

An online intervention to improve the health and well-being of informal caregivers of individuals with Alzheimer's disease: A pilot study

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ABSTRACT

Objective: Describe an intervention to improve the health and well-being of informal caregivers of individuals with Alzheimer's disease (AD) and present pilot program findings.

Methods: Participants ($N = 31$, mean age = 45.7) were randomly assigned to one of two conditions: an online synchronous didactic lesson and peer support session series or an asynchronous didactic only session series. Outcome variables included physical health, nutrition intake, and stress. One-way ANOVA was conducted to examine the effects of the intervention. The least significant difference (LSD) post hoc test was used to analyze the difference pattern between means.

Results: Participants in both conditions reported healthier dietary behavior and lower level of stress from pre-intervention to the post-intervention. These effects were not maintained at one-month follow up.

Conclusion: An online educational intervention may improve the health and well-being of informal caregivers of people with AD. Further research is necessary to determine which specific intervention components to include and what strategies may help participants maintain improved health behaviors.

Innovation: This program focused on the health and well-being of informal caregivers of individuals with AD rather than on emphasizing how caregivers can perform their caregiving duties better. The intervention was provided in an underserved lower-income, rural area.

1. Introduction

In the U.S., one in ten adults aged 65 and above has Alzheimer's disease (AD) [1]. Ninety-two percent of people with AD receive help from family members or other informal caregivers, and 41% of such caregivers have a household income of \$50,000 or less [2]. Informal caregivers of individuals with AD are often called "second patients" and have high rates of psychological morbidity and social isolation due to their challenging caregiving role [3]. Social isolation has only been compounded by the COVID-19 global crisis, restricting mobility and interaction with others for older patients with AD and their caregivers [4,5]. A systematic meta-review of interventions targeting self-management of informal caregivers of individuals with AD found that such interventions can effectively improve their stress levels, social support, and quality of life [6]. Another systematic review specifically examined the delivery modality of Internet-based remote self-

management education and peer support for informal caregivers of individuals with AD and found it can help reduce informal caregivers' stress levels and improve feelings of support [7]. Two other systematic reviews indicated that online interventions for informal caregivers of individuals with AD may be effective, but future research is needed to develop insights to overcome challenges (e.g., technical problems, dropout rate, etc.) that persist with such interventions [8,9]. Yet another systematic review stressed that participants' readiness and acceptance levels for psychological interventions for informal caregivers of individuals with neurodegenerative diseases differ and can impact their intervention engagement levels [10].

While there are interventions aimed at supporting informal caregivers of AD in providing care, there is a gap in the literature about interventions to specifically improve the health and well-being of the informal caregivers, especially those in underserved lower-income, rural area. Here, we describe an intervention to improve the health and well-

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being of informal caregivers of individuals with AD in DeKalb County and summarize the findings from our pilot study. We chose DeKalb County because it 1) has a median household income that is \$2000 less than the national median income [11], 2) is more rural than urban [12], and 3) is where our university is located which would be helpful for participant recruiting. Research shows that informal caregivers with lower income and living in rural areas face significant challenges in accessing support services and carrying out their caregiving roles [13,14]. Knowledge about an online intervention aimed at helping to improve the health and wellness of informal caregivers of individuals with AD can inform health promotion professionals designing such programs.

2. Methods

We developed a remote intervention consisting of four synchronous weekly sessions conducted via Zoom for caregivers. Each session focused on one of the following topics: physical activity, nutrition, stress management, and action plan. The intervention content was developed based on previous research evidence on related topics [16-21]. Each session lasted about 45 min and included a didactic lesson about that session's topics taught by a study author (AB) and a group discussion facilitated by two study authors (AB and YL). The group facilitators both have a master's degree in gerontology, with one also having a doctoral degree in family studies and experience leading caregiver interventions. All the sessions were pre-reviewed and approved by the four authors. All sessions were facilitated by the same facilitators to keep them consistent. See Table 1 for the session agenda used each week. To assess fidelity, each session was recorded and reviewed by the four authors to determine instructional methods and content delivery were consistent between sessions. Participants' feedback regarding their perceptions of the intervention's delivery was also collected to make sure the content and delivery aligned with the participants' expectations. Participants in the treatment condition attended the online training sessions described above and were involved in group discussions after each session, where they voiced their opinions and received feedback and support from the group facilitators and other participants. Conversely, participants in the control group only reviewed a video of the didactic education asynchronously and did not participate in the discussion. We offered each participant \$30 as a participation incentive. This study received approval from Northern Illinois University's Institutional Review Board and all participants provided their consent to participate. The study protocol was not pre-registered for this pilot study.

Eligible participants were individuals who identified themselves as informal caregivers of individuals with AD. The participants also had to have Internet access either at home or at another location, such as their public library. We conducted power analysis using G*Power 3.1 [22]. See Supplemental Fig. 1 for power analysis information. We recruited participants through memory care institutions, DeKalb County community organizations, and other organizations serving older adults. We also posted recruiting posters on community public posting boards, like

Table 1
Intervention session description.

Segment	Description	Duration (minutes)
Introductions	First names and icebreaker questions	6
Didactic lesson	Topic of that session's focus (physical activity, stress management, nutrition, or overall review)	15
Discussion part 1	Difficulties encountered	6
Discussion part 2	Strategies employed	6
Discussion part 3	Strategies to try	6
Homework	Action step to try	3
Wrap up	Next meeting day and time; logistical questions	3

those found in the public libraries. To accommodate caregivers' busy schedules, we offered multiple weekly session times. Study participants were asked to complete online surveys at three points: 1) pre-intervention, before the start of the first session, 2) post-intervention, at the end of the last session, and 3) follow-up, one month after the last session. Most of the questions came from the Centers for Disease Control's Behavioral Risk Factor Surveillance System Survey that has been conducted annually in all 50 states for the last 30 years [15]. The pre-intervention survey included demographic questions and questions about the participant's physical health (calculated based on three questions about health status), dietary behavior (calculated using four questions about the frequency of healthy eating behaviors), and stress level (calculated using four questions from the Perceived Stress Scale about the frequency of stress-related feelings). The post-intervention survey included the questions from the pre-intervention survey except the demographic questions and four participant experience questions regarding aspects such as session format, session delivery, and intervention satisfaction. The follow-up survey included the questions from the post-intervention survey except the participant experience questions.

We examined the descriptive information of all participants using means and frequency analyses. Then we compared the treatment and control groups using a series of independent *t*-tests and chi-square tests. Analysis of Variance (ANOVA) was conducted using data from all participants to compare the effect of attending training sessions on the three dependent variables: physical health, nutrition, and stress. For ANOVA, the treatment and control groups were combined, and we compared the pre-intervention survey, post-intervention survey, and follow-up survey scores for all participants. We also conducted the least significant difference (LSD) post hoc test to analyze the difference pattern between means.

3. Results

We conducted the study from September 2021 to February 2022. There were 31 informal caregiver participants. Fig. 1 reports our enrollment and retention. As shown in Table 2, half of the participants were non-White, and the participants ranged in age from 20 to 79, with 58% over age 50. About 60% of the caregivers were female and over 65% of the participants were married. About 40% of the caregivers had at least a college degree.

Our comparison of the treatment and control groups showed that the participants in the two conditions did not differ by age, education, gender, race, or self-reported health at pre-intervention. Furthermore, the two groups had no significant differences in self-reported health status, dietary behavior, and stress levels at pre-intervention. The LSD post hoc test results revealed that the participants reported a significantly higher level of positive dietary behavior post-intervention ($M = 6.56$, $SD = 1.20$) compared to pre-intervention ($M = 5.30$, $SD = 1.50$). There was no significant difference in dietary behavior between pre-intervention and follow-up. Additionally, participants reported significantly lower stress levels post-intervention ($M = 8.99$, $SD = 1.75$) compared to pre-intervention ($M = 10.10$, $SD = 2.41$). There was no significant difference in stress level between pre-intervention and follow-up (shown in Table 3). For the experience questions, 90% of the participants indicated that they agree or strongly agree that the "information provided in this program was helpful," and more than 80% of the participants agreed or strongly agreed that they "enjoyed the online format of this program" and were "satisfied with this program". Due to the large number of dropouts in the treatment group, we could not conduct a statistical analysis to test the statistical differences between the two groups on those outcome measures.

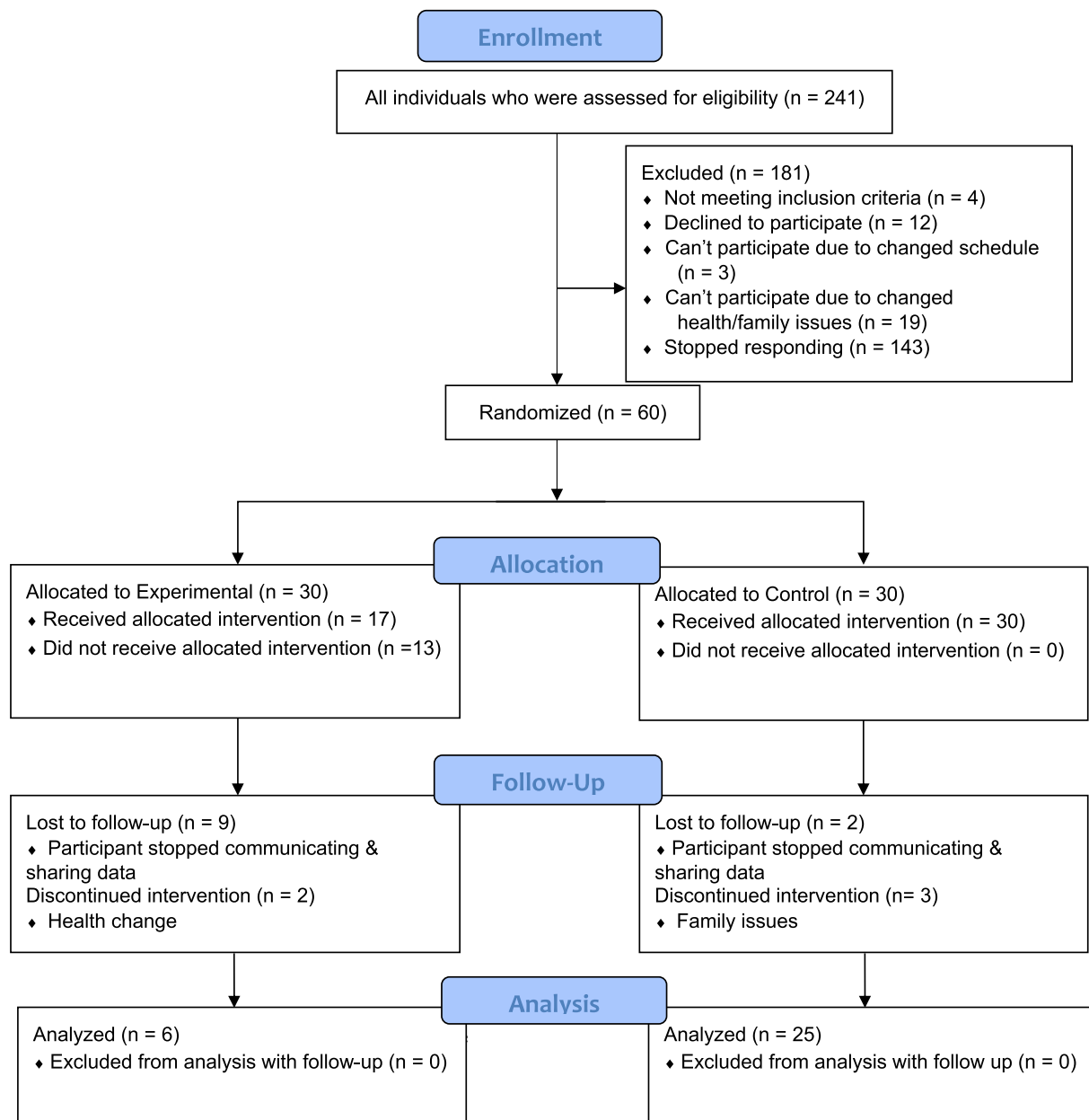


Fig. 1. Consolidated Standards or Reporting Trials (CONSORT) diagram. Note. See the description in text for more details about the participants.

4. Discussion and conclusion

4.1. Discussion

An online educational intervention for informal caregivers of individuals with AD has the potential to improve informal caregivers' health and well-being. There were significantly more control group participants who completed the intervention than treatment group participants. This is not surprising given the high care burden place on informal caregivers of AD patients during the COVID-19 pandemic [16,17]; informal caregivers likely found it difficult to commit to four 45-min synchronous sessions. In contrast, the control group participants had the flexibility to review sessions on their own time, which was likely easier to incorporate into their schedules. Future interventions that involve synchronous educational sessions for informal caregivers of individuals with AD can learn from this pilot study and incorporate strategies to help reduce the dropout rate. One such strategy is content

personalization or individualized feedback, which has been shown to be effective in educating caregivers and associated with a lower dropout rate [23-25]. Another study found that more personalized training was more important for more experienced informal caregivers of dementia, whereas newer caregivers were interested in all aspects of training [26].

This study showed a lack of maintaining the improvements in dietary behavior and stress levels from post-intervention to follow-up. Future research on related interventions for this population should look to incorporate steps proven to help with behavior change maintenance such as healthy behavior repetition, information the trigger habit formation, and positive rewards some of the time [18]. There were limitations in our study. First, participants needed to have Internet access to participate. This requirement may have prevented some informal caregivers from joining the study. Second, despite offering this intervention in a locale with lower income levels than the U.S. population, the participant group was more educated than the U.S. population average, limiting the results' generalizability. Third, the study protocol was not

Table 2
Baseline demographic characteristics of the participants N = 31.

Characteristic	No. % n = 31
Age	
20–30	5 (15.8)
31–40	6 (21.0)
41–50	2 (5.3)
51–60	8 (26.3)
61+	10 (31.6)
Gender	
Male	11 (36.8)
Female	20 (63.2)
Other	0 (0.0)
Marital Status	
Married/Living with a partner	22 (68.4)
Divorced/Separated	3 (10.5)
Never Married	6 (21.1)
Widowed	0 (0.0)
Education	
Less than high school	5 (15.8)
High school	8 (26.3)
College	4 (15.8)
College above	14 (42.1)
Race	
White	16 (52.6)
African American	0 (0.0)
Asian	10 (31.6)
Other	5 (15.8)
Providing Care to	
Mother	14 (47.4)
Father	2 (5.3)
Spouse/Partner	8 (26.3)
Grandmother	2 (5.3)
Son	5 (15.8)

Table 3
Means, standard deviations, and one-way analyses of variance in physical health, nutrition and stress (n = 31).

Measure	Pre-test		Post-test		Follow-up		F (30)
	M	SD	M	SD	M	SD	
Physical health	3.30	0.78	3.35	0.35	3.31	0.71	6.87
Dietary behavior	5.30	1.50	6.56	1.20	5.60	1.75	6.60*
Stress	10.10	2.41	8.99	1.75	10.25	2.15	5.35*

Notes. M: mean; SD: standard deviation. * $p < .001$; F-statistic: Variation between sample means / Variation within samples.

pre-registered. Fourth, the lack of difference between groups could be due to the small sample size.

4.2. Innovation

Most informal interventions for informal caregivers of individuals with AD focus on improving support regarding helping the care recipient (Alzheimer's disease patient) perform activities of daily living and receive the care they need [19–21]. Here, we focused on the informal caregivers' health and well-being, which is essential to helping to prevent them from becoming ill from a chronic disease. Furthermore, by conducting the intervention online, we enabled informal caregivers who may find it challenging to attend in person yet who may benefit from a visual presentation to receive health and well-being training. The novelty of our findings contributes to the insights needed to overcome on-line interventions for informal caregivers of individuals with AD, as noted by previous systematic reviews [8,9]. The study herein is also consistent with previous psychological interventions for informal caregivers of individuals with neurodegenerative diseases where there were challenges with participant engagement, yet participants also showed benefits from the intervention [10].

4.3. Conclusion

There is the potential for online interventions to help informal caregivers of individuals with AD be healthy and well. Future research is needed to determine the length of such interventions and whether a peer support or discussion component can help improve the caregiver's health and well-being.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pecinn.2023.100229>.

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