

A Psychosocial Intervention for Carers of Individuals Diagnosed with Dementia in Social Isolation

Grace Wei^{a,b} Olivier Piguet^{a,b} Fiona Kumfor^{a,b}

^aThe University of Sydney, Brain and Mind Centre, Sydney, NSW, Australia; ^bThe University of Sydney, School of Psychology, Sydney, NSW, Australia

Keywords

Dementia · Psychosocial intervention · Social isolation · Loneliness · Carers · COVID-19 · Pandemic

Abstract

Introduction: Growing research has shown the negative impact of social isolation on the health and psychological well-being of individuals with dementia and their carers. This study investigated the effectiveness of a psychosocial intervention for dementia carers during a lockdown period of the COVID-19 pandemic. **Methods:** Twenty-three family carers of individuals diagnosed with dementia living in the community were recruited and provided with an online psychoeducation toolkit that aims to improve health literacy, management of social and behavioural symptoms in dementia, carer social engagement, and coping skills. Carers were divided into “mild” or “moderate” groups based on the disease severity of the person with dementia they cared for. Outcome measures including distress and severity of neuropsychiatric symptoms, carer self-efficacy and burden, social network, and feelings of loneliness were assessed at baseline and 2 weeks later. **Results:** Carers in the moderate group reported higher levels of distress ($p = 0.001$) and severity ($p < 0.001$) of neuropsychiatric symptoms and greater carer burden ($p = 0.003$) than carers in the mild group. Following the intervention, both groups reported

increased social networks ($p = 0.001$). In addition, carers in the moderate group reported significantly reduced distress for neuropsychiatric symptoms ($p = 0.013$), enhanced carer self-efficacy for controlling upsetting thoughts ($p = 0.040$), and decreased loneliness ($p = 0.023$). **Conclusions:** This study demonstrated that psychosocial interventions improve outcomes for carers of individuals with dementia, particularly those caring for individuals with greater disease severity. Findings from this study will inform the development of support services that meet the evolving needs of individuals with dementia and their carers in social isolation, during and in a post-pandemic context.

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Introduction

Social isolation poses a considerable public health concern for people living with dementia and their carers, and has been associated with decreased quality of life, and physical and psychological well-being [1–3]. In recent years, the COVID-19 pandemic has further exacerbated these issues. Strategies to limit the spread of COVID-19 have relied heavily on restrictions on social interactions, which have had a significant impact on mental health across a range of populations [4–6]. Indeed, people with

dementia and their carers have experienced increased social isolation during the pandemic, with sudden and profound changes to their daily routines and disruptions to social support systems [7–10]. This has had a detrimental effect on individuals with dementia, resulting in worsened cognitive function and neuropsychiatric symptoms such as apathy, irritability, agitation, delusions, depression, and anxiety [11–13]. Carers have also experienced reduced access to social and practical supports such as respite care, activity programs, and support groups, which has further compounded existing challenges in providing care for individuals with dementia [7, 14]. Indeed, carers have reported increased social isolation, loneliness, and greater physical and emotional burden of caregiving [13, 15, 16]. Despite this, appropriate avenues to support individuals with dementia and carers in social isolation during the pandemic remain unclear.

Psychosocial carer interventions have demonstrated promising outcomes in reducing carer burden and improving symptomatology and the quality of life of both carers and individuals with dementia [17, 18]. The current interventions, however, do not sufficiently address the unique challenges posed by social restrictions during the pandemic. For instance, neuropsychiatric symptoms such as apathy and disinhibition, which are hallmark features of frontotemporal dementia (FTD) [19, 20], have contributed to greater difficulties adhering to preventative measures and reduced compliance with social restrictions, further compounding the burden of care [21, 22]. This emphasizes the need for interventions that consider the interaction between neuropsychiatric symptoms and social restrictions. Currently, tailored interventions that consider the unique challenges of dementia care during periods of social isolation such as the COVID-19 pandemic are lacking.

While the COVID-19 pandemic represents a unique case of social restrictions imposed in response to an external threat, many other situations exist in which social isolation may occur. Finding effective solutions and ways to deliver support to individuals with dementia and their carers who are socially isolated, during the pandemic or more broadly in regional or remote communities, is crucial. Indeed, since the outbreak of COVID-19, dementia care has increasingly adopted technology, with virtual support groups, online programs, and digital tools to facilitate social interactions and enable continuity of care [23–26]. Early evidence suggests that older adults are receptive to novel technology as a means of accessing support services remotely [27]. Further research, however, is needed to determine the effectiveness of remotely delivered psychosocial interventions. One promising approach is psychoeducation through on-

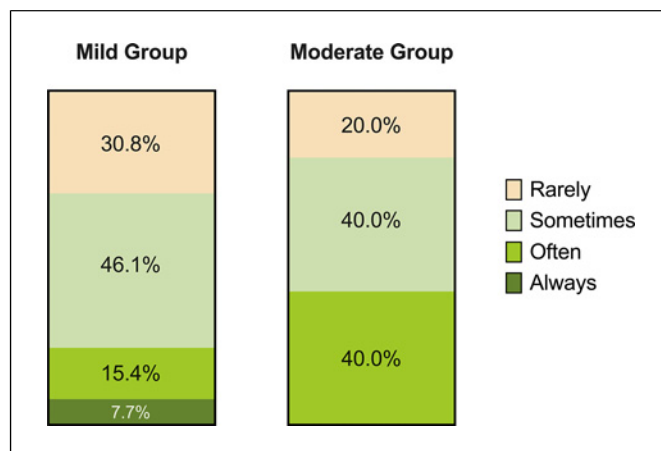


Fig. 1. Frequency of use of strategies provided in the toolkit across groups.

line toolkits, which can provide carers with information and tailored strategies to manage neuropsychiatric symptoms while considering various contexts such as the pandemic lockdown and related restrictions.

This study aimed to examine the effectiveness of an online carer psychosocial toolkit intervention on the management of neuropsychiatric symptoms in dementia during the COVID-19 lockdown period. We hypothesized that the provision of lockdown-appropriate strategies and information would (i) reduce distress for neuropsychiatric symptoms of dementia and (ii) improve carer self-efficacy, burden, and well-being. We anticipated that the intervention would have the greatest potential benefit for carers of individuals with greater disease severity, given the increased prevalence and severity of neuropsychiatric symptoms [28, 29].

Methods

Participants

Twenty-three participants were recruited from the FRONTIER dementia research clinic in Sydney, Australia. Participants were primary family carers of individuals diagnosed with dementia living in the community and aged 18 years or older. Two were carers of individuals with Alzheimer’s disease, 5 with a behavioural variant FTD, 7 with semantic dementia, 7 with primary progressive aphasia (not otherwise specified), 1 with Lewy body dementia, and 1 with Parkinson’s disease.

All data were collected between September and October 2021 in New South Wales, Australia, during the COVID-19 Delta outbreak and the associated lockdown period. During this time, stay-at-home orders were enforced with strict social restrictions introduced to control the spread of the virus. These restrictions included limits on gatherings and movement, closure of non-

essential sectors, suspended health services, mask mandates, and curfews. Residents were required to stay home except for essential activities such as grocery shopping, accessing medical care, and exercising.

Ethical Approval

Participation was voluntary, and all participants gave informed consent in accordance with the Declaration of Helsinki and its later amendments. This study was approved by the University of Sydney Human Research Ethics Committee (2020/213).

Procedure

The Living with Dementia During COVID-19 Lockdown Toolkit (<https://bit.ly/41IdBAe>) was developed based on available evidence [30, 31], public health guidelines, and clinical expertise and addressed four components: (i) improving health communication and COVID-19 health literacy in dementia; (ii) management of social and behavioural symptoms in dementia; (iii) improving carer social engagement; and (iv) improving carer coping skills. Participants completed a baseline online survey using Research Electronic Data Capture (REDCap). The survey collected basic demographic information about the carer and the person with dementia, as well as measures detailed below. Carers completed the Neuropsychiatric Inventory (NPI). Participants were then provided with a tailored toolkit which only included management of symptoms which they endorsed as present on the NPI. No specific instructions were given to participants regarding the use of the toolkit. After a 2-week period, participants completed a follow-up online survey with the same measures as baseline, and the full toolkit was then made freely available. The freely available full toolkit included management of all symptoms and was not tailored to the carers needs identified on the NPI.

Measures

The Frontotemporal Dementia Rating Scale (FRS) was used to provide an index of disease severity [32]. A median split of the FRS Rasch scores was used to divide carers into two groups, “mild” or “moderate.”

Neuropsychiatric symptoms were assessed using the informant-rated NPI [33]. Each symptom is scored on the severity of the symptom and carer distress associated with the symptom. Higher scores denote greater severity and distress, respectively.

The 21-item Depression Anxiety and Stress Scale (DASS-21) [34] was used to quantify the frequency of carer depression, anxiety, and stress symptomatology. Higher scores denote greater symptomatology.

Carer self-efficacy was measured using the Revised Scale for Caregiving Self-Efficacy [35]. Higher scores denote greater carer self-efficacy.

The Zarit Burden Interview (ZBI) (short version) was used to index carer burden [36, 37]. Higher scores denote greater carer burden.

Finally, carers’ social network size was quantified as the number of people in their social circle that they saw or spoke to on a regular basis (at least once every 2 weeks). Loneliness was assessed using a 4-point Likert scale from “not lonely at all” to “very lonely.”

Statistical Analyses

Data were analyzed using SPSS (IBM, Version 26.0). Independent samples *t*-tests and χ^2 tests were used to assess differences between groups on demographic variables. Differences on measures between baseline and follow-up were analyzed using repeated-measures ANOVAs with time (baseline, follow-up) as the within-subjects variable and group (mild, moderate) as the between-subjects variable. χ^2 and Wilcoxon signed-rank tests were used to assess differences for ordinal variables. Analyses were not corrected for multiple

Table 1. Demographic information of the study cohort

	Mild (n = 13)	Moderate (n = 10)	p value
Carer			
Age, years	64.92±5.63	60.60±14.67	0.056
Sex (female/male)	9/4	9/1	0.231
Region (urban/regional)	7/6	9/1	0.062
Relationship (spouse/child)	13/0	8/2	0.092
Caring for children (no/yes)	12/1	9/1	0.846
Patient			
Age, years	67.23±6.10	68.70±6.77	0.878
Sex (female/male)	5/8	3/7	0.673
Diagnosis, n			
Alzheimer’s disease	1	1	
Behavioural-variant FTD	3	2	
Lewy body dementia	1	0	
Parkinson’s disease	0	1	
Primary progressive aphasia (NOS)	6	1	
Semantic dementia	2	5	
Disease severity (FRS Rasch score)	2.53±2.10	-0.34±0.94	0.003

Values are mean ± standard deviation.

Table 2. Outcome measures at baseline and follow-up

Group time	Mild (n = 13)		Moderate (n = 10)		Time		Group		Group*Time	
	baseline	follow-up	baseline	follow-up	F	p value	F	p value	F	p value
NPI: Distress (/35)	2.62±2.82	2.62±3.20	10.70±5.83	7.30±4.30	7.441	0.013	16.178	0.001	7.441	0.013
NPI: Severity (/21)	1.85±2.15	2.00±2.31	8.00±4.24	6.80±3.46	1.822	0.191	20.136	<0.001	3.052	0.095
Self-efficacy: obtaining respite (%)	62.50±27.92	58.50±32.40	48.40±29.50	47.80±32.54	0.324	0.575	0.989	0.332	0.177	0.678
Self-efficacy: managing behaviours (%)	69.00±22.44	74.33±18.99	55.00±22.39	61.40±23.61	3.784	0.066	2.320	0.143	0.031	0.861
Self-efficacy: controlling upsetting thoughts (%)	78.17±12.37	74.83±14.00	63.40±12.89	72.80±15.12	1.090	0.309	2.773	0.111	4.802	0.040
Carer burden (/48)	3.58±2.64	3.83±2.62	7.30±2.79	7.20±2.25	0.060	0.810	11.048	0.003	0.325	0.575
DASS-21: Depression (/21)	3.00±3.36	2.58±2.64	4.40±4.38	3.70±3.34	1.295	0.269	0.821	0.376	0.083	0.776
DASS-21: Anxiety (/21)	1.25±1.91	1.82±2.97	1.70±2.75	2.60±4.27	2.035	0.169	0.231	0.636	0.045	0.834
DASS-21: Stress (/21)	3.83±2.37	3.92±3.18	6.60±3.27	5.80±3.58	0.450	0.510	3.659	0.070	0.684	0.418
Social network	6.08±1.73	7.17±1.95	5.40±1.96	7.50±0.97	16.301	0.001	0.080	0.780	1.663	0.212

Values are mean ± standard deviation. NPI, Neuropsychiatric Inventory; DASS, Depression, Anxiety, and Stress Scale.

comparisons as all analyses were hypothesis-driven and defined *a priori*. For all analyses, statistical significance was set at $p < 0.05$.

Results

Demographics

Sociodemographic characteristics of the study cohort are summarized in Table 1. Groups were matched on all relevant demographic variables, except for disease severity, which as expected differed significantly between the mild and moderate group ($p = 0.003$).

Toolkit

No significant difference was observed between the mild and moderate groups in the frequency of use of strategies provided in the toolkit ($\chi^2(3) = 2.383, p = 0.497$) (shown in Fig. 1).

Outcome Measures

The results of the repeated-measures ANOVAs are provided in Table 2. On the NPI, the main effect of group was significant, with the moderate group showing greater distress ($p = 0.001$) and severity ($p < 0.001$) of neuropsychiatric symptoms than the mild group, irrespective of time of assessment. Notably, the time × group interaction for NPI distress was significant ($p = 0.013, \eta^2 = 0.262$). Carers in the moderate group reported a significant reduction in distress for neuropsychiatric symptoms fol-

lowing the intervention, whereas in the mild group, the distress level did not change between time points (shown in Fig. 2). The effect of time and the time × group interaction was not significant for NPI severity (both p values >0.05).

For carer self-efficacy, the main effects of group and time were not significant for any of the three subscales (all p values >0.05). However, the time × group interaction for the controlling upsetting thoughts subscale was significant ($p = 0.040, \eta^2 = 0.194$). Carers in the moderate group reported greater self-efficacy for controlling upsetting thoughts following the intervention, whereas this did not differ between time points in the mild group (shown in Fig. 3).

For carer burden, a main effect of group was observed, with carers in the moderate group reporting greater carer burden than the mild group ($p = 0.003$), although mean scores on the ZBI were below the clinical cut-off for both the mild and moderate groups across both time points [37]. The main effect of time and the time × group interaction for carer burden were not significant (both p values >0.05).

For depression, anxiety, and stress, no main effects of time or the group or time × group interaction were observed (all p values >0.05). Of note, the subscale mean scores were all within the normal to mild range for both groups at both time points [34].

Carers in both groups reported larger social networks over time ($p = 0.001$). The main effect of group and the time × group interaction were not significant (both p values >0.05). For loneliness, results are depicted in Figure 4. At baseline, no difference between the mild and moderate groups in loneliness was observed ($\chi^2(3) =$

Fig. 2. Change in distress scores on the NPI across groups.

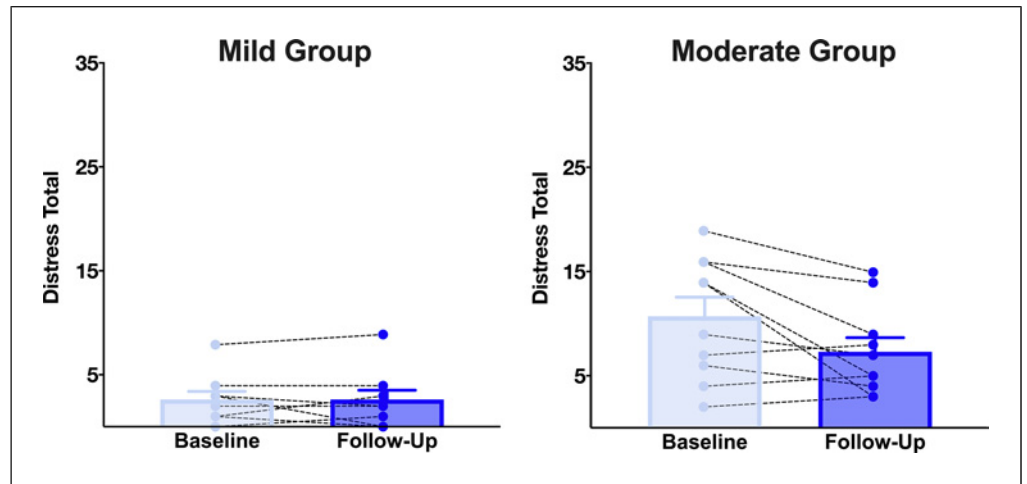


Fig. 3. Change in self-efficacy for controlling upsetting thoughts across groups.

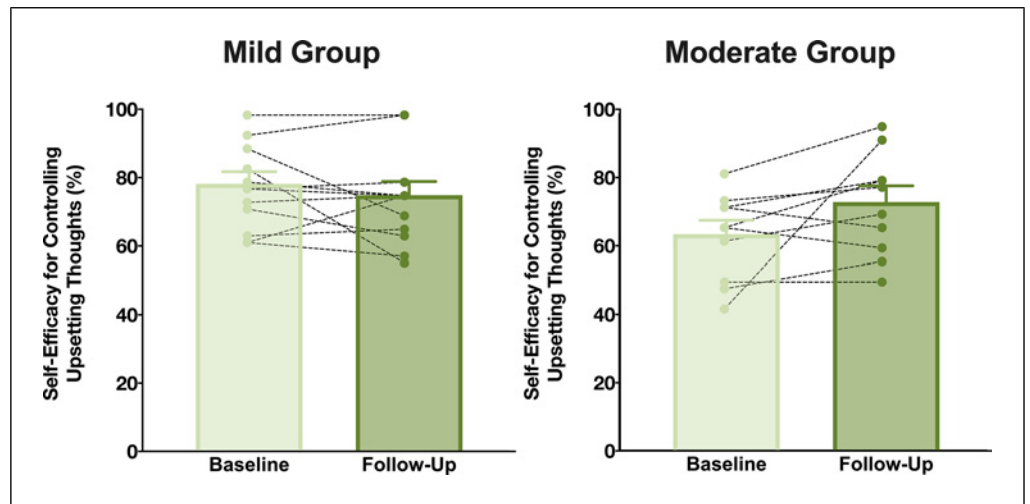
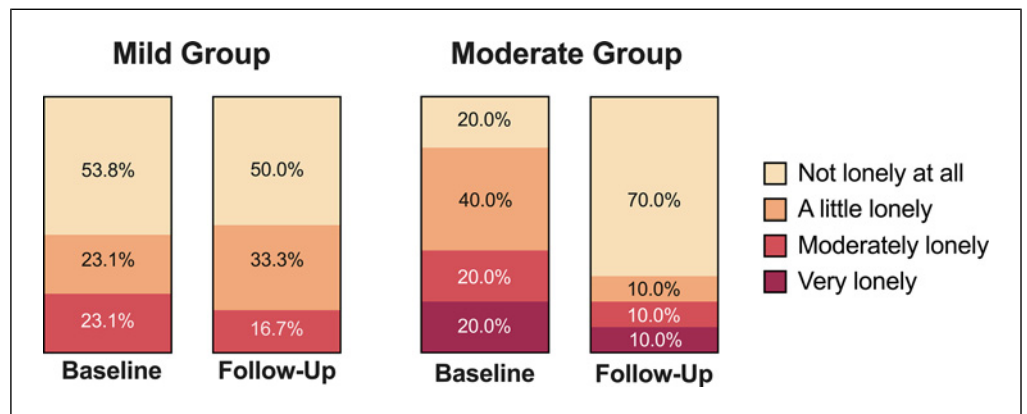


Fig. 4. Change in loneliness across groups. Mild group: $n = 13$, moderate group: $n = 10$.



4.811, $p = 0.186$). In the mild group, loneliness did not change across time points ($Z = -0.447$, $p = 0.655$). However, carers in the moderate group reported significantly less loneliness following the intervention ($Z = -2.271$, $p = 0.023$).

Discussion

We found that following the intervention, carers of individuals with dementia of moderate disease severity reported increased social support and self-efficacy, and reduced loneliness and distress for neuropsychiatric symptoms. This effect was seen despite the severity of neuropsychiatric symptoms in individuals with dementia remaining stable over this short 2-week period. This study provides promising evidence that psychosocial interventions can improve outcomes for carers of individuals with dementia in social isolation.

Overall, we found that carers of individuals with moderate disease severity reported greater distress and severity of neuropsychiatric symptoms and carer burden than those caring for individuals in a mild stage, in line with previous research [29, 38, 39]. Notably, carers of individuals with moderate disease severity benefitted the most from the intervention. Specifically, we found large effects [40] on reduced distress for neuropsychiatric symptoms and increased self-efficacy for controlling upsetting thoughts. These findings suggest that psychosocial interventions are particularly effective in the moderate disease stage, at a time when carers appear more vulnerable to psychological distress. Previous studies have found psychosocial interventions involving psychoeducation, support in activities of daily living, and managing challenging behaviours can improve carer outcomes including burden, well-being, and self-efficacy [18, 31, 41–43]. This study extends upon the existing body of evidence for psychosocial interventions by considering social isolation in a novel lockdown context and emphasizes the importance of considering disease severity when delivering interventions, and targeting carers who are experiencing high levels of distress.

Despite a significant improvement in distress for neuropsychiatric symptoms in carers of those with greater disease severity, we did not find a reduction in the severity of these symptoms. While distress is a subjective carer experience and is thus more susceptible to change following a carer-focused intervention, the severity of neuropsychiatric symptoms is more patient-related. Neuropsychiatric symptoms in dementia are complex and have multiple underlying biological, neuropathological, and psychosocial mechanisms [44, 45]. As such,

non-pharmacological carer-focused interventions may be limited in their capacity to directly reduce the severity of these symptoms. Future interventions may need to consider combining pharmacological or psychosocial patient-focused components in order to optimize the efficacy of these interventions.

While the intervention reduced distress for neuropsychiatric symptoms, we did not find a reduction in carers' depression, anxiety, or stress. Notably, however, scores on these measures were within a normal to mild range at the beginning of the intervention [34]. Similarly, no significant change in carer burden was observed, although ratings of carer burden were also below the clinical cut-off at baseline, suggesting that the carers may be managing their responsibilities well [37]. Thus, given the floor effect, we did not find any noticeable changes in depression, anxiety, stress, or carer burden. Future studies could consider screening potential participants and identify those who are experiencing significant levels of depression, anxiety, stress, and carer burden at baseline. This would ensure that the intervention is targeting individuals who are most in need of support and increase their capacity for improvement.

While this study provides valuable insights into the effectiveness of this intervention in improving outcomes for carers, it is important to acknowledge some limitations. Firstly, this study was limited in its sample size, and the cohort was predominantly carers of individuals with FTD. However, given that neuropsychiatric symptoms are prevalent across dementia syndromes, affecting up to 90% of people with dementia over the disease course [46], the types of strategies which are included in the toolkit have broad relevance. The efficacy of the toolkit in other dementias, such as Alzheimer's disease, will need to be confirmed. Secondly, other factors not examined here such as educational attainment and socioeconomic status may have a potential impact on the observed outcomes. Higher levels of education and socioeconomic status could potentially enhance an individual's access to information, resources and opportunities for skill development and thus more effective utilization of strategies. Future studies should explore these factors to identify areas where targeted or additional support in understanding and integrating relevant strategies may be required. Thirdly, given the practical constraints and increased vulnerability of this population during this time-sensitive lockdown period, we did not include a control arm. Further, given the dynamic nature of the pandemic outbreak response, we opted for a short follow-up period (2 weeks) to minimize the potential of the results being confounded by changes in restrictions and lockdown measures across this period.

Future studies which compare access to the toolkit to treatment as usual, with longer follow-up periods, will be important to explore these intervention effects and identify the most appropriate follow-up time period.

Although this intervention was developed to address the unique challenges of lockdown during the pandemic, the underlying techniques and principles can be applied universally and remain relevant beyond this context. Psychosocial interventions such as toolkits can represent a valuable and pragmatic resource for dementia carers. Toolkits can offer synthesized and tailored information that can enhance carers' knowledge and confidence. One of the issues faced by carers is the challenge of accessing and integrating the vast and multifaceted information available on dementia care [47]. Therefore, having support for carers in an easily accessible and digestible format from a reliable source is crucial. Future studies can further tailor these interventions to cater to the specific needs of dementia carers, considering factors such as the carer and care recipient relationship, cultural background, and dementia diagnosis [48]. In doing so, these interventions can potentially offer more nuanced support, thereby enhancing their efficacy in supporting carers.

The COVID-19 pandemic has also highlighted the urgency for an improved model of dementia care and adoption of technology to enable continuity of care and support [49]. Remote interventions have become a clear and cost-efficient alternative for delivering services, which is both feasible in the context of the COVID-19 pandemic and more broadly accessible. This approach offers substantial benefits in reaching carers living in regional communities who face difficulties accessing in-person support services or those preferring the convenience and flexibility of remote services. Moving forward, these digital tools will continue to be relevant beyond the pandemic period, particularly for carers who face challenges in accessing traditional support services.

These findings show promising outcomes in terms of improving carers' distress, self-efficacy for controlling upsetting thoughts, and promoting social connection. Fostering positive interactions within these vital informal support networks, both between carer and care recipient, and the carer and their own social network, is crucial to mitigating the effects of the pandemic and social isolation more broadly. Although this toolkit was designed to address pandemic-related challenges, the strategies and information are broadly applicable. These findings highlight the effectiveness and importance of psychosocial interventions as a practical and valuable resource for dementia carers, which remains of relevance beyond the pandemic context. Further, the COVID-19 pandemic has emphasized the importance

of remote interventions and digital tools, which offer a cost-efficient and accessible alternative to conventional in-person services, particularly advantageous for carers in regional communities and those seeking flexible care options. Overall, continued research in this area is clearly needed to enhance the well-being of carers and individuals with dementia, both during and in a post-pandemic era.

Acknowledgments

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Statement of Ethics

This study was approved by the University of Sydney Human Research Ethics Committee (2020/213). Participation was voluntary, and all participants gave written informed consent in accordance with the Declaration of Helsinki and its later amendments.

Conflict of Interest Statement

The authors declare that they have no conflict of interest, financial or otherwise.

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Author Contributions

G.W: conceptualization, investigation, formal analysis, methodology, and writing – original draft, review, and editing. O.P: resources, supervision, and writing – review and editing. F.K: conceptualization, methodology, supervision, and writing – review and editing.

Data Availability Statement

The data that support the findings of this study are not publicly available due to privacy reasons but are available from the corresponding author upon reasonable request.

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