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TITLE: Improving Family Quality of Life through Training to Reduce Care-Resistant Behaviors by People with Alzheimer Dementia and Traumatic Brain Injury

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14. ABSTRACT: This project intends to determine whether distance-accessible real time caregiver coaching is associated with improved caregiver burden and quality of life among people providing care to individuals with behavioral and psychiatric symptoms of dementia or neuropsychiatric symptoms after traumatic brain injury. Development of caregiver training materials and intervention strategies occurred as planned and on schedule. Enrollment of participants began close to the original schedule and is ongoing. Potential barriers to recruitment, including the definition of "care resistant behavior" have been addressed and appear to have resolved a slow start to enrollment. Important qualitative observations about the intervention and participant responses have been derived by the intervention team and these are being considered for scholarly reporting and publication. An insufficient number of participants has completed the information for the research team to have collected quantitative data on caregiver burden and family quality of life for statistical analysis. This is consistent with our work plan and expectations for year 1. The project remains active and on schedule.					
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1. INTRODUCTION

This research addressed whether theoretically-driven caregiver education and coaching, focused on non-pharmacologic approaches to reduce care resistant behaviors, would reduce caregiver burden related to of behavioral and psychiatric symptoms of dementia (BPSD) and neuropsychiatric symptoms after Traumatic Brain Injury (NPTBI). This project also assessed the feasibility of the innovative approach of distance learning methods to **teach** caregivers of people with BPSD and NPTBI theoretically determined behavioral techniques and **coach** them on strategies to reduce those adverse behaviors. Combined qualitative, quantitative, and economic analyses were intended to provide pertinent information regarding the general acceptance, utility, reproducibility, and transferability of the coaching intervention (initially named NeuroNS-Care, and renamed CRB-IT based on user feedback) family caregivers in subsequent research studies and clinical settings. The project has now led to follow-on NIH funding using an adapted version of the telehealth coaching developed for this project (*Testing Dementia Caregiver TeleCoaching to Reduce Episodes of Abuse and Neglect by Recognizing and Managing Care-Resistant Behaviors*, 1R01AG074255-01. National Institute of Aging)

2. KEYWORDS:

Dementia – Traumatic Brain Injury – Caregiving – Caregiver Burden – Quality of Life

3. ACCOMPLISHMENTS:

What were the major goals of the project?

Specific Aims:

1. Translate a theoretically-driven intervention, demonstrated to be effective to reduce care resistant behaviors among nursing home resident with dementia to a distance-learning education, training, and coaching program for family caregivers of people with dementia or TBI.
2. Assess the efficacy of the intervention for reducing frequency or severity of CRB-triggered symptoms of agitation, aggression, and irritability.
3. Assess the efficacy of the intervention for improving quality of life of patients, caregivers, and families
4. Determine how patient and caregiver characteristics influence the effectiveness of the intervention
5. Evaluate how the intervention affects the health care costs of people with dementia or TBI.

Major Task 1: Adapt MOUTH techniques to NeuroNS-Care protocol	Target Month	
Subtask 1: Prepare Regulatory Documents and Research Protocol for Study		
<i>Milestone Achieved: Local IRB approval at UAB</i>	3	Completed 9/9/2016
<i>Milestone: HRPO approval (HRPO Log Number A-19729)</i>	4	Completed 12/20/2016
<i>Milestone : Educational materials completed and deployed to web site</i>	4	Completed 1/13/2017
<i>Milestone: Educational materials updated and maintained on web</i>	4-36	N/A

Major Task 2: Hire/Train/Maintain Staff for Clinical Trials	Timeline	
Subtask1: Hiring and Training of Study Staff		100 complete
<i>Milestone: Research staff trained</i>	4	100% complete
Subtask 2: Facilitate hiring, training, supervision and fidelity checks as needed for attrition	4-36	100% Complete
<i>Milestone Achieved: Maintained trained and available Independent Evaluators throughout duration of both clinical trials</i>	4-36	100% Complete
Major Task 3: Randomized Controlled Trial		
<i>Milestone: 1st participant consented, screened and enrolled</i>	5	Completed 3/15/2017
<i>Milestone: Report findings from overall studies</i>	36/post funding	Methods and content reported in peer-reviewed manuscript
Major Task 4: Data Analysis		N/A
<i>Milestone: Report results from data analyses</i>	48 (NCE)	Findings reported at Gerontology and Alzheimer's scientific meetings; summary manuscript draft is attached

We were unable to reach our enrollment goals, eventually reaching 59% of the target. We discovered that there was low enthusiasm among potential participants for multiple reasons, including unfamiliarity with videoconferencing software, resistance to telehealth methods for care delivery, extended time commitments for the coaching sessions, and uncertainty of the outcome of the intervention. The most prominent limiting factor was the desire for a rapid response to difficult behaviors (such as prescription medication). The analysis and dissemination of findings was slowed by the COVID emergency, but all “Major Tasks” were completed by the end of the previously approved No Cost Extension period.

What was accomplished under these goals?

A 12-week cross-over design study, using a distance-learning , internet based, family caregiver coaching program was conducted. A total of 34 community-dwelling people with AD who had at least one recurring BPSD symptom associated with care resistant behavior and causing distress to a family caregiver were enrolled. Ten community dwelling survivors of traumatic brain injury with neuropsychiatric symptoms were also enrolled to assess the generalizability of the intervention to other disease states of interest to the CMDRP.

- 1) Major activities;
 - a. We recruited 34 dyads with AD and 10 dyads with TBI.
 - b. The full planned distance accessible coaching intervention was completed for 26 AD and 9 TBI
- 2) Specific objectives
 - a. Specific Aims are noted in the preceding section
 - b. In the interval since the last report, manuscript preparation, reporting of results, and submission of further findings for presentation at the Gerontological Society of America annual meeting were undertaken
- 3) Significant results or key outcomes, including major findings, developments, or conclusions (both positive and negative)
 - a. Primary hypotheses 1: NOT SUPPORTED Although the effect of the intervention on caregiver burden was in a direction that indicated benefit, there was not statistically significant effect of the intervention on Zarit Burden Inventory (ZBI) scores
 - b. Primary hypothesis 2: SUPPORTED Three baseline variables were significantly associated with caregiver burden on the Zarit Burden Inventory; these were *caregiver neuroticism* ($P < 0.005$), *severity of BPSD* in the patient ($P < .001$) and *older caregiver age* ($P < .05$). No other baseline variables, including severity of cognitive deficits or caregiver personality traits of *mastery* and *resilience* achieved significance relative to the ZBI. In contrast, *caregiver resilience* was associated with higher Family-Quality of Life in Dementia scale scores ($P < .001$)
 - c. Exploratory hypothesis 1: NOT SUPPORTED In the AD cohort, no effects of the intervention were detected on patient quality of life (DEMQOL or DEMQOL-proxy) or caregiver QOL (EQ-5D) – all P values $> .05$. However, caregiver rated *Self-Efficacy in Surrogate Decision-Making* was associated with higher proxy-rated DEMQOL-proxy, while *caregiver distress* on the NPI-D was associated with lower DEMQOL-proxy
 - d. Exploratory hypothesis 2: NOT SUPPORTED In the TBI cohort, no benefit of the intervention was identified for ZBI, caregiver QOL, or patient QOL (all $P > .05$).
 - e. Exploratory hypothesis 3: NOT SUPPORTED No sustained benefit of the intervention on ZBI or QOL measures was detected at late follow-up 12-18 weeks post intervention (all $P > .05$).

- f. Exploratory hypothesis 4: NOT SUPPORTED There was insufficient data reported by participants to reliably analyze changes in health resource utilization.
- g. Exploratory hypothesis 5: NOT SUPPORTED No statistically significant effects of the intervention were identified on FQOL instruments for dementia or TBI. (all $P > .05$)

4) Other achievements

- a. Qualitative analyses of the coaching sessions based on debriefing sessions with the coaches identified critical differences in caregiving challenges between the TBI and AD samples, suggesting that a single common intervention plan will be unlikely to meet the specific needs of these different populations. These observations will undergo systemic qualitative analysis for development into a manuscript under follow-on private funding
- b. This study provided unexpected insights into the acceptance, mechanisms, and content of teleconference-based coaching, which will be important to our future work with caregivers for each illness state. We anticipate that these insights will be of increased utility for clinical practice and research following the rapid expansion of video-based telemedicine in the post-COVID environment. Given that the study data were collected before the widespread acceptance of - and health insurance payment for - telemedicine services in home environments, it would be of interest to see if participants voice similar reticence about the distance learning method in future studies.
- c. We identified that different caregiver personality characteristics were associated with different perceptions of burden and QOL. Caregivers with more neurotic tendencies expressed higher burden levels (indicating a negative emotional valence to their experiences). Caregivers with higher resilience reported better ratings of Quality of Life. This has implications for future caregiver psychoeducational and coaching interventions. More robust responses in future interventions might be garnered by shaping coaching approaches and outcome expectations to the caregiver's personality traits, rather than using a "one-size fits all" approach that is common in psycho-educational and support group models.
- d. We identified associations between caregiver self-efficacy, QOL, and caregiver distress. A higher baseline Surrogate Decision making-Self Efficacy Scale score was associated with more highly rated health-related quality of life for the care recipient. Lower self-efficacy scores were associated with greater caregiver distress associated with neuropsychiatric symptoms. Higher NPI severity and caregiver distress were associated with the caregiver assigning lower proxy QOL scores for the care recipient. These findings indicate that interventions specifically targeting self-efficacy may promote improved QOL and decrease caregiver distress in AD dyads.

The original proposal goals included the statement: **"The combined qualitative, quantitative, and economic analyses will also provide pertinent information regarding the general acceptance, utility, reproducibility, and transferability of NeuroNS-Care to larger groups of family caregivers. These will help guide strategy for the near-certain implementation of synchronous and asynchronous caregiver training programs for both AD and TBI. The proposed study also has the potential to inform healthcare policy and practice for family caregivers of persons with dementia or recovering from TBI."**

The study's stated goal to identify "pertinent information regarding the general acceptance, utility, reproducibility, and transferability" of the intervention was well satisfied.

We learned that 1) acceptance was lower than we expected; 2) utility was low, both because outcome measures did not identify clinically meaningful change, and implementation was very personnel-intensive, requiring extensive professional time; 3) reproducibility was good, with consistent thematic qualitative responses identified within AD and TBI caregiver groups; and 4) transferability of the one-on-one coaching to group sessions was unlikely to yield greater success. Dr. Jablonski's 2018 NIH grant proposal for group remote coaching sessions, (*Efficacy of Tele-Coaching for Caregivers of Persons with Dementia Exhibiting Care-Resistant Behaviors*) based on preliminary observations from this study was not funded.

However, a 5-year, multi-PI project titled "*Testing Dementia Caregiver TeleCoaching to Reduce Episodes of Abuse and Neglect by Recognizing and Managing Care-Resistant Behaviors*" using telehealth coaching content and methods adapted from this study has been funded for \$3.6 million from 2021-2026 by the National Institute on Aging (1R01AG074255-01)

Unmet goals: We were unable to identify sufficient use of healthcare resources in the small samples and short duration study to conduct a valid statistical analysis. Other contemporaneous caregiver intervention research that assessed healthcare utilization and reported since our study was proposed, have identified similar difficulties (e.g. Manning CA, et al, (<https://alz-journals.onlinelibrary.wiley.com/doi/full/10.1002/alz.044033>))

Overall status as reported under HRPO Log Number A-19729

Number of subjects recruited/original planned target: 88 /150

Number of subjects screened/original planned target: 80/150

Number of patients enrolled/original planned target: 44/75

Number of patients completed/original planned target: 35/75

Notification was received on 17 September 2021 that the "*USAMRDC ORP HRPO received and acknowledged continuing review documents for the 2021-2022 review period for HRPO Log Number A-19729.*" The notification stated "*DoD support for this project has ended, no further review of the protocol will be conducted, and the HRPO protocol file will be closed. Any reporting to the HRPO outlined in the protocol will no longer be required.*"

What opportunities for training and professional development has the project provided?

The findings, along with Dr. Jablonski's professional experience in remote caregiver coaching derived from this study informed development of a 3-credit course at the UAB School of Nursing titled, "Post-diagnostic Needs of the Neurological Patient, Caregiver, and Care Systems." This is the final course in the 15-credit post-master's program leading to a "Certificate for Neurological Conditions of Aging." Components of the caregiver coaching curriculum developed in our study now are included in Unit 1 of the course, "Managing Disease Progression and Difficult Behaviors." Details are in the appendix. The intent of the course is to develop expertise among advanced practice providers in the care of persons with dementia and management of caregiver needs in dealing with care resistant behaviors.

How were the results disseminated to communities of interest?

Drs. Geldmacher and Jablonski now collaborate with the Middle Alabama Area Agency on Aging (M4A) on M4A's Federal HHS grant (ACL 90ADPI0042) supporting Home and Community Based services for persons with dementia. (see <https://m4a.org/services/panda-project/>). Dr. Jablonski has translated her qualitative observations from this study's tele-coaching approaches to train the M4A project team, in support of their "Dementia-Friendly Community" initiative.

Quantitative and qualitative observations from the study have been shared with medical student and nursing student trainees at the UAB Memory Disorders Clinic, as well as new-hire Nurse Practitioners and Social Workers undergoing orientation for practice at that clinic.

What do you plan to do during the next reporting period to accomplish the goals?

Nothing to report

4.IMPACT

What was the impact on the development of the principal discipline(s) of the project?

Important qualitative observations about strengths and limitations of online coaching methods for informal caregivers of persons with dementia were obtained. These observations led to the development of a coaching training program that could be embedded into existing community resources for informal caregivers.

- An NIH grant (PI: Jablonski) was submitted but not funded.
- An ongoing collaboration with the federally funded Administration for Community Living funded dementia caregiver support program (ACL Grant 90ADPI0042) was initiated.
- An NIH grant (MPI Jablonski & Pickering) using telehealth coaching was funded in 2021

Better understanding of the need to individualize caregiver coaching to personality characteristics, and a focus on self-efficacy in decision-making may help develop better future studies and more effectively deliver clinical care. We intend for this to lead to an editorial in the *Journal of Gerontological Nursing*

What was the impact on other disciplines?

The intervention could enhance the holistic approach to care in the clinical setting by adding an additional resource focused on the informal caregiver as a part of the persons with dementia's care plan. This expands the concept of "Person-Centered Care" into "Relationship-Centered Care." This might include "lay navigators" trained to deliver key personalized elements of caregiver coaching, especially regarding self-efficacy in surrogate decision making. Demonstration of feasibility, and data on outcomes, on that potential impact have not been generated.

What was the impact on technology transfer?

This project will impact community resources for informal caregivers by encouraging adoption of online coaching as a supplement to existing care delivery strategies. The project's determination that distance accessible coaching is *feasible* will likely influence expansion of methods to provide caregiver support, knowledge, and reinforcement of strategies to address care-resistant behaviors that do not require the physical presence of the caregiver. These include expansion of telemedicine services for dementia care, and technology-rich approaches like smartphone apps. We anticipate these will represent important expansions of service in a predominantly rural state like Alabama. The COVID emergency accelerated development of more-easily-used, HIPAA-compliant telehealth applications, bypassing the older-generation technologies we used in this study. Dr. Geldmacher is now an investigator on NIH funded projects to develop a smartphone app aimed to better support dementia caregivers. The need for tailored approaches to individual caregivers that we identified in this research is being applied in those studies, allowing caregivers to choose modules within the app best meet their needs.

What was the impact on society beyond science and technology?

As noted in the previous section, online coaching for informal caregivers has the potential to provide coaching resources to future caregivers who need support but lack access to resources that require a physical presence. Rural states like Alabama have major shortages in dementia-specialty providers; there is only one Neurology-based dementia specialty clinic in the state. Studies like this, that demonstrate the feasibility of delivering remote caregiver coaching and support, will likely influence the future of dementia care in communities far from specialty care.

Changes in Medicare/Medicaid and Veteran's Administration rules that expand payment for telehealth services will allow wider dissemination of interventions like the one we developed for this study. It can be cost effective and has the potential to improve the lives of those caring for persons with dementia by reducing burdens of transporting care-resistant people to distant clinics for expert care

In the DoD healthcare system, telehealth coaching approaches to difficult behaviors would allow sites worldwide to have access to expertise which can be centralized at key locations for remote service. This strategy has the potential to improve care delivery by both professional and informal caregivers of people with behavioral symptoms arising from neurological disorders.

5. CHANGES/PROBLEMS:

Changes in approach and reasons for change

Extreme difficulty in recruitment was experienced in the first two years of the study; family caregivers were reticent to commit to the time required for coaching, the technology was daunting for some, and many caregivers who were approached wanted the more expedient and easier approach of drug treatment. – this required a reduction in sample size to 34 Alzheimer dyads and 10 TBI dyads (59% of the goal) Our reduced sample limited of meaningful analyses of resource utilization, but allowed us to increase focus on qualitative aspects of the intervention

Actual or anticipated problems or delays and actions or plans to resolve them

We added recruitment sites and methods, but were unable to meet our projected enrollment. While disappointing, this has been identified as a recurring problem in studies focused on adverse behaviors in dementia. (see https://www.isctm.org/public_access/Feb2017/ISCTM-BPSD-Distribute-Working-Group-2017-final.pdf). *Our projection that the availability of care-delivery at home would overcome recruitment difficulty seen in traditional clinical trials was not supported.* This itself was a valuable learning, which will need to be re-evaluated in the post-COVID care environment.

Changes that had a significant impact on expenditures

Staff commitments were reported by quarter throughout the study; because of lower than expected enrollment, efforts that would have been dedicated to intervention were instead allocated to recruitment and retention activities.

Significant changes in use or care of human subjects, vertebrate animals, biohazards, and/or select agents

Significant changes in use or care of human subjects

Nothing to Report

Significant changes in use or care of vertebrate animals

Nothing to Report

Significant changes in use of biohazards and/or select agents

Nothing to Report

6. PRODUCTS:

- **Publications, conference papers, and presentations**

Journal publications.

- Jablonski RA, Winstead V, Geldmacher DS.. Description of Process and Content of Online Dementia Coaching for Family Caregivers of Persons with Dementia. *Healthcare* 2019;7:13. <https://doi.org/10.3390/healthcare7010013> DoD funding acknowledged: **yes**
- Jablonski R, Winstead V, Pilonieta G, Geldmacher DS. Telehealth Coaching for Caregivers of persons with dementia and care-resistant behaviors: an exploratory study (in preparation; target journal: *Gerontologist*) – **draft appended**

Books or other non-periodical, one-time publications.

Nothing to report

Other publications, conference papers and presentations.

Podium Presentations:

- Jablonski R, Winstead V, Geldmacher D. Perspectives of family caregivers confronted with care-resistant behavior from persons with dementia. Presented at 2020 Annual Scientific Meeting of the Gerontological Society of America (held virtually because of COVID pandemic) November 19, 2020

Poster Presentations:

- Geldmacher DS, Jablonski RA, Winstead V, Pilonieta G. Family Quality of Life in Dementia and Caregiver Burden are Associated with Different Caregiver Personal Characteristics. Presented at 2020 Alzheimer's Association International Conference (held virtually), July 30, 2020
- Pilonieta G, Geldmacher DS. Dementia Caregiver Surrogate Decision Making Self-Efficacy: Distress and Quality of Life. Accepted for presentation 2021 Annual Scientific Meeting of the Gerontological Society of America (to be held virtually, November 2021)

Published Abstracts

- Jablonski R, Winstead V, Pilonieta G, Geldmacher D. Feasibility of online synchronous caregiver dementia coaching for rejection-of-care behaviors. *Innovation in Aging*, 2019;3 (S1):924
- Geldmacher DS, Jablonski RA, Winstead V, Pilonieta G. Family Quality of Life in Dementia and Caregiver Burden are Associated with Different Caregiver Personal Characteristics. *Alzheimer's & Dementia*, 16, e045333.
- Jablonski R, Winstead V, Geldmacher D. Perspectives of family caregivers confronted with care-resistant behavior from persons with dementia. *Innovation in Aging*, 2020;4 (S1):253

- **Website(s) or other Internet site(s)**

Nothing to report

- **Technologies or techniques**

Nothing to Report

- **Inventions, patent applications, and/or licenses**

Nothing to Report

- **Other Products**

Nothing to Report

7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

What individuals have worked on the project?

Name	David Geldmacher, MD (Dr. Geldmacher's effort was reduced from 1.6 CM to 0.4CM during this extension of the project. This change occurred as the study's work transitioned from operational management to thematic and statistical analysis, which he oversaw rather than conducted personally)
Name	Rita Jablonski-Jaudon, PhD (no change)
Name	Vicki Winstead (no change)
Name	Felicia Underwood (vacated position March 2021; no replacement. Ms. Underwood's role in scheduling and coordinating meetings and visits was no longer required following database lock and submission of data for analysis)

Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?

Dr. Geldmacher (PI): reports these changes in other research support during the final reporting period

Project Name/Number	Oct19 to Sep20	Oct 20 to Aug 21	Difference
Medical and Quality Officer	18.50%	20.10%	1.60%
MBAR	5.30%	0.00%	-5.30%
Warren Endowment	7.70%	5.90%	-1.80%
UAB Alzheimer Core	4.70%	0.00%	-4.70%
221AD302	0.50%	0.00%	-0.50%
CN002003	0.10%	0.00%	-0.10%
W81XWH-16-1-0527	13.70%	3.40%	-10.20%
ABBV-8E12 M15-562	1.00%	0.20%	-0.80%
U54MD000502-17S2	9.20%	4.40%	-4.70%
ABBV-8E12 M15-562	0.20%	0.00%	-0.20%
251PP201	2.00%	1.00%	-1.00%
251AD201	8.00%	5.90%	-2.10%
P50NS108675	0.80%	4.90%	4.10%
1U24AG057437-01	9.50%	9.90%	0.40%
R21 HS026571	3.00%	1.00%	-2.00%
2U19AG024904	0.20%	0.10%	-0.10%
Ban2401-G000-201	1.00%	0.00%	-1.00%
1R01AG053798	0.00%	1.70%	1.70%
221AD304	1.50%	2.90%	1.40%
R01MH121928	3.50%	4.90%	1.40%
1R01AG053798	1.30%	3.00%	1.70%
P20AG068024	1.30%	14.80%	13.50%
ALZ2002	0.30%	1.00%	0.70%
ATH-1017	0.00%	2.20%	2.20%
R01NS095435	0.00%	1.00%	1.00%
R01AG068672	0.00%	4.40%	4.40%
1RF1AG072773-01	0.00%	0.40%	0.40%
TOTAL	100.00%	100.00%	0.00%

- Dr. Geldmacher's effort on this project was reduced with approval of the sponsoring agency upon transition from operations to statistical and qualitative/thematic analysis
- Drs. Jablonski and Winstead identify no significant changes in funding status during this reporting period.

What other organizations were involved as partners?

Nothing to Report

8. SPECIAL REPORTING REQUIREMENTS

COLLABORATIVE AWARDS:

QUAD CHARTS:

9. APPENDICES:

See attached pages

APPENDICES-Table of Contents

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4	Published Abstract: Pilonieta G, Jablonski RA, Winstead V, Geldmacher DS. Family Quality of Life in Dementia and Caregiver Burden are Associated with Different Caregiver Personal Characteristics. <i>Alzheimer's & Dementia</i> , 2020; 16: e045333.
5	Published Abstract: Jablonski R, Winstead V, Geldmacher D. Perspectives of family caregivers confronted with care-resistant behavior from persons with dementia. <i>Innovation in Aging</i> , 2020;4 (S1):253
6	Course Curriculum Excerpt (based on observations/methods from this project): UAB School of Nursing course NCN 624 "Post-Diagnostic Needs of the Neurological Patient, Caregiver, and Care Systems" – Unit 1/Module 4 "Non-Pharmacological Management of Dementia-Associated Behaviors by Settings."
7	Funded Follow-on Grant Summary: Testing Dementia Caregiver TeleCoaching to Reduce Episodes of Abuse and Neglect by Recognizing and Managing Care-Resistant Behaviors 1R01AG074255-01
9	Statistical analysis summary
37	Peer-reviewed published manuscripts Jablonski RA, Winstead V, Geldmacher DS. Description of Process and Content of Online Dementia Coaching for Family Caregivers of Persons with Dementia. <i>Healthcare</i> 2019;7:13. https://doi.org/10.3390/healthcare7010013
52	Draft final manuscript Jablonski RA, Winstead V, Pilonieta G, Geldmacher DS. Telehealth Coaching for Caregivers of persons with dementia and care-resistant behaviors: an exploratory study. In preparation for <i>Gerontologist</i>

relationships and activities that drive collaborative community change processes. The survey asks a representative from each organizational member of an AFI coalition to select “partner” organizations with whom they have worked on AFI goals. Respondents then select from a list of activities in which they engage with each partnering organization. The questions regarding collaboration activities were developed based on theories of inter-sectoral and community-wide collaboration, SNA studies of collaboration in health prevention networks, and qualitative interviews with leaders of an established AFI coalition in Upstate New York. This tool was administered with respondents from 18 organizations comprising the New York coalition. Administration of the pilot indicated that the questions were acceptable and feasible for participants to complete. Analysis of the data through SNA software (UCINET) yielded visual maps to understand dimensions of the AFI’s inter-organizational network. Local government offices and nonprofits emerged as central network nodes for connecting stakeholders. Findings also indicated denser networks around lower-intensity collaboration activities, such as sharing information, relative to higher-intensity activities, such as sharing financial resources. Implications of the tool for future research on the development of AFIs across diverse community contexts are discussed.

QUANTIFYING THE BURDEN OF HOSPITALIZED DAYS IN MEDICARE BENEFICIARIES WITH MULTIMORBIDITY

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Multimorbidity predicts several health outcomes including physical and cognitive functioning and mortality. Multimorbidity also predicts healthcare burden, but this has not been studied using a patient-centered measure that weights conditions by their impact on physical functioning. Health and Retirement Study participants were continuously enrolled in Medicare Parts A/B 1-year before and after the 2012-2013 HRS interview. Medicare claims were used to compute ICD-coded multimorbidity-weighted index (MWI-ICD) by summing physical functioning-weighted conditions. Given excess observations of zero hospital days (78.1%), we used zero-inflated Poisson regression to examine the association between multimorbidity and hospitalized days. First, logit models predicted membership into the zero-coded “no hospitalizations” group. Second, Poisson models predicted hospital days for participants not in the zero-coded group. We converted adjusted regression coefficients to odds ratios to report odds of zero hospitalized days. To compare model fit between MWI-ICD and simple disease count we used AICs. The final sample N=5201 participants had mean age 77.6+/-11.6 years, MWI-ICD 16.5+/-11.6, and 1.9+/-6.0 (range 0-90) hospitalized days. Each 1-point increase in MWI-ICD was associated with 4.3% decreased odds of zero hospitalized days (OR=0.96, 95%CI: 0.95-0.96) and 2% increased number of expected hospitalized days (IRR=1.02, 95%CI: 1.01-1.03) over one year in adjusted models. MWI-ICD

had a lower AIC than simple disease count. Multimorbidity measured with MWI-ICD was associated with a decreased odds of zero hospitalized days and an increased number of expected hospitalized days. Multimorbidity contributes greatly to patient burden through increased hospitalization and is better captured through an index weighting conditions to physical functioning.

VALIDATION OF A BRIEF SCREEN TO IDENTIFY PERSONS WITH DEMENTIA AT RISK FOR BEHAVIORAL DISTURBANCE

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Per current guidelines, clinical assessment of persons with dementia (PWD) should include potential causes of behavioral and psychiatric problems including pain, depression, and caregiver-patient relationship quality. Many validated assessment tools are available; however, administering a battery of instruments is not practical in most clinical settings. Objectives of this secondary analysis are to 1) evaluate the construct validity of brief screens (1-3 questions each) for pain, depression, and relationship strain by examining their associations with validated measures (Geriatric Depression Scale, Modified Philadelphia Pain Scale, Zarit Burden Interview, Mutuality Scale) and medication use and 2) evaluate the predictive validity of each individual screen and the screens as a set (number positive) by examining their associations with frequency of disruptive behaviors on the Revised Memory and Behavior Problem Checklist. PWDs (n=228) were included in the original trial if the PWD or the caregiver endorsed one or more of the three screens. There was evidence of good convergent and discriminate validity for each individual screen (p 's < 0.01). Although only the relationship screen was individually associated with frequency of disruptive behaviors (p < 0.00010), the total number of screens endorsed was positively associated with this frequency ($F(2,225) = 5.50, p = 0.005$). In this sample, the brief screening questions showed good construct and predictive validity. Further studies are needed to determine if they can be used to identify patients with depression, pain, and/or caregiver-patient relationship problems in the clinical setting.

FEASIBILITY OF ONLINE SYNCHRONOUS CAREGIVER DEMENTIA COACHING FOR REJECTION-OF-CARE BEHAVIORS

Rita A. Jablonski,¹ Winstead Vicki,¹ Giovanna Pilonieta,¹ and David Geldmacher¹, *1. University of Alabama at Birmingham, Birmingham, Alabama, United States*

Problem: Two-thirds of family caregivers of persons living with dementia have encountered rejection-of-care behavior, usually during assistance with activities of daily living. Purpose: To describe the feasibility of an online videoconferencing platform to help caregivers prevent and reduce ROC behavior. Design: Quasi-experimental. Sample: Twenty-six family caregivers: 54% female, 77% white, 62% spouses (31% wives, 31% husbands), mean age 65 years, and college-educated (92%). Their care recipients were 61% female, 77% white, mean age of 76 years, and college-educated

(88%). Procedure: Family caregivers who endorsed problematic ROC behaviors in their care recipients participated in six online, individual, synchronous, sequential, and weekly 1-hour coaching sessions. We measured general burden (Zarit Burden Inventory) and the frequency, severity, and associated distress of responsive behaviors (Neuropsychiatric Inventory Questionnaire). Data collection intervals were before coaching (baseline), immediately after the final session (Time 1), and six weeks (Time 2) and 12 weeks (Time 3) after the final session, respectively. Results: Caregivers reported less overall distress scores at Time 2 compared to baseline: 13.58 (SD 6.44) versus 17.42 (SD 6.90), $t=2.56$, $p=0.017$. Distress scores returned to baseline by Time 3. Caregivers reported less severe ROC behavior at Time 2 which was not statistically significant. Burden remained unchanged throughout the 24 weeks. Conclusion: Online caregiver coaching that targets ROC behavior is feasible. Qualitative review of the encounters suggests that a longer period of intervention and an outcome measure more sensitive to ROC effects on activities of daily living may be needed in future studies.

ATTACHMENT SECURITY AND DEPRESSIVE SYMPTOMS IN OLDER-ADULT MARRIAGES

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Attachment theory emphasizes attachment security, providing and receiving communication of safety and emotional support, as one of the most fundamental needs in close relationships across the lifespan. Having an insecure attachment style, anxious or avoidant attachment, has been related to depressive symptoms in mostly young adult marriages. This study examined the interpersonal associations between attachment anxiety, attachment avoidance, and depressive symptoms in 98 older adult couples, using self-report measures. The Actor Partner Interdependence model was used to analyze the data. Results show that one partner's anxious attachment was significantly positively associated with their own greater depressive symptoms ($\beta=2.10$, $p=0.000$). This effect was stronger for husbands than for wives ($\beta=1.13$, $p=0.002$). Results remained when controlling for age, physical functioning, marital length, and socio-demographics. There were no significant cross-partner associations. Findings suggest that attachment anxiety may be particularly impactful for depressive symptoms in husbands.

ABO GENE AND AGING-RELATED OUTCOMES IN OVER 379,000 EUROPEAN-DESCENT PARTICIPANTS OF UK BIOBANK

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Genetic variants associated with multiple traits are potential targets to delay aging. Drugs supported by genetic evidence are twice as likely to succeed in human trials. Single nucleotide polymorphisms (SNPs) in the ABO gene were

reported by genome-wide associations studies, associated with breast cancer, coronary artery disease, stroke, and type II diabetes. To evaluate the potential of ABO gene as a target for aging intervention, we conducted a genome-wide association study (PheWAS) to associate the genotype-derived blood types (based on two SNPs in the ABO gene) with a wide range of aging-related outcomes. The genotype-derived blood type distribution (41% A, 9% B, 3% AB, and 47% O) is similar to that reported by the UK National Health Service (39% A, 10% B, 3% AB, and 48% O). The blood type was not associated with parental lifespan or extreme parental longevity. Non-O types had modestly lower risk of hypertension than O type but higher risk of type II diabetes and pancreatic cancer (e.g., OR= 1.37, 95% CI: 1.17 to 1.59 comparing A to O). Additionally, "A" type had modestly higher risk of breast cancer than other types. "A" allele (in A or AB type) was associated with lower heel bone mineral density, alkaline phosphatase (e.g., 0.41 standard deviation lower in A than that in O, 95% CI: -0.42 to -0.40), and hemoglobin concentration, but higher HbA1c, direct LDL, and cholesterol. Blood types with A allele(s) are less favored than other blood types, which however are adversely associated with some aging traits.

SEX HORMONES AND ARTHRITIS IN A LONG-LIVED ANIMAL MODEL, THE ELEPHANT

Daniella E. Chusyd,¹ Janine Brown,² Tim R. Nagy,³ Timothy Griffin,⁴ Virginia Kraus,⁵ Janet Huebner,⁵ David Allison,⁶ and Steven N. Austad⁷, 1. *Indiana University, Bloomington, Indiana, United States*, 2. *Smithsonian Conservation Biology Institute, Front Royal, Virginia, United States*, 3. *Department of Nutrition Sciences, University of Alabama at Birmingham, Birmingham, Alabama, United States*, 4. *Oklahoma Medical Research Foundation, Oklahoma City, Oklahoma, United States*, 5. *Duke University, Durham, North Carolina, United States*, 6. *Indiana University, Bloomington, Indiana, United States*, 7. *Department of Biology, University of Alabama at Birmingham, Birmingham, Alabama, United States*

Arthritis affects women more so than men, particularly after menopause. Sex hormones may play a role in arthritis development, yet this is still unclear. Elephants have a similar lifespan to humans and develop arthritis and joint issues (musculoskeletal impairments (MI)), but do not undergo menopause. Interestingly, many female zoo elephants do not exhibit normal ovarian cycles, closely resembling that in post-menopausal women. Objectives: 1) examine ovarian cyclicity status with MI (Asians: N=84; Africans: N=83); 2) determine whether gonadotropin and sex hormones are reduced in cycling elephants with MI (Asians: N=16; Africans: N=26); and 3) evaluate whether serum CTXI, a marker of type 1 collagen degradation, is associated with MI in elephants (Asians: N=40; Africans: N=32). We used longitudinal serum and health data on ovarian cycling and non-cycling zoo African and Asian elephants with and without MI. Serum progesterone, leutinizing hormone, follicle stimulating hormone, and CTXI concentrations were measured. Cyclicity status was based on progesterone patterns. Zoo veterinarians classified the elephant with MI based on clinical exams and observations. In both Asian and African elephants, MI was significantly associated with cyclicity

Dementia care research (research projects; nonpharmacological)/Family/Lay caregiving

Family quality of life in dementia and caregiver burden are associated with different caregiver personal characteristics

Giovanna Pilonieta | Rita A Jablonski | Vicki Winstead | David S Geldmacher

University of Alabama at Birmingham,
Birmingham, AL, USA**Correspondence**David S Geldmacher, University of Alabama at
Birmingham, Birmingham, AL, USA.
Email: dgeldmacher@uabmc.edu**Abstract**

Background: Most care for persons with dementia takes place in the context of family. Dementia is associated with diminished quality of life for both affected persons and their caregivers, as well as increased burden. There is a growing consensus in dementia care that service-delivery models for persons with dementia need to be family-centered, but few studies have explored the concept of “family quality of life” (FQOL) in dementia. As part of a planned coaching intervention to reduce burden in caregivers of people with behavioral and psychiatric symptoms of dementia (BPSD) associated with care resistance, we collected baseline data on factors that might influence burden, FQOL, and response to the intervention.

Method: The 42-item Family Quality of Life in Dementia (FQOL-D) questionnaire, Connor-Davidson Resilience scale (CD-RISC), Pearlin Mastery scale, and neuroticism items from Eysenck Personality Inventory (EPI) were collected from 26 family caregivers of people with AD who endorsed BPSD with care resistant behaviors. The Spearman correlation between caregiver personality traits and FQOL-D was calculated. In addition, relationships between caregiver burden, measured with the Zarit Burden Interview (ZBI), and caregivers' personality characteristics were ascertained.

Result: Of the 26 enrolled caregivers, 14 (53.85) were female, their mean age was 64.5 years and 24 (92%) were college-educated. Their care recipients were 61% female, 77% white, mean age of 76 years, and college-educated (88%). Mean scores were CDRISC 76.03 (+/-12.05), EPI 6.30 (+/-1.95), Pearlin 20.23 (+/-3.26) and FQOL 173.80 (+/-24.92). There were moderate correlations between FQOL and CDRISC ($r=0.5$). Secondary analysis showed moderate correlations between ZBI and Pearlin ($r=-0.42$) and EPI ($r=0.48$). All reported associations are $P<.05$

Conclusion: A relationship between Family Quality of Life and caregiver personal characteristics was identified. Higher baseline FQOL-D was associated with greater self-reported resilience. Similarly, higher mastery scores were associated with lower burden on the ZBI. Higher caregiver neuroticism was associated with higher reported burden. No relationships between mastery or neuroticism and FQOL-D were established in this small sample. We identified that the positive construct of FQOL-D may be associated with different caregiver characteristics than the negative emotional valence attributed to burden.

suggest one avenue by which investing in caregiver training may be cost-effective for integrated payers and providers.

PERSPECTIVES OF FAMILY CAREGIVERS CONFRONTED WITH CARE-RESISTANT BEHAVIOR FROM PERSONS WITH DEMENTIA

Rita Jablonski,¹ Vicki Winstead,² and David Geldmacher,³
1. UAB School of Nursing, Birmingham, Alabama, United States, 2. University of Alabama at Birmingham, Alabaster, Alabama, United States, 3. UAB School of Medicine, Birmingham, Alabama, United States

Problem: Care-resistant behavior is often bundled with other behavioral symptoms of dementia, but it is a unique behavior requiring targeted interventions. **Purpose:** To describe the experiences of caregivers receiving online coaching to manage care-resistant behaviors exhibited by persons with dementia. **Design:** Qualitative. **Sample & Procedure:** 20 caregivers (12 female, 8 male) were recruited from Memory Disorders and Geriatrics clinics to participate in 6 weeks of online coaching sessions delivered by a doctorally prepared nurse practitioner. Coaching sessions were recorded and transcribed. NVivo12 software was used to manage the thematic analyses. **Results:** Caregivers followed a general trajectory. They initially reported feelings of anger, frustration, and guilt. They believed that the person with dementia was purposefully “being stubborn and mean.” As the coaching sessions progressed, these negative emotions and the attributions of intent altered. By the conclusion of the six weeks, caregivers expressed feelings of success and ingenuity in applying coaching strategies. **Conclusion:** Online coaching is an effective way to individualize strategies that enable the caregiver to manage and reduce care-resistant behavior. **Implications:** The use of a doctorally-prepared nurse practitioner to deliver coaching, while effective, is not sustainable. Next steps include developing a coaching training program that could be embedded into existing community resources for community-dwelling caregivers. **Limitations:** Participants were limited to referrals from two clinics in the same institution.

RURAL-URBAN DIFFERENCES IN INFORMAL CAREGIVING, CAREGIVING INTENSITY, AND HEALTH-RELATED QUALITY OF LIFE

Steven Cohen, Julia McIlmail, and Mary Greaney,
University of Rhode Island, Kingston, Rhode Island, United States

Introduction Rural areas in the US have a disproportionately high population of older adults and have reduced access to services. Older adults in rural areas are more reliant on family and friends for care. However, little is known about rural-urban disparities among the 40+ million caregivers nationwide. As rural-urban health disparities are pervasive among older adults, there is a need to understand how rural-urban disparities impact caregiving experiences and health-related quality of life (HRQoL). The objectives of this study were to examine rural-urban differences caregiving, caregiving intensity (caregiving hours/week and types of care provided), and caregiver HRQoL. Methods

Data were abstracted from the 2009 Behavioral Risk Factor Surveillance System (latest dataset to include county of residence and caregiver module). The primary measure of rural-urban status was Index of Relative Rurality (IRR) decile. Associations between rural-urban status and caregiving and rural-urban differences in caregiving intensity and HRQoL were examined using generalized linear models, controlling for confounding and accounting for complex sampling. Results Rural respondents were more likely to be caregivers than urban respondents (IRR decile OR=1.015, 95%CI 1.014-1.016). Rural caregivers, on average, provided 2.43 hours/week more caregiving for each one-decile increase in IRR decile (95%CI 2.34-2.52) and had worse overall HRQoL (OR=1.34, 95%CI 1.33-1.35). Conclusion Rural informal caregivers offer higher levels of care than urban counterparts, and increased caregiving in rural areas is associated with reduced HRQoL. These results can inform policies designed to improve caregiver health, and facilitate the translation of existing programs and interventions to address rural caregivers' needs.

THE HALF LIFE OF STRESS: CAREGIVER STRESS INCREASES NEXT-DAY SEVERITY OF BEHAVIORAL SYMPTOMS OF DEMENTIA

Carolyn Pickering,¹ Frank Puga,² Danny Wang,¹ and Maria Yefimova,³ 1. University of Alabama at Birmingham, Birmingham, Alabama, United States, 2. The University of Alabama at Birmingham, Birmingham, Alabama, United States, 3. VA Palo Alto Healthcare System, Redwood City, California, United States

The progressively lowered stress threshold theory posits that behavioral symptoms of dementia (BSD) are reactions to environmental and care related stressors. In line with this theory, this study tests whether the stress experienced by the caregiver impacts BSD expression. Caregivers to persons with dementia recruited online completed daily diary surveys for 21 days reporting on daily contextual and environmental factors of caregiving life. Using multi-level modeling of diaries (n=911) nested within participants (N=51), two daily caregiver stressors (conflict with someone other than the person with dementia, stress about own personal health) were examined as predictors of BSD. The outcome of BSD was measured as severity (a rating on a Likert scale of 1-5 that was then person-centered to represent deviations from average severity). Covariates in the model included relationship type, caregiver age, as well as stressors to the care recipient known to increase BSD. On days when a caregiver had a conflict with others the severity of the care recipient's BSD increased by 1.44 points from average ($p < .001$, CI 1.05-1.75). In a time-lagged model, we observe that a caregiver having a conflict yesterday impacts today's BSD severity by an increase of 0.43 points from average ($p = 0.027$, CI 0.05-0.81). Caregivers' stress about their own health did not have a significant impact on the same day or next day BSD severity rating. These findings demonstrate that the well-being of the caregiver has measurable immediate impacts on the well-being of the person living with dementia, and suggests not all stress is equal.

NCN624 Course Blueprint

Course Title: NCN624: Post-Diagnostic Needs of the Neurological Patient, Caregiver, and Care Systems

Intended audience: Students enrolled in SON graduate clinical programs or post-masters advanced practice nurses; interprofessional team members including physicians, social workers, physical and occupational therapists.

UNIT 1: Managing Disease Progression and Difficult Behaviors

Module 4: Non-Pharmacological Management of Dementia-Associated Behaviors by Settings

Course Objective	Behavioral Objective for the Module	Module Content Outline	Teaching/Learning Activities	Evaluation Methods
1. Describe and intervene in common behaviors encountered across stages and types of dementia	8) Describe the utility of interventions designed to address multiple dementia-associated behaviors (bundled) 9) Describe the utility of interventions designed to address singular (targeted) dementia-associated behaviors 10) Describe the utility of different types of non-pharmacological approaches to dementia-associated behaviors by settings 11) Compare and contrast bundled interventional approaches with targeted interventional approaches	4) Bundled interventions versus targeted interventions a) Bundled Exemplar: REACH b) Targeted Exemplar: Dementia caregiver coaching for CRB 5) Community Settings a) Person-centered care modalities b) Dementia-care mapping modalities c) Faith-based Respite programs 6) Long-term care settings a) Person-centered care modalities b) Nursing home toolkit with alternatives to antipsychotics i) Music ii) Art iii) Aromatherapy iv) Massage v) Activities 7) Acute care settings 8) Hierarchy Model of Needs in Dementia 9) All Clinical Settings a) DICE approach for neuropsychiatric symptoms Describe, investigate, create, evaluate	1) 1.Readings a) select journal articles b) pre-recorded instructor presentations c) real-time discussions of case studies	

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Testing Dementia Caregiver TeleCoaching to Reduce Episodes of Abuse and Neglect by Recognizing and Managing Care-Resistant Behaviors

Project Number	Contact PI/Project Leader	Awardee Organization
1R01AG074255-01	JABLONSKI, RITA AOther PIs	UNIVERSITY OF ALABAMA AT BIRMINGHAM

 Description

Abstract Text

PROJECT ABSTRACT In family caregiving situations, those with Alzheimer’s disease and related dementia (ADRD) are more likely to experience elder abuse and neglect (EAN) than older adults living alone or not requiring assistance with care. Elder abuse and neglect (EAN) is defined as acts committed by a person in a trusted relationship that cause actual or increased risk of harm to an older adults’ health and wellbeing. EAN consists of different subtypes such as physical and psychological abuse and neglect. About half of family caregivers for persons with dementia self-report doing at least one of these three EAN subtypes. This proposal evaluates an evidence-based tele-coaching intervention, Care-Resistant Behavior Internet Training (CuRB-IT) to enhance coping skills of family caregivers and reduce elder abuse and neglect (EAN). CRB includes actions taken by a person with ADRD to resist or refuse assistance with care, such as refusing to open their mouth for oral care or using physical aggression. Our tele-coaching intervention (CuRB-IT), which increases problem-solving coping skills by teaching practical strategies to manage CRBs, effectively reduces CRB-related caregiver distress. We will test the effectiveness of CuRB-IT in a delayed-intervention randomized clinical trial, within a multi-time series approach. Caregivers in immediate- and delayed-intervention groups (N=266) will complete 4 waves of instrument completion and daily diary surveys describing the frequency of CRB and EAN over a 21-day period at baseline, 3 months, 6 months, and 9 months. Delayed-intervention caregivers will receive weekly texts to reduce inflated intervention effects inherent in many wait-list control designs.22 After the 3-month follow-up, the delayed-intervention group will then receive the CuRB-IT intervention. This design allows us to maximize power to examine efficacy (between-group), mechanism-of-action, and intervention delay (within-group). Thus, we propose the following Specific Aims: 1) Test the efficacy of an online care-resistant behavior coaching intervention in reducing frequency of EAN (a) among the experimental (immediate-intervention group) as compared to the control (delayed-intervention group) (between groups) and (b) within-person from pre- to post- intervention.; 2) Test hypothesized mechanism of action through multi-level structural equation modeling to assess the relationships between CRB-stress appraisal, use of CuRB-IT problem-focused coping strategies and EAN; and 3) Examine intervention decay at 3- and 6-months post intervention to determine performance of intervention and inform scheduling of booster sessions. We will also assess the efficacy of the CuRB-IT intervention in preventing onset of EAN use by family caregivers as an exploratory aim. This proposal directly addresses high-priority research gaps identified by the NIH Office of Disease Prevention and US Preventative Task Force. Next steps in this research program will focus on translation to practice settings such as the UAB Health system’s Caregiver Bereavement Service Line and Adult Protective Services.

Public Health Relevance Statement

PROJECT NARRATIVE Persons living with Alzheimer’s disease and other dementias may refuse help, which can cause family caregivers to feel helpless and neglect the elder or feel frustrated and las’ out. We will see if our caregiver coaching program, Care-Resistant Behavior Internet Training (CuF

IT), helps family caregivers better cope with refusals by learning ways to prevent these behaviors. We also will see if CuRB-IT prevents and lessens elder abuse and neglect.

Project Terms

Address	Adult	Advisory Committees	Alzheimer's Disease		
Alzheimer's disease related dementia		Area	Behavior	Behavioral Symptoms	
Caregivers	Caring	Cessation of life	Consultations	Coping Skills	
Coupled	Dementia	Dementia caregivers	Distress	Educational Intervention	
Educational process of instructing		Elder Abuse	Elderly	Equation	Ethics
Family	Family Caregiver	Frequencies	Funding	Guilt	Health
Health system	Injury	Internet	Intervention	Intervention Studies	
Knowledge	Lead	Learning	Mandatory Reporting	Mental Depression	
Read More					

Details

Contact PI/ Project Leader

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Title	ASSOCIATE PROFESSOR
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Other PIs

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Organization

Name	UNIVERSITY OF ALABAMA AT BIRMINGHAM	Department Type	OTHER HEALTH PROFESSIONS	State Code	AL
City	BIRMINGHAM	Organization Type	SCHOOLS OF NURSING	Congressional District	07
Country	UNITED STATES (US)				

Other Information

FOA	PAR-19-070	Administering Institutes or Centers	NATIONAL INSTITUTE ON AGING	Project Start Date	01-September-2021
Study Section	Special Emphasis Panel[ZRG1-HDM-Z(02)]	DUNS Number	063690705	Project End Date	30-June-2026
	Award Notice Date	CFDA Code	866	Budget Start Date	01-September-2021
Fiscal Year	2021			Budget End Date	30-June-2022

Project Funding Information for 2021

Total Funding	\$690,729	Direct Costs	\$469,262	Indirect Costs	\$221,467
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TOP LINE STATISTICAL ANALYSIS

Table Sample characteristics Baseline	AD	TBI
Diagnosis (N/ %)	34 (77.27)	10 (22.73)
Sex (N/%)		
Female	21 (61.76)	3 (30)
Male	13 (38.24)	7(70)
Race (N/%)		
White	25 (73.53)	9 (90)
AA	7 (20.59)	1 (10)
Asian	1 (2.94)	
AI	1 (2.94)	
Ethnicity (N/%)		
Non-Hispanic	32 (94.12)	10 (100)
Hispanic	2 (5.88)	
Education (N/ %)		
Less than HS		1 (10)
High School	7 (20.59)	6 (60)
13-15	16 (47.06)	2 (20)
More than 15 years	11 (32.35)	1 (10)
Age (Mean/SD)	74.88 (11.08)	39.9 (12.42)
Marital Status (N/%)		
Married	23 (67.65)	2 (20)
Widowed	7 (20.59)	
Divorced	3 (8.82)	3 (30)
Single	1 (2.94)	5 (50)
Cognitive testing		
Blessed	13.58 (4.23)	10.6 (3.94)
SLUMS	9 (5.70)	16.55 (6.63)
CAREGIVER		
Sex (N/%)		
Female	22 (64.71)	10 (100)
Male	12 (35.29)	
Education (N/ %)		
Less than HS		1 (10)
High School	4 (11.76)	4 (40)
13-15	11 (32.35)	4 (40)
More than 15 years	19 (55.88)	1 (10)
Age (Mean/SD)	61.44 (15.52)	56.3 (7.51)
Marital Status (N/%)		
Married	26 (76.47)	8 (80)

Single	5 (14.71)	1 (10)
Widowed	2 (5.88)	
Divorced	1 (2.94)	1 (10)
Relationship to the patient (N/%)		
Husband	8 (23.53)	
Wife	11 (32.35)	2 (20)
Daughter	10 (29.41)	
Mother		7 (70)
Son	3 (8.82)	
Daughter in Law	1 (2.94)	
Other relative	1 (2.94)	1 (10)
Employment (N/%)		
Retired	17 (50)	4 (40)
Full Time	11 (32.35)	1 (10)
Leave of absence	5 (14.71)	2 (20)
Part time	1 (2.94)	1 (10)
Disabled		1 (10)
Self-employee-FT		1 (10)
Personality traits (Mean/SD)		
CDR-Resilience	77.32 (11.70)	77.7 (10.63)
Eysenck- Neuroticism	6.44 (1.96)	8.3 (2.26)
Zarit -Caregiver Burden	37 (12.24)	45.4 (16.37)
Pearlin-Mastery	20.41 (3.19)	17.1 (2.64)
Quality of life (Mean/SD)		
DEMQL	91.44 (14.15)	87.8 (21.81)
FQOL TBI	NA	153.8 (8.6)
FQOL Q1-Q40	158.11 (22.45)	NA
FQOL2 Q1-42	172.88 (24.84)	NA
PSESDM	16.61 (2.65)	NA
NPI RAW (SEVERITY)	15.23 (6.38)	14.9 (6.83)
NPI DISTRESS	18.20 (7.88)	20.3 (10.42)
EQ VAS (Mean, SD)	84.11 (11.41)	79.8 (13.01)
Health state index score	0.82 (0.14)	0.76 (0.16)
Completed		
Yes	26 (76.47)	9 (90)
No	8 (23.53)	1 (10)

Table 1 Comparison between immediate and delayed group demographic characteristics at baseline AD Completed

Characteristic	All	Immediate Intervention	Delayed Intervention	χ2 / t-Test P-value	Fischer /KW
	N=26	n=14	n=12		
Sex (N/%)					
Female	16 (61.54)	8 (30.77)	8 (30.77)	0.6188	0.7015
Male	10 (38.46)	6 (23.08)	4 (15.38)		
Race (N/%)					
White	20 (76.92)	9 (34.62)	11 (42.31)	0.3818	0.4452
AA	4 (15.38)	3 (11.54)	1 (3.85)		
Asian	1 (3.85)	1 (3.85)	0		
AI	1 (3.85)	1 (3.85)	0		
Ethnicity (N/%)					
Non-Hispanic	24 (92.31)	14 (53.85)	10 (38.46)	0.1119	0.2031
Hispanic	2 (7.69)	0	2 (7.69)		
Education (N/ %)					
High School	3 (11.54)	2 (7.69)	1 (3.85)	0.149	0.1656
13-15	12 (46.15)	4 (15.38)	8 (30.77)		
More than 15 years	11 (42.31)	8 (30.77)	3 (11.54)		
Age (Mean/SD)	75.69 (11.58)	75.74 (11.64)	75.66 (12.01)	0.99	0.6607
Marital Status (N/%)					
Married	20 (76.92)	12 (46.15)	8 (30.77)	0.39	0.4609
Widowed	5 (19.23)	2 (7.69)	3 (11.54)		
Divorced	1 (3.85)	0	1 (3.85)		
Cognitive testing					
Blessed	13.07 (3.59)	13.14 (4.26)	13 (2.82)	0.91	0.897
Slums- n=23	9.69 (5.91)	9.636 (7.20)	9.75 (4.77)	0.96	0.7333
Caregiver					
Sex (N/%)					
Female	14 (53.85)	8 (30.77)	6 (23.08)	0.7157	1
M	12 (46.15)	6 (23.08)	6 (23.08)		
Education (N/ %)					
High School	2 (7.69)	0	2 (7.69)	0.2818	0.4009
13-15	7 (26.92)	4 (15.38)	3 (11.54)		
More than 15 years	17 (65.38)	10 (38.46)	7 (26.92)		
Age (Mean/SD)	64.5 (14.79)	65.07 (13.91)	63.83 (16.36)	0.57	0.918
Marital Status (N/%)					

Married	19 (73.08)	10 (38.46)	9 (34.62)	0.8244	1
Single	4 (15.38)	2 (7.69)	2 (7.69)		
Widowed	2 (7.69)	1 (3.85)	1 (3.85)		
Divorced	1 (3.85)	1 (3.85)	0		
Relationship to the patient (N/%)					
Husband	8 (30.77)	5 (19.23)	3 (11.54)	0.8429	0.9467
Wife	8 (30.77)	4 (15.38)	4 (15.38)		
Daughter	7 (26.92)	4 (15.38)	3 (11.54)		
Son	3 (11.54)	1 (3.85)	2 (7.69)		
Employment (N/%)					
Retired	15 (57.69)	10 (38.46)	5 (19.23)	0.1277	0.1456
Full Time	7 (26.92)	4 (15.38)	3 (11.54)		
Leave of absence	3 (11.54)	0	3 (11.54)		
Part time	1 (3.85)	0	1 (3.85)		
Personality traits (Mean/SD)					
	76.03				
CDR-Resilience	(12.05)	75.92 (12.39)	76.16 (12.18)	0.96	0.8168
Eysenck- Neuroticism	6.30 (1.95)	6.64 (1.78)	5.92 (2.15)	0.36	0.3204
Pearlin-Mastery	20.23 (3.26)	20.92 (3.38)	19.41 (3.05)	0.24	0.2893
PSESDM	16.38 (2.74)	15.57 (2.65)	17.33 (2.64)	0.1	0.0678
Zarit -Caregiver Burden	36 (13.007)	35.21 (14.40)	36.91 (11.73)	0.74	0.6613
	91.26				
DEMQL-Proxy	(14.16)	88.14 (15.90)	94.91 (11.41)	0.22	0.1894
	158.53	160.71			
FQOL Q1-Q40	(22.07)	(16.32)	156 (27.91)	0.61	0.8369
	173.80	175.71			
FQOL2 Q1-42	(24.92)	(19.06)	171.58 (31.18)	0.7	0.959
	14.23				
NPI RAW (Severity)	(6.048)	14.85 (6.89)	13.5 (5.09)	0.57	0.7966
NPI DISTRESS	17.42 (6.90)	18.92 (7.205)	15.66 (6.38)	0.233	0.3021
	84.42				
EQ VAS (Mean, SD)	(12.15)	86.57 (9.213)	81.91 (14.93)		0.361
			0.8314		
Health state index score	0.83 (0.10)	0.830 (0.075)	(0.1312)		0.971

Table Comparison between immediate and delayed group demographic characteristics at baseline TBI Completed

	All, N=9	Intervention		χ2 /t Test	Fischer /KW
		A n=4	B n=5		
Sex (N/%)					
Female	3 (33.3)	1 (11.11)	2 (22.22)	0.6353	1
Male	6 (66.67)	3 (33.33)	3 (33.33)		
Race (N/%)					
White	9 (100)	4 (44.44)	5 (55.56)		
AA					
Asian					
AI					
Ethnicity (N/%)					
Non-Hispanic	9 (100)	4(44.44)	5(55.55)		
Hispanic					
Education (N/ %)					
Less than HS	1 (11.11)	0	1(11.11)	0.2467	0.5238
High School	5 (55.56)	3 (33.33)	2 (22.22)		
13-15	2 (22.22)	0	2 (22.22)		
More than 15 years	1 (11.11)	1 (11.11)	0		
	39.88				
Age (Mean/SD)	(13.17)	47.5 (14.61)	33.8 (9.09)		0.1416
Marital Status (N/%)					
Married	2 (22.22)	1 (11.11)	1 (11.11)	0.5386	0.7143
Single	4 (44.44)	1 (11.11)	3 (33.33)		
Divorced	3 (33.33)	2 (22.22)	1 (11.11)		
Cognitive testing					
	11.22				
Blessed	(3.63)	12 (3.91)	10.6(3.74)		0.5386
	17.25				
Slums- n= 8	(6.73)	19.33 (5.85)	16 (7.54)		0.2967
Caregiver-TBI					
Sex (N/%)					
Female	9 (100)	4 (44.44)	5 (55.56)		
M					
Education (N/ %)					
Less than HS	1 (11.11)	0	1 (11.11)	0.3529	0.5714
High School	4 (44.44)	3 (33.33)	1 (11.11)		
13-15	3 (33.33)	1 (11.11)	2 (22.22)		
More than 15 years	1 (11.11)	0	1 (11.11)		

Age (Mean/SD)	55.66 (7.68)	60.5 (6.60)	51.8 (6.57)		0.1099
Marital Status (N/%)					
Married	8 (88.89)	4 (44.44)	4 (44.44)	0.3428	0.5556
Single					
Widowed					
Divorced	1 (11.11)	0	1 (11.11)		
Relationship to the patient (N/%)					
Mother	6 (66.67)	2 (22.22)	4 (44.44)	0.455	0.6825
Wife	2 (22.22)	1 (11.11)	1 (11.11)		
Niece	1 (11.11)	1 (11.11)	0		
Employment (N/%)					
Retired	4 (44.44)	2 (22.22)	2 (22.22)	0.2925	0.4603
Full Time	1 (11.11)	0	1 (11.11)		
Leave of absence	2 (22.22)	0	2 (22.22)		
Part time	1 (11.11)	1 (11.11)	0		
Self-employee FT	1 (11.11)	1 (11.11)	0		
Personality traits (Mean/SD)					
CDR-Resilience	77.44 (11.24)	85.75 (10.90)	70.8 (6.30)		0.0864
Eysenck- Neuroticism	8.11 (2.31)	7.75 (2.87)	8.4 (2.07)		0.9004
Pearlin-Mastery	17 (2.78)	18.25 (1.25)	16 (3.39)		0.1925
Zarit -Caregiver Burden	47.22 (16.25)	39.75 (16.91)	53.20(14.60)		0.2187
DEMQL	86.33 (22.60)	99.75 (23.96)	75.6 (16.34)		0.1099
FQOL TBI	153.33 (9)	152.25 (6.65)	154.2 (11.23)	0.75	
NPI RAW	15.77 (6.62)	12.75 (8.65)	18.2 (3.89)		0.2683
NPI DISTRESS	21 (10.80)	13.5 (8.10)	27 (9.11)		0.05
EQ VAS (Mean, SD)	83.11 (8.19)	85.75 (8.5)	81 (8.21)	0.42	
Health state index score	0.80 (0.10)	0.8160 (0.035)	0.8044 (0.139)	0.8656	

Bivariate analysis AD

CORRELATION BASELINE ZBI & CAREGIVER PERSONALITY TRAITS & COGNITION

Spearman Correlation Coefficients, N = 26	AD COMPLETED	
Prob > r under H0: Rho=0		
		ZBI
Eysenck	r	0.48072
	p-value	0.0129
CDR	r	-0.15838
	p-value	0.4397
Pearlin	r	-0.42624
	p-value	0.0299
PSESDM	r	-0.14475
	p-value	0.4805
NPI_Q_RAWSCORE (severity)	r	0.44868
	p-value	0.0215
NPI_CG_DISTRESS	r	0.30538
	p-value	0.1293
SLUMS	r	-0.10975
	p-value	0.6181
	n	23
Blessed	r	-0.06102
	p-value	0.7671
	n	26
EQVAS	r	-0.046
	pvalue	0.8237
	n	26
INDEX	r	0.37302
	p value	0.0605
	n	26

CORRELATION BASELINE FQOL-DEMOQL & CAREGIVER PERSONALITY TRAITS & COGNITION

Spearman Correlation Coefficients, N = 26				
Prob > r under H0: Rho=0			Include 42 qxs	
		DEMQOL_PROXY	FQOL_AD2	FQOL_SC
Eysenck	r	-0.01478	0.25325	0.20037
	p-value	0.9429	0.2119	0.3264
CDR	r	0.35981	0.48853	0.45344
	p-value	0.071	0.0113	0.02
Pearlin	r	0.16057	0.09902	0.11037
	p-value	0.4333	0.6303	0.5915
PSESDM	r	0.54369	-0.02729	-0.08328
	p-value	0.0041	0.8947	0.6859
NPI_Q_RAWSCORE (severity)	r	-0.4191	-0.23175	-0.16215
	p-value	0.0331	0.2546	0.4287
NPI_CG_DISTRESS	r	-0.49923	-0.18981	-0.1409
	p-value	0.0094	0.353	0.4924
SLUMS	r	-0.24247	-0.158	-0.136
	p-value	0.265	0.47	0.535
	n	23	23	23
Blessed	r	-0.06628	0.05	0.07
	p-value	0.7477	0.80	0.771
	n	26	26	26
EQVAS	r	0.034	0.36678	0.35681
	pvalue	0.8692	0.0653	0.0736
	n	26	26	26
INDEX	r	0.05341	-0.095	-0.073
	p value	0.7955	0.6428	0.7216
	n	26	26	26
FQOL_AD2	r	0.10407		
	p value	0.6129		

CORRELATION BASELINE ZBI & QUALITY OF LIFE MEASURES

Spearman Correlation Coefficients, N = 26 Prob > r under H0: Rho=0			
	ZARIT	DEMQOL_PROXY_RAW	FQOL_AD2
ZARIT	1	-0.28402	-0.10936
p value		0.1597	0.5949
DEMQOL_PROXY_RAW	-0.284	1	0.10407
p value	0.1597		0.6129
FQOL_AD	0.1094	0.10407	1
p value	0.5949	0.6129	

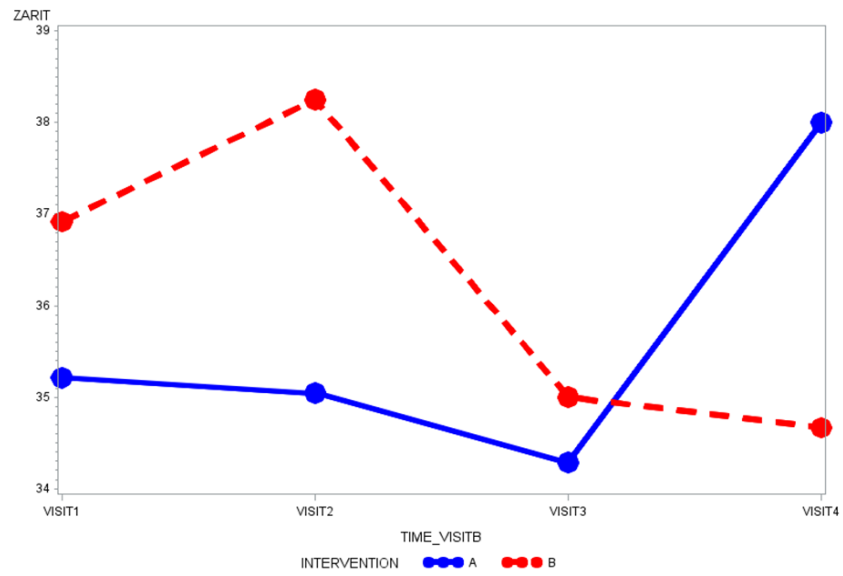
Table 2 Descriptive statistics for outcomes of interest by study group and week (N=26)

		Caregiver burden (ZBI)	Patient Quality of Life (DEMOQL- Proxy)	Family Quality of Life	EQ5D5L	EQ5D5L INDEX
Week	Group	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
0	Immediate	35.21 (14.40)	88.14 (15.90)	175.71 (19.06)	86.57(9.21)	0.830 (0.081)
	Delayed	36.91 (11.73)	94.91 (11.40)	171.58 (31.18)	81.91 (14.930)	0.8314 (0.1312)
7	Immediate	35.04 (12.48)	95.92 (10.46)	176.57 (23.61)	NA	NA
	Delayed	38.25 (12.14)	93.83 (12.99)	169.66 (24.38)	NA	NA
13	Immediate	34.28 (11.03)	93.92 (12.71)	182.35 (22.22)	NA	NA
	Delayed	35 (8.53)	95.25 (11.72)	175.41 (15.13)	NA	NA
24	Immediate	38 (13.87)	91.78 (20.20)	176.07 (14.11)	81.16 (7.80)	0.8328 (0.0745)
	Delayed	34.66 (11.48)	94.33 (8.37)	173.50 (13.43)	74.833 (13.3949)	0.8393 (0.0972)

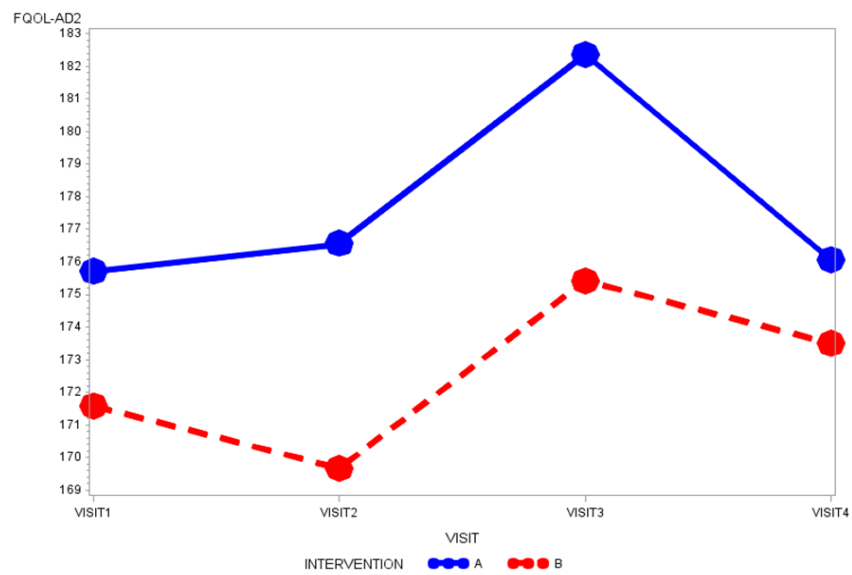
A decrease in burden scores from the baseline measurement to week 7 for the early treatment group, and between week 7 and week 13 for the late treatment group, will be interpreted as an immediate measure of efficacy regarding the intervention. Sustained effects will be measured by the burden scores measured at week 12 for the early treatment group and at week 24 for both groups

Graphical Representation of Mean Measurement over Time by intervention

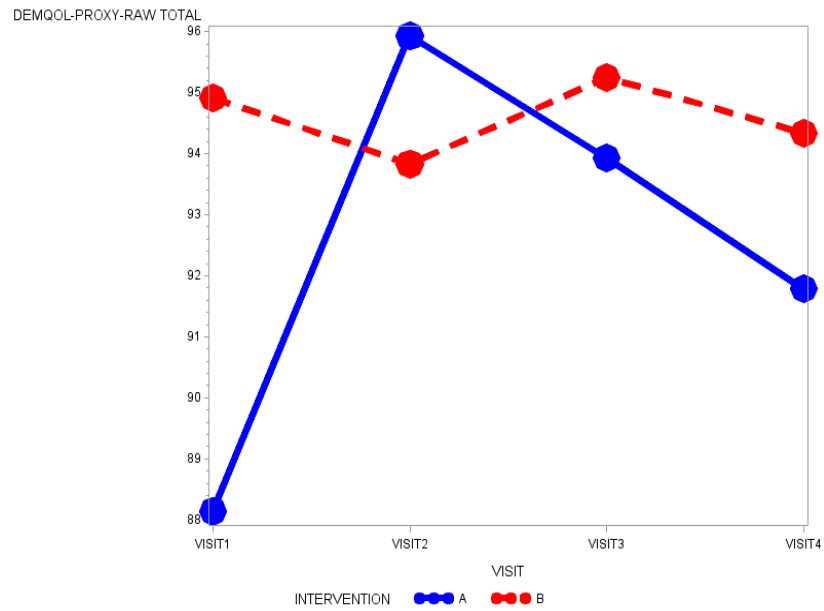
AD
Zarit



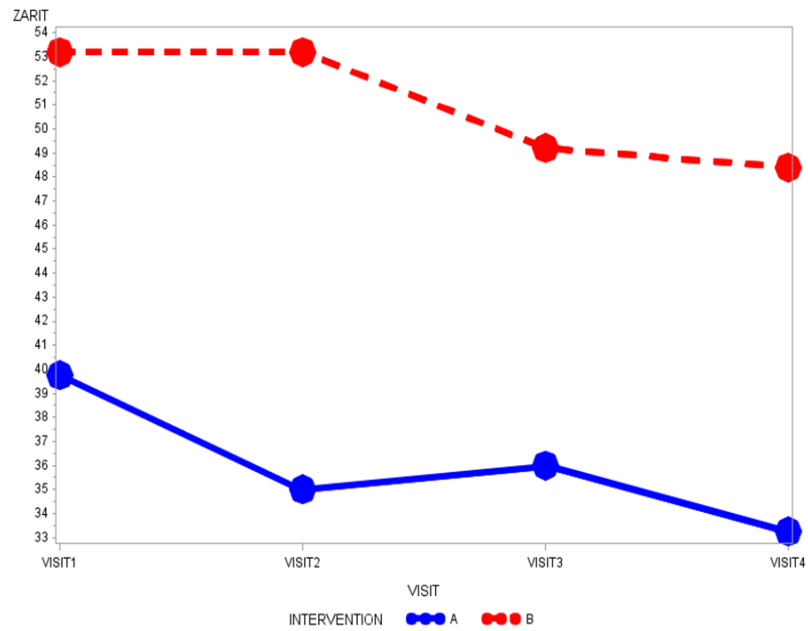
FQOL2 Q1-42

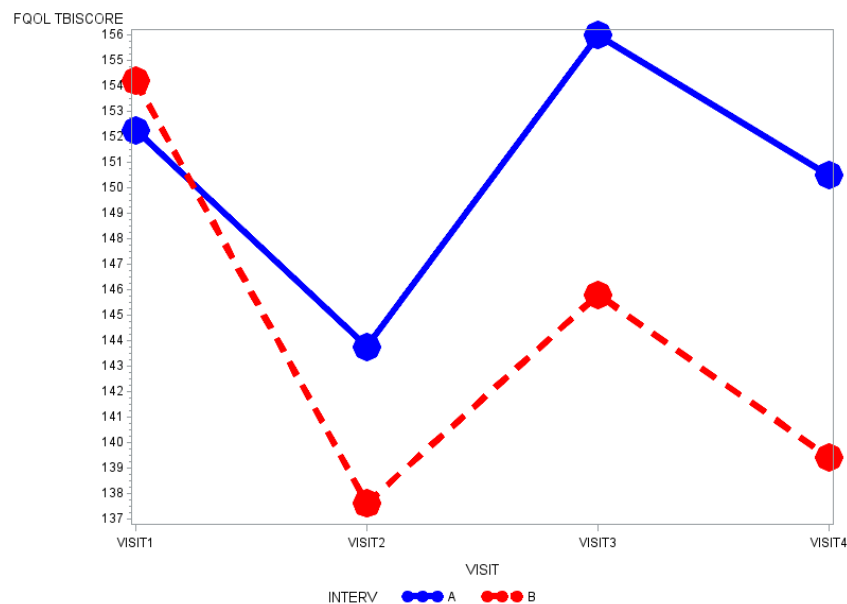


DEMOQL PROXY



TBI Zarit





Primary Hypothesis 1

A 12-week cross-over design study, using a distance-learning , internet based, family caregiver coaching program (“the intervention”) will reduce CAREGIVER BURDEN measured with the Zarit Burden Interview (ZBI) [59] in a sample of 50 community-dwelling people with AD who have at least one recurring BPSD symptom that is associated with care resistant behavior (CRB) and causes distress to a family caregiver. Repeated measures analysis of variance (ANOVA) will be examined to determine the impact of the intervention on ZBI scores of the caregivers. Terms in the model will include group membership (early versus late treatment) and time (baseline, weeks 7, 13, and 24). A decrease in burden scores from the baseline measurement to week 7 for the early treatment group, and between week 7 and week 13 for the late treatment group, will be interpreted as an immediate measure of efficacy regarding the intervention. Sustained effects will be measured by the burden scores measured at week 12 for the early treatment group and at week 24 for both groups

MANOVA Test Criteria and Exact F Statistics for the Hypothesis of no time Effect

H = Type III SSCP Matrix for tests

E = Error SSCP Matrix

S=1 M=0.5 N=10

Statistic	Value	F Value	Num DF	Den DF	Pr > F	
Wilks' Lambda	0.905728	0.76	3	22	0.5267	NS

There is no statistically significant difference at the four times

MANOVA Test Criteria and Exact F Statistics for the Hypothesis of no time*INTERVENTION Effect

H = Type III SSCP Matrix for tests*INTERVENTION

E = Error SSCP Matrix

S=1 M=0.5 N=10

Statistic	Value	F Value	Num DF	Den DF	Pr > F	
Wilks' Lambda	0.871834	1.08	3	22	0.3789	NS

Any difference between ZBI scores/means do not reliably depend on time in conjunction with the type of intervention. (in samples of this size)

Tests of Hypotheses for Between Subjects Effects

Source	DF	Type III SS	Mean Square	F Value	Pr > F	
INTERVENTION	1	8.43956	8.43956	0.02	0.8964	NS
Error	24	11692.06	487.1692			

Univariate Tests of Hypotheses for Within Subject Effects

Source	DF	Type III SS	Mean Square	F Value	Pr > F	Adj Pr > F		
						G - G	H-F-L	
time	3	60.84799	20.28266	0.58	0.6281	0.6068	0.6275	NS
time*INTERVENTION	3	151.6429	50.54762	1.45	0.2346	0.2386	0.2347	NS
Error(time)	72	2504.732	34.78795					

Although the effect of the intervention on caregiver burden was in a direction that indicated benefit, there was not statistically significant effect of the intervention.

Primary Hypothesis 2

Baseline variables including severity of cognitive deficits and caregiver personality traits of mastery, neuroticism, and resilience will be associated with the magnitude of ZBI response, as well as other QOL measures. Cognitive deficit scores and caregiver personality trait scores will be correlated with ZBI and QOL scores. Variables with significant correlations will then be used as inputs for multiple regression models to explain individual and cumulative contributions to variance. Coefficients from the regression analyses will also be used to examine relationships between these variables and ZBI scores, that is, if certain variables are exerting mediation or moderation effects on the ZBI. Give the large ZBI effect size reported in another study [60], we should be able to detect interaction effects with our sample size. Furthermore, analyses of covariances (ANCOVAs) will also be conducted determine changes in ZBI while controlling for cognitive deficit scores and caregiver personality trait scores."

***Spearman's correlations were conducted to examine the relationships between cognitive deficit scores and caregiver personality trait scores with ZBI scores. There were positive statistically**

significant correlations between ZBI with Neuroticism ($r=0.48$) and severity of behavioral symptoms ($r=0.44$) ($p<0.05$). There was a negative statistically significant correlations between ZBI with caregiver's mastery ($r=-0.42$) ($p<0.05$)

****Spearman's correlations were conducted to examine the relationships between cognitive deficit scores and caregiver personality trait scores with and QOL scores. There was a positive statistically significant correlation between patient quality of life with caregiver self-efficacy (PSESDM) ($r=0.54$) ($p<0.05$). There were negative statistically significant correlations between patient quality of life and severity of behavioral symptoms ($r=-0.41$) and caregiver distress ($r=-0.49$) ($p<0.05$) Family quality of life: There was a positive statistically significant correlation between family quality of life with resilience ($r=0.48$) ($p<0.05$)**

ZBI

Null Model Likelihood Ratio Test

DF	Chi-Square	Pr > ChiSq
1	43.27	<.0001

Type 3 Tests of Fixed Effects

Effect	Num DF	Den DF	F Value	Pr > F
VISIT	3	70	0.29	0.8301
INTERVENTION	1	23	0.5	0.4878
VISIT*INTERVENTION	3	70	1.55	0.2104
PEARLIN	1	70	2.5	0.1185
Eysenck_RAW_SCORE	1	23	10.31	0.0039
NPI_Q_RAWSCORE (Severity)	1	70	12.99	0.0006

Neuroticism ($p=0.0039$) and severity of the behavioral symptoms (0.0006) were significant associated with caregiver burden.

Caregiver age, sex education, relationship****;

Null Model Likelihood Ratio Test

DF	Chi-Square	Pr > ChiSq
1	31.54	<.0001

Type 3 Tests of Fixed Effects

Effect	Num DF	Den DF	F Value	Pr > F
VISIT	3	70	0.31	0.8149
INTERVENTION	1	16	0.3	0.5904

VISIT*INTERVENTION	3	70	1.58	0.201
PEARLIN	1	70	1.5	0.2243
Eysenck_RAW_SCORE	1	16	11.61	0.0036
NPI_Q_RAWSCORE	1	70	10.9	0.0015
CAREG_AGE	1	16	5.21	0.0365
CAREG_GENDER	1	16	0.96	0.3419
Level_of_education__	2	16	0.97	0.4011
RELATIONSHIP_TO_PATI	3	16	1.97	0.1599

After controlling for other covariates, neuroticism (p=0.0036) and severity of the behavioral symptoms (0.0015) were significantly associated with caregiver burden. Also, caregiver age (p=0.0365) was significantly associated with caregiver burden

Demoql

Null Model Likelihood Ratio Test

DF	Chi-Square	Pr > ChiSq
1	27.64	<.0001

Type 3 Tests of Fixed Effects

Effect	Num DF	Den DF	F Value	Pr > F
VISIT	3	69	0.6	0.6161
INTERVENTION	1	24	0	0.9817
VISIT*INTERVENTION	3	69	1.25	0.2973
PSESMD	1	69	2.54	0.1158
NPI_Q_RAWSCORE	1	69	4.04	0.0482
NPI_CG_DISTRESS	1	69	2.22	0.1407

Caregiver age, sex education, relationship**.**

Null Model Likelihood Ratio Test

DF	Chi-Square	Pr > ChiSq
1	24.48	<.0001

Type 3 Tests of Fixed Effects

Effect	Num DF	Den DF	F Value	Pr > F
VISIT	3	69	0.59	0.6256
INTERVENTION	1	18	0.25	0.624
VISIT*INTERVENTION	3	69	1.29	0.2857

PSESDM	1	69	1.85	0.1781
NPI_Q_RAWSCORE (severity)	1	69	4.94	0.0296
NPI_CG_DISTRESS	1	69	1.4	0.2413
CAREG_GENDER	1	18	0.15	0.703
Level_of_education__Caregiver	2	18	1.36	0.2819
RELATIONSHIP_TO_PATIENT	3	18	0.37	0.777

FQOL

Null Model Likelihood Ratio
Test

DF	Chi-Square	Pr > ChiSq
1	9.14	0.0025

Type 3 Tests of Fixed Effects

Effect	Num DF	Den DF	F Value	Pr > F
VISIT	3	71	0.98	0.4052
INTERVENTION	1	24	1.45	0.2404
VISIT*INTERVENTION	3	71	0.24	0.868
CD_RISC	1	71	17.38	<.0001

**Resilience ($p<.0001$) was significantly associated with family quality of life
Caregiver age, sex education,
relationship****;**

Null Model Likelihood Ratio
Test

DF	Chi-Square	Pr > ChiSq
1	8.12	0.0044

Type 3 Tests of Fixed Effects

Effect	Num DF	Den DF	F Value	Pr > F
VISIT	3	71	0.96	0.417
INTERVENTION	1	18	1.82	0.194
VISIT*INTERVENTION	3	71	0.23	0.8776
CD_RISC	1	71	13.1	0.0005
CAREG_GENDER	1	18	1.11	0.3056
Level_of_education__	2	18	0.55	0.5855
RELATIONSHIP_TO_PATI	3	18	1.55	0.2364

After controlling for other covariates, resilience ($p < .0005$) was significantly associated with family quality of life

"Exploratory Hypothesis 1

Because the intervention has been shown to successfully reduce CRB with BPSD in people with dementia, we will develop preliminary data to determine whether it will improve, either or both of the following:

- patient QOL (measured with the DEMQOL and DEMQOL proxy)
- caregiver health related QOL (measured with EQ-5D-5L)"

DEMQOL proxy TBI SUBJECTS

MANOVA Test Criteria and Exact F Statistics for the Hypothesis of no time Effect

H = Type III SSCP Matrix for time

E = Error SSCP Matrix

S=1 M=0.5 N=1.5

Statistic	Value	F Value	Num DF	Den DF	Pr > F
Wilks' Lambda	0.95246	0.08	3	5	0.9663

MANOVA Test Criteria and Exact F Statistics for the Hypothesis of no time*INTERVENTION Effect

H = Type III SSCP Matrix for time*INTERVENTION

E = Error SSCP Matrix

S=1 M=0.5 N=1.5

Statistic	Value	F Value	Num DF	Den DF	Pr > F
Wilks' Lambda	0.391354	2.59	3	5	0.1654

Repeated Measures Analysis of Variance

Tests of Hypotheses for Between Subjects Effects

Source	DF	Type III SS	Mean Square	F Value	Pr > F
INTERVENTION	1	2584.022	2584.022	4.12	0.082
Error	7	4392.2	627.4571		

Repeated Measures Analysis of Variance

Univariate Tests of Hypotheses for Within Subject Effects

Source	DF	Type III SS	Mean Square	F Value	Pr > F	Adj Pr > F	G - G	H-F-L
time	3	13.07778	4.359259	0.06	0.9789	0.9613		0.9789
time*INTERVENTION	3	776.1889	258.7296	3.72	0.0273	0.0391		0.0273
Error(time)	21	1460.7	69.55714					

		Visit 1		Visit 2		Visit 3		Visit 4	
Intervention	N	Mean	Std Dev	Mean	Std Dev	Mean	Std Dev	Mean	Std Dev
Immediate	4	99.75	23.96351	90	16.55295	95.5	12.47664	102.75	17.46186
Delayed	5	75.6	16.34931	86.2	6.379655	82.6	10.73778	75.4	7.635444

Caregiver health related QOL (measured with EQ-5D-5L) TBI SUBJECTS

MANOVA Test Criteria and Exact F Statistics for the Hypothesis of no tests Effect

H = Type III SSCP Matrix for tests

E = Error SSCP Matrix

S=1 M=-0.5 N=1.5

Statistic	Value	F Value	Num DF	Den DF	Pr > F
Wilks' Lambda	0.92216473	0.42	1	5	0.5446

MANOVA Test Criteria and Exact F Statistics for the Hypothesis of no tests*INTERVENTION Effect

H = Type III SSCP Matrix for tests*INTERVENTION

E = Error SSCP Matrix

S=1 M=-0.5 N=1.5

Statistic	Value	F Value	Num DF	Den DF	Pr > F
Wilks' Lambda	0.99976625	0.00	1	5	0.9740

Repeated Measures Analysis of Variance
Tests of Hypotheses for Between Subjects Effects

Source	DF	Type III SS	Mean Square	F Value	Pr > F
INTERVENTION	1	116.6666667	116.6666667	0.96	0.3724
Error	5	608.3333333	121.6666667		

Repeated Measures Analysis of Variance
Univariate Tests of Hypotheses for Within Subject Effects

Source	DF	Type III SS	Mean Square	F Value	Pr > F
tests	1	8.5952381	8.5952381	0.42	0.5446
tests*INTERVENTION	1	0.0238095	0.0238095	0.00	0.9740
Error(tests)	5	101.8333333	20.3666667		

Exploratory Hypothesis 2

The intervention, which has been shown to successfully reduce CRB in people with dementia (see preliminary data, above) can be applied in the TBI population to reduce frequency and severity of CRB associated NPTBI with resulting improvement in one or more of the following (using the same measures as above): a. Caregiver Burden b. patient QOL (Exploratory H1)

c. caregiver QOL

Repeated measures ANOVA will be used to analyze changes in **caregiver burden, caregiver QOL, and patient QOL**. Terms in the model will include group membership (early versus late treatment) and time (baseline, weeks 7, 13, and 24). Positive changes in scores from the baseline measurement to week 7 for the early treatment group, and between week 7 and week 13 for the late treatment, will be interpreted as an immediate measure of efficacy regarding the intervention. Sustained effects will be measured by positive scores measured at week 13 for the early treatment group and at week 24 for both groups.

Caregiver burden TBI SUBJECTS

MANOVA Test Criteria and Exact F Statistics for the Hypothesis of no tests Effect

H = Type III SSCP Matrix for tests

E = Error SSCP Matrix

S=1 M=0.5 N=1.5

Statistic	Value	F Value	Num DF	Den DF	Pr > F
Wilks' Lambda	0.661071	0.85	3	5	0.5214

MANOVA Test Criteria and Exact F Statistics for the Hypothesis of no tests*INTERVENTION Effect

H = Type III SSCP Matrix for tests*INTERVENTION

E = Error SSCP Matrix

S=1 M=0.5 N=1.5

Statistic	Value	F Value	Num DF	Den DF	Pr > F
Wilks' Lambda	0.897477	0.19	3	5	0.8986

Repeated Measures Analysis of Variance

Tests of Hypotheses for Between Subjects Effects

Source	DF	Type III SS	Mean Square	F Value	Pr > F
INTERVENTION	1	2000	2000	3.01	0.1265
Error	7	4656.5	665.2143		

Repeated Measures Analysis of Variance

Univariate Tests of Hypotheses for Within Subject Effects

Source	DF	Type III SS	Mean Square	F Value	Pr > F	Adj Pr > F	
							G - G H-F-L
tests	3	152.6778	50.89259	1.2	0.3331	0.3317	0.3331
tests*INTERVENTION	3	35.34444	11.78148	0.28	0.8403	0.7925	0.8403
Error(tests)	21	888.6	42.31429				

Level of INTERVENTION	N	ZARITVISIT1		ZARITVISIT2		ZARITVISIT3		ZARITVISIT4	
		Mean	Std Dev	Mean	Std Dev	Mean	Std Dev	Mean	Std Dev
A	4	39.75	16.91892	35	13.61372	36	18.05547	33.25	14.24488
B	5	53.2	14.60137	53.2	11.7771	49.2	13.08434	48.4	10.62073

Note: Scores at baseline were different

Exploratory Hypothesis 3

The intervention will result in retained benefits on caregiver burden and QOL ratings 3-6 months after the last intervention session is completed. Repeated measures ANOVA will be used to analyze ZBI and QOL scores for both sets of caregivers. Terms in the model will include group membership (early versus late treatment) and time (baseline, weeks 7, 13, and 24). Of particular note will be changes in ZBI, DEMQOL, and EQ-5D-5L scores for the early treatment group at both week 13 and week 24."

DEMOQL AD SUBJECTS

MANOVA Test Criteria and Exact F Statistics for the Hypothesis of no time Effect

H = Type III SSCP Matrix for tests

E = Error SSCP Matrix

S=1 M=0.5 N=10

Statistic	Value	F Value	Num DF	Den DF	Pr > F
Wilks' Lambda	0.89495152	0.86	3	22	0.4761

MANOVA Test Criteria and Exact F Statistics for the Hypothesis of no time*INTERVENTION Effect

H = Type III SSCP Matrix for tests*INTERVENTION

E = Error SSCP Matrix

S=1 M=0.5 N=10

Statistic	Value	F Value	Num DF	Den DF	Pr > F
Wilks' Lambda	0.83815313	1.42	3	22	0.2648

Repeated Measures Analysis of Variance**Tests of Hypotheses for Between Subjects Effects**

Source	DF	Type III SS	Mean Square	F Value	Pr > F
INTERVENTION	1	118.02289	118.02289	0.23	0.636
Error	24	12322.25595	513.42733		

Repeated Measures Analysis of Variance**Univariate Tests of Hypotheses for Within Subject Effects**

Source	DF	Type III SS	Mean Square	F Value	Pr > F	Adj Pr > F G - G
Time	3	185.279304	61.759768	0.83	0.4825	0.4671
Time*INTERVENTION	3	260.048535	86.682845	1.16	0.3299	0.3273
Error(tests)	72	5367.172619	74.544064			

		Vsit 1		Visit2		Visit 3		Visit 4	
INTERVENTION	N	Mean	Std Dev	Mean	Std Dev	Mean	Std Dev	Mean	Std Dev
Immediate	14	88.1428571	15.9028645	95.929	10.462	93.92857	12.71259	91.78571	20.2035
Delayed	12	94.9166667	11.4054081	93.833	12.995	95.25	11.72507	94.33333	8.370221

FQOL AD SUBJECTS**MANOVA Test Criteria and Exact F Statistics for the Hypothesis of no time Effect**

H = Type III SSCP Matrix for tests

E = Error SSCP Matrix

S=1 M=0.5 N=10

Statistic	Value	F Value	Num DF	Den DF	Pr > F
Wilks' Lambda	0.8584922	1.21	3	22	0.3299

MANOVA Test Criteria and Exact F Statistics for the Hypothesis of no time*INTERVENTION Effect

H = Type III SSCP Matrix for time*INTERVENTION

E = Error SSCP Matrix

S=1 M=0.5 N=10

Statistic	Value	F Value	Num DF	Den DF	Pr > F
Wilks' Lambda	0.98239836	0.13	3	22	0.9404

Repeated Measures Analysis of Variance

Tests of Hypotheses for Between Subjects Effects

Source	DF	Type III SS	Mean Square	F Value	Pr > F
INTERVENTION	1	682.02289	682.02289	0.63	0.4352
Error	24	25988.13095	1082.83879		

Repeated Measures

Analysis of Variance

Univariate Tests of Hypotheses for Within Subject Effects

Source	DF	Type III SS	Mean Square	F Value	Pr > F	Adj Pr > F	G - G	H-F-L
Time	3	529.04853	176.34951	0.76	0.5212	0.5027	0.5169	
Time*INTERVENTION	3	90.2793	30.0931	0.13	0.9423	0.9206	0.9377	
Error(tests)	72	16743.79762	232.55274					

INTERVENTION	N	VISIT1		VISIT2		VISIT3		VISIT4	
		Mean	Std Dev	Mean	Std Dev	Mean	Std Dev	Mean	Std Dev
A	14	175.714286	19.0643791	176.57	23.61458	182.3571	22.22475	176.0714	14.11744
B	12	171.583333	31.184082	169.67	24.38827	175.4167	15.1385	173.5	13.43334

EQVAS AD SUBJECTS

MANOVA Test Criteria and Exact F Statistics for the Hypothesis of no tests Effect

H = Type III SSCP Matrix for tests

E = Error SSCP Matrix

S=1 M=-0.5 N=10

Statistic	Value	F Value	Num DF	Den DF	Pr > F
Wilks' Lambda	0.89189701	2.67	1	22	0.1167

MANOVA Test Criteria and Exact F Statistics for the Hypothesis of no tests*INTERVENTION Effect
H = Type III SSCP Matrix for tests*INTERVENTION
E = Error SSCP Matrix

S=1 M=-0.5 N=10

Statistic	Value	F Value	Num DF	Den DF	Pr > F
Wilks' Lambda	0.99070674	0.21	1	22	0.6541

Repeated Measures Analysis of Variance
Tests of Hypotheses for Between Subjects Effects

Source	DF	Type III SS	Mean Square	F Value	Pr > F
INTERVENTION	1	275.520833	275.520833	2.04	0.1675
Error	22	2975.458333	135.248106		

Repeated Measures Analysis of Variance
Univariate Tests of Hypotheses for Within Subject Effects

Source	DF	Type III SS	Mean Square	F Value	Pr > F
tests	1	368.520833	368.520833	2.67	0.1167
tests*INTERVENTION	1	28.520833	28.520833	0.21	0.6541
Error(tests)	22	3040.458333	138.202652		

Exploratory Hypothesis 5

The distance-accessible, internet based, caregiver training program will result in improvements in Family Quality of Life in Dementia (FQOL-D) and TBI (TBI-FQOL), new instruments designed to capture aspects of family function not assessed by individual AD or TBI patient QOL measures, or individual caregiver QOL assessments

FQOL AD SUBJECTS

MANOVA Test Criteria and Exact F Statistics for the Hypothesis of no time Effect

H = Type III SSCP Matrix for tests

E = Error SSCP Matrix

S=1 M=0.5 N=10

Statistic	Value	F Value	Num DF	Den DF	Pr > F
Wilks' Lambda	0.8584922	1.21	3	22	0.3299

MANOVA Test Criteria and Exact F Statistics for the Hypothesis of no time*INTERVENTION Effect

H = Type III SSCP Matrix for time*INTERVENTION

E = Error SSCP Matrix

S=1 M=0.5 N=10

Statistic	Value	F Value	Num DF	Den DF	Pr > F
Wilks' Lambda	0.98239836	0.13	3	22	0.9404

Repeated Measures Analysis of Variance

Tests of Hypotheses for Between Subjects Effects

Source	DF	Type III SS	Mean Square	F Value	Pr > F
INTERVENTION	1	682.02289	682.02289	0.63	0.4352
Error	24	25988.13095	1082.83879		

Repeated Measures

Analysis of Variance

Univariate Tests of Hypotheses for Within Subject Effects

Source	DF	Type III SS	Mean Square	F Value	Pr > F	Adj Pr > F	
						G - G	H-F-L
Time	3	529.04853	176.34951	0.76	0.5212	0.5027	0.5169
Time*INTERVENTION	3	90.2793	30.0931	0.13	0.9423	0.9206	0.9377
Error(tests)	72	16743.79762	232.55274				

INTERVENTION	N	VISIT1		VISIT2		VISIT3		VISIT4	
		Mean	Std Dev	Mean	Std Dev	Mean	Std Dev	Mean	Std Dev
A	14	175.714286	19.0643791	176.57	23.61458	182.3571	22.22475	176.0714	14.11744
B	12	171.583333	31.184082	169.67	24.38827	175.4167	15.1385	173.5	13.43334

FQOL TBI SUBJECTS

MANOVA Test Criteria and Exact F Statistics for the Hypothesis of no TIME Effect

H = Type III SSCP Matrix for tests

E = Error SSCP Matrix

S=1 M=0.5 N=1.5

Statistic	Value	F Value	Num DF	Den DF	Pr > F
Wilks' Lambda	0.65412348	0.88	3	5	0.5104

MANOVA Test Criteria and Exact F Statistics for the Hypothesis of no**TIME*INTERVENTION** Effect

H = Type III SSCP Matrix for

tests*INTERVENTION

E = Error SSCP Matrix

S=1 M=0.5 N=1.5

Statistic	Value	F Value	Num DF	Den DF	Pr > F
Wilks' Lambda	0.85345285	0.29	3	5	0.834

Repeated Measures Analysis of Variance**Tests of Hypotheses for Between Subjects Effects**

Source	DF	Type III SS	Mean Square	F Value	Pr > F
INTERVENTION	1	361.25	361.25	0.24	0.6373
Error	7	10417.25	1488.17857		

Repeated Measures Analysis of Variance

Univariate Tests of Hypotheses for Within Subject Effects

Source	DF	Type III SS	Mean Square	F Value	Pr > F	Adj Pr > F G - G	H-F-L
time	3	865.805556	288.601852	1.09	0.3761	0.3665	0.3761
time*INTERVENTION	3	236.25	78.75	0.3	0.8273	0.7626	0.8273
Error(tests)	21	5573.25	265.392857				

Greenhouse-Geisser

Epsilon 0.717

Huynh-Feldt-

Lecoutre Epsilon 1.0454

Level of INTERVENTION	N	FQOLTBASLINE		FQOLTBI VISIT 2		FQOLTBI VISIT 3		FQOLTBI VISIT 4	
		Mean	Std Dev	Mean	Std Dev	Mean	Std Dev	Mean	Std Dev
A	4	152.25	6.652067	143.75	45.74841	156	14.30618	150.5	10.66146
B	5	154.2	11.23388	137.6	22.91942	145.8	28.76978	139.4	26.01538

Table	Distribution of EQ-5D-5L dimension responses at baseline and at visit 4 by intervention-AD					
Dimension	Baseline		p value	Visit 4		p value
	n (%)		(Fisher's)	n (%)		
n=26	Immediate	Delayed		Immediate	Delayed	
	n=14	n=12		n=13	n=12	
MOBILITY			0.6174			0.107
(No problems)	11 (78.57)	8 (66.67)	Chisq=0.469	10 (76.92)	9 (75)	Chisq=0.1105
(Slight problems)	3 (21.43)	2 (16.67)		0	3 (25)	
(Moderate problems)	0	1 (8.33)		2 (15.38)	0	
(Severe problems)	0	1 (8.33)				
(Extreme problems/unable to do)						
Missing				1 (7.69)	0	
SELF-CARE						
(No problems)	14 (100)	12 (100)		12 (92.31)	12 (100)	1
(Slight problems)						Chisq=0.3268
(Moderate problems)						
(Severe problems)						
(Extreme problems/unable to do)						
Missing				1 (7.69)	0	
USUAL ACTIVITIES			0.0846			0.7868
(No problems)	14 (100)	9 (75)	Chisq=0.138	11 (84.62)	9 (75)	Chisq=0.5306
(Slight problems)		2 (16.67)		0	1 (8.33)	
(Moderate problems)		1 (8.33)		0	1 (8.33)	
(Severe problems)				1 (7.69)	1 (8.33)	
(Extreme problems/unable to do)						
Missing				1 (7.69)	0	
PAIN/DISCOMFORT			0.2806			0.1793
(No problems)	5 (35.71)	6 (50)	Chisq=0.237	5 (38.46)	6 (50)	Chisq=0.171
(Slight problems)	8 (57.14)	3 (25)		5 (38.46)	1 (8.33)	
(Moderate problems)	0	2 (16.67)		2 (15.38)	5 (41.67)	
(Severe problems)	1 (7.14)	1 (8.33)				

(Extreme problems/unable to do)						
Missing				1	0	
ANXIETY/DEPRESSION			0.82			1
(No problems)	4 (28.57)	4 (33.33)	Chisq=0.6564	2 (15.38)	2 (16.67)	Chisq=0.8106
(Slight problems)	6 (42.86)	5 (41.67)		8 (61.54)	8 (66.67)	
(Moderate problems)	4 (28.57)	2 (16.67)		2 (15.38)	2 (16.67)	
(Severe problems)	0	1 (8.33)				
(Extreme problems/unable to do)						
Missing				1 (7.69)	0	
Effect of intervention on EQ-5D-5l index score						
EQ VAS	86.57 (9.2130)	81.91 (14.930)	0.361	81.16 (7.80)	74.833 (13.395)	0.1743
Mean (SD)						
INDEX VALUE	0.830 (0.0757)	0.8314 (0.1312)	0.971	0.8328 (0.0745)	0.8393 (0.0972)	0.8559
Mean (SD)						

Table	Distribution of EQ-5D-5L dimension responses at baseline and at visit 4 by intervention-TBI					
Dimension	Baseline		p value	Visit 4		p value
	n (%)		(Fisher's)	n (%)		
	Immediate	Delayed		Immediate	Delayed	
MOBILITY			1			0.3651
(No problems)	3 (75)	4 (80)	Chisq=0.8577	2 (50)	3 (60)	0.1262
(Slight problems)	1 (25)	1 (20)		2 (50)		
(Moderate problems)						
(Severe problems)						
(Extreme problems/unable to do)						
Missing					2 (40)	
SELF-CARE						0.4444
(No problems)	4 (100)	5 (100)		4 (100)	3 (60)	0.1515
(Slight problems)						
(Moderate problems)						
(Severe problems)						
(Extreme problems/unable to do)						
Missing					2 (40)	
USUAL ACTIVITIES			0.44			0.444
(No problems)	4 (100)	3 (60)	chisq=0.1515	3 (75)	3 (60)	0.2317
(Slight problems)		2 (40)				
(Moderate problems)				1 (25)		
(Severe problems)						
(Extreme problems/unable to do)						
Missing					2 (40)	
PAIN/DISCOMFORT			1			0.2381
(No problems)		1 (20)	chisq=0.637		2 (40)	0.1372
(Slight problems)	2 (50)	2 (40)		2 (50)		
(Moderate problems)	2 (50)	2 (40)		1 (25)	1 (20)	
(Severe problems)				1 (25)		
(Extreme problems/unable to do)						
Missing					2 (40)	
ANXIETY/DEPRESSION			1			0.1905
(No problems)	1 (25)	1 (20)	chisq=0.5489	3 (75)		0.0979
(Slight problems)	3 (75)	2 (40)		1 (25)	2 (40)	
(Moderate problems)		1 (20)			1 (20)	

(Severe problems)		1 (20)				
(Extreme problems/unable to do)						
Missing					2 (40)	
Effect of intervention on EQ-5D-5l index score						
EQ VAS						
Mean (SD)	85.75 (8.5)	81 (8.21)	0.42	84.25 (6.50)	78.33 (10.403)	0.4472
INDEX VALUE						
Mean (SD)	0.8160 (0.0349)	0.8044 (0.1396)	0.8656	0.77 (0.0667)	0.8420 (0.035)	0.1671



Article

Description of Process and Content of Online Dementia Coaching for Family Caregivers of Persons with Dementia

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Abstract: Family caregivers of persons with dementia encounter resistance to care behaviors (RCBs). The purpose of this methods paper was to describe the process and content of six weekly 60-min caregiver coaching sessions delivered synchronously through an online platform to 26 family caregivers of persons with dementia. All session notes were analyzed for process; two coaching sessions from five purposely-selected participants were transcribed and analyzed thematically for content. The six sessions followed an overall pattern. The first session included the most teaching and goal-setting; the coaches also queried the family caregiver about the premorbid personality, work history, and interpersonal attributes of the person with dementia. Sessions two through five were the most active coaching sessions; previously suggested strategies were evaluated and tailored; caregivers also role-played with the coaches and developed scripts designed to curtail RCB. The sixth session served as a review of successful caregiver strategies and concluded the coaching relationship. Four primary content themes emerged in the coaching process: (1) education; (2) caregiver communication; (3) affirmation of the caregiver; and (4) individualized strategies. These four content categories were used throughout the coaching process and were interwoven with each other so that the participant knew why the behavior was occurring, how to verbally address it, how to use a strategy effectively, and affirmation of the result. The coaching process and content demonstrated alignment with person-centered practices and relationship-centered care.

Keywords: dementia; caregiver; coaching; rejection/resistance to care behavior; internet-based

1. Introduction

In the United States, 16 million informal caregivers provide 18 billion hours of care to 5.5 million persons with Alzheimer's disease or related dementias annually; this care is valued at \$230 billion US dollars [1]. Nearly 80% of persons with dementia living in the community require help with at least one activity of daily living (ADL) [2]. Persons with dementia requiring ADL assistance often exhibit resistance to care behaviors (RCBs) [3,4]. RCB refers to actions taken by a person with dementia to avoid receiving assistance or care activities [5–7]. RCB encompasses an entire spectrum of behaviors, from subtle verbal or nonverbal signals to full-on assaults [7,8]. Examples include pulling away or turning away from the caregiver, saying “no,” crying, yelling, pushing the caregiver away, grabbing an object to evade care, clenching the mouth shut (to avoid medication, food, or mouth care), adducting limbs (to prevent the axillae or perineal areas from being cleansed), and striking the caregiver [6–8]. These behaviors vary in frequency and intensity. Terms variously used to describe RCB include agitation, refusals, resistiveness to care, rejection of care, and care-resistant behavior [7,9,10]. For clarity,

this article will use “resistance to care” behavior. Investigators in the past ten years have made important distinctions between agitation and resistance to care. The major difference between the two involves contextual clues. That is, agitation usually occurs without a specific trigger, whereas RCB occurs in response to a precipitating event, such as bathing or mouth care [7,11,12]. Agitation is evident in persons with mild dementia, increases with moderate dementia, and wanes as the dementia progresses to severe. RCB, however, consistently increases with worsening dementia severity; one study found an eightfold increase in overall RCB when dementia progressed to the severe stage [12].

Fauth et al. discovered that 66% of their 234 informal caregivers encountered RCB, the majority of which occurred when caregivers attempted to assist with ADL [3]. These informal caregivers experienced feelings of distress, captivity, and depression when faced with RCB. Shirai and Koerner [13] reported similar prevalence of RCB with fluctuations over time. They collected RCB data over an 8-day period from 63 informal caregivers and concluded that informal caregivers who experienced both higher frequencies and higher fluctuations in RCB experienced significant increases in physical problems such as headaches and chest tightness [13]. Spigelmyer et al. [14] conducted a phenomenological study examining the experience of informal caregivers with RCB; the investigators reported that caregivers felt intensely guilty and incompetent when faced with RCB [14].

In long-term care settings, Mahoney et al. were among the first to distinguish RCB from other behavioral and psychological symptoms of dementia (BPSD). Jablonski and colleagues have been instrumental in testing theoretically driven strategies that enable long-term care staff to successfully provide mouth care to persons with dementia exhibiting RCB [8,9,15–17]. For this study Jablonski et al.’s non-drug, behavioral interventions were adapted to a distance-accessible education, training, and coaching program for family caregivers of people with Alzheimer’s disease. The coaching program contained both asynchronous content and six 60-min weekly real-time coaching sessions with family caregivers delivered via an internet-based platform. We distinguished teaching, which is content-focused and generalized, from coaching, which is process focused and specific to the individual caregiver/learner. This content represents one part of a larger research program measuring the impact of the coaching program on caregiver burden and quality of life for families caring for persons with dementia. By its nature, most qualitative research has reflective qualities, including this one. However, the primary aim of this paper is to describe the methods, including process and content, of the six weekly 60-min dementia coaching sessions that constitutes the primary intervention in the broader research program. This is done by using the interactions between coach and caregiver (using actual quotes) as exemplars of the process and the content of this process.

2. Operationalization of Coaching Sessions: Planned Process and Content

After receiving ethical approval from both the university (University of Alabama at Birmingham, UAB IRB-160819003) and the funder (United States Department of Defense, DOD HRPO A-19729) family members of persons with dementia were recruited from outpatient clinics within the same healthcare system. The family member participants were randomized to either immediate or delayed coaching sessions. All had immediate access to the asynchronous materials available on a password-protected website. The asynchronous content included six brief videos that provided and illustrated specific strategies for preventing and managing RCBs. The strategies have been published in-depth elsewhere [9,15–17].

Two members of the team served as coaches (RJ and VW). One coach was a nurse practitioner and researcher who had several years of clinical experience extending Jablonski and colleagues’ RCB mouth care work to other ADLs, such as bathing and medication administration. The other coach was a medical sociologist with experience implementing RCB research. The protocol allowed either coach to conduct coaching sessions.

The caregiver coaching sessions were operationalized a priori to follow a systematic process. Each coaching session was digitally recorded. During the sessions, the caregiver was queried about any problematic CRB and the strategies (if any) deployed to address it. Additional details, such as timing

context, and success (or failure) were sought. The coaches adapted specific strategies to personalize the techniques to the needs of both the caregiver and the care recipient. The coaches assessed the ongoing efficacy of previously used interventions, and the resulting behavior, during each subsequent coaching session. The coaching goal for every session was to help the family caregiver become more independent with using and modifying the RCB techniques. Throughout the 6 coaching sessions, the efforts of family caregivers were acknowledged, praised, and reinforced.

The internet-based Go-To-Meeting™ platform was selected so that participants did not have to purchase any software; they downloaded the free version and responded to a link sent by the research team. Prior to the first scheduled coaching session, VW conducted a 20-minute practice session with the participants, using the link to assist with any technical problems. Every participant had a unique Go-to-Meeting™ link.

To date, 26 family caregivers have completed 6 coaching sessions. Each coaching session was approximately one hour in duration. Because of the length and depth of each one-hour coaching session, five participants that represented the diversity of the participant sample in terms of sequential entry into the study, gender, ethnicity, and family role of the caregiver (e.g., spouse versus adult child) were selected for the purpose of describing the content and process of the coaching sessions. Schatzman and Strauss [18] note that the use of purposeful sampling is feasible when choosing participants because of practical options such as constraints of time, the research framework, and burgeoning interests/concepts during the research process. These participants were also selected based on the richness of the data collected in their sessions and also represented the trajectory and content of the majority of the sessions. The notes taken by the coaches during all coaching sessions were also analyzed. A description of the general pattern of all six coaching sessions emerged from the notes, which are described in the Results section, below. This pattern then informed our decision to select, and analyze, transcripts from the second and fifth sessions from the 5 purposively selected participants. The rationale for selecting these sessions was that sessions 2 and 5 best reflected caregiver struggles, problems, strategies, breakthroughs, and insights. During Session 2, participants provided richer descriptions of the RCBs as compared to the initial session. Participants also shared helpful information about underlying sources of strengths and challenges, for example, how existing family dynamics could be both supportive and frustrating. The Session 5 reflected the culmination of the previous 4 coaching sessions and consistently resulted in “a-ha” moments of exceptional clarity and understanding of the content. By Session 5, participants had tried the strategies and were becoming more confident with their abilities to reduce and manage RCB. The participants were selected to represent

The transcripts from Sessions 2 and 5 of the five purposively selected participants were transcribed, 10 transcripts total. Content analysis was employed on the 10 transcripts to better describe the behavioral strategies developed between the participants and the coaches. Content analysis is a research method that is useful in conceptualizing the meaning and relationship of language in a text in order to derive meaning [19]. All 10 transcripts were coded for concepts that described the coaching process. This provided a systematic method for thematic development based on the presence of these concepts. All 10 transcripts were compared against the original digital recordings for accuracy. Corrections were made if mistakes were noted.

3. Results

3.1. Sample and Demographics

The sample ($N = 5$) included 3 women and 2 men (see Table 1). The average age of the participants was 65.4 years. All of the caregivers were in their seventies except for one who was 29. Two of the caregivers were adult children of the care recipient.

Table 1. Demographics.

Participant/Caregiver ID	Age	Gender	Race	Relationship to Care Recipient
A	75	F	African-American	Daughter
B	74	M	White	Spouse
C	78	M	White	Spouse
D	71	F	White	Spouse
E	29	F	Asian	Daughter

3.2. Roles of Primary and Secondary Coaches

The analyses of the transcripts revealed that the coaching process evolved and individual roles of each coach emerged. Both coaches participated together in the coaching sessions. Initially, the plan was for VW to gain familiarity and experience by “listening in” to all 6 of RJ’s coaching sessions with the first participant, and then for both coaches to conduct sessions independently. For the sessions reported here, RJ consistently served as the primary coach and VW as secondary coach. Participants were also aware that both coaches were present during each session.

After each session with any participant, both coaches engaged in debriefing activities and brainstormed ideas for the next session, which were incorporated into joint notes. This practice was found to be very helpful for both coaches; they continued to work together with all subsequent participants. The secondary coach would “listen in,” and assist the primary coach with post-coaching debriefing. Feedback from the secondary coach served as an assessment tool for the session. The secondary coach was able to provide feedback for factors such as participant reaction, the trajectory of the sessions and provide affirmation for successful interactions. Debriefing was especially helpful to the primary coach since a majority of the interactions occurred between the participant and primary coach. The post-session debriefing also alerted both coaches to the maturation and evolution of the intervention that produced a growing collection of strategies.

During the shared sessions, the secondary coach (VW) would interject ideas if appropriate. Notes taken during the sessions were shared between coaches and informed the context of the next session. The notes served to remind coaches of previous sessions, provided insight into the sessions, and served as a “placeholder” for the next session. These notes were especially helpful when multiple coaching sessions with other participants were being conducted in the interval between sessions for any one participant. In the notes, coaches recorded problems described by the caregivers that were not easily addressed in the session and required further thought. Coaches would discuss the problem and work together, brainstorming, to provide unique/individualized strategies for the caregiver. After the first several sessions, it became apparent that directed homework was important for the participants. It served to encourage participants to implement the strategies thus providing the coaches an opportunity for feedback to the caregiver and to assess the efficacy of the strategies for the care recipient.

3.3. General Pattern of Six Week Caregiver Coaching Sessions

The following is a description of the pattern of content and coaching activities that emerged from coaching notes across all sessions:

Session 1 served as the introduction and goal-setting session. The primary coach first inquired about the premorbid personality, work history, and interpersonal attributes of the person with dementia. The coach also inquired about past and current living situations and premorbid relationship quality. This information helped the coaches to assess the strengths and challenges presented by the relationship between the caregiver and care-recipient. Goals were negotiated and determined by asking the caregiver, “Which refusal behavior is most important for us to help you with?” The coaches laid the

foundation for the future sessions by emphasizing that the coaching sessions were to help caregivers “manage” and “reduce” negative impacts of RCB on their well-being; because of the progressive nature of dementia, eradication of BPSD was not a realistic goal, and any expectation of eradication would set the caregivers up for failure. Session 1 also included the most teaching of dementia content.

Initial RCB strategies were also introduced during the first session and tied to the “shrinking box” and “short-staffed” analogies; a description of these and other analogies can be found in Table 2. These strategies included communicating using “short, sweet, and concrete” sentences; using gestures and pantomimes as adjuncts to verbal communication; avoiding arguments; and “entering their reality” in lieu of therapeutic fibbing. Therapeutic fibbing was a term coined in 1999 by Beach and Kramer, and referred to the practice of lying to people with dementia [20]. “Entering their reality” [15,17] involved finding situations from their past that would provide a reason for engaging in a care activity or allowing the caregiver to provide assistance without triggering refusals.

Table 2. List of Analogies and Description.

Analogy	Purpose	Description
Shrinking box	Explanation of neurodegeneration and its impact on short-term memory	Coaches compared shrinking brains to shrinking boxes. As the boxes became smaller, recent memories fell out while new memories could not be placed in the shrinking box.
Short-staffed working conditions	Explanation for periods of irritability and fatigue observed in the person living with dementia	The ongoing loss of neurons from neurodegeneration resulted in compensation from remaining neurons. These remaining neurons were likened to employees working with insufficient staff: the remaining employees would be expected to perform multiple and unfamiliar tasks, resulting in mistakes and fatigue. They would be irritable and cranky by the end of the shift.
Messy closet/Jewelry Box	Explanation for confabulation or erroneous long-term memories; also used to help explain altered sensation of time passing	The brain was compared to a compartmentalized closet or box, where memories were logically arranged in sequential patterns. If the clothes became haphazardly arranged in the closet, or if the compartments in the jewelry box disappeared, the contents would become disorganized and difficult to locate. This analogy was then applied to the brain, where the loss of neurons contributes to the jumbling of memories. The person with dementia was not lying or trying to be difficult.
Highways and back roads	Explanation for cognitive slowing and altered sensation of time passing	Neural networks were compared to highways. Loss of neurons resulted in “closed lanes” and “detours.” Both created traffic slowing. Ongoing neuronal death resulted in some highways becoming completely severed. The memories may still be available, but unable to be accessed. In these situations, sensations (music, smells, touch, pictures) may access specific memories via “back roads.”
Boat without an anchor	Additive explanation for confabulation or erroneous long-term memories; also used to help explain altered sensation of time passing	Short-term memory is necessary for people to “be anchored” in time and place. If short-term memory is impaired, the person with dementia becomes disoriented because they are like a boat without an anchor; they are bobbing around in a sea of memories without landmarks.

Table 2. Cont.

Analogy	Purpose	Description
Moving backwards in time	Explanation for apraxia around ADLs and other activities.	Persons with dementia generally experience apraxia in a sequential pattern, with loss of complex abilities occurring prior to loss of simpler abilities. The loss of abilities was couched as reverse chronological aging. People lose the ability to use objects or perform activities that were learned latest in life, while retaining abilities (such as feeding oneself) learned early in life.
Brain as computer	Explanation to assist the caregiver to understand the person's inability to create new memories.	Loss of neurons compared to an older computer with no more memory.
Strategy Toolbox	Explanation of why strategies may require modifications over time and	Strategies compared to different tools in a toolbox. Just as every tool has a specific function, specific strategies are used in specific situations.

In Sessions 2–5, the coaches built on the initial RCB strategies *provided* during Session 1 while introducing new strategies as needed. Some content-focused and generalized teaching occurred throughout these sessions, but the amount of teaching progressively decreased while the amount of coaching increased (see Section 3.4 for specific coaching approaches). The caregiver was initially queried about the use and outcome of specific RCB strategies. The strategies were then tailored to fit unique situation of the caregiver and care-recipient. The coaches provided tailored “scripts” for the informal caregiver via role-playing, in which the coach assumed the role of the informal caregiver while the caregiver assumed the role of the person living with dementia. Throughout these five sessions, the coaches also validated and affirmed the informal caregiver’s techniques and encouraged continued adaption and tailoring of general RCB strategies. Every session concluded with a “homework” assignment based on the management of the behaviors thus far. The subsequent session began with a report on the efficacy of the homework assignment.

Although the focus was on the RCBs, it became obvious during the first few sessions that participants often asked questions about medications and other behaviors that occurred in addition to the RCB. Even though the focus was on RCB, the family caregivers were frequently and inadvertently triggering RCB. Thus, it became important for the coaches to discuss caregiver and care-recipient interactions in order to avoid triggering RCB.

The final session, Session 6, served as a review of successful strategies for managing RCB and also as the conclusion of the coaching relationship.

3.4. Four Themes of Coaching Content

In the 10 transcripts, four primary themes emerged from qualitative analysis of the coaching process: (1) education; (2) caregiver communication; (3) affirmation of the caregiver; and (4) individualized strategies. These four content categories were used throughout the coaching process and were interwoven with each other so that the participant knew why the behavior was occurring, how to verbally address it, how to use a strategy effectively, and affirmation of the result. The next sections include descriptions of each component of the process, and it provides examples. Direct quotes (some lengthy) from transcripts are used to illustrate typical coaching approaches.

3.4.1. Education

Even though we differentiated teaching from coaching, the coaches provided each participant with a foundation for understanding the disease process that was systematic and continuous throughout the coaching sessions. This served to provide the caregivers with a “why and what” of care resistance.

They provided a basic and succinct explanation of the disease process beginning with the neurobiology of threat perception (for more information, see Jablonski et al. 2011). Information provided was tailored to the background of caregivers. For example, two of the caregivers had advanced degrees in the biological and social sciences respectively so greater detail was provided when discussing the neurobiology of threat perception. Analogies were especially useful in explaining specific concepts for all caregivers. These are listed in Table 2. Neurodegeneration, for example, was explained using the analogy of the shrinking box:

“The brain is like a box full of Christmas decorations. The decorations from 1964 are at the very bottom, while the decorations from last year are sitting at the top. As the box shrinks, the decorations from last year fall out. Meanwhile, you can more easily reach into the box and pull out the decorations from 1964 because you have fewer layers to move aside. The brain is like the box. As brain cells die, newer memories “fall out” while older memories are more accessible. That is why your family member cannot remember if she ate breakfast, but can tell you about some event 40 years ago. This is also why long, drawn out explanations and sentences do not work. The brain does not have enough space to ‘hold onto’ the entire conversation.”

Caregivers often reported that their family members had episodes of irritability and anger; they shared their frustration that the person with dementia did not respond to reason. An analogy of a business or factory with overworked employees was used to explain how a reduced number of neurons could cause frustration and agitation in someone with Alzheimer’s disease.

“Imagine if you showed up to work and half of your coworkers had just quit. You and your remaining colleagues would have to scramble and do two- or three-times the amount of work you usually do. You would be expected to perform tasks for which you have had little, or even no training. You and your colleagues may be able to compensate for an hour or two. By lunchtime, all of you would be overwhelmed, tired, and cranky. Customers would notice mistakes; they would notice orders being incorrectly filled or not completed at all. If a customer tried to explain something to you or one of your overworked colleagues, you may not have the energy to follow the conversation and may become even more irritated. By the end of the shift, all of you would be exhausted. That is what is going on in your loved one’s brain. Brain cells are trying to compensate and work harder. These hard-working cells become overwhelmed, especially in loud or crowded social situations. That is why your family member becomes irritable and may demonstrate anger, especially when you are trying to reason with them.”

Caregivers often conveyed that their family member would refuse care and make statements such as, “I’ve already bathed,” when this event had not occurred. The coaches built on the analogies of “shrinking box” and “overworked staff” to help caregivers understand the confabulation that was often associated with care refusal behaviors. The coaches explained that the care recipient’s sensation of time passage was impaired because of the combination of short-term memory loss and more readily accessed older memories, which might cause a long-ago memory of bathing to feel as if the experience had just occurred. The coaches couched this explanation within the context of comparing the brain to a compartmentalized box; as the “walls” of the box breaks down, the contents (memories) become mixed up and tangled. Furthermore, cognitive slowing was explained using a highway metaphor: as neurons die, the lanes of the highway decrease and the brain attempts to access alternative routes the way motorists may access detours. Just as detour routes can become crowded and the traffic moves slower, the brain’s use of alternative (and less developed) networks can delay recall and slow down the ability to perform a desired action. Sometimes, these analogies were insufficient. In those cases, a new analogy of a boat without an anchor was introduced to help describe why persons with dementia may assert that an event had recently occurred when it had not.

Simple language to explain difficult concepts was useful in helping the caregiver understand a behavior with which they were struggling. The coaches also used the analogy of “moving backwards in time” to explain the person with dementia’s problems with praxis. New analogies often incorporated previously used analogies:

Coach (to Caregiver A:) "As she's moving backwards in time, she may have forgotten about credit cards. 'Cause when you forget stuff, you forget stuff the reverse way you learned it. It's like the box that's shrinking. The newest stuff on top is the first to fall out. She probably started using credit cards in later adulthood."

While educating the caregiver was a significant portion of session 1, education was interwoven into most ongoing interactions with the caregivers. A context for why the behavior might be occurring was combined with an immediate strategy, or what to do, to address it.

Coach to Caregiver B: "Ok, you're getting angry because you have to repeat yourself constantly."

Caregiver B: "Yeah, that's right."

Coach: "Right, she can't help it...her brain is shrinking so she has no place to put the memory she's making now."

3.4.2. Caregiver Communication

In session 1, informal assessments were made about the quality and type of communication between the caregiver and the person living with dementia. In this assessment, patterns of communication that could trigger RCB were noted. This included tone and pitch level of voice, arguing, or cajoling. Throughout sessions 2 through 5, the coaches presented caregivers with new patterns of communication that included using scripts to communicate and a way of redefining interactions. Scripts were based on the relationship between caregiver and care recipient. In one interaction with caregiver C, the Coach stated,

Coach: "It's the truth, it's genuine, it's loving. Those are the three components of the communication that are so important. It takes practice to, what I call, (develop) the scripts."

The coach then provided him with a script to encourage his wife to eat. The strategy was to get her to come to sit with him and ultimately, eat.

Caregiver C: "How do I say, 'it's time for lunch?' Her response is always, "I'm not hungry."

Coach (providing script to Caregiver C): 'I know you're not hungry, but I would love your company while I eat.'

In another interaction in the same session with the same caregiver, the coach asserted the importance of redefining modes of interaction as a way of more effective and less provocative communication. The caregiver was struggling with the strategy of "entering their reality," where caregivers are coached to provide a dementia-centric rationale for accomplishing a task that is being resisted by the person with dementia. During this session, Caregiver C's wife (the person with dementia), joined him in front of the computer screen and began interacting with the coach about the numerous bathrooms in their house. This comment prompted Caregiver C to contradict his wife and the Coach to intervene:

Wife: There's so many bathrooms in that house.

Caregiver C: Ain't but two bathrooms in that house.

Coach (responding to Caregiver C): Okay, [Name]. Right there. Stop. Don't argue. Because of the changes in the brain, every time she saw the same bathroom it was like a new bathroom. In the future, if she says something like, "Oh, there was a whole bunch of bathrooms," you don't have to lie, or you can just say, "Boy, it sure felt like that." You're not arguing. You're acknowledging what she said. It's factual from her perspective. Just because a person sees something a certain way doesn't necessarily mean it's wrong...You can explain, but in your wife's situation, she doesn't have enough brain power to process the explanations, and every time your wife says something and you present reality, it feels to her like you're picking on her, you're arguing. That's going to increase her agitation. It'll start low

in the morning and it's gonna build up. By suppertime, as the evening wears on, she may be very agitated, hard to settle down, and just into everything.

Caregiver C: I feel like I'm on an edge or on a line that I don't want to cross and become combative or ugly or dictatorial. I want to be real and not manipulative although it is. I'm just really struggling.

Coach: You're presenting things in a way that makes sense [to the person with dementia]. That's not manipulation. It's as if I go into the clinic and I have patients who speak Spanish. Okay, I can speak Spanish. Not well, but I can. I start talking to them in Spanish. That's not manipulation. That's communication. It's crossing the [communication] bridge. For me to expect that person to communicate in English when so much is going on is a little unfair. I communicate in Spanish, even if I screw it up.

3.4.3. Affirmation of the Caregiver

It was important for the caregivers to believe that they were doing a good job. Caregivers often reported guilt or a sense of ineptitude in addressing RCB, as well as the negative emotions such as anger and resentment directed toward the care recipient. Affirmation was important and was used often. Caregivers were assured that they were being successful even when they had failed to use a discussed approach or strategy. The coaches also helped caregivers with setting realistic caregiving goals within the affirmations. Acknowledgement of their feelings in tandem with encouragement was also important. The following quotes illustrate this.

Coach to Caregiver B: A lot of care partners have this nagging concern. What if I don't know something?

What if I can't do something? What if I make it worse? Honestly, I understand the little voice in your head saying those things, but it's BS. You have a lot of knowledge in you that you can adapt for this new journey, and you are successfully doing it.

Caregiver D: "Some of it is with my mind frame too; knowing that I've got to change that too. It's just the way that it is going to be from here on out. That's part of it; knowing that I am going to have to change how we do things and when we do things and all of that. It's just accepting that and finding the best way to do it."

Coach to Caregiver D: "Okay. A lot of people never get to that point. That's good that you are at that place where you are really taking stock of how this is all going to work and you're figuring it out."

3.4.4. Individualized Strategies

The coaches incorporated previously published strategies developed for institutional paid caregivers to prevent and manage RCB within the context of mouthcare to the coaching of the current study's participants for assisting with other ADLs. These strategies included priming (using the environment to "trigger" procedural memories); distraction; chaining (caregiver begins the activity and allows the care recipient to finish the activity); bridging (caregiver has the person with dementia hold an object related to the caregiving activity, such as a wash cloth or soap during bathing); gentle touch; caregiver exhibiting happy/smiling facial expressions; caregiver speaking in short, respectful, 1-step sentences; caregiver avoiding excessive explanations; caregivers avoiding elderspeak (baby talk); and caregivers allowing as much self-care as safely possible [15–17]. The coaches consistently described the strategies as grounded in neurobiology. Placing behaviors in a physiologic context removed the personalization felt by caregivers; that is, caregivers often shared their perceptions that the person with dementia was rationally and purposefully engaging in a negative behavior. The coaches explained, using analogies, that many of the RCBs resulted from neurodegenerative changes:

Coach (to Caregiver B): Okay. The communication thing, does that make sense? Shorter sentences, at least try to look less scary, a little smile, and gestures and pantomime can also reinforce [the message]. If I were to say to your wife, "Take off your glasses," I would say, "Take off your glasses" [Coach pantomimed removing glasses] like that. Or if I was gonna say, "Brush your hair," I'd say "Brush your hair" Of course, I'd have a brush or I'd mimic a brush brushing my hair. The gestures and pantomime can reinforce what we're saying because there's pieces of the brain right here in the temporal lobes, and those pieces of the brain, they take sound and put meaning towards it. They take words and assign meaning. As those sides of the brain shrink, words pop in, and the brain looks at the word and says, "I don't know what to do with this." The word just gets dropped. By communicating in layers and putting the layers on top, you're more likely to get the message across.

Caregiver B: I agree. I have found that gestures work a lot better, particularly in the—when there's a sequence of events that you've got to do.

Strategies to address resistance to care behavior were personalized and adapted to the specific context and needs of both caregiver and care recipient. At each session, caregivers were asked if the suggested strategies had been effective in managing or reducing the RCB. The caregiver below had success in using distraction and bridging to keep her mother seated on the toilet:

Caregiver E: "last week you told me to put something in her hand to distract her from being angry... or to distract her from standing up. She's been sitting down to go to the bathroom."

While the strategy of having her hold an empty prescription bottle worked initially worked, it was further adapted to be more successful for the care recipient. At times, the care recipient would throw the bottle on the floor and try to get up. The Coach suggested that Caregiver E put something in the bottle such as M&Ms or Tic Tacs. The Coach then explained that the sound of the candy rattling in the container might pique E's mother's interest and allow her to complete the task.

Caregivers were also coached to provide the person with dementia purposeful activities, which could then be interwoven into methods for preventing and managing future RCBs. Caregiver A was struggling with her mother's refusal to remove clothes and to bathe. Caregiver A shared that her mother had worked as a housekeeper throughout her life. The Coach suggested that Caregiver A "hire" her mother to do the laundry and start by taking off her clothes to make a full load. Caregiver A successfully used this strategy:

Caregiver A: I gave her some clothes to fold up.

Coach: All right. How'd that work?

A: She said give them—it worked out fine.

Coach: Oh, really?

A: I had to pay her but she folded 'em up real neat.

Coach: She was pretty happy about that?

A: Yes, she was happy with that.

The Coach and Caregiver A also discussed how caregivers' emotions can impact the behavior of persons with dementia. This strategy became known as "the vibes," and was often used within the context of helping caregivers to assist the care recipient with finding appropriate and meaningful activities to minimize boredom, another RCB trigger:

Caregiver A: She used to make these little dolls and things like poodles out of the yarn. I tried to get her to remember that and she can't. I might try it again but she made beautiful things like that.

Coach: Well ma'am, the goal is not for her to remember how to do it 'cause she may or may not. The goal is for her to sit and feel a sense of accomplishment. Because sometimes we get hung up on the end product because it's normal . . . What you can do is get the dementia out of the way so her personality

can get through the cracks. She still has the same need to be loved, to be respected, to be taken seriously, to be treated with respect and so those things don't change. Us wanting our loved ones to go back to making the bread they made or the poodles or the doll baby clothes, we're just setting ourselves up to be frustrated. If you're frustrated, what happens to your mom?

A: She gonna read them vibes and she'll get frustrated.

Coach: Right and now you got a mess. I wanna keep you from—I want you to enjoy the ride, enjoy the journey and accept what your mom can do, what she can't. I'm not saying give up. I'm just saying switch up some of the expectations.

The coaches explained to caregivers that their emotions, such as anger or frustration, could be felt by the person with dementia and trigger RCB. This was also described as “the vibes.” Caregiver B realized that he was acting more like a parent than a spouse because of his caregiver role, causing his “vibe” to change:

Coach: Well, the other thing is, and this goes back to your wife, a kind word, a gesture, a compliment, that goes a long way too. Sometimes when we're caring for people with dementia we're so wrapped up in, we're constantly doing for them, that we forget that they would like a compliment or to be treated less like a care recipient and more like a partner.

Caregiver B: True. I've seen that.

Coach: When that dynamic changes, sometimes the spouse that is now—the spouse may not be able to articulate it, the care recipient spouse, but that spouse will often start to act up and will start to accuse the caregiver spouse of affairs, of not loving them, and what has happened is the vibe has changed. Some people don't care. They feel the shift, and they go, “it still feels good.” Other people feel the shift, and they go, “Something's not right.”

B: That's a good way to explain that, and I can absolutely say that I have seen that. I didn't know what I was seeing. I wonder if that's what last night was.

4. Discussion

This paper illustrates both the process and content of an online dementia coaching program for family caregivers of persons with dementia. The coaches successfully translated strategies developed to allow paid institutional caregivers to prevent and manage RCB within the context of mouth care to family caregivers to facilitate other ADLs in the home environment including bathing, dressing/undressing, medication administration, and eating. The coaching content was observed to fit in 4 categories: (1) education; (2) caregiver communication; (3) caregiver affirmation; and (4) individualized strategies. Even though the categories describe discrete themes, the coaching interactions usually addressed them concurrently rather than sequentially. These four content categories were used throughout the coaching process and were interwoven with each other so that the participant knew why the behavior was occurring, how to verbally address it, how to use a strategy effectively, and affirmation of the result. We were unable to find similar descriptions of caregiver coaching in the literature. However, Boots et al. [21], conducted a systematic review of 12 studies that used internet-based interventions to improve outcomes for informal caregivers of persons living with dementia; they concluded that the most successful interventions contained tailored information and used coaches to guide the use of the information.

Many of our caregivers were taught “therapeutic fibbing” from support groups and other dementia professionals. Therapeutic fibbing is lying to a person with dementia in order to obtain cooperation. We preferred the gentler strategy of “entering the care-recipient's reality.” Caregiver A entered her mother's reality and “hired” her mother to assist with the laundry; Caregiver A's mother was a retired housekeeper. Caregiver A first told her mother to remove soiled clothing in order to have sufficient garments to make a full load of laundry. She asked her mother to fold clothes taken from the dryer. Caregiver A paid her mother once the clothes were folded. By entering her

mother's reality, Caregiver A was able to accomplish the important task of removing her mother's soiled clothing in a respectful and dignified way, and she also provided her mother with a meaningful activity. When caregivers used entering their reality instead of therapeutic fibbing, the caregivers affirmed the care recipients' emotions instead of offering a glib response. Entering their reality was also another way to avoid provocative communication. Caregiver B, for example, was vexed by his wife's assertion that their house had more than two bathrooms and he corrected her during a coaching session. The Coach used entering their reality to illustrate to Caregiver B how he could validate his wife's perception with a statement such as, "it sure felt like that." The Coach explained how entering their reality can be used to acknowledge the care recipient's reality.

The coaching process and content as described here is aligned with person-centered practices. Person-centered care recognizes the individual person's self-determination, choices, worth, histories and interests [22]. The focus of care shifts from de-contextualized outcomes to those that are important to individuals. For people living with dementia, these outcomes often concern quality of life or the ability to function or care for themselves. Nolan and colleagues [23] took this idea one step further and proposed a relationship-centered model of care that includes not only the care recipient but also all who are involved in the care relationship. Their model's underlying assumption is that every individual in the caring relationship should experience a sense of worth, purpose, and achievement. This approach is particularly salient for informal caregivers of persons who exhibit RCB and present safety concerns for all involved. The coaching intervention described here clearly emerged to be aligned with Nolan and colleagues' relationship-centered model of care. The coaches inquired about the care-recipient's past history, behavioral patterns and preferences; they helped the informal caregivers facilitate personalized relationship-based care and prevent many RCBs [24,25].

Kales et al. suggested a framework for clinicians to determine the etiology and optimal management of neuropsychiatric behaviors exhibited by persons with dementia [26]. This framework employed the mnemonic DICE: a description of the behavior; investigation of possible underlying causes of the behavior; creation of a behavioral plan; and evaluation of the behavioral plan [26]. Even though there was no a priori decision to implement the DICE framework, the natural progression of the coaching sessions mirrored the 4 steps.

The coaching intervention exhibited a maturational process as the study progressed. The coaches built on previous metaphors and analogies, not only within the six coaching sessions, but also with each successive participant. Their repertoire of behavioral strategies also increased as the study progressed. Maturation of behavioral interventional strategies has been identified by one other group of researchers [15]. The evolution and maturation of behavioral interventions may affect internal validity as a study progresses; if not reported or described, such maturations may explain subsequent problems with reproducibility.

We limited our thematic analyses to 10 coaching sessions involving 5 family caregivers. Our understanding of the coaching content would be enhanced by analyzing additional coaching sessions with participants near the end of the study, in order to capture more strategies and educational analogies as they evolve. Another limitation of our design was restricting participation to one family caregiver. Nearly every participant was assisted by other informal family caregivers. We plan to evaluate the efficacy of an online coaching program delivered to multiple family members.

The informal feedback from our participants has been favorable. The information captured from this methods paper will inform the development of a coaching manual and training materials. Given the growing number of persons with dementia living in the community, there is a pressing need for ongoing coaching programs that can be delivered by community laypersons and delivered in cost-efficient modalities.

5. Conclusions

Caregiver education, caregiver communication, caregiver affirmation, and individualized strategies are the foundational components of a successful dementia coaching program. All four

components occur concurrently during coaching sessions; the amounts of the components differ as coaching sessions progress. The participants understood the etiology of refusal behaviors and were equipped with strategies to effectively manage those behaviors.

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Telehealth Coaching for Caregivers of persons with dementia and care-resistant behaviors: an exploratory study

Rita A Jablonski, Vicki Winstead, Giovanna Pilonieta, David S Geldmacher

Introduction

A. Importance of dementia and caregiving

Dementia is a growing public health challenge across the world. In 2021 over 6 million people in the US have dementia; this is expected to increase to almost 14 million individuals by 2060. (1) It is important to note, however, that the illness state affects many more people than the person with dementia-causing pathology in the brain. In one specialty clinic, caregivers of persons with dementia (PWD) identified an average of 3.77 family members who participated in care activities (2). Behavioral and psychiatric symptoms of dementia (BPSD) are major drivers of distress among caregivers, and negatively affect quality of life (3). No drugs are specifically approved to treat BPSD and frequently used agents like antidepressants and atypical antipsychotics have limited effectiveness and significant toxicity (4, 5). Given the frequency, negative impact and limited pharmacotherapy for BPSD, there is an unmet need for effective psychosocial interventions to reduce distress and burden among family caregivers of PWD. Care resistant behavior is one manifestation of BPSD that appears particularly amenable to nonpharmacological intervention. The primary purpose of the study was to test the feasibility and acceptability of a telehealth coaching intervention for CRB, Care-Resistant Behavior Internet Training (CuRB-IT). The secondary purpose was to describe the impact of CuRB-IT on caregiver burden and distress using both quantitative instruments and qualitative analyses of coaching session transcripts.

B. Care Resistant Behavior

Care-resistant behavior (CRB) refers to actions taken by a person with dementia to avoid receiving assistance or care activities(Ishii, Streim, & Saliba, 2010, 2012; Kales, Gitlin, & Lyketsos, 2015; Konno, Kang, & Makimoto, 2012; Mahoney et al., 1999; Mahoney, 2015). CRB ranges from subtle verbal or nonverbal signals to physical assault(Jablonski-Jaudon, Winstead, et al., 2016; Mahoney et al., 1999). Investigators have made important distinctions between agitation and resistance to care. Agitation usually occurs without a specific trigger, whereas CRB occurs in response to a precipitating event(Volicer, Bass, & Luther, 2007; Volicer, 2012). Agitation most often emerges in persons with mild dementia, increases with moderate dementia, and wanes as the dementia progresses. CRB, however, increases with advancing dementia severity; one study found an eightfold increase in overall CRB among individuals with severe stage dementia(Volicer et al., 2007).

Two-thirds of family caregivers of persons living with dementia encounter CRB, especially when assisting with activities of daily living(Fauth, Femia, & Zarit, 2016; Shirai & Koerner, 2016). CRB creates feelings of distress, captivity, depression, intense guilt, and incompetence in family caregivers(Fauth et al., 2016; Spigelmyer, Hupcey, Smith, Loeb, & Kitko, 2018). Increases in the frequency and intensity of CRB are associated with family caregiver reports of physical symptoms such like headaches and chest tightness(Shirai & Koerner, 2016). However, family caregivers identify limited resources to assist them with coping with CRB(Kerns, Winter, Winter, Kerns, & Etz, 2018). Family caregivers use words like “useless” to describe the effectiveness of that physicians and other clinicians in helping to manage

CRB(Kerns et al., 2018). They report receiving some guidance from support groups, including telling falsehoods to obtain cooperation(therapeutic fibbing(Beach & Kramer, 1999; Spigelmyer et al., 2018)); feelings of moral conflict often lead to abandoning this approach. In contrast, when family members use logic and reasoning to “convince” the PWD to reduce resistance to care(Spigelmyer et al., 2018), CRB actually increases(Jablonski et al., 2018; Jablonski, Winstead, & Geldmacher, 2019; Jablonski-Jaudon, Kolanowski, Winstead, Jones-Townsend, & Azuero, 2016) . Interventions to support mastery in the caregiver role(Griffiths, Whitney, Kovaleva, & Hepburn, 2016; K. Hepburn, Lewis, Tornatore, Sherman, & Bremer, 2007; K. W. Hepburn, Lewis, Sherman, & Tornatore, 2003), and reduce stress associated BPSD have been described. However, despite its link to health and wellbeing outcomes(Acierno et al., 2019; Xinqi Dong & Simon, 2013; Xinqi Dong & Simon, 2013; Lachs, Williams, O’Brien, & Pillemer, 2002) for caregiver dyad members, interventions that promote self-efficacy in CRB management techniques have not been reported.

C. Prior data on coaching and CRB

The CRB strategies that were provided as part of the coaching interactions had been previously tested in long-term care (Jablonski et al., 2018; Jablonski, Therrien, Mahoney, et al., 2011; Jablonski-Jaudon, Kolanowski, et al., 2016). Initial work focused on conceptualizing care-resistant behavior within the “Neurobiology of Threat Perception” theoretical framework(Jablonski, Therrien, & Kolanowski, 2011). This framework suggests that dementia alters abilities to accurately interpret and contextualize caregiving activities, resulting in the PWD perceiving caregiving as potential or actual assaults. Next we developed strategies to prevent and manage CRB associated with oral hygiene in samples of nursing home residents with dementia and documented CRB which were successfully piloted testing in nursing homes with study interventionists (Jablonski, Therrien, Mahoney, et al., 2011). Efficacy testing in nursing homes showed that these strategies reduced CRB intensity and improved quality of care (e.g., significantly more episodes of completed mouth care vs.control conditions)(Jablonski et al., 2018; Jablonski-Jaudon, Kolanowski, et al., 2016).For this study, we expanded the intervention to support family caregivers. The theoretical underpinnings of the CRB strategies were expanded to incorporate anosognosia(Starkstein, 2014) (lack of awareness regarding one’s deficits and limitations).

We were unable to locate prior research that specifically tested the effect of caregiver coaching on preventing and managing CRBs. While the multi-component Care of Persons with Dementia in Their Environments (COPE)(Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010) intervention targeted all-cause agitation, it found no significant intervention effects, possibly because the all-cause measure classifies CRB with unprovoked agitation and not as a distinct behavior(Volicer, 2012). Other widely adopted tailored and multi-component interventions, such as the Resources for Enhancing Alzheimer’s Caregiver Health (REACH(Wisniewski et al., 2003), REACH-II(Nichols et al., 2017), REACH VA(Nichols, Martindale-Adams, Burns, Zuber, & Graney, 2016), and REACH-OUT(Burgio et al., 2009)) and Tailored Activity Program (TAP) (Gitlin et al., 2008), reduced overall frequency of behavioral symptoms of dementia (BSD) and stress appraisals. But impact on individual BSD was not reported, so it unclear whether BSD were uniformly lowered or CRB reduced. We did find that role-playing and problem-solving, two key components of the CRB coaching intervention, are superior to simply imparting information and enhancing knowledge of family caregivers coping with general BSD(Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007; Whitlatch & Orsulic-Jeras, 2018).

D. Emerging roles for telehealth interventions

At the time this study was designed in 2015, in-home telehealth services were largely unavailable outside research settings, and their feasibility for treating the consequences BPSD was first being explored. Subsequently, Steffen and Gant showed that caregiver coaching techniques showed “initial evidence for the efficacy of a telehealth behavioral coaching intervention compared with basic education and telephone support” for emotionally distressed caregivers of persons with neurocognitive disorders(6). They found that caregiver self-ratings of depression and distress improved during the intervention but were not sustained at six-month follow-up. Their study did not assess caregiver burden or quality of life. A subsequent systematic review of telephone interventions for caregivers identified minimal benefit for either burden or quality of life (7). Another more recent review also found that 54.6 per cent of 46 psychosocial support interventions to support dementia caregiver mental health had at least one positive outcome; improvement in subjective burden was the most frequent of these(8). Of note, the latter review did not include any telehealth-based interventions. The authors suggested one reason for the high proportion of ineffective interventions was that they were not well-tailored to the specific needs of individual caregivers. The methods we employed for this study, namely individualized coaching for a sample of caregivers selected for distress in response to a specific class of behaviors help to address those gaps in knowledge.

II. Methods

1. Protocol

This was a single-center, prospectivequais-experimental study of the effects of a 6- week, individualized, telehealth, active coaching intervention, with 3 endpoint assessments (7 weeks, 13 weeks, and 25 weeks post first coaching session) to measure retained efficacy. A convenience sample of 50 dyads was planned; each dyad consisted of a person with possible or probable Alzheimer’s disease dementia as defined by the NIA-Alzheimer’s Association (9) criteria and a family (i.e., unpaid) caregiver. Caregiver eligibility was based on caregiver ratings in three domains of the Neuropsychiatric Inventory (NPI)(10): 1) Agitation/Aggression, 2) Disinhibition, 3) Irritability /Lability. Dyads for which the caregiver reported all three of the following: 1) frequency of “Often” or more, 2) severity of “Moderate” or higher and 3) Distress of “Moderate” or higher for any one domain were eligible. In addition, the caregiver must have also reported that the adverse behaviors were triggered by resistance to care-related activities, e.g., bathing, taking medications, attending health-care appointments, etc.

Consent/ Screening Procedure. Informed consent was obtained from the affected person (if legally appropriate) or his/her legal representative, and from the caregiver. If unable to provide informed consent due to incapacity, the affected person assented to participation in the study for enrollment to take place Schedule of evaluations. Study assessments were obtained according to the schedule depicted in Table 1.

[insert table 1 here]

Study procedures: A brief neuropsychological evaluation was initially planned before the initiation of study intervention. However, the severity of cognitive impairment and BPSD of the PWD in many dyads was such that consent for participation was frequently refused. The protocol was subsequently modified and this requirement for in person evaluations was discontinued.

Details of the coaching procedures were previously reported. In summary, coaching sessions were delivered weekly by teleconferencing systems (Go-To-Meeting™ and Zoom™) for one hour and scheduled at the caregiver's convenience. Two members of the team served as primary coaches (RJ and VW). RJ, a nurse practitioner and researcher, had extensive clinical experience in working with family caregivers of persons with dementia in addition her substantive research in CRB. VW was a medical sociologist with experience implementing CRB research and research of older adults and technology use. For the sessions, both coaches alternated serving as a primary and secondary coach. VW conducted a (11)20-minute practice session with the participants to ensure success in accessing and using the platform and to assist with any technical problems. . In these sessions, coaches used the DICE framework (describe, investigate, create, evaluate)(Kales et al., 2015; Kales, Lyketsos, Miller, & Ballard, 2019) and a set of standardized scripts and analogies(Jablonski et al., 2019); to support the caregiver in applying CRB management techniques to their own situations and increase their problem-solving skills.

Quantitative outcomes: The revised Zarit Burden Interview (ZBI) was the primary outcome measure. (12) It was selected as the primary outcome because scores on the ZBI strongly correlate with behavioral problems in older adult patients and responded favorably to a telephone-based caregiver training intervention(13). Caregiver personality traits also affect perceptions of burden and quality of life (14). Caregiver self- ratings were therefore obtained on the Pearlin Mastery Scale (PMS) (15), Neuroticism Subscale of the Eysenck Personality Questionnaire Revised - Short Form (EPQR-SF) (16) and the Connor-Davidson Resilience Scale (CD-RISC)(17). Neuropsychiatric symptoms expressed by the person with dementia were assessed with the Neuropsychiatric Inventory (NPI) (10). Caregiver distress in response to behavioral symptoms was obtained with the NPI-Q (18). As a further supplement to the NPI, caregiver confidence in dealing with behaviors in each NPI domain was assessed (19). The severity of functional losses sustained by the person with dementia was assessed with the activities of daily living portion of the Blessed Dementia rating scale(20). Quality of Life was assessed with the caregiver-rated DEMQOL-proxy(11) and the EuroQol-EQ-5D-5L. Family Quality of Life in dementia (FQOL-D) is an emerging construct with potential for better understanding optimal care delivery in family setting for people with dementia (2, 21, 22). We collected FQOL-D data as an exploratory outcome.

Statistical analysis plan: **Giovanna**

III. Results

A. Sample

The enrolled sample consisted of 34 dyads, of which 26 completed the study. Demographic details are included in Table 2. Dyads which withdrew before completion of the intervention were not included in the final analysis. Reasons for withdrawal before completion included XXX, XXX.

B. Quantitative Outcomes

Several possible results were considered in the analytic plan. A decrease in burden score or an improvement in QOL measures from the baseline measurement to week 7 would be interpreted as an

effectiveness of active intervention. Improved burden or QOL scores measured at weeks 13 and weeks 25 would be considered indicative of sustained effects.

Mean ZBI scores of X and X were observed at the beginning and end of the intervention periods. Although the effect of the intervention on caregiver burden was in a direction that indicated benefit, there was not a statistically significant effect of the intervention at any time point

Spearman's correlations were conducted to examine the relationships between cognitive deficit scores and caregiver personality trait scores with ZBI scores. After controlling for other covariates, neuroticism ($p=0.0036$) and severity of the behavioral symptoms (0.0015) were significantly associated with caregiver burden. Also, caregiver age ($p=0.0365$) was significantly associated with caregiver burden

No effect of the intervention was identified on any of the quality of life measures, e.g., DEMQOL, DEMQOL-Proxy, EQ-5D-5L, or FQOL-D.

Spearman's correlations were conducted to examine the relationships of caregiver personality trait scores with burden and QOL scores. There was a positive statistically significant correlation between patient quality of life with caregiver self-efficacy (PSESDM) ($r=0.54$) ($p<0.05$). There were negative statistically significant correlations between patient quality of life and severity of behavioral symptoms ($r=-0.41$) and caregiver distress ($r=-0.49$) ($p<0.05$). There was a positive statistically significant correlation between FQOL-D and resilience ($r=0.48$) ($p<0.05$)

IV. Discussion

A. Quantitative effects not demonstrated

We did not find that the personalized telehealth coaching intervention reduced burden among caregivers of PWD with care resistant behaviors. Similarly, no effect of the intervention was found for multiple measures of quality of life. Despite differences in methods, these findings are consistent with the majority of prior reports on the effectiveness of psychosocial interventions for caregivers of PWD. Our methods predicted and specifically addressed some of the shortcomings identified by Wiegelmann and colleagues (8) regarding selection of participants and fine-tuning the intervention to their needs. In our study, we selected caregivers reporting high levels of distress in response to a specific form of BPSD, namely CRB. Additionally, the content and process of the coaching sessions was individualized to the both the character of the behaviors and the caregiver's responses to them, as reported by the each caregiver.(23)

B. Influences of caregiver personality

Our results suggest that even more fine-tuning may be needed for effective caregiver interventions. The impact of caregiver personality traits on perceptions of burden and quality of life warrants more detailed examination. Higher caregiver neuroticism was associated with higher reported NPI scores and higher burden. In contrast, higher mastery scores were associated with lower burden on the ZBI. Self-efficacy in surrogate decision making correlated with caregiver ratings of the PWD's quality of life and inversely with both the severity of the BPSD and the caregiver's distress at those symptoms. Greater self-reported resilience was associated with higher baseline FQOL-D, but no relationships between mastery or neuroticism and FQOL-D were established in this small study. In summary, caregivers with more neurotic features, i.e., with an increased tendency to experience negative feelings like guilt, anger, and anxiety appear to rate the severity of the PWD's symptoms more severely and experience greater

burden. In contrast, personality characteristics with positive emotional valence, like resilience, mastery, and self-efficacy result in higher scores on quality of life measures for the PWD and the family. The effect of the caregivers' emotional valence on their experiences of BPSD is further supported by the negative correlation between mastery and ZBI scores. These patterns suggest that a clear understanding of the caregiver's personality characteristics may be necessary to provide effective psychosocial interventions.

C. Practical considerations

The absence of quantifiable benefits from this personnel-intensive intervention, despite its use of personalized methods and highly experienced coaches, reinforces the difficulty of using quantitative scales to measure the effectiveness of interventions designed to reduce caregiver burden or improve quality of life. Although the telehealth method was effective in building relationships between the coaches and the caregivers, and reduced the need for often-difficult travel with the person with CRB, systematic, ongoing, one-on-one coaching methods would not generally be financially viable in the current US healthcare system. Future studies of nonpharmacologic management of CRBs by family caregivers might explore interventions that incorporate differential approaches to caregiver characteristics like neuroticism and resilience.

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Table 1 (stand-in)

Table 1 Comparison between immediate and delayed group demographic characteristics at baseline AD Completed

Characteristic	All N=26	Immediate Intervention n=14	Delayed Intervention n=12	χ^2 / t- Test P-value	Fischer /KW
Sex (N/%)					
Female	16 (61.54)	8 (30.77)	8 (30.77)	0.6188	0.7015
Male	10 (38.46)	6 (23.08)	4 (15.38)		
Race (N/%)					
White	20 (76.92)	9 (34.62)	11 (42.31)	0.3818	0.4452
AA	4 (15.38)	3 (11.54)	1 (3.85)		
Asian	1 (3.85)	1 (3.85)	0		
AI	1 (3.85)	1 (3.85)	0		
Ethnicity (N/%)					
Non-Hispanic	24 (92.31)	14 (53.85)	10 (38.46)	0.1119	0.2031
Hispanic	2 (7.69)	0	2 (7.69)		
Education (N/ %)					
High School	3 (11.54)	2 (7.69)	1 (3.85)	0.149	0.1656
13-15	12 (46.15)	4 (15.38)	8 (30.77)		
More than 15 years	11 (42.31)	8 (30.77)	3 (11.54)		
Age (Mean/SD)	75.69 (11.58)	75.74 (11.64)	75.66 (12.01)	0.99	0.6607
Marital Status (N/%)					
Married	20 (76.92)	12 (46.15)	8 (30.77)	0.39	0.4609
Widowed	5 (19.23)	2 (7.69)	3 (11.54)		
Divorced	1 (3.85)	0	1 (3.85)		
Cognitive testing					
Blessed	13.07 (3.59)	13.14 (4.26)	13 (2.82)	0.91	0.897
Slums- n=23	9.69 (5.91)	9.636 (7.20)	9.75 (4.77)	0.96	0.7333
Caregiver					
Sex (N/%)					
Female	14 (53.85)	8 (30.77)	6 (23.08)	0.7157	1
M	12 (46.15)	6 (23.08)	6 (23.08)		
Education (N/ %)					
High School	2 (7.69)	0	2 (7.69)	0.2818	0.4009
13-15	7 (26.92)	4 (15.38)	3 (11.54)		
More than 15 years	17 (65.38)	10 (38.46)	7 (26.92)		
Age (Mean/SD)	64.5 (14.79)	65.07 (13.91)	63.83 (16.36)	0.57	0.918
Marital Status (N/%)					

Table 2 (stand-in)

Table 2 Descriptive statistics for outcomes of interest by study group and week (N=26)

		Caregiver burden (ZBI)	Patient Quality of Life (DEMOQL- Proxy)	Family Quality of Life	EQ5D5L	EQ5D5L INDEX
Week	Group	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
0	Immediate	35.21 (14.40)	88.14 (15.90)	175.71 (19.06)	86.57(9.21)	0.830 (0.081)
	Delayed	36.91 (11.73)	94.91 (11.40)	171.58 (31.18)	81.91 (14.930)	0.8314 (0.1312)
7	Immediate	35.04 (12.48)	95.92 (10.46)	176.57 (23.61)	NA	NA
	Delayed	38.25 (12.14)	93.83 (12.99)	169.66 (24.38)	NA	NA
13	Immediate	34.28 (11.03)	93.92 (12.71)	182.35 (22.22)	NA	NA
	Delayed	35 (8.53)	95.25 (11.72)	175.41 (15.13)	NA	NA
24	Immediate	38 (13.87)	91.78 (20.20)	176.07 (14.11)	81.16 (7.80)	0.8328 (0.0745)
	Delayed	34.66 (11.48)	94.33 (8.37)	173.50 (13.43)	74.833 (13.3949)	0.8393 (0.0972)

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