen-2016-011458>
- Drapeau, A., Marchand, A., & Beaulieu-Prévost, D. (2012). Epidemiology of psychological distress. In *Mental illnesses - Understanding, prediction and control*. <https://doi.org/10.5772/30872>
- Dunne, E., & Rogers, B. (2013). "It's us that have to deal with it seven days a week": carers and borderline personality disorder. *Community Mental Health Journal*, 49(6), 643-648. <https://doi.org/10.1007/s10597-012-9556-4>
- Eckardt, J. P. (2020). Caregivers of people with severe mental illness in the COVID-19 pandemic. *The Lancet Psychiatry*, 7(8), e53-e53. [https://doi.org/10.1016/S2215-0366\(20\)30252-2](https://doi.org/10.1016/S2215-0366(20)30252-2)
- Eisinga, R., te Grotenhuis, M., & Pelzer, B. (2013). The reliability of a two-item scale: Pearson, Cronbach, or Spearman-Brown? *International Journal of Public Health*, 58(4), 637-642. <https://doi.org/10.1007/s00038-012-0416-3>
- Ekdahl, S., Idvall, E., Samuelsson, M., & Perseus, K.-I. (2011). A life tiptoeing: being a significant other to persons with borderline personality disorder. *Archives of Psychiatric Nursing*, 25(6), e69-76. <https://doi.org/10.1016/j.apnu.2011.06.005>
- Ellison, W. D., Rosenstein, L. K., Morgan, T. A., & Zimmerman, M. (2018). Community and clinical epidemiology of borderline personality disorder. *Psychiatric Clinics of North America*, 41(4), 561-573. <https://doi.org/10.1016/j.psc.2018.07.008>
- Elo, A.-L., Leppänen, A., & Jahkola, A. (2003). Validity of a single-item measure of stress symptoms. *Scandinavian Journal of Work, Environment & Health*, 29(6), 444-451. <https://doi.org/10.5271/sjweh.752>
- Endler, N. S., & Parker, J. D. A. (1994). Assessment of multidimensional coping: Task, emotion, and avoidance strategies. *Psychological Assessment*, 6(1), 50-60. <https://doi-org.ucc.idm.oclc.org/10.1037/1040-3590.6.1.50>

Eurofound. (2016). *European Quality of Life Survey*. Retrieved 15/04/2021 from

<https://www.eurofound.europa.eu/data/european-quality-of-life-survey>

Fernández-Felipe, I., Guillén, V., Marco, H., Díaz-García, A., Botella, C., Jorquera, M., Baños, R., &

García-Palacios, A. (2020). Efficacy of "Family Connections", a program for relatives of people with borderline personality disorder, in the Spanish population: study protocol for a randomized controlled trial. *BMC psychiatry*, 20(1), 302. <https://doi.org/10.1186/s12888-020-02708-8>

Field, A. (2018). *Discovering Statistics Using IBM SPSS Statistics* (4th ed.). Sage Publications Ltd.

Fitzpatrick, S., Wagner, A. C., & Monson, C. M. (2019). Optimizing borderline personality disorder treatment by incorporating significant others: A review and synthesis. *Personality Disorders: Theory, Research, and Treatment*, 10(4), 297-308. <https://doi.org/10.1037/per0000328>

Flynn, D., Kells, M., Joyce, M., Corcoran, P., Herley, S., Suarez, C., Cotter, P., Hurley, J., Weihrauch, M., & Groeger, J. (2017). Family Connections versus optimised treatment-as-usual for family members of individuals with borderline personality disorder: non-randomised controlled study. *Borderline Personality Disorder And Emotion Dysregulation*, 4, 18-18. <https://doi.org/10.1186/s40479-017-0069-1>

Folkman, S., & Moskowitz, J. T. (2004). Coping: Pitfalls and promise. *Annual Review of Psychology*, 55, 745-774. <https://doi.org/10.1146/annurev.psych.55.090902.141456>

Fonagy, P., & Bateman, A. W. (2007). Mentalizing and borderline personality disorder. *Journal of Mental Health*, 16(1), 83-101. <https://doi.org/10.1080/09638230601182045> (Developing new treatments of personality disorder)

Fortune, D. G., Smith, J. V., & Garvey, K. (2005). Perceptions of psychosis, coping, appraisals, and psychological distress in the relatives of patients with schizophrenia: An exploration using self-regulation theory. *British Journal of Clinical Psychology*, 44(3), 319-331. <https://doi.org/10.1348/014466505X29198>

- Fredman, L., Cauley, J. A., Hochberg, M., Ensrud, K. E., & Doros, G. (2010). Mortality associated with caregiving, general stress, and caregiving-related stress in elderly women: Results of Caregiver-Study of Osteoporotic Fractures. *Journal of the American Geriatrics Society*, 58(5), 937-943. <https://doi.org/10.1111/j.1532-5415.2010.02808.x>
- Fruzzetti, A. E., Shenk, C., & Hoffman, P. D. (2005). Family interaction and the development of borderline personality disorder: A transactional model. *Development and Psychopathology*, 17(4), 1007-1030. <https://doi.org/10.1017/S0954579405050479>
- Gibbons, J. S., Horn, S. H., Powell, J. M., & Gibbons, J. L. (1984). Schizophrenic patients and their families: A survey in a psychiatric service based on a DGH unit. *The British Journal of Psychiatry*, 144, 70-77. <https://doi.org/10.1192/bjp.144.1.70>
- Giffin, J. (2008). Family experience of borderline personality disorder. *ANZJFT Australian and New Zealand Journal of Family Therapy*, 29(3), 133-138. <https://doi.org/10.1375/anft.29.3.133>
- Given, B., Wyatt, G., Given, C., Sherwood, P., Gift, A., DeVoss, D., & Rahbar, M. (2004). Burden and depression among caregivers of patients with cancer at the end of life. *Oncology Nursing Forum*, 31(6), 1105-1117. <https://doi.org/10.1188/04.ONF.1105-1117>
- Goldberg, D. (1972). *The detection of psychiatric illness by questionnaire*. Oxford University Press.
- Goodman, M., Patil, U., Triebwasser, J., Hoffman, P., Weinstein, Z. A., & New, A. (2011). Parental burden associated with borderline personality disorder in female offspring. *Journal of Personality Disorders*, 25(1), 59-74. <https://doi.org/10.1521/pedi.2011.25.1.59>
- Government of Ireland. (2006). A vision for change: report of the expert group on mental health policy. In.
- Green, S. B. (1991). How many subjects does it take to do a regression analysis. *Multivariate behavioral research*, 26(3), 499-510. https://doi.org/10.1207/s15327906mbr2603_7
- Greenaway, K. H., Louis, W. R., Parker, S. L., Kalokerinos, E. K., Smith, J. R., & Terry, D. J. (2014). Chapter 12 Measures of coping for psychological well-being. In G. J. Boyle, D. H. Saklofske, & G. Matthews (Eds.), *Measures of personality and social psychological constructs*. Elsevier

Science & Technology. <http://ebookcentral.proquest.com/lib/uccie-ebooks/detail.action?docID=1781027>

- Grenyer, B. F. S., Bailey, R. C., Lewis, K. L., Matthias, M., Garretty, T., & Bickerton, A. (2019). A randomized controlled trial of group psychoeducation for carers of persons with borderline personality disorder. *Journal of Personality Disorders*, 33(2), 214-228.
https://doi.org/10.1521/pedi_2018_32_340
- Guillén, V., Díaz-García, A., Mira, A., García-Palacios, A., Escrivá-Martínez, T., Baños, R., & Botella, C. (2020). Interventions for family members and carers of patients with borderline personality disorder: A systematic review. *Family Process*. <https://doi.org/10.1111/famp.12537>
- Gunderson, J. G., Berkowitz, C., & Ruiz-Sancho, A. (1997). Families of borderline patients: a psychoeducational approach. *Bull Menninger Clin*, 61(4), 446-457.
- Hanzawa, S., Bae, J.-K., Tanaka, H., Bae, Y. J., Tanaka, G., Inadomi, H., Nakane, Y., & Ohta, Y. (2010). Caregiver burden and coping strategies for patients with schizophrenia: Comparison between Japan and Korea. *Psychiatry and Clinical Neurosciences*, 64(4), 377-386.
<https://doi.org/10.1111/j.1440-1819.2010.02104.x>
- Haug, M. R. (1994). Elderly patients, caregivers, and physicians: Theory and research on health care triads. *Journal of Health and Social Behavior*, 35(1), 1-12. <https://doi.org/10.2307/2137331>
- Hawken, T., Turner-Cobb, J., & Barnett, J. (2018). Coping and adjustment in caregivers: A systematic review. *Health Psychology Open*, 5(2), 2055102918810659.
<https://doi.org/10.1177/2055102918810659>
- Herley, S. M. (2015). *Experiences of the 'Family Connections' Programme: A group intervention for family members of individuals with borderline personality disorder*. University of Limerick. Limerick.
- Herman, J. L., Perry, J. C., & van der Kolk, B. A. (1989). Childhood trauma in borderline personality disorder. *Am J Psychiatry*, 146(4), 490-495. <https://doi.org/10.1176/ajp.146.4.490>

Higgins, J. P. T., & Green, S. (2011). *Cochrane Handbook for Systematic Reviews of Interventions Version 5.0 [Updated March 2011]*. The Cochrane Collaboration.

<https://training.cochrane.org/handbook/archive/v5.1/>

Hoffman, P. D., Buteau, E., Hooley, J. M., Fruzzetti, A. E., & Bruce, M. L. (2003). Family members' knowledge about borderline personality disorder: Correspondence with their levels of depression, burden, distress, and expressed emotion. *Family Process*, 42(4), 469-478.
<https://doi.org/10.1111/j.1545-5300.2003.00469.x>

Hoffman, P. D., Fruzzetti, A. E., & Buteau, E. (2007). Understanding and engaging families: An education, skills and support program for relatives impacted by borderline personality disorder. *Journal of Mental Health*, 16(1), 69-82.
<https://doi.org/10.1080/09638230601182052> (Developing new treatments of personality disorder)

Hoffman, P. D., Fruzzetti, A. E., Buteau, E., Neiditch, E. R., Penney, D., Bruce, M. L., Hellman, F., & Struening, E. (2005). Family Connections: A Program for relatives of persons with borderline personality disorder. *Family Process*, 44(2), 217-225. <https://doi.org/10.1111/j.1545-5300.2005.00055.x>

Hooley, J. M., & Hoffman, P. D. (1999). Expressed emotion and clinical outcome in borderline personality disorder. *The American Journal of Psychiatry*, 156(10), 1557-1562.
<https://doi.org/10.1176/ajp.156.10.1557>

Hsiao, C.-Y., Lu, H.-L., & Tsai, Y.-F. (2020). Caregiver burden and health-related quality of life among primary family caregivers of individuals with schizophrenia: A cross-sectional study. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*. <https://doi.org/10.1007/s11136-020-02518-1>

Hughes, R. A., Heron, J., Sterne, J. A. C., & Tilling, K. (2019). Accounting for missing data in statistical analyses: multiple imputation is not always the answer. *International journal of epidemiology*, 48(4), 1294-1304. <https://doi.org/10.1093/ije/dyz032>

- Infurna, M. R., Brunner, R., Holz, B., Parzer, P., Giannone, F., Reichl, C., Fischer, G., Resch, F., & Kaess, M. (2016). The specific role of childhood abuse, parental bonding, and family functioning in female adolescents with borderline personality disorder. *Journal of Personality Disorders*, 30(2), 177-192. https://doi.org/10.1521/pedi_2015_29_186
- Jakobsen, J. C., Gluud, C., Wetterslev, J., & Winkel, P. (2017). When and how should multiple imputation be used for handling missing data in randomised clinical trials – a practical guide with flowcharts. *BMC Medical Research Methodology*, 17(1), 162. <https://doi.org/10.1186/s12874-017-0442-1>
- Jansen, J. E., Gleeson, J., & Cotton, S. (2015). Towards a better understanding of caregiver distress in early psychosis: A systematic review of the psychological factors involved. *Clinical Psychology Review*, 35, 56-66. <https://doi.org/10.1016/j.cpr.2014.12.002>
- Jansen, J. E., Haahr, U. H., Harder, S., Trauelsen, A. M., Lyse, H.-G., Pedersen, M. B., & Simonsen, E. (2015). Caregiver distress in first-episode psychosis: The role of subjective appraisal, over-involvement and symptomatology. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*, 50(3), 371-378. <https://doi.org/10.1007/s00127-014-0935-8>
- Jarde, A., Losilla, J.-M., & Vives, J. (2012). Methodological quality assessment tools of non-experimental studies: A systematic review. *Anales de Psicología*, 28(2), 617-628. <https://ucc.idm.oclc.org/login?URL=http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2012-10073-034&site=ehost-live>
- Jørgensen, M. S., Storebø, O. J., Poulsen, S., & Simonsen, E. (2020). Burden and treatment satisfaction among caregivers of adolescents with borderline personality disorder. *Family Process*. <https://doi.org/10.1111/famp.12593>
- Karvounides, D., Simpson, P. M., Hobart Davies, W., Khan, K. A., Weisman, S. J., & Hainsworth, K. R. (2016). Three studies supporting the initial validation of the stress numerical rating scale-11

(Stress NRS-11): A single item measure of momentary stress for adolescents and adults.

Pediatric Dimensions, 1, 105-109.

Kate, N., Grover, S., Kulhara, P., & Nehra, R. (2013). Relationship of caregiver burden with coping strategies, social support, psychological morbidity, and quality of life in the caregivers of schizophrenia. *Asian journal of psychiatry*, 6(5), 380-388.

<https://doi.org/10.1016/j.ajp.2013.03.014>

Kate, N., Grover, S., Kulhara, P., & Nehra, R. (2014). Relationship of quality of life with coping and burden in primary caregivers of patients with schizophrenia. *International Journal of Social Psychiatry*, 60(2), 107-116. <https://doi.org/10.1177/0020764012467598>

Kato, T. (2015). Frequently used coping scales: A meta-analysis. *Stress Health*, 31(4), 315-323.

<https://doi.org/10.1002/smi.2557>

Kay, M. L., Poggenpoel, M., Myburgh, C. P., & Downing, C. (2018). Experiences of family members who have a relative diagnosed with borderline personality disorder. *Curationis*, 41(1), e1-e9.

<https://doi.org/10.4102/curationis.v41i1.1892>

Kessler, R. C., Andrews, G., Colpe, L. J., Hiripi, E., Mroczek, D. K., Normand, S. L. T., Walters, E. E., & Zaslavsky, A. M. (2002). Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychological Medicine*, 32(6), 959-976.

<https://doi.org/10.1017/s0033291702006074>

Kessler, R. C., Barker, P. R., Colpe, L. J., Epstein, J. F., Gfroerer, J. C., Hiripi, E., Howes, M. J., Normand, S.-L. T., Manderscheid, R. W., Walters, E. E., & Zaslavsky, A. M. (2003). Screening for serious mental illness in the general population. *Archives of General Psychiatry*, 60(2), 184-189.

<https://doi.org/10.1001/archpsyc.60.2.184>

Kirtley, J., Chiochi, J., Cole, J., & Sampson, M. (2019). Stigma, emotion appraisal, and the family environment as predictors of carer burden for relatives of individuals who meet the diagnostic criteria for borderline personality disorder. *Journal of Personality Disorders*, 33(4), 497-514. https://doi.org/10.1521/pedi_2018_32_355

- Korda, R. J., Paige, E., Yiengprugsawan, V., Latz, I., & Friel, S. (2014). Income-related inequalities in chronic conditions, physical functioning and psychological distress among older people in Australia: cross-sectional findings from the 45 and up study. *BMC Public Health*, 14(1), 741-750. <https://doi.org/10.1186/1471-2458-14-741>
- Kring, A. M., Sheri, L. J., Davison, G. C., & Neale, J. M. (2010). *Abnormal Psychology* (11th ed.). John Wiley & Sons Pte Ltd.
- Lam, P. C. W., Ng, P., Pan, J., & Young, D. K. W. (2015). Ways of coping of Chinese caregivers for family members with schizophrenia in two metropolitan cities: Guangzhou and Hong Kong, China. *International Journal of Social Psychiatry*, 61(6), 591-599. <https://doi.org/10.1177/0020764014565797>
- Lamborn, P., & Cramer, K. M. (2020). Factors associated with distress in caregivers of people with personality disorders. *Community Mental Health Journal*. <https://doi-org.ucc.idm.oclc.org/10.1007/s10597-020-00640-5>
- Lawn, S., & McMahon, J. (2015). Experiences of family carers of people diagnosed with borderline personality disorder. *Journal of Psychiatric and Mental Health Nursing*, 22(4), 234-243. <https://doi.org/10.1111/jpm.12193>
- Lazarus, A. A. (1994). The illusion of the therapist's power and the patient's fragility: My rejoinder. *Ethics & Behavior*, 4(3), 299-306. https://doi.org/10.1207/s15327019eb0403_17
- Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal, and Coping*. Springer Publishing Company, Inc.
- Lee, J., & Paek, I. (2014). In search of the optimal number of response categories in a rating scale. *Journal of Psychoeducational Assessment*, 32(7), 663-673. <https://doi.org/10.1177/0734282914522200>
- Lee, S. A. (2020). Coronavirus Anxiety Scale: A brief mental health screener for COVID-19 related anxiety. *Death Studies*, 44(7), 393-401. <https://doi.org/10.1080/07481187.2020.1748481>

- Lefebvre, C., Glanville, J., Briscoe, S., Littlewood, A., Marshall, C., Metzendorf, M.-I., Noel-Storr, A., Rader, T., Shokraneh, F., Thomas, J., & Wieland, L. (2020). Chapter 4: Searching for and selecting studies. In H. JPT, T. J, C. J, C. M, L. T, P. MJ, & W. VA (Eds.), *Cochrane Handbook for Systematic Reviews of Interventions version 6.1*. Cochrane.
www.training.cochrane.org/handbook
- Lenzenweger, M. F., Lane, M. C., Loranger, A. W., & Kessler, R. C. (2007). DSM-IV personality disorders in the National Comorbidity Survey Replication. *Biological psychiatry*, 62(6), 553-564. <https://doi.org/10.1016/j.biopsych.2006.09.019>
- Lerner, D., Chang, H., Rogers, W. H., Benson, C., Lyson, M. C., & Dixon, L. B. (2018). Psychological distress among caregivers of individuals with a diagnosis of schizophrenia or schizoaffective disorder. *Psychiatric Services*, 69(2), 169-178. <https://doi.org/10.1176/appi.ps.201600422>
- Leventhal, H., Benyamini, Y., Brownlee, S., Diefenbach, M., Leventhal, E. A., Patrick-Miller, L., & Robitaille, C. (1997). Illness representations: Theoretical foundations. In J. A. Weinman (Ed.), *Perceptions of health and illness: Current research and applications*. (pp. 19-45). Harwood Academic Publishers.
<https://ucc.idm.oclc.org/login?URL=http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=1997-36219-001&site=ehost-live>
- Liljedahl, S. I., Kleindienst, N., Wångby-Lundh, M., Lundh, L. G., Daukantaitė, D., Fruzzetti, A. E., & Westling, S. (2019). Family Connections in different settings and intensities for underserved and geographically isolated families: a non-randomised comparison study. *Borderline personality disorder and emotion dysregulation*, 6, 14. <https://doi.org/10.1186/s40479-019-0111-6>
- Lin, E., Durbin, J., Guerriere, D., Volpe, T., Selick, A., Kennedy, J., Ungar, W. J., & Lero, D. S. (2018). Assessing care-giving demands, resources and costs of family/friend caregivers for persons with mental health disorders: A scoping review. *Health & Social Care in the Community*, 26(5), 613-634. <https://doi.org/10.1111/hsc.12546>

- Linehan, M. M. (1993). *Cognitive-behavioral treatment of borderline personality disorder*. Guilford Press. <http://search.ebscohost.com/login.aspx?direct=true&db=psych&AN=1993-97864-000&site=ehost-live>
- Linton, M. J., Dieppe, P., & Medina-Lara, A. (2016). Review of 99 self-report measures for assessing well-being in adults: exploring dimensions of well-being and developments over time. *BMJ Open*, 6(7), e010641. <https://doi.org/10.1136/bmjopen-2015-010641>
- Liu, M., & Wronski, L. (2017). Examining completion rates in web surveys via over 25,000 real-world surveys. *Social Science Computer Review*, 36(1), 116-124. <https://doi.org/10.1177/0894439317695581>
- Lozano, L. M., García-Cueto, E., & Muñiz, J. (2008). Effect of the number of response categories on the reliability and validity of rating scales. *Methodology: European Journal of Research Methods for the Behavioral and Social Sciences*, 4(2), 73-79. <https://doi.org/10.1027/1614-2241.4.2.73>
- Ma, L.-L., Wang, Y.-Y., Yang, Z.-H., Huang, D., Weng, H., & Zeng, X.-T. (2020). Methodological quality (risk of bias) assessment tools for primary and secondary medical studies: what are they and which is better? *Military Medical Research*, 7(1), 7. <https://doi.org/10.1186/s40779-020-00238-8>
- Maguire, R., Hanly, P., & Maguire, P. (2019). Beyond care burden: Associations between positive psychological appraisals and well-being among informal caregivers in europe. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*. <https://doi.org/10.1007/s11136-019-02122-y>
- Martens, L., & Addington, J. (2001). The psychological well-being of family members of individuals with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*, 36(3), 128-133. <https://doi.org/10.1007/s001270050301>

- Masterson, J. F., & Rinsley, D. B. (1975). The borderline syndrome: the role of the mother in the genesis and psychic structure of the borderline personality. *Int J Psychoanal*, 56(2), 163-177.
- McEvoy, P. M., Targowski, K., McGrath, D., Carter, O., Fursland, A., Fitzgerald, M., & Raykos, B. (2019). Efficacy of a brief group intervention for carers of individuals with eating disorders: A randomized control trial. *International Journal of Eating Disorders*, 52(9), 987-995.
<https://doi.org/10.1002/eat.23121>
- Meshkinyazd, A., Heydari, A., & Fayyazi Bordbar, M. (2020). Lived experiences of caregivers of patients with borderline personality disorder: a phenomenological study. *International journal of community based nursing and midwifery*, 8(2), 177-188.
<https://doi.org/10.30476/IJCBNM.2020.83358.1154>
- Miller, M. L., & Skerven, K. (2017). Family skills: A naturalistic pilot study of a family-oriented dialectical behavior therapy program. *Couple and Family Psychology: Research and Practice*, 6(2), 79-93. <https://doi.org/10.1037/cfp0000076>
- Mitchell, M. L., & Jolley, J. M. (2010). *Research Design Explained* (7th ed.). Wadsworth CENGAGE Learning.
- Mitsonis, C., Voussoura, E., Dimopoulos, N., Psarra, V., Kararizou, E., Latzouraki, E., Zervas, I., & Katsanou, M.-N. (2012). Factors associated with caregiver psychological distress in chronic schizophrenia. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*, 47(2), 331-337.
<https://doi.org/10.1007/s00127-010-0325-9>
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *BMJ*, 339, b2535.
<https://doi.org/10.1136/bmj.b2535>
- Möller-Leimkühler, A. M. (2005). Burden of relatives and predictors of burden Baseline results from the Munich 5-year-follow-up study on relatives of first hospitalized patients with

- schizophrenia or depression. *European Archives of Psychiatry and Clinical Neuroscience*, 255(4), 223-231. <https://doi.org/10.1007/s00406-004-0550-x>
- Monteiro, A. M. F., Santos, R. L., Kimura, N., Baptista, M. A. T., & Dourado, M. C. N. (2018). Coping strategies among caregivers of people with Alzheimer disease: A systematic review. *Trends in Psychiatry and Psychotherapy*, 40(3), 258-268. <https://doi.org/10.1590/2237-6089-2017-0065>
- Moos, R. H., Brennan, P. L., Fondacaro, M. R., & Moos, B. S. (1990). Approach and avoidance coping responses among older problem and nonproblem drinkers. *Psychology and Aging*, 5(1), 31-40. <https://doi.org/10.1037/0882-7974.5.1.31>
- Morris, N., Moghaddam, N., Tickle, A., & Biswas, S. (2018). The relationship between coping style and psychological distress in people with head and neck cancer: A systematic review [https://doi.org/10.1002/pon.4509]. *Psycho-Oncology*, 27(3), 734-747. <https://doi.org/https://doi.org/10.1002/pon.4509>
- Moskalewicz, A., & Oremus, M. (2020). No clear choice between Newcastle-Ottawa Scale and Appraisal Tool for Cross-Sectional Studies to assess methodological quality in cross-sectional studies of health-related quality of life and breast cancer. *J Clin Epidemiol*, 120, 94-103. <https://doi.org/10.1016/j.jclinepi.2019.12.013>
- Mucci, F., Mucci, N., & Diolaiuti, F. (2020). Lockdown and isolation: Psychological aspects of COVID-19 pandemic in the general population. *Clinical Neuropsychiatry: Journal of Treatment Evaluation*, 17(2), 63-64. <https://ucc.idm.oclc.org/login?URL=http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2020-27302-004&site=ehost-live>
- Musser, N., Zalewski, M., Stepp, S., & Lewis, J. (2018). A systematic review of negative parenting practices predicting borderline personality disorder: Are we measuring biosocial theory's 'invalidating environment'? *Clinical Psychology Review*, 65, 1-16. <https://doi.org/https://doi.org/10.1016/j.cpr.2018.06.003>

National Alliance for Caregiving & AARP. (2015). *Caregiving in the U.S. 2015 Report*.

<https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>

National Health and Medical Research Council. (2012). *Clinical Practice Guidelines for the Management of Borderline Personality Disorder*. National Health and Medical Research Council. <https://www.nhmrc.gov.au/about-us/publications/clinical-practice-guideline-borderline-personality-disorder#block-views-block-file-attachments-content-block-1>

National Health and Medical Research Council. (2013). *Caring for People with Borderline Personality Disorder: A reference Guide for Health Professionals*. National Health and Medical Research Council. <https://www.nhmrc.gov.au/about-us/publications/clinical-practice-guideline-borderline-personality-disorder#block-views-block-file-attachments-content-block-1>

National Institute for Health and Care Excellence. (2009). *Depression in adults with a chronic physical health problem: recognition and management: CG91*
<https://www.nice.org.uk/guidance/cg91/chapter/1-Guidance>

National Institute for Health Care Excellence [NICE]. (2009). Borderline personality disorder: recognition and management (CG78).
<https://www.nice.org.uk/guidance/cg78/resources/borderline-personality-disorder-recognition-and-management-pdf-975635141317>

National Institutes of Health. (2014). *Quality Assessment tool for observational and cross-sectional studies* Retrieved 24/08/2020 from <https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools>

Ntsayagae, E. I., Poggenpoel, M., & Myburgh, C. (2019). Experiences of family caregivers of persons living with mental illness: A meta-synthesis. *Curationis*, 42(1), e1-e9.
<https://doi.org/10.4102/curationis.v42i1.1900>

- Ong, H. C., Ibrahim, N., & Wahab, S. (2016). Psychological distress, perceived stigma, and coping among caregivers of patients with schizophrenia. *Psychology Research and Behavior Management, 9*. <https://doi.org/10.2147/PRBM.S112129>
- Östman, M., & Hansson, L. (2004). Appraisal of caregiving, burden and psychological distress in relatives of psychiatric inpatients. *European Psychiatry, 19*(7), 402-407.
<https://doi.org/10.1016/j.eurpsy.2004.06.030>
- Pakenham, K. I., & Bursnall, S. (2006). Relations between social support, appraisal and coping and both positive and negative outcomes for children of a parent with multiple sclerosis and comparisons with children of healthy parents. *Clinical Rehabilitation, 20*(8), 709-723.
<https://doi.org/http://dx.doi.org/10.1191/0269215506cre976oa>
- Paris, J., & Zweig-Frank, H. (2001). The 27-year follow-up of patients with borderline personality disorder. *Comprehensive Psychiatry, 42*(6), 482-487.
<https://doi.org/10.1053/comp.2001.26271>
- Park, C. L., Finkelstein-Fox, L., Russell, B. S., Fendrich, M., Hutchison, M., & Becker, J. (2021). Americans' distress early in the COVID-19 pandemic: Protective resources and coping strategies. *Psychological Trauma: Theory, Research, Practice, and Policy*.
<https://doi.org/10.1037/tra0000931>
- Parks, M., Anastasiadou, D., Sánchez, J. C., Graell, M., & Sepulveda, A. R. (2018). Experience of caregiving and coping strategies in caregivers of adolescents with an eating disorder: A comparative study. *Psychiatry Research, 260*, 241-247.
<https://doi.org/10.1016/j.psychres.2017.11.064>
- Pearce, J., Jovev, M., Hulbert, C., McKechnie, B., McCutcheon, L., Betts, J., & Chanen, A. M. (2017). Evaluation of a psychoeducational group intervention for family and friends of youth with borderline personality disorder. *Borderline Personality Disorder And Emotion Dysregulation, 4*, 5-5. <https://doi.org/10.1186/s40479-017-0056-6>

- Pearlin, L. I. (1999). The Stress Process Revisited. In C. S. Aneshensel & J. C. Phelan (Eds.), *Handbook of the Sociology of Mental Health* (pp. 395-415). Springer US. https://doi.org/10.1007/0-387-36223-1_19
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30(5), 583-594. <https://doi.org/10.1093/geront/30.5.583>
- Project Air Strategy for Personality Disorders. (2015). *Treatment Guidelines for Personality Disorders* (2nd Edition ed.). University of Wollongong, Illawarra Health and Medical Research Institute. <https://documents.uow.edu.au/content/groups/public/@web/@project-air/documents/doc/uow247241.pdf>
- Project Air Strategy for Personality Disorders. (2016). *Family, Partner and Carer Intervention Manual for Personality Disorders*. University of Wollongong, Illawarra Health and Medical Research Institute. <https://documents.uow.edu.au/content/groups/public/@web/@ihmri/documents/doc/uow212928.pdf>
- Quinn, C., & Toms, G. (2018). Influence of positive aspects of dementia caregiving on caregivers' well-being: a systematic review. *The Gerontologist*, 59(5), e584-e596. <https://doi.org/10.1093/geront/gny168>
- Rammohan, A., Rao, K., & Subbakrishna, D. K. (2002). Religious coping and psychological wellbeing in carers of relatives with schizophrenia. *Acta Psychiatrica Scandinavica*, 105(5), 356-362. <https://doi.org/10.1034/j.1600-0447.2002.1o149.x>
- Roth, A. J., Kornblith, A. B., Batel-Copel, L., Peabody, E., Scher, H. I., & Holland, J. C. (1998). Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study. *Cancer*, 82(10), 1904-1908. [https://doi.org/10.1002/\(sici\)1097-0142\(19980515\)82:10<1904::aid-cnrcr13>3.0.co;2-x](https://doi.org/10.1002/(sici)1097-0142(19980515)82:10<1904::aid-cnrcr13>3.0.co;2-x)

- Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *The Gerontologist*, 55(2), 309-319.
<https://doi.org/10.1093/geront/gnu177> (2015 White House Conference on Aging)
- Ryle, A. (2004). The contribution of cognitive analytic therapy to the treatment of borderline personality disorder. *Journal of Personality Disorders*, 18(1), 3-35.
<https://doi.org/10.1521/pedi.18.1.3.32773>
- Salvador-Carulla, L., Lucas, R., Ayuso-Mateos, J., & Miret, M. (2014). Use of the terms "Wellbeing" and "Quality of Life" in health sciences: A conceptual framework. *The European Journal of Psychiatry*, 28, 50-65. <https://doi.org/10.4321/S0213-61632014000100005>
- Sander, A. M., Maestas, K. L., Clark, A. N., & Havins, W. N. (2013). Predictors of emotional distress in family caregivers of persons with traumatic brain injury: A systematic review. *Brain Impairment*, 14(1), 113-129. <https://doi.org/10.1017/BrImp.2013.12> (State of the art review on mental health in traumatic brain injury)
- Sanderson, S., Tatt, I. D., & Higgins, J. P. (2007). Tools for assessing quality and susceptibility to bias in observational studies in epidemiology: a systematic review and annotated bibliography. *Int J Epidemiol*, 36(3), 666-676. <https://doi.org/10.1093/ije/dym018>
- Sansone, R. A., & Sansone, L. A. (2011). Gender patterns in borderline personality disorder. *Innovations in clinical neuroscience*, 8(5), 16-20.
- Saunders, J. C. (1999). Family functioning in families providing care for a family member with schizophrenia. *Issues in Mental Health Nursing*, 20(2), 95-113.
<https://doi.org/10.1080/016128499248691>
- Scheirs, J. G. M., & Bok, S. (2007). Psychological distress in caretakers or relatives of patients with borderline personality disorder. *International Journal of Social Psychiatry*, 53(3), 195-203.
<https://doi.org/10.1177/0020764006074554>

- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *JAMA: Journal of the American Medical Association*, 282(23), 2215-2219.
<https://doi.org/10.1001/jama.282.23.2215>
- Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *Am J Nurs*, 108(9 Suppl), 23-27; quiz 27. <https://doi.org/10.1097/01.NAJ.0000336406.45248.4c>
- Seigerman, M. R., Betts, J. K., Hulbert, C., McKechnie, B., Rayner, V. K., Jovev, M., Cotton, S. M., McCutcheon, L., McNab, C., Burke, E., & Chanen, A. M. (2020). A study comparing the experiences of family and friends of young people with borderline personality disorder features with family and friends of young people with other serious illnesses and general population adults. *Borderline Personality Disorder And Emotion Dysregulation*, 7(1), 17.
<https://doi.org/10.1186/s40479-020-00128-4>
- Shaughnessy, J. J., Zechmeister, E. B., & Zechmeister, J. S. (2009). *Research Methods in Psychology* (8th ed.). McGraw-Hill.
- Shiraishi, N., & Reilly, J. (2019). Positive and negative impacts of schizophrenia on family caregivers: A systematic review and qualitative meta-summary. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*, 54(3), 277-290. <https://doi.org/10.1007/s00127-018-1617-8>
- Simms, L. J., Zelazny, K., Williams, T. F., & Bernstein, L. (2019). Does the number of response options matter? Psychometric perspectives using personality questionnaire data. *Psychological Assessment*, 31(4), 557-566. <https://doi.org/10.1037/pas0000648>
- Skapinakis, P., Bellos, S., Oikonomou, A., Dimitriadis, G., Gkikas, P., Perdikari, E., & Mavreas, V. (2020). Depression and its relationship with coping strategies and illness perceptions during the COVID-19 lockdown in Greece: A cross-sectional survey of the population. *Depression Research and Treatment*, 2020. <https://doi.org/10.1155/2020/3158954>

- Skinner, E. A., Edge, K., Altman, J., & Sherwood, H. (2003). Searching for the structure of coping: A review and critique of category systems for classifying ways of coping. *Psychological Bulletin*, 129(2), 216-269. <https://doi.org/10.1037/0033-2909.129.2.216>
- Skitka, L. J., & Sargis, E. G. (2006). The internet as psychological laboratory. *Annu Rev Psychol*, 57, 529-555. <https://doi.org/10.1146/annurev.psych.57.102904.190048>
- Slade, T., Grove, R., & Burgess, P. (2011). Kessler Psychological Distress Scale: Normative data from the 2007 Australian National Survey of Mental Health and Wellbeing. *Australian and New Zealand Journal of Psychiatry*, 45(4), 308-316. <https://doi.org/10.3109/00048674.2010.543653>
- Srivastava, S., Bhatia, M. S., Sharma, V., Rajender, G., & Kumar, P. (2010). Health-related quality of life in bipolar disorder patients and their caregivers. *International Journal of Mental Health*, 39(4), 3-15. <https://doi.org/10.2753/IMH0020-7411390401>
- Stanley, S., Balakrishnan, S., & Ilangoan, S. (2017). Psychological distress, perceived burden and quality of life in caregivers of persons with schizophrenia. *J Ment Health*, 26(2), 134-141. <https://doi.org/10.1080/09638237.2016.1276537>
- Statistics Solutions. (2021). *Homoscedasticity*. Retrieved 10 April 2021 from <https://www.statisticssolutions.com/assumptions-of-multiple-linear-regression/#:~:text=Multiple%20linear%20regression%20analysis%20makes,a%20linear%20or%20curvilinear%20relationship.>
- Steele, A., Maruyama, N., & Galyunker, I. (2010). Psychiatric symptoms in caregivers of patients with bipolar disorder: A review. *Journal of Affective Disorders*, 121(1-2), 10-21. <https://doi.org/10.1016/j.jad.2009.04.020>
- Sterne, J. A. C., White, I. R., Carlin, J. B., Spratt, M., Royston, P., Kenward, M. G., Wood, A. M., & Carpenter, J. R. (2009). Multiple imputation for missing data in epidemiological and clinical research: potential and pitfalls. *BMJ*, 338, b2393. <https://doi.org/10.1136/bmj.b2393>

Suler, J. (2004). The online disinhibition effect. *Cyberpsychol Behav*, 7(3), 321-326.

<https://doi.org/10.1089/1094931041291295>

Sutherland, R., Baker, J., & Prince, S. (2019). Support, interventions and outcomes for families/carers of people with borderline personality disorder: A systematic review. *Personality and Mental Health*. <https://doi.org/10.1002/pmh.1473>

Szmukler, G. I., Burgess, P., Herrman, H., Benson, A., Colusa, S., & Bloch, S. (1996). Caring for relatives with serious mental illness: The development of the Experience of Caregiving Inventory [Article]. *Social Psychiatry and Psychiatric Epidemiology*, 31(3-4), 137-148. <https://doi.org/10.1007/BF00785760>

Teixeira, R. J., Applebaum, A. J., Bhatia, S., & Brandão, T. (2018). The impact of coping strategies of cancer caregivers on psychophysiological outcomes: An integrative review. *Psychology Research and Behavior Management*, 11. <https://doi.org/10.2147/PRBM.S164946>

ten Have, M., Verheul, R., Kaasenbrood, A., van Dorsselaer, S., Tuithof, M., Kleinjan, M., & de Graaf, R. (2016). Prevalence rates of borderline personality disorder symptoms: A study based on the Netherlands Mental Health Survey and Incidence Study-2. *BMC Psychiatry*, 16. <https://doi.org/10.1186/s12888-016-0939-x>

The Joanna Briggs Institute. (2017). *The Joanna Briggs Institute Critical Appraisal tools for use in JBI Systematic Reviews Checklist for Analytical Cross Sectional Studies* (T. J. B. Institute, Ed.) https://jbi.global/sites/default/files/2019-05/JBI_Critical_Appraisal-Checklist_for_Analytical_Cross_Sectional_Studies2017_0.pdf

Thunyadee, C., Sitthimongkol, Y., Sangon, S., Chai-Aroon, T., & Hegadoren, K. M. (2015). Predictors of depressive symptoms and physical health in caregivers of individuals with schizophrenia. *Nursing & Health Sciences*, 17(4), 412-419. <https://doi.org/10.1111/nhs.12205>

Topp, C. W., Østergaard, S. D., Søndergaard, S., & Bech, P. (2015). The WHO-5 Well-Being Index: A systematic review of the literature. *Psychotherapy and Psychosomatics*, 84(3), 167-176. <https://doi.org/10.1159/000376585>

- Torgersen, S., Kringlen, E., & Cramer, V. (2001). The prevalence of personality disorders in a community sample. *Archives of General Psychiatry*, 58(6), 590-596.
<https://doi.org/10.1001/archpsyc.58.6.590>
- Treasure, J., Murphy, T., Szumukler, T., Todd, G., Gavan, K., & Joyce, J. (2001). The experience of caregiving for severe mental illness: A comparison between anorexia nervosa and psychosis. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*, 36(7), 343-347.
<https://doi.org/10.1007/s001270170039>
- Treasure, J., & Nazar, B. (2016). Interventions for the carers of patients with eating disorders. *Current Psychiatry Reports*, 18. <https://doi.org/10.1007/s11920-015-0652-3>
- Turon, H., Carey, M., Boyes, A., Hobden, B., Dilworth, S., & Sanson-Fisher, R. (2019). Agreement between a single-item measure of anxiety and depression and the Hospital Anxiety and Depression Scale: A cross-sectional study. *PLOS ONE*, 14(1), e0210111-e0210111.
<https://doi.org/10.1371/journal.pone.0210111>
- Tweed, R. G., White, K., & Lehman, D. R. (2004). Culture, stress, and coping: Internally- and externally-targeted control strategies of European Canadians, East Asian Canadians, and Japanese. *Journal of Cross-Cultural Psychology*, 35(6), 652–668. <https://doi-org.ucc.idm.oclc.org/10.1177/0022022104270109>
- Umucu, E., & Lee, B. (2020). Examining the impact of COVID-19 on stress and coping strategies in individuals with disabilities and chronic conditions. *Rehabilitation Psychology*.
<https://doi.org/10.1037/rep0000328>
- Van Der Voort, T. Y. G., Goossens, P. J. J., & Van Der Bijl, J. J. (2007). Burden, coping and needs for support of caregivers for patients with a bipolar disorder: A systematic review. *Journal of Psychiatric and Mental Health Nursing*, 14(7), 679-687. <https://doi.org/10.1111/j.1365-2850.2007.01158.x>

- von Elm, E., Altman, D. G., Egger, M., Pocock, S. J., Gøtzsche, P. C., Vandenbroucke, J. P., & Initiative, S. (2007). Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *BMJ (Clinical research ed.)*, 335(7624), 806-808. <https://doi.org/10.1136/bmj.39335.541782.AD>
- Walsh, D. (2015). Psychiatric deinstitutionalisation in Ireland 1960–2013. *Irish Journal of Psychological Medicine*, 32(4), 347-352. <https://doi.org/10.1017/ipm.2015.20>
- Wasley, D., & Eden, S. (2018). Predicting psychological distress of informal carers of individuals with major depression or bipolar disorder [<https://doi.org/10.1111/inm.12329>]. *International Journal of Mental Health Nursing*, 27(1), 358-367. <https://doi.org/https://doi.org/10.1111/inm.12329>
- Weimand, B. M., Hedelin, B., Sällström, C., & Hall-Lord, M. L. (2010). Burden and health in relatives of persons with severe mental illness: a Norwegian cross-sectional study. *Issues Ment Health Nurs*, 31(12), 804-815. <https://doi.org/10.3109/01612840.2010.520819>
- Widom, C. S., Czaja, S. J., & Paris, J. (2009). A prospective investigation of borderline personality disorder in abused and neglected children followed up into adulthood. *Journal of Personality Disorders*, 23(5), 433-446. <https://doi.org/10.1521/pedi.2009.23.5.433>
- Winefield, H. R., & Harvey, E. J. (1993). Determinants of psychological distress in relatives of people with chronic schizophrenia. *Schizophr Bull*, 19(3), 619-625. <https://doi.org/10.1093/schbul/19.3.619>
- Winsper, C. (2018). The aetiology of borderline personality disorder (BPD): contemporary theories and putative mechanisms. *Current Opinion in Psychology*, 21, 105-110. <https://doi.org/https://doi.org/10.1016/j.copsyc.2017.10.005>
- World Health Organisation. (2015). Supporting informal caregivers of people living with dementia. Retrieved 6/11/2020, from https://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_informal_care.pdf

- World Health Organisation. (2018). *International classification of diseases for mortality and morbidity statistics (11th Revision)* <https://icd.who.int/browse11/l-m/en>
- World Health Organisation [WHO]. (2016). *International statistical classification of diseases and related health problems (10th ed.)*. <https://icd.who.int/browse10/2016/en>
- Worthington, A., Rooney, P., & Hannan, R. (2013). *The triangle of care, carers included: A guide to best practice in mental health care in england* (2nd ed.). Carers Trust.
<https://carers.org/resources/all-resources/53-the-triangle-of-care-carers-included-a-guide-to-best-practice-in-mental-health-care-in-england>
- Yao, H., Chen, J.-H., & Xu, Y.-F. (2020). Patients with mental health disorders in the COVID-19 epidemic. *The Lancet Psychiatry*, 7(4), e21-e21. [https://doi.org/10.1016/S2215-0366\(20\)30090-0](https://doi.org/10.1016/S2215-0366(20)30090-0)
- Yu, W., Chen, J., Hu, J., & Hu, J. (2019). Relationship between mental health and burden among primary caregivers of outpatients with schizophrenia. *Family Process*, 58(2), 370-383.
<https://doi.org/10.1111/famp.12340>
- Yusuf, A. J., & Nuhu, F. T. (2011). Factors associated with emotional distress among caregivers of patients with schizophrenia in Katsina, Nigeria. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*, 46(1), 11-16. <https://doi.org/10.1007/s00127-009-0166-6>
- Zanarini, M. C., Horwood, J., Wolke, D., Waylen, A., Fitzmaurice, G., & Grant, B. F. (2011). Prevalence of DSM-IV borderline personality disorder in two community samples: 6,300 English 11-year-olds and 34,653 American adults. *Journal of Personality Disorders*, 25(5), 607-619.
<https://doi.org/10.1521/pedi.2011.25.5.607>
- Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67(6), 361-370. <https://doi.org/10.1111/j.1600-0447.1983.tb09716.x>

Zimmerman, M., Chelminski, I., & Young, D. (2008). The frequency of personality disorders in psychiatric patients. *Psychiatric Clinics of North America*, 31(3), 405-420.

<https://doi.org/10.1016/j.psc.2008.03.015>

Appendix A Systematic Review Search Algorithm

Table A.1 outlines the algorithm and outcomes of the searches in the four databases, with an example of the hits for each search term based on the February 2021 searches. Table A2 provides an example of the hits for each search term in the PsycINFO database in February 2021.

Table A.1

Details of Search Algorithm

Search ID	Database	Search terms	Database search field
1	PsycINFO	"care giver*" OR carer* OR supporter* OR famil* or caregiv* OR parent* OR sibling* OR spouse* OR partner*	Population 1 (only in title, keyword or abstract)
2	PsycINFO	Schizophrenia	Population 2 (only in title OR abstract OR keyword)
3	PsycINFO	Coping or adaptation or "adaptive behaviour" or "adaptive behavior" or Cope	Outcome 1 (terms for independent variable - coping) (abstract title keyword)
4	PsycINFO	Wellbeing OR well- being OR "well being" OR "quality of life" OR distress* OR depress* OR anxiety OR "mental health"	Outcome 3 (terms for dependent variable) (only in title OR abstract OR keyword)
5	PsycINFO	Population 1 AND Population 2 AND Outcome 1 AND Outcome 2	Combining Search ID 1, 2, 3, 4 using BOOLEAN terms.
6	CINAHL	"care giver*" OR carer* OR supporter* OR famil* or caregiv* OR parent* OR sibling* OR spouse* OR partner*	Population 1 (only in title OR abstract or word in subject heading)
7	CINAHL	Schizophrenia	Population 2 (only in title OR abstract or word in subject heading)
8	CINAHL	Coping or adaptation	Outcome 1 (only in title OR abstract

Search ID	Database	Search terms	Database search field
		or “adaptive behaviour” or “adaptive behavior” or Cope	or word in subject heading)
9	CINAHL	Wellbeing OR well- being OR “well being” OR “quality of life” OR distress* OR depress* OR anxiety OR “mental health”	Outcome 2 (only in title OR abstract or word in subject heading)
10	CINAHL	Population 1 AND Population 2 AND Outcome 1 AND Outcome 2	Combining Search ID 6, 7, 8, 9 using BOOLEAN terms.
11	Pubmed	“care giver*” OR carer* OR supporter* OR famil* or caregiv* OR parent* OR sibling* OR spouse* OR partner*	Population 1 (only in title/ abstract or other term)
12	Pubmed	Schizophrenia	Population 2 (limited to title or abstract or other term)
13	Pubmed	Coping or adaptation or “adaptive behaviour” or “adaptive behavior” or Cope	Outcome 1 – Independent variable (limited to title or abstract or other term)
14	Pubmed	Wellbeing OR well- being OR “well being” OR “quality of life” OR “mental health” OR distress* OR depress* OR anxiety	Outcome 2 – Dependent variable (limited to title or abstract or other term)
15	Pubmed	Population 1 and Population 2 and Outcome 1 and Outcome 2	Combining Search ID 11, 12, 13, 14 using BOOLEAN terms.
16	SCOPUS	“care giver*” OR carer* OR supporter* OR famil* or caregiv* OR parent* OR sibling* OR spouse* OR partner*	Population 1 (limited to title, abstract, keyword)
17	SCOPUS	Schizophrenia	Population 2 (limited to title,

Search ID	Database	Search terms	Database search field abstract, keyword)
18	SCOPUS	Coping or adaptation or “adaptive behaviour” or “adaptive behavior” or Cope	Outcome 1 – Independent variable (limited to title, abstract, keyword)
19	SCOPUS	Wellbeing OR well- being OR “well being” OR “quality of life” OR distress* OR depress* OR anxiety OR “mental health”	Outcome 2 – Dependent variable (limited to title, abstract, keyword)
20	SCOPUS	Population 1 and Population 2 and Outcome 1 and Outcome 2	Combining Search ID 16, 17, 18, 19 using BOOLEAN terms.

Table A.2*Number of articles identified for each search term*

Search ID	Database	Search terms	Database search field	Hits
1	PsycINFO	“care giver*” OR carer* OR supporter* OR famil* or caregiv* OR parent* OR sibling* OR spouse* OR partner*	Population 1 (only in title, keyword or abstract)	748,750
2	PsycINFO	Schizophrenia	Population 2 (only in title OR abstract OR keyword)	110,516
3	PsycINFO	Coping or adaptation or “adaptive behaviour” or “adaptive behavior” or Cope	Outcome 1 (terms for independent variable - coping) (abstract title keyword)	174,088
4	PsycINFO	Wellbeing OR well-being OR “well being” OR “quality of life” OR distress* OR depress* OR anxiety OR “mental health”	Outcome 3 (terms for dependent variable) (only in title OR abstract OR keyword)	744,715
5	PsycINFO	Population 1 AND Population 2 AND Outcome 1 AND Outcome 2	Combining Search ID 1, 2, 3, 4 using BOOLEAN terms.	380

Appendix B List of Intended Journals

It is intended the two articles included in the thesis will be submitted in peer-reviewed journals. The systematic review (chapter 3) will be submitted to Clinical Psychology Review. The empirical research paper (chapter 5) will be submitted to Borderline Personality Disorder and Emotion Dysregulation. The referencing format presented in chapter 5 corresponds with the requirements of the identified journal.

Appendix C Confirmation of Ethical Approval

21st November 2019



Coláiste na nEalaíon, an Léinn Cheiltigh
agus na nEolaíochtaí Sóisialta
College of Arts, Celtic Studies
and Social Sciences

Scoil an Siceolaíochta Feidhmi
School of Applied Psychology

University College Cork,
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T +353 (0)21 490 4551 / 4552
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Dear Aoife,

Clinical Psychology Research and Ethics Meeting 15.11.2019

Distress in caregivers of people with Borderline Personality Disorder: the relationship with caregiver appraisals and coping

Aoife Hayes

Thank you for presenting the above research proposal to the Research and Ethics panel.

Based on your written proposal and further clarification and discussion during the meeting, the decision of the panel was:

- **Pass, conditional on required revisions**

In formulating a revised submission please attend to the following issues raised by both reviewers on the current proposal:

- 1.1. On the information sheet it says "All information you provide will be confidential" – it is probably more accurate just to refer to anonymization or aggregation – you won't be keeping the data secret.
- 1.2. Later in the sheet you mention that "This survey is targeted at people living in the countries" in small font. I think it would be better to have a separate section on "Who should participate" – before the section "Do I have to participate" In this you could clarify the point made at the bottom of the table. The panel felt that it may be worthwhile to establish what online supports could be made available to people who reside in countries where the researcher cannot recommend specific support organisations.

Professor John McCarthy
Head of School of Applied Psychology

Ollscoil na hÉireann, Corcaigh
National University of Ireland, Cork

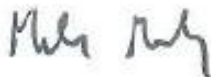
- 1.3. Gender – non-binary is now a common option you may wish to include.
- 1.4. Review your answer to tick box 4 on the form regarding withdrawal from the study.
- 1.5. Add relevant logos to your forms.

It was also noted that you will submit your signed research agreement once you have met with your supervisor on the 12th December.

You may re-submit your revised proposal to n.hennessy@ucc.ie at any time but no later than Friday 10th January 2020. Please also include a cover letter indicating how and where you have responded to these revisions.

Every best wish with making these revisions.

Yours sincerely,



Dr Mike Murphy
Chair Clinical Psychology Research and Ethics Panel

Copy: Maria Dempsey

29th June 2020



Coláiste na nEalaíon, an Léinn Cheiltigh
agus na nEolaíochtaí Sóisialta
College of Arts, Celtic Studies
and Social Sciences

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T +353 (0)21 490 4551 / 4552
E infoapsych@ucc.ie
<http://www.ucc.ie/en/apsych/>

Dear Aoife,

Clinical Psychology Research and Ethics

Distress in caregivers of people with Borderline Personality Disorder: the relationship with caregiver appraisals and coping

Aoife Hayes

Thank you for submitting your amendment of 20th June 2020 to the Research and Ethics panel.

Based on your written proposal the decision of the panel is:

- **Approved**

Yours sincerely,

Dr Mike Murphy

Chair Clinical Psychology Research and Ethics Panel

Dr Carol Linehan
Head of School of Applied Psychology

Ollscoil na hÉireann, Corcaigh
National University of Ireland, Cork

Appendix D Participant Information Leaflet



Participant Information

Study Title: Understanding distress in caregivers of people with Borderline Personality Disorder

Hello, Thank you for considering taking part in this research. Before you decide if you want to participate, here is some information about the purpose of the research and also what your participation would involve.

Who is carrying out the research?

My name is Aoife Hayes. I am a Psychologist in Clinical Training at University College Cork (UCC), Ireland. I am undertaking this research as part of my Doctoral thesis. I am working under the supervision of Dr Maria Dempsey, UCC, Ireland and Dr Mary Kells, Clinical Psychologist, Health Service Executive (HSE), Ireland.

Purpose of the research

I am interested in understanding more about the experience of family (e.g. parents, spouses, adult children, adult siblings) and significant others (e.g. partners, friends, ex-spouses, ex-partners) who care for and support people with a diagnosis of Borderline Personality Disorder (BPD) or Emotionally Unstable Personality Disorder (EUPD). The aim of the research is to better understand the experiences of English-speaking adults who care for and support people with BPD or EUPD.

What participation involves

If you choose to participate in this study you will be asked to answer some questions about yourself, the person with BPD or EUPD, your relationships and your caregiving experience. The survey will take approximately 40 minutes to complete. You do not have to complete the survey in one sitting. However, your data will be deleted if you do not return to the survey within one week of your last entry. Your data will only be included in the research when you have submitted your responses at the end of the survey.

Who should participate?

Adults (aged 18 years or older) who:

- Are caring for or supporting a relative (e.g. parent, spouse, child, sibling) or significant other (e.g. friend, partner, ex-partner/spouse) with Borderline Personality Disorder (BPD) or Emotionally Unstable Personality Disorder (EUPD).
- Speak English.

Do I have to participate?

Participation in this study is completely voluntary. There is no obligation to participate. If you choose to, you can refuse to answer specific questions or decide to withdraw from the study up until you submit your responses. After you have submitted your anonymous responses, I will not be able to trace your responses back to you. Therefore, once you submit your responses, you will no longer be able to withdraw from the study.

How will my data be stored?

All information you provide will be anonymous. The study does not ask you to provide any personally identifying information and IP addresses will not be collected at any point, meaning the data you provide cannot be traced back to you.

The anonymous data will initially be stored on the Qualtrics server which is located in the E.U. It will then be transferred to a password protected, encrypted H.S.E. laptop for analysis. It will subsequently be transferred to the University College Cork OneDrive system and onto the UCC server and deleted from the laptop. The data will then be stored indefinitely in a data repository on the UCC server.

What will the data be used for?

The information you provide may contribute to research publications, conference presentations, and to contribute to my clinical psychology research thesis. Other researchers may also request and be granted access to the data for use in their own research projects.

Will I experience any negative outcome by participating?

We do not anticipate any negative outcomes from participating in this study. However, some of the topics broached in the survey are personal in nature. If you wish to do so you can choose not to answer questions or withdraw from the study. If you do experience distress arising from participating in the research, contact your primary health care provider or doctor for support. You may also get assistance by contacting the support services listed in Table 1 below.

What are the benefits of participating?

Your participation will contribute to our understanding of the experience of adults who care for and support people with a diagnosis of Borderline Personality Disorder and Emotionally Unstable Personality Disorder.

My contact details

If you have any queries about this research, you can contact me or my research supervisors at the email addresses listed below.

Aoife Hayes, Psychologist in Clinical Training, UCC, Ireland:
118224830@umail.ucc.ie

Supervisors:

Dr. Maria Dempsey, Lecturer, UCC, Ireland:
m.dempsey@ucc.ie

Dr. Mary Kells, Clinical Psychologist, HSE, Ireland: mary.kells@hse.ie

This study has obtained ethical approval from the University College Cork (UCC) Clinical Psychology Research Ethics Committee.

If you agree to take part in this study, please respond to the consent questions below. Once you have completed these questions, you will gain access to the rest of the survey.

Thank you,
Aoife Hayes

Table 1: List of support services

Country	Support service
Australia	The Samaritans Help Line (Tel: 135247); Tasmania (Tel: 1300 364 566) Lifeline (Tel: 131114) is a 24-hour nationwide service that provides

	access to crisis support, suicide prevention, and mental health support services.
Canada	Crisis Services (call toll-free 1.833.456.4566 or text 45645) is a Canada nationwide suicide prevention and support network. https://www.crisisservicescanada.ca/ Crisis Text Line (HOME to 686868 in Canada to text with a trained Crisis Responder). https://www.crisistextline.ca
Ireland	Samaritans (freephone 116123 from anywhere in Ireland or Northern Ireland). https://www.samaritans.org/ireland/samaritans-ireland/
New Zealand	Lifeline Aotearoa (Tel: 0800 543 354) https://www.lifeline.org.nz The Samaritans Helpline (Tel: 0800 726 666) https://www.samaritans.org.nz/contact/
United Kingdom	Samaritans Helpline (Tel: 116 123) provides free support to anyone in distress or at risk of suicide throughout the United Kingdom. https://www.samaritans.org/
United States	Crisis Text Line (741741) Can be used anywhere in the U.S. https://www.crisistextline.org

Consent form

I have read the information provided about the research. I am participating voluntarily and consent to participate in this study "Understanding distress in caregivers of people with Borderline Personality Disorder". Select 'Yes' to indicate consent to participate or 'No' if you do not wish to participate.

Yes

☐

No

☐

Are you an English-speaking adult (18 years or older) caring for or supporting a relative (e.g. parent, spouse, child, sibling or other) or significant other (e.g. friend, partner, ex-partner/spouse) with Borderline Personality Disorder or Emotionally Unstable Personality Disorder

Yes

☐

No

☐

Appendix E Debrief Information

Thank you for taking the time to participate in this survey. The aim of this research is to better understand the experience and impact of caring for/ supporting people with Borderline Personality Disorder/ Emotionally Unstable Personality Disorder.

We do not anticipate any negative outcomes from participating in this study. However, some of the topics broached in the survey are personal in nature. If you experienced distress arising from participating in the research, please contact your primary health care provider or doctor for support. You may also get assistance by contacting the support services listed in Table 1 below.

My contact details

If you have any queries about this research, you can contact me or my research supervisors at the email addresses listed below.

Aoife Hayes, Psychologist in Clinical Training, UCC, Ireland: 118224830@umail.ucc.ie

Supervisors:

Dr. Maria Dempsey, Lecturer, UCC, Ireland: m.dempsey@ucc.ie

Dr. Mary Kells, Clinical Psychologist, HSE, Ireland: mary.kells@hse.ie

This study has obtained ethical approval from the University College Cork (UCC) Clinical Psychology Research Ethics Committee.

Thank you,

Aoife Hayes

Table 1: List of support services

Country	Support service
Australia	The Samaritans Help Line (Tel: 135247); Tasmania (Tel: 1300 364 566) Lifeline (Tel: 131114) is a 24-hour nationwide service that provides access to crisis support, suicide prevention, and mental health support services.
Canada	Crisis Services (call toll-free 1.833.456.4566 or text 45645) is a Canada nationwide suicide prevention and support network. https://www.crisisservicescanada.ca/ Crisis Text Line (HOME to 686868 in Canada to text with a trained Crisis Responder). https://www.crisistextline.ca
Ireland	Samaritans (freephone 116123 from anywhere in Ireland or Northern Ireland). https://www.samaritans.org/ireland/samaritans-ireland/
New Zealand	Lifeline Aotearoa (Tel: 0800 543 354) https://www.lifeline.org.nz The Samaritans Helpline (Tel: 0800 726 666) https://www.samaritans.org.nz/contact/
United Kingdom	Samaritans Helpline (Tel: 116 123) provides free support to anyone in distress or at risk of suicide throughout the United Kingdom. https://www.samaritans.org/
United States	Crisis Text Line (741741) Can be used anywhere in the U.S. https://www.crisistextline.org

Appendix F Reliability of Brief COPE and COPE Change

Table F.1

Reliability of Brief COPE Subscales using Mean Inter-item Correlation and Chronbach's Alpha

Subscale	Brief COPE		COPE change	
	Correlation	Chronbach's alpha	Correlation	Chronbach's alpha
Self-distraction	0.27	0.42	0.71	0.44
Active	0.54	0.70	0.68	0.77
Denial	0.52	0.67	0.54	0.75
Substance use	0.92	0.96	0.9	0.94
Emotional support	0.71	0.84	0.71	0.78
Informational support	0.65	0.79	0.64	0.82
Behavioural disengagement	0.56	0.72	0.65	0.73
Venting	0.32	0.49	0.50	0.62
Positive reframing	0.51	0.68	0.64	0.75
Planning	0.66	0.80	0.73	0.81
Humour	0.67	0.79	0.73	0.89
Acceptance	0.48	0.64	0.57	0.68
Religion	0.74	0.85	0.82	0.88
Self-blame	0.69	0.81	0.69	0.79

Note: Chronbach's alpha is underestimated for two-item scales (Eisinger et al., 2013). Mean inter-item correlations of 0.3 and above are considered adequate (Mitchell & Jolley, 2010).

Appendix G Open-Ended Survey Questions

Qualitative survey questions extracted from the online survey.

Briefly, could you tell us what you usually do to cope with your role as a caregiver for a person with Borderline Personality Disorder or Emotionally Unstable Personality Disorder?

Tell us about how coronavirus (COVID-19) has impacted upon your role as a caregiver for a person with Borderline Personality Disorder or Emotionally Unstable Personality Disorder.

Has coronavirus (COVID-19) impacted upon the strategies you use to cope with your role as caregiver? If it has, can you tell us how?

This is the last question. Thank you for your time!

Different states and countries around the world have responded to coronavirus (COVID-19) by introducing different levels of restrictions on peoples activities. Where you live, what three changes has your government brought in that have impacted on how you usually cope with your role as a caregiver?

Appendix H Results of Regression Analysis Excluding Participants with Relationship Status Recoded

Psychological distress

The sociodemographic variables, COVID-19 anxiety, and perceived social support explained a significant amount of the variance in psychological distress in step 1 of the hierarchical regression model, $R^2=.29$, $F(10, 767)=30.94$; $p<.001$. Coping strategies uniquely explained a significant amount of the variance in psychological distress, controlling for the sociodemographic variables, COVID-19 anxiety and social support, $\Delta R^2=.22$, $\Delta F(14, 753)=24.62$, $p<.001$. The overall model explained 51% of the variance in psychological distress, $R^2=.51$, $F(24, 753)=32.808$, $p<.001$. The model results are summarised in Table H.1.

Positive Mental Well-Being

The sociodemographic variables, COVID-19 anxiety, and perceived social support explained a significant amount of the variance in positive mental well-being in step 1 of the hierarchical regression model, $R^2=.22$, $F(9, 768)=23.91$. Coping strategies uniquely explained a significant amount of the variance in positive mental well-being, controlling for the sociodemographic variables, COVID-19 anxiety and social support, $\Delta R^2=.17$, $\Delta F(14, 754)=14.40$, $p<.001$.

The overall model explained 38% of the variance in positive mental well-being, $R^2=.38$, $F(23, 754)=20.41$, $p<.001$. The model results are summarised in Table H.2.

Table H.1

Hierarchical Multiple Regression Model of Informal Carer Psychological Distress (N=778, excluding participants with inconsistent responses on the age and relationship status variables)

	B	SE B	β	t	p
Step 1					
(Constant)	38.16	1.75		21.82	<.001
Age	-0.10	0.02	-0.14	-4.15	<.001
Education (less than graduate)	0.24	0.53	0.01	0.45	.65
Relationship (spouse/ partner)	-0.08	0.70	0.00	-0.11	.91
Working	-0.80	0.53	-0.05	-1.52	.13
Received intervention	-2.16	0.56	-0.12	-3.85	<.001
Chronic illness	2.29	0.54	0.13	4.27	<.001
Cohabitation	0.98	0.58	0.06	1.70	.09
Hours of contact	0.00	0.01	0.01	0.33	.74
COVID-19 anxiety	0.70	0.08	0.26	8.38	<.001
Perceived social support	-1.66	0.18	-0.30	-9.41	<.001
Step 2					
(Constant)	23.96	2.22		10.81	<.001
Age	-0.07	0.02	-0.09	-3.14	<.001
Education (less than graduate)	-0.13	0.46	-0.01	-0.29	.77
Relationship (spouse/ partner)	-0.29	0.62	-0.01	-0.46	.64
Working	-0.69	0.45	-0.04	-1.53	.13
Received intervention	-1.14	0.49	-0.07	-2.34	.02
Chronic illness	2.23	0.45	0.13	4.91	<.001
Cohabitation	0.28	0.49	0.02	0.57	.57
Hours of contact	0.01	0.00	0.04	1.23	.22
COVID-19 anxiety	0.45	0.07	0.17	6.22	<.001
Perceived social support	-1.16	0.18	-0.21	-6.54	<.001
Self-distraction	0.15	0.14	0.03	1.07	.28
Active coping	0.16	0.16	0.03	0.99	.32
Denial	0.56	0.19	0.09	2.90	<.01
Substance use	0.58	0.12	0.13	4.93	<.001
Use emotional support	-0.07	0.18	-0.02	-0.41	.68
Use instrumental support	0.29	0.16	0.07	1.84	.07
Behavioural disengagement	0.75	0.15	0.15	4.92	<.001
Venting	0.14	0.16	0.03	0.91	.36
Positive reframing	-0.58	0.14	-0.12	-4.14	<.001
Planning	0.31	0.16	0.07	1.97	.05
Humour	-0.17	0.14	-0.03	-1.20	.23
Acceptance	-0.39	0.15	-0.07	-2.53	.01
Religion	-0.14	0.10	-0.04	-1.44	.15
Self-blame	1.10	0.12	0.27	9.16	<.001

Table H.2

Multiple Regression Model of Informal Carer Positive Mental Well-being (N=778, excluding participants with inconsistent responses on the age and relationship status variables)

	B	SE B	β	t	p
Step 1					
Constant	18.46	4.78		3.86	<.001
Age	0.16	0.07	0.08	2.41	.02
Education (post-graduate)	0.09	1.43	0.00	0.06	.95
Relationship (spouse/partner)	2.41	1.98	0.04	1.22	.22
Received intervention	3.12	1.57	0.07	1.99	.05
Chronic illness	-6.00	1.49	-0.13	-4.02	<.001
Cohabitation	-4.55	1.63	-0.11	-2.80	.01
Hours of contact	-0.03	0.02	-0.08	-2.09	.04
COVID-19 anxiety	-1.25	0.23	-0.17	-5.33	<.001
Perceived social support	4.36	0.50	0.29	8.75	<.001
Step 2					
Constant	30.15	6.58		4.58	<.001
Age	0.13	0.06	0.07	2.12	.03
Education (post-graduate)	0.46	1.31	0.01	0.35	.72
Relationship (spouse/partner)	4.18	1.87	0.08	2.24	.03
Received intervention	0.46	1.46	0.01	0.31	.75
Chronic illness	-6.07	1.36	-0.13	-4.48	<.001
Cohabitation	-3.06	1.48	-0.07	-2.07	.04
Hours of contact	-0.04	0.01	-0.10	-2.75	.01
COVID-19 anxiety	-0.89	0.22	-0.12	-4.06	<.001
Perceived social support	2.82	0.53	0.19	5.27	<.001
Self-distraction	-0.51	0.42	-0.04	-1.21	.23
Active coping	0.68	0.49	0.05	1.40	.16
Denial	-0.62	0.58	-0.03	-1.06	.29
Substance use	-0.98	0.35	-0.08	-2.78	.01
Use emotional support	0.57	0.54	0.05	1.06	.29
Use instrumental support	-0.41	0.48	-0.04	-0.86	.39
Behavioural disengagement	-1.58	0.46	-0.12	-3.45	<.01
Venting	-0.51	0.48	-0.03	-1.06	.29
Positive reframing	2.27	0.42	0.18	5.40	<.001
Planning	-1.60	0.47	-0.13	-3.39	<.01
Humour	1.19	0.43	0.08	2.74	<.01
Acceptance	1.29	0.46	0.09	2.80	<.01
Religion	0.62	0.30	0.06	2.10	.04
Self-blame	-1.69	0.36	-0.15	-4.70	<.001

Appendix I Results of Regression Analyses for Non-Imputed Data

Psychological Distress

The sociodemographic variables, COVID-19 anxiety, and perceived social support explained a significant amount of the variance in psychological distress in step 1 of the hierarchical regression model, $R^2=0.28$, $F(10, 833)=32.84$; $p<.001$. Coping strategies uniquely explained a significant amount of the variance in psychological distress, controlling for the sociodemographic variables, COVID-19 anxiety and social support, $\Delta R^2=.21$, $\Delta F(14, 819)=24.37$, $p<.001$. The overall model explained 49% of the variance in psychological distress, $R^2=.49$, $F(24, 819)=31.19$, $p<.001$. The model results are summarised in Table I.1.

Positive Mental Well-Being

The sociodemographic variables, COVID-19 anxiety, and perceived social support explained a significant amount of the variance in positive mental well-being in step 1 of the hierarchical regression model, $R^2=.22$, $F(9, 834)=26.07$. Coping strategies uniquely explained a significant amount of the variance in positive mental well-being, controlling for the sociodemographic variables, COVID-19 anxiety and social support, $\Delta R^2=.16$, $\Delta F(14, 820)=15.06$, $p<.001$.

The overall model explained 38% of the variance in positive mental well-being, $R^2=.38$, $F(23, 820)=21.77$, $p<.001$. The model results are summarised in Table I.2.

Change in Caregiving Stress due to COVID-19

The sociodemographic variables, COVID-19 anxiety, and perceived social support explained a significant amount of the variance in change in caregiving stress due to COVID-19 in step 1 of the hierarchical regression model, $R^2=.03$, $F(5,14)=5.43$, $p<.001$. Coping strategies uniquely explained a significant amount of the variance in change in stress, controlling for the sociodemographic variables, COVID-19 anxiety and social support, $\Delta R^2=.05$, $\Delta F(14, 826)=3.18$, $p<.001$.

The overall model explained 8% of the variance in change in caregiving stress due to COVID-19, $R^2=.08$, $F(19, 826)=3.82$, $p<.001$. The model results are summarised in Table I.3.

A second regression analysis was run with change in use of coping strategies regressed onto change in caregiving stress due to COVID-19. The results are summarised in Table I.4. In step 2 of the model, change in use of coping strategies uniquely explained a significant amount of the variance in change in stress, controlling for the sociodemographic variables, COVID-19 anxiety and social support, $\Delta R^2 = .10$, $\Delta F(14, 812) = 6.70$, $p < .001$. The overall model explained 13.4% of the variance in change in caregiving stress due to COVID-19, $R^2 = .13$, $F(19, 812) = 6.61$, $p < .001$.

Table I.1*Hierarchical Multiple Regression Model of Informal Carer Psychological Distress (Non-imputed Data)*

	B	SE B	β	t	p
Step 1					
(Constant)	37.68	1.71		22.09	<.001
Age	-0.11	0.02	-0.15	-4.43	<.001
Education (less than graduate)	0.73	0.518	0.04	1.42	.16
Relationship (spouse/ partner)	-0.04	0.69	-0.00	-0.06	.95
Working	-0.67	0.51	-0.04	-1.31	.19
Received intervention	-1.93	0.548	-0.11	-3.52	<.001
Chronic illness	2.39	0.518	0.14	4.62	<.001
Cohabitation	0.99	0.559	0.06	1.77	.08
Hours of contact	0.00	0.01	0.02	0.47	.64
COVID-19 anxiety	0.66	0.08	0.25	8.40	<.001
Perceived social support	-1.61	0.17	-0.29	-9.53	<.001
Step 2					
(Constant)	23.27	2.17		10.71	<.001
Age	-0.08	0.02	-0.11	-3.60	<.001
Education (less than graduate)	0.25	0.45	0.01	0.56	.58
Relationship (spouse/ partner)	-0.17	0.62	-0.01	-0.27	.78
Working	-0.63	0.44	-0.04	-1.43	.15
Received intervention	-1.02	0.48	-0.06	-2.13	.03
Chronic illness	2.18	0.44	0.13	4.91	<.001
Cohabitation	0.48	0.48	0.03	0.99	.32
Hours of contact	0.005	0.00	0.03	1.10	.27
COVID-19 anxiety	0.44	0.07	0.17	6.39	<.001
Perceived social support	-1.13	0.17	-0.21	-6.61	<.001
Self-distraction	0.18	0.14	0.04	1.35	.18
Active coping	0.21	0.16	0.04	1.29	.20
Denial	0.67	0.19	0.10	3.53	<.001
Substance use	0.49	0.11	0.11	4.28	<.001
Use emotional support	-0.08	0.18	-0.02	-0.46	.65
Use instrumental support	0.25	0.16	0.06	1.58	.12
Behavioural disengagement	0.678	0.15	0.14	4.58	<.001
Venting	0.09	0.16	0.02	0.59	.55
Positive reframing	-0.68	0.13	-0.14	-5.06	<.001
Planning	0.25	0.15	0.05	1.63	.10
Humour	-0.09	0.14	-0.02	-0.62	.53
Acceptance	-0.22	0.15	-0.04	-1.45	.15
Religion	-0.072	0.10	-0.02	-0.75	.45
Self-blame	1.12	0.12	0.27	9.62	<.001

Table I.2*Multiple Regression Model of Informal Carer Positive Mental Well-being (Non-imputed Data)*

	B	SE B	β	t	p
Step 1					
Constant	18.76	4.65		4.03	<.001
Age	0.17	0.07	0.09	2.63	.01
Education (post-graduate)	1.04	1.37	0.02	0.76	.45
Relationship (spouse/partner)	1.71	1.96	0.03	0.87	.38
Received intervention	2.70	1.53	0.06	1.77	.08
Chronic illness	-6.80	1.44	-0.15	-4.72	<.001
Cohabitation	-5.06	1.57	-0.12	-3.23	<.001
Hours of contact	-0.02	0.01	-0.06	-1.61	.11
COVID-19 anxiety	-1.15	0.22	-0.16	-5.22	<.001
Perceived social support	4.25	0.48	0.29	8.92	<.001
Step 2					
Constant	31.05	6.39		4.86	<.001
Age	0.15	0.06	0.08	2.51	.01
Education (post-graduate)	1.44	1.25	0.03	1.15	.25
Relationship (spouse/partner)	3.50	1.86	0.06	1.88	.06
Received intervention	0.22	1.43	0.00	0.16	.88
Chronic illness	-6.53	1.31	-0.14	-4.99	<.001
Cohabitation	-3.98	1.43	-0.09	-2.79	.01
Hours of contact	-0.03	0.01	-0.07	-2.07	.04
COVID-19 anxiety	-0.84	0.20	-0.12	-4.11	<.001
Perceived social support	2.74	0.51	0.18	5.36	<.001
Self-distraction	-0.61	0.40	-0.04	-1.52	.13
Active coping	0.51	0.47	0.04	1.09	.28
Denial	-0.83	0.57	-0.05	-1.46	.14
Substance use	-0.95	0.34	-0.08	-2.81	.01
Use emotional support	0.64	0.52	0.05	1.23	.22
Use instrumental support	-0.54	0.47	-0.05	-1.15	.25
Behavioural disengagement	-1.52	0.44	-0.12	-3.47	<.001
Venting	-0.37	0.47	-0.02	-0.78	.44
Positive reframing	2.54	0.40	0.20	6.35	<.001
Planning	-1.24	0.46	-0.10	-2.72	.01
Humour	1.07	0.41	0.08	2.59	.01
Acceptance	0.98	0.44	0.07	2.21	.03
Religion	0.42	0.29	0.04	1.46	.15
Self-blame	-1.71	0.35	-0.15	-4.92	<.001

Table I.3

Regression of Use of Coping Strategies onto Change in Caregiver Stress due to COVID-19 (Non-imputed Data)

	B	SE B	β	t	p
Step 1					
(Constant)	2.82	0.51		5.55	<.001
Age	-0.01	0.01	-0.03	-0.91	.36
Cohabitation	0.33	0.18	0.07	1.81	.07
COVID-19 anxiety	0.11	0.03	0.15	4.30	.00
Perceived social support	-0.09	0.05	-0.05	-1.58	.11
Hours of contact	0.00	0.00	-0.03	-0.75	.45
Step 2					
(Constant)	1.31	0.79		1.65	.10
Age	0.00	0.01	-0.02	-0.45	.65
Cohabitation	0.24	0.18	0.05	1.33	.18
COVID-19 anxiety	0.09	0.03	0.13	3.64	.00
Perceived social support	-0.06	0.06	-0.04	-0.97	.33
Hours of contact	0.00	0.00	-0.02	-0.54	.59
Self-distraction	0.08	0.05	0.06	1.65	.10
Active coping	0.02	0.06	0.02	0.34	.73
Denial	0.00	0.07	0.00	0.05	.96
Substance use	0.08	0.04	0.07	1.87	.06
Use emotional support	-0.02	0.07	-0.02	-0.35	.73
Use instrumental support	0.07	0.06	0.05	1.11	.27
Behavioural disengagement	0.05	0.06	0.04	0.89	.37
Venting	0.12	0.06	0.07	1.99	.05
Positive reframing	-0.07	0.05	-0.06	-1.45	.15
Planning	0.10	0.06	0.08	1.74	.08
Humour	-0.06	0.05	-0.04	-1.15	.25
Acceptance	-0.15	0.06	-0.10	-2.59	.01
Religion	0.07	0.04	0.07	1.94	.05
Self-blame	0.01	0.04	0.01	0.23	.82

Table I.4*Regression of Change in Use of Coping Strategies onto Change in Caregiver Stress due to COVID-19**(Non-imputed Data)*

	B	SE B	β	t	p
Step 1					
(Constant)	2.87	0.51		5.66	<.001
Age	-0.01	0.01		-1.21	.23
Cohabitation	0.30	0.18	-0.04	1.62	.11
COVID-19 anxiety	0.12	0.03	0.07	4.57	<.001
Perceived social support	-0.08	0.05	0.16	-1.38	.17
Hours of contact	0.00	0.00	-0.05	-0.52	.61
Step 2					
(Constant)	2.17	0.51		4.26	<.001
Age	-0.01	0.01	-0.03	-0.92	.36
Cohabitation	0.28	0.18	0.06	1.58	.11
COVID-19 anxiety	0.09	0.03	0.13	3.77	<.001
Perceived social support	-0.02	0.06	-0.01	-0.40	.69
Hours of contact	0.00	0.00	-0.03	-0.79	.43
Change in Self-distraction	0.10	0.04	0.08	2.39	.02
Change in Active coping	-0.04	0.06	-0.03	-0.70	.49
Change in Denial	-0.15	0.06	-0.12	-2.64	.01
Change in Substance use	0.05	0.04	0.05	1.37	.17
Change in Use emotional support	0.00	0.06	0.00	-0.01	.99
Change in Use instrumental support	-0.05	0.06	-0.04	-0.74	.46
Change in Behavioural disengagement	-0.03	0.06	-0.02	-0.51	.61
Change in Venting	0.04	0.06	0.03	0.70	.49
Change in Positive reframing	-0.14	0.06	-0.10	-2.54	.01
Change in Planning	0.33	0.07	0.25	5.05	.00
Change in Humour	-0.11	0.05	-0.09	-2.22	.03
Change in Acceptance	-0.16	0.07	-0.10	-2.48	.01
Change in Religion	0.11	0.04	0.09	2.67	.01
Change in Self-blame	0.14	0.05	0.10	2.79	.01

Appendix J Linear Regression of Dummy Variables onto the Dependent Variables

Table J.1

Linear Regression of Education Dummy Variables onto Psychological Distress, K10

	Variable	Reference Category	R ²	F	df	p
1*	Less than graduate	Graduate/ postgraduate	.01	8.54	861	<.001
2	Graduate	Less than / postgraduate	.00	.08	861	.78
3	Postgraduate	Less than / Graduate	.01	5.96	861	.02

Note: * Included as control into regression of social support and coping strategies onto psychological distress

Table J.2

Linear Regression of Relationship Dummy Variables onto Psychological Distress, K10

	Variable	Reference Categories	R ²	F	df	p
1	Parent	Sibling/ Child/ Spouse/ Partner/ Significant other	.00	.19	861	.66
2	Sibling	Parent/ Child/ Spouse/ Partner/ Significant other	.00	.29	861	.59
3	Child	Sibling/ Parent/ Spouse/ Partner/ Significant other	.01	6.99	861	.01
4*	Spouse / Partner	Sibling/ Child/ Parent/ Significant other	.01	11.78	861	<.001
5	Significant other	Sibling/ Child/ Spouse/ Partner/ Parent	.00	.38	861	.54

Note: * Included as control into regression of social support and coping strategies onto psychological distress

Table J.3*Linear Regression of Education Dummy Variables onto Positive Mental Well-Being, WHO-5*

	Variable	Reference Category	R ²	F	df	p
1	Less than graduate	Graduate/ postgraduate	.007	5.71	861	.02
2	Graduate	Less than / postgraduate	.00	.208	861	.65
3*	Postgraduate	Less than / Graduate	.008	7.23	861	<.01

Note: * Included as control into regression of social support and coping strategies onto positive mental well-being.

Table J.4*Linear Regression of Relationship Dummy Variables onto Positive Mental Well-Being, WHO-5*

	Variable	Reference Categories	R2	F	df	p
1	Parent	Sibling/ Child/ Spouse/ Partner/ Significant other	.003	2.85	861	.09
2	Sibling	Parent/ Child/ Spouse/ Partner/ Significant other	.004	.01	861	.91
3	Child	Sibling/ Parent/ Spouse/ Partner/ Significant other	.001	.81	861	.37
4*	Spouse / Partner	Sibling/ Child/ Parent/ Significant other	.008	6.62	861	.01
5	Significant other	Sibling/ Child/ Spouse/ Partner/ Parent	.002	1.57	861	.21

Note: * Included as control into regression of social support and coping strategies onto positive mental well-being.

Appendix K Hierarchical Regression Excluding Perceived Social Support

Table K.1

Hierarchical regression on to Psychological Distress¹

	B	SE B	β	t	p
Step 1					
(Constant)	29.33	1.50		19.56	<.001
Age	-0.09	0.03	-0.12	-3.42	<.001
Education (less than graduate)	0.10	0.54	0.06	1.85	0.07
Relationship (spouse/ partner)	0.94	0.71	0.05	1.32	0.19
Working	-0.94	0.53	-0.06	-1.76	0.08
Received intervention	-2.60	0.56	-0.15	-4.60	<.001
Chronic illness	2.82	0.54	0.16	5.23	<.001
Cohabitation	1.07	0.58	0.07	1.83	0.07
Hours of contact	0.00	0.01	0.03	0.79	0.43
COVID-19 anxiety	0.75	0.08	0.29	9.34	<.001
Step 2					
(Constant)	18.70	2.09		8.94	<.001
Age	-0.07	0.02	-0.09	-3.13	<.001
Education (less than graduate)	0.23	0.45	0.01	0.51	.61
Relationship (spouse/ partner)	0.03	0.63	0.00	0.05	.96
Working	-0.77	0.44	-0.05	-1.73	.08
Received intervention	-1.26	0.48	-0.07	-2.60	.01
Chronic illness	2.38	0.45	0.14	5.30	<.001
Cohabitation	0.38	0.49	0.02	0.78	.43
Hours of contact	0.01	0.00	0.04	1.11	.27
COVID-19 anxiety	0.48	0.07	0.19	6.99	<.001
Self-distraction	0.25	0.14	0.05	1.85	.06
Active coping	0.24	0.16	0.05	1.48	.14
Denial	0.73	0.19	0.11	3.76	<.001
Substance use	0.47	0.12	0.11	4.03	<.001
Use emotional support	-0.62	0.16	-0.14	-3.96	<.001
Use instrumental support	0.36	0.16	0.08	2.29	.02
Behavioural disengagement	0.72	0.15	0.15	4.81	<.001
Venting	0.17	0.16	0.03	1.09	.28
Positive reframing	-0.75	0.14	-0.16	-5.52	<.001
Planning	0.29	0.16	0.06	1.86	.06
Humour	-0.13	0.14	-0.02	-0.90	.37
Acceptance	-0.20	0.15	-0.04	-1.31	.19
Religion	-0.07	0.10	-0.02	-0.69	.49
Self-blame	1.17	0.12	0.28	9.90	<.001

Note: 1 Step1 $R^2=.21$, $F(9, 853)=24.37$, $p<.001$; Step 2 $R^2=0.46$, $F(23, 839)=32.15$, $p<.001$; $\Delta R^2=0.26$, $\Delta F(14,839)=29.76$, $p<.001$).

Table K.2

Hierarchical Regression on to Positive Mental Well-being¹

	B	SE B	β	t	p
Step 1					
Constant	41.25	4.03		10.24	<.001
Age	0.12	0.07	0.06	1.74	.08
Education (post-graduate)	2.31	1.41	0.05	1.64	.10
Relationship (spouse/partner)	-0.84	2.00	-0.01	-0.42	.67
Received intervention	4.41	1.57	0.09	2.81	.01
Chronic illness	-7.88	1.49	-0.17	-5.30	<.001
Cohabitation	-5.38	1.63	-0.13	-3.30	<.001
Hours of contact	-0.03	0.01	-0.08	-2.07	0.04
COVID-19 anxiety	-1.42	0.23	-0.20	-6.31	<.001
Step 2					
Constant	42.55	6.10		6.97	<.001
Age	0.13	0.06	0.07	2.13	.03
Education (post-graduate)	1.67	1.26	0.04	1.33	.19
Relationship (spouse/partner)	3.03	1.86	0.05	1.62	.10
Received intervention	0.82	1.43	0.02	0.57	.57
Chronic illness	-6.96	1.32	-0.15	-5.27	<.001
Cohabitation	-3.86	1.44	-0.09	-2.68	.01
Hours of contact	-0.03	0.01	-0.08	-2.33	.02
COVID-19 anxiety	-0.97	0.21	-0.14	-4.72	<.001
Self-distraction	-0.69	0.41	-0.05	-1.71	.09
Active coping	0.51	0.48	0.04	1.07	.28
Denial	-0.90	0.57	-0.05	-1.58	.11
Substance use	-0.83	0.34	-0.07	-2.41	.02
Use emotional support	1.86	0.47	0.16	3.97	<.001
Use instrumental support	-0.74	0.47	-0.06	-1.58	.11
Behavioural disengagement	-1.65	0.45	-0.12	-3.70	<.001
Venting	-0.61	0.47	-0.04	-1.30	.19
Positive reframing	2.68	0.40	0.21	6.68	<.001
Planning	-1.42	0.46	-0.11	-3.08	<.01
Humour	1.14	0.42	0.08	2.72	.01
Acceptance	0.91	0.45	0.06	2.03	.04
Religion	0.45	0.29	0.05	1.56	.12
Self-blame	-1.82	0.35	-0.16	-5.22	<.001

Note: 1 Step1 $R^2=0.15$, $F(8, 854)=18.51$, $p<.001$; Step 2 $R^2=0.36$, $F(22, 840)=21.12$, $p<.001$; $\Delta R^2=0.21$,

$\Delta F(14,840)=19.41$, $p<.001$.

Appendix L Hierarchical Regression with Change in Use of Coping Strategies as Control Variables

Table L.1

Hierarchical Regression on to Psychological Distress, including Interaction Terms¹

	B	SE B	β	t	p
Step 1					
(Constant)	38.15	.69		22.60	<.001
Age	-0.11	.02	-0.15	-4.66	<.001
Education (less than graduate)	0.67	.51	0.04	1.30	.19
Relationship (spouse/ partner)	-0.09	.69	0.00	-0.13	.90
Working	-0.67	.51	-0.04	-1.32	.19
Received intervention	-2.00	.54	-0.11	-3.71	<.001
Chronic illness	2.38	.51	0.14	4.64	<.001
Cohabitation	0.96	.55	0.06	1.72	.09
Hours of contact	0.00	.01	0.02	0.43	.67
Coronavirus anxiety	0.65	.08	0.25	8.46	<.001
Perceived social support	-1.63	.17	-0.29	-9.73	<.001
Step 2					
(Constant)	23.27	.15		10.80	<.001
Age	-0.08	.02	-0.11	-3.70	<.001
Education (less than graduate)	0.17	.44	0.01	0.39	.70
Relationship (spouse/ partner)	-0.17	.61	-0.01	-0.29	.78
Working	-0.54	.43	-0.03	-1.25	.21
Received intervention	-1.06	.47	-0.06	-2.24	.03
Chronic illness	2.07	.44	0.12	4.73	<.001
Cohabitation	0.49	.47	0.03	1.03	.30
Hours of contact	0.00	.00	0.03	1.00	.32
Perceived social support	0.43	.07	0.17	6.39	<.001
Coronavirus anxiety	-1.10	.17	-0.20	-6.51	<.001
Self-distraction	0.19	0.13	0.04	1.40	.16
Active coping	0.17	0.16	0.04	1.08	.28
Denial	0.62	0.21	0.09	2.90	<.001
Substance use	0.43	0.14	0.10	3.03	<.001
Use emotional support	-0.05	0.17	-0.01	-0.32	.75
Use instrumental support	0.27	0.15	0.06	1.76	.08
Behavioural disengagement	0.71	0.15	0.14	4.61	<.001
Venting	0.10	0.15	0.02	0.62	.54
Positive reframing	-0.71	0.13	-0.15	-5.35	<.001
Planning	0.28	0.15	0.06	1.82	.07
Humour	-0.09	0.14	-0.02	-0.64	.52
Acceptance	-0.22	0.15	-0.04	-1.52	.13
Religion	-0.09	0.09	-0.03	-1.01	.31
Self-blame	1.07	0.12	0.26	9.26	<.001

	B	SE B	β	t	p
Interaction denial	0.02	0.09	0.01	0.26	.80
Interaction behavioural disengagement	-0.07	0.07	-0.03	-1.04	.30
Interaction substance use	0.06	0.06	0.03	1.01	.31
Interaction self-blame	0.17	0.06	0.08	2.86	<.01
Interaction positive reframing	0.11	0.07	0.04	1.51	.13

Note: 1 Step1 $R^2=.28$, $F(10, 852)=33.80$, $p<.001$; Step 2 $R^2=0.50$, $F(29, 833)=29.32$, $p<.001$; $\Delta R^2=0.22$,

$\Delta F(19,833)=19.59$, $p<.001$.

Table L.2*Hierarchical Regression on to Positive Mental Well-being, including Interaction Terms¹*

	B	SE B	β	t	p
Step 1					
Constant	18.76	4.63		4.06	<.001
Age	0.18	0.07	0.09	2.76	0.01
Education (post-graduate)	0.81	1.36	0.02	0.60	0.55
Relationship (spouse/partner)	1.96	1.94	0.03	1.01	0.31
Received intervention	2.95	1.51	0.06	1.95	0.05
Chronic illness	-6.92	1.43	-0.15	-4.84	<.001
Cohabitation	-5.07	1.56	-0.12	-3.25	<.001
Hours of contact	-0.03	0.01	-0.07	-1.86	0.06
COVID-19 anxiety	-1.16	0.22	-0.16	-5.31	<.001
Perceived social support	4.19	0.48	0.28	8.81	<.001
Step 2					
Constant	31.65	6.44		4.92	<.001
Age	0.15	0.06	0.08	2.48	0.01
Education (post-graduate)	1.33	1.25	0.03	1.07	0.29
Relationship (spouse/partner)	3.74	1.85	0.07	2.02	0.04
Received intervention	0.38	1.41	0.01	0.27	0.79
Chronic illness	-6.37	1.31	-0.14	-4.87	<.001
Cohabitation	-3.79	1.43	-0.09	-2.65	0.01
Hours of contact	-0.03	0.01	-0.08	-2.46	0.01
COVID-19 anxiety	-0.85	0.20	-0.12	-4.15	<.001
Perceived social support	2.67	0.51	0.18	5.22	<.001
Self-distraction	-0.52	0.40	-0.04	-1.30	0.19
Active coping	0.62	0.47	0.05	1.31	0.19
Denial	-0.96	0.57	-0.05	-1.68	0.09
Substance use	-0.92	0.34	-0.08	-2.71	0.01
Use emotional support	0.54	0.52	0.05	1.04	0.30
Use instrumental support	-0.45	0.47	-0.04	-0.96	0.34
Behavioural disengagement	-1.73	0.46	-0.13	-3.75	<.001
Venting	-0.37	0.47	-0.02	-0.79	0.43
Positive reframing	2.52	0.40	0.20	6.31	<.001
Planning	-1.54	0.47	-0.12	-3.29	<.001
Humour	1.17	0.45	0.08	2.57	0.01
Acceptance	1.13	0.45	0.08	2.52	0.01
Religion	0.48	0.29	0.05	1.70	0.09
Self-blame	-1.65	0.35	-0.15	-4.74	<.001
Interaction behavioural disengagement	0.23	0.21	0.03	1.13	0.26
Interaction self-blame	-0.04	0.18	-0.01	-0.21	0.84
Interaction positive reframing	-0.04	0.22	-0.01	-0.19	0.85
Interaction planning	-0.37	0.22	-0.05	-1.71	0.09

	B	SE B	β	t	p
Interaction humour	-0.14	0.22	-0.02	-0.63	0.53
Interaction acceptance	0.50	0.28	0.06	1.77	0.08

Note: 1 Step1 $R^2=.22$, $F(9, 853)=26.56$, $p<.001$; Step 2 $R^2=0.38$, $F(29, 833)=17.74$, $p<.001$; $\Delta R^2=0.16$,

$\Delta F(20,833)=10.98$, $p<.001$).

Appendix M Results of Hierarchical Regression including Control for Geographical Location

This Appendix repeats the analysis presented in chapter 5 with a smaller sample (n=820) comprising participants residing in USA/Canada and European countries only. For this analysis, the geographical location of participants was collapsed into two groups: participants located in the USA/Canada and Europe. Geographical location was included as a control in the regression analyses presented in Tables M.1 to M.4.

In addition, the analysis presented in chapter 5 was repeated with separate regression analyses for the sample from the USA/ Canada (Tables M.5 to M.8) and Europe (Tables M.9 to M.12).

Table M.1*Hierarchical Multiple Regression Model of Informal Carer Psychological Distress including**Geographical Residence (n=820)*

	B	SE B	β	t	p
Step 1					
(Constant)	39.43	2.04		19.34	<.001
Age	-0.11	0.02	-0.16	-4.59	<.001
Education (less than graduate)	0.59	0.53	0.03	1.13	.26
Relationship (spouse/ partner)	0.09	0.70	0.00	0.13	.90
Working	-0.51	0.52	-0.03	-0.98	.33
Received intervention	-2.13	0.55	-0.12	-3.85	<.001
Chronic illness	2.24	0.53	0.13	4.25	<.001
Cohabitation	0.79	0.56	0.05	1.40	.16
Hours of contact	0.00	0.01	0.02	0.59	.55
COVID-19 anxiety	0.67	0.08	0.26	8.42	<.001
Perceived social support	-1.62	0.17	-0.29	-9.46	<.001
Geographical residence	-1.28	0.97	-0.04	-1.32	.19
Step 2					
(Constant)	24.98	2.38		10.49	<.001
Age	-0.08	0.02	-0.11	-3.78	<.001
Education (less than graduate)	0.17	0.45	0.01	0.38	.70
Relationship (spouse/ partner)	-0.23	0.62	-0.01	-0.37	.71
Working	-0.48	0.44	-0.03	-1.08	.28
Received intervention	-1.20	0.48	-0.07	-2.47	.01
Chronic illness	2.04	0.45	0.12	4.52	<.001
Cohabitation	0.29	0.48	0.02	0.60	.55
Hours of contact	0.01	0.00	0.04	1.38	.17
COVID-19 anxiety	0.43	0.07	0.17	6.19	<.001
Perceived social support	-1.15	0.17	-0.21	-6.65	<.001
Geographical residence	-1.26	0.84	-0.04	-1.51	.13
Self-distraction	0.21	0.14	0.04	1.51	.13
Active coping	0.26	0.16	0.05	1.60	.11
Denial	0.68	0.19	0.10	3.54	<.001
Substance use	0.49	0.12	0.11	4.23	<.001
Use emotional support	-0.01	0.18	0.00	-0.06	.95
Use instrumental support	0.14	0.16	0.03	0.89	.37
Behavioural disengagement	0.69	0.15	0.14	4.60	<.001
Venting	0.14	0.16	0.02	0.85	.40
Positive reframing	-0.65	0.14	-0.14	-4.74	<.001

	B	SE B	β	t	p
Planning	0.25	0.15	0.05	1.59	.11
Humour	-0.14	0.14	-0.03	-0.96	.34
Acceptance	-0.26	0.15	-0.05	-1.71	.09
Religion	-0.09	0.10	-0.03	-0.95	.34
Self-blame	1.10	0.12	0.27	9.31	<.001

Note: Step 1 $R^2=.28$, $F(11, 808)=28.92$, $p<.001$; Step 2 $R^2=.49$, $F(25, 794)=31.05$, $p<.001$.

Table M.2*Multiple Regression Model of Informal Carer Positive Mental Well-being including Geographical**Residence (n=820)*

	B	SE B	β	t	p
Step 1					
Constant	4.39	1.43		3.08	<.001
Age	0.05	0.02	0.10	2.88	<.001
Education (post-graduate)	0.02	0.35	0.00	0.06	.95
Relationship (spouse/partner)	0.55	0.50	0.04	1.10	.27
Received intervention	0.71	0.39	0.06	1.83	.07
Chronic illness	-1.87	0.37	-0.16	-5.05	<.001
Cohabitation	-1.19	0.40	-0.11	-2.97	<.01
Hours of contact	-0.01	0.00	-0.08	-2.05	.04
COVID-19 anxiety	-0.29	0.06	-0.16	-5.11	<.001
Perceived social support	1.04	0.12	0.28	8.48	<.001
Geographical residence	0.23	0.69	0.01	0.33	.74
Step 2					
Constant	7.40	1.79		4.14	<.001
Age	0.04	0.02	0.09	2.77	.01
Education (post-graduate)	0.22	0.32	0.02	0.67	.50
Relationship (spouse/partner)	1.04	0.47	0.07	2.19	.03
Received intervention	0.10	0.36	0.01	0.28	.78
Chronic illness	-1.80	0.34	-0.15	-5.31	<.001
Cohabitation	-0.93	0.36	-0.09	-2.54	.01
Hours of contact	-0.01	0.00	-0.09	-2.56	.01
COVID-19 anxiety	-0.21	0.05	-0.12	-3.96	<.001
Perceived social support	0.69	0.13	0.18	5.25	<.001
Geographical residence	0.23	0.63	0.01	0.37	.71
Self-distraction	-0.12	0.10	-0.04	-1.17	.24
Active coping	0.11	0.12	0.04	0.95	.34
Denial	-0.16	0.15	-0.04	-1.13	.26
Substance use	-0.22	0.09	-0.07	-2.52	.01
Use emotional support	0.12	0.13	0.04	0.88	.38
Use instrumental support	-0.12	0.12	-0.04	-0.99	.32
Behavioural disengagement	-0.45	0.11	-0.14	-3.97	<.001
Venting	-0.09	0.12	-0.02	-0.72	.47
Positive reframing	0.63	0.10	0.19	6.06	<.001
Planning	-0.34	0.12	-0.11	-2.91	<.01
Humour	0.27	0.11	0.08	2.55	.01
Acceptance	0.26	0.11	0.07	2.32	.02
Religion	0.10	0.07	0.04	1.41	.16

Self-blame	-0.41	0.09	-0.15	-4.54	<.001
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Note: Step 1 $R^2=.22$, $F(10, 809)=22.37$, $p<.001$; Step 2 $R^2=.37$, $F(24, 795)=19.76$, $p<.001$.

Table M.3

Regression of Use of Coping Strategies onto Change in Caregiver Stress due to COVID-19 including Geographical Residence (n=820)

	B	SE B	β	t	p
Step 1					
(Constant)	3.78	0.62		6.10	<.001
Age	-0.01	0.01	-0.05	-1.41	.16
Cohabitation	0.28	0.18	0.06	1.51	.13
COVID-19 anxiety	0.11	0.03	0.15	4.24	<.001
Perceived social support	-0.10	0.05	-0.06	-1.86	.06
Hours of contact	0.00	0.00	-0.02	-0.46	.64
Geographical residence	-0.60	0.32	-0.07	-1.92	.06
Step 2					
(Constant)	2.17	0.87		2.49	.01
Age	-0.01	0.01	-0.04	-1.07	.28
Cohabitation	0.19	0.18	0.04	1.04	.30
COVID-19 anxiety	0.10	0.03	0.13	3.66	<.001
Perceived social support	-0.08	0.07	-0.05	-1.28	.20
Hours of contact	0.00	0.00	-0.01	-0.22	.83
Geographical residence	-0.49	0.32	-0.05	-1.56	.12
Self-distraction	0.10	0.05	0.07	1.92	.05
Active coping	0.02	0.06	0.02	0.38	.70
Denial	0.01	0.07	0.01	0.20	.84
Substance use	0.06	0.04	0.05	1.39	.16
Use emotional support	-0.02	0.07	-0.01	-0.23	.82
Use instrumental support	0.07	0.06	0.06	1.14	.26
Behavioural disengagement	0.06	0.06	0.04	0.98	.33
Venting	0.10	0.06	0.06	1.69	.09
Positive reframing	-0.07	0.05	-0.05	-1.40	.16
Planning	0.12	0.06	0.09	2.06	.04
Humour	-0.09	0.05	-0.06	-1.62	.10
Acceptance	-0.13	0.06	-0.09	-2.30	.02
Religion	0.06	0.04	0.06	1.74	.08
Self-blame	-0.01	0.04	-0.01	-0.35	.73

Note: Step 1 $R^2=.04$, $F(6, 813)=5.29$, $p<.001$; Step 2 $R^2=.09$, $F(20, 799)=3.82$, $p<.001$.

Table M.4

Regression of Change in Use of Coping Strategies onto Change in Caregiver Stress due to COVID-19 including Geographical Residence (n=820)

	B	SE B	β	t	p
Step 1					
(Constant)	3.78	0.62		6.10	<.001
Age	-0.01	0.01	-0.05	-1.41	.16
Cohabitation	0.28	0.18	0.06	1.51	.13
COVID-19 anxiety	0.11	0.03	0.15	4.24	<.001
Perceived social support	-0.10	0.05	-0.06	-1.86	.06
Hours of contact	0.00	0.00	-0.02	-0.46	.64
Geographical residence	-0.60	0.32	-0.07	-1.92	.06
Step 2					
(Constant)	3.00	0.61		4.95	<.001
Age	-0.01	0.01	-0.04	-1.02	.31
Cohabitation	0.29	0.18	0.07	1.64	.10
COVID-19 anxiety	0.09	0.03	0.12	3.61	<.001
Perceived social support	-0.05	0.06	-0.03	-0.83	.41
Hours of contact	0.00	0.00	-0.03	-0.74	.46
Geographical residence	-0.62	0.30	-0.07	-2.05	.04
Change in Self-distraction	0.10	0.04	0.08	2.48	.01
Change in Active coping	-0.04	0.06	-0.03	-0.65	.52
Change in Denial	-0.14	0.06	-0.11	-2.38	.02
Change in Substance use	0.05	0.04	0.05	1.29	.20
Change in Use emotional support	0.04	0.06	0.03	0.60	.55
Change in Use instrumental support	-0.09	0.06	-0.08	-1.48	.14
Change in Behavioural disengagement	-0.06	0.06	-0.05	-1.09	.28
Change in Venting	0.05	0.06	0.04	0.95	.34
Change in Positive reframing	-0.14	0.06	-0.10	-2.52	.01
Change in Planning	0.36	0.06	0.28	5.66	<.001
Change in Humour	-0.09	0.05	-0.07	-1.77	.08
Change in Acceptance	-0.17	0.06	-0.11	-2.61	.01
Change in Religion	0.10	0.04	0.09	2.52	.01
Change in Self-blame	0.17	0.05	0.13	3.50	<.001

Note: Step 1 $R^2=.04$, $F(6, 813)=5.29$, $p<.001$; Step 2 $R^2=.15$, $F(20, 799)=7.00$, $p<.001$; Step 2 $\Delta R^2=.02$,

$\Delta F(14, 799)=7.49$, $p<.001$, $f^2=.13$.

Table M.5*Hierarchical Multiple Regression Model of Informal Carer Psychological Distress for sample from**USA/ Canada only (n=770)*

	B	SE B	β	t	p
Step 1					
(Constant)	38.22	1.76		21.72	<.001
Age	-0.12	0.03	-0.16	-4.67	<.001
Education (less than graduate)	0.46	0.55	0.03	0.84	0.40
Relationship (spouse/ partner)	0.33	0.72	0.02	0.45	0.65
Working	-0.68	0.54	-0.04	-1.27	0.20
Received intervention	-1.83	0.57	-0.10	-3.19	<.01
Chronic illness	2.03	0.54	0.12	3.73	<.001
Cohabitation	0.87	0.58	0.06	1.51	0.13
Hours of contact	0.00	0.01	0.02	0.64	0.52
COVID-19 anxiety	0.67	0.08	0.26	8.35	<.001
Perceived social support	-1.59	0.17	-0.29	-9.13	<.001
Step 2					
(Constant)	23.55	2.25		10.49	<.001
Age	-0.08	0.02	-0.11	-3.64	<.001
Education (less than graduate)	0.10	0.47	0.01	0.20	0.84
Relationship (spouse/ partner)	-0.07	0.64	0.00	-0.11	0.91
Working	-0.57	0.46	-0.04	-1.25	0.21
Received intervention	-0.94	0.50	-0.05	-1.88	0.06
Chronic illness	1.96	0.46	0.11	4.23	<.001
Cohabitation	0.38	0.49	0.02	0.77	0.44
Hours of contact	0.01	0.00	0.05	1.57	0.12
COVID-19 anxiety	0.43	0.07	0.17	6.05	<.001
Perceived social support	-1.12	0.18	-0.21	-6.41	<.001
Self-distraction	0.17	0.14	0.03	1.18	0.24
Active coping	0.32	0.16	0.07	1.92	0.06
Denial	0.68	0.20	0.11	3.49	<.01
Substance use	0.52	0.12	0.12	4.43	<.001
Use emotional support	0.07	0.18	0.02	0.40	0.69
Use instrumental support	0.05	0.16	0.01	0.34	0.74
Behavioural disengagement	0.73	0.16	0.15	4.69	<.001
Venting	0.14	0.16	0.03	0.88	0.38
Positive reframing	-0.66	0.14	-0.14	-4.69	<.001
Planning	0.21	0.16	0.04	1.32	0.19
Humour	-0.21	0.14	-0.04	-1.44	0.15
Acceptance	-0.26	0.15	-0.05	-1.68	0.09
Religion	-0.10	0.10	-0.03	-1.01	0.31

	B	SE B	β	t	p
Self-blame	1.09	0.12	0.27	8.96	<.001

Note: Step 1 $R^2=.28$, $F(10, 759)=29.49$, $p<.001$; Step 2 $R^2=.49$, $F(24,745)=30.62$, $p<.001$.

Table M.6*Multiple Regression Model of Informal Carer Positive Mental Well-being for sample from USA/**Canada only (n=770)*

	B	SE B	β	t	p
Step 1					
Constant	19.88	4.91		4.05	<.001
Age	0.19	0.07	0.10	2.79	0.01
Education (post-graduate)	-0.10	1.44	0.00	-0.07	0.94
Relationship (spouse/partner)	2.32	2.07	0.04	1.12	0.26
Received intervention	2.17	1.62	0.04	1.34	0.18
Chronic illness	-7.27	1.53	-0.16	-4.74	<.001
Cohabitation	-4.75	1.65	-0.11	-2.88	<.001
Hours of contact	-0.04	0.02	-0.09	-2.40	0.02
COVID-19 anxiety	-1.19	0.23	-0.17	-5.15	<.001
Perceived social support	4.07	0.50	0.27	8.12	<.001
Step 2					
Constant	32.76	6.79		4.83	<.001
Age	0.15	0.06	0.08	2.38	0.02
Education (post-graduate)	0.96	1.32	0.02	0.72	0.47
Relationship (spouse/partner)	4.26	1.96	0.07	2.18	0.03
Received intervention	-0.02	1.51	0.00	-0.02	0.99
Chronic illness	-7.05	1.40	-0.15	-5.04	<.001
Cohabitation	-3.88	1.50	-0.09	-2.59	0.01
Hours of contact	-0.04	0.01	-0.10	-2.90	<.001
COVID-19 anxiety	-0.87	0.22	-0.12	-4.01	<.001
Perceived social support	2.71	0.53	0.18	5.07	<.001
Self-distraction	-0.36	0.43	-0.03	-0.84	0.40
Active coping	0.62	0.50	0.05	1.23	0.22
Denial	-0.57	0.60	-0.03	-0.95	0.34
Substance use	-0.91	0.36	-0.08	-2.54	0.01
Use emotional support	0.22	0.55	0.02	0.40	0.69
Use instrumental support	-0.24	0.49	-0.02	-0.49	0.63
Behavioural disengagement	-1.77	0.47	-0.13	-3.74	<.001
Venting	-0.36	0.50	-0.02	-0.72	0.47
Positive reframing	2.68	0.43	0.20	6.20	<.001
Planning	-1.52	0.48	-0.12	-3.14	<.001
Humour	1.15	0.44	0.08	2.61	0.01
Acceptance	0.85	0.47	0.06	1.81	0.07
Religion	0.39	0.30	0.04	1.31	0.19
Self-blame	-1.76	0.37	-0.16	-4.73	<.001

Note: Step 1 $R^2=.22$, $F(9, 760)=23.15$ $p<.001$; Step 2 $R^2=.37$, $F(23, 746)=19.35$, $p<.001$.

Table M.7

Regression of Use of Coping Strategies onto Change in Caregiver Stress due to COVID-19 for sample from USA/ Canada only (n=770)

	B	SE B	β	t	p
Step 1					
(Constant)	3.28	0.51		6.41	<.001
Age	-0.01	0.01	-0.07	-1.80	0.07
Cohabitation	0.32	0.18	0.07	1.71	0.09
COVID-19 anxiety	0.12	0.03	0.17	4.78	0.00
Perceived social support	-0.11	0.05	-0.07	-1.93	0.05
Hours of contact	0.00	0.00	-0.01	-0.32	0.75
Step 2					
(Constant)	1.92	0.81		2.36	0.02
Age	-0.01	0.01	-0.05	-1.35	0.18
Cohabitation	0.24	0.18	0.06	1.32	0.19
COVID-19 anxiety	0.11	0.03	0.15	4.20	<.001
Perceived social support	-0.09	0.07	-0.06	-1.42	0.16
Hours of contact	0.00	0.00	0.00	-0.07	0.95
Self-distraction	0.05	0.05	0.04	0.99	0.32
Active coping	0.01	0.06	0.01	0.11	0.91
Denial	0.01	0.07	0.01	0.14	0.89
Substance use	0.05	0.04	0.05	1.25	0.21
Use emotional support	0.00	0.07	0.00	0.04	0.97
Use instrumental support	0.04	0.06	0.03	0.60	0.55
Behavioural disengagement	0.04	0.06	0.03	0.67	0.51
Venting	0.11	0.06	0.07	1.88	0.06
Positive reframing	-0.05	0.05	-0.04	-0.94	0.35
Planning	0.12	0.06	0.09	2.10	0.04
Humour	-0.08	0.05	-0.05	-1.48	0.14
Acceptance	-0.12	0.06	-0.08	-2.06	0.04
Religion	0.06	0.04	0.06	1.66	0.10
Self-blame	0.01	0.04	0.01	0.19	0.85

Note: Step 1 $R^2=.05$, $F(6, 764)=5.29$, $p<.001$; Step 2 $R^2=.09$, $F(20, 750)=2.35$, $p<.01$.

Table M.8

*Regression of Change in Use of Coping Strategies onto Change in Caregiver Stress due to COVID-19
for sample from USA/ Canada only (n=770)*

	B	SE B	β	t	p
Step 1					
(Constant)	3.28	0.51		6.41	0.00
Age	-0.01	0.01	-0.07	-1.80	0.07
Cohabitation	0.32	0.18	0.07	1.71	0.09
COVID-19 anxiety	0.12	0.03	0.17	4.78	0.00
Perceived social support	-0.11	0.05	-0.07	-1.93	0.05
Hours of contact	0.00	0.00	-0.01	-0.32	0.75
Step 2					
(Constant)	2.48	0.52		4.80	<.001
Age	-0.01	0.01	-0.04	-1.19	0.24
Cohabitation	0.31	0.18	0.07	1.77	0.08
COVID-19 anxiety	0.10	0.03	0.15	4.18	<.001
Perceived social support	-0.06	0.06	-0.04	-1.09	0.28
Hours of contact	0.00	0.00	-0.02	-0.52	0.60
Change in Self-distraction	0.10	0.04	0.09	2.45	0.01
Change in Active coping	-0.04	0.06	-0.04	-0.74	0.46
Change in Denial	-0.14	0.06	-0.11	-2.43	0.02
Change in Substance use	0.05	0.04	0.05	1.28	0.20
Change in Use emotional support	0.05	0.06	0.04	0.79	0.43
Change in Use instrumental support	-0.10	0.07	-0.08	-1.47	0.14
Change in Behavioural disengagement	-0.07	0.06	-0.05	-1.12	0.26
Change in Venting	0.07	0.06	0.05	1.23	0.22
Change in Positive reframing	-0.14	0.06	-0.10	-2.43	0.02
Change in Planning	0.36	0.07	0.27	5.37	<.001
Change in Humour	-0.08	0.05	-0.06	-1.50	0.14
Change in Acceptance	-0.17	0.07	-0.11	-2.51	0.01
Change in Religion	0.08	0.04	0.07	1.92	0.06
Change in Self-blame	0.17	0.05	0.13	3.42	0.01

Note: Step 1 $R^2=.05$, $F(5, 764)=7.21$, $p<.001$; Step 2 $R^2=.15$, $F(19, 750)=6.96$, $p<.001$.

Table M.9*Hierarchical Multiple Regression Model of Informal Carer Psychological Distress for sample from**Europe only (n=770)*

	B	SE B	β	t	p
Step 1					
(Constant)	31.33	7.98		3.92	<.001
Age	-0.02	0.13	-0.03	-0.19	0.85
Education (less than graduate)	3.34	2.09	0.19	1.60	0.12
Relationship (spouse/ partner)	-2.37	2.85	-0.11	-0.83	0.41
Working	3.50	2.21	0.19	1.59	0.12
Received intervention	-5.23	2.23	-0.31	-2.34	0.02
Chronic illness	5.25	2.09	0.29	2.52	0.02
Cohabitation	-0.08	2.70	0.00	-0.03	0.98
Hours of contact	-0.01	0.02	-0.04	-0.28	0.78
COVID-19 anxiety	0.52	0.43	0.15	1.20	0.24
Perceived social support	-2.25	0.95	-0.30	-2.35	0.02
Step 2					
(Constant)	19.15	10.83		1.77	0.09
Age	-0.04	0.14	-0.04	-0.26	0.80
Education (less than graduate)	1.36	2.10	0.08	0.65	0.52
Relationship (spouse/ partner)	-5.98	3.15	-0.27	-1.90	0.07
Working	6.42	2.24	0.35	2.86	0.01
Received intervention	-2.79	2.24	-0.17	-1.25	0.22
Chronic illness	5.10	2.11	0.28	2.42	0.02
Cohabitation	-0.24	2.62	-0.01	-0.09	0.93
Hours of contact	-0.02	0.02	-0.11	-0.76	0.45
COVID-19 anxiety	0.47	0.39	0.13	1.22	0.23
Perceived social support	0.10	1.15	0.01	0.08	0.93
Self-distraction	0.70	0.65	0.12	1.08	0.29
Active coping	-0.22	0.78	-0.04	-0.28	0.78
Denial	0.14	1.00	0.02	0.14	0.89
Substance use	-1.28	0.78	-0.20	-1.64	0.11
Use emotional support	-3.54	1.08	-0.69	-3.28	<.01
Use instrumental support	3.43	0.99	0.69	3.47	<.01
Behavioural disengagement	-0.03	0.63	-0.01	-0.05	0.96
Venting	-0.05	1.01	-0.01	-0.05	0.96
Positive reframing	-0.18	0.73	-0.04	-0.24	0.81
Planning	-0.05	0.80	-0.01	-0.07	0.95
Humour	1.77	0.71	0.34	2.48	0.02
Acceptance	-1.03	0.80	-0.19	-1.29	0.21
Religion	-0.59	0.64	-0.12	-0.91	0.37

	B	SE B	β	t	p
Self-blame	0.81	0.55	0.20	1.48	0.15

Note: Step 1 $R^2=.51$, $F(10, 39)=4.11$, $p<.01$; Step 2 $R^2=.79$, $F(24,25)=3.98$, $p<.01$.

Table M.10*Multiple Regression Model of Informal Carer Positive Mental Well-being for sample from Europe only**(n=770)*

	B	SE B	β	t	p
Step 1					
Constant	4.11	21.97		0.19	0.85
Age	0.17	0.35	0.08	0.50	0.62
Education (post-graduate)	2.52	6.22	0.05	0.41	0.69
Relationship (spouse/partner)	-0.47	7.92	-0.01	-0.06	0.95
Received intervention	13.49	6.15	0.32	2.19	0.03
Chronic illness	-9.99	5.84	-0.22	-1.71	0.10
Cohabitation	-5.78	7.49	-0.13	-0.77	0.45
Hours of contact	0.05	0.06	0.16	0.94	0.35
COVID-19 anxiety	-0.02	1.19	0.00	-0.02	0.99
Perceived social support	5.19	2.69	0.28	1.93	0.06
Step 2					
Constant	1.82	27.66		0.07	0.95
Age	0.28	0.37	0.12	0.75	0.46
Education (post-graduate)	-4.30	6.69	-0.09	-0.64	0.53
Relationship (spouse/partner)	9.41	8.14	0.17	1.16	0.26
Received intervention	7.14	5.77	0.17	1.24	0.23
Chronic illness	-13.18	5.49	-0.29	-2.40	0.02
Cohabitation	0.34	6.84	0.01	0.05	0.96
Hours of contact	0.03	0.05	0.09	0.55	0.59
COVID-19 anxiety	0.56	1.01	0.06	0.56	0.58
Perceived social support	3.28	2.99	0.18	1.10	0.28
Self-distraction	-2.63	1.85	-0.18	-1.42	0.17
Active coping	-3.04	2.04	-0.24	-1.49	0.15
Denial	-0.07	2.60	0.00	-0.03	0.98
Substance use	-0.01	2.02	0.00	-0.01	0.99
Use emotional support	5.74	2.60	0.45	2.20	0.04
Use instrumental support	-5.89	2.37	-0.48	-2.48	0.02
Behavioural disengagement	0.02	1.65	0.00	0.01	0.99
Venting	-2.20	2.69	-0.12	-0.82	0.42
Positive reframing	-1.07	1.92	-0.10	-0.56	0.58
Planning	1.87	2.11	0.15	0.89	0.38
Humour	0.13	1.82	0.01	0.07	0.95
Acceptance	7.98	2.22	0.58	3.59	<.01
Religion	0.41	1.58	0.03	0.26	0.80
Self-blame	-1.37	1.41	-0.14	-0.98	0.34

Note: Step 1 $R^2=.22$, $F(9, 40)=2.47$, $p<.05$; Step 2 $R^2=.76$, $F(23, 26)=3.56$, $p<.01$.

Table M.11*Regression of Use of Coping Strategies onto Change in Caregiver Stress due to COVID-19 for sample**Europe only (n=770)*

	B	SE B	β	t	p
Step 1					
(Constant)	0.94	2.90		0.32	0.75
Age	0.04	0.05	0.12	0.76	0.45
Cohabitation	-0.54	1.11	-0.09	-0.49	0.63
COVID-19 anxiety	-0.17	0.18	-0.15	-0.97	0.34
Perceived social support	-0.04	0.38	-0.02	-0.12	0.91
Hours of contact	0.00	0.01	-0.02	-0.12	0.90
Step 2					
(Constant)	-2.30	3.98		-0.58	0.57
Age	0.01	0.05	0.03	0.18	0.86
Cohabitation	-1.66	1.03	-0.29	-1.61	0.12
COVID-19 anxiety	-0.24	0.16	-0.21	-1.51	0.14
Perceived social support	0.19	0.47	0.08	0.41	0.69
Hours of contact	0.01	0.01	0.15	0.86	0.40
Self-distraction	0.93	0.26	0.50	3.62	<.01
Active coping	0.16	0.31	0.10	0.51	0.61
Denial	0.23	0.37	0.09	0.62	0.54
Substance use	-0.18	0.31	-0.09	-0.59	0.56
Use emotional support	-0.24	0.40	-0.14	-0.59	0.56
Use instrumental support	0.63	0.37	0.39	1.70	0.10
Behavioural disengagement	0.27	0.27	0.16	1.00	0.32
Venting	0.05	0.40	0.02	0.12	0.90
Positive reframing	-0.28	0.27	-0.20	-1.03	0.31
Planning	0.03	0.32	0.02	0.09	0.93
Humour	-0.21	0.29	-0.13	-0.74	0.46
Acceptance	-0.28	0.33	-0.16	-0.84	0.41
Religion	-0.02	0.24	-0.01	-0.09	0.93
Self-blame	-0.35	0.19	-0.28	-1.82	0.08

Note: Step 1 $R^2=.05$, $F(5, 44)=.55$, $p<.001$; Step 2 $R^2=.56$, $F(14, 30)=2.41$, $p<.02$.

Table M.12

*Regression of Change in Use of Coping Strategies onto Change in Caregiver Stress due to COVID-19
for sample Europe only (n=770)*

	B	SE B	β	t	p
Step 1					
(Constant)	0.94	2.90		0.32	0.75
Age	0.04	0.05	0.12	0.76	0.45
Cohabitation	-0.54	1.11	-0.09	-0.49	0.63
COVID-19 anxiety	-0.17	0.18	-0.15	-0.97	0.34
Perceived social support	-0.04	0.38	-0.02	-0.12	0.91
Hours of contact	0.00	0.01	-0.02	-0.12	0.90
Step 2					
(Constant)	0.95	3.98		0.24	0.81
Age	-0.01	0.06	-0.03	-0.14	0.89
Cohabitation	-0.04	1.39	-0.01	-0.03	0.98
COVID-19 anxiety	-0.16	0.19	-0.14	-0.84	0.41
Perceived social support	0.27	0.53	0.12	0.52	0.61
Hours of contact	0.00	0.01	-0.09	-0.42	0.67
Change in Self-distraction	0.25	0.42	0.16	0.60	0.56
Change in Active coping	-0.20	0.45	-0.12	-0.44	0.66
Change in Denial	0.03	0.44	0.02	0.06	0.95
Change in Substance use	-0.11	0.37	-0.08	-0.29	0.78
Change in Use emotional support	-0.25	0.53	-0.15	-0.48	0.63
Change in Use instrumental support	0.05	0.49	0.03	0.10	0.92
Change in Behavioural disengagement	-0.08	0.52	-0.05	-0.16	0.87
Change in Venting	-0.16	0.40	-0.09	-0.41	0.69
Change in Positive reframing	0.10	0.46	0.06	0.21	0.83
Change in Planning	0.47	0.39	0.32	1.20	0.24
Change in Humour	-0.19	0.39	-0.13	-0.50	0.62
Change in Acceptance	-0.29	0.43	-0.16	-0.68	0.50
Change in Religion	0.51	0.31	0.36	1.66	0.11
Change in Self-blame	0.18	0.39	0.12	0.48	0.64

Note: Step 1 $R^2=.06$, $F(5, 44)=.55$, $p=.74$; Step 2 $R^2=.30$, $F(19, 30)=.67$, $p=.82$.