

Acceptability of a Multicomponent Intervention for Australian Carers of People with Dementia

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B. Psych (Hon)

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Declarations

Statement of Originality

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to the final version of my thesis being made available worldwide when deposited in the University's Digital Repository**, subject to the provisions of the Copyright Act 1968.

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Acknowledgement of Collaboration

I hereby certify that the work embodied in this thesis has been done in collaboration with other researchers. I have included as part of this thesis a statement clearly outlining the extent of collaboration, with whom and under what auspices.

I contributed to the development of the research question, the database search, the statistical analysis, the interpretation of results and editing of the manuscript. Dr Michelle Kelly contributed to the development of the research question, the formulation of the methodology, the interpretation of results, and editing of the manuscript. Ms Karen Bell-Weinberg assisted in the data collection.

Acknowledgement of Authorship

I hereby certify that the work embodied in this thesis contains a scholarly work of which I am a joint author. I have included as part of the thesis a written statement, endorsed by my supervisor, attesting to my contribution to the joint scholarly work.

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Journal Format

This thesis has been formatted for submission to the British Journal of Clinical Psychology, according to the Publication Manual of the American Psychological Association (6th edition). See Appendix A for submission guidelines.

Acceptability of a Manualised Multicomponent Intervention for Australian Carers of People with
Dementia

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Abstract

Objectives: The objective of this study was to test the feasibility and acceptability of the adapted Strategies for Relatives (START) program within the Australian health care context, for the alleviation of carer distress and burden. Further, we aimed to determine the feasibility and acceptability of the telehealth modality.

Method: Twenty-two family carers were randomly assigned to the START eight-week manualised coping program or cognitive behaviour therapy (CBT). Carers completed purpose developed pre- and post-intervention questionnaires to determine the acceptability of the program. Standardised measures of mood and perceived carer burden were also administered to explore treatment effects.

Results: Of the 22 carers recruited, six who completed the START program and four who completed the CBT program provided follow-up data. START carers reported higher overall satisfaction and acceptance of the intervention compared to carers in the CBT group. Furthermore, the telehealth modality was shown to be a practical and acceptable method of intervention delivery.

Conclusions: These pilot findings indicate preliminary evidence for the acceptability and feasibility of the START intervention for supporting carers in their caring roles. Further investigation is needed to determine intervention efficacy for the treatment of mental health related symptomology.

Practitioner Points

- Preliminary evidence for the acceptability of a manualised coping program for Australian carers of people with dementia.
- Preliminary evidence for the acceptability and feasibility of the telehealth modality for the delivery of the START program.

Acceptability of a Manualised Multicomponent Intervention for Australian Carers of People with Dementia

Dementia is an umbrella term, describing a range of conditions characterised by impairments in neurological functioning, affecting cognition, memory and personality (Australian Institute of Health and Welfare (AIHW), 2007). Dementia symptoms, including confusion and loss of inhibition, are typically progressive and irreversible (Haro et al., 2014). These symptoms not only have major health and social consequences for those with a diagnosis of dementia, but also present a significant burden on their caregivers. The natural progression of the disease requires increasing amounts of care, with the majority of care provided at home by a partner or spouse (around 35% of carers), an adult child (41%), or other family members such as in-laws and grandchildren (15%) (The National Centre for Social and Economic Modelling (NATSEM), 2017). These family members are typically referred to as informal “carers” or “caregivers”, and there are approximately 1.6 million people, roughly 6% of the Australian population, caring for a person living with dementia (PLWD) (NATSEM, 2017). This is larger than the 1% of carers in the UK (Lewis et al., 2014) and comparable to almost 5% of the US (National Alliance for Caregiving & AARP, 2015) total population. Of the 70% of people living in the community with dementia, approximately 46% rely solely on their informal supports (NATSEM, 2017).

While this caring role can provide positive outcomes of increased family togetherness and companionship (Netto, Jenny, & Phillip, 2009), carers take on many complex, often physically and emotionally challenging tasks to support the (PLWD) (Mahoney, Regan, Katona, & Livingston, 2005). Carers of those with dementia are identified as experiencing more physical strain, and have higher levels of depression and stress, than non-carers or carers of those with

other health concerns. (Cuijpers, 2005; Pinquart & Sörensen, 2003). It is estimated that approximately 40% of carers suffer from clinically significant levels of depression or anxiety, and many others are at risk of developing a mental illness (Cooper et al., 2010; Mahoney et al., 2005). It is believed that this may be due to the presence of behavioural and psychological symptoms of dementia (BPSD), such as aggression, wandering, sleep disturbance, hallucinations and delusions (Haro et al., 2014). Furthermore, in one Australian survey, carers reported less community involvement and fewer social connections than non-carers, and less social support compared to non-carers or carers of those with a physical disability (Schofield et al., 1998). Greater stress and increased isolation for carers of PLWD, has been associated with loneliness, with one recent study suggesting that more than 60% of a UK sample reported moderate to severe loneliness (Victor et al., 2020).

The physical and psychological impacts of dementia on those with a diagnosis and their caregivers are well documented, however, there are also financial burdens both for the families and the wider community. In 2018, it was estimated that dementia will cost Australia over \$15 billion, with the cost of hospitalisation and institutionalisation accounting for 88% of this total expenditure (NATSEM, 2017). Furthermore, family carers provide between 4 and 55 hours of unpaid care per week, saving the Australian economy \$5.5 billion per year, which is often completed in addition to work and household commitments (Access Economics, 2009). Comparatively, carers in the UK save their economy £12.4 billion (Luengo-Fernandez, Leal, & Gray, 2010). This is significant, because the psychological, physical and financial burden of meeting the ongoing needs of people with dementia (PWD), has long been associated with carer burnout (Etters, Goodall, & Harrison, 2008; Cooper et al., 2010). Burnout has flow-on effects, including higher rates of placement in aged care facilities (Etters et al., 2008). Consequently,

research that advances the development of effective interventions to maintain carer capacity and quality of life and accommodate their responsibilities, is vital to the ongoing well-being of the carer and the (PLWD), as well as the wider community.

There are various interventions aimed at reducing the negative impact of the caring role, including those focused on reducing depression, stress and anxiety, or increasing the self-efficacy, resilience and wellbeing of caregivers. In their systematic review of 62 studies, Selwood, Johnston, Katona, Lyketsos, and Livingston (2007) reported that education alone was ineffective, while coping strategy-based interventions with a minimum of six sessions focused on individualised behaviour management training had been effective. Furthermore, group interventions were less effective than individualised programs. Specifically, expert led behavioural and support programs were less effective when delivered via group formats. Other reviews suggest that psychoeducational interventions, including those delivered in group formats (Dickinson et al., 2017) may have a moderate positive impact on depressive symptoms (Jensen, Agbata, Canavan, & McCarthy, 2015; Piquart & Sörensen, 2006), but the reported effects on carer health or burden are inconsistent (Parker, Mills, & Abbey, 2008; Piquart & Sörensen, 2006). Specifically, Parker and colleagues (2008) suggested that educational interventions produce greater impact when delivered individually. Further, group interventions increased carer treatment satisfaction and enhanced support networks that serve as protective factors against caring related stress. However, group therapy alone was found to be less efficacious overall.

In line with Selwood et al. (2007), Parker and colleagues (2008) suggested that individualised, multicomponent interventions, that is programs that offer a combination of interventions including psychoeducation, skills training in behaviour management and psychosocial therapies, indicate greater improvements in carer outcomes. This included reduced

depression, increased subjective wellbeing and self-efficacy. Furthermore, tailored, multicomponent interventions have been shown to be the only effective approach in reducing the rate of institutionalisation of PWD (Spijker et al., 2008). This is an admirable goal given the evidence that a longer stay at home has psychological and quality of Life (QoL) benefits for PWD (Hoe, Katon, Orrell, & Livingston, 2007).

Bringing all this together, evidence suggests individually delivered, multicomponent interventions are most effective for decreasing burden, improving QoL, and enabling caregivers to provide at-home care for longer. Accordingly, Livingston et al. (2014) adapted a US group-based caregiver skills program (Coon, Thompson, Steffen, Sorocco, & Gallagher-Thompson, 2003) into an individual program in order to improve outcomes and align with growing evidence for this method of intervention. The program, STrAtegies for RelaTives (START), involves 8 (1hr) face-to-face sessions focused on dementia education and coping skills, and relaxation strategies. Program evaluation data suggests superiority of START over treatment as usual in reducing symptoms of anxiety and depression (Li et al., 2014, Livingston et al., 2014). In fact, those who received treatment as usual were found to be 4 and 5 times more likely to display clinical depression at the 8 month and 2 year follow up respectively. Furthermore, recent findings have shown that START remains clinically effective at 6 year follow-up (Livingston, 2019). The program was found to improve carers QoL in the short term (8 months post intervention) and in the long term (2 years post intervention), however, results did not indicate an improvement in QoL for individuals with dementia. The intervention was found to be cost effective, and at 2 years post intervention data indicated a small, but not significant, decrease in the chance of institutionalisation for PWD. Finally, researchers found that the program was practical and acceptable to most carers (Sommerlad, Manela, Cooper, Rapaport, & Livingston,

2014). Overall, the data suggest that the START intervention is a clinically effective program for improving the coping, mood and QoL for carers of PWD.

The AIHW recognises the importance of carer mental health in the prevention of institutionalisation of PWD (2007). Despite this, there remains no manualised evidence-based therapy available for use by psychologists, or other allied or medical health care staff within the Australian context. Indeed, there is no evidence-base to demonstrate whether such standardised interventions are viable, feasible or acceptable. The aim of the current research was to adapt the proven START intervention to suit Australian carers and determine the feasibility and acceptability of this program within the Australian health care context. That is, we intended to determine carer reactions to and engagement with the intervention. This included comparison with cognitive behaviour therapy (CBT), an evidence-based intervention for the treatment of anxiety and depression (Hollon, Stewart, & Strung, 2006).

We further aimed to investigate the practicality and acceptability of intervention delivery via the use of Telehealth services. Telehealth services are particularly important within the Australian context (Bradford, Caffery, & Smith, 2016) due to the geographic spread of the population. Healthcare services and facilities are typically less accessible for those living in regional, rural and remote areas, and those services that are available are often in short supply of healthcare professionals (Schirmer, 2017). Limited and unreliable public transportation (van Gaans & Dent, 2018), and psychological and health/mobility limitations (Somenahalli, 2015) provide additional barriers for older health service seekers in both rural/remote and urban areas. Furthermore, as previously stated, 46% of those with a diagnosis of dementia living in the community rely solely on their informal carers (NATSEM, 2017). Although respite is identified as an essential service rates of usage are low (Neville, Beattie, Fielding, & MacAndrew, 2015),

creating a practical barrier preventing carers from attending services face-to-face. Telehealth is a flexible modality, with a growing body of research highlighting the benefits of this approach in meeting the needs of carers of PWD (Czaja & Rubert, 2002; Torp, Hanson, Hauge, Ulstein, & Magnusson, 2008; Wilz & Soellner, 2016).

We measured acceptability via carer self-report and attendance records. It was predicted that carers would indicate greater acceptability and relevance of the START intervention to their situation than carers in the control (CBT) program. It was further predicted that carers would report suitability and acceptance of the Telehealth application of the program. We further hypothesised that both groups would report lower levels of depression and anxiety post intervention. Although not a focus of this study, we will also examine whether carers in the START program demonstrate a greater reduction in symptoms of anxiety, depression and burden, compared to carers in the CBT program.

Method

Participants

Carers

Carers were recruited through Geriatricians, a specialist mental health service for older people, General Practitioners, carer support and community organisations. Medical professionals either referred (contact details provided to researchers with consent) or encouraged eligible individuals to self-refer to the study. Individuals recruited through carer support and community organisations self-referred. The recruitment and engagement details are provided in Figure 1.

Carers were eligible for inclusion if they were over the age of 18 years, currently provide practical or emotional support on at least a daily basis for a (PLWD) and had adequate English language proficiency. Initially only eligible carers with clinically significant affective symptoms

and or self-reported carer burden were to be included, however, this criterion was relaxed due to 1) requests by carers who self-reported that they were experiencing distress as a result of their caring role and otherwise had no formal support available to them, and 2) difficulty recruiting enough carers that met the strict inclusion criteria¹. Exclusion criteria were: current major psychiatric illness on the part of the carer, high suicidality or significant cognitive difficulties. Carers were aware that they are undergoing an intervention but were blinded to randomisation status.

¹ This was also considered an acceptable variation to protocol given the original START RCT had no inclusion requirement related to current symptomology, with results indicating program outcomes were both interventive and preventative.

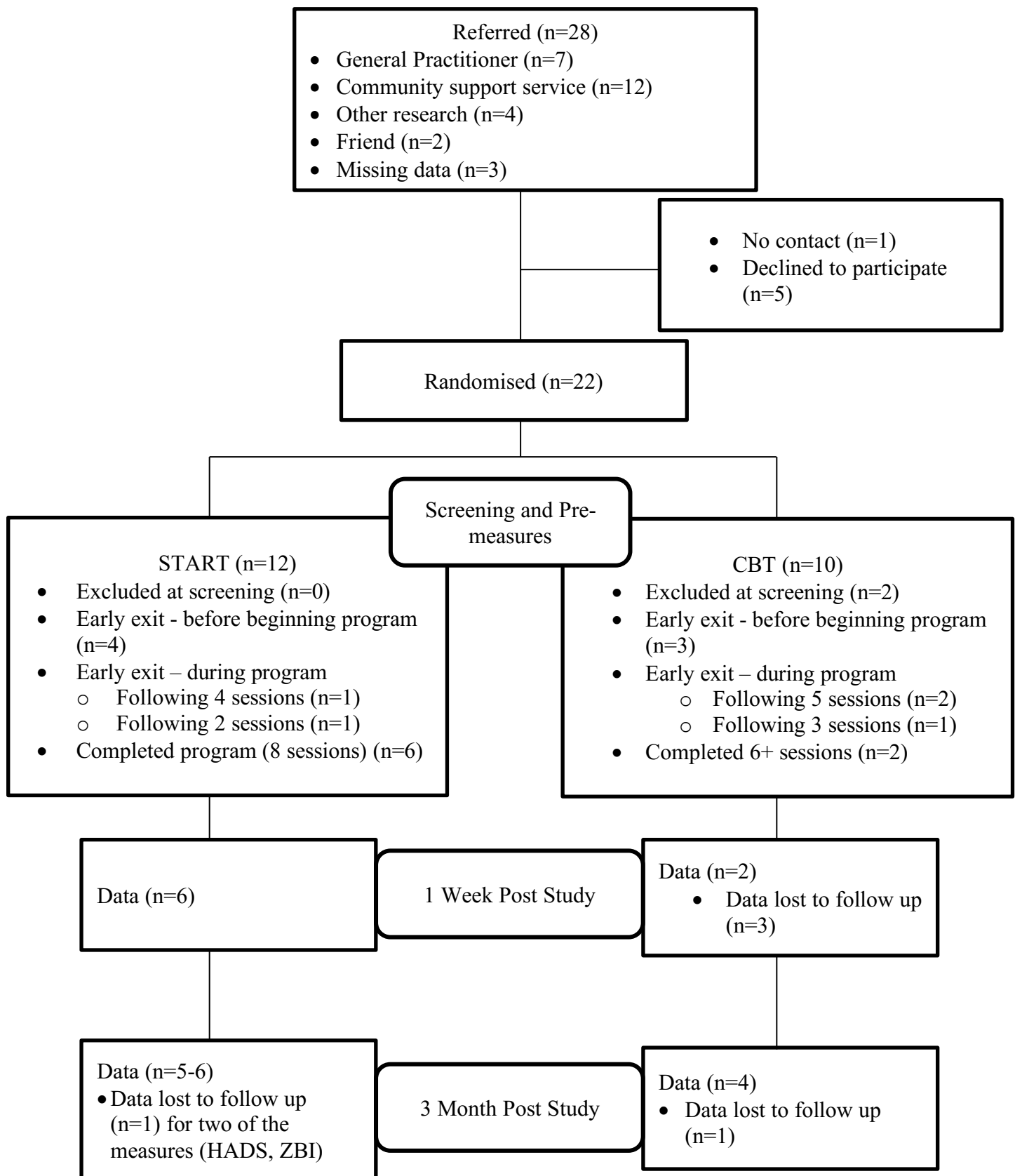


Figure 1: Flow of participation through the study

Therapists

Therapists were provisionally registered postgraduate students, enrolled in the Master of Clinical Psychology program at the University of Newcastle. Participation was voluntary, and therapy hours as part of this study contributed to clinical placement requirements of the degree.

Measures/Instruments

Feasibility and Acceptability

The primary outcome for this study was to test the feasibility of a novel intervention for use within the Australian context. We examined the extent to which the START program was considered suitable and satisfying via program adherence and participant acceptance (Bowen et al., 2009) as self-reported by participants. We further assessed the acceptability of Telehealth via comparison of participant self-report across modality, in addition to participant rated satisfaction and confidence in accessing the program using web-based technology. Finally, we aimed to determine if the UK START program retained efficacy in reducing Australia carer distress and burden (Bowen et al., 2009).

Hospital Anxiety and Depression Scale (HADS).

The HADS (Zigmond & Snaith, 1983) is a validated 14-item self-report questionnaire used to indicate anxiety and depression symptomology. The HADS has good reliability ($\alpha = .83$) (Bjelland, Dahl, Haug, & Neckelmann, 2002) and the total score is reported as a primary outcome measure in the UK START studies (e.g., Livingston et al., 2014). A clinical cut-off of 16+ was employed based on previous research (Bjelland et al., 2002) and used in Li and colleagues (2014) START randomised control trial.

Zarit Burden Interview (ZBI)

The ZBI (Zarit, Reever, & Bach-Peterson, 1980) is a 22-item self-report questionnaire used to determine perceived carer burden. The ZBI displays excellent reliability ($\alpha = .94$) (Hérbet, Bravo, & Prévile, 2000) and is the most consistently used measure of carer burden (Zarit, Anthony, & Boutselis, 1987). Clinical cut-offs of 21+ indicated at least mild burden (Stagg & Larner, 2015).

Carer Experience Survey

Additional outcomes were assessed via questionnaires designed specifically for this study (Appendix H). These questionnaires were used to measure feasibility and acceptability of the intervention (e.g., ‘Were your expectations met?’) rated on an 11-point Likert Scale (0-10) ranging from ‘not met’ to ‘exceeded’, and perceived relevance of the intervention (e.g., ‘How relevant was the program?’) rated on an 11-point Likert Scale (0-10) ranging from ‘not relevant’ to ‘extremely relevant’. Carers were also asked to rate their experience according to mode of program delivery (face-to-face or Telehealth; e.g., ‘Attending the clinic is an acceptable way to receive this program’ or ‘Online was an acceptable way to receive this program’) on an 11-point Likert Scale (0-10) ranging from ‘strongly agree’ to ‘strongly disagree’. Finally, carers also completed two short surveys (2 minutes) on a session-by-session basis which focused on the usefulness of each session. This data will be examined as part of the broader study.

Qualtrics

All data were collected using the web-based survey software and questionnaire tool Qualtrics (Qualtrics, 2018). Carers were emailed links directing them to each of the surveys. For those carers who were not familiar computer users, surveys were printed and posted in hard copy with return envelopes.

START Caring for Carers Manual (Australian Version)

Revised editions of the UK START manuals were developed to acknowledge differences in language and health care resources between the UK and Australian health care systems. This manual was reviewed and approved by a panel of experts, including representatives from Dementia Australia (carers group), the University of Newcastle, University of Melbourne (National Ageing Research Institute) and the University College London. The carer manual details session content and contains support resources and relaxation audio tracks (see University College London's START website for full details on session content). The manual also includes information regarding additional services and supports available beyond this program. The therapist manual contains the same information as the carer manual, however, has additional prompts regarding how to deliver the program and elicit additional information as required.

Procedure**Carers**

Ethical approval for this study was granted by the University of Newcastle Human Research Ethics Committee (H-2016-0299; see Appendix B). All participants provided informed consent before their participation in the study. Carers were randomly assigned to the START intervention group or the CBT group via blocked randomisation. They were then screened for suitability and completed pre-intervention measures. Carer availability and preferences determined the method of program delivery (face-to-face or video conferencing; see Figure 2). All carers completed an initial assessment (Appendix I) with their allocated therapist. If allocated to the START group, carers were provided with the program manuals. No manuals were provided for the CBT group.

Regardless of group allocation, carers were required to complete measures across three time points; pre-intervention, 1-week post intervention and 3 months post intervention. In addition, all carers completed weekly reflection and feedback questionnaires following each session.

Carers allocated to the START program completed an initial assessment (up to 1.5 hours) and 8 (1 hour) individualised weekly or fortnightly sessions dependent on carer availability. They were also required to practice the strategies and relaxation exercises in between sessions. Those carers allocated to the CBT program completed an initial assessment (up to 1.5 hours) and up to 12 (1 hour) individualised weekly or fortnightly sessions, in line with standard best practice for the management of anxiety (Kishita & Laidlawb, 2017) and depression (Linde et al., 2015).

Therapists

Therapists were randomly allocated to treatment type and were required to complete a pre-study survey, recording therapists' experience and expectations, and complete weekly feedback surveys following each session. All sessions were recorded for the purposes of fidelity rating. START therapists were required to complete a 4-hour training module and were provided with a program manual, outlining the content for each session. Regardless of group, all therapists completed post-session feedback surveys, which contributed to overall data on the acceptability of the intervention. The therapist experience was not a focus of this study.

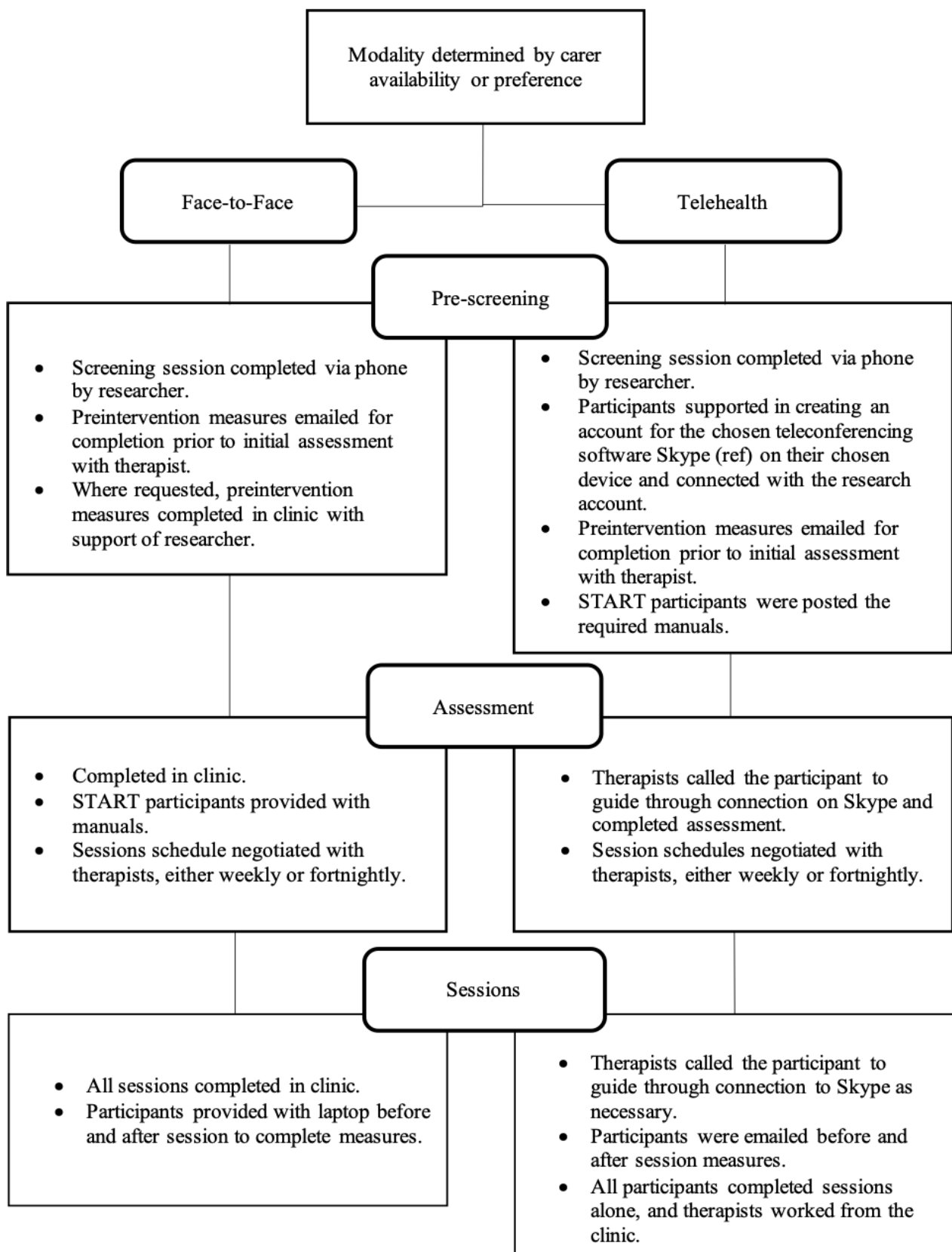


Figure 2: Procedure according to modality.

Results

Data Analysis

Survey data on the acceptability of the START intervention in comparison to CBT was entered into Microsoft Excel for analysis. Descriptive and demographic data was examined using IBM SPSS statistical package (2016). Data for mood and carer burden were examined to investigate the immediate and 3-month post effects of the intervention for each carer. To determine the effect of the intervention on carer reported anxiety, depression and burden over time, the Reliable Change Index (RCI; Jacobson & Traux, 1991) was used to detect reliable change (RC), and where appropriate, clinically significant change (CSC) for each carer. All calculations were completed according to the formula as outlined by Jacobson and Traux (1991), using Morley and Dowzer's (2014) Excel RCI calculator. RC indicates the amount of change that occurs outside of chance or error ($RCI = \pm 1.96$), based on the measurement's test/retest reliability and is necessary for ascertaining CSC. In order to calculate CSC specific criteria are required (Jacobson and Traux 1991). Criterion "A" for the determination of CSC was used when only clinical reference data was available and is defined as a change in post-intervention scores of more than two standard deviations beyond clinical sample means. Criterion "B" for the determination of CSC was used when normative and clinical reference data were available and is defined as a change in post-intervention scores within two standard deviations of non-clinical means. Determination of CSC is only possible for those carers who meet clinically significant scores at baseline. Reference data used to determine the RCI's and CSC are detailed in Table 1.

Table 1.

Reference data for calculating RC and CSC

Measure	Cronbach's alpha	Clinical norm reference	Non-clinical norm reference	CSC criterion
HADS-T	$\alpha = 0.83$ (Bjelland et al., 2002)	$M = 14.80, SD = 7.40$ (Livingston et al., 2014)	$M = 9.82, SD = 5.98$ (Crawford, Henry, Taylor & Crombie, 2001)	B
ZBI	$\alpha = 0.92$ (Hérbet, Bravo & Prévile, 2000)	$M = 38.10, SD = 17.00$ (Livingston et al., 2014)	<i>n/a</i>	A

Note. CSC = clinically significant change (Jacobson & Traux, 1991).

Sample Characteristics

Demographic data for all carers is presented in Table 2. Of the twelve carers randomised to the START group, four did not begin the program. No contact was made with two of the four, one carer was unable to commit due to their own health concerns, while the other reported a time commitment issue in addition to finding the pre-intervention questionnaires confronting. Two additional carers began but did not complete the program. One of these reported that they did not have enough time to complete the program, while the other withdrew due to health concerns of the person they were caring for; both were attending sessions face-to-face. In the CBT group, five of the ten randomised carers did not begin the program. Of the eight who met eligibility criteria, two indicated that they did not wish to participate but gave no further reason. Two withdrew citing irrelevance to their current situation. Four carers were deemed to have

completed their treatment following between five and twelve sessions and their data were included.

Table 2.

Demographic data for randomised participants

Participant	Sex	Age	Ethnicity	Marital Status	Education	Occupation	Employment	Caring for	Resides with	Modality
START										
001 _a	F	49	White Australian	Married	University	Home duties	Nil	Mother	Yes	Clinic
002 _a	F	52	White Australian	Single	University	Fulltime carer	Nil	Mother	No	Telehealth
003 _b	M	79	White Australian	Married	TAFE	Sign writer	Retired	Wife	Yes	d/a
004 _a	F	51	White Australian	Married	n/a	n/a	n/a	Mother	Yes	Telehealth
006 _a	F	58	Indigenous Australian	Married	High school	n/a	Retired	Mother	No	Clinic
010 _b	M	52	White Australian	Married	n/a	Farm contractor	Fulltime	Wife	Yes	d/a
012 _a	F	77	Irish	Married	TAFE	Small business	Retired	Husband	Yes	Telehealth
017 _b	M	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	d/a
018 _b	F	74	White Australian	Married	TAFE	Small business	Retired	Husband	Yes	Clinic
020 _a	F	60	White Australian	Married	University	Speech Pathologist	Retired	Husband	Yes	Telehealth
021 _b	F	72	White Australian	Married	University	Teacher	Retired	Husband	Yes	Clinic
022 _b	F	61	White Australian	Married	TAFE	Director	Retired	Mother	Yes	d/a
CBT										
005 _b	M	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	d/a
007 _b	M	n/a	n/a	n/a	n/a	n/a	n/a	Wife	n/a	d/a
008 _a	M	79	Dutch	Married	High school	Panel Beater	Retired	Wife	Yes	Clinic/ Telehealth
009 _a	M	80	White Australian	Married	TAFE	Supervisor	Retired	Wife	Yes	Clinic
011 _b	M	85	Scottish	Married	TAFE	Building Inspector	Retired	Wife	Yes	Clinic
013 _b	F	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	d/a
014 _a	M	60	White Australian	Single	University	Software Engineer	Nil	Mother	Yes	Telehealth
015 _b	F	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	d/a
016 _b	F	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	d/a
019 _a	F	76	White Australian	Married	TAFE	Secretary	Retired	Husband	Yes	Clinic/ Telehealth

Note. _a = follow-up data obtained, _b = no follow-up data obtained, n/a = missing data, d/a = did not attend

Acceptability of the START program

Of the eight carers who commenced the program six completed all eight sessions. The remaining two carers completed two and four sessions each, with one withdrawing due to issues unrelated to the program. With this in mind, the attrition rate was calculated at 14%, which is comparable to the attrition rate of 15% reported in a previous multicomponent intervention (Gitlin et al., 2003). When considering all those who began the program, like the original study (Livingston et al., 2014) 75% of participants completed all sessions. In comparison, carers in the CBT group completed an average of six sessions (completing 3, 5, 5, 6 and 12 sessions). The average rating for ‘the program *met expectations*’ for carers who were in the START program was higher ($M = 8.67$, $SD = 1.97$) than for carers in the CBT program ($M = 4$, $SD = 1.41$). The average rating of ‘relevance’ for START program carers was higher ($M = 8.17$, $SD = 1.83$) compared to carers ($M = 4$, $SD = 1.41$) in the CBT program (Figure 3). Furthermore, all six START carers indicated that they intended to continue using the strategies they had learnt and would refer other carers to the program, compared to two out of four carers in the CBT program.

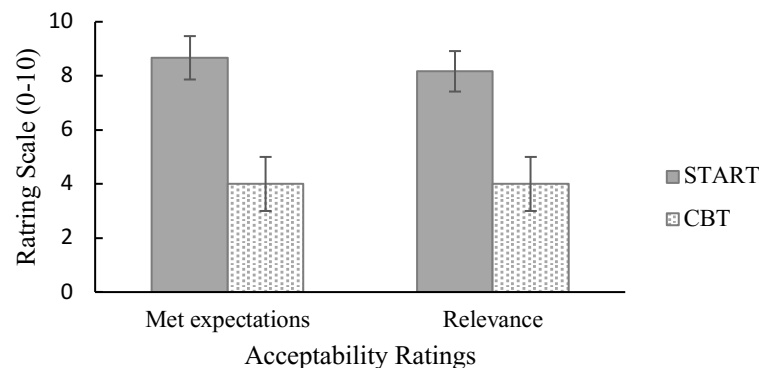


Figure 3. Responses to the Caregiver Experience Survey for the those in the START and CBT programs.

Acceptability of the telehealth modality

As the current research is focused on determining the acceptability of online delivery of the START program, only analysis of START carer data was completed. As can be seen in Figure 4 all mean satisfaction scores were above 9/10 for both the telehealth ($n = 6$) and face-to-face ($n = 2$) conditions, indicating very high satisfaction with the program. Carers indicated confidence in using telehealth ($M = 10$, $SD = 0$) and high ability to talk and express themselves with their therapists ($M = 9.50$, $SD = 0.58$). Average overall satisfaction with and reported acceptance of the telehealth mode was 9.25 ($SD = 1.50$) and 9.75 ($SD = 0.50$) respectively.

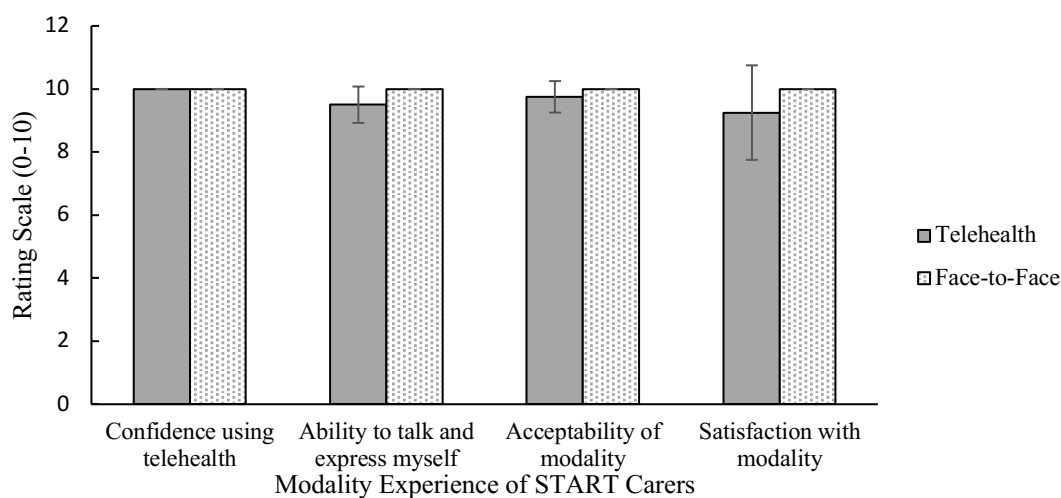


Figure 4. START carer satisfaction ratings according to mode of delivery.

Changes in self-reported mood over time

Analysis of mood (HADS-T) scores indicated that three of the six carers in the START program met clinical cut-offs at baseline. Carers P001 and P004 indicated reliable improvement and clinically significant change. P001 maintained these gains when followed-up at 3-months

post-intervention, however, 3-month follow-up data for P004 was not obtained. Conversely, P006 displayed reliable deterioration immediately following the intervention, however, did not meet criteria for clinically significant change and no longer met criteria for reliable change when followed-up at 3-months post-intervention. For the CBT program, three out of four met clinical cut-offs at baseline, nevertheless reliable change was not observed for any CBT carers at 3-month follow-up. All results for the HADS-T are displayed in Figures 5 and 6. Note, missing 3-month post follow-up data for P004 and 1-week post follow-up data for P008 and P019.

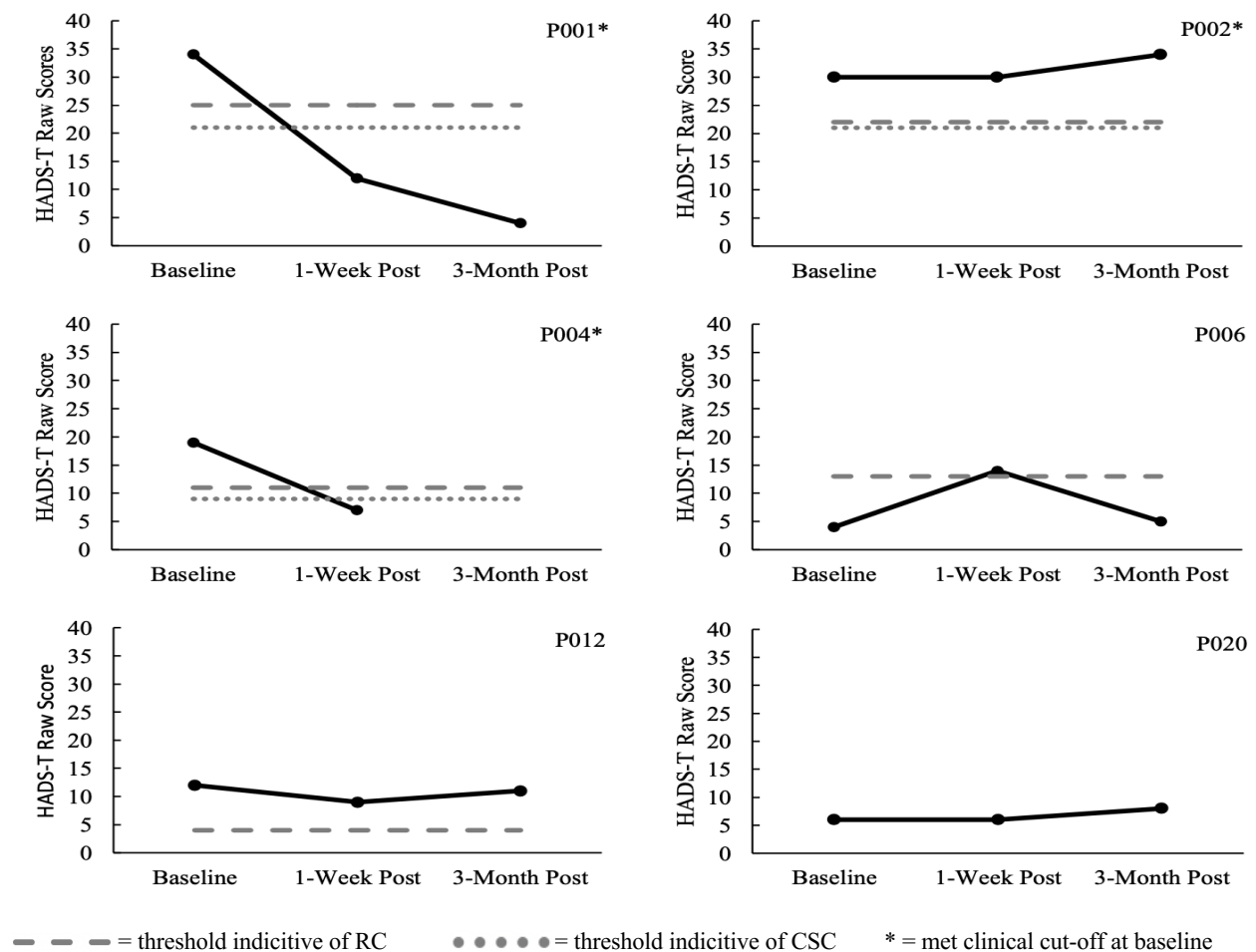


Figure 5. Self-reported HADS-T at baseline, 1-week and 3-month post-intervention for START carers.

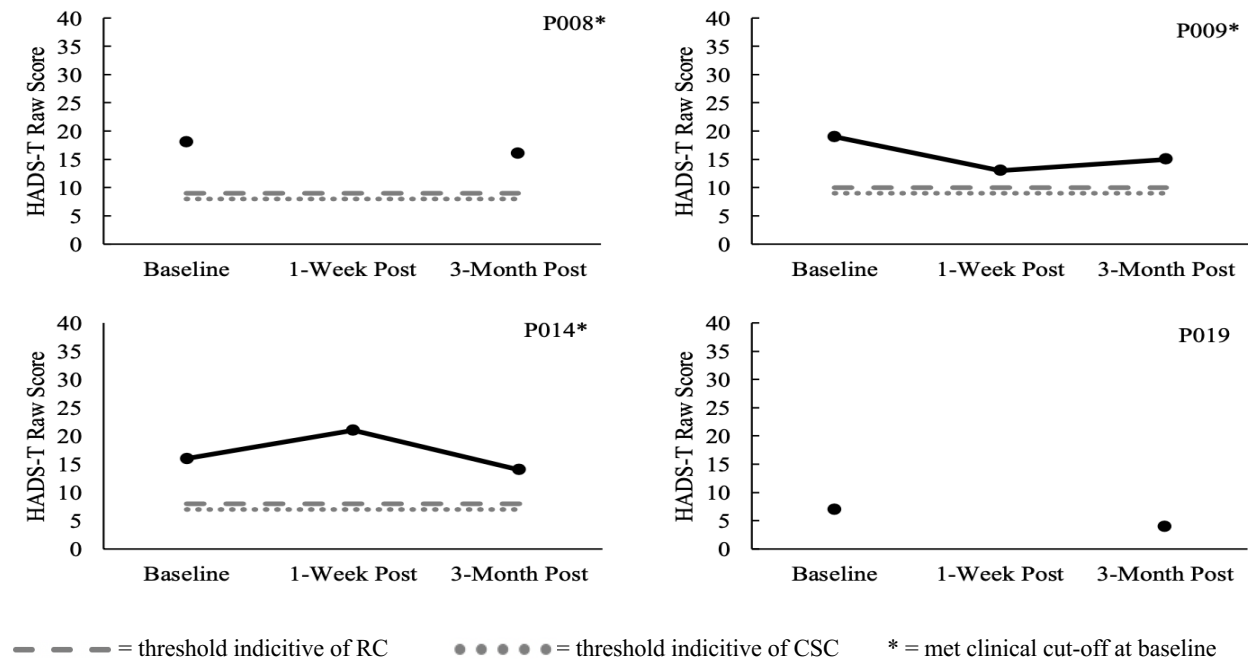


Figure 6. Self-reported HADS-T at baseline, 1-week and 3-month post-intervention for CBT carers.

Changes in carer perceived burden over time

Analysis of burden (ZBI) scores indicated that four of the six carers in the START program met clinical cut-offs at baseline. Only P001 demonstrated reliable improvement, which was maintained at 3-months. As in the mood scales, one carer (P002) displayed increased burden immediately following the intervention, however, when followed-up 3-months later reliable change was no longer demonstrated. For carers in the CBT program, all four met clinical cut-offs at baseline. P014 demonstrated reliable improvement initially but not at 3-month follow up. All results for the ZBI are displayed in Figures 7 and 8. Note, missing 3-month post follow-up data for P004, 1-week post follow-up data for P008 and P019.

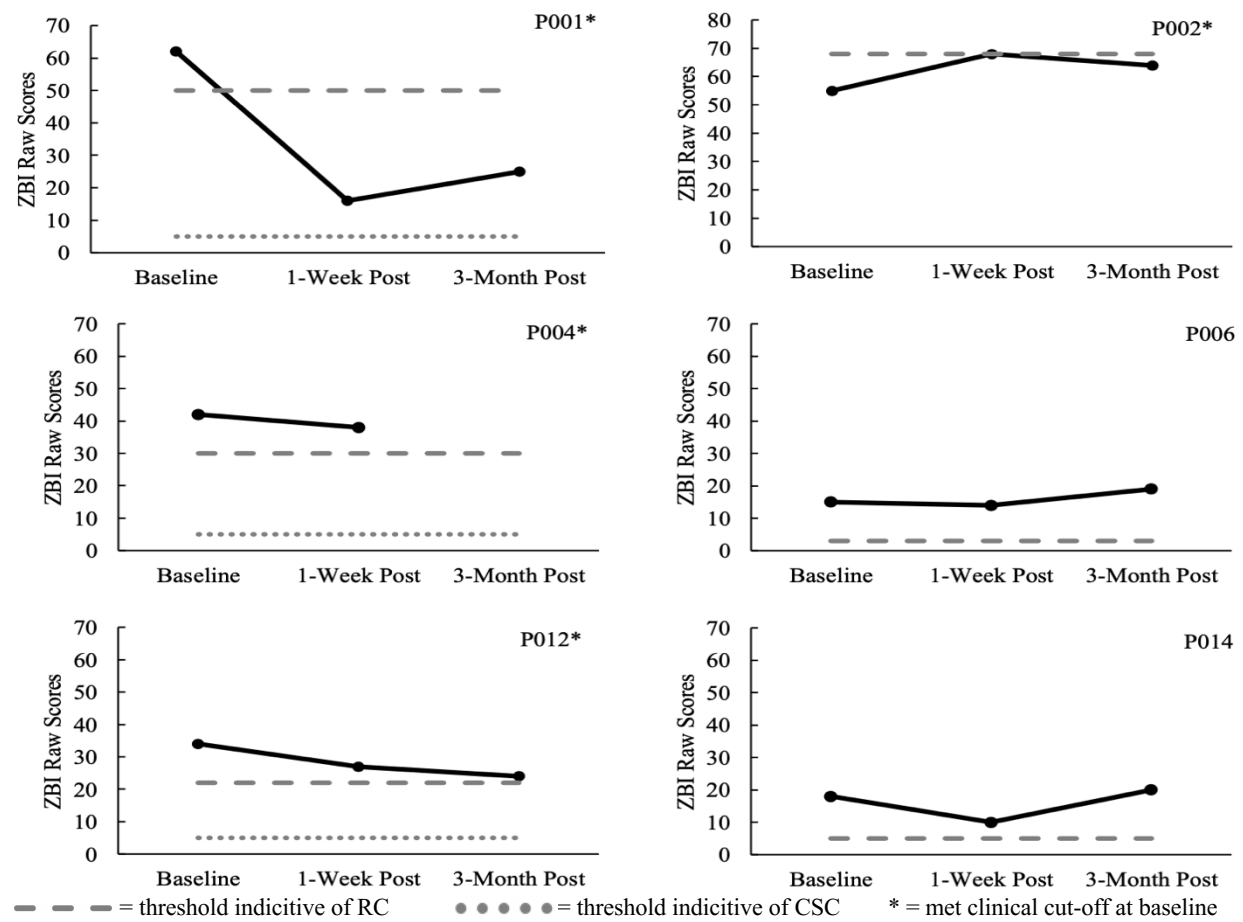


Figure 7. Self-reported ZBI at baseline, 1-week and 3-month post-intervention for START carers.

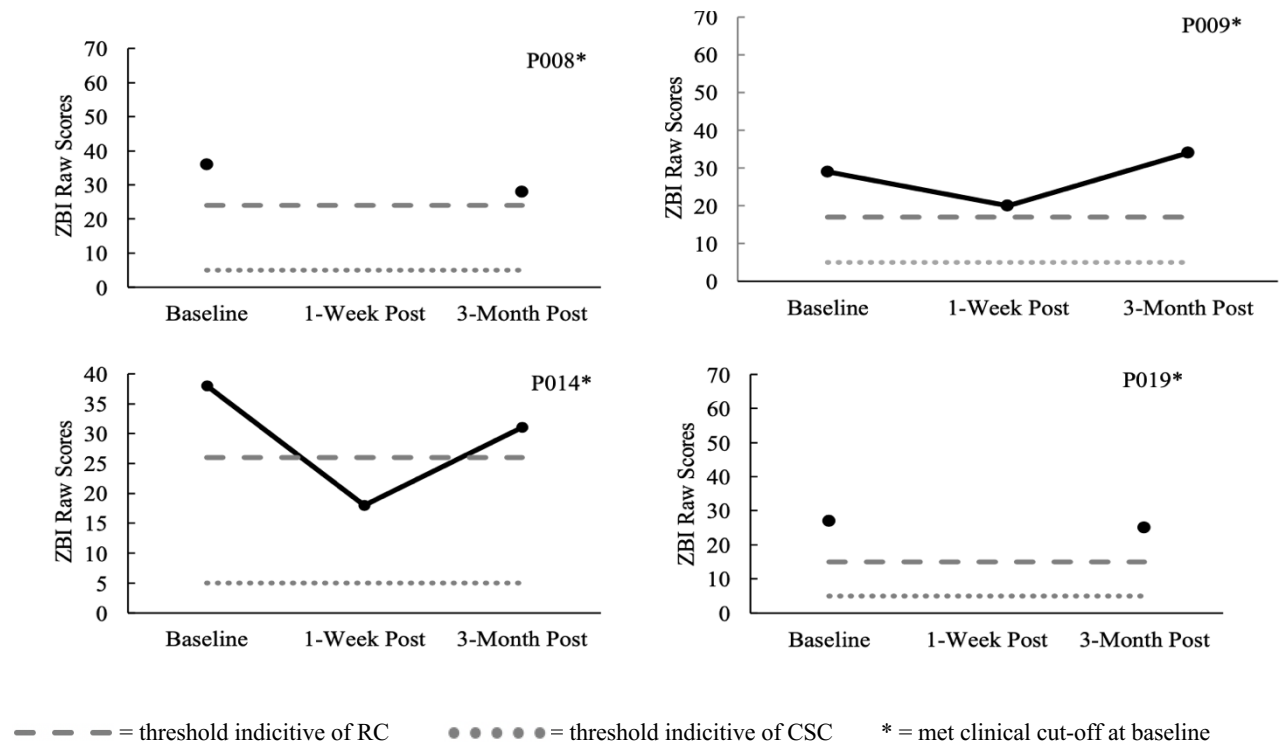


Figure 8. Self-reported ZBI at baseline, 1-week and 3-month post-intervention for CBT carers.

Discussion

Despite growing numbers of carers of PWD in Australia (Access Economics, 2010), there is no evidenced-based intervention for the management of associated negative outcomes (Jenson et al., 2015; Livingston et al., 2014; Parker et al., 2008; Pinquart & Sörensen, 2006; Selwood et al., 2007; Spijker et al., 2008). The primary aim of the current study was to investigate the feasibility and acceptability of the adapted START program, to support Australian carers to cope in their caring roles. As previously stated, the geographical nature of Australia impacts on service provision and care for those living in rural and remote areas (Schirmer, 2017). Therefore, this study additionally aimed to explore whether it was practical to deliver the START program via telehealth, and whether carers found this an acceptable means of delivery. Individual carer

outcomes were also examined to determine whether the program reduced self-reported symptoms of anxiety and depression, and perceived burden.

Acceptability of the intervention was indicated by carer report and program adherence. As hypothesised, we observed high completion rates within the START program, with 86% completing all eight sessions. These results were higher than those observed in the original UK study (Livingston et al., 2014) and comparable to other multicompetent interventions aimed at carers of people with dementia (Gitlin et al., 2003). As expected, START carers indicated greater acceptability of their intervention, reporting higher rates of the program meeting expectations and higher levels of relevance to their situation and current needs, than those in the CBT intervention. Furthermore, all six carers in the START program reported that they intended to use the strategies learnt and would recommend the program to others. These benefits are similar to those identified in a previous qualitative study, exploring carers experiences with the START program (Sommerlad et al., 2014). In comparison, carers in the CBT program completed an average of six sessions, where the standard number of sessions for the treatment of depression (Linde et al., 2015) and anxiety (Kishita & Laidlawb, 2017) is twelve. Notably, our results indicated that carers in the CBT program remained within the clinical range for reported mood symptoms. Given the low ratings of carer perceived relevance of the CBT program to their situation and average number of complete sessions, it is possible that CBT carers may have disengaged with the program early on. It is also possible that those being cared for experienced a deterioration of condition, therefore requiring more care, which has been identified as a mediator of carer affect and burden (Pinquart & Sörensen, 2003).

There is emerging evidence that online modalities are growing in acceptance within the Australian context (Bradford et al., 2016; Dow et al., 2008), and further afar, specifically older

adult carers of PWD are displaying increasing levels of acceptability of technology-based supports (Czaja & Rubert, 2002; Torp, Hanson, Hauge, Ulstein, & Magnusson, 2008; Wilz & Soellner, 2016). The current research suggests that the START program delivered via telehealth, offers a highly satisfactory experience, without compromising confidence or carers perceived ability to talk and express themselves with the therapist. In fact, we found that there was no difference in reported acceptance of the program between those who attended via telehealth and those who attended face-to-face sessions. Our findings are consistent with multiple other studies examining the effect of mode of delivery of various psychological therapies in alliance and outcome (Andersson et al., 2012; Kiropoulos et al., 2008; Pihlaja et al., 2017; Stiles-Shields, Kwasny, Cai, & Mohr, 2014). One study (Marziali, Donahue, & Crossin, 2005) specifically compared a face-to-face psychosocial support group intervention with a telehealth (videoconferencing) format for 34 carers of persons with neurodegenerative disease (1/3 were diagnosed with Alzheimer's). They found that 95% of carers indicated that the telehealth format exceeded their expectations and felt able to communicate 'at a deep level'. Our findings suggest that the use of telehealth services is comparable to face-to-face modalities for the delivery of the START program when considering the quality of the therapeutic alliance, however, further research is required to determine modality on psychological outcomes.

In line with previous research (Hollon et al., 2006; Livingston et al., 2014), we expected that both interventions would result in an improvement in mood for all carers. We found that two out of the three START carers who met clinical cut-offs at baseline, reported mood symptoms within the normal range post-intervention. Notably, those START carers that did not reach clinical cut-offs at baseline, remained in the normal range at follow-up. Li et al. (2014) reported similar results, suggesting that the START program had both therapeutic and preventative

effects. Our results offer preliminary evidence that the START program may also be protective against the development of negative affective symptoms in Australian carers. Interestingly, one START carer P006 (attending sessions face-to-face) displayed reliable deterioration at 1-week post follow-up that was not maintained when followed up at 3-months. Feedback from the carer indicated that she was highly engaged throughout the intervention and valued the support of the therapist. Therefore, this immediate decline post-intervention may be attributed to the intervention ending and perceived loss of support (Webb, Schroder, & Gresswell, 2019).

A review of the literature presents conflicting findings regarding the benefits of intervention for the reduction in carer reported burden (Brodaty, Green, & Koschera, 2003; Pinquart & Sörensen, 2006). Given that the evidence supports the use multicomponent interventions (Etters et al., 2008; Gitlin et al., 2003), we hypothesised that the carers in the START program would display a reduction in subjective burden following intervention. However, of the four carers in the START program indicating clinically significant burden at baseline, only one indicated reliable and clinically significant improvement post intervention, while another met criterion for reliable deterioration immediately following the invention. In an earlier review aimed at investigating the efficacy of various interventions, authors surmised that burden may be difficult to influence via intervention (Cooke et al., 2001). While appropriate for the identification of carer burden, measures such as the ZBI, may be insensitive to change, thereby offering some explanation for the null findings in the current and previous studies. Interestingly, consistent with our results, Cooke and colleagues (2001) also found that researchers rarely reported deterioration on outcome measures of burden. One possibility is the timing of assessment, with the skills and knowledge thought necessary to reduce carer burden, taking time to implement and take effect, before benefits can be observed (Cooke et al., 2001).

Recruitment and retention of carers for this study proved difficult presenting important implications for future research. Firstly, health concerns on behalf of the carer and the (PLWD) were not uncommon, with five citing this as a reason for not commencing the program and three withdrawing after commencement of the program. Furthermore, both health concerns and other commitments also contributed to carers perceptions that they did not have the time to commit to the program. As previously stated, 46% of carers in Australia provide fulltime solo care (NATSEM, 2017) for someone with dementia. For those receiving support (including respite) this valuable time is used for other important activities, including attending their own health appointments, completing household chores and maintaining employment (Neville et al., 2015). Anecdotally, some carers cited irrelevance or reported that they expected to learn more strategies to help in their interactions with the (PLWD). Previous research highlights potential barriers facing carers in seeking out support. Carers can have difficulty recognising when they need support (Neville et al., 2015), or when they do, they may feel ambivalent or guilty about seeking support (Greenwood & Smith, 2015), and can feel unworthy of self-care and engage in self-sacrificing behaviour (Furlong & Wuest, 2008), especially where the intervention or support does not specifically focus on the (PLWD) (Neville et al., 2015). This may offer some insight into why carers in the CBT program displayed less engagement compared to those in the START program.

This has implications for future deployment of the START program or other carer programs in terms of how the program is marketed, with the benefits for the (PLWD) needing to be front and centre. The research also relied heavily on the support of third parties for access to and recruitment of participants. Importantly, as recruitment was completed mostly through community support services, results may have been influenced in a positive way. With the

majority of carers in this study previously connected to support networks, it may be assumed that they are help-seeking individuals. Given the high rates of satisfaction compared to the modest findings regarding affect and burden, it is possible that START carers in particular overestimated the benefits of the program. However, meta-analyses reveal that this is a common phenomenon (Brodaty et al., 2003). Conversely, this method of recruitment and our relaxation of exclusion criteria may help to explain the modest findings with regards to outcome measures. For example, with few START carers meeting clinically significant levels of depression prior to the intervention, this limited our ability to demonstrate a significant reduction post-intervention. Future researchers may wish to consider collaboration with relevant health services to improve access, as our results indicate that those who begin the START program are likely to remain engaged and benefit from it.

Rates of dementia are increasing across Australia, and with the majority of PWD cared for by family carers who experience significant rates of mental physical health concerns, it is of clinical interest to develop appropriate support programs so as to limit the burden on carers and the health system. These pilot findings indicate preliminary evidence for the acceptability of the START intervention for the support of caregiver needs in relation to their caring roles with PWD. Furthermore, evidence suggests that the telehealth modality is an acceptable and feasible method for the delivery of the START program. This research indicates that Telehealth offers an innovative and flexible approach, that effectively meets the needs of carers and may reduce barriers to carer access to support. Preliminary results also indicate that the program may be effective in providing relief for anxiety and depression, however, further investigation is required to make conclusions regarding benefits of perceived burden.

References

Access Economics. (2010). *Caring Places: planning for aged care and dementia 2010-2050*.

Retrieved from:

https://www.dementia.org.au/sites/default/files/20110225_Nat_AE_CaringPlacesV2.pdf

Access Economics. (2009). *Making choices. Future dementia care: projections, problems and preferences*. Retrieved from

https://www.dementia.org.au/sites/default/files/20090400_Nat__AE_FullMakingChoices.pdf

Andersson, G., Paxling, B., Wiwe, M., Vernmark, K., Felix, C. B., Lundborg, L., ... & Carlbring, P. (2012). Therapeutic alliance in guided internet-delivered cognitive behavioural treatment of depression, generalized anxiety disorder and social anxiety disorder. *Behaviour Research and Therapy*, 50(9), 544-550.

Australian Institute of Health and Welfare. (2007). '*Dementia in Australia. National data analysis and development*' (Cat No. AGE 53, Canberra). Retrieved from:

<https://www.aihw.gov.au/getmedia/1bb2974d-2988-4508-9c36-f3695fa006ce/dandad-c07.pdf.aspx>

Bjelland, I., Dahl, A. A., Haug, T. T., & Neckelmann, D. (2002). The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *Journal of Psychosomatic Research*, 52(2), 69-77. doi:Pii S0022-3999(01)00296-3

Bradford, N. K., Caffery, L. J., & Smith, A. C. (2016). Telehealth services in rural and remote Australia: A systematic review of models of care and factors influencing success and sustainability. *Rural and Remote Health*, 16(3808), 1– 24.

- Brodaty, H., Green, A., & Koschera, A. (2003). Meta-analysis of psychosocial interventions for people with dementia. *Journal of the American Geriatrics Society*, 51, 657–664.
- Bowen, D. J., Kreuter, M., Spring, B., Cofta-Woerpel, L., Linnan, L., Weiner, D., . . . Fernandez, M. (2009). How we design feasibility studies. *American Journal of Preventive Medicine*, 36, 452-457. doi:10.1016/j.amepre.2009.02.002
- Cooke, D. D., McNally, L., Mulligan, K. T., Harrison, M. J., & Newman, S. P. (2001). Psychosocial interventions for caregivers of people with dementia: systematic review. *Aging and Mental Health*, 5, 120–135.
- Coon, D. W., Thompson, L., Steffen, A., Sorocco, K., & Gallagher-Thompson, D. (2003). Anger and depression management: psychoeducational training interventions for women caregivers of a relative with dementia. *Gerontologist*, 43, 678-89.
- Cooper, C., Selwood, A., Blanchard, M., Walker, Z., Blizard, R., & Livingston, G. (2010). The determinants of family carers' abusive behaviour to people with dementia: results of the CARD study. *Journal of Affective Disorders*, 121(1-2), 136-142. doi:10.1016/j.jad.2009.05.001
- Crawford, J. R., Henry, J. D., Taylor, E. P., & Crombie, C. M. (2001). Normative data for the HADS from a large non-clinical sample. *British Journal of Clinical Psychology*, 40(4), 429-434. doi:10.1348/014466501163904
- Czaja, S.J., & Rubert, M.P. (2002). Telecommunications technology as an aid to family caregivers of persons with dementia. *Psychosomatic Medicine*, 64, 469-476.
- Cuijpers, P. (2005). Depressive disorders in caregivers of dementia patients: A systematic review. *Aging & Mental Health*, 9(4), 325-330. doi:10.1080/13607860500090078

Dickinson, C., Dow, J., Gibson, G., Hayes, L., Robalino, S., & Robinson, L. (2016).

Psychosocial intervention for carers of people with dementia: What components are most effective and when? A systematic review of systematic reviews. *International Psychogeriatrics*, 29(1), 31-43. doi:10.1017/S1041610216001447.

Dow, B., Moore, K., Scott, P., Ratnayake, A., Wise, K., Sims, J., & Hill, K. (2008). Rural carers online: A feasibility study. *Australian Journal of Rural Health*, 16, 221-225.

Etters, L., Goodall, D., & Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of the American Academy of Nurse Practitioners*, 20(8), 423–428.

Furlong, K. E., & Wuest, J. (2008). Self-care behaviors of spouses caring for significant others with Alzheimer's disease: The emergence of self-care worthiness as a salient condition. *Qualitative Health Research*, 18, 1662–1672. doi: 10.1177/1049732308327158

Galvin, J. E., Meuser, T. M., Boise, L., & Connell, K. M. (2009). Predictors of physician referral for patient recruitment to Alzheimer's disease clinical trials. *Alzheimer Disease and Associated Disorders*, 23(4), 352-356. doi: 10.1097/WAD.0b013e31819e0cac

Gitlin, L.N., Belle, S.H., Burgio, L., Czaja, S., Mahoney, D., Gallagher-Thompson, D., ... Ory, M. (2003). Effect of multi-component interventions on caregiver burden and depression: The REACH multi-site initiative at 6 month follow-up. *Psychology and Aging*, 18, 361–374.

Greenwood N., & Smith R. (2015). Barriers and facilitators for male carers in accessing formal and informal support: A systematic review. *Maturitas*, 82, 162–169. doi: 10.1016/j.maturitas.2015.07.013

Haro, J. M., Kahle-Wroblewski, K., Bruno, G., Belger, M., Dell'Agnello, G., Dodel, R., . . .

Argimon, J. M. (2014). Analysis of burden in caregivers of people with Alzheimer's disease using self-report and supervision hours. *Journal of Nutrition, Health and Aging, 18*(7), 677-684. doi:10.1007/s12603-014-0036-0

Hérbert, R., Bravo, G., & Prévile, M. (2000). Reliability, validity, and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia. *Canadian Journal on Aging, 19*, 494-507.

Hoe, J., Katona, C., Orrell, M., & Livingston, G. (2007). Quality of life in dementia: care recipient and caregiver perceptions of quality of life in dementia: the LASER-AD study. *International Journal of Geriatric Psychiatry, 22*(10), 1031-1036. doi:10.1002/gps.1786

Hollon, S. D., Stewart, M. O., & Strunk, D. (2006). Enduring effects for cognitive behaviour therapy in the treatment of depression and anxiety. *Annual Review of Psychology, 57*, 285-315.

IBM Corp. Released 2016. IBM SPSS Statistics for Windows, Version 24.0. Armonk, NY: IBM corp.

Jacobson, N., & Truax, P. (1991). Clinical significance: A statistical approach to defining meaningful change in psychotherapy research. *Journal of Consulting and Clinical Psychology, 59*(1), 12-19.

Jensen, M., Agbata, I. N., Canavan, M., & McCarthy, G. (2015). Effectiveness of educational interventions for informal caregivers of individuals with dementia residing in the community: systematic review and meta-analysis of randomised controlled trials. *International Journal of Geriatric Psychiatry, 30*(2), 130-143. doi:10.1002/gps.4208

Kiropoulos, L. A., Klein, B., Austin, D. W., Gilson, K., Pier, C., Mitchell, J., & Ciechomski, L.

(2008). Is internet-based CBT for panic disorder and agoraphobia as effective as face-to-face CBT? *Journal of Anxiety Disorders*, 22(8), 1273–1284.

Kishita, N., & Laidlawb, K. (2017). Cognitive behaviour therapy for generalized anxiety

disorder: Is CBT equally efficacious in adults of working age and older adults? *Clinical Psychology Review*, 52, 124–136.

Lewis, F., Karlsberg Schaffer, S., Sussex, J., O'Neill, P., & Cockcroft, L. (2014). *The trajectory of dementia in the UK - Making a difference* (Rep.). London: Office of Health

Economics. Retrieved from:

<https://www.alzheimersresearchuk.org/wp-content/uploads/2015/01/OHE-report-Full.pdf>

Li, R., Cooper, C., Barber, J., Rapaport, P., Griffin, M., & Livingston, G. (2014). Coping

strategies as mediators of the effect of the START (STrategies for RelaTives)

intervention on psychological morbidity for family carers of people with dementia in a randomised controlled trial. *Journal of Affective Disorders*, 168, 298-305.

Linde, K., Rücker, G., Sigterman, K., Jamil, S., Meissner, K., Schneider, A., & Kriston, L.

(2015). Comparative effectiveness of psychological treatments for depressive disorders in primary care: Network meta-analysis. *Family Practice*, 16, 103. doi:10.1186/s12875-015-0314-x

Livingston, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., Romeo, R., . . . Cooper, C.

(2014). START (STrAtegies for RelaTives) study: a pragmatic randomised controlled trial to determine the clinical effectiveness and cost-effectiveness of a manual-based coping strategy program in promoting the mental health of carers of people with dementia. *Health Technology Assessment*, 18(61), 1-242. doi:10.3310/hta18610

Livingston, G., Manela, M., O’Keeffe, A., Rapaport, P., Cooper, C., Knapp, M., . . . Barber, J.

(2019). Clinical effectiveness of the START (STrAtegies for RelaTives) psychological intervention for family carers and the effects on the cost of care for people with dementia: 6-year follow-up of a randomised controlled trial. *The British Journal of Psychiatry*, 1-8. doi: 10.1192/bjp.2019.160

Luengo-Fernandez R., Leal J., Gray A. (2010) *Dementia 2010: the economic burden of dementia and associated research funding in the UK*. Alzheimer’s Research Trust: Cambridge.

Retrieved from <https://www.alzheimersresearchuk.org/wp-content/uploads/2015/01/OHE-report-Full.pdf>

Mahoney, R., Regan, C., Katona, C., & Livingston, G. (2005). Anxiety and depression in family caregivers of people with Alzheimer disease: the LASER-AD study. *American Journal of Geriatric Psychiatry*, 13(9), 795-801. doi:10.1176/appi.ajgp.13.9.795

Marziali, E., Donahue, P., & Crossin, G. (2005). Caring for others: Internet health care support intervention for family caregivers of persons with Alzheimer’s, stroke, or Parkinson’s disease. *Families in Society*, 86(3), 375-383. doi: 10.1606/1044-3894.3435

Morley, S., & Dowzer, C. (2014) Manual for the Leeds Reliable Change Indicator: Simple Excel^(tm) applications for the analysis of individual patient and group data. University of Leeds, Leeds, UK. Retrieved from <https://dclinpsych.leeds.ac.uk/wp-content/uploads/sites/26/2018/09/Manual-for-Leeds-RCI-CSC-calculators.pdf>

National Alliance for Caregiving & AARP. (2015). *Cargiving in the US*. Retrieved from: https://www.caregiving.org/wp-content/uploads/2020/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf

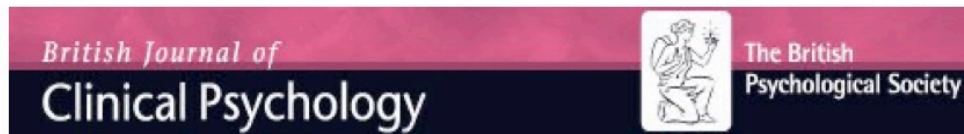
- NATSEM. (2017). *Economic Cost of Dementia in Australia 2016-2056*. Canberra: Institute for Governance and Policy Analysis University of Canberra.
- Netto, N. R., Jenny, G. Y. N., & Philip, Y. L. K. (2009). Growing and gaining through caring for a loved one with dementia. *Dementia*, 8(2), 245-261. doi:10.1177/1471301209103269
- Neville, C., Beattie, E., Fielding, E., & MacAndrew, M. (2015). Literature review: use of respite by carers of people with dementia. *Health and Social Care in the Community*, 23, 51– 64. doi: edsgcl.397741909
- Parker, D., Mills, S., & Abbey, J. (2008). Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review. *International Journal of Evidence-based Healthcare*, 6, 137-72. doi:10.1111/j.1744-1609.2008.00090.x.
- Pihlaja S., Stenberg J-H., Joutsenniemi K., Mehik H., Rotola V., & Joffe, G. (2017) Therapeutic alliance in guided internet therapy programs for depression and anxiety disorders - a systematic review. *Internet Interventions*, 11(2018) 1-10.
- Pinquart, M., & Sörensen, S. (2003). Association of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *The Journals of Gerontology*, 58(2), 112-118. doi: 10.1093/geronb/58.2.P112
- Pinquart, M., & Sörensen, S. (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International Psychogeriatrics*, 18(04). doi:10.1017/s1041610206003462
- Qualtrics. (2018) [Computer software]. Provo, Utah: USA. Retrieved from <https://au1.qualtrics.com>

- Selwood, A., Johnston, K., Katona, C., Lyketsos, C., & Livingston, G. (2007). Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders*, 101(1-3), 75-89. doi:10.1016/j.jad.2006.10.025
- Schirmer, J. (2017). *Carers in regional Australia: 2016 regional wellbeing survey report*. Health Research Institute & Institute for Applied Ecology, University of Canberra. Retrieved from <https://www.canberra.edu.au/research/institutes/health-research-institute/regional-wellbeing-survey/survey-results/reports/2016-reports/Carers-report-ONLINE-10-July-2017.pdf>
- Schofield H, Bloch S, Herrman H, Murphy B, Nankervis J, Singh B 1998, *Family caregivers. Disability, illness and ageing*. St Leonards, NSW: Allen & Unwin.
- Spijker, A., Vernooij-Dassen, M., Vasse, E., Adang, E., Wollersheim, H., Grol, R., & Verhey, F. (2008). Effectiveness of nonpharmacological interventions in delaying the institutionalization of patients with dementia: a meta-analysis. *Journal of The American Geriatrics Society*, 56(6), 1116-1128. doi:10.1111/j.1532-5415.2008.01705.x
- Somenahalli, S. (2015). *Key transport and mobility issues facing seniors: evidence from Adelaide*. National Seniors Productive Ageing Centre. Retrieved from https://nationalseniors.com.au/uploads/04151097PAC_KeyTransportAndMobilityIssues_Report%20Final.pdf
- Sommerlad, A., Manela, M., Cooper, C., Rapaport, P., & Livingston, G. (2014). START (STrategies for RelaTives) coping strategy for family carers of adults with dementia: qualitative study of carers' views about the intervention. *BMJ Open*, 4(6). doi:10.1136/bmjopen-2014-005273

- Stagg, B. & Lerner, A. J. (2015). Zarit burden interview: Pragmatic study in a dedicated cognitive function clinic. *Progress in Neurology and Psychiatry*, 19(4), 23-27. doi: 10.1002/pnp.390
- Stiles-Shields, C., Kwasny, M. J., Cai, X., & Mohr, D. C. (2014). Therapeutic alliance in face-to-face and telephone-administered cognitive behavioral therapy. *Journal of consulting and clinical psychology*, 82(2), 349–354. doi:10.1037/a0035554
- Torp S., Hanson E., Hauge S., Ulstein I. & Magnusson L. (2008). A pilot study of how information and communication technology may contribute to health promotion among elderly spousal carers in Norway. *Health & Social Care in the Community*, 16(1), 75– 85.
- University of Central London. (n.d.). *START. Strategies for Relatives (START) is an eight session manualised intervention that supports the development of coping strategies for carers of people with dementia*. Retrieved from <https://www.ucl.ac.uk/psychiatry/research/mental-health-older-people/projects/start>
- Van Gaan, D., & Dent, E. (2018). Issues of accessibility to health services by older Australians: A review [Review]. *Public Health Reviews*, 39(20). doi: 10.1186/s40985-018-0097-4
- Victor, C. R., Rippon, I., Quinn, C., Nelis, S. M., Martyr A., Hart, N., ... Clare, L. (2020) The prevalence and predictors of loneliness in caregivers of people with dementia: findings from the IDEAL programme. *Aging & Mental Health*, 1-7.
doi: [10.1080/13607863.2020.1753014](https://doi.org/10.1080/13607863.2020.1753014)
- Webb, K., Schroder, T. A., & Gresswell, D. M. (2019). Service users' first accounts of experiencing endings from a psychological service or therapy: a systematic review and meta-ethnographic synthesis. *Psychology and Psychotherapy: Theory, Research and Practice*, 92, 584-604. doi:10.1111/papt.12201

- Wilz, G., & Soellner, R. (2016). Evaluation of a short-term telephone-based cognitive behavioral intervention for dementia family caregivers. *Clinical Gerontologist, 39*, 25–47.
- Zarit, S. H., Anthony, C. R., & Boutselis, M. (1987). Interventions with caregivers of dementia patients: Comparison of two approaches. *Psychology and aging, 2*(3), 225-232.
- Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist, 20*, 649-655.
- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica, 67*, 361-370. doi: 10.1111/j.1600-0447.1983.tb09716.x

Appendix A: Journal Submission Guidelines



AUTHOR GUIDELINES

Sections

1. Submission
2. Aims and Scope
3. Manuscript Categories and Requirements
4. Preparing the Submission
5. Editorial Policies and Ethical Considerations
6. Author Licensing
7. Publication Process After Acceptance
8. Post Publication
9. Editorial Office Contact Details

1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

Once the submission materials have been prepared in accordance with the Author Guidelines, manuscripts should be submitted online at <http://www.editorialmanager.com/bjcp>

Click here for more details on how to use [Editorial Manager](#).

All papers published in the *British Journal of Clinical Psychology* are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

Data protection:

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and

have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at <https://authorservices.wiley.com/statements/data-protection-policy.html>.

Preprint policy:

This journal will consider for review articles previously available as preprints on non-commercial servers such as ArXiv, bioRxiv, psyArXiv, SocArXiv, engrXiv, etc. Authors may also post the submitted version of a manuscript to non-commercial servers at any time. Authors are requested to update any pre-publication versions with a link to the final published article.

2. AIMS AND SCOPE

The *British Journal of Clinical Psychology* publishes original research, both empirical and theoretical, on all aspects of clinical psychology:

- clinical and abnormal psychology featuring descriptive or experimental studies
- aetiology, assessment and treatment of the whole range of psychological disorders irrespective of age group and setting
- biological influences on individual behaviour
- studies of psychological interventions and treatment on individuals, dyads, families and groups

For specific submission requirements, please view the [Author Guidelines](#).

The Journal is catholic with respect to the range of theories and methods used to answer substantive scientific problems. Studies of samples with no current psychological disorder will only be considered if they have a direct bearing on clinical theory or practice.

The following types of paper are invited:

- papers reporting original empirical investigations;
- theoretical papers, provided that these are sufficiently related to empirical data;
- review articles, which need not be exhaustive, but which should give an interpretation of the state of research in a given field and, where appropriate, identify its clinical implications;
- Brief Reports and Comments.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Articles should be no more than 5000 words (excluding the abstract, reference list, tables and figures). Brief reports should not exceed 2000 words and should have no more than one table or figure. Any papers that are over this word limit will be returned to the authors. Appendices are included in the word limit; however online appendices are not included.

In exceptional cases the Editor retains discretion to publish papers beyond this length where the clear and concise expression of the scientific content requires greater length (e.g., explanation of a new theory or a substantially new method). Authors must contact the Editor prior to submission in such a case.

Please refer to the separate guidelines for [Registered Reports](#).

All systematic reviews must be pre-registered.

4. PREPARING THE SUBMISSION

Contributions must be typed in double spacing. All sheets must be numbered.

Cover Letters

Cover letters are not mandatory; however, they may be supplied at the author's discretion. They should be pasted into the 'Comments' box in Editorial Manager.

Parts of the Manuscript

The manuscript should be submitted in separate files: title page; main text file; figures/tables; supporting information.

Title Page

You may like to use [this template](#) for your title page. The title page should contain:

- i. A short informative title containing the major key words. The title should not contain abbreviations (see Wiley's [best practice SEO tips](#));
- ii. A short running title of less than 40 characters;
- iii. The full names of the authors;
- iv. The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
- v. Abstract;
- vi. Keywords;
- vii. Practitioner Points;
- viii. Acknowledgments.

Authorship

Please refer to the journal's Authorship policy in the Editorial Policies and Ethical Considerations section for details on author listing eligibility. When entering the author names into Editorial Manager, the corresponding author will be asked to provide a CRediT contributor role to classify the role that each author played in creating the manuscript. Please see the [Project CRediT](#) website for a list of roles.

Abstract

Please provide a structured abstract under the headings: Objectives, Methods, Results, Conclusions. For Articles, the abstract should not exceed 250 words. For Brief Reports, abstracts should not exceed 120 words.

Articles which report original scientific research should also include a heading 'Design' before 'Methods'. The 'Methods' section for systematic reviews and theoretical papers should include, as a minimum, a description of the methods the author(s) used to access the literature they drew upon. That is, the abstract should summarize the databases that were consulted and the search terms that were used.

Keywords

Please provide appropriate keywords.

All articles must include Practitioner Points – these are 2-4 bullet points, following the abstract, with the heading 'Practitioner Points'. These should briefly and clearly outline the relevance of your research to professional practice. (Please include the 'Practitioner Points' in your main document but do not submit them to Editorial Manager with your abstract.)

Acknowledgments

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Main Text File

As papers are double-blind peer reviewed, the main text file should not include any information that might identify the authors.

The main text file should be presented in the following order:

- i. Title
- ii. Main text
- iii. References
- iv. Tables and figures (each complete with title and footnotes)
- v. Appendices (if relevant)

Supporting information should be supplied as separate files. Tables and figures can be included at the end of the main document or attached as separate files but they must be mentioned in the text.

- As papers are double-blind peer reviewed, the main text file should not include any information that might identify the authors. Please do not mention the authors' names or affiliations and always refer to any previous work in the third person.
- The journal uses British/US spelling; however, authors may submit using either option, as spelling of accepted papers is converted during the production process.

References

References should be prepared according to the *Publication Manual of the American Psychological Association* (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper. Please note that for journal articles, issue numbers are not included unless each issue in the volume begins with page 1, and a DOI should be provided for all references where available.

For more information about APA referencing style, please refer to the [APA FAQ](#).

Reference examples follow:

Journal article

Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. *The American Journal of Psychiatry*, 159, 483–486.
doi:[10.1176/appi.ajp.159.3.483](https://doi.org/10.1176/appi.ajp.159.3.483)

Book

Bradley-Johnson, S. (1994). *Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school* (2nd ed.). Austin, TX: Pro-ed.

Internet Document

Norton, R. (2006, November 4). How to train a cat to operate a light switch [Video file]. Retrieved from <http://www.youtube.com/watch?v=Vja83KLQXZs>

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figures

Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted.

[Click here](#) for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Colour figures. Figures submitted in colour may be reproduced in colour online free of charge. Please note, however, that it is preferable that line figures (e.g. graphs and charts) are supplied in black and white so that they are legible if printed by a reader in black and white. If an author would prefer to have figures printed in colour in hard copies of the journal, a fee will be charged by the Publisher.

Supporting Information

Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc.

[Click here](#) for Wiley's FAQs on supporting information.

Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

General Style Points

For guidelines on editorial style, please consult the [APA Publication Manual](#) published by the American Psychological Association. The following points provide general advice on formatting and style.

- **Language:** Authors must avoid the use of sexist or any other discriminatory language.
- **Abbreviations:** In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.
- **Units of measurement:** Measurements should be given in SI or SI-derived units. Visit the [Bureau International des Poids et Mesures \(BIPM\) website](#) for more information about SI units.
- **Effect size:** In normal circumstances, effect size should be incorporated.
- **Numbers:** numbers under 10 are spelt out, except for: measurements with a unit (8mmol/l);

age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).

Wiley Author Resources

Manuscript Preparation Tips: Wiley has a range of resources for authors preparing manuscripts for submission available [here](#). In particular, we encourage authors to consult Wiley's best practice tips on [Writing for Search Engine Optimization](#).

Editing, Translation, and Formatting Support: [Wiley Editing Services](#) can greatly improve the chances of a manuscript being accepted. Offering expert help in English language editing, translation, manuscript formatting, and figure preparation, Wiley Editing Services ensures that the manuscript is ready for submission.

5. EDITORIAL POLICIES AND ETHICAL CONSIDERATIONS

Peer Review and Acceptance

Except where otherwise stated, the journal operates a policy of anonymous (double blind) peer review. Please ensure that any information which may reveal author identity is blinded in your submission, such as institutional affiliations, geographical location or references to unpublished research. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review. Before submitting, please read [the terms and conditions of submission](#) and the [declaration of competing interests](#).

We aim to provide authors with a first decision within 90 days of submission.

Further information about the process of peer review and production can be found in '[What happens to my paper?](#)' Appeals are handled according to the [procedure recommended by COPE](#). Wiley's policy on the confidentiality of the review process is [available here](#).

Clinical Trial Registration

The journal requires that clinical trials are prospectively registered in a publicly accessible database and clinical trial registration numbers should be included in all papers that report their results. Authors are asked to include the name of the trial register and the clinical trial registration number at the end of the abstract. If the trial is not registered, or was registered retrospectively, the reasons for this should be explained.

Research Reporting Guidelines

Accurate and complete reporting enables readers to fully appraise research, replicate it, and use it. Authors are encouraged to adhere to recognised research reporting standards.

We also encourage authors to refer to and follow guidelines from:

- [Future of Research Communications and e-Scholarship \(FORCE11\)](#)
- [The Gold Standard Publication Checklist from Hooijmans and colleagues](#)
- [FAIRsharing website](#)

Conflict of Interest

The journal requires that all authors disclose any potential sources of conflict of interest. Any interest

The journal requires that an authors disclose any potential sources of conflict of interest. Any interest or relationship, financial or otherwise that might be perceived as influencing an author's objectivity is considered a potential source of conflict of interest. These must be disclosed when directly relevant or directly related to the work that the authors describe in their manuscript. Potential sources of conflict of interest include, but are not limited to: patent or stock ownership, membership of a company board of directors, membership of an advisory board or committee for a company, and consultancy for or receipt of speaker's fees from a company. The existence of a conflict of interest does not preclude publication. If the authors have no conflict of interest to declare, they must also state this at submission. It is the responsibility of the corresponding author to review this policy with all authors and collectively to disclose with the submission ALL pertinent commercial and other relationships.

Funding

Authors should list all funding sources in the Acknowledgments section. Authors are responsible for the accuracy of their funder designation. If in doubt, please check the Open Funder Registry for the correct nomenclature: <https://www.crossref.org/services/funder-registry/>

Authorship

All listed authors should have contributed to the manuscript substantially and have agreed to the final submitted version. Authorship is defined by the criteria set out in the APA Publication Manual:

"Individuals should only take authorship credit for work they have actually performed or to which they have substantially contributed (APA Ethics Code Standard 8.12a, Publication Credit). Authorship encompasses, therefore, not only those who do the actual writing but also those who have made substantial scientific contributions to a study. Substantial professional contributions may include formulating the problem or hypothesis, structuring the experimental design, organizing and conducting the statistical analysis, interpreting the results, or writing a major portion of the paper. Those who so contribute are listed in the byline." (p.18)

Data Sharing and Data Accessibility

The *British Journal of Clinical Psychology* recognizes the many benefits of archiving data for scientific progress. Archived data provides an indispensable resource for the scientific community, making possible future replications and secondary analyses, in addition to the importance of verifying the dependability of published research findings.

The journal expects that where possible all data supporting the results in papers published are archived in an appropriate public archive offering open access and guaranteed preservation. The archived data must allow each result in the published paper to be recreated and the analyses reported in the paper to be replicated in full to support the conclusions made. Authors are welcome to archive more than this, but not less.

All papers need to be supported by a data archiving statement and the data set must be cited in the Methods section. The paper must include a link to the repository in order that the statement can be published.

It is not necessary to make data publicly available at the point of submission, but an active link must be included in the final accepted manuscript. For authors who have pre-registered studies, please use the Registered Report link in the Author Guidelines.

In some cases, despite the authors' best efforts, some or all data or materials cannot be shared for

legal or ethical reasons, including issues of author consent, third party rights, institutional or national regulations or laws, or the nature of data gathered. In such cases, authors must inform the editors at the time of submission. It is understood that in some cases access will be provided under restrictions to protect confidential or proprietary information. Editors may grant exceptions to data access requirements provided authors explain the restrictions on the data set and how they preclude public access, and, if possible, describe the steps others should follow to gain access to the data.

If the authors cannot or do not intend to make the data publicly available, a statement to this effect, along with the reasons that the data is not shared, must be included in the manuscript.

Finally, if submitting authors have any questions about the data sharing policy, please access the [FAQs](#) for additional detail.

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This journal is a member of the [Committee on Publication Ethics \(COPE\)](#). Note this journal uses iThenticate's CrossCheck software to detect instances of overlapping and similar text in submitted manuscripts. Read Wiley's Top 10 Publishing Ethics Tips for Authors [here](#). Wiley's Publication Ethics Guidelines can be found [here](#).

ORCID

As part of the journal's commitment to supporting authors at every step of the publishing process, the journal requires the submitting author (only) to provide an ORCID iD when submitting a manuscript. This takes around 2 minutes to complete. [Find more information here](#).

6. AUTHOR LICENSING

If a paper is accepted for publication, the author identified as the formal corresponding author will receive an email prompting them to log in to Author Services, where via the Wiley Author Licensing Service (WALS) they will be required to complete a copyright license agreement on behalf of all authors of the paper.

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7. PUBLICATION PROCESS AFTER ACCEPTANCE

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When an accepted article is received by Wiley's production team, the corresponding author will receive an email asking them to login or register with [Wiley Author Services](#). The author will be asked to sign a publication license at this point.

Proofs

Once the paper is typeset, the author will receive an email notification with full instructions on how to provide proof corrections.

Please note that the author is responsible for all statements made in their work, including changes made during the editorial process – authors should check proofs carefully. Note that proofs should be returned within 48 hours from receipt of first proof.

Publication Charges

Colour figures. Colour figures may be published online free of charge; however, the journal charges for publishing figures in colour in print. If the author supplies colour figures, they will be sent a Colour Work Agreement once the accepted paper moves to the production process. If the Colour Work Agreement is not returned by the specified date, figures will be converted to black and white for print publication.

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8. POST PUBLICATION

Access and Sharing

When the article is published online:

- The author receives an email alert (if requested).
- The link to the published article can be shared through social media.
- The author will have free access to the paper (after accepting the Terms & Conditions of use, they can view the article).
- For non-open access articles, the corresponding author and co-authors can nominate up to ten colleagues to receive a publication alert and free online access to the article.

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To find out how to best promote an article, click [here](#).

Measuring the Impact of an Article

Wiley also helps authors measure the impact of their research through specialist partnerships with [Kudos](#) and [Altmetric](#).

9. EDITORIAL OFFICE CONTACT DETAILS

For help with submissions, please contact: Vicki Pang, Associate Managing Editor (bjc@wiley.com) or phone +44 (0)1243 770 410.

Author Guidelines updated 14th October 2019

Appendix B: Ethics Approval

HUMAN RESEARCH ETHICS COMMITTEE



Notification of Expedited Approval

To Chief Investigator or Project Supervisor:	Doctor Michelle Kelly
Cc Co-investigators / Research Students:	Laureate Professor Robert Sanson-Fisher Prof Skye McDonald Mrs Karen Bell-Weinberg Mrs Kaylene Kilham
Re Protocol:	Examining the acceptability and feasibility of a manualised coping program (START) in reducing symptoms of depression, anxiety and carer burden in an Australian context
Date:	29-Apr-2018
Reference No:	H-2016-0299

Thank you for your **Response to Conditional Approval (minor amendments)** submission to the Human Research Ethics Committee (HREC) seeking approval in relation to a variation to the above protocol.

Variation to:

1. Add Kaylene Kilham to the research team.
2. Add the Dementia Knowledge Assessment Scale to measure knowledge change.
 - The Dementia Knowledge Assessment Scale (DKAS) version 2.0
 - Information Statement for Organisations (v2.3, dated 13/04/2018)
 - Information Statement for Therapist (v2.3, dated 13/04/2018)
 - Information Statement for Carer (v2.4, dated 13/04/2018)

Your submission was considered under **Expedited** review by the Ethics Administrator.

I am pleased to advise that the decision on your submission is **Approved** effective **24-Apr-2018**.

The full Committee will be asked to ratify this decision at its next scheduled meeting. A formal *Certificate of Approval* will be available upon request.

Associate Professor Helen Warren-Forward
Chair, Human Research Ethics Committee

For communications and enquiries:

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Research & Innovation Services
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The University of Newcastle
Callaghan NSW 2308

T +61 2 492 17894

Human-Ethics@newcastle.edu.au

RIMS website - <https://RIMS.newcastle.edu.au/login.asp>

Linked University of Newcastle administered funding:

Funding body	Funding project title	First named investigator	Grant Ref
Dementia Australia Research Foundation Ltd/Dementia Research Grant(**)	Caring for Carers: Examination of a manualised coping program (START) in reducing symptoms of depression, anxiety and carer burden in Australian carers of people with dementia	Kelly, Michelle	G1600826
Hunter Medical Research Institute/Project Grant(**)	Improving dementia care	Kelly, Michelle	G1701447

Appendix C: Participant Information Sheet

START *Caring for Carers: Examining a new coping program for carers of people with dementia*
INFORMATION FOR CARER**What is this research about?**

This research will work out whether a new program that has been designed to improve coping, wellbeing and mood in carers of people with dementia, works better than the established program that is currently available to carers.

Who is doing the research?

Dr Michelle Kelly from the University of Newcastle along with a very experienced research team are doing this research. The research team comprise researchers from the University of Newcastle and University of New South Wales: Dr Michelle Kelly, Laureate Professor Robert Sanson-Fisher, Professor Skye McDonald and student researchers undertaking postgraduate study under Dr Kelly's supervision.

Who is paying for the research?

The University of Newcastle is funding this research.

Why is the research being done?

Carers of people with dementia take on many additional responsibilities that can be physically and emotionally challenging and impact their mood and wellbeing. This research is looking at a way we can support carers to improve their quality of life.

How do I take part in this research?

You can take part in this research by attending 6-10 individual sessions of the program either by attending the clinic or another venue, or via videoconferencing in your home.

What will I be asked to do?

You will be invited to attend 6-10 individual sessions over a period of 8 to 16 weeks, either face to face or via videoconferencing. Each session will last around an hour. The sessions will focus on coping, relaxation and accessing support. You will either receive the new programme or an established program. The sessions will be delivered by a provisionally registered psychologist undertaking training at the University of Newcastle, and include a screening interview, which will be conducted by telephone.

On 3 further occasions, we will also ask you to complete some questionnaires about your wellbeing and quality of life and the wellbeing and quality of life of the person you care for.

These assessments will be conducted over the phone/teleconference, by a different researcher to the person you will be meeting with for the 6-10 session program.

In total there are 9-13 appointments (either face to face, by phone or teleconference) with members of the research team.

Where will the sessions be held?

We have put in place a range of appointment options to accommodate the different needs of carers. Depending on your needs you can participate by attending:

- a) the Psychology Clinic at the University of Newcastle at either the Callaghan or Ourimbah campus
- b) the Alzheimer's Australia office in Hamilton
- c) the Clinic at HMRI
- d) via Telehealth video or phone conferencing
- e) by special arrangement of home visits in certain circumstances

Can I choose which type of program I receive?

No, you will be randomly assigned to either the new program or the established program.

Can anyone participate?

The study is suitable for people who are experiencing signs of stress or low mood (depression or anxiety) associated with their caring role. We will conduct an interview and assess whether this program is right for your needs; you will be offered other services where appropriate.

To be eligible to take part you must:

- A) Be an unpaid adult carer of a person with dementia (i.e. a partner, family member or friend) over 18 years of age. It is ok to participate if you receive carers pension.
- B) Provide practical or emotional support on at least a daily basis to the person with dementia
- C) Be able to read and write in English (as you will be taken through a manual during the program).

What if I feel uncomfortable in a session?

If you feel uncomfortable during a session you can take a break, ask the therapist to reschedule, or discontinue your involvement in the research.

What choice do I have about taking part?

Your decision to take part in the research is entirely voluntary. You do not have to take part if you do not want to. You can change your mind at any time and stop taking part in the research. This won't change anything about your involvement/ relationship with any other services you receive including the service that referred you, either now or in the future.

What if I'm upset by what is talked about during a session?

If you have any further concerns about what is discussed during a session, you can call the National Dementia Helpline on 1800 100 500 for advice and counselling. You can also speak with the person providing the program.

What will happen to what I say?

With your consent, we will record and/or video the sessions and take some notes. Any recordings of sessions will be used to determine how closely the researcher delivering the program is following the manual. You will still be able to participate in the study even if you do not wish the sessions to be recorded. What you tell us and the results of your assessments will be used to help us understand how well the program works. The research findings will be published in an Alzheimer's Australia NSW discussion paper. We will also talk about the research at conferences and community events and publish articles about the research in national and international journals. The information obtained will also be analysed for the purpose of producing student theses.

Notes of the session content will be stored securely at the Psychology clinic. All other information which is considered part of the research will be deidentified and stored securely at the University of Newcastle.

What about confidentiality? Will anyone know it was me who took part in the research?

What you say and any of the information we collect will be confidential. This means that we won't tell anyone it was you who participated in the research. We will take out any information that could give away that it was you who took part, like your name and specific things about you. In some cases, if we were to be concerned about your safety or the safety of others, we would need to disclose some information. In this case we would endeavour to speak with you about this first. This will be further explained.

What type of information will you collect?

We will collect information about your role as a carer, things that you find difficult when caring and how this affects your mood, and also things that you find help you to care for others. We will interview you to ask for this information and also collect information from questionnaires, files notes and recordings from therapy sessions.

We will also ask for your GP details, should we need to contact them in the event that we were worried about your safety. With your permission, we would notify them that you are plan to attend the program, and of the outcome at the end of the sessions.

Who do I contact if I have questions about the research?

If you have any questions about the research, please contact Dr Michelle Kelly on (02) 4921 6838 or michelle.kelly@newcastle.edu.au.

What if I am not happy with the research and want to make a complaint?

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be discussed with the researcher, or, if an independent person is preferred, with the Human Research Ethics Officer, Research Services, NIER Precinct, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 4921 6333, email Human-Ethics@newcastle.edu.au.

So, how do I volunteer?

If you agree to participate in the research, please sign both copies of the consent form attached and return the researchers' copy to the University of Newcastle in the reply paid envelope provided. Please keep this information sheet for your records. Once you have returned the signed consent form, a researcher will then contact you to arrange an interview time convenient for you.

A copy of the Alzheimer's Australia discussion paper will be provided to you if you tick the box on the attached consent form and provide your address details.

Taking part in future research

If you would like, you can agree that your data can be used as part of future research projects. This is entirely voluntary. Deciding that you do not want your data to be used in future research will not affect your participation in the current study.

You can also agree to be contacted about future research. Agreeing to be contacted does not obligate you to take part; participation in any future research is entirely voluntary.

Thank you for considering participating in our research.

DR MICHELLE KELLY**Senior Lecturer**

Clinical Psychology Program

School of Psychology

Faculty of Science and IT

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W: www.newcastle.edu.au/profile/michelle-kelly

Appendix D: Consent Forms

CONSENT CARER***START Caring for Carers: Examining a new coping program for carers of people with dementia***

I, [name]

of.....[address]

have read and understood the Information for Carers on the above named research study

and have discussed the study with

I have been made aware of the procedures involved in the study, including any known or expected inconvenience, risk, discomfort or potential side effect and of their implications as far as they are currently known by the researchers.

I understand I am consenting to take part in a study that involves a program of 6-10 sessions focussed on strategies to improve my mood and well-being (face to face, via teleconference or over the phone), as well as 3 assessment sessions over the phone.

Please indicate where you would like the sessions to take place (tick any that apply):

- ☐ the Psychology Clinic at the University of Newcastle at either the Callaghan or Ourimbah campus
- ☐ the Alzheimer's Australia office in Hamilton
- ☐ the Clinic at HMRI
- ☐ via Telehealth video or phone conferencing
- ☐ by special arrangement of home visits in certain circumstances

I understand that the sessions may be audio/video recorded and that the content of these recordings will remain confidential.

I **do / do not** give my consent to audio/video recording of sessions (delete as applicable).

I provide consent for the researchers to contact my GP. My GP details are as follows:

GP Name:

Address:

Telephone number:

I also understand that the research study is strictly confidential. The only exception is where illegal activity (e.g. elder abuse) is uncovered. In this case, I understand that the matter will be referred to relevant authorities.

I freely choose to participate in this study and understand that I can withdraw at any time.

I **do** / **do not** give consent for research collected as part of this project to be used in future research (delete as applicable).

I hereby agree to participate in this research study.

NAME:

SIGNATURE:

DATE:

NAME OF WITNESS:

SIGNATURE OF WITNESS:

☐ Yes, I would like to be contacted about future research. I understand that agreeing to be contacted about future research does mean I am obliged to take part and that participation in any future research is entirely voluntary.

☐ Yes, I would like a copy of the research report sent to me at the address provided below. I understand that my address will not be used for any other purpose.

Your email/address:

.....

Revocation of Consent

Caring for Carers: Examining a new coping program for carers of people with dementia

I hereby wish to WITHDRAW my consent to participate in this research project and understand that such withdrawal WILL NOT jeopardize any treatment or my relationship with Alzheimer's Australia NSW or any other organisations that I am receiving services through.

SIGNATURE: _____

NAME: _____

DATE: _____

If you change your mind and no longer wish to participate in the research, please complete this Revocation of Consent form and send it to:

**Dr Michelle Kelly
University of Newcastle – School of Psychology
Behavioural Sciences Building W132
University Drive
Callaghan NSW 2308**

Appendix E: Referrers Information Sheet

START CARING FOR CARERS: EXAMINING A NEW COPING PROGRAM FOR CARERS OF PEOPLE WITH DEMENTIA**Why this project is being conducted**

Carers of people with dementia face many challenges. The development of effective programs that support carers is vital to the quality of life of both the carer and the person they are caring for. In the United Kingdom, a specific program to meet this aim (called START) has been developed. This study will examine whether the START program is acceptable to Australian carers and therapists.

Who to refer

Carers eligible to take part if:

- A) They are an unpaid adult carer of a person with dementia (i.e. a partner, family member or friend) over 18 years of age (carers pension is ok)
- B) They provide practical or emotional support on at least a daily basis to the person with dementia
- C) They are showing signs of stress (moderate anxiety or depression) related to their caring role (we can assess this)
- D) They have adequate English proficiency (the manual requires reading and writing)
- E) Are judged by yourself to be able to complete the study

Carers are not eligible if they:

- F) Have current high level of suicidality, or significant cognitive difficulties (e.g., learning difficulties or dementia)

Please note that this is an individual therapy so only the **main carer** from any one family can take part.

What will carers be required to do

Carers will be asked to complete 6-10 one-hour sessions of the program and three assessment sessions. Sessions can be conducted at the Psychology Clinic (University of Newcastle, Ourimbah or Callaghan campus), at Alzheimer's Australia, HMRI, at your centre, or via videoconferencing (telehealth).

What help we need from you

Please mention the research to eligible carers and if they agree, please forward their name and phone number to Michelle.Kelly@newcastle.edu.au. Carers can also contact Dr Michelle Kelly directly on 02 49216838. Please note this is not the participant consenting to participate in the research; they are only consenting to be contacted by the researcher to discuss the study further. Please phone Dr Michelle Kelly on 02 49216838 if you have any questions.

This project has been approved by the University's Human Research Ethics Committee, Approval No. H-2016-0299.

Appendix F: Advertising Flyer



RESEARCH STUDY

www.newcastle.edu

***Are you caring for someone with dementia
or memory problems?***

Would you like some additional support?

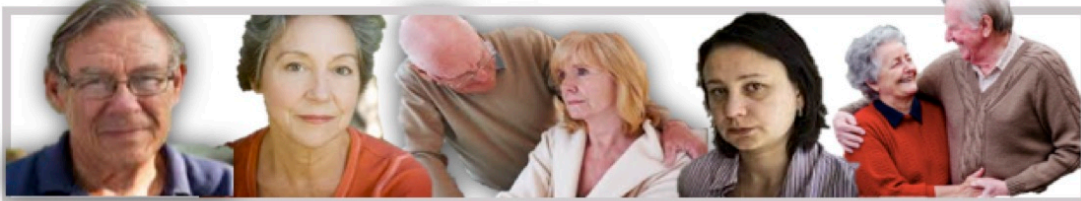
The University of Newcastle is undertaking a project to investigate whether a new program designed for carers of a person with dementia is helpful.

To participate in the study, you need to:

- be 18 years of age or over
- be caring for a family member or friend with dementia
- have regular contact with the person

This program will involve 8-10 weekly or fortnightly sessions delivered via face-to-face or skype. The sessions will focus on coping, relaxation and accessing support. Before and after the program, you will complete some questionnaires and interviews about your wellbeing and quality of life and the wellbeing and quality of life of the person you care for.

**If you would like to participate or find out more about this project, please contact
Dr Michelle Kelly on (02) 4921 6838 or at Michelle.Kelly@newcastle.edu.au**



Caring for Carers

Dr Michelle Kelly 02 4921 6838
michelle.kelly@newcastle.edu.au

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Appendix G: Standardised Measures

Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week.
Don't take too long over you replies: your immediate is best.

D	A		D	A	
		I feel tense or 'wound up':			I feel as if I am slowed down:
3		Most of the time	3		Nearly all the time
2		A lot of the time	2		Very often
1		From time to time, occasionally	1		Sometimes
0		Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			I get a sort of frightened feeling like 'butterflies' in the stomach:
0		Definitely as much	0		Not at all
1		Not quite so much	1		Occasionally
2		Only a little	2		Quite Often
3		Hardly at all	3		Very Often
		I get a sort of frightened feeling as if something awful is about to happen:			I have lost interest in my appearance:
3		Very definitely and quite badly	3		Definitely
2		Yes, but not too badly	2		I don't take as much care as I should
1		A little, but it doesn't worry me	1		I may not take quite as much care
0		Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			I feel restless as I have to be on the move:
0		As much as I always could	3		Very much indeed
1		Not quite so much now	2		Quite a lot
2		Definitely not so much now	1		Not very much
3		Not at all	0		Not at all
		Worrying thoughts go through my mind:			I look forward with enjoyment to things:
3		A great deal of the time	0		As much as I ever did
2		A lot of the time	1		Rather less than I used to
1		From time to time, but not too often	2		Definitely less than I used to
0		Only occasionally	3		Hardly at all
		I feel cheerful:			I get sudden feelings of panic:
3		Not at all	3		Very often indeed
2		Not often	2		Quite often
1		Sometimes	1		Not very often
0		Most of the time	0		Not at all
		I can sit at ease and feel relaxed:			I can enjoy a good book or radio or TV program:
0		Definitely	0		Often
1		Usually	1		Sometimes
2		Not Often	2		Not often
3		Not at all	3		Very seldom

Please check you have answered all the questions

Scoring:

Total score: Depression (D) _____ Anxiety (A) _____

0-7 = Normal

8-10 = Borderline abnormal (borderline case)

11-21 = Abnormal (case)

The Zarit Burden Interview

- 0: NEVER
 1: RARELY
 2: SOMETIMES
 3: QUITE FREQUENTLY
 4: NEARLY ALWAYS

Please circle the response the best describes how you feel.

Question	Score
1 Do you feel that your relative asks for more help than he/she needs?	0 1 2 3 4
2 Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0 1 2 3 4
3 Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0 1 2 3 4
4 Do you feel embarrassed over your relative's behaviour?	0 1 2 3 4
5 Do you feel angry when you are around your relative?	0 1 2 3 4
6 Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0 1 2 3 4
7 Are you afraid what the future holds for your relative?	0 1 2 3 4
8 Do you feel your relative is dependent on you?	0 1 2 3 4
9 Do you feel strained when you are around your relative?	0 1 2 3 4
10 Do you feel your health has suffered because of your involvement with your relative?	0 1 2 3 4
11 Do you feel that you don't have as much privacy as you would like because of your relative?	0 1 2 3 4
12 Do you feel that your social life has suffered because you are caring for your relative?	0 1 2 3 4

Question	Score
13 Do you feel uncomfortable about having friends over because of your relative?	0 1 2 3 4
14 Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0 1 2 3 4
15 Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0 1 2 3 4
16 Do you feel that you will be unable to take care of your relative much longer?	0 1 2 3 4
17 Do you feel you have lost control of your life since your relative's illness?	0 1 2 3 4
18 Do you wish you could leave the care of your relative to someone else?	0 1 2 3 4
19 Do you feel uncertain about what to do about your relative?	0 1 2 3 4
20 Do you feel you should be doing more for your relative?	0 1 2 3 4
21 Do you feel you could do a better job in caring for your relative?	0 1 2 3 4
22 Overall, how burdened do you feel in caring for your relative?	0 1 2 3 4

Interpretation of Score:

- 0 - 21 little or no burden
- 21 - 40 mild to moderate burden
- 41 - 60 moderate to severe burden
- 61 - 88 severe burden

Patient last name:
 Patient first name:

Date of birth: / /
 Date: / /

Appendix H: Carer Experience Survey

CG4 Carer Experience - One-Week Post Program Feedback**CG4 Carer Experience - One-Week Post Program Feedback**

The following questions will give you an opportunity to reflect and provide feedback on your overall experience in this program. Your responses will only be viewed by the researcher. Your therapist will not have access to your responses on this survey, nor will they receive any feedback you provide via the survey.

Please answer openly and truthfully.

Please enter your client reference ID:

Q1 How well did the program meet your expectations?

	Not met							Exceeded			
	0	1	2	3	4	5	6	7	8	9	10
Were your expectations met?											

Q2 How relevant was the program to your situation?

	Not relevant						Extremely relevant				
	0	1	2	3	4	5	6	7	8	9	10
How relevant was the program?											

Q3 Optional: In what way could we improve the content of program? (open

response)

Q4 Please rank each session in order of usefulness in descending order e.g., most useful at top and least useful at the bottom.

(Simply 'click on a session' and use the 'up and down arrows' to change its position in the list)

↑

↓

Session 1: Stress and wellbeing

Session 2: Reasons for behaviour

Session 3: Making a behaviour plan

Session 4: Behaviour strategies and thoughts

Session 5: Communication styles

Session 6: Planning for the future

Session 7: Introduction to pleasant events and your mood

Session 8: Using your skills in the future

↑

↓

Q4 How many sessions did you attend?

Q5 Overall how helpful did you find the following items from the program?

Not helpful Extremely helpful

0 1 2 3 4 5 6 7 8 9 10

The program manual

Attending sessions

Developing new skills and strategies

Qualtrics Survey Software

26/10/19, 10:10 pm

The between
session tasks

The relaxation
recordings (CD/USB)

Q6 What was the most useful skill or strategy you learnt from this program?

Q7 Do you intend to continue to use any of the skills or strategies you learnt throughout the program?

- ☐ Yes
- ☐ No
- ☐ Not sure

Q7.1 What are your reasons for selecting no or not sure?

Q8 What did you find most valuable about the program overall?

Q9 Where did you attend therapy?

Qualtrics Survey Software

26/10/19, 10:10 pm

- ☐ Clinic
- ☐ Via Telehealth
- ☐ Both clinic and telehealth

What percentage of your telehealth sessions were disrupted by dropout or internet connection loss?

0 10 20 30 40 50 60 70 80 90 100

Please rate telehealth with regards to the following:

	Poor	Acceptable	Excellent	Not Applicable
Audio quality	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Video quality	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ease of use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q10 Please rate your clinic experience?

	Strongly Disagree						Strongly Agree				
	0	1	2	3	4	5	6	7	8	9	10
Being able to attend in person was a good way to access the program											
I felt confident attending the clinic											
I could easily talk and express myself											

Qualtrics Survey Software

26/10/19, 10:10 pm

effectively to the
therapist

Attending clinic is an
acceptable way to
received this
program

If I had a problem
with parking I was
able to address this
on the day

I feel the program
will have a lasting
effect

I would recommend
the program to other
carers

Overall, I was
satisfied with the
program in the clinic

Q10 Please rate your telehealth experience:

Strongly Disagree

Strongly Agree

0 1 2 3 4 5 6 7 8 9 10

Being available on-
line was a good way
to access the
program

I felt confident using
Telehealth for
therapy

I could easily talk
and express myself
effectively to the
therapist

On-line is an

Qualtrics Survey Software

26/10/19, 10:10 pm

acceptable way to
received this
program

If I had a problem
with Telehealth I was
able to recover the
session easily

I feel the program
will have a lasting
effect

I would recommend
the program to other
carers

Overall, I was
satisfied with the
program on-line

Q11 Do you see this program as something you would refer another carer to?

- ☐ Yes
- ☐ No

Q12 If this program was offered to the community, how much could/would you pay per session?

- ☐ <\$20 per session
- ☐ \$20-\$50 per session
- ☐ \$50-\$100 per session
- ☐ \$100-\$150 per session
- ☐ \$150-\$240 per session (\$240 is the recommended fee schedule for 46-60 psychology consultation)
- ☐ Other amount

Qualtrics Survey Software

26/10/19, 10:10 pm

Q12.1 How much would you pay?

Q13 Optional Do you have any other comments?

Q14 Would you be interested in participating in a focus group or interview (via phone or online) to give further feedback on your experience with the therapy program?

- ☐ Yes
- ☐ No

Q15 Would you like to hear about the results of this study when they become available?

- ☐ Yes
- ☐ No

Powered by Qualtrics

Appendix I: Initial Assessment and Intake Forms

START Caring for Carers
Clinical Interview

Date: Client Name: Client ID: Therapist Name: Therapist ID:
--

Introduction

Explain your role: I am one of the therapists for the study. We will be working together over the 8-10 sessions of the program. The aim of this program is to address some concerns you may be having to help you feel better. It will either be a program that already has an evidence base, or an alternative new program that we are testing in Australia for the first time. You won't know which program you are having, and neither does the researcher who completes the assessments with you. This is to help us work out how the two approaches compare. Before and after each of the sessions in the coming weeks we'll ask you to complete some questionnaires to let us know how you found that session. This is important as we want to know from you, about your experience, how it fits with your expectations and what you like.

Purpose of interview: I would like to ask you a few questions that will help me to make sure you will find the program useful. It will feel like I'm just asking lots of questions today, but next session we'll be doing more to help you in your caring role.

Confidentiality: I need to remind you that everything we discuss is confidential. By this I mean it will not be discussed outside the research team. The only exception to this is if I am worried about your or someone else's safety, or if I become aware of serious criminal offense, in which case I might need to contact someone else such as a healthcare or other professional. I would always try and discuss this with you first if possible.

For eHab (telehealth) only: We have taken every measure to ensure that the program, ehab, which allows us to speak over the internet remains confidential, however, we must make you aware that security measures taken over the internet are not impervious to malicious attacks. Are you happy to proceed knowing this risk Yes / No

Confidentiality explained: Yes / No

Consent obtained and form signed: Yes / No

Consent to record session obtained and form signed: Yes / No

What do you like to be called? _____

What do you call the person with dementia who you support? _____

How do you define your relationship?(e.g. *partners, parent-child, friends*)?

Do you see yourself as a carer or do you define your role differently?

PRESENTING PROBLEM/CURRENT SITUATION

Would you be able to tell me what some of your concerns are at the moment?

Prompts:

What are the main challenges / difficulties that you face in relation to your caring role?

How does this impact on your life and relationships?

Do you have any other difficulties/stressors not connected to your caring role at present?

Think about difficulties in different contexts e.g. work, family life, and the impact this is having.

.....

.....

.....

.....

.....

.....

.....

.....

What are your expectations/ hopes/ goals I.e. What would you hope to get out of participating in the sessions?

.....

.....

.....

.....

What are you already doing to manage the difficulties that you are facing at the moment?

.....

.....

.....

.....

.....

Do you have ways of coping with stress that you find useful or helpful?

.....

.....

.....

.....

.....

Is there anyone else in your family or community who also supports you or is involved in caring for your relative? Do you or your relative receive any other formal support/ input from other services?

.....

.....

.....

.....

BACKGROUND

Is there anything else about your relationship with ____, growing up, or your life prior to their diagnosis of dementia that you think is important for me to know about?

.....

.....

.....

.....

Contact with services

Lead in: “I will now ask you some questions about your previous contact with health services. This is important in helping us make sure that offering the program is going to be helpful to you”.

“Are you receiving any current treatment from mental health or counselling services or are you on a waiting list for treatment?” YES/NO

If YES, details – e.g. name/ profession of person seeing/ where seen

.....

.....
If YES, service may still be appropriate - Discuss with supervisor as necessary

“Have you ever been diagnosed with a mental illness such as depression or anxiety”?

.....
“Have you had any previous psychological/psychiatric/counselling treatment?”
YES/NO....

If yes, who with and where?

.....
“Do you remember what type of treatment this was e.g. counselling/ CBT/ psychotherapy?” *(Many won’t be able to report type, normalise this).*

.....
“How helpful was this treatment?”

.....
“Have you ever or do you currently have any of the following symptoms, I’ll be going through a list with you”: *(if they answer yes, gather some additional details, when, how long did it last, still a problem?)*

- 1) “Very low mood”: Yes/No, if yes, how long did this last_____
- 2) “A time you were feeling so good/hyper/full of energy (on top of the world) that other people thought you were not your normal self”: Yes/No
- 3) “Ever had strange or unusual symptoms, hearing things when there was no one around, seeing things that were not real, strange sensations on or under your skin, the sense the TV was sending you special messages”: Yes/No
- 4) “Ever a time when your alcohol or other drug use was out of your control”: Yes/No
- 5) “Ever a time when you felt a sudden rush of anxiety/panic/fear that you could not explain” Yes/No
- 6) “Ever a time when you have been afraid to leave the house or be in crowds” Yes/No
- 7) “Ever a time when you thought your worries were out of control, taking over your life or when you could not relax or feel settled for a long period of time” Yes/No
- 8) “Have you ever been worried about thoughts that kept coming back even though you didn’t want them too, like the concern for germs or worried you would hurt another person” Yes/No
- 9) “Have you ever thought that your life was threatened or been present during an extremely upsetting or traumatic event” Yes/No
- 10) “Do you feel easily distracted, unable to concentrate even on enjoyable activity, did you have trouble concentrating at school or were hyperactive” Yes/No

“Are you currently taking any medication to help with your mental health?”

.....

“Has anyone else in your family (e.g., parents/siblings) had any difficulties with mental illness?”

.....
RISK ASSESSMENT *(the questions below are a guide, refer to your clinical training and clinic procedures for full details):* **“It is important for me to ask the following questions, which we ask everyone, they may seem silly or strange or not relevant to you. They are regarding safety to yourself and to others. Sometimes when people are going through hard times in life they may become sad or depressed. At these times it’s not unusual for people to have thoughts they would not normally have.**

Risk to Self: “Have you ever had thoughts about hurting yourself?” YES/NO
Are you having these thoughts at the moment? *If historical, get details of context – when, what was going on at this time, what was the content of the thoughts?*

.....
Have you ever made plans to end your life? YES/NO *If yes, next question...*
Are you having these thoughts at the moment? *If historical, get details of context – what did they plan to do, did they implement any of the stages?*

.....
Have you made any plans to act on these thoughts? Have you thought how you would act on them?

.....
Have you made any actual preparations to end your life? *(Risk increases with: lethality of method, level of detail, access to method, potential for rescue, prior rehearsal, time chosen)*

.....
What is stopping you from harming or killing yourself at the moment? *(Protective factors)*

.....
If you are concerned about their safety currently. Ask if they have been to their GP, who else knows about their suicidal thoughts/plans, what support they have been offered, and what (if anything) they want you to do e.g. follow up with GP/local service.

.....

“Have you ever attempted suicide or harmed yourself in the past?”

If they are currently at risk, ask them to wait while you go and get advice from your supervisor present or Michelle Kelly. Tell them about GP/ A&E and give numbers for the Lifeline (13 11 14) and Mental Health Access Line (1800 011 511).

Risk to others:

Sometimes when people are having difficulties or are stressed they have thoughts about harming others [such as the person they are caring for], do you have any thoughts like that? YES/NO

Have you ever acted upon these thoughts/feelings? YES/NO – If yes – seek detail
e.g. how long ago, one off or repeated occurrence, what was the outcome of the incident? Ask about the immediacy of risk and protective factors, how the risk is being managed currently, who else knows. If YES, discuss with your supervisor immediately.

.....

Do you think anybody you have contact with is at risk of harm? e.g. children/partner/older people.

Specifically ask about risks to person with dementia.
Discuss with your supervisor immediately if required.

.....

Risk from others:

“Do you feel at risk [e.g. physical harm or abuse] from the person you are caring for or anybody else?”

.....

Substances:

“Caring can be very stressful. People tend to cope with situations in different ways, and sometimes people might use alcohol and/or drugs to help them to cope. You may feel that this doesn’t apply to you, but I have to ask everyone these questions.”

“How much do you drink per week?” *(record amounts, what they drink and pattern)*

.....

“Do you ever drink to manage the stress associated with your caring role?” (*Ask details – within normal limits?*)

.....

“Are you at all concerned about how much you are drinking?”

.....

“Do you use any prescription medications or other drugs?” *Ask details e.g. illegal drugs/ misusing prescription drugs*

.....

 (NB 1 unit = 1 can mid-strength beer, 100ml glass wine, 30ml spirit)

If excessive drinking, ask if they would like support in managing this and let them know you will find out about local services that might be able to help, and get back to them.

.....

If the questions have not been relevant, normalise again that they do not apply to everyone and thank them for answering.

Access

Are there any barriers or difficulties that may make it difficult for you to attend sessions? E.g. getting time off work, child care, transport. *Discuss possible ways round this if necessary - Depending on the currently available options, these may include telehealth appointments, or attending a local Alzheimer’s Australia office for telehealth or face-to-face appointments (check what is possible with supervisor prior to making phone call). Another option could be respite care through the Commonwealth Respite and Carelink Centre Ph: 1800 052 222.*

.....

If Telehealth / Home Visits: “Would you be able to have a protected time and space in your home away from your relative for an hour at a time to speak to a worker?” *This is important – make sure there is a WORKABLE plan. Consider use of respite.*

“Do you have any concerns or questions about the sessions?”

.....
.....

“Is there anything else you would like to tell me that I have not asked about but that you think is important for me to know?”

.....
.....

Mental Status Examination

Appearance:

Behaviour during interview:

Affect:

Mood:

Speech:

Thought Form:

Thought Content:

Perception:

Cognition and Intellectual Functioning:

Insight and Judgement:

Thank them for completing the screening assessment. Check in how they found the assessment/talking e.g. any thoughts/feeling that arose, or any questions. Book first session with them and note time/date below. Notify them that you will send them an email/letter with appointment details.

START intake form

Start of Block: START Intake Form

Q1 Inform of status of psychologist in training and use of videotaping for study and supervision.
Consent provided and signed consent form obtained?

☐ Yes (1)

☐ No (2)

Q2 Where would you like to attend therapy?

☐ Clinic (1)

☐ Telehealth (2)

Q3 Date

Q4 Intake person

Q5 Client Name

Q6 Participant ID

Q7 Home Phone:

Q8 Mobile Phone:

Q9 Email:

Q10 Address (incl. post code):

Q11 Postal Address (incl. post code):

Q14 Gender:

☐ Female (1)

☐ Male (2)

☐ ID Other (3)

Q12 DOB:

Q13 Age:

Q38 Ethnicity:

- ☐ White Australian (1)
- ☐ Aboriginal or TSI (2)
- ☐ Other (3)

Display This Question:

If Ethnicity: = Other

Q43 Other Ethnicity?, please specify:

Q42 Marital status:

- ☐ Not currently married or cohabitating (1)
- ☐ Married, or cohabitation (2)

Q44 Level of education:

- ☐ no qualification (1)
 - ☐ School level qualification yr10+ (2)
 - ☐ TAFE or equiv. qualification (3)
 - ☐ University or equiv. qualification (4)
-

Q15 Occupation:

Q39 Employment:

- ☐ fulltime (1)
 - ☐ parttime (2)
 - ☐ volunteer (in addition to carer role) (3)
 - ☐ retired (4)
 - ☐ not working (5)
 - ☐ contractor (6)
-

Q16 Name of the person you provide care to:

Q37 Relationship to the person you provide care to:

- ☐ Spouse or partner (1)
- ☐ child (2)
- ☐ Partner of child (3)
- ☐ Sibling (4)
- ☐ Niece / nephew (5)
- ☐ friend (6)
- ☐ other (7)

Display This Question:

If Relationship to the person you provide care to: = other

Q40 If other, what is your relationship?

Q41 Do you live with the person you provide care to?

Q17 GP details

Q18 Consent to liaise or send information to GP if required?

☐ Yes (1)

☐ No (2)

Q19 Next of Kin?

Q20 Contact details for next of Kin:

Q22 Which day and time of the week might suit you best to attend the program?

	Mon (1)	Tues (2)	Wed (3)	Thur (4)	Fri (5)
AM (1)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
PM (2)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q23 Can the clinic contact you during the day to arrange an appointment time?

☐ Yes (1)

☐ No (2)

Q24 Who do you live with?

Q25 Can a message be left with other members of the household?

☐ Yes (1)

☐ No (2)

Q26 Can a message be left on the Answering machine?

☐ Yes (1)

☐ No (2)

Q27 Reported Problem: (enter - to attend START program)

Q28 Risk Assessment: *"It is important for me to ask the following questions, which we ask everyone, they may seem silly or strange or not relevant to you. They are regarding safety to yourself and to others. Sometimes when people are going through hard times in life they may become sad or depressed. At these times it's not unusual for people to have thoughts they would not normally have. Have things ever gotten so bad that you've thought about or tried to hurt yourself or someone else?"*

☐ Yes (1)

☐ No (2)

Display This Question:

If Risk Assessment: *"It is important for me to ask the following questions, which we ask everyone,... = Yes*

Q30 *Are you having these thoughts at the moment?*

- ☐ Yes (1)
- ☐ No, historical (2)

Display This Question:

If Are you having these thoughts at the moment? = No, historical

Q29 *If historical, get details of context - what did they plan to do, did they and to what extent did they implement/act on their thoughts?*

Display This Question:

If Are you having these thoughts at the moment? = Yes

Q31 *If yes, Have you made any plans or attempts to act on these thoughts?*

- ☐ Yes (1)
- ☐ No (2)

Display This Question:

If If yes, Have you made any plans or attempts to act on these thoughts? = Yes

Q33 *If yes, ask them to agree with you that they will not harm themselves immediately whilst you go and get advice from you supervisor. (Discuss with your supervisor immediately). Tell them about GP / E&E and give numbers for the Lifeline (13 11 14) and always dial 000 in case of emergency or if they are worried for their safety or the safety of someone else?*

Display This Question:

If If yes, Have you made any plans or attempts to act on these thoughts? = No

Q35 *If no, details of thoughts?*

Q34 *Risk assessment:*

	Assessed			Level		
	Yes (1)	No (2)	None (1)	Low (2)	Medium (3)	High (4)
Risk to self (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Risk to others (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q32 *Notification required*

☐ Yes (1)

☐ No (2)

End of Block: START Intake Form