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Evaluating a targeted support program for mental health carers: a randomised controlled trial

Elloyse Fitzgeraldson^{a,b,c}, Sally Fitzpatrick^{a,b}, Joshua Dizon^{a,c} and Frances Kay-Lambkin^{a,c}

^aSchool of Medicine and Public Health, University of Newcastle, Newcastle, Australia; ^bHunter New England Local Health District, Everymind, Newcastle, Australia; ^cHunter Medical Research Institute, New Lambton Heights, Australia

ABSTRACT

Introduction: Minds Together is a novel online early intervention program developed for carers of a person with depressive or anxiety symptoms. A previous study indicated the feasibility, acceptability and initial trends in efficacy for this support program. **Aims:** The current study used a parallel RCT design to explore the effect of adding a social support platform to this program on carers' quality of life and perceived social support outcomes.

Methods: 127 carers (82% female), living in Australia, were recruited online and randomly allocated to the program alone, or program paired with the social forum. Participants completed surveys at baseline, post and 3-month follow up.

Results: Intervention and survey completion were low for this study. Across both groups, 49% completed the program and 20% used the social forum. Similarly, 42 participants completed post-surveys and 43 completed follow up surveys. The overall intervention effect between groups was non-significant for guality of life (p-value = 0.773) and perceived social support (p-value = 0.931).

Conclusions: This is the first RCT to evaluate the effects of adding a social support component to an existing support program for carers of a person with depressive or anxiety symptoms. While unable to draw conclusions about the added social support, the study emphasises the urgent need for collaboration between researchers, consumers and sector professionals to address challenges related to missing data in online health intervention research.

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Carer; caregiver; mental health: intervention research

Introduction

Depression and anxiety are the most reported mental health conditions globally. The provision of care and support to those impacted by mental health concerns is primarily undertaken by informal carers, such as relatives, partners, friends and colleagues (Diminic et al., 2016). Such support is a vital aspect in responding to the negative impacts of mental health concerns (Lederman et al., 2019; Salamin et al., 2019; Yesufu-Udechuku et al., 2015). There is growing evidence that carers report higher stress, poorer physical and mental health

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CONTACT Elloyse Fitzgeraldson 🖂 Elloyse.saw@uon.edu.au

outcomes, and lower wellbeing than non-carers (Pinquart & Sörensen, 2003; Thomas et al., 2015). Carers of a person where mental health concerns are the most interfering health challenges report psychological distress (Jan Shah et al., 2010; Karambelas et al., 2022), insomnia, suicidal ideation (Corchón et al., 2022), poor physical health and strained familial relationships (Bremmers et al., 2022) in response to their caring role.

However, not all carers experience the same adverse outcomes. Carers describe both challenging and positive aspects of their roles (Cohen et al., 2002; Shiraishi & Reilly, 2019) and a variety of factors contribute to the differential impacts on carers, including their beliefs about their role and the resources available to them. For instance, carers who perceive lower burden and higher perceived social support report higher perceived quality of life and better mental and physical health (Cianchetti et al., 2015; de Maria et al., 2020; Kuscu et al., 2009). Since carers' health and wellbeing have been strongly associated with their approach to providing care and support, targeting these factors directly is likely to improve outcomes for carers, and in turn, the care-recipients they support (de Rotrou et al., 2011).

Numerous studies have demonstrated the capacity of targeted support interventions to strengthen and modify how carers perceive and cope with the demands of their roles. Psychosocial interventions have been known to reduce carers' perceived burden and psychological distress, and improve their care experience, quality of life, and coping (Chien & Norman, 2009; Lobban et al., 2013; Macleod et al., 2011; Visa & Harvey, 2019).

A systematic literature review of interventions for carers of a person with depressive or anxiety symptoms found that supports are most effective when they embed targeted features, such as targeted psychoeducation and an appropriate intervention design (Fitzgeraldson et al., 2022). However, the review also noted limited published evidence for interventions targeting carers of a person with anxiety symptoms, or undiagnosed or sub-threshold depressive or anxiety symptoms.

Minds Together is an online early intervention support program aimed at supporting carers of a person with depressive or anxiety symptoms. A recent feasibility study indicated the feasibility and acceptability of this program and found trends in the program's capacity to reduce carers' perceived burden and increase their coping self-efficacy, compared to a waitlist control (Fitzgeraldson et al., 2023). Carer burden is the level of stress the care situation presents from the perspective of the informal carer (Liu et al., 2020). This perception also takes into consideration one's available resources, such as their capacity for coping, and is subject to change over time (Gérain & Zech, 2019). Coping self-efficacy refers to a person's perceived level of confidence in their capacity to cope with challenges (Chesney et al., 2006), and is associated with improved confidence in managing the demands of informal care (Zarit & Zarit, 2015).

The feasibility study also identified the potential benefits of adding a social support component to the program. Participants in the study noted that they would benefit from more tailored support, such as peer-to-peer support with carers experiencing similar challenges (Fitzgeraldson et al., 2023). International policy and research have also recognised peer support as a valuable source of support for people living with mental health concerns and their carers (Department of Health and Human Services, 2015; Health Education England, 2017; Visa & Harvey, 2019). Specifically, studies have found that carers who report higher perceived social connectedness have more knowledge about the care recipient's illness, and a greater capacity to cope with the demands of their role (Greenwood et al., 2013; Jones et al., 2019). The literature has also attributed interventions that embed social support components to improved management of work-related (Daniels, 1999) and care-related (Cooke et al., 2001) stress.

However, similar evidence on the efficacy of social support approaches for carers of a person with depressive or anxiety symptoms is limited. A recent systematic review (Fitz-geraldson et al., 2022) identified only one study exploring a social support intervention for carers of a person with depression (Stjernswärd & Östman, 2011), and this study had only 20 participants and did not employ a randomised controlled design. The current study hypothesises that adding a social support component to the *Minds Together* program may reduce carer participants perceived burden, and improve their perceived social support, quality of life and coping self-efficacy compared to the program alone. To test this hypothesis, the following questions are explored:

- (1) Does participation in the program paired with the social forum increase carers' perceived quality of life compared to the program alone?
- (2) Does participation in the program paired with the social forum increase carers' perceived social support compared to the program alone?

Materials and methods

Ethics

This study has ethics approval from the University of Newcastle's Human Research Ethics Committee (HREC), approval no. H-2021-0117 and was registered with Australian New Zealand Clinical Trial Registry (ACTRN12621001257853, 16 September 2021).

Study design

The study used a parallel randomised controlled design using two active comparator arms: (Group A) access to the *Minds Together* program alone, and (Group B) combined access to the *Minds Together* program and the *Minds Together* social forum. The use of an active comparator arm in this study was based on recommendations from the *National Institutes of Health* (NIH) (Freedland et al., 2019) which state that the best comparator is one that serves the primary research aims. Since this study aimed to examine a modified version of the *Minds Together* program, a control group comparator was not appropriate. Surveys were distributed at three-time points (baseline, post-program access, and 3-month follow-up) to assess the effects of participant engagement with these interventions. See the Procedures section below for more details on the randomisation process.

Setting and participants

Eligible participants were caring for someone with symptoms of depression or anxiety; aged 16 years or over; living in Australia; comfortable reading and writing in English and using web-based programs and had access to a computer. Depressive and anxiety symptomology in the care recipient was determined by carers and no formal assessment or diagnosis of the care recipient was required. However, these symptoms needed to

cause the most interference with usual activities compared to any other health condition, as per the carer's perspective.

Carers' shared perceptions that depressive or anxiety symptoms were present in the care recipient were used to ensure a certain level of homogeneity across the sample. Although is it possible that this approach introduced some subjectivity or variation in how mental health symptoms were defined or perceived, this approach is consistent with the view in the extant literature that carers' perceptions about the impacts of their role, rather than the nature of the specific health condition in the care recipient, influence their need for support and outcomes (Bastawrous, 2013; De Korte-Verhoef et al., 2014; Liu et al., 2020; Szmukler et al., 1996).

Carers were excluded from the study if they had previously accessed to the *Minds Together* program or social forum or were experiencing high levels of distress that would warrant more immediate support, such as sessions with a clinical psychologist. Recruitment took occurred between July 2021 and March 2022.

The sample size for this study was determined based on the results of a previous feasibility study (Fitzgeraldson et al., 2023). In this study, of a sample of 108 participants, 50% did not log in to the *Minds Together* program. Therefore, the goal for the current study was to double the sample size to 216 participants, with the expectation that a larger sample would increase the number of participants engaging with the program and returning surveys, to provide a more robust dataset for analysis.

Procedures

Mental health and carer-focused organisations across Australia promoted recruitment materials through their networks. Researchers utilised paid social media and online and print media outlets to further promote the study. After engaging with recruitment material, potential participants answered screening questions, gave their consent, and completed the pre-program survey. The survey comprised of demographic measures (e.g. age, gender, state of residence); details of the carer's relationship to the care recipient; and the care-recipients' symptoms (i.e. depressive, or anxiety symptomology, or both). Participants who completed the pre-program survey were randomised and notified about their group allocation via email. A third-party researcher established the simple randomisation process using REDcap (Geraghty et al., 2013). Due to the long recruitment process, participants were provided access to the program in cohorts every two weeks. Participants received access to the program and social forum for 10 weeks and were then asked to complete a post – and follow-up survey (12 weeks post-program access). To improve low program access (observed in the feasibility study; Fitzgeraldson et al., 2023), individuals who had not logged in within the first three weeks received a phone call to address any questions or potential technical concerns. Researchers also called participants at the end of the study period to ensure they received the post-survey.

Interventions

The minds together program

Participants in both groups had access to the *Minds Together* program. The four-module, self-paced, online program aims to assist individuals caring for a person living with

depressive or anxiety symptomology to cope with the demands of their role and promote their health and wellbeing (See Fitzgeraldson et al., 2023 for an in-depth description of the program). The program's four online modules were released to participants using a staged approach (i.e. one module per week for the first four weeks), followed by six weeks of unrestricted program access.

The minds together social forum

Group B participants also received access to the *Minds Together* social forum. The social forum resembles a Facebook feed, where participants can post, comment, react and upload photos. Participants were not granted the option of posting links to other web sources, to encourage them to stay within the *Minds Together* website. Participants could contribute to the platform at any time during the study period. However, researchers also ran a weekly 'happy hour' to encourage participants to be online at the same time every week. Participants received a weekly email reminding them about this time slot. Researchers also posted general questions to the platform throughout the study period (e.g. 'what do you do for self-care?') to stimulate discussion.

Outcome measures: primary outcomes

Care-related quality of life

The CarerQol instrument (Brouwer et al., 2006) measures quality of life in the context of informal caring. The instrument has two parts: CarerQol-7D provides a description of the care situation for seven burden domains (fulfilment, support, relational problems, mental health problems, financial problems, physical health problems and problems with activities in everyday life), and the CarerQol-VAS. For the CarerQol-7D, scale scores are added for a sum score range of 0–14 (a higher score is a more fulfilling care situation). Additionally, the CarerQol-VAS is a subjective measure of care-related quality of life. For this part of the measure, participants can rate their happiness from 0 to 10 (10 being most happy) using a visual analogue scale. The measure has good validity and reliability for measuring the impact of informal care (Hoefman, Van Exel, Foets, et al., 2011; Hoefman, Van Exel, Looren De Jong, et al., 2011).

Perceived social support

The Brief Form of the Perceived Social Support Questionnaire (F-SozU K-6) (Kliem et al., 2015) was used to measure carers' perceived social support. The instrument assesses an individual's perceived social support with respect to general social interactions, including support from friends, family, neighbours, significant others and general others. Responses are scored on a 5-point Likert scale (i.e. 1 = not true at all to 5 = very true), with higher scores indicating higher perceived social support. The measure has shown statistically significant correlations with scores on depression and generalised anxiety scales (Kliem et al., 2015).

Outcome measures: secondary outcomes

Zarit Burden Interview

The Zarit Burden Interview (ZBI) (Zarit et al., 1985) measured carers' perceived burden. The 22-item measure was developed to assess carers' perceived burden when providing

care in the home (Zarit et al., 1985). Questions relate to common burden areas including, health, financial situation and social and interpersonal relationships (Zarit et al., 1985). Responses are scored on a five-point Likert scale (0 = never, to 4 = nearly always) with a score range between 0-88. Higher scores suggest greater burden. The measure has been used extensively assess the burden associated with supporting someone with mental health concerns (Schene et al., 1994; Udoh et al., 2021).

Coping Self-Efficacy Scale

The Coping Self-Efficacy Scale (CSES) (Chesney et al., 2006) measured participant's coping self-efficacy. The 26-item instrument evaluates a person's confidence in their ability to cope when facing adversity. Responses are rated on an 11-point Likert scale ($0-4 = cannot \ do, \ 5 = moderately \ can \ do, \ 6-10 = certain \ can \ do$) for a total score between 0-260. Higher scores indicate higher self-belief in one's ability to cope (Chesney et al., 2006). The scale assesses self-belief in one's coping ability in three behavioural areas, namely problem-focused coping, emotional-focused coping and social support. The measure is routinely used in intervention studies (e.g. Scult et al., 2015).

Kessler Psychological Distress Scale

The Kessler Psychological Distress Scale (K10) (Kessler et al., 2002) was used to assess participants' psychological stress. The K10 screens for non-specific psychological distress, for use in health risk appraisal and primary care screening settings. Respondents are asked about feelings associated with psychological distress over the past 30 days. Items are scored on a five-point Likert scale (1 = None of the time to 5 = All of the time) and summed for a possible score range between 10-50. A higher score indicates higher psychological distress. The measure is regularly used in mental health carerfocused intervention studies (e.g. Brown et al., 2022; Deane et al., 2015) and is consistent with national health surveys (e.g. Australian Bureau of Statistics, 2021; Australian Government, 2022).

Data analysis

Demographics

Descriptive statistics for categorical data are presented as count (%), or mean (SD) n (min, max) if continuous.

Intervention engagement

Researchers measured intervention engagement through the extraction of website metadata from the *Minds Together* platform. Consistent with the feasibility study, adherence to the *Minds Together* program was defined as clicking on every page of at least half of the activity modules (Fitzgeraldson et al., 2023). For the social support component, intervention adherence was defined as accessing the social forum at least twice throughout the study period.

Statistical analysis was conducted as Intention-to-Treat (ITT). Outcome differences between intervention arms was examined using linear mixed models. The linear mixed models included fixed effects for time point (categorical: baseline, post-intervention and 3 months follow-up), allocation (categorical: program only, program + social), and

the interaction term of time point and allocation. An unstructured covariance matrix for within-subject residuals was used to model correlated errors from repeated baseline and follow-up measures. Model estimates of intervention effects are presented as mean differences with 95% confidence interval (CI) by time point and allocation.

The change in questionnaire scores over time, for the entire study sample, was examined using mixed linear regression with time point (categorical: baseline, follow-up and 3 months post-follow-up) as the only fixed effect as well as an unstructured covariance matrix for within-subject residuals. Model estimates are presented as LS means with 95%CI for each follow-up time point compared to baseline. Assumptions for linear mixed models were checked and found to be appropriate.

Due to data missingness (see Table 2 for demographic information for post and follow-up time points), multiple imputation by fully conditional specification (FCS MI) was performed, assuming missing responses were at random (MAR), to impute missing outcomes at follow-up and at 3 months post-follow-up period. MAR can make inferences on missing data based on values from available data (Sterne et al., 2009). Numerous studies have identified the validity of using MAR for most data types and in randomised controlled trials specifically (Horton & Lipsitz, 2012; Jørgensen et al., 2014; Zhang et al., 2017).

Participants' observed characteristics recorded at baseline (Table 1; as auxiliary variables), treatment assignment and observed survey total scores at each time point informed the FCS MI. Following creation of the data sets (m = 30), mixed effects regression analyses for the intervention effect over time using the MI data were performed (Huque et al., 2018). Regression results from the data sets were pooled using

			Program + social	
	Response/	Program alone	forum	Total
Characteristic	statistic	(n = 66)	(<i>n</i> = 61)	(<i>N</i> = 127)
Gender/gender identity	Male	7 (11%)	10 (16%)	17 (13%)
<u> </u>	Female	59 (89%)	50 (82%)	109 (86%)
	Non-binary/ gender fluid	0	1 (1.6%)	1 (0.8%)
Age (years)	Mean (SD)	50.25 (10.49)	49.74 (12.53)	50.00 (11.48)
	Median (min, max)	51.00 (28.00, 78.00)	52.00 (20.00, 75.00)	51.50 (20.00, 78.00)
Employment status	Unemployed	3 (4.5%)	3 (4.9%)	6 (4.7%)
	Employed full- time	32 (48%)	29 (48%)	61 (48%)
	Employed part- time	14 (21%)	16 (26%)	30 (24%)
	Casual employment	5 (7.6%)	1 (1.6%)	6 (4.7%)
	Seeking opportunities	3 (4.5%)	3 (4.9%)	6 (4.7%)
	Retired	9 (14%)	8 (13%)	17 (13%)
	Prefer not to say	0	1 (1.6%)	1 (0.8%)
Currently studying	No	53 (80%)	48 (79%)	101 (80%)
, , ,	Full-time student	4 (6.1%)	3 (4.9%)	7 (5.5%)
	Part-time student	9 (14%)	10 (16%)	19 (15%)
Care receiver experiences	Anxiety	7 (11%)	5 (8.2%)	12 (9.4%)
symptoms of depression or	Depression	5 (7.6%)	4 (6.6%)	9 (7.1%)
anxiety	Both	54 (82%)	52 (85%)	106 (83%)

Table 1. Participant demographics at baseline.

Rubin's rules (Barnard & Rubin, 1999). SAS v9.4 was used to program Statistical analyses (SAS Institute Inc, 2013).

Results

Demographics

One hundred and twenty-seven participants (82% female) were randomised to either the program alone (n = 66) and program paired with social support (n = 61) groups (Table 1). The average participant age was 50 years (SD = 11.48). Most participants were employed, either full time (48%), or part time (24%), with 17 (13%) retirees. The most common relationship to the care recipient was parent (40%) followed by partner (36%) and child (15%). Most participants were supporting a person with comorbid depressive and anxiety symptoms (83%). The CONSORT flow chart included in Figure 1 details the flow of participants throughout this study.

Intervention engagement

Intervention engagement rates were low for this study (Table 2). Approximately 49% of participants across both intervention groups completed the *Minds Together* program. In

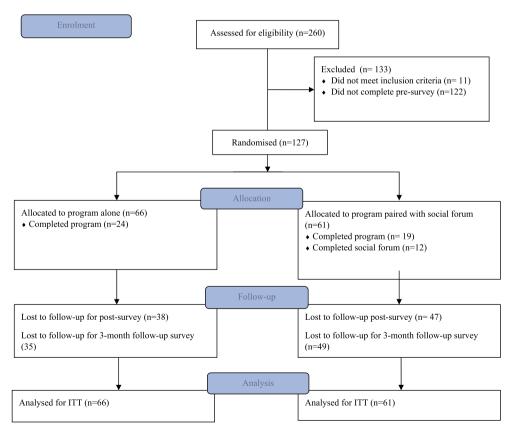


Figure 1. CONSORT flow chart.

Program only (N = 127)				Program + social forum $(n = 61)$			
Group	Program access (n)	Partial adherence (<i>n</i>)	Adhered (n)	Adherence rate	Social forum access	Adhered (n)	Adherence rate %
Prog only $(n = 66)$	43	18	24	56%	0	N/A	N/A
Prog + social (n = 61)	45	26	19	42%	15	12	20%
Total	88	44	43	49%	15	12	20%

Table 2. Intervention adherence.

contrast, 20% of participants allocated to the social forum group met the adherence threshold.

Intention-to-treat results

Survey completion rates were also low for this study. Of the 127 participants, 42 completed post (group A = 23, group B = 19) and 43 completed follow-up (group A = 26, Group B = 17) surveys. This low response rate meant that there was insufficient evidence to suggest a significant difference in intervention effect between the two allocation groups over time (see Table 3 below). Therefore, the overall effect was non-significant for carer burden (*p*-value = 0.472), quality of life (*p*-value = 0.773), coping self-efficacy (*p*-value = 0.166), perceived social support (*p*-value = 0.931), and psychological distress (*p*-value = 0.473). The difference in total scores between groups were also marginal and not statistically significant for both the follow-up and 3-month follow-up time points. There is some evidence to suggest that within the allocation group, quality of life total scores were higher in the 3-month post-follow-up compared to baseline, for both groups (Program alone LS mean difference: 3.64, *p* < 0.001; Program + social LS mean difference: 3.95, *p* < 0.001). However, these contrast estimates cannot be used as evidence of an effect caused by the interventions.

ITT sensitivity analysis: multiple imputation assuming MAR

Due to the loss of statistical power caused by a large amount of outcome non-responses during the follow-up period and 3-months follow-up, multiple imputation by full conditional specification (FCS MI; Liu & De, 2015) was performed to impute non-responses assuming data was missing at random (MAR). A key practical advantage [of MI] is the ability to include auxiliary variables in the imputation model (i.e. additional variables from our dataset that are not in the scientific model) (Carpenter & Smuk, 2021).

The FCS MI model included participants' baseline characteristics as auxiliary variables to improve the efficiency of the imputations (Carpenter & Smuk, 2021). The missing information from the non-responses were assumed to be conditional on observed baseline characteristics as well baseline outcomes, and FCS MI was performed using this observed information. The results of the sensitivity analysis using m = 30 imputed data sets are presented in Table 4. As with the available case analysis, the differences in outcomes between the two intervention groups were not significantly different at either follow-up time points. There were also no obvious improvements in the 95% CI of the

Questionnaire	Contrast effect	Mean difference (95% Cl)	<i>p</i> - value	Interaction effect <i>p</i> -value	N
Caregiver Burden Scale	Program + Social vs. Program only: Follow-up	2.31 (-5.84, 10.47)	0.575	0.472	125
	Program + Social vs. Program only: 3mo post-follow-up	5.24 (-3.55, 14.03)	0.240		
	Program + Social: Follow-up vs. baseline	-3.69 (-9.10, 1.73)	0.181		
	Program + Social: 3mo post- follow-up vs. baseline	-1.22 (-6.95, 4.50)	0.673		
	Program only: Follow-up vs.	-2.92 (-7.57, 1.72)	0.215		
	Program only: 3mo post-follow- up vs. baseline	-3.39 (-8.26, 1.48)	0.171		
Coping Self-Efficacy Scale	Program + Social vs. Program only: Follow-up	4.30 (-20.43, 29.04)	0.731	0.773	125
	Program + Social vs. Program only: 3mo post-follow-up	3.28 (-24.57, 31.13)	0.816		
	Program + Social: Follow-up vs. baseline	16.02 (-0.68, 32.72)	0.060		
	Program + Social: 3mo post- follow-up vs. baseline	11.67 (-6.19, 29.54)	0.198		
	Program only: Follow-up vs. baseline	8.44 (-5.89, 22.76)	0.246		
	Program only: 3mo post-follow- up vs. baseline	5.11 (-8.77, 18.99)	0.468	0.144	10
F-SozU K-6	Program + Social vs. Program only: Follow-up	1.53 (-1.34, 4.40)	0.293	0.166	124
	Program + Social vs. Program only: 3mo post-follow-up	0.42 (-2.81, 3.66)	0.796		
	Program + Social: Follow-up vs. baseline Program + Social: 2mo port	1.49 (-0.02, 2.99)	0.052		
	Program + Social: 3mo post- follow-up vs. baseline Program only: Follow-up vs.	2.28 (0.02, 4.53)	0.048 0.635		
	baseline Program only: 3mo post-follow-	-0.32 (-1.67, 1.02)	0.035		
K 10	up vs. baseline Program + Social vs. Program	1.57 (-0.29, 3.43)	0.251	0.931	123
	only: Follow-up Program + Social vs. Program	1.97 (-1.41, 5.34) 1.55 (-2.96, 6.05)	0.498	0.951	123
	only: 3mo post-follow-up Program + Social: Follow-up vs.	-0.55 (-2.54, 1.43)	0.583		
	baseline Program + Social: 3mo post-	-0.53 (-3.74, 2.67)	0.742		
	follow-up vs. baseline Program only: Follow-up vs.	-0.20 (-1.94, 1.53)	0.819		
	baseline Program only: 3mo post-follow-	0.24 (-2.28, 2.76)	0.852		
CarerQol-7D	up vs. baseline Program + Social vs. Program	0.12 (-1.08, 1.32)	0.843	0.473	124
CalelQ0-7D	only: Follow-up Program + Social vs. Program	-0.11 (-1.48, 1.25)	0.871	0.175	.2
	only: 3mo post-follow-up Program + Social: Follow-up vs.	0.67 (-0.01, 1.36)	0.055		
	baseline Program + Social: 3mo post-	3.95 (3.02, 4.89)	<.001		
	follow-up vs. baseline Program only: Follow-up vs.	0.12 (-0.47, 0.72)	0.678		
	baseline Program only: 3mo post-follow-	3.64 (2.90, 4.37)	<.001		
	up vs. baseline				

Table 3. Linear mixed mo	dels for differences in su	rvey scores over time k	by intervention group.

Questionnaire	Contrast effect	Mean difference (95% Cl)	<i>p-</i> value	Trt*Time <i>p</i> -value
Caregiver Burden Scale	Program + Social vs. Program only: Follow-up	0.41 (-8.37, 9.19)	0.926	0.668
	Program + Social vs. Program only: 3mo post- follow-up	3.87 (-4.30, 12.04)	0.351	
	Program + Social: Follow-up vs. baseline	-7.59 (-14.98, -0.20)	0.044	
	Program + Social: 3mo post-follow-up vs. baseline	-7.05 (-13.17, -0.92)	0.024	
	Program only: Follow-up vs. baseline	-4.13 (-10.36, 2.10)	0.191	
	Program only: 3mo post-follow-up vs. baseline	-7.04 (-13.07, -1.02)	0.022	
Coping Self-Efficacy	Program + Social vs. Program only: Follow-up	11.04 (-12.82, 34.90)	0.362	0.543
Scale	Program + Social vs. Program only: 3mo post- follow-up	10.34 (-18.80, 39.49)	0.483	
	Program + Social: Follow-up vs. baseline	25.64 (9.16, 42.11)	0.003	
	Program + Social: 3mo post-follow-up vs. baseline	26.11 (1.34, 50.87)	0.039	
	Program only: Follow-up vs. baseline	12.29 (-4.36, 28.94)	0.146	
	Program only: 3mo post-follow-up vs. baseline	13.46 (-4.25, 31.17)	0.135	
F-SozU K-6	Program + Social vs. Program only: Follow-up	1.53 (-1.46, 4.52)	0.313	0.295
	Program + Social vs. Program only: 3mo post- follow-up	0.96 (-2.51, 4.42)	0.583	
	Program + Social: Follow-up vs. baseline	2.26 (0.65, 3.88)	0.007	
	Program + Social: 3mo post-follow-up vs. baseline	3.47 (0.88, 6.05)	0.009	
	Program only: Follow-up vs. baseline	0.35 (-1.20, 1.91)	0.654	
	Program only: 3mo post-follow-up vs. baseline	2.13 (0.04, 4.22)	0.046	
K10	Program + Social vs. Program only: Follow-up	2.34 (-0.76, 5.44)	0.138	0.969
	Program + Social vs. Program only: 3mo post- follow-up	1.85 (-2.63, 6.32)	0.414	
	Program + Social: Follow-up vs. baseline	-0.72 (-2.91, 1.48)	0.520	
	Program + Social: 3mo post-follow-up vs. baseline	-0.48 (-4.16, 3.19)	0.795	
	Program only: Follow-up vs. baseline	-0.82 (-2.86, 1.21)	0.425	
	Program only: 3mo post-follow-up vs. baseline	-0.10 (-2.82, 2.63)	0.945	
CarerQol-7D	Program + Social vs. Program only: Follow-up	-0.05 (-1.08, 0.99)	0.926	0.815
-	Program + Social vs. Program only: 3mo post- follow-up	-0.12 (-1.51, 1.27)	0.864	
	Program + Social: Follow-up vs. baseline	0.66 (-0.12, 1.44)	0.094	
	Program + Social: 3mo post-follow-up vs. baseline	4.42 (3.33, 5.51)	<.001	
	Program only: Follow-up vs. baseline	0.32 (-0.44, 1.08)	0.406	
	Program only: 3mo post-follow-up vs. baseline	4.15 (3.31, 4.98)	<.001	

Table 4. Pooled MI regression estimates (m = 30) for differences in survey scores over time by intervention group.

estimates suggesting that the loss of statistical power due to non-responses was not sufficiently recovered by FCS MI.

Sample population

With only 20% of participants in Group B meeting intervention engagement thresholds for the social forum (see Table 2), it was not possible to conduct a per-protocol analysis between groups. Instead, both the intervention and control groups were examined as a single group and their responses over time were analysed. As shown in Table 5, perceived

	Follow-up vs. Basel	Follow-up vs. Baseline		3mo post-follow-up vs. Baseline		
Questionnaire	Mean difference (95% Cl)	<i>p</i> - value	Mean difference (95% Cl)	<i>p</i> - value	Time main effect <i>p</i> -value	N
Caregiver Burden Scale	-3.35 (-6.83, 0.12)	0.059	-2.45 (-6.18, 1.27)	0.195	0.158	125
Coping Self-Efficacy Scale	11.59 (0.84, 22.34)	0.035	7.53 (-3.34, 18.40)	0.173	0.105	125
F-SozU K-6	0.51 (-0.50, 1.52)	0.318	1.88 (0.44, 3.31)	0.011	0.033	124
K10	-0.36 (-1.65, 0.93)	0.581	-0.10 (-2.05, 1.85)	0.920	0.826	123
CarerQol-7D	0.37 (-0.08, 0.82)	0.103	3.76 (3.19, 4.33)	<.001	<.001	124

Table 5. Linear mixed models for differences in surve	v scores over time (entire sample; not stratified).

social support scores (*p* 0.033) and quality of life (<.001) scores increased over time. At 3-months follow-up there was an average increase in perceived social support scores compared to baseline (mean difference = 1.88, 95% CI = 0.44 - 3.31). Additionally, there was an increase in quality of life from baseline to 3-month follow-up (mean difference = 3.76, 95% CI = 3.19, 4.33).

Discussion

The current study was the first to explore the effects of adding a social support component to an online program targeting carers of a person with depressive or anxiety symptoms (Fitzgeraldson et al., 2022). It is well established in the extant literature that social support interventions can reduce carers' perceived burden and improve their wellbeing and coping (Greenwood et al., 2013; Jones et al., 2019). Identifying effective social support interventions is therefore a growing priority in the informal care literature. However, evidence suggests that the benefits of these interventions are context specific and require evaluation with the target group. Although carers' lack of engagement with the social support forum in this study inhibited a comparison of study arms, the results have illuminated a range of methodological learnings that add to current knowledge for engaging and supporting this population.

Program engagement

The hypothesis that adding a social forum component to the *Minds Together* program will improve outcomes for informal carers was not supported by the results in this study. While it is possible that the social support component is not effective, the low number of people allocated to the social forum study arm accessing this platform suggests that other factors may have contributed to these results. For example, adherence was low in terms of logging in to the social forum and, participant engagement (i.e. posts and comments) from participants who accessed the forum. Low intervention adherence is common in community targeted health interventions, particularly for online intervention studies (e.g. Zijlstra et al., 2009; Petrovčič, Petrič, & Lozar Manfreda, 2016; Sinclair, O'Toole, Malawaraarachchi, & Leder, 2012), and may explain the low engagement observed in the current study.

It is also possible that the long recruitment period and compensatory study design impacted engagement on the platform. The long recruitment period and use of cohorts to upload participants periodically to the platform meant a restricted number of people were accessing the platform at the same time. Previous literature has indicated that a lack of momentum in online discussion forums can inhibit engagement. One study has noted that too much time elapsed between posting is associated with a loss of interest in the discussion (Gilbert, 2015). Additionally, evidence from online learning studies have indicated students' frustration not having their questions answered when few people are online (Dyrbye et al., 2009; Murphy et al., 2004), which is echoed in a study on an online social support platform for mental health carers (Stjernswärd & Östman, 2011). Although the social forum was informally piloted prior to the current study, it was only with 10 carers for a short period, limiting the ability to detect some of the issues surrounding participant adherence. A more comprehensive piloting period, experimenting with moderator involvement and using a more in-depth co-design approach may have resulted in more preparedness against the adherence challenges.

Although the social forum was informally piloted prior to this study with 10 carers for a brief period, this limited the ability to identify the issues related to participant engagement and adherence. A more extensive piloting period that included experimenting with different levels of moderator involvement and incorporating a more collaborative design approach with users could have helped anticipate and address these challenges.

Outcome measures

Poor intervention adherence also impacted the ability to determine the efficacy of the *Minds Together* program. However, the ITT analysis revealed increased quality of life scores for participants in both groups over time. These results contribute to a wealth of evidence for the capacity of psychosocial interventions to strengthen carers' perceived well-being (Dam et al., 2016; Treanor, 2020). Additionally, the trends observed in the ITT analysis supported the initial hypotheses. Specifically, scores for carer burden decreased while coping self-efficacy, perceived social support, and carer quality of life increased. This evidence shows promise for these interventions when accompanied by higher program and survey completion. However, given the current study does not provide evidence of a meaningful difference between the interventions, further research comparing these interventions is not recommended.

Nonetheless, the study did indicate increased quality of life and perceived social support in the per protocol analysis for the whole sample. Carers' increased perceived social support scores despite their limited engagement with the social platform could also suggest the *Minds Together* program contributed to these shifts. This view is consistent with results from the feasibility study of the program where participants found the lived experience videos and stories most relatable and could relate to them as 'real people' (Fitzgeraldson et al., 2023).

It is also possible that some aspects of the program, such as cognitive behavioural therapy components shifted carers' mindsets about their available social resources, which is supported in the evidence. For example, one study on a community sample engaging with a preventative, psychoeducation program embedding cognitive reframing strategies for the individual and their relationships observed an increase in perceived social support (Brand et al., 1995). Furthermore, several studies have found that perceived social support predicts quality of life (Chung et al., 2013; Yasien et al., 2013), suggesting a strong relationship between these variables.

Limitations and strengths

The most significant limitation was the low participant adherence to the social forum and low completion rate of post- and follow-up study data, which MI was unable to pragmatically address. The MI model results are also likely to be conservative estimates (Siddiqui, 2011). Although missing data is commonly seen in similar community targeted online studies (e.g. McKechnie et al., 2014; Stjernswärd & Östman, 2011), it is possible that the COVID-19 pandemic and associated household chaos (Johnson et al., 2022) reduced work-life balance (Sandoval-Reyes et al., 2021), and carer specific challenges (Greenberg et al., 2020) also reduced carers' capacity to commit to completing the interventions and survey. For example, a review of 117,000 trials across the United States, Asia and Europe, during the pandemic found that recruitment and participant follow-up was substantially affected during this period (Hawila & Berg, 2021). Evidence on the time constraints of informal carers during the pandemic (Bailey et al., 2022) and phone conversations with participants further support this view.

Additionally, the sample size goal of 216 participants was not reached in this study. We acknowledge that a larger sample size could have provided more statistical power to detect more meaningful effects, and the results of this study should be interpreted with caution in the context of these limitations.

It is worth noting that when comparing two interventions that have not been previously established as efficacious, the conclusions that can be drawn about their relative benefits are limited, and it may be difficult to justify their dissemination. While withholding treatment in a control group is an ethical concern in RCTs, providing the intervention to all participants can compromise the study's rigour and make it difficult to determine the effectiveness of the treatment being studied. This is a complex issue that has been discussed extensively in the literature (Goldstein et al., 2018; Solomon, Cavanaugh, & Draine, 2009). Readers should consider these limitations when interpreting the results of this study.

Using the CarerQol as the primary outcome measure in this study may have also introduced some limitations. This measure is a general assessment of caregiver wellbeing, so it may not have accurately captured the impact of supporting someone with mental health concerns specifically. Nevertheless, complementing this measure with other measures of caregiver well-being aimed to mitigate these potential limitations. The inclusion of carer strain, psychological distress and social connectedness measures in this study provide a more comprehensive understanding of the impacts of caregiving.

Furthermore, although it was a requirement of the study that participants were comfortable using online tools, it is also possible that the digital format presented usage barriers for some carer participants, depending on their age and mastery surrounding digital tools (Sitges-Maciá et al., 2021).

Despite the mentioned limitations, this study was the first to explore the effect of adding a social support component to a program targeting carers of a person with depressive or anxiety symptoms. The methodological learnings that can be gleaned from this study are another strength. The challenges encountered surrounding intervention adherence and survey completion, highlight the importance of not only designing interventions for populations in need, but also ensuring that evaluation methods are appropriately tailored to the schedules, abilities and access capabilities of these individuals. Therefore, this research has highlighted the importance of taking a user-centred approach to research and program design, particularly for underserved populations, to ensure interventions are not only relevant and meaningful, but also readily adopted.

Future research

The results from the current research identified several opportunities for future research, particularly regarding the addition of social support to online programs. While carers did not engage with the social support component in the current research, countless studies demonstrate the benefits of social support for informal carers (George et al., 2020; Parker Oliver et al., 2017) in a context with sufficient engagement. Examining the effects of an active social support platform on carers outcomes, such as a social forum they already use, in future research may provide more accurate insight into the efficacy of this support option. Additionally, more detailed participant feedback about an appropriate intervention design may be helpful. For example, although participants indicated interest in a social support component in the previous feasibility study (Fitzgeraldson et al., 2023), more consultation is needed to understand carers' expectations for this platform, such as an appropriate frequency of notifications for the website, and level of input from moderators. Similarly, a participatory design approach could improve intervention relevance, effectiveness and adoption. Active participation of end users in the design of support interventions, can ensure their needs and preferences are met and supports are inclusive, accessible and user-friendly (Nicholas et al., 2012).

Although this study has identified opportunities to improve participant access and engagement with social support interventions in the future, it is worth noting that intervention non-adherence does not always indicate a problem with the intervention. Researchers should also consider the potential positive or neutral causes of non-adherence, such as the participant's support needs being met without completing the intervention, or their support needs changing over the study period.

This study has also highlighted how future research comparing interventions where their relative efficacy has not yet been established, should carefully consider the ethical and methodological trade-offs involved. Such studies may be limited in their ability to justify the dissemination of one intervention over the other, and this limitation should be considered in the study design and interpretation of the results.

The challenges faced by researchers in the current study have also highlighted opportunities for future work in this area. Specifically, the low program and survey completion rates demonstrate a need for additional efforts to understand how to engage marginalised community groups, such as carers of a person with mental health concerns. Researchers should work closely with consumers and sector professionals to better understand the support needs and barriers for informal mental health carers and tailor research methods accordingly.

To enhance the evaluation of targeted support programs for mental health carers, researchers could also benefit from refining existing survey instruments or developing new ones that specifically address the unique challenges faced by this population.

These refinements would enable more accurate measurement of the impact of these programs and potentially improve their effectiveness, while also providing a more relevant and meaningful assessment experience for participants.

Additionally, researchers should report accurately and completely to identify learnings and impacts from the research, reduce research waste, and improve policy and practice (Chalmers & Glasziou, 2009) in this area.

Conclusion

This is the first randomised controlled trial to evaluate the effects of adding a social support component to an existing support program for carers of a person with depressive or anxiety symptoms. While unable to demonstrate the benefits of the added social component, the study offers valuable methodological insights relating to research engagement and management of missing data within the context of online health intervention studies. Drawing on the challenges observed in this research regarding community engagement and retention should be used to strengthen future research, policy and practice in this area.

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Declaration of interest

EF and SF are employees of Everymind.

Data availability statement

To access data from this study, please contact Sally Fitzpatrick at sally.fitzpatrick@health.nsw.gov.au.

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