

**An Examination of Predictors of Mental Health, Efficacy and Dissemination of a Group  
Education Program for Carers of People with Depression**

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## THESIS ABSTRACT

Depression affects one million Australians every year and family and friends (“carers”) provide the majority of day-to-day practical and emotional support to people in the community experiencing depression. Carers of people with depression face many specific challenges and are consistently shown to have much higher rates of mental ill-health than the general population. There is an emerging evidence base about the potential benefits of group education programs for carers of people with mental illness; however, there are only a few interventions that have been developed specifically for carers of people with depression that are also delivered independently of the treatment for the person being supported.

The purpose of this program of research was to examine the mental health of Australian carers of people with depression and to investigate the efficacy of a specific carer intervention and the factors that affected the dissemination of this intervention. Three studies were conducted. In the first study, linear regression was used to examine the predictors of mental health in self-identified Australian carers of people with depression. The second study investigated the efficacy of the nationally disseminated *Partners in Depression* program, a group education course for carers of people with depression. In the third study, multinomial logistic regression was used to investigate individual, service and macro level predictors of delivery of the *Partners in Depression* program during the national dissemination period.

Taken together, the findings from this program of research demonstrate the vulnerability of Australian carers of people with depression to mental ill-health, the potential benefits offered by a group education program developed specifically to address the information and support needs of this target group, and the barriers to dissemination of such an intervention in Australia. Having family and carer inclusive approaches embedded into routine mental health care would increase the capacity of the health system to respond to carer

needs and strengthen the resilience and recovery of all of people whose lives have been affected by depression.

## Declaration

I certify that the work in this thesis entitled “An Examination of Predictors of Mental Health, Efficacy and Dissemination of a Group Education Program for Carers of People with Depression” has not previously been submitted for a degree, nor has it been submitted as part of requirements for a degree to any other university or institution other than Macquarie University.

I certify that this thesis is an original piece of research and that it has been written by me. For each primary study, I was responsible for the formulation of the research questions, ethics application, study and project management, data preparation, statistical analysis and preparation of the papers. Dr Carolyn Schniering supervised the writing of each paper.

All of the research (excepting the Appendix study) was conducted while I was employed as Program Manager with Hunter Institute of Mental Health, where I was responsible for the national dissemination of the *Partners in Depression* program. Study two and study three utilise some of the same data sources used by the independent evaluator (Dr Deanna Pagnini) for the *Partners in Depression* national dissemination evaluation. My thesis significantly builds on the work completed by Dr Deanna Pagnini by utilising additional data sources, completing more complex and detailed statistical analyses, and through the use of specific theoretical models to guide the research questions. Dr Pagnini’s evaluation report is available at [www.partnersindepression.com.au](http://www.partnersindepression.com.au).

Early versions of the three manuscripts in this thesis were provided to *beyondblue* in a summary report format as part of a funding agreement. Short versions of the summary reports are available online at [www.partnersindepression.com.au](http://www.partnersindepression.com.au). I certify that I was the primary author of these reports and summaries.

I certify that all information sources and literature used are credited in the thesis.

The conduct of this research was approved by the Hunter New England Human Research Ethics Committee (approval numbers HNEREC: 11/04/20/5.05 and 09/12/16/5.10).

Signed: ..... Date: .....

Katie McGill

## Acknowledgements

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I would also like to acknowledge the financial support of *beyondblue*: the national depression and anxiety initiative. *beyondblue* co-funded the development and testing of the *Partners in Depression* pilot evaluation, the writing of six reports about how to best support carers of people with depression, and a televised promotion strategy for the national dissemination.

Numerous staff from Hunter Institute of Mental Health supported the national dissemination of the *Partners in Depression* program and these studies. The studies and the program outcomes are due to the team and would not have been possible without the combined effort. Thank you.

Dr Frances Kay-Lambkin oversaw the development and testing of the pilot of the *Partners in Depression* program. Thank you to Frances for her ongoing support of the program and her willingness to allow me to progress the write-up of the pilot program.

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Finally, thank you to my friends and especially my family for your unconditional acceptance of my many absences, crankinesses and tiredness. I can only hope I am a better

partner, mum, sister, daughter and person from having thought about this stuff for so long. To a summer of laughter and sunshine with those who give my life meaning.

## **Acronyms**

APA	American Psychiatric Association
ABS	Australian Bureau of Statistics
ANOVA	Analysis of variance
ARAFMI	Association for Relatives and Friends of People with Mental Illness
AIHW	Australian Institute of Health and Welfare
DASS	Depression, Anxiety, Stress Scale
HIMH	Hunter Institute of Mental Health
K-10	Kessler 10
MHCA	Mental Health Council of Australia
NAMI	National Alliance on Mental Illness (United States of America)
NCCMH	National Collaborating Centre for Mental Health (United Kingdom)
NHS	National Health Service (United Kingdom)
NMHC	National Mental Health Commission
NMHCCF	National Mental Health Consumer and Carer Forum
PID	Partners in Depression
RANZCP	Royal Australian and New Zealand College of Psychiatrists
WHO	World Health Organisation



## **Foreword**

In this thesis, I explore what affects the mental health and wellbeing of carers of people with depression and how support for this target group can be made available across Australia. The thesis comprises three sections. The first section outlines the relevant research conducted in the area. It provides context for the development of the three studies that are the topics of the manuscripts that make up the second section. The third section of the thesis summarises the key conclusions from the three studies and articulates implications for policy and practice.



## INTRODUCTION

Depression is a common mental illness and many people in the community provide support to a person with depression. Carers are now recognised in legislation and policy for their support role and there is increasing investigation into the impact of the carer role on carers' own mental health and wellbeing. There is also a growing body of evidence regarding the potential recovery benefits for the person being supported when carers are explicitly involved in treatment. However, these issues have been less considered with regard to carers of people with depression. This introduction provides an overview of the key issues relevant to carers of people with depression, including definitions of terms. I summarise the literature relevant to predictors of mental health in carers of people with depression, outline the evidence regarding the effectiveness of interventions for this target group, and provide an overview of the evidence base regarding dissemination of family interventions for people with mental illness. I conclude the introduction with an outline of the aims and nature of the three studies conducted to further explore what could be done to better support carers of people with depression in Australia.

### **Background**

Depression affects one million Australians every year and is a leading cause of morbidity and disability in Australia (ABS, 2008; AIHW, 2007). Depression is characterised by low mood, lack of enjoyment of usual activities, feelings of helplessness and hopelessness, fatigue, low self esteem, changes in sleep and eating patterns and, sometimes, thoughts of suicide. Depression frequently occurs with other physical and mental illness and people with depression have a higher relative risk of dying than people who do not have depression (Clarke & Currie, 2009; Cuijpers & Smit, 2002). Depression is also associated with an increased risk of suicide (Bertolote et al., 2004). Depression can vary considerably in its acuity and severity; however, a diagnosis of major depression indicates that depression is significantly affecting a person's functioning, and this may be apparent in a person's capacity

to complete usual activities, the quality or nature of their intimate relationships, and their participation in the workforce and engagement in social activities (Burcusa & Iacono, 2007). While the vast majority of people with depression recover, depression is a recurrent illness that can affect a person over their lifetime. Half of all people who have experienced one episode of depression go on to experience another episode and, on average, individuals with a history of depression experience five to nine separate depressive episodes (Burcusa & Iacono, 2007). In short, depression affects a person's quality of life, and can do so, over a lifetime.

Depression is one of the most common mental illnesses and the vast majority of people experiencing depression live and function in the general community. However, only a small proportion access treatment (Andrews, Sanderson, Slade, & Issakidis, 2000). This means that the majority of routine practical and emotional support provided to people experiencing depression is provided by family members and friends.

### **Definitions**

"Carer" is the term used in today's literature and Australian policy documents to refer to people who provide personal care, support and assistance to people who are incapacitated due to disability (including mental illness), illness, or frailty from age (*Carer Recognition Act*, 2010). Over 450 000 people receive financial support from the government for their carer responsibilities, however many more people are engaged in a carer role and do not self-identify as a carer (ABS, 2004; McMahon, Hardy, & Carson, 2007). There are many possible reasons for this. The concept of caregiving is embedded within that of other roles, such that it may be unclear as to when a person "becomes" a carer (e.g. when does being a supportive partner turn into being a "carer"?). Furthermore, using the term carer can reduce a person's identity to solely that of a care provider, rather than recognising their other (possibly more dominant) roles or identities e.g. mother, friend, worker (Bland & Foster, 2012). Other people identify that the care or support they provide is not significant enough for them to be identified as a carer, or they are not comfortable with the implied level of responsibility

(Bland & Foster, 2011). However, there are also many people who have simply not heard, or are not aware, of the term. In this thesis, the term carer is used to refer to those family members or friends who provide emotional or practical support, who may or may not self-identify as a carer. The term is not used to refer to those people who provide care or support in a professional sense. Furthermore, the term carer is used interchangeably with family or family member, in recognition of the support role that family members frequently provide.

While “carer” is the term used in this thesis, it is important to acknowledge that the term is not without limitations. It is a concept that is relatively new and its origins are firmly based in descriptions of relationships where the carer engages in a variety of physical and direct caring activities without which the care recipient would be unable to function. For example, showering, dressing or feeding tasks as may be required for a person with significant physical disability; or budgeting, planning and supervision tasks as may be required for a person with dementia. Thus, the term has most commonly been used to describe situations where a carer “does” things “for” a care recipient. This characterisation of the caring role is less accurate for people who care for a person with mental illness where the “caring” tasks in which they engage are more likely to be emotionally supportive in nature (rather than engagement in specific physical activities), episodic rather than long term and can be more subjective (as to what support is required) and dynamic based on the fluctuating nature of symptoms of mental illness. Thus, while the term “carer” has relevance for people who provide support to a person with mental illness, it is a term that has only limited capacity to capture the nuances of the care associated with supporting a person with mental illness and it does not necessarily or intuitively characterise the caring role for people with mental illness. Nevertheless, exploration of what the carer roles looks like for people with mental illness and what supports may assist carers of people with mental illness will serve to extend our understanding of what constitutes “caring” and who should be identified as a “carer”. Thus, the term has been used in this thesis to ensure that the investigations in the studies are relevant

to current policy and service frameworks, while also helping to ensure that the research can be used to contribute to debate and discussion about carers, their rights and the service system available to support them.

### **Policy context**

In Australia, there is increasing recognition of the role that carers play in our society. Over the past five years, federal and state governments have introduced legislation that formally and explicitly outlines and acknowledges the role of carers (e.g. *Carer Recognition Act*, 2010). Policy and service frameworks for mental health services have also been developed about how to deliver carer inclusive support. Early on, Standard 3 of the *National Standards for Mental Health Policy* (1996) was used to outline the importance of consumer and carer participation, including a recommendation for interventions to be developed that were tailored to the needs of carers. In 2004, the *Consumer and Carer Participation Policy* (2004) was released. It outlined a framework of principles for the mental health sector about how to integrate consumer and carer participation into service delivery from the individual treatment level through to policy development. In 2008, the *National Mental Health Policy* (2008) specifically indicated that carers should be involved in the treatment of the person for whom they were caring, as well as be able to access information about ongoing care and be provided with appropriate support to enable them to fulfil their role. In 2011, the Australian Government released the *National Carer Strategy* (2011). This strategy identified six priority areas, including articulating specific policy action designed to improve support for the physical and mental health and wellbeing of carers. In short, providing support to carers, including carers of people with mental illness, is a national priority.

However, recent evaluations of the degree to which policy objectives are being translated into practice have emphasised the ongoing gap between policy and practice. The *Mental Health Carers Report* (MHCA, 2012), based on survey data from over 700 Australian mental health carers, noted that, despite significant investment into, and expansion of, carer-

focused supports, the majority of mental health carers identified difficulties in accessing, or being informed about, appropriate information or services. The *Mental Health Report Card* (NMHC, 2012) highlighted that there were no national, standardised datasets on the nature of care provided to support people or carers. In this report, the National Mental Health Commission also suggested that “a new way of thinking” and a “new way of working” was required for support for carers to be effective (p. 75). In the *Roadmap for National Mental Health Reform* (2012), the Australian Government reiterated commitment to supporting carers, indicating that there was a need to “provide greater support for family members and carers so that they too can live full and rewarding lives” (p. 39). Thus, while there is a consensus regarding the importance of and benefits to be gained from supporting carers, there appears to be significant work to be done in identifying and integrating effective carer support into the existing mental health system.

### **Caregiving models of stress**

Providing care for another person is known to impact on the physical and mental health of the carer, regardless of the illness of the person being supported (e.g. physical or mental illness, disability, frailty due to age). Carers of any sort are consistently identified as having poorer mental and physical health compared to non-caregivers (Pinquart & Sorensen, 2003). This is as true for Australian carers as carers in other countries. For example, 29% of primary carers, in an Australian Bureau of Statistics (2008) survey, reported a change to their overall physical and emotional wellbeing as a result of providing care. In 2007, for the *Australian Unity Wellbeing Index Survey* (Cummins et al., 2007), 3 750 participants were recruited through carer organisations (including people who provided support to people with physical and mental impairments). The researchers found that this carer sample had the lowest collective wellbeing of any population group they had ever studied, with over half of the sample reporting moderate or severe levels of depression. The sample also reported significantly higher levels of chronic pain and injuries than the general population. In another

Australian study, using a sample of carers drawn from people receiving Australian government payments, Edwards and Higgins (2009) found that, even after controlling for demographic characteristics, their carer sample subgroup were still at significantly greater risk of having a mental health problem and lower levels of vitality than participants not in a caregiving role. Taken together, these findings seem to indicate that providing care to a loved one translates into poorer wellbeing for the carer.

Based on their extensive work with carers of people with dementia, Pearlin, Mullan, Semple, and Skaff (1990) described a specific caregiver stress- health model to explain what determines carer functioning and outcomes. They identified four specific domains of importance. These are depicted in Figure 1. These domains include the background and context of stress; the nature of the stressors; the mediators of stress; and the outcomes or manifestation of stress; which together interact and form a “stress process in caregiving” (p. 585, Pearlin et al., 1990). This model of caregiver stress has its foundations in coping and adaptation models of stress (e.g. Coelho, Hamburg & Adams, 1974), and assumes that carer functioning is a natural and normal response to what can be an overwhelming and difficult experience. Details about each domain of the Pearlin et al. (1990) model and the implications for development of interventions that are based on this sort of model are outlined below.

The background and stress context domain refers to characteristics of the carer, such as age, gender, socioeconomic background, genetic factors that may affect the mental and physical health of carers, and carer history of caregiving. These characteristics are generally not modifiable, but can significantly influence each aspect of the stress process. For example, a person’s socioeconomic status is likely to affect their capacity to access helpful social supports, the likelihood of secondary role strains (e.g. economic problems if the family is not well off), and their existing propensity to specific mental or physical health outcomes.



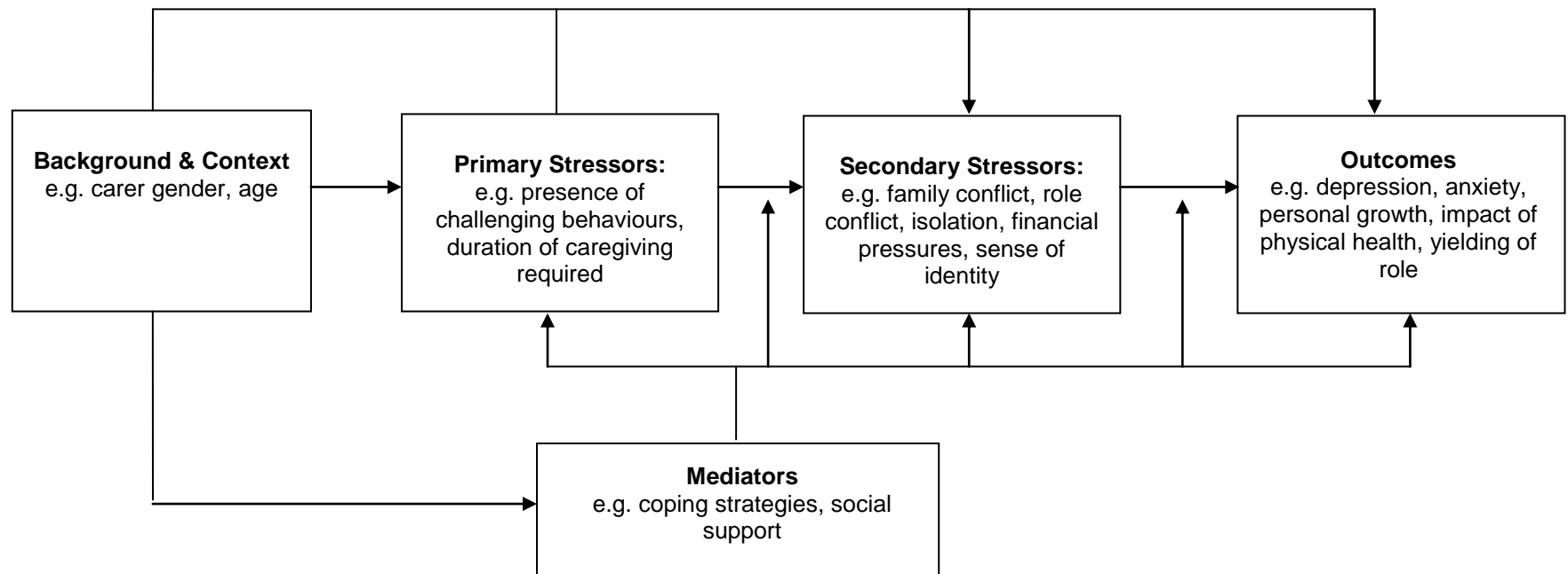


Figure 1: A conceptual model of carers' stress. Adapted from Pearlin, Mullan, Semple, & Skaff (1990)

The second domain is divided into primary and secondary stressors. The primary stressors' category refers to the direct characteristics of the caregiving situation. For example, frequency of challenging behaviours, level of physical care required, and level of vigilance required. Pearlin et al. (1990) also included changes to the relationship between the carer and the person being cared for as a primary stressor characteristic. The secondary stressors' category refers to the indirect outcomes of the need for caregiving. For example, family conflict may occur due to role changes, financial hardship may result from engaging in the carer role, isolation may be experienced as a consequence of carer role, or a carer's self concept (e.g. sense of self esteem and mastery) may be affected by the carer role. Pearlin et al. (1990) identified that primary and secondary stressors independently create tension and their potency can be equal. Thus, while primary stressors frequently give rise to secondary stressors, their impact on stress levels can be equivalent. It is also important to note that some of the secondary stressors (e.g. mastery or self efficacy) are based on a carer's appraisal of their experience of support, which, in themselves, may be protective or detrimental to levels of stress.

The third domain is that of stress mediators. This domain refers primarily to the coping strategies and social support that carers are able to utilise to manage the demands placed on them. While Pearlin et al. (1990) argue that coping strategies and social support alone cannot account entirely for why some people are less affected by equivalent caring challenges, they indicate that stress research has tended to underestimate the power of these variables as mediators. Pearlin et al. described the potential for these two variables to lessen the intensity of primary stressors and possibly buffer the likelihood of secondary stressors. For example, if a carer is able to utilise positive reframing coping strategies to respond to their caring situation, they may be less likely to experience a sense of a loss of mastery or self efficacy.

Finally, Pearlin et al. (1990) described the domain of outcomes or manifestation of stress as being the way in which the above variables come together and affect a carer's physical and mental health and other relevant behaviours (e.g. yielding of the carer role). They noted that the different outcomes (e.g. mental health, physical health) were not interchangeable and should not be considered without consideration of the antecedent stress process. They also suggested that the outcomes themselves were inter-related (e.g. mental health outcomes are likely to appear before physical health outcomes) and that outcomes would be affected by the duration of the caring role.

In summary, the Pearlin et al. (1990) model provides a simple overview of the way in which the carer role may translate into compromised carer mental health. By using a coping and adaptation model it does not assume that family relationships or interactions themselves contribute or account for any "pathology" that underlies the carer's or care recipient's experience of difficulties. Rather, it assumes that family members and carers are competent and motivated and that interventions that are designed to improve knowledge, skills and supports will improve adaptation by increasing the resources available to a carer to cope (Hatfield, 1994). In this way, the Pearlin et al. (1990) model is closely aligned with the family functioning paradigms articulated by Marsh (1992), Lefley (1988), Hatfield (1987) and others in the carer advocacy and NAMI movement. This is also important in that it emphasises and acknowledges that outcomes for carers that occur as a consequence of being in the carer role are important in and of themselves, regardless of the degree to which carer outcomes interact with outcomes for the person they support (or not). Thus, the use of this model provides specific indications as to what sorts of strategies may best support carers and the types of issues that are important to consider specifically with regard to quality of life for carers. The following section uses Pearlin's model to summarise what is known about the factors, and how they relate to, the mental health of carers of people with depression, providing a basis for issues to consider in the development of interventions for this target group.

## **Depression and Its Impact on Family and Friends**

### **Carer outcomes: The mental health of carers of people with depression**

Carers of people with depression are consistently identified as having significantly higher levels and rates of psychological distress compared to control groups and the general population (e.g. Benazon & Coyne, 2000; Idstad, Ask, & Tambs, 2010; Mitchell, Cronkite, & Moos, 1983). Typically, in studies involving carers of people with depression there are high rates of mental ill-health with between 40% and 72% of participants reporting significant depressive and anxious symptoms themselves (e.g. Coyne et al., 1987; Heru & Ryan, 2002; Jeglic et al., 2005; Spangenberg & Theron, 1999). The rates of mental ill-health in these studies suggest that carers of people with depression are themselves vulnerable to experiencing emotional disorders.

While personality and individual variables clearly play a role in how a person is affected by the carer role, the evidence also highlights the specific impact of the carer role on mental health. Carers' experience of depressive and stress symptoms largely alleviate when the person they are supporting recovers (Coyne et al., 1987; Moller-Leimkuhler, 2006). Furthermore, caregiver burden accounts for most of the variance in the prediction of the mental health of carers of people with depression (Coyne et al., 1987; Jeglic et al., 2005). However, the degree to which carer burden determines carer mental health, and what influences the nature of carer burden, is affected by many factors.

### **Background and context factors**

No consistent relationships have been identified between background or contextual factors (e.g. gender, age, socioeconomic status) and the wellbeing or level of carer burden in carers of people with depression. For example, in a study of 260 spouses and relatives of people with depression, van Wijngaarden, Schene, and Koeter (2004) identified no relationship between carer gender or age and the experience of carer burden or stress, although, in a later report, van Wijngaarden et al. (2009) identified that females were over-

represented in the group providing support to people with high support needs. In contrast, in a study of 79 couples where one person had depression, Benazon and Coyne (2000) identified that gender significantly moderated the effect of patient mood on the spouse with wives of depressed men reporting poorer wellbeing and greater burden than husbands of depressed women. Fiorillo et al. (2011) identified a relationship between lower education levels and higher levels of family burden in a study of carers of people with depression. However, taken together, the available evidence does not provide a clear or consistent indication as to the impact of background variables on the mental health of carers of people with depression. It appears likely that if background factors affect carer mental health, their effects will be determined by interaction with other factors (e.g. role expectations), and they are also likely to be influenced by macro factors that affect all community members (e.g. financial hardship is associated with higher risk of depression in the general community; Butterworth, Rodgers, & Windsor, 2007).

### **The nature of stressors faced by carers of people with depression**

#### **Primary stressors**

The nature of the primary stressors faced by carers of people with depression has been well investigated. The type of support provided by carers of people with depression is varied, and includes emotional and practical support. Carers of people with depression may help their loved one manage the illness (e.g. identifying symptoms, working out symptom management strategies, facilitating access to treatment), provide practical or functional support (e.g. take on more household or financial responsibilities), or they may provide ongoing emotional support (e.g. being available to listen, organising mutually enjoyable activities, being with them during crisis periods). In a study involving 260 Dutch carers of people with depression, it was identified that about one-third of the sample had taken over household tasks, one-third of participants reported providing frequent encouragement to the person with depression to complete tasks, about one-fifth of the sample monitored medication compliance, and five

percent of participants reported guarding the person they supported from self-harm or dangerous acts (van Wijngaarden et al., 2004).

The specific type of support required by a person with depression is determined by the acuity of the illness, the relationship between the carer and the person with depression, and the interpersonal resources of the couple. Carers of people with mental illness (including depression) describe specific difficulties in managing the fluctuating nature of the care required (Highet, McNair, Davenport, & Hickie, 2004; Lawn, Walsh, Barbara, Springgay, & Sutton, 2010). Furthermore, while the nature of support provided by carers and family members to people with depression has been thought to be relatively minimal, there is evidence to indicate that, while the type of support provided by carers of people with depression may be different (e.g. more emotional than practical), the consequences of caregiving are similar to that reported by carers of people with other mental illness, such as schizophrenia (e.g. van Winjaarden et al., 2009). This is discussed in more detail later.

In addition to the specific support provided to a person with depression, family members and friends of people with depression describe many difficult emotional experiences. They commonly identify feeling confused and overwhelmed by the depressive symptoms, experiencing worry about stigma and the future, feeling a strong sense of guilt and responsibility for the person they support, and continual concern about the risk of suicide (Ahlstrom, Skarsater, & Danielson, 2009; Highet et al., 2004; Stjernswand & Ostman, 2008; van Winjaarden et al., 2009). They describe a process of adaptation and change as they learn how to manage the impact of the depression on their own life (Harris, Pistrang, & Barker, 2006; Muscroft & Bowl, 2000). Many identify that their relationship with the person with depression changes (Highet et al., 2004; Ostman, Wallsten, & Kjellen, 2005). In the van Wijngaarden et al. (2004) study described above, about half of the carers identified worrying about the health and future of the person they were supporting and about one-third identified feeling burdened and worried about their own future. These sorts of emotional experiences are

similar to the emotional experiences described by carers of people with other types of mental illness (e.g. Bland, 1998; Pagnini, 2005; Lawn et al., 2010).

Furthermore, these difficulties are frequently coupled with carer confusion about how to help. Carers commonly identify not understanding what the cause was of their loved one's problem (and thus blaming themselves), not being included in the treatment process for the person they support (meaning they do not have a sense of what will help), and not knowing what to do in crisis situations (Highet et al., 2004). This sense of confusion compounds the existing stress faced by carers of people with depression.

In summary, the primary stressors that face carers of people with depression are frequently interpersonal and emotional in nature, require adaptation to a changing situation, and can be exacerbated by a lack of knowledge or understanding of what is happening. The relationship between these primary stressors and the mental health of carers of people with depression has been most well investigated with regard to the illness severity of the person being supported. This is important because depression can significantly vary in the degree to which it impacts a person's wellbeing and functioning. In separate studies, Benazon and Coyne (2000) and Jeglic et al. (2005) identified that level of depressive mood in the person with depression significantly predicted level of spouse depression. In another study, the type of care provided to the person with depression (inpatient, acute outpatient, or non-acute outpatient) was associated with different levels of carer worry, tension, and reported need for urging and supervision (van Wijngaarden et al., 2004). If type of professional care is taken as a proxy for severity of illness, the findings from this study also support the suggestion that severity of illness is a determining factor in level of burden and stress on carers, as more intensive support was associated with greater carer consequences. In contrast, there have been less consistent findings about the effects of frequency of contact with the person being supported on carer mental health. Coyne et al. (1987) found that living with the person with depression was associated with greater levels of carer burden, while van Wijngaarden et al.

(2004; 2009) did not identify a relationship between carer mental health and residing with the person with depression, or number of hours of contact with them. This latter finding may be skewed by the confounding variable of type of treatment offered at the time (e.g. inpatient or outpatient), as this would have affected number of hours of contact and residence status at the time of the data collection. In short, however, the most important determinant of carer stress within the primary stressor domain for carers of people with depression is severity of the depressive illness of the person being supported, although other factors may also play a role.

### **Secondary stressors**

Carers of people with depression describe a range of secondary stressors, including experiencing a sense of isolation (Highet et al., 2004), reduction in social activities (Fiorillo et al., 2011), increased financial pressure (Fadden et al. 1987; Fiorillo et al., 2011; van Wijngaarden et al., 2004) and negative family environments (Coiro & Gottesman, 1996). The impact of secondary stressors on carer mental health has been less frequently investigated. In a cross-sectional study of sixteen carers (primarily spouses) of people with depression, Heru and Ryan (2002) identified that participants who reported poor family functioning were also more likely to report depressive symptoms themselves. Mitchell et al. (1983) also found that family environment (as indexed by level of cohesion, expressiveness and conflict) significantly predicted carer depression. While high expressed emotion in the family environment is consistently associated with relapse in people with depression (Butzlaff & Hooley, 1998; DiBenedetti et al., 2012), these studies highlight that the nature of family interactions may also impact carers directly (not just the person with depression). The other types of secondary stressors (e.g. carer isolation, financial strains, loss of identity) have not been investigated in a quantitative way, with regard to how they relate to mental health in carers of people with depression.



**Stress mediators****Coping strategies**

There have been mixed findings about what coping strategies are used by carers of people with depression and the role they play in mitigating carer distress. Two studies using control comparison groups reported contrasting findings. Mitchell et al. (1983) reported that there were no differences in the types of coping strategies used by couples where one person was depressed compared to community control couples, while Gotlib and Whiffen (1989) reported that couples that included one person with depression were more likely to identify using confrontation and escape avoidance compared to control couples (where neither person was depressed). In contrast, there does seem to be a consistent relationship between increased carer demands (e.g. as indicated by depression acuity) and use of a greater range of coping strategies (Gotlib & Whiffen, 1989; van Wijngaarden et al., 2004). There is also some indication that there is a tendency for carers to use more emotion-focused coping strategies when carer demands are greater (Mitchell et al., 1983; van Wijngaarden et al., 2004).

The use of unhelpful coping strategies seems to be related to carer distress, with less helpful or more emotion-focused strategies (e.g. venting, avoidance, day dreaming, self blame) being associated with poorer mental health (Mitchell et al., 1983; Spangenberg & Theron; 1999) and greater carer consequences (van Wijngaarden et al., 2004). While these studies emphasise that the use of more dysfunctional or unhelpful coping strategies may negatively impact on the mental health of carers of people with depression, a study by Moller-Leimkuhler (2006) highlights that the coping strategies used by carers of people with depression change over time (their carer participants reported reduced use of any type of coping strategy at the one year follow-up compared to the initial contact) and may not be directly predictive of carer wellbeing. Thus, while coping strategies clearly play a role in determining the mental health of carers of people with depression, the exact nature of the relationship is unclear.

### **Social support**

The role of social support has been explored in a limited way with regard to its relationship to the mental health of carers of people with depression. Social support can be provided by family, friends, and community groups, as well as by professional organisations or services, and it may refer to practical assistance or emotional support. Only three quantitative studies have reported specifically on perceived social support among carers of people with depression. Moller-Leimkuhler (2006) identified that the perception of social support reduced in their sample of carers of people with mental illness (which included 45/ 69 carers of people with depression) over a twelve month period; and they did not investigate the relationship between perceived social support and carer mental health. The two other relevant studies demonstrated that for carers of people with depression, poorer wellbeing was associated with less perceived social support (van Wijngaarden et al., 2009) and a more negative family environment (Mitchell et al., 1983). Thus, while social support appears to be an important factor in determining the mental health of carers of people with depression, there is only limited evidence from which to draw conclusions.

### **Is caring for a person with depression different to caring for a person with another mental illness?**

It is important to note that many of the stressors and the relationships with carer mental health that are identified with carers of people with depression are similar to the experiences and relationships identified in carers of people with other mental disorders e.g. schizophrenia, bipolar. The majority of carers of people with mental illness report worry about the person, their future and their safety, that they have taken over responsibility for certain tasks, and that they feel burdened by the carer role (van Wijngaarden et al., 2009). The also describe similar dissatisfaction with support services and a desire to know more about how they can help (Hodgson, King & Leggatt, 2002; McAuliffe et al., 2009). Furthermore, carers, regardless of diagnosis, report experiencing a common grief and adaptation process as

they come to terms with the meaning of a diagnosis and work out how to move forward (e.g. Karp & Tanarugsachock, 2000; Pagnini, 2005). However, while there are similarities in their experiences there are also specific differences in the types of difficulties that affect carers of people with depression compared to carers of people with other mental disorders. Carers of people with depression are much more likely to identify interpersonal difficulties, changes in their relationship that cause strain, and reduction in leisure activities compared to carers of people with schizophrenia (Ostman, Wallsten & Kjellan, 2005; van Wijngaarden et al., 2009). It is thought that this is partly due to more carers for people with depression being partners whereas for other mental disorders (e.g. schizophrenia) the carer role is more frequently taken on by parents. This highlights that the type of pre-existing relationship for people who care for a person with depression can raise specific and difficult challenges because of changes in the relationship as a result of the depression.

Community attitudes about depression and schizophrenia are also different and this can affect the type of interpersonal interactions that are associated with various disorders. For example, while schizophrenia is frequently associated with fear that a person may be dangerous or violent, depression is more frequently associated with an attitude that a person who does not “get over it” is being “weak” (Jorm, Christensen & Griffiths, 2005). Thus, while people may avoid individuals with schizophrenia because of fear that they will act irrationally, people affected by depression may be more likely to be subjected to judging and blaming attitudes which may mean that carers of people with depression are faced with increased risk of isolation and disconnection. In addition to the above, in Australia, access to services and service systems are generally determined by the type of diagnosis or nature of mental health problems being experiencing. This means that people with depression are more likely to be guided to access private or non-government services while people experiencing schizophrenia or bipolar are more likely to be linked into the public health system (at least initially) because of the differing acuity and safety issues. This can mean that people with

depression are provided with services that may be less comprehensive or holistic in their approach (e.g. less likely to be provided by a multidisciplinary team) and which may be less accessible (in terms of cost). Taken together, these issues will likely to affect the primary and secondary stressors outlined by Pearlin et al. (1990) as well as affect the mediators of outcomes. Thus, while there are similarities in the carer experience across diagnoses, there are also issues that are disorder specific and this highlights the need for consideration of specific service responses for different groups of carers. It also demonstrates that while there has tended to be an assumption that providing support for a person with depression is less intensive or demanding than there are specific issues that carers of people with depression need to contend with that justify specific investigation.

### **Summary**

In summary, carers of people with depression appear vulnerable to mental ill-health themselves and the nature of the carer situation appears to influence the degree of mental ill-health experienced by a carer, although this may be mitigated (or exacerbated) by the types of coping strategies used, and available social support. Thus far, all of the quantitative studies have been conducted overseas and have recruited carer participants through the person with depression (meaning the person being supported must be in contact with a treatment service). Furthermore, no study has looked at the relationship between all carer burden, coping strategies, social support, and mental health, specifically for a sample of carers of people with depression and while there are similarities in the experience of carers of people with mental illness, the specific issues associated with caring for a person with depression suggest that it is important to design a study that will help to develop a better understanding of what factors predict the mental health of Australian carers of people with depression in order to help inform goals, outcomes, nature of interventions, and supports for this target group.

## **Supporting Carers of People With Depression**

### **Support for carers of people with depression**

While carers of people with depression often experience compromised mental health seemingly largely as a consequence of the carer role, their inclusion in the assessment and treatment process for the person they care for, and the direct support offered to them, appears to be relatively infrequent or ad hoc in nature (Harvey & O'Hanlon, 2013). Themes consistently reported in studies involving carers of people with mental illness include that mental health carers feel disengaged and isolated from the mental health service and their usual social supports (e.g. Highet et al., 2004; McAuliffe et al., 2009), that they feel unacknowledged and unsupported in managing the challenges of the carer role (Buila & Swanke, 2010; Hodgson, King, & Leggatt, 2002; MHCA, 2009), and that many mental health carers (including carers of people with depression) feel that the principle of client confidentiality is used by clinicians as a reason (or excuse) for not engaging in carer inclusive practice (Wynaden & Orb, 2005).

There have been some studies designed to investigate what mental health carers want from mental health service providers. The common themes in carer responses include a desire for acknowledgment, respect, and to be taken seriously by mental health service providers (Doornbos, 2002; NMHCCF, 2004; van de Bovenkamp & Trappenburg, 2010; Walker & Dewar 2001). In a series of 116 workshops conducted around Australia about mental health carers' experience of support, a key theme emerged regarding the importance of knowledge, information, and access to relevant supports and services at the right time (MHCA, 2009). Qualitative studies with Australian carers of people with depression have also highlighted carers' desire to better understand the symptoms, course, and prognosis of depression, and how to provide support effectively (Highet et al., 2004; Highet et al., 2005). Taken together, these studies draw attention to the apparent system gap in what carers want from the mental health service system and the degree to which they are currently involved.

**The importance of carers in the recovery of a person with mental illness**

There is increasing recognition of the importance of family members and carers in the recovery of a person with mental illness. There is also a growing evidence base about the potential recovery benefits (including reduced relapse rates, better functional outcomes and longer maintenance of improvements) to be gained by offering information and support to carers, as part of the treatment for a person with mental illness (Harvey & O'Hanlon, 2013). The evidence is strongest for people experiencing a psychotic disorder, however, similar findings are identified in studies involving people with depression and their families, as well as for other types of mental illness (Falloon, 2003; Hayes, Harvey, & Farhall, 2013). Consequently, it is now recommended that mental health carers are involved in the treatment for people living with mental illness, including those with depression (e.g. APA, 2010; NCCMH, 2010; NHS, 2009; RANZCP, 2010).

While there is limited evidence available about the impact of involving family members and carers in the treatment for people with depression, the role of family is acknowledged as being a significant factor in the recovery of people with depression. Positive changes in overall family functioning during the course of a depressive illness have been associated with faster recovery times, while problematic family functioning has been associated with lower and slower rates of recovery. For example, relapse is higher in families who have non-supportive or extreme communication patterns (Keitner & Miller, 1990; Keitner et al., 1995; Vaughn & Leff, 1976) and the experience of support received from a partner has been found to predict outcomes for people experiencing non-melancholic depression (Hickie & Parker, 1992; Parker & Ritch, 2001).

Only a few studies have directly investigated the role that providing support to carers has on the outcomes for the person with depression. The most well controlled studies show that when carer-focused interventions are provided as an adjunct to standard care, they are associated with a significant reduction in rates of relapse, improved patient attitude to

medication and reduced patient global disability, as well as reductions in reports of personal and family difficulties (Fiorillo et al., 2011; Shimazu et al, 2011; Spencer, Glick, & Haas., 1988; Stam & Cuijpers, 2001). More recently, providing family psychoeducation to family members of people with depression has been shown to be cost-effective if a relapse-free day is valued at \$US20 or more (Shimodera et al., 2012). Furthermore, randomised controlled trials of interventions that specifically involve family members (e.g. marital therapy) report benefits consistent with individual therapies (Barbato & D'Avanzo, 2006). In short, these studies demonstrate the potential benefits that can be gained for the person with depression by offering support to, and involving, carers as part of routine mental health service support.

### **Interventions for carers of people with depression**

Despite the increasing policy emphasis on providing support to carers of people with mental illness, there are only a limited number of studies that specifically investigate the efficacy of interventions with regard to carer outcomes (rather than outcomes for the consumer). To date, in the mental health literature, “carer interventions” have usually been called “family” or “family-based” interventions, as the term carer is a relatively recent addition to the lexicon. However, both terms refer to interventions that specifically seek to engage and support the people who provide the majority of assistance to a person with mental illness (which is most frequently, family members). As outlined by Dausch et al. (2012), there are a range of different types of family interventions including family consultation, family education, and family psychoeducation (including behavioural family therapy, family-focused therapy and multiple family group treatment), in addition to other therapeutic approaches that involve the family (e.g. marital therapy; family therapy). These approaches differ in terms of their target outcomes, theoretical underpinnings, duration, intensity and settings. However, family interventions for people with mental illness (which were usually developed for people living with schizophrenia and their families) share common elements that are endorsed as best practice. These shared features include that the family interventions have a positive and

collaborative approach to working with families and carers, take a holistic approach to treatment, provide family members and carers with information about the disorder and its treatments, and have a behavioural component to them e.g. communication and/ or problem solving skills (Dixon et al., 2001; Harvey, O'Hanlon, & Young, 2012; Hayes et al., 2013; Heru, 2006). The evidence about the effectiveness of family interventions for people with mental illness is strongest for family psychoeducation and interventions of longer duration (e.g. nine months or more); while there is mixed evidence about whether multiple or single family groups are more effective (e.g. McFarlane, Dixon, Lukens, & Lucksted, 2003; Pilling et al., 2002; Rossberg et al., 2010). Furthermore, there is some indication that even short-term family education programs may increase carers' sense of empowerment, knowledge and self care (Dixon et al., 2001). However, it should be noted that this body of evidence has generally been generated with samples of carers of people with severe and persistent mental illness (McFarlane et al., 2003). To date, the majority of carer intervention studies have also investigated the efficacy of programs delivered by treatment facilities (rather than interventions delivered independently from the treatment provided for the person with mental illness), although this is slowly changing as the carer movement grows. For example, a recent study by Dixon et al. (2011) investigated the effectiveness of a peer-taught family-to-family mental illness education program using a randomised waitlist control design. At follow-up, participants randomised to the active intervention reported significantly enhanced emotion-focused coping, reduced distress and improved problem solving. This sort of study highlights the capacity for independently delivered interventions to result in meaningful and important outcomes for family members.

There have been some interventions specifically designed for carers of people with depression and they generally have the same characteristics as outlined above. A number of studies have investigated the acceptability and relevance of brief family education interventions for carers of people with depression. Responses to these programs have usually



been characterised by high levels of attendance and high carer satisfaction ratings. (e.g. Bull et al., 2005; Harter, Kick, & Rave-Schwank, 2002; Jacob, Frank, Kupfer, Comes, & Carpenter, 1987; Sherrill et al., 1997; Stephens, Farhall, Farnan, & Ratcliff, 2011); although one study reported an extremely low uptake of referral for support (6%) even though rates of depression amongst the carers, and satisfaction with the provided written psychoeducational material, was high (Heru, Ryan, & Madrid, 2005). Despite this, carers' responses to information and support interventions have usually been positive, suggesting that there is interest and appreciation from the target group in accessing these sorts of interventions.

Efficacy studies involving carers of people with depression have generally reported positive outcomes. When carer outcomes have been assessed, engagement in carer interventions has usually been associated with reductions in psychological distress (Luciano et al., 2011; Katsuki et al., 2011; Shimazu et al., 2012; Stam & Cuijpers, 2001; Teichman, Bar-El, Shor, & Sirota, 1995) and less consistently, in carer burden (Clarkin et al., 1990; Prisco et al., 2012). Studies that have not identified benefits for carers of people with depression have been limited in capacity to draw firm conclusions by sample size (e.g. Horton- Deutsch, Farran, Choi, & Fogg, 2002: n= 25), or have used non-validated outcome measures (e.g. Bernet et al., 2006: used the Maslach Burnout Inventory, a scale used to measure burnout in occupational groups; Clarkin et al., 1990: used specifically developed questions about family attitudes towards treatment and the patient to assess carer outcomes). Furthermore, findings from a recent Australian study of a peer-led group education program for mental health carers ("*Well Ways*") highlighted the potential importance of targeting programs specifically to address the support needs of different carer groups. Stephens et al. (2011) noted that program benefits were less apparent for carers of people with affective disorders who attended the *Well Ways* program, compared to carers supporting a person with schizophrenia.

With regard to the nature of the interventions described above, all except one of the studies (Teichman et al., 1995) used brief psychoeducational type interventions (ranging from single contacts to interventions of six months duration) as the means of providing support to the carer. The delivery formats included use of written materials (Heru et al., 2005), multifamily group programs (e.g. Jacob et al., 1987; Katsuki et al., 2011; Morgan, Mattney, Barnett, & Richardson, 1997; Sherrill et al., 1997; Shimazu et al., 2011), single family group programs (e.g. Clarkin et al., 1990; Horton- Deutsch et al., 2002; Prisco et al., 2012) and more recently, online support formats (although efficacy has not yet been established for this delivery mode; Stjernsward, 2009). The Stephens et al. (2009; 2011) study used a peer-led group format and two of the studies (Stam & Cuijpers, 2001; Stephen et al., 2011) targeted carers of people with mental illness (not depression specifically). The aims of the interventions varied. Some focused on providing information about depression, its causes and available treatments, while others focused on providing information designed to increase carers' coping and stress management. Only the minority of studies (Fiorillo et al., 2011; Shimazu et al., 2011; Spencer et al., 1988; Stephens et al., 2011) included a follow-up period beyond that of the post program assessment time point.

In summary, brief family education programs are the most well investigated intervention for carers of people with depression and the evidence, to date, suggests that providing support to carers of people with depression is likely to increase the effectiveness of treatment for the person with depression and may also have direct benefits for the carer. The strength of conclusions that can be drawn regarding the efficacy of interventions for carers of people with depression is limited by a lack of outcome data specific to carers and limited use of before-after intervention designs, comparison groups, and adequate follow-up periods. Addressing these issues would assist service providers to decide how best to provide support to carers of people with depression, and which supports are most likely to result in better outcomes.

## **Disseminating a Program for Carers of People with Depression**

### **Dissemination literature**

Thus far, this thesis has focused on what needs to be done to better understand what sorts of supports may be helpful to carers of people with depression. However, once efficacy for an intervention has been established, use in usual treatment and support settings of evidence based interventions can be slow. This is also true for family-based interventions for people with mental illness. Interventions targeting the needs of carers specifically are slowly being developed and tested, and are now recommended as part of best practice; however, their availability in routine practice appears limited (Diamond & Siqueland, 2001; Falloon, 2003; Harvey & O'Hanlon, 2013). There are only a small number of studies investigating frequency of contact between mental health services and family members, and, from the evidence available, it would appear that contact rates are low. For example, an American study using healthcare billing data, identified that 7% of family members of people with schizophrenia had a paid outpatient claim for family therapy, although provision of psychoeducational information to families was thought to be higher (~30%; Dixon et al., 1999). Similar rates have been reported in Europe with between 8- 15% of families of people with schizophrenia offered a family intervention (Magliano et al., 2006). There is little information available specific to the Australian setting. A recent study of 119 mental health and community professionals recruited from across government and non-government agencies suggested that amongst this highly self-selected sample (including participants who had nominated to attend *Partners in Depression* facilitator training), contact with families of people with depression was not routine or consistent (Wirrell, McGill, Kelly, & Bowman, 2014). Similarly, a study of a mental health service in Queensland identified that contact with mental health carers was limited, with about half of the files audited (n=55) having a recorded contact with a family member or carer in the previous three months, and an average of three contacts with a family member during this time period (Lakeman, 2008). Thus, despite the apparent benefits to be

gained from family interventions for people with mental illness (including depression), rates of contact with family members and the availability of family interventions in the community appears limited.

### **Dissemination of mental health carer and family interventions**

There is a growing body of literature examining why family-based interventions<sup>1</sup> are not routinely offered to people with mental illness and those who support them, despite the clear evidence of effectiveness and cost-effectiveness (Dixon et al., 1999; Lucksted, McFarlane, Downing, Dixon, & Adams, 2011; Mihalopoulos, Magnus, Carter, & Vos, 2004). These studies highlight the numerous challenges faced in having carer inclusive practice become usual, rather than innovative, practice. Diffusion of innovations theory suggests that for a health professional to change their clinical practice, they must have heard about the alternative practice, see the benefits of, and believe it to be possible to deliver the alternative practice in their setting, and, consequently, have made a decision to adopt the new behaviour (Rogers, 2003). Ongoing engagement in an alternative practice is usually a function of the degree to which a service provider experiences a good fit of the innovation with their setting, themselves and their clientele (Greenlagh, Robert, MacFarlane, Bate, & Kyriakidiou, 2004). Furthermore, innovations that are compatible with existing philosophies and practices, and are limited in complexity are more likely to be adopted (Greenlagh et al., 2004; Rogers, 2003). Similarly, where there is organisational support, an internal advocate (or “champion”) and available resources, there is a greater likelihood that innovations will be delivered (Backer, Liberman, & Kuehnelt, 1986; Greenlagh et al., 2004).

However, as identified by Fadden (1997), and McFarlane, McNary, Dixon, Hornby, and Climett (2001), the above qualities are rarely representative of the dissemination

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<sup>1</sup> It is important to note that in this section “family intervention” is used to refer to interventions that involve or target carers. It is used to reflect the existing literature and evidence base in this area, however, it is concomitant with the term “carer intervention” previously used (and as discussed earlier).

environment for mental health focused family interventions. Mental health services are rarely characterised by available resources and, on an organisational level, mental health services are frequently wary of ‘taking risks’ (which is needed for an organisation to be ready to trial new practices; Panzano & Roth, 2006). Family and carer mental health interventions are rarely limited in complexity and frequently require a substantial shift from usual practice. Furthermore, benefits are usually long term rather than immediate. Thus, whether or not a new program is delivered in the community will be influenced by the characteristics of individual service providers, the fit of the innovation itself with the providers, the work setting and local target audience, level of organisational interest and support, and the pressure to implement within the broader political landscape. With this in mind, it would seem that the combination of the characteristics of individual service providers, mental health services, and family interventions themselves may contribute to the low level of penetration of family and carer interventions within the mental health service system.

There is some evidence to suggest that it is possible to improve the frequency of delivery of family interventions for carers of people with mental illness. A number of studies have identified increased rates of family interventions for people with schizophrenia after clinicians have attended quality training activities and been provided with good “technical assistance” (e.g. Amenson & Liberman, 2001; Dixon et al., 1999; Farhall et al., 1998; Magliano et al., 2006; McFarlane et al., 2001; Milne, Gorenski, Westerman, Luck, & Keegan, 2000). Quality training is acknowledged as being a necessary component of an effective dissemination process. Quality training provides an orientation to, and demonstration of, the innovation, as well as opportunities for behavioural rehearsal of the skills discussed (Fixsen, Naoom, Blase, Friedman, & Wallace, 2005). Technical assistance refers to coaching or on-the-job support to deliver an intervention. Technical assistance that involves interpersonal contact (particularly face-to-face) and which is collaborative, ongoing, and proactive in nature has been associated with the greatest success in introducing new practices (Wandersman,

Chien, & Katz, 2012). Furthermore, a number of other features associated with success of dissemination of family interventions have been identified through expert consensus and reviews of characteristics of best practice sites. Through these processes, a number of key success features have been identified. This includes the importance of engagement and collaboration with stakeholders (from the strategic level to frontline staff to the intended target audience for the intervention); the importance of ongoing supervision; and the importance of a strong enabling work environment, including the time and space to do family work, appropriate referrals, and the enabling effect of a service champion who has specific interest and motivation to embed family work into the fabric of the service system (Cohen et al., 2008; Fadden & Heelis, 2011; Kelly & Newstead, 2004; Smith & Velleman, 2002).

However, even with these sorts of supports, rates of transfer of the skills to real-world settings are not without problems. In an Australian study of a cognitive behavioural therapy family intervention for people with schizophrenia delivered through community health settings, Kavanagh et al. (1993) found that 69% of the 45 therapist participants reported having delivered three or more sessions of the intervention to at least one family and 80% reported using components of the intervention in routine practice; although the knowledge test completed at the same time raised serious questions as to whether the self-report assessment about what they were delivering actually reflected use of the family intervention components. Furthermore, the average number of families seen by therapists was 1.4, with six therapists having seen 57% of the family participants. In an United Kingdom study of 86 therapists who had received training in Behavioural Family Therapy, 70% reported having used the approach in their work; however, the mean number of families seen was low (1.7) and 8% of the therapist participants had seen 40% of the families (Fadden, 1997).

In an American study comparing delivery of family interventions for people with schizophrenia after exposure to different types of training (didactic or intensive), it was found that three of five of the agencies who were provided with the intensive training had begun to

deliver more family interventions, while no changes were observed for the four agencies who had received the didactic training and support (Dixon et al., 1999). Similar results were reported by Farhall et al. (1998) where mental health teams who had attended more intensive training reported more positive family attitudes and increased contacts with families compared to baseline responses and teams who had attended brief training only. More recently, O'Hanlon et al. (2012) has discussed the Bouverie Centre's experience in disseminating Behavioural Family Therapy in mental health services in Victoria, Australia. Using an intensive support model of an embedded family therapy consultant within the team, O'Hanlon et al. identified that 74% of the therapists trained (n= 27) had delivered the intervention at least once, however, reach remained relatively low with an average of 1.2 families seen per practitioner trained.

Taken together, these studies highlight the potential to increase mental health service rates of family interventions through provision of appropriate training and support, but they also highlight specific and significant difficulties. Magliano et al. (2006) reported a high dissemination rate of 76% of their therapist participants delivering a family intervention of six months or longer to an average of 2.1 families, but there was a high rate of therapist "drop-out". Of the 46 participants originally recruited, only 29 (63%) went on to deliver the entire intervention. Of the 160 therapists trained in the Kavanagh et al. (1988, cited in Kavanagh, 1993) study, only 44 (28%) went on to take part in the treatment trial. Of the 1500 therapists McFarlane trained in the New York Family Support Demonstration Project (McFarlane et al. 1993), 300 reported using the family model at follow-up and of these 100 had engaged in the supervision process (i.e. only 7% of the total number trained).

The barriers identified by clinicians to delivering family interventions within mental health service settings are common across studies and settings. Conflicting demands due to caseload pressures, limited time to see families, and difficulties integrating family interventions into routine work are the most frequently identified problems (Bailey, Burbage,

& Lea, 2003; Dixon et al., 1999; Dixon et al., 2001; Fadden, 1997; Kavanagh et al., 1993; Magliano et al., 2005; Magliano et al., 2006; McFarlane et al., 2001; O'Hanlon et al., 2012). Lack of support from other health professionals and lack of reimbursement or financing concerns have also been identified (Bailey et al., 2003; Dixon et al., 1999; McFarlane et al., 2001). Furthermore, difficulties in identifying and engaging families have been consistently identified by therapists as a barrier to delivering family interventions in Italy, the United States, the United Kingdom and Australia (Bailey et al., 2003; Fadden, 1997; Kavanagh et al., 1993; Magliano et al., 2005; O'Hanlon et al., 2012). These issues are in addition to the effects that attitudes towards carers or a lack of valuing of family collaborative practice may have on professionals' behaviour (Andrew, Farhall, Ong, & Waddell, 2009; Heru & Drury, 2006).

The impact of organisational and service factors on capacity to deliver family interventions for people with mental illness has been highlighted in the few dissemination predictor studies that exist. In a large American study of predictors of agency implementation of family interventions for people with mental illness, McFarlane et al. (2001) found that state (Maine or Illinois) was the most significant predictor variable and that individual service providers could fairly accurately predict whether their service would be able to deliver the intervention or not. The researchers suggested that the differential state implementation rate (93% versus 10%) reflected the different level of agency buy in and consensus building, and they highlighted that the barriers that were identified reflected perceptions rather than actual barriers, as they could clearly be overcome with the right level of commitment. Fadden (1997) found that those who worked in community settings were significantly more likely to deliver a family intervention after training than those who worked in inpatient settings; while those services who had eight or more people trained in the family intervention were also more likely to deliver the intervention than those sites where fewer people were trained. Both Dixon et al. (1999) and McFarlane et al. (2001) identified that the services who rated family interventions as consistent with their philosophy and way of working and who identified



fewer barriers were more likely to deliver family interventions than those services where family interventions were not seen as consistent with existing practices or barriers were rated higher.

Similarly, in two studies of predictors of delivery of the Triple P parenting program, it was identified that program delivery was most likely for those who had experienced only minor or moderate workplace barriers, had seen positive client outcomes after use and were able to consult with other Triple P practitioners (Sanders, Prinz & Shapiro, 2009); or who felt confident in their skills in the delivery of the program (Turner, Nicholson, & Sanders, 2011). Sanders et al. (2009) also identified that low program use was associated with a range of organisational or infrastructure barriers, including lack of flexibility in work times, competing priorities, lack of integration with other work responsibilities, and lack of recognition by colleagues. In summary, these studies highlight that there are many challenges to establishing family interventions as part of routine service provision for people with mental illness and dissemination is more than just about engaging an individual. The workplace or organisational setting may help or hinder an individual who wishes to introduce a new way of doing things and this appears particularly true for penetration of family interventions within the mental health service system.

In short, dissemination of a program requires consideration of multiple issues (at multiple levels) and while there is evidence about characteristics that improve or reduce likelihood of delivery, it is unclear as to which factors are the most significant predictors of implementation. All predictor studies to date have been conducted in the United States. Furthermore, they have had some limitations. The Dixon et al. (1999) study used high-level agency billing data to identify whether an intervention had been offered, rather than tracking individual service providers. The McFarlane et al. (2001) study used individual therapist perceptions of workplace as a predictor, but found the most significant predictor was at the state level; they also investigated what predicted site implementation of family interventions

rather than an individual's program delivery. The Sanders et al. (2009) and Turner et al. (2011) studies highlighted the interaction between individual perceptions and workplace characteristics, but investigated the dissemination of a parenting intervention. Parenting programs are a different type of family intervention and potentially have a different level of attractiveness to service providers and families. Consequently, it is not clear how relevant Sanders et al.'s findings are to dissemination of family interventions for people with mental illness. Thus, there is a need to look at not only macro level predictors (e.g. state), but also the impact of service and individual level characteristics on family intervention implementation.

In Australia, depression is a prevalent mental health problem and prevention of mental ill-health in carers generally is a national priority. However, little is currently known about how to engage the mental health workforce in supporting carers of people with depression, or what specific factors may influence service providers in delivering a new intervention in the Australian context. A better understanding of this could help improve the degree to which family and carer interventions are available in Australia and provide information about how to best target dissemination efforts to get the best return for investment.

### **Review Summary and Aims of Current Studies**

In summary, there are many people in Australia supporting a person with depression; and ensuring the service system can provide effective support to carers is a national priority. The literature indicates that carers of people with depression are themselves vulnerable to mental ill-health, although this has not been specifically investigated in Australia. The literature also indicates that the way in which a carer copes with the demands placed on them can exacerbate or ameliorate stress; and social support may provide a direct means of enhancing carer mental health. However, there is only limited research available, and no study has investigated the impact, as a group, of carer burden, coping strategies, and social support, on the mental health of carers of people with depression. There is a growing body of evidence demonstrating the potential benefits of offering carers of people with depression access to carer-focused information and support. To date, the interventions investigated have usually been psychoeducational in nature, delivered by treatment facilities, or have not targeted carers of people with depression specifically. Furthermore, the use of carer or family-focused interventions by mental health services appears to be limited and it is not clear which factors most affect an individual's capacity to deliver interventions specifically for carers of people with depression in Australia.

The aim of this thesis was to examine the mental health of Australian carers of people with depression and build the evidence base regarding how best to support this target group. The studies that comprise this thesis investigate the predictors of mental health of Australian carers of people with depression, whether a specific carer intervention (the *Partners in Depression* program) is a relevant, appropriate and effective way to improve the mental health of carers of people with depression, and the factors that affected the dissemination of such an intervention.

**Study 1**

Predictors of mental health of Australian carers of people with depression were the focus of the first study. Participants were recruited through a variety of agencies in contact with carers across Australia. Participants completed a battery of questionnaires comprising standardised measures regarding the caregiving situation, carer burden, coping strategies, social support, and mental health. It was hypothesised that poorer mental health would be predicted by indices of severity of illness, higher carer burden, unhelpful coping strategies, and lower levels of social support.

**Study 2**

The efficacy of the *Partners in Depression* program, as delivered through the national dissemination project, was investigated in the second study. Local facilitators recruited self-identified carers of people with depression to attend *Partners in Depression* programs across Australia. All people who attended a *Partners in Depression* program were invited to complete quality assurance measures. The primary outcome measure for this study was impact on mental health, as assessed using a standardised measure of psychological distress. Relevance and acceptability of the intervention were measured by questions regarding participant satisfaction with the program, learning objectives, and use of program content. It was hypothesised that, after attendance at the program, participants would report a significant decrease in psychological distress.

**Study 3**

The third study investigated the predictors of *Partners in Depression* program delivery by facilitators who were trained as part of the national dissemination project. It was an exploratory study. A data mining approach was used to identify whether facilitator characteristics (e.g. role, location, type of service), agency level characteristics (e.g. type of service, state), or level of support provided by the project team predicted delivery of the program. It was anticipated that program delivery would be affected by the compatibility of

program delivery with facilitators' usual way of working and level of support provided by the project team.

### **Significance**

This program of research is the first of its kind to empirically investigate:

- the mental health of Australian carers of people with depression.
- the transferability of carer mental health benefits identified in a pilot program to the national setting.
- the factors that impact large-scale Australian dissemination of mental health carer interventions.

The findings from this research program can be used to inform the development and targeting of carer interventions to guide policy makers and administrators regarding how best to make available mental health carer-focused supports and to assist practitioners in identifying how to provide support to Australian carers of people with depression that have the greatest likelihood of benefits.

### **Context of the studies**

The three studies that comprise this thesis were conducted in the context of the *Partners in Depression* initiative. The *Partners in Depression* program was originally developed in 2006 by Hunter Institute of Mental Health (HIMH), in partnership with *beyondblue*, to address an identified gap in the service system for carers of people with depression. Program content development was informed by a literature review of what information and supports were wanted by carers of people with depression, a focus group with the target group, a review of existing programs, and advice from a reference group. An evaluation of the pilot showed that the program was positively received and attendance was associated with a significant improvement in mental health. Details about the *Partners in Depression* pilot evaluation are provided in Appendix A. In 2009, HIMH was funded by a philanthropic organisation (*nib* foundation) to engage in a national dissemination of the

*Partners in Depression* program across Australia. The studies that make up this thesis utilised the infrastructure of the *Partners in Depression* initiative and extended the investigations of the independent evaluator. This was done to ensure that the learnings and knowledge generated from this large implementation project could provide a solid contribution to the evidence base and could be used to inform activity in this space more generally.

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**STUDY ONE-**

**Predictors of mental health in Australians who care for a person with depression**

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### **Abstract**

Background: Caring for a person with depression can take its toll on a carer's own mental health and wellbeing. However, not all carers are affected by the caring role to the same degree. The aim of this study was to identify the predictors of mental health in Australian carers of people with depression. Method: Participants were 159 carers of people with depression who were recruited through services in contact with Australian carers. Participants completed a questionnaire battery that included indices of psychological distress, caregiving burden, coping strategies and perceived social support. Results: Nearly half of the sample scored in the 'likely to be unwell' range on the measure of psychological distress. Acceptance, planning, active coping and self distraction were the most commonly reported coping strategies and, in general, participants indicated that they were relatively well connected with both informal and formal supports. Using multivariate analysis, psychological distress was predicted by objective burden and use of the coping strategies, venting, self blame and active coping. Conclusions: To enhance carer resilience, it may be helpful to consider how to support carers of people with depression to reduce the amount of objective burden placed on them, and to help them reduce use of venting and self-blame and increase use of active coping strategies.

Caring for a person when they are unwell or needing assistance can be a rewarding, positive experience and can provide an opportunity to strengthen relationships and consolidate meaning. However, caring for a person when they are unwell can also be stressful and exhausting. Studies of carers in Australia and elsewhere repeatedly show that those in a caring role are much more likely to report significant psychological distress, experience lower levels of wellbeing and have poorer physical health than the general population (Cummins et al., 2007; Edwards & Higgins, 2009; Idstad, Ask, & Tambs, 2010).

Between 40% and 72% of participants in studies involving carers of people with depression are consistently found to report depression or anxiety themselves, which is a much higher rate than that seen in the general population (e.g. Coyne et al., 1987; Heru & Ryan, 2002; Spangenberg & Theron, 1999). Carers of people with depression also face a range of challenges. They often provide the majority of practical and emotional support to people in the community experiencing depression and this, in itself, can be demanding and time consuming. They report struggles with managing worry about the person they care for, stigma within the community, and increased isolation due to their role (Highet, McNair, Davenport, & Hickie, 2004). Carers of people with depression frequently describe specific reductions in their social activities and having to adjust to changes in their relationship with the person with depression, because of the illness (van Wijngaarden, Schene, & Koeter, 2004). Many who have cared for a person with depression describe feeling unprepared or overwhelmed by the experience.

However, not all carers are affected by the same degree or in the same way. Pearlin, Mullan, Semple, and Skaff (1990) describe a caregiver stress-health model to explain what determines carer functioning and carer outcomes. They describe how the mental and physical health of carers are determined by interactions between background variables (e.g. gender, age, socioeconomic status), characteristics of the caregiving situation (including primary

stressors such as amount of support required and frequency of challenging behaviours, and secondary stressors, such as isolation due to the caregiver role) and mediating variables that may mitigate or compound the effects of the carer role (specifically, coping strategies and social support).

Although there have been inconsistent findings regarding the relationship between background variables and carer mental health, there is now fairly reliable evidence, using different types of carer population groups, that one of the strongest predictors of carer mental health is the experience of caregiver burden (Baronet, 1999; Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Piquart & Sorensen, 2000; Schulze & Rossler, 2005). Caregiver burden refers to the demands placed on the carer and it is consistent with the primary and secondary stressor domains described by Pearlin et al. (1990). The relationship between primary stressor characteristics and carer mental health has been relatively well investigated, with the specific nature of carer burden found to be influenced by the type, length and severity of illness, the symptomatic or disruptive behaviours displayed by the care recipient, the amount and duration of care provided, the type of relationship and the residential situation between the carer and the care recipient; with all of these factors individually being predictive of carer mental health (Baronet, 1999; Piquart & Sorensen, 2000; Schulze & Rossler, 2005). For carers of people with depression, the predictive relationship between caregiver burden and mental health has been found to be similarly true to that seen in other carer groups (e.g. Benazon & Coyne, 2000; Jeglic et al, 2005; van Wijngaarden et al., 2009).

There is also some evidence to support the mediating role, as proposed by Pearlin et al. (1990), of carer coping strategies for carer mental health. In studies involving carers of people with mental illness, poorer coping tends to be associated with greater burden and/ or poorer carer mental health (Saunders, 2003), although more research is needed to confirm the

strength of this relationship (Schulze & Rossler, 2005). Similarly, carers of people with depression who use avoidant or 'evasive' coping strategies (e.g. distraction) report more psychological distress (Spangenberg & Theron, 1999; van Wijngaarden et al., 2009), whereas those who use more problem solving focused coping strategies report less psychological distress (Mitchell, Cronkite, & Moos, 1983). Thus, coping strategies appear to buffer the impact of the carer role on carers' mental health. However, it is unclear the degree to which specific coping strategies (e.g. distraction, positive reframing) play a particular role in diminishing or protecting carer mental health.

Social support also appears to play a role in tempering the effects of the carer role, although mixed findings are reported in studies involving carers of people with mental illness. Some studies have reported no relationship between level of social support and carer burden or depression and other studies have reported a protective relationship, with higher levels of social support being associated with lower levels of depression or burden (Baronet, 1999). Only two studies have specifically explored the role that social support may play in protecting the mental health of carers of people with depression, and in both of these studies, lower levels of social support were associated with higher levels of carer depression or more carer consequences (Mitchell et al., 1993; van Wijngaarden et al., 2009). However, Mitchell et al. (1993) looked at social support with regard to the role of the family environment (rather than more general social support), whereas van Wijngaarden et al. (2009) did not specifically investigate carer mental health (rather they looked at the consequences of the carer role as indexed by carer worries about the care recipient, need for urging, supervision and tension). Social support is an important area for investigation as, if it is shown to moderate the impact of the caregiver situation, it provides practical implications for service development. Although social support may play a part in determining the impact of the carer role, no study,

thus far has, specifically looked at the role of general social support for carers of people with depression, while also using a standardised measure of psychological distress.

In summary, there are many factors that appear to impact the mental health of carers. To date, the majority of research has involved carers of people with mental illness (with the samples usually having a majority of participants who care for a person with schizophrenia) and only a limited number of studies have focused specifically on carers of people with depression. It is unclear how relevant the findings from studies of carers of people with schizophrenia are to carers of people with depression, because of the different experiences of these carer groups. For example, carers of people with depression have different relationship types (e.g. they are more likely to be partners of the care recipient rather than children or parents, which is more common for carers of people with schizophrenia; van Wijngaarden et al., 2004); report different challenges (e.g. they are more likely to report interpersonal strains, whereas carers of people with schizophrenia are more likely to report having to engage in supervision or urging activities; van Wijngaarden et al. 2004); and the service system available to support people with depression is different to that for people with schizophrenia, and this may influence the type of support with which carers or the care recipient engage. Thus, although the level of caregiver burden for carers of people with depression appears to be equivalent to that reported by carers of people with schizophrenia (van Wijngaarden et al., 2009), the pathways that lead to impact of the carer role may be different for different carer groups (Pinquart & Sorenson, 2003). Furthermore, no study, thus far, has investigated the relationship between carer mental health, carer burden, coping strategies, and social support for carers of people with depression.

Therefore, the aim of the current study was to investigate the mental health of carers of people with depression in Australia and to investigate the predictive strength of



characteristics of the illness of the person being cared for, caregiver objective burden, coping strategies, and perceived social support, in determining carer mental health.

## **Method**

### **Design**

This study used a cross-sectional questionnaire with one data collection point. Five domains of interest were explored- care recipient characteristics, caregiving demands, carer coping strategies, social support and mental health status. Of these, the first four variables were treated as predictors for mental health status.

### **Participants**

Participants were self-identified carers who lived with, loved, cared for or provided support to a person with depression within Australia. Participation was not limited to a specific relationship type, meaning participants could be supporting a partner, child, parent, sibling, friend, etc. with depression. The depression of the person they were supporting could be diagnosed (or not) and did not have to be the only illness the person was experiencing (i.e. the person they were supporting could be experiencing depression and other mental or physical illnesses).

In total, 159 participants were recruited. The vast majority of the sample were female (84%), Australian born (79%) and spoke English at home (95%). None of the sample identified as Aboriginal or Torres Strait Islander. Participants were recruited from across Australia, with the majority living in New South Wales (54%) followed by Victoria (16%) and Queensland (15%). There was a good spread of participants who reported living in metro (35%), regional (33%) and rural (29%) areas. The majority of participants were in paid employment (53%), although household income remained modest with half the sample (51%) reporting that their household income was under \$50 000. Over three-quarters (78%) of the sample reported that they were married or de facto, 11% were divorced, 3% had a partner

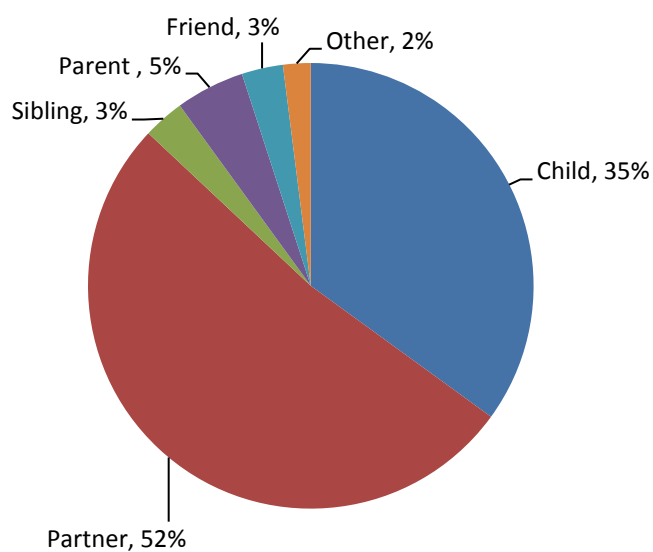


Figure 1: Participant relationship with the person with depression

Table 1: Characteristics of the Caring Role

Domain	Percentage
Duration of the caring role	
< 1 year	8%
1 - 2 years	17%
3 - 5 years	14%
6 - 10 years	17%
10 + years	45%
Frequency of care provided	
Monthly	5%
Three weekly	2%
Fortnightly	2%
Weekly	13%
2 - 4 x week	18%
Daily	60%

whom they were living apart from, 3% were widowed and 4% were single. The average age of participants was 52.9 years (SD= 11.99).

As seen in Figure 1, the majority of the sample were supporting a partner or child with depression. Most participants (76%) reported that they were living with the person with depression. Of these, just a little over half (55%) lived with the person with depression and others, whereas just under half of the sample (45%) lived with the person with depression only. About one-fifth (22%) reported that they did not live with the person with depression, including 4% of the sample who lived alone.

As seen in Table 1, the vast majority of the sample reported that they had been caring for the person with depression for a long time and frequency of providing care was also high. Nearly half of the sample (48%) reported also providing support to other relatives or friends with a disability, mental illness, chronic condition or other frailty. This support was provided most commonly to other children, partners and parents. Frequently, depression was the reason for the support, although frailty due to age was also commonly mentioned, as was Asperger's Disorder.

## **Procedure**

Participants were recruited through a variety of agencies in contact with carers (including ARAFMI Queensland, ARAFMI NSW, Carers NSW, Carers Victoria, Mental Health Council of Australia), who provided information about the study to relevant consumers of their service (e.g. in newsletters, on website). People interested in participating were able to complete the questionnaire online or in hard copy by contacting the inviting agency.

People who had attended a *Partners in Depression* program between March 2010 and April 2012 and provided consent to be contacted about research were also invited to participate. The *Partners in Depression* program is a six session, group education program

specifically designed for carers of people with depression. Former group members who had consented to be contacted were sent a copy of the questionnaire, information sheet, invitation letter and pre-paid self-addressed envelope. If they did not wish to participate in the study, they did not return the paperwork.

The study was approved by the Hunter New England Human Research Ethics Committee- Approval Number 11/04/20/5.05.

## **Measures**

A self-administered questionnaire battery was developed, comprising a number of standardised measures. Information was collected about demographics, the caregiving context, impact of the caring role, coping strategies used by participants, perceived social support and the mental health of participants. Details of the measures are outlined below.

### ***Caregiving context***

Demographic and clinical information was collected about the nature of the depression of the person who participants were supporting (e.g. diagnosis, duration of symptoms, treatment access). Information about symptom unpredictability was collected using a five item scale, where participants rated agreement with statements on a five point Likert scale (e.g. Their illness keeps changing; 1= *strongly disagree*; 5= *strongly agree*). This scale has been used with carers of people with mental illness (MacKay & Pakenham, 2012) and has good internal consistency and validity (Pakenham et al., 2006).

### ***Caregiving impact***

The demands of the caring role were assessed using a rating of frequency of caregiving and the objective burden subscale of the *Burden Assessment Scale* (Reinhard, Gubman, Howitz, & Minsky, 1994). These 19 items are rated on a four point Likert scale (e.g. Had financial problems; 1= *not at all*; 4= *a lot*) and participants rate the extent to which they have experienced each item in the past six months as a direct result of the illness of the person

they were supporting. Higher scores indicate higher levels of caregiver burden. The *Burden Assessment Scale* has been used with family members of people with mental illness. It has good validity and reliability (Reinhard et al., 1994).

### ***Coping strategies***

Coping strategies were assessed using the *Brief COPE* (Carver, 1997). The *Brief COPE* is a 28 item scale, where participants rate, on a four point Likert scale, how often they have used each strategy over the past four weeks to cope with their role (1= *not at all*; 4= *a lot*). Items for each factor are summed and averaged to give an indication of which strategies are used more and less frequently. Fourteen coping strategies are covered including *self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, turn to religion and self-blame*. The *Brief COPE* is a popular coping strategy measure and has been used with a variety of populations, including caregivers (e.g. Cooper, Katona, & Livingston, 2008; MacKay & Pakenham, 2012). It has established test-retest reliability, acceptable internal consistency and good construct validity (Carver, 1989).

### ***Social support***

Social support was assessed using the abbreviated *Duke Social Support Index* (Koenig et al., 1993). This is an 11 item scale that uses ratings of frequency and helpfulness of contact to gauge level of social support. It comprises two factors: a social interaction score (items 1-4) and a satisfaction score (items 5-11). A total score is also calculated. This scale has a range of 11- 33 with higher scores indicating greater social support. It has good validity and reliability (Koenig et al., 1993) and has been used with Australian samples (e.g. Pachana et al., 2008) and carer populations (e.g. Brodaty & Hadzi- Pavlovic, 1990).

### ***Mental health status***

Mental health status was assessed using the *Kessler 10* (K10; Andrews & Slade, 2001). The K10 captures participants' experience of psychological distress. Participants rate how much each item applied to them over the past four weeks on a five point Likert scale (e.g. About how often did you feel tired out for no good reason?; 1= *none of the time* to 5= *all of the time*). A total score is used as an indicator of level of psychological distress. Scores range from 10- 50 and higher scores indicate poorer mental health. The K10 has been used in a number of Australian population health studies and has good validity and reliability (Andrews & Slade, 2001). It is also frequently used to identify risk of mental disorder.

### **Data analysis**

Routine exploratory analysis was performed. This included using descriptive statistics to explore responses and to check for normality, outliers, linearity, and variance homogeneity. Internal reliability was checked for each standardised measure (see Table 3). Only the *Duke Social Support Index* had a questionable alpha, which is consistent with previous studies (Pachana et al., 2008). In addition, over three-quarters of the sample (76%) reported that they had attended a *Partners in Depression* course and comparisons were conducted on all demographic and independent variables to identify if there were group differences due to the characteristics of the recruitment method. There were no significant differences on any of the demographic or independent variables between those who had and had not attended the *Partners in Depression* program.

Bivariate tests (analyses of variance and Pearson correlations or non-parametric equivalents) were used to investigate the relationships between variables. This included first investigating whether the K10 score was significantly associated with any of the demographic or background variables. Secondly, the relationships between the primary variables of interest

were explored. Due to the large number of analyses, an adjusted alpha of  $p < .01$  was applied to reduce the likelihood of a Type I error.

Finally, hierarchic multiple regression was performed to identify which variables predicted mental health status as captured by the K10 total score. Checks were performed for multicollinearity using the tolerance coefficient and the Variance Inflation Factor (VIF) while normality, linearity, and homoscedacity were assessed by inspecting the normality probability and scatter plots. Bivariate correlations between the K10 score and 20 independent variables (across caregiving context, coping strategies, and social support domains) were calculated. Demographic variables were investigated with regard to their relationship with the K10 total score to establish if they should be controlled for. Variables with extremely high intercorrelations were not included to prevent collinearity. Four blocks of predictors were used: characteristics of the person with depression (unpredictability of depression, duration of depression, diagnosis); caregiving demands (frequency of caregiving, objective burden); coping strategies (self distraction, active coping, denial, substance use, emotional support, instrumental support, behavioural distancing, venting, positive reframing, planning, humour, acceptance, religion, self-blame); and social support (social support total). Order was indicated by Pearlin et al.'s (1990) caregiver model of stress, such that non-modifiable background variables were included first, followed by indicators representative of the primary stressors on participants, followed by indices of the mediating variables including how participants identified coping with the stressors, and finally, the mediating variable of social support was added, in recognition of its potential amenability to provision of external supports. In total, twenty variables in four blocks were used in the analysis.

## Results

### Care recipient characteristics

Table 2 provides an overview of the characteristics of the people with depression who were being supported by participants. Overall, 88% of the sample reported that the person they were supporting had been diagnosed with depression, although for almost half of the sample the depression occurred with another mental illness (e.g. anxiety, schizophrenia, borderline personality disorder) or was a specific type of depression (e.g. bipolar, post natal depression). Only 6% of the sample reported that the person they were supporting had not received a diagnosis. A response was missing for 6% of the sample. Over three-quarters of the sample indicated that the person they were supporting had another mental or physical illness and anxiety was spontaneously reported as a comorbid condition by 39% of the sample. The depression experienced by those supported by participants had a relatively long duration (over five years), was most frequently being treated by medication and counselling, and was perceived as being relatively unpredictable (see Table 3).

### Participant characteristics

Table 3 provides details about participant characteristics. The caregiving role was rated as having significant impact on day-to-day life and responsibilities. With regard to coping strategies, denial and substance use were reported as being used least frequently whereas acceptance, planning, active coping and self-distraction were reported as being used most frequently. The mean score on the social interaction subscale ( $\bar{X}= 7.97$ ;  $SD= 3.17$ ) indicated that participants had some, but not necessarily frequent, contact with others, and the mean score on the subjective support subscale ( $\bar{X}= 16.56$ ;  $SD= 3.25$ ) suggested that participants felt somewhat, but not overly, connected. Overall, 60% of the sample returned a score indicating they were likely to be satisfied with their social support and 40% were likely to be dissatisfied.



Table 2: *Characteristics of the Person with Depression*

Domain	Percentage	Mean (SD)	Range
Diagnosis			
Depression only	44%		
Depression & anxiety	27%		
Bipolar	9%		
Depression & schizophrenia	3%		
Depression & borderline personality disorder	5%		
Depression & other diagnosis	5%		
No diagnosis	6%		
Missing	6%		
Has other problems			
Other mental health problems	28%		
Physical ill-health	28%		
Both other mental & physical ill-health	23%		
At least two other problems	44%		
Years since diagnosis		7.1 (8.26)	1- 50 years
Years since symptoms began		10.2 (9.91)	0.5- 72 years
Treatment access		Current	Past
Medication	21%		12%
Counselling	10%		8%
Medication & counselling	40%		43%
Hospitalisation	3%		10%
Other	1%		3%
No treatment	23%		20%

The mean score on the K10 was 20.7 ( $SD= 7.1$ ). The distribution of scores placed 53% of participants in the *likely to be well* range, and 23%, 13% and 11% of participants scored in the range of likely to be experiencing a *mild*, *moderate* or *severe mental disorder* respectively (Andrews & Slade, 2001). Compared to the general Australian population, participants were 2.75 times more likely to report severe psychological distress.

### **Bivariate relationships between variables**

There were positive significant correlational relationships between many of the dependent variables. The objective burden score was significantly related to symptom unpredictability ( $r= .294, p= .002$ ), frequency of caring role ( $r= -.241, p=.01$ ), and providing support to others in addition to the person with depression ( $r=. 245, p= .007$ ).

Bivariate correlations showed that the majority of the coping strategies were significantly related to each other, indicating that the more a participant reported using one type of coping strategy, the more likely they were to also identify using other coping strategies. Only the substance use score was unrelated to use of any other coping strategy. In contrast, planning scores were significantly related to 10 of the other 13 remaining coping strategy scores.

Some of the coping strategies were also significantly related to other variables. Higher unpredictability scores were associated with more frequent use of the coping strategies, emotional support ( $r= .210, p=.009$ ), planning ( $r= .311, p=.001$ ), self distraction ( $r=.244, p=.002$ ), and denial ( $r=.286, p=.001$ ). Higher objective burden scores were associated with more frequent use of half of all the coping strategies, specifically active coping ( $r= .246, p=.009$ ), planning ( $r=.379, p=.001$ ), self distraction ( $r= .394, p=.001$ ), denial ( $r= .244, p=.009$ ), behavioural distancing ( $r= .350, p=.001$ ), venting ( $r= .366, p=.001$ ), and self-blame ( $r=.324, p=.001$ ).

Table 3: *Descriptive Statistics (Means, Standard Deviations, Range and Cronbach Alpha) for Standardised Measures*

Scale	Item Mean (SD)	Item Range	Cronbach's Alpha
	Total Mean (SD)	Total Range	
Caregiving Context			
Symptom unpredictability scale	3.85	1 - 5	0.76
	19.25 (3.69)	5 – 25	
Caring Role			
Objective burden scale	2.50 (0.72)	1 - 4	0.88
	25.07 (7.23)	19 - 40	
Coping Strategies			
Brief COPE			0.73
Active Coping	2.67 (0.90)	1 – 4	
Planning	2.72 (0.89)	1 – 4	
Instrumental support	2.26 (0.92)	1 – 4	
Emotional support	2.07 (0.82)	1 – 4	
Behavioural disengagement	1.53 (0.69)	1 – 4	
Self distraction	2.67 (0.79)	1 - 4	
Venting	1.97 (0.79)	1 – 4	
Humour	1.53 (0.78)	1 – 4	
Substance use	1.37 (0.69)	1 – 4	
Acceptance	2.90 (0.94)	1 – 4	
Religion	1.92 (1.06)	1 – 4	
Self-blame	1.91 (0.80)	1 – 4	
Reframing	2.20 (0.85)	1 – 4	
Denial	1.32 (0.58)	1 – 4	
Social Support			
Social Support Total	24.5 (3.95)	11 – 33	0.61
Mental health			
Kessler 10	2.06 (0.73)	1- 5	0.90
	20.7 (7.1)	10 – 50	

The social support total score was unrelated to any demographic, coping strategy, mental health or caregiving context variable.

### **Prediction of mental health status**

The K10 total score was not significantly related to any demographic variable (age, gender, employment status, marital status, location, regionality, residency situation or income level), nor was it related to the majority of the caregiving context characteristics (including duration of depression, comorbidity, person with depression experiencing two or more additional problems, duration or frequency of caregiving role or providing support to others), the social support total score, or having attended a PID program.

Bivariate correlational analyses showed that the K10 total score was significantly associated with symptom unpredictability ( $r=.302, p=.001$ ) and objective burden scores ( $r=.542, p=.001$ ). There was also a significant positive relationship between K10 total scores and half of the coping strategies including planning ( $r=.229, p=.004$ ), venting ( $r=.332, p=.001$ ), self distraction ( $r=.285, p=.001$ ), denial ( $r=.428, p=.001$ ), behavioural distancing ( $r=.345, p=.001$ ), substance use ( $r=.276, p=.001$ ), and self-blame ( $r=.492, p=.001$ ) coping strategies.

Table 4 summarises the hierarchic regression. In summary, the first block of predictors explained 9% of total variance, with the unpredictability of the depression accounting for this relationship. When the second block was included, 30% of the variance was explained. This was due to the inclusion of objective burden. When the third block of predictors was included, an additional 19% of the variance was explained (taking the total up to 49%) with frequency ratings of venting, self blame and active coping accounting for the increase. Finally, when the social support index was included in the fourth block, there was no significant change in total variance explained (48%). The final model included as predictors in order of importance: objective burden and frequency ratings of use of venting, active and self-blame coping strategies.

Table 4: *Summary of the Hierarchic Regression for Carer Mental Health*

Predictor	<u>Block 1</u>	<u>Block 2</u>	<u>Block 3</u>	<u>Block 4</u>
	Beta	Beta	Beta	Beta
<b>Care recipient characteristics</b>				
Symptom unpredictability	0.36**	0.19	0.14	0.14
Duration of depression	- 0.16	- 0.11	- 0.09	- 0.09
Diagnosis	- 0.02	- 0.02	0.05	0.05
<b>Caregiving context</b>				
Frequency of care		0.02	0.01	0.02
Objective burden		0.51***	0.41***	0.41***
<b>Coping Strategies</b>				
Self distraction			- 0.04	- 0.04
Active coping			- 0.26*	- 0.26*
Denial			0.13	0.13
Substance use			0.00	0.00
Emotional support			- 0.16	- 0.15
Instrumental support			0.23	0.23
Behavioural distancing			0.09	0.09
Venting			0.27**	0.27**
Positive reframing			0.10	0.10
Planning			0.03	0.03
Humour			0.02	0.02
Acceptance			- 0.14	- 0.14
Religion			- 0.02	- 0.02
Self-blame			0.20*	0.21*
<b>Social Support</b>				
Social Support				- 0.02
<b>Variance Explained</b>				
R	0.35	0.59	0.78	0.78
R <sup>2</sup>	0.12*	0.35***	0.60***	0.60
Corrected R <sup>2</sup>	0.09	0.30	0.49	0.48

\* =  $p < 0.05$  \*\* =  $p < 0.01$  \*\*\* =  $p < 0.001$

### Discussion

This study demonstrates that Australian carers of people with depression are at risk of experiencing poor mental health; and indicates that the people who are particularly vulnerable are carers who are required to provide a lot of practical support and who engage in more venting and self blame and less active coping. Interestingly, social support did not appear to mediate the impact of carer demands, and carer mental health was not significantly predicted by other specific aspects of the carer context (e.g. longevity of depression, frequency of caring role). In general, the findings from this study are consistent with findings from previous studies, including studies that have recruited carers through the care recipient (rather than directly), and studies involving carers of people with mental illness (rather than depression specifically).

Nearly half of the participants in this sample reported psychological distress, and participants in this study were 2.75 times more likely to report severe psychological distress compared to the general Australian population (Andrews & Slade, 2001). These rates of mental health problems are consistent with the rates reported in other studies of carers of people with depression (e.g. Coyne et al., 1987; Heru & Ryan, 2002; Spangenberg & Theron, 1999). It provides quantitative evidence to support the qualitative reports about the impact of the carer role on carers' mental health, as identified in focus groups conducted with Australian carers of people with depression (e.g. Highet et al., 2004). The level of impact of depression on carers' lives (e.g. as indicated through scores on the objective burden scale) is also consistent with studies of other caregiver populations (e.g. MacKay & Pakenham, 2010; Pirkis et al., 2010). Furthermore, the types of coping strategies reported as being used most frequently by participants in this study (including acceptance, planning, active coping and self distraction) are similar to the most frequent coping strategies reported as being used by participants in other studies of carers of people with mental illness, in both qualitative (e.g. Pagnini, 2005) and quantitative (e.g. MacKay & Pakenham, 2012; Chakrabarti & Gill, 2002)

investigations. Thus, it is suggested that the experience and impact of stress on this group of carers was not unusual; rather this study demonstrates that, similar to other types of carers, carers of people with depression are vulnerable to experiencing mental health problems and identify coping with the challenges in comparable ways.

This study identified only four variables as significant predictors of participants' mental health. Objective burden and frequency of use of the coping strategies, venting, self blame, and active coping (negative relationship), accounted for 48% of the K10 total score variance, with objective burden being the most important predictor. Furthermore, the initial significant impact of the unpredictability of depression reduced to non-significance when objective burden was added. This suggests that objective burden moderated the effect of perceived unpredictability of the illness. Thus, carers who experience higher caring 'load' (or objective burden) and use more venting and self blame and less active coping strategies appear to be at greater risk of experiencing poor mental health. This study confirms that the strong relationship between carer burden and psychological distress identified in studies involving carers of people with other mental illness is also relevant for carers of people with depression; and, as posited by Pearlin et al. (1990), that coping strategies play an important mediating role in the impact of the demands of the carer role. In summary, it is a combination of the demands placed on a caregiver and the way they respond to these demands that determines the resilience of carers.

Three coping strategies uniquely contributed to the prediction of the mental health of participants. Specifically, more venting and self blame and less active coping predicted poorer carer mental health. If venting and self blame are considered representative of maladaptive 'emotion-focused' coping strategies, and active coping is considered to be representative of adaptive 'problem-focused' coping, then the findings from this study are consistent with previous research with carers of people with mental illness and carers of people with depression (Mitchell et al., 1983; Spangenberg & Theron, 1999; van Wijngaarden et al.,

2009). However, the high number of significant correlations between the frequency ratings of the different coping strategies, as well as with other variables, indicate that if a person identified using one coping strategy, they often identified using other coping strategies. Furthermore, the more difficult the caring situation (e.g. as indicated by higher unpredictability or objective burden), the greater the number of coping strategies participants identified as having used. In short, it would seem that the greater the caring demands, the more broad the range of coping strategies used, and when less helpful coping strategies are also used, the risk of the carer experiencing mental ill-health increases.

In contrast to Pearlin et al.'s (1990) caregiver stress-health model, social support was not found to be predictive of carer mental health. Interestingly, it was also not related to any other demographic, coping strategy or caregiving context variable. In general, participants were relatively well connected with family, friends and non-family members and were, for the most part, satisfied with their social support. These findings are contradictory to much of the current research that documents feelings of abandonment and isolation experienced by carers of people with depression (e.g. Coyne et al., 1987; Heru et al., 2004; Highet al. 2004) as well as the two studies that investigated the relationship between social support and carer depression/ burden in carers of people with depression (Mitchell et al., 1993; van Wijngaarden et al., 2009). It is, however, in the context of inconsistent findings about the protective role of social support in studies involving carers of people with mental illness (Baronet, 1999). It could be that this null finding was a consequence of sample bias. Participants were recruited via organisations in contact with carers, thus this sample may have had elevated levels of social support compared to other carers of people with depression. To confirm whether social support can moderate the impact of the demands from the caring role, more specific information could be collected about where carers of people with depression draw their support from, and whether the mixed findings are due to their needs being met by available networks or are a consequence of low support demands.



Although this study has addressed an important gap in the evidence base by looking at the nature of the caregiving burden and how it influences the mental health of those Australians who care for a person with depression, there were limitations to the study. Firstly, the generalisability of the findings may be limited by the characteristics of its sample. Participants were self-identified carers in contact with services. They were also primarily female and supporting partners with what appeared to be relatively severe depression. The majority had been in the caring role for a long period of time and supported other people with physical or mental health issues. As such, it is unclear the degree to which these findings can be extrapolated to the wider population of people caring for a person with depression, particularly those who may be supporting a person with less severe depression or who are earlier in their carer journey. Secondly, objective burden clearly plays an important role in predicting the mental health of carers of people with depression. However, it is unclear as to the degree to which objective burden was influenced or determined by the severity of the depression for whom the carers were caring for. It would have been helpful to collect additional information on the severity of the depression, as well as information regarding whether the person they were caring for was currently unwell or not. Thirdly, the finding of no relationship between social support and any other variable was unexpected. The instrument used may not have been sensitive enough to capture differences, or other factors may have influenced the social support responses (e.g. social support may have increased over time). Thus, it would be useful to further investigate the role of social support using a more sensitive instrument. Finally, objective burden and some specific coping strategies predicted poorer mental health. Within this context, it would be useful to gain a better understanding of how these variables contributed to the poor mental health experienced by some carers.

In conclusion, this study highlights the significant caring role that family members and friends provide to people with depression. It demonstrates the mental health vulnerability of carers of people with depression and emphasises the importance of considering how carers of

people with depression can be supported to enhance their mental health and wellbeing. The findings from this study indicate that the determinants of mental health in carers of people with depression are similar to carers of people with other mental illness, even though this carer group face different challenges and have access to different support systems. The study confirms the important mediating role of coping strategies for carer outcomes as described by Pearlin et al. (1990), but does not support the mediating role of social support. In summary, it would appear that an effective way to enhance carer resilience and improve the quality of life of carers of people with depression may be to help reduce the amount of objective burden placed upon carers of people with depression, and to support them to reduce use of venting and self-blame, and increase use of active, coping strategies.

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**STUDY TWO-*****Partners in Depression: Efficacy of a nationally disseminated group education program for carers of people with depression***

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### Abstract

Background: Carers of people with depression are vulnerable to mental ill-health as a consequence of the carer role. However, there is only limited evidence regarding what sorts of interventions most effectively address their information and support needs. This study was designed to investigate the efficacy of the Australian nationally disseminated *Partners in Depression* program, a group education course for carers of people with depression. Method: Participants were 1120 self-identified carers who attended a *Partners in Depression* program in Australia, between March 2010 and April 2012. Results: After attending the program, participants (n= 664) reported significantly reduced psychological distress, significantly higher agreement with items covering mental health promoting attitudes and behaviours specifically targeted by the program, and a high level of satisfaction with the program. Conclusions: This study shows that the positive outcomes identified in the pilot of the *Partners in Depression* program were maintained in a large scale dissemination of the program. However, a study with a comparison control group is needed as a priority to establish that the outcomes were due to program attendance and not other factors.



Depression affects one million Australians each year (ABS, 2008). It can significantly affect a person's quality of life, their relationships and engagement with work. It is a recurrent illness, a known risk factor for suicide and is associated with increased risk for a range of physical illness and disease (AIHW, 2011; Bertolote et al., 2004). However, the impact of depression is not limited to the person experiencing the illness. Family members and friends of people with depression are also affected.

Family members and friends provide the majority of day-to-day emotional and practical support to those people in the community experiencing depression. Support people ("carers") describe many difficult experiences including feeling isolated, confused and overwhelmed by the depressive symptoms, frustration with, and having to advocate for, access to relevant treatments for the person they are supporting, and worry about stigma and the future (Ahlstrom, Skarsater, & Danielson, 2009; Hight, McNair, Davenport, & Hickie, 2004). Carers also identify many specific changes that occur in their relationships, lifestyle, roles and practical responsibilities, to which they must adapt as a consequence of the depression (Ostman, Wallsten, & Kjellan, 2005; van Wijngaarden et al., 2009). The impact of the demands placed on a person as a result of their carer role is typically called "carer burden" (Baronet, 1999).

The carer role can take a toll on the mental wellbeing of carers of people with depression. Studies of spouses and family members of people with depression typically find about half of the participants report depressive and anxiety symptoms, with anywhere from 40% to 72% of sample participants experiencing such elevated levels of psychological distress that they meet criteria to be referred for therapeutic intervention themselves (Coyne et al., 1987; Heru & Ryan, 2002; Spangenberg & Theron, 1999). Furthermore, carer burden is consistently found to predict the mental health of carers of people with depression, and carers' own experience of mental ill-health typically reduces when the person they are supporting recovers (Coyne et al., 1987; Jeglic et al., 2005). In short, carers of people with depression

appear to be vulnerable to mental ill-health themselves, largely as a consequence of their carer role.

There is a growing body of evidence that demonstrates the benefits of involving carers in the assessment and treatment of a person with mental illness, with studies consistently showing that providing information and support to family members and carers is associated with improved treatment outcomes for the person with mental illness (Harvey & O'Hanlon, 2013; McFarlane, Dixon, Lukens, & Lucksted, 2003). The evidence is strongest for people experiencing a psychotic disorder (McFarlane et al., 2003), however, studies involving people with depression and which use control comparison groups, similarly identify reduced rates of relapse and improved patient functionality for the person with depression when a carer intervention is offered in addition to standard care (Shimazu et al., 2001; Spencer, Glick, & Haas, 1988; Stam & Cuijpers, 2001). Consequently, it is now recommended that mental health carers are involved in the treatment for people living with mental illness, including those with depression (e.g. APA, 2010; NCCMH, 2010; NHS, 2009; RANZCP, 2010). However, less is known about the degree to which carer interventions offer benefits to the carer directly.

The information and support needs of mental health carers have started to be explicitly investigated (e.g. MHCA, 2009). Mental health carers, including carers of people with depression, most commonly report wanting information about the illness, to be provided with better support and skills to manage crisis situations, and to be included as part of the assessment and treatment process for the person they support (Highet et al., 2004; Muscroft & Bowl, 2000). However, contact between mental health services and family members and carers of people with mental illness (including depression) appears limited and a number of inhibiting factors must be addressed before carer inclusive practice is possible. For example, competing workload priorities, service access issues, and permission from the consumer for family members or carers to be involved are all identified by clinicians as affecting capacity

to engage in carer inclusive practice with people with depression (Wirrell, McGill, Kelly, & Bowman, 2014).

Internationally, some interventions have been developed specifically to address the information and support needs of carers of people with depression (Harter et al., 2002; Heru, Ryan, & Madrid, 2005; Luciano et al., 2011; Morgan et al., 1997; Sherrill et al., 1997; Shimazu et al., 2012; Stam & Cuijpers, 2001). These interventions have usually been psychoeducational in nature, delivered in multifamily group settings as well as to single families, and have recruited carer participants through the person experiencing depression (meaning the person being supported was in contact with treatment facilities). The interventions have varied in their intended outcomes, and aims have included improving carer mental health and wellbeing, coping skills and the family environment (e.g. expressed emotion). Frequently, carer outcomes have been considered secondary to the outcomes for the person with depression.

In general, responses to these interventions by carers have been positive and sessions well attended (Harter et al., 2002; Heru et al., 2005; Morgan et al., 1997; Sherrill et al., 1997). When carer outcomes have been assessed, attendance at these programs has usually been associated with reductions in psychological distress (Luciano et al., 2011; Shimazu et al., 2012; Stam & Cuijpers, 2001) and less consistently, in carer burden (Clarkin et al., 1990; Prisco et al., 2012). Findings from a recent Australian study of a peer-led group education program for mental health carers ("*Well Ways*") indicated that program benefits were less apparent for carers of people with affective disorders compared to carers supporting a person with schizophrenia (Stephens, Farhall, Farnan, & Ratcliff, 2011); highlighting the potential importance of ensuring programs specifically address the support needs of different carer groups.

In 2006, we (Hunter Institute of Mental Health) developed the *Partners in Depression* program, a group education program for carers of people with depression, expressly to

address a locally identified gap in support specific to carers of people with depression. Program development included a concept testing and pilot evaluation phase. Program content was informed by a literature review, focus group, review of existing programs and advice from stakeholders, such that the program was designed specifically to address the stated needs of carers of people with depression, meaning the carer experience is central to the program. Program delivery style was informed by adult learning principles (Knowles, Horton, & Swanson, 2005). The pilot evaluation (n= 103) demonstrated the efficacy of the program in reducing carer symptoms of depression and anxiety and showed that it was possible to deliver the program within existing health and community services (see Appendix A for details).

In 2009, the Hunter Institute of Mental Health began a national dissemination of the *Partners in Depression* program across Australia. The aim of this study was twofold. Firstly, to assess the efficacy of the nationally disseminated *Partners in Depression* program in improving participants' mental health, and to explore whether specific participant subgroups (as indicated by age, gender, employment status or diagnosis of the person being supported) benefitted differentially from program attendance. Secondly, to assess the effectiveness of the program in addressing specific program learning objectives and identify if the program was viewed as relevant and useful by the target population.

## **Method**

### **Participants**

Participants in this study were 1120 people who attended a *Partners in Depression* program during the national dissemination period (March 2010 to April 2012). Participants were recruited through health and community settings throughout Australia. Group attendees were self-identified carers of people with depression who were over the age of sixteen years. Group attendance was not limited to a specific relationship type or duration. The program specifically targeted those who supported a person who had a formal diagnosis of depression

Table 1: *Participant Characteristics*

Characteristic			Characteristic		
<b>Gender</b>	Male	20%	<b>Heard about program through...</b>		
	Female	80%		Organisation or service provider I am in contact with offered it to me	37%
<b>Age</b>	16-25 years	2%	Another organisation or service provider referred me		8%
	26-40 years	14%		Friend or family member recommended it to me	18%
	41- 64 years	65%		Advertisement in newspaper/newsletter	22%
	65+ years	19%		News stories or articles in local media (e.g. radio, newspaper, internet)	5%
				<i>Partners in Depression</i> website	2%
<b>Employment</b>			<b>Reasons for attending program</b>		18%
	Full-time	26%		Information about the causes, symptoms and treatment for depression	75%
	Part-time	27%		Information about how I can best support the person in my life with depression	91%
	Studying	6%		Information about what I can do to look after myself	76%
	Volunteer	10%		Information on the services and resources available to support me	72%
	Retired	25%		Information on the services and resources available to support the person in my life with depression	76%
<b>Marital status</b>	Single, never married	7%	Opportunity to talk with others with a similar experience		68%
	Partner, living apart	3%		Other	7%
	Married or de facto	73%			
	Divorced or separated	12%			
	Widowed	5%			
<b>Relationship to person with depression</b>	Child of person	33%	<b>Kessler- 10</b>	Low distress (10-15)	30%
	Parent of person	15%		Moderate distress (16-29)	59%
	Partner	42%		High distress (30-50)	12%
	Sibling	6%		Average score (SD)	20.36
	Friend	9%			(7.23)
	Other	11%			

by a health professional; however, formal diagnosis was not a compulsory requirement and comorbidity of the depression with other mental or physical problems (e.g. anxiety, stroke, etc.) was acceptable. People who did not meet eligibility criteria for group attendance were referred to other relevant support services.

Demographic data is shown in Table 1. The vast majority of participants were female (80%), Australian born (76%) and spoke English at home (90%). The average age of the sample was 53 years (SD= 12.72 years). The majority of the sample (75%) was supporting either a partner (42%) or a child (33%) with depression; and lived with the person with depression (65%). Most (88%) reported that the depression had been diagnosed by a health professional. For nearly half of the sample (46%), other mental health diagnoses were reported to be present in conjunction with the depression, including anxiety (17%), bipolar (11%) and post traumatic stress disorder (4%). About one-third of the sample (37%) reported that they provided support to more than one person.

## Measures

### *Mental health*

The primary outcome measure was the Kessler-10 (K10; Andrews & Slade, 2001). The K10 is a measure of psychological distress. Items are rated on a five point scale and participants indicate how much each item applied to them over the past four weeks (e.g. About how often did you feel tired out for no good reason?; 1= *none of the time* to 5= *all of the time*). A total score is calculated to give a basic indication of a person's level of psychological distress. Scores range from 10- 50 and higher scores indicate poorer mental health. Using the ABS (2001) coding system, total scores of 10-19 were classed as low psychological distress, total scores of 20-29 were classed as moderate psychological distress and total scores of 30-50 were classed as high psychological distress. The K10 has been used in a number of Australian population health studies and has good validity and reliability

(Andrews & Slade, 2001). It is frequently used to identify risk of mental disorder (ABS, 2001).

### ***Mental health promoting attitudes and behaviours***

A twelve item scale developed for this study was used to assess degree to which program learning objectives had affected specific mental health promoting attitudes and behaviours, which matched program learning objectives. At each time point, participants indicated their agreement with statements that covered the attitudes and behaviours specifically targeted by the program on a five point Likert scale (e.g. I have a good understanding of the causes, symptoms and treatments for depression; 1= *strongly disagree*; 5 = *strongly agree*). This scale had a very low Cronbach alpha ( $\alpha = .15$ ) and thus items were explored separately.

### ***Helpseeking attitudes***

Attitudes towards helpseeking were assessed by participants' nominations of people/ roles from whom they would seek help for their own mental health and wellbeing. Number of positive nominations was collated into a helpseeking total score.

## **Program objectives**

### ***Learning objectives and program acceptability***

Feedback about program delivery effectiveness and acceptability was assessed by participant ratings of the degree to which the program had addressed explicit learning goals (e.g. Providing information about and increasing your skills in effective communication strategies; 1= *very poor* to 6= *excellent*); usefulness of specific session topics (e.g. Tick which topics you found most useful); confidence in being able to apply program content (1= *not at all* to 4= *extremely*); whether program participation had impacted on their relationship with the person with depression, other relationships or the person with their life with depression (yes/ no and free text); satisfaction with the program and program delivery (1= *extremely unsatisfied* to 6= *extremely satisfied*); and whether participants would (post-program) or had

(at follow-up) recommend(ed) the *Partners in Depression* program to others supporting a person with depression.

### **Intervention**

The *Partners in Depression* program is a group education course for people who live with, love or support a person with depression. It was developed by Hunter Institute of Mental Health. The group sessions are run by two health or community professionals with mental health knowledge and group experience. The program comprises six, two-hour, weekly sessions that cover information about depression and its treatments, communication skills and self care. The program aims to improve participants' mental health and resilience by providing them with relevant information about depression and the carer experience, opportunities to discuss and share their experience, and by engaging participants in a range of activities that encourage self-care, help seeking and positive coping. As discussed, program content was informed by a literature review of what information and support carers of people with depression reported wanting, a focus group with the target population, review of existing programs and advice from a reference group of stakeholders. The program was developed to be a stand-alone intervention, with the expectation that facilitators would refer group members who needed additional support to relevant services. Group members are provided with session booklets that include the information covered in the session and work pages for the group activities. All facilitators met minimum knowledge and experience eligibility criteria, attended a standardised two-day facilitator training course conducted by the first author, were provided with a facilitator manual, and had access to program delivery support (including facilitator-only website access, peer teleconferences, and troubleshooting advice from project team).

During the national dissemination period, 211 programs were delivered across Australia with an average of 6.31 participants attending each group. Program delivery occurred in: government and non-government organisations; urban, regional and rural



settings; and in settings where the program was delivered independently and as part of the treatment for the person with depression. The vast majority (99%) of programs were freely available to the public, although a small number required payment (ranging from gold coin donation to \$250).

### **Procedure**

Facilitators advertised the availability of the program through local avenues including direct invitations to clientele or family members of clients to whom they were providing services, promotion at service meetings, and through local media, public forums and noticeboards. Information about program availability was also displayed on the *Partners in Depression* website. People interested in attending the program contacted the local facilitator to register interest and complete the screening process. During this contact, interested group attendees were told about the quality assurance process and that they would be invited, but not required, to complete some questionnaires before and after attending the program.

Three evaluation data collection points were used: baseline, post program and six-month follow-up. The baseline questionnaire included background information questions (e.g. demographics and characteristics of the person being supported) and outcome measures. The post program and six-month follow-up questionnaires comprised program feedback questions and outcome measures. At each time point, participants were invited to provide a self-generated stable identification code comprising their father's initials and mother's date of birth. This meant that data could be linked without the project team holding contact or identifying details about group attendees.

Local facilitators distributed the information and consent sheets, baseline and post program questionnaires to participants (before the first group session and after the last group session respectively) and the project team sent the six-month follow-up questionnaire to participants who had provided consent to be contacted at a later date. Participants could return

questionnaires to the local facilitators or directly back to the project team with provided reply-paid envelopes.

The study was approved by Hunter New England Human Research Ethics Committee.

### **Data Analysis**

The data for this study represents a subset of the data available from the national dissemination of the *Partners in Depression* program. It focuses on the quantitative data relevant to participant outcomes. Automatic electronic and manual review was used to match participant data.

The primary outcome for this study was improvement in mental health, as indicated by reduction in psychological distress as assessed by the K10. Secondary outcomes were improvement in ratings on the mental health promoting attitudes and behaviours items (where the Likert scale items were treated as pseudo-continuous variables) and increase in the helpseeking total score. Paired t tests and repeated measures analyses of variance (ANOVAs) or their non parametric equivalents (Wilcoxon signed ranks test or Friedman's test) were used to compare matched outcomes data across time points. Mixed measures ANOVAS were used to identify the degree to which change in the K10 total score was affected by between-subjects factors including age group, gender, employment status and diagnosis of the person being supported. Due to the large number of calculations, an adjusted alpha of  $p < .01$  was used for the outcomes measures to reduce the likelihood of a Type I error. Program objectives' data were explored with descriptive statistics.

## **Results**

### **Sample**

A total of 1120 participants returned the baseline questionnaire, 958 returned the post program questionnaire and 118 participants returned the six-month follow questionnaire. This represented a response rate of 86% for the post program questionnaire and 11% for the six-month follow-up questionnaire. A total of 664 post program and 42 six-month follow-up

responses could be matched with a baseline response, reflecting a response rate of 59% and 4% of the total baseline sample respectively. The participant codes on the remaining follow-up questionnaire could not be matched with any baseline code. No information was available about the characteristics of those who did not complete the baseline questionnaire.

There were some significant differences on demographic variables between those who only completed the baseline questionnaire and those who completed both the baseline, and post program, or six-month follow-up questionnaires. English speaking participants were more likely to return the follow-up questionnaires,  $\chi^2(2) = 26.67, p = .001$ , and participants who were living with the person with depression were more likely to return the six-month follow-up questionnaire,  $\chi^2(2) = 7.48, p = .02$ . Furthermore, those who completed both the baseline and post program questionnaire had a slightly, but significantly, lower mean K10 score at baseline compared to those who completed only the baseline questionnaire ( $\bar{x} = 19.82, SD = 6.84$ ;  $\bar{x} = 21.03, SD = 7.65$ , respectively),  $F(3, 1112) = 2.01, p = .04$ .

At baseline, 71% of the sample scored in the moderate or high range of psychological distress on the K10, meaning this sample were three times more likely than the general Australian population to report high levels of psychological distress (ABS, 2001). Gender,  $F(1, 600) = 7.51, p = .006$ , and employment status,  $F(1, 600) = 7.14, p = .008$ , significantly affected K10 total scores. Females and participants who were not working had higher K10 scores than males and participants who were working, respectively. There was a trend for those supporting a person with diagnoses in addition to that of depression to also have higher K10 scores,  $F(1, 498) = 4.5, p = .03$ . Age group and location (major city, inner regional, outer regional or rural) did not significantly affect K10 scores,  $F(3, 588) = 1.01, p = .384$  and  $F(3, 596) = 2.26, p = .08$ , respectively.

### **Mental health outcomes**

About half of all respondents at each time point reported a moderate amount of psychological distress as measured by the K10 and the average K10 score was in the

moderate range at each time point. For those participants for whom there was matching data available, analyses showed that the K10 total average score significantly reduced from 19.84 ( $SD= 6.88$ ) to 17.49 ( $SD= 5.67$ ) between starting and finishing the program,  $t(601)= 11.99$ ,  $p=.001$ . This significant change was maintained in the repeated measures ANOVA comparing K10 scores across all three time points, with the baseline K10 score of 19.98 ( $SD= 6.84$ ) being significantly different from both the post program ( $\bar{x}= 16.88$ ,  $SD= 5.11$ ) and six-month follow-up ( $\bar{x} = 17.75$ ,  $SD= 6.78$ ) scores,  $F(2, 78)= 8.29$ ,  $p= .001$ . See Figure 1 for details.

The degree of change in K10 total mean scores between baseline and post program time points was significantly affected by K10 group,  $F(2, 599)= 274$ ,  $p=.001$ , age group,  $F(3, 588)= 3.17$ ,  $p=.02$ , gender,  $F(1, 600)= 14.73$ ,  $p=.001$ , and employment status,  $F(1, 600)= 15.81$ ,  $p=.001$ . See Figure 2 for details. All age groups, except the youngest (16- 25 years), displayed a reduction in K10 scores across time (note, this interaction only approached significance and was apparent with a very small  $n$  in the youngest age group). Those experiencing the greatest psychological distress at baseline showed the greatest decline in K10 scores after the program. Similarly, female participants exhibited a greater decline in K10 scores over time than male participants. Participants who were not working exhibited a greater decline in K10 scores over time than participants who were working. Only, diagnosis of the person being supported (“depression” or “depression and other diagnoses”) and location did not affect the degree of K10 change over time,  $F(1, 498)= 0.23$ ,  $p=.63$  and  $F(3, 596)= 0.83$ ,  $p=.48$ , respectively.

With the smaller sample size available for matched comparison across the three time points, no group or interaction effects were significant, except for the K10 grouping interaction effect,  $F(2, 37)= 32.25$ ,  $p=.001$ , where those experiencing the highest psychological distress at baseline reported the greatest drop in K10 scores over time.

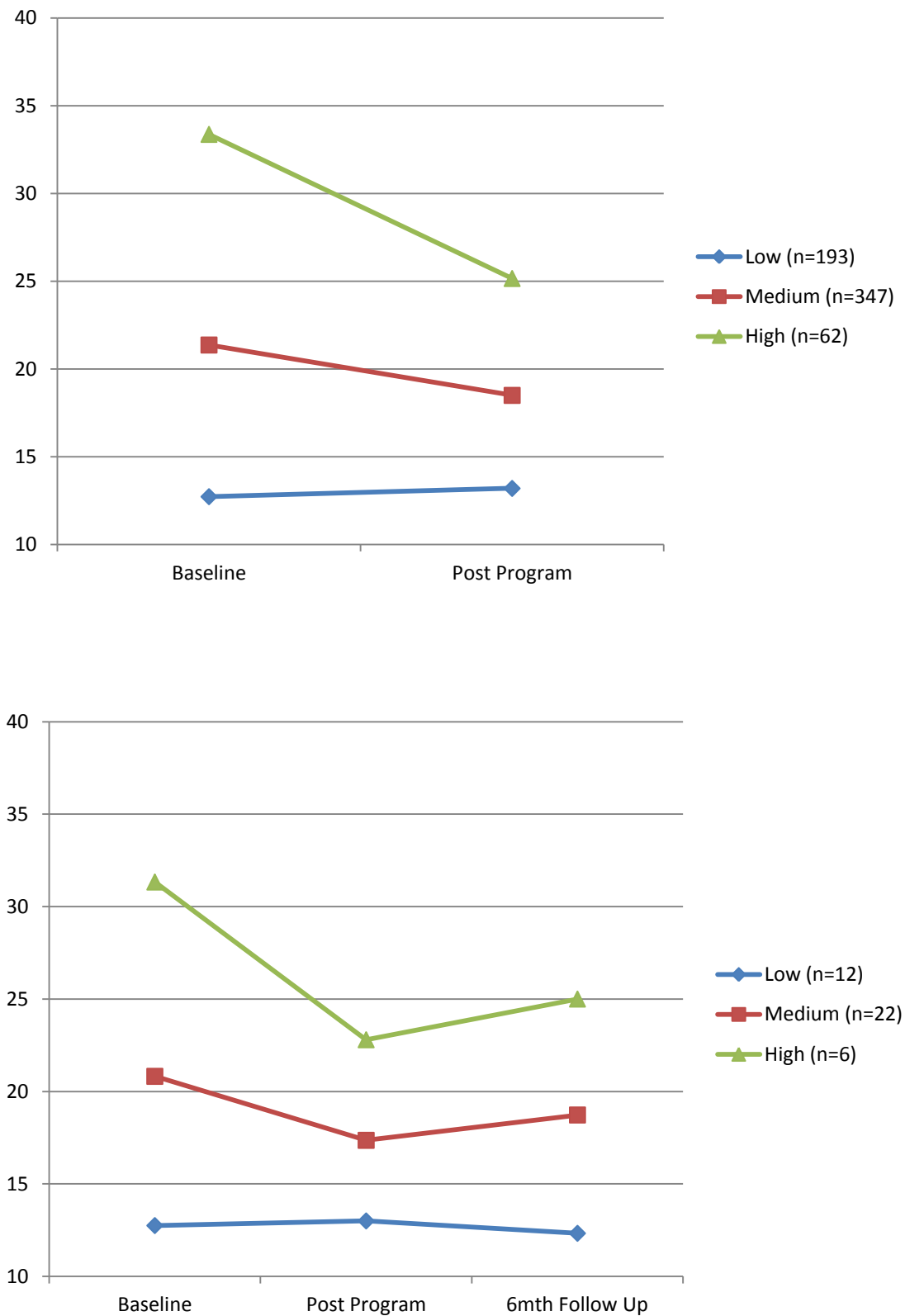


Figure 1: Matched sample average Kessler-10 total score over time points, by Kessler-10 grouping

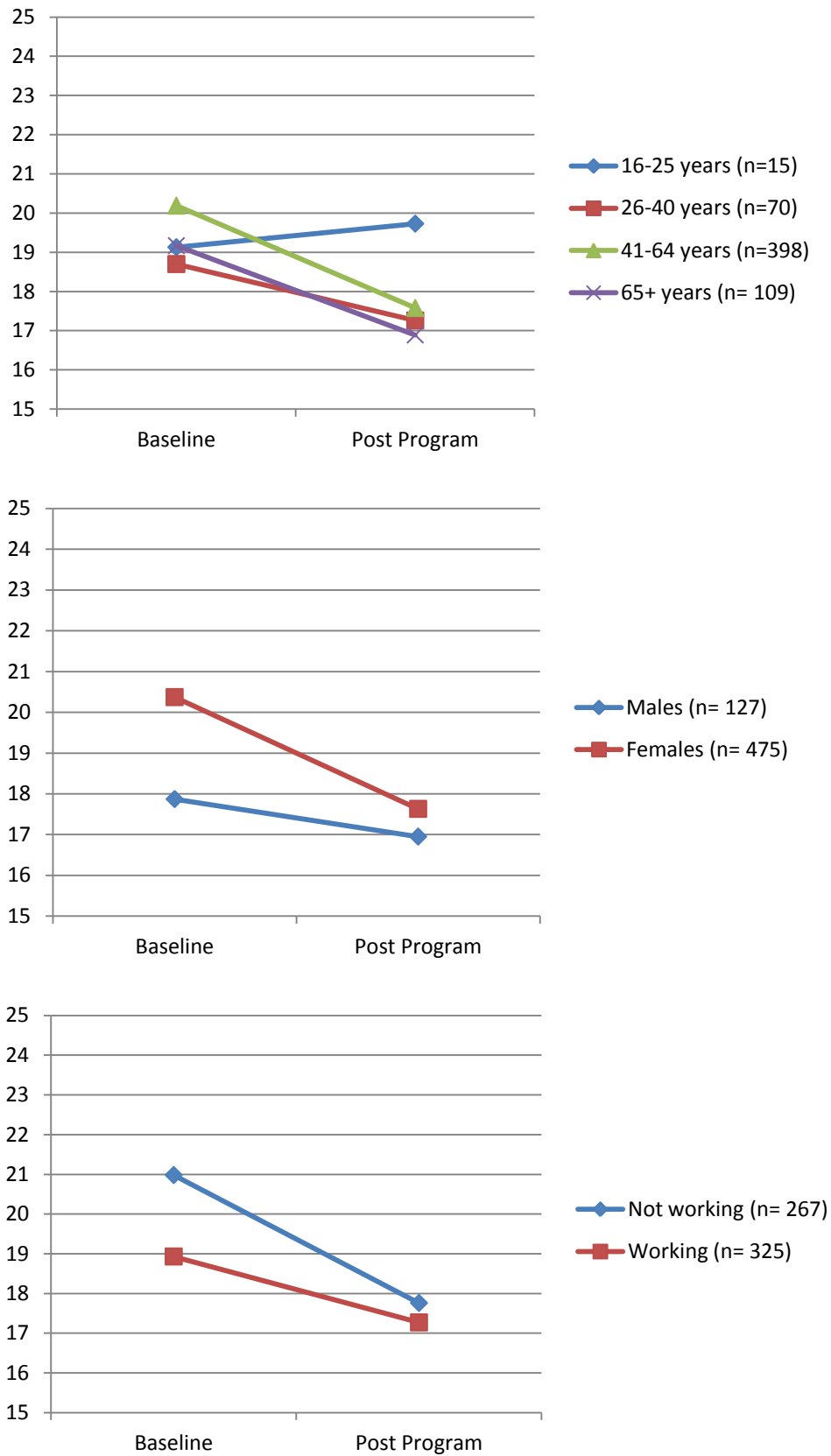


Figure 2: Matched sample average Kessler-10 total score over time points, by age group, gender and employment status

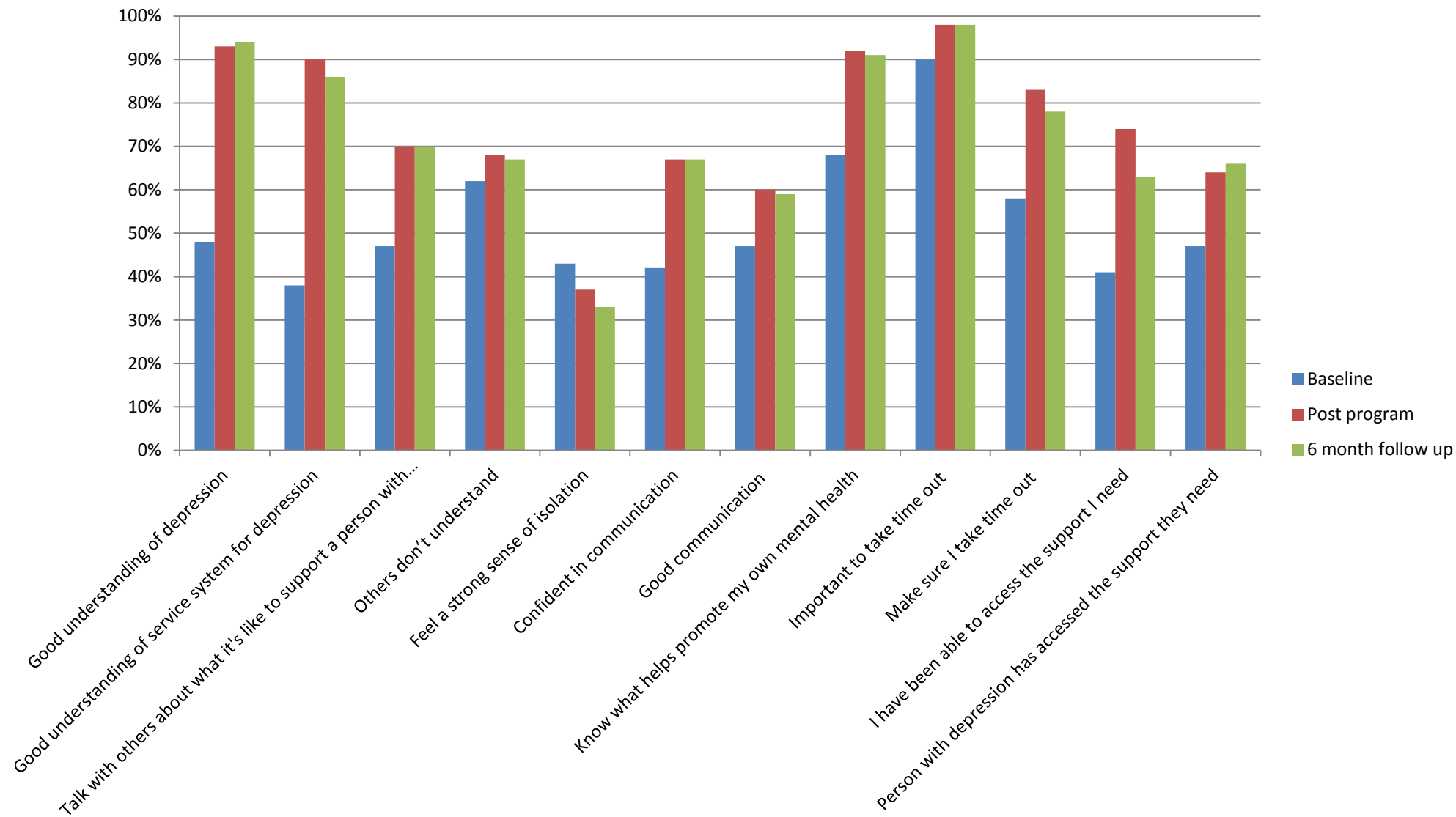


Figure 3: Proportion of whole sample agreeing with items covering mental health promoting attitudes and behaviours targeted by the program

Table 2: Mean Scores and Statistical Analyses for Mental Health Promoting Attitudes and Behaviour Items (1= strongly disagree; 5= strongly agree)

Item *	Baseline Mean (SD) n= 1057	Post program Mean (SD) n=871	6 month follow-up Mean (SD) n= 110	Baseline/ post program comparison Baseline/ post program/ 6 mth comparison
a. I have a good understanding of the causes, symptoms and treatments for depression	3.33 (0.92)	4.14 (0.58)	4.10 (0.50)	$W = -15.92, p = .001^{***}$ $\chi^2(2) = 38.86, p = .001^{***}$
b. I have a good understanding of the service system available to support a person experiencing depression	3.07 (0.99)	4.07 (0.59)	3.95 (0.67)	$W = -17.13, p = .001^{***}$ $\chi^2(2) = 26.66, p = .001^{***}$
c. I talk with others about what it's like to support a person with depression	3.14 (1.09)	3.74 (0.84)	3.64 (0.91)	$W = -11.96, p = .001^{***}$ $\chi^2(2) = 16.08, p = .001^{***}$
d. I feel others don't understand what it's like to support a person with depression	3.62 (0.99)	3.68 (0.87)	3.85 (0.93)	$W = -0.56, p = .577$ $\chi^2(2) = 1.64, p = .44$
e. Due to my role supporting a person with depression, I feel a strong sense of isolation	3.16 (1.10)	3.05 (1.05)	2.91 (1.09)	$W = -1.92, p = .055$ $\chi^2(2) = 3.14, p = .21$
f. I am confident in my ability to communicate effectively with the person in my life with depression	3.10 (1.14)	3.64 (0.91)	3.54 (1.05)	$W = 11.72, p = .001^{***}$ $\chi^2(2) = 17.34, p = .001^{***}$
g. There is good communication between myself and the person in my life with depression	3.23 (1.13)	3.53 (0.99)	3.49 (1.05)	$W = -7.10, p = .001^{***}$ $\chi^2(2) = 6.02, p = .05^*$
h. I know what helps promote my own mental health	3.68 (0.80)	4.16 (0.59)	4.09 (0.55)	$W = -12.76, p = .001^{***}$ $\chi^2(2) = 6.64, p = .04^*$
i. I believe it is important to take time out and look after myself	4.19 (0.70)	4.53 (0.55)	4.56 (0.53)	$W = -11.05, p = .001^{***}$ $\chi^2(2) = 2.66, p = .08$
j. I make sure I take time out to look after myself and engage in self care activities regularly	3.54 (1.00)	4.12 (0.76)	4.01 (0.87)	$W = -12.82, p = .001^{***}$ $\chi^2(2) = 13.95, p = .001^{***}$
k. I have been able to access the support I need	3.25 (0.92)	3.82 (0.79)	3.69 (0.78)	$W = -12.69, p = .001^{***}$ $\chi^2(2) = 6.24, p = .04^*$
l. The person in my life experiencing depression has been able to access the support and treatment that they need	3.18 (1.09)	3.61 (0.97)	3.69 (1.02)	$W = -9.35, p = .001^{***}$ $\chi^2(2) = 2.66, p = .26$

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$



**Mental health promoting attitudes & behaviours**

Figure 3 shows the proportion of all respondents at each time point agreeing with the statements that covered the mental health promoting attitudes or behaviours targeted by the program. It shows a large increase in agreement for all items except for the items referring to experiencing a strong sense of isolation (small reduction) and feeling that others do not understand what it's like to support a person with depression (small increase). There was a significant difference in mean ratings between baseline and post program for every item, except for these two items. All comparative analyses across time points were significant or showed a trend for significance, except for the same two items and two additional ones (*The person in my life experiencing depression has been able to access the support and treatment they need* and *I believe it is important to take time out and look after myself*). See Table 2 for details.

**Helpseeking**

Using matched data, there was an increase in the proportion of participants who indicated they would seek help from each specific group, except for that of general practitioners. See Figure 4 for an overview. This was associated with a significant increase from 2.47 ( $SD=1.43$ ) to 2.69 ( $SD=1.58$ ) in the total number of groups from whom participants identified they would seek help,  $t(663)=3.34$ ,  $p=.001$ . At the six-month follow-up, 61% of the sample who responded at that time point reported that they had sought help since attending the *Partners in Depression* program.

**Program objectives**

On completion of the program, over 94% of the sample rated positively (good, very good or excellent) the effectiveness of the program in meeting its specific learning objectives. Mean scores are outlined in Table 3. Over four-fifths of the sample (84%) indicated that they had applied program information; this increased to 93% of respondents at the six-month follow-up time point. After completing the program, 80% of respondents indicated they felt

confident or extremely confident in using the material covered in the PID program and 82% indicated that they felt attending the program had had an impact on their relationship with the person in their life with depression. This proportion was maintained at the six-month follow-up time point (85%). At the six-month follow-up time point, 73% of respondents indicated that they felt the person with depression had benefitted through their own attendance at the *Partners in Depression* program.

Upon completion of the program and at the six-month follow-up, 98% of the sample reported being satisfied with the delivery and content of the program. In addition, 98% at completion of the program indicated that they would recommend the program to others who support a person with depression; at the six-month follow-up, 73% of respondents had recommended the program to others (primarily to other people supporting a person with depression and friends) and 93% of respondents indicated that they had discussed content covered in the *Partners in Depression* course with at least one other person (primarily the person with depression, friends, and partners).

Table 3: *Mean Ratings for Effectiveness of Program in Addressing Program Learning Goals (1= very poor; 6=excellent)*

Learning goal	Mean (SD)
a. Increasing your knowledge of the symptoms, diagnosis and treatment of depression	5.09 (0.8)
b. Increasing your awareness of the impact of depression on relationships	5.15 (0.8)
c. Providing information about and increasing your skills in effective communication strategies	5.05 (0.8)
d. Facilitating communication with others about the experience of supporting a person with depression	5.02 (0.8)
e. Developing awareness of strategies for accessing effective treatment for a person with depression	4.92 (0.9)
f. Increasing your awareness of the personal impact on your emotional and physical wellbeing of supporting a person with depression	5.19 (0.8)
g. Providing education and strategies for self-care and coping techniques	5.16 (0.8)
h. Providing education and increased awareness of the services and resources available to support people of a person with depression	5.06 (0.9)
i. Providing encouragement for you to increase help-seeking behaviours for yourself and the person with depression	5.16 (0.9)
j. Meeting the needs you had prior to attending the program	5.02 (0.9)

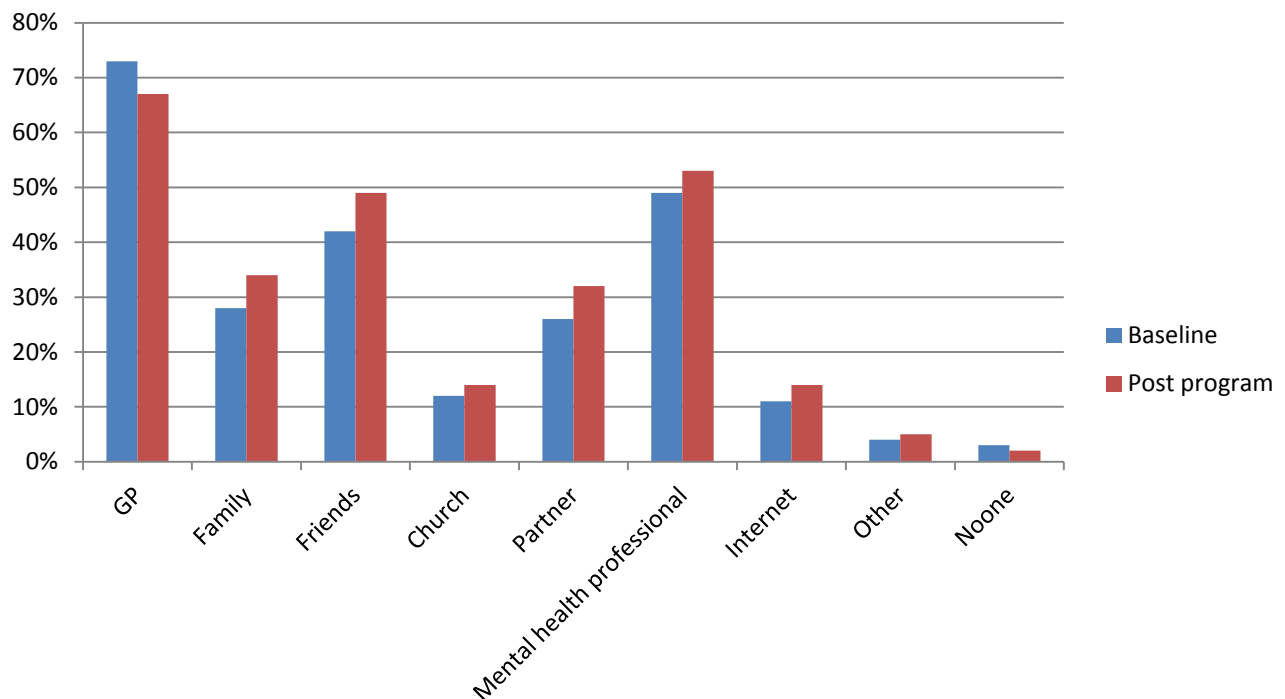


Figure 4: Positive nominations indicating from whom matched sample would seek help for their own mental health

## Discussion

Overall, this study indicates that attendance at the *Partners in Depression* program, as delivered through the national dissemination project, was associated with a significant decline in level of participant psychological distress, significant increases in ratings of the importance of, or engagement in, mental health promoting attitudes and behaviours specifically targeted by the program, and a significant increase in the number of sources from whom participants identified they would seek help from for mental health difficulties. In addition, participants indicated that the program effectively addressed the stated learning goals and reported explicit and active use of content covered in the program, as well as feeling that their program participation had positively impacted on their relationship with the person with depression.

The findings from this study demonstrate that program attendance was efficacious in reducing participants' level of psychological distress as assessed by a standardised measure. This finding has two implications. Firstly, it demonstrates that in this large support-seeking

group of carers of people with depression there was a vulnerability to mental ill-health. There was a threefold higher rate of people experiencing high levels of psychological distress compared to the general population, and over two-thirds of those who attended the program scored in the *likely to be unwell* range at baseline. These findings are consistent with those of previous international studies which have found compromised mental health in carers of people with depression (Coyne et al., 1987; Heru & Ryan, 2002; Spangenberg & Theron, 1999) and in other Australian carer groups (Cummins et al., 2007; Edwards & Higgins, 2009). However, this is the first time a study has explicitly explored the mental health status of Australian carers of people with depression using a standardised measure with a large targeted sample. The consistency of the findings suggest that this sample was not unusual in their presentation and confirms the vulnerability of carers of people with depression to mental ill-health.

The second important implication is that attendance at this brief psychoeducation program was associated with a significant, albeit small, decline in psychological distress; with improvement being most apparent for those who were reporting higher levels of mental ill-health at baseline. Thus, this study demonstrated that the mental health and wellbeing of carers of people with depression can be enhanced through attendance at a short-term and carer specific group program, which could be independent from the treatment provided to the person with depression and/ or access to other supports. The mental health benefits reported by participants in this study were consistent with those reported in previous studies of carer interventions for people with depression (e.g. Luciano et al., 2001; Shimazu et al., 2012; Stam & Cuijpers, 2001).

The findings from this study suggest that the program was also effective in improving mental health promoting attitudes and behaviours targeted by the program, although this was more apparent for information and knowledge items than behavioural-focused items. For example, from baseline to post program time points, there was an increase of 45% and 52% of

the sample respectively agreeing that they had a good understanding of the causes, symptoms and treatments for depression, and the service system available to support a person experiencing depression. In contrast, the items targeting specific behaviour changes had a lower proportion of the sample changing their ratings from disagreement to agreement (ranging from 13% to 33%), and the change in agreement for these items did not increase further at the six-month follow-up time point. These patterns suggest that the program was more effective in increasing knowledge and understanding than affecting actual behaviour, and this would be consistent with previous studies that have indicated that individual family work is needed for behaviour change to occur (e.g. Pilling et al., 2002; Rossberg et al., 2010). However, it should also be noted that the validity of the measure used may generally limit the strength of any conclusions that can be drawn as the measure comprised solely of items of positive valence, which may have led to a response bias and overestimation of self reported agreement.

Nevertheless, there were some promising indicators that suggested that program information was being used by participants in day-to-day life. For example, the vast majority of the sample reported that they had discussed the content of the program with someone else, identified additional people from whom they would seek help, and over half of all those who responded at the six-month time point indicated that they had sought help for their own mental health since attending the program. Thus, the program appears to have specifically impacted participants' sense of understanding about depression and the support role, which was used, to some degree, in day-to-day life; although it remains unclear as to how these variables may account for the improvement in participants' mental health. Regardless, the outcomes indicate that the *Partners in Depression* program was an appropriate and adequate way to deliver support to carers of people with depression, with the potential to reduce psychological distress.

Furthermore, the findings from this study also indicate that the program in its current form is acceptable and relevant to participants. In general, participants reported high satisfaction with program content and delivery and, as a group, nearly universally, indicated that they would recommend the program to others supporting a person with depression. They gave extremely high ratings to the degree to which the program had met the specific learning objectives and the vast majority of participants indicated that the program had met their needs. Thus, the findings from this study suggest that, as an intervention, this program met its learning objectives and the needs of the target group. It would be useful for future research to further investigate what elements of the group program account for the benefits e.g. the content, the group process, the access to social support, etc.

There were some groups, however, who did not report the same reduction in psychological distress with program attendance and it is possible that this was due to different program attendance motivations (see Appendix B for details) or a lack of “fit” with the current delivery style. For example, young people did not report the same level of improvement in psychological distress as people older than 26 years. In some ways, this is unsurprising. Overall, young people constituted a very small minority of participants. This in itself may have disconnected young people from the other participants. However, they may also have other characteristics which meant the current delivery format was not as good a fit with this population group. For example, compared to older adults, young people are likely to be at a different developmental stage, may be more likely to be at a different “stage” in their caring journey (e.g. at the beginning), and may not have experienced the workshop format as youth-friendly; any one of which could have contributed to a mismatch between the program and this particular target group. Thus, it may be useful for future research to investigate whether the experiences of younger participants improve if the program is delivered solely to participants of a younger age, content is reviewed and adapted to be more youth friendly and

different delivery formats which may be more engaging for young people (e.g. online options) are used.

Males and working participants also did not report the same amount of reduction in psychological distress. However, it would seem likely that this may be a consequence of a “floor” effect, as these groups had lower K10 scores before the program, meaning the capacity for their scores to reduce further was limited. It would be useful, however, to conduct focus groups or invite feedback from these specific groups of participants to identify what worked for them or what could be changed. It may also be useful to run the program with participants from these target groups who have higher K10 scores to begin with, to identify if the issue is with the current delivery format or a sampling bias consequence. Furthermore, some cultural groups (e.g. Aboriginal and Torres Strait Islander) were vastly under-represented in group attendance and it may be useful to investigate the relevance or fit of the program for specific cultural groups. While the program was designed and reviewed by expert stakeholders for cultural sensitivity and inclusiveness, it was not designed to be culturally specific. It would be useful to identify specific community groups who would be interested in accessing the program and to then work with representative community and service provider stakeholders from those cultural groups to ensure the promotion, content, language, approach and key messages resonate with the community (recognising that some of these elements may need to be adapted to ensure uptake and benefits for different cultural groups).

The comments about the findings from this study are made in acknowledgement of the potential impact of the non-responders. That is, participants who returned follow-up questionnaires and could be matched with a baseline response had a significantly lower K10 score than those for whom only a baseline response was available. It is possible that the positive finding of the program being helpful for those experiencing a high level of psychological distress is only true for those people for whom the program met their needs; whereas others (who may have been just as unwell) may not have benefitted and “dropped

out” of program attendance or participation altogether. Promisingly, although the response rate for matched post program responses was 60% of the baseline sample, the whole available post program sample represented a response rate of 86% and there were no clear differences in post program responses for those who could be matched and those who could not be matched. The same issue arises with regard to participants who spoke English and another language, such that it is unclear as to whether participants who also spoke another language at home (and therefore may be more likely to identify with diverse cultural groups) experienced the same benefits, as it was English-speaking participants who were more likely to return the post program and six-month follow-up questionnaire. Future work should, as much as possible, follow-up with all who discontinue- whether it be through dropping out from the program or not returning the post program questionnaire- to establish whether non-responders report a similar pattern of impact or not.

Overall, it is pleasing that the outcome findings from this national dissemination project mirror those of the pilot program (see Appendix A). There are specific challenges that arise in maintaining positive participant outcomes in dissemination trials, due to the problems that can arise with the fit of a program that was developed elsewhere with local needs, as well as problems due to loss of fidelity to program components that account for the benefits (Elliott & Mihalic, 2004). Instead, the findings from this study indicate that the dissemination strategy used was successful at, simultaneously, managing the need for program fidelity to core components while also allowing flexibility in specific delivery configurations to fit with local needs. The impact of program fidelity on program benefit should be further investigated to better clarify which components of the program are most related to program benefit. However, overall, the findings from this study suggest that the strategy for dissemination of this program was appropriate and effective in making available a carer support program that addressed local community needs. While the dissemination strategy was relatively effective, there remain questions about whether this sort of dissemination strategy is sustainable in the



long term and more investigation is needed to identify the degree to which the dissemination strategy had other generalised but important effects (e.g. affected the degree to which facilitators engaged in family inclusiveness practices in their routine work) that were not specific to delivery of the *Partners in Depression* program per se.

There are, however, a number of significant limitations to this study. Firstly, there is a pressing need to ensure that the mental health and wellbeing benefits identified by participants were due to program attendance and not just an effect of time, the person with depression improving, or access to other supports. At a minimum, a study is needed with a waitlist control comparison group, if not a randomised controlled comparison group. Having established the effectiveness of the program in addressing the information goals, the evidence of the impact of the program would be strengthened by supplementing the evaluation with standardised measures of helpseeking, communication and coping styles to better understand what may account for the mental health improvement. Furthermore, retention of participants in this study to the follow-up time point was poor and it is difficult to say with confidence whether program benefits were maintained over time, or whether outcomes would have been the same if non-responders had been included. It would also be useful to track the recovery of the person with depression in tandem with that of the carer, in order to better identify not only the degree to which the recovery of the person with depression affects the mental health of the carer, but also whether program attendance by the carer is associated with any specific benefits for the person with depression. Finally, although the vulnerability of this target group provides enough justification in itself to ensure that specific carer supports are made widely available, it will be important to establish the degree to which these sorts of early intervention supports can contribute to avoidance of need for later support services, thereby establishing the cost-effectiveness of such a program.

In summary, this study has demonstrated that the *Partners in Depression* program, as delivered through the national dissemination strategy, was efficacious in improving

participants' mental health, affected specific attitudes and behaviours targeted by the program, and increased the number of people from whom participants identified they would seek help.

Furthermore, this study demonstrated that the intervention was acceptable, relevant and effective at addressing the information needs of the target group. Program attendance was most beneficial for those experiencing high levels of distress, but high satisfaction and positive feedback ratings suggest that the program had more widespread relevance. The positive mental health effects identified in the pilot were maintained in the national dissemination of the program, even though the program was delivered across more diverse locations and with much less capacity to manage fidelity adherence. Furthermore, the findings from this study indicate that even a brief psychoeducational group program can be associated with immediate mental health benefits. In short, the study emphasises that providing support to carers of people with depression should be maintained as a priority, and indicates that the *Partners in Depression* program is an intervention worthy of further investigation.

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**STUDY THREE-****The Australian national dissemination of the *Partners in Depression* program:****Predictors of program delivery**

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### **Abstract**

Background: There are many barriers to disseminating family interventions for people with mental illness. Method: This study used a data mining approach to explore which factors influenced the delivery of the *Partners in Depression* program, a group program specifically designed for carers of people with depression. Results: Of the 427 facilitators trained in the *Partners in Depression* program, less than half (44%) delivered the program in the twelve months following training and only 18% delivered three or more programs. Logistic regression analyses indicated that the compatibility of program delivery with facilitators' usual work and the state in which facilitators worked were significant predictors of program delivery, whereas level of proactive follow-up phone support was not associated with increased likelihood of program delivery. Furthermore, difficulty in recruiting enough family members or carers to a group was a common barrier to program delivery. Conclusions: Future dissemination efforts may wish to specifically target facilitators where the program is consistent with their usual work activities and identify ways to address recruitment issues.

Family-based psychoeducational interventions have been shown to improve the mental health and recovery of people with mental illness (Dixon et al. 2001). The evidence is strongest for people with psychotic disorders, but is strengthening for other mental illnesses, including depression (Dixon et al., 2001; Luciano et al., 2012). In addition to the benefits for the person with mental illness, family-based interventions have the potential to also impact positively on the wellbeing of the family members or carers (Falloon, 2003). However, the availability of family or carer interventions within routine mental health service practice remains limited (Harvey & O'Hanlon, 2013). There is a growing body of literature examining why family-based interventions are not routinely offered to people with mental illness and those who support them, when there is clear evidence of effectiveness and cost-effectiveness (Dixon et al., 1999; Lucksted, McFarlane, Downing, Dixon, & Adams, 2011; Mihalopoulos, Magnus, Carter, & Vos, 2004). These studies outline the numerous challenges faced in establishing family and carer inclusive practice as routine, rather than innovative, practice.

According to diffusion of innovations theory, for health professionals to change their clinical practice, they must have heard about the alternative practice, see the benefits of, and believe it to be possible to deliver the alternative practice in their setting (Rogers, 2003). Consequently, they must have made a decision to adopt the new behaviour. Innovations that are compatible with existing philosophies and practices and limited in complexity are more likely to be adopted; and ongoing engagement in an alternative practice will be affected by the degree to which a service provider experiences a good fit of the innovation with their setting, their clientele and themselves (Greenlagh, Robert, MacFarlane, Bate, & Kyriakidou, 2004; Rogers, 2003). In addition, where there is organisational support, an internal advocate (or "champion") and available resources, there is a greater likelihood that innovations will be delivered (Backer, Liberman, & Kuehnel, 1986; Greenlagh et al., 2004).

However, the mental health service environment, which serves as the dissemination setting for family interventions, rarely has these characteristics (McFarlane, McNary, Dixon, Hornby, & Climett, 2001). Organisationally, mental health services are often wary or slow to change existing clinical practices even when the value of a new way of working has been proven (Panzano & Roth, 2006). Working with families and carers frequently represents a significant shift in the way therapists usually work (McFarlane et al., 2001). The interventions can be complicated to implement and benefits are usually not seen immediately (Fadden, 1997; McFarlane et al., 2001). Furthermore, mental health services are infrequently characterised by available resources in terms of time or money. Thus, the dissemination of family interventions for people with mental illness face a variety of challenges due to characteristics of the dissemination setting.

Despite this, increases in rates of family interventions provided by mental health and community providers have been achieved when quality training and technical support have been provided (e.g. Dixon et al., 1999; Magliano et al., 2006; McFarlane et al., 2001). Quality training involves an orientation to and demonstration of the innovation and opportunities for behavioural rehearsal of the skills discussed (Fixsen, Naoom, Blase, Friedman & Wallace, 2005). Technical support refers to coaching or on-the-job support to deliver an intervention. It is most effective when it involves interpersonal contact (particularly face-to-face) and is collaborative, ongoing and proactive in nature (Wandersman, Chien & Katz, 2012). Nevertheless, even with these supports, the routine use of family interventions has been modest with the average number of families seen by therapists exposed to family intervention training ranging from 1.4 to 3.5 families seen in a year (Bailey, Burbach, & Lea, 2003). Furthermore, dissemination studies report very high levels of therapist “drop-out”, with between 24% and 93% of clinicians trained in family interventions failing to go on to deliver

the program at all (Fadden, 1997; Kavanagh et al., 1993; McFarlane et al., 1993; McFarlane et al., 2001).

The issues that arise for therapists delivering family interventions for people with mental illness are similar across countries and service settings. Conflicting demands, limited time to see families, and difficulties integrating family work into regular work are most frequently identified (Dixon et al., 2001; Fadden, 1997; Kavanagh et al., 1993; Magliano et al., 2005; McFarlane, 2001; O'Hanlon et al., 2012). Lack of support from colleagues, lack of financial reimbursement and difficulties identifying and engaging families are also commonly identified barriers (Fadden, 1997; Kavanagh et al., 1993; Magliano et al., 2006; McFarlane et al., 2001).

Two studies have specifically investigated predictors of delivery of family interventions for people with mental illness after exposure to training and two additional studies have investigated the predictors of delivery of a positive parenting program. These studies highlight that capacity to engage in family work is associated with service setting (inpatient or community; Fadden, 1997), state residence (thought to index stakeholder engagement; McFarlane et al., 2001), and level of compatibility of existing clinical practice (McFarlane et al., 2001; Sanders, Prinz, & Shapiro, 2009; Turner, Nicholson & Sanders, 2011). Although these studies have tended to find that the number of barriers reported by clinicians was associated with program delivery rates, it is important to note that the barriers in and of themselves do not account for low program delivery rates, as some agencies managed to overcome or neutralise barriers that were similar across services (e.g. McFarlane et al., 2001). Comparative studies have highlighted the impact that brief versus intensive training can have on increasing rates of delivery of family interventions (e.g. Dixon et al., 1999; Farhall et al., 1998), however no study, within the area of family interventions for

people with mental illness, has investigated whether the amount of technical support provided within a cohort is associated with likelihood of program delivery.

To date, studies demonstrate that it is possible to increase the rates of delivery of family interventions within health services. They highlight the importance of quality training, the potential role of technical support, as well as the impact of service provider and organisational factors on the capacity of individuals to go on to deliver a family intervention. All of the studies have had limitations. Studies have been primarily conducted overseas, they have usually targeted families of people with schizophrenia and none of the predictor studies specific to mental health carers have looked at predictors at the level of individual facilitators (rather than site or agency predictors).

Depression is a prevalent mental health problem in Australia and prevention of mental ill-health in carers generally is a national priority. The evidence of the efficacy of carer-focused interventions for people with depression is slowly being established (Luciano et al., 2012). However, little is known about how to engage the mental health workforce in supporting carers of people with depression, or what specific factors may influence service providers in delivering a new intervention in the Australian context. This study used the national dissemination of the *Partners in Depression* (PID) program in Australia to investigate which characteristics of the dissemination process (e.g. stakeholder engagement, training, program support provided) were associated with program delivery and whether any specific factors at the service provider and organisational level (including sector, role, location) predicted individual facilitator program delivery.

## Method

### Participants

Program data was reviewed from 427 service providers who completed a *Partners in Depression* facilitator training course in Australia between March 2010 and April 2011.

Facilitators learned of the training opportunity through a variety of sources, including service network mailing lists, the communication networks of peak professional bodies, and through direct contact with the project team. See Table 1 for an overview of facilitator demographics.

Table 1: *Facilitator Characteristics*

Characteristic	Total n= 427	Characteristic	Total n= 427
<b>Gender</b>		<b>Sector</b>	
Male	74 (17%)	Public Health Service-	
Female	353 (83%)	Mental Health Service	147 (35%)
		Community Health Service	25 (6%)
		Other	46 (11%)
<b>Location</b>		Non government organisation	146 (35%)
Major City	266 (55%)	Division of General Practice	9 (2%)
Inner Regional	130 (31%)	Private service provider	50 (12%)
Outer Regional	50 (12%)		
Remote	10 (2%)		
Very Remote	0 (0%)		
		<b>Organisation focus</b>	
<b>State</b>		Carers/ family	48 (13%)
New South Wales	179 (42%)	Person with mental illness	178 (47%)
Queensland	96 (22%)	Community clientele	123 (32%)
Victoria	60 (14%)	Other clientele	31 (8%)
Western Australia	42 (10%)		
Australian Capital Territory	11 (3%)	<b>Role</b>	
Northern Territory	12 (3%)	Core business	105 (26%)
South Australia	15 (3%)	Within scope	294 (69%)
Tasmania	12 (3%)	Outside usual work	21 (5%)

## Procedure

This study used quality assurance data collected as part of the *Partners in Depression* national dissemination project, as conducted between March 2010 and April 2012. At application point, all facilitators provided written agreement that they would support the evaluation strategy for the project (e.g. distribute the outcome questionnaire to group participants). Details about the evaluation protocol and use of data collected were discussed in each training course. At the end of each facilitator training course, all facilitators were invited to complete an anonymous training evaluation questionnaire. Facilitators contacted the project team to register when they planned to run a group, in the event they had to cancel a group, to

return quality assurance measures, and if they wanted assistance with any emerging program delivery issues. All contacts were recorded in a project communications database. Facilitators were invited to complete a program delivery feedback questionnaire after they had delivered a program. All quality assurance and evaluation materials were sent directly to facilitators and marked clearly with regard to which were required as part of the program delivery and accreditation process (e.g. session fidelity checklists) and which were voluntary (and offered for quality improvement purposes). Consent was gained for any additional information that was collected beyond that required for routine running of the project.

The evaluation of the *Partners in Depression* national dissemination project was approved by Hunter New England Human Research Ethics Committee.

## **Measures**

### ***Sector engagement***

Information about the strategies used to engage stakeholders was drawn from project documents (e.g. progress reports) and project team reports.

### ***Facilitator training***

A training evaluation questionnaire was developed for this project. It comprised seventeen questions including rating of training (1= *poor*; 6= *excellent*), and Likert scale ratings about specific aspects of the training experience (e.g. How well was the training objective met: to become familiar with the *Partners in Depression* program and supporting materials? 1= *not at all* to 4= *extremely well*). Intention to proceed and become an accredited facilitator was coded with a yes or no response. Free text comments were invited regarding the most and least valuable aspects of the training, as well as issues that they felt would impact on program delivery.



***Facilitator characteristics***

Demographic information about facilitators was drawn from the information that was provided at the application point. Location was coded using the Australian Bureau of Statistics (2006) remoteness structure code where locations are coded as indexing major cities, inner regional areas, outer regional areas, remote or very remote locations, based on their postcode. The remoteness coding system is based on distance to the nearest service centre from that location. Role, service and sector information was used to code whether program delivery represented core business (e.g. Family Worker or Carer Consultant), was within scope of best practice (e.g. clinician with Mental Health Service or in a community setting) or was outside usual work practices (e.g. Sexual Health clinician); and which sector the facilitator worked in (public health, other public service [e.g. Defence, TAFE, Drug and Alcohol Services, etc.], non-government, division of general practice or private sector).

Information regarding facilitator status was drawn from the project database as recorded in June 2012. Facilitators who had not delivered the program at all or who were not going to be able to deliver the three programs within the required time period were withdrawn. The decision to withdraw could be made by the facilitator (voluntary) or by the project team (forced). Reason for withdrawal was recorded.

***Program delivery***

Information about program delivery was drawn from the records of contact that the project team had with facilitators. The total numbers of delivered and cancelled groups were calculated. Information regarding recruitment strategies was drawn from the post program facilitator feedback questionnaire and the pre-program questionnaire for group attendees.

***Program support***

The record of contact between the project team and facilitators from March 2010 to April 2012 was used to calculate the number of discussions held, attempts to contact, and discussions held with a facilitator's partner.

***Quality assurance***

After each program, facilitators returned the quality assurance measures, including outcomes questionnaires for group members and session fidelity checklists. Group attendee outcomes are not discussed in this paper (see Study 2). Facilitators could also complete a facilitator post program feedback questionnaire which included questions about their experience of program delivery (e.g. I felt equipped to facilitate the *Partners in Depression* program; 1= *strongly disagree* and 5= *strongly agree*), as well as ratings on usefulness of program topics and recruitment experiences.

**Intervention description and dissemination strategy*****Partners in Depression- Supporting those who care***

The *Partners in Depression* program is a six-session group education program for those who love, care for or live with a person experiencing depression. It is run by two health or community professionals and focuses on providing information about depression and its treatments, communication skills, and self care. The program was developed by Hunter Institute of Mental Health (HIMH) to address a locally identified gap in services and support for carers of people with depression. The pilot evaluation showed that the program met participants' expectations, addressed the stated information goals and was associated with a significant improvement in participants' psychological distress (see Appendix A for details). In 2009, HIMH were funded to engage in a national dissemination of the program.

*National dissemination strategy*

The national dissemination of the *Partners in Depression* program occurred between August 2009 and June 2012. It used a facilitator training and capacity building approach. In summary, free facilitator program training and support was made available to health and community professionals across the country who met eligibility criteria and who agreed to deliver the program at least three times in the twelve months following training.

A number of strategies were utilised to maximise the likelihood of effective dissemination. A national reference group was established. The reference group provided advice on the dissemination strategy, how to extend the reach and penetration of the program, as well as facilitated links with stakeholder groups. The reference group comprised a range of experts from service settings, peak bodies and professional groups. Furthermore, prior to facilitator training, meetings were held with high level stakeholders across the country (e.g. state mental health department directors or policy officers, non-government organisation directors, etc.) to garner specific support and commitment to the program being run by their staff.

Facilitator recruitment involved promotion of the facilitator training through a variety of communication networks (as advised by the reference group and stakeholders). Interested health and community professionals completed an application process indicating how they met eligibility criteria. Eligibility criteria included having existing mental health knowledge, experience in running groups, and management support to deliver the program. People who met criteria were invited to attend the two-day facilitator training course. The training course included orientation to the *Partners in Depression* program, observation and delivery of program activities by participants, discussion of how to manage common issues that might arise in program delivery, an open book knowledge test, and completion of an implementation

plan. Training followed a standardised format and was delivered by the same primary trainer (first author) throughout the country.

Facilitators were also provided with a variety of program delivery supports (or “technical assistance”), which were designed to reduce the demands and complexities of delivering the program. These program delivery supports included a facilitator manual, pre-prepared group member resource packs, access to a “facilitator only” section of the project website which made available newly developed materials (e.g. tips on delivering the program with specific sub-populations, templates for supporting activities such as confirmation letters), and opportunities to take part in peer facilitator teleconferences. Additional technical assistance was provided in the form of proactive follow-up phone calls from the project team to facilitators who had not planned for program delivery within two months of having attended training. The aim of these follow-up phone calls was to assist with troubleshooting and encourage facilitators to plan and prepare to deliver a program.

Finally, there were a variety of quality assurance measures that monitored program effect and which were designed to ensure that the program was delivered as intended. The quality assurance measures included group participant outcome and evaluation questionnaires, feedback from the project team to facilitators regarding their own group statistics (e.g. % of participants reporting improvements), benchmark indicators (based on all program recorded data to date) which were available on the project website, session fidelity checklists (where facilitators recorded any deviations from expected program delivery and any issues that arose in the delivery), opportunity for facilitator program delivery feedback through questionnaires and focus groups, and a requirement that all facilitators engage in individual supervision throughout the program delivery timeframe. To become an accredited facilitator, facilitators had to deliver the program at least three times, complete session fidelity checklists for each

program delivered, ensure group member outcome questionnaires were distributed, and have no quality issues identified through the quality assurance parameters.

### **Data analysis**

Initially, descriptive statistical analyses were conducted. T tests, chi squares and ANOVAs (or their non parametric equivalents) were used to explore group differences in program delivery. Due to the limited number of facilitators who delivered more than one program, program delivery was treated as a dichotomous variable (did not deliver any programs or delivered at least one program), unless otherwise stated. A logistic regression was conducted to predict program delivery using state, region (major city or regional), sector (public mental health services, public community health service, other public service, non-government organisation including divisions of general practice, private service provider) and role capacity (core business, within scope, outside of usual work) as predictors. Variables were entered as a group as no specific hypotheses about order or importance had been generated. The regression was repeated adding level of support as a predictor to identify if it increased accuracy of the model.

## **Results**

### **Stakeholder engagement**

A different facilitator recruitment strategy was used in each state or territory, based on the level of interest and commitment indicated by high level stakeholders. Meetings were held with state mental health departments, the state carer auspicing organisation and the state GP network organisation, as well as other relevant stakeholders in that jurisdiction. The support provided by these organisations is outlined in Table 2.

### **Facilitator training**

For the national dissemination, 32 standard two-day facilitator training courses were delivered across Australia by the same primary trainer (first author) in an eleven month

period. A total of 406 facilitators attended these training courses. An additional 21 people were trained in the program outside of these training courses. Of those who attended the standard training courses, 379 facilitators completed a training evaluation questionnaire, representing a response rate of 93%.

Overall, facilitators indicated a high level of satisfaction with the training, with 99% indicating that the training met their expectations. All respondents indicated that all training objectives were met at least somewhat well. The skills display and role play exercises were rated as useful or extremely useful by 96% of facilitators for preparing them for facilitating the *PID* program and understanding how participants may experience the program. A lesser percentage (88%) rated the implementation planning exercise as useful. The most frequently mentioned valuable aspects of the training were the role play exercises, the *PID* program content and resources, and the credibility of the trainers. The most frequently mentioned least valuable aspects of the training included the didactic nature of the first day of training, housekeeping issues, and the short duration of the training in comparison to the amount of information to be covered. Ratings about the trainers were high with 98% or more of facilitators rating as well or somewhat well the trainers' capacity to deliver the material clearly, answer questions, run the role play exercises, and lead discussion. Overall, 96% of the sample rated the training as good or very good. No one rated it as poor or fair. The average rating of training was 4.44 ( $SD= 0.59$ ), with a ceiling score of 5.

As a result of the training, 84% of the sample reported that they felt prepared or extremely prepared to deliver the program; 16% reported feeling only somewhat prepared. Furthermore, 93% of facilitators indicated that they intended to deliver the program and become an accredited facilitator, 6% were not sure and 1% were not intending to proceed with delivery of the program.

Table 2: *Stakeholder Engagement*

Jurisdiction	Training venue provided free of charge	Facilitator training information distributed to relevant staff	In principle support for program delivery by staff	Other support provided	Other comments
Australian Capital Territory	By MHS	✓	✓	MHS policy officer identified to establish & coordinate local implementation group	
New South Wales	By NGOs	✓	✓		Existing relevant infrastructure for program delivery through Family and Carers Mental Health Program funded organisations
Northern Territory	By NGOs	✓	✓		
Queensland		✓	✓	State MH Department made available \$500 funding support for QH staff, to cover accommodation or travel costs associated with attending training	
South Australia		By NGOs	✓		
Tasmania	By MHS	✓	✓		
Victoria	By NGOs & VicHealth	✓	✓		Facilitators reported advocating 'up' for permission to attend training, rather than having been provided information by auspicing organisation
Western Australia	By MHS	✓	✓		Rural facilitators established their own local implementation groups

*Note.* MHS= Mental Health Services; NGOs= Non government organisations; QH= Queensland Health

## Facilitators

Of the 427 facilitators, 56% failed to deliver any programs, 18% delivered one program, 7% delivered two programs and 19% had delivered three or more programs as of April, 2012. Of the total sample, 18% of facilitators reached full accreditation status (delivered three or more programs and met quality assurance requirements) and 19% remained actively involved in the program, but had not yet reached accreditation state. Nearly two-thirds (63%) of all facilitators were withdrawn. For those for whom type of withdrawal was recorded ( $n = 219$  of 269), the majority (63%) withdrew voluntarily. Table 3 shows the most common reasons for withdrawal.

Table 3: *Reasons for Withdrawal*

Reasons for withdrawal	Proportion of facilitators ( $n = 269$ )
Operational difficulties	42%
Recruitment/ time/ workload issues	27%
Job role changes/ staffing/ management support issues	7%
Unable to identify a partner	6%
Unable to secure cost recovery	1%
Program competition in area	2%
Left organisation/ extended leave	16%
Personal reasons (e.g. sickness)	6%
Not able to be contacted	12%
Special consideration rejected	4%
Missing	19%

## Program delivery

### *Number of programs delivered*

A total of 211 *Partners in Depression* groups were run between March 2010 and April 2012. Overall, 44% of the 427 trained facilitators delivered at least one *Partners in Depression* program and the average number of programs delivered by each facilitator across the sample was 0.9 ( $SD = 1.2$ ).



An additional 121 groups were cancelled or postponed during the timeframe of interest. Proportionally, Queensland, Victoria, New South Wales and Western Australia had the greatest proportion of groups cancelled (34% or more of groups planned). However, there was no valid statistical difference in the proportion of groups cancelled by state because of low numbers for smaller states. In contrast, there were significantly more groups cancelled in city areas compared to regional or rural areas (44% compared to 27% of scheduled groups),  $\chi^2 = 25.51, p = .001$ . See Table 4 for details. Of the facilitators who did not deliver a group in the twelve months following training, over one third of these facilitators (39%) cancelled at least one group (representing at least some intention to deliver the program). There was a small percentage of facilitators (6%) who made multiple delivery attempts and cancelled three or more groups (see Figure 1). The most common reason for cancelling a group was problems with recruitment. This accounted for 91% of the cancellations/ postponements. Even for those who had run a group, the majority (58%) reported that they had faced specific challenges in recruitment of group members.

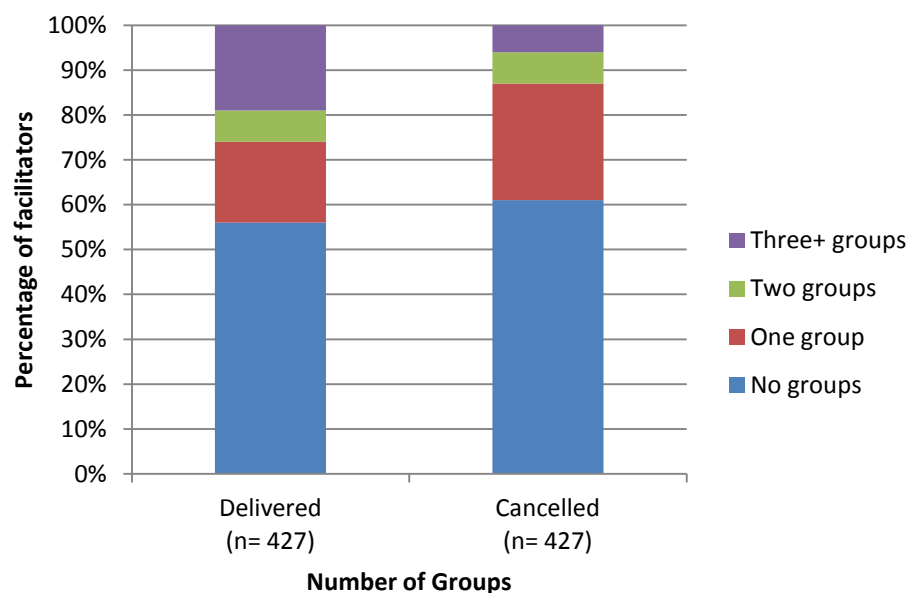


Figure 1: Percentage of facilitators who delivered and cancelled 0-3 groups

Table 4: *Program Delivery by State and Location*

	Number of delivered groups	Number of cancelled groups	Av number of group attendees
<b>State</b>			
New South Wales	104	63	6.6 (3.3)
Queensland	19	21	5.2 (2.1)
Victoria	39	21	5.9 (2.8)
Western Australia	17	10	6.4 (2.0)
Australian Capital Territory	8	0	8.5 (2.7)
Northern Territory	6	1	6.5 (2.5)
South Australia	9	2	4.9 (1.9)
Tasmania	9	3	5.9 (1.7)
<b>Location</b>			
Major City	96	77	6.7 (3.3)
Inner Regional	76	37	6.2 (2.7)
Outer Regional	33	7	5.4 (2.0)
Remote	7	0	5.5 (2.2)
<b>Overall</b>	211	121	6.3 (2.9)

**Characteristics of support provided to facilitators to deliver the program**

There were a total of 411 recorded proactive project team follow-up phone discussions held with 303 facilitators who had not registered a plan to deliver the program within two months of attending training; and an additional 471 attempts to contact the same group.

Overall, there was a discussion held with at least one person for each facilitator pair for over four-fifths (81%) of the sample and the mean number of discussions held with each facilitator was one ( $SD= 1.04$ ). One-quarter (25%) of the sample had two or more discussions with the project team. No discussion was held with one-fifth (19%) of facilitators, although there had been at least one attempt to contact each individual for all but one facilitator. Of those facilitators who completed the facilitator program feedback questionnaire ( $n= 98$ ), nearly all agreed (50%) or strongly agreed (43.9%) that HIMH provided the support they needed. The remaining 6% were neutral.

Table 5: *Program Delivery by Facilitator Characteristics and Level of Support Provided*  
(percentage= row proportion)

	Delivered no groups	Delivered 1+ groups	Total	Chi square
<b>State</b>				$\chi^2 = 25.51, p=.001$
Australian Capital Territory	4 (36%)	7 (64%)	11	
New South Wales	88 (49%)	91 (51%)	174	
Northern Territory	8 (67%)	4 (33%)	12	
Queensland	73 (76%)	23 (24%)	96	
South Australia	8 (53%)	7 (47%)	15	
Tasmania	4 (33%)	8 (67%)	12	
Victoria	29 (48%)	31 (52%)	60	
Western Australia	25 (66%)	17 (48%)	42	
<i>Total</i>	238	188	426	
<b>Region</b>				$\chi^2 = 3.97, p=.05$
Major city	142 (60%)	94 (40%)	236	
Regional areas	96 (51%)	94 (49%)	190	
<i>Total</i>	238	188	426	
<b>Role capacity</b>				$\chi^2 = 18.94, p=.001$
Core business	40 (38%)	65 (62%)	105	
Within scope	180 (61%)	114 (38%)	294	
Outside of usual work	15 (71%)	6 (29%)	21	
<i>Total</i>	238	188	426	
<b>Sector</b>				$\chi^2 = 14.10, p=.01$
Public mental health	83 (57%)	64 (44%)	147	
Public community health	14 (56%)	11 (44%)	25	
Public other	31 (67%)	15 (33%)	46	
Non government*	71 (46%)	84 (54%)	155	
Private service provider	36 (72%)	14 (28%)	50	
<i>Total</i>	238	188	426	
<b>Level of support</b>				$\chi^2 = 7.57, p=.05$
No discussions	40 (66%)	20 (33%)	60	
1-2 discussions	123 (60%)	80 (40%)	203	
3+ discussions	34 (82%)	7 (18%)	41	
<i>Total</i>	197	107	304	

## Predictors of program delivery

### *Associations between program delivery and facilitator characteristics*

Table 5 provides an overview of program delivery across facilitator characteristics including chi square analyses. In summary, program delivery was significantly associated with each facilitator characteristic.

The proportion of facilitators who had delivered *Partners in Depression* programs differed by state. Facilitators from regions other than major cities were somewhat more likely to deliver the program (49% delivered it compared to 40%), reaching statistical significance when the programs delivered in non-major cities were collapsed into one regional category. The highest proportion of facilitators who delivered three programs were those whose roles meant that delivering a *Partners in Depression* program was consistent with their core business (62% of this group delivered at least one program of which 31% delivered three programs). The proportion of facilitators who delivered any groups by sector (mental health service, community health service, other public health service, non government organisation, private service providers) was statistically significant with private service providers and general public health services being much less likely to deliver groups than the others and non-government organisations being more likely to deliver groups.

### *Associations between program delivery and provided support*

Table 6 shows that, in general, facilitators who had not delivered a group received slightly more phone support than those who had delivered a group. However, these mean differences were not significant except for average number of attempts to contact,  $t(290)=6.59, p=.001$ , where there was a higher number of failed attempts to contact for those who had not delivered a group compared to those who had delivered a group.

Overall, there had been at least one discussion with the facilitator or their partner for 62% of those facilitators who had delivered at least one group. Twenty facilitators had

delivered one or more groups with no discussions needed with the project team. There had been at least one discussion with the person or their partner facilitator for 80% of those who had never delivered a group. There had been no discussion with the person or their partner facilitator for 20% ( $n=40$ ) of those who had never delivered a group.

The proportion of facilitators who had actually delivered at least one group was very similar, regardless of whether a discussion had been held or not (about 34%). However, when total number of discussions was collapsed into none, one to two discussions, or three discussions or more, there was a statistically significant difference,  $\chi^2=7.57$ ,  $df=2$ ,  $p=.023$ , with those facilitators with whom there were three or more discussions held being much less likely to deliver the program.

Table 6: *Number of Contacts with Each Facilitator by Program Delivery*

Average total number of...	Delivered no groups	Delivered 1+ groups	Overall	Significance
Attempts to contact	1.94 (1.70)	0.84 (1.20)	1.55 (1.64)	$t(290)=6.59$ , $p=.001^*$
Discussion with facilitator	1.03 (1.02)	0.84 (1.05)	0.96 (1.04)	$t(301)=1.48$ , $p=.14$
Discussion with facilitator's partner	0.38 (0.67)	0.42 (0.60)	0.49 (1.04)	$t(302)=-0.55$ , $p=.58$
Total number of discussions per facilitator	1.39 (1.11)	1.28 (1.04)	1.35 (1.09)	$t(302)=0.85$ , $p=.40$

Note. \*= significant result

***Logistic regression***

A logistic regression analysis indicated that the impact of state, region, sector and role capacity, as a group, reliably distinguished between those facilitators who did and did not deliver the program,  $\chi^2 = 51.36$ ,  $df = 14$ ,  $p = .001$ , Nagelkerke's  $R^2 = .16$ . Individually, those who were more likely to deliver the program worked in roles where program delivery was consistent with their 'core business'. Further, the impact of state was significant, with being located in Queensland, Western Australia and the Northern Territory being most associated negatively with program delivery (see Table 7). The overall correct classification of facilitators' program delivery was 66%, with a higher accuracy (72%) for identifying non-delivering facilitators compared to prediction of those who did deliver the program (59% accuracy).

When level of support was added to the above analysis, the impact of role capacity-core business,  $\chi^2 = 19.28$ ,  $df = 2$ ,  $p = .006$ , and state,  $\chi^2 = 10.31$ ,  $df = 7$ ,  $p = .007$ , remained significant. Level of support also significantly contributed to the accuracy of program delivery prediction,  $\chi^2 = 6.34$ ,  $df = 7$ ,  $p = .04$ . Including level of support increased the Nagelkerke's  $R^2$  to .18 and overall predictor accuracy of the model increased to 71%. However, the accuracy was differential; adding level of provided support increased the accuracy to 90% for prediction of those who did not deliver the program, but the accuracy of prediction for those who did deliver the program dropped to 35%. This finding highlights that facilitators who did not deliver the program were more likely to receive more phone calls, however, it was not a differential variable, as facilitators who did deliver the program also received more phone calls, probably due to the confounding variable of time.

Table 7: *Summary of the Logistic Regression for Program Delivery (Reference Category is: At Least One Group Delivered)*

Predictor	$\beta$	SE $\beta$	Wald's $\chi^2$	p	e $^{\beta}$
<b>State</b>					
NSW	0.99	0.68	2.11	0.15	2.69
Queensland	2.15	0.71	9.08	0.00	8.58
Victoria	1.17	0.72	2.62	0.12	3.22
Western Australia	1.64	0.76	4.73	0.03	5.18
South Australia	1.63	0.88	3.47	0.62	5.12
Tasmania	1.03	0.96	1.15	0.28	2.81
Northern Territory	2.20	0.97	5.13	0.02	8.98
Australian Capital Territory <sup>a</sup>	0	-	-	-	-
<b>Sector</b>					
Public- Mental health service	-0.52	0.38	1.95	0.16	0.59
Public- Community health service	-0.59	0.55	1.14	0.29	0.56
Public- other	-0.24	0.48	0.01	0.96	0.98
Non government	-0.79	0.39	3.99	0.05	0.46
Private <sup>a</sup>	0	-	-	-	-
<b>Role</b>					
Core business	-1.30	0.57	5.13	0.02	0.27
Within scope	-0.57	0.53	1.14	0.29	0.57
Outside of usual work <sup>a</sup>	0	-	-	-	-
<b>Location</b>					
Major city	0.42	0.23	3.35	0.07	1.53
Regional & rural areas <sup>a</sup>	0	-	-	-	-

Note. a= The parameter is set to zero because it is redundant

### Discussion

Overall, this study highlights the difficulties that exist in making an intervention shown to be helpful in one setting available to the general community. Even with a range of supports, pre-training explicit commitment to program delivery, and high intention to deliver after training, only about half of all facilitators actually delivered the program. Even more concerning, only one-fifth of facilitators had delivered the program three times within twelve months suggesting that the capacity for this program to be embedded into ‘normal’ work was limited. These findings suggest that there are specific difficulties in Australia in disseminating and making routinely available a specific program for carers of people with depression. The overall interplay between factors that appeared to impact on program delivery has been schematically represented in Figure 2. This figure includes factors that have been described in the results section, as well as other variables that the project team observed to be important.

Despite the limited level of program delivery, there were a number of aspects of the dissemination process that were successful. Firstly, the findings from this study suggest that it was not the design of the facilitator training that accounted for the low delivery rate. Facilitators almost universally indicated a high level of satisfaction with the training experience and at the end of the training program, a clear implementation intention. This suggests that the training had resulted in establishing a group of service providers with specific intention to deliver the program, and, in terms of Rogers (2003) diffusion of innovation theory, the dissemination strategy was effective in leading people to an “adoption decision”. Thus, it does not appear that an inadequate orientation to the program or a lack of confidence about how to deliver the program underlay the reason for the low program delivery rate, although this should be considered in light of evidence that shows that this immediately after training is when confidence is usually highest while capacity to translate ideas into action is most fragile (Fixsen, Naoom, Blase, Friedman & Wallace, 2005).



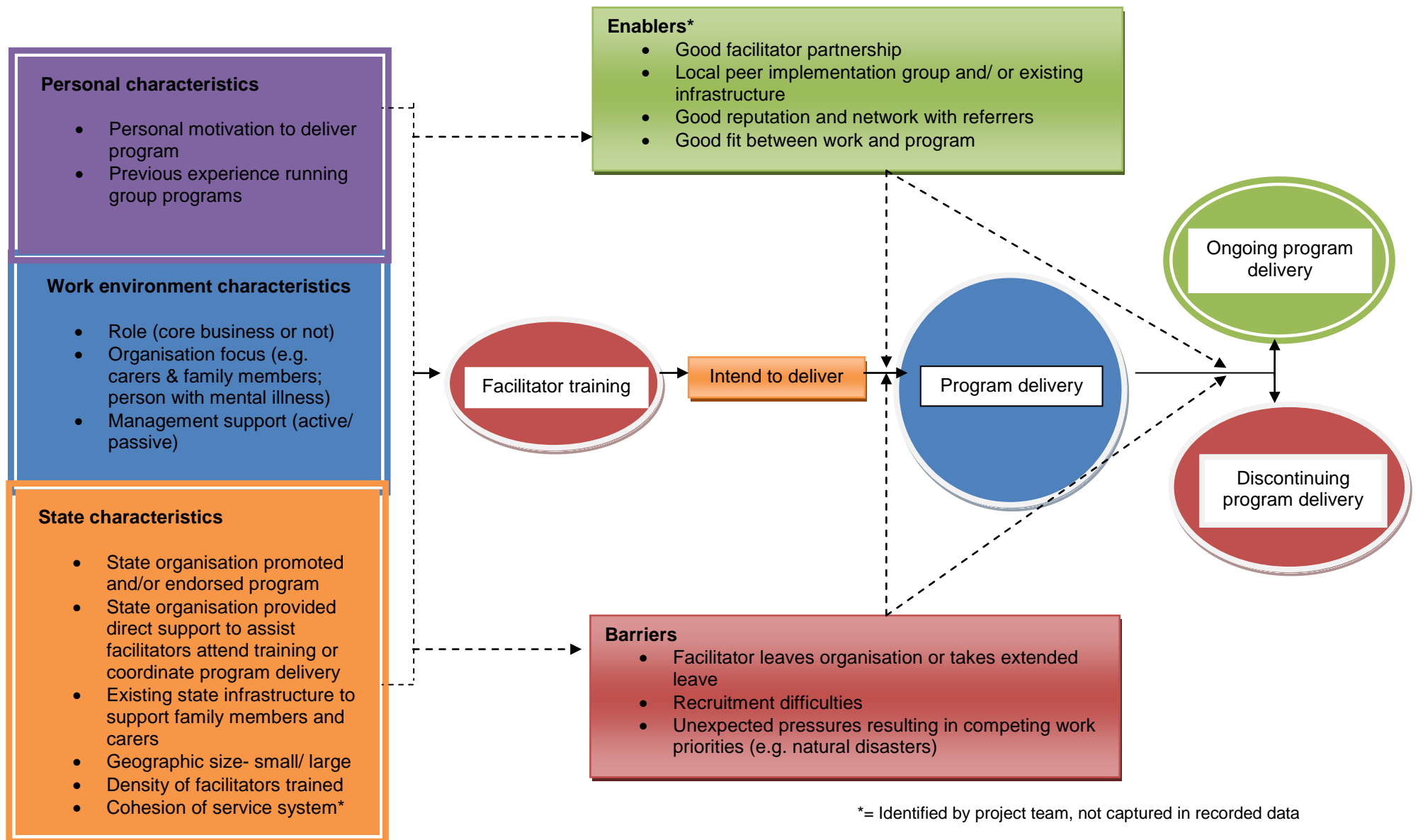


Figure 2: Factors influencing program delivery

Secondly, the national dissemination strategy effectively attracted a range of service providers from across sectors, organisations, and regions. Diversity of facilitators was important because the specific target audience for the *Partners in Depression* program (carers of people with depression) are rarely offered services by any one particular sector, rather they are likely to be in contact with a range of organisations and sectors. By attracting facilitators from across the spectrum there was greater capacity for the program to be made available to more people in the community who were caring for a person with depression, and for increased opportunities to help embed carer inclusive practice within routine mental health work. Thus, the recruitment strategies used were effective in recruiting appropriate facilitators.

Thirdly, the project was successful at getting high level stakeholder buy in, support, and endorsement in nearly all jurisdictions. This was important because the project did not have the capacity to pay facilitators for program delivery and consequently, needed stakeholder buy in for program delivery to occur. Furthermore, because the program was, for some organisations, not typical of the work they engaged in, high level stakeholder support was needed to ensure program delivery could be accepted as appropriate work.

However, this dissemination effort, like other family intervention dissemination efforts, had only a minority of trained facilitators actually go on to deliver the program. Consistent with Greenlagh et al.'s (2004) review, and like the experiences of McFarlane et al. (2001) and Dixon et al. (1999), the compatibility of the program with facilitators' usual ways of working (as indicated by their work role) was a significant predictor of whether an individual went on to deliver the program. This highlights that those facilitators for whom program delivery was consistent with their core/ usual business had more capacity (or more effective ways of addressing the barriers) than those for whom delivering the intervention was consistent with best practice (but not typical of core business), or when it was specifically out of scope.

This study extends the diffusions of innovations theory (Rogers, 2003) by demonstrating the importance of “macro” factors, with state residence being a significant predictor of program delivery. It is difficult to know exactly what state residence captured. It may reflect the impact on individual service providers’ program delivery capacity of: level of stakeholder buy in, existing carer relevant service and support infrastructure, the density of facilitators trained within an area, the efficiency of referral networks, the impact of specific geographical crises that occurred during the dissemination periods (e.g. devastating floods occurred in Queensland), or a combination of these factors. Regardless, this study highlights that factors beyond the control of individual service providers, and the project team, appeared to play an important role in whether facilitators were able to deliver the program or not. This finding is not unusual or unique. In his study of delivery of family interventions after training 66 mental health agencies in Maine and Illinois (United States), McFarlane et al. (2001) found that state residence was the most significant predictor of program delivery (with 10% versus 93% of agencies delivering family interventions at follow-up in Illinois and Maine respectively). McFarlane suggested that this difference was a consequence of stakeholder buy in and the different approach to dissemination used in each state (e.g. collaboratively developed or driven by management). In this study, there were also varying levels of stakeholder buy in, however level of buy in did not correlate well with program delivery rates, indicating that other state-related factors appeared to be at work.

The importance of technical support has been demonstrated in previous studies where more intensive support has been associated with higher rates of program delivery (Wandersman et al., 2012). This was not seen in this study. Rather, the more discussions held with a facilitator, the less likely they were to deliver the program. Thus, measuring the frequency of individual technical support appeared to index the difficulty with which a facilitator had in delivering the program, rather than indicating that more support translated into more capacity to be able to overcome the program delivery barriers. This is an important

finding as it suggests that the most resources (in terms of project team time and energy) were spent on non-delivering facilitators, and this was not necessarily associated with a clear benefit with regard to enabling a facilitator to move from program delivery contemplation to implementation. This may suggest that it would be sensible to identify a benchmark whereby if a facilitator has not been able to move to implementation after a certain amount of support (e.g. two phone calls), they are withdrawn early rather than provided with ongoing support. It may also be that the technical support was offered too late and should have been provided much earlier (e.g. within two weeks of attending training). However, it is also possible that two groups of facilitators exist- those who can implement family interventions with relatively little support and those who experience significant barriers and require much more technical support; such that rather than the support provided not being helpful, it may be that the minimum level of support needed by the high-needs facilitators had not been met in this study. The limited impact that technical support had, again, highlights the key role that organisational or macro factors played in the dissemination of this family-focused intervention and suggests that priority must be placed on addressing barriers at the organisational level, before more individual support will make a difference to the dissemination process.

Similar to previous studies, including other Australian studies (e.g. Kavanagh et al., 1993; O'Hanlon et al., 2012), difficulties in identifying and engaging families (coded in this study as "recruitment") were identified by facilitators as a primary and specific barrier to delivering the program. It is difficult to know whether this issue is a reflection of low community interest or need for the program, or actually due to difficulties of service providers connecting with the target population. It is of interest to note that in a previous study, Magliano et al. (2005) found that the issue of identifying and engaging with families was a barrier that reduced over time. This, coupled with the apparent enabling impact of program delivery being consistent with core business, suggests that the recruitment issue may be more

about a problem of connecting with the target audience rather than a lack of demand or interest from the target group. Furthermore, the finding that groups scheduled in major cities were more likely to be cancelled than groups in regional and rural areas would also be consistent with the suggestion that the issue was with connecting with the target audience rather than lack of interest. That is, the project team noticed that facilitators in city areas had weaker direct connections with their community (or potential clientele) and their referral network whereas facilitators in regional and rural areas appeared to have much stronger and more integrated networks. It is suggested that this factor may somewhat account for the differential cancellation rate, highlighting that when the target audience for the program found out about it, there tended to be interest.

Although in some ways disappointing, it is important to consider these dissemination effectiveness findings in the broader context. Having 46% of facilitators deliver at least one program is better than the very low rates of transfer (e.g. 0- 30%) found in previous studies that relied on training alone (Fixsen et al., 2002). It is also comparable with the rates reported in other studies that have specifically looked at disseminating family interventions for people with mental illness in other countries (e.g. Dixon et al., 1999; Fadden, 1997; McFarlane et al., 2001) and in Australia (e.g. Kavanagh et al., 1993); although a higher rate (74%) has been reported for an Australian dissemination study of a family intervention for people with schizophrenia that used a much more intensive support strategy (embedded practitioner within the service; O’Hanlon et al., 2012) . Thus, although the effectiveness of the dissemination approach used for this program did not result in ideal outcomes it could not be considered a failure when taking into account the size and breadth of the program delivery achieved with a relatively basic level of provided technical support.

The present study has a number of limitations. Firstly, it used a data mining approach and utilised a convenience sample. Although a limitation, the fact that there was still not a high level of program delivery amongst this self-selecting sample suggests that dissemination

of such an intervention among non-interested clinicians would be even lower. Future research could extend the evidence base by using dissemination approaches with different levels or types of technical support and different participant groups (e.g. self-selecting and non-self-selecting), as well as by using additional measures to better capture barriers and enabling factors, such as those observed by the team and outlined in Figure 2. It would appear to be particularly important to more closely investigate what factors enabled service providers to overcome barriers as this may suggest ways of increasing capacity in general mental health and community settings. Furthermore, from the current study we do not know if attending the training had any generalised effects that were not specific to delivery of the *Partners in Depression* program (e.g. impact on family inclusive practices engaged in by facilitators as part of their routine work) and this will be an important area for exploration in determining the true success of the dissemination approach.

This study has provided useful information and contributed to the limited family intervention dissemination evidence base. It reinforces that the most efficient way of increasing delivery of family interventions may be to target workers for whom it is compatible with their existing practice; but that training alone is not sufficient in enabling clinicians to engage in family interventions- even if they have reached an “adoption” decision. The study highlights the impact of external factors, on a macro and individual level, and that these need to be taken into account in the development of dissemination strategies. Finally, this study draws attention to the need for more exploration around how and what sort of technical assistance can be provided to assist clinicians to engage in new clinical practices. It would appear that dissemination of family interventions in Australia is affected by similar factors as those experienced overseas. Hopefully, through the lessons learned from this real-life example about the issues that emerge in the dissemination process, we can become closer to ensuring that all people whose lives have been impacted by depression have access to supports that help.

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## DISCUSSION

Taken together, these studies draw attention to the vulnerability of Australian carers of people with depression to mental ill-health. The findings show the importance of, and potential benefits to be gained from, providing support to carers of people with depression and highlight a specific intervention that warrants further investigation. The findings support the feasibility of delivering a carer/ depression specific intervention within the existing service system and provide some indications as to how dissemination could be implemented more efficiently. However, these studies also underscore the need for ongoing research in this area and represent just the first step to ensuring that Australian carers of people with depression are supported appropriately and effectively. In this section of the thesis, I provide an overview of the key conclusions drawn from the studies. I consider the implications and make recommendations about how to best support carers of people with depression. A model is presented to complement these recommendations. I conclude the discussion with a consideration of the limitations of the studies and an overview of the key messages.

### Key conclusions

Five key conclusions have been drawn based on the findings from the three studies in this thesis and the existing evidence base. The conclusions are that:

- Australian carers of people with depression are at risk of mental ill-health, frequently to a level suggesting they would benefit from therapeutic support themselves.
- Many Australian carers of people with depression are interested in accessing information and receiving support to help them manage their role; and it is important that these carers are provided with ongoing access to appropriate, relevant and effective support.

- Continuing investigation is needed regarding the best way to provide support to carers of people with depression. The *Partners in Depression* program has promising efficacy and warrants further investigation.
- When providing support to carers of people with depression, objective burden and coping strategies may be important intervention targets that will improve the resilience and wellbeing of carers of people with depression.
- There are significant barriers to disseminating a specific group education program for carers of people with depression within Australia; and it may be that to overcome these barriers mental health services will need to be supported to become more family and carer inclusive.

These five conclusions are discussed in more detail below. They have been used to formulate recommendations about implications for practice.

### **Australian carers of people with depression are vulnerable to mental ill-health**

The studies in this thesis provide evidence that Australian help-seeking carers of people with depression are at much greater risk of mental ill-health than the general population. The participants in these studies were three times more likely to report a high level of psychological distress compared to the general population. Although the rates of psychological distress in the participants in these studies were high (70% scoring in the likely to be unwell range), they are within the range of what has been reported in other studies, including studies conducted with carers with people with depression in countries other than Australia (e.g. Coyne et al., 1987; Heru & Ryan, 2002; Spangenberg & Theron, 1999) as well as Australian large-scale studies of general carer populations (e.g. Cummins et al., 2007; Edwards & Higgins, 2008). It would appear then that the level of distress reported by the carers in these studies was not unusual, but rather that this high rate of mental ill-health across

studies is indicative of a vulnerability to poor mental health that is in some way associated with the caring role.

It is important, however, to acknowledge that the high rate of participant psychological distress in these studies may be a consequence of sample bias. These studies recruited people who self-identified as “carers” or who were interested in, or already in contact with, support services. It is possible that self-identified carers who are proactively help seeking are struggling with the carer role, meaning that they may be more likely to report psychological distress. This could mean that Australian carers of people with depression who do not self-identify or who are not in touch with services do not experience the same difficulties, such that the mental ill-health reported by this sample may be an over-estimation of the actual risk of the whole target group. Having said that, the opposite is also possible, that carers of people with depression who are not accessing services are struggling more than those in contact with services and it is the experience of additional difficulties that precludes them accessing more support. Either way, the rates of mental ill-health reported by carers in this study were similar to those reported in studies where the carer participant was recruited through the person with depression (meaning the carer participant did not necessarily self-identify as a carer and/ or were not themselves accessing support). Furthermore, the relationships between variables (e.g. gender, unemployment, location and mental health) were similar to more general studies (not specific to carers) suggesting that the sample was not necessarily unusual.

It is also possible that some of the sample’s specific characteristics contributed to the high rate of mental ill-health reported by participants. Participants in both of the first two studies were, on average, likely to be female, middle aged, English speaking and married, and the person they were supporting usually had a formal diagnosis of depression (meaning the person had accessed some form of treatment). Large scale studies of the general population

show that women are more vulnerable to depression and anxiety (ABS, 2007) and those who support a person with more severe mental illness (including depression) are also more likely to report significant psychological distress (Baronet, 1999; Piquart & Sorensen, 2003; Schulze & Rossler, 2005). Thus, if diagnosis is taken as a very basic indicator of illness severity (as not all people with depression receive a formal diagnosis and those who do, are likely to be more unwell), it is possible that the high rate of mental ill-health in this participant group was a consequence of contextual factors. Although the consistency of high rates of mental ill-health across sampling methods speaks against this, it is important to note that the vulnerability to mental ill-health seen in this sample may be due to factors other than just the carer role. In short, it seems likely that carers of people with depression are at greater risk of mental ill-health than the general population, and that this is particularly true for carers of people with depression who are already seeking support and assistance.

**Australian carers of people with depression who want information and support should have access to relevant, appropriate and effective supports**

The studies in this thesis highlight that many Australian carers of people with depression are interested in seeking help and support. Over 1200 people attended a *Partners in Depression* program in two years. Program delivery occurred across urban, regional, and remote locations and included program delivery with specific subpopulations (e.g. Chinese and Macedonian cultural groups, parents of young people with depression). That there was enough interest in the program across a variety of settings suggests that the program was addressing some need in the community. However, it is unclear as to whether the level of participant interest in the program represents the totality of interest or was rather the “tip of the iceberg”. Facilitators reported difficulties in recruitment, but it is possible that these difficulties were due to problems with service providers connecting with the target audience, rather than a lack of community interest in the program. This suggestion is supported by

participants' qualitative comments about their awareness of, and interest in, attending the program (e.g. in a focus group, one participant reported: *"I saw it on a poster at Domino's pizza. I was madly trying to write the number down without anybody seeing me. But it was so funny because I had been on the phone with Carers Australia, a million places, beyondblue, you name it! No one could send me anywhere"*). Either way, the sizeable number of people who attended the program coupled with the level of mental ill-health amongst the sample highlights that there is a need to ensure that carers of people with depression have ongoing access to appropriate and relevant supports.

### **We need to know more about the best way to support carers of people with depression**

There is an emerging evidence base exploring the impact and efficacy of interventions for carers of people with depression. Although promising, more work is needed to be able to draw conclusions about what sort of support best addresses the needs of this target group. Family psychoeducation has been the type of support most well investigated. However, to be able to draw firm conclusions about the efficacy of this sort of intervention for carers of people with depression specifically, there remains a need for studies with before-after designs, comparison groups, and standardised outcome measures.

Different sorts of interventions may offer different benefits, particularly if matched with a carer's interests and needs. Findings from the second study in this thesis showed that people have different motivations for attending a group education program. Fewer participants identified wanting to attend the program because of the "opportunities to talk with others with a similar experience" compared to those who attended because of interest in learning more about the relevant issues. Interestingly, the groups who were more likely to identify that they had attended the program because of the opportunity to connect with others (which included females and unemployed people) were also the groups who reported greater

mental health benefits from attending the program (see Appendix B for details). Thus, it may be that group programs are particularly helpful for those carers who feel socially isolated. Furthermore, it is possible that the difficulties reported by facilitators in recruiting group participants resulted from a lack of fit between the group format and what was appealing or convenient for the majority of the target population. These issues stress the importance of ensuring that a range of supports are available for carers of people with depression, although also highlighting that more research is needed to be able to identify what supports work best in what way for whom.

With specific reference to the brief group education format, the findings from the second study suggest that the *Partners in Depression* program is an appropriate group education program with promising mental health benefits for carers of people with depression. However, there is a pressing need to ensure that the mental health and wellbeing benefits identified by participants were due to program attendance rather than other factors (e.g. the passing of time, the person with depression recovering, access to other support). The capacity of these studies to draw firm conclusions about the efficacy of the program was limited by the lack of a control or comparison group. At a minimum, a study is needed with a waitlist control comparison group, if not a randomised controlled trial. Having established the effectiveness of the program in addressing the information goals and specific targeted behaviours, there is a need to better understand the mechanisms of change. Evidence regarding the impact of the program would be strengthened by supplementing the evaluation with standardised measures of helpseeking, communication and coping styles and more qualitative exploration of the benefits identified by participants and the impact on family relationships. Furthermore, there is a need to consider paradigms that can begin to explore what components of the intervention account for any benefits experienced (e.g. the program content, the group process, the access to additional supports).



There is also a need to further investigate the apparent differential benefit of the *Partners in Depression* program to specific participant groups. It is somewhat unclear why some participants experienced a greater reduction in psychological distress after attending the program compared to others, and whether the differential program impact was a consequence of a lack of fit of the program with certain population groups or due to a ‘floor’ effect (i.e. for some participant groups, psychological distress was already low at baseline, so the capacity to reduce it further was limited). Regardless, it should be investigated further as to why some participant groups reported benefits and others did not. These investigations may indicate that there is a need to develop program adaptations for which efficacy could be investigated. It may be useful, for example, to develop a specific youth version of the *Partners in Depression* program, which would cover material in a more youth friendly and engaging manner, be delivered specifically to a young group of participants and which could utilise online and social media support strategies. In summary though, it would appear that the *Partners in Depression* program is an appropriate intervention that is acceptable, and of interest to, both the target audience and mental health service providers; and consequently, should be further investigated.

### **Objective burden and coping strategies may be important intervention targets**

There are a range of different ways in which support can be provided to carers of people with depression. The first study in this thesis provided some indications as to what differentiates carers who are significantly stressed from those who are not. The two most important predictive factors of carer mental ill-health were objective carer burden (referring to the amount of practical support required of the carer) and use of dysfunctional, and less active, coping strategies. It may be that these factors are important to target when providing support to carers of people with depression. The importance of these factors in determining carer mental health has been identified in other studies (e.g. Spangenberg & Theron, 1999;

van Wijngaarden et al., 2004; van Wijngaarden et al., 2009). The consistency of the findings from this study with previous studies lends support to the suggestion that it may be important to target these issues when providing support to carers of people with depression. Thus, interventions and supports that aim to improve carer mental health and wellbeing may seek to try and lighten the carer 'load'. This may involve supporting carers to address specific issues brought about by the impact of the illness (e.g. increased friction with family members, impact on household routine, reduced leisure time) or by helping carers to feel more comfortable in seeking and accepting help from informal and formal sources.

The predictive relationship between coping skills and carer mental health has been reported by other investigators. This study highlighted that "coping" is a broad concept and that the more challenging the stressor, the greater the number of strategies reported as being used by participants. The data also suggested that the use of emotion-focused coping strategies and reduced active coping were specifically associated with poorer mental health. Thus, the way a person responds to stressors may exacerbate or reduce the stressor and/ or the impact of the stressor. A longitudinal, experimental study is needed to confirm that coping strategies account for improvements in carer mental health and wellbeing, however, the findings from this cross-sectional study seem to suggest that one way of increasing carer resilience may be to support carers of people with depression to avoid using specific types of coping.

As described by Pearlin et al. (1990), this study confirmed the importance of the nature of the primary stressor in determining carer mental health. In contrast to the other determinants described by Pearlin et al., while coping strategies were significantly related to carer mental health, social support was not. It is unclear as to whether this finding was due to the way in which social support was assessed, whether the type of social support accessed by this group did not address their needs or whether it is a true null finding. Regardless, the

findings from this study highlight the importance of doing individualised assessments with carers of people with depression to identify what specifically contributes to their stress, and how this information can then be used to guide choices about which supports may be relevant and appropriate.

**There are significant barriers to the dissemination of group education interventions for carers of people with depression in Australia**

Despite specific support pledged by policy makers, individual service provider pre-training commitment to delivering the program, provision of high quality training, and proactive follow-up support, the dissemination of the *Partners in Depression* program was relatively limited, with not even half of all facilitators trained delivering the program at least once. This dissemination experience is not unique and is, in fact, similar to those reported by others who have disseminated family interventions for people with mental illness in Australia (e.g. Kavanagh et al., 1993; O’Hanlon et al., 2012) and internationally (e.g. Dixon et al., 1999; Fadden, 1997; McFarlane et al., 2001).

The clearest enabler at the service provider level that predicted program delivery was if program delivery was consistent with usual work practices or “core business”. This is not surprising as it seems to index the compatibility of the program with usual way of working, and this is known to be a factor that is associated with increased implementation rates (e.g. McFarlane et al., 2001). This study also highlighted that “macro” factors played an important part in determining capacity for individual service provider implementation; and showed that there are factors that influence implementation capacity that are outside the control of the project team and the individual service provider.

The barriers reported by clinicians in this study were the same as the barriers reported by clinicians looking to deliver family intervention programs internationally for different population groups and in different settings (Bailey et al., 2003; Dixon et al., 1999; Dixon et

al., 2001; Fadden, 1997; Kavanagh et al., 1993; Magliano et al., 2005; Magliano et al., 2006; McFarlane et al., 2001; O'Hanlon et al., 2012). Specifically, workload and time were some of the most frequently identified barriers to program delivery. These service level barriers coupled with the apparent “enabling” effects of program delivery being consistent with core business seem to suggest that to get general mental health services to deliver more family interventions, there may be a need to have family work part of their expected role. Thus, to increase capacity for delivery of a family intervention such as *Partners in Depression*, there appears a need for a broader cultural shift in mental health services towards recognising and valuing family work as part of usual mental health treatment.

In the dissemination study, facilitators reported specific difficulties in recruiting and identifying relevant carers and family members to attend the program. Other studies have also reported this dissemination barrier (Bailey et al., 2003; Fadden, 1997; Kavanagh et al., 1993; Magliano et al., 2005). However, it is in direct contrast to carers' reported interest in participating in mental health care and the usually positive level of interest and demand for offered carer interventions. In a study that tracked the number of times specific barriers were mentioned, Magliano et al. (2005) identified that difficulties in engaging families was a barrier that was mentioned less frequently over time, suggesting that it may be a start-up barrier rather than an ongoing one. This provides further support to the suggestion that the difficulties in recruitment were due more to a problem of service providers connecting effectively with the community to offer a new service, rather than a lack of interest from the target group in accessing a carer-specific support.

Furthermore, in contrast to Wandersman et al.'s (2012) dissemination model which emphasises the role of technical assistance in enabling program delivery, in this dissemination study, level of support was not a significant predictor of program delivery in the way expected. Although this finding appears likely to be a consequence of the way in which level

of support (or technical assistance) was measured, another recent Australian effort at increasing delivery of a family intervention within an adult mental health service has also shown that even intensive support (e.g. an embedded family practice consultation and implementation coordinator) does not necessarily result in easy or general engagement of clinicians with a mental health family intervention (O’Hanlon et al., 2012). Thus, much more work is needed to understand the role of technical support in program dissemination.

There are many implications to the dissemination findings. It may be that the most efficient way of disseminating a carer intervention for people with depression (and, through generalisation, people with mental illness) will be to target only those staff for whom program delivery is similar to, or consistent with, their usual work practices. However, this would limit the opportunities available to influence or change usual clinical practices. Alternatively, it may be that there is a need for a culture shift in mental health services to having family work acknowledged as ‘core business’ rather than an ‘optional extra’ (Fadden, 2006; Wagner, Munt & Briner, 2006). This may involve a range of different strategies, many of which have been used successfully elsewhere to address barriers to family work within mental health services (Leggatt, 2011). For example, organisational strategies include developing practice standards, having family work identified as a specific key performance indicator, articulating family work policies and establishing links to governance structures (Fadden, 2006; Molinaro, Soloman, Mannion, Cantwell, & Evans, 2012). Specific strategies to support individual service providers to engage in family work include ensuring that therapists have access to relevant training and professional development, access to supervision and defined discipline specific family work competencies (Fadden, 2006; Heru, Keitner, & Glick, 2012; Wagner et al., 2006). In summary, the experience of the barriers to dissemination of a family intervention as reported by Australian facilitators who tried to deliver a depression focused

intervention were not unique and the study highlighted the importance of identifying enabling factors, as well as barriers, to dissemination.

### **Implications and recommendations**

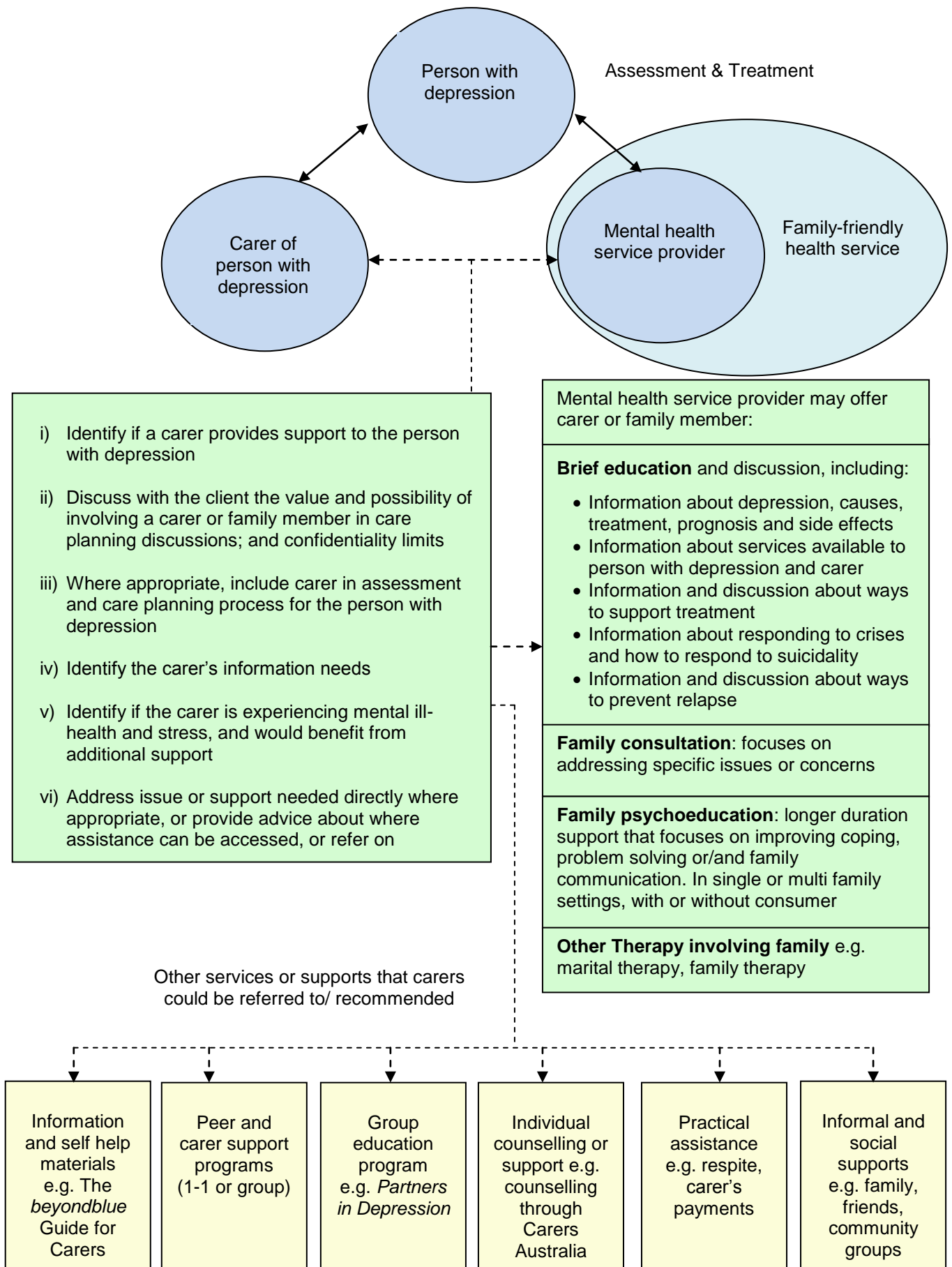
How can this information be used to inform policy and practice to support carers of people with depression? The following recommendations were formulated using the findings from the three thesis studies, as well as the literature reviewed in the introduction. These recommendations have been brought together in a model that is presented in Figure 1. The recommendations consider the implications of the evidence for the mental health service provider, the policy maker and the researcher.

#### **Practice implications for mental health practitioners**

In summary, carers of people with depression are themselves vulnerable to mental ill-health and report many challenges due to the carer role. Providing carers with information about the illness of the person they support and helping them to manage the challenges associated with the carer role (e.g. communication, responding to crises) appear to be associated with benefits for the carer and, potentially, the person they support. These issues highlight the need for mental health service providers to have a carer inclusive approach through which they are able to consider the needs of carers in routine practice. In light of these factors, the following recommendations are made for mental health service providers.

When providing support to a person with depression:

1. Identify if a carer is involved in supporting a person with depression.
2. Discuss with the client the value and possibility of involving a carer in care planning discussions and how confidentiality can be managed in a way that works for the client. Even when a client does not provide permission to discuss their information with a significant other, there can be non-private or general



*Figure 1: Supporting carers of people with depression*

information that can be discussed with the carer, which, in itself, may be useful (Slade, 2007).

3. Where there is contact with a carer or support person, provide the carer with relevant basic information about depression, its causes, treatment, prognosis and how the carer can help. For example, discuss and refer the carer to the *beyondblue* (2009) “*Guide for carers- Supporting and caring for a person with depression, anxiety or a related disorder*”.
4. Assess the carer’s need for specific information or support and where appropriate, screen for psychological distress.
5. Address the information or support issues directly (where appropriate) or refer the carer to an appropriate other information or service provider (e.g. *beyondblue* website, Carers Australia, Commonwealth Carelink Service, community health services, ARAFMI, private services providers).
  - a. When a carer presents for direct assistance, identify the carer’s needs and what sorts of supports will be most helpful (e.g. coping strategies, communication, crisis management, etc); and assist the carer to access relevant supports or to address presenting issues.
6. Where permission has been granted, invite carer participation and/ or involvement in the assessment, monitoring, review, relapse prevention and discharge planning process for the person with depression; and provide advice to the carer as needed about arising issues.

Embedding these practices within the routine care provided by the mental health service would help to ensure that a collaborative and client/ family centred approach is established. It would recognise the role of those who provide the primary support to people with depression and potentially provide a way to reduce rates of carer burnout, while improving the potential for recovery benefits for the person with depression. The activities



identified (e.g. screening of carer mental health problems; information provision) do not necessarily need to be lengthy or demanding contacts. For example, screening could be as simple as asking carers directly what information they have, if they feel they could benefit from additional supports, or asking carers to complete a Kessler-10 (Andrews & Slade, 2001). It should be noted that these recommendations suggest primarily utilising existing service infrastructure and frameworks and are not about expanding the role of mental health services to include also providing direct carer support (unless it is indicated by the presenting issues for the person with depression).

The recommendations made here are consistent with the “pyramid of family care” proposed by Mottaghipour and Bickerton (2005), where they recommended that all relevant family members of a person with severe mental illness should be engaged with, involved in assessment, and provided with general education about the illness, and support services and treatments available to support the person with mental illness and the carer. They also recommended supporting carers to access interventions to improve coping or problem solving (which they call psychoeducation) and additional support (e.g. family therapy) when indicated. Furthermore, the recommendations are consistent with the intervention framework for family involvement in the care of persons with psychiatric illness described by Dausch et al. (2012), and the conclusions from Harvey, O’Hanlon and Young’s (2010) literature review, where it is recommended that carers and family members should have access to a spectrum of support that can be tailored to fit their needs.

### **Implications for service administrators and policy makers**

The consistency of barriers to dissemination of family interventions for people with mental illness (including depression) highlight the impact of service and macro or infrastructure level factors. Delivery of family interventions is most likely when working in a carer inclusive way is compatible with existing approaches or philosophies (Dixon et al., 1999; McFarlane et al., 2001). Therefore, it needs to be made explicit how providing support

to families of people with mental illness (including depression) is part of, and consistent with, good existing mental health practice. There is also a need to ensure that mental health services have a “family friendly” culture, as evidenced by positive attitudes, integrative practices and client and carer collaborative approaches. Furthermore, there is a need to better connect carers of people with depression with the services available to support them. In light of these issues, the following recommendations are made for consideration by service administrators and policy makers.

1. A communications ‘call to action’ media strategy that targets family members and carers of people with depression could explicitly explain who is a carer and what they can do (and the supports available to them) if they are struggling. This would help make sure that those who are supporting a person with depression know what assistance is available and how they can access help, ensuring that the service system is used in the most effective way possible.
2. The mental health workforce needs to be appropriately informed and skilled in working with carers of people with mental illness (including depression). Thus, it is important that ongoing professional development about supporting carers of people with mental illness (including depression) is available and that there is access to appropriately experienced mentors or supervisors.

Furthermore, there are a variety of relevant information resources that could be developed for mental health service providers to help guide practice. These include:

- Development of best practice guidelines about supporting carers of people with depression and including explicit mention of the consideration of carers’ needs in clinical guidelines for treatment of depression.

- Development of an electronic clearinghouse of relevant research, clinical guidelines, and theoretical frameworks relevant to supporting carers of people with depression.
  - Establishment of peer networks of interested service providers to provide leadership and share expertise about the best way to respond to the needs of carers of people with mental illness in the community. Using online or digital media technology, it would be possible to link service providers across the country and it may be possible to utilise existing peer or interagency networks (e.g. Mental Health Professional Network).
3. Opportunities for collaboration and cooperation between service providers should be established. There are existing service systems to support people with mental illness (including depression) and Australian carers (including carers of people with mental illness). However, carers of people with depression face two issues that increase the likelihood that they may experience difficulties accessing care. Firstly, unless the depression of the person being supported is particularly severe, the treatment services available for people with depression tend to be located in the primary health care sector, many of whom are private providers. Secondly, the services available to support carers specifically are typically provided by non-government organisations which vary from state to state, and even region to region. This means that it is easy for carers of people with depression to “fall through the cracks” between services, as no service or organisation has a specific brief to consider or target the needs of carers of people with depression. Furthermore, the fragmented and localised nature of the service system means that referral pathways are frequently developed on a personal level and are based on individual service providers’ awareness of what is available. These structural barriers could be addressed by establishing ways in which services can partner together more frequently. This could act as a means of increasing

individual local service provider links between sectors, as well as increasing the effectiveness and reach of the existing service system.

4. There is a need to increase the perceived value and interest in providing support to carers of people with depression in mental health services and services in contact with carers of people with depression. There may be a need for specific investment or innovation, as well as activities aimed at increasing the family sensitivity of mental health services. In addition to the above strategies, other options that may assist with increasing the rate and quality of support to carers of people with depression include:
  - Having delivery of carer and family interventions identified as a key performance indicator for mental health services; and included in job descriptions for individual service providers.
  - Ensuring that protocols that identify carers are part of the routine assessment process for people with depression; developing family work practice standards for services; and ensuring that data systems have capacity to “count” contact with family members or carers and family work interventions.
  - Continuing funding for carer specific initiatives or services, including carer support services, positions (e.g. carer consultants, family workers) and family sensitive training programs; and extending the knowledge about these approaches by having more comparable evaluation processes for the different strategies.

The benefits of these strategies are that they would enhance, extend and utilise more effectively the capacity of existing services. The recommendations seek to establish stronger enablers as well as overcome potential barriers to delivering carer-focused support and interventions. They are also consistent with the success factors identified by other services who have increased family work contact and interventions within their region (e.g. Fadden &

Heelis, 2011; Lakeman, 2008; Leggatt, 2011; Molinaro et al., 2012; Stanbridge & Burbach, 2007; Wagner et al., 2006).

### **Implications for researchers**

Finally, there remains a clear evidence gap regarding definitive conclusions about the best way to support carers of people with depression. Although there is some evidence specific to carers of people with depression, much of the efficacy evidence has been generated with samples of carers of people with schizophrenia or has significant methodological limitations. It is suggested that there are three key areas for further research that require prioritisation. These include:

1. More research is needed into the efficacy, effectiveness and benefits of interventions for carers of people with depression with regard to outcomes for the carer and the person with depression. To address this, studies with stronger methodological designs are needed, including ones that involve control groups, standardised measures and which examine potential causal factors.
2. More research is needed into the actual clinical practice of mental health service providers with carers of people with depression. Specifically, there are no high quality studies in the published literature that capture the nature of actual service provision to Australian carers of people with mental illness (including depression), who provides the supports, whether it is consistent with best practice or what the effectiveness of that support is. An audit of carer support services provided by different organisations (including government and non-government organisations) could help to establish what is currently provided, whether there are missed opportunities, and the degree to which the support provided is helpful to the carer or the person with depression.

3. More research is needed to identify the “enablers” that make it possible to provide support to carers of people with depression and how barriers are overcome. Clearly there are many barriers to delivering support to carers of people with depression, however some organisations/ service providers have been able to overcome or neutralise the barriers. It is important to identify what factors enabled service providers to deliver services despite the barriers, and identify the degree to which the enablers are system based, service based or personality based. This could be done by identifying a number of services that appear to provide effective carer support and investigating and comparing their characteristics using a case study approach.

By addressing these issues, we will be better placed to make informed decisions about what supports should be offered to carers of people with depression, when, why and how.

### **Limitations**

The studies in this thesis provide a first step towards a better understanding of the mental health of Australian carers of people with depression and how best to support this target group. However, each of these thesis studies had specific, significant limitations. The studies essentially represent field research. They sought to collate the learnings and utilise the data collected as part of an implementation project in a way that could contribute to the evidence base. Consequently, each study could be significantly strengthened and the methodological issues limit the generalisability and strength of the conclusions that can be drawn. The specific limitations of each study have been discussed in the individual manuscripts. This section collates the primary issues and outlines the priority areas for further research.

Firstly, each of the studies had sampling bias. Carer participants were limited to those who self-identified as carers and/ or who were in touch with support services. Facilitators were also self-selecting. Thus, the findings from these studies may not be generalisable to

carers who do not identify as a carer or who are not in touch with support services, or service providers/ agencies who are not interested in providing support to carers of people with depression. Secondly, the data collected in the carer-focused studies would have been enhanced by collection of more information about the characteristics of the person with depression, particularly the severity of the illness of the person being supported and better identification of how the mental health of the carer related to the acuteness or phase of the illness of the person being supported.

Thirdly, the studies were limited in their capacity to draw definite conclusions by the lack of control comparison groups. A better understanding of the predictors of carers' mental health would have been gained through the use of longitudinal study. Similarly, a control comparison group is needed in future work to ensure that the benefits demonstrated by the *Partners in Depression* intervention are associated with program attendance and not other factors. Furthermore, the third study would have been strengthened by offering different service providers/ facilitators different levels of support, which would have enabled comparisons of implementation effectiveness by training/ support provided.

Fourthly, future research could strengthen the conclusions that can be drawn from this study series by use of additional standardised measures to clarify the possible causal factors and enable better comparison with other studies and by exploring qualitatively the experiences of participants and facilitators. Finally, only limited information was available about carer and facilitator drop-outs, those who were lost to follow-up, or those who chose not to take part in the first instance. Better information about the characteristics of these groups would provide a better indication of the degree to which the findings from these studies are specific to those with similar characteristics or were relevant across the board.

Thus, the findings from these studies have been considered with reference to what is already known about supporting carers of people with depression and recommendations about implications for practice made on this basis. However, it is important to acknowledge that

these studies had serious limitations and ongoing, better controlled research is needed to be able to more definitively answer how best to support carers of people with depression.

### Summary

In summary, this thesis has explored the mental health of Australian carers of people with depression and ways to support them. The studies were conducted in the context of the *Partners in Depression* national dissemination project and sought to complement the independent evaluator's findings by extending and enhancing the scope and detail of the national dissemination research questions. The studies demonstrated the vulnerability of Australian carers of people with depression to mental ill-health and the interest of this target group in accessing support. The studies highlighted the potential importance of reducing carer burden and promoting adaptive coping strategies as a way of improving the mental health and wellbeing of carers of people with depression. Furthermore, the studies also evidenced the difficulties faced by health and community professionals in delivering a specific family intervention for people with depression in routine practice. The recommendations from these studies emphasised the importance of looking for ways to regularly and routinely have carers of people with depression identified, and their needs assessed, as part of routine practice for people with depression; as well as highlighted the need for ongoing work to establish the 'enablers' that support the delivery of carer supports within the existing mental health service system. Although providing some guidance, the conclusions that can be drawn from these studies are limited by the self-selecting nature of the samples, the lack of comparison control groups and the lack of standardised measures. Thus, it is important that future research prioritises these issues. Nevertheless, these studies are the first to systematically and empirically investigate the mental health and wellbeing of Australian carers of people with depression, as well as investigate the efficacy of an intervention developed specifically to address this target group's information needs, and the workforce's capacity to engage in the delivery of such an intervention. By highlighting the gaps between what appears to be



occurring and what would be ideal, it is hoped that we can begin to get closer to supporting carers of people with depression to have the best possible mental health themselves and, in turn, also improve the lives of those experiencing depression.

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**APPENDIX A:****Pilot evaluation of the *Partners in Depression* program:****A group education course for carers of people with depression**

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**Note:** This study provided the foundation for the *Partners in Depression* national dissemination project. Thus, there is some overlap in material covered in this manuscript and that of Study Two.

### **Abstract**

Background: Carers of people with depression are vulnerable to experiencing compromised mental health as a consequence of the carer role. To date, there is only limited evidence exploring what supports may effectively address the needs of carers of people with depression and improve their mental health. Method: This study was designed to investigate the efficacy of a group education program for carers of people with depression (*Partners in Depression*). It used a before- after design and recruited 103 carers of people with depression through mental health services, a carer support service and an advertisement in a local newspaper. Results: At baseline, participants reported significantly high depression, anxiety and stress levels, on the Depression Anxiety and Stress Scale, compared to the general population. Following program attendance, depression and stress levels had significantly reduced to normal levels. There were, however, no significant changes in participants' reports of caregiving burden, self-esteem, or attitudes towards helpseeking. Conclusions: The findings from this pilot suggest that the *Partners in Depression* program may be an appropriate and relevant group education intervention for carers of people with depression that deserves further investigation.

One in five Australians will experience an episode of depression at some stage in their life and depression is a leading cause of morbidity and disability in Australia (ABS, 2008; AIHW, 2007). Depression significantly affects a person's quality of life and can affect the nature of a person's relationships and their capacity to fully engage in usual work and family life (AIHW, 2007). Depression is often recurrent and frequently presents with other physical and mental ill-health and substance use problems (AIHW, 2011). The impact of depression, however, is not limited to just the individual, it also affects those who provide support to the person with depression, including family members and friends.

Family members and friends who love, care for, or live with a person with mental illness provide the majority of day-to-day emotional and practical support to those people in the community experiencing mental ill-health. In legislation, policy and treatment service provision, people who provide this sort of support are identified as mental health carers and they are increasingly acknowledged and recognised for their role in supporting the wellbeing of the person for whom they care (e.g. *Carer Recognition Act*, 2010). The carer experience is becoming more widely investigated, including that of carers of people with depression.

Family members and friends of people with depression describe many difficult experiences. They commonly identify feelings of worry and stress, anger and frustration and a sense of loss and helplessness (Ahlstrom, Skarsater, & Danielson, 2009; Harris, Pistrang, & Barker, 2006). They describe concerns about stigma and that the person they support may consider self harm or suicide (Highet, McNair, Davenport, & Hickie, 2004). They often provide specific practical assistance (Ostman, Wallsten, & Kjellin, 2005). For example, they may take greater responsibility for household tasks or for ensuring financial stability while the person they support is unwell. Family members of people with depression have described a sense that the depression has taken over their life too and many describe feeling unprepared or overwhelmed by the experience (Stjernswand & Ostman, 2008).

The carer role can take a toll on the mental health and wellbeing of carers. Studies of carers consistently report significantly elevated rates of psychological distress compared to levels found in the general population (Cummins et al., 2007; Edwards & Higgins, 2009). Studies specifically involving carers of people with depression similarly find high rates (between 40%- 72%) of compromised mental health (e.g. Coyne et al., 1987; Spangenberg & Theron, 1999). The amount of practical and emotional support provided by a carer, also called caregiver burden, appears to be an important factor in determining the impact of the carer role and it is consistently found to predict the mental health of carers of people with depression (e.g. Coyne et al.; Jeglic et al., 2005). Taken together, these studies highlight the vulnerability of carers of people with depression to mental ill-health, and the degree to which the carer role appears to account for the vulnerability.

Studies involving carers of people with mental illness have investigated the information and support needs of mental health carers to identify what they believe would help them manage the stress associated with being a mental health carer (e.g. MHCA, 2009). Mental health carers, including carers of people with depression, most commonly report wanting information about the illness, to be provided with better support and skills to manage crisis situations, and to be included as part of the assessment and treatment process for the person they support (Highet et al, 2004; Muscroft & Bowl, 2000).

Some interventions have been developed overseas specifically to address the information and support needs of carers of people with depression (Harter et al., 2002; Heru, Ryan, & Madrid, 2005; Jacob et al., 1987; Luciano et al., 2011; Morgan et al., 1997; Sherrill et al., 1997; Shimazu et al., 2012; Stam & Cuijpers, 2001). These interventions have usually been psychoeducational in nature, delivered either in multifamily group settings or to single families, and have recruited carer participants through the person experiencing depression (meaning the person being supported is in contact with treatment facilities). In general,

responses to the interventions by carers have been positive and sessions well attended. When outcomes for the carer have been assessed, attendance at these programs has usually been associated with reductions in psychological distress (Luciano et al., 2011; Shimazu et al., 2012; Stam & Cuijpers, 2001), and less consistently, caregiver burden (Clarkin et al., 1990; Prisco et al., 2012). Studies recruiting carers directly (rather than through the person with mental illness) have been limited. However, one Australian study that targeted carers of people with mental illness (not depression specifically) investigated the impact of a peer-led, group education and support program that was delivered in community settings (the *Well Ways* program; Stephens, Farhall, Farnan, & Ratcliff, 2011). Stephens et al. (2011) reported that although attendance at the program was associated with mental health benefits including reduced tension, worry and distress and reduced likelihood of meeting criteria for psychological disorder, the benefits were more apparent for the carers who supported a person with psychotic illness, rather than the carers who were supporting a person with an affective disorder. This differential impact highlights the importance of offering interventions that are specifically targeted to the needs of different carer groups.

In addition to the potential benefits offered by carer interventions for carers, there is a growing body of literature that describes the potential benefits of these interventions for the person being supported. These studies show that interventions involving family members have the capacity to support improved treatment outcomes for the person with mental illness beyond those associated with individual interventions (Harvey & O'Hanlon, 2013; McFarlane, Dixon, Lukens, & Lucksted, 2003). The evidence is most comprehensive for people experiencing a psychotic disorder (McFarlane et al., 2003), however, similar benefits are now being reported in studies involving people with depression. In these studies, reduced rates of relapse and improved patient functionality for the person with depression are reported when a carer intervention is offered in addition to standard care (Shimazu et al, 2011;

Spencer, Glick & Hass, 1988; Stam & Cuijpers, 2001). Given the growing body of evidence in this area, it is now recommended that mental health carers are actively involved in the treatment pathway for people living with mental illness, including those with depression (e.g. NCCMH, 2010; RANZCP, 2010).

To date, research describing the efficacy of community based group intervention programs for mental health carers of people living with depression has been limited and none of these studies have been conducted in Australia. Thus, the current study aimed to:

1. Investigate the psychological and health related wellbeing of carers of people with depression living in Australia; and
2. Investigate the efficacy of an Australian group information and support program for mental health carers providing care or support to a person with depression.

## **Method**

### **Participants**

In total, 103 carers of people with depression attended a *Partners in Depression* program in the Hunter Valley, Australia. Participants had to be over eighteen years of age, identify that they were supporting a person who had been diagnosed with unipolar depression, and interested in attending a group education program about supporting a person with depression.

See Table 1 for participant demographic details. In summary, the majority of the sample were female, Australian born, living with a partner and children and indicated that the depression of the person they were supporting had had an obvious effect on the capacity of that person to participate in household activities, maintain their relationships with others and reduced their enjoyment of social activities.

Of the 103 participants, 76 participants returned both the baseline and post program questionnaires representing a follow-up rate of 74%. There were no significant differences

Table 1: *Sample Characteristics at Baseline*

Characteristic		n= 103	Characteristic		n= 103
Gender	Male	28%	K10	Average	17.76 (5.90)
	Female	72%		Likely to be well	68%
Country of birth	Australia	92%		Mild disorder	20%
	Other	9%		Moderate disorder	4%
				Severe disorder	8%
Marital status	Married	71%	Baseline DASS	Depression average (SD)	8.41 (8.36)
	Defacto	9%		Anxiety average (SD)	4.73 (6.00)
	Single	9%		Stress average (SD)	11.83 (8.08)
	Divorced	8%	Caregiving burden	Average (SD)	35.03 (14.77)
	Separated	2%		Minimal burden	14%
	Widowed	2%		Mild burden	52%
Family situation	Live alone	12%	Self-esteem	Moderate burden	30%
	Live with partner & children	85%		Severe burden	4%
	Live with parents	1%		Average (SD)	18.14 (5.25)
	Lives with friends	2%		Average (SD)	16.46 (5.58)
Age- years	Average (SD)	50.46 (22.63)	Helpseeking	Average (SD)	16.46 (5.58)
Employment status	Employed	61%			
	Retired	26%			
	Not working due to stress	4%			
	Not working due to health problems	4%			
	Not working due to carer responsibilities	5%			

between those who completed the baseline measures only and those who completed both the baseline and post program questionnaires on any of the demographic factors or outcome measures.

### **Intervention development**

The *Partners in Depression* program was developed by Hunter Institute of Mental Health to specifically address the information and support needs of people who live with, love or care for a person with depression in Australia. It consists of a six-session, two-hour, weekly education group delivered by two health and community professionals. The aims of the program are to improve participants' mental health and resilience by providing them with relevant information about depression and the carer experience, opportunities to discuss and share their experience and by engaging participants in a range of activities that encourage self-care, helpseeking and positive coping. The specific topics covered by the program are outlined in Table 2.

Table 2: *Partners in Depression* program content

Session	Topic
1	Introductions, and building awareness of depression and the carer role
2	Insight into caring, and understanding depression and its treatments
3	The caring and support experience
4	The support experience, and introduction to cognitive behaviour therapy
5	Suicidality and self harm, and communication strategies
6	Helpseeking, support and resources, and planning for the future

Program content development was informed by a literature review of the evidence base regarding what information and support carers of people with depression identified wanting, a focus group with the target population, a review of how other empirically supported carer programs had covered the material, and advice from a reference group of



stakeholders. Thus, while the program development was informed by the evidence base, the carer experience was central to the development of program content. Adult learning principles were used to inform how content was delivered (Knowles, Holton, & Swanson, 2005). Consequently, the program uses a combination of didactic, reflective, and active learning strategies to engage participants in the material. Groups can be attended by up to 14 people and can be delivered by facilitators who are not involved in any other service provision for the carer or the person with depression, although there is an expectation that facilitators will assist participants to connect with the relevant services where appropriate.

Program development was informed by an initial concept testing phase that involved delivery of a four session program and refinement of program content and delivery based on feedback from participants in a focus group and through questionnaires completed after each session. The concept development outcomes are not discussed in this paper, but, in general, they were positive and indicated that the program met participants' needs and did not duplicate existing carer supports. The concept testing phase acted as the foundation for the development and delivery of the pilot program evaluation.

### **Procedure**

After the concept testing and program refinement phase, the program developers advertised for interested group facilitators through the Hunter New England Health Service and other local relevant service providers. A total of fourteen clinicians attended a one-day *Partners in Depression* facilitator training course. This course provided an orientation to program content, a facilitator program manual, and participant resources. The training was delivered by the program developers. Facilitator attendees were invited to take part in the pilot project, which required that they deliver the *Partners in Depression* program in their usual work setting. Nine of the fourteen clinicians who attended the facilitator training took part in the pilot evaluation project.

Between 2006 and 2008, ten *Partners in Depression* programs were delivered in the Hunter Valley, Australia as part of the pilot evaluation study. Seven groups were run in the Newcastle region, two groups run in Maitland and one group run in Taree. The groups were run by both the program developers (4 groups, 35 participants) and clinicians who had been trained in the program by the program developers (6 groups, 41 participants). The non-program developer facilitators were clinicians who worked for the Mental Health Service or ARAFMI (Association for Relatives and Family affected by Mental Illness), and all had attended the *Partners in Depression* facilitator training program. All sessions delivered by non-program developer facilitators were observed by one of the project team to ensure fidelity of program delivery content and structure.

Two participant recruitment strategies were used. An advertisement in the local regional newspaper was used to recruit carers of people with depression from the general public. Facilitators also provided information about the study to eligible family members or relevant clients of their service. All interested people contacted the project team office to register interest in attending the program. A phone screening questionnaire was completed to ensure eligibility and additional information about the study was sent to interested candidates. Participants returned the baseline questionnaire prior to the first group session. The post program questionnaire was distributed six weeks later after the last group session. Participants were asked to return the questionnaire within four weeks, receiving two reminder phone calls if they were not received.

The study was approved by the Hunter New England Human Research Ethics Committee: Approval Number 07/02/21/5.06.

## Measures

A questionnaire battery was developed for this study comprising a range of standardised measures, as well as questions about demographics and the caregiving context.

Demographic information was collected, including participant age, gender, country of birth, marital status, employment status, and living situation. Information was also collected about the characteristics of the person with depression (e.g. diagnosis, date of diagnosis and duration of symptoms, capacity of the person with depression to participate in usual activities), and information about the participants' caring experience (e.g. duration of carer role, capacity to which they felt able to cope/ manage).

Information about the mental health of participants was captured using two standardised measures. The Depression, Anxiety, and Stress Scale (DASS; Lovibond & Lovibond, 1995) is a 42 item self-report questionnaire that measures symptoms of depression, anxiety and stress. Participants rate on a four point severity/ frequency scale the extent to which they have experienced that item over the past week (e.g. I just couldn't seem to get going; 0= *did not apply to me* to 4= *applied to me very much or most of the time*). Responses to the 14 items of each subscale are totalled and normative data can be used to categorise total scores for depression, anxiety and stress as normal, mild, moderate, severe and extremely severe, with higher scores indicating more severe distress. This scale has good validity and reliability and has been used extensively with Australian populations (Lovibond & Lovibond, 1995). The Cronbach alpha for this scale was .96.

The Kessler-10 (K10; Andrews & Slade, 2001) was also used. The K10 is a measure of psychological distress. Items are rated on a five point scale and participants indicate how much each item applied to them over the past four weeks (e.g. About how often did you feel tired out for no good reason?; 1= *none of the time* to 5= *all of the time*). A total score is calculated to give a basic indication of a person's level of psychological distress. Scores range

from 10- 50 and higher scores indicate poorer mental health. Using the ABS (2001) coding system, total scores of 10-19 were classed as low psychological distress, total scores of 20-29 were classed as moderate psychological distress and total scores of 30-50 were classed as high psychological distress. The K10 has been used in a number of Australian population health studies and has good validity and reliability (Andrews & Slade, 2001), and is frequently used to identify risk of mental disorder (ABS, 2001). The Cronbach alpha for this scale was .88.

Four global questions about participants' overall wellbeing were also asked. For these questions, participants rated on a five point scale (1= poor to 5 = excellent) their overall physical health, mental health, relationships with others, and capacity to perform everyday tasks over the past four weeks. These four items had a Cronbach alpha of .84.

Information about participants' self-esteem was captured using the Rosenberg Self-Esteem Scale (Rosenberg, 1989). This is a ten item scale used to measure global self-worth. Participants rate on a four point scale the degree to which items apply to them (e.g. On the whole I am satisfied with myself; 1= *strongly disagree* to 4= *strongly agree*). Items are summed to give a total score (with items 2,5,8, 9 and 10 reverse coded) and higher scores indicate higher self-esteem. The scale has high reliability and good validity (Rosenberg, 1989; Sinclair et al., 2010) and has been used with carer populations, including Australian carers (e.g. Reid, Moss, & Hyman, 2005). The Cronbach alpha for this scale was .88.

Attitudes towards helpseeking were measured with the Attitudes towards Seeking Psychological Help Scale (Fischer & Farina, 1995). This ten item scale asks participants to rate items on a four point Likert scale (e.g. I might want to have psychological counselling in the future; 1= *disagree* to 4= *agree*). Responses are summed to get a total score (with five items reverse scored) and higher scores indicate more positive attitudes towards psychological helpseeking. This scale has good internal consistency, reliability and good construct and predictive validity (Elhai, Schweinke, & Anderson, 2008; Vogel et al., 2004). It has been well

used with a variety of populations, including Australian samples (e.g. Woodward & Pachana, 2009). The Cronbach alpha for this scale was .87.

Caregiver burden was measured using the Zarit Burden Interview (Zarit, 1980). This 22 item scale asks participants to rate the degree to which each item applies to them on a five point Likert scale (e.g. Felt overtaxed with responsibility; 0= *never* to 4= *nearly always*). Responses are summed to give a total score ranging from 0 to 88. Scores are categorised as: 0-20 represent little or no burden, 21-40 represent mild to moderate burden, 41-60 represent moderate to severe burden and 61-88 represent severe burden. This scale has good validity and internal and test retest reliability with carer populations (Bedard et al., 2001; Zarit, 1980). The Cronbach alpha for this scale was .91.

### **Data analysis**

Routine exploratory analysis was performed and descriptive statistics used to check for normality, outliers and linearity. Paired t tests and repeated measures analyses of variance (ANOVAs) or their non parametric equivalents (Wilcoxon signed ranks test or Friedman's test) were used to examine changes in the dependent variables over time points (baseline and post program). Follow-up ANOVAs were conducted to identify whether baseline level of psychological distress (indicated by K10 group) was associated with differential change in dependent variables over the two time points. Due to the small sample size, the K10 grouping (low, moderate or severe) was collapsed into two groups, likely to be well (scored less than 20 at baseline) or likely to be unwell (scored more than 20 at baseline).

## Results

### Sample characteristics

In summary, at baseline, about one-third of the sample scored in the *likely to be unwell* range on the K10. On the DASS, about one-third of the sample reported depressive symptoms, one-quarter reported stress levels, and about one-fifth reported anxiety symptoms above the normal range. Compared to population means of 5.55, 3.56 and 9.27 for depression, anxiety and stress respectively (Crawford & Henry, 2003), this sample scored significantly above population means,  $t(75)=3.12, p=.003$ ;  $t(75)=2.12, p=.04$ ;  $t(75)=2.77, p=.007$ , respectively. On the general wellbeing questions, participants rated their physical health, mental health, relationships, and level of involvement in everyday tasks as ‘good’. The majority of the sample reported experiencing a mild (52%) level of caregiving burden. The average self-esteem score was midrange with 18.14 (SD= 5.25). The average helpseeking score was also mid range with 16.46 (SD= 5.58).

### Outcome measures

See Table 3 for details of the outcome measure scores. On the DASS, there was a significant difference on mean scores for the depression,  $t(75)=2.46, p=.02$ , and stress,  $t(75)=2.3, p=.02$ , subscales, with participants reporting fewer symptoms of depression and stress after completion of the program. As seen in Figure 1, this also meant that the proportion of the sample scoring depressive, stress and anxiety symptoms in the normal range increased after attending the program (14%, 9% and 7% respectively). The post program DASS mean scores were not significantly different from the population mean scores of 5.55, 6.39 and 9.22 for depression, anxiety, and stress, respectively. Follow-up repeated measures ANOVAs showed that the change in mean scores for each DASS subscale was not dependent on level of psychological distress at baseline (as indicated by K10 group- well or unwell).

Table 3: *Mean Scores and Statistics for Outcome Measures*

Scale	Subscale	Baseline	Post program	Statistic
K10 <sup>1</sup>		18.04 (5.94)	17.13 (5.73)	$t(75)= 1.82, p=.07$
DASS <sup>2</sup>	Depression	8.54 (8.34)	6.41 (6.75)	$t(75)= 2.46, p=.02^*$
	Anxiety	5.13 (6.47)	3.93 (4.35)	$t(75)= 1.65, p=.10$
	Stress	12.04 (8.72)	9.93 (7.03)	$t(75)= 2.31, p=.02^*$
Caregiving burden		35.29 (15.00)	33.83 (15.82)	$t(75)= -1.33, p=.19$
Self-esteem		18.01 (5.29)	18.11 (5.23)	$t(70)= -0.26, p=.80$
Helpseeking		15.70 (5.08)	15.24 (4.48)	$t(75)= 1.40, p=.16$
Global questions	Physical health	3.15 (0.91)	3.15 (0.92)	$t(74)= -0.30, p=.70$
	Mental health	2.76 (0.96)	2.95 (0.96)	$t(74)= -1.60, p=.09$
	Relationships	3.08 (0.92)	3.26 (0.85)	$t(74)= -2.02, p=.05^*$
	Duty capacity	3.16 (1.04)	3.29 (0.94)	$t(74)= -1.22, p=.23$

Notes. <sup>1</sup>= Kessler 10; <sup>2</sup>= Depression, Anxiety and Stress Scale; \*significant findings

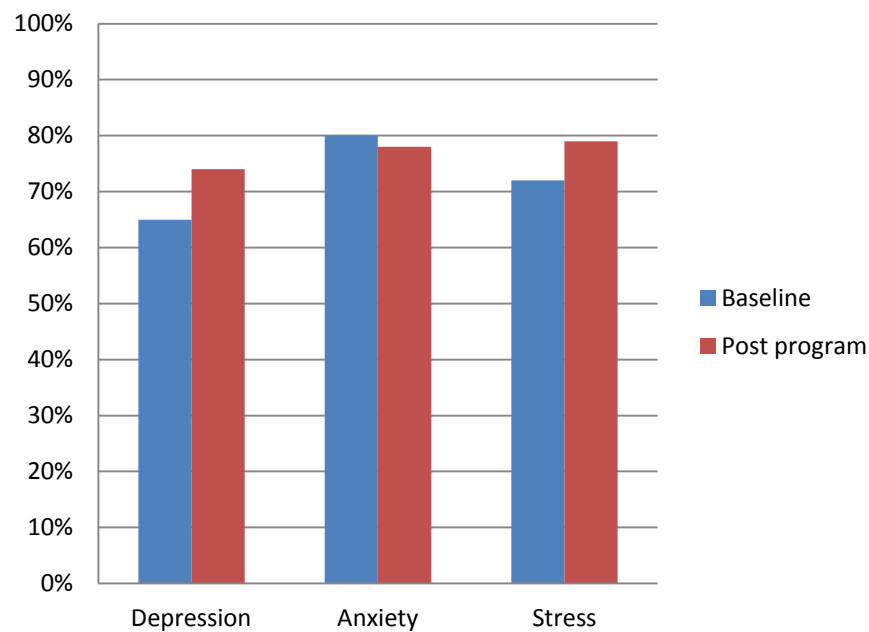


Figure 1: Proportion of sample scoring in the normal range on the DASS subscales over time

The change in the K10 mean score between time points was not significant,  $t(75)=1.82, p=.07$ , although there was an average 1.09 reduction in psychological distress after attendance at the program. A follow-up repeated measures ANOVA by K10 group (well or unwell) showed that there was a significant main effect of time,  $F(1, 74)=84.88, p=.002$ , group,  $F(1, 74)=118.73, p=.001$  (as expected) and an interaction effect,  $F(1, 74)=11.35, p=.001$ , with the K10 score reducing more for those who scored in the likely to be unwell range at baseline, although there was no change for those participants who scored within the normal range at baseline (see Figure 2).

There were no significant differences between baseline and post program scores for the global questions about physical health, mental health and ability to complete usual duties; or for caregiving burden, self-esteem or helpseeking. There was a significant difference in pre and post program scores for the global question that asked about overall relationships with family, close friends and acquaintances with an increase in the mean score over time points,  $t(72)=2.02, p=.05$ . There were also no significant interactions in change in mean scores for these variables when level of psychological distress at baseline (K10 group- well or unwell) was used as a between-groups factor in the follow-up repeated measures ANOVAs.

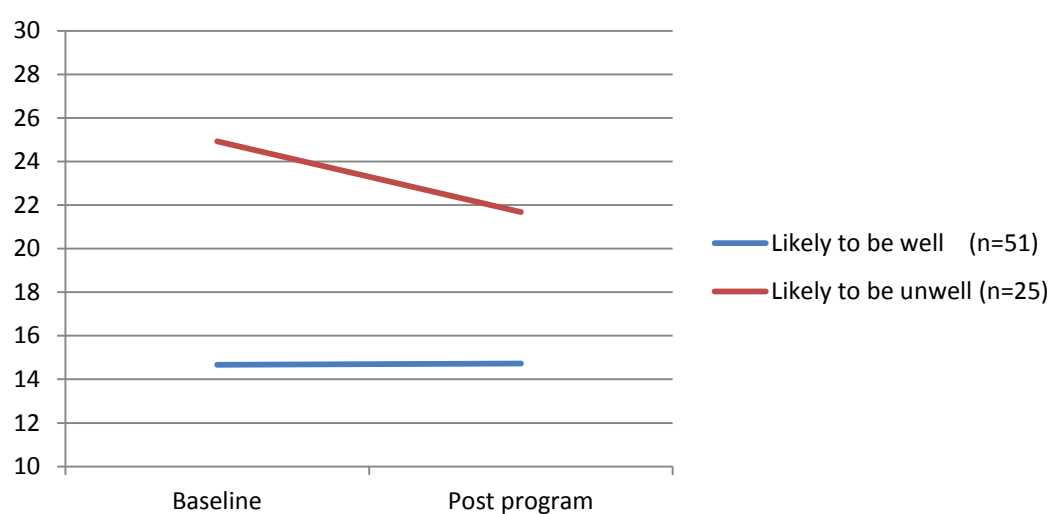


Figure 2: Kessler 10 mean score over time by baseline Kessler 10 grouping (scoring in the likely to be well or likely to be unwell range)



**Other analyses**

Using repeated measures ANOVAS with facilitator type (program developer or non-program developer) as the between-subjects factor, there were no significant group differences or interaction effects for any of the outcome measures.

**Discussion**

This study confirms that Australian carers of people with depression are vulnerable to compromised mental health, with the sample reporting significantly higher levels of psychological distress than that seen in the general population. Promisingly, attendance at the *Partners in Depression* program was associated with significant improvement in participants' mental health and wellbeing, as indicated by significantly reduced post program levels of symptoms of depression and stress (to levels comparable with the general population). Interestingly, only the specific mental health and wellbeing indices changed after program attendance, although no changes were reported by participants with regard to their experience of caregiving burden, self-esteem, or attitudes towards helpseeking.

The positive impact of the program on participant mental health is consistent with findings from other intervention studies for carers of people with depression (e.g. Luciano et al., 2011; Shimazu et al., 2012; Spencer et al., 1988; Stam & Cuijpers, 2001). This is important as this study recruited carer participants directly, rather than through the person with depression. It suggests that there is interest in carer group education programs offered independently of the treatment process for the person with depression, as well as indicating that independent carer interventions can be associated with carer benefits that are not dependent on the person with depression accessing treatment. Furthermore, the outcomes reported by participants in this study were comparable to the benefits reported in studies investigating the effectiveness of other carer interventions. This is important because the program content was primarily informed by what carers of people with depression said they

wanted, both in the evidence base and during the concept development phase. The positive findings suggests that addressing specific information goals within a supportive group setting is an effective way of improving the mental health of carers of people with depression. Thus, the *Partners in Depression* program is an intervention that is worth considering when looking at how to support carers of people with depression.

This study also highlighted the potential benefit that carer support may offer specifically to those carers who are experiencing mental ill-health. That is, the findings in this study suggest that the mental health benefits associated with program attendance were most apparent for those who were most psychologically unwell, although this was not consistent across measures. This is not surprising as the group for whom there was most capacity to report improvement in their mental health were those who had worse (higher) scores to begin with. The inconsistency of the impact of psychological distress across the different outcome measures is also not surprising when the sensitivity for capturing change of the different measures is taken into account. For example, the interaction effect of K10 group (likely to be well or likely to be unwell) was only apparent for K10 and not the DASS, whereas the DASS was associated with a significant reduction in levels of depression and stress over time, and the K10 was associated only with a trend for significant reduction over time. It seems likely that the K10 is a less sensitive instrument than the DASS, meaning the DASS had capacity to capture differences in mental ill-health symptoms (which the K10 would miss). Thus, the DASS was able to capture reduction in psychological ill-health for all, although the K10 was only able to capture reduction in psychological distress for those who had higher scores to begin with. Taken together, these findings suggest that program attendance was associated with reductions in symptoms of depression and anxiety for all (even when symptomatology did not reach 'psychiatric disorder' indicator levels); and was particularly helpful for those experiencing higher levels of psychological distress. This is important as it suggests that the

*Partners in Depression* program is an appropriate way to provide support to carers of people with depression, with likely general mental health promotion benefits.

Although it is promising that program attendance was associated with improved mental health, it is also interesting that some of the variables did not change over time, namely, caregiving burden, self-esteem, and attitudes towards helpseeking. There are many ways to understand these null findings, however, one interpretation could be that the changes in the mental health indices were evidence of the program's outcomes' specificity. This interpretation is supported by the overall pattern of findings. For example, of the general wellbeing questions, only the ratings of relationships significantly improved, with participants indicating they felt more connected at the end of the program compared to the beginning of the program. This could be understood to be an effect of the group program, either an effect of attending a group program where there were opportunities to connect with other people or an effect of the content covered during the program (e.g. communication skills), resulting in participants finding they were able to connect better with people in their day-to-day life. In contrast, although changes in caregiving burden and self-esteem were expected, it is not necessarily surprising they were not found. After all, the program did not change the caregiving context of the person but rather sought to resource them to be able to manage the challenges of the situation better; similarly, self-esteem is a global concept and specific improvements in self efficacy with regard to a particular situation may not translate to an increased sense of general self-worth. Thus, these null effects may represent variables that remain stable over time and indicate that the impact of program attendance was specific to reduction of mental ill-health. However, assuming the null effects are valid, it is interesting that these other processes did not then appear to account for the improvement in wellbeing reported by participants.

In contrast, it was somewhat surprising that there were no changes in attitudes towards helpseeking when this was specifically targeted and focused on in program content. Possibly, the program simply did not affect participants' attitudes towards helpseeking. However, it raises an alternative explanation, which is that the null findings could be a consequence of limited sensitivity of the measures used particularly when participants had high scores (i.e. scored at ceiling level) at the initial assessment time point. It will be important to further investigate this issue and future research could involve use of different instruments or explore the impact of additional variables to better understand the specific impact of the program and the processes that account for benefits.

Finally, this pilot study is important as it has established an initial indication of the relevance and fit of the *Partners in Depression* program to the current Australian mental health service system. Program benefit findings were not dependent on who ran the group, whether it was the program developers or facilitators who had been trained in the program. This is important as it indicates that when fidelity to the program was maintained, program attendance was associated with the same positive outcomes, regardless of who delivered the program. Further to this, the program was run by practising clinicians in existing services, providing some evidence as to the feasibility of delivering the program within current services. Admittedly, the pilot program structure provided additional support to enable the groups to be run (e.g. project team conducted screening of participants), but this study demonstrates the capacity of the program to be integrated into existing systems of care and provides preliminary evidence that it can be disseminated with good effect.

Although this study is an important first step to identifying supports likely to be helpful for carers of people with depression, it has a number of limitations. Firstly, there was no control group, so it is possible that the improvement in participants' mental health were due to factors other than attendance at the program (e.g. natural improvement of distress over

time, person with depression improving, access to other carer support). Secondly, the evaluation had a before-after design, but there was no follow-up assessment which would give indication as to whether benefits identified at the post program time point were maintained over time. Thirdly, only a limited number of variables were investigated in this study. It would be useful to look at additional relationships between variables to help better understand what accounts for program impact (or non-impact). For example, it may be useful to look at the relationship between characteristics of the caregiving context (e.g. duration of carer experience) and program impact, or whether the program enhanced use of specific types of coping strategies which may account for the improved mental health. Consequently, future studies should give priority to including a control group, using a longer follow-up time period, and including additional measures that may help capture the processes that may account for program impact outcomes.

In short, the findings from this pilot of the *Partners in Depression* program suggest that:

- in line with previous research, carers of people with depression are vulnerable to compromised mental health and there is interest within this population in attending a group education program.
- the *Partners in Depression* program is an appropriate support to offer carers of people with depression.
- attendance at the *Partners in Depression* program is associated with mental health benefits (specifically, reduced levels of symptoms of depression and anxiety), although a study using a control group is needed to confirm that benefits are associated directly with program attendance rather than other factors.
- the *Partners in Depression* program can be delivered by facilitators, other than the program developers, with good effects.

- the *Partners in Depression* program is a feasible intervention to be delivered within the existing mental health service system within Australia.

Although more work needs to be done, this study has demonstrated the efficacy of a group education program for carers of people with depression that has the carer experience at its centre, and which offers a way of ensuring that carers of people with depression have access to information and support that builds their resilience, promotes their mental health, and, ultimately, aims to improve the lives of all those who have been affected by depression.

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**Appendix B:**

**Reasons for attending the *Partners in Depression* program by subgroup**

Table 1: *Reasons for Attending the Partners in Depression Program by Gender*

Reason	Female (n=969)	Male (n=247)	Total (n=1216)
Information about the causes, symptoms and treatment for depression	76%	72%	74%
Information about how I can best support the person in my life with depression	92%	89%	91%
Information about what I can do to look after myself	77%	73%	76%
Information on the services and resources available to support me	74%	65%	72%
Information on the services and resources available to support the person in my life with depression	75%	72%	76%
Opportunity to talk with others with a similar experience	70%	62%	68%
Other	7%	8%	7%

Table 2: *Reasons for Attending the Partners in Depression Program by Age Group*

Reason	16- 25 yrs (n=29)	26-40 yrs (n=166)	41-64 yrs (n=707)	65+ yrs (n=223)	Total (n=1185)
Information about the causes, symptoms and treatment for depression	80%	73%	76%	77%	74%
Information about how I can best support the person in my life with depression	93%	94%	92%	88%	91%
Information about what I can do to look after myself	76%	71%	77%	79%	76%
Information on the services and resources available to support me	66%	71%	72%	74%	72%
Information on the services and resources available to support the person in my life with depression	76%	74%	77%	75%	77%
Opportunity to talk with others with a similar experience	45%	62%	70%	70%	68%
Other	3%	9%	7%	6%	7%

Table 3: *Reasons for Attending the Partners in Depression Program by Employment Status*

Reason	Not working (n=572)	Working (n=648)	Total (n=1220)
Information about the causes, symptoms and treatment for depression	74%	74%	74%
Information about how I can best support the person in my life with depression	93%	89%	91%
Information about what I can do to look after myself	74%	79%	76%
Information on the services and resources available to support me	70%	74%	72%
Information on the services and resources available to support the person in my life with depression	78%	76%	77%
Opportunity to talk with others with a similar experience	65%	72%	68%
Other	7%	7%	7%





**Appendix C:**  
**Ethics Approvals**