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# Feasibility and Acceptability of a Novel Online Program for Mental Health Carers

Viabilidad y aceptabilidad de un nuevo programa en línea para cuidadores de salud mental

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#### Abstract.

Objective: To evaluate the feasibility and acceptability of a new online program (Minds Together) for carers of a person with depressive or anxiety symptoms. Methods: Using a two-arm randomised controlled trial design, 108 carers of a person with depressive or anxiety symptomology aged 16 years or over (89% female; mean age 50 years) received immediate or delayed access to the Minds Together program. Feasibility was measured using program activation and survey completion rates. Acceptability was measured using a project-specific satisfaction scale, semi-structured interviews, and program completion metadata. The study used intention-to-treat (ITT) analysis for participant-reported outcomes (carer burden, coping self-efficacy) across groups. Results: Feasibility and acceptability thresholds were consistent with similar studies: 59% activated their program account, 47% met the program completion threshold, and almost all reported satisfaction with the program. The ITT indicated trends in increased coping self-efficacy and reduced carer burden for the Intervention group, compared to the Waitlist control. Conclusions: The Minds Together program is a feasible and acceptable program for carers supporting a person with depressive or anxiety symptomology. Results support exploration of the program's efficacy in a full-scale RCT.

#### Resumen

Objetivo: Evaluar la factibilidad y aceptabilidad de un nuevo programa en línea (Minds Together) para cuidadores de una persona con síntomas depresivos o ansiosos. Métodos: utilizando un diseño de ensayo controlado aleatorio de dos brazos, 108 cuidadores de personas con sintomatología depresiva o ansiosa de 16 años o más (89% mujeres; edad media, 50 años) recibieron acceso inmediato o diferido al programa Minds Together. La viabilidad se midió utilizando la activación del programa y las tasas de finalización de la encuesta. La aceptabilidad se midió utilizando una escala de satisfacción específica del proyecto, entrevistas semiestructuradas y metadatos de finalización del programa. El estudio utilizó el análisis por intención de tratar (ITT) para los resultados informados por los participantes (carga del cuidador, autoeficacia de afrontamiento) en todos los grupos. Resultados: Los umbrales de viabilidad y aceptabilidad fueron consistentes con estudios similares: el 59% activó su cuenta del programa, el 47% alcanzó el umbral de finalización del programa y casi todos informaron satisfacción con el programa. El ITT indicó tendencias en el aumento de la autoeficacia de afrontamiento y la reducción de la carga del cuidador para el grupo de Intervención, en comparación con el control de la Lista de Espera. Conclusiones: El programa Minds Together es un programa factible y aceptable para los cuidadores que apoyan a una persona con sintomatología depresiva o ansiosa. Los resultados respaldan la exploración de la eficacia del programa en un RCT a gran escala.

#### Keywords.

Carers; Caregivers; Depression; Anxiety; Mental Health; Relatives. Palabras Clave.

Cuidadores; depresión; ansiedad; salud mental; familiares.

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### 1. Introduction

Addressing the rising prevalence and impact of internalising disorders and their symptoms is a global priority (Ghebreyesus, 2019). Over 4% percent of the global population live with depression, and more than 3% live with anxiety, making these internalising disorders the most common worldwide (World Health Organization, 2017). Despite the high prevalence of people living with mental ill-health, factors such as poor mental health literacy, access to treatment, and mental health-related stigma remain barriers to help-seeking (Australian Bureau of Statistics, 2007; Evans-Lacko et al., 2018). In Australia, less than half of those living with mental ill-health seek or receive professional (formal) support (Diminic et al., 2016).

In the absence of formal care, most people experiencing depressive, or anxiety symptomology are supported by family members, friends, and significant others (Australian Bureau of Statistics, 2018). Australia's 240000 informal mental health carers contribute approximately \$13.2 billion worth of services to the economy through their unpaid support (Diminic et al., 2016). Provision of care ranges from fulfilling essential needs through to advocacy and has been found to improve outcomes for care recipients (Griffiths et al., 2011).

While there are benefits to caring, the role can also present challenges to a carers' own physical and mental health in turn, and even impact their capacity to provide support (Kumar & Gupta, 2014; Mishra & Shakya. 2021; Vikas et al., 2011). Providing support to someone with depressive or anxiety symptoms can contribute to physical, psychological, and financial challenges for the carer (Radfar et al., 2014; Priestley & Priestley, 2016), with some carers describing their role as contributing to a "turbulent life" (Radfar et al, 2014, p. 252) and like it is impossible to "have a break mentally" (Blake-Holmes, 2019, p. 236). Choi and colleagues (2021) suggest that supporting someone with comorbid anxiety and depressive symptoms can further increase this burden compared to supporting someone experiencing only one disorder (Ezpeleta et al., 2006; O'Neil et al., 2010).

Carer-focussed interventions have shown promising results for their capacity to reduce carers' stress, improve coping self-efficacy, quality of life, and symptoms of their mental ill-health (Jeong et al., 2018; Metcalfe et al., 2019; Perlick et al., 2018). However, many of these interventions target carers of a person with severe psychopathology (e.g., psychosis and schizophrenia; Lavis et al., 2015; Sadath et al., 2017). Population-targeted, early intervention support may improve outcomes for mental health carers in the general community. Early intervention support can improve community education and resilience (Kelly et al., 2007; Mcguffog et al., 2021; Vivanti et al., 2018). However, these approaches are most effective when they reflect the needs and preferences of the population in question (Visa & Harvey,

2019). Exploring the feasibility and acceptability of support approaches and embedding lived experience perspectives into the design and evaluation of interventions is crucial. There is a dearth of evidence on interventions targeting carers of a person with depressive and anxiety symptoms, much less on early intervention support for these carers. A recent systematic review (Fitzgeraldson et al., 2022) found just six studies on interventions for carers of a person with depression, and no interventions targeting carers of a person with anxiety symptomology. The review also found no published studies on interventions targeting carers of a person with comorbid or subthreshold depressive or anxiety symptoms with an early intervention support focus, or otherwise.

Minds Together is a new online early intervention focussed program developed to reduce burden and increase coping for carers of a person with depressive or anxiety symptomology. Carer burden refers to "the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time" (Liu et al., 2020, p.13) and is a key determinant of poorer carer outcomes (Lee et al., 2019; Pinquart & Sörensen, 2003). Burden can be influenced by factors relating to both the carer and care-recipient, including the duration and intensity of the care recipient's journey, the frequency and intensity of mental and physical ill-health, and the presence of other comorbidities (Petriwskyj et al., 2016; Youell et al., 2016). Further, caring does not occur in isolation from the other roles and responsibilities that carers have in their lives (e.g., spouse, parent, employer, employee, or community member), adding to the perceived burden of care (Cormac & Tihanyi, 2006; Hayes et al., 2015). Carer burden may also be exacerbated by the complexity of the caring situation.

Carer burden, and the associated psychological consequences of caring, are not uniformly experienced (Visa & Harvey, 2019). Despite the challenges associated with caring, some carers report positive outcomes from these challenges, such as motivation to continue the care role (Kim et al., 2015) and improvements in their relationship with the care-recipient (Linderholm & Friedrichsen, 2010). Coping self-efficacy is an important factor in explaining the heterogeneity in outcomes associated with adverse circumstances in this context. Coping selfefficacy is a person's belief about their ability to cope with challenges (Chesney et al., 2006), such as those associated with informal mental health care. This construct has received attention in the literature for its positive effects on carers' mental and physical health, psychological adjustment, and care responses (Chenoweth et al., 2016; Gilliam & Steffen, 2006; Guillamón et al., 2013; Hubbard et al., 2016). Importantly, self-efficacy is not a unitary nor fixed construct, and is amenable to change over time. Research is needed to understand whether prevention programs in the community can strengthen this belief in informal mental health carers.



The current research has two aims: firstly, to evaluate the feasibility and acceptability of the novel *Minds Together* program for community-dwelling carers of a person with depressive and anxiety symptomology; and secondly, to explore the plausibility of implementing a proposed full-scale trial. Rigorous randomised controlled trials (RCTs) are the gold standard for concluding intervention efficacy. However, due to the high expense and time-consuming nature of RCTs, researchers have recommended initially undertaking feasibility and pilot studies to improve the intervention and research processes prior to a full-scale RCT being undertaken (Craig et al., 2008). For this reason, no specific hypothesis has been proposed (Tickle-Degnen, 2013).

The study asks the following research questions: (i) What is the feasibility of a pilot randomised controlled design (RCT) in comparing the *Minds Together* program to a Waitlist control? and (ii) What is the acceptability of *Minds Together* for carers of a person with depressive or anxiety symptoms? Preliminary evidence for the program's capacity to reduce carer burden and improve coping self-efficacy compared to a Waitlist control will also be explored.

# 2. Methods

This study has received ethics approval from Hunter New England Research Ethics Committee of Hunter New England Local Health District (2019/ETH13205).

# 2.1 Sample

One hundred and eight participants (89% female) were recruited and randomised to either the Intervention (n=54) or Waitlist groups (n=54). The mean age of participants was 50 years (SD=12.2, range = 17–72). Most participants were born in Australia (84%) and identified as Australian (81%), with almost 5% also identifying as Indigenous Australian (1.9%, Aboriginal; 2.9%, Torres strait Islander). Participants resided in all states and territories in Australia but were mainly living in New South Wales (78%) and Victoria (12%). Many participants were the parent (34%), or partner (31%) to the care-recipient and 80% supported someone with comorbid depressive and anxiety symptoms. More demographic data is included in Table 1.

#### 2.2 Study Design

The study used a pilot RCT design with two arms: (i) access to the *Minds Together* online program targeting carers of a person with depressive or anxiety symptomology and (ii) a Waitlist control. Researchers assessed outcomes using a mixed methods approach. Feasibility was assessed using program and survey adherence and attrition rates, based on similar approaches in existing feasibility evidence for carer-focussed, technology-based interventions (Heynsbergh et al., 2018; Scott & Beatty, 2013). Acceptability was measured using participant

feedback in surveys, interviews with a sub-sample of participants, and program completion metadata across the study period. Secondary outcomes were assessed using carer burden (Zarit et al., 1985), and coping self-efficacy measures (Chesney et al., 2006) in pre- and post-surveys for both study groups.

# 2.3 Setting and Participants

Study participants were a self-selected volunteer sample of carers who responded to posts and advertisements on social media (Facebook, Twitter, and LinkedIn), websites and online newsletters from May to July 2020. Participants were eligible if they were aged 16 years or older, supporting a person (of any age) experiencing depressive or anxiety symptoms that were impacting their life. Since Minds Together is targeted at the community level and non-clinical in nature, it was not necessary for carerecipients to meet clinical criteria for their symptoms of mental ill-health. Furthermore, carers were not required to be supporting someone with a formal diagnosis of depression or anxiety, and evaluation of the level of interference of the symptoms was at the carers' discretion. Additional inclusion criteria included the carer living in Australia, being comfortable reading and writing in English and using web-based programs. Of the 282 carers who expressed interest in the study, 108 participants completed the pre-program survey and were therefore included in the study. The study aimed to test aspects of the study design for a larger trial, rather than test the efficacy of the program. Therefore, determining the sample size through formal power considerations was not necessary (Whitehead et al., 2016). Instead, the planned sample size (84 participants) was in line with other similar studies (Julious, 2005; Teare et al., 2014) with consideration for the expected high attrition associated with automated internet interventions (Eysenbach, 2005; Geraghty et al., 2013).

#### 2.4 Procedures

People in the community who engaged with the online recruitment material and completed screening criteria were directed to a website containing information about the trial, consent agreement, and the pre-program survey. Participants who met screening criteria and completed the pre-survey were then randomly assigned to either the *Minds Together* Intervention or Waitlist group and notified about their allocation via email. A thirdparty researcher established an automated randomisation process using a simple randomisation sequence in REDCap (Geraghty et al., 2013). Researchers were blind to the allocation sequence while assigning participants to their groups. Once randomised, researchers notified participants of their allocated group via email. The Intervention group received immediate access to the program for a period of eight weeks. At the end of this period, participants from both groups completed a post-survey



Table 1

Carer demographics

Characteristic	Response/statistic	Program $N = 54$	Waitlist $N = 54$	Total $N = 108$
Gender identity	Male	6 (11%)	6 (11%)	12 (11%)
Gender identity	Female	48 (89%)	48 (89%)	96 (89%)
Age	Mean $(SD)$	48.04 (11.88)	51.11 (12.43)	49.58 (12.20)
Age	Median (min, max)	$49.00\ (20.00,68.00)$	$52.00\ (17.00,\ 72.00)$	$51.50 \ (17.00, 72.00)$
	New South Wales	48 (89%)	36 (67%)	84 (78%)
	Victoria	1 (1.9%)	12 (22%)	13 (12%)
State or territory	Queensland	1(1.9%)	3 (5.6%)	4(3.7%)
of residence	South Australia	1(1.9%)	2(3.7%)	3(2.8%)
of residence	Tasmania	1 (1.9%)	1 (1.9%)	2(1.9%)
	Western Australia	1 (1.9%)	0	1 (.9%)
	Northern Territory	1(1.9%)	0	1 (.9%)
	Australia	44 (86%)	41 (82%)	85 (84%)
	United Kingdom	4 (7.8%)	6 (12%)	10 (9.9%)
	Egypt	0	1(2.0%)	1 (1.0%)
C (1:41	Germany	1(2.0%)	0	1 (1.0%)
Country of birth	India	0	1(2.0%)	1 (1.0%)
	New Zealand	1(2.0%)	0	1 (1.0%)
	South Africa	0	1(2.0%)	1(1.0%)
	Zambia	1(2.0%)	0	1 (1.0%)
Identify with culture	No	45 (83%)	43 (80%)	88 (81%)
other than Australian	Yes	9 (17%)	11 (20%)	20 (19%)
T.1C A.1 1	No	51 (94%)	51 (94%)	102 (95%)
Identify as Aboriginal	Yes, Aboriginal	1(1.9%)	1 (1.9%)	2 (1.9%)
or Torres Strait	Yes, Torres Strait Islander	2(3.7%)	1 (1.9%)	3(2.8%)
Islander	Prefer not to answer	2(3.7%)	1 (1.9%)	3 (2.8%)
Dependent children	Mean $(SD)$	1 (1%)	1 (1)	1 (1%)
(aged under 15 years)	,	,	( )	,
, -	Parent	17 (31%)	20 (37%)	37 (34%)
	Partner	20 (37%)	14 (26%)	34 (31%)
Relationship to	Child	13 (24%)	11 (20%)	24 (22%)
care-recipient	Friend	2(3.7%)	5 (9.3%)	7 (6.5%)
•	Sibling	2(3.7%)	2(3.7%)	4(3.7%)
	Other family member	0	2(3.7%)	2 (1.9%)
	Anxiety	9 (17%)	7 (13%)	16 (15%)
a	Depression	3 (5.60%)	3 (5.60%)	6 (5.60%)
Care-recipient	Both	42 (78%)	44 (81%)	86 (80%)
		` /	` /	
symptoms	Neither	2(3.7%)	1(1.9%)	3(2.80%)

and upon completion of the survey, and participants in the Waitlist group received access to the program.

#### 2.5 Intervention

Minds Together was developed by Everymind, an Australian Institute specialising in preventing and reducing mental ill-health and suicide. The web-based program comprises four activity modules: The caring journey; Caring for yourself and others; What matters to you and how to talk about it; and Helpful strategies for everyday life. The modules aim to increase carers' mental health literacy (Jorm, 2012), develop skills to support their relationship with the care-recipient though low intensity cognitive behavioural therapy (Marrinan & Papworth, 2018), and build capability of their own well-being and coping skills. Minds Together uses a mixed-

media format, including short videos, infographics, and short podcasts to highlight some of the key information and feature examples from carers' lived experience. Participants read case studies, answered activities, and responded to worksheets and reflective questions. The modules were released in a staged approach, giving participants access to one module per week for the first four weeks and ongoing access for a further four weeks.

#### 3. Measures

Feasibility measures. Study adherence rates were monitored using REDCap and website metadata. Given the expected high attrition for automated internet interventions (Eysenbach, 2005), particularly for prevention programs in the community (e.g., 58.8% program adherence



and 30% post-survey completion; Ali et al., 2022), program adherence was defined as at least 50% of participants activating their program accounts. Similarly, a survey adherence goal of 50% of completed post-surveys was set. Study attrition rates referred to participants who did not meet respective thresholds.

#### 3.1 Acceptability Measures

Participants' acceptability of the *Minds Together* program was measured using program metadata and a satisfaction measure for the Intervention group. Researchers extracted website metadata at the end of the access period for the Intervention group to define program completion rates. Program completion was defined as participants who clicked on every page in at least two of the four activity modules. Due to the heterogeneity of online health interventions, definitions of program completion differ significantly in the literature (e.g., Alvarez-Jimenez et al., 2013; Cardi et al., 2020; Gandy et al., 2016). This study subscribed to a commonly cited threshold where participants must complete at least half the modules/sessions (Barnes et al., 2015; Hoyle et al., 2013; Proudfoot et al., 2012).

The satisfaction measure was a seven-item scale, developed specifically for this study. The scale included general questions on the program's relevance and usefulness and asked participants to rate perceived satisfaction of specific components, e.g., activities and handouts on a five-option scale  $(0=not\ at\ all,\ 1=a\ little\ bit,\ 2=neutral,\ 3=somewhat,\ 4=a\ lot)$ . Results were summarised to identify which program features were most and least accepted. Program satisfaction data was only available from participants who completed the post-survey.

Participants from the Intervention group were also invited to complete semi-structured telephone interviews about their experience using the program. Interviews aimed to explore participant acceptability of the *Minds Together* program to inform improvements for the main trial. Participants were asked about their satisfaction and challenges with specific program elements.

Researchers followed Braun and Clarke's (2006) six-step analysis process. Interviews were transcribed verbatim. After reading the transcripts multiple times, authors EF and ZT coded data separately using Nvivo (QSR International Pty Ltd, 2020). Thematic analysis was undertaken deductively and inductively. EF tabulated codes into positive, negative, and neutral appraisals of program aspects and rearranged these codes to form overall themes (see Table 2 from this table). However, researchers were also open to other feedback from participants to inform findings beyond the pre-defined questions (Thomas, 2016). ZT reviewed these themes and made suggestions and comments. The researchers then met to discuss differences until they reached consensus.

#### 3.2 Secondary Measures

Participants completed pre- and post-measures commonly found in carer research.

The Zarit Burden Interview (ZBI; Zarit et al., 1985) assessed carer burden. The ZBI is a 22-item self-report instrument designed for measuring carers' functional or behavioural impairments in a home care context (Zarit et al., 1985). Responses are rated on a five-point Likert scale (0=never, 1=rarely, 2=sometimes, 3=quite frequently, 4=nearly always). The 22-items were summed for a total score ranging between 0–88, with higher scores indicating greater burden. The scale measures carers' common areas of concern such as health, finances, social life, and interpersonal relations (Zarit et al., 1985) and has been used to measure the burden associated with supporting a person with a mental illness (Schene et al., 1994; Udoh et al., 2021). The ZBI has also shown high validity and reliability for use with carers (e.g., Boluarte-Carbajal et al., 2022; Seng et al., 2010).

The Coping Self-Efficacy Scale (CSES: Chesney et al., 2006) measured carers' capacity for coping. The CSES is 26-item scale measure of one's condence in performing coping behaviours when faced with adverse circumstances. Using an 11-point Likert scale (0-4=cannot do, 5=moderately can do, 6-10=certain can do) participants rate their confidence in their capacity to undertake tasks relevant to adaptive coping. The sum of participant scores range between 0–260, with higher scores indicative of higher optimism for self-efficacy (Chesney et al., 2006). The instrument includes three sub-scales: problem-focussed coping, emotional focussed coping, and social support, to assess self-efficacy in different behavioural domains. The measure allows for assessment of coping self-efficacy over time and use in intervention studies (e.g., Scult et al., 2015). The CSES has strong internal consistency, and has shown good reliability and validity (Chesney et al., 2006).

The Patient Health Questionnaire-9 (PHQ-9; Kroenke et al., 2001) measured carers' symptoms of depression. The 9-item scale determines participant's degree of depression through the severity of initial symptoms and monitors changes over time. Participant responses are rated on a four-point Likert scale (0=not at all, 1=several days, 2=more than half the days, 3=nearly every day), with a possible total score range between 0-27 (Kroenke et al., 2001). Higher scores are consistent with increased depressive severity. The measure is well-established, with acceptability evidence in a range of settings, populations, and countries (Gilbody et al., 2007) and is commonly used in carer-focussed intervention studies (McKechnie et al., 2014; Roddy et al., 2015).

The Generalised Anxiety Disorder Scale (GAD-7; Spitzer et al., 2006) is commonly used for assessing anxiety in the general population. Akin to the PHQ-9, the GAD-7 scores anxiety related items on a four-point Lik-



Table 2

Sample from Data Analysis Table

Theme: Program r	relatability		
Program feature	Positive appraisals	Negative appraisals	Neutral
	Interview 2:	Interview 6:	
	'I also like the stories about the carers. I	'The carer videos I didn't get a lot out of	
	kind of related to one of them. I can't re-	that because they are kind the same thing	
	member the younger one that was careering	we do in the carer group and it seemed like	
	for her grandmother. I related to her a lot.'	those people were saying the same as I was	
		saying. They were echoing the same feel-	
Case studies and	Interview 3:	ings and thoughtsSo, I didn't find that	
multimedia	'I'm starting to appreciate that it is just	very useful.'	N/A
munimedia	not me because you kind of start to think		
	it is just me and Im just whatever but it		
	is not just me and there are lots of people		
	dealing with all of this stuff. So, thats good		
	too and hearing other people's perspectives		
	and how they deal with things is good, is		
	really good.		

ert scale from 0 (not at all) to 3 (nearly every day), albeit with a possible sum score range of 0–21. The measure has good validity and reliability evidence (Löwe et al., 2008) and frequently features in studies on carer focussed supports (McKechnie et al., 2014; Reblin et al., 2021).

Secondary measures, were subject to an intention-totreat analyses of treatment effect over time, were performed with linear mixed modelling. Mixed models included fixed effects for timepoint (pre, post), allocation (Intervention, Waitlist), an interaction term for timepoint and allocation and a random effect for participant to account for correlations within each participant over time (repeated measures). Assumptions for linear mixed modelling were checked and acceptable. Model results are presented as the change over time within each allocation (least squares mean [LSM]) differences with 95% confidence interval (CI), the simple effect for treatment versus control at the post timepoint, the overall (interaction) p-value comparing the difference in change over time between the allocations (treatment difference), and the repeated measures correlation coefficient (intra-class correlation coefficient [ICC], from null model). Statistical analyses were programmed using SAS v9.4 (SAS Institute Inc, 2013). A priori, p < .05 (two-tailed) was used to indicate statistical significance.

# 4. Results

# 4.1 Feasibility

Thirty-two of the 54 participants in the Intervention group activated their Minds Together program account (account activation = 59%). The rate of completed post-surveys was 53% across groups, although completion rates for the Waitlist group were higher (69%) than the Intervention group (37%; see Table 3).

Table 3

Assessment	Completed
	surveys
Pre-program survey	108
Post-program Intervention group	20/54
Post-program Waitlist group	37/54
	Total = 53%

# 4.2 Acceptability

Fifteen of the 32 participants who activated their program accounts met the completion threshold (completion rate = 47%). Responses to the satisfaction measure indicated that 64–88% of participants were "somewhat" or "a lot" satisfied with the program (see Table 4).

Ten participants in the Intervention group completed post-program interviews (9 female and 1 male; mean age of 52 years, age range=24–68 years). Eight carers supported someone with symptoms of depression and anxiety and two supported someone with anxiety symptoms only. The average length of interviews was 25 minutes (range = 17–38).

Interview analysis identified three themes relating to participant feedback on the *Minds Together* program: program relatability, accessibility, and impact.

Program relatability included reflections about the relevance of case studies in the *Minds Together* program and multimedia content. Most carers (80%) reported that the case studies and videos of carers were relatable, as evidenced by comments such as, "what emotionally shifted me... was the videos... I just related to them as real people" (female, aged 61, supporting her child with depression and anxiety). However, one participant who had been caring for many years said, "I'm looking for more



Table 4

Program Satisfaction Responses (Intervention group only; n = 17/54)

Not at all	Not at all	A little bit	Neutral	$\mathbf{Somewhat}$	A lot
Were Satisfied	(%0) 0	2 (12%)	2(12%)	7 (41%)	(35%)
Maintained interest	2(12%)	1(6%)	3(18%)	4 (23%)	7 (41%)
Found content relevant	0 (0%)	2(12%)	3(18%)	5 (29%)	7 (41%)
Found videos and stories of carers useful	1(6%)	0 (0%)	1(6%)	8 (47%)	7 (41%)
Found activities, handouts, and module	0 (0%)	2(12%)	2(12%)	9(53%)	4(23%)
summaries useful					

Table 5

	$\operatorname{Program}$
$y \ Outcomes$	
Secondary	

		Progr	gram		Waitlist	list			
Questionnaire Total Score; Pre	$\operatorname{Pre}$	Post	Difference* (95%CI)	$\operatorname{Pre}$	Post	Difference* (95%CI) Difference* at Post Overall	Difference* at Post	Overall	ICC
$\operatorname{Mean}(SD)$	(n = 54)	(n=54) $(n=20)$		(n = 38)	(n = 38)		(95%CI)	p-value#	
Caregiver Burden	51 (15) 42 (16)	42(16)	-6.45 (-11.60, -1.30) 45 (15)	45 (15)	45 (16)	$-3.67\ (-7.75,0.41)$	-1.19 (-9.9, 7.5)	.399	69.
Scale (ZBI)									
Coping Self-Efficacy	122(35)	152 (41)	19.69 (3.40, 35.99)	146 (46)	138 (51)	$-7.03\;(-19.53,5.47) 16.14\;(-9.9,42.2)$	16.14 (-9.9, 42.2)	.012	.65
Scale (CSES)									
Patient Health Question-	10(6)	(2)	-0.88 (-3.12, 1.35)	8 (5)	8 (5)	$-0.51 \ (-2.24, 1.21)$	-1.64 (-4.6, 1.3)	.793	.62
naire (PHQ-9)									
Generalised Anxiety Disor-	8 (5)	5 (4)	-1.71 (-3.69, 0.26)	7 (5)	(2) 9	$-0.15 \ (-1.64, 1.33)$	-0.73 (-3.4, 1.9)	.210	09.
der Scale GAD-7									

Note. \*LS-Mean difference from mixed modelling #p-value for interaction.



of an expert opinion and knowledge, as opposed to the peer" (female, aged 64, supporting her child with depression and anxiety).

The theme of accessibility summarised participants' comments on the program's content and structure. Almost all (80%) of carers commented positively about the content relevance and structure, such as "the language was so accessible" (Female, 61, supporting her child with depression and anxiety), and "the whole program was structured well" (Male, 68, supporting his partner with depression and anxiety). However, some carers experienced some technical issues completing activities and downloading resources.

Under the theme of impact, 80% of participants commented specifically on the program's positive effects on their lives. Carers reflected on how the program reinforced the importance of their caring role and strengthened their motivation for self-care. Comments from carers included: "answering questions about being a carer has made me actively think about the importance of my role and the need for self-care" (Female, aged 31, supporting a friend with depression and anxiety), and "It's not being selfish (practicing self-care), I suppose that's part of the thing that I picked up out of it, it's not being selfish" (Female, aged 57, supporting a partner with depression and anxiety). No participants reported on adverse program effects.

#### 4.3 Secondary Outcomes

Secondary measures indicated trends in program efficacy.

The Intervention group reported a significant reduction in ZBI scores of the caregiver burden subscale from pre to post (49.8 vs 43.3, p = .015). The Waitlist group had a (non-significant) reduction in score, and the overall treatment effect was not significant (p = .399).

A significant treatment effect was observed for CSES total score (p=.012), with the Intervention group reporting a notable improvement in coping self-efficacy from pre to post intervention (LSM score 134.8 vs 154.5, p=.019). Over the same period, the Waitlist group had stable CSEC total scores post-intervention (138.3 vs 145.4, p=.264). At post-intervention, no significant difference in CSES total scores between Program and Waitlist groups was observed (LSM difference 16.14, p=.219, see Table 5).

No significant effects were observed for the remaining participant reported outcomes (see Table 5). Importantly, carers' symptoms of depression (PHQ-9) and anxiety (GAD-7) did not increase over the study period, indicating no harms or safety concerns. For all models, moderate-high ICC was observed, indicating that within-person correlation was moderate-high over time.

## 5. Discussion

There is increasing evidence for the benefits of supporting carers through online health interventions (e.g., time efficient, low cost and wide reach; Dam et al., 2017; Heynsbergh et al., 2018; Scott & Beatty, 2013) and the value of participant feedback in developing online support interventions that meet carers' needs (Sin et al., 2019; Stjernswärd & Hansson, 2017). This is the first study to explore the utility of an online program for carers of a person with depressive or anxiety symptoms. Findings demonstrated that the study design is plausible for a main trial and participant feedback indicated opportunities for program improvements for this population.

The study design met feasibility thresholds. Program activation and survey completion rates were low for this study (53% and 59%) compared to adherence rates seen in face-to-face intervention studies involving carers (e.g., 100% program adherence and 95% follow-up survey completion rate; Perlick et al., 2018). However, results were within the expected range for similar online health intervention studies (e.g., 20–60%; Eysenbach, 2005; Geraghty et al., 2013; McKechnie et al., 2014; Perlick et al., 2018; Stjernswärd & Östman, 2011). These results indicate that it is feasible to undertake this study design at scale.

Program completion rates combined with participant feedback in the surveys and interviews indicate participant acceptability of the Minds Together program. Although program completion rates were lower than expected for this study (47%), they are comparable to similar online health interventions (Donkin et al., 2011; Melville et al., 2010). The study's inclusion of qualitative interviews to examine the acceptability of the program was a key strength in this paper. Participants were most satisfied with the program's inclusion of lived experience stories and videos. In the literature, other mental health carers have positively appraised interventions that embed lived experience perspectives using face-to-face peer support (Foster, 2011; Visa & Harvey, 2019). The current study contributes new acceptability evidence for the value of carer-focussed interventions embedding lived experience via an online video format. The voice of lived experience is generally underrepresented in feasibility and acceptability studies for carers, despite the significance of this evidence for intervention acceptability (Wayland et al., 2021) and more research is needed in this area.

The study also provides preliminary evidence for efficacy of the *Minds Together* program. A trend was observed in the *Minds Together* program's capacity to increase coping self-efficacy (16 units higher than Waitlist group at post-intervention) and reduce carer burden



(1.2 units lower than Waitlist group at post-intervention). These results need further evaluation in a subsequent full-scale RCT. Other studies have shown the capacity of carer focussed interventions to improve carers' belief in their ability to respond to care-related stressors (Tang & Chan, 2016) and reduce their experience of care-related burden (Williams et al., 2019). However, the current study contributes novel efficacy evidence for a program targeting carers of a person with anxiety, or comorbid or undiagnosed depressive and anxiety symptoms. Specifically, eighty percent of participants in the current sample were supporting someone with comorbid depressive and anxiety symptoms and 6.5% supported someone with undiagnosed symptoms or were unaware if a diagnosis was present.

#### 5.1 Limitations

In considering the results of this study, some limitations should be acknowledged. Firstly, demographic characteristics indicate that the sample was not representative of the broader population of carers of a person with depressive or anxiety symptoms. Despite evidence of the capacity of online recruitment methods to engage hardto-reach populations (Australian Bureau of Statistics, 2018; Batterham, 2014), 78% of study participants were from New South Wales (a state in Australia), mostly women (89%), aged 45–55 years. These results are inconsistent with national demographic data, which indicates that women comprise 54% of Australia's mental health carers (Australian Bureau of Statistics, 2018). Furthermore, there is evidence that women and people aged between 30 and 65 with internet experience are more likely to seek help (Ybarra & Suman, 2006), which is also true for this sample. A follow-on study will need to employ more diverse recruitment methods to add generalisability of findings (e.g., more gender and age diversity).

Secondly, the study and program design may have influenced study results. For example, Waitlist participants were required to complete the post survey before gaining access to the program. There is other evidence that a Waitlist control design can build participants' eagerness to access the intervention, which might account for the higher survey completion rates for this group (Jensen et al., 2016). Contrarily, some participants reported missed emails and technical issues on the platform (e.g., loading links and pages, and saving responses to activities), which could have negatively impacted their engagement (Wagenaar et al., 2017). A subsequent study should employ an active comparator arm and address platform technical issues to address the impact of these variables on study results.

Finally, participant attrition may have introduced positive bias toward acceptability results because respondents to the satisfaction measure and interviews only represent a portion of the participants overall. Specifically, 53% of participants who activated their program

accounts also responded to the satisfaction measure and interview participants comprised just 31% of those who activated their program account. It is possible that carers who completed the measures experienced more satisfaction than those who dropped out of the study, which may introduce positive bias toward participant feedback. A future study should address this limitation by focusing on improving study retention, such as through phoning participants throughout the study period to check if they need assistance.

#### 5.2 Implications for Future Research

A carer's acceptance of an intervention is influenced by their care experience and knowledge. Carers' journeys vary significantly, and programs need to meet a wide range of needs (Visa & Harvey, 2019). Engaging people in the community to use community-targeted prevention programs is an ongoing challenge. More research should include lived experience perspectives of at-risk community members to help tailor intervention content, design, and dose to their specific needs.

Some intervention approaches have supported carers' variable needs through online and face-to-face peer support (Carter et al., 2020; Flynn et al., 2020; Hammarberg et al., 2014). In this context, carers can seek advice and guidance from carers who have experienced similar challenges or share their experiences with other services and strategies. Future research should explore whether a peer support component can strengthen community-focussed programs to respond to carers' diverse and changing needs.

Exploring the cost-effectiveness of part of a full-scale RCT is also recommended for future research. There is a growing argument in the literature that identifying the costs associated with support interventions, such as the *Minds Together* program can reduce costs and improve quality and implementation opportunities (Aarons et al., 2009; Cidav et al., 2020). Furthermore, despite the common assumption that online health interventions are more cost effective than face-to-face alternatives, there is little evidence to support this (Arjadi et al., 2015; Kolasa & Kozinski, 2020).

# 6. Conclusion

Despite increasing evidence for the potential of population-targeted interventions to promote health and well-being, evidence is limited for the capacity of these interventions to support informal mental health carers. This study has contributed to a current gap in evidence for interventions targeting community-dwelling carers of a person with depressive and anxiety symptomology specifically. The current study established the feasibility and acceptability of the *Minds Together* and that it is plausible to implement the program in a full-scale RCT. The study also indicated research opportunities within the area of population-targeted mental health



promotion, such as a need for more interventions that embed lived experience perspectives, e.g., through online social support. The cost-utility of such programs is missing from the current literature and will be an essential component to ensure engagement with policymakers and funders.

# **Trial Registration**

Australian New Zealand Clinical Trials Registry (ANZ-CTR), ACTRN12621001256864. Registered September 16, 2021 [retrospectively registered].

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# References

- Aarons, G. A., Wells, R. S., Zagursky, K., Fettes, D. L., & Palinkas, L. A. (2009). Implementing evidencebased practice in community mental health agencies: A multiple stakeholder analysis. American Journal of Public Health, 99(11). https://doi. org/10.2105/AJPH.2009.161711
- Ali, K., Fassnacht, D. B., Farrer, L. M., Rieger, E., Moessner, M., Bauer, S., & Griffiths, K. M. (2022). Recruitment, adherence and attrition challenges in internet-based indicated prevention programs for eating disorders: lessons learned from a andomized controlled trial of ProYouth OZ. *Journal of Eating Disorders*, 10(1), 1–17. https://doi.org/10.1186/S40337-021-00520-7/FIGURES/2
- Alvarez-Jimenez, M., Bendall, S., Lederman, R., Wadley, G., Chinnery, G., Vargas, S., Larkin, M., Killackey, E., McGorry, P. D., & Gleeson, J. F. (2013). On the HORYZON: Moderated online social therapy for long-term recovery in first episode psychosis. *Schizophrenia Research*, 143(1). https://doi.org/10.1016/j.schres.2012.10.009
- Arjadi, R., Nauta, M. H., Chowdhary, N., & Bockting, C. L. H. (2015). A systematic review of online interventions for mental health in low and middle income countries: A neglected field. *Global Mental Health*, 2. https://doi.org/10.1017/gmh. 2015.10
- Australian Bureau of Statistics. (2007). National survey of mental health and wellbeing: Summary of results. https://www.abs.gov.au/statistics/health/mental-health/national-study-mental-health-and-wellbeing/2007
- Australian Bureau Statistics. (2018). Disability, Ageing and Carers Summary of Findings. Australian Bureau of Statistics. https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-

- carers-australia-summary-findings/latest-release #carers
- Australian Bureau Statistics. (2020). National Survey of Mental Health and Wellbeing: Summary of Results, 2007. Australian Bureau of Statistics. https://www.abs.gov.au/statistics/health/ment al-health/national-survey-mental-health-and-we llbeing-summary-results/latest-release
- Barnes, C. W., Hadzi-Pavlovic, D., Wilhelm, K., & Mitchell, P. B. (2015). A web-based preventive intervention program for bipolar disorder: Outcome of a 12-months randomized controlled trial. *Journal of Affective Disorders*, 174. https://doi.org/10.1016/j.jad.2014.11.038
- Batterham, P. J. (2014). Recruitment of mental health survey participants using Internet advertising: Content, characteristics and cost effectiveness. International Journal of Methods in Psychiatric Research, 23(2). https://doi.org/10.1002/mpr. 1421
- Blake-Holmes, K. (2019). Young adult carers: Making choices and managing relationships with a parent with a mental illness. . $Advances\ in\ Menthal\ Health,\ 18(3),\ 230-240.\ https://doi.org/10.1080/18387357.2019.1636691$
- Boluarte-Carbajal, A., Paredes-Angeles, R., & Tafur-Mendoza, A. A. (2022). Psychometric Properties of the Zarit Burden Interview in Informal Caregivers of Persons With Intellectual Disabilities. Frontiers in Psychology, 13, 521. https://doi.org/10.3389/FPSYG.2022.792805/BIBTEX
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101. https://doi.org/10.1191/1478088706QP063OA
- Cardi, V., Albano, G., Ambwani, S., Cao, L., Crosby, R. D., MacDonald, P., Schmidt, U., & Treasure, J. (2020). A randomized clinical trial to evaluate the acceptability and efficacy of an early phase, online, guided augmentation of outpatient care for adults with anorexia nervosa. Psychological Medicine, 50(15). https://doi.org/10.1017/S0033291719002824
- Carter, G., Monaghan, C., & Santin, O. (2020). What is known from the existing literature about peer support interventions for carers of individuals living with dementia: A scoping review. *Health and Social Care in the Community*, 28(4), 1134–1151. https://doi.org/10.1111/hsc.12944
- Chenoweth, L., Stein-Parbury, J., White, D., McNeill, G., Jeon, Y. H., & Zaratan, B. (2016). Coaching in self-efficacy improves care responses, health and well-being in dementia carers: A pre/post-test/follow-up study. *BMC Health Services Re-*



- search, 16(1), 1–16. https://doi.org/10.1186/ S12913-016-1410-X/TABLES/6
- Chesney, M. A., Neilands, T. B., Chambers, D. B., Taylor, J. M., & Folkman, S. (2006). A validity and reliability study of the coping self-efficacy scale. British Journal of Health Psychology, 11(3). https://doi.org/10.1348/135910705X53155
- Choi, J. W., Hong, W., Abela, J. R. Z., & Cohen, J. R. (2021). Comorbid Depression and Anxiety Symptoms in Chinese Adolescents: Testing the Explanatory Power of a Diathesis-Anxiety Model. Research on Child and Adolescent Psychopathology, 49(4), 503–517. https://doi.org/10.1007/s10802-020-00730-8
- Cidav, Z., Mandell, D., Pyne, J., Beidas, R., Curran, G., & Marcus, S. (2020). A pragmatic method for costing implementation strategies using timedriven activity-based costing. *Implementation* Science, 15(1), 28. https://doi.org/10.1186/ s13012-020-00993-1
- Cormac, I., & Tihanyi, P. (2006). Meeting the mental and physical healthcare needs of carers. Advances in Psychiatric Treatment, 12(3), 162–172. https://doi.org/10.1192/APT.12.3.162
- Craig, P., Dieppe, P., Macintyre, S., Mitchie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*, 337(7676), 979–983. https://doi.org/10.1136/BMJ.A1655
- Dam, A. E. H., Boxtel, M. P. J., Rozendaal, N., Verhey, F. R. J., & Vugt, M. E. (2017). Development and feasibility of Inlife: A pilot study of an online social support intervention for informal caregivers of people with dementia. *PloS ONE*, 12(9). https://doi.org/10.1371/journal.pone.0183386
- Diminic, S., Hielscher, E., Lee, Y., Harris, M., Schess, J., Kealton, J., & Whiteford, H. (2016). The economic value of informal mental health caring in Australia. The University of Queensland. https://www.mindaustralia.org.au/sites/default/files/Mind\_value\_of\_informal\_caring\_full\_report.pdf
- Donkin, L., Christensen, H., Naismith, S. L., Neal, B., Hickie, I. B., & Glozier, N. (2011). A systematic review of the impact of adherence on the effectiveness of e-therapies. *Journal of Medical Internet Research*, 13(3). https://doi.org/10.2196/jmir.1772
- Evans-Lacko, S., Aguilar-Gaxiola, S., Al-Hamzawi, A., Alonso, J., Benjet, C., Bruffaerts, R., Chiu, W. T., Florescu, S., Girolamo, G., Gureje, O., Haro, J. M., He, Y., Hu, C., Karam, E. G., Kawakami, N., Lee, S., Lund, C., Kovess-Masfety, V., Levinson, D. & Wojtyniak, B. (2018). Socio-economic variations in the mental health treatment gap

- for people with anxiety, mood, and substance use disorders: Results from the WHO World Mental Health (WMH) surveys. *Psychological Medicine*, 48(9). https://doi.org/10.1017/S0033291717003336
- Eysenbach, G. (2005). The Law of Attrition. J Med Internet Res, 7(1), 11. https://doi.org/10.2196/ JMIR.7.1.E11
- Ezpeleta, L., Domènech, J. M., & Angold, A. (2006). A comparison of pure and comorbid CD/ODD and depression. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 47(7). https://doi.org/10.1111/j.1469-7610.2005.01558.x
- Fitzgeraldson, E., Fitzpatrick, S., Kay-Lambkin, F., Harding, T., McNaughton, K., Triandafilidis, Z., Heath, J., Lyford, B., & Charnley, J. (2022). Supports and Interventions for Carers of a Person with Depressive or Anxiety symptoms: A systematic Review. Europe's Journal of Psychology. Accepted manuscript. https://www.psycharchives.org/en/item/9f876465-d195-42c0-824b-7b6d19040acb
- Flynn, S., Hastings, R. P., Burke, C., Howes, S., Lunsky, Y., Weiss, J. A., & Bailey, T. (2020). Online Mindfulness Stress Intervention for Family Carers of Children and Adults with Intellectual Disabilities: Feasibility Randomized Controlled Trial. *Mindfulness*, 11(9), 2161–2175. https://doi.org/10.1007/s12671-020-01436-0
- Foster, K. (2011). "I wanted to learn how to heal my heart": Family carer experiences of receiving an emotional support service in the Well Ways programme. International Journal of Mental Health Nursing, 20(1), 56–62. https://doi.org/10.1111/j.1447-0349.2010.00710.x
- Gandy, M., Karin, E., Fogliati, V. J., McDonald, S., Titov, N., & Dear, B. F. (2016). A feasibility trial of an internet-delivered and transdiagnostic cognitive behavioral therapy treatment program for anxiety, depression, and disability among adults with epilepsy. *Epilepsia*, 57(11), 1887–1896. https://doi.org/10.1111/epi.13569
- Geraghty, A. W. A., Torres, L. D., Leykin, Y., Pérez-Stable, E. J., & Muñoz, R. F. (2013). Understanding attrition from international internet health interventions: A step towards global eHealth. *Health Promotion International*, 28(3), 442–452. https://doi.org/10.1093/heapro/das029
- Ghebreyesus, T. (2019). The WHO Special Initiative for Mental Health (2019–2023): Universal Health Coverage for Mental Health. World Health Organization. http://www.who.int/iris/handle/10 665/89966
- Gilbody, S., Richards, D., Brealey, S., & Hewitt, C. (2007). Screening for depression in medical settings with the Patient Health Questionnaire (PHQ): A diagnostic meta-analysis. *Journal of General*



- Internal Medicine, 22(11), 1596–1602. https://doi.org/10.1007/s11606-007-0333-y
- Gilliam, C. M., & Steffen, A. M. (2006). The relationship between caregiving self-efficacy and depressive symptoms in dementia family caregivers. *Aging and Mental Health*, 10(2), 79–86. https://doi.org/10.1080/13607860500310658
- Griffiths, K. M., Crisp, D. A., Barney, L., & Reid, R. (2011). Seeking help for depression from family and friends: A qualitative analysis of perceived advantages and disadvantages. *BMC Psychiatry*, 11(Article 196). https://doi.org/10.1186/1471-244X-11-196
- Guillamón, N., Nieto, R., Pousada, M., Redolar, D., Muñoz, E., Hernández, E., Boixadós, M., & Gómez-Zúñiga, B. (2013). Quality of life and mental health among parents of children with cerebral palsy: The influence of self-efficacy and coping strategies. Journal of Clinical Nursing, 22(11–12), 1579–1590. https://doi.org/10.1111/JOCN. 12124/FORMAT/PDF
- Hammarberg, K., Sartore, G., Cann, W., & Fisher, J. R. W. (2014). Barriers and promoters of participation in facilitated peer support groups for carers of children with special needs. Scandinavian Journal of Caring Sciences, 28(4), 775–783. https://doi.org/10.1111/scs.12110
- Hayes, L., Hawthorne, G., Farhall, J., O'Hanlon, B., & Harvey, C. (2015). Quality of Life and Social Isolation Among Caregivers of Adults with Schizophrenia: Policy and Outcomes. Community Mental Health Journal, 51(5), 591–597. https://doi.org/10.1007/s10597-015-9848-6
- Heynsbergh, N., Heckel, L., Botti, M., & Livingston, P. M. (2018). Feasibility, useability and acceptability of technology-based interventions for informal cancer carers: A systematic review. *BMC Cancer*, 18(1), 244. https://doi.org/10.1186/s12885-018-4160-9
- Hoyle, D., Slater, J., Williams, C., Schmidt, U., & Wade, T. D. (2013). Evaluation of a web-based skills intervention for carers of people with anorexia nervosa: A randomized controlled trial. The International Journal of Eating Disorders, 46(6), 634–638. https://doi.org/10.1002/EAT.22144
- Hubbard, A. A., McEvoy, P. M., Smith, L., & Kane, R. T. (2016). Brief group psychoeducation for caregivers of individuals with bipolar disorder: A randomized controlled trial. *Journal of Affec*tive Disorders, 200, 31–36. https://doi.org/10. 1016/j.jad.2016.04.013
- Jensen, K. B., Morthorst, B. R., Vendsborg, P. B., Hjorthøj, C., & Nordentoft, M. (2016). Effectiveness of Mental Health First Aid training in Denmark: a randomized trial in waitlist design. Social Psychiatry and Psychiatric Epidemiology, 51(4), 597–

- 606. https://doi.org/10.1007/s00127-016-1176-9
- Jeong, J. S., Kim, Y., & Chon, M. G. (2018). Who Is Caring for the Caregiver? The Role of Cybercoping for Dementia Caregivers. *Health Communication*, 33(1), 5–13. https://doi.org/10.1080/10410236.2016.1242030
- Jorm, A. F. (2012). Mental health literacy; empowering the community to take action for better mental health. *American Psychologist*, 67(3), 231–243. https://doi.org/10.1037/a0025957
- Julious, S. A. (2005). Sample size of 12 per group rule of thumb for a pilot study. *Pharmaceutical Statistics*, 4(4), 287–291. https://doi.org/10.1002/pst.185
- Kelly, C. M., Jorm, A. F., & Wright, A. (2007). Improving mental health literacy as a strategy to facilitate early intervention for mental disorders. *Medical Journal of Australia*, 187(S7), 26–30. https://doi.org/10.5694/J.1326-5377.2007. TB01332.X
- Kim, Y., Carver, C. S., & Cannady, R. S. (2015). Caregiving Motivation Predicts Long-Term Spirituality and Quality of Life of the Caregivers. Annals of Behavioral Medicine, 49(4), 500–509. https://doi.org/10.1007/s12160-014-9674-z
- Kolasa, K., & Kozinski, G. (2020). How to value digital health interventions? A systematic literature review. International Journal of Environmental Research and Public Health, 17(6), Article 2119. https://doi.org/10.3390/ijerph17062119
- Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*, 16(9), 606–613. https://doi.org/10.1046/J.1525-1497.2001.016009606.X
- Kumar, K., & Gupta, M. (2014). Clinical and socio-demographic determinants of psychological health and burden in family caregivers of patients with unipolar depression. *Asian Journal of Psychiatry*, 9, 51–56. https://doi.org/10.1016/j.ajp.2014.01.002
- Lavis, A., Lester, H., Everard, L., Freemantle, N., Amos, T., Fowler, D., Hodgekins, J., Jones, P., Marshall, M., Sharma, V., Larsen, J., McCrone, P., Singh, S., Smith, J., & Birchwood, M. (2015).
  Layers of listening: Qualitative analysis of the impact of early intervention services for first-episode psychosis on carers' experiences. The British Journal of Psychiatry: The Journal of Mental Science, 207(2), 135–142. https://doi.org/10.1192/BJP.BP.114.146415
- Lee, G. B., Woo, H., Lee, S. Y., Cheon, S. M., & Kim, J. W. (2019). The burden of care and the understanding of disease in Parkinson's disease. *PloS*



- ONE, 14(5). https://doi.org/10.1371/journal.pone.0217581
- Linderholm, M., & Friedrichsen, M. (2010). A desire to be seen: Family caregivers' experiences of their caring role in palliative home care. Cancer Nursing, 33(1), 28–36. https://doi.org/10.1097/NCC.0B013E3181AF4F61
- Liu, Z., Heffernan, C., & Tan, J. (2020). Caregiver burden: A concept analysis. *International Journal of Nursing Sciences*, 7(4), 438–445. https://doi.org/10.1016/j.ijnss.2020.07.012
- Löwe, B., Decker, O., Müller, S., Brähler, E., Schellberg, D., Herzog, W., & Herzberg, P. Y. (2008). Validation and standardization of the generalized anxiety disorder screener (GAD-7) in the general population. *Medical Care*, 46(3), 266–274. https://doi.org/10.1097/MLR.0b013e318160d093
- Marrinan, T., & Papworth, M. (2018). Low Intensity Cognitive Behaviour Therapy. SAGE Publications
- McGuffog, R., Fitzgeraldson, E., Lyford, B., Triandafilidis, Z., Fitzpatrick, S., & Hazel, G. (2021). Australian family day care educators' experiences of supporting children's mental health. and their own mental health and wellbeing:Australasian Journal of Early Childhood, 47(2), 107–120. https://doi.org/10.1177/18369391211063663
- McKechnie, V., Barker, C., & Stott, J. (2014). The effectiveness of an internet support forum for carers of people with dementia: A pre-post cohort study. Journal of Medical Internet Research, 16(2). https://doi.org/10.2196/jmir.3166. https://doi.org/10.2196/jmir.3166
- Melville, K. M., Casey, L. M., & Kavanagh, D. J. (2010). Dropout from internet-based treatment for psychological disorders. *British Journal of Clinical Psychology*, 49(4), 455–471. https://doi.org/10.1348/014466509X472138
- Metcalfe, A., Jones, B., Mayer, J., Gage, H., Oyebode,
  J., Boucault, S., Aloui, S., Schwertel, U., Böhm,
  M., Montcel, S., Lebbah, S., Mendonça, A., Vugt,
  M., Graff, C., Jansen, S., Hergueta, T., Dubois,
  B., & Kurz, A. (2019). Online information and support for carers of people with young-onset dementia: A multi-site randomised controlled pilot study. *International Journal of Geriatric Psychiatry*, 34(10), 1455–1464. https://doi.org/10.1002/GPS.5154
- Mishra, D. K., & Shakya, U. (2021). Assessment of Anxiety and Depression among Caregivers of Mentally Ill Patients Attending Mental Hospital, Lalitpur, Nepal. *Journal of Nepal Health Research Council*, 18(4), 702–708. https://doi.org/10.33314/jnhrc.v18i4.3006
- O'Neil, K., Podell, J. L., Benjamin, C. L., & Kendall, P. C. (2010). Comorbid depressive disorders in

- anxiety-disordered youth: Demographic, clinical, and family characteristics. *Child Psychiatry and Human Development*, 41(3), 330–341. https://doi.org/10.1007/s10578-009-0170-9
- Perlick, D. A., Jackson, C., Grier, S., Huntington, B., Aronson, A., Luo, X., & Miklowitz, D. J. (2018). Randomized trial comparing caregiver-only family-focused treatment to standard health education on the 6-month outcome of bipolar disorder. Bipolar Disorders, 20(7), 622–633. https://doi.org/10.1111/bdi.12621
- Petriwskyj, A., Franz, J., & Adkins, B. (2016). Parents, services and system: An exploration of power dynamics in future planning among parent carers for people with disability. *Disability and Society*, 31(8), 1081–1097. https://doi.org/10.1080/09687599.2016.1234367
- Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological and physical health: a meta-analysis.  $Psychology\ and\ Aging,\ 18(2),\ 250–267.$  https://doi.org/10. 1037/0882-7974.18.2.250
- Priestley, J., & McPherson, S. (2016). Experiences of adults providing care to a partner or relative with depression: A meta-ethnographic synthesis. *Journal of Affective Disorders*, 192, 41–49. https://doi.org/10.1016/j.jad.2015.12.011
- Proudfoot, J., Parker, G., Manicavasagar, V., Hadzi-Pavlovic, D., Whitton, A., Nicholas, J., Smith, M., & Burckhardt, R. (2012). Effects of adjunctive peer support on perceptions of illness control and understanding in an online psychoeducation program for bipolar disorder: A andomized controlled trial. *Journal of Affective Disorders*, 142(1-3), 98–105. https://doi.org/10.1016/j.jad.2012.04.007
- QSR International Pty Ltd. (2020). Nvivo [Computer software]. QSR International Pty Ltd. https://www.qsrinternational.com/nvivo-qualit ative-data-analysis-software/home
- Radfar, M., Ahmadi, F., & Fallahi Khoshknab, M. (2014). Turbulent life: The experiences of the family members of patients suffering from depression. Journal of Psychiatric and Mental Health Nursing, 21(3), 249–256. https://doi.org/10.1111/jpm.12077
- Reblin, M., Ketcher, D., McCormick, R., Barrios-Monroy, V., Sutton, S. K., Zebrack, B., Wells, K. J., Sahebjam, S., Forsyth, P., & Byrne, M. M. (2021). A randomized wait-list controlled trial of a social support intervention for caregivers of patients with primary malignant brain tumor. BMC Health Services Research, 21(1). https://doi.org/10. 1186/s12913-021-06372-w
- Roddy, S., Onwumere, J., & Kuipers, E. (2015). A pilot investigation of a brief, needs-led caregiver fo-



- cused intervention in psychosis. Journal of Family Therapy, 37(4), 529-545. https://doi.org/10.1111/1467-6427.12054
- Sadath, A., Muralidhar, D., Varambally, S., Gangadhar, B., & Jose, J. P. (2017). Do stress and support matter for caring? the role of perceived stress and social support on expressed emotion of carers of persons with first episode psychosis. *Asian Journal of Psychiatry*, 25, 163–168. https://doi.org/10.1016/J.AJP.2016.10.023
- SAS Institute Inc. (2013). SAS/ACCESS 9.4 Interface to ADABAS: Reference. SAS Institute Inc. https://support.sas.com/software/94/
- Schene, A. H., Tessler, R. C., & Gamache, G. M. (1994).
  Instruments measuring family or caregiver burden in severe mental illness. Social Psychiatry and Psychiatric Epidemiology, 29(5), 228–240.
  https://doi.org/10.1007/BF00796381
- Scott, K., & Beatty, L. (2013). Feasibility study of a self-guided cognitive behaviour therapy Internet intervention for cancer carers. *Australian Journal of Primary Health*, 19(4), 270–274. https://doi.org/10.1071/PY13025
- Scult, M., Haime, V., Jacquart, J., Takahashi, J., Moscowitz, B., Webster, A., Denninger, J. W., & Mehta, D. H. (2015). A healthy aging program for older adults: Effects on self-efficacy and morale. Advances in mind-body medicine, 29(1), 26–33. https://pubmed.ncbi.nlm.nih.gov/25607120/
- Seng, B. K., Luo, N., Lim, J., & Ng, W. Y. (2010). Validity and Reliability of the Zarit Burden Interview in Assessing Caregiver Burden. *Annals of the Academy of Medicine, Singapore*, 39(10), 758–763. https://pubmed.ncbi.nlm.nih.gov/21063635/
- Sin, J., Henderson, C., Woodham, L. A., Hernández, A. S., & Gillard, S. (2019). A multicomponent ehealth intervention for family carers for people affected by psychosis: A coproduced design and build study. *Journal of Medical Internet Research*, 21(8), 14374. https://doi.org/10.2196/14374
- Spitzer, R. L., Kroenke, K., Williams, J. B. W., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of Internal Medicine*, 166(10), 1092–1097. https://doi.org/10.1001/ARCHINTE.166.10.1092
- Stjernswärd, S., & Hansson, L. (2017). Outcome of a web-based mindfulness intervention for families living with mental illnessA feasibility study. *Informatics for Health and Social Care*, 42(1), 97–108. https://doi.org/10.1080/17538157.2016.1177533
- Stjernswärd, S., & Östman, M. (2011). Illuminating user experience of a website for the relatives of persons with depression. *International Journal of*

- Social Psychiatry, 57(4), 375-386. https://doi.org/10.1177/0020764009358388
- Tang, W. K., & Chan, C. Y. J. (2016). Effects of psychosocial interventions on self-efficacy of dementia caregivers: A literature review. *International Journal of Geriatric Psychiatry*, 31 (5), 475–493. https://doi.org/10.1002/gps.4352
- Teare, M. D., Dimairo, M., Shephard, N., Hayman, A., Whitehead, A., & Walters, S. J. (2014). Sample size requirements to estimate key design parameters from external pilot andomized controlled trials: A simulation study. *Trials*, 15(1), 264. https://doi.org/10.1186/1745-6215-15-264
- Thomas, D. R. (2016). A General Inductive Approach for Analyzing Qualitative Evaluation Data. *American Journal of Evaluation*, 27(2), 237–246. https://doi.org/10.1177/1098214005283748
- Tickle-Degnen, L. (2013). Nuts and Bolts of Conducting Feasibility Studies. *The American Journal of Occupational Therapy*, 67(2), 171–176. https://doi.org/10.5014/AJOT.2013.006270
- Udoh, E. E., Omorere, D. E., Sunday, O., Osasu, O. S., & Amoo, B. A. (2021). Psychological distress and burden of care among family caregivers of patients with mental illness in a neuropsychiatric outpatient clinic in Nigeria. *PloS ONE*, 16(5 May). https://doi.org/10.1371/journal.pone.0250309
- Vikas, A., Avasthi, A., & Sharan, P. (2011). Psychosocial impact of obsessive-compulsive disorder on patients and their caregivers: A comparative study with depressive disorder. *International Journal of Social Psychiatry*, 57(1), 45–56. https://doi.org/10.1177/0020764009347333
- Visa, B., & Harvey, C. (2019). Mental health carers' experiences of an Australian Carer Peer Support program: Tailoring supports to carers' needs. Health and Social Care in the Community, 27(3), 729–739. https://doi.org/10.1111/hsc.12689
- Vivanti, G., Kasari, C., Green, J., Mandell, D., Maye, M., & Hudry, K. (2018). Implementing and evaluating early intervention for children with autism: Where are the gaps and what should we do? Autism Research, 11(1), 16–23. https://doi.org/10.1002/AUR.1900
- Wagenaar, K. P., Rutten, F. H., Klompstra, L., Bhana, Y., Sieverink, F., Ruschitzka, F., Seferovic, P. M., Lainscak, M., Piepoli, M. F., Broekhuizen, B. D., Strömberg, A., Jaarsma, T., Hoes, A. W., & Dickstein, K. (2017). 'heartfailurematters.org', an educational website for patients and carers from the Heart Failure Association of the European Society of Cardiology: objectives, use and future directions. European Journal of Heart Failure, 19(11), 1447–1454. https://doi.org/10.1002/ejhf.917



- Wayland, S., Coker, S., & Maple, M. (2021). The human approach to supportive interventions: The lived experience of people who care for others who suicide attempt. *International Journal of Mental Health Nursing*, 30(3), 667–682. https://doi.org/10.1111/INM.12829
- Whitehead, A. L., Julious, S. A., Cooper, C. L., & Campbell, M. J. (2016). Estimating the sample size for a pilot andomized trial to andomiz the overall trial sample size for the external pilot and main trial for a continuous outcome variable. Statistical Methods in Medical Research, 25(3), 1057–1073.

# https://doi.org/10.1177/0962280215588241

- Williams, F., Moghaddam, N., Ramsden, S., & Boos, D. (2019). Interventions for reducing levels of burden amongst informal carers of persons with dementia in the community. A systematic review and meta-analysis of andomized controlled trials. Aging and Mental Health, 23(12). https://doi.org/10.1080/13607863.2018.1515886
- World Health Organization. (2017). Depression and Other Common Mental Disorders Global Health Estimates
- Ybarra, M. L., & Suman, M. (2006). Help seeking behavior and the Internet: a national survey. *International Journal of Medical Informatics*, 75(1), 29–41. https://doi.org/10.1016/J.IJMEDINF. 2005.07.029
- Youell, J., Callaghan, J. E. M., & Buchanan, K. (2016). "I don't know if you want to know this": Carers' understandings of intimacy in long-term relationships when one partner has dementia. *Ageing and Society*, 36(5). https://doi.org/10.1017/S0144686X15000045
- Zarit, S. H., Orr, N. K., & Zarit, J. M. (1985). The hidden victims of alzheimer's disease: Families under stress. New York University Press.