In sickness and in health: a qualitive exploration of the experiences of adults living with, and primarily caring for, a spouse diagnosed with Major Depressive Disorder.

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Abstract

Caring for a spouse, over and above any other type of informal care recipient, is a unique and complex experience that lacks sufficient exploration. Equally, the experience of caring for a spouse who suffers specifically with Major Depressive Disorder (MDD) remains in a literature gap. Of the research that is available in the context of caring for a spouse/partner, the focus has predominantly been on the theoretical concept of caregiver burden and the associated negative experiences that can often manifest as a result of caring for a medically or psychologically ill partner. Further, a number of these studies view participants as 'objects' and there is a noticeable lack of qualitative research in this context whereby the voice of the participant is the one guiding the process of discovery. Accordingly, this study explores this caregiving experience qualitatively, within the interpretivist paradigm and using semi-structured questions and reflexive thematic analysis, so as to gain a better, more in-depth and phenomenological understanding of this challenging journey. Six participants were involved in the study. This research both affirms existing findings and explores fresh aspects of the experience, providing new insight and perspectives into spousal caregiving in the context of MDD. It is hoped that these findings will contribute positively towards the way in which people who care for a spouse/partner with MDD, and indeed other mood disorders, are supported.

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Introduction

This research study qualitatively explores the experiences of spousal caregivers (or those in de fact relationships) who are living with, and primarily caring for, a partner struggling with Major Depressive Disorder (MDD). Sitting within a literature gap, and whilst this subjective experience is not well researched to date, the findings of this study do align with those that have already been identified within the context of MDD and indeed with those that relate to caring for a spouse with a mental illness in general and a physical illness in comparison. This research also introduces different perspectives to the topic, providing new avenues for research so as to better understand, and therefore better support, this uniquely challenging caregiver demographic.

A South African immigrant, wife and mum who has lived in New Zealand for nearly 17 years, I have unfortunately been surrounded by depression for most of my life and have witnessed close family members struggle to overcome this illness. More recently, my father has taken on the role of primary caregiver for my mum who is racked with severe and debilitating anxiety and depression as a result of a medical illness. I spent a month in late 2019 caring for her and it was then that my idea for this research - and indeed my dedication to it - came into existence. A qualitative researcher, I view my proximity to this topic as an advantage. Having said that, I have reflected constantly throughout the process and have done everything I can to fairly and openly explore, analyse and report upon the experiences shared with me by the research participants.

This thesis commences with the exploration of the evolution of mental health care, both abroad and in New Zealand. From there, depression and MDD are introduced and discussed and the spousal relationship is explored in the context of informally caring for a partner – be it for a physical or mental illness. The research methodology is then described, with a focus on ethics, methodological rationale, recruitment and the participants themselves. How the research data was collected, transcribed and analysed – using Reflexive Thematic Analysis - is also detailed. The themes that emerged from the interviews are then discussed, critically explored and considered in relation to the literature review. The significance of this research study, future recommendations for research and limitations are also explored in the *Discussion* chapter. In conclusion, the findings of this research are summarised – with a focus on the unique and special nature of the spousal/de facto partnership and the implications of this, both personally and indeed from a clinical perspective, for those who find themselves caring for a partner challenged with MDD.

1. Literature review

1.1. The evolution of mental health care

Māori, the indigenous people of New Zealand, have long understood the importance of community-based care. Historical recordings made by some of the first Pākehā immigrants in Aotearoa suggest that the way in which Māori treated the mentally ill was notably different to that of the rest of the European world (Baker, 2017). Internationally, people with mental illness were chained in jail-like settings due to their perceived sinfulness and acts of witchcraft (Mehta et al., 2018). In contrast, Māori regarded all members of their whānau and wider community as valuable and necessary (Baker, 2017), regardless of the presence of mental illness. Growing interest in the etiology of mental distress – alongside the advent of psychoanalysis – resulted in the international creation of mental asylums and the hospitalisation of previously jailed patients (Mehta et al., 2018). This trend was similarly adopted in New Zealand where the strength of European influence was rapidly growing. Mental health asylums were first introduced in Aotearoa around the mid to late 1800's (Baker, 2017) marking a point in New Zealand history when the mental health of Māori began a marked and steady decline (Baker, 2017). This new, mono-culturally focused mental health service separated people from their whānau and their culture and, by the end of the 1970's, admission rates of Māori surpassed all others in hospitals and asylums alike (Baker, 2017). Moreover, by 1990, mental illness was to be recorded as the most significant health concern for Māori and as one of the leading concerns for all other ethnicities residing in New Zealand (Robertson, 2018).

It was during this decade (1990's) that New Zealand began the transition back from remote institutional care to care within communities (Baker, 2017). Since then, New Zealand national health plans have been working towards the development of community mental health services aiming to include a suitably trained workforce, increased responsiveness and the coordination of care provision (Oakley Browne & Wells, 2006). To date, these goals appear to remain very much a work in progress.

1.2. Mental illness/disability

It is commonplace, nowadays, to live amongst individuals in New Zealand experiencing some form of mental distress (Oakley Browne, 2006). In 2006, as many as 39.5% of New Zealanders aged 16 and older were believed to meet the criteria for mental illness annually (Oakley Browne, 2006) with lifetime prevalence rates estimated to be as high as 25% by 2018 (He Ara Oranga: Government Inquiry into Mental Health and Addiction, 2018). Ethnically, the 2018/19 New Zealand Health Survey indicated that Māori still appear to face more mental health challenges than non-Māori residents followed closely by Pacific Islanders, Europeans/others and lastly Asians. On top of an already struggling health system, New Zealand is experiencing significant resourcing issues alongside a rapidly increasing rate of mental health diagnosis – a trend that is mirrored internationally (Lawn & McMahon, 2013; Lima et al., 2008).

Mental illness is an area of significant concern/disability across the globe (Smart, 2019; World Health Organisation, 2020). A broad term, disability refers to the physical, psychological and/or psychiatric impairments caused by the interaction between one's physical and mental health and their physical, attitudinal and socio-political environments (World Health Organisation, 2017). Whilst some countries have made significant progress, the World Health Organisation (WHO) acknowledged earlier this year (2020b) that people with mental health conditions are still experiencing severe human rights violations and that the gap between those who need care, and those who can access it, remains substantial. Further, negative stigma around mental illness is particularly challenging for individuals - and their caregivers - given the barrier that this often creates in terms of accessing health care, employment and educational services (Jackson-Best & Edwards, 2018). Addressing this stigma through research, education and contextual knowledge is paramount (Smart, 2019).

It is promising to see that the New Zealand government continues to initiate reviews such as the New Zealand Health and Disability System Review (delivered to the New Zealand Government in June 2020) and He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction (delivered to the New Zealand Government in December 2019). The results from both, however, indicate that there is still much to do. The New Zealand Health and Disability System Review (2020) identified a lack of structured planning within the health and disability system, arguing that this is a key factor behind the financial and workforce stress associated with the mental health system currently (Mental Health Foundation of New Zealand, 2020). This review also found that disabled people, in general, have not been well served by the existing system, and that home-based support (especially) should be assessed by need rather than diagnosis. This review also spoke of the importance of consumer-led research and of giving a voice to those living with disabilities so as to create better support systems for the future.

Currently, and according to the New Zealand Health and Disability Commissioner, individuals who require professional help for their mental illness in Aotearoa are able to take one of the following steps to seek support (Health and Disability Commissioner, 2014):

- contact a regional health centre or General Practitioner’s office for assessment;
- see a counsellor through a local school, health centre or privately; or
- approach a local community mental health and addiction service.

In response, the Commissioner advises that mental health and addiction services should encourage and support family/whānau participation, ensuring that these individuals have access to information, support and psychoeducation (Health and Disability Commissioner, 2014). This is sufficient in principle, perhaps, but as noted previously New Zealand is experiencing a significant capacity problem such that the need for support far surpasses the availability of it (Mental Health Foundation of New Zealand, 2020). Accordingly, the Mental Health Foundation of New Zealand (2020) continues to advocate for an urgent shift in the provision of support for those suffering from long-term mental illness and to seek assurance from the New Zealand Government that these individuals will receive the provisions they require as they strive to be both physically healthy and mentally well.

1.2.1. Depression

Depression, perhaps more so than any other mental disability of the current era, is a disabling condition that requires specific, urgent and dedicated attention (Smart, 2019). According to the WHO (2020c), depression itself is one of the leading causes of disability worldwide with more than 264 million people reportedly affected. Despite this, the WHO Special Initiative for Mental Health (2019-2023): Universal Health Coverage for Mental Health (2019a) reports that the global annual median of government mental health expenditure is less than 2% and that global depression and anxiety disorders currently cost around US$1 trillion per year.

Depression is categorised by symptoms such as uncharacteristic irritability, anhedonia, eating irregularities and loss of energy (Sadock et al., 2015). The most recent New Zealand Health survey conducted in 2018/19 found that 15.7% of adults (15 years and older) in Aotearoa experienced depression (formally diagnosed) during this time - equating to an estimated 620,000 individuals - and that depression in this affected demographic peaked between the ages of 45 - 64 years.

To be formally diagnosed with depression, symptoms must be different from one's usual mood changes and short-lived responses to challenges posed by common, if albeit difficult, life experiences such as bereavement (WHO, 2020c). Minor depression is diagnosed when someone persistently experiences at least two, but fewer than five, symptoms over a two-week period (Sadock et al., 2015). When someone persistently experiences five or more symptoms, again over a two-week period and in a manner that is disproportionate in terms of intensity, duration and functional impairment (Wakefield & Demazeux, 2016), a diagnosis of Major Depressive Disorder, a mood disorder classification, is made (Sadock et al., 2015).

1.2.2. Major depressive disorder (MDD)

The category of mood disorders in the DSM-5 (American Psychiatric Association, 2013) includes both Major Depressive Disorder (MDD) and Bipolar Disorder (Sadock et al., 2015). To differentiate between the two, MDD is diagnosed when someone experiences major depressive episodes without the inclusion of any manic symptoms such as an elevated, irritable or expansive mood lasting for at least a week or less if hospitalisation is required (Sadock et al., 2015). MDD is diagnosed, according to the DSM-5 (American Psychiatric Assocation, 2013) as being either MDD (Single Episode) or MDD (Recurrent). To be diagnosed with MDD (Recurrent), Sadock et al. (2015) note that the episodes of depression must be distinctly separate, by at least 2 months or more and, during which time the ill individual must not present with significant symptoms of depression.

MDD is associated with a poor quality of life and a marked reduction in psychosocial functioning (Milanovic et al., 2018). Research suggests that reductions in the context of one's ability to perform everyday functions such as self-care, household chores, and recreational activities and interpersonal functions such as the initiation and ongoing maintenance of relationships, may well exceed those that are associated with other physical disabilities including cancer, diabetes, stroke and hypertensive heart disease (Mehta et al., 2014; Valipay et al., 2019). Additional symptoms such as anhedonia, psychomotor agitation and loss of energy also contribute towards the experience of impaired physical activity for sufferers (Sadock et al., 2015), whilst the cognitive symptoms of depression have been identified as interfering with people's ability to work (Mehta et al., 2014). Accordingly, sufferers of MDD commonly present with irritability, pessimism, withdrawal, low productivity levels, poor decision-making, lack of concentration and a greater risk of work-related accidents or injuries (Mehta et al., 2014). The deficits associated with MDD clearly affect a sufferer's workplace, their home environment and their interpersonal relationships (Mehta et al., 2014; Milanovic et al., 2018).

Further, patients diagnosed early on in adulthood, rather than in later life, appear to experience significantly lower occupational success or prestige, are more likely to be divorced/separated (often multiple times) and are more likely to remain childless (Harkness et al., 2016). Milanovic et al. (2018) investigated the differences between individuals with MDD, and those without, in terms of self-perceived competence and functional disability, determining that sufferers are likely to display significantly lower levels of competence in terms of performing functional living skills, more functional disability overall and significantly lower levels of self-perception around their own ability to perform tasks. The most impaired area of functioning to emerge from this study was the sufferers' ability to engage socially with others and the research of Van Den Brink (2018) suggests that this negative impact on social relationships is likely to impede one's rate of recovery. Whilst it is widely acknowledged that genetics, neurology, hormones, immunological and neuroendocrinological mechanisms play a role in the causation of MDD, many of these are believed to centre around one's initial reaction to an acute stressor and their associated processing (or lack thereof) of emotional information in relation to this (Sadock et al., 2015).

In some instances, a recipient of care can manage a mental illness/disability alongside their daily routine and is able to function suitably well – albeit perhaps not ideally - in terms of their independence (Ware & Johnson, 2019). For others, however, a disability such as MDD can affect one's ability to manage their everyday functioning without ongoing and consistent help or support (Ware & Johnson, 2019). Where formal care is not provided for, or provided for inconsistently, informal caregivers are called upon to provide this service to those closest to them (Schutt, 2016).

1.2.3. "…till death do us part": Depression and suicide

Whilst suicidal acts may be seen to occur at an individual level, they almost always exist within interpersonal relationships - none more intimate than that of a spouse or life partner (May et al., 2019). Indeed, romantic partners are often the first (or only) people to know about their partner's potential life threatening crisis (Finlayson-Short et al., 2020; May et al., 2019). According to Stone et al. (2017), and noted in their report published by the Centres for Disease and Control Prevention, suicide is the intentional loss of life caused by self-directed behaviour, with a suicidal attempt defined as the intentional but unsuccessful act meant to cause loss of life. The most recent statistics provided by the WHO (2019b) indicate that as many as 800,000 people die anually as a result of suicide (globally) with many more failed attempts made each year. In 2017, suicide was identified as one of the leading causes of death across all age groups (Stone et al., 2017) and this appears to remain the case according to the most recent global data (WHO, 2020c). Not only is there a significant link between suicide and depression but, for many, suicide is an impulsive act that occurs during moments of crisis in which individuals feel unable to deal with the stresses of life (WHO, 2019b). This differentiation is particularly important in the context of this research given that spousal caregivers face both scenarios concurrently: the debilitating depression experienced by their partner and the crises that this evokes in themselves.

Stone et al. (2017) identified various risk factors that relate directly to acts of suicide, which in turn then relate to this research demographic specifically. For example, at an individual level, Stone et al. (2017) also identified a history of depression and hopelessness as key factors; at a relationship level, they identified a sense of isolation and lack of social support; at a community level, they identified inadequate community connectedness and barriers to health care; and, at a social level, they identified the stigma that is associated with help-seeking and mental illness. All of these factors are identified, elsewhere in this research, as ones that are directly experienced by people who care for a spouse with mental illness – making suicide (or the potentiality for it) a crucial risk, and vital point of consideration, for people caring for a spouse with mental illness (particularly depression) and indeed those who are placed in the community to care for them.

Both the WHO (2019b) and Stone et al. (2017) also stressed, however, how preventable suicide can be despite the challenges that exist in the face of it. Arguably one of the greatest of these is still the stigma that surrounds both speaking out about, and seeking support for, suicide and mental health issues (Finlayson-Short et al., 2020; Stone et al., 2017). For many, stigma remains a predominant barrier between those who require professional help and those who can provide it, with the act of asking for professional assistance often the absolute last line of defence that many will even consider (Finlayson-Short et al., 2020). Finlayson-Short et al. (2020) went on to identify, in the context of both suicide and mental illness in general, how caregivers oftentimes also feel excluded from their partners' health care services due to confidentiality clauses or/and the limited time that providers have for individuals in crises today. The WHO (2019b) suggests different means of suicidal prevention. The most relevant of these in this research context include the early identification and treatment of people with a mental disorder, the training of non-specialised health workers in the assessment and management of suicidal behaviours and the provision of effective and accessible community support.

The intricate way in which partners are linked to the risk factors that lend themselves towards acts of suicide highlights and points to the importance of the life partner relationship. Not only because of the stress and crisis that is placed upon the shoulders of caregivers, but also because of the unique position they hold as romantic partners in terms of their ability to observe warning signs across both time and environment and to aid in the immediate intervention of suicidal acts and the long term prevention of their partners suicidal thoughts and ideations in the first instance (Finlayson-Short et al., 2020).

1.3. The spousal/de facto relationship

Both the social and personal expectations of marriage/de facto partnerships have been identified as complex research areas lacking sufficient exploration (Cash et al., 2019). Where marriage, specifically, was seen as the predominant social norm for two adults co-existing in a long-term relationship (Arocho, 2019), it is suggested that, from a Western perspective, practical and ideological changes of recent times (Arocho, 2019) have resulted in a decrease in the prevalence rate of marriages alongside an increase in the rate of de facto relationships. Regardless, it is argued that Western societies continue to regard long-term relationships as one’s primary source of emotional and personal fulfilment in adulthood (Neff & Morgan, 2014). East Asian societies report a similar increase in de facto relationships (Yen et al., 2011), however marriage continues to remain one of their most important social institutions with people marrying – nowadays - for companionship, development and emotional fulfilment rather than out of institutionalised duty as was previously the case (Yen et al., 2011).

A multi-cultural country, New Zealand society appears to follow suit. As many as 20,949 marriages and civil unions were registered by Stats NZ (2020) in 2018 with the findings of the Law Commission (New Zealand Law Commission: Te Aka Matua o te Ture, 2017) indicating that 22% of couples were in de facto partnerships in the year prior (2017). New Zealanders continue to commit to another person, as adults, with the expectation, intention and hope that their relationship will last a lifetime (New

Zealand Law Commission: Te Aka Matua o te Ture, 2017). A significant proportion of the adult population in New Zealand, therefore, functions in long term, committed relationships – caring for each other both in sickness and in health (Cash et al., 2019; Rollero, 2016).

1.4. Caregiving

Formal carers are defined as those individuals who receive training and financial reimbursement for their services (Ware & Johnson, 2019), whist informal carers are defined as individuals who voluntarily care for someone, without training, and who most often live alongside them (Uysal et al., 2019). This informal care service is normally provided at a level beyond that which would be considered typical of a normal relationship; over an extended period of time; on a regular basis; in one, largely unreciprocated direction; and in a context where the caregiver seldom has sufficient knowledge, preparation, resources or skills to perform the necessary tasks (Revenson, 2016). The world is currently experiencing an explosion of caregiving need in a variety of settings with informal carers serving as the backbone of health and social care delivery across the globe (Revenson, 2016; Ware & Johnson, 2019). Accordingly, mental health systems continue to rely heavily on the services that informal caregivers provide to both the physically and mentally ill - including those individuals who find themselves caring for their spouse/de facto partner (Swain, 2018).

1.4.1. Informal caregiving

This experience of caring informally for another has been extensively researched over the last 60 years with mixed results. Families remain the first and most reliable source of informal caregiving under the current healthcare system, with carers predominantly studied as a broad group and mostly in the context of parents caregiving for a child rather than individuals caregiving for their spouse/life partner (Zarit et al., 1993). Studies exploring what it is like to serve as an informal caregiver have also historically focused on the concept of burden of care - a term commonly used to identify the negative aspects of this experience (Vella & Pai, 2013). From these studies, trauma (Barton & Jackson, 2008), strained family relationships (Maskil et al., 2017), repressed emotions (Pepin & Ross, 2008), depression and anxiety (Watson et al., 2019), emotional control (Lockeridge & Simpson, 2012), challenges in terms of real-time problem solving (Catalona et al., 2018) and experiences of intense anger (Swain, 2018) have been identified as common symptoms. More recently, a shift has occurred in the literature (Schulz & Sherwood, 2017; Ware & Johnson, 2019), whereby caregiver satisfaction, the finding of meaning (Kulhara et al., 2012), the formation of a closer bond with the care recipient (Perkins et al., 2004) and personal development (Perkins et al., 2004) are starting to be more regularly identified as positive aspects of informal caregiving. There is still more to be done in this space, however, with media and political outlets continuing to present a largely negative picture of the risks associated with caregiving whilst seldomly acknowledging the contradictory, positive findings (Roth et al., 2015). To date, most researchers - both qualitative and quantitative - struggle to explain the dichotomy that exists between the positive experiences of caregivers and the negative ones - no more so than in the context of caring for a spouse or de facto partner (Lawn & McMahon, 2013).

1.4.2. Informal caregiving for a spouse/de facto partner

Research indicates that caregivers of a spouse/de facto partner are – for the most part and cross-culturally - socially and personally expected to perform the caregiving role regardless of the quality of their relationship with the care recipient or their willingness or ability to actually do so (Cash et al., 2019). This is argued to be due to a range of factors including, but not limited to, one’s genuine concern for others, their commitment to their marital/long term relationship and/or their desire to remain in a private residence whilst living independently alongside their illness and its symptoms (Cash et al., 2019). Accordingly, this decision to care for one’s partner (whilst likely voluntary) is almost always born out of necessity, responsibility or obligation (Appleton et al., 2018; Pertl et al., 2019; Revenson, 2016).

Research in the context of spousal/de facto caregiving seems to predominantly suggest that the role has the potential to disrupt leisure pursuits and additional family relationships more significantly than any other (Ucheddu et al., 2019); that spousal caregivers will often experience a more in-depth sense of loss comparative to other caregiving types (Appleton et al., 2018); and that spousal caregivers will provide more hours of care, and adopt a greater level of responsibility for caregiving tasks, (Revenson, 2016) than caregivers from any other demographic. Studies have identified the need to explore the expectation of mutual caregiving that is socially regarded as a mandatory aspect of long-term partnerships (Cash et al., 2019) as well as the experience of transitioning both into, and out of, the spousal caregiving role due to, for example, bereavement or separation (Byrne et al., 2011). To date, it does appear that research in the context of caring for a partner with a physical illness notably surpasses that of caring for a partner with a mental one.

1.4.3. Informal caregiving for a spouse/de facto partner with a physical illness

Studies exploring the caregiving experience of looking after a partner with a physical illness are more readily available than those exploring mental illness. Whilst most appear predominantly quantitative in nature (Appleton et al., 2018; Kim et al., 2015; Lawn & McMahon, 2013), there are qualitative studies that consider the caregiving experiences of spousal caregivers looking after a partner with a physical illness. For example, authors such as Quinn et al. (2013), Berger et al. (2019) and Trudeau-Hern and Daneshpour (2012) have considered this phenomenon in the context of stroke, Parkinson's disease and cancer respectively.

Particularly relevant to this research, Quinn et al. (2013) conducted a meta-synthesis of qualitative studies that explored the spousal experience of coping with, and then adapting to, caring for a partner who had experienced a stroke. The researchers searched four electronic databases (CINAHL, Medline, PsycArticles and PsycINFO) and identified twelve papers (all published in English) for inclusion. Inclusion criteria denoted the use of qualitative research methods, the use of an inductive analytic approach to analysis and the completion of a peer review process. Studies were excluded if they included non-spousal/de facto experiences, employed deductive methods of analysis or were intervention studies, discussion papers or book chapters.

Seven themes in total were identified. The first, *seeking information*, spoke of the caregivers oftentimes desperate search for information about their partners' stroke, how it happened and its future impact on both partner and self. Many felt that a lack of information, or the poor provision of it, led to a heightened sense of caregiver vulnerability in an already emotionally charged situation. The second, *searching for own space and well-being*, captured the means by which the caregivers strove to find respite and a sense of freedom from the caregiving role and how this gave them a sense of normalcy and a moment of existing as they had prior to the stroke itself. The third, *suffering in silence*, spoke of the caregivers attempts to keep their feelings and emotions hidden from their partners so as not to add to their burden. Equally, caregivers spoke of trying to act normally in front of close friends and families so as to suggest that things were back to normal and to prevent themselves from complaining (or being perceived to be constantly complaining) to and with others. The fourth, *putting one's own needs aside*, reflected the various approaches that caregivers took towards their own health and wellness. For some, putting their own needs aside helped them to better manage their situations and relationships whereas, for others, they recognised – and tried to prioritise - the need to focus on their own health needs first. The latter approach was least utilised by caregivers and, even for those who were able to recognise its importance, actually being able to take time for oneself was recognised as a major challenge by all. The fifth, *adapting to a changed role*, spoke of the obligation and duty that most caregivers felt in terms of needing to look after their spouse/partner, often cited to be a result of the marriage commitment itself. For some, taking on the new role was a burden whilst, for others, it was a fulfilling act that provided a new direction and a real sense of caregiver duty. The sixth theme, that of *social support,* noted how invaluable it was for both care recipient and caregiver to be surrounded by a supportive social group (made up of family and/or close friends). This support was noted to be both practical (assistance with shopping, meal prep, cleaning) and emotional (a listening ear) in nature with the ability to talk about their experiences, and their partners, serving as a real light in an otherwise somewhat dark time. The final theme, *hope and optimism: instilling a positive focus*, found that caregivers used visualisation techniques, religion and hope to keep them going and to maintain a stable, long-term existence. Many chose to concentrate on the present rather than the future and this appeared an effective strategy for many in terms of managing their feelings of overwhelm and concern that may otherwise dominate their lives.

Two key findings emerged from this meta-synthesis. The first centred around the accurate and timely provision of information and training for caregivers. In the various studies that were analysed, the caregivers particularly stressed the need to receive information prior to beginning their home-based caregiving journey so as to avoid the feelings of intense vulnerability and lack of preparedness that many of them experienced otherwise. For these caregivers, this provision of training and information would be possible whilst the care recipients themselves were still in hospitalised care immediately post their stroke episode. Quinn et al. (2013) concluded that the need for accurate and well timed information and caregiver training were important not only for the ongoing health and wellness of the stroke survivor, but also the ongoing psychological health and wellbeing of their caregiver. A mentally and physically exhausted caregiver was determined to be of limited, and indeed potentially detrimental, support to the stroke survivor themselves.

The second key finding centred around the need for caregiver respite from the caregiving role itself. Barriers to respite were identified and included the care recipients' need for constant attention and care, the intense feelings of caregiver guilt which the caregivers associated with taking time out from their partners situation, and caregiver concern for the safety of their partners if left alone. The authors went on to recognise that, for some carers, professional assistance may be required to help them manage their own debilitating feelings of guilt and concern so as to enable them to take breaks from their spouse/partner and look after their own health and wellness. This need for respite was identified as crucial and seemingly lacking so as to enable the caregivers to recharge and find the necessary inner strength to continue on caring for their loved ones.

From a professional/clinical standpoint, the authors of this meta-synthesis identified the crucial role that clinicians may play in terms of supporting both the stroke survivor and their spousal caregiver. They stressed the urgency behind professionally acknowledging the acute and short-term implications of being a caregiver and the long-term support and training required in terms of how to be an effective informal caregiver. They also stressed how planned respite, and a health plan, should be a critical point of active consideration for support services caring for this particular demographic.

More recently, Berger et al. (2019) conducted a spousal caregiving study in the context of Parkinson's disease. The authors used semi-structured interviews with 20 spousal caregivers, all based in the United States of America, three times each and then analysed the results using a grounded theory approach. They focussed specifically on the social nature of humans and the limitations that caring for someone with a disease such as Parkinson's can have in terms of social participation. Given the impact that this review has already identified on individuals with MDD and their social engagements and interactions, and by proxy their caregivers, the findings of this study are particularly relevant to this research itself.

Only spousal caregivers were included in the research. They ranged in age from 60 to 80 years and both male and female participants were involved. Whilst the health status of the care recipients varied in severity, their baseline levels were such that daily functionality and movement were noticeably impaired.

Three main themes emerged from the research. The first, *activities: caregiving and beyond,* highlighted the need for many caregivers to take on additional practical tasks (such as house cleaning, driving, shopping) which most found frustrating. The caregivers spoke of how these increased requirements reduced the time they had to complete their other responsibilities and social activities, referring to both their professional lives and their social ones. The researchers pointed out how many of the participants chose not to actually speak of their caregiving role at all, but rather to focus on the social activities that their role was disrupting/altering. One spoke of changing his approach to his art and painting so that his wife, the care recipient, could participate with him whilst another spoke of how her husband's Parkinson's had reduced their previous social circle whilst equally introduced them to a new one – made up of people in similar situations.

The second theme, *strategies to support self and spouse*, addressed the very delicate balance that existed between the caregiver's care for their partners and their self-care. Most of these caregivers spoke of how they managed their own health by staying in touch with friends and family, planning ahead and seeking out both formal and informal support systems. Positive self-talk, visualisation techniques and a positive attitude were also frequently mentioned by the participants. Participants also spoke of using the support of others to keep their partners engaged socially – encouraging their partners to attend lunch dates and small family events despite their symptoms and because of the love and care that others showed towards them. For these participants, their partners wanted to retain their own independence and hence the caregivers were responsible for identifying how best to do this in a way that was safe and effective for all. Methods included utilising publicly provided wheelchairs and installing handlebars and ramps throughout their households.

The third and final theme to be identified was *emotional impact: burden and compassion.* Burden of care was noted by almost all of the participants in terms of the increase in physical tasks and the emotional impact of changing one's lifestyle drastically to suit the needs of another. Alternatively, the positive impact of caregiving was also identified in that caregivers experienced a real sense of satisfaction and peace when a new strategy worked for their partner. For most, this experience of burden and satisfaction was interlinked and the participants did not see the need to separate them. This was their new life and they embraced all that it brought with it – the good and the bad.

Key findings from this research centred around the challenges that were brought on by social engagements and the associated strategies that caregivers employed to cope with these. The difficulty of finding a new sense of life balance was also identified alongside the ongoing struggle of finding the time, and energy, to care for both partner and self. Having said that, the research findings also indicated that the experience of caregiving was individualistic and, whilst similarities existed, each participant was on a completely unique journey alongside their partner. The authors highlighted the sense of compassion and satisfaction that emerged from their research, noting how this contrasted with many other studies where burden of care was entirely dominant. Finally, the authors stressed how taking care of oneself by engaging socially was crucial for all of the participants and stressed how, clinically, assisting caregivers with retaining their social identities was invaluable. They also identified the need for increased access to both paid and unpaid help (housekeeping, transport and respite services) so as to maintain and protect the health and wellbeing of the spousal caregiver.

1.4.4. Informal caregiving for a spouse/de facto partner with a mental illness

In the context of caring for a spouse with a *mental* illness, studies specifically exploring the experience of older partners with age-related and socially anticipated mental illnesses appear prominent (Donnellan et al., 2017; Shim et al., 2012; Potier et al., 2018 Saunders et al., 2020). Again, however, most studies are quantitative in nature with limited access to qualitative perspectives.

One qualitative study that is relevant is Donnellan et al.'s (2017), which explored the experience of spousal dementia caregivers. These researchers explored social support as a coping strategy for caregivers so as to determine its effectiveness. They interviewed 23 different carers, aged between 62 and 89 years, from two carer support groups based in England, and concluded that the provision of support from family and friends does not always facilitate resilience in carers. Rather, support was only effective for caregivers if it was provided in such a way that it met the caregivers' needs at the time, leading to the recommendation that carers be supported by friends and family who are able to foster resilience and independence and, importantly, that caregivers be encouraged by family members and professionals alike to engage with community group settings where the correct experience and expertise could be shared and learned.

Following on from this idea of seeking and requiring community support assistance, Dovi et al.'s (2020) qualitative study looked at the changes that were experienced by 14 caregivers as they journeyed through a dementia psycho-education group called 'Help and Support for Caregivers and Patients' based in Belgium. Interpretative phenomenological analysis was used to analyse the results of the interviews which were held with the caregivers both before and after their group participation. The results of this study indicated that caregivers experienced positive growth in their informal caregiving role, benefitted from their interaction with peers who were in a similar situation, addressed their feelings of guilt at leaving their partners alone, and increased their use of out-of-home dementia support services. Dovi et al. (2020) concluded by noting that caregiver well-being in the context of dementia was a public health priority in Belgium but that further knowledge and acknowledgement of the complex needs of this demographic was essential so as to continue to provide and develop effective support resources.

In contrast, qualitative studies exploring the experience of caring for a spouse for whom age-related mental illness is <u>not</u> the anticipated norm appear far less accessible (Ucheddu et al., 2019). Of the few that have been published, one of the most relevant to this study is that conducted by Lawn and McMahon in 2013.

In an attempt to explore the burden of informal spousal caregiving for a partner with severe mental illness (all types included), Lawn and McMahon (2013) interviewed 28 caregivers based in South Australia. Both female and male caregivers were included, with ages ranging from 30 to 60 years. Twenty-six of the participants were married whilst the remaining two were in long-term de factor relationships. In analysing their acquired data, acquired through the use of open-ended, semi-structured interviews and using grounded theory as their approach, these researchers identified two core themes – one with five subthemes, all central to the idea of doing everything possible to maintain and protect a real and genuine relationship with one’s ill spouse/partner and the other which looked at the unique nature of caring for a spouse rather than an adult child.

The first, most dominant theme was that of *a real and genuine relationship: love, loyalty, and commitment.* The participants all spoke of their commitment to their partners and, for those who were married, their desire to uphold their marriage vows. Loyalty was a major factor for all – alongside love for their partners and admiration of all that they had achieved and were currently coping with. Within this theme, the participants spoke of their passionate desire to protect their partners and their relationships, with some even downplaying the dangerous situations that their partners’ mental health symptomology had placed them in. The participants spoke of how their experience of loving a partner with severe mental illness was expressed as being equally as enriching as it was traumatizing. To accommodate for this, participants used humour and mutual compromise and assumed fundamental ownership of their relationship in a way that felt more parent-child oriented than adult-adult to the caregivers during the episodes themselves. Regardless, the caregivers were stoic - particularly in the context of maintaining and protecting their partners’ quality of life and despite the fact that this often resulted in a reduction of their own. They spoke of standing their own ground – sometimes in the form of fighting verbally against their partners’ negative or irrational thoughts or, alternatively, establishing and then navigating rules around physical intimacy and attachment so as to preserve their relationships. Within this theme, many participants did comment on their feelings of intense loneliness and isolation, particularly when their partner was most unwell. This resulted in weeks if not months of feeling almost surreal – as if they were living the life of someone else during the most pressing times. Whilst a few participants did refer to a wish for a different life, none did so in the context of not being with their partner. Rather, they wanted to be without the illness but couldn’t imagine a life without their spouse. Male caregivers appeared more isolated than their female counterparts, relying less on their social networks for support and more on going it alone and dealing with their feelings and emotions internally.

The second main theme, that of *a different experience from carers of mentally ill adult children,* concentrated on the caregivers’ perception of their support role to their partners. All saw it as an especially unique relationship – unlike any other they could imagine themselves being in. For these participants, this relationship was special because it was chosen and physically intimate. This separated it from a caregiving role they may have assumed for a child or a friend, as examples. They spoke of the unique potential for emotional manipulation within the relationship with their spouse or partner where things like discipline or rule setting – possible with children – were not coping strategies that could be enabled. Regardless, the participants saw themselves as husbands and wives – not carers – who were simply coping with the challenges presented to them by life and taken on mutually because of their commitment to each other.

Lawn and McMahon's (2013) key findings focussed on the concept of caregiver accommodation. They determined that caregivers were accommodating their partner's mental health symptoms into their own lives alongside the usual expectations that they held around being in an intimate relationship. These acts of accommodation involved navigating carefully between one's own reality (made up of regular daily activities and social interactions) and those of their partner's (made up of significant emotional pressures and social isolation). All of the participants spoke of the marital/de facto expectations of care in a long-term commitment and felt that this would be reciprocated should the tables be turned. Another key finding was the caregivers desire to stand up to the mental illness, as a unit/team, and their proactive and conscious efforts to view their partners as individuals who existed separately from the illness itself. Looking after a partners' self-esteem was identified as a crucial part of the spousal caregiving role as was the caregivers' desire to stand alongside their partners in their fight against, and indeed treatment of, the mental illness.

Overall, Lawn and McMahon (2013) concluded that spousal caregiving relationships are driven by love, loyalty and emotional (if not physical) intimacy and that the experience of caregiving largely brings couples closer as they strive together against the illness. These authors stressed that it was important to further understand the emotions that caregivers accommodate into their own lives and to understand how they make sense of their experiences over time. They noted how simply providing information, and increasing the knowledge and skill set of caregivers, would be insufficient in terms of positively impacting their lives; rather, these authors stressed that health service providers should acknowledge caregivers, the invaluable role they play in mental health care and the intricate nature of their commitment to their mentally ill partner.

1.4.5. Informal caregiving for a spouse/de facto partner with MDD

In the context of MDD specifically, there do not appear to be any New Zealand based published spousal caregiving studies however, further abroad, there are studies that explore the spousal caregiving role in the context of depression as well as a meta-synthesis that considers mood disorders in this same context collectively. The most pertinent are discussed below.

In 2015, Lewis conducted a meta-synthesis examining articles and published dissertations, from 2005 to 2015, exploring the spousal caregiving role in the context of mood disorders. To do so, she conducted a comprehensive search of CINAHL, PsychInfo, PubMed and Sociological Abstract and ended up with a total of 14 articles for consideration. Within these, 106 participants were spousal caregivers looking after a partner with a depressive disorder, with Lewis (2015) referring to the experiences of these specific participants in her analysis. Any study with a qualitative element was included for consideration providing that the participants were in a romantic/intimate relationship with a person with a mood disorder. Lewis (2015) was not concerned, however, with marital status or length of relationship. Further, individuals were excluded if they were in non-partnership relationships (siblings, adult child-parent relationships and non-intimate friendships); if their partner had comorbid substance or alcohol abuse; if the participants' relationships were affected by violence or imprisonment; and if the participants' partners depression was secondary to bereavement, illness, childbirth or experience serving in the military.

The most predominant theme to emerge from Lewis (2015) meta-synthesis was *disenfranchised caregiving*, used to address the participants' feelings of serving as primary caregiver for their partners without being socially recognised for, and therefore feeling socially stripped of, the title itself. Lewis (2015) spoke of how messages of 'care for the caregiver' were heavily prevalent in populations affected by illnesses such as cancer, dementia and diabetes but that, at the time of review, the same could not be said in the context of mood disorders. Within this key theme, participants spoke of their responsibilities during depressive episodes, which included the provision of intense levels of physical care, medicinal management and emotional support. Most also took on all of the responsibilities within the home and with (where relevant) extended family – despite the fact that the care recipient was often unemployed as a result of their illness and therefore based at home full time.

Loss and isolation was another theme identified in this review. Lewis (2015) reported that the participants spoke of intense levels of financial stress and loss as well as the loss of a romantic identity with their partner. The physical sacrifices necessary to protect their partners compounded these feelings of loss - from cancelled vacation plans with friends to losses resulting from their own poor work performance and poor health. The care recipients often desired/required long periods of privacy and solitude, resulting in the same isolation and loss of social connection for the caregivers. Caregivers also felt isolated from their family and friends who lacked understanding in terms of their caregiver role and its requirements. Participants felt helpless and ill-equipped and oftentimes defeated in the face of their partners' depression. The research participants also reported feeling largely excluded/isolated from health care decisions relating to their partners, despite the fact that they were primarily responsible for them.

Balancing needs was another strong theme that emerged, with participants striving (often unsuccessfully) to achieve a sense of balance between the needs of their ill partner and their needs. Many spoke of how this led to resentment and feelings of entrapment over time as well as to physical symptoms such as tension, muscular pain, tiredness and insomnia.

In summary, Lewis (2015) determined that spousal caregivers of partners with severe depression exemplify the traits of informal caregivers but are disempowered by society in terms of what it means, and what is required, to perform this role. Lewis (2015) concluded that mental health services need to actively acknowledge the role of spousal caregivers which would, in turn, change how health care professionals both view and treat these individuals. She also determined that mental health services need to recognise the value of including caregivers in their partners' care team - working early on to establish clear lines of communication, clear expectations, and stringent guidelines around what to do in the context of information sharing should the symptomatology of the ill partner worsen or change.

Another study that is particularly relevant, and that was included within Lewis' (2015) own research, was that of Harris et al. (2006). These researchers explored how partners supported a spouse suffering from depression and how the care recipients themselves experienced this support. Based in the United Kingdom, nine participants took part ranging in age from 28 to 53 years. The depressed partner was required to have experienced at least one depressive episode within the previous four years and the relationship was required to have been in existence for at least one year. The couples were interviewed jointly, and twice, with the semi-structured interviews analysed using interpretative phenomenological analysis. The researchers identified two experiences: the various challenges that the couples faced in light of the depressive episodes alongside each partner's personal account of their own experience of the caregiving support process.

A primary challenge faced by many was the way in which the depression presented itself. For some, this was quick and sudden – leaving both partner and caregiver with little time to come to terms with what was happening. For others, it was slow and sneaky – entering the lives of both partners without significant warning signs such that the depression was firmly entrenched before either partner fully recognised its existence. Regardless, the participants felt baffled by the illness, and its symptomology, with the depressed partners' struggling to communicate with their partners about their experiences, leaving them feeling left out and frustrated given that they could see and feel the resultant changes but couldn't necessarily understand them.

Distance and disconnection during a depressive episode were also noted on the part of both caregiver and care recipient. Pertinent specifically to this research, the caregivers felt an intense level of urgency and complexity during the depressive episodes in terms of simply getting by each day and many spoke of putting their relationships on hold while they waited for the episodes to pass. For many caregivers, the knowledge that another episode was likely to occur was also a heavy weight to bear but their previous experiences in this context were seen to be tools that would enable them to cope easier the next time, if albeit only slightly.

In terms of both partners' experience of giving and receiving support by the caregiver, the caregivers spoke of starting off with no idea of how to help and creating strategies for themselves based on basic and uninformed trial and error. The caregivers all identified the need for support, but acknowledged their inability (and the inability of their partner) to understand or comprehend what this support looked like and indeed how to make this support effective. They spoke of stumbling along and of how their access to professionals and self-help resources did very little to help them functionally cope with the day to day challenges of caregiving. A significant challenge for the caregivers was also the discrepancy between what the care recipient said they wanted in terms of support versus the types of support that actually proved to be helpful; rather, the caregivers found themselves having to support their partners in ways that they didn’t desire but that saw positive results. This was a challenging dilemma for the caregivers, and made knowing whether they were doing the right thing and making a positive difference particularly difficult. Regardless, the caregivers kept trying and continued to traverse through the depressive episodes alongside their partners. Discovering a form of communication that worked for both care recipient and caregiver was deemed essential by both partners, with coping together (rather than apart) identified by many as key to their ongoing marital success.

In concluding, these researchers noted the struggles and challenges brought on by depressive episodes, but also commented on the positive elements of caregiving that did come to light and on how little research existed (then, and still today) in terms of this dichotomy. Clinically, they concluded that professionals must be aware of the wider circles within which the depressed individuals exist, particularly when a spouse or life partner is involved. They stressed how clinicians should always consider the benefits of working closely alongside a client’s significant other to ensure that the strategies that are used to assist a client through their depressive episodes are consistent and understood by all parties.

A third study, conducted in 2011 by Bridget Logan, looked at the experience of seven individuals who were in long-term relationships with individuals experiencing depression. The participants were all based in the United States of America, with Logan choosing to focus on their experience of the depression itself as well as their reflections on the term ‘caregiver’ within the unique setting of a committed, adult relationship. The findings of this study supported those which have already been identified – noting the likelihood of a caregiver developing increased level of stress, fear and worry as a result of their role and the change in relationship that occurs during a depressive episode when the carer becomes more of a parent than a partner. Clinically, Logan stressed the need for a caregiver to be included in the care recipient’s treatment process and to consider the suitability of the extremely firm restraints that patient confidentiality places upon this relationship. A new finding from this study emerged in the context of the caregiving terminology. For the participants involved, there was a clear and important distinction between being a caregiver and giving care and many felt that adults in a committed relationship were doing the latter and should not be classified as being the former (i.e. were spouses giving care as part of a normal adult relationship thereby making the separate definition of being their partner’s caregiver superfluous).

1.5. Summary

A review of the literature in the context of informally caring for a spouse with a diagnosis of MDD revealed that it is common to live both amongst and alongside individuals experiencing mental distress. Post deinstitutionalisation, the demand for community care – globally – was not matched by a reciprocal supply of suitable alternative care replacements (Schutt, 2016). Over a decade later, mental health systems, both within New Zealand and abroad, remain under-resourced with communities relying heavily on the services provided by unpaid carers. Moreso, the current global situation is threefold: the baby boom generation is ageing (Lima et al., 2008), the age of retirement is increasing (Lima et al., 2008) and more and more people are requiring care due to the symptoms of both mental and medical illnesses or, quite commonly, a combination of both (Zarit et al.,1993). In terms of caregiver demographic, this review has identified that an estimated 21% of all caregivers, at any one point in time, are looking after a spouse/life partner and that these caregivers are faced not only with the severity of an ill partner but also the social and personal expectations attributed to marriage and long-term partnerships (Revenson, 2016).

The review has also highlighted the fact that depression is widely recognised as the most prevalent mental illness in the modern world and that the gap in terms of researching mental illness, and MDD specifically, in the context of spousal informal caregiving is significant. MDD itself has been shown to be associated with marked functional and psychosocial impairments with the negative impact it creates on social relationships likely to impede the rate of recovery for sufferers and potentially increase the potential for suicidal ideations or acts. The deadly consequence of suicide have also then been noted in this context, with risk factors for caregivers shown to be evident in all facets of life: individual, relationship, community and social. A vital point to emerge from this review, however, is the preventable nature of suicide, making our understanding of the link between suicide and the spousal caregiving experience of caring for someone with MDD a crucial part of the fight against it.

Caring for a spouse, over and above any other type of care recipient, has then been shown to be a unique and complex experience that has not been explored in sufficient detail. Equally, the experience of caring for a spouse significantly impacted by MDD has been shown to remain in a literature gap and this review has highlighted the importance of exploring this so as to gain a better, more in-depth and phenomenological understanding of the challenging journey that these couples face.
In its exploration of the experience of informally caring for a spouse with a physical illness, a mental illness and MDD, the prescence of both burden of care and positive care experiences was evident as was the need for the right support to be given to caregivers in an effective, relevant and timely manner. The need for caregiver respite also emerged as a constant and crucial factor for consideration as was the fact that caregivers very seldomly achieve the levels of self-care and self-time that they require. Commitment, be it ensconsed within marriage vows or simply time spent together, was also a consistent theme identified in this review – with the support of one's spouse considered to be a natural part of an adult relationship rather than a separate role in and of itself.

Lastly, the active inclusion of spousal caregivers in the care and treatment of their depressed partners has been repeatedly identified in this review as a driving factor that could help alleviate some of the burden of care that caregivers experience. Indeed, this could also increase the positive associations that caregivers – and indeed society alike - align with this vital and rapidly increasing informal caregiving role which may then change the way it is approached, viewed and indeed experienced by those placed within it.

1.6. Research Aim

The aim of this research was to qualitatively explore the experience of caregivers who informally care for, and live alongside, a de facto partner/spouse with a diagnosis of severe Major Depressive Disorder. This research contributes to a greater understanding of what it is like to care for a spouse/partner in this particular situation with potential implications in terms of the way in which caregivers (and their life partners) are acknowledged and supported by mental health services in the future.

2. Methodology

This section details the ethical considerations that were undertaken at every stage of this research study. It explains the paradigm within which the study is placed and details both the design used and the qualitative methodology – Reflexive Thematic Analysis (RTA) - chosen. The rationale for all of these choices is also provided.

2.1 Ethics

3 This project was reviewed and approved by the Massey University Human Ethics Committee: Southern B (Application SOB 20/01). I was guided through the process by my supervisor and I arranged to have access to additional cultural support if required.

2.1.1. Informed consent

All interested members of the public were provided with an information sheet (Appendix C) that detailed the purpose of the study and the process that would be followed. Participants then returned a signed consent form (Appendix D) and verbally were also asked to confirm this consent at the start of the interview itself. At the start of each interview, participants were reminded of their ability to pause or stop the interview at any time, and of their right not to answer questions that made them uncomfortable for any reason. How the data would be recorded and stored was also explained at this point. At the end of the interview, participants were reminded of their right to review the transcriptions prior to analysis and to pull out of the research entirely prior to the date provided on the consent form. How the data was to be managed from this point onwards was also explained to the participants.

2.1.2. Confidentiality

Pseudonyms have been used in place of the participants' real names throughout this research process. The interview transcriptions make no mention of participant names and the participants have been provided with alternative names within the Findings section to ensure that their confidentiality is secure. In line with this, any details that were deemed potentially identifiable in relation to the participants (for example, name of partner or name of residential town) have also been removed from both the transcriptions and the findings. All communication (both e-mails and private Facebook messages) between myself and the participants has been deleted, however a record of their contact information will be kept until the thesis has been assessed so that the participants can be sent a summary of the results. Once this has been done, these contact details will be deleted to protect the confidentiality of the participants.

2.1.3. Data management

The audio and visual recordings of the interviews have been deleted from their place of storage – the Massey University server - and from Otter (an online, password protected programme used to electronically transcribe interviews) following transcription. Soft copies of the transcriptions are stored on the Massey University Server for the purpose of the analysis process however will be deleted once the thesis has been submitted. Hard copies of the written transcriptions and the written informed consent sheets will be stored safely, but separately, by the research supervisor at the Wellington Campus of Massey University and will be destroyed at the end of the storage period (i.e. five years).

2.1.4. Participant and researcher safety

Given that I was interested in speaking to participants from anywhere within New Zealand, and in alignment with the social distancing measures and health protection measures that were in place due to the COVID 19 pandemic, a secure online interview platform was chosen for this research. I checked with each participant that they were happy to proceed with the interview and that their partners were supportive of their involvement in the research. I also notified the participants of various online and telephonic support groups they could utilise should the interview process prove to be an upsetting or challenging experience. A list of these support options was also sent electronically to all participants immediately after the interviews.

2.2. Rationale for methodology

Qualitative in approach, this research was conducted using reflexive thematic analysis (RTA) and within the boundaries of the interpretivist paradigm (IP), the details of which are explained below. My aim was to gain a better understanding of the spousal caregiver experience of looking after a partner with MDD but in a manner unrestricted by quantitative hypotheses. I hope that I have demonstrated theoretical sensitivity, central to both IP and RTA (Lawn & McMahon, 2013), by immersing myself in the existing literature whilst also acknowledging my personal situation wherein I am supporting, albeit from afar, my father in his relatively new caregiver role for my mentally ill mum.

I chose to work from within the IP because it encourages researchers to step inside their participants' own experiences whilst exploring, describing, understanding and explaining social phenomena (Blaikie & Priest, 2017). Nowadays, IP is well-established within the social sciences (Blaikie & Priest, 2017). It insists on the existence of multiple meanings which humans attribute to their shared experiences (McAllum et al., 2019) and is not one that attempts to quantify human experience (Dean, 2018). Rather, interpretivism allows researchers to bring to light new experiences and meanings that the quantitative generalisation of data simply cannot (Trainor & Graue, 2013). Whilst data is indeed captured, this process occurs contextually on the understanding that reality itself is both subjective and socially constructed (Dean, 2018). Perhaps one of its most distinguishing features is its openness to, and acknowledgement of, the researcher’s contextual and a-priori knowledge (Dean, 2018). Because of this, the onus was on myself to include evidence of my reflections throughout the research process and to navigate - openly and willingly - multiple and sometimes conflicting commitments to my participants, my readers and indeed myself (McAllum et al., 2019).

2.3. Recruitment and participants

2.3.1. Inclusion criteria

In order to be included in the research, participants were required to be:

- 18+ years of age;
- living permanently in New Zealand;
- married to, or in a 3+ year relationship with, a partner/spouse who has a diagnosis of Major Depressive Disorder (MDD); and
- be responsible for caring mostly for their partner/spouse

and their spouse/partner was required to be:

- 18+ years of age; and
- receiving support from a mental health service such as a District Health Board (DHB), community based mental health centre, general practitioner (GP) or primary health care provider for their MDD.

2.3.2. Participant recruitment

Initially, various organisations who support caregivers of patients experiencing mental health issues, and those who support individuals experiencing mental illness themselves, were contacted by phone and email and asked to display a flyer (Appendix A) and an information sheet (Appendix C) in their place of business. This request was made in the form of a letter addressed individually to each organisation (Appendix B). These organisations were identified via online google search and included:

- Massey University Psychology Clinic
- Hawkes Bay District Health Board Consumer Council and Patient Advisory Group
- Wellington Community Mental Health Team
- Porirua Community Mental Health Team
- Kāpiti Community Mental Health Team
- Hutt South Community Mental Health Team
- Hutt North Community Mental Health Team
- Wairarapa Community Mental Health Team

Both the flyer (Appendix A) and the information sheet (Appendix C) included my contact details (a mobile phone number and a Massey University student email address). This recruitment method proved particularly challenging at the time. The four week lockdown period in New Zealand, which occurred in response to the COVID 19 pandemic and at the time of advertising, drastically restricted the physical visibility of the flyers as almost every service provider turned to online support options to continue treating their clients. This made hard copies of the research flyers largely redundant. At this point, I submitted an ethics amendment request to the Massey University Human Ethics Committee asking for permission to use an electronic flyer (Appendix E) on the service providers websites and my own social media platform – Facebook – to advertise the research opportunity and to recruit participants. Ethical approval was obtained.

This electronic flyer was then posted on my social media page (Facebook) with a note requesting that others share this to increase visibility. The same flyer was also distributed by private message or email to the organisations already noted above, as well as those noted below, with a request that they share the flyer on their private Facebook page or website:

- Carers NZ
- Key to Life
- Depression Support
- Anxiety and Depression Support Group
- Depression/Bipolar Support Group NZ/OZ

All of the participants were recruited via social media and each chose to contact me by e-mail or private Facebook message. After confirming that they met the inclusion criteria, I emailed them the information sheet (a hard copy postal option was also offered) and a consent form (Appendix D). This form noted their ability to decline to answer any question and to end the interview at any time; to have the interview recorded either visually and/or verbally; and to receive - and make redactions - to their transcriptions prior to analysis. Once returned, a mutually suitable time for an interview was agreed upon via email (with an hour deemed sufficient per interview). Due to the ongoing impact of COVID-19, these interviews were in the form of non-contact interaction, with the participants given the option to interview by phone or online portal. All chose the online portal.

2.3.3. Participant information

A total of six spouses (four men and two woman) participated in the study. The participants' demographic characteristics are presented in Table 1.

Table 1. *Participants' demographics*

Participant			**Relationship**		**Partner**		
Pseudonym	Ethnicity	Age	Status	Duration (years)	Gender	Ethnicity	Diagnosis (Primary)
Anna	NZ European	34	De facto	13	Male	NZ European	MDD Recurrent
Sam	NZ European	41	Married	21	Male	NZ European	MDD Recurrent
Natalie	NZ European	35	Married	13	Male	American	MDD Recurrent
Sian	NZ European	34	Engaged	4.5	Male	NZ European	MDD Recurrent
Paul	South African	61	Married	45	Female	South African	MDD Recurrent
Nathan	NZ European	36	Married	9	Female	NZ European	MDD Recurrent

2.4. Data collection

I conducted semi-structured interviews – ranging in length from 0.48 to 1.46 hours - with each participant via www.zoom.us, recording these audibly and visually with their consent. I chose www.zoom.us because it is a secure online interview portal with security measures such as waiting rooms, individual access codes and direct PC recording options. I developed an interview schedule in response to the literature review. A pilot interview of the first draft was held with my husband to ensure that the questions and prompts encouraged and allowed for a natural conversational flow directed by the participant rather than the researcher. This draft was then viewed by my supervisor with additional prompts included as per her advice. The final schedule (Appendix F) is included as an appendix.

This semi-structured interview approach suited my research aim because it allows researchers to use questions and prompts to help draw participants into the phenomenon being considered (Galetta & Cross, 2016). Initially, the questions were exploratory and followed the participant's lead. At this early stage, I was attempting to create space for their own narrative (Galetta et al., 2016) and my role was to listen carefully, to probe for clarification and to note down anything that appeared worthy of return later on (Irvine et al., 2013).

In the middle segment of the interviews, I attended to any nuances that had been identified. My questions were more specific and I often referred back to previous statements made by the participants. These questions also extended beyond simple clarification to meaning making on the part of my participants and it was at this stage that I used more theoretically driven questions (Galetta et al., 2016).

My final questions took on a lighter, less intensive focus and I gave the participants given one last opportunity to note or include anything that they felt they may have left out (Irvine et al., 2013). I concluded by thanking the participants for their time.

2.5. Data transcription

At the completion of each interview, I utilized an online audio transcription programme called Otter (www.otter.ai) - paying for a secure, password protected account for the duration of the interviews and transcription process. I uploaded the audio recordings from the Massey server (where they were being stored securely) to my Otter account, using the programme to transcribe the verbal files into written text. I then checked each transcription alongside the audio recording for any errors. Had any of the participants expressed a desire to view and make redactions to their transcriptions, this would have occurred at this point. None did, however, so this stage in the process was not required. Once I determined that the transcriptions were an exact written replica of the verbal interviews, I deleted the audio recordings from the Massey server and the verbal recordings and transcribed files from the Otter server and saved the final, written transcriptions on the Massey server for subsequent analysis.

2.6. Data analysis

2.6.1. Reflexive thematic analysis (RTA)

I chose to use reflexive thematic analysis (RTA) because it allows a researcher to consider data theoretically whilst remaining open to the emergence of new concepts (Braun & Clarke, 2006; Joffe & Yardley, 2004). This method is considered to be independent of any specific theoretical framework/paradigm making it flexible for use and application (Ali & Phipps, 2020; Miller, 2020). Braun and Clarke's (2006) reflexive version of thematic analysis was deemed suitable for this research given the researcher's level of qualitative experience and as it provides a clear framework from which to analyse data.

RTA involves identifying and analysing patterns of meaning within transcriptions and then theoretically interpreting these (rather than simply summarising them). Core to this method are the processes of data familiarisation, data coding, theme development and revision - all flexible, organic and consistently evolving processes that develop alongside the researcher's own subjectivity and knowledge (Clarke & Braun, 2018; Braun & Clarke, 2020). I chose to approach the data inductively, identifying the codes and developing subsequent themes in a manner that was directed by the content of the dataset itself (Clarke & Braun, 2018).

There are a number of qualitative studies - in a variety of contexts including mental health - where IP and RTA have been used together (Comiskey et al., 2020; Cox et al., 2019; Phillipowski, 2020; Usher, 2020). Like any other, this approach has both its benefits and shortcomings. The latter includes the possibility of extreme subjectivity and unintentional bias given that the researcher is responsible for data selection and theme identification (Miller, 2020). It is argued, however, that - when used correctly - the set of defined steps involved in the process of RTA ensure a high level of consistency as well as the clear and valid assessment and reporting of data (Miller, 2020). Other benefits include the approach's flexibility, its simple execution and its accommodation of variability in terms of both insight and interpretation (Miller, 2020). The steps involved in RTA are described below.

2.6.2. Steps 1 and 2: data familiarisation and data coding

The first job of a researcher using RTA is to familiarize oneself with the data set (Braun & Clarke, 2006) and I achieved this by reading the transcriptions multiple times. Elliott (2018) stresses how crucial this first step is – given that the qualitative researcher goes on to decide not only which segments require a code, but also, crucially, which do not. Once complete, I began the process of data coding. As noted by Elliott (2018), and in alignment with the steps outlined by Braun and Clarke (2020), coding is the process by which a researcher takes data apart so as to then put it back together in a meaningful and relevant way. At first I used a paper and pen approach (Elliott, 2018) printing out each interview and coding each sentence/segment using different coloured pens. I made sure that the codes I identified clearly emerged from the participants' own voices, rather than my own subjective views (Elliott, 2018). Once complete, I transferred the data, combining coloured segments where suitable, to Microsoft Excel, and utilised this computer programme for the rest of the analysis process.

2.6.3. Steps 3 and 4: generating and reviewing themes

The process of theme generation involves examining the collated codes, now located on Microsoft Excel, so as to identify broader patterns of meaning which Braun and Clarke (2020) call themes. It is important - in terms of the validity and reliability of qualitative data - to note that themes are formed from the analysis of the codes themselves, rather than the individual data sets from which they initially emerged (Elliott, 2018). As this author notes, whilst a piece of data is able to be coded more than once, it can only be coded once within each theme. Accordingly, I examined the codes and grouped them together according to their broader theme relevance. Some codes I discarded due to a lack of consistency and some I chose to combine due to their mutual relevance/theme application (Braun & Clarke, 2020). At the conclusion of this process, I identified six themes which are discussed in detail in the Findings section.

At this point, I went back and checked these against the dataset to confirm that they were a true and fair reflection of the experiences of the research participants themselves and not a subjective reflection of my own (Elliott, 2018; Braun and Clarke, 2020).

2.6.4. Steps 5 and 6: defining and naming themes and writing up the results

During this phase, I selected an informative name for each theme that clearly expressed the story that each was telling (Elliott, 2018). I then utilised my theoretical knowledge to analyse each theme - looking beyond their content to discover what the data might actually be saying and what the implications of these meanings might be (Braun & Clarke, 2020; Elliott, 2018).

The final phase of RTA involves merging the thematic discoveries from the data set with existing literature (Braun & Clarke, 2006) and presenting these findings for consideration, comparison and reflection by others interested in the same social phenomenon. Accordingly, my findings are presented in the next chapter.

3. Findings

The following chapter presents the findings of this research study which were obtained via Reflexive Thematic Analysis (RTA) and using the steps that were detailed in the Methodology section. Six themes were identified, reflecting the experience of living with, and caring for, a spousal/de facto partner who has a primary diagnosis of Major Depressive Disorder.

Before I begin, I want to acknowledge my subjectivity to the topic given the caregiving situation that exists between my father and mentally ill mother. I have reflected upon this throughout the research process and have followed the guidelines of RTA closely so as to be transparent and reliable in the presentation of my findings. I also want to note, again, that pseudonyms have been used to ensure the confidentiality of my participants, with any additional identifiable details removed for the same purpose.

3.1. Introduction to the themes

3.1.1. In it together

This theme describes the various reasons that the participants identified for staying in their relationships despite the challenging dynamics that were brought on by the symptoms of MDD. A feeling of shared acceptance and a willingness to fight life's challenges together appeared to be most dominant, with this concept of care reciprocation highlighting how most participants felt that a commitment to an adult relationship meant committing to caring for one another no matter what the outcome. The implications of marriage and partnership were also raised as part of this theme indicating that, for some people at least, the decision to stay is necessary for reasons other than love and commitment.

3.1.2. Tough love

The second theme to emerge from the research, *tough love,* highlights an apparent coping method that caregivers may choose to adopt when dealing with their partner's mental illness. Tough love is described by the online version of the Oxford American

Advanced Dictionary (Oxford University Press, 2020) as ‘the fact of helping someone who has problems by dealing with them in a strict way because you believe it is good for them’, with the findings identifying various, and sometimes contrasting, ways in which this strategy may be used, by caregivers, as they struggle to cope with the role of caring for a spouse with MDD.

3.1.3. Loss of self

The need to restrict an element of one’s personality so as to be able to serve in the role of spousal caregiver was prevalent throughout this theme. Both physical and emotional forms of loss were identified, and, for many, this loss was an issue around which they still appeared to struggle – recognising the importance of facing and dealing with these head on but equally not feeling up to the challenge of doing so personally.

3.1.4. Facing death

Facing the death of oneself or one’s partner was a very real and harsh reality for all of the participants. Further, this concern was also mirrored in some of the participant’s worry for their own personal safety, particularly where mental health issues or suicide attempts made up the fabric of their own personal histories. This theme went on to introduce a potential battle that caregivers and co-parents of partners with MDD face in terms of a conflict between their moral and legal obligations.

3.1.5. The power of a phrase

This theme identified the impact that the use of religious phrases or proverbs can have on caregivers of the mentally ill. During analysis, the impact of common relationship phrases such as “all you need is love” and “love conquers all” emerged as quite challenging for the caregivers, as did the impact – both negative and positive - of religious proverbs such as “faith will move mountains” and “the Lord only challenges you with that which you can overcome”. The role of society, in general, was also highlighted within this theme in terms of its oftentimes flippant use of these phrases and proverbs, as was the clinical importance of both utilising select phrases to aide caregivers (i.e. care for the caregiver) whilst restricting the use of phrases that can add to the load they already bear (i.e. she’ll be right).

3.1.6. Who is going to save us?

The sixth and final theme to emerge from the dataset concerns the fragility of the caregivers' own mental health and their sense that, if they were to succumb to mental illness, there would be no one left to save them. Many spoke of their own struggles with mental health and the mental block they had towards taking control and actively engaging with their own self care. For some, the intensity of their partner’s depression appeared to diminish the importance or perceived intensity of their own mental health concerns, appearing to almost remove their ability to care for themselves because they were required to care – to such extremes – for another. For others, this idea of being saved resulted in an ongoing, continuous struggle to find someone who could save their partner; someone or something who would have the answers and indeed be able to provide the miracle cure.

These themes are discussed in more detail below, and are supported by direct quotes taken from the interviewees themselves. Qualitatively, this helps show the reader that the themes are derived from the experience of the participants themselves and are not directed by, nor the creation of, the researcher’s own personal thematic subjectivity.

3.2. Exploration of the themes

3.2.1. In it together

Whether for emotional, financial or obligatory reasons, this theme highlighted how the caregivers, and their partners, were *in it together* when faced with the challenges of MDD. Participants spoke of making the choice to remain with their partners due to a feeling of shared acceptance and a willingness to fight life's challenges together.

> Anna: everyday I redecide if I am going to do this. But it's always my choice…why would I want to give up on a person that deep down is absolutely amazing. We choose each other so we make it work in our own way. He allows me to be the littlest weirdo under the face of the planet...it's unusual, you know, especially in our community, it's unusual to find someone that accepts everything that you are, like, he accepts everything that I am and I'm a little bit crazy sometimes you know. So I choose to accept him, too.

> Natalie: Um, and we have always approached his depression as a team. This illness is not his fault. Yeah, um, and I can't fight it for him but I can absolutely fight with him. And I can, um, I've never blamed him and I've never let him blame himself. He's amazing, he's always been willing to step up and do whatever he can so that we do life as a team. So, because we have that dynamic, it's been easier on me that I imagine it might be for a lot of people. Because we've always tackled life together. We love each other.

Participants also spoke of the expectations they had in terms of being in a marriage or in a long-term, committed adult relationship. Reciprocal care was a key focal point for many, with the participants believing that their partners would do the same for them should the situations be reversed.

> Natalie: I mean, to me, marriage is not something to take lightly and when you commit to someone, yeah, you commit yourself to who they are. And I have the expectation, I think we both do, that if we were in a car crash and I was, say, in a wheelchair or incapacitated in some way, that [he] would love me through that

> and care for me through that and take on the lion's share of the work or whatever. And I know that life isn't always that simple, but I figure that there are times and there are seasons.

Within this same context, the idea of being committed to the health and wellness of each other also emerged as a reason for staying and for facing MDD as a team.

> Sian: he's helped me so much so why would I leave him in his darkest times...If I can help him with his mental state, then he can help me with my physical state...and so I see that he's made the effort, so why would I give up on him. No one else would want to take on my burden…Um, and I think I've decided that this is going to be his life, well our life, because I choose to stay. And because we've gone through that episode, which I think may have been his hardest one yet, I think that the future can't be so bad. With him accepting the mental help, and the medication, I feel like he's made that step to say 'look, I want to get better' and he's doing it for himself and his kid and me. So why would I give up? You don't give up on love.

Fear of leaving one's partner also emerged within this theme in various ways. For one participant whose love, commitment and desire to be needed and to be a life partner was key to their relationship, this fear did not surpass that of living without her spouse/partner.

> Anna: I'm more scared of what I would do if I didn't have [him] to care for. So each time, like, after each episode we go back to dating and we start again. We choose each time to start again. And I guess part of that moment is about trying to decide whether I can do this for the rest of my life. And about whether I can be without him for the rest of my life. Which I don't think I can.

For another, however, this fear was driven by financial, business and child-rearing responsiblities, and the fear of coping if left alone to manage and traverse these. For this participant, being in business together, owning properties together, and having children together kept her and her partner locked in their legal union.

> Sam: I don't feel or act like his wife but I can't leave. We are in it together because of everything, you know, and because of the kids. Like, initially, when he first got diagnosed, I was wandering the streets looking for places to live with my son. But then I realised I couldn't leave because we were in business together. So I felt that I couldn't leave because of that. And we had brought houses together as well. And I now have my…kids. I can't survive as a solo mum without the dividends from all that.

Being *in it together* against the MDD also emerged in the context of how spousal or de facto partners can be perceived by clinicians and mental health specialists and services. Some caregivers felt respected, acknowledged and included; like they were being treated as being a part of their partner's journey, rather than someone standing to the side of it.

> Natalie: our doctor up here is amazing. Like, he's a mental health specialist, so we are very lucky in that the doctor's office that we go to have those specialists here. And I loved when he said he was quite impressed, you know, impressed that we always came together and that we were catching it early this time, you know. Mostly the doctor was talking with him, you know, but she did make reference to me and, um, she was really really good.

Others, in contrast, felt that they were invisible in the treatment process – not *in it together* at all.

> Paul: The doctor didn't even refer to my role, or anything. He never really even looked at me, I suppose. He talked, um he talked a lot about himself actually. And at [my partner]. He spoke at her a lot, you know, like, not with her or with us, just at [my partner]. It was weird."

An important consideration, here, is the manner in which the counsellor disregarded Paul. For this counselor, Paul was regarded as being sufficiently separate from his wife so as to be able to conduct session as if he weren't even there. But, for Paul, he clearly is invested in his relationship in such a way that it isn't a case of her and him, but rather a case of them.

> Nathan: I go but that's to support [my wife]. When we do go to the doctor, I could not be there and nothing would change. [He] never asks me questions, or checks that what she's saying is accurate. Which I get, I suppose, and I do understand that there are trust issues and stuff. But I'm there, all the time, supporting [her] and I feel that that should stand for something. I can care for her, you know, but I can't contribute to her care? You tell me the logic there.

For Nathan, being *in it together* with his partner also felt like being in a tussle of sorts against both the illness itself and the health providers that were trying to assist his wife with it. He stressed his belief that there was a cause to his wife's MDD that the clinicians hadn't yet identified or were perhaps not even trying to identify – something definitive and locked in time that, if correctly identified, could then be cured somehow.

> Nathan: it's not that we don't trust the shrinks and neuro's and stuff, but I'm sure there's something else there, you know. And they just want us to take the pills and do the CBT, you know, but I'm sure there's a real cause to this. I'm sure there's something that we should be able to fix. So we go, you know, but it feels like us against them sometimes. Yeah. Like us two against the world.

3.2.2. Tough love

The second theme to emerge was that of *tough love.* Described by various participants as a strict approach towards behaviour management and relationship boundaries, all were seen to utilise different forms of this apparent coping technique to get through their partner's depressive episodes.

> Anna: I just don't wear it…I just ignore it and do what I'm going to do anyway because, at the end of the day, I can't be responsible for all of that, I just kind of have to get tough love on him. And that's what I've told him. It's tough love.

> Anna: I put some really specific rules and boundaries in place...So I said to him, look, I've seen you go through this stage before, I've been through the stage with you four and a half years ago when you did this, and now the exact same thing...the only difference is this time I'm not leaving. I'm simply moving to the backyard. And I will stay here to support him and to look after him and whatever else, you know, but I said that I can't be with him, physically, if there are going to be more bad days than good.

This idea of not taking on responsibility/not having to continuously suffer the impact of the behaviours that symptoms of MDD can induce in a partner was carried through. One participant spoke of using tough love as a tactic to help encourage her partner to assume and/or at least share responsibility for recognising the onset of his own depressive symptoms and for acknowledging when he requires additional support and potential professional care. She spoke of how this approach towards her partner was more about illness accountability than symptomatic behaviour necessarily.

> Sian: So I said that, this time, he must choose to tell me if [the depression] is going to affect him in some way and it's his responsibility to tell me if he wants help.

Sian also spoke of waiting for her partner to accept that something was wrong with him, and to seek out her support, before she would engage with him in a caregiver capacity. For this participant, this tough approach was a way of enabling him/forcing him to face up to the reality of his own ongoing battle with MDD.

> Sian: once he can accept that and understand it, that then he will feel comfortable enough to ask for help and then that help will work. I'm here but I'm not everything, you know. I still have my life and sometimes he just needs to face up to his.

Anna also spoke about the need to put herself ahead of her partner, on occasion, even if it did not feel like it was the best decision for her partner at the time.

> Anna: so I have to sometimes be selfish to get myself through this...sometimes I have to look at him and say ‘I’m walking away right now. I know you feel like shit, but I’m being selfish and that’s okay’. And I get that he might not understand in the moment, that he will freak out and feel like he’s losing everything...but because we’ve gone through this before, I’ve realised that it’s ok for me to get in the car and go somewhere else even if he’s in the worst of it. It’s okay for me to be tough, to be really selfish, if it’s gonna save us both.

This comment also highlights the concept of engaging in tough love initially so as to help and save both self and partner in the long run. Anna realised that the need to separate herself from her partner – even during some of his toughest moments when he arguably needs her the most – is actually a coping technique that, for her, is essential if she is to remain healthy herself and therefore able to continue supporting her partner effectively in the years to come.

For Sam, the participant whose marriage was no longer based on a foundation of mutual love and care, this tough love approach was necessary in a more formalised manner. She created a list of things that needed to change in order for her to remain present during her partner’s depressive episodes.

> Sam: I put together a list of six things that needed to change in order for me to stay with him during his episodes...like talking to me with respect or not hitting the children [and of] only communicating with him about necessary things when he’s like that. So I don’t give him any insight, anymore, into my emotional life...so what I do is like reflective listening. I don’t tell him anything about how I am even though he desperately wants me to and he wants me to ask him how he is which I won’t do.

For Sam, removing details of her own emotional life from her partner appears to extend beyond being a strategy of tough love and becomes more one of potential emotional harm. It appears that Sam intends to hurt her partner through her use of emotional withdrawing, perhaps looking for sense of control over the situation that otherwise feels too challenging to bear. This is discussed further in the Discussion chapter.

Paul also referred to the use of tough love but, rather than doing so in the context of his partner, he did so in the context of asserting himself firmly with other people who interracted with them (i.e. their family members and close friends) so as to protect himself, his partner and their relationship.

> Paul: So I keep them away from her, you know, if they want to think and say things like that. The girls [her closest friends] are amazing but the rest of them, they like, if they start up then I tell them to bugger off. If they start telling her she might always be sick and stuff then I tell them to mind their own business. I may lose a few friends, and annoy a few family members, but at this point I can’t care. I won’t let them say that, you know, and I’m happy to get tough on them.

This coping method of *tough love* leads quite smoothly on to the third theme that was identified – that of *loss of self.* All the participants spoke of needing to give away something of themselves so as to take on the requirements of caring for a partner stuck within a depressive episode.

3.2.3. Loss of self

Loss of self emerged, during analysis, as the participants’ described needing to drop an aspect of their own personality so as to be able to serve effectively in the role of spousal caregiver. A professionally successful manager at work, one participant spoke of experiencing the loss of her home-based persona which was far more submissive and compliant in nature.

> Anna: the work person ended up being the home person...which became absolutely exhausting for me because I felt like I was managing him and his moods and who he was and what he was meant to be doing. But I wanted to come home and be looked after, you know, because it’s very difficult when you are that way and then you have to come home and sort of be like, right, I guess I have to be the only adult again today.

Dealing with this loss of self led this participant to commit adultery – an act that she was evidently ashamed of.

> Anna: that girl had an affair with another man which is crap and it's dented me as a person...and has left me living in fear of having hope for us. I hate myself for it, you know, because I'm a very, a very loyal person but I did it because I didn't want to lose my marriage. Because you shouldn't lose a marriage over sex.

What this quote also highlights, however, is Anna's need for the affair and its potential role in saving her relationship with her mentally ill partner rather than destroying it. This is discussed further in the Discussion chapter.

The social loss that results from caring for a partner with depression also emerged within this theme.

> Anna: I haven't had one [a social life] for the last couple of years because, in his last [episode], every time I went out he guilt tripped me. He made me feel awful for leaving him and leaving the house and he would message me constantly saying he needed me with him at home.

Linked to this concept, the idea of fearing loss of control was also implicated within the context of losing social connections, and indeed social and professional opportunities, with one participant noting how this has impacted her willingness to take on new adventures or to seek out different opportunities. She spoke of herself in terms of before and after, implying that the person she was before MDD entered her life may well have embraced more than the person she is today because of it.

> Natalie: I am now so used to things going wrong, badly wrong. So, if life's going well, I am kind of looking ahead to the next thing that could go wrong and trying to prepare myself for that. I know there are some things that we don't do, or that I don't do, but it can be hard to exist in his world and not go under with it. So I control everything, now, to control that.

Within this extract, Natalie has also touched on the negative perspective that MDD can bring to caregivers. The expectation of things going wrong seems to control Natalie's decisions – such that it is not, perhaps, her fear of doing things that is stopping her from taking action but rather her belief that new opportunities will automatically end poorly and hence are not worth engaging in at all. She is attempting to controll the bad by not engaging in activities that could, in fact, prove to be great.

Another participant, Sian, also spoke of the loss of her social life but linked it to the insensitivity (albeit perhaps unintentional) of others. This relates, too, to the theme of *the power of a phrase,* which is explored further below.

> Sian: So we are really careful with other people. We don't need their random thoughts, you know. So we often stay away. Even just me. I choose carefully where I go and with who. Having a social life isn't worth it, sometimes, because of the stupid things that people think and say.

Loss of self was also reflected in terms of one participant's growing need to self-harm so as to try and get her sense of self back and another particiant's active decision to put himself second in his relationship and to pretend that an entire aspect of his personality simply doesn't exist.

> Sian: it got to the point where I was extremely frustrated and started self-harming. Not like, cutting and stuff, but hitting myself repeatedly with my hairbrush. My emotional state was building and I was keeping it suppressed because I had to put it all aside to look after him. I hit myself to feel something. To feel the part of me that is gone. The pain makes me feel whole. The pain helps me come back.

> Nathan: and I tend to, most of the time I just put myself second, put myself to the side and I just look after her. And when she's better, then maybe we can talk about what's potentially wrong with me. I just pretend, when she's like this, that that part of me is fine. Like that part of me isn't even there.

Paul, too, made references to the loss of his own mind or his own mental stability. He spoke of how his partner's response to her own illness is breaking his heart, speaking to a different form of loss but one of loss all the same.

> Paul: So she decided that the homeopathic stuff was making her blind, which led to me chucking a haffy. Maybe that's the first sign of me cracking up? I told her that I was only trying to help her but have hidden them away for now while she is not really with us. She is breaking my heart, and not really getting much better yet, but I have faith. I may be losing my own mind right alongside her, but at least I still have faith.

Sam spoke of how she has both physically and aesthetically let go of herself so as to be able to cope with her partner's mental illness. She spoke of her intensive weight gain and her struggles with housekeeping and how these were a significant trigger for them both.

> Sam: I got fatter and messier, which seemed to just make him sadder and angrier. So I got sadder too. And fatter and messier. And I wasn't always like that. I wasn't always sad and messy. It's like I just lost the ability to care about it, you know.

The circularity of Sam's antecedents, behaviours and consequences (Sam gains weight, her partner gets sad, she gets sad, she gains more weight) was also reflected in the next theme that emerged from the analysis – that of *facing death*. For some of the participants, facing the loss of their own partner by suicide led to their being concerned of their own potential aptitude towards the same act which, in turn, decreased their care capacity for their partner and increased their partner's likelihood (in the caregiver's minds, at least) of succumbing to this very form of loss of life. This is explored in more detail below.

3.2.4. Facing death

Facing death presented itself in a variety of ways throughout the dataset. All of the caregivers had experiences in which they believed their partners were seriously at risk of taking their own lives and each spoke, in some manner, of their desire not to let them become another suicide statistic. Their partners' potential death by suicide was never far from their thoughts, particularly during a depressive episode.

> Sian: Because he, he was refusing eating. And also, so at one point, when we were all outside, he found an old [knife] hiding in the garage. And so he started sharpening it up and painting it and stuff. Making a handle. And then he started talking about killing zombies and stuff with it. Which I felt was his way of saying, 'look, I've got a weapon now so if anything else bad happens, I'm going to hurt myself.' I got really scared of losing him like that. And at one stage, he was like, I want to take this knife and just get drunk. I just want to drink a whole bottle of Jim Beam and see where I end up.

> Paul: So I found the pills, lots of them, and realised she'd been collecting them. Yeah, really tough. So we had some old one's from before that she had but also some of the new one's. And she had them in the bedside drawer, you know, right there, like not even that well hidden. And so when I approached her about them, she just got really sad, you know. She said my life would be better. But I told her it wouldn't, you know. I got angry and threw the pills in the toilet and I told her she wasn't allowed to try it again. I said I couldn't handle it. So now I count them [her pills] every day.

For some, their partner's consideration of suicide resulted in intense anger.

> Sam: you can't, you can't! What about your children!? How can you be so blind? And how can you not care? You can't do that. You can't put us through all that!

For others, the reality of their situation led to the proactive development of precautionary methods alongside a completely new way of living. Natalie, for example, spoke of coming to terms with the fact that a suicide plan was going to be an essential, and permanent part of her ongoing relationship with her husband.

> Natalie: Even now, I prepare myself before going inside the house, always leaving the kids in the car so I can check that he hasn't killed himself. Because, like, it can happen very fast. And I just, he has always promised he wouldn't but I also know his illness and that it's, it takes a really strong person to fight it. So yeah...the plan keeps us safe. And the plan keeps him safe. During an episode, if I have to leave him, like if I absolutely have to, I'll say, like, to him I'll say 'please don't die out here. We've gone through too much. The kids have gone through too much'.

Both of these comments speak to the importance of children in the context of spousal caregiving for a partner with MDD, and the additional strain that this can place on caregivers particularly during a partner's depressive episode. Not only are these caregivers required to look after their own health and wellness alongside that of their partner's, but they are also responsible for caring for their children – largely alone when their partners are in an episode. The implications for children in terms of a parent committing suicide are hidden within these comments but are there, never the less, and it is clear that it is the caregivers who shoulder the burden of what an act like this could potentially do to a child should their parent take their own life in response to their MDD.

Natalie also spoke of the conversational way in which she and her partner have come to discuss suicide, and their associated safety plan, and of how important this skill is in terms of coping with a partner with MDD.

> Natalie: Like, I'm really proud of us. We have these discussions and like we're quite, quite comfortable talking about it. So I'll be like, okay, well, if you were going to do it, what method would you use? What would be your most likely trigger? How can I help stop that from happening? You know, like those conversations happen and I think they are really important to have. And it was such a good thing for our doctor to recommend to us to make a safety plan. I'm

> not sure if everyone gets told that. But they should, like, everyone should be told that you aren't immune to suicide. It's not saying anything bad about you to just make a plan.

Facing the possibility of their own death, by suicide, also emerged as a very real reality for two of the six participants. Natalie spoke of struggling to give herself permission to deal with the emotions that her partner's episodes have evoked in her over the years due to a fear of what that might evoke in herself in terms of her own self-inflicted loss of life.

> Natalie: I've had counselling, but it is very hard to give myself permission to do it all. Like, I feel like I have to take it in very small steps. Because otherwise, yeah, it could, it could take six months or, worse, it could really sink me, you know. There's that feeling of, like, I need to keep myself healthy by not facing it all. Because those emotions, if I really faced them, I'd be the one who could really end it all, you know. I'd be the one who might need a safety plan.

And Paul spoke of his own thoughts around taking his own life earlier on in his relationship and his very real fear that his partner's depression, and his experience living alongside it in the caregiver role, could send him spiraling back to that place of hopelessness.

> Paul: So I tried to take my own life, like, when I was a bit younger. So I understand it, you know. I know how it feels to get there. And I see myself, sometimes, in her face, you know. I see that person I was feeling like that and it scares the shit out of me. You know, I've tried it before. This [her depression], it could make me try again, you know. I suppose."

This theme of facing death also introduced a potential battle that caregivers and co-parents of partners with MDD face in terms of saving their partners physically versus protecting them legally. For example, Sian spoke of choosing not to call an ambulance or emergency mental healthline in the face of suicide because of her fear of the legal repercussions.

> Sian: And it got to the point where he was saying again that he didn't want to be here anymore but I wasn't gonna call the ambulance because we were due to have [his son] the next day and his ex would freak out and go to the courts.So I knew that calling the ambulance would affect his relationship with his son. And he always says he might as well be dead if he can't see [him]. And he then grabbed, so he grabbed his dressing gown cord and wrapped it around his neck and pulled as hard as he could. So I punched him to make him stop because, obviously, I was scared. Scared he wanted to die. But I'd already decided no ambulance. So I decided I'd only ever call the ambulance if he did actually die, otherwise [his ex-partner] would make sure he lost his kid.

The challenges brought on by suicide, by parenting and by the medical and legal constraints that are placed upon spouses in various scenarios are evident throughout the research, but particularily within this theme. Emerging from analysis of the data, *the power of a phrase* or proverb also became evident as did the role that clinicians and society members in general play in supporting caregivers by choosing – carefully – what is said, how it's said and indeed when it's said.

3.2.5. The power of a phrase

The participants all spoke of the challenging impact that their own use of - and indeed other's use of - various social phrases/proverbs has had, and continues to have, as they traverse the journey that is caring for and living alongside a partner with MDD.

> Sian: So, like, because my parents are quite, like, old school and because his parents and most of his mates, like, they sometimes think he's just putting it on for attention and stuff, so like we just don't really go to any of them for support. Like, there's nothing worse than asking for help and having it thrown in your face, you know, like thrown back at you with 'it's all good, it'll be sweet'. Like, we are in a place of crisis, then, and we can't take that on too. You know? People don't know what this is. And they can't actually know that it will be ok. It might really not be ok, you know.

> Sam: always make sure we don't just talk to any old person because, depending on who they are, they can always have their own stupid judgements. People don't like to talk about problems that might last forever. They like life to be 'sweet as', you know, so they expect or hope or something him to just snap out of it. And sooner rather than later, you know. It's all 'she'll be right' in this place [New Zealand].

During analysis, the impact of common relationship phrases such as "all you need is love" and "love conquers all" also emerged. Here, participants felt (initially at least) that their love would/should be enough to save their partner. Some spoke of trying to create happiness for their partners through gift giving whilst others thought their power as a loving partner alone would be cure enough.

> Nathan: I thought I would be able to help [her] and just look after [her] and love her like always to make her better.

> Sam: I thought I would be able to fix him. Because I was thinking I'm his love, his other half. And so I thought I should have been able to fix him.

> Sian: I knew he had some mental issues going on. And me being in social work at the time, I thought I could help. I mean, I knew the theory and that we loved each other. I thought that love should be enough.

For three of the participants, being confronted with religious beliefs alongside their caregiver role has also been a life changing experience. Natalie continues to struggle with the religious beliefs that her faith "threw at them both" in response to her partners' depression.

> Natalie: Just pray and it will be fine. The Lord only challenges you with that which you can overcome. All of those. Still even! But, for us, it turned out that this wasn't necessarily true. And we struggled with that. I learned pretty early on that we couldn't fix him with faith. And faith couldn't save him from this. I

> learned that I can be alongside him but there's only so much I can do and unfortunately there’s pretty much nothing my faith can do. That was hard.

Sam, too, has struggled with her own religious beliefs and the more conservative nature of her upbringing. She did speak, however, of her gratitude for her ongoing faith in light of the new direction that her experience with her partner’s depression has led her on spiritually. Both Sam and Natalie feel that, whilst their religious views may have changed in response to living alongside and caring for a depressed partner, these changes have ended up being for the better. They feel they are better people, and stronger in their beliefs than ever before if perhaps not as conservative.

The opposing religious experience was also reflected in the interviews. Nathan reported an increase in his spirituality since the first of his wife’s major depressive episodes, noting how being confronted with Christian phrases such as “faith will move mountains” and “abide with me” had given him an outlet for some of his frustrations and his associated confusion.

> Nathan: If [the depression] is from the Lord, then there is a greater plan. So who am I to challenge it. I’ll do my best, and so will she, and that’s all God ever asks of us.

Religion, for Nathan, has reduced the degree of accountability and responsibility that he suggested he might otherwise have felt for the existence of the depression itself.

> Nathan: and this makes me feel better. This depression is with us for a reason, and that reason is bigger than we are. It can’t be my fault, or [hers], given that it’s from the Lord.

The idea of faith, and of there being a separate ‘entity’ that could save the care recipients from their MDD, was further established in the next theme which is explored below.

3.2.6. Who is going to save us?

The sixth and final theme, the question of *who is going to save us,* depicts the fragility of the caregivers' own mental health and their sense that, if they were to succumb to a mental illness themselves, there would be no one left to save them.

> Anna: If we are both sinking, who is going to save us? So I stay in my own head, you know, I do my best to sort it out in there.

> Anna: it's not always about the sick person…[we] could be the difference if only [we] were really *seen* by the health care providers who assist our ill partners.

This second quote also points to the visibility, or potential lack thereof, that health care providers have around the spouses/life partners of the mentally ill. Anna touched on her belief that, as a caregiver, she holds a power of sorts to really help and assist with her partner's MDD but that this power is currently not being utilised by his professional support team nor in his treatment plan. This, too, is discussed in more detail in the Discussions section.

Natalie also spoke of a 'block' that prevents her from self care and how her main reason for this is to prevent her own breakdown and therefore impact her ability to care for her husband.

> Natalie: And it does feel like I have a block in terms of taking care of myself. I can take care of myself but only so far. But to really get at the underlying issues I'm like, well, if I fall apart then who is going to keep everyone together? If I fall apart, there's no one left to stop him from dying. To stop us from dying.

> Natalie: I am far less likely to seek medical help for myself. I'm not entirely sure why - I think it's just all bound up together. Um, so if I were to feel more depressed, I think I would be less likely to seek help for it. Which is weird because I would recognise it. But I'd also be like, I don't want to do this thing. Yeah, I mean, I test myself on those, like, anxiety and depression tests and I

> do come out highly on both sides, especially anxiety. But I don’t do anything about it. I can’t admit to being sick, you know. Because I’m it, you know.

What Natalie has also identified here is another reason behind her desire not to deal with her own depression. Seeing it first-hand through her caregiving experience appears to have made her fearful or perhaps desperately avoidant of facing up to her own potentially similar condition. It is not only about not having the time/emotional capacity to deal with her own depressive symptoms, but her inherent fear of where the journey can take a person that blocking Natalie from putting her mental health first or facing up to it at all.

Paul was the same, noting how, when struggling mentally in the past, he has tended to fall back on a mantra of dealing with his own emotions later.

> Paul: I will just deal with myself later. Even that counselor said, like, get out before it destroys you, but I just have my mini breakdowns, you know. I have my girl cry and I get over it. And I continue looking after [her]. I mean, there's no point in me being upset about my life, you know. Not with her like that.

From a slightly different perspective, Nathan spoke of being on the journey towards finding someone, or something, that could help his partner heal, or at least developing faith in the idea that someone, somewhere will have the ability to do so.

> Nathan: She is as negative as hell. I will get the girls [her friends] to try to make her do simple things, take her for walks and get her to bake, make tea etc. It is my humble opinion that the psychiatrists do not really have a clue what is wrong with her and they just chuck drugs her way hoping that one of them will work. I am now trying the alternate healing brigade in the desperate hope that one of them will help somehow. At least we have God! It doesn’t feel like any human being is going to be able to save us.

From analysis of this theme, it appears that being saved is a construct that is largely based upon the caregivers’ acceptance of both the longevity, and indeed cause of, their partners' MDD. For those who have come to accept that MDD is an ongoing part of their lives, being saved appears to refer to their own emotional wellbeing and the heavy responsibility they hold in terms of keeping themselves well so that they can, in turn, keep their partners well. For others, like Nathan, being saved is about finding the right person, or spiritual entity, who can take away the MDD. It is about fighting against MDD by searching for the pill or remedy that will eradicate it entirely.

In the following chapter, these findings are discussed in more detail.

4. Discussion

4.1.1. Overview

This research has explored the experience of living alongside, and caring for, a spouse or de facto partner suffering from MDD. The findings presented above are considered in relation to findings from previous studies and are critically discussed below. The significance of this research, recommendations for future research, and limitations of this research are also explored in this chapter.

4.1.2. Findings and previous literature

In considering the findings of this research, multiple perspectives emerged from within each theme, enabled by the use of an interpretive stance and supporting the literature which has already recognised the uniquely complex and dynamic nature of the spousal caregiving relationship (Cash et al., 2019).

The first theme, being *in it together*, identified the intensity of emotion and commitment that encompasses these adult unions emerged. Participants highlighted their social, personal and financial expectations including factors such as choice, commitment, a mutual willingness to care in both sickness and in health, financial bonds, parental responsibilities and duty of care. These factors, or indeed oftentimes a combination of them all, appeared to underpin the participants' decisions to stay in their relationships despite their partner's MDD; decisions that were driven primarily by love and/or a fear of living without their significant other. This finding aligns with the existing literature, which also identified both genuine concern for, and commitment to, a partner as the primary reasons for staying within a spousal caregiving relationship (Cash et al., 2019; Lawn & McMahon, 2013). It also aligned with the findings of Lawn and McMahon (2013) in terms of the importance of choice, specifically, for spousal caregivers: not only the choice to be married or to be in a de facto relationship, but also the associated choice to shoulder the burden, and relish the joy, brought about by these choices. For Lawn and McMahon (2013), this choice was reflected in the concept of caregiver accommodation or the act of navigating carefully between one's own reality (made up of regular daily activities and social interactions) and one's partner's reality (made up of significant emotional pressures and social isolation). Whilst the results of this study do not conflict with this, they do suggest that not all caregivers necessarily have the same level of ability to successfully accommodate their own realities with those of their partner's, the results of which can be detrimental and indeed deadly.

The importance of the clinical approach taken by mental and physical health care practitioners towards couples for whom one partner has a mental illness was also raised within this theme. The contradictory nature of this form of care became evident with some of the research participants feeling included in the care given to their partners whilst others felt left out or placed on the outside looking in. Many participants expressed their view that an adult couple should be treated and perceived as a unit – a 'them' rather than a 'him and a her. This idea is explored in more detail within the final theme of *who is going to save us*? It is important to note, at this point of the critical discussion, that whilst the need to access support for mental illness in New Zealand still surpasses its availability (Mental Health Foundation of New Zealand, 2020), all of the care recipients in this study (i.e. the participants' partners) had accessed professional support of some kind for their mental illness. Therefore, these results can only be explored and critiqued in light of individuals for whom professional care and diagnosis has been obtained. The experience of those caring for a partner who has MDD, but exists without treatment support or even a diagnosis for that matter, is not covered by this study.

Progessing on from why people stay in relationships to how they manage to do so, these research findings also revealed the possibility of using *tough love* as a coping mechanism. The creation of strict boundaries, for example, appeared to give the caregivers some semblance of control over their daily activities and interactions with their partner's.This aligns with the results of Lawn and McMahon's (2013) study in that the caregivers in their research spoke of standing their own ground with their ill partners – fighting verbally against their partner's negative thoughts and establishing firm rules and boundaries around their physical intimacy with them during depressive episodes.

In discussing their experiences, the participants also referred to their use of tough love as an attempt to place accountability and responsibility for MDD back on to the shoulders of their partners. Tough love appeared to be used, in this context and both consciously and perhaps unconsciously, as a barrier of sorts against the types of burden of care already identified in the literature – including, but not limited to, repressed emotions (Pepin & Ross, 2008), depression and anxiety (Watson et al., 2019) and intense anger (Swain, 2018). Tough love also emerged as a coping strategy aimed to support and enable self-care. Partcipants who appeared to be using tough love for this purpose seemed to be actively choosing to be strict and tough in the short term, even if it wasn't deemed to be in their partner's best interests, so as to retain enough strength and courage to cope with their partner's MDD in the long-term. This finding is in accordance with that made by Harris et al. (2006), who determined that caregivers often find themselves having to support their partners in ways that they don't desire but that result in positive outcomes.

Tough love also emerged as a self-care strategy for those who remain in their relationships for reasons other than love and commitment. For Sam- who chose to stay in her relationship because of finances, children, and the implications of being alone - her use of tough love emerged as a strategy of protection, and one that allowed her to establish a sense of space from, and indeed rules for engagement with, her mentally ill partner. In this particular situation, tough love also appeared as a strategy that Sam was using to try and harm her partner emotionally – seemingly to inflict pain upon him in retribution for the pain that he, and his MDD symptomology, was and had inflicted upon her.

The final way that tough love, as a coping strategy, emerged from within this theme was through the concept of control. MDD has been shown, in the literature, to eradicate control from both caregiver – uncharacteristic irritability and loss of energy (Sadock et al., 2015) and intense pessimism and withdrawal (Mehta et al., 2014) - and care recipient – a poor quality of life and marked reduction in psychosocial functioning (Milanovic et al., 2018). Tough love emerged, here, as a means by which caregivers might try to gain back some of these losses. This presented itself both in terms of controlling and stipulating the way that others interact with their ill partner (and indeed themselves) and also in terms of mentally standing up to their experiences of MDD in some way. Throughout the research interviews, the participants all seemed to be making a metaphorical declaration of sorts against the illness, saying ‘I’m still here, I still exist and I still have choice’. Not only in terms of the choice to stay in the relationship, but also in terms of their choice to fight back against the MDD’s symptomology that, through their partner, had become a significant part of their own daily existence.

Spousal caregivers reported experiencing loss, with possibe versions of this emerging within the theme of *loss of self.* The existing literature has already identified that spousal caregivers are likely to experience loss (Lewis, 2015) and in ways that are more intense than for other caregiving types (Appleton et al., 2018). Similarly, for the participants in this research, the caregiving role appears to have led to a loss of self either emotionally and/or physically.

Emotionally, experiencing a partner’s illness (particularly when recurrent episodes of depression had already occurred) was shown to potentially result in the expectation of distaster or the constant anticipation of fateful outcomes. This, in turn, was shown to lead to a loss of belief in the exciting and hopeful nature of new opportunities and a loss of belief in terms of how others might approach, engage with, and indeed relate to the ill person and the couple as a unit. Expecting the worst from situations and individuals alike appears to be a causal factor that could result in social isolation and loss for these mental health caregivers as their experience with MDD teaches them to anticipate negative outcomes and restrict their interactions accordingly. This finding aligns with that of Lawn and McMahon (2013) who determined that a depressive episode in one’s partner could lead to weeks if not months of isolation from others. It was contradictory, however, to those findings identitifed by Quinn et al. (2013), in the context of caring for a stoke survivor, and Berger et al. (2019), in the context of caring for someone with Parkinson’s disease. For the caregivers of partners with these illnesses, social support was identified as being a crucial part of a caregiver’s existence. Rather than pulling away socially, these caregiving demographics proactively moved towards social interactions, seeking sollace from being with others and engaging in a way that allowed them to benefit from human interaction already shown to be crucial for humankind (Berger et al., 2019). The opposite – the loss of social interaction for caregivers of partners with MDD - has instead been shown already in the literature to be a point of great loss for caregivers (Lewis, 2015) and indeed was reflected in the findings of this research. These contradictory findings raise a potentially new caregiving research question around how, and to what extent, a partner's diagnosis – physical versus mental – might impact their own ability or choice to seek out and maintain social connections? As the research of Donnellan et al. (2017) has already shown, caregiver social support does not always facilitate resilience in carers. Perhaps it is a combination of stigma, ignorance, fear, time and the quality of social interactions themselves that stands in the way of mental health caregivers continuing to connect socially with others during the midst of, particularly in this context, a partner's major depressive episode.

For other participants, loss presented itself in terms of physical behaviours. Whilst many of these were perceived to be 'wrong' by the participants (such as being messy, overweight or having an affair), what in fact emerged was the crucial role that these acts were playing in terms of enabling the caregivers to go on doing what was 'right'. Without these physical acts of loss, for example, the findings suggest that the caregivers might not have been able to stay in their relationships which would have resulted in their partners being left alone to battle their MDD in solitude. The literature has already identified the importance of the caregiving role for individuals experiencing mental illness (Donnellan et al., 2017; Dovi et al., 2020; Lawn & McMahon, 2013) hence losing this informal source of care has significantly negative implications for the care recipients themselves, none more so than those noted in the theme *facing death*.

Physical loss in terms of disengaging from self was also reflected in the findings – suggesting that the experience of caring for a spouse with MDD can lead to a loss of sense of self. For some, a physical reminder such as self-harming or self-neglect may be needed to acknowledge that they, the caregiver, continue to exist at all. The need for respite, and a break from the role of caregiver, has been identified within the existing literature alongside the proposition that planned respite may, in fact, protect caregivers from these experiences of intense loss (Quinn et al., 2013). Regardless of why a caregiver requires it, the results of this research suggest that the barriers to caregiver respite are largely consistent across all spousal caregiving demographics – with the opportunity to take time for oneself deemed almost impossible not only due to a lack of time but also due to caregiver feelings of intense guilt and concern for the safety of their partner if left alone, even for a short period of time (Harris et al., 2006; Quinn et al., 2013).

The harsh reality of self-harming or self-neglect became even more evident and real with the fourth theme: *facing death.* Death by suicide emerged as a vital and important consideration for spousal caregivers looking after a partner with MDD not only in the context of the safety of their significant other but also in the context of the safety and wellbeing of their own mental health. A study by the WHO (2019) identified the significant link between suicide and depression and indeed between suicide and those who feel lost and unable to cope in the midst of a personal crisis. Faced with the potential suicide of their partner, some participants appeared to respond in one of two ways: anger or proactive planning. Communication ,also identified as a crucial element of the caregiver/care recipient relationship by Harris et al. (2006), professional guidance and mutual trust between partners appeared to be crucial factors that differentiated between these two responses, and indeed as factors that could help enable couples to put plans in place aimed at preventing this disastrous outcome. The burden of responsibility that having children in a relationship where MDD is present also emerged from the findings, as did the clinical implications of this given the pressures that are experienced by caregivers who are tasked with protecting self, partner and offspring. These must surely be acknowledged formally and clinically - with the proviso of sufficient support for caregivers in this capacity arguably a necessity.

This theme also revealed the struggle that caregivers may be forced to face when dealing with separation and child protection orders in terms of physically saving their partners (i.e. calling an ambulance in response to a suicide attempt) versus legally protecting them (i.e. hiding the severity of a partner's mental illness by not calling an ambulance - even when required - so as to enable them to retain visiting rights with their children). The social, individual, relationship and community factors that emerged from this theme, and indeed this research in general, all align with those that were identified by Stone et al. (2017), highlighting how relevant the consideration of suicide is for individuals within this caregiving demographic. Furthermore, the preventable nature of suicide (Finlayson-Short et al., 2020) via the identification of symptoms early on, the training of non-specialised support workers and the provision of effective and accessible community support (WHO, 2019) is linked closely to this caregiving demographic with the need to respond to these options, and to the requirements placed upon the shoulders of caregivers looking after a spouse with MDD, both clinically urgent and significant.

The power of a phrase was another theme to emerge from the reports of the participants and this related to both socially common phrases and religious proverbs. The findings suggest that both can impact the lives of spousal caregivers positively and negatively but that choice around what is said, when it is said and how it is said is crucial. The harmful use of phrases and proverbs was identified particularly in the context of people who have a seemingly limited understanding of MDD. Participants explained how friends and family used phrases and proverbs (from a place of habit or perhaps hope) in ways that appeared – to the caregivers – to want to reduce the longevity of their caregiving experience of MDD somehow (‘just pray and it will be fine’) or to imply that their experience of their partner’s MDD was somehow exagerated or perhaps even unfounded (‘it’s all good, it’ll be sweet’). These findings are aligned with the existing literature that speaks to disenfranchised caregiving (Lewis, 2015) and stigma in general (Jackson-Best & Edwards, 2018; Smart, 2019). The use of these phrases and proverbs in the context of mental illness, whilst not necessarily intended to create stigma, most likely does so by negating the severe impact of one’s mental illness on their spousal partner or by making caregivers and care recipients alike hesitant to ask for help for something that others dismiss as, for example, curable by prayer alone or manageable by the act of simply getting on with life. Indeed, the experience of the caregivers in Lewis’s (2015) findings, such that messages of support are not heavily prevalent in populations affected by mental illnesses, appears to still occur for a lot of caregivers in this situation.

The sixth and last theme to emerge from the findings was centred around the question of *who is going to save us?* As per the initial theme of being *in it together,* this question (posed in some way by all of the particpants) served to highlight the way in which many perceive adult life partners as being two separate entities - rather than being a single unit – requiring individualistic treatment, support and clinical interventions. Admittedly, formally changing this perception has challenging implications in terms of ethics and informed consent (as examples) but it doesn't remove the fact that the need for this has been expressed by spousal caregivers both within this research and indeed that of many others to date (Berger et al., 2019; Lawn & McMahon, 2013; Lewis, 2015; Logan, 2011 Quinn et al., 2013). This theme also highlights the very real possibility that, for spousal caregivers, dealing with the depression of their significant other may well prevent them from dealing with their own depressive tendencies. This too has clinical implications in terms of support and guidance for the life partners of MDD clients.

Finally, the degree of understanding that caregivers have in terms of depression as an illness and its varying etiological causes also appears, from this research, to directly impact the way in which a caregiver will approach both it – the depression - and the support that their partners will receive in the context of it. The findings here aligned with those of Quinn et al. (2013) who determined that, in the context of spousal caregivers looking after a stroke survivor, the lack of knowledge or provision of information in a timely and effective manner led to increased vulnerability for a demographic already facing a particularly challenging time. A notable difference between caregiving for a stroke survivor and caregiving for someone with MDD, however, is the benefit of time and space more readily available to the stroke caregiver than the MDD caregiver. As Quinn et al. (2013) identified, there is a window of opportunity for stroke caregivers within which support providers can access and provide education around what to expect moving forwards (i.e. the initial period of time in which the stroke patient recovers in hospital). For people who experience MDD, this is not often possible given that many individuals living with MDD develop their symptoms either slowly over time (where the symptoms essentially sneak up on both caregiver and care recipient) or quickly and suddenly, taking away any potential window for learning on the part of the informal caregiver (Harris et al., 2006). Not having this window of time within which to learn about the impending role of caregiving is arguably a challenge for spousal caregivers looking after someone with mental illness and stresses the importance of engaging proactively with these caregivers in the context of their everyday lives so as to effectively inform, educate and support them.

Additionally, those who have come to terms with the recurrent nature of their partner’s illness (Natalie and Sian as examples) appear to have modified their lives, and their behaviours, accordingly. This, in turn, seems to have enhanced their ability to live alongside the illness rather that in constant attack of it (Harris et al., 2006). For others, however, their need to find a reason for the illness and an associated, fast acting cure appear to have resulted in feelings of isolation and to have negatively influenced their experience of support received in this context to date. The importance of accurate psychoeducation is raised in response to this, both in terms of the timeliness of information provided and in terms of its relevance to the unique situation within which each spouse finds themselves to be on the journey that is living alongside MDD. The research findings of Harris et al. (2006) are particularly important in this context, highlighting that access to professionals and self-help resources does not automatically assist with the functional requirements of day to day living but that it can be made more beneficial providing that any strategies chosen or used to assist a client through a depressive episode are consistent and understood by all. This concept aligns with the provision of accurate and timely information deemed necessary by the New Zealand Health and Disability Review in 2014 but also suggests that the Health Commissioner’s (Health and Dissability Commissioner, 2014) advice to mental health services (that they should encourage and promote family participation in treatment and intervention) is only partially occuring within the New Zealand health sector currently. As noted by Lawn and McMahon (2013), simply providing information as a way of trying to increase the knowledge and skills of caregivers is insufficient if looking to truly and positively impact upon their lives. Rather, this research supports their notion that combining a clinical acknowledgement of spousal partnerships alongside the effective and specifically timed provision of caregiver information, skills, and psycho-education support groups (Dovi et al., 2020) is an approach that may well holistically benefit and enhance the experience of all mental health caregivers.

4.1.3. Significance of research

This research is significant specifically because of its qualitative nature, which allows the voices and experiences of the participants to be heard. Much of the research that relates to looking after a spouse with a mental illness, and the limited research that is available in terms of MDD specifically, is quantitative in nature and, whilst highly valuable, does not allow for the subjective experience of humans to be explored or acknowledged. As a result of the findings that have emerged via the use of semi-structured interviews and RTA, this research is therefore highly significant because it contributes additional knowledge to the existing literature pool - both supporting that which has already been identified and, more importantly, introducing new perspectives and possibilities that require further exploration. It also makes suggestions in terms of how to clinically approach, treat and recognise the role of spousal caregivers looking after partners with mental illness and provides a current and up to date resource for other researchers and practitioners alike – providing them with new and reinforced insights into what it is like to live with, and informally care for, a significant other suffering from MDD.

Additionally, and from a New Zealand perspective specifically, this research is also significant given the disasters that have occurred over the last decade. A review of the existing literature has identified the role that significant stressors can, and often do, play in terms of developing major depression. New Zealanders have experienced a multitude of stressors over recent times. The 2010 and 2011 Christchurch earthquakes, the 2010 Pike River Mine disaster, the 2019 Christchurch shootings, the 2019 White Island explosion and - most recently - the COVID-19 pandemic of 2020, have all introduced additional, unprecedented demand and stress on both individuals and the health sector alike, with the true impact of the social and health changes that have occurred - and indeed continue to occur – yet to be fully understood or appreciated. Autio & Rissanen (2017) note how the impact of the work done by family caregivers becomes far more essential in situations similar to these (with financial recession provided as their example) increasing expectations and pressures on family caregivers and their care recipients alike. Given that the rate of depression and MDD continues to rise exponentially both within New Zealand and globally, and given the immense stressors of the last decade within Aotearoa specifically, research in the context of this illness is both immediately relevant and hugely significant.

Further, research in the context of this illness and within the confines of a spousal/de facto relationship is crucial for all adults that intend to commit to lifelong partnerships. Also, a significant by-product of this research demographic is children and, whilst this has not been touched on in terms of the literature review, the implications of having one, or even two, mentally ill parents are dire for their offspring. Understanding this caregiving experience, both qualitatively and quantitatively, is therefore significant for all – caregiver, care recipient and whānau alike.

4.1.4. Recommendations for future research

The findings of this study both support existing research and introduce new perspectives and, from this, further recommendations for research have emerged. One area where future research would be valuable concerns the coping strategies that are employed by caregivers to cope with the pressures of looking after a mentally ill spouse. That of *tough love* was identified as a potential coping strategy for caregivers within this research but it has not gone on to try and determine whether or not the use of this strategy is healthy or beneficial on the part of the caregiver, nor what the effects of tough love may be on the care recipients themselves - both considerations that arguably require attention. Future research may also prove invaluable, in this context, from the perspective of gender differences. From my subjective perspective, it does appear to me that my father has adopted tough love strategies in terms of how others approach my ill mother but not in terms of how he deals with her symptoms (and the impact they have on him) personally. This begs the question as to whether gender may be a factor in terms of the use of this coping style and may well also be worthy of further exploration.

Whilst only two of the six participants raised their own mortality as part of this research, the qualitative approach allows these voices to be heard and enables the researcher to identify their situations as worthy of further consideration. The very real nature of suicide within this particular caregiving role – on the part of both care recipient and caregiver - was identified in the theme of *facing death* and, given the apparent ownership that caregivers seem to take over their partners mortality alongside their own, more concentrated focus and information seeking this area is arguable necessary and extremely pertinent.

Lastly, the question of how, and to what extent, a person's diagnosis (physical versus mental) might affect a caregiver's ability or choice to seek out and maintain social connections was also raised within the discussion chapter. The impact of issues such as gender, social perception of mental versus physical illness and the benefits of social interaction during times of significant crises are all worthy of additional consideration and exploration within this caregiving context.

4.1.5. Research limitations

The fact that this research has taken place during an unprecedented global pandemic is a significant limitation in and of itself. Gaining access to the caregivers of partners with MDD (via flyers and information sheets) was incredibly challenging, for example; more so than it might have been were these individuals still physically interacting with health centres and units. This resulted in recruitment via social media alone which the researcher was attempting to avoid so as not to exclude members of the community. Equally, the true and lasting effects of COVID 19 are yet to be determined given that the world remains in the grips of the pandemic itself. Repeat consideration of these results, and indeed further exploration of them, would be beneficial once a new, post COVID way of life is better established and has become normative within society.

Another limitation of this research is that, whilst open to same sex couples, the participants were all in heterosexual relationships. They were also all European and therefore do not fully reflect the multi-cultural diversity of New Zealand society. Different culturally oriented recruitment methods would be worthy of consideration for future research in this context. Additionally, fewer men than women were interviewed and research with equal numbers may assist, in the future, with a fairer representation of gender-based experiences. Lastly, this research only includes the experiences of caregivers whose partners have managed to access support for their mental health so as to both receive a diagnosis and then receive additional health care for this. It has been shown that need for support is currently not met by access to it, however, and whilst this remains to be the case, so too do the unspoken and unheard experiences of people struggling with MDD, and spousal caregiving, entirely on their own.

5. Conclusion

In 2017, the New Zealand Law Commission determined that most adults (living permanently in Aotearoa) intended to commit to a permanent relationship. Whether formally via marriage or informally via a de facto partnership, a review of the literature, and indeed the findings from this research study, suggest that people make this commitment with the intention of staying together in times of both sickness and in health. Moreso, of the six participants that were involved in this study, only one spoke of remaining committed to their relationship out of financial obligation and need – for all of the others, love and a sense of enduring commitment proved to be the most normative reasons for doing so.

Like many existing studies, this research has identified different types of burden of care that appear to partner the experience of living alongside, and caring for, a spouse/life partner suffering from mental illness; with loss of self, facing death, depression and anxiety emerging as examples. It has also identified, however, shared acceptance, a mutual willingness to tackle life’s challenges together and the unique nature of a couple’s shared committment to one another as reasons to stay in the challenging situations that often typify life alongside a partner with MDD.

In terms of the dichotomy that exists in the literature between positively and negatively experiencing the spousal caregiving role, this research has also identified the potential significance of active decision making in the face of MDD. It suggests, perhaps, that a caregiver’s choice (sometimes made daily) to stay and fight alongside their partner in the face of depression could potentially empower them to see beyond the illness and, perhaps, to experience the relationship and role of caregiver in a more positive light.

Moreover, this research supports the existing literature which suggests that couples should be treated as a unit by both professionals and societies alike rather than as entities approaching the illness separately. It also concurs with suggestions that simply providing information and caregiver skills are likely insufficient in terms of holistically meeting the needs of spousal caregivers (and therefore their partners) and that, rather, treating both partners collectively, and providing them with individually targeted and well timed levels of support, may serve to better protect spousal caregivers and indeed better reflect the very real and vital role that they play in terms of tackling the challenging, debilitating and ongoing mental illness faced by their partners. Planned respites, health and wellness plans, and the clinical acknowledgment of both the short term implications of dealing with depressive episodes alongside the long-term implications of helping a partner battle a potentially recurrent illness, have all also been identified as vital points of consideration for clinical professionals and mental health support teams alike.

Lastly, this research has identified how important specific support for spousal caregivers tasked with simultaneously caring for children is and, moreso, how crucial it is to clinically recogise the potential risk of suicide for both caregiver and care recipient when these two individuals exist in the union of either marriage or de facto partnership and when they are faced by the challenges of the mental illness that is MDD.

6. References

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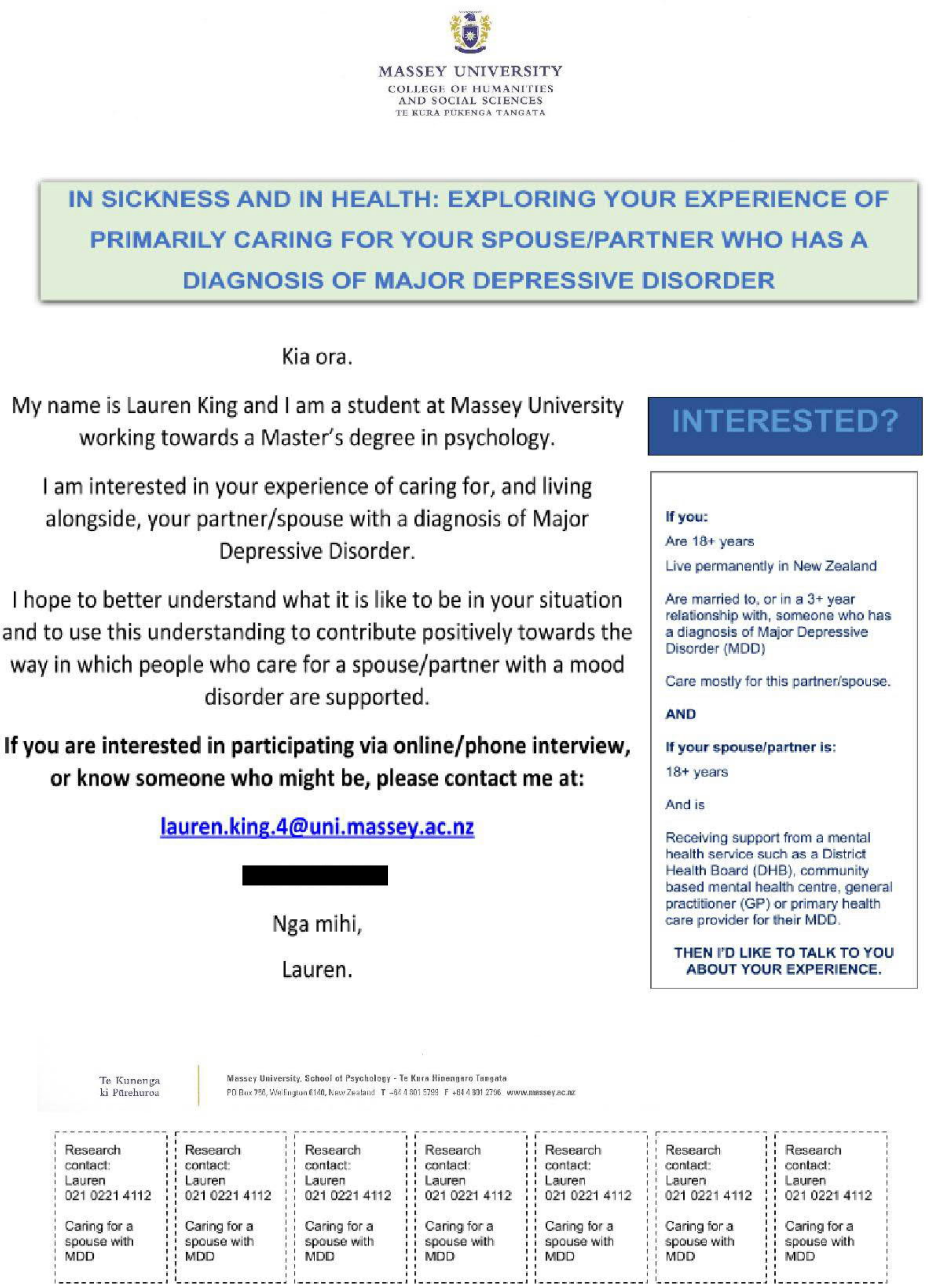
7. Appendices

7.1. Appendix A: Flyer



MASSEY UNIVERSITY
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AND SOCIAL SCIENCES
TE KURA PUKENGA TANGATA

IN SICKNESS AND IN HEALTH: EXPLORING YOUR EXPERIENCE OF PRIMARILY CARING FOR YOUR SPOUSE/PARTNER WHO HAS A DIAGNOSIS OF MAJOR DEPRESSIVE DISORDER

Kia ora.

My name is Lauren King and I am a student at Massey University working towards a Master's degree in psychology.

I am interested in your experience of caring for, and living alongside, your partner/spouse with a diagnosis of Major Depressive Disorder.

I hope to better understand what it is like to be in your situation and to use this understanding to contribute positively towards the way in which people who care for a spouse/partner with a mood disorder are supported.

If you are interested in participating via online/phone interview, or know someone who might be, please contact me at:

lauren.king.4@uni.massey.ac.nz

[redacted]

Nga mihi,

Lauren.

INTERESTED?

If you:

Are 18+ years

Live permanently in New Zealand

Are married to, or in a 3+ year relationship with, someone who has a diagnosis of Major Depressive Disorder (MDD)

Care mostly for this partner/spouse.

AND

If your spouse/partner is:

18+ years

And is

Receiving support from a mental health service such as a District Health Board (DHB), community based mental health centre, general practitioner (GP) or primary health care provider for their MDD.

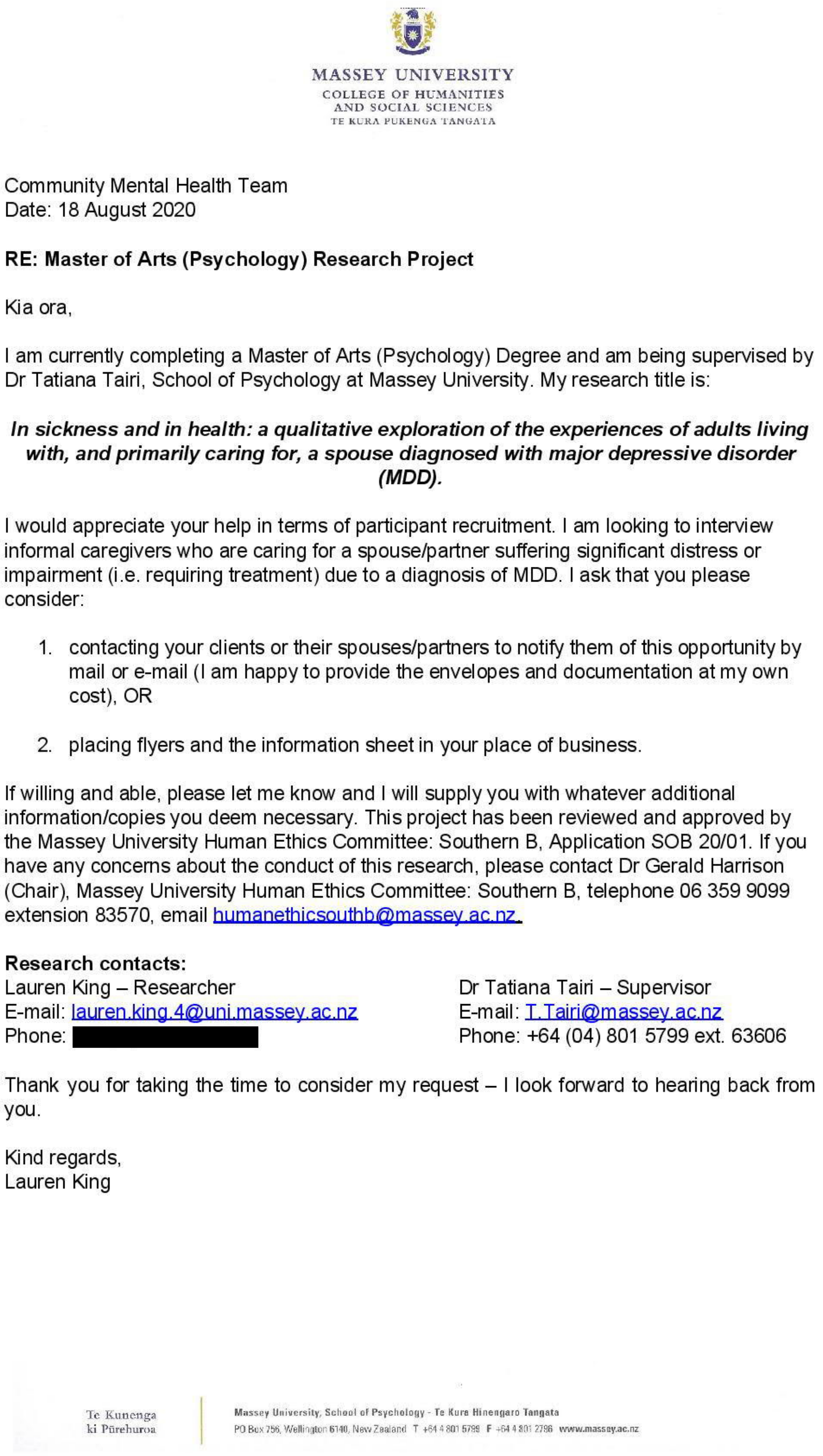
THEN I'D LIKE TO TALK TO YOU ABOUT YOUR EXPERIENCE.

Te Kunenga
ki Pūrehuroa

Massey University, School of Psychology - Te Kura Hinengaro Tangata
PO Box 756, Wellington 6140, New Zealand T +64 4 801 5799 F +64 4 801 2796 www.massey.ac.nz

Research contact: Lauren 021 0221 4112	Research contact: Lauren 021 0221 4112	Research contact: Lauren 021 0221 4112	Research contact: Lauren 021 0221 4112	Research contact: Lauren 021 0221 4112	Research contact: Lauren 021 0221 4112	Research contact: Lauren 021 0221 4112
Caring for a spouse with MDD	Caring for a spouse with MDD	Caring for a spouse with MDD	Caring for a spouse with MDD	Caring for a spouse with MDD	Caring for a spouse with MDD	Caring for a spouse with MDD

7.2. Appendix B: Request for support letter



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TE KURA PUKENGA TANGATA

Community Mental Health Team
Date: 18 August 2020

RE: Master of Arts (Psychology) Research Project

Kia ora,

I am currently completing a Master of Arts (Psychology) Degree and am being supervised by Dr Tatiana Tairi, School of Psychology at Massey University. My research title is:

In sickness and in health: a qualitative exploration of the experiences of adults living with, and primarily caring for, a spouse diagnosed with major depressive disorder (MDD).

I would appreciate your help in terms of participant recruitment. I am looking to interview informal caregivers who are caring for a spouse/partner suffering significant distress or impairment (i.e. requiring treatment) due to a diagnosis of MDD. I ask that you please consider:

1. contacting your clients or their spouses/partners to notify them of this opportunity by mail or e-mail (I am happy to provide the envelopes and documentation at my own cost), OR

2. placing flyers and the information sheet in your place of business.

If willing and able, please let me know and I will supply you with whatever additional information/copies you deem necessary. This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application SOB 20/01. If you have any concerns about the conduct of this research, please contact Dr Gerald Harrison (Chair), Massey University Human Ethics Committee: Southern B, telephone 06 359 9099 extension 83570, email humanethicsouthb@massey.ac.nz.

Research contacts:

Lauren King – Researcher	Dr Tatiana Tairi – Supervisor
E-mail: lauren.king.4@uni.massey.ac.nz	E-mail: T.Tairi@massey.ac.nz
Phone: [redacted]	Phone: +64 (04) 801 5799 ext. 63606

Thank you for taking the time to consider my request – I look forward to hearing back from you.

Kind regards,
Lauren King

Te Kunenga
ki Pūrehuroa

Massey University, School of Psychology - Te Kura Hinengaro Tangata
PO Box 756, Wellington 6140, New Zealand T +64 4 801 5799 F +64 4 801 2796 **www.massey.ac.nz**

7.3. Appendix C: Information sheet

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INFORMATION SHEET

In sickness and in health: a qualitative exploration of the experiences of adults living with, and primarily caring for, a spouse diagnosed with major depressive disorder.

Who is the researcher?
The researcher is Lauren King – a student completing a Master of Arts (Psychology) Degree at Massey University. This project is being supervised by Dr Tatiana Tairi, School of Psychology at Massey University.

What is the research about?
The research will explore the experiences of caregivers who informally care for, and live alongside, a de facto partner/spouse with a formal diagnosis of Major Depressive Disorder (MDD). The researcher hopes to contribute knowledge in this context of human experience as it has not been well researched and there is a gap in the literature that needs to be addressed.

Who can participate?
Participants must be:

1. 18 years or older;
2. living permanently in New Zealand;
3. married to, or in a de facto* relationship with, a partner who has a formal diagnosis of Major Depressive Disorder (under DSM-5 classification criteria); and
4. must be the primary carer of their de facto partner/spouse.

The de facto partner/spouse of the participant must be:

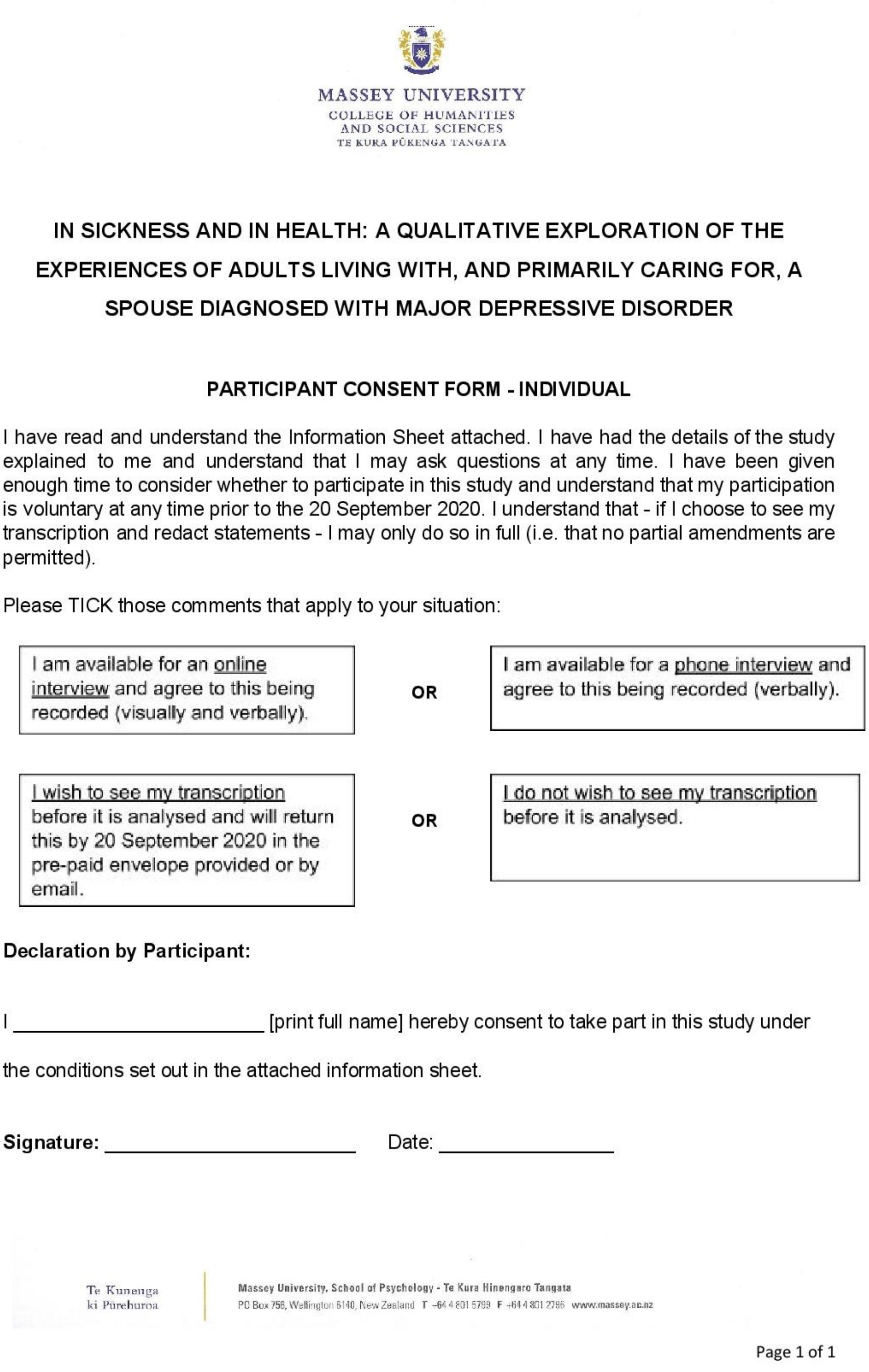
1. 18 years or older, and
2. actively receiving support from a mental health service (for example a District Health Board (DHB), community based mental health centre, general practitioner (GP) or primary health care provider).

What will happen in the study?
Informed consent:
Potential participants will contact the researcher by phone or email. After confirming their suitability and their understanding of the study process, the researcher will send participants (by email or post) this information sheet and a consent form (alongside a postage paid return envelope if required). Participants will be asked to consider their consent carefully – returning the signed form within 5 working days. Written consent must be finalised before the interview - verbal consent will be confirmed at the start of the interview.

The interview:
A mutually suitable time will be determined (no more than an hour). If participants have access to the internet – and a suitable electronic device – the interview will take place online via private meeting portal (www.zoom.us). Participants will receive an e-mail invite for the time agreed. Participant's should click on the text "Join Zoom Meeting" and will be directed through to the online meeting room where the researcher will be waiting at the agreed time. If participants do not have internet/device access, the researcher will arrange to phone the participant on a New Zealand phone number of the participant's choice.

Recording, use and safety of information:
Interviews will be recorded verbally and, if online, visually and will be transcribed by the researcher. Findings will be presented to the Psychology Department at Massey University for assessment and participants will receive a copy of the results in poster form. Please note that this research may go on to be published in a psychological journal. All recordings will be deleted post transcription. In the interim, recordings will be stored on the network disk space allocated to schools and individuals by Massey University for critical research data. No recordings will be stored on the app's themselves for security

7.4. Appendix D: Consent form



MASSEY UNIVERSITY
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IN SICKNESS AND IN HEALTH: A QUALITATIVE EXPLORATION OF THE EXPERIENCES OF ADULTS LIVING WITH, AND PRIMARILY CARING FOR, A SPOUSE DIAGNOSED WITH MAJOR DEPRESSIVE DISORDER

PARTICIPANT CONSENT FORM - INDIVIDUAL

I have read and understand the Information Sheet attached. I have had the details of the study explained to me and understand that I may ask questions at any time. I have been given enough time to consider whether to participate in this study and understand that my participation is voluntary at any time prior to the 20 September 2020. I understand that - if I choose to see my transcription and redact statements - I may only do so in full (i.e. that no partial amendments are permitted).

Please TICK those comments that apply to your situation:

I am available for an online interview and agree to this being recorded (visually and verbally).	**OR**	I am available for a phone interview and agree to this being recorded (verbally).
I wish to see my transcription before it is analysed and will return this by 20 September 2020 in the pre-paid envelope provided or by email.	**OR**	I do not wish to see my transcription before it is analysed.

Declaration by Participant:

I _______________________ [print full name] hereby consent to take part in this study under the conditions set out in the attached information sheet.

Signature: _______________________ Date: ________________

Te Kunenga
ki Pūrehuroa

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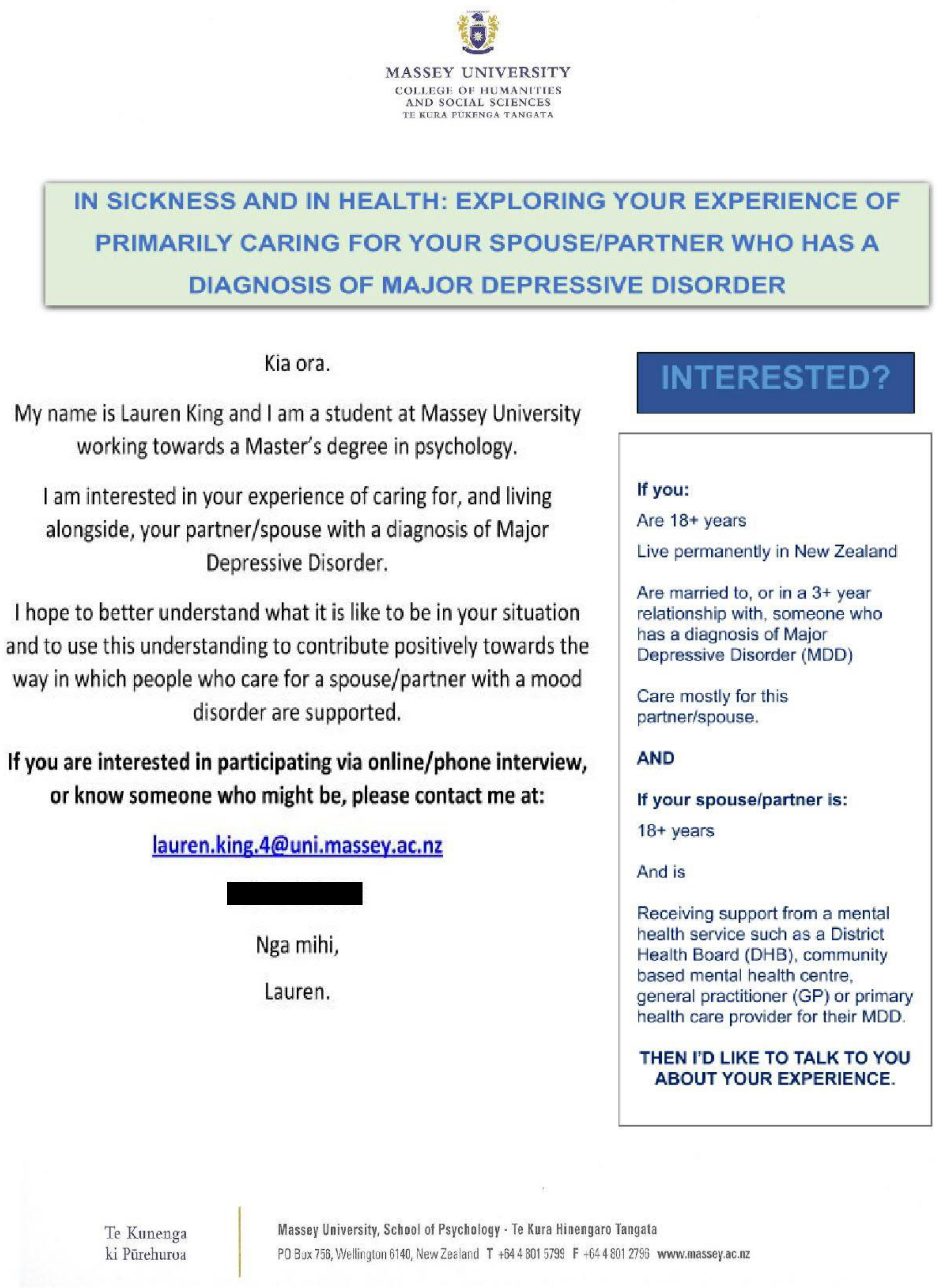
7.5. Appendix E: Electronic flyer



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IN SICKNESS AND IN HEALTH: EXPLORING YOUR EXPERIENCE OF PRIMARILY CARING FOR YOUR SPOUSE/PARTNER WHO HAS A DIAGNOSIS OF MAJOR DEPRESSIVE DISORDER

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I am interested in your experience of caring for, and living alongside, your partner/spouse with a diagnosis of Major Depressive Disorder.

I hope to better understand what it is like to be in your situation and to use this understanding to contribute positively towards the way in which people who care for a spouse/partner with a mood disorder are supported.

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lauren.king.4@uni.massey.ac.nz

[redacted]

Nga mihi,

Lauren.

INTERESTED?

If you:

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Care mostly for this partner/spouse.

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7.6. Appendix F: Final interview schedule

Opening contextual questions:

1. How did you and your partner meet?
2. How long have you and your partner been a couple?
3. Do you have any children or grandchildren?
4. Does anyone else reside with you and your partner at home?
5. If you are in paid employment currently, what is your occupation?
    1. Prompt: what are your work hours?
    2. Prompt: do you work from home whilst your partner is there too?

Exploratory questions:

1. Did your partner have depression when you first met him?
    a. Prompt: if so, how long beforehand did he suffer?
    b. Prompt: if not, when did it first become really apparent?
2. How does the depression affect your partner (i.e. symptoms)?
3. How does depression affect you?
    a. Prompt: Are you equipped to deal with depression and it's many symptoms?
4. What was your relationship like before your partner became depressed?
5. What was your reaction to the diagnosis of Major Depressive Disorder?
    a. Prompt: how did the diagnosis make you feel?
    b. Prompt: who diagnosed your partner?
    c. Prompt: what did receiving a diagnosis mean to you?
    d. Prompt: What was your journey like in terms of getting the right kind of support?
6. Do you think of yourself as an informal carer?
7. How do you care for your partner in relation to their depression?
    a. Prompt: what does a normal day look like for you?
    b. Prompt: how has this affected your relationship with other family members/friend?
8. Would the way that youo care for your partner be different, do you think, if he/she weren't ill?
    a. Prompt: (if married) is this what you envisioned when you committed to the concept of 'in sickness and in health'
9. If the depression didn't exist, what might you do differently as a couple and as an individual?
10. If you could talk directly to the depression, what might you say to it?

Concluding questions:

1. Do you have any advice for others going through a similar situation with their spouse/partner?
2. Is there anything else you would like to add?