



Carer Counselling Literature Review

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Executive summary

It is well established that providing informal care and support can have a significant impact on the physical and mental health of carers. While there are many positive aspects to caring, carers consistently report lower wellbeing and higher rates of depressive symptoms and distress compared to the general population.

Over the past 15 years, counselling has emerged as a key service option for carers who are facing emotional challenges as a result of their caring role. In Australia, carers are regularly supported to access counselling through the National Carer Counselling Program (NCCP), delivered by the National Network of Carer Associations. In light of the major ongoing reforms in the disability, aged care and carer support sectors, it is timely to appraise the value that counselling offers for carers.

This literature review sought to scope the findings of studies regarding the effectiveness of psychological interventions for improving carer health and wellbeing. The literature reviewed included studies that evaluated carer counselling as a broad intervention as well as specific interventions for carers including; cognitive behavioural therapy, strengths-based approaches, mindfulness, psychoeducation and multicomponent interventions. We included international literature published in English that evaluated carer psychotherapeutic interventions and excluded descriptive studies of carer burden and those where the outcomes for carers were not the primary focus.

Evaluations of the National Carer Counselling Program (NCCP) have shown to increase the subjective wellbeing of carers and improve carers' satisfaction with individual life domains. In addition to the NCCP, there is further evidence regarding the general effectiveness of counselling and psychological interventions for carers. The majority of this research reports modest improvements to carer health and wellbeing outcomes and a reduction of burden associated with the caring role. This research also emphasises the need for carers to be made aware of counselling services and financially enabled to access them.

In regards to specific carer interventions, cognitive behavioural therapy, an intervention which involves modifying maladaptive thoughts and beliefs, has been shown to reduce carer burden, depression and have a range of other positive effects for carers, sustained over multiple years. It has also been evaluated as effective when delivered in a variety of formats.

While cognitive behavioural therapy focuses on problematic thoughts and beliefs, strengths-based approaches draw upon a carer's strengths and attributes to help them cope. This intervention has been found to be appropriate for carers, however there is limited research evaluating its effectiveness.

Mindfulness is another extensively researched psychotherapeutic intervention which assists people to alter thinking patterns and focus on the present moment. The majority of the studies evaluating mindfulness interventions for carers have resulted in positive outcomes resulting in reduced stress, depression, burden and anxiety associated with the caring role and improvement in carer's self-compassion, quality of life and coping strategies. This research also indicates that the effectiveness of mindfulness interventions decrease over time, requiring sustained interventions.

Psychoeducation is an intervention which often combines a psychotherapeutic intervention such as cognitive behavioural therapy alongside education and information regarding the condition of the person being cared for. There is limited evidence to suggest that psychoeducation alone can reduce carer burden and improve carer wellbeing, and research emphasises the need for the carer's active engagement in such interventions.

The literature consistently reported that carer counselling achieves the most positive health and wellbeing outcomes for carers when it is embedded within a multicomponent intervention. Multicomponent interventions typically involve elements such as counselling, education, in-home coaching, peer support, respite, crisis assistance and community linkages aiming to address a broad range of stressors in the carer's life. The strong evidence around the effectiveness of multicomponent interventions, highlights the importance of considering the broader service environment in which carer counselling is delivered in order to provide a tailored and integrated response to carers' needs.

This literature review also draws attention to significant gaps in the literature regarding psychological interventions for carers. In particular, the existing literature almost exclusively focuses on carers of people with dementia. Similarly, few studies analyse outcomes in light of the relationship between the carer and care recipient. There is also need for further research into the effectiveness of carer counselling interventions for male carers, young carers, LGBTI carers and culturally and linguistically diverse carers. Finally, more longitudinal and qualitative data is required.

Despite these limitations, this review highlights the importance of delivering counselling services to carers that are accessible and timely; holistic and tailored to carers individual needs; provided by practitioners with demonstrable expertise and understanding of caring roles; support carers to utilise strategies to relieve distress; and facilitate social support from other carers.

Introduction

It is well established that providing informal care and support can have a significant impact on the physical and mental health of carers. Caring is associated with a number of benefits, including enhanced personal relationships, personal development and improved self-esteem.¹ However, it is also associated with a range of common challenges and stressors.

Recent data from the Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC) indicates that a quarter of all Australian carers experience high or very high levels of distress, and are therefore highly likely to have a moderate to severe mental disorder.² A further quarter of all carers experience moderate levels of distress. These figures are significantly higher than the general population; by comparison, around one in ten Australians experience high to very high levels of distress, with the vast majority experiencing low levels of distress.³

Over the past 15 years, counselling has emerged as a key service option for carers who are facing emotional challenges as a result of their caring role. Carers are regularly supported to access counselling through the National Carer Counselling Program (NCCP), delivered by the National Network of Carer Associations.

In light of the major ongoing reforms in the disability, aged care and carer support sectors, it is timely to appraise the value that counselling offers for carers. This literature review focuses on the existing evidence for the effectiveness of carer counselling in improving outcomes for carers. It will first address research and data evaluating the National Carer Counselling Program (NCCP) and carer counselling services more broadly.

The second section will review evidence supporting particular psychotherapeutic interventions for carers and their effectiveness at improving carer health and wellbeing. The third section will highlight some of the limitations of the existing research and suggest ways in which the evidence base could be improved. The final section outlines possible implications for services and a practical application of the evidence from this review.

Methodology

This literature review reports on studies which identified outcomes for carers, with a focus on the results from randomised controlled trials (RCTs). We limited our inclusion criteria to studies and systematic reviews which evaluated the effectiveness of psychological interventions for carers. We excluded descriptive studies of carer burden and unmet needs that did not specifically evaluate an intervention. We also excluded studies where the outcomes for carers were secondary to outcomes for the person being cared for. Finally, we limited studies to those written in English and conducted in similar settings to the Australian context.

Quantitative measures varied between the studies reviewed, however most measured depression, anxiety, burden, chronic distress, subjective wellbeing, quality of life and coping. Fewer studies qualitatively evaluated carer counselling interventions.

Search terms included; carer, caregiver, counselling, psychological intervention, psychosocial intervention, cognitive behavioural therapy, mindfulness carers, mindfulness caregivers, mindfulness counselling, acceptance and commitment therapy caregivers, strengths-based, multicomponent intervention.

1. Counselling overview

Counselling is used as an umbrella term to cover a range of therapies and interventions that are also referred to as 'psychotherapy', or 'psychological interventions'. Although there is significant overlap between psychotherapy and counselling, counselling is generally considered to be a short-term intervention which addresses specific problems and changes in life in order to promote wellbeing.⁴

Carers seek counselling to address a range of issues. Whilst each caring role poses unique challenges, common themes for carers that can be addressed through counselling include:

- stress management and self-care
- coping with a crisis, such as a significant deterioration in care recipient's health
- problem solving, caring skills and strategies
- grief and loss issues, including bereavement for former carers
- transition issues relating to the care recipient moving to residential care, community care services or to another primary carer in the community
- social isolation and lack of support networks
- stigma, discrimination and feeling judged⁵

Counsellors and other professionals who provide counselling to carers typically draw upon a range of frameworks and techniques to support carers' wellbeing, which are explored in **Section 2**.

1.1 National Carer Counselling Program (NCCP)

Since 2003 the Australian Government has funded the National Carer Counselling Program (NCCP) in recognition of the challenges that carers face. In 2017 the NCCP continues to be funded by the Department of Social Services and is delivered in each state and territory by the National Network of Carer Associations.

The objectives of the NCCP are "to provide counselling and emotional and psychological support services for carers", with the goals of reducing carer stress, improving carer coping skills and facilitating continuation of the caring role, where appropriate.⁶ It is designed to be a short-term intervention for carers which specifically addresses issues within the caring role. Where issues emerge which are considered to be beyond the caring role, carers are referred to specialist intervention.

Carers NSW guidelines for brokered counsellors define counselling as "contracted and purposeful" with identified expectations and agreed themes for exploration between a qualified counsellor and the carer.⁷ No particular therapeutic intervention is promoted for use in the NCCP, however the Program Guidelines stipulate that counselling services must be provided by professional, qualified and accredited counsellors.⁸ Counselling can be offered over-the-phone, in face-to-face settings, as an individual, or in family or carer peer groups.

Some associations require that counsellors undergo specialist training. For example, Carers NSW brokered counsellors take part in carer sensitivity training in order to gain specific knowledge of the caring role and the emotional impact that caring has on the individual.

1.2 Evaluation of the NCCP

A study of the effectiveness of the NCCP was piloted in Victoria in 2010 by Carers Victoria, Carers Australia and Deakin University. This study used the Personal Wellbeing Index (which measures satisfaction across a range of life domains) to measure carers' subjective wellbeing before and after

counselling interventions.⁹ Cummins et al. reported that carers' baseline wellbeing was the lowest group mean score of all groups that had the authors had studied, indicating 'certainty of high levels of depression'.¹⁰ The pilot study did not recruit enough participants to reach conclusive findings, however they found that in the immediate term, counselling was effective in raising wellbeing by 10.8 points, noting that it still remained well below the bottom of the normal range.¹¹

Qualitative data obtained from the pilot study also indicated carers' positive experiences with professionals who understood the carer experience.¹² Some carers reported the need for counselling beyond six sessions to address complex caring issues.¹³

A more comprehensive Carers Counselling Intervention Study was conducted in South Australia in 2013. This study undertook surveys assessing the subjective wellbeing of 292 clients before and after their NCCP counselling sessions.¹⁴ In addition to the Personal Wellbeing Index (PWI), carers were asked to evaluate six areas of life which were designed to specifically measure the challenges associated with the caring role.¹⁵

As with the pilot study, the average baseline PWI score reported by carers was significantly below the normal range across each of the seven domains measured. Again the counselling proved to be effective, with carers experiencing an increase in their subjective wellbeing immediately after the sessions, although this improvement was less marked than in the pilot study (5.5 points on average).¹⁶ Significantly, Cummins et al. found that carers' wellbeing continued to increase at three-month follow-up. However their wellbeing remained below average.¹⁷ The domains in which carers made the greatest gains were satisfaction with achieving in life and personal relationships.¹⁸

The NCCP intervention also resulted in positive improvements to 'Carer Key Life Areas'. Areas which carers ranked the lowest at baseline- 'life as a carer is getting easier' and 'having enough time oneself' – showed the largest improvement immediately after the counselling sessions, and this improvement increased at the three-month follow-up.¹⁹ Cummins et al. concluded that the counselling intervention effectively increased overall subjective wellbeing and satisfaction with individual life domains, and was able to sustain this increase over the mid-term.²⁰ These findings are complemented by evaluation data obtained by Carers NSW (see Appendix 1).

1.3 Evidence supporting carer counselling

Most research regarding the effectiveness of counselling and psychological interventions other than the NCCP for carers reports modest improvements to carer health wellbeing outcomes²¹ and a reduction of burden.²² Limiñana-Gras et al. argue that profound changes to carer wellbeing are unlikely given the chronic nature of caring roles.²³ Candy et al concur, particularly in relation to cases where care recipient's condition is terminal.²⁴ Other noted benefits of counselling for carers include prevention of loss of personal identity.²⁵

Longitudinal research has demonstrated the sustained effects of counselling interventions for carers. For example, a randomised controlled trial of an intervention for carers of people with dementia resulted in improved mood and decreased depressive symptoms after two years.²⁶ This intervention was conducted in a clinical setting on a one-on-one basis and used a combination of psychological modalities including positive reframing, acceptance, relaxation, assertive communication and education components specific to caring for a person with dementia.

A randomised controlled trial by Mittelman et al. also reported sustained improvement to carer wellbeing.²⁷ The intervention component of this study involved individual and family counselling, a support group and ad hoc counselling for carers of people with Alzheimer's disease. The study demonstrated that this 'enhanced' approach to carer support resulted in a reduction of depression

amongst carers that was sustained for three years. The authors note that the high skill level of the counsellors involved in the intervention contributed to its success.

The counsellors were also able to provide condition specific information, advice and strategies to carers at times when they needed it. One counsellor was assigned to each family to ensure consistent support, and this counsellor was active in providing follow-up support. Continuity of care throughout important transitions for carers has also been highlighted by a study of the same program's usefulness in supporting carers through the transition of the care recipient to residential care.²⁸

While the majority of the research evaluating the effectiveness of carer counselling is quantitative, some research has focused on carers' views about their experience of counselling. For example, a Welsh study by Waters et al. found that carers believed counselling could offer: relief and space to offload, a private and non-judgemental space, practical information and referral to other services which could help them, a focus and time for themselves and change by helping them to see and understand aspects of the care relationship differently.²⁹

Waters et al. also found that carers who had not undertaken counselling were unlikely to consider counselling as a means of creating change, or focusing on themselves.³⁰ The authors therefore emphasise the need to provide clear information to carers about the potential benefits and limitations of counselling in order to manage carers' expectations. They also encourage professionals to be "sensitive to the complex interface between carers' practical and emotional needs" and to work alongside service providers better equipped to meet practical needs.³¹

A Germany study by Gräßel et al. reported similar results from 404 carers of people with dementia regarding the quality and utilisation of carer counselling.³² The most important aspect of carer counselling in this study was advice about available supports and strategies to manage the behaviour of the person with dementia. Northouse et al. also note the importance of practitioners' specific knowledge about the challenges that carers face to assist them in identifying carers' unmet needs.³³

Despite a number of studies evaluating the effectiveness of carer interventions, few are translated into practice.³⁴ Even when carer counselling is available, research by Gräßel et al. highlights that not all carers are aware of such services,³⁵ while Northouse et al. argue that there should be enhanced financial incentives for carers to attend counselling.³⁶

2. Specific interventions

This section provides an overview of the available literature on specific psychotherapeutic interventions that have evaluated outcomes for carers. These include; cognitive behavioural therapy, strengths-based approaches, mindfulness interventions, psychoeducation and multicomponent interventions. Social/peer support groups (except where these were an aspect of multicomponent interventions) were considered to be a separate area of investigation.

2.1 Cognitive behavioural therapy

One of the most common forms of psychotherapy that has been evaluated as an effective technique for counselling carers is cognitive behavioural therapy (CBT). This intervention involves modifying maladaptive thoughts and beliefs which are thought to be the primary cause of carer distress and depressive symptoms.³⁷ Changing such thought processes is designed to enhance coping amidst stressful situations.³⁸ This therapeutic intervention has been most widely evaluated amongst carers of people with dementia.

CBT has been shown to reduce carer burden and depression and have a range of other positive effects for carers. For example, a meta-analysis by Pinquart and Sörenson found a correlation between CBT and reduced carer burden and depression.³⁹ Manne et al. developed and evaluated a program using a social-cognitive processing therapy (a type of CBT) for people caring for a child undergoing a hematopoietic stem cell transplant⁴⁰ and found that it reduced carer distress. A randomised controlled trial by Fegg et al. applying existential behavioural therapy (an extension of CBT) amongst carers of people in palliative care and during bereavement also found a reduction in carer distress and improvements in quality of life.⁴¹

Additionally, Aboulaifa-Brakha et al. found that cortisol secretion (a symptom of chronic stress) decreased significantly amongst carers of people with Alzheimer's disease who were provided CBT sessions when compared to carers who received a psycho-education programme.⁴²

Schinköthe et al. also suggest that individually tailored CBT can assist carers of people with dementia when managing behaviour-change associated with cognitive decline.⁴³ Furthermore, their study also indicates that the competence of the therapist in regards to CBT is similarly associated with reduced carer burden.

Wilz et al. is one of the few studies which records effects of their CBT intervention beyond one year.⁴⁴ They found improvements in perceived emotional wellbeing after two years, however there were no statistically significant outcomes for depressive symptoms, health status or quality of life. Furthermore, of those participants who were still caring after two years, the carers that had participated in the intervention had higher perceived emotional wellbeing and quality of life.

Delivery of CBT has also been evaluated in a variety of formats. Schinköthe and Wilz found that CBT could be effectively delivered in a telephone format.⁴⁵ A systematic review by Scott et al. also noted a reduction of depression amongst carers of people with dementia following a telephone CBT intervention that was equivalent to face-to-face interventions.⁴⁶

Research on CBT with carers has also shown that it can be successfully adapted to suit communities from culturally and linguistically diverse backgrounds. Leone et al. adapted a CBT intervention to Chinese and Spanish-speaking communities in Australia, which resulted in clinically significant reductions in carers' depression, anxiety, and stress levels.⁴⁷ Gonyea et al. utilised a culturally sensitive framework to deliver a CBT intervention to Latino carers which reduced carer distress and improved carer self-efficacy.⁴⁸

2.2 Strengths-based/wellness approach

Given the stressful nature of many caring roles, Peacock et al. argue that a strengths-based therapy approach is beneficial for carers.⁴⁹ As part of this approach, participants are engaged to recognise and draw upon their own personal strengths and attributes rather than focusing on problems or 'deficits'.⁵⁰ According to Myers, this approach can help carers to cope with stress associated with their caring role.⁵¹

Strengths-based therapies are often embedded within wellness approaches seeking to improve the overall wellbeing of carers and their families.⁵² While the strengths-based approach is cited as a helpful intervention for carers, few studies have evaluated its overall effectiveness and ability to reduce carer burden and depressive symptoms.

2.3 Mindfulness based interventions

Mindfulness can be defined as: "paying attention in a particular way: on purpose, in the present moment, and nonjudgmentally."⁵³ Practicing mindfulness is a strategy used to change thinking

patterns, encourage emotional regulation, reduce stress and ultimately achieve inner peace.⁵⁴ Although mindfulness has been practiced for centuries, in the past few decades there has been a growing body of research demonstrating the usefulness of mindfulness-based interventions in treating a range of psychological conditions, improving general wellbeing and perceived health, and reducing chronic pain.⁵⁵ More recently there have also been specific investigations into the usefulness of mindfulness-based interventions for carers, which show promising results in improving carers' health and wellbeing.

Mindfulness-based interventions delivered in a one-on-one counselling setting typically begin with psychoeducation around the key elements of mindfulness, before instruction in mindfulness-based meditation techniques which promote non-judgemental awareness.⁵⁶ Counsellors may support clients to integrate mindfulness into their daily activities, beginning with everyday tasks such as driving, or household tasks.⁵⁷ Only therapeutic interventions which are strongly based in mindfulness practice have been considered in this discussion.

Mindfulness-based interventions involving carers are more commonly delivered as a structured group program. Mindfulness-based stress reduction (MBSR)- an eight-week, semi-structured group intervention which incorporates meditation, gentle yoga, and relaxation exercises- is the most well-known of these programs.⁵⁸ Other popular mindfulness-based interventions include Mindfulness-based Cognitive Therapy (MBCT), which is broadly similar to MBSR, Existential Behaviour Therapy (EBT) and Acceptance and Commitment Therapies (ACT). ACT incorporates mindfulness to change one's relationship to thoughts and feelings,⁵⁹ helping carers to accept difficult experiences and commit to behaviour that is consistent with their values'.⁶⁰ Some of the interventions reviewed were adjusted to fit in with carers' daily schedules, for example by reducing session length.⁶¹

Several systematic reviews of mindfulness-based interventions for carers have been completed within the past two years. In 2015 Li et al. conducted a review of the effects of mindfulness interventions on carers focuses specifically on MBSR/MBCT programs which have been delivered to a range of (predominantly female) carers.⁶² Li et al. found that the quality of studies was generally weak, limited by small sample sizes, uncontrolled trials and lack of long-term follow up.⁶³ However most studies reported positive outcomes on psychological outcomes measures including stress, depression, anxiety, mood, mindfulness, caregiver burden, self-compassion and quality of life.⁶⁴ Studies also had a high completion rate, except for one program which was delivered in a DVD format.⁶⁵

Several studies considered by Li et al. produced unique findings. Lengacher et al. measured immunological parameters associated with stress, and reported decreases in stress markers post-intervention, suggesting the potential benefits of MBSR on carers' physical health.⁶⁶ Birnie et al. examined relationships between carers and care recipients, and reported that recipients' higher mindfulness scores were associated with less mood disturbance in carers, although the reverse correlation was not found.⁶⁷ Birnie et al. result suggest that carers may be particularly sensitive to care recipients' wellbeing, and the authors suggest that including both carers and care recipients in MBSR programs could yield positive results.⁶⁸

In 2016 Jaffray et al. conducted a systemic review of mindfulness-based interventions for palliative carers, finding ten studies which predominantly researched interventions for carers of people with dementia.⁶⁹ Jaffray et al. included a broader range of mindfulness interventions, including ACT and those delivered on an individual level. Jaffray et al. noted similar limitations to Li et al. and identified additional challenges. These were the diversity in the types of interventions they reviewed, and the nature of the carer population, who were likely to experience increased stress and distress as the disease trajectory progressed.⁷⁰

Considered within this review was a study conducted by Kögler et al. which measured traits of mindfulness and wellbeing in a group of 133 carers prior to an EBT intervention.⁷¹ This study found that mindfulness traits such as 'acting with awareness' and 'non-judging of experience' were significantly correlated with higher life satisfaction and lower psychological distress.⁷² This is one of the few studies to present qualitative data on a mindfulness-based intervention.

Investigating the experiences of bereaved carers who undertook six weekly group sessions of EBT, Kögler et al. found that social support and self-regulation were key themes and drew attention to the benefits former carers gained from being with others who had shared similar experiences and felt safe expressing emotions.⁷³ Many of the former carers described that it was helpful to allow the coming and going of different emotions, accept their situation and stop ruminating, including by living in the present.⁷⁴ Kögler et al. identified that the mindfulness techniques were particularly helpful to promote positive coping strategies.⁷⁵

Jaffray et al. concluded that that mindfulness-based interventions offer potential benefits for carers.⁷⁶ Significant and positive outcomes were found across several measures including a reduction in depression and carer burden and improvements in quality of life measures.⁷⁷ However these positive effects generally decreased over time.⁷⁸

Other recent studies similarly highlight the benefits of mindfulness-based interventions in promoting positive mental health outcomes for carers. In 2015 Warren Brown et al. conducted an RCT of MBSR for early-stage dementia carers when compared to standard social support groups.⁷⁹ They measured a range of outcomes, including self-reported measures and stress hormones. The study found that MBSR had treatment advantages over traditional social support for mental health outcomes, with significant lower levels of perceived stress, tension and anger post-intervention.⁸⁰ In other areas improvements were similar across interventions, and social support outperformed MBSR in the reduction of caregiver burden.⁸¹ The authors have suggested this is because social support offered condition-specific advice, which was lacking from the MBSR program.⁸² A significant decline in stress hormones was not observed for either treatment.⁸³

Losada et al. conducted an RCT comparing the impact of ACT and CBT on a range of outcomes for carers of people with dementia.⁸⁴ Both interventions provided a clinically significant reduction in symptoms of depression and anxiety in carers, with CBT showing greater long-term impact on depression levels, and ACT showing strongest impact on reducing anxiety, which is consistent with previous studies comparing the two approaches.⁸⁵

Although studies of mindfulness-based interventions for carers tend to be small-scale, recent positive findings should be considered alongside the significant body of evidence supporting mindfulness-based interventions in the broader population. Therapeutic interventions grounded in mindfulness practice should be promoted as a potentially beneficial intervention for carers who are experiencing mental distress, and in particular should be targeted at carers experiencing stress and anxiety. There is some evidence that the social support provided in a group setting is particularly valued by carers, although there is little evidence as to whether these are ideally condition-specific groups.

The research has highlighted that one of the key limitations in mindfulness-based interventions is their capacity to maintain carers' wellbeing long-term. Interventions should therefore consider how carers can be supported to continue formal and informal mindfulness practices beyond an intensive intervention.

2.4 Psychoeducation

Psychoeducation was a component of a range of interventions mentioned in this review. Psychoeducation tailored to the care recipient's condition is available in a variety of formats across Australia including through group counselling, education sessions and increasingly, online.

There is limited evidence to suggest that psychoeducation alone can reduce carer burden and improve carer wellbeing,⁸⁶ and recent studies have found it has no impact on carers' long-term wellbeing.⁸⁷ However approaches to psychoeducation vary significantly. Whilst there appears to be general consensus among researchers that educational programs that do not go beyond increasing carers' knowledge are unlikely to impact carers wellbeing and coping, there are mixed results for more active interventions.

Dickinson et al. review of psychoeducational interventions for carers of people with dementia is the most comprehensive of these studies and found varied results as to the value of psychoeducation for carers.⁸⁸ The authors identified key components which are associated with an effective psychoeducation intervention. These are: an underpinning theoretical foundation (eg. CBT principles), group delivery as opposed to individual sessions, and carers having an active and participatory role during the intervention.

Research by Perlick et al. with carers of people with bipolar disorder similarly highlighted the importance of an active psychoeducation intervention over a standard approach.⁸⁹ They found that a family focused intervention comprising of psychoeducation, goal setting, CBT and stress reduction strategies over 15 sessions resulted in a significant reduction of carers depressive symptoms relative to caregivers who received educational information via DVD alone. Limiñana-Gras et al. also utilised a psychoeducational intervention involving cognitive-conductual treatment in a face-to-face format, and found that it reduced carer distress significantly compared to the group who received the treatment by distance.⁹⁰

In light of this evidence, psychoeducation when tailored to a carer's specific caring role may be best conceptualised as one element of an intervention which can be activated in a therapeutic setting.

2.5 Multicomponent/holistic interventions

Research has indicated that carer counselling achieves more positive outcomes for carers when it is embedded within a multicomponent intervention.⁹¹ Multicomponent interventions typically involve elements such as counselling, education, in-home coaching, peer support, respite, crisis assistance and community linkages.⁹² These interventions aim to equip carers with emotional support as well as the specific knowledge, contacts, problem solving skills and coping strategies they need to feel better able to manage their caring role.

Multicomponent interventions often combine modalities of delivery, and many of the successful interventions reviewed combine in-home, group settings and phone support. There is general consensus amongst researchers that multicomponent interventions are best practice to improve carer wellbeing outcomes, and three reviews of carer interventions have occurred within the last year which reiterate these findings. However these studies have exclusively focused on carers of people with dementia.

Weinbrecht et al. conducted a meta-analysis of carer interventions and their impact on carer depression and found that more customised approaches led to higher efficacy.⁹³ The authors identified face-to-face contact and skills training as key components of the most successful interventions.⁹⁴ This finding is consistent with one of the most comprehensive studies targeting carer wellbeing- the Resources for Enhancing Caregiver Health (REACH) project in the United States.

REACH II, a randomized-controlled study, tested the effectiveness of an intervention composed of active caregiving training combined with stress management techniques and links to community support. The intervention was tailored to the carer's level of need, and carers who participated experienced statistically significant and clinically meaningful reductions in depressive symptoms and burden compared with those who only received telephone assessment and information mailed out to them. A modified version of REACH has been successfully replicated in Hong Kong with positive outcomes for carers, highlighting the need to tailor approaches to carers' local context and culture.⁹⁵

A systematic review by Laver et al. of 40 studies found that multicomponent interventions which tended to involve psychoeducation, psychotherapy, support groups, problem solving and skills training were associated with the reduction of depressive symptoms and improved quality of life for the carer and also had beneficial impacts for the person with dementia.⁹⁶

Sørensen et al. combined individually-tailored counselling with support groups and an educational component to support carers of people with Alzheimer's disease.⁹⁷ Qualitative analysis found that carers were better able to cope with their caring role. This study also found that carers sought permanent counselling and support groups following the intervention. Haley et al. conducted a similar study combining individually tailored counselling and weekly support groups to carers of people with dementia.⁹⁸ Evaluation noted a reduction of depressive symptoms before and after the death of the person being cared for compared to carers who received usual care.⁹⁹ Notably, the reduction of depressive symptoms for the intervention group were sustained for at least a year after the cessation of the caring role.¹⁰⁰

Dickinson et al. conducted a comprehensive 'systematic review of systematic reviews' of interventions for carers in 2017 which again highlights the value of multicomponent interventions that combine education and therapy:

'Our findings reveal the most effective interventions to maintain the psychological health of carers should incorporate both an educational component, focused on enhancing carers' knowledge of dementia and the caring role, and a therapeutic component, for example, CBT/cognitive reframing. The effectiveness of such interventions can be further increased if delivered in a support group format rather than as individual therapy. Incorporating a technological component, via ongoing telephone/online support, could potentially be more cost-effective.'¹⁰¹

Dickinson et al. draw attention to the need to promote the support that is inherent in a group intervention. The group intervention enhances the network of support that is available to carers, which can serve as a protective factor against the stress related to caring.¹⁰²

Although Weinbrecht et al. were cautious around the use of telecommunication, noting carers were more likely to discontinue an intervention if it was delivered via telecommunication,¹⁰³ Dickinson et al. highlight its potential in supplementing face-to-face approaches.

The effectiveness of these multicomponent interventions can be attributed to the fact that they target a range of stressors that the carer experiences through a comprehensive approach.¹⁰⁴ The strong evidence around the effectiveness of multicomponent interventions, whilst limited to one subset of carers, highlights the importance of considering the broader service environment in which carer counselling is delivered in order to provide a tailored and integrated response to carers' needs. This kind of holistic approach is likely to have greater and more sustained outcomes for carer wellbeing.

Mittelman et al.'s study referred to in **Section 1.2** is one example of multicomponent intervention built around counselling as a key feature, incorporating significant psychoeducation and peer support elements to enhance the counselling intervention.¹⁰⁵

3. Limitations & considerations

3.1 Diversity in the literature

The majority of the existing research into carer counselling has focused almost exclusively on carers of people with dementia and to a lesser extent on carers of people with chronic conditions or in the palliative care phase. The first formal systematic review of carer-focused interventions for people caring for someone with severe mental illness was conducted recently in 2016 by Yesufu-Udechuku et al., who noted that the limitations of the data set were 'substantial'.¹⁰⁶

There is a clear need for further research into the effectiveness of carer counselling for individuals caring for people with other disabilities and health conditions, especially as the Australian Bureau of Statistics reports that the common causes of disability amongst people requiring informal care in Australia are diseases of the musculoskeletal system and connective tissue (165,000), autism and related disorders (64,500) and diseases of the circulatory system (61,800).¹⁰⁷ By comparison, there are only 17,900 people with dementia requiring informal care.¹⁰⁸

Most of the literature reviewed focuses on female participants. Whilst this is to some extent reflective of the carer population, it is likely that counselling interventions will have different outcomes and require unique considerations for female, male and non-binary carers. Research has shown that male carers often perceive their caring role as a job and are more task-orientated when compared to women.¹⁰⁹ As a result, many male carers are reluctant to use traditional forms of carer support, preferring opportunities to share information regarding services or practical aspects of care rather than emotion-focussed support.¹¹⁰ It is also well known that men are less likely to access counselling, and in the words of Rochlen, the 'culture of masculinity' clashes with the 'culture of counselling'.¹¹¹

The majority of carer participants in the studies reviewed here are from English speaking backgrounds. While there has been some attempt to assess the effectiveness of interventions across diverse ethnicities and cultural groups, this evidence is limited.¹¹² Existing research with carers from varying cultural backgrounds has highlighted the importance of adapting interventions to carers' values, beliefs and circumstances.¹¹³ It should also be noted that there is no Australian research evaluating the cultural appropriateness of carer counselling interventions for Aboriginal and Torres Strait Islander carers.

Carers who identify as lesbian, gay, bisexual, trans*, intersex or queer (LGBTIQ) are likely to face additional challenges in their caring roles and may be reluctant to access counselling services for fear of discrimination. Barrett and Cramer's 2016 study of older LGBTIQ carers and carers of older LGBTIQ people found that 28% delayed accessing services for fear of discrimination¹¹⁴ and a further 18% felt very uncomfortable accessing carer services.¹¹⁵ Their research highlights that many service settings, including carer services such as counselling and carer support groups, are heteronormative, which can limit opportunities for LGBTIQ carers to gain assistance in their caring role.¹¹⁶

Research has also tended to focus on spousal carers.¹¹⁷ According to Sørensen et al. if the carer is a spouse, the intervention is more likely to generate positive impacts in regards to behaviour management and delaying placement into a residential care facility.¹¹⁸ Thus there is a need for research which closely analyses the effect of the relationship between the carer and the person being cared for.

Further research which focuses on outcomes for a more diverse range of carer groups is needed to reflect the heterogeneity of the broader carer population and ensure that counselling approaches are suitable and effective for all carers. In particular, we recommend that future research draw attention to the appropriateness and effectiveness of delivering carer counselling services to young carers, male carers, culturally and linguistically diverse carers, Aboriginal and Torres Strait Islander carers and LGBTIQ carers.

3.2 Other research limitations

Whilst a few studies have evaluated psychological interventions over an extended period of time, more longitudinal data is required.¹¹⁹ Furthermore, research evaluating the effectiveness of interventions for carers tend to be assessed on a quantitative basis and from the perspective of the therapist. Few studies incorporate feedback from carers themselves about their experience of these interventions.¹²⁰ This is important as quantitative data on health and wellbeing impacts may understate the genuine experience of the carer and beneficial impacts to themselves, the person they care for and family functioning.

3.3 The need for systemic change

Whilst this literature review has focused on counselling, it is important to note that counselling is just one component of the many interventions and supports required to improve the health and wellbeing of carers. Australian carers continue to be marginalised socially and economically, and recent research has revealed that most believe recognition and acknowledgment of carers by services and the wider community is low.¹²¹

These socio-economic factors are intrinsically linked to carers' health and wellbeing, and research has highlighted the importance of factors such as the support of family and friends, and financial assistance, in sustaining carers' wellbeing.¹²² While counselling may assist carers to manage and cope with various stressors associated with their caring role, it is limited in its ability to address the complex socio-economic factors which may contribute carer burden and distress.

4. Implications for services

This literature review explores a range of counselling interventions for carers. It has shown that carer counselling is highly valued by carers and highlights the benefits that counselling can offer carers. While meta-analyses and systematic literature reviews generally indicate only modest improvements to carer wellbeing, the stressful nature of many caring roles mean that even modest improvements are beneficial.

Despite the noted limitations, the findings of the reviewed literature broadly support the effectiveness of carer counselling programs and provide a framework for best practice approaches. In particular, this review has highlighted the importance of carer counselling services that are accessible and timely; holistic and tailored to carers individual needs; provided by practitioners with demonstrable expertise and understanding of caring roles; support carers to utilise strategies to relieve distress; facilitate social support from other carers, and are an appropriate format and length.

Accessible and timely

Psychotherapeutic interventions should be accessible to all carers. Common barriers to service access, including cost, should be removed wherever possible. Awareness of counselling services is typically low amongst carers, particularly 'hidden' carers and carers from diverse backgrounds. Carers should therefore be made aware and supported to access available services.

Carers indicate that immediate access to counselling is highly valued, and the reviewed research supports this. Counselling services should ideally be flexible enough to be available when a carer or former carer requires them.

Holistic and tailored to carers needs

There is strong evidence supporting multi-component interventions for carers. Counselling should therefore be offered as part of a package of support for carers based on their needs. The ways in which counselling is delivered should also take into account the heterogeneity of caring roles.

Expertise and understanding of carers

The reviewed research has highlighted the importance of professionals understanding the caring role, and the stressors and issues, such as grief and loss, which are often associated with it. Beyond just feeling understood, research indicates that interventions involving professionals with expertise in particular conditions and caring situations are needed in order to provide carers with knowledge, insight and practical advice to reduce stress and cope in their caring role.

Strategies to relieve distress

Successful interventions also utilise specific techniques to minimise the stress, anxiety and depression that are likely to be experienced by carers. Both CBT and mindfulness-based interventions are supported by enough evidence to promote their use with carers.

Social support

Another key feature of successful interventions is the social support that can be facilitated by delivering counselling services in a group setting. This offers carers the opportunity interact with their peers in a safe group setting which reduces isolation and promotes social support and connections.

Format and length of intervention

Reviewed research generally indicated that face-to-face interventions are preferable, however carers who are remotely located or unable to attend face-to-face value the availability of alternative options. The length of an intervention has also been shown to be significant in achieving sustained outcomes for carers. A number of studies highlight the importance of providing a sustained counselling intervention. Counselling interventions which offer active follow up to carers may also help carers to maintain improvements to their wellbeing over the long term.

Appendix 1: NSW NCCP data

Carers NSW obtained evaluation data on the NCCP in NSW for the period between January 2012 and May 2017. A total of 2,034 carers completed evaluation forms during this period, representing just under a quarter of NCCP clients. The evaluation forms asked respondents to rate their contact with Carers NSW, as well as their experience of the counselling itself.

The data related to the counselling service was significantly positive, and the vast majority (96%) of carers found it easy to access the counselling service. Carers were also asked about their wellbeing and if it had changed because of counselling. Most carers experienced improvements to their wellbeing as reflected in Figure 1.

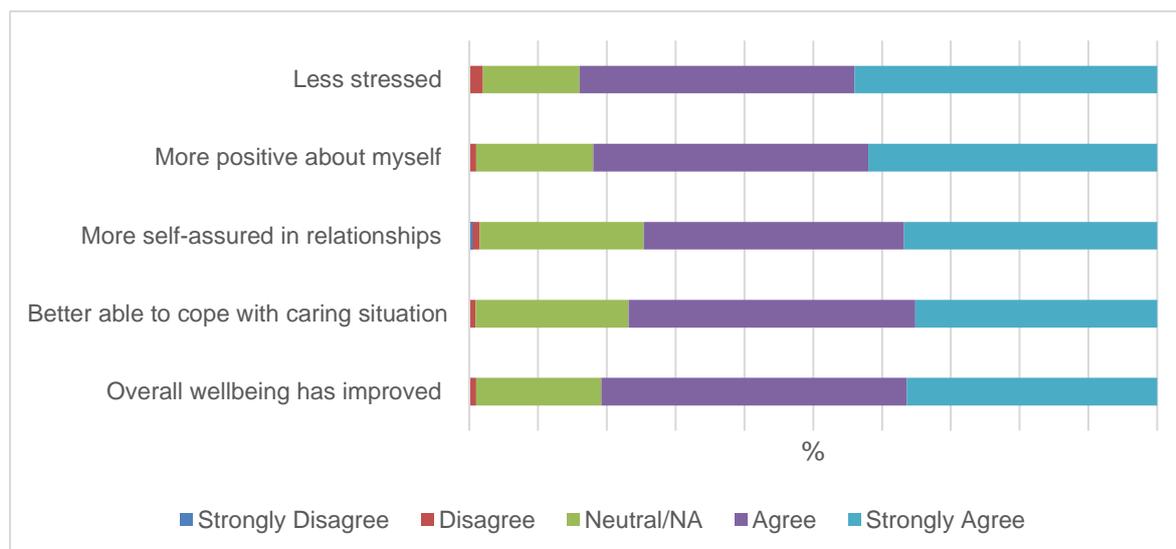


Figure 1: Carer wellbeing outcomes

These results should be interpreted with some caution as there is a risk of bias due to inconsistent distribution of the evaluation form. It has been delivered both by Carers NSW via post, and by brokered counsellors providing copies to their clients, who may therefore be influenced to report more positive outcomes.

There was also a high proportion of neutral and not applicable responses. Qualitative responses indicate that this is often because carers have not completed all counselling sessions yet, and some questions ask carers to report on outcomes 'following the counselling'.

This evaluation data includes a large amount of qualitative evidence that counselling has impacted carers' lives. A thematic analysis of this data is beyond the scope of this literature review, however an initial scan of comments provide useful insights into the value of counselling for carers.

In the twelve months from 2016-17 carers made a range of comments on the impact of counselling, the vast majority of which were positive. Carers frequently commented on the fact that there was dedicated support available for them:

'Just knowing help is a call away when I need it is fantastic even if I'm always shy to ask for help.'

'Living in a rural area with no resources I was grateful to hear that a phone counselling service was available to me and that I didn't have to travel (nearest metro area is a 4 hour

return trip (petrol costs etc.)). (Also, this is not my hometown so social resources, e.g. family and friends, are not on hand to chat with)'

Carers frequently reported that they felt listened to and understood, and many specifically reported feeling understood in relation to caring issues:

I was able for the first time to have face to face counselling with someone who understood my carer role.

Carers NSW entitled me to talk to someone who listened to me and understood. Nothing changed but everything just feel easier when you could speak honestly and be heard.

[The counsellor] really understood the huge issues it takes to look after a son with moderate to severe intellectual disability with complex medical needs and a wife with bipolar disorder.

Carers very frequently reported that accessing counselling was quick, prompt, speedy and accessible when they needed it:

Immediate assistance when in a crisis situation. Help to cope with changing relationship with husband due to his mental health issues.

Carers also mentioned that they valued talking to someone who was independent from their family and friends, and non-judgemental:

When in a caring role the only people you are close enough to talk to are involved in the problems in some way. It is good to have someone outside of this circle to talk the problems out with.

My counsellor listened without judgement and I felt supported. I came away after each session feeling good about myself less anxious and able to take up the next challenge.

Many carers also reported positive outcomes for their mental health, with carers identifying that it helped them manage stress and anxiety. Some carers expressed that the intervention had saved their life.

Although there were overall few identified 'areas for improvement', the most commonly reported by far was that more than 6 counselling sessions would be beneficial. Some carers identified in other sections of the form that they had obtained further counselling with the same professional. A minority of carers reported that the carer counselling was too general:

Need to be carer focused - not generalise counselling. I was upset because of this.

It was not really relevant to my particular carer situation.

Carers' comments on counselling offer useful insight into the value of counselling for carers, and are worthy of further exploration.

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