

Supplementary Material

Efficacy of a Virtual Education Program for Family Caregivers of Persons Living with Dementia

Supplementary Table 1. Participant pre- and post-surveys.

The questions below were included in the evaluation surveys. The source for each question appears after the question in italics. BRFSS is the Behavioral Risk Factor Surveillance System. NAC is the National Alliance for Caregiving. Any proprietary questions developed by other researchers are not included below but links or citations are provided so that readers can find them if interested.

Pre-Survey: Intervention Group

1. What is your relationship to the person for whom you are providing care? Is he or she your...

- Mother or father (including in-laws)
- Husband, wife, or partner
- Other relative (including sibling, child, grandparent, etc.)
- Non-relative or family friend
- Other, *please specify*: _____

Source: BRFSS Caregiver Module (with collapsed categories)

2. Where does your relative live?

- In your household
- Within twenty minutes of your home
- Between twenty minutes and an hour from your home
- One to two hours from your home
- More than two hours away
- Other, *please specify*: _____

Source: NAC Questionnaire plus "Other"

3. If your relative does not live in your household, which of the following best describes where your relative lives?

- His or her own home
- Someone else's home
- An independent living or retirement community
- In an assisted living facility where some care may be provided
- A nursing home or long-term care facility
- Somewhere else; *please specify*: _____

Source: NAC Questionnaire

4. In what county does your relative live?

- Buncombe
- Haywood

- Henderson
- Madison
- McDowell
- Polk
- Rutherford
- Transylvania
- Yancey
- Somewhere else; *please specify:* _____ , _____
County *State*

Source: Created for evaluation

5. Has your relative been diagnosed with Alzheimer’s disease or another type of dementia or memory disorder?

- Yes
- No

Source: Created for evaluation

6. For how long have you provided care for your relative? Would you say...

- Less than 30 days
- 1 month to less than 6 months
- 6 months to less than 2 years
- 2 years to less than 5 years
- More than 5 years

Source: BRFSS Caregiver Module (changed “that person” to “your relative” for internal consistency)

7. During the past 30 days, which of these did you help your relative with? By help, we mean anything from reminding the person to complete the task to physically assisting with the task.

Please check “Yes” or “No” for each task

Activity	Yes	No
Getting in and out of beds and chairs		
Getting dressed		
Getting to and from the toilet		
Bathing or showering		
By assisting with incontinence or diapers		
By feeding him or her		
By giving medicines, like pills, eye drops, or injections for his/her condition		
Managing finances, such as paying bills or filling out insurance claims		
Grocery or other shopping		
Housework, such as doing dishes, laundry, or straightening up		
Preparing meals		
Transportation, either by driving him/her, or helping him/her get transportation		
Arranging outside services, such as nurses, home care		

aides, or meals-on-wheels		
Advocating for him/her with health care providers, community services, or government agencies		
Monitoring the severity of his/her condition so that you can adjust care accordingly		
Communicating with health care professionals like doctors, nurses, or social workers about his/her care		

Source: *NAC Questionnaire with modifications*

8. In an average week, how many hours do you provide care or assistance? Would you say...

- Up to 8 hours per week
- 9 to 19 hours per week
- 20 to 39 hours per week
- 40 hours or more

Source: *BRFSS Caregiver Module*

9. Who would you consider to be the person who provides most of the unpaid care for your relative?

- You (yourself)
- Someone else
- I split care evenly with someone else

Source: *NAC Questionnaire; changed option #3*

10. The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

Included 12 items about feelings and caregiving effects with Likert scale response options.

Source: *Zarit Burden Interview – 12, Bedard (CAPC) version (request permission: <https://mapi-trust.org/questionnaires/zbi/>)*

11. During the past month, did your relative receive paid help from any aides, housekeepers, or other people who were paid to help him/her?

- Yes
- No

Source: *NAC Questionnaire; changed 12 months to past month*

12. If you answered “Yes” to #11 above... In an average week, about how many hours does someone provide paid help to your relative?

_____ hours per week

Source: *Created for evaluation based on BRFSS/NAC questions*

13. Overall, in providing care for your relative, how confident are you in your ability to take care of your relative’s:

Included 5 items about ability to take care of dementia and non-dementia related symptoms (one subscale) with Likert scale response options.

Source: Piggot et al 2017. Development and Testing of a Measure of Caregiver Confidence in Medical Sign/Symptom Management.

For the next two questions (#14-15), please choose the answer that best indicates how much you agree with the following statements as they apply to you over the last month. If a particular situation has not occurred recently, answer according to how you think you would have felt. These relate to you as a person in general, not only as a caregiver.

Source: Connor-Davidson Resilience Scale 2 item (register at <http://www.connordavidson-resiliencescale.com/>).

16. For this part, we are interested in how confident you are that you can keep up your own activities and also respond to caregiving situations. Please be as frank and honest as you can about what you really think you can do. Below is a list of items which cover activities and thoughts that could come up for you as a caregiver. Please think about each one and tell us how confident you are that you could do each item.

Rate your degree of confidence from 0 to 100 where a 0% confidence means that you cannot do it at all, a 50% confidence means that if you gave it your best effort, chances are about 50-50 that you could perform the activity, and a 100% confidence means you are certain you can do it. You can use any score between 0 and 100 (10, 20, 30, etc.) to express your confidence. For example, a rating of 20% confidence means that it is unlikely, but not totally out of the question for you to be able to perform the activity.

Source: Revised Scale for Caregiver Self-efficacy Steffen 2002, Responding to Disruptive Patient Behaviors subscale. Adapted for self-completion and changed “When” to “If” at start of each statement based on pilot test.

17. What is your age?
- 18-30 years
 - 31-44 years
 - 45-64 years
 - 65-74 years
 - 75-84 years
 - 85 years or older

Source: BRFSS question; created categories for study instead of collecting specific age

18. Are you Hispanic, Latino/a, or Spanish origin?
- Yes
 - No

Source: BRFSS

19. Which one or more of the following would you say is your race?
- White
 - Black or African American

- American Indian or Alaska Native
- Asian
- Pacific Islander
- Other; *please specify:* _____

Source: BRFSS

20. What is your sex?

- Female
- Male
- Other

Source: BRFSS, added "Other"

21. Are you currently or have you ever been enrolled in MemoryCare?

- Yes
- No

Source: Created for evaluation

Post-Survey: Intervention Group

The post-survey for the intervention group included items #1-16 from the pre-survey above. In addition, they included the following items:

17. Please check the box to indicate your response to the following statements about the Caregiver Education Program. If you had no experience with the topic of a question, please check N/A.

	Yes	No	N/A
The program has made me more knowledgeable about my loved one's memory disorder.			
My participation in this program has increased my confidence as a caregiver.			
This program has helped me to better manage my loved one's difficult behaviors.			
This program has had a positive impact on my ability to manage caregiver-related stress.			
This program has helped me understand my own dementia risk factors.			
This understanding of my own dementia risk factors has led to changes in my health related behaviors e.g. diet, exercise, increased respite, and stress management.			

Source: Existing evaluation form and created for this evaluation

18. Please list changes you have made or experienced as a result of the Caregiver Education Program:

Thank you for completing this survey. We are grateful for your time.

Pre- & Post-Surveys: Control Group

The pre-survey for the control group was identical to the pre-survey for the intervention group (above). The post-survey for the control included items 1-16 from the intervention group post-survey above.

Supplementary Table 2. Baseline characteristics of 144 caregivers (90 included, 54 excluded) of people with dementia or other memory disorders who participated in the virtual MemoryCare Caregiver Education Program (intervention group) delivered virtually from March-December, 2020.

Variable	Category	Completed Follow-up ¹ (n=90) N (%)	Did not Complete Follow-up (n=54) N (%)	p for difference*
Age (y)	18-44	5 (5.6)	4 (7.4)	0.45
	45-64	32 (35.6)	23 (42.6)	
	65+	53 (58.9)	25 (46.3)	
	Missing	0	2 (3.7)	--
Sex	Female	67 (74.4)	32 (59.3)	0.11
	Male	23 (25.6)	20 (37.0)	
	Missing	0	2 (3.7)	--
Hispanic, Latino/a, or Spanish ethnicity	Yes	2 (2.2)	2 (3.7)	0.56
	No	88 (97.8)	49 (90.7)	
Race	Non-white (Black or African American, American Indian or Alaska Native, Asian, Pacific Islander, or Other)	1 (1.1)	2 (3.7)	0.28
	White	89 (98.9)	50 (92.6)	
	Missing	0 (0)	2 (3.7)	--
Caregiver (CG) is providing care for their...	Parent, including in-law	39 (43.3)	25 (46.3)	0.42
	Spouse or partner	44 (48.9)	21 (38.9)	
	Other relative	7 (7.8)	7 (13.0)	
	Missing	0	1 (1.9)	--
Care recipient lives...	With caregiver	56 (62.2)	24 (44.4)	0.21
	Within 20 min of CG	20 (22.2)	10 (18.5)	
	20 min to 1 h away from CG	5 (5.6)	5 (9.3)	
	>1 h away	7 (7.8)	7 (13.0)	
	Other	2 (2.2)	4 (7.4)	
	Missing	0	4 (7.4)	--
Caregiving duration	<6 months	17 (18.9)	13 (24.1)	0.54
	6 months to <2 y	43 (47.8)	21 (38.9)	
	2 to <5 y	18 (20.0)	6 (11.1)	
	5 years or longer	10 (11.1)	6 (11.1)	
	Missing	2 (2.2)	8 (14.8)	--
Amount of caregiving in an average week	Up to 8 h	38 (42.2)	24 (44.4)	0.37
	9-19 h	20 (22.2)	8 (14.8)	
	20-39 h	4 (4.4)	5 (9.6)	
	40 hours or more	26 (28.9)	10 (18.5)	
	Missing	2 (2.2)	7 (13.0)	--
Participant is primary caregiver	Yes	61 (67.8)	34 (63.0)	0.75
	Split care evenly with someone else	12 (13.3)	5 (9.3)	
	No, someone else is primary	16 (17.8)	11 (20.4)	
	Missing	1 (1.1)	4 (7.4)	--

¹ Those who answered both the 5-week and 3-month follow-up surveys are considered to have completed follow-up (n=90); all others were excluded from analyses (n=54).

² p-value from chi-square test comparing people who did and did not complete both the 5-week and 3-month follow-up surveys, excluding the “missing” category.

Supplementary Table 3. Results from sensitivity analysis: generalized estimating equation (GEE) models measuring the association between participation in the virtual MemoryCare Caregiver Education Program (intervention) and changes in caregiver confidence, self-efficacy, and burden, including all participants regardless of follow-up duration (n=144 in intervention group and n=80 in control group).

Variable	Category	Confidence		Self-efficacy		Burden	
		Crude Coefficient (95%CI) <i>p</i>	Adjusted Coefficient (95%CI) <i>p</i>	Crude Coefficient (95%CI) <i>p</i>	Adjusted Coefficient (95%CI) <i>p</i>	Crude Coefficient (95%CI) <i>p</i>	Adjusted Coefficient (95%CI) <i>p</i>
Intervention Group * Time period	Intervention * Baseline	Ref	Ref	Ref	Ref	Ref	Ref
	Intervention * 6-week follow-up	1.70 (0.40, 3.00) 0.01	1.94 (0.59, 3.28) 0.005	6.07 (1.69, 10.45) 0.007	8.17 (3.64, 12.80) <0.001	-0.30 (-1.94, 1.35) 0.73	-0.08 (-1.75, 1.59) 0.93
	Intervention * 3-month follow-up	2.40 (1.08, 3.72) <0.001	2.71 (1.33, 4.10) <0.001	7.93 (3.66, 12.21) <0.001	9.68 (5.20, 14.17) <0.001	-0.81 (-2.48, 0.86) 0.34	-0.74 (-2.45, 0.98) 0.40
Intervention Group	No intervention (Controls)	Ref	Ref	Ref	Ref	Ref	Ref
	Intervention	-3.14 (-4.44, -1.85) <0.001	-3.07 (-4.37, -1.77) <0.001	-8.69 (-13.68, -3.80) <0.001	-8.33 (-13.13, -3.53) 0.001	2.69 (0.22, 5.16) 0.03	2.90 (0.58, 5.23) 0.01
Time	Baseline	Ref	Ref	Ref	Ref	Ref	Ref
	6-week follow-up	0.78 (-0.31, 1.86) 0.16	0.61 (-0.52, 1.74) 0.29	-2.10 (-5.63, 1.43) 0.24	-3.58 (37.27, 0.11) 0.06	0.60 (-0.81, 2.01) 0.41	0.40 (-0.98, 1.77) 0.57
	3-month follow-up	0.78 (-0.31, 1.86) 0.16	0.61 (-0.52, 1.74) 0.29	-2.10 (-5.63, 1.43) 0.24	-3.58 (37.27, 0.11) 0.06	0.60 (-0.81, 2.01) 0.41	0.40 (-0.98, 1.77) 0.57

95%CI, 95% Confidence interval for the coefficient; Ref, reference category

Bold numbers indicate statistically significant program effects (group*time variable).

“Intervention” refers to caregivers who participated in the 5-week program.

Separate GEE models estimated for each of the three outcomes; table represents 6 models total (crude and adjusted for each outcome). All adjusted models included caregiver sex, age (18-64 versus 65 or older), relationship to care recipient (parent, spouse, or other), living with care recipient, caregiving duration (<6 months, 6 months-<2 years, 2 years-<5 years, 5 years or longer), average hours per week of caregiving (0-8, 9-19, 20-39, 40 or more), and additional MemoryCare program enrollment (receiving other services for the care recipient).

Supplementary Figure 1. Perceived changes in knowledge, confidence, and behavior management skills and general course satisfaction for Caregiver Education Program during the study period (virtual course, March-December, 2020) and during the preceding year (in-person course, 2019). * $p=0.001$

