



Research Article

Telehealth Coaching for Caregivers of Persons with Dementia and Care-Resistant Behaviors: An Exploratory Study

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Abstract

Background and Objectives: Behavioral and Psychiatric Symptoms of Dementia (BPSD) are major drivers of distress among caregivers, and negatively affect quality of life. Care Resistant Behavior (CRB) 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. The secondary purpose was to describe the impact of the coaching intervention on caregiver burden and distress using both quantitative instruments and qualitative analyses of coaching session transcripts.

Research design and Methods: This study utilized a mixed method with a convergent design. Twenty-six family caregivers received 6 weekly 1-hour coaching sessions that focused on preventing and managing CRB. Burden and quality of life measures were obtained at baseline and 7, 13, and 25 weeks post first coaching session. Forty-four transcripts of coaching sessions were analyzed using directed content analysis.

Results: Caregiver-reported burden scores improved but were not statistically significant. Neuroticism ($p = 0.001$), severity of the behavioral symptoms (0.0024) and caregiver age ($p = 0.017$) were significantly associated with caregiver burden. Care-recipient quality of life was correlated with caregiver self-efficacy ($r = 0.54$, $p < 0.05$). Three themes emerged that were directly associated with the effica-

cy of the coaching intervention: 1. Caregivers felt heard, 2. coaching helped caregivers manage behaviors, 3. caregivers accepted their need to change.

Discussion and Implications: Future studies of nonpharmacologic management of CRBs by family caregivers might explore interventions that incorporate differential approaches to caregiver characteristics like neuroticism and resilience.

Keywords: Burden; Mixed method; Neuroticism; Quality of life; Self-efficacy

Background and Objectives

Dementia is a growing public health challenge across the world. In 2022 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 one specialty clinic, caregivers of Persons with Dementia (PLWD) 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]. Care Resistant Behavior (CRB) 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. The secondary purpose was to describe the impact of the coaching intervention on caregiver burden and distress using both quantitative instruments and qualitative analyses of coaching session transcripts.

CRB refers to actions taken by a person with dementia to avoid receiving assistance or care activities [4-8]. CRB ranges from subtle verbal or nonverbal signals to physical assault [8,9]. 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 [10,11]. 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 [11].

Two-thirds of family caregivers of persons living with dementia encounter CRB, especially when assisting with activities of daily living [12,13]. These caregivers experience adverse physical and emotional symptoms when faced with CRB [12-14]. However, family caregivers identify limited resources to assist them with coping with CRB [15]. Family caregivers use words like “useless” to describe the effectiveness of physicians and other clinicians in helping to manage CRB [15]. Interventions to support mastery in the caregiver role [16-18], and reduce stress associated BPSD have been described. However, despite its link to health and wellbeing outcomes [19-22] for caregivers, interventions that promote self-efficacy in CRB management techniques have not been reported.

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Theoretical framework and intervention development

Coaching strategies for CRB strategies were previously tested in long-term care settings [23-25]. Initial work focused on conceptualizing CRB within the “Neurobiology of Threat Perception” theoretical framework [24]. This framework suggests that dementia alters a person’s abilities to accurately interpret and contextualize caregiving activities, leading the in the Person with Dementia (PLWD) to perceive caregiving as assaultive. A randomized clinical trial conducted across 9 nursing homes showed that coaching strategies reduced the intensity of CRB related to oral care and improved quality of care [23,25]. For this study, we extended the CRB coaching strategies beyond mouth care to support family caregivers in managing CRB in the context of BPSD. The theoretical underpinnings of the CRB strategies were expanded to incorporate anosognosia, the lack of awareness regarding one’s deficits and limitations [26].

At the time this study was designed in 2015, in-home telehealth services were largely unavailable, 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 [27]. 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 [28]. Another more recent review also found that more than half 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 [29]. 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 the current 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.

Methods

Design

This study utilized a mixed method with a convergent design. A convergent design requires collecting both qualitative and quantitative data concurrently. This design is useful in allowing the researcher to contrast and compare results from both types of data collection and can serve several purposes. Wisdom and Cresswell [30] note the utility of using a convergent design to assess the efficacy of an intervention while also examining participant experiences. This also allows researchers to explain the quantitative results through the lens of participant experiences thus providing both breadth and depth of understanding than do separate quantitative and qualitative data collection and analysis procedures.

Recruitment and sample

Ethical approval was received from the University of Alabama at Birmingham, UAB IRB-160819003) and the funding source (Department of Defense, DOD HRPO A-19729). 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 [31] criteria and a family (i.e., unpaid) caregiver. Caregiver eligibility was based on caregiver ratings in three domains of the Neuropsychiatric Inventory (NPI [32]: 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.

Protocol

A brief neuropsychological evaluation was initially planned before the initiation of study intervention. However, the severity of cognitive impairment and BPSD of the PLWD 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. 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. Participants were required to provide consent for both study participation and the transcription of their recorded sessions. Study assessments were obtained according to the schedule depicted in table 1.

Data Point	Subject of data	Domain	Instrument	
Baseline	Patient	Cognitive Function:	SLUMS ¹	
		Behavior/Neuropsychiatric Symptoms	NPI-Q ²	
		Functional ability	BADL ³	
		QOL	DEMQLQ ⁴ ; DEMQLQ-Proxy ⁵	
	Caregiver	Burden	ZBI ⁶ , NPI ² -Distress	
		Personal Characteristics: Mastery, Neuroticism, Resilience, Self-efficacy	PMS ⁷ , EQPR-SF ⁸ , CD-RISC ⁹ , SDM-SES- Self-efficacy ¹²	
		Quality of life	EQ-5D-5L ¹⁰	
	Family	Family Quality of life (rated by caregiver)	FQOL-D ¹¹	
	Weeks 7, 15, 25	Patient	QOL	DEMQLQ ⁴ ; DEMQLQ-Proxy ⁵
			Behavior/Neuropsychiatric Sx	NPI-Q ²
Caregiver		Burden	ZBI ⁶ , NPI ² -Distress	
		Personal Characteristics: Mastery, Resilience, Self-efficacy	PMS ⁷ , CD-RISC ⁹ , NPI-Self efficacy	
Family		FQOL	FQOL-D ¹¹	

Table 1: Data collection schedule.

Footnotes: ¹St. Louis University Mental State; ²Neuropsychiatric Inventory; ³Blessed ADL Scale; ⁴Quality of life reported by PLWD; ⁵Quality of life for PLWD completed by caregiver; ⁶revised Zarit Burden Interview; ⁷Pearlin Mastery Scale; ⁸Eysenck Personality Questionnaire Revised-Short Form; ⁹Connor-Davidson Resilience Scale; ¹⁰EuroQol-EQ-5D-5L; ¹¹Family Quality of Life in Dementia; ¹²Surrogate Decision-Making Self-Efficacy Scale (SDM-SES).

Caregivers received six 1-hour sessions where the intervention (described below) was delivered. Quantitative data were collected with three end-point assessments (7, 13, and 25 weeks post first coaching session) to measure retained efficacy.

Description of the intervention

Details of the coaching procedures were previously reported [33]. Coaching sessions were delivered weekly by teleconferencing systems (Go-To-Meeting TM or Zoom TM) 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 PLWD in addition to her substantive research in CRB. VW was a medical sociologist with experience implementing research on CRB and technology use in older adults. For the sessions, both coaches alternated serving as a primary and secondary coach. VW conducted a 20-minute practice session with the participants to demonstrate access and use of the platform and resolve technical problems.

Sessions followed a sequential and systematic trajectory. Earlier sessions contained more factual information to help caregivers understand how brain changes affected behavior, which in turn enabled them to understand how and why to use the strategies provided by the coaches. Coaches used the DICE framework (describe, investigate, create, evaluate) [6,34] and a set of standardized scripts and analogies [33] to support the caregiver in applying CRB management techniques to their own situations and increase their problem-solving skills. Digital recordings were made of sessions and the primary coach took field notes. A debriefing session between the coaches followed each session.

Quantitative measures

We assessed the cognitive and functional status of each care-recipient using the St. Louis University Mental State (SLUMS) and Blessed ADL Scale (BADL), respectively. The SLUMS is a brief mental status examination sensitive to the effects of AD, which surpasses the Mini Mental Status exam in detecting mild cognitive impairment [35]. The BADL scale captures functional ability [36]. The revised Zarit Burden Interview (ZBI) was the primary outcome measure [37]. It was selected as the primary outcome because scores on the ZBI strongly correlate with BPSD and responded favorably to a telephone-based caregiver training intervention [38]. Caregiver personality traits also affect perceptions of burden and quality of life [39]. Caregiver self-ratings were therefore obtained on the Pearlin Mastery Scale (PMS) [40], Neuroticism Subscale of the Eysenck Personality Questionnaire Revised - Short Form (EPQR-SF) [41] and the Connor-Davidson Resilience Scale (CD-RISC) [42]. Neuropsychiatric symptoms expressed by the person with dementia were assessed with the Neuropsychiatric Inventory (NPI) [32]. Caregiver distress in response to behavioral symptoms was obtained with the NPI-Q [43]. Caregiver self-efficacy was captured by the Surrogate Decision-Making Self-Efficacy Scale (SDM-SES) [44]. 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 [36]. Quality of Life (QOL) was assessed with the caregiver-rated DEMQOL-proxy [45] and the EuroQoL-EQ-5D-5L (EuroQoL Research Foundation, Rotterdam, The Netherlands), which is a generic instrument designed for self-completion by respondents to describe and value health. It defines five dimensions of health: mobility, self-care, usual Activities, pain/discomfort, and anxiety/ depression rated

at five levels of severity (no problem, slight/moderate/severe problems, and 'unable to do'). It provides a simple descriptive profile and a single index value for health status. Family Quality of Life in dementia (FQOL-D) is an emerging construct with potential for better understanding optimal care delivery in family setting for PLWD [2,46,47]. We collected FQOL-D data as an exploratory outcome (Table 2).

Week	ZBI	DEMOQL-Proxy	FQOL-D	EQ-5D-5L
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
0	36 (13.01)	91.27 (14.16)	173.81 (24.92)	84.42 (12.16)
7	36.52 (12.20)	94.96 (11.50)	173.38 (23.75)	
13	34.62 (9.77)	94.54 (12.04)	179.15 (19.24)	
25	36.46 (12.69)	92.96 (15.64)	174.88 (13.59)	78 (11.20)

Table 2: Descriptive statistics for outcomes of interest by week (N=26).

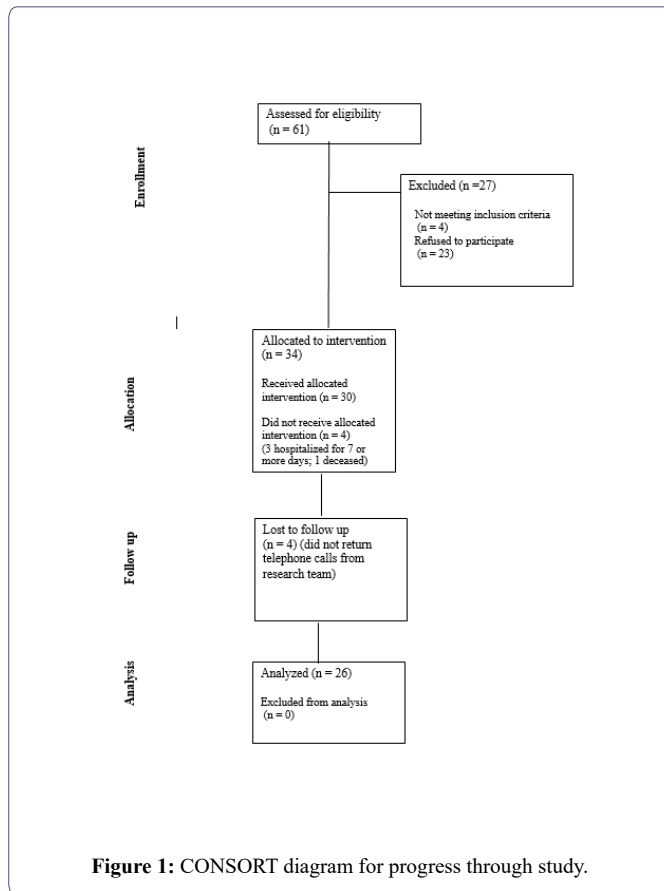
Analyses

Univariate statistics were used to describe study sample characteristics. Spearman correlations assessed the relationship between caregiver personality traits and care-recipient cognitive deficits, magnitude of burden, and QOL measures. Linear mixed models evaluated the effect of the intervention and time on caregiver burden and QOL measures. We then included variables with significant correlations ($p < 0.05$) to evaluate the relationship between outcomes of interests and caregivers' personality traits, controlling for caregivers' demographic characteristics. Analyses were performed using SAS, version 9.4. (SAS Institute, Inc., Cary, NC). 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.

For qualitative data, transcripts of the recorded coaching sessions were analyzed using directed content analysis, which begins with a theoretical framework or prior research findings to direct analysis for predetermined, initial codes. This leads the researcher to derive categories from the predetermined codes to develop a thematic model through which the data are analyzed [48]. Codes were then refined or added based on the data [49]. Initial, predetermined codes of caregiver experiences related to the effects of coaching on burden, distress, and QOL were identified and assigned codes from predetermined options. Each transcript (the unit of analysis) was read several times for clarity and context. Text that did not fit predetermined codes were given new codes. Using this coding matrix, codes were grouped into themes or headings.

Results

The enrolled sample consisted of 34 dyads, of which 26 completed the study (see CONSORT diagram, Figure 1). Demographic details are included in table 3. Dyads which withdrew before completion of the intervention were not included in the final analysis.



Education	12 Years	2 (7.69)
	13-15 years	7 (26.92)
	> 15 years	17 (65.38)
Age		64.5 (14.79)
Marital Status	Married	19 (73.08)
	Single	4 (15.38)
	Widowed	2 (7.69)
	Divorced	1 (3.85)
Relationship to the patient	Husband	8 (30.77)
	Wife	8 (30.77)
	Daughter	7 (26.92)
Employment	Son	3 (11.54)
	Retired	15 (57.69)
	Full Time	7 (26.92)
Personality Traits	Leave of absence	3 (11.54)
	Part time	1 (3.85)
	CDR-RISC ¹	
EPQR-SF ²		6.3 (1.95)
Pearlin Mastery Scale		20.23 (3.26)
SDM-SES ³		16.38 (2.74)
Zarit Burden Interview		36 (13.01)
NPI (Severity) ⁴		14.23 (6.05)
NPI DISTRESS		17.42 (6.91)
Quality of Life		
DEMQL-Proxy		91.27 (14.16)
FQOL-D ⁵		173.81 (24.92)
EQ -5D-5L ⁶		84.42 (12.15)

Table 3: Demographic and clinical characteristics at baseline.

Footnotes: ¹CDR-RISC: Connor-Davidson Resilience Scale; ²EPQR-SF: Eysenck Personality Questionnaire Revised-Short Form; ³SDM-SES: Surrogate Decision-Making- Self-Efficacy Scale; ⁴Neuropsychiatric Inventory; ⁵Family Quality of Life in Dementia; ⁶EuroQol-EQ-5D-5L

The primary purpose of the study was to test the feasibility and acceptability of a telehealth coaching intervention CRB. The intervention was found to be both feasible and acceptable by caregivers of people living with dementia. None of the 34 caregivers left the study because of dissatisfaction with the telehealth coaching intervention. Four did not receive the intervention because their care-recipient either died (N=1) or were hospitalized for 7 or more days (N=3). Events such as hospitalizations for 7 or more days resulted in study ineligibility and withdrawal from the study. The qualitative findings (below) also support our findings that caregivers found the telehealth intervention both feasible and acceptable.

The secondary purpose was to describe the impact of the coaching intervention on caregiver burden and distress using both quantitative instruments and qualitative analyses of coaching session transcripts. We have separated the quantitative and qualitative results in this section.

Quantitative findings

The intervention did not improve burden as captured using the ZBI. Mean ZBI scores of 36 (±13.01) and 36.46 (±12.69) were

Variables	Mean (SD) or Frequency (%)	
	N=26 (100)	
Care recipient		
Sex	Female	16 (61.54)
	Male	10 (38.46)
Age		75.69 (11.58)
Race	White	20 (76.92)
	African American	4 (15.38)
	Asian	1 (3.85)
	American Indian	1 (3.85)
Ethnicity	Non-Hispanic	24 (92.31)
	Hispanic	2 (7.69)
Education	12 years	3 (11.54)
	13-15 years	12 (46.15)
	> 15 years	11 (42.31)
Marital Status	Married	20 (76.92)
	Widowed	5 (19.23)
	Divorced	1 (3.85)
Cognitive testing		
Blessed ADL Scale		13.07 (3.59)
SLUMS (n=23)		9.69 (5.91)
Caregiver		
Sex	Female	14 (53.85)
	Male	12 (46.15)

observed at the beginning and end of the intervention periods. There was not a statistically significant effect of the intervention at any time point ($F_{3,73} = 0.32, p=0.81$). After controlling for other covariates, neuroticism ($F_{1,73} = 12.02, p=0.001$) and severity of the behavioral symptoms ($F_{1,73} = 9.88, p=0.0024$) were significantly associated with caregiver burden. Also, caregiver age ($F_{1,73} = 0.017, p=0.017$) was significantly associated with caregiver burden.

Bivariate analysis showed that caregiver personality characteristics were significantly associated with caregiver burden response, care recipient quality of life, family quality of life, the severity of neuropsychiatric symptoms, and associated caregiver distress. Higher caregiver neuroticism was associated with higher reported burden ($r=0.48$) ($p<0.05$). Higher mastery scores were associated with lower burden on the ZBI ($r=-0.42$) ($p<0.05$). Regarding quality-of-life measures, higher baseline FQOL-D scores were associated with greater self-reported resilience ($r=0.5$) ($p<0.05$). A higher baseline SDM-SES was associated with greater health-related quality of life for the care recipient ($r=0.54$) ($p<0.05$). Higher NPI severity ($r=-0.41$) and caregiver distress ($r=-0.49$) ($p<0.05$) were associated with lower quality of life for the care recipient. Lower self-efficacy scores were related to more caregiver distress ($r=-0.40$) related to neuropsychiatric symptoms.

No effect of the intervention was identified on any of the quality-of-life measures, e.g., DEMQOL-Proxy ($F_{3,73} = 0.72, p=0.544$), EQ-5D-5L ($F_{1,20} = 3.48, p=0.077$), or FQOL-D ($F_{3,74} = 1.01, p=0.393$). In addition, two clinical control variables were associated with quality-of-life measures. The severity of neuropsychiatric symptoms was significantly associated with health-related quality of life for the care recipient ($F_{1,72}, p=0.0376$). That is, the more severe the neuropsychiatric symptoms, the lower the health-related quality of life. Self-reported resilience ($F_{1,740}, p=0.0010$) was significantly associated with family quality of life: higher resilience scores were associated with better family quality of life.

Qualitative findings

Twenty-two family caregivers from the 26 participants consented to the transcribing of digitally recorded sessions. Among the caregivers consenting, there were 7 men and 15 women, with ages ranging from 27 to 81 (mean, 63.4 years). Fourteen caregivers were caring for a spouse and 8 were caring for a parent. Two transcripts were coded from each participant ($n=44$ transcripts): one from weeks 1-3 and one from weeks 4-6. Sessions 1-3 best reflected the caregiver's struggles, initial failures and successes, coaching insight based on family dynamics and environmental challenges and served as the "testing time" for tailoring the strategies. Weeks 4-6 provided insight for the coaches on increased self-efficacy and self-described reduction of distress and burden.

Three themes emerged that were directly associated with the efficacy of coaching. 1. Caregivers felt heard, 2. Coaching helped behaviors, 3. Acceptance of personal change.

Caregivers felt heard: Caregivers described the efficacy of verbal interactions with the coaches. These interactions seemed to promote feelings of being heard and understood. One caregiver expressed gratitude for having someone who would listen. "I wanna tell you how much I appreciate you listening. It's good to have somebody to talk with." (woman caring for her mother). After expressing frustration in communicating with his wife, the caregiver acknowledged that the

sessions were helping him. "Yeah. I'm learning. By the way, these sessions are helping. At least I've got somebody I can bring in my corner and just say, 'Hey, what do you think about?' and it's good." (man caring for his wife).

The connection with the coaches in the coaching sessions was described as a lifeline. "You just helped me more than you know. It's, so great to have a lifeline." (woman caring for her husband). Another caregiver expressed how talking with someone apart from their family enabled him to be thoughtful and motivated him to implement the strategies.

- ...As far as this conversation on a weekly basis, I told Mother the other day, "If nothing else, talking to someone outside our group has given me the opportunity to slow down and think about it and say, 'Well, that would work.'" When you're in the thick of it, you don't force yourself to do that. You just get frustrated and commiserate with each other." (man caring for his father)

Coaching helped caregivers manage behaviors: The interventions were centered around providing the caregiver with individualized strategies to reduce or manage CRB. Weekly "homework" was assigned. At the start of each coaching session, caregivers were given the opportunity to discuss the effectiveness (or lack of) of each strategy. The coaches then worked with the caregiver to modify or develop their own strategies. For example, one caregiver described the use of distraction to address the problem of her mother standing up when she toileted:

- "Last week, you told me to put something in her hand, so I've been trying to put stuff in her hand, while she's-to distract her from being angry or to distract her from standing up. She's been sitting down and going to the bathroom." (woman caring for her mother)

Two caregivers articulated their perceptions of improved daily routines.

- "I think it's been very helpful. I think some things are better. How I handle eating and getting up in the morning. Generally, how I try to approach whatever needs to be addressed from where she's sitting and standing, not from where I am. I think pretty much, I can see improvement across the board in that." (man caring for his wife)
- "That's right. If you don't learn, you're lost. I don't wanna be lost. I don't wanna be as lost as he is. Like I say I'm learning a whole lot, Rita, I mean a tremendous amount. I noticed that his eating has changed. Like I say, I'm just gonna stick to not buying anything other than his favorites. That's it. This has helped tremendously (woman caring for her husband)

A female caregiver caring for her 95-year-old mother expressed feelings of success after implementing coaching suggestions that included meaningful activities.

- "...It has really gotten easier on me by me suggestin' to do the things that you all have suggested to me, like quiltin' and doin' stuff. It has really gotten easier on me with her."

Caregivers accepted their need to change. In many instances, it was obvious that CRB were a reaction to caregiver behaviors: caregivers' lack of patience, caregivers' negative visceral reactions, and caregivers' expressions of frustration and anger. The caregivers consistently acknowledged the helpfulness of using a neurological perspective to

understand the negative behaviors; this better enabled them to modify their own communication and behavior. This approach allowed the caregivers to view CRB as a result of brain pathology rather than intentionality.

- “I think it’s been a great help because the key is you just gotta have so much patience. You just gotta have so much patience. The key is just to get it in your mind that it’s hard to understand why they don’t understand. That’s the hard part, as to why is it that they don’t understand. Once you get it into your system that they don’t understand, then you can start to build up on your patience because it takes a great deal of patience.” (man caring for his mother)
- “Even he seems a little more receptive too, in certain things. Now, I’m not gonna say he’s not stubborn on some things. If I’m in a hurried mood, I might be stubborn back with him. That’s where we get into problems. Basically, a little patience on my side helps a lot on his side.” (woman caring for her husband)

Caregivers described their own changes in behavior as a way of diminishing the PLWD’s CRB by understanding the “why behind the what.”

- “Yes. Yes. Yes. Yes. You’ve taught me a lot. Every time I’m-I’ll use the word dealing with Mom, caring for Mom-all the things that you’ve shared with me are in my head. Then I’ll question myself or I’ll say to myself, “Now, did you do that?” I don’t want her ever to feel that she’s a bother to me, she’s an inconvenience. I’m very careful about my behavior when I’m around her” (woman caring for her mother)

Discussion and Implications

We did not find that the personalized telehealth coaching intervention reduced burden among caregivers of PLWD with CRBs. Similarly, no effect of the intervention was found for multiple measures of QOL. Despite differences in methods, these findings are consistent with the majority of prior reports on the effectiveness of psychosocial interventions for caregivers of PLWD. Our methods predicted and specifically addressed some of the shortcomings identified by Wiegelmann and colleagues [29] 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 [33].

The findings from the qualitative analysis suggest that the coaching sessions benefitted the caregivers by helping them become more adept at preventing and managing CRBs over the course of the six weeks. Caregivers became more open about problematic behaviors and their own reactions to these behaviors as the sessions progressed. This appraisal may have dampened the amplitude of change in the ZBI scores. Also, CRB increases as the dementia worsens. ZBI and QOL scores obtained at the third data collection point (25 weeks post first coaching session) suggest that the strategies may have had diminished efficacy as the dementia progressed.

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 PLWD’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 PLWD’s symptoms as more severe and experience greater burden. In contrast, personality characteristics with positive emotional valence, like resilience, mastery, and self-efficacy were associated with in higher scores on QOL measures for the PLWD 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.

The presence of qualitative benefits and the absence of quantifiable benefits from this personnel-intensive intervention, despite its use of personalized methods and highly experienced coaches, reinforce the difficulty of using quantitative scales to measure the effectiveness of interventions designed to reduce caregiver burden or improve QOL. 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. On the other hand, it may be fruitful to incorporate these CRB strategies in trainings for community-based providers of services for PLWD and their families such as Area Agencies on Aging and Home Health services. 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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This study is not pre-registered. Original de-identified data are available and can be obtained by emailing David Geldmacher (dgeldmacher@uabmc.edu) and complying with UAB IRB data use agreements. Intervention materials can be obtained by emailing Rita Jablonski (rjablonski@uabmc.edu).

Conflict of Interest

Winstead, Pilonieta, Geldmacher, none. Jablonski reports ownership of Dementia Centric Solutions, LLC and royalties from the sale of her book “Make Dementia Your B*tch!” on Amazon.

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