Bittersweet: Experiences of Forgiveness in Caring for a Family Member with Dementia

A thesis presented in partial fulfilment of

the requirements for the degree of

Master of Science

in

Psychology

at Massey University, Palmerston North

New Zealand.

Alexandra Quirke

2024

Abstract

Dementia is a syndrome characterised by cognitive decline and a growing public health concern, the impacts of which are felt in relationships, as cognitive changes impair a person's capacity for independent and social interaction, thus altering behaviour. Although as many as 75 percent of persons with dementia are cared for by a family member, very little is known about the experiences of those who provide this care. Even less is known about positive experiences of family caregivers, and how they adapt and cope with the challenges inherent in dementia care. This study explored the lived experience of forgiveness when caring for a Family Member with Dementia (FMwD).

This study utilised podcast interviews with 27 caregivers for a FMwD who discussed experiences of forgiveness. Episodes were transcribed verbatim. Data was analysed using interpretative phenomenological analysis. Caregivers described their experience of being called up to care for a FMwD who had harmed them in the past, of the challenges and benefits of seeking to forgive themselves for perceived inadequacies in their provision of care, and of managing dementia-related and social challenges for which they felt they could not attribute individual blame and thus, did not require forgiveness.

Findings suggest that caring for a FMwD can create unique opportunities for forgiveness which may not have been possible prior to neurocognitive decline. Overall, these findings illuminated forgiveness as only one of many positive consequences of caring for a FMwD, all of which are woven throughout this rich experience. These findings contribute to the small body of literature exploring the experiences of caregivers for a FMwD and emphasise forgiveness as a strengths-based method of adaptive coping, which can benefit caregivers and care-receivers alike.

Acknowledgements

Firstly, I want to thank my supervisor, Associate Professor Don Baken for supporting me in exploring a topic which was both intriguing and rewarding – this made all the difference. Thank you for your wisdom, understanding, and patience with my different way of working. Your feedback has been invaluable.

I want to thank the podcast host for not only consenting to my use of the podcast but also for her graciousness in encouraging me to create something meaningful.

I want to thank the caregivers who shared such challenging and intimate moments. It has been a privilege to learn from your experiences. Your resilience and sacrifice are inspiring to all who hear you. I have strived to interpret the caregivers’ words with accuracy, care, and respect, and hope to do justice to their insights and perspectives.

To my dearest friend Kern, your friendship means the world to me. I’m unbelievably grateful for you. I couldn’t have done this without you and your unwavering belief in me. No one makes me smile like you do.

To my parents, thank you for instilling in me that I can do great things. Thank you for always believing in me, for your understanding, and for answering calls at all hours. It is because you listened so intently when I spoke that I seek a career where I can empower others by listening to them.

To my brother Mike, thanks for being you and caring for everyone, especially Grandad. And to Grandad Dava, I attribute you to my determination and high standards. Thank you.

To Kay and Peta, Katherine and Lobelia, I could not have made it through this thesis without you, your belief in me, and your laughter. I am so grateful for your friendship.

I dedicate this thesis to the ever-present memory of my Nana Barb, who taught me that hard work is always worthwhile when it comes to who and what you love. You taught me that terminal illness should not feared but instead is an opportunity to appreciate and make the most of what we have. Though I didn’t get you for long, I am more like you than anyone else, and that brings me immense pride.

Table of Contents

List of Tables

Chapter 1: Introduction

Both demographic and epidemiological changes have created what is often labelled a crisis of dementia care – growing care needs, limited public resources, and inadequate support for families intersect as older persons with dementia are seen as a financial burden for health and social services (Ceci & Purkis, 2021). In a global response, organisations such as the World Health Organisation (WHO), Organisation for Economic Co-Operation and Development (OECD), as well as individual governments have asserted that the sustainability of systems necessitates the shifting of care from institutions to the home thus, delegating the work of delaying institutionalisation to families (Organisation for Economic Co-Operation and Development, 2018; World Health Organization, 2018). Exploration of the experience of those caring for a Family Member with Dementia (FMwD) remains scarce, with the bulk of research in this field conducted empirically. Forgiveness, though even less well explored in this population, is a prosocial change towards a transgressor which may promote positive outcomes for caregivers and their relationship with their FMwD.

Defining Dementia

Christopher (2023) defines dementia as *“a syndrome where the principal symptom is severe cognitive impairment that encompasses myriad domains, including memory, language, reasoning, and visuospatial processing, among other things.”* Symptoms of dementia are progressive and severe, impacting each individual uniquely. Cognitive impairment includes global cognitive issues such as difficulty concentrating, planning, problem-solving, and forming decisions. Communication, as well as visual and spatial awareness, are impaired, limiting both social interactions as well as the ability to function independently and maintain individual safety. The disease process targets areas of the brain that control higher-level cognitive functions. Cognitive impairment in dementia is further associated with psychological and behavioural challenges. Emotional disturbance tends to persist throughout disease progression, with initial stages often characterised by feelings of uneasiness and more advanced stages commonly associated with severe mood changes, including irritability and aggression (Christopher, 2023).

Dementia as a syndrome covers a number of diseases, largely differentiated by the underlying processes causing neuronal death, or pathology, as well as the brain regions affected (Henley, 2018). Alzheimer's Disease (AD) remains the most common cause of dementia, estimated to account for 60 to 80 percent of cases and is thus the focus of much dementia research (Alzheimer's Association, 2020). Other common causes of dementia include cerebrovascular disease, Lewy body disease, frontotemporal lobar degeneration, and Parkinson's disease.

Brief History of Dementia

Throughout documented history, the phenomena now known as dementia have been understood as a consequence of either older age or spiritual and/ or moral weakness (Boller & Forbes, 1998; Fletcher, 2023). There is evidence that Ancient Egyptians were aware as early as 2000 B.C. that age could be accompanied by significant memory deficits (Boller & Forbes, 1998).

The medicalisation of dementia and associated research took off in the nineteenth century, characterised by efforts to designate dementia as a discrete psychopathological entity. In particular, psychiatrists Pinel and Esquirol described patients presenting with later life experiences of broadly defined insanity and incapacity (Albert & Mildworf, 1989; Boller & Forbes, 1998). Conceptualisation of dementia was rooted in emotional pathology until 1864, when in the first major neuropsychological explanation of dementia Wilks (1864) described the phenomena as rooted in observable brain atrophy. The phenomena were later delineated into 'pre-senile dementia' in under 60s and 'senile dementia' in over 60s – with the latter soon normalised as age-appropriate, while the prematurity of the former indicated a pathological basis (Yang et al., 2016).

Diagnosing Dementia

Age-associated progressive dementia was listed in the DSM-1 and DSM-2 under the term "organic brain syndrome" and included only a brief description, which allowed clinicians to include a wide range of causal factors (American Psychiatric Association, 1952, 1968). The term dementia was first used in DSM-3, defined as "a loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning" (American Psychiatric Association, 1980).

The DSM-4's dementia is largely equivalent to the DSM-5's renamed major Neurocognitive Disorder (NCD), though criteria for dementia were revised to also create a separate and novel diagnosis of mild NCD (American Psychiatric Association, 2013). A diagnosis of mild NCD represents neurocognitive disturbance that has not yet reached the severity to create significant impairment or disruption to functioning.

For a diagnosis of major NCD, the DSM-5 requires that an individual demonstrate evidence of significant cognitive decline from a previous standard of performance in at least one cognitive domain; these include complex attention, executive function, learning and memory, language, perceptual-motor, or social cognition (American Psychiatric Association, 2013). Cognitive decline is based on both concern of the individual, a knowledgeable informant, or a clinician, as well as a significant impairment in cognitive performance. The DSM-5 outlines 10 etiological subtypes of major NCD including the most common cause of dementia, AD, as well as frontotemporal lobar degeneration, and Lewy body disease, to name a few (American Psychiatric Association, 2013).

Prevalence, Onset, Disease Course, and Disease Progression

The prevalence of dementia increases exponentially with age, doubling every five years once over 65 (Hugo & Ganguli, 2014). It is estimated that dementia affects 57.4 million people globally, or about 5 percent of the elderly population in 2019 (Nichols et al., 2022). This number is expected to almost double every 20 years, with dementia affecting 153 million people by the year 2050 (World Health Organization, 2017). The substantial growth in the prevalence of dementia is driven by both population growth and an ageing global population (Nichols et al., 2022). Increasing age is not only the greatest risk factor for dementia, but the only risk factor consistently indicated in those aged over 80 years (Hugo & Ganguli, 2014).

While age remains the strongest risk factor for dementia, dementia is not an inevitable consequence of ageing (Nichols et al., 2022). The 2020 update to the Lancet Commission on Dementia Prevention, Intervention, and Care outlined evidence for 12 modifiable risk factors for dementia: low education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, limited social contact, excessive alcohol consumption, traumatic brain injury, and air pollution (Livingston et al., 2020).

Podcasy and Epperson (2016) clearly summarise the sex differences across different dementias. Women are twice as likely to develop AD as men however, men do not tend to live as long following diagnosis. It appears that men are more likely to develop almost all other forms of dementia, including dementia with Lewy bodies, mixed dementia, and Parkinson's dementia. Sex differences have also been noted in manifestations of dementia diagnoses. In particular, there is greater evidence of overt aggression, comorbidity, and higher mortality rates in men. Whereas women are more likely to demonstrate emotional disturbances and levels of disability (Sinforiani et al., 2010).

Disease course. The broad range of research defines the progression of dementia as heterogeneous both within and between PwD, originating from both disease characteristics, as well as characteristics of the PwD (Melis et al., 2019). Whilst numerous theories outline stages of AD, it is increasingly clear that both the clinical symptomatology and underlying pathophysiological process of AD are best conceptualised as a continuum, in which these processes may evolve in parallel but temporally offset trajectories (Sperling et al., 2011).

Behavioural and Psychological Symptoms of Dementia. Behavioural and Psychological Symptoms of Dementia (BPSD) present unique challenges to the experience and management of AD. BPSD refers to a heterogeneous group of symptoms including altered perception, thought content, affect or behaviour which commonly occur in PwD (Cerejeira et al., 2012).

The vast majority of PwD will develop at least one or more BPSD across the disease course (Savva et al., 2009). BPSD are associated with a significant burden for both the PwD and their caregivers, sometimes more so than the functional and cognitive decline characteristic of dementia (Tible et al., 2017). BPSD may present in the form of aggression, agitation, apathy, depression, anxiety, delusions, hallucinations, sexual or social disinhibition, and other behaviours which may be considered inappropriate (Kales et al., 2015). Thus, stereotypical depictions and understandings of the unruly PwD are largely based on the presentation of BPSD. BPSD can have significant consequences, including worsening cognition and progression to more severe stages of dementia (Romero & Garrido, 2018).

Though like dementia itself, the prevalence of BPSD is highly individual, with noted differences across samples and cultures (Javadpour et al., 2017).

Despite the highly personal experience of dementia, trends have been noted in the experience of BPSD, particularly in relation to dementia severity. Aggressive behaviours tend to increase with dementia severity, with peak prevalence found in the profound and terminal illness stages (Chen et al., 2000). Both anxiety and affective symptoms appear to be more common in the early stages (Chen et al., 2000; Javadpour et al., 2017). Anxieties and phobias appear to be more common in the mildest stages of AD. While affective disturbances are common at all stages, prevalence seems to peak in the very mild to mild stages. Activity disturbances such as wandering and inappropriate behaviours were most common in the middle stages. Paranoid and delusional ideation appeared to also peak in the middle stages (Chen et al., 2000). Despite these noted trends, the experience of BPSD remains highly individualised and regardless of symptom sequencing, contribute significantly to the burden associated with both dementia and dementia care.

Theories of the Psychological, Emotional, and Social Consequences of Dementia

Psychodynamic Theories. Psychodynamic theories conceptualise dementia as resulting in weakened ego functioning with decreased mastery over the environment and greater dependency (Javed & Kakul, 2023). Ego is central to our ability to act in congruence with our values and self-perception. As the disease progresses defence mechanisms are believed to fail, and the individual transitions from being largely ego-syntonic to ego-dystonic (Unterbach, 1995). This progression is characterised by dependency, distress, agitation, and despair, as the self is no longer recognised.

Social Theories. The brain has no pain receptors, and so as a disease of the brain dementia is often silent and painless, sometimes going undiagnosed for years; it is in this sense that the qualitative literature theorises dementia as a social experience (Macdonald et al., 2018). In particular, the impacts of dementia are felt in relationships, as cognitive changes impair a person’s capacity for independent and social interaction, thus altering behaviour. Though this perspective on dementia care is increasingly recognised, research remains rooted in understanding the brain, with limited attention to acquiring the knowledge, skills, and attitudes that will improve the social experience of living with dementia (Macdonald et al., 2018).

Attachment Theory is a widely recognised framework for understanding the aetiology of dementia. Attachment is defined by Bowlby (1980) as an enduring affectional bond of substantial intensity with a significant other. Attachment bonds are considered integral for personality development, emotion regulation, and mental health (Bowlby, 1988). Though these bonds are established by interactions with the primary caregiver(s) in childhood, attachment patterns endure into adulthood and are activated especially in times of vulnerability and stress (Cherry et al., 2013). Thus, infant attachment is believed to inform long-term attachment, which determines adult social behaviour and emotion regulation strategies (Bowlby, 1988).

It is believed that early attachment may contribute to the development of dementia or lack thereof. In particular, it is hypothesised that our ability to engage in social activity, as informed by early attachment, may be protective against cognitive decline especially due to the variety and coordination of cognitive skills necessary for social engagement (Browne & Shlosberg, 2006; Walsh et al., 2019). This relates to theories of social support, in which the quality of social support impacts the later occurrence of dementia, to a greater degree than the quantity of social support (Amieva et al., 2010).

The experience of dementia may also be explained in terms of Attachment Theory. In particular, attachment is directly linked to the human response to fear, as is plainly evident during threats or actual separation (White, 2018). As adults we develop skills to self-soothe, internalising the attachment relationship. However, disorientation and subsequent lack of confidence as characteristics of cognitive decline and memory loss increase the experiences of fear and anxiety in PwD. Thus, PwD commonly demonstrate care-seeking behaviours relative to this fear and anxiety, many of which are reminiscent of infant attachment-seeking behaviours, including vocalising and crying out, shadowing, and smiling (White, 2018). However, not only are dementia behaviours reminiscent of early attachment seeking, but an individual’s experience of dementia may be shaped by their historic attachment orientation. In particular, PwD with a secure attachment history have demonstrated more positive relationships throughout their illness relative to those with insecure historic attachment, similar to outcomes of adult relationships (Perren et al., 2007).

Dementia Caregiving

Background

Settineri et al. (2014) define a caregiver as someone responsible for providing care to a person whose health is impaired by illness, accident, or older age. As noted above, caregiving often falls to the impaired person’s partner, family, or friends who are referred to as informal caregivers, and offer often unpaid assistance with their activities of daily living (Revenson et al., 2015). There is no one description for the role of the familial caregiver, though caregiving generally requires logistic tasks such as personal cares, housekeeping, medication administration, and processing financial payments (Lindeza et al., 2024). It has been previously estimated that as much as 75 percent of all dementia care is provided informally by family or friends (Schulz & Martire, 2004). About two-thirds of informal dementia care is provided by women, almost 30 percent of caregivers are age 65 or older, and over half of caregivers’ report caring for a parent with dementia (Alzheimer's Association, 2020).

Caregivers are fundamental to positive outcomes for the PwD. Particularly as the PwD loses independence with disease progression, caregivers often become the primary social contact for the PwD. Caregivers are thus uniquely placed to promote the QoL of the PwD by both providing physical and emotional support, as well as recognising and managing challenging behaviours by which the PwD may harm themselves (Gitlin et al., 2012; Kales et al., 2015). Thus, without caregivers, PwD would have a poorer quality of life, require institutional care at a younger age or stage of disease progression, and the cost to national economies would be substantial (Smits et al., 2007). Given the extent of this responsibility, it is fundamental to the wellbeing of caregivers and receivers of care that caregivers are provided adequate psychoeducation about dementia, peer-support groups, and psychological therapy if necessary (Henley, 2018). Thus, informal familial caregivers are invaluable to the person with dementia and their ability to complete activities of daily living.

Informal care provision is not without personal cost and is often stressful, time-consuming, and physically taxing, which can negatively impact the experience of caregiving, as well as the physiological and psychological outcomes of both caregiver and receiver (Zarzycki & Morrison, 2021). Dementia caregiving is widely recognised as largely more extensive and burdensome than providing care to those without cognitive impairment, with higher rates of caregiver depression when compared to samples of non-dementia caregivers (Ma et al., 2018). As dementia progresses and independence declines, there are increasing demands on caregivers to support the wellbeing of the care receiver, often leading to mounting physical, mental and financial stress for caregivers. In conjunction with this increasing burden, the caregiver often experiences an accompanying sense of anticipatory grief and loss as the disease progresses (Paun et al., 2022). Research tends to reflect this cost, with the bulk of caregiving literature exploring burden, strain, and unmet needs (Gilsensan et al., 2023; Romano et al., 2021). While the large majority of further literature seeks to educate caregivers and reduce this burden, relatively less literature (e.g., Mausbach et al., 2006; Pinquart & Sörensen, 2004) has explored the gains associated with caregiving.

A further critique of existing literature within this group is the predominant focus on generalisable, population-level analysis of the costs and benefits of caregiving, with limited exploration of individual experiences and nuances of caregiving (Ceci & Purkis, 2021). It has been suggested that this imbalance in available data is directly related to the financial burdens of dementia and dementia caregiving, with experimental and generalisable research often of greater utility to inform public as well as private sector spending (Besley et al., 2023). Literature which instead explores the individual experience of those caring for a FMwD appears to be a more recent area of academic interest. Although studies in this area are few, findings suggest that a greater understanding of this rich and nuanced experience would inform targeted interventions to support caregivers in this onerous role, producing significant benefits for caregivers and care-receivers alike (Lloyd et al., 2016; Monteiro et al., 2024; van Wijngaarden et al., 2018).

Social Psychology Theories of Dementia Caregiving

Stress and Coping Theory. Lazarus and Folkman’s stress and coping framework is prominent in dementia caregiving research (Ar & Karanci, 2019). Lazarus and Folkman’s

(1984) transactional theory of stress and coping posits that individuals are constantly appraising stimuli in their environment – a process that generates emotions. When these stimuli are appraised as stressors, in that they are threatening, challenging or harmful to us, the subsequent distress initiates coping strategies. If coping strategies resolve the stressor, this is likely to elicit positive emotions, whereas unresolved or unfavourable resolutions are likely to elicit further distress. In particular, social support resources may reduce the consequences of stressful life events associated with caregiving, whilst contributing to the preservation of psychological wellbeing (Valois & Galvin, 2014).

Attachment Theory and Dementia Caregiving. Attachment Theory is widely utilised as a framework for understanding the social and relational experiences of dementia caregiving. Diminishing ability to act independently as a function of neurodegenerative disease is believed to activate attachment affections such as an urge to seek safety and security from caregivers (Kuske et al., 2021), as well as attachment behaviours such as shadowing caregivers (Vance et al., 2008). It is theorised that attachment orientations of PwD have important consequences for their wellbeing as attachment is associated with differences in our ability to regulate stress and utilise social support (Monin et al., 2013). Thus, insecure attachment of PwD seems to have negative consequences for their own wellbeing (Monin et al., 2013). Consequences of the PwD's attachment orientation also impact the caregiving relationship, as does the attachment orientation of the caregivers themselves.

Following a dementia diagnosis, family members often experience an activation of the caregiving system, a social responsibility norm to provide care and support to those who are dependent or temporarily disabled (Nelis et al., 2014). While attachment dynamics are likely to differ across parent-child and spousal caregiving relationships, a number of trends have been observed within the small body of attachment research relating to dementia caregiving (Nelis et al., 2014; Perren et al., 2007). When followed over two years, securely attached carers reported greater levels of wellbeing than those with insecure attachment (Perren et al., 2007). Insecure attachment styles in both spousal (Perren et al., 2007) and adult child (Romano et al., 2021) caregivers have predicted carer burden as well as poor psychological adjustment. Meanwhile, some dementia caregivers with evidence of avoidant attachment have demonstrated an increased likelihood of placing PwD in formal care (Markiewicz et al., 1997). Secure attachment thus, appears to be somewhat protective from the difficulties of dementia caregiving (Reidun & Solem, 2009). Some research indicates that caregivers' attachment orientated is associated with how they perceive the psychological and physical wellbeing of the PwD, including those caregivers high in anxious attachment seem to perceive more symptoms in the PwD, though findings are limited (Monin et al., 2013).

Critically, research in this area seems to be sparse and often dated. This may indicate that dementia caregiving remains largely unchanged from previous decades, though findings have been applied to contemporary research with care, nonetheless. Notably, the complexity of dementia behaviours and the unique nature of familial caregiving limits the degree to which attachment research relating to caring for family with other conditions of old age, and within formal caregiving samples can be generalised to the phenomenon of interest. As mentioned above, dementia-related changes – often described as a regression into a childlike state of dependence – activate the caregiving system in family members, a phenomenon largely specific to caring for a FMwD (Nelis et al., 2014). Cognitive changes activate attachment similarly in the PwD, including diminished orientation to the outside world, as well as reduced capacity to store and retrieve memory, limiting the degree to which attachment research of other conditions can be applied to dementia populations (Chen et al., 2014). Thus, the nuances of dementia and dementia care limit the transferability of attachment findings from other disorders of age or caregiving populations, exacerbating already limited access to research relating to this phenomenon.

Altruism. Though there are many definitions, this paper takes a social perspective in utilising the definition by Bykov (2017) of altruism as a moral norm that implies particular social expectations of helping others across a range of social contexts. Altruism qualitatively differs from prosocial behaviour, which, when defined from the same social perspective, more broadly refers to behaviour that is expected and valued by society (Dovidio, 1984), whereas altruism specifies that this behaviour promotes the welfare of others. Three prominent theories relating to altruistic behaviour can be applied to caregiving. These include norms of social reciprocity and social responsibility, as well as Social Exchange Theory.

Gouldner (1960) outlines reciprocity as both a norm and universal aspect of the moral code – that people are inclined to help, not harm, those who have helped them. The reciprocity norm can be applied to understanding the sacrifices made by adult children to care for parents with dementia, as reciprocating the parental sacrifices made throughout their childhood (Evandrou et al., 2018). When perceived that the recipient is unable to reciprocate what they receive, caregiving is instead theorised to be driven by norms of social responsibility.

Norms of social responsibility suggest a moral expectation to care for those dependent on us, without regard for future exchanges (Berkowitz, 1972 as cited in Myers, 1983). While more commonly applied to interpreting selfless acts towards strangers in need, social responsibility may help explain decisions to provide care towards those who have not cared for us in the past.

The basic tenets of Social Exchange Theory (SET) state that individuals seek to maximise both rewards and minimise costs in relationships with others (Blau, 1986; Homans, 1961). When the costs and benefits in a relationship are equal, the relationship is defined as equitable. When there is an imbalance in costs and benefits, the relationship is unlikely to be sustainable. SET thus suggests that when caregiving both improves life satisfaction and promotes successful aging for the care-receiver, the caregiver must feel that they are receiving some reward in return for their sacrifice (Lowenstein et al., 2019).

The caregiving relationship is unique as unlike other social relations, it is imbalanced by the care-recipient’s dependence on the caregiver, particularly as this tends to create a physical, emotional, and financial burden on the caregiver (Naim et al., 2021). On the basis of SET, resentment is a natural response to the costs associated with caregiving, and while expectedly common, SET posits that resentment can be prevented by sufficient emotional gain for the caregiver (Callaby et al., 2012). Thus, when balanced, social exchange can promote improved wellbeing for both caregivers and recipients of care.

Familial Caregiving

While caregiving, in general, is associated with numerous forms of burden, including stress, chronic health issues, low subjective wellbeing, and negative affect, these factors can be exacerbated when caring for a Family Member with Dementia (FMwD). When comparing measures of burden to samples of family caregivers for non-demented persons, caregivers of FMwD report a greater burden – indicating that taking on the responsibility of caring for a FMwD is particularly burdensome (Pinquart & Sörensen, 2003). Despite this heavy responsibility, Positive Aspects of Caring (PAC) such as hope (García-Castro et al., 2022) and greater self-esteem (Jütten et al., 2020) among caregivers are associated with less stress and burden of caring. In addition, family members report factors such as love and reciprocity as primary motivators for taking on the responsibility of caring for a FMwD (Greenwood & Smith, 2019).

Caregiver Burden. Research indicates caregivers for FMwD experience significant burden. In a large population-based study of dementia caregivers in the UK, burden was not only highly common (71 percent reported high burden) but significantly associated with both psychological resilience and anticipatory grief of caregivers (Gilsenan et al., 2023). Despite such burden, a sample of caregivers was found to be no more likely than the general population to develop a range of chronic health conditions (Sabatini et al., 2024). However, more neuropsychiatric symptoms in the PwD were associated with a greater number of health conditions experienced by the caregiver at the study baseline. Study methodology prevented analysis of causation for these findings thus, this association could be the result of any number of intersecting factors. In another study of 89 caregivers for a FMwD, carer anxiety, as measured using the Generalised Anxiety Scale-7 was the only significant independent variable that predicted caregiver Quality of Life (QoL), whilst other variables, including burden, depression, and care receiver neuropsychiatric symptoms, did not (Contreras et al., 2023). These findings derived from one of the first studies to examine caregiver QoL using a measure that focused on capability over functionality. Capability is a more holistic measure of wellbeing that determines QoL based on the individual’s ability to do things that make them feel valued rather than in terms of functionality as a measure of strictly physical health. Assessing the burden of caring for a FMwD within this more inclusive conceptualisation of QoL may have contributed to this unique finding of caregiver anxiety as the only significant predictor of QoL. This finding suggests interventions to directly target anxiety during the dementia journey should have a significant impact on caregivers' ability to do things that are important to them, thus, improving their QoL and capacity for caregiving.

Dementia caregivers have described caring as eroding their sense of self and ability to feel close to their relative, with an overarching theme of feeling tied down to their FMwD. Additionally, caregivers have described feeling like slaves (Moreno-Cámara et al., 2019) or prisoners (van Wijngaarden et al., 2018) of the PwD, with references to the significant freedom lost as a consequence of caregiving. Spousal caregivers, in particular, have described loneliness stemming from a loss of reciprocity or equality in their spousal relationship, as well as an inability to relate to them or imagine their world (Gallego-Alberto et al., 2022; Pini et al., 2018; Tuomola et al., 2016; van Wijngaarden et al., 2018). The latter has been associated with feelings of grief and perceived failure, as carers interpret their growing inability to relate to their spouse as indicative of not meeting the duty of care to their loved one (Pini et al., 2018). Interestingly, carers seem to more commonly attribute this diminishing ability to empathise to personal deficits, with very few reflecting on this experience as a consequence of the insidious nature of cognitive decline. Male caregivers were more likely to report feeling lonely, whereas female caregivers reported relatively higher levels of perceived burden (Bramboeck et al., 2020). While this distinction may be associated with greater proportions of female caregivers reporting more direct involvement in caring than males, findings remain inconsistent across samples (Beeson et al., 2000).

A complex emotion shown to feature early in the dementia caregiving process, which persists, grows, and appears to be a key factor throughout, is resentment (Chung et al., 2008). In interviews, caregivers have described the struggle to prevent or curb a sense of bitterness at what is being imposed on their lives by the FMwD (Callaby et al., 2012; Chung et al., 2008). The propensity of the mind to generalise makes it difficult for caregivers to abandon thoughts that some of the difficult behaviour of the FMwD may be due to the 'real' person, and to resist linking present behaviour with slights and hurts of the past (Callaby et al., 2012). Case studies of spousal caregivers in the UK report resentment as a predominant psychological factor conducive to burnout in those observed (Callaby et al., 2012).

Grief and regret appear to be near-universal experiences throughout dementia caregiving. Anticipatory grief was consistently described in relation to the ever-present awareness that despite the challenges of caring, carers were losing the PwD more and more each day (Ali & Bokharey, 2015; Mwendw et al., 2021; Pini et al., 2018). This prolonged grief is recounted by caregivers as exacerbated by the stress and burden of caring and has, in some cases, seemed to propagate negative thoughts and thought patterns, including catastrophising (Ali & Bokharey, 2015). Notably, fantasising or momentarily hoping for the death of the PwD appears to be a shared experience in the context of caregiver burnout and hopelessness (Moreno-Cámara et al., 2019; van Wijngaarden et al., 2018). Despite the prevalence of these experiences, such thoughts seem to remain deeply taboo and, as such, are almost always followed by shame, guilt, and regret. Similar experiences are shared by those caring for parents with dementia who disclose grieving time lost with their own children or spouses at the expense of caring, followed directly by shame for such thoughts (Ali & Bokharey, 2015; Tuomola et al., 2016). The stress associated with both grief and regret has been linked to poor physical and mental health, including self-esteem among dementia caregivers (Ali & Bokharey, 2015).

Despite largely positive connotations, increased empathy has, in some research, demonstrated a negative relationship between increased empathy and psychological wellbeing in dementia caregivers. Findings are solely linked to affective empathy, defined as feeling what another person feeling, rather than cognitive empathy, which describes the ability to understand or know what another is feeling (Decety et al., 2011). Even when controlling for known risk factors of mental illness, greater affective empathy has demonstrated associations with increased mental health difficulties among some dementia caregivers (Hua et al., 2021; Jütten et al., 2019). It is theorised that this heightened ability to feel and share the emotions of others may make particularly empathetic caregivers especially prone to sharing in the distress of the care receiver – creating a type of vicarious distress which can limit the ability to care or express concern for another (Hua et al., 2021; Williams et al., 2014). Notably, these findings remain significantly outweighed by the bulk of caregiving literature, in which empathy is associated with positive outcomes, including improved coping and reduced mental health concerns. This contrast is likely related to the predominant basing of previous research on cognitive definitions of empathy, which have consistently demonstrated associations with positive measures of wellbeing in familial caregivers (Lee et al., 2001), as well as other samples such as healthcare professionals (Hojat et al., 2011). Findings suggest affective empathy as a promising target for caregiver psychoeducation to reduce distress and improve caregiving outcomes.

With regards to sociodemographic factors, it appears that no one gender, racial or ethnic group of dementia caregivers avoids burden (Liu et al., 2022). Women, and particularly daughters, seem more likely to report experiencing emotional burden, a finding which is since theorised to relate to social desirability and the additional role expectations women face whilst caregiving (Huertas-Domingo et al., 2023). Such emotional burden is also associated with guilt over perceived inadequacy to meet these unrealistic intrapersonal and social expectations.

Positive Aspects of Caregiving (PAC). Empirical research into PAC appears to be few and far between. The literature review yielded limited studies seeking to examine positive factors; instead, positive factors were sparingly mentioned within predominantly deficit-focused findings. Available literature appears to largely focus on caregiver strengths in relation to burden, rather than positive outcomes or experiences of caregiving.

Caregivers who report greater PAC are more likely to report both lower levels of depression and anxiety, as well as less feelings of being affected by their FMwD's behaviour (Mausbach et al., 2006; Pinquart & Sörensen, 2004). Those with lower levels of educational attainment have demonstrated greater perceived benefits (García-Castro et al., 2021) and reduced burden (Devi et al., 2020) from caregiving, relative to those with higher educational attainment. These findings, though unexpected, have been reported over the last two decades. It has been theorised that those with higher educational attainment may perceive a greater status differential between their role as a professional and their role as a caregiver, or that it may be harder for this group to perceive benefits from caregiving as they are accustomed to more mentally stimulating tasks (Kramer, 1997; Pöysti et al., 2012).

Caregivers who reported greater hope (García-Castro et al., 2022) and those who described themselves as having more positive attributes and strengths were more likely to report positive perceptions of the caregiving experience (García-Castro et al., 2021). Similarly, caregivers with higher self-esteem reported lower depressive symptoms and a better relationship with the care recipient (Jütten et al., 2020), findings which may also reflect those with more secure attachment orientations. Notably, positive conceptualisations of caring have also been associated with a reduced likelihood of institutionalising the PwD (Roff et al., 2004). Thus, the relational nature of caring allows the PAC to flow from the caregiver to improve the care receiver's experience.

Motivations for Caregiving. Literature is beginning to explore motivations for, and meaning derived from providing care for a FMwD, which seem to be associated with outcomes for both caregivers and care-receivers. A systematic review of motivations for providing care to a FMwD determined similar motivations across spousal and adult child caregivers, including a mixture of reciprocity, love, duty, responsibility, family values, and obligation (Greenwood & Smith, 2019). Particularly in Eastern cultures, caregiving remains tied to gender roles and part of the female identity (Eriksson et al., 2013; Wallhagen & Yamamoto-Mitani, 2006). The principle of filial piety emphasises honour and devotion to parents, implying a responsibility of adult children to make sacrifices for their parents or family (Sun et al., 2012). While this principle originates in Chinese and other Asian cultures, similar motivations for caring have been referenced in the USA (Harris, 1998), UK (Lin et al., 2011), and the Netherlands (van Wezel et al., 2014), demonstrating cross-cultural commonalities in motivation.

Unwillingness to care for a FMwD, or the perceived lack of choice regarding this, has been associated with higher rates of abuse towards care receivers (Camden et al., 2011). Similarly, family who characterised their caregiving as predominantly driven by external rather than personal motivations have also reported greater emotional health difficulties (Monteiro et al., 2024; Romero-Moreno et al., 2011). Thus, caring for a FMwD when not internally motivated may risk harm to both the PwD and the caregiver themselves.

Despite the significant burden associated with caring for a FMwD, many still reflect on caregiving as a rewarding experience with numerous personal and relational benefits (Nizarl et al., 2022). It appears that caregiving is commonly perceived as an opportunity to find meaning, purpose, and humanity amongst the challenges inherent to dementia (van Wijngaarden et al., 2018). In contrast to a loss of reciprocity which seems to be a frequent theme among spousal caregivers, adult children on average appear more likely to frame caring for parents as a form of reciprocity or mutual care – making up for the parental sacrifices made to provide for them as children (van Wijngaarden et al., 2018). While some report experiencing gratitude during their caregiving journey, it appears that many only reach such peace following a period of grief and reflection, allowing distance from the pain and suffering characteristic of dementia caregiving (Angelica, 2013; Nizarl et al., 2022). Positive conceptualisations of the caregiving experience, particularly the ability to find meaning, have been associated with lower levels of depression and burden, as well as an improved ability to manage (Lloyd et al., 2016).

In a handful of cases, a dementia diagnosis appears to create an opportunity for caregivers to experience a previously strained relationship in a new, more positive light. In particular, it appears that in some cases, as a by-product of memory loss the PwD can forget past grievances or estrangement, providing caregivers with a previously unattainable opportunity to experience a close relationship (van Wijngaarden et al., 2018). This experience is eloquently summarised as dementia removing a mask (Angelica, 2013; van Wijngaarden et al., 2018). Thus, caregivers may be motivated to provide care despite a historically strained relationship by the hope that dementia-related changes provide an opportunity for a positive relationship with a family member which had, by manner of situational or dispositional factors, been previously unattainable. Notably, however, reports of this phenomenon seem to be exceptionally rare, and the present review could only locate accounts by two caregivers – one of which comprised only two statements (Angelica, 2013; van Wijngaarden et al., 2018). It is theorised that the selflessness and strength of character required to take on a caregiving role despite a strained relationship likely contribute to the paucity of these experiences in literature.

In summary, a large portion literature remains focused on the negative outcomes of caregiving. In particular, almost all literature reviewed sought to undertake a balanced exploration of the experience of dementia caregiving, though produced predominantly negative findings. Only a single paper by Ali and Bokharey (2015) was noted to have sought to explore specifically negative features and experiences of dementia caregivers, with a study focused on maladaptive cognitions in caregiving. That findings are largely weighted toward deficits despite balanced approaches to exploring this phenomenon likely reflecting the significant burden and anticipatory grief associated with the progressive decline of dementia. However, these findings also indicate significant potential for dementia caregivers to benefit from strengths-based, positive psychology research which seeks to empower caregivers by building from positive experiences.

A further limitation to the literature which attempts to understand dementia caregivers is undoubtedly the reliance on quantitative literature to explore what is ultimately a subjective experience (Lloyd et al., 2016). Furthermore, by attempting to identify factors that can be generalised across caregiving situations, many of the nuances of the caregiving experience are lost. Thus, understandings of caring for a FMwD have much to gain from qualitative literature.

Forgiveness

Defining Forgiveness

Forgiveness is a relatively new area of psychological research, having previously been considered the domain of theology and philosophy (Strelan & Covic, 2006). The inception of forgiveness studies is traced to Smedes (1984) book *Forgive and Forget: Healing the Hurts We Don't Deserve*. Smedes is believed to be one of the first to assert that forgiveness does not need to be religiously motivated, and he outlines the benefits of forgiveness to the forgiver. Early researchers struggled to define forgiveness, though tended to agree on what forgiveness is not. In particular, forgiveness is widely understood as distinct from condoning, excusing, justifying, pardoning, forgetting, and (often) reconciling (Freedman, 1998). Most researchers, however, agree that forgiveness necessitates a prosocial change in thoughts, emotions, motivations, or behaviours (McCullough et al., 2000). Of the definitions of forgiveness reviewed, all define forgiveness as an intrapersonal process, though only some also necessitate an interpersonal element to forgiveness.

The current research utilises McCullough and colleagues' (2000) simple yet inclusive definition of forgiveness as "intraindividual prosocial change toward a perceived transgressor that is situated within a specific interpersonal context" (p. 9). This definition recognises forgiveness as an internal experience of the offended person, to which contextual variables and interpersonal context can be assessed on their own merits (Worthington, 2019). Thus, utilising an intrapersonal definition of forgiveness allows the offended person grace to focus on forgiveness as empowering to the self, while making an informed decision about reconciliation with the offending person. It is for this reason that forgiveness research supports an intrapersonal definition of forgiveness, particularly in clinical psychology, to empower victims to focus on their own wellbeing before addressing interpersonal concerns (Worthington, 2019). Fundamentally, intrapersonal forgiveness is a response different from justifying, excusing, accepting, and condoning, as each of the latter requires ceasing to see the act in question as wrong (Allais, 2023). Contrary to early beliefs, forgiveness is also distinct from an absence of unforgiveness.

Unforgiveness is defined as a complex combination of delayed negative emotions – resentment, anger, bitterness, hostility, and hatred – towards an individual who has transgressed personal boundaries (Worthington & Scherer, 2004). Immediate negative responses to a transgression tend to include anger, fear, or both. Unforgiveness, in contrast, is a more nuanced and limited response to a transgression which is thought to arise from anger, rather than fear or frustration (Worthington & Scherer, 2004). Worthington and Wade (1999) explain that while anger is commonly experienced in immediate response to a transgression, only those who ruminate angrily – and possibly anxiously, and depressively – will likely progress to a state of unforgiveness. The victim of a transgression may reduce or avoid unforgiveness in a number of ways, one of which is reaching forgiveness. Other processes include retaliation, successful completion of revenge, seeking social or political justice, or using psychological defences such as projection or denial (Worthington & Wade, 1999).

Interpersonal Forgiveness. In addition to being intrapersonal, forgiveness is largely an interpersonal and social phenomenon. Enright et al. (1998) define interpersonal forgiveness as “a willingness to abandon one’s right to resentment, negative judgement, and indifferent behaviour toward one who unjustly injured us, while fostering the undeserved qualities of compassion, generosity and even love toward him or her” (pp. 46-47). Interpersonal conceptualisations of forgiveness are generally associated with more collectivist worldviews which promote social cohesion and connectedness over individualism

(Hook et al., 2012). A concept in close proximity to interpersonal forgiveness is reconciliation, which refers to the restoration of a fractured relationship (Freedman, 1998).

Self-forgiveness. Self-forgiveness is defined by (Tangney et al., 2005) as a process of letting go of resentment toward the self for a perceived wrongdoing. Thus, self-forgiveness is an intrapersonal process, relevant to when one is perceived to have transgressed against one's own values. Self-forgiveness is a process where without denying responsibility for one's actions, a person works to reduce self-condemnation and its associated cognitive, behavioural, and emotional consequences, and does so in a manner that is likely to prevent future value breaches (Woodyatt et al., 2017). It has been argued that self-forgiveness is more difficult to attain than forgiveness of others (Pandey et al., 2023). In particular, the perceived transgression may lead to self-defeating or ruminating thoughts, as well as guilt and shame which may create negative affect, withdrawal, lowered self-esteem, and hopelessness (Hall & Fincham, 2005; Wohl & Mclaughlin, 2014). On the other hand, self-forgiveness is said to facilitate alignment with ones higher self, raising awareness for the range of rewards of forgiveness, and helps to understand the processes and experience of forgiveness; in this sense, self-forgiveness often serves as a pre-requisite for forgiveness of others (Pandey et al., 2023).

Decisional and Emotional Forgiveness. The role of emotion in forgiveness is emphasised by Worthington & Sandage (2016) in their distinction between decisional and emotional forgiveness. Decisional forgiveness is an interpersonal process, defined as a behavioural intention statement that an individual will reject revenge and avoidance, and consider resuming interaction if the threat of future harm can be prevented. Notably, decisional forgiveness can be granted whilst maintaining a grudge against the transgressor, as long as the individual refrains from acting on this grudge. In contrast, emotional forgiveness is an intrapersonal process, referring to the replacement of negative and unforgiving emotions, with positive, other-oriented emotions (Worthington & Sandage, 2016). Thus, decisional forgiveness is an interpersonal choice not to engage in unforgiveness, whilst emotional forgiveness is a multifaceted internal process that involves changes to cognition, emotion, and motivation and eventually leads to behaviour change (Worthington et al., 2007).

Distinctions between decisional and emotional forgiveness are supported by empirical findings, in which emotional forgiveness has demonstrated a strong influence on subsequent attributions, impacting cognition in ways that decisional forgiveness does not (Lichtenfeld et al., 2019). While decisional forgiveness may reduce hostility, as it does not address negative emotions it also does not necessarily reduce stress responses. Emotional forgiveness, in contrast, is strongly connected to overcoming negative affect and stress reactions by cultivating positive affect, correlating to more positive health outcomes (Worthington et al. 2007).

Situational and Dispositional Correlates of Forgiveness

Psychology maintains a particular interest in 'when' people forgive namely, the situations and dispositions that correlate with victim motivations to forgive their transgressor. State or situational forgiveness is the act of forgiving a particular incident. In particular, this focuses on victim attitudes, thoughts, emotions, and moods relating to the transgressor and the transgression (Fehr et al., 2010). Trait or dispositional forgiveness is defined as a person's propensity to forgive across time, relationships, and situations (McCullough et al., 2007). Thus, dispositional correlates of forgiveness are stable individual differences of the transgressed, whereas situational correlates relate to the contexts of an offence (Fehr et al., 2010). In a meta-analysis of 185 studies, Fehr et al. (2010) outline numerous situational and dispositional correlates of forgiveness, with results highlighting the multifaceted nature of forgiveness. In line with previous theory, situational correlates accounted for a larger variance in forgiveness than dispositions of the transgressed. However, considerable within-category differences limit the implications of these findings. This section will progress from characteristics of the transgressor to characteristics of the transgression, to lastly, exploring characteristics of the transgressed.

Situational Correlates. Situational correlates outlined by Fehr et al. (2010) include responsibility and intent, apology, harm severity, rumination, positive and negative mood, state empathy, state anger, and relationship closeness, commitment, and satisfaction.

Responsibility and intent are predominantly explored within the perspective of Attribution Theory (also known as the Theory of Correspondent Inference). When applied to forgiveness, Attribution Theory (Weiner, 1995) posits that forgiveness emanates from a perception that the offender and offence are independent – that the offence was the result of circumstance rather than an act of volition. This perspective is most widely expressed through the situational constructs of responsibility and intent. Responsibility is linked to the degree to which the offender is believed to have caused the offence including their control over this. Whereas intent is centred on the offenders' goals, with intentional actions implying malice or indifference, and the same lacking in unintentional actions (Weiner, 1995). Conflict-promoting attributions that see transgression behaviour as both intentional and selfishly motivated have widely demonstrated a propensity to accentuate the perceived impact and long-term threat of a transgression, making forgiveness more difficult (Martinez-Diaz et al., 2021).

Apology is outlined as an offender-initiated reconciliation tactic intended to shift a victim's perception of responsibility and intent (Fehr et al., 2010). By communicating remorse and concern for victims' suffering, an apology encourages victims to perceive their offender as deserving of forgiveness. Apologies are largely understood as the most effective strategy in shifting victims' perceptions of their offenders, claims that are supported in the literature by positive associations with forgiveness (Kaleta & Mróz, 2021; Knight, 2018; Schumann, 2012).

Harm severity and its association with forgiveness is arguably one of the most robust phenomena in forgiveness literature, with greater harm severity negatively associated with forgiveness (Fincham et al., 2005). While both objective and subjective perspectives of harm severity have predicted forgiveness outcomes in research samples, findings indicate these contrasting perspectives are driven by distinct moderating variables. Objective harm severity has implications such as lasting harm, erosion of trust, and public humiliation, to name a few. Rejection sensitivity – the tendency to anxiously or angrily expect, perceive, and overreact to rejection – has proven significant in moderating the impact of objective harm severity on forgiveness (Downey & Feldman, 1996). The impact of subjective harm severity, in contrast, is moderated by attributions of responsibility and intent – with the nature of this relationship explored above (Berndsen et al., 2018). Thus, while harm severity is widely accepted in the literature as predictive of forgiveness outcomes, the degree to which harm severity impacts a decision to forgive will be dependent on characteristics of the forgiver, such as rejection sensitivity and individual processes of attribution (Fincham et al., 2005).

Rumination has demonstrated a propensity to inhibit forgiveness by triggering negative cognitions and emotions associated with the original offence (McCullough et al., 2007; Wu et al., 2019). In line with the mood-as-input model (Martin et al., 1993) positive moods are expected to support the perception that an offence is not a threat or issue, and thus forgivable. Negative moods, however, are more likely to signal a threat, which can facilitate unforgiveness or even seeking revenge (Fehr et al., 2010).

Cognitive empathy or empathic emotions are characterised by feelings of warmth and compassion towards another and are central to the process of forgiveness (McCullough et al., 2007). State anger is, like empathy, an other-oriented emotional experience, though it is conversely characterised by negative valence and increased activation (Barrett & Russell, 1998). Thus, anger is aligned with conflict-promoting interpersonal behaviours and has demonstrated negative associations with forgiveness (McCullough et al., 2007).

Dispositional Correlates of Forgiveness. Dispositional constructs of the forgiver, as outlined by Fehr et al. (2010), included agreeableness, perspective-taking, trait forgiveness, empathic concern, self-esteem, depression, neuroticism, and trait anger. Agreeableness is the Big Five personality factor most frequently linked to forgiveness. Agreeableness is associated with favouring cooperative and integrative techniques in conflict resolution, demonstrating positive associations with forgiveness (Brose et al., 2005). Perspective-taking involves a cognitive ability to readily consider others' points of view (Davis, 1983). Those with this trait tend to demonstrate greater insight into the actions of their perpetrators and are more likely to engage in forgiveness processes (Raj et al., 2016). As expected, trait forgiveness demonstrates a positive association as those with this disposition are more likely to interpret offences as worthy of forgiveness, and resolution as the most useful outcome (Fehr et al., 2010).

Empathic concern relates to a general ability to connect emotionally with others, and particularly to react emotionally to their suffering. Empathic concern is thus associated with prosocial behaviours such as altruism, cooperation, and forgiveness (Batson, 2023; Fehr et al., 2010). Forgiveness is associated with higher self-esteem and self-worth, as those with confidence in their self-worth experience only minor alterations to their self-concept when faced with an offence (Mróz, 2022). In contrast, those with low self-esteem and self-worth experience more extreme shifts in mood and self-concept. Like self-esteem, depression can be expected to impact forgiveness by negatively skewing affective reactions to conflict (Fehr et al., 2010).

Neuroticism is associated with a tendency to react stressfully to events, and the experience of greater negative affect when faced with negative stimuli (Lahey, 2009). Thus, those with higher trait neuroticism are likely to experience greater stress in reaction to offences, reducing the likelihood of forgiveness (Braithwaite et al., 2016). Where neuroticism predisposes individuals to negative affect, trait anger, more specifically, predisposes persons to anger, facilitating angry responses toward conflict and preventing forgiveness (Fehr et al., 2010).

Theories of Forgiveness

Attribution Theory and the Theory of Correspondent Inference. As mentioned above, Attribution Theory considers how the social perceiver utilises information to reach a causal explanation for events; it considers what information is collected, and how it is attributed to reach a judgement of cause (Fiske & Taylor, 1991). When applied to the concept of forgiveness, Attribution Theory (Weiner, 1995) suggests that attributions of responsibility and intent influence the degree of forgiveness, which subsequently alter retaliatory and reconciliatory efforts in opposing manners (Fincham et al., 2005). There are two forms of attributions: dispositional attributions, which assign the cause of behaviour to stable, internal characteristics of an individual, and situational attributions, which assign the cause of behaviour to external factors outside of an individual’s control. To elaborate, dispositional attributions of responsibility and intent reduce the likelihood of forgiveness, as harm is perceived as personal and with malice. In contrast, acknowledging situational correlates of a transgression provides context, instead focusing on the range of factors which are likely to have contributed to a transgression thus, promoting forgiveness and the reduction of personal blame. These attributional patterns have shown to similarly motivate forgiveness of self, others, as well as intrapersonal processes of forgiveness (Lichtenfeld et al., 2019).

Interdependence Theory. Thibaut and Kelley's (1959) Interdependence Theory is a versatile framework popularly applied in social psychology, and an established theory for understanding interpersonal forgiveness. Interdependence Theory is situated in a mutual exchanging of rewards and costs, managed against the expectations of each partner (Worthington, 2019). Similar to transgressions, Interdependence Theory examines dilemmas and how these create opportunities for partners to focus on either what benefits the self or benefits the relationship (Green et al., 2019). Dilemmas allow partners to determine the degree to which the other values the relationship. Thus, when a partner dependably values the relationship or the other partner over self-interest, trust is developed, which may, in turn, create forgiveness. This willingness to sacrifice in favour of the relationship is fundamental to trust and subsequent forgiveness of transgressions. Thus, repeated forgiveness manifests trust, creating a mutual experience of cyclical growth for partners, experienced both individually and relationally (Green et al., 2019). Interdependence Theory has provided a framework for understanding dynamics of forgiveness across different relationship types, such as parent-child, romantic, and workplace relationships. Though relatively similar, distinct power differentials drive varying levels of dependence in relationships which thus, promote varying degrees of motivation and expectations for forgiveness. Findings indicate that parents, particularly mothers, hold asymmetrical power even over their adult children – often in terms of both emotional and financial support – thus, unforgiveness and relational distancing is often costlier for children, relative to distancing from other family such as siblings (Breslin et al., 2017). This power is theorised to stem from the relative inability to substitute the mother-child connection.

Stress and Coping Theory. Perhaps the most widely recognised model of forgiveness remains Lazarus and Folkman (1984) seminal Stress and Coping Theory. Within this theory, forgiveness is conceptualised as analogous to coping particularly, as both processes involve reaction to and attempts to resolve stress following harm (Strelan & Covic, 2006). Findings indicate that forgiveness is largely considered to be an effective coping strategy, as its implementation is associated with improved physical health (Toussaint et al., 2019), wellbeing (Long et al., 2020), and reduced psychological distress (Strelan, 2019; Toussaint et al., 2016). While Stress and Coping Theory may inform the forgiveness experiences of some participants of the present study, the process-oriented nature of this framework makes it applicable to predominantly experimental research designs, therefore limiting utility to the present experiential study (Strelan & Covic, 2006).

Evolutionary Roots of Forgiveness. Research indicates that both revenge and reconciliation have foundations in evolution (Worthington, 2019). Ethics of fairness were central to ensuring that all members of a group received enough calories to survive. Self-serving actions that are unfair to the group result in punishment, whether immediate or through later retaliation against the offenders' kin (de Waal, 1996). Forgiveness and reconciliation are determined to be fundamental to evolution, as social groups would not survive nor advance if all offenders were harmed or banished. Reconciliatory processes thus, are adaptive, serving to maintain social integrity within a group. Evolutionary Theory has also argued for the favouring of in-group forgiveness, over out-group forgiveness. In particular, those who are perceived as valuable and trusted, such as kin, are more easily forgiven than those from outside the group who are less well-known (van Tongeren et al., 2014).

Physiological and Psychological Correlates of Forgiveness

As an emotion-focused coping skill, forgiveness has demonstrated associations with improved physiological health as well as psychological wellbeing. In a meta-analysis of forgiveness and physical health, 73 percent of the 55 studies demonstrated some indication that forgiveness has a favourable relationship with health (Toussaint et al., 2019). Whilst this may indicate that there is a robust connection between forgiveness and good health, as most of the research was correlational, it is also theorised that healthy people may demonstrate greater predispositions to forgiveness – likely due to more positive moods. In line with the relationship theorised above, empirical research indicates that trait forgiveness seems to be most important for health, with forgiving dispositions associated with greater homeostasis and reduced biological dysregulation (McEwen, 2005).

Forgiveness has been associated with improved psychological wellbeing through several indicators and mediators. Forgiveness has been indirectly linked to improved mood and social integration (Long et al., 2020; Tsang et al., 2006), including by way of reduced anger and hope for the future (Kim et al., 2022). Increased forgiveness has also been associated with reduced stress (Toussaint et al., 2016), and with decreased rumination across numerous longitudinal studies (McCullough et al., 2007). Individuals have also reported a greater sense of wellbeing and feeling as though a burden has been lifted when engaging in forgiveness (Raj et al., 2016).

While research is largely indicating that forgiveness is associated with improved wellbeing, such associations are not yet confirmed by sophisticated research designs that indicate directionality. Though overall, forgiveness is associated with less negative and more positive aspects of physical and mental wellbeing and in particular, the emotional processes seem to play an integral role in this relationship.

Review of Forgiveness in Dementia Caregiving Literature

While literature in this area remains scarce and largely quantitative, common themes include forgiveness in relation to burden, the experience of self-forgiveness, interventions to facilitate forgiveness among caregivers, and phenomenological analyses of the experience of forgiveness.

Quantitative Inquiry

Reflecting the predominant focus of caregiving research, burden is commonly explored in relation to experiences of forgiveness in familial caregivers – though findings are mixed. Questionnaires of 76 caregivers for a FMwD in Hong Kong (Cheng et al., 2013), as well as 130 Portuguese caregivers (Monteiro et al., 2024) have each indicated caregiver forgiveness as associated with lower reported burden, as well as improved quality of life in the Portuguese sample. In contrasting findings, greater caregiver forgiveness has also been associated with caring for a husband with more extensive cognitive impairment – a symptom of dementia commonly associated with higher caregiver burden (DeCaporale-Ryan et al., 2016). The latter findings support Lazarus and Folkman's (1984) Stress and Coping Theory, in which forgiveness, as an emotion-centric coping mechanism for lowering stress, reduces the propensity for caregivers to interpret their FMwD's behavioural issues as threatening. Samples of the former two studies were almost 80 percent female, indicating that the contrasting findings cannot be explained by gender differences alone thus, are instead more likely to reflect forgiveness as a complex, multifaceted experience. Self-forgiveness in contrast has been linked to measures of adaptive coping and greater social support in a survey analysis of 133 caregivers (Jacinto, 2009). While much of this literature reports an interest in caregiver experiences of burden and forgiveness, as qualitative methods are rarely utilised, findings lack richness or in-depth exploration of lived experiences (e,g,, DeCaporale-Ryan et al., 2016).

Interventions to Promote Forgiveness Among Caregivers

Since its identification as a precursor to burnout, interventions have increasingly sought to address caregiver resentment by facilitating caregivers to develop skills for forgiveness. Dementia caregivers who reported a greater capacity to forgive themselves were more likely to engage in adaptive coping strategies such as seeking support and maintaining optimism when facing stressful situations (Jacinto, 2010). Callaby et al. (2012) reports positive feedback from two pilot interventions in the UK, which sought to foster forgiveness and reduce both caregiver resentment and burnout through emotional healing. Whilst findings are presented as statistical averages rather than individual voices of a sample, the descriptions of emotional release and vulnerability indicate these experiences were likely of significant benefit to several dementia caregivers. Additionally, interventions such as the above, which equip dementia caregivers with skills to manage stress and challenging behaviours, have demonstrated greater efficacy than educational alternatives (Olazarán et al., 2010).

Qualitative Inquiry

A subset of literature in this area has explored how forgiveness might factor into the way in which dementia caregivers make meaning of their experiences. Twelve months post-death of their FMwD, caregivers have described feeling greater forgiveness and compassion for human frailties (Jameson et al., 2020). This period of grief and subsequent forgiveness appeared to foster a desire to help others, particularly those facing the caregiving journey, providing a sense of purpose in the post-care transition (Jameson et al., 2020). In an analysis of experiences of guilt among caregivers for a FMwD, though not explicitly explored nor mentioned by caregivers, themes of self-forgiveness were evident as a manner of managing guilt (Statz et al., 2022). Though only very briefly mentioned, forgiveness arose as a factor of meaning-making when exploring the role of religion and spirituality in dementia caregiving. It was the phenomenological positioning of the author that spiritual forgiveness appeared to enable some caregiving wives to find higher meaning in their experience by transcending past adverse circumstances, which had, until a dementia diagnosis, strained their marriage (Paun, 2004). Similarly, Angelica's (2013) reflection on choosing to care for her mother despite estrangement in the context of childhood sexual abuse demonstrates the unexpected relational benefits of forgiveness whilst caregiving. Across a number of these unique experiences, an inverse relationship is observed between the gradual loss of self to dementia and the caregiver's psychological growth from strictly decisional forgiveness of the care receiver to emotional and spiritual forgiveness, with reconciliation.

Summary and Rationale for the Present Study

Dementia is of growing public health concern, with increasing pressure on families to care for older generations with dementia. There is convincing evidence that caring for a FMwD is a significantly challenging role, with psychological and behavioural factors not present in caring for family with other diseases of older age. The comprehensive literature review above demonstrates the consequences associated with the emotional toll of caring for a FMwD, and the promise of some interventions to improve caregiver skills. Despite the fundamental role of family caregivers in the promoting the wellbeing of PwD, there remains limited research on the experience of familial caregivers.

Existing literature on dementia caregiving, however, does paint a largely deficit-focused picture, with emphasis on exploring experiences of loss of identity and burden. Despite this, a handful of voices speak to positive experiences of growth, love, and connection amongst the challenges of dementia caregiving, describing a rewarding experience they would not change. However, little research has examined the dementia caregiving experience with a positive psychology focus.

As mentioned, forgiveness is an adaptive and emotion-focused coping strategy associated with several physiological and psychological advantages. As a prosocial action, forgiveness is also correlated with social advantages and has been utilised in interventions to improve caregiver burnout.

A number of studies have briefly explored experiences of forgiveness, with caregivers describing greater appreciation for human frailties (Jameson et al., 2020), forgiveness as enabling transcendence of past transgressions (Paun, 2004). Self-forgiveness has arisen implicitly when examining experiences of caregiver guilt (Statz et al., 2022) and has been associated with adaptive coping and social support in survey analysis (Jacinto, 2009). To the best of my knowledge, qualitative analysis of the experience of forgiveness, rather than specifically self-forgiveness, in dementia caregiving has only been explored in a single study by (Angelica, 2013). While the study provided several rich accounts of the lived experience of familial caregiving, forgiveness was not an explicit focus but was mentioned briefly and somewhat incidentally within the experience of a single caregiver. Thus, there remains no located study with a primary focus on the lived experience of forgiveness within dementia caregiving.

This research is particularly important as it will provide a voice for caregivers, thus giving prominence to the nuances and complexities of such a challenging experience. Therefore, the present study aims to contribute to this incipient literature by creating space for novel insights into forgiveness in dementia caregiving through in-depth exploration of the accounts of spouses and adult children who have experienced caring for a FMwD. By focusing on experiences of forgiveness, the present study also aims to challenge existing deficit-focused conceptualisation of the experiences of this group. Instead, the present study aims to reframe understandings of dementia as an opportunity for connection and healing which might not have been possible without neurocognitive impairment. The primary research objectives for the present study are outlined below.

Research Objectives

The current thesis aims to meet the following objectives:

1. Explore the lived experience of those who care for FMwD, and how forgiveness is experienced within this role.
2. Explore the context in which forgiveness is experienced when caring for a FMwD.
3. Explore how caregivers make sense of forgiving the transgressions of a FMwD.
4. Explore how caregivers engage in self-forgiveness whilst caring for a FMwD.
5. Examine how forgiveness may be experienced when providing care to a FMwD who has harmed you in the past.

The thesis seeks to address these objectives by answering the stated research questions below.

Research Questions

- How does forgiveness contribute to the experience of caring for a FMwD?
- How do caregivers make sense of forgiving the transgressions of a FMwD?
- How does self-forgiveness alter the experience of caring for a FMwD?
- How does forgiveness contribute to the experience of providing care to FMwD who has harmed you in the past?

Chapter 2: Methodology and Methods

This chapter begins with an overview of the qualitative methodology used in the present study. I outline the fundamental principles of Interpretative Phenomenological Analysis (IPA) and provide a rationale for how this methodology aligns with the research aims. This is followed by a description of the procedure used to collect data. I then discuss the ethical considerations of the thesis and critically reflect on my position as a researcher. Finally, I outline the data analysis and processes of quality assurance taken throughout the study.

The Rationale for a Qualitative Approach of Inquiry

Qualitative research is generally concerned with examining, describing, and interpreting human experiences (Smith, 2015). Qualitative researchers seek to understand how participants make sense of and derive meaning from their experiences, and how this meaning is influenced by context (Pietkiewicz & Smith, 2014). Qualitative research predominantly works alongside a smaller sample, prioritising depth of analysis to capture the richness of an experience.

Qualitative analysis offers a wide range of research methods through which to examine different aspects of human experience. Phenomenological analysis, as an example, is particularly concerned with examining the lived experience of individuals. Phenomenological inquiry focuses on how people perceive and describe their experiences, with particular attention to unique elements (Pietkiewicz & Smith, 2014). Qualitative analysis is best suited to research exploring the intricacies of human experience and sense-making, as opposed to research that seeks to generalise across groups.

This research aims to understand the lived experience of people caregiving for a Family Member with Dementia (FMwD), with particular attention to experiences of forgiveness. Qualitative methodologies were therefore deemed most appropriate to examine and do justice to this complex, intimate, and nuanced phenomenon. This research will reveal insights into both shared experiences of those caregiving for a FMwD, as well as case-specific idiosyncrasies.

Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) was developed as a specifically psychological qualitative research methodology to examine how people make sense of their experiences (Willig, 2008). IPA attempts to step into the shoes of the participant and understand phenomena from their unique perspective. IPA is phenomenological in that it attends to human experience on its own terms, allowing the phenomena to speak for itself through the unedited words of the participant (Langdridge, 2007). IPA is also informed by hermeneutics, which is concerned with the interpretation of meaning (Smith et al., 2009). Hermeneutics considers how participants make sense of their experiences, and IPA is concerned with what this sense-making can reveal about both the participant and the phenomenon of interest. IPA is best suited for the analysis of phenomena that are complex or ambiguous and of significance to the participant (Smith & Shinebourne, 2012); thus, IPA is particularly suited to examining new and unique topics of inquiry. IPA seeks to understand the particular and idiosyncratic elements of an individual experience, as well as how this experience converges and diverges from others with a similar experience (Smith & Osborn, 2015). IPA draws upon theoretical principles of phenomenology, hermeneutics, and idiography; these will be detailed below.

Phenomenology

Originating with Husserl, phenomenology involves the careful study of human experience with particular attention to what is experienced in the consciousness of the individual (Langdridge, 2007). Through the use of eidetic reduction, phenomenology seeks to identify the fundamental components of phenomena or experiences that make them unique or special (Pietkiewicz & Smith, 2014). Thus, phenomenological analysis focuses on how individuals perceive or talk about experiences, rather than trying to produce an objective statement about an object or event (Smith & Osborn, 2015). This, in essence, requires disengaging from activity to reflect on the taken-for-granted experience of the world, allowing the phenomena to speak for themselves (van Manen, 2017). This practice of disengaging from activity involves a process of bracketing, in which Husserl suggests putting aside preconceptions and assumptions as central to fully realising the taken-for-granted world (Langdridge, 2007).

Hermeneutics

Husserl's phenomenology was further developed by his student, Heidegger, into existential philosophy and hermeneutics which is broadly concerned with the interpretation of meanings (Larkin & Thompson, 2011; Smith et al., 2009). Hermeneutics suggest that to interpret another we must comprehend both their mindset and use of language, which inherently mediate their experiences of the world (Larkin & Thompson, 2011). Researchers attain this insider perspective through engagement in a double hermeneutic; the researcher attempts to make sense of the participant attempting to make sense of their experience. Where phenomenology requires bracketing of preconceptions, hermeneutics acknowledges presuppositions as part of the self, as inevitably present, and as fundamental to the interpretation of the meaning (Smith et al., 2009). Thus, a richer process of hermeneutic interpretation and reinterpretation acknowledges and reflects upon one's fore conceptions in a cyclical and dynamic process. This process is similarly repeated in the hermeneutic circle, a cyclical and iterative process in which the researcher moves between an interpretation of the part and the whole, each inseparable and in relation to the other (Smith et al., 2009). In particular, to understand any given part, one looks to the whole; to understand the whole, one looks to the parts (Smith et al., 2009). Thus, the meaning of a word is only realised in the context of a complete sentence, while the meaning of a sentence is dependent on the cumulative meanings of each of its words (Larkin & Thompson, 2011).

Interpretation requires the researcher to construe meaning from the thoughts and language of participants whilst forming critical questions about the experience. IPA acknowledges that it is impossible to access the entirety of another's experience. However, through iterative interpretation of descriptive, linguistic, and conceptual components of another's experience, the researcher can develop a rich and comprehensive analysis, often revealing meaning not consciously available to the participants themselves (Smith & Osborn, 2015). To do so requires the researcher to critically reflect on and maintain awareness of their preconceptions and biases in an ongoing practice of reflexivity. This ensures that findings, though interpreted by the researcher are fundamentally grounded in the experience and actual words of the participant (Smith & Osborn, 2015). This integration of participant experience and researcher interpretation is termed a ‘fusion of horizons’, as unique meaning is formed from the synthesis of interpretations.

Idiography

Idiography is the study of the individual and the particular. IPA celebrates each individual as unique, and the product of an equally unique life experience. IPA research endeavours to appreciate the complexity of each individual case, with a commitment to the particular at two levels (Smith et al., 2009). Firstly, a commitment to the particular in the sense of seeking detail and referring to the depth of analysis. Secondly, IPA is committed to understanding how a particular experience may have been understood from the perspective of particular persons within a particular context (Willig, 2008). The researcher achieves this commitment to the individual and particular through engagement in detailed analysis of a single case, before proceeding to a subsequent case.

The level of detail and nuance required to do justice in IPA limits analysis to small sample sizes. The researcher is then challenged to construct a narrative that highlights important higher-order themes while retaining the idiosyncrasies in the lived experience of the particular participants (Larkin & Thompson, 2012). Thus, high-level IPA presents the reader with an analysis of both convergence and divergence within a sample of participants (Smith & Shinebourne, 2012).

Strengths and Limitations of IPA for the Current Study

IPA seeks to capture the individual nuance of an experience (Smith & Shinebourne, 2012). As an inductive method, IPA has several strengths. Firstly, the inductive nature of IPA provides sufficient flexibility to allow for unanticipated topics or themes to arise during the analysis (Smith, 2004). For this reason, IPA is particularly suited to examining niche phenomena, such as caregivers’ experiences of forgiveness for FMwD. IPA allows the opportunity for the researcher to approach the data with a degree of open-mindedness not attainable within other more prescriptive methodologies.

While this study did not actively engage with participants, IPA still promotes the examination of intimate experiences with respect in handling the data of participants, which is pertinent given both the phenomenon of interest and the sensitivity required in utilising secondary data. In particular, IPA advances a participant-oriented approach to research which prioritises the dignity of participants to express their lived experience as they see appropriate, without fear of distortion or persecution (Alase, 2017). This is particularly imperative when examining a phenomenon such as dementia or children who perceive hurt from their parents, which are both so deeply rooted in stigma, fear, and shame (Low & Purwaningrum, 2020). Thus, not only does IPA provide a safe space to examine this complex and likely unheard-lived experience, but it also enables a platform to contest the biomedical counter-narrative and reframing of dementia care as a unique and rewarding experience (Burles & Bally, 2018).

Thirdly, the discussion of findings in relation to extant psychological literature is a relatively unique element and strength of IPA. This inductive process of interrogating and illuminating existing research in relation to findings has produced novel contributions to psychology (Smith, 2004). It is likely this analysis will produce fresh insight into experiences of both dementia caregiving and forgiveness, contributing to the limited qualitative literature. Each of the above strengths was fundamental to the selection of IPA as the methodology for this research.

A critique of IPA is the degree to which this method can accurately capture the experiences and meanings of phenomena (Tuffour, 2017). It is questioned whether participants and researchers bear the requisite skills to successfully communicate the nuances of an experience. Subsequent concerns have been raised that eloquence may form a prerequisite for participation in IPA, enabling discrimination by level of fluency. As the present sample includes only those who have authored a form of literature as a pre-requisite of the podcast, the sample is indeed exclusive to those with fluency required for authorship, as well as those who have likely reflected more deeply on their experiences. This however, may be reframed as a strength of the current study, as established communication skills enabled caregivers to articulate the depth of their experience to the host using detailed and emotive language particularly, as most had already embarked on a search for meaning through their own writing. It would be prudent, however, that future research is designed to capture the voice of those caregivers who may be less fluent in a way that still enables examination of the richness of their experience.

Positioning

Positioning describes both the world view of an individual, the position they occupy regarding a research task, and the socio-political context of this task (Holmes, 2020). Hermeneutic research locates the researcher as integral to interpretation and the uncovering of meaning in IPA (Smith et al., 2009). The position of the researcher, thus, inevitably influences each stage of the research process, especially their interpretation of participant experiences. To be considered an 'insider' a researcher must share attributes such as an identity, language, and experiential base with their participants; in the absence of shared attributes the researcher is an 'outsider' (Dwyer & Buckle, 2009). There are several strengths and limitations to each position that necessitate consideration, with arguments for one position often raised in opposition of the other (Serrant-Green, 2002)

The insider is advantaged by privileged access to a more complete knowledge of a group, and this is argued to enable them to gather a richer set of data as well as faster acceptance by group members (Dwyer & Buckle, 2009). However, for this reason, insiders may be more likely to be confronted with issues of undue bias as their personal experiences, feelings, and thoughts are not easily separated from those of their participants (Abalkhail, 2021; Liu & Burnett, 2022). Adler and Adler (1987) argue, however, that researcher and participant distinctions are predominantly more black and white in theory than practice, and objectivity is often more challenging in analysis than data collection.

A commonly referenced limitation of outsider research is that participants can be less willing to open up to someone who has not lived this experience, which may limit the depth of experience that they divulge to the researcher (Alder & Alder, 1987). Thus, the use of secondary data is a strength of the present study as primary data has been collected by an insider, a fellow caregiver for a FMwD, which likely facilitated swifter establishment of rapport than when discussing sensitive experiences with an outsider (Asselin, 2003).

The outsider perspective, however, does not free the researcher of the influences of their preconceptions and biases, particularly in line with Adler and Adler's argument of objectivity above (Dwyer & Buckle, 2009). Awareness of personal biases and preconceptions, as well as an unwavering commitment to reflective practice throughout all stages of research is widely recognised as fundamental to maintaining participant-oriented research (Dwyer & Buckle, 2009; Holmes, 2020).

In analysing the strengths and weakness of each position, as well as the limitations of such a dichotomous perspective on more ambiguous human experience, Dwyer and Buckle (2009) advocate for occupation of the space between. Dwyer and Buckle (2009) suggest that in noting the ways that we are different from others; we must also consider the ways in which we are similar. While as researchers, we may be closer to the insider or outsider position, as our perspective is shaped by our position as a researcher who has examined much literature on the topic, we cannot fully occupy either position (Dwyer & Buckle, 2009). Occupying the space between thus aligns with IPA attention to both convergence and divergence, applying these sample principles to reflect on the engagement of the researcher with the participants and literature. Irrespective of positioning, it is fundamental that the researcher remains accountable for honouring the lived experience of participants through an ongoing commitment to practice that promotes honesty, integrity and transparency.

My Positioning

In light of the above research, I occupy the space between in the present study. I acknowledge that I am an outsider to the experience of caregiving for FMwD, and cannot attest to having lived this experience. I can, however, attest to a childhood inextricably shaped by observing my grandad provide full-time care to his wife, my nana, who struggled with Emphysema until her eventual passing when I was aged 8. Thus, I bring to this research not only compassion and empathy for caregivers and recipients of long-term care but also awareness of the depth of love and joy felt whilst caring for a family member with terminal illness. I have not lost family members to dementia; however, I lived across from a dementia care home for the first 21-years of my life, and so I have an awareness of dementia for as long as I can remember. Thus, my positionality has influenced numerous elements of the research process particularly the perspective of openness to experience from which I have viewed the experiences of caregivers.

Podcast as a Secondary Data Source

In the digital age, podcasts are gaining significant prominence amongst a wave of new media formats as a novel and rich source of qualitative data. This study explores familial dementia caregivers' experiences of forgiveness through interviews published on a publicly available podcast channel.

Within an IPA methodology, there are various strengths to using podcasts as a source of qualitative data. IPA seeks to capture the individual nuance of an experience through analysis and interpretation of both speech content and context (Smith & Shinebourne, 2012). Podcasts allow for analysis of aspects of speech such as tone, repetition, and emphasis, which enable greater depth of interpretation. In addition, the rising popularity of podcasts as a source for research and education is attributed to their capacity to promote in-depth discussions, supplying a degree of detail and access to unique experiences often lacking in traditional media (Kulkov et al., 2024). In the present research, podcasts allowed access to a wider range of voices spanning continents, ages, timeframes, and cultures than the researcher could have possibly gathered on their own. Ultimately, this ensured that the perspectives captured in this research were not constrained by a particular local culture or belief system but instead are likely to be more representative of the general population.

Further to the above discussion of positioning, a subset of podcasts, such as the series examined in the present study, specifically interview persons who have experienced a particular phenomenon in which the host also has lived. These podcasts are particularly useful as primary data is collected by an insider who, with the advantage of a shared experience, are better equipped to establish rapport and promote the necessary emotional safety for the participant to comfortably share the depth of their personal experiences (Alder & Alder, 1987). In this sense, podcasts may provide a richer account of an experience than that which could be attained by a research interviewer who has not lived this experience and so comes to an interview with an incomplete understanding of nuances of sensitive experiences (Asselin, 2003). The use of pre-existing content can also prevent respondent burden, which occurs when participants experience re-traumatisation when asked to recount sensitive experiences, such as those relating to the gradual loss of a FMwD, as well as experiences of forgiveness or unforgiveness (Ziebland & Hunt, 2014). Thus, by utilising existing Podcast interviews, the present study will prevent the risk of re-traumatising an additional sample of caregivers for a FMwD.

Podcasts also offer a form of passive, observational study common to ethnographic research, in which experiences can be collected in a more naturalistic manner (Burles & Bally, 2018). Particularly, as podcast content is produced for a range of purposes rather than specifically for research, content tends to offer a more informal and naturally progressing dialogue which enables insight into facets of an experience prioritised by the participants (O'Brien & Clark, 2012). Such accounts are removed from the influences of the research context thus, are more likely to reflect authentic and meaningful descriptions of experiences (O'Brien & Clark, 2012). Thus, podcast interviews provide a unique source of secondary data. The podcast reviewed demonstrated the descriptions of experiences to a level of richness and vulnerability that might not have been divulged in a more structured research environment.

Despite the growing popularity of podcasts, their use in academia remains in its infancy, so their use continues to create several methodological challenges, including verification of credibility, ethical considerations, and lack of a standardised approach for data collection and analysis (Kulkov et al., 2024). These limitations notably appear to present greater challenges to quantitative research, with its reliance on findings derived from concrete, verifiable evidence, than to qualitative literature focused on the nuance and more subjective aspects of experience.

In light of the above challenges, the podcast selected for this project was determined to present a number of methodological advantages when compared to alternative podcasts. Podcast credibility and transparency were heightened by their publicly accessible website, which details the host and contributors. Furthermore, the podcast host is a registered nurse with experience in both professional dementia care and caring for family with dementia. This experience has not only equipped the host with an insider position within her subject group, but has enabled her to conduct interviews with integrity, empathy, and compassion. Moreover, interviews are semi-structured, regularly including a number of standardised, open-ended questions exploring the participant’s experience of dementia caregiving. Overall, this podcast was selected due to overcoming a number of the above challenges commonly associated with this medium, as well as the alignment of content with the research aims, especially the shared vulnerability that personified the dialogue of dementia caregiving.

Utilising secondary data is not without limitations. The researcher is limited to only that data which makes it to production, as raw interviews are often edited down by the podcast host. Editing choices tend to be driven by the perceived interests of potential audiences and so the final media commonly reflects the values of the podcast host (Cheng & Phillips, 2014). On review of the podcasts, the researcher could not determine any evidence that episodes had been significantly edited down. Evidence against this possibility included factors such as episodes ranging considerably in length, indicating that the creator did not seek a prescriptive time limit, instead allowing discussion to flow and conclude more naturally. This potential for bias was also considered in examining the quality of the dataset and whether the content would provide sufficient detail to answer the research questions. It was determined that while the production of podcast content is subjective, the educational aspirations of the podcast aligned with the values of the research aims. Furthermore, interview content was deemed of sufficient depth and richness of experience to address research aims within an IPA methodology.

Data Collection

Data was collected using purposive sampling, a widely used technique in qualitative research to attain a sample with insight into a particular experience (Smith et al., 2009). Podcast data was sourced through a publicly available podcast channel hosted on Spotify. Keyword searches were performed in Spotify's Podcast library, particularly for the terms 'dementia' or 'Alzheimer's'. Related keywords 'cognitive impairment' and 'neurocognitive' produced very limited and largely irrelevant results, as was anticipated due to the clinical nature of these terms within Spotify as a non-clinical application. These same keyword searches were performed in Google with the added keyword of 'podcast' in order to locate any podcasts that may be exclusive to providers beyond Spotify.

The podcast was selected due to several factors. As no podcast could be located that directly examined forgiveness in this population, it was determined that this study would require a podcast with significantly more than the standard 10 hours of interviews used in

IPA, as forgiveness may not be a central focus of all discussions (Smith et al., 2009). The selected podcast had over 100 episodes each at least 50 minutes long, providing a large volume of material from which to identify episodes with discussions of forgiveness as well as access to a range of perspectives on this experience. The podcast explicitly interviewed authors, which, in line with fundamentals of IPA, promoted depth of discussion, as well as participants having already begun to reflect on the meanings of their experiences through writing (Larkin & Thompson, 2011). Ultimately, this podcast seemed the most likely to produce the rich experiential accounts that characterise IPA and would best contribute to understanding this under-researched experience (Nizza et al., 2021).

The podcast is not named in this project to limit the potential for participant identification. The podcast creator recommended an initial sample of five episodes as they discussed caregiver experiences of forgiveness. As forgiveness was not mentioned in any of the remaining episode titles, I first listened to a handful of episodes to determine if the topic of forgiveness was mentioned. This method, however, could not be sustained due to the significant time commitment required, and an alternative method for sampling was sought.

Audio files of all available podcast episodes were then downloaded and transcribed using Otter.ai software. Transcripts were searched for the keyword ‘forgive’, yielding an initial sample of 15 episodes inclusive of the five episodes recommended by the creator. Transcripts of these episodes were then reviewed whilst simultaneously listening to the audio of episodes for familiarisation and to ensure the accuracy of transcriptions. On initial review of the 15 episodes sampled, four episodes were excluded as forgiveness was mentioned only in passing without sufficient depth of discussion. It was determined that the present sample of 11 episodes had not reached sufficient depth of experience for analysis of the forgiveness experience. It was decided to resample the remaining transcripts for terms associated with forgiveness to form a second, less explicit sub-sample. The remaining 85+ transcripts of the podcast series were reviewed for keywords ‘acceptance,’ ‘reconcile,’ ‘reconciliation,’ ‘transgress,’ ‘reconnect,’ and ‘apologise’, due to the association of these terms with processes and experiences of forgiveness. This yielded an additional sample of 12 episodes.

IPA does not prescribe any set sample size, instead recommending a purposive, homogenous sample. It is important, however, that the sample is small enough to enable a sufficiently detailed, interpretative account of the cases included, prioritising depth over breadth. Smith and Osborn (2015) suggest a sample of anywhere between a single case and 15, though size tends to vary relative to the richness of data. While these guidelines relate to semi-structured hour-long interviews as the primary data source for IPA, the selection of secondary data from podcast interviews was informed by the above. In particular, as the phenomenon of interest (forgiveness) was not an explicit topic of the podcast, it was likely that relevant discussion would be limited to smaller excerpts, rather than full podcast interviews. Following the exclusion of two further episodes due to insufficient depth of discussion, the final sample included excerpts from 21 episodes, with an estimated total relevant speaking time of approximately 9 hours.

Table 1 below presents sample demographics. The names of podcast guests have been substituted with pseudonyms.

Table 1

Participant Demographics

Podcast Ep	Pseudonym	Background
1	Wendy	Dementia daughter. Member of sandwich generation.
2	Pip	Dementia daughter who shared caregiving duties for both parents.
2, 4	Ann	Dementia daughter. Healthcare background.
2, 5, 9	Michelle	Dementia daughter. Healthcare background.
2, 9	June	Dementia daughter to parents.
3	Belle	Dementia daughter.
6	Ellen	Dementia daughter. Caregiver advocate.
7	Sue	Dementia daughter caring for both parents at different life stages.
8	Elaine	Dementia wife for her husband. Healthcare background.
9	Helen	Dementia daughter caring for both parents.
9	Kate	Dementia daughter, sandwich generation.
10	Cat	Dementia daughter.
10	Kelly	Dementia daughter and long-distance caregiver.
10	Donna	Dementia daughter and caregiver during time of unrest.
11	Theresa	Long-term dementia daughter.
12	Amy	Caregiver for numerous family members with dementia.
12	Sean	Dementia son.
13	Nora	Dementia daughter and long-distance caregiver.
14	Hannah	Dementia daughter, caregiver to parents. Background in psychology.
15	Olivia	Long-term dementia daughter and wife.
16	Sarah	Dementia daughter, caring for both parents. Caregiver advocate.
17	Viv	Dementia wife to husband with complex diagnosis history.
18	Lola	Dementia daughter. Creative arts.
19	Rose	Dementia daughter. Caregiver advocate.
19	Dave	Caregiver to mother. Researcher.
20	Freda	Dementia daughter to mother with early-onset Alzheimer’s.
21	Lucy	Long-term caregiver for many family members. Caregiver advocate.

Ethical Considerations

Though still an evolving area of research ethics, the use of publicly available data does not waive an obligation to explore and address ethical concerns. The persistently available and easily traceable nature of online information requires particular attention to limiting the likelihood that participants may be identified within this research (Roberts, 2015). While some argue that by knowingly sharing personal information in the public sphere individuals forgo their rights to privacy and informed consent, such a stance goes against the ethos of both ethical responsibility and positive psychology (The British Psychological Society, 2021).

In line with standard recommendations for ethical practice in IPA, all data was anonymised, and each participant was allocated a pseudonym to protect their identity (Smith et al., 2015). Several factors were further considered to understand the degree of privacy expected by those who contributed to the podcast, including the purposes of the podcast, the nature of the sample, the potential for harm, and further measures available to safeguard privacy.

Study within the paradigm of social psychology has benefitted from exploring the situatedness of the self in relation to digital information, in addition to concepts of privacy (Markham, 2018). In particular, concepts of context and control are increasingly more relevant to information collected in the digital age. Nissenbaum (2009) elaborates that in the digital age concerns are not centred on simply restricting the flow of information by increasing privacy, but instead on ensuring that the flow of information is appropriate. The appropriateness of this flow is determined by understanding interpretations of privacy relative to digital information a complex, idiosyncratic, individual, contextual and relational (Markham, 2018). Thus, considering context and control of data helps to assess a more multifaceted conceptualisation of privacy, prioritising the situatedness of the self in relation to one's digital information.

With regard to the context and control of podcast data, it is notable that the podcast was created for educational purposes, with dissemination and sharing of the podcast openly encouraged both within episodes and across the official website. In addition, the podcast creator specifically interviews those who have published some form of literature relating to dementia. Considering this, it is quite likely that participants have awareness, if not direct experience, of the implications of sharing their private information within the public sphere, particularly the limited means for controlling such information. It would, therefore be reasonably understood that participants have contributed to the podcast with awareness of the publicly available and educational function of this media.

This podcast is characterised by the disclosure of sensitive experiences often of a contentious nature, and despite the above, it cannot be reasonably expected that podcast creator anticipated the utilisation of their experiences for post-graduate research in Aotearoa. In light of these considerations and my commitment to both ethical research and positive psychology, I opted to reach out to the podcast creator to inform them of my intentions to utilise their data, thus providing them with an opportunity to refuse permission if desired. Email contact details were obtained from the official website of the podcast. An email was sent to the creator outlining my research intentions for their data, including reasons for selecting their particular podcast. I received an enthusiastic response from the creator in which she gave full permission for the use of the podcast content and data and requested a copy of the completed thesis.

Considerable attention was then given to whether to include the podcast name in the project. In particular, whilst all accounts would be anonymised to remove identifiable information, direct quotations would be included as fundamental evidence of interpretative processes in IPA. The inclusion of direct quotations as well as the podcast name would significantly increase the risk of participant identification following dissemination of the thesis. It was therefore determined that as the podcast creator was the confidant to which participants shared their experiences, on dissemination it would be at the discretion of the podcast owner whether to associate this project with their podcast. Given the above considerations and preventative actions, it is anticipated that this project has limited potential to cause harm.

Ethical Approval Process

The ethical considerations of this project were informed by two fundamental policies: the Code of Ethical Conduct for Research, Teaching and Evaluations Involving Human Participants (Massey University, 2017) and The Ethics Guidelines for Internet-Mediated Research (EGIMR; The British Psychological Society, 2021). The EGIMR provide guidance for conducting ethical research in psychology when utilising data which is remotely acquired (i.e., via the internet) which presents additional and sometimes non-obvious complexities to interpreting and applying ethical principles not necessarily addressed in standard ethics codes (The British Psychological Society, 2021).

A low-risk ethics application was made on March 23rd, 2024, and acknowledged by the Massey University Human Ethics Committee. Subsequently, the application was checked by a Massey University Research Ethics Advisor and in passing this assessment, the project was judged to have met low-risk notification criteria.

A summary of the key ethical considerations of this project is outlined below.

Data Analysis – Interpretative Phenomenological Analysis (IPA)

The following section outlines the key steps of IPA and how I applied these to the dataset.

Transcription and Familiarisation with the Data

During the initial analysis of the data, I read and re-read the transcripts whilst simultaneously listening to the audio files of the podcast interview to immerse myself in the data. I sought descriptive words, phrases or explanations. As recommended by Smith and Osborn (2015) I focused on the content of speech, including how participants expressed the meaning of their thoughts through language choices such as metaphors, positive and negative descriptors, emotive terms, and repetition. My initial notes detailed a clear phenomenological focus, which highlighted what meant most to the caregivers and what these experiences may have been like for the participants (Smith, 2009).

I noted down my reflections and observations, returning back to the recommendations of Smith et al. (2009) that interpretation considers the often-transparent contexts of the concerns expressed to uncover the participant’s mental and social world. This hermeneutic process of attempting to make sense of both the words of the participant as well as the participant themselves aligns with the holistic views of Schleiermacher, seeking to offer a perspective of the text that the participant does not (Smith et al., 2009). This involved considering both the contexts of the podcast interview, but also the socio-cultural and political context in which caregiving took place, and how this might have influenced caregiver choices and perspectives. This return to context allowed me to interpret the data at a more conceptual level, beyond the explicit claims of the participants. In particular, when examining each transcript, I noted down emotive words and then considered the often complex relational context in which these emotions were elicited. The examination of context enabled analysis beyond the purely descriptive to consider the often-transparent patterns within a participant's account of their experience, of which the participant may not have been consciously aware.

Developing Emergent Themes

Following familiarisation and initial noting, I re-read each transcript and its notes from the beginning before shifting analytic focus to work primarily with my initial exploratory comments. Smith et al. (2009) outlines developing emergent themes as reducing the volume of detail present in the initial analysis whilst retaining complexity, specifically by revealing interrelationships, and patterns between exploratory notes. This involved considering the significance of various comments attached to discrete chunks of the interview which inevitably broke down the narrative flow of the interview into a new set of parts. Interrelationships and patterns between discrete chunks of exploratory notes were explored, as well as the relationships of these notes to my interpretations of the transcript as a whole. These interpretations and connections culminated in a number of emergent themes, each of which captures and reflects an understanding of what is crucial at this point in the text. As fundamental to the central tenets of IPA, I sought to develop emergent themes which gave prominence to the psychological essence of each piece, with sufficient particularity to be grounded in the lived-experience, and sufficient abstraction to be conceptual (Pietkiewicz & Smith, 2014). Demonstrated in this process is manifestation of the back-and-forth of the hermeneutic circle, as the original transcript becomes a new set of parts which, while informed by the participants experience, forms a new whole as an emergent theme (Frechette et al., 2020).

Connecting Emergent Themes

Smith and Shinebourne (2012) recommend connecting emergent themes according to conceptual similarities. A completed list of emergent themes for the transcript was organised in chronological order. Initially, those themes with a common thread were grouped, with those of exceptional similarity grouped as subordinate themes. In some cases, a superordinate theme title was abstracted from the commonality of a group. In other cases, a particularly dominant or overarching theme subsumed similar themes to bring them together under a superordinate header. The annotated transcripts were referenced throughout this iterative process to ensure themes remain grounded in the particular of the original interview. All emergent themes were retained at this early stage, should they become relevant to subsequent transcripts. Subordinate themes were then organised into a table under their superordinate headings with supporting participant extracts and notations.

Moving on to the Next Case and Repeating

To do justice to the uniqueness of each participant and their experience, as well as maintain the commitment of IPA to idiography, each case was reviewed in detail and on its own terms prior to seeking convergence and divergence across cases (Smith & Osborn, 2015). Despite best efforts to bracket each case from the next, it is recognised that the researcher will inevitably be influenced by the findings of preceding cases. As recommended by Smith et al. (2009), I systematically repeated the previously listed steps of analysis for each case to best allow unique themes to emerge from each unique lived experience.

Looking for Patterns Across Cases

Following the individual analysis of each transcript I compared the table of themes for each transcript, looking for convergences and divergences across themes. Similar subordinate themes were grouped in a process not dissimilar to the connecting of emergent themes with abstraction and subsummation across themes. Subordinate themes that did not relate to the research questions were discarded, resulting in three final superordinate themes with a range of subordinate themes within each.

Trustworthiness in Qualitative Research

Psychological research maintains a tendency to assume that widely validated quantitative concepts may be directly applied to the assessment of qualitative research, though such is generally inappropriate. Common measures of quantitative validity, such as objectivity, reliability, and (statistical) generalisability, largely lack relevance to the contrasting objectives of qualitative inquiry (Yardley, 2015). The divergent epistemological assumptions and methodologies of qualitative research instead necessitate distinct criteria to determine research validity (Yardley, 2015). Initially proposed by (Yardley, 2000) and ratified in a systematic review of 29 peer-reviewed sets of criteria (Cohen & Crabtree, 2008), there are four broad principles for the assessment of validity in qualitative research: sensitivity to context, commitment and rigour, coherence and transparency, and impact and importance. The succeeding sections will outline each principle and how these were adhered to throughout the research.

Sensitivity to Context

To demonstrate *Sensitivity to context,* Yardley (2015) recommends that research incorporate extant literature, consider the perspective and sociocultural context of participants, and return to the context and content of raw data. A thorough literature review of dementia caregiving and forgiveness was completed at the inception of this project. Psychological theory and existing literature have been woven between participant extracts throughout the discussion section to support findings of both convergence and divergence. To best examine the complexities of participant words, as well as open myself to different interpretations of meaning as recommended by Yardley (2015), participant transcripts were reviewed repeatedly, and at least once whilst listening to audio files of interviews. This ensured that linguistic factors such as tone, emphasis, and pauses could inform interpretation, particularly of more ambiguous speech elements such as grammar and emotive language.

Commitment and Rigour

The principles of *Commitment and rigour* refer to the researcher’s devotion to integrity in their data analysis. Factors contributing to this principle include thorough data collection, depth or breadth of analysis, or both, methodological competence, and in-depth engagement with the topic (Yardley, 2015). Yardley (2015) emphasises that while it is not realistic for a study to demonstrate excellence across all of the above factors, it is important to state those forms of rigour in which excellence was sought.

This project sought excellence in the rich analysis of, and depth of engagement with, how dementia caregivers experience forgiveness. The decision not to pursue the first-hand collection of primary data granted me the scope to commit to extensive engagement with psychological theory and methodological skills thus, facilitating in-depth and thoughtful analysis of the participant experiences. In particular, commitment to a comprehensive literature review ensured depth of interpretation and analysis at a higher conceptual level, capturing the psychological essence of caregiver experiences and linking to existing literature. Commitment to the theoretical sophistication of my analysis and depth of interpretation has achieved unique insights into the experience of forgiveness among dementia caregivers. Rigour was, however, maintained in the collection of secondary podcast data as informed by established IPA principles of information power and prioritising richness of experience (Smith et al., 2009).

Coherence and Transparency

The principles of *Coherence and transparency* refer to the persuasiveness of research. Coherence relates to the degree to which research makes sense as a whole (Yardley, 2015). Coherence is demonstrated by outlining the epistemological and methodological assumptions of IPA and how these align with the aims of this particular study to best explore the phenomenon of interest. Coherence is further emphasised in the consistent and precise use of qualitative language throughout this project. Transparency is demonstrated in the weaving of participant extracts with existing literature and theoretical support for interpretations. These factors enable the reader to follow the process of analysis from the initial grounding in raw data and literature review to later interpretations and eventual themes. Transparency is further evident in my explicit acknowledgment and reflection on the manners in which I have inevitably contributed to the outcomes of this study.

Impact and Importance

The principles of *impact and importance* refer to the necessity that research makes a theoretical or practical difference (Yardley, 2015). The literature review revealed that there is a significant dearth of research regarding the experience of dementia caregivers, particularly with a positive psychological focus, such as the examination of forgiveness. In the least, I firmly believe that this research will have theoretical implications, raising awareness for the challenges and advantages of caring for a FMwD and the benefits of forgiveness. The findings of this research are likely to create a socio-cultural impact, altering the way we view the experience of caring for a FMwD and, ideally, reducing stigma and shame surrounding dementia and dementia care. There is also potential for practical implications, promoting forgiveness in dementia caregiving both directly in the caregivers themselves, but also potential to inform skills-based interventions for caregivers. Empirical research continues to demonstrate the challenges of caregiving (Pinquart & Sörensen, 2003) thus, it is imperative that we understand the experiences of dementia caregiving and how to empower those who care for family with dementia.

Quality Indicators of IPA Research

The researcher has made all possible efforts to ensure that this research was completed to the highest standard. This section will outline the ways in which I have met the four quality indicators of IPA research as outlined by Nizza et al. (2021). These four indicators are: (a) constructing a compelling, unfolding narrative; (b) developing a vigorous experiential or existential account, or both; (c) close analytic reading of participant's words; and (d) attending to convergence and divergence.

The first quality indicator, *Constructing a compelling, unfolding narrative,* suggests that findings should convey a sense of progression within the story of the research. In particular, Nizza et al. (2021) suggest within each theme there should be a complementary alternating of artfully selected participant extracts and the analytic interpretation of these extracts. Each quote should add new or contrasting detail to the narrative of a sub-theme, as should each additional sub-theme to the overarching superordinate theme, ultimately building a coherent and cohesive story. The present study has built an unfolding narrative of subordinate themes, each constructed from an interplay of participant quotes and the interpretative analysis of these words in an interconnected manner.

Secondly, *Developing a vigorous experiential or existential account, or both* relates to the depth and level of insight offered by the analysis. Nizza et al. (2021) explain that greater depth is achieved by interpretative analysis, which pays particular attention to the participant's meaning-making, and explicitly considers the experiential and existential significance of participant reports. Throughout the analysis, I achieved this depth by scrutinising the existential questions that arose from the participant's experiences of caregiving and how the caregivers found meaning in their lived experience.

The third quality indicator, *Close analytic reading of the participant's words,* relates to the researcher's commitment to idiographic depth and interpretation. In particular, the researcher should interpret and analyse the words of participants to explore both their significance in the immediate quote and in the context of the wider transcript (Nizza et al., 2021). I have upheld this quality indicator by close examination of participant extracts, in search of particular linguistic features such as emotive language, emphasis and repetition, metaphor, and imagery. Such depth of interpretation not only illuminates the meaning and psychological essence of the participant experience but also brings transparency to my interpretative claims. Further transparency is achieved by including direct quotes from caregivers, demonstrating a commitment to idiographic principles as well as providing context to interpretation.

Lastly, the fourth quality indicator, *Attending to convergence and divergence*, relates to an illustration of the similarities and variations between the participants of a sample. Smith et al. (2009) suggest that balancing attention to both commonality and individuality can demonstrate shared higher-order qualities whilst remaining grounded in each participant's unique, idiosyncratic attributes. By engaging in a hermeneutic circle of analysis, considering each case in its own right before examining themes in relation to the experiences of others in the sample, this research upholds a commitment to this quality indicator.

Researcher Reflexivity

Researcher reflexivity is a fully integrated feature of the research process in IPA and qualitative research as a whole (Smith et al., 2009). It is recognised in IPA that as interpreting beings, we cannot be separated from our assumptions and preconceptions (Heidegger, 2008) particularly as we exist both within our context and within the research project. Reflexivity is a practice of self-conscious critique, appraisal, and evaluation by a researcher, of how their subjectivity and context influence the research process (Olmos-Vega et al., 2023). Reflexivity is not a one-off, but is a continuous, interactional, and multifaceted practice that extends the full duration of a research endeavour. Through engagement in the double hermeneutic, the IPA researcher is specified by Smith et al. (2009) as the central analytic instrument through which insights are created in relation to the participant's experiences. Thus, as an active contributor to interpretation, it is essential to examine how the researcher’s attitudes and beliefs might surface during IPA research (Engward & Goldspink, 2020). IPA, therefore, necessitates the researcher acknowledge and examine how their presuppositions will influence the research process to maintain credibility and transparency in the interpretative process.

Prior to data collection, I engaged in journaling to reflect on my own experiences of caregiving, dementia, and forgiveness, as well as my preconceptions and anticipated outcomes of this project. These initial reflections were frequently revisited throughout the ensuing process, with additional factors considered and examined as they arose. Regularly revisiting my pre-understandings served to maintain a critical awareness of how they may be reflected in my interpretation and analysis. Specifically, this reflection drove me to consider a wider range of alternative interpretations of particularly value-laden and emotional topics such as retention of self in late-stage dementia, and honouring promises made prior to the emergence of cognitive decline and dementia. This critical reflection ensured interpretations were firmly grounded in the participant accounts. Emerging themes, personal reflections, and alternative interpretations were evaluated in collaboration with my supervisor to ensure credibility, rigour, and transparency of findings.

Additionally, ever-present was an awareness of differences between my cultural background, and those of the predominantly North American participants of the Podcast. While like North America, the dominant culture of Aotearoa is of Western origins, cultural norms foster however subtle idiosyncrasies in language, communication, and the ability to relate to lived experiences. I mitigated these cultural differences through both an ongoing commitment to open-mindedness, as well as attention to aspects of speech that may indicate colloquialisms and subsequent research to uncover meanings of the same. Despite such reflexive efforts, it remains possible that my interpretations may be limited by my different cultural background.

This project considered a number of sensitive issues such as cognitive decline, abuse, neglect, forgiveness, and suffering. I mitigated these challenges by regularly consulting openly with both my supervisor and support network. I actively sought transparency and empathic awareness in my analysis of forgiveness among caregivers of FMwD, recognising participants as experts in their experience and my role as an illuminator of meaning and nuance derived from each unique experience, though potentially invisible in the blur of lived moment.

Chapter 3: Analysis

The following chapter examines the superordinate themes and corresponding subordinate themes established from the analysis. IPA produced three superordinate themes outlined below in Table 2. The first theme, '*caring was not a given,*' describes the experiences of those who heeded the call to care for a parent who had harmed them in the past and how this decision to care predominantly fostered forgiveness and reconciliation. The second theme, *'forgiving myself,'* outlines how caregivers managed shame and guilt arising from both the challenges of caregiving and unrealistic expectations of the self. Theme three, '*no one to forgive,*' describes how the ongoing stigma surrounding dementia makes for an isolating journey and how caregivers are overcoming this. These themes examine significant elements of the lived experience of forgiveness in caregiving for a Family Member with Dementia (FMwD).

Table 2

Summary Table of Superordinate and Subordinate Themes

Superordinate Themes	Subordinate Themes
1. Caring was not a given	1.1: History to overcome 1.2: The decision to care 1.3: It brought us back together 1.4: I thought the responsibility would be shared 1.5: Contrasting reflections on long-awaited reconciliation
2. Forgiving myself	2.1: I wish I had done it differently 2.2: We didn't go to school for this
3. No one to forgive	3.1: That's the dementia 3.2: A lonely role

Superordinate Theme 1: Caring was not a Given

The first superordinate theme, *Caring was not a given*, describes how a subset of caregivers were called up to care for a parent with dementia who had harmed them in the past. This theme discusses how each of these women moved from a place of unforgiveness prior to caregiving, to achieve varying degrees of forgiveness during their experience of caregiving. It then examines an unanticipated abandonment experienced during forgiveness and discusses how the women made sense of their forgiveness within the context of the transgressor's dementia.

Within this superordinate theme are five subordinate themes: *History to overcome, The decision to care, It brought us back together, I thought the responsibility would be shared, and Contrasting reflections on long-awaited reconciliation*.

Subordinate Theme 1.1: History to Overcome

A handful of women described adverse childhood experiences which left them largely estranged from their parents, and questioning their ability to overcome resentment to provide care. Michelle recalls how her mother's struggle with depression caused significant psychological harm to her as a child, damaging her self-worth:

> *"She would say that she was going to commit suicide and somehow make it sound like it was my fault if she did. And it those kinds of things were traumatizing, especially to young person or a child. And for some reason, I always thought there was something wrong with me. I was unlovable. Why couldn't my mother love me? But she loved my little brother."*

Michelle seems to reflect on the impact of this trauma with childlike self-focused thinking, misattributing her mother's cruelty to an internal deficit within herself with the statement "*I always thought there was something wrong with me. I was unlovable."* Michelle's use of the preface *"for some reason,"* seems to express that she still questions why she internalised her mother's abusive behaviour. In her admission, "*why couldn't my mother love me? But she loved my little brother,"* Michelle (though possibly subconsciously) conveys that it was the different standards of treatment for herself and her brother which her to believe that *"I was unlovable."*

Ann describes how her mother faced significant trauma leading up to Ann's birth:

> *"Mom was one of 11 children born in Camden, New Jersey. It was the Jim Crow South. It was very harsh. There was lots of neglect…So, my mom was wounded and scarred by that…And on top of that, she realised as an adolescent that she had an attraction*

> *to girls. Rejection from sexual orientation, poverty, and racism. [She was a] pretty scarred person. And then the other layer to that, with respect to me…She had me at the age of 14…I believe I am the product of rape. And then that gets to set the stage for all of the psychological and emotional trauma that my mother was experiencing at the time she gave birth to me."*

In her statement *"rejection from sexual orientation, poverty, and racism. [She was a] pretty scarred person,"* Ann conveys the intersections of multiple marginalisations that her mother endured as a child and the scars that this left behind. Ann's belief that she is *"the product of rape,"* seems to be supported by both her mother's age at the time of pregnancy as well as her sexual orientation; a traumatic circumstance of Ann's birth would also explain why this has not been confirmed by her mother. While Ann does not have proof of the circumstances of her conception, her admission that this *"[sets] the stage for all of the psychological and emotional trauma that my mother was experiencing at the time she gave birth to me,"* seems to indicate that she is relatively certain of this possibility. Ann recalls how as an adult, she has tried to make sense of feeling abandoned by her mother's inability to care for her as a child, as well as the abuse and neglect she suffered when finally returned to her mother's care:

> *"My background with my mother was fraught with abuse and neglect, abandonment. I didn't live with her for the first nine years of my life…The very notion of my existence was traumatic to my mother."*

Ann recounts how her mother was unable to separate her own trauma from her young daughter, stating, "*the very notion of my existence was traumatic to my mother."* Ann's description covers numerous factors which would have damaged the parent-child relationship including disrupted infant attachment, as well as the initial trauma of conception, and Ann as a trigger for re-traumatisation. Ann describes how she and her mother struggled to form a relationship prior to Ann taking up the role of caregiver:

> *"[Her trauma] coloured our relationship for all of our lives up until the point that I started providing care for her, and we started developing a relationship with each*

> *other that had eluded us for about 50 years…We were stuck in power struggles; it was a very contentious relationship."*

In her use of the plural pronoun *"us"* to express that a relationship had *"eluded us for about 50 years,"* Ann suggests that both she and her mother had attempted to reconcile with the other over this period of estrangement. Her admission that they did not start developing a relationship until Ann *"started providing care for her,"* seems to express that dementia-related changes contributed to overcoming the *"power struggles"* which they had been stuck in. While Wendy recalls reciprocal conflict with her mother in adolescence, it wasn't until a later betrayal that they became estranged:

> *"When I was a teenager, we were at odds…When I was 27 years old, I remembered that her father, my grandfather had sexually abused me as a child. And it just turned my whole life completely upside down...And her response was, you know, the worst response it could have been, which is to attack me, to deny that it had happened; to tell me I was making it up for spite."*

Wendy describes her life as turned *"upside down"* by remembering the repressed memory of her maternal grandfather's victimisation of her as a child. Wendy's description of being *"at odds"* seems to acknowledge that a variety of factors contributed to relational issues with her mother in adolescence. This contrasts with her mother's response to her disclosure of sexual abuse, *"to attack"* Wendy and her character, and deny Wendy's reality in her accusation that Wendy was "*making [the allegations] up for spite."*

Each of the caregivers had sought to remove themselves from the vicinity of their transgressor:

> *"After all these years of being estranged from them, the emotions were so difficult to deal with. Because I was afraid of what might happen, I shielded myself by moving by putting distance between us."*

In the extract above, Michelle describes how she had moved out of the area to protect herself from future harm, "*because I was afraid of what might happen."* This action, as well as her admission that despite the distance, these emotions were still *"so difficult to deal with,"* seems to illustrate how, when used in isolation, maladaptive coping mechanisms, such as avoidance, can delay healing. Where Michelle's distance from her mother seems to have prolonged their estrangement, Wendy's description of *"this war we were engaged in"* expresses how despite creating a physical distance, her relationship with her mother was characterised by ongoing active conflict:

> *"Years went by, and there was still this undeniable connection between the two of us despite this war we were engaged in. And when I was about 35, I got pregnant…And I think that maybe becoming a mother motivated both of us to want to try more than anything to try to reconcile to see if there was some way to find some peace between us… [But] I always felt like I needed that 3000 miles between us."*

In her statement, "*becoming a mother motivated both of us to want to try more than anything to try to reconcile,"* Wendy expresses how she felt the shared connection of motherhood prompted her and her mother to address the war they were engaged in. This allowed Wendy and her mother to work on the *"undeniable connection"* that had prevented their conflict from leading to estrangement:

> *"It was kind of a partial working relationship…She planted herself in my vicinity, and I think I really credit her with doing that because I really didn't welcome her, and I didn't want her to come. But I didn't turn her away either."*

While Wendy perceived progress from connecting over their role as mothers, she admits that she "*really didn't welcome her"* mother back into her life. The statement that "*she planted herself in my vicinity"* acknowledges that her mother must be credited with moving the 3000-miles to actively seek reconnection, especially as while Wendy *"didn't turn her away,"* she admits that she *"didn't want her to come."* In their *"partial working relationship,"* Wendy and her mother achieved a level of reconciliation that the other women would not achieve prior to becoming caregivers.

Superordinate Theme 1.2: The Decision to Care

Michelle, recalls how her mother's dementia diagnosis forced her to consider if she could care for her, or otherwise risk her mother passing away without them reaching closure:

> *"I can either turn my back on the situation or take the risk and change the course of our lives."*

The above extract seems to express Michelle's acknowledgement that given the terminal nature of a dementia diagnosis, should she *"turn [her] back"* on her parents by deciding not to take up their care, she risks forgoing the possibility of reconciliation or closure with them. Caring for her parents would "*change the course of our lives,"* though the manner of this change cannot be predicted. The very *"risk"* of reconnection which concerned Michelle, was shared and articulated by Ann:

> *"She was very, very verbally abusive. And she was very, very stubborn. And she was very, I was afraid of her to be honest with you, as I [had been] as a child…Did I want to harm myself, put myself in harm's way, you know, because so much about our relationship for both of us, on both sides, was about protecting ourselves from harm, from one another."*

Ann's repetition of the word *"very"* seeks to stress the intensity of her mother's verbal abuse and stubbornness. The vulnerability that Ann expresses in her disclosure that even as an adult, she remained fearful of her mother, *"I was afraid of her to be honest with you, as I was as a child,"* seems to validate the previous, unfavourable descriptions of her mother which may otherwise have been perceived as exaggerated. When combined with the strong statement regarding her mother's abuse, Ann's vulnerability provides validity to her belief that reconnection with her mother may "*put myself in harm's way."* Where estrangement had kept Ann and her mother from being *"at war"* like Wendy and her mother, Ann suggests that she would not be the only one at risk when reconnecting with her mother. In fact, estrangement had benefited them both, *"protecting ourselves from harm, from one another."* Ann held particularly significant concerns for her ability to take on her increasingly vulnerable mother whilst still weighted down by resentment:

> *"The mountain of resentments that was blocking our relationship, I really felt like, was I the one that should do this...I mean, we would just, like hurt each other. Like, emotionally."*

Ann's metaphor of a *"mountain of resentments"* illustrates the overwhelming and intrusive nature of these negative feelings, which she is unable to ignore when making her decision to care. Her acknowledgement that *"we would just, like hurt each other"* and questioning "*was*

I the one that should do this," highlights her concern that while she is next-of-kin, their unresolved resentment puts them at risk of causing harm to each other – a risk which would not be present with a formal caregiver.

Subordinate Theme 1.3: It Brought us Back Together

Contrary to the loss of connection commonly experienced between the PwD and their family as the illness progresses, all but one of those who were harmed by a parent seemed to experience dementia caregiving as enabling reconnection. Michelle describes how drastically her mother changed during her illness in her statement that *"she became a different person altogether. It was like meeting someone brand new."* Michelle's description of her mother as becoming *"a different person altogether"* conveys a transformation so remarkable that she could not recognise her mother's behaviour as originating from the same woman who had caused her such harm in childhood.

Wendy recalls a similar, unanticipated transformation as her mother's dementia progressed stating, *"She actually turned sweet. And I was very surprised at that. I thought she would become a horror to be with, I thought she'd be one of those people."* Wendy approached caregiving with the expectation that her mother would be "*one of those people*", referring to the stereotypical depiction of the unruly PwD. The unexpected nature of her mother's transformation is illustrated in her statement that *"she actually turned sweet,"* suggesting that like Michelle's mother, she had not been sweet prior to this. Wendy recalls how, despite her mother's positive change she struggled to let down the walls that had kept her safe from this woman for so long:

> *"There still was this emotional, kind of spiritual gap between us. I was I was going through the motions…I [provided care], but always at a distance. And the real challenge for me was, could I go from my head to my heart? And could I give up all that self-protection and be with her?"*

The *"emotional, kind of spiritual gap"* that Wendy perceived between herself, and her mother may illustrate the emotional distance she created as a means of self-preservation following the experiences of her childhood. Wendy's expression of a *"spiritual gap"* suggests that beyond a lack of empathic connection, she perceived an ongoing existential misalignment with her mother. She describes providing for her mother's basic survival needs, *"going through the motions,"* relating this caring *"always at a distance"* to performing on autopilot. This description of a more passive approach to her mother may be interpreted as a movement away from the anger and vengeful emotions of unforgiveness towards a place of decisional forgiveness in which she remains emotionally distant, though she no longer wishes harm on her mother. Wendy's challenge, to go *"from my head to my heart,"* contrasts the robotic-type motions of completing the activities of caring for her mother to instead achieve emotional forgiveness, allowing herself to be vulnerable with her mother, and provide for her emotional and relational needs. Wendy's description distinguishes providing care as an objective, medicalised role, and caring for someone by interacting to also meet their humanistic and emotional needs. To enable this care, Wendy recalled the decision to go back to therapy during caregiving as central to overcoming her past with her mother:

> *"It just was bringing up so much from the past. And I didn't want to respond from that same place I had been in as a young adult, I wanted to be able to respond as a mature adult. I wanted to be able to show up as a reliable, responsible daughter."*

In her statement that caregiving was "*bringing up so much from the past,"* Wendy bravely acknowledges how despite her best efforts to care for her mother, she felt the bubbling of negative emotions as her mother's actions would unconsciously trigger the trauma of her childhood. In her admission that *"I didn't want to respond from that same place I had been in as a young adult,"* Wendy acknowledges that she had previously not responded from a place of maturity and sought to do better. When reflecting on how she responded as a young adult, Wendy's repeating of *"I wanted to be able"* conveys responsibility for her contribution to the conflict between herself and her mother in childhood, and her desire to equip herself with skills she didn't have previously.

> *"I did open my heart to her. And I think for me, that's the greatest gift. Even though it felt like I was able to open my heart to her because it was finally safe to love her, because she wasn't the woman she had been before."*

In the extract above, Wendy's description of how dementia-related changes meant it was *"finally safe to love her [mother]"* illustrates how removing the potential for future harm was necessary for Wendy to allow herself to experience the vulnerability required for emotional reconnection and subsequently, emotional forgiveness. Her admission that opening her heart to her mother was *"the greatest gift,"* illustrates that what Wendy treasured most was the growth and compassion that she felt in herself, in finally being able to let down her walls and let her mother in. While Wendy acknowledges that "*it felt like I was able to open my heart to her"* because of the way her mother changed, her emphasis on opening her heart as the *"greatest gift"* can be seen as Wendy perceiving this as an intrapersonal, rather than interpersonal process of forgiveness. This distinction may be supported by Wendy's explanation that it was safe to love her mother "*because she wasn't the woman she had been before,"* as her mother had changed so much from dementia that Wendy no longer needed to employ defensive coping mechanisms and could allow herself to forgive. Where Wendy's experience focused more on what she needs to change internally to enable forgiveness, Michelle's account expresses a more active and reciprocating role of her mother, demonstrating more of an interpersonal conception:

> *"She had abandoned me, rejected me, many, many, times throughout my life…She abandoned me every possible way, physically, emotionally, mentally…And when we found each other, again, we had been through so much together, things were so different. It was something I didn't want to lose once I had found her again. But I knew the clock was ticking, and I knew we were living on borrowed time, and just the prospect of losing everything we had worked so hard to gain, I was going to lose it, and this time, it would be for good."*

In the extract above, Michelle's repetition of *"many, many"* emphasises the repetition of her mother's abandonment, whilst her descriptor of this being "*physically, emotionally, mentally"* illustrates the extent of this rejection across all facets of her relationship with her mother. In her statement that "*when we found each other, again, we had been through so much together,"* Michelle seems to be pleading for time with her mother, framing this as only fair given all that they had overcome, *"we had worked so hard to [reach this place]."* This passage sees Michelle move from this more idealistic view of this relationship as mentioned, to acknowledging *"It was something I didn't want to lose,"* and to eventually accepting the finality of the inevitable loss *"I was going to lose [the relationship], and this time, it would be for good."*

Where Wendy has framed reconnection with her mother as a gift, something given to her, Michelle focuses on all that there is to lose in light of her new relationship with her mother. This may be seen as Wendy interpreting the reconciliation with her mother as something which she will continue to carry with her – an intrapersonal process – whereas Michelle focuses on what will be lost with the death of her mother, "*and this time, it would be gone for good."* In this sense, Michelle conceptualises this reconciliation as an interpersonal process, the result of which will be lost with her mother's passing, whilst Wendy has conceptualised this as something that will live on within her, irrespective of her mother. This interpretation is reflected in the sense of abandonment that Michelle recalls facing following her mother's death:

> *"However, when she, when she passed away, it was the abandonment issues came up. And the rejection, I felt that she had, how could we have this beautiful relationship and then she dies."*

In her existential questioning, *"how could we have this beautiful relationship and then she dies,"* Michelle expresses a sense of injustice at the loss of her mother. This could be seen to demonstrate that while she had acknowledged that loss was inevitable in her earlier statement *"I was going to lose [her],"* she was not expecting the sense of abandonment and rejection that she would feel at the finality of this loss.

Subordinate Theme 1.4: I Thought the Responsibility Would be Shared

In the below extract, June's statement that *"I just did what I needed to do"* expresses how, despite a previous transgression, children of parents with dementia almost unanimously perceived caregiving as a responsibility to their parents which they were obliged to fulfil. Michelle expressed this same sentiment in her earlier mentioned reciprocal question *"they were just so vulnerable. How could I say no?"* Despite this, most caregivers who had reconciled with a parent following a previous transgression to become their caregiver were subsequently let down by a sibling who did not perceive the same responsibility to care.

June describes how she didn’t think twice about caring for her parents with dementia, but was constantly disappointed when she sought help from her brother:

> *“I never thought about heeding the call, I just did what I needed to do…He said he preferred to remember them the way they were and that he couldn’t handle it.”*

June’s account of her brother’s position that he “*preferred to remember them the way they were”* communicates that her brother felt unable to cope with his parent’s neurocognitive decline, or at the very least, a limited awareness of both the sacrifices June was making, as well as their parent’s increasing dependence and need for support. June’s account frames her brother as maintaining this position despite her pleas for support:

> *“He said, “Do you need money? I’ll send you money.” I was like, no, I need you. I need emotional help. “Hello, hello. I can’t hear you. I think the phone has a bad connection,” he said…I realized there was no, there was no point in it. It was at that point, I realized he wasn’t going to be there. So, I just had to move on and find solace in [other supports].”*

In her admission that “*I just had to move on and find solace in [other supports],”* June demonstrates what appears to be an intrapersonal process of letting go of unforgiveness towards her brother in order to enable her own peace in the absence of apology or emotional support from her brother. Wendy also described being let down by her brother who had agreed to care for their mother as unlike Wendy, they had an established relationship:

> *“I said to him, when, when our parents get old, I'll take dad, you take mom, there's no way I could take care of her. And he said, Okay, agreed… And then when it came time for my mother's decline, you know, my brother did not show up very much…He basically came when he wanted to, you know, when it was convenient for him, and I was the one who had to show up every single day, and I had a lot of resentment towards him.”*

Wendy’s comparison between her brother showing up *“when it was convenient for him, and I was the one who had to show up every single day”* expresses her perception of caring as a necessity, contrasting with her belief that her brother perceived this as a choice, and how this fostered *"a lot of resentment towards him*." Wendy would ultimately resolve her resentment, though her brother would need to find a way to forgive himself for the opportunities he failed to take:

> *"After she died, we had some heart-to-heart conversations. We're the only two left in our immediate family, and he said that he regretted not doing more. You know, when he looked back, because he realised that I had this resolution with her that he didn't get to have, and that there was something about stretching beyond what I thought were my limits…And he realised that his choices which was often to hold back or to prioritise what he was doing, that he had paid a price."*

Wendy describes how the loss of their mother, making herself and her brother *"the only two left"* facilitated their reconnection. Her brother's admission that *"he regretted not doing more,"* communicates his remorse for reacting to their mother's illness from a place of fear and self-preservation. By further reflecting on the self-serving nature of his actions in his admission that he had often opted to *"hold back or to prioritise what he was doing,"* Wendy would have been encouraged to attribute her brother's actions as driven by self-preservation, rather than conscious intent to harm Wendy and their mother; fundamentally, promoting forgiveness by shifting attributions from dispositional to situational factors (Lichtenfeld et al., 2019). His subsequent acknowledgement that *"there was something about stretching beyond what I thought were my limits,"* communicates to Wendy his admiration for her contrasting reaction from a place of selflessness and empathy and emphasises his regret that he had not been capable of the same. Wendy's experience demonstrates how a transgressors disclosure of remorse and regret, as well as taking responsibility for the harms caused by personal shortcomings rather than conscious intent, contribute to empathy and the forgiveness process. Thus, the above extract demonstrates how *"a lot of resentment"* may be overcome by mutual vulnerability and openness to reconciliation, resulting in interpersonal forgiveness.

A very similar difference of opinions was recalled by Michelle:

> *"The thing that pushed me over the edge was when I confronted him and said, look, I need your help, I can't do this on my own. And he walked out the door. And on his way out the door, he said, "you signed up for this, I didn't."*

Her brother's comment, *"you signed up for this, I didn't,"* seems to be quite invalidating for Michelle, who took a risk when reconnecting with her parents to care for them and seemed to have expected her brother to make a similar sacrifice to support Michelle in her decision. Michelle had previously described all that she had to consider when her mother became unwell as "*I can either turn my back on the situation or take the risk and change the course of our lives,"* illustrating that particularly in the context of her past trauma, this was no small decision. Michelle's decision to care would be better described by June's description of caregiving as a necessity, rather than a choice, in her statement that "*I just did what I needed to do."* This interaction *"pushed her over the edge"* into complete estrangement from a brother she, until this point, had been close with. Despite Michelle pleading for help in her admission that *"I can't do this on my own,"* she not only provided care on her own but achieved intrapersonal forgiveness for her own well-being:

> *"The only thing that got me through this is that I finally instead of being angry at him, I just accepted it. And I said, you know, this is my journey. This is obviously not his journey…And once I accepted it, I was at peace."*

Just as June had found solace in her other support, Michelle's statement, *"once I accepted it, I was at peace,"* expresses the power that the transgressed have to create their own peace in the absence of reconciliation or apology.

Subordinate Theme 1.5: Contrasting Reflections on Long-Awaited Reconciliation

Despite describing similar experiences of their mothers softening following their dementia diagnosis, the women interpret their experiences of forgiveness and reconciliation quite differently. Michelle describes how dementia allowed her to see her mother's *"original"* self:

> *"As the disease progressed, she was able to forget all the reasons why she was so unhappy, and her original self slowly emerged."*

Michelle has previously described the changes in her mother throughout dementia as her becoming *"softer, kinder, more open to having a relationship with me."* This seems to be the schema she has constructed of her mother's *"original self"* which she feels has emerged in the context of dementia. She seems to frame the progressive decline of dementia as enabling her mother to *"forget all the reasons why she was so unhappy,"* which appears to have revealed a woman no longer weighted down by negative memories. It is possible that Michelle's attribution of her mother's more pleasant state during her later stages of neurocognitive decline as her *"original self"* may demonstrate a correspondence bias. In particular, Michelle seems to be attributing this positive change to the revealing of core goodness to her mother's disposition or *"original self,"* whilst under-emphasising the degree to which this change may be attributed to the symptoms of cognitive decline. A self-serving bias such as this tends to occur unconsciously to protect oneself from alternative, often more negative explanations which may harm their perception of the self or others. Within this schema of her mother's "*original self*," a self-serving bias would allow Michelle to attribute the transgressions of her childhood to situational factors that prevented her mother from expressing her original self rather than attributing this harm to her mother's disposition. In contrast, Wendy describes a sense of disillusionment at the changes to her mother's personality:

> *"She was saying the kind of loving things I'd wanted to hear my whole life, and now she was saying them, but she wasn't the same person anymore. It was it was a very bittersweet experience for me"*

Wendy's reiteration *"and now she was saying them,"* could illustrate a sense of disbelief at this long-awaited experience. Despite how long she has waited, Wendy attributes her mother's changed behaviour more predominantly to the influences of her dementia, than her mother's 'self' with her admission, *"but she wasn't the same person anymore,"* illustrating that she may have struggled to derive personal meaning from her mother's affirmations. June expresses similar doubt when recalling changes to her mother's behaviour:

> *"The disease had kind of taken over her life. I think. In the end, the last four months of her life, she, I don't know if this was conscious or unconscious. She just pretty much quit eating. And she became softer then."*

June describes how her mother also "*became softer"* however, she was unable to discern if behaviour changes during this time were *"conscious or unconscious."* This, in addition to her admission that dementia had *"kind of taken over [my mother's] life,"* expresses the difficulty of discerning the person from their illness experience, particularly in the later stages of dementia. Unlike Michelle and Wendy, June did not get to experience her transgressor as *"brand new person"* during her illness however, like the other women June expresses how she appreciated her mother's eventual softening:

> *"Although, sometimes she didn't know who I was. She was very much easier to be around, for me."*

June illustrates how her mother's softening and vulnerability, as described in the previous extract, enabled June to better tolerate being in her presence, making her mother "*much easier to be around."* This ability of June to spend more time with her mother, as well as her perception of her as becoming *"softer,"* could be seen as a transition away from previous avoidance, and towards forgiveness in the sense of adopting more prosocial change toward her mother. June's qualifier, *"for me,"* emphasises that achieving forgiveness was a personal experience, and others may not have previously struggled with her mother's presence, nor derived the same meaning and resolution as June during her mother's final months. June's perception of her mother's softening as a symptom of her cognitive decline demonstrates quite a contrasting experience to Michelle's attribution of her mother's harmful behaviour to *"her disease…not her:"*

> *"Some days, my mom had a really, really bad day. She didn't recognize me, she wanted nothing to do with me. And of course, this was after we had established our new relationship as mother and daughter. And it would hurt because I always felt like oh, now we're going in reverse again. And she's becoming the old mom. And I thought, Okay, this is her disease. This is not her."*

This extract appears to demonstrate cognitive dissonance in Michelle's understandable unconscious efforts to maintain the narrative of her mother as a good person who has actively sought reconciliation with Michelle during her dementia. In repeating that her mother would have a *"really, really bad day,"* Michelle emphasises the challenges of managing her mother's fluctuating cognitive abilities, putting strain on their *"new relationship"*. Her mother's regression to wanting *"nothing to do with [Michelle],"* may seem to retrigger Michelle's earlier mentioned childhood concern that she was *"unlovable,"* in conflict with their recent reconciliation. A self-serving bias seems to protect Michelle's self-esteem by again attributing this harmful behaviour to both *"the old mom"* and *"her disease…not her,"* likely illustrating correspondence bias in Michelle's inability to consciously attribute intent to her mother's negative behaviour, nor attribute this negative behaviour with her mother's *"original self"* or disposition.

The experience of correspondence bias seems to be illustrated in Michelle's conflicting attributions of her mother's behaviour to the impacts of dementia. In particular, in her first extract of Subordinate Theme 1.5 Michelle attributes dementia with allowing her mother to *"forget all the reasons she was unhappy"* and allowing her *"original self"* to emerge in this more pleasant presentation. However, when her mother has a bad day in the above extract and *"wanted nothing to do with [Michelle],"* this is also attributed to *"her disease…not her."* The misalignments of these attributions may demonstrate cognitive dissonance, in which Michelle is doing her best to provide care to a mother who is demonstrating such drastically different behaviours, each of which is activating her emotional response. While the other women have questioned the different presentations of their parents, Michelle demonstrates a determination to always find the best in her mother. Where Michelle felt that regression to her *"old mom"* was going in reverse, Wendy expresses how her perspective on her mother's behaviour changed as her dementia progressed:

> *"She just got so passive. And even though she was easier to deal with, I missed the feisty mother I had had, you know, I missed her."*

Wendy's admission that "*though she was easier to deal with, I missed the feisty mother I had"* expresses that her long-awaited reconciliation with her mother allowed her to appreciate the parts of her mother that had previously caused her harm. Where Michelle attributed dementia with allowing the emergence of her mother's *"original self,"* Wendy grieves for the personality that she believes dementia stole from her mother – reminiscent of psychodynamic theories of dementia, as the thief of self (Javed & Kakul, 2023). It is the loss of self that helps Wendy to recognise in a game of cards that she has let go of resentments for her mother:

> *"Her cards were on the table. And they never had been for whatever 85 years up until that point that she'd always had all this control and hiding things and suddenly her*

> *she could just let everything be seen. And she still could put them in the right order. You know, and, and I just don't remember, like, I stopped keeping score, you know, we used to always keep score, we're very competitive with our cards, I stopped keeping score."*

While describing an actual event in their card game, *"her cards were on the table,"* is also a figure of speech through which Wendy captures how dementia progressively robs an individual of their self-protection. Wendy describes realising that she had stopped holding onto resentment, anger, and vengeance as illustrated in her admission and repetition that "*I stopped keeping score."* When conceptualising forgiveness in this account, it may be noted that it is when Wendy recognises the degree of her mother's vulnerability (*"her cards were on the table"*) that she realises she is no longer *"keeping score."* Recognising the absence of resentment, and the inevitable presence of forgiveness may illustrate acknowledgement of decisional forgiveness, as indicated by Wendy's recognition that she is no longer at risk of harm from her mother (Worthington & Sandage, 2016). The ability of Wendy to make this change despite her mother's declining cognition and limited capacity for response emphasises that while decisional forgiveness is an interpersonal process in the sense that behaviour towards a transgressor is altered, this does not necessitate intentional change by the transgressor.

Summary

The first superordinate theme illustrates how longstanding interpersonal differences could be overcome following the call up to care for a parent diagnosed with dementia. Women in the study described how they feared what might happen should they reconnect with their mothers and the unexpected dementia-related changes, which seemed to allow varying degrees of eventual reconciliation. Intrapersonal forgiveness was reached for each mother, as well as in some cases for a sibling who had neglected their responsibility to care. Attributions of responsibility and intent seemed to shape degrees of forgiveness, as well as altering perceptions of previous transgressions.

Superordinate Theme 2: Forgiving Myself

Superordinate theme two, *Forgiving myself,* draws from the entire sample to explore the guilt and shame experienced by family caregivers for their perceived inadequacies, and how they managed to overcome these. For almost all caregivers, the overwhelming desire to ensure their loved one received the highest quality care manifested in unrealistic expectations of the self. At the time of recording, a handful of caregivers had not yet reached self-forgiveness for their perceived inadequacies, though the majority of the sample reflected on having provided the best care they were able to.

Within this superordinate theme falls two subthemes: *I wish I had done it differently,* and *We didn't go to school for this.*

Subordinate Theme 2.1: I Wish I had Done it Differently

Caregivers commonly experienced self-blame for the pressures they put on themselves to provide the best possible care to their FMwD. June describes misattributing her mother's early dementia symptoms to the stress of caring for her husband, June's father, who was already diagnosed with dementia:

> *"To begin with I was clueless. I didn't realise what the symptoms she was showing actually was. I thought it was stress [of] caring for my dad…it feels weird to tell you this, but it was another year before we had her evaluated. She, she, was resistant and I didn't push it...I normalised what was going on based on stress."*

June's self-deprecating description of herself as *"clueless"* seems to express a self-consciousness about her caregiving decisions. Her admission that *"it feels weird to tell you this"* may illustrate incongruence between her desire to give an honest account of her caregiving experience, and her fear of being negatively perceived for her caregiving decisions whilst speaking on a public platform such as a podcast. June's account that she *"normalised what was going on,"* in addition to labelling herself as *"clueless,"* seems to convey a sense of regret for her caregiving decisions which she has been unable to forgive herself for. Despite perceptions of inadequacy, June's admission that "*I didn't realise what the symptoms she was showing actually was"* was, in fact, shared by numerous others on the podcast and may instead highlight the lack of available information regarding the symptoms of dementia, which can prevent the PwD from receiving the necessary support. Where June's extract conveys a sense of self-blame for not recognising her mother's dementia earlier, Wendy reflects on guilt for pressing for her mother's diagnosis:

> *"I really forced her to go get tested...I manipulated that situation so that she had to say yes...And on one hand, I think it was a good decision... it would give us access to resources...I'll never forget that day...just how devastated she was. And I remember she said, I wish I didn't know...And I really felt devastated at that moment. I, I, felt like why did I have to push her into this, like, it's not going to change anything for her…but of course, by the time we got home, she forgot she had a diagnosis."*

In the above extract, Wendy's account of seeking a dementia assessment for her mother illustrates persistent self-blame which may be seen as inordinate to her mother's temporary distress. Wendy, albeit unconsciously, attributes herself and her mother with the same *"devastated"* reaction to this experience. This could demonstrate emotional mirroring – a skill learned in childhood to manage and validate a parent's (often unpredictable) emotions (Sowden et al., 2021). Wendy's description of having *"forced"* and *"manipulated"* her mother into a dementia assessment frames her behaviour as coercive. However, Wendy's admission that *"by the time we got home, she forgot"* reveals both the severity of her mother's cognitive decline at the time of assessment and that her mother's distress could have only lasted as long as her memory – less than it took them to get home. Given the limited duration of her mother's distress, it is possible that Wendy's perception of her behaviour during this encounter instead, to some degree, reflects the internalising of her mother's comments. Wendy describes her mother's behaviour at this time in the below extract:

> *"The early stages brought up many of the same qualities that had been the hardest for me in the past…She was temperamental, she was rageful, she was erratic, her emotions were all over the place. She was anxious, she was needy. She was completely self-absorbed."*

The affective behaviours described in the above extract, including *"temperamental… rageful…erratic…anxious…needy…completely self-absorbed,"* may have influenced Wendy's description of her mother's assessment as *"forced"* and *"manipulated,"* and limited her ability to forgive herself for this perceived transgression.

A number of caregivers also described unresolved guilt for the inevitable need to relocate their FMwD. Sarah recalls how she was directed by a doctor that for her parent's well-being and against their will, they needed to leave their house and go into care:

> *"We, or rather I, because I was the one with the power of attorney, I would sell [her house] without her knowledge, without her consent. I would sell it from under her which, you know, talk about the carers guilt. I mean, I've never, ever known such guilt...her dementia, which had obviously been there, it would have been covered up by dad…but with this, I mean, incredibly traumatic shock of learning that we'd sold her house from under her, her dementia has unleashed itself."*

Sarah's description of selling her mother's house *"without her knowledge, without her consent. I would sell it from under her"* conveys the severity of her mother's dementia to such a degree that she was deemed legally incapable of managing her own financial decisions. Sarah uses strong, emotive language to attribute the *"incredibly traumatic shock,"* of the house sale, for which she, as the power of attorney, takes sole responsibility, with the unleashing of her mother's dementia. Alternative explanations for the rapid progression of her mother's dementia, including masking of her symptoms by both Sarah's father and the familiar home environment, are instead described more objectively by Sarah. Sarah's description emphasises her self-blame and guilt for the trauma experienced by her mother as she was moved into care, for which she attributes sole responsibility. Where Sarah described having *"never, ever known such guilt"* despite care decisions being in her mother's best interest, Sean describes guilt and shame for how he handled his emotions and grief throughout caregiving:

> *"I, you know, hid my weakness, my, my emotions…I handled it poorly, and I also handled the anger poorly, because I was very angry about this. I mean, here I was a neurologist, supposed to be an expert in this. You know, nobody wanted to provide care to my dad more than I did. I wanted it to be excellent in every way, and it wasn't, to me, excellent in every way...here was my supportive family. They were still*

> *supportive. Here were my colleagues, but I wouldn't see that, and I couldn't hear that because I had not dealt with my grief, my anger, or my sorrow."*

He explains how his avoidance of emotions and aspects of himself that he considered *"weaknesses"* ultimately impacted the level of care that he sought to provide for his dad. Sean perceived multiple factors that should have enabled him to provide the best quality care for his father, including his career in neurology, his perfectionism, and social support. However, it was his inability to open himself up emotionally to those supporting him that prevented Sean from providing care which was *"excellent in every way,"* despite what he perceived to be his privileged position to do so. In describing his social supports, "*I wouldn't see that, and I couldn't hear that,"* Sean highlights how self-blame and feeling unworthy of help can keep caregivers rooted in grief.

Subordinate Theme 2.2: We Didn't go to School for This/ We're Only Human

Where subordinate theme 2.1 explored ongoing guilt and shame for caregiving decisions, with reflection on their experiences most caregivers have acknowledged that nothing could have prepared them for the immense and unanticipated responsibility of caregiving. Olivia explains how it is only human to want the best for a FMwD, and it can be challenging to accept the limitations of our knowledge:

> *"We confuse the fact that when all of a sudden our loved one receives a diagnosis, we receive a diagnosis, we're 'a caregiver', that we're meant to be all things to all people and we're meant to immediately. You know, we want the PhD in the diagnosis. We want the PhD in being a caregiver. It's reasonable to understand that we, we, aren't that, we're not meant to be that."*

She describes how the suddenness in which a dementia diagnosis turns a family member into *"a caregiver,"* is widely conflated with an equally sudden expectation within the caregiver that they should have extensive knowledge of the role and responsibilities of caregiving. Olivia's illustration of the extent of self-expectations with the metaphor that *"we want the PhD in being a caregiver"* emphasises how like attaining a PhD, caregivers put pressure on themselves to become an overnight expert in caregiving. Her statement that *"It's reasonable to understand that we, we, aren't that, we're not meant to be that"* expresses that not only is this expectation unrealistic, but to seek this unattainable knowledge can sacrifice presence and emotional connection with the care receiver. The consequences of not forgiving the self for these expectations are demonstrated in the account of Sean in theme 2.1 above, whose unrealistic self-expectations prevented his emotional connection with his dad, adding significant guilt to his grief. Amy advocates for self-forgiveness as a fundamental skill of caregiving, as the sacrifice and emotional load create innumerable opportunities for self-blame:

> *"You will never meet your own standards. You know you will always be because you're not spending enough time with your loved one, or maybe you're spending too much time with your loved one, and not enough with your other family members or your you know, too much this, too much that, not enough this. You, you, cannot be Wonder Woman, and you cannot be Superman... Forgive yourself, do the best you can."*

Where Olivia compared caregiver self-expectations to wanting the highest possible knowledge, Amy uses metaphor in her statement that "y*ou*, *cannot be Wonder Woman, and you cannot be Superman"* to emphasise that to meet these self-expectations a caregiver would require superhuman powers. In her statement that *"you*'re *not spending enough time with your loved one, or maybe you're spending too much time with your loved one, and not enough with your other family"* Amy captures the interplay of guilt and shame between the caregiver's unattainable expectations and resentment. Self-forgiveness, Amy explains, is the only way to overcome unrealistic self-expectations:

> *"Every time you fail to meet your own unrealistic expectations, tell yourself, I mean, look yourself in the mirror and say, I forgive you. You know, I forgive you…I'm going to continue to do the best I can for my loved one."*

In the above extract, Amy's clarification of "*tell yourself, I mean, look yourself in the mirror and say, I forgive you"* illustrates that to achieve self-forgiveness for her guilt and shame, Amy had to not just think of forgiveness but use a mirror to attain higher-level emotional forgiveness of herself. Amy emphasises self-forgiveness as an ongoing commitment and process, rather than a momentary pledge in her repetition of *"I forgive you…I forgive you."*

Summary

Superordinate theme two, *forgiving myself,* explores the unanticipated and immense challenge of caring for a FMwD and the varying degrees to which caregivers have forgiven themselves for not meeting the unrealistic expectations that they each put on themselves when providing care. Self-forgiveness has proven in literature to be more difficult to attain than forgiving another (Pandey et al., 2023), and the key drivers of this including self-blame, guilt, and shame, are prevalent in the accounts of caregivers who still believed they should've done more.

Superordinate Theme 3: No One to Forgive

The third superordinate theme, *No one to forgive,* explores how various factors of caregiving for which caregivers experience harm are attributed to situational rather than dispositional correlates and, therefore, must be accepted rather than forgiven. This theme considers concepts of responsibility and intent as central to attributing a transgression and how, in the absence of perceived responsibility or intent, there is no forgiveness to give. Caregivers describe learning to understand dementia-related behaviours and social isolation in dementia caregiving.

Within this superordinate theme are two subordinate themes: *That's the dementia, and An invisible role.*

Subordinate Theme 3.1: That's the Dementia

Caregivers described how understanding dementia allowed them to interpret dementia-related behaviours within the context of the condition, and avoid misattributing these to personal affronts:

> *"I'm not sure that last time someone told you when to go to the bathroom, when to go to bed, but for me it was a really long time ago…For my dad it was even longer. So, when he's 83 years old and I'm trying to force him into my schedule, we're going to get some pushback. So, you know, learning how to honour that he still has his own will, and just because some memories are missing, some problem solving isn't there,*

> *doesn't mean that those things that give us dignity are gone…So, I think a lot of it is perspective."*

After first watching her father provide care to her mother with early onset dementia and then having to provide care for her father during his dementia, Sue recalls how she learned to manage resistance by taking her father's perspective with her statement, *"I'm not sure that last time someone told you when to go to the bathroom."* Sue highlights dementia caregiving as an ongoing process of learning with her description of *"learning how to honour that he still has his own will,"* acknowledging that while caregivers may enter caregiving determined to preserve the dignity of their FMwD, navigating how to action and manage this is an ongoing process. The lived experience of the non-conformity of dementia to rational thinking, which Olivia will outline below, is illustrated in Sue's example that *"when he's 83 years old and I'm trying to force him into my schedule, we're going to get some pushback."* Where Sue attributes a learning process of perspective-taking with enabling her to adapt to dementia caregiving, Olivia attributes psychoeducation to widening her perspective on dementia-related behaviours:

> *"It wasn't until I learned that our rational minds programmed us to think a certain way, and diagnoses such as neurocognitive disorders, they don't honour that. They don't have that. And I, I, had to learn to let go of that."*

Olivia's statement that *"our rational minds programmed us to think a certain way, and diagnoses such as neurocognitive disorders, they don't honour that"* not only highlights the loss of rational thinking associated with dementia but also alludes to the way dementia-related behaviours often don't honour or conform to social norms. Understanding these cognitive differences associated with dementia removed both responsibility and intent from dementia-related behaviours, which Olivia attributes to enabling her to take her husband's perspective and *"learn to let go"* of pre-existing schemas for her husband's behaviour, which were based on pre-dementia expectations that he thought rationally, like her. Thus, psychoeducation and positive framing allowed Olivia to see dementia-related behaviour as the result of disease progression, rather than any desire of her husband to cause her harm, removing attribution of blame and enabling acceptance.

Rose describes how she took the perspective that dementia released her mother from social inhibitions:

> *"She was always that wild child. But, you know, not having dementia, she was tempered, in a way by social norms. And, you know, knowing that she couldn't really say what she thought, because it would be over the top, but all of those filters went out the window with dementia."*

In her description of *"knowing that she couldn't really say what she thought, because it would be over the top, but all those filters went out the window with dementia,"* Rose reveals how prior to dementia, her mother had expressed herself differently in public and private, filtering her behaviour, and dementia allowed her mother to be herself. Her mother's dementia-related behaviours were not a surprise to Rose, but her mother's authentic self which she had previously *"tempered"* for fear of judgement. Freda recalls overcoming challenges caused by her mother's progressive neurocognitive decline through positive framing:

> *"I didn't expect her to know who I was anymore, and I just refused to believe that she really didn't know who I was. So, I'm like, I know that on some level, she does know me. She knows my heart."*

She describes coming to terms with her mother's cognitive decline in the statement *"I didn't expect her to know who I was anymore,"* acknowledging the need to meet the PwD at their capacity level. While her mother no longer acknowledges her presence, Freda attributes this to an inability to vocalise her feelings, rather than not knowing, demonstrating positive framing in her statement that *"I just refused to believe that she really didn't know who I was."* In her statement that *"she knows my heart,"* Freda conveys how her belief in her mother's knowing is based not on physical communication but on the strength of their relational bond. This may also illustrate an act of self-preservation by Freda's subconscious to maintain her self-esteem rather than consider the alternative explanation, that her mother no longer recognises her.

Subordinate Theme 3.2: A Lonely Role

Caregivers recalled trying to manage isolation both from their peers and from their communities. Kate describes how caring for her mother with early-onset dementia left her feeling isolated from friends from whom she was now living a different life:

> *"They had grandparents who were taking care of their kids, whereas I was taking care of someone who was not even yet a grandparent."*

In the above extract, Kate expresses the alienation she felt from others her age who were occupying age-appropriate roles of caring for their own children, while she was in the unexpected role of *"taking care of someone who was not even yet a grandparent."* Kate also seems to express anticipatory grief and sadness, for her statement that *"they had grandparents who were taking care of their kids,"* may be interpreted that not only is caring for her mother a barrier to having her own children at present, but she has had to consider the possibility that her eventual children would miss out on having a grandmother to care for them, and her mother may not meet her grandchildren. Kate's words illustrate her attempts to come to terms with both loneliness and isolation driven by her mother's dementia, the social drivers of which are highlighted by Sarah in her description of dementia:

> *"It's got this mystique. And this, people are frightened, aren't they, and it's very much still, still hidden and not understood, and so many myths about it."*

Sarah highlights the social stigma that continues to surround dementia, emphasising how the lack of understanding of dementia is fuelled by the *"many myths"* that continue to circulate. Her acknowledgement that dementia is *"still hidden"* emphasises the importance of raising awareness, as communities and individuals remain *"frightened"* by what they don't know. Sarah's extract seems to highlight acceptance that individuals lack responsibility for harmful intent in their fear of dementia; instead, responsibility lies with wider social misunderstandings of dementia. Dave describes what it feels to try and raise awareness for the hidden role of dementia caregiving at the individual level:

> *"It's almost always met with kind of like raised eyebrows and disbelief by outsiders, which makes us feel more alone, more removed, more stigmatized."*

Dave describes predominant reactions of *“raised eyebrows and disbelief by outsiders,”* highlighting how caregivers are granted exclusive membership to an in-group where they are unwillingly alienated from their communities and the social supports to which they would most benefit. His admission that sharing his experience is *“almost always”* received with incredulity emphasises both the overwhelming lack of awareness for caregiving, as well as the disheartening outcomes of trying to raise this awareness whilst reducing isolation as an individual caregiver. When combined with the accounts of Sarah, and numerous other caregivers, the cycle of isolation, help-seeking, and eventual rejection and helplessness which plagues dementia caregivers is concerning. Rose expands on these perspectives to highlight the social drivers of the mystique that surrounds dementia:

> *“The fact that there is there are almost no representations in media in the world around us of the daily experience of this [caregiving] world. It is an invisible role, and I think it’s invisible, because of the extent to which in our society, we abhor dependence.”*

Where Sarah noted that dementia is *“still hidden,”* and Dave described feeling *“more stigmatised,”* Rose attributes intent to the lack of social and media representation of caregiving – suggesting political and ideological motives. In her statement that “*because of the extent to which in our society, we abhor dependence,”* Rose attributes the invisibility and resulting isolation of caregiving to the political and social philosophy of individualism which values independence and self-reliance over interdependence.

Summary

In the final superordinate theme, caregivers shared experiences of managing situational harm whilst caring for a FMwD. In subordinate theme 3.1, *That’s the dementia,* they describe how adaptive coping strategies such as perspective taking, psychoeducation, and particularly positive framing helped them to learn not to take personal offence from dementia-related behaviours. Their experiences emphasised the importance of a positive and open mind in interpreting these behaviours. Caregivers in subordinate theme 3.2, *A lonely role,* expressed how social stigma surrounding dementia can leave caregivers feeling isolated from both those they were once close with and their communities. Isolation from social supports is consistently attributed to the influence of wider social structures which perpetuate stigma surrounding dementia, largely as a function of limited social understandings of dementia. In particular, caregivers choose not to attribute intent or responsibility to those who distance themselves instead, caregivers attribute society's disbelief at the lived experience of dementia caregiving to humanity's fear of the unknown.

Chapter 4: Discussion

This study examined the lived experience of 27 caregivers for a Family Member with Dementia (FMwD), and the role of forgiveness in their experience. Prior to this investigation, the most thorough analysis of the experience of forgiveness when caring for a FMwD was reported by a single participant of Angelica (2013). In addition to this, forgiveness was only briefly mentioned in the findings of two further qualitative studies (Jameson et al., 2020; Paun, 2004), which explored caring for a FMwD from a more general focus. Thus, only limited qualitative literature could be located that specifically explored the experience of forgiveness among this group. Addressing this prominent gap in the literature, the purpose of this exploration was thus to: (a) examine how forgiveness contributes to the experience of caring for a FMwD; (b) uncover how caregivers make sense of forgiving transgressions made by a FMwD; (c) explore how self-forgiveness is experienced within the context of caregiving, and (d) uncover how forgiveness contributes to providing care for a FMwD who has harmed you in the past. This chapter summarises the main findings of this study and compares these findings with existing research and theoretical models, as well as outlining the implications of these. The following section then discusses the strengths and limitations of the current study, and how these inform recommendations for future research. The chapter closes with an examination of reflexivity, as well as a concluding statement.

Summary of Main Findings and Comparisons with Previous Research

The first superordinate theme was *Caring was not a given.* Findings of this theme relate to the research aims of understanding how forgiveness is experienced when called to provide care for a FMwD who has harmed you in the past. This theme included the experiences of a subset of four adult children who, in light of their mother's dementia-related decline, made the decision to take on the caregiving role despite a historically fractured relationship. For these participants, caregiving was bittersweet as they experienced varying degrees of reconnection whilst simultaneously losing their parent to dementia. Notably, it was only children of parents with dementia who described experiencing forgiveness for a historic transgression during their caregiving experience, and there were no spouses nor other family members who described such an experience.

In the first subordinate theme, *History to overcome,* caregivers described how, at the time they were called to care for their parent with dementia, the parent-child relationship was fractured thus, they entered this responsibility from a place of unforgiveness. As previously mentioned, unforgiveness is characterised by a state of inter-related negative, resentment-based emotions, motivations, and cognitions (Worthington, 2005). Participants shared self-doubt about their capacity to provide care for a parent with dementia in the context of this unresolved resentment, with concerns that this may drive them to harm their increasingly vulnerable parent.

The experiential accounts of this theme expand on two previous IPA studies of caring for a FMwD. In the most recent study, four daughters described their relationship with their parents prior to caring for them as conflictual, expressing desires to escape caregiving however, they felt obliged to fulfil this role (Belabbas et al., 2024). Notably, the study did not explore the circumstances that culminated in the fractured relationship, nor did the daughters describe positive interpersonal or intrapersonal outcomes of caring for their parent, such as reconnection, forgiveness, or personal growth (Belabbas et al., 2024). In this sense, caregiving remained an obligation throughout this experience. This contrasts with the present study which illuminated a range of positive outcomes of caregiving despite a previously fractured relationship. This divergence is theorised as somewhat a function of the unique nature of the current sample. In particular, the same characteristics that would later motivate family caregivers to author literature relating to their experience may have predisposed this sample to positive framing and perceiving challenges as opportunities for growth. It is possible that the present findings are shaped by more secure attachment styles among both the PwD (Perren et al., 2007) and caregivers (Reidun & Solem, 2009), or both, though this theory may be undermined by most historic transgressions among this group dating back to childhood. In a recent though isolated study, Peters et al. (2023) demonstrated a correlation between openness to experience and exploratory processing. These findngs support the above theory that the present sample may have been more likely to engage in meaning-making with an emphasis on positive framing thus, motivating forgiveness when compared to caregivers who have not pursued authorship (Weststrate & Glück, 2017). Ultimately, these divergences highlight that reconnection and forgiveness are not a given of caring for a parent with dementia, though may be encouraged by attachment and dispositional factors.

In an earlier study by Angelica (2013), a single participant (the author) reported being called to care for her mother with whom her relationship had been previously strained. Similar to the present study, Angelica (2013) described how, prior to caregiving, she had initially used physical distance to protect herself from her mother. However, her account of consistently seeking connection with her mother from this safe distance prior to caregiving was not reflected in the present study, where participants described more caution in reconnection. These divergences reflect the multifaceted and complex nature of childhood maltreatment, coping, and parent-child relationship dynamics evident in psychological research of both the general population (Azar & Weinzierl, 2005; Worthington & Scherer, 2004), and family caregivers (Chilatra et al., 2024; Romano et al., 2021; Romero-Moreno et al., 2011). Though notably, the present findings suggest that in addition to the strengths of particular attachment styles for adapting to challenges of the caring for a FMwD (Perren et al., 2007), specific personality traits such as an openness to experience may predispose individuals to care and seek forgiveness.

No further accounts could be located in which participants experienced relationship difficulties prior to family caregiving, with most studies, such as Dombestein et al. (2020) emphasising the relational fondness that preceded the care relationship. Limited existing accounts of this phenomenon may be attributed to various factors such as this likely being a relatively uncommon experience, and the stigma surrounding the disclosure of family conflicts (Park & Park, 2014). Thus, the courage of the women in the present study to share the adversity which they overcame to care for their parent may contribute to existing positive psychology research providing hope to those faced with a similarly challenging decision to care, as well as to normalise this experience.

In the second subordinate theme, *The decision to care,* the women described complex considerations in reaching their decision to care for a parent with dementia who had harmed them in the past. The women expressed concern not only for the risk of harm to themselves by reconnecting with the perpetrators of previous harms but also for the risk that their own resentments may pose when caring for their increasingly vulnerable mothers.

Findings of a longitudinal multi-choice survey suggest that adult-children whose parent had harmed them in the past have reported greater depressive symptoms during caregiving compared to peers (Kong & Moorman, 2015). Providing care to a perpetrating parent has also been associated with greater risk of resentment, post-traumatic symptoms, and use of harmful coping strategies such as substance abuse due to unresolved issues with the parent (Brown, 2012). These findings validate concerns raised by caregivers in the current study that reconnection would put them at risk of psychological harm. In a subsequent study, Kong and Moorman (2016) also demonstrated that maternal childhood abuse was associated with daughters providing less-frequent emotional support to their mothers, while instrumental support was unaffected. While the current study did not seek to replicate these findings, they substantiate the women's concerns prior to caregiving that their resentment may limit their capacity to provide emotional support to their mothers – as well as their relief when they let down their walls to allow an emotional connection. Notably, the literature referenced above examined the parent-child relationship in caregiving, though not dementia caregiving specifically. While this does not rule out the applicability of these findings, it does again illuminate the need for further research into this population and phenomenon to better understand how cognitive impairment may create barriers or opportunities for forgiveness when caring for a perpetrating parent.

In the third subordinate theme, *It brought us back together,* women recalled how they achieved forgiveness as dementia changed their mothers until they were nearly unrecognisable. Consistent with literature outlining the role of emotion in forgiveness, women described how changes to their mothers, perceived as a softening or greater emotional vulnerability, enabled their reconnection and forgiveness (Worthington et al., 2007). Forgiveness enabled by positive dementia-related changes to a previously difficult parent almost replicates the experiences of Angelica (2013) in the case of caring for her mother. As Angelica (2013) provides the only other located instance of this particular phenomenon, the current findings serve to illuminate this as an understudied rather than an isolated experience. While Belabbas et al. (2024) examined a similar phenomenon, the parent-daughter relationship in dementia caregiving, daughters caring for a mother who had harmed them in the past did not report expectations nor experiences of reconciliation or forgiveness during caregiving. Notably, while perceptions of dementia progression were not a central focus of this recent study, the daughters of Belabbas et al. (2024) did not describe any positive changes to their mother, instead reporting a familiar coldness and disconnect throughout the disease process. This fundamental difference may underlie the distinct contrast in findings, as in the present study dementia mothers became easier to be around, connect with and subsequently forgive as a function of their softening. Differences may also relate to methodological distinctions particularly the wider focus of Belabbas et al. (2024) on the overall caregiving relationship, while the present study purposively sampled caregivers who described forgiveness within their discussion of the wider caregiving experience.

In further support of the above distinction, the findings of the present study replicate theoretical distinctions of emotional and decisional forgiveness. In particular, as the abovementioned dementia-related changes removed historic barriers to emotional closeness as well as the threat of future harm by their mother's, the women found reconnection, illustrating the central tenets of decisional forgiveness (Worthington & Sandage, 2016). The experience of decisional forgiveness is distinguished from emotional forgiveness throughout the present study in participant descriptions of noticing a greater capacity to tolerate the physical presence of a parent, while still experiencing emotional distance. These experiences illuminate distinctions between decisional forgiveness as overcoming negative feelings towards a transgressor to reach a place of neutrality, as distinct from the intrapersonal processes of replacing negative with positive feelings toward a transgressor as necessary for emotional forgiveness (Worthington et al., 2007).

In the fourth subordinate theme, *I thought the responsibility would be shared,* caregivers recalled being let down by a sibling while caring for a parent with dementia. Unfortunately, most of those women who had taken on caring for a perpetrating parent also experienced varying degrees of unexpected betrayal by a sibling who shared this parent but did not perceive the same obligation to care – requiring a concurrent process toward forgiveness.

The obligation that these women felt to care for a parent relates to the Western principle of parental respect, and dates back to the virtue of filial piety which is universally expressed across ancient cultures and religions; the expectation of honour and devotion to parents, which implies a responsibility of adult children to make sacrifices for their parents or family (Sun et al., 2012). Principles of filial piety including obligation, duty, and responsibility, have been cross-culturally referenced as a key motivator in caring for a parent with dementia (Greenwood & Smith, 2019). Inequity in caring for an elderly parent, as demonstrated in the present study, is an established phenomenon, with men less prone to involve themselves in the caregiving role to the same degree as women (Lin et al., 2012). Social psychology posits that women are more likely to internalise and identify with the caregiving role when compared to men, as a consequence of established gender roles and instincts towards nurturing (Sharma et al., 2016; Walker et al., 1995; Wallhagen & Yamamoto-Mitani, 2006). As found in the current study, women are also socialised as children to be relationship-oriented, whereas men to be task oriented (Lutzky & Knight, 1994). Women's attitudes towards care have also been characterised in literature by a greater responsibility to care, altruism, and self-sacrifice (del-Pino-Casado et al., 2012; Pöysti et al., 2012) – all of which were illustrated in the current study. While most findings are derived from general caregiving experiences, daughters have described an inequitable distribution of responsibility among siblings when caring for a parent with dementia (Kokorelias et al., 2022), supporting the experiences of the current sample.

Despite their brother's unanticipated absence whilst caring for a parent who had harmed them in the past, each of the women described reaching varying degrees of forgiveness and reconciliation with their brother. As noted in Embeddedness Theory, a victim remains embedded in the victim-offender relationship characterised by unforgiveness to the degree that dissolution of the relationship would result in significant personal sacrifice (Mitchell et al., 2001). As women in the present study began to lose their mothers to progressive dementia, they experienced a shrinking of their immediate social supports, which they would risk shrinking further should they remain unforgiving and sacrifice their relationship with a brother. In previous meta-analyses, measures of embeddedness, including both relationship closeness and commitment, have been shown to increase the likelihood of victim forgiveness (Fehr et al., 2010). Embeddedness as a situational correlate of forgiveness has not been explored beyond this initial analysis by Fehr et al. (2010) thus, the present study may provide some insight into the relationship between embeddedness and forgiveness among caregivers for a FMwD. These findings may suggest that losing a parent to dementia could motivate adult-child caregivers to reconcile other fractured relationships, as they lose the support of a parent with whom they may have only recently reconciled.

The fifth subordinate theme, *Contrasting reflections on long-awaited reconciliation,* highlighted idiosyncrasies in how caregivers made sense of forgiving a parent with dementia who had harmed them in the past. As a process, forgiveness is unique to the forgiver, based on the cumulation of an individual's experiences in interplay with personal characteristics (Worthington et al., 2007). Thus, while the caregivers each forgave a parent's previous transgression, not all women reached the same place of forgiveness nor, the same appraisal of previous harm.

Literature differentiates related, though distinct processes of decisional and emotional forgiveness, which differentially influence cognitive processes of the forgiver (Lichtenfeld et al., 2015). Two women described reconnecting with their mothers throughout caregiving. The women found it easier to be in the presence of their mother, where prior to caregiving they had struggled to tolerate them for prolonged periods. These accounts support principles of decisional forgiveness, as both women no longer engaged in negative behaviour towards their mothers, instead seeking more positive engagement (Worthington & Sandage, 2016). While decisional forgiveness allowed the women to care for their mothers, they did not change their interpretations of past transgressions.

Prior research has demonstrated that distinct from decisional forgiveness, emotional forgiveness impacts cognition, particularly their attributional patterns, altering the attribution of responsibility in a manner that makes restoration of closeness more likely (Lichtenfeld et al., 2019). In particular, when compared to those who do not forgive or instead attained decisional forgiveness, individuals in prior research who thought about emotionally forgiving a transgressor described both holding the transgressor less responsible for the transgression, appraising the transgressor as having less control over the transgression, and considered the transgression as driven by situational rather than dispositional factors (Lichtenfeld et al., 2019). These findings seem to demonstrate that expressing more positive attributions towards a transgressor may foster emotional forgiveness. This research illuminates' findings of the present study, in which those participants who demonstrated emotional forgiveness for their mother also expressed altered attributional cognitions about the transgression and the responsibility of the transgressor (Lichtenfeld et al., 2019). In particular, emotional forgiveness seemed to allow one participant to minimise her mother's responsibility for previous transgressions, instead attributing these to situational factors, while simultaneously, attributing positive dementia-related changes in her mother to an intrinsic or original self.

These altered attributions, however, may demonstrate a correspondence bias. In particular, when reflecting on her mother's altered presentation and the forgiveness they subsequently achieved, the participant attributed these changes solely to the emergence of her mother's true self, without acknowledgement of situational correlates namely, dementia-related changes (Scopelliti et al., 2018). Attributional biases in forgiveness, let alone among a sample of caregivers for a FMwD, are largely unexplored (Riek & Mania, 2012). However, social psychological theories have established that dispositional inferences may be drawn from situational behaviour when the behaviour is diagnostically valuable to an existing idea or schema (Gawronski, 2004). When applied to the above findings, social psychology posits that the participant may be blinded to dementia as a fundamental cause of positive changes to her mother's behaviour by her overwhelming desire to confirm long-held beliefs that her mother is a good person therefore, these changes are instead attributed to the revelation of her mother's true, good, disposition. In particular, this may also be interpreted as a self-serving bias and unconscious preservation of the participant's self-esteem, as by attributing recent positive behaviour to her mother's fundamentally 'good' disposition, the participant can then subsequently rationalise the attribution of past harms to situational factors – minimising intent and responsibility for past transgressions. This dispositional attribution of situationally constrained behaviour, thus, is a way of validating the participant's existing schema, potentially originating in childhood, that her mother is a good person.

On another note, with its strong connection to overcoming negative affect and stress reactions, emotional forgiveness has demonstrated a greater association with positive psychological and physiological changes than decisional forgiveness (Worthington et al., 2007). Findings of the present study diverge from previous research in this regard, as loss following emotional forgiveness was associated with distress relating to feelings of abandonment, which were not reported by caregivers who attained decisional forgiveness. It would be beneficial for future research to explore this phenomenon to determine if loss subsequent to emotional forgiveness for a historic transgression might create psychological distress which the emotional distance of decisional forgiveness might avoid.

The main findings of subordinate theme two, *Forgiving myself,* related to the research aims of exploring how self-forgiveness is experienced while caring for a person with dementia. This theme illuminated the burden of unrealistic role expectations that caregivers place on themselves and how forgiveness for not meeting these expectations, or a lack thereof, shaped the meaning derived from caregiving.

The first subordinate theme, *I wish I had done it differently,* explored guilt, shame, and self-blame regarding care decisions which numerous caregivers felt unable to forgive themselves for. Caregivers expressed guilt for decisions such as seeking a diagnosis for their parent, which in light of their parent's negative reaction to this care decision they described as not congruent with the role of a good caregiver. A number of women remained stuck in feelings of guilt for a care decision which their parent with dementia reacted negatively to. Research suggests that caregiving presents situations in which the comments or behaviours of a FMwD may provoke strong negative emotions such as guilt (Gallego-Alberto et al., 2022). The current study complements these findings with similar descriptions of persistent guilt induced by the reactions of a FMwD to evidence-based care decisions. It cannot be determined whether the current study presents a more representative sample than the above findings derived from caregivers with clinical anxiety or depression due to limited demographic information for the present sample. In fact, the experiences described by caregivers of the current study cannot rule out previous trauma, ongoing depression, anxiety, or both. Thus, current findings support existing literature regarding negative consequences of guilt as a common experience when caring for a FMwD.

Limited self-forgiveness following negative reactions from a FMwD may be illuminated by the findings of Fisher and Lieberman (1996), who determined that experiencing emotional manipulation by a parent with dementia was associated with greater psychological and physical distress in caregivers. These findings suggest that caregivers in the present study who described ongoing self-blame for the negative reactions of their FMwD may have experienced additional psychological barriers to self-forgiveness, such as historic psychological manipulation by their FMwD. As the present study utilised secondary data, characteristics that may have prevented these caregivers from engaging in self-forgiveness as an adaptive coping strategy cannot be determined. Thus, it is recommended that future research utilise primary data to explore self-forgiveness among this population, with particular attention to caregiver characteristics such as self-esteem (Mróz, 2022), neuroticism (Braithwaite et al., 2016), and attachment orientation (Chen et al., 2014) which are established correlates of self-forgiveness. Such findings may highlight caregivers who could benefit most from interventions to promote adaptive coping, as well as how this experience might alter the above characteristics.

The second subordinate theme, *We didn't go to school for this,* highlighted how caregivers made sense of the immense and unanticipated responsibility of caring for a FMwD and how self-forgiveness allowed recognition of their best efforts at a role for which traditional education did not prepare them. Caregivers reflected on the pressure they put on themselves to be their best without compromise and how unrealistic these demands were, particularly, given the unpredictable nature of caring for someone with dementia. Reflecting definitions of self-forgiveness (Woodyatt et al., 2017), caregivers reduced self-condemnation and acknowledged unrealistic expectations. Ultimately, caregivers upheld responsibility for their actions and inactions while seeking to heal the guilt and regret perpetuated by their unrealistic expectations (Tangney et al., 2005).

The main findings of superordinate theme three, *No one to forgive,* related to the research aims to examine how caregivers made sense of forgiving the transgressions of a FMwD, as well as the aim to explore the lived experience of caregivers. This theme showed the unanticipated findings that caregiving-related harms were largely attributed to situational factors, which meant that there was no-one to forgive.

The first subordinate theme, *That's the dementia,* explored how caregivers made sense of responsibility and intent when harmed by the actions of a FMwD. Caregivers expressed several factors, such as empathy and psychoeducation, that altered their interpretations of these harmful behaviours. As noted in the literature, attribution of responsibility, intent, or both are necessary for an action to be appraised as a transgression and thereupon, require forgiveness (Weiner, 1995). Responsibility requires conscious control of actions meanwhile; intent is centred on the offenders' goals, with intentional actions resulting in harm implying malice or indifference, and the same lacking in unintentional actions (Weiner, 1995).

In line with this theory, caregivers in the present study largely attributed harmful actions by their FMwD to situational factors of cognitive decline, including confusion, loss of problem-solving skills, and memory loss, preventing attribution of responsibility or intent to the PwD. It is possible that witnessing the cognitive decline of a FMwD drove caregivers to they no longer perceived capacity for conscious, goal-directed harmful actions instead, attributing harm to consequences of the disease process. Such reasoning were previously expressed by Latino caregivers of FMwD, who refused to take difficult dementia-related behaviours personally, dismissing intent in the actions of their FMwD, and instead accepting this behaviour as dementia-related (Turner et al., 2015). As this phenomenon had not been explored elsewhere, the findings of Turner and colleagues were understandably theorised to have a basis in Latin or collectivist cultural norms. The present findings, therefore, elaborate on those of Turner and colleagues to suggest that attributional processes are instead cross-cultural. This theory is promoted by findings demonstrating the consistency of several aspects of Attribution Theory across cultures (Dean & Koenig, 2019). Should future research confirm the current findings, it would be beneficial to examine the experiences of this group with particular attention to the attribution of responsibility and intent, to understand any limitations of these attributions specific to dementia caregiving. A greater understanding of these cognitive processes would inform more effective interventions to reduce caregiver distress, internalisation, and maintain social support in dementia caregiving.

The second subordinate theme, *A lonely role,* highlighted caregiver attributions of responsibility and intent in the context of social isolation experienced throughout caregiving. Caregivers described feeling that family and peers would not understand what they were going through, with some finding that reaching out them feeling further alienated. Alienation and isolation in caregiving, particularly from close family, would commonly result in caregiver distress, requiring a subsequent forgiveness process (Lee et al., 2022; Wittenberg-Lyles et al., 2014). However, in another unanticipated finding, caregivers in the present study commonly attributed isolation from family and peers experienced to situational correlates of dementia, including a lack of social understanding of dementia, creating stigma and fear of PwD. These findings also support Evolutionary Theories of forgiveness, which highlight adaptive advantages of forgiveness for promoting reconciliation and group cohesion, as forgiveness allows caregivers to maintain relationships even with those who cannot relate to their experience (Worthington, 2019). When compared with non-caregivers, caregivers have scored higher on the personality trait of agreeableness – commonly associated with greater compassion – which could account for the generosity demonstrated by those in the present sample when interpreting the actions of others (Luchetti et al., 2021; Riek & Mania, 2012). This theory alone, however, would be insufficient to also account for the disappointment expressed by caregivers' when siblings failed to support them while caring for a parent with dementia, as covered in the earlier theme, *I thought the responsibility would have been shared.* It is possible, however, that this may be explained by role-specific expectations for siblings in terms of sacrifice and support, though research into adult-sibling relationships is sparse.

Perceptions of isolation in dementia caregiving as driven by social, rather than individual factors are supported in the literature. Experiences of loneliness in dementia caregiving are particularly well-established in the literature (Brodaty & Donkin, 2009), with all 42 caregivers in a study by Pini et al. (2018) describing loneliness and social isolation, many of which attributed this to causes outside of their control. Caregivers in the present study similarly attributed feelings of isolation to others' fear of dementia and understood this to be driven by a lack of social understanding of the disease. A scoping review of literature relating to social isolation in dementia caregiving by Lee et al. (2022) yielded a closely related theme of 'retreating social networks.' Present findings complement this theme, as caregivers similarly described the retreat of social supports as driven by fear of confronting dementia, stigma, and discomfort with dementia (Lee et al., 2022). These findings support the need for societal-level changes to improve social understandings of dementia, to remove both the fear associated with the unknown (Carleton, 2016), but also to raise awareness for the challenges of dementia caregiving, and the integrity of social support to the wellbeing of caregivers (Valois & Galvin, 2014).

Overarching Findings

In a finding of unanticipated significance, Attribution Theory has, as noted above, woven throughout the findings of the current study, arising across each of the superordinate themes, contributing to participant sense-making and forgiveness processes. Attribution Theory suggests that forgiveness is directly influenced by attributions of responsibility and intent, which subsequently determine retaliatory and reconciliatory efforts in opposing manners (Fincham et al., 2005).

Existing theories posit that while unforgiveness is associated with attributing harm to dispositional correlates, forgiveness is associated with attributing harm to predominantly situational correlates – relationships which remained almost entirely consistent across all measures and experiences of forgiveness (Takaku, 2001). Forgiveness of others was almost entirely described with an emphasis on the situational correlates of the transgression – including factors such as the FMwD's cognitive decline, and lack of social awareness of dementia in outsiders – which minimised individual responsibility for transgressions, in line with the above Attribution Theory of forgiveness. Whereas those struggling to forgive themselves or others were more likely to describe negative dispositional factors. Only a single caregiver was noted as diverging from these established theories of attribution and forgiveness. Similar descriptions of divergences from this established theory of attribution in forgiveness were previously reported in Lichtenfeld et al., (2019) with reference to the propensity for emotional forgiveness to alter cognitions regarding responsibility and intent. However, the present methodology limits causal inferences, and future research is required to determine if such divergent processes of attribution in forgiveness are indeed result from distinct cognitive processes of emotional forgiveness.

Complementing previous research in experimental psychology (e.g., Lichtenfeld et al., 2019), attributional differences were noted between those caregivers who described experiences of decisional forgiveness, compared to those who described emotional forgiveness. In particular, only those who emotionally forgave their FMwD for a historic transgression also described subsequently attributing less responsibility and intent to their family member for this harm. Caregivers of the present study who described decisional forgiveness, in contrast, did not report change to their perception or attributions of the previous harm. These findings seem to demonstrate similar experiences of altered cognitions specific to emotional forgiveness as reported in Lichtenfeld et al. (2019), though causal direction cannot be derived from the present non-experimental findings. Thus, present findings complement Lichtenfeld et al. (2019) with naturalistically derived findings similar to those previously originating in reactions to hypothetical scenarios therefore, indicating a promising direction for future experimental research.

Self-forgiveness is more difficult than interpersonal forgiveness however, it is theorised that an inability to relinquish self-blame in the present research may relate to the fundamental role of other-focused empathy in caregiving. Experiences of self-blame, guilt, and a subsequent lack of self-forgiveness in the present study seemed to be associated with caregivers misattributing a negative reaction in their FMwD to a personal deficit within the caregiver themselves. Caregivers seemed to become particularly fixated on instances in which they felt they had provided an inadequate standard of care to their FMwD. Scenario-based findings of Zechmeister and Romero (2002) have previously linked such dispositional attributions underlying self-blame and an inability to forgive the self to higher levels of other-focused empathy. Hall and Fincham (2005) have similarly reported that empathy mediates guilt in this process to inhibit self-forgiveness. This suggests that as a result of high levels of empathy in caring, caregiver's may have felt that attributing negative experiences of a FMwD to situational factors such as cognitive decline, would be demonstrating a lack of empathy or victim blaming. Thus, it is possible that the empathically demanding role of caring for a FMwD makes this group particularly susceptible to self-blame, as self-forgiveness is conflated with acting unempathetic. While further research is required, this theory would suggest that caregivers for a FMwD could particularly benefit from psychoeducation regarding not only distinctions between forgiveness and condoning or accepting harm, but also the benefits of self-forgiveness to caregiver and care-receiver.

Study Strengths

There are several strengths to the present study. Firstly, the findings contribute to the existing literature on experiences of forgiveness when caring for a family FMwD, which has been notably limited to date. The findings contribute to bridging a gap in current understandings of positive experiences of caregiving by providing unique insights into the experience of forgiveness among this population. The findings of the present study can also be utilised to inform understanding of not only the overall experience of caring for a FMwD but also how forgiveness can improve the experiences and wellbeing of caregivers, and what they may lose to unforgiveness.

The use of Interpretative Phenomenological Analysis (IPA) as the methodology for the current exploration is another strength. IPA was especially pertinent given the lack of existing literature regarding this phenomenon. IPA enabled the researcher to examine each of the 100+ episodes available on the podcast at the time of review, without the restrictions of more prescriptive methodologies (Smith, 2004). This further enabled the analysis of rich experiences, which, despite not using the word forgiveness, illustrated themes of forgiveness that would not have met inclusion criteria of more prescriptive methodologies such as Narrative Analysis and ultimately provided some of the richest data in the final analysis. IPA also allowed the researcher to examine these often intimate, emotionally laden, and socially isolating experiences in a manner that upheld the dignity of participants. In particular, the thematic process of this approach allowed the researcher to illuminate both shared elements of this experience as well as give space to the idiosyncrasies and essence of the individual participants (Alase, 2017). Findings relating to experiences of forgiveness, particularly the centrality of attribution to cognitive and emotional consequences of harm, may inform more focused research, such as evidence-based interventions to improve adaptive coping in caregivers. The broader commonalities highlighted in these experiences may help to raise awareness for the challenges and rewards of caring for a FMwD.

While literature on forgiveness, as well as attributions, have found that both naturalistic and scenario-based experiments reveal similar findings (e.g., Struthers et al., 2010), forgiveness research remains largely scenario-based, necessitating naturalistic studies to affirm these findings (Robbins et al., 2024). The current study presents the experiences of forgiveness by family caregivers, which differentiate the cognitive processes associated with emotional forgiveness from experiences of decision forgiveness, derived naturalistically from podcast interviews that did not explicitly seek to explore forgiveness experiences. In this aspect, while the internal validity of the present findings is limited by the non-experimental design, the naturalistically derived findings complements prior experimental research (e.g., Lichtenfeld et al., 2015). Not only does the present study present a unique qualitative analysis of this particular phenomenon, but the innovative medium of podcast interviews has provided a perspective oftentimes limited both in other mediums, as well as by a researcher's access to resources.

Findings are further strengthened by the eloquence with which experiences of forgiveness were expressed by caregivers in the present study (Tuffour, 2017). In particular, authorship as a pre-requisite to the podcast interview produced a sample who were almost certain to have considered and reflected upon their caregiving experience prior to interviewing, likely to a greater breadth and depth than caregivers who have not pursued authorship. Such introspective analysis of the caregiving experience is evident in the eloquence with which caregivers shared both the nuances and meaning derived from caregiving, subsequently addressing a common limitation of IPA research in which participants provide opinions of phenomena rather than experiences, in the absence of sufficient rich participant data (Tuffour, 2017).

Study Limitations and Directions for Future Research

Though explored throughout the discussion, a number of limitations and directions for future research are considered below. Firstly, individuals tend to write literature regarding more favourable personal experiences, and so it is likely that those included in this sample had a more positive or more memorable experience of caregiving than those who may not wish to speak publicly about their experience. It would be prudent, therefore, that future research is designed to capture the voice of those whose caregiving experience may not have felt as positive, as well as those who may consider themselves less fluent, and in a manner that still facilitates examination of the richness of their experience. IPA has established methods to overcome the limitations of fluency, such as expression of experiences using art, as demonstrated in an IPA study in which participants painted pain (Kirkham et al., 2015). Thus, it is recommended that future research examine the experiences of forgiveness of a broader sample of caregivers, in order to better understand the range of nuances of this experience.

The nature of secondary podcast data limited some aspects of the present study. Firstly, this meant that very little was known about the demographics or backgrounds of the participants. While qualitative research does not fundamentally require such information, the absence of these details does limit some of the conclusions that may be made, particularly when attempting to make connections across cases or reflect on the diversity of the sample (Frechette et al., 2020). In addition, the use of secondary data sources also meant that the researcher was not able to pose follow-up questions when intriguing aspects of an experience arose. For instance, a number of participants additional to the sample included had mentioned forgiveness, though had not elaborated on this experience with sufficient depth for inclusion. The final sample included 27 caregivers who had authored literature relating to dementia and discussed their experiences on the podcast. While this sample may large relative to most studies using IPA, as the podcast interviews were not specifically focused on the discussion of forgiveness, there were notable variations in the relevant speaking time per participant, with some contributing only a few minutes of discussion. Each of the aforementioned factors also limited the degree to which participant accounts continued beyond any one superordinate themes to provide a voice across numerous aspects of the forgiveness experience – as forgiveness was found to be a central feature of the podcast discussion for some caregivers, but not for others. Despite this, there was sufficient data to allow rich and nuanced interpretation of a number of experiences, though readers will be more familiar with some characters than others.

While caring for a FMwD remains largely undertaken by women, a small body of research indicates that increasing numbers of men are taking on the responsibility of caring (Robinson et al., 2014). The present study included the accounts of only two male caregivers within a total sample of 27 caregivers. While the gender composition of this sample is not representative of Western nations such as the USA, Japan, and Europe in which men are estimated to provide up to 48 informal care to FMwD (Ohno et al., 2021), the proportion of male accounts included in the present study inadvertently reflected a similar proportion of accounts available on the podcast. It would be pertinent that future research seeks predominantly, if not entirely male samples caregivers to better understand the unique experiences of forgiveness within this understudied though growing subset of family caregivers. In addition, the shared experience of three caregiver daughters being let down by a brother whilst caring for their FMwD suggests that numerous stakeholders could benefit from better understanding experiences of feeling unable to care for a FMwD, particularly from the perspective of males. Greater understanding of both the experience of these men in their inability to provide care and whether they perceive this to be a transgression, as well as closer analysis of the forgiveness process of the sisters left to care without the support of a brother, may inform early interventions to promote family cohesion following a parental dementia diagnosis. Such research would likely require primary data and purposive sampling, as recent findings also suggest that male carers are less likely to participate in research and require significantly more rapport-building (Poisson et al., 2023).

As previously mentioned, it is recommended that future research also examine the experience of altered attributional cognitions associated with emotional forgiveness, and the saliency of these attributions in the context of dementia-related personality changes. A greater understanding of the role of attributions in forgiving a FMwD would inform evidence-based strategies for supporting caregivers to forgive a FMwD, thus improving the caregiving relationship and overall experience.

Reflexivity

A fundamental component of IPA is the active contribution of the researcher to interpretation of narratives. It is therefore the responsibility of the researcher to practice self-conscious critique, appraisal, and evaluation of how their subjectivity and context influence the research process (Olmos-Vega et al., 2023). I made considerable efforts throughout this study to engage with and reflect on my personal biases and beliefs to ensure that my interpretations did not obscure the experiences of the participants. I believe that throughout this research I have occupied the space between an insider and an outsider, noting the ways in which I am different from the caregivers of this study, though also the ways that I can relate to their experience (Dwyer & Buckle, 2009). It is this engagement within the hermeneutic circle that I attribute to finding myself writing “we” and “us,” whilst also writing “they” and “them” during my analysis (Smith et al., 2009). While I could identify with experiencing forgiveness, unforgiveness, and empathy, I could only imagine the experiences of caring for a loved one with dementia. Through engagement in supervision, as well as reflection on the power of my narrative, I sought to only write “they” and “them,” or “the participants” and “the caregivers;” to respectfully acknowledge my outsider status relative to the caregiver's insider status, and to avoid the impression of fully understanding or speaking from the experience of caring for a FMwD.

Ultimately, my personal experience and knowledge are bound to have influenced my interpretations and findings to some degree. My actions to manage these biases were discussed in the methodology chapter under researcher reflexivity.

An unanticipated challenge, however, was managing feedback on my initial data analysis, which indicated that I had reached conclusions that were not sufficiently grounded in the accounts presented. In particular, I had strayed from my theoretical orientation in social psychology and methodology of IPA towards a psychodynamic orientation in which participant experiences were framed from a therapeutic lens. Exploring these divergences from the selected theoretical orientation and methodology required reflection on the manner in which ego was showing up in my analysis, and how this was damaging the trustworthiness and quality of the present study. Reflection facilitated attribution of this divergence to my positioning, particularly my concurrent engagement with post-graduate study in Clinical Psychology, and eagerness to apply this knowledge where possible. Data was re-analysed, and I committed to regular reflection on my identity as a researcher, and to ensuring that my interpretation of participant experiences was inherently grounded in their data and remained within the scope of my non-clinical qualification.

My own experiences of forgiveness, unforgiveness, harm, and resentment have allowed me to consider a range of implicit meanings behind the voices of the participants. I believe that my lack of any particular lived experience has allowed me to be more open to the possibilities of these meanings in a way that an insider may have favoured a particular interpretation. Witnessing family members' care for my loved ones with terminal illnesses allowed me to approach this phenomenon having seen the dominant experiences of love and care which are felt when caring for someone you love, as well as with appreciation for the stress this can put on a family. These experiences enabled me to keep an open mind when approaching a topic for which extant literature is predominantly deficit-focused. It is possible that this factor may have predisposed me to give participants grace when interpreting their words, though I believe that literature suggests this is the responsibility of the researcher in IPA to promote the dignity of those disclosing such personal experiences (Smith et al., 2009).

On balance, I believe that my positioning in the present study positively influenced both the research process and findings. Although, it would be beneficial for future research to create a more active voice for familial caregivers, to further promote their voices and direct research towards those causes in which the caregiving experience has placed value.

Concluding Remarks

The present study contributes to the literature by examining the experience of forgiveness among those providing care to a FMwD. There was no one caregiver who was unable to reach a place of forgiveness or remained entirely stuck in unforgiveness. Intrapersonal forgiveness was reached by those caring for a parent who had harmed them in the past. Unforgiveness was only reported to have persisted in relation to the self. Findings have demonstrated that caring for a FMwD may present a unique opportunity for forgiveness and the overcoming of previously fractured relationships with a parent. The degree to which responsibility and intent were not attributed to both the FMwD in the context of challenging behaviours, nor to friends and family who count not face dementia, was an unprecedented finding which requires further research to determine if specific to the present sample. It is hoped that this study will encourage future research in this area, as well as promoting interventions to facilitate forgiveness of both others and the self as a worthwhile strategy for adaptive coping when caring for a FMwD. Future research is required to better understand how attributions of responsibility and intent, as a consistent feature of the experiences of this group, may be utilised to improve both knowledge and likelihood of forgiveness among caregivers. Future research is also required to determine whether the empathically demanding nature of caring for a FMwD may make this group particularly susceptible to both forming unrealistic standards of care and personal sacrifice, as well as subsequently limiting self-love and self-forgiveness.

References

Abalkhail, M. J. (2021). Being native: Insider research in qualitative studies of gender and management. In V. Stead, C. Elliot, & S. Mavin (Eds.), *Handbook of research methods on gender and management* (pp. 130-144). Edward Elgar Publishing. https://doi.org/https://doi.org/10.4337/9781788977937.00017

Alase, A. (2017). The Interpretative Phenomenological Analysis (IPA): A guide to a good qualitative research approach. *International Journal of Education and Literacy Studies*, *5*(2), 9-19. https://doi.org/https://doi.org/10.7575/aiac.ijels.v.5n.2p.9

Albert, M. L., & Mildworf, B. (1989). The concept of dementia. *Journal of Neurolinguistics*, *4*(3), 301-308. https://doi.org/https://doi.org/10.1016/0911-6044(89)90022-5

Alder, P. A., & Alder, P. (1987). *Membership roles in field research* (Vol. 6). Sage.

Ali, S., & Bokharey, I. Z. (2015). Maladaptive cognitions and physical health of the caregivers of dementia: An interpretative phenomenological analysis. *International journal of qualitative studies on health and well-being*, *10*(1), 28980. https://doi.org/10.3402/qhw.v10.28980

Allais, L. (2023). Feeling blame and feeling forgiveness. In G. Pettigrove & R. Enright (Eds.), *The Routledge Handbook of the Philosophy and Psychology of Forgiveness* (pp. 215-229).

Alzheimer's Association. (2020). 2020 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, *16*(3), 391-460. https://doi.org/10.1002/alz.12068

American Psychiatric Association. (1952). *Diagnostic and statistical manual of mental disorders* (1st ed.). American Psychiatric Association.

American Psychiatric Association. (1968). *Diagnostic and statistical manual of mental disorders* (2nd ed.). American Psychiatric Association.

American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders* (3rd ed.). American Psychiatric Association.

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders. In (5th ed.). Washington D.C.: American Psychiatric Association.

Amieva, H., Stoykova, R., Matharan, F., Helmer, C., Antonucci, T. C., & Dartigues, J. F. (2010). What aspects of social network are protective for dementia? Not the quantity but the quality of social interactions is protective up to 15 years later. *Psychosomatic Medicine*, *72*(9), 905-911. https://doi.org/10.1097/PSY.0b013e3181f5e121

Angelica, J. C. (2013). Children of heroes: Alzheimer's disease--a path toward healing and wholeness for caregivers. *The Journal of Pastoral Care & Counseling*, *67*(3). https://doi.org/https://doi.org/10.1177/154230501306700306

Ar, Y., & Karanci, A. N. (2019). Turkish adult children as caregivers of parents with Alzheimer's disease: Perceptions and caregiving experiences. *Dementia: The International Journal of Social Research and Practice*, *18*(3), 882-902. https://doi.org/10.1177/1471301217693400

Asselin, M. E. (2003). Insider research: Issues to consider when doing qualitative research in your own setting. *Journal for Nurses in Professional Development*, *19*(2), 99-103. https://journals.lww.com/jnsdonline/fulltext/2003/03000/insider_research__issues_to_consider_when_doing.8.aspx

Azar, S. T., & Weinzierl, K. M. (2005). Child maltreatment and childhood injury research: A cognitive behavioral approach [Article]. *Journal of Pediatric Psychology*, *30*(7), 598-614. https://doi.org/10.1093/jpepsy/jsi046

Barrett, L., & Russell, J. (1998). Independence and bipolarity in the structure of current affect. *Journal of Personality and Social Psychology*, *74*, 967-984. https://doi.org/10.1037/0022-3514.74.4.967

Batson, C. D. (2023). *Empathic concern: What it is and why it's important*. Oxford University Press. https://doi.org/10.1093/oso/9780197610923.001.0001

Beeson, R., Horton-Deutsch, S., Farran, C., & Neundorfer, M. (2000). Loneliness and depression in caregivers of persons with Alzheimer's disease or related disorders. *Issues in Mental Health Nursing*, *21*(8), 779-806. https://doi.org/10.1080/016128400750044279

Belabbas, E. R., Manceau, C., & Wawrziczny, E. (2024). The relationship at the heart of the experience of daughter caregivers of a parent with dementia: An interpretative phenomenological analysis. *Dementia*, *23*(2), 175-190. https://doi.org/10.1177/14713012231220223

Berndsen, M., Wenzel, M., Thomas, F. E., & Noske, B. (2018). I feel you feel what I feel: Perceived perspective-taking promotes victims' conciliatory attitudes because of inferred emotions in the offender. *European Journal of Social Psychology*, *48*(2), O103-O120. https://doi.org/https://doi.org/10.1002/ejsp.2321

Besley, S., Kourouklis, D., O'Neill, P., & Garau, M. (2023). *Dementia in the UK: Estimating the potential future impact and return on research investment.* OHE Contract Research: OHE Contract Research. Retrieved from https://www.ohe.org/publications/dementia-uk-estimating-impact-research-investment

Blau, M. P. (1986). *Exchange and power in social life*. Routledge. https://doi.org/10.4324/9780203792643

Boller, F., & Forbes, M. M. (1998). History of dementia and dementia in history: An overview. *Journal of the Neurological Sciences*, *158*(2), 125-133. https://doi.org/https://doi.org/10.1016/S0022-510X(98)00128-2

Bowlby, J. (1980). *Attachment and loss*. Basic Books.

Bowlby, J. (1988). *A secure base: Parent-child attachment and healthy human development*. Basic Books.

Braithwaite, S. R., Mitchell, C. M., Selby, E. A., & Fincham, F. D. (2016). Trait forgiveness and enduring vulnerabilities: Neuroticism and catastrophizing influence relationship satisfaction via less forgiveness. *Personality and Individual Differences*, *94*, 237-246. https://doi.org/https://doi.org/10.1016/j.paid.2015.12.045

Bramboeck, V., Moeller, K., Marksteiner, J., & Kaufmann, L. (2020). Loneliness and Burden Perceived by Family Caregivers of Patients With Alzheimer Disease. *American Journal of Alzheimer's Disease & Other Dementias*, *35*, 1-8. https://doi.org/10.1177/1533317520917788

Breslin, A. K., Kumar, K. V., Ryan, B. R., Browne, J., & Porter, J. (2017). Effect of apology on interpersonal forgiveness and distancing within familial relationships. *Current Psychology*, *36*(3), 618-629. https://doi.org/ https://doi.org/10.1007/s12144-016-9450-2

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues Clin Neurosci*, *11*(2), 217-228. https://doi.org/10.31887/DCNS.2009.11.2/hbrodaty

Brose, A. L., Rye, S. M., Lutz-Zois, C., & Ross, R. S. (2005). Forgiveness and personality traits. *Personality and Individual Differences*, *39*(1), 35-46. https://doi.org/https://doi.org/10.1016/j.paid.2004.11.001

Brown, L. S. (2012). *Your turn for care: Surviving the aging and death of the adults who harmed you*. Createspace Independent Publishing Platform.

Browne, C. J., & Shlosberg, E. (2006). Attachment theory, ageing and dementia: a review of the literature. *Aging and Mental Health*, *10*(2), 134-142. https://doi.org/10.1080/13607860500312118

Burles, M. C., & Bally, J. M. G. (2018). Ethical, practical, and methodological considerations for unobtrusive qualitative research about personal narratives shared on the internet. *International Journal of Qualitative Methods*, *17*(1), 1609406918788203. https://doi.org/10.1177/1609406918788203

Bykov, A. (2017). Altruism: New perspectives of research on a classical theme in sociology of morality. *Current Sociology*, *65*(6), 797-813. https://doi.org/https://doi.org/10.1177/0011392116657861

Callaby, P., Coleman, P. G., & Mills, M. A. (2012). Caregiving in Dementia: From Resentment to Forgiveness. *Journal of Religion, Spirituality & Aging*, *24*(1-2), 93-104. https://doi.org/10.1080/15528030.2012.633053

Camden, A., Livingston, G., & Cooper, C. (2011). Reasons why family members become carers and the outcome for the person with dementia: Results from the CARD study. *International Psychogeriatrics*, *23*(9), 1442-1450. https://doi.org/10.1017/S1041610211001189

Carleton, N. R. (2016). Fear of the unknown: One fear to rule them all? *Journal of Anxiety Disorders*, *41*, 5-21. https://doi.org/10.1016/j.janxdis.2016.03.011

Ceci, C., & Purkis, M. E. (2021). *Care at home for people living with dementia: Delaying institutionalization, sustaining families* (1 ed.). Bristol University Press. https://doi.org/10.2307/j.ctv1txdfqc

Cerejeira, J., Lagarto, L., & Mukaetova-Ladinska, E. B. (2012). Behavioral and psychological symptoms of dementia. *Frontiers in Neurology*, *3*, 73. https://doi.org/10.3389/fneur.2012.00073

Chen, C. K., Uzdawinis, D., Schölmerich, A., & Juckel, G. (2014). Effects of attachment quality on caregiving of a parent with dementia. *The American Journal of Geriatric Psychiatry*, *22*(6), 623-631. https://doi.org/https://doi.org/10.1016/j.jagp.2012.12.003

Chen, J. C., Borson, S., & Scanlan, J. M. (2000). Stage-specific prevalence of behavioral symptoms in Alzheimer's Disease in a multi-ethnic community sample. *The American Journal of Geriatric Psychiatry*, *8*(2), 123-133. https://doi.org/https://doi.org/10.1097/00019442-200005000-00007

Cheng, H. G., & Phillips, M. R. (2014). Secondary analysis of existing data: Opportunities and implementation. *Shanghai Archives of Psychiatry*, *26*(6), 371-375. https://doi.org/10.11919/j.issn.1002-0829.214171

Cheng, S. T., Ip, I. N., & Kwok, T. (2013). Caregiver forgiveness is associated with less burden and potentially harmful behaviors. *Aging Ment Health*, *17*(8), 930-934. https://doi.org/10.1080/13607863.2013.791662

Cherry, M. G., Fletcher, I., & O'Sullivan, H. (2013). Exploring the relationships among attachment, emotional intelligence and communication. *Medical Education*, *47*(3), 317-325. https://doi.org/10.1111/medu.12115

Chilatra, J. A. H., Browning, W. R., Yildiz, M., Sullivan, T. P., & Pickering, C. E. (2024). Emotion Regulation, Coping Strategies, and Hazardous Drinking Among Family Caregivers of People With Alzheimer's Disease and Related Dementias. *Research in Gerontological Nursing*, *17*(2), 81-90. https://doi.org/10.3928/19404921-20240229-02

Chung, P. Y. F., Ellis-Hill, C., & Coleman, P. G. (2008). Carers perspectives on the activity patterns of people with dementia. *Dementia*, *7*(3), 359-381. https://doi.org/10.1177/1471301208093289

Cohen, D. J., & Crabtree, B. F. (2008). Evaluative criteria for qualitative research in health care: Controversies and recommendations. *Annals of Family Medicine*, *6*(4), 331-339. https://doi.org/10.1370/afm.818

Contreras, M., Khondoker, M., Mioshi, E., & Kishita, N. (2023). Factors affecting the quality of life of family carers of people with dementia: the role of carer anxiety. *Psychology, Health & Medicine*, *28*(4), 843-853. https://doi.org/10.1080/13548506.2022.2093926

Davis, H. M. (1983). Measuring individual differences in empathy: Evidence for a multidimensional approach. *Journal of Personality and Social Psychology*, *44*(1), 113-126. https://doi.org/http://dx.doi.org/10.1037/0022-3514.44.1.113

de Waal, F. (1996). *Good natured: The origins of right and wrong in humans and other animals*. Harvard University Press.

Dean, K. K., & Koenig, A. M. (2019). Cross-cultural differences and similarities in attribution. In K. D. Kieth (Ed.), *Cross-Cultural Psychology* (pp. 575-597). https://doi.org/10.1002/9781119519348.ch28

DeCaporale-Ryan, L. N., Steffen, A. M., Marwit, S. J., & Meuser, T. M. (2016). Dementia spousal caregivers and past transgressions: Measuring and understanding forgiveness experiences. *J Women Aging*, *28*(6), 510-520. https://doi.org/10.1080/08952841.2015.1065143

Decety, J., Michalska, K. J., & Kinzler, K. D. (2011). The developmental neuroscience of moral sensitivity. *Emotion Review*, *3*(3), 305-307. https://doi.org/10.1177/1754073911402373

del-Pino-Casado, R., Frías-Osuna, A., Palomino-Moral, P. A., & Ramón Martínez-Riera, J. (2012). Gender differences regarding informal caregivers of older people. *Journal of Nursing Scholarship*, *44*(4), 349-357. https://doi.org/https://doi.org/10.1111/j.1547-5069.2012.01477.x

Devi, F., Yuan, Q., Wang, P., Tan, G. T. H., Roshan Goveas, R., Ng, L. L., Chong, S. A., & Subramaniam, M. (2020). Positive aspect of caregiving among primary informal dementia caregivers in Singapore. *PLoS One*, *15*(8), e0237677. https://doi.org/10.1371/journal.pone.0237677

Dombestein, H., Norheim, A., & Aase, K. (2020). Caring for home-dwelling parents with dementia: A qualitative study of adult-child caregivers' motivation. *Nursing Open*, *7*(6), 1954-1965. https://doi.org/https://doi.org/10.1002/nop2.587

Dovidio, F. J. (1984). Helping Behavior and Altruism: An Empirical and Conceptual Overview. *Advances in Experimental Social Psychology*, *17*, 361-427. https://doi.org/10.1016/S0065-2601(08)60123-9

Downey, G., & Feldman, I. S. (1996). Implications of rejection sensitivity for intimate relationships. *Journal of Personality and Social Psychology*, *70*(6), 1327-1343. https://doi.org/10.1037//0022-3514.70.6.1327

Dwyer, S. C., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, *8*(1), 54-63. https://doi.org/10.1177/160940690900800105

Engward, H., & Goldspink, S. (2020). Lodgers in the house: Living with the data in interpretive phenomenological analysis research. *Reflective Practice*, *21*(1), 41-53. https://doi.org/https://doi.org/10.1080/14623943.2019.1708305

Enright, R. D., Freedman, S., & Rique, J. (1998). The psychology of interpersonal forgiveness. In R. D. Enright & J. North (Eds.), *Exploring forgiveness* (pp. 46-62). University of Wisconsin Press.

Eriksson, H., Sandberg, J., & Hellström, I. (2013). Experiences of long-term home care as an informal caregiver to a spouse: Gendered meanings in everyday life for female carers. *International Journal of Older People Nursing*, *8*(2), 159-165. https://doi.org/https://doi.org/10.1111/j.1748-3743.2012.00340.x

Evandrou, M., Falkingham, J., Gomez-Leon, M., & Vlachantoni, A. (2018). Intergenerational flows of support between parents and adult children in Britain. *Ageing and Society*, *38*(2), 321-351. https://doi.org/10.1017/S0144686X16001057

Fehr, R., Gelfand, M. J., & Nag, M. (2010). The road to forgiveness: A meta-analytic synthesis of its situational and dispositional correlates [Journal Articles; Reports - Evaluative]. *Psychological Bulletin*, *136*(5), 894-914. https://doi.org/10.1037/a0019993

Fincham, D. F., Jackson, H., & Beach, R. H. S. (2005). Transgression severity and forgiveness: Different moderators for objective and subjective severity. *Journal of Social and Clinical Psychology*, *24*(6), 860-875. https://doi.org/doi.org/10.1521/jscp.2005.24.6.860

Fisher, L., & Lieberman, A. M. (1996). The effects of family context on adult offspring of patients with Alzheimer's disease: A longitudinal study. *Journal of Family Psychology*, *10*(2), 180-191. https://doi.org/https://doi.org/10.1037/0893-3200.10.2.180

Fiske, S. T., & Taylor, S. E. (1991). *Social cognition* (2nd ed., Vol. 2nd). Mcgraw-Hill Book Company.

Fletcher, J. R. (2023). Pathologisation, (bio)medicalisation and biopolitics. In J. R. Fletcher & A. Capstick (Eds.), *A critical history of dementia studies* (First ed.). https://doi.org/https://doi-org./10.4324/9781003290353

Frechette, J., Bitzas, V., Aubry, M., Kilpatrick, K., & Lavoie-Tremblay, M. (2020). Capturing lived experience: Methodological considerations for interpretive phenomenological inquiry. *International Journal of Qualitative Methods*, *19*, 1609406920907254. https://doi.org/10.1177/1609406920907254

Freedman, S. (1998). Forgiveness and reconciliation: The importance of understanding how they differ. *Counseling and Values*, *42*(3), 200-216. https://doi.org/https://doi.org/10.1002/j.2161-007X.1998.tb00426.x

Gallego-Alberto, L., Losada, A., Cabrera, I., Romero-Moreno, R., Pérez-Miguel, A., Pedroso-Chaparro, M. D. S., & Márquez-González, M. (2022). "I feel guilty". Exploring guilt-related dynamics in family caregivers of people with dementia. *Clinical Gerontologist*, *45*(5), 1294-1303. https://doi.org/10.1080/07317115.2020.1769244

García-Castro, F. J., Alba, A., & Blanca, M. J. (2021). The role of character strengths in predicting gains in informal caregivers of dementia. *Aging and Mental Health*, *25*(1), 32-37. https://doi.org/10.1080/13607863.2019.1667298

García-Castro, F. J., Hernández, A., & Blanca, M. J. (2022). Life satisfaction and the mediating role of character strengths and gains in informal caregivers. *Journal of Psychiatric and Mental Health Nursing*, *29*(6), 829-841. https://doi.org/10.1111/jpm.12764

Gawronski, B. (2004). Theory-based bias correction in dispositional inference: The fundamental attribution error is dead, long live the correspondence bias. *European Review of Social Psychology*, *15*(1), 183-217. https://doi.org/10.1080/10463280440000026

Gilsenan, J., Gorman, C., & Shevlin, M. (2023). Explaining caregiver burden in a large sample of UK dementia caregivers: The role of contextual factors, behavioural problems, psychological resilience, and anticipatory grief. *Aging Ment Health*, *27*(7), 1274-1281. https://doi.org/10.1080/13607863.2022.2102138

Gitlin, L. N., Kales, H. C., & Lyketsos, C. G. (2012). Nonpharmacologic management of behavioral symptoms in dementia. *Journal of the American Medical Association*, *308*(19), 2020-2029. https://doi.org/10.1001/jama.2012.36918

Gouldner, A. W. (1960). The norm of reciprocity: A preliminary statement. *American Sociological Review*, *25*(2), 161-178. https://doi.org/10.2307/2092623

Green, D. J., Reid, A. C., Coy, E. A., Hedgebeth, V. M., & Kneuer, A. M. (2019). An interdependence analysis of forgiveness, amends, and relational repair in family and work relationships. In E. L. Worthington, Jr. & N. G. Wade (Eds.), *Handbook of Forgiveness* (2nd ed., pp. 131-141). Routledge. https://doi.org/https://doi.org/10.4324/9781351123341-13

Greenwood, N., & Smith, R. (2019). Motivations for being informal carers of people living with dementia: A systematic review of qualitative literature. *BMC Geriatrics*, *19*(169), 1-18. https://doi.org/10.1186/s12877-019-1185-0

Hall, H. J., & Fincham, D. F. (2005). Self–forgiveness: The stepchild of forgiveness research. *Journal of Social and Clinical Psychology*, *24*(5), 621-637. https://doi.org/10.1521/jscp.2005.24.5.621

Harris, P. B. (1998). Listening to caregiving sons: Misunderstood realities. *The Gerontologist*, *38*(3), 342-352. https://doi.org/10.1093/geront/38.3.342

Heidegger, M. (2008). *Being and time*. Harper Collins.

Henley, D. M. S. (2018). Contemporary understanding of the aetiology, diagnosis and treatment approaches in relation to dementia. In K. White, A. Cotter, & H. Leventhal (Eds.), *Dementia: An attachment approach* (1st ed., pp. 43-53). Routledge. https://doi.org/10.4324/9780429449499-5

Hojat, M., Louis, Z. D., Markham, W. F., Wender, R., Rabinowitz, C., & Gonnella, S. J. (2011). Physicians’ empathy and clinical outcomes for diabetic patients. *Academic Medicine*, *86*(3), 359-364. https://doi.org/10.1097/ACM.0b013e3182086fe1

Holmes, A. (2020). Researcher positionality - A consideration of its influence and place in qualitative research - A new researcher guide. *Shanlax International Journal of Education*, *8*, 1-10. https://doi.org/10.34293/education.v8i4.3232

Homans, G. C. (1961). *Social behavior: Its elementary forms*. Harcourt, Brace.

Hook, J. N., Worthington, E. L., Utsey, S. O., Davis, D. E., Gartner, A. L., Jennings, D. J., Van Tongeren, D. R., & Dueck, A. (2012). Does forgiveness require interpersonal interactions? Individual differences in conceptualization of forgiveness. *Personality and Individual Differences*, *53*(5), 687-692. https://doi.org/https://doi.org/10.1016/j.paid.2012.05.026

Hua, A. Y., Wells, J. L., Brown, C. L., & Levenson, R. W. (2021). Emotional and cognitive empathy in caregivers of persons with neurodegenerative disease: Relationships with caregiver mental health. *Clinical Psychological Science*, *9*(3), 449-466. https://doi.org/10.1177/2167702620974368

Huertas-Domingo, C., Losada-Baltar, A., Romero-Moreno, R., Gallego-Alberto, L., & Márquez-González, M. (2023). Sociocultural factors, guilt and depression in family caregivers of people with dementia. Kinship differences. *Aging & Mental Health*, *27*(9), 1655-1665. https://doi.org/10.1080/13607863.2023.2195821

Hugo, J., & Ganguli, M. (2014). Dementia and cognitive impairment: Epidemiology, diagnosis, and treatment. *Clinics in Geriatric Medicine*, *30*(3), 421-442. https://doi.org/10.1016/j.cger.2014.04.001

Jacinto, G. A. (2009). The self-forgiveness process of caregivers after the death of care-receivers diagnosed with Alzheimer's disease [Article]. *Journal of Social Service Research*, *36*(1), 24-36-36. https://doi.org/10.1080/01488370903333538

Jacinto, G. A. (2010). Caregivers' Coping and Self-Forgiveness After the Death of a Care-Receiver. *Journal of Social Service Research*, *36*(3), 206-215. https://doi.org/10.1080/01488371003697939

Jameson, S., Parkinson, L., & Banbury, A. (2020). After the care journey: exploring the experiences of family carers of people living with dementia. *Ageing and Society*, *40*(11), 2429-2447. https://doi.org/10.1017/S0144686X19000667

Javadpour, A., Shenavar, R. M., Dehghani, M., & Bahredar, J. M. (2017). Frequency and correlates of behavioral and psychological symptoms in a group of Iranian patients with dementia. *Shiraz E-Medical Journal*, *18*(2), 1-6. https://doi.org/ https://doi.org/10.17795/semj33852

Javed, S., & Kakul, F. (2023). Psychological theories of dementia. *Journal of Gerontology and Geriatrics*, *71*(2), 109-114. https://doi.org/10.36150/2499-6564-N610

Jütten, L. H., Mark, R. E., & Sitskoorn, M. M. (2019). Empathy in informal dementia caregivers and its relationship with depression, anxiety, and burden. *International Journal of Clinical & Health Psychology*, *19*(1), 12-21. https://doi.org/10.1016/j.ijchp.2018.07.004

Jütten, L. H., Mark, R. E., & Sitskoorn, M. M. (2020). Predicting self-esteem in informal caregivers of people with dementia: Modifiable and non-modifiable factors. *Aging & Mental Health*, *24*(2), 221-226. https://doi.org/10.1080/13607863.2018.1531374

Kales, H. C., Gitlin, L. N., & Lyketsos, C. G. (2015). Assessment and management of behavioral and psychological symptoms of dementia. *British Medical Journal*, *350*, h369. https://doi.org/10.1136/bmj.h369

Kaleta, K., & Mróz, J. (2021). The effect of apology on emotional and decisional forgiveness: The role of personality. *Personality and Individual Differences*, *168*, 110310. https://doi.org/https://doi.org/10.1016/j.paid.2020.110310

Kim, J. J., Payne, E. S., & Tracy, E. L. (2022). Indirect effects of forgiveness on psychological health through anger and hope: A parallel mediation analysis. *Journal of Religion and Health*, *61*(5), 3729-3746. https://doi.org/10.1007/s10943-022-01518-4

Kirkham, J. A., Smith, J. A., & Havsteen-Franklin, D. (2015). Painting pain: An interpretative phenomenological analysis of representations of living with chronic pain. *Health Psychology*, *34*(4), 398-406. https://doi.org/10.1037/hea0000139

Knight, K. (2018). Transgressor communication after committing a hurtful relational event: Associations with attributed intent, blame, guilt, responsibility, and perceived forgiveness. *Western Journal of Communication*, *82*(4), 475-492. https://doi.org/10.1080/10570314.2017.1325925

Kokorelias, K. M., Rittenberg, N., Law, A., Wan, N. T. C., Machon, J., Arfeen, Y., & Cameron, J. I. (2022). Brothers and sisters sharing in the care of a parent with dementia. *Dementia (London)*, *21*(3), 765-780. https://doi.org/10.1177/14713012211053970

Kong, J., & Moorman, M. S. (2015). Caring for my abuser: Childhood maltreatment and caregiver depression. *The Gerontologist*, *55*(4), 656-666. https://doi.org/https://doi.org/10.1093/geront/gnt136

Kong, J., & Moorman, M. S. (2016). History of childhood abuse and intergenerational support to mothers in adulthood. *Journal of Marriage and Family*, *78*(4), 926-938. https://doi.org/https://doi-org.ezproxy.massey.ac.nz/10.1111/jomf.12285

Kramer, J. B. (1997). Differential predictors of strain and gain among husbands caring for wives with dementia. *The Gerontologist*, *37*(2), 239-249. https://doi.org/10.1093/geront/37.2.239

Kulkov, I., Kulkova, J., Rohrbeck, R., & Menvielle, L. (2024). Leveraging podcasts as academic resources: A seven-step methodological guide. *International Journal of Qualitative Methods*, *23*, 16094069241266197. https://doi.org/10.1177/16094069241266197

Kuske, S., Borgmann, S. O., Wolf, F., & Bleck, C. (2021). Emotional safety in the context of dementia: A multiperspective qualitative study. *Journal of Alzheimer's Disease*, *79*(1), 355-375. https://doi.org/10.3233/jad-201110

Lahey, B. B. (2009). Public health significance of neuroticism. [doi:10.1037/a0015309]. *American Psychologist*, *64*(4), 241-256. https://doi.org/10.1037/a0015309

Langdridge, D. (2007). *Phenomenological psychology: Theory, research and method.* . Pearson Education.

Larkin, M., & Thompson, A. R. (2011). Interpretative phenomenological analysis in mental health and psychotherapy research. In D. Harper & A. R. Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy* (pp. 99-116). Wiley-Blackwell. https://doi.org/https://doi.org/10.1002/9781119973249.ch8

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping.* Spinger.

Lee, J., Baik, S., Becker, D. T., & Cheon, H. J. (2022). Themes describing social isolation in family caregivers of people living with dementia: A scoping review. *Dementia*, *21*(2), 701-721. https://doi.org/10.1177/14713012211056288

Lee, S. H., Brennan, F. P., & Daly, J. B. (2001). Relationship of empathy to appraisal, depression, life satisfaction, and physical health in informal caregivers of older adults. *Research in Nursing & Health*, *24*(1), 44-56. https://doi.org/https://doi.org/10.1002/1098-240X(200102)24:1<44::AID-NUR1006>3.0.CO;2-S

Lichtenfeld, S., Buechner, L. V., Maier, A. M., & Fernández-Capo, M. (2015). Forgive and Forget: Differences between Decisional and Emotional Forgiveness. *PLoS One*, *10*(5), e0125561. https://doi.org/10.1371/journal.pone.0125561

Lichtenfeld, S., Maier, A. M., Buechner, L. V., & Capo, F. M. (2019). The influence of decisional and emotional forgiveness on attributions. *Frontiers in Psychology*, *10*, 1425. https://doi.org/10.3389/fpsyg.2019.01425

Lin, I. F., Fee, H. R., & Wu, H.-S. (2012). Negative and positive caregiving experiences: A closer look at the intersection of gender and relationship. *Family Relations*, *61*(2), 343-358. https://doi.org/https://doi.org/10.1111/j.1741-3729.2011.00692.x

Lin, M.-C., Macmillan, M., & Brown, N. (2011). A grounded theory longitudinal study of carers' experiences of caring for people with dementia. *Dementia*, *11*(2), 181-197. https://doi.org/10.1177/1471301211421362

Lindeza, P., Rodrigues, M., Costa, J., Guerreiro, M., & Rosa, M. M. (2024). Impact of dementia on informal care: A systematic review of family caregivers' perceptions. *BMJ Supportive & Palliative Care*, *14*(e29), e38. https://doi.org/10.1136/bmjspcare-2020-002242

Liu, R., Chi, I., & Wu, S. (2022). Caregiving Burden Among Caregivers of People With Dementia Through the Lens of Intersectionality. *Gerontologist*, *62*(5), 650-661. https://doi.org/10.1093/geront/gnab146

Liu, X., & Burnett, D. (2022). Insider-outsider: Methodological reflections on collaborative intercultural research. *Humanities and Social Sciences Communications*, *9*(1), 314. https://doi.org/10.1057/s41599-022-01336-9

Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S. G., Dias, A., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Kivimäki, M., Larson, E. B., Ogunniyi, A.,…Mukadam, N. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet*, *396*(10248), 413-446. https://doi.org/10.1016/s0140-6736(20)30367-6

Lloyd, J., Patterson, T., & Muers, J. (2016). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia: The International Journal of Social Research and Practice*, *15*(6), 1534-1561. https://doi.org/10.1177/1471301214564792

Long, K. N. G., Worthington, E. L., VanderWeele, T. J., & Chen, Y. (2020). Forgiveness of others and subsequent health and well-being in mid-life: A longitudinal study on female nurses. *BMC Psychology*, *8*(1), 104-125. https://doi.org/10.1186/s40359-020-00470-w

Low, L.-F., & Purwaningrum, F. (2020). Negative stereotypes, fear and social distance: A systematic review of depictions of dementia in popular culture in the context of stigma. *BMC Geriatrics*, *20*(1), 477. https://doi.org/10.1186/s12877-020-01754-x

Lowenstein, A., Katz, R., Tur-Sinai, A., Fernández-Ballesteros, R., Benetos, A., & Robine, J.-M. (2019). Intergenerational family relationships and successful aging. In *The Cambridge handbook of successful aging* (pp. 455-474). Cambridge University Press. https://doi.org/10.1017/9781316677018.026

Luchetti, M., Terracciano, A., Stephan, Y., Aschwanden, D., & Sutin, A. R. (2021). Personality and psychological health in caregivers of older relatives: A case-control study. *Aging & Mental Health*, *25*(9), 1692-1700. https://doi.org/10.1080/13607863.2020.1758907

Lutzky, M. S., & Knight, G. B. (1994). Explaining gender differences in caregiver distress: The roles of emotional attentiveness and coping styles., *9*(4), 513-519. https://doi.org/https://doi-org.ezproxy.massey.ac.nz/10.1037//0882-7974.9.4.513

Ma, M., Dorstyn, D., Ward, L., & Prentice, S. (2018). Alzheimers' disease and caregiving: a meta-analytic review comparing the mental health of primary carers to controls. *Aging & Mental Health*, *22*(11), 1395-1405. https://doi.org/10.1080/13607863.2017.1370689

Macdonald, G., Mears, J., & Naderbagi, A. (2018). Reframing dementia: The social imperative. In G. Macdonald & J. Mears (Eds.), *Dementia as social experience: Valuing life and care* (pp. 1-19). Routledge. https://doi.org/https://doi-org.ezproxy.massey.ac.nz/10.4324/9781351241816

van Manen, M. (2017). But is it phenomenology? *Qualitative Health Research*, *27*(6), 775-779. https://doi.org/https://doi.org/10.1177/1049732317699570

Markham, A. N. (2018). Afterword: Ethics as impact—Moving from error-avoidance and concept-driven models to a future-oriented approach. *Social Media + Society*, *4*(3), 2056305118784504. https://doi.org/10.1177/2056305118784504

Markiewicz, D., Reis, M., & Gold, D. P. (1997). An exploration of attachment styles and personality traits in caregiving for dementia patients. *International Journal of Ageing & Human Development*, *45*(2), 111-132. https://doi.org/10.2190/t4q4-e8f0-jwt5-dbag

Martin, L. L., Ward, D. W., Achee, J. W., & Wyer Jr, R. S. (1993). Mood as input: People have to interpret the motivational implications of their moods [Article]. *Journal of Personality & Social Psychology*, *64*(3), 317-326. https://doi.org/10.1037/0022-3514.64.3.317

Martinez-Diaz, P., Caperos, M. J., Prieto-Ursúa, M., Gismero-González, E., Cagigal, V., & Carrasco, J. M. (2021). Victim's perspective of forgiveness seeking behaviors after transgressions. *Frontiers in Psychology*, *12*. https://doi.org/https://doi.org/10.3389/fpsyg.2021.656689

Massey University. (2017). *Code of ethical conduct for research, teaching and evaluations involving human participants*. https://www.massey.ac.nz/documents/423/MUHEC_Code.pdf

Mausbach, B. T., Aschbacher, K., Patterson, T. L., Ancoli-Israel, S., von Känel, R., Mills, P. J., Dimsdale, J. E., & Grant, I. (2006). Avoidant coping partially mediates the relationship between patient problem behaviors and depressive symptoms in spousal Alzheimer caregivers. *The American Journal of Geriatric Psychiatry*, *14*(4), 299-306. https://doi.org/https://doi.org/10.1097/01.JGP.0000192492.88920.08

McCullough, M. E., Bono, G., & Root, L. M. (2007). Rumination, emotion, and forgiveness: Three longitudinal studies. *Journal of Personality and Social Psychology*, *92*(3), 490-505. https://doi.org/10.1037/0022-3514.92.3.490

McCullough, M. E., Pargament, K. I., & Thoresen, C. E. (2000). The psychology of forgiveness: History, conceptual issues, and overview. In M. E. McCullough, K. I. Pargament, & C. E. Thoresen (Eds.), *Forgiveness: Theory, research, and practice.* (pp. 1-14). The Guilford Press.

McEwen, B. S. (2005). Stressed or stressed out: What is the difference? *Journal of Psychiatry & Neuroscience*, *30*(5), 315-318.

Melis, R. J. F., Haaksma, M. L., & Muniz-Terrera, G. (2019). Understanding and predicting the longitudinal course of dementia. *Current Opinion in Psychiatry*, *32*(2), 123-129. https://doi.org/10.1097/yco.0000000000000482

Mitchell, R. T., Holtom, C. B., Lee, W. T., Sablynski, J. C., & Erez, M. (2001). Why people stay: Using job embeddedness to predict voluntary turnover. *Academy of Management Journal*, *44*(6), 1102-1121. https://doi.org/10.2307/3069391

Monin, J. K., Schulz, R., & Kershaw, T. S. (2013). Caregiving spouses' attachment orientations and the physical and psychological health of individuals with Alzheimer's disease. *Aging and Mental Health*, *17*(4), 508-516. https://doi.org/10.1080/13607863.2012.747080

Monteiro, I., Brito, L., & Pereira, M. G. (2024). Burden and quality of life of family caregivers of Alzheimer’s disease patients: the role of forgiveness as a coping strategy. *Aging & Mental Health*, *28*(7), 1003-1010. https://doi.org/10.1080/13607863.2024.2320138

Moreno-Cámara, S., Palomino-Moral, P. Á., Moral-Fernández, L., Frías-Osuna, A., Parra-Anguita, L., & Del-Pino-Casado, R. (2019). Perceived needs of the family caregivers of people with dementia in a Mediterranean setting: A qualitative study. *International Journal of Environmental Research and Public Health*, *16*(6), 1-12. https://doi.org/10.3390/ijerph16060993

Mróz, J. (2022). Forgiveness and flourishing: The mediating and moderating role of self-compassion. *International Journal of Environmental Research and Public Health*, *20*(1). https://doi.org/10.3390/ijerph20010666

Myers, D. (1983). *Social Psychology* (International Student Edition ed.). McGraw-Hill.

Naim, S. P., Lowenstein, A., & Katz, R. (2021). Social exchange theory and its implications for caregiving. In D. Gu & M. E. Dupre (Eds.), *Encyclopedia of gerontology and population aging* (pp. 4565-4568). Springer International Publishing. https://doi.org/10.1007/978-3-030-22009-9_20

Nelis, S. M., Clare, L., & Whitaker, C. J. (2014). Attachment in people with dementia and their caregivers: a systematic review. *Dementia (London)*, *13*(6), 747-767. https://doi.org/10.1177/1471301213485232

Nichols, E., Steinmetz, J. D., Vollset, S. E., Fukutaki, K., Chalek, J., Abd-Allah, F., Abdoli, A., Abualhasan, A., Abu-Gharbieh, E., Akram, T. T., Al Hamad, H., Alahdab, F., Alanezi, F. M., Alipour, V., Almustanyir, S., Amu, H., Ansari, I., Arabloo, J., Ashraf, T.,…Vos, T. (2022). Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *The Lancet Public Health*, *7*(2), e105-e125. https://doi.org/https://doi.org/10.1016/S2468-2667(21)00249-8

Nissenbaum, H. (2009). *Privacy in context: Technology, policy, and the integrity of social life*. Stanford University Press.

Nizarl, K., Joe, O., Kin, T., & Fazli Khalaf, Z. (2022). Adult children as caregivers: Preliminary study on the experiences and coping strategies of adult children as primary caregivers of parents with Alzheimer's disease in Malaysia. *Global Journal of Health Science*, *14*, 18-29. https://doi.org/10.5539/gjhs.v14n12p18

Nizza, I. E., Farr, J., & Smith, J. A. (2021). Achieving excellence in Interpretative Phenomenological Analysis (IPA): Four markers of high quality. *Qualitative Research in Psychology*, *18*(3), 369-386. https://doi.org/10.1080/14780887.2020.1854404

O'Brien, M. R., & Clark, D. (2012). Unsolicited written narratives as a methodological genre in terminal illness: Challenges and limitations. *Qualitative Health Research*, *22*(2), 274-284. https://doi.org/10.1177/1049732311420737

Ohno, S., Chen, Y., Sakamaki, H., Matsumaru, N., Yoshino, M., & Tsukamoto, K. (2021). Burden of caring for Alzheimer's disease or dementia patients in Japan, the US, and EU: Results from the National Health and Wellness Survey: A cross-sectional survey. *Journal of Medical Economics*, *24*(1), 266-278. https://doi.org/10.1080/13696998.2021.1880801

Olazarán, J., Reisberg, B., Clare, L., Cruz, I., Peña-Casanova, J., Del Ser, T., Woods, B., Beck, C., Auer, S., Lai, C., Spector, A., Fazio, S., Bond, J., Kivipelto, M., Brodaty, H., Rojo, J. M., Collins, H., Teri, L., Mittelman, M.,…Muñiz, R. (2010). Nonpharmacological therapies in Alzheimer's disease: a systematic review of efficacy. *Dement Geriatr Cogn Disord*, *30*(2), 161-178. https://doi.org/10.1159/000316119

Olmos-Vega, F. M., Stalmeijer, R. E., Varpio, L., & Kahlke, R. (2023). A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Medical Teacher*, *45*(3), 241-251. https://doi.org/10.1080/0142159X.2022.2057287

Organisation for Economic Co-Operation and Development. (2018). *Renewing priority for dementia: Where do we stand?* Paris: OECD Publishing Retrieved from 501347-renewing-priority-for-dementia-where-do-we-stand-2018.pdf (oecd.org)

Pandey, R., Tiwari, G. K., Parihar, P., & Rai, P. K. (2023). The relationship between self-forgiveness and human flourishing: Inferring the underlying psychological mechanisms. *Polish Psychological Bulletin*, *51*(1), 23-36. https://doi.org/10.24425/ppb.2020.132649

Park, S., & Park, K. S. (2014). Family stigma: A concept analysis. *Asian Nursing Research*, *8*(3), 165-171. https://doi.org/https://doi.org/10.1016/j.anr.2014.02.006

Paun, O. (2004). Female Alzheimer's patient caregivers share their strength. *Holistic Nursing Practice*, *18*(1), 11-17. https://doi.org/10.1097/00004650-200401000-00003

Paun, O., Loukissa, D., Chirica, M. G., & Nowell, H. M., 3rd. (2022). Loss and grief in the context of dementia caregiving. *Journal of Psychosocial Nursing and Mental Health Services*, *60*(10), 7-10. https://doi.org/10.3928/02793695-20220909-01

Perren, S., Schmid, R., Herrmann, S., & Wettstein, A. (2007). The impact of attachment on dementia-related problem behavior and spousal caregivers' well-being. *Attachment & Human Development*, *9*(2), 163-178. https://doi.org/10.1080/14616730701349630

Peters, I., Kemper, F. N., Schmiedek, F., & Habermas, T. (2023). Individual differences in revising the life story: Personality and event characteristics influence change in the autobiographical meaning of life events. *Journal of Personality*, *91*(5), 1207-1222. https://doi.org/10.1111/jopy.12793

Pietkiewicz, I., & Smith, J. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Czasopismo Psychologiczne: Psychological Journal*, *20*(1), 7-14. https://doi.org/10.14691/CPPJ.20.1.7

Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and aging*, *18*(2), 250-267. https://doi.org/10.1037/0882-7974.18.2.250

Pinquart, M., & Sörensen, S. (2004). Associations of caregiver stressors and uplifts with subjective well-being and depressive mood: A meta-analytic comparison. *Aging & Mental Health*, *8*(5), 438-449. https://doi.org/10.1080/13607860410001725036

Podcasy, J. L., & Epperson, C. N. (2016). Considering sex and gender in Alzheimer disease and other dementias. *Dialogues in Clinical Neuroscience*, *18*(4), 437-446. https://doi.org/10.31887/DCNS.2016.18.4/cepperson

Poisson, O. V., Poulos, G. R., Withall, L. A., Reilly, A., Emerson, L., & O'Connor, C. M. C. (2023). A mixed method study exploring gender differences in dementia caregiving. *Dementia*, *22*(8), 1862-1885. https://doi.org/https://doi.org/10.1177/14713012231201595

Pöysti, M. M., Laakkonen, M. L., Strandberg, T., Savikko, N., Tilvis, R. S., Eloniemi-Sulkava, U., & Pitkälä, K. H. (2012). Gender differences in dementia spousal caregiving. *International Journal of Alzheimer's Disease*, *2012*(162960), 1-5. https://doi.org/10.1155/2012/162960

Raj, P., Elizabeth, C. S., & Padmakumari, P. (2016). Mental health through forgiveness: Exploring the roots and benefits. *Cogent Psychology*, *3*(1), 1153817. https://doi.org/10.1080/23311908.2016.1153817

Reidun, I., & Solem, p. e. (2009). Spouses of persons with dementia: Attachment, loss and coping. *Norwegian Journal of Epidemiology*, *8*(2), 149-156. https://doi.org/10.5324/nje.v8i2.457

Revenson, T., Griva, K., Luszczynska, A., Morrison, V., Panagopoulou, E., Vilchinsky, N., & Hagedoorn, M. (2015). *Caregiving in the Illness Context*. Springer. https://doi.org/10.1057/9781137558978

Riek, B. M., & Mania, E. W. (2012). The antecedents and consequences of interpersonal forgiveness: A meta-analytic review. *Personal Relationships*, *19*(2), 304-325. https://doi.org/10.1111/j.1475-6811.2011.01363.x

Robbins, L. M., Jonnalagadda, P., & Spahr, M. C. (2024). Rebalancing social & personality psychology methods: The case for naturalistic observation. *Social and Personality Psychology Compass*, *18*(1). https://doi.org/10.1111/spc3.12917

Roberts, L. D. (2015). Ethical issues in conducting qualitative research in online communities. *Qualitative Research in Psychology*, *12*(3), 314-325. https://doi.org/10.1080/14780887.2015.1008909

Robinson, A. C., Bottorff, L. J., Pesut, B., Oliffe, L. J., & Tomlinson, J. (2014). The male face of caregiving. *American Journal of Men's Health*, *8*(5), 409-426. https://doi.org/https://doi.org/10.1177/1557988313519671

Roff, L. L., Burgio, L. D., Gitlin, L., Nichols, L., Chaplin, W., & Hardin, J. M. (2004). Positive aspects of Alzheimer's caregiving: the role of race. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, *59*(4), 185-190. https://doi.org/10.1093/geronb/59.4.p185

Romano, D., Karantzas, G. C., Marshall, E. M., Simpson, J. A., Feeney, J. A., McCabe, M. P., Lee, J., & Mullins, E. R. (2021). Carer burden: Associations with attachment, self-efficacy, and care-seeking. *Journal of Social and Personal Relationships*, *39*(5), 1213-1236. https://doi.org/10.1177/02654075211049435

Romero, A. P., & Garrido, S. G. (2018). The importance of behavioural and pyschological symptoms in Alzheimer disease. *Neurología (English Edition)*, *33*(6), 378-384. https://doi.org/https://doi.org/10.1016/j.nrleng.2016.02.026

Romero-Moreno, R., Márquez-González, M., Losada, A., & López, J. (2011). Motives for caring: Relationship to stress and coping dimensions. *International Psychogeriatrics*, *23*(4), 573-582. https://doi.org/10.1017/S1041610210001821

Sabatini, S., Martyr, A., Hunt, A., Gamble, L. D., Matthews, F. E., Thom, J. M., Jones, R. W., Allan, L., Knapp, M., Quinn, C., Victor, C., Pentecost, C., Rusted, J. M., Morris, R. G., & Clare, L. (2024). Health conditions in spousal caregivers of people with dementia and their relationships with stress, caregiving experiences, and social networks: longitudinal findings from the IDEAL programme. *BMC Geriatr*, *24*(1), 171. https://doi.org/10.1186/s12877-024-04707-w

Savva, G. M., Zaccai, J., Matthews, F. E., Davidson, J. E., McKeith, I., & Brayne, C. (2009). Prevalence, correlates and course of behavioural and psychological symptoms of dementia in the population. *British Journal of Psychiatry*, *194*(3), 212-219. https://doi.org/10.1192/bjp.bp.108.049619

Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry*, *12*(3), 240-249.

Schumann, K. (2012). Does love mean never having to say you're sorry? Associations between relationship satisfaction, perceived apology sincerity, and forgiveness. *Journal of Social and Personal Relationships*, *29*, 997-1010. https://doi.org/10.1177/0265407512448277

Scopelliti, I., Min, L. H., Mccormick, E., Kassam, S. K., & Morewedge, K. C. (2018). Individual differences in correspondence bias: Measurement, consequences, and correction of biased interpersonal attributions. *Management Science*, *64*(4), 1879-1910. https://doi.org/10.1287/mnsc.2016.2668

Serrant-Green, L. (2002). Black on black: Methodological issues for black researchers working in minority ethnic communities. *Nurse Researcher*, *9*(4), 30-44. https://doi.org/10.7748/nr2002.07.9.4.30.c6196

Settineri, S., Rizzo, A., Liotta, M., & Mento, C. (2014). Caregiver's burden and quality of life: Caring for physical and mental illness. *International Journal of Psychological Research*, *7*(1), 30-39. https://doi.org/10.21500/20112084.665

Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family: Caregivers of people with mental illnesses. *World Journal of Psychiatry*, *6*(1), 1-7. https://doi.org/10.5498/wjp.v6.i1.7

Sinforiani, E., Citterio, A., Zucchella, C., Bono, G., Corbetta, S., Merlo, P., & Mauri, M. (2010). Impact of gender differences on the outcome of Alzheimer's disease. *Dementia & Geriatric Cognitive Disorders*, *30*(2), 147-154. https://doi.org/10.1159/000318842

Smedes, L. B. (1984). *Forgive and forget: Healing the hurts we don't deserve.* Harper and Row.

Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, *1*(1), 39-54. https://ezproxy.massey.ac.nz/login?url=https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=psyh&AN=2006-22626-004&site=eds-live&scope=site&authtype=sso&custid=s3027306

Smith, J. A. (2015). Introduction. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (3rd ed., pp. 1-3). Sage Publications.

Smith, J. A., Flowers, P., & Larkin, M. H. (2009). *Interpretative phenomenological analysis: Theory, method and research* [BibliographiesNon-fiction]. SAGE. https://ezproxy.massey.ac.nz/login?url=https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=cat09011a&AN=mul.oai.edge.massey.folio.ebsco.com.fs00001086.75504f51.9e61.5490.95e0.986e2a6e141c&site=eds-live&scope=site&authtype=sso&custid=s3027306

Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (3rd ed., pp. 25-52). Sage Publications.

Smits, C. H., de Lange, J., Dröes, R. M., Meiland, F., Vernooij-Dassen, M., & Pot, A. M. (2007). Effects of combined intervention programmes for people with dementia living at home and their caregivers: A systematic review. *International Journal of Geriatric Psychiatry*, *22*(12), 1181-1193. https://doi.org/10.1002/gps.1805

Sowden, S., Khemka, D., & Catmur, C. (2021). Regulating mirroring of emotions: A social-specific mechanism? *Quarterly Journal of Experimental Psychology*, *75*(7), 1302-1313. https://doi.org/10.1177/17470218211049780

Sperling, R. A., Aisen, P. S., Beckett, L. A., Bennett, D. A., Craft, S., Fagan, A. M., Iwatsubo, T., Jack Jr, C. R., Kaye, J., Montine, T. J., Park, D. C., Reiman, E. M., Rowe, C. C., Siemers, E., Stern, Y., Yaffe, K., Carrillo, M. C., Thies, B., Morrison-Bogorad, M.,…Phelps, C. H. (2011). Toward defining the preclinical stages of Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia*, *7*(3), 280-292. https://doi.org/https://doi.org/10.1016/j.jalz.2011.03.003

Statz, T. L., Peterson, C. M., Birkeland, R. W., McCarron, H. R., Finlay, J. M., Rosebush, C. E., Baker, Z. G., & Gaugler, J. E. (2022). "We Moved Her Too Soon": Navigating Guilt Among Adult Child and Spousal Caregivers of Persons Living with Dementia Following a Move into Residential Long-Term Care. *Couple Family Psychol*, *11*(4), 300-314. https://doi.org/10.1037/cfp0000150

Strelan, P. (2019). The stress-and-coping model of forgiveness. In E. L. Worthington Jr & N. G. Wade (Eds.), *Handbook of Forgiveness* (2nd ed., pp. 63-73). Routledge. https://doi.org/10.4324/9781351123341-7

Strelan, P., & Covic, T. (2006). A review of forgiveness process models and a coping framework to guide future research. *Journal of Social and Clinical Psychology*, *25*(10), 1059-1085. https://doi.org/10.1521/jscp.2006.25.10.1059

Struthers, W. C., Eaton, J., Mendoza, R., Santelli, G. A., & Shirvani, N. (2010). Interrelationship among injured parties' attributions of responsibility, appraisal of appropriateness to forgive the transgressor, forgiveness, and repentance. *Journal of Applied Social Psychology*, *40*(4), 970-1002. https://doi.org/10.1111/j.1559-1816.2010.00607.x

Sun, F., Ong, R., & Burnette, D. (2012). The Influence of Ethnicity and culture on dementia caregiving: A review of empirical studies on Chinese Americans. *American Journal of Alzheimer's Disease & Other Dementias*, *27*(1), 13-22. https://doi.org/10.1177/1533317512438224

Takaku, S. (2001). The effects of apology and perspective taking on interpersonal forgiveness: A dissonance-attribution model of interpersonal forgiveness. *The Journal of Social Psychology*, *141*(4), 494-508. https://doi.org/10.1080/00224540109600567

Tangney, J. P., Boone, A. L., & R., D. (2005). Forgiving the self: Conceptual issues and empirical findings. In E. L. Worthington jr (Ed.), *Handbook of forgiveness* (pp. 143-158). Routledge. https://doi.org/https://doi.org/10.4324/9780203955673.CH10

The British Psychological Society. (2021). *Ethics guidelines for internet-mediated research*. https://explore.bps.org.uk/content/report-guideline/bpsrep.2021.rep155CTLG

Thibaut, J. W., & Kelley, H. H. (1959). *The social psychology of groups*. John Wiley. https://doi.org/https://doi.org/10.4324/9781315135007

Tible, O. P., Riese, F., Savaskan, E., & von Gunten, A. (2017). Best practice in the management of behavioural and psychological symptoms of dementia. *Therapeutic Advances in Neurological Disorders*, *10*(8), 297-309. https://doi.org/10.1177/1756285617712979

van Tongeren, D. R., Burnette, J. L., O'Boyle, E., Worthington Jr, E. L., & Forsyth, D. R. (2014). A meta-analysis of intergroup forgiveness. *The Journal of Positive Psychology*, *9*(1), 81-95. https://doi.org/10.1080/17439760.2013.844268

Toussaint, L. L., Shields, G. S., & Slavich, G. M. (2016). Forgiveness, stress, and health: A 5-week dynamic parallel process study. *Annals of Behavioural Medicine*, *50*(5), 727-735. https://doi.org/10.1007/s12160-016-9796-6

Toussaint, L. L., Worthington, L. E., Williams, R. D., & Webb, R. J. (2019). Forgiveness and Physical Health. In L. E. Worthington & N. G. Wade (Eds.), *Handbook of Forgiveness* (Second ed., pp. 178-187). Routledge. https://doi.org/10.4324/9781351123341-17

Tsang, J. A., Mccullough, E. M., & Fincham, D. F. (2006). The longitudinal association between forgiveness and relationship closeness and commitment. *Journal of Social and Clinical Psychology*, *25*(4), 448-472. https://doi.org/https://doi.org/10.1521/jscp.2006.25.4.448

Tuffour, I. (2017). A critical overview of interpretative phenomenological analysis: A contemporary qualitative research approach. *Journal of Healthcare Communications*, *2*(4). https://doi.org/10.4172/2472-1654.100093

Tuomola, J., Soon, J., Fisher, P., & Yap, P. (2016). Lived Experience of Caregivers of Persons with Dementia and the Impact on their Sense of Self: A Qualitative Study in Singapore. *Journal of Cross-Cultural Gerontology*, *31*(2), 157-172. https://doi.org/10.1007/s10823-016-9287-z

Unterbach, D. (1995). An Ego Function Analysis for Working with Dementia Clients. *Journal of Gerontological Social Work*, *22*(3-4), 83-94. https://doi.org/10.1300/J083V22N03_06

Valois, L., & Galvin, J. E. (2014). The role of the family in the care and management of patients with dementia. In B. Dickerson & A. Atri (Eds.), *Dementia: Comprehensive principles and practices* (pp. 609-621). Oxford University Press.

Vance, D. E., Moore, B. S., Farr, K. F., & Struzick, T. (2008). Procedural memory and emotional attachment in Alzheimer disease: implications for meaningful and engaging activities. *The Journal of Neuroscience Nursing*, *40*(2), 96-102. https://doi.org/10.1097/01376517-200804000-00008

Walker, J. A., Pratt, C. C., & Eddy, L. (1995). Informal caregiving to aging family members: A critical review. *Family Relations*, *44*(4), 402-411. https://doi.org/https://doi-org.ezproxy.massey.ac.nz/10.2307/584996

Wallhagen, M. I., & Yamamoto-Mitani, N. (2006). The meaning of family caregiving in Japan and the United States: A qualitative comparative study. *Journal of Transcultural Nursing*, *17*(1), 65-73. https://doi.org/10.1177/1043659605281979

Walsh, E., Blake, Y., Donati, A., Stoop, R., & von Gunten, A. (2019). Early Secure Attachment as a Protective Factor Against Later Cognitive Decline and Dementia. *Frontiers in Aging Neuroscience*, *11*, 161. https://doi.org/10.3389/fnagi.2019.00161

Weiner, B. (1995). *Judgments of responsibility: A foundation for a theory of social conduct*. Guilford Press.

Weststrate, M. N., & Glück, J. (2017). Hard-earned wisdom: Exploratory processing of difficult life experience is positively associated with wisdom. *Developmental Psychology*, *53*(4), 800-814. https://doi.org/10.1037/dev0000286

van Wezel, N., Francke, A. L., Kayan-Acun, E., Ljm Devillé, W., van Grondelle, N. J., & Blom, M. M. (2014). Family care for immigrants with dementia: The perspectives of female family carers living in the Netherlands. *Dementia*, *15*(1), 69-84. https://doi.org/10.1177/1471301213517703

White, K. (2018). An attachment approach to understanding and living well with dementia. In K. White, A. Cotter, & H. Leventhal (Eds.), *Dementia: An attachment approach* (1st ed., pp. 13-42). https://doi.org/10.4324/9780429449499-4

van Wijngaarden, E., van der Wedden, H., Henning, Z., Komen, R., & The, A. M. (2018). Entangled in uncertainty: The experience of living with dementia from the perspective of family caregivers. *PLoS One*, *13*(6), e0198034. https://doi.org/10.1371/journal.pone.0198034

Wilks, S. (1864). Clinical notes on atrophy of the brain. *Journal of Mental Science*, *10*(51), 381-392. https://doi.org/10.1192/bjp.10.51.381

Williams, A., O'Driscoll, K., & Moore, C. (2014). The influence of empathic concern on prosocial behavior in children. *Frontiers in Psychology*, *5*. https://doi.org/https://doi.org/10.3389/fpsyg.2014.00425

Willig, C. (2008). *Introducing qualitative research in psychology*. Open University Press.

Wittenberg-Lyles, E., Washington, K., Demiris, G., Oliver, P. D., & Shaunfield, S. (2014). Understanding social support burden among family caregivers. *Health Communication*, *29*(9), 901-910. https://doi.org/10.1080/10410236.2013.815111

Wohl, A. J. M., & Mclaughlin, J. K. (2014). Self-forgiveness: The good, the bad, and the ugly. *Social and Personality Psychology Compass*, *8*(8), 422-435. https://doi.org/10.1111/spc3.12119

Woodyatt, L., Wenzel, M., & de Vel-Palumbo, M. (2017). Working through psychological needs following transgressions to arrive at self-forgiveness. In L. Woodyatt, J. E. L. Worthington, M. Wenzel, & B. J. Griffin (Eds.), *Handbook of the psychology of self-forgiveness* (pp. 43-58). Springer International Publishing. https://doi.org/10.1007/978-3-319-60573-9_4

World Health Organization. (2017). *Global action plan on the public health response to dementia 2017-2025*. 9789241513487-eng.pdf (who.int)

World Health Organization. (2018). *Meeting on the implementation of the global action plan on the public health response to dementia 2017– 2025*. Geneva: WHO Retrieved from Meeting on the implementation of the global action plan on the public health response to dementia (who.int)

Worthington, E. L. J. (2019). Understanding Forgiveness of Other People. In E. L. J. Worthington & N. G. Wade (Eds.), *Handbook of Forgiveness* (2nd ed., pp. 11-21). Routledge. https://doi.org/10.4324/9781351123341-2

Worthington, E. L. J., & Sandage, J. S. (2016). *Forgiveness and spirituality in psychotherapy: A relational approach.* American Psychological Association. https://doi.org/https://doi.org/10.1037/14712-000

Worthington, E. L. J., & Scherer, M. (2004). Forgiveness is an emotion-focused coping strategy that can reduce health risks and promote health resilience: Theory, review, and hypotheses [Article]. *Psychology & Health*, *19*(3), 385-405. https://doi.org/10.1080/0887044042000196674

Worthington, E. L. J., Witvliet, O. V. C., Pietrini, P., & Miller, J. A. (2007). Forgiveness, health, and well-being: A review of evidence for emotional versus decisional forgiveness, dispositional forgivingness, and reduced unforgiveness. *Journal of Behavioral Medicine*, *30*(4), 291-302. https://doi.org/10.1007/s10865-007-9105-8

Worthington, L. E., & Wade, G. N. (1999). The psychology of unforgiveness and forgiveness and implications for clinical practice. *Journal of Social and Clinical Psychology*, *18*(4), 385-418. https://doi.org/https://psycnet.apa.org/doi/10.1521/jscp.1999.18.4.385

Wu, Q., Chi, P., Zeng, X., Lin, X., & Du, H. (2019). Roles of anger and rumination in the relationship between self-compassion and forgiveness. *Mindfulness*, *10*(2), 272-278. https://doi.org/https://link.springer.com/article/10.1007/s12671-018-0971-7

Yang, H. D., Kim, D. H., Lee, S. B., & Young, L. D. (2016). History of Alzheimer's Disease. *Dementia and Neurocognitive Disorders*, *15*(4), 115-121. https://doi.org/10.12779/dnd.2016.15.4.115

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, *15*(2), 215-228. https://doi.org/10.1080/08870440008400302

Yardley, L. (2015). Demonstrating validaty in qualitative psychology. In J. A. Smith (Ed.), *Qualitative psychology: A practice guide to research methods* (3rd ed., pp. 257-272). Sage Publications.

Zarzycki, M., & Morrison, V. (2021). Getting back or giving back: Understanding caregiver motivations and willingness to provide informal care. *Health Psychology and Behavioural Medicine*, *9*(1), 636-661. https://doi.org/10.1080/21642850.2021.1951737

Zechmeister, J. S., & Romero, C. (2002). Victim and offender accounts of interpersonal conflict: Autobiographical narratives of forgiveness and unforgiveness. *Journal of Personality and Social Psychology*, *82*(4), 675-686. https://doi.org/10.1037/0022-3514.82.4.675

Ziebland, S., & Hunt, K. (2014). Using secondary analysis of qualitative data of patient experiences of health care to inform health services research and policy. *Journal of Health Services Research & Policy*, *19*(3), 177-182. https://doi.org/10.1177/1355819614524187