

RESEARCH ARTICLE

iCare4Me for FTD: A pilot randomized study to improve self-care in caregivers of persons with frontotemporal degeneration

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Funding information

National Institutes of Health, Grant/Award Numbers: P01AG066597, R01NR018196-02S1

Abstract

Introduction: A tremendous burden is placed on frontotemporal degeneration (FTD) caregivers who sacrifice their own self-care to manage the functional impairments of their loved one, contributing to high levels of stress and depression. Health coaching provides support for coping with stress while fostering self-care behaviors. We report on preliminary evidence for efficacy of a virtual health coach intervention aimed at increasing self-care.

Methods: Thirty-one caregivers of persons with behavioral variant FTD (bvFTD) were assigned randomly to an intervention group, which included 10 coaching sessions over 6 months plus targeted health information or the control group receiving standard care augmented with the health information. Caregiver self-care (primary outcome), stress, depression, coping, and patient behavioral symptoms were collected at enrollment and 3 and 6 months. Change over time was evaluated between the intervention and control groups using linear mixed-effects models.

Results: There was a significant group-by-time interaction for self-care monitoring ($t_{58} = 2.37, p = 0.02$ and self-care confidence ($t_{58} = 2.32, p = 0.02$) on the Self-Care Inventory, demonstrating that caregivers who received the intervention improved their self-care over time. Behavioral symptoms were reduced in bvFTD patients whose caregivers received the intervention ($t_{54} = -2.15, p = 0.03$).

Discussion: This randomized controlled trial (RCT) shows promise for health coaching as a way to increase support that is urgently needed to reduce poor outcomes in FTD caregivers.

KEYWORDS

caregiver, frontotemporal degeneration, motivational health coaching, self-care, support intervention

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1 | BACKGROUND

Frontotemporal degeneration (FTD) is a common cause of early-onset dementia with no known cure. FTD affects the frontal and temporal lobes of the brain and results in progressive deterioration in executive functioning, language, and social comportment.¹ A tremendous burden is placed on young caregivers, typically spouses, who sacrifice their own self-care needs in order to manage the cognitive and functional impairments of their loved one, contributing to high levels of stress and depression in caregivers of individuals with FTD.² Indeed, studies have consistently demonstrated higher levels of caregiver distress, burden, and depression in FTD caregivers when compared to other dementia caregivers.³⁻⁵ This is likely related to several factors including the younger age at which the disorder appears, behavioral changes that are severe and appear early in the disease process,⁵ and the limited supportive resources available to this unique group of caregivers.⁶

FTD caregivers report feeling left alone to cope with problems, which exacerbates their stress.^{2,7} When stressed, caregivers are less vigilant and less motivated to engage in self-care behaviors that are important for maintaining physical and emotional health.^{8,9} Support interventions can encourage self-care by helping caregivers to focus on values, develop coping skills, and solve problems, with the potential for a downstream beneficial effect on caregiver physical and psychological well-being. A scoping review found only five caregiver intervention studies targeting FTD caregiver stress, and these were limited mainly to small pilot studies exploring the use of support groups.¹⁰ Web-based interventions for dementia caregivers have been reported to be beneficial in reducing caregiver depression and stress,¹¹ yet these studies have been limited to forms of dementia like Alzheimer's disease where the caregiving experience significantly differs from that of FTD.¹²

Caring for a person with behavioral variant FTD (bvFTD) is extremely challenging. Caregivers often misinterpret patient behavioral symptoms such as apathy or disinhibition as a sign of volitional opposition and poor cooperation,¹³ leading to high levels of stress and dissatisfaction with caregiving.¹⁴ Studies have demonstrated that caregivers must adjust their own affect and demeanor to meet the needs of the patient with behavioral symptoms and negative emotional-behavioral responses, and altered dyadic interactions may therefore increase behavioral and psychological symptoms of dementia.^{15,16} Although a growing body of research illustrates the influence of caregivers on patients and vice versa, (i.e., dyadic processes), we are not aware of intervention studies that have explored the influence of FTD caregiver stress on behavioral symptoms in the patient.

In this study, we tested the novel support intervention, Virtual Caregiver Coach for You (ViCCY),^{17,18} utilizing health coaching to increase self-care in bvFTD caregivers. We hypothesized that caregivers who received health coaching would improve their self-care over the course of the 6-month intervention. In addition, we explored the downstream effects of the intervention on care recipients' behavior. We hypothesized that improving caregiver affect through self-care would reduce behavioral symptoms in the care recipient.

RESEARCH IN CONTEXT

- 1. Systematic Review:** We used PubMed to review the literature on support interventions for caregivers of persons with frontotemporal degeneration (FTD). Although there is a small number of support interventions for FTD caregiver intervention studies have been limited to a small number of non-randomized trials that mainly explore the use of support groups. These relevant citations are appropriately cited.
- 2. Interpretation:** We found that caregivers in the treatment group who received the virtual health coaching intervention (Virtual Caregiver Coach for You; ViCCY) improved their self-care over the course of 6 months. We also observed that behavioral symptoms improved in patients whose caregiver received the health coaching intervention. We suggest that remotely delivered health coaching is an innovative way to increase support that is urgently needed to reduce poor outcomes in FTD caregivers and patients.
- 3. Future Directions:** Further research should incorporate testing of mechanisms of ViCCY in order to better understand the essential ingredients. Our results in FTD demonstrate preliminary efficacy and highlight key issues for further study in other Alzheimer's disease and related dementias (ADRDs).

2 | METHODS

A pilot randomized controlled trial design was used to test the efficacy of ViCCY in improving self-care of bvFTD caregivers (clinical trial identifier # NCT04686266). Caregivers were randomized 1:1 to the intervention or control group. The randomization sequence was generated a priori by a statistician independent of the study investigators using a randomly permuted blocks algorithm.

2.1 | Health information (control arm)

Caregivers in the control group were given iPads with wireless network access to health information (HI) available on the internet. Standard care typically involves unstructured, intermittent outreach by nurses who are staffing physicians' offices.¹⁹ Augmented standard care (e.g., HI) in this study was based on informational resources from Caregiver Action Network (<https://caregiveraction.org>) and the National Alliance for Caregivers (<https://www.caregiving.org/resources/general-caregiving/>). Both caregiving associations provide resources to help caregivers cope with the challenges of caring for a loved one and include information on stress reduction and self-care. We provided disease-specific resources from the Association for

Frontotemporal Degeneration (<https://www.theaftd.org>). This organization has produced a series of educational publications to help caregivers understand FTD. Caregivers in both study arms were encouraged to spend at least 30 minutes weekly using the Internet modules for 6 months.

2.2 | ViCCY intervention (treatment arm)

In addition to HI, the intervention group received 10 sessions of ViCCY over a 6-month timeframe based on literature demonstrating that a shorter duration of health coaching is not routinely effective.²⁰ Consistency is important for trust building, behavioral change, and growth²¹; therefore, each caregiver was assigned to a single health coach for the duration of the 6-month period. Early and intense contact with the coach builds the relationship, engages the participant in the treatment program,²² and maximizes outcomes²³; consequently health coaches began intervention sessions as soon as possible after enrollment. As previously described,¹⁸ the intervention content was carefully standardized, guided by a manual with session agendas and checklist of specific content to be covered in each session, but also tailored to allow the coach to address unique caregiver characteristics, preferences, and goals.

ViCCY¹⁸ is a psychosocial approach that is multidimensional, providing support for coping with perceived stress while fostering self-care. The intervention was delivered by two advanced practice nurses who were trained and experienced in health coaching. Motivational interviewing was used in all ViCCY sessions. The health coaches focused on identifying personal values, solving problems, and transforming goals into action using a combination of psychological and behavioral interventions.²⁴ For example, observations were presented to the caregiver in a way that builds confidence, motivates action, and enhances self-care by breaking the cycle of negative self-perception and emotions with the knowledge, skills, and beliefs needed to engage in healthy behaviors.^{25,26} Goal-setting and action-planning were discussed in early sessions. Topics covered in ViCCY sessions include benefits of self-care, importance of sleep, relaxation techniques, and changing automatic thoughts, which have been previously described in detail.¹⁸

2.3 | Treatment fidelity

To ensure delivery of the intervention as intended (aka, treatment fidelity) 20% of audio-recorded coaching sessions were reviewed by independent raters. Raters used a preconstructed rating tool designed to capture (1) professionalism and preparation, (2) brief assessment completion, (3) session flow, and (4) alignment with the content of the ViCCY manual. Two trained raters judged randomly selected session recordings for each coach, assessing the completeness and thoroughness of the therapeutic techniques used. Each section of the rating tool included multiple elements for which the raters could indicate: effectively met = 2, partially met = 1, not met = 0, or not applicable = n/a.

Because not all elements pertained to every participant or every session, fidelity was considered met if 90% of a session was delivered as intended (total score divided by the maximum score possible). Overall fidelity by session ranged from 84% to 100% among the 40 sessions reviewed, with an average of 96% for all sessions combined.

2.4 | Study participants

Participants were family caregivers of persons living with bvFTD. Caregivers were recruited from the University of Pennsylvania Frontotemporal Degeneration Center (UPenn FTDC). To be eligible, a caregiver needed to: (1) provide care at least 8 hours per week; (2) read English; and (3) report poor self-care on screening (Health Self-Care Neglect scale²⁷ score ≥ 2). Exclusion criteria were: (1) participation in another support randomized controlled trial; and (2) untreated major psychiatric illness (use of anti-anxiety/anti-depressant medicines was acceptable).

Clinical Dementia Rating (CDR) was obtained to measure dementia severity. CDR scores range from 0 to 3 (0 = normal, 0.5 = very mild dementia, 1 = mild dementia, 2 = moderate dementia, 3 = severe dementia) and are based on semi-structured interviews with the patient and caregiver.²⁸

2.5 | Consent statement

All participants and/or legally responsible representatives participated in an informed consent procedure approved by an institutional review board convened at the University of Pennsylvania.

2.6 | Procedure

Clinicians in the UPenn FTDC identified potential caregiver participants. If caregivers agreed to speak with research staff, the trained research assistant (RA) screened the caregiver for inclusion and exclusion criteria (see 2.4 Study participants). Eligible caregivers completed a verbal consent and baseline survey with the RA via a video call. Once informed consent and baseline data were collected the participant was randomized. The project manager notified the caregiver of their group assignment (ViCCY or HI) by telephone or email. The RA who collected and entered data and the principal investigator were blinded to participant assignment. The health coaches and the caregivers were not blinded. Timing of follow-up assessments was based on date of randomization. Participants were provided a link to self-administered surveys (see 2.8 Outcomes) at 3 and 6 months.

2.7 | Sample

We aimed to recruit 30 caregivers for this study because previous pilot caregiver intervention work has shown that 15 per arm is adequate to

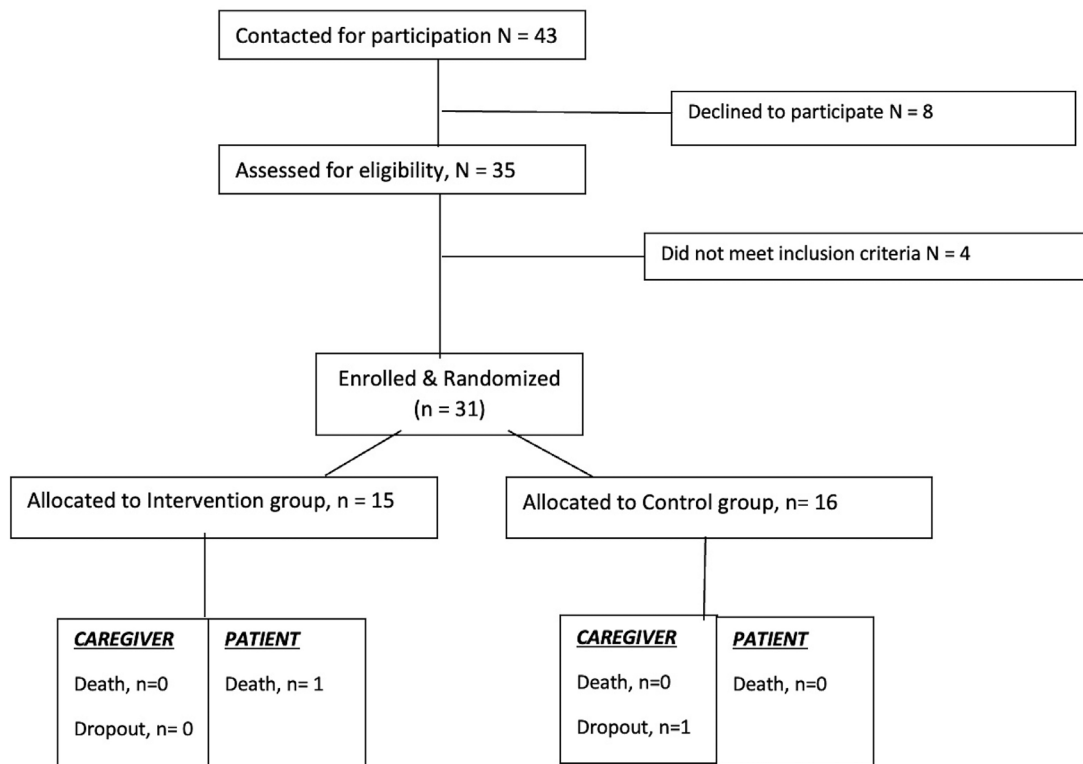


FIGURE 1 iCare4Me for FTD consort statement.

demonstrate preliminary efficacy.^{29,30} Forty-three caregivers of persons with bvFTD were approached to participate in our pilot study. Eight caregivers declined to participate, and four caregivers did not meet the inclusion criteria because they did not provide at least 8 hours of care per week. Of these, we enrolled 31 caregivers. For detailed reporting please see the consolidated standards of reporting trials (CONSORT) flow diagram (Figure 1). Of the 31 participants enrolled (intervention, $n = 15$; control, $n = 16$), one participant from the control group dropped out at 1 month and was therefore removed from all analyses. Among the 15 caregivers assigned to the intervention group, 13 caregivers completed the full 10 health coaching sessions. One caregiver completed only four sessions and one caregiver completed eight sessions. All caregiver participants completed all study visits (baseline, 3 and 6 months) and surveys. Final group sizes for analyses were 15 ViCCY intervention and 15 HI control participants (see Figure 1).

2.8 | Outcomes

Self-report assessments were completed via REDCap at baseline, 3 months, and 6 months. Our primary outcome was focused on caregiver self-care defined as a process of maintaining health through health-promoting practices and managing illness when it occurs.³¹ Self-care is multi-dimensional composed of health promotion (self-care maintenance), symptom recognition (self-care monitoring), and taking action to manage symptoms (self-care management). Self-care confidence reflects self-efficacy of the caregivers' ability to perform and persist

in performing self-care. The Self-Care Inventory (SCI) is a valid and reliable instrument that measures these four interrelated but distinct concepts as a process for achieving optimal self-care.³² After recollecting behaviors related to self-care over the last month, caregivers were asked to score along a 5-point Likert scale the frequency of each behavior (e.g., getting enough sleep, eating a balanced diet). Final raw scores are standardized to yield a score for each of the three theoretical domains and for self-care confidence. Secondary caregiver outcomes included: Health Self-Care Neglect (HSCN) scale,²⁷ Perceived Stress Scale,³³ Ways of Coping Questionnaire,³⁴ Center for Epidemiological Studies-Depression (CES-D),³⁵ and Zarit Burden Interview (ZBI).³⁶

The second aim of our study was to examine change in behavioral symptoms in persons with bvFTD. To measure behavioral symptoms, we used the Neuropsychiatric Inventory (NPI),³⁷ a commonly used instrument that evaluates 12 common behaviors often observed in bvFTD and other dementias. The caregiver is asked to rate the frequency of the occurrence of behaviors (1 = occasionally, 2 = often, 3 = frequently, 4 = very frequently), and the level of severity of behaviors (1 = mild, 2 = moderate, 3 = severe). The behavioral domain total score is the product of the frequency score multiplied by the severity score for that behavior.³⁸ The NPI total score is the sum of all the individual behavioral domains, where a higher score indicates greater severity of behavioral symptoms. Caregiver demographic information included age, sex, race, years of education, relationship to the person with bvFTD, and number of years as a caregiver for the person with bvFTD (see Table 1). For caregivers assigned to ViCCY, the health coaches documented time spent in each health-coaching session.

TABLE 1 Demographic Features of Participant Characteristics.

		Overall (n = 30)	Control (n = 15)	Treatment (n = 15)	p-Value
Race of Caregiver	Black or African American	1 (3.33%)	0 (0%)	1 (100%)	
	White or Caucasian	26 (86.67%)	13 (50%)	13 (50%)	
	Asian	1 (3.33%)	1 (100%)	0 (0%)	
	Other	1 (3.33%)	1 (100%)	0 (0%)	
	Multi-racial	1 (3.33%)	0 (0%)	1 (100%)	
Sex of Caregiver	Male	8 (26.67%)	5 (62.50%)	3 (37.50%)	0.6817*
	Female	22 (73.33%)	10 (45.45%)	12 (54.55%)	
Age of Caregiver		63.93 (10.52)	65.07 (9.95)	62.80 (11.30)	0.6780**
Education of Caregiver (years)	Grade School	1 (3.33%)	1 (100%)	0 (0%)	
	High School graduate or GED	3 (10%)	1 (33.33%)	2 (66.67%)	
	Trade School or some college	3 (10%)	2 (66.67%)	1 (33.33%)	
	Bachelor's Degree	7 (23.33%)	3 (42.86%)	4 (57.14%)	
	Doctoral or Professional Degree	16 (53.33%)	8 (50%)	8 (50%)	
Relationship to Patient	Daughter	1 (3.33%)	0 (0%)	1 (100%)	
	Mother	1 (3.33%)	1 (100%)	0 (0%)	
	Spouse	27 (90.0%)	13 (48.15%)	14 (51.85%)	
	Other Relative	1 (3.33%)	1 (100%)	0 (0%)	
Time as caregiver (years)		4.98 (2.75)	4.99 (3.26)	4.97 (2.26)	0.8673**
CDR global score		1.77 (0.85)	1.70 (0.75)	1.82 (0.96)	0.7598**

Abbreviations: CDR, clinical dementia rating; GED, general education development test.

*Fisher's exact test.

**Non-parametric Wilcoxon rank sum test.

2.9 | Statistical analysis

Means and SDs were calculated to describe continuous measures. Frequency distributions were obtained for categorical variables. The normal distribution assumption was evaluated using boxplots and histograms and formally tested using the Kolmogorov-Smirnov test. Similarity between two groups at baseline was compared using the non-parametric Wilcoxon rank sum test for continuous measures and Fisher's exact test for categorical measures. Significance of change over time between the two groups was evaluated using the linear mixed-effects regression approach. The group-by-time interaction effect was used to test whether there was a difference in rate of change over time between the study arms. All p-values less than 0.05 were considered statistically significant. Analysis was conducted using SAS 9.4.

3 | RESULTS

The total sample was predominately White, female, well-educated, and spousal caregivers. There were no significant differences in baseline characteristics between the control and treatment arms. Baseline characteristics are summarized in Table 1.

3.1 | Longitudinal analysis of primary outcome (Self-Care Inventory)

A linear mixed-effects model with a random-intercept revealed a significant group-by-time interaction ($t_{58} = 2.37, p = 0.02$) for the Monitoring domain of the SCI. On average, participants in ViCCY improved their score ≈ 3 points each month, corresponding to an overall improvement of 18 points in self-care monitoring. No significant differences were seen in the Maintenance ($p = 0.12$) or Management ($p = 0.10$) domains of the SCI. We observed a significant group-by-time interaction ($t_{58} = 2.32, p = 0.02$) for Self-Care Confidence, with caregivers in the ViCCY group improving their score on average by 3 points per month, corresponding to an overall improvement of 18 points in self-care confidence. (See Figure 2 for SCI results.)

3.2 | Longitudinal analysis of secondary outcomes

Our analysis included six secondary outcomes. We observed a significant group-by-time interaction with the ViCCY group showing a reduction in self-care neglect (measured by the HSCN score) compared to HI ($t_{58} = -2.38, p = 0.04$; Figure 3, Panel A). In addition, we observed a significant group-by-time interaction with the ViCCY group showing

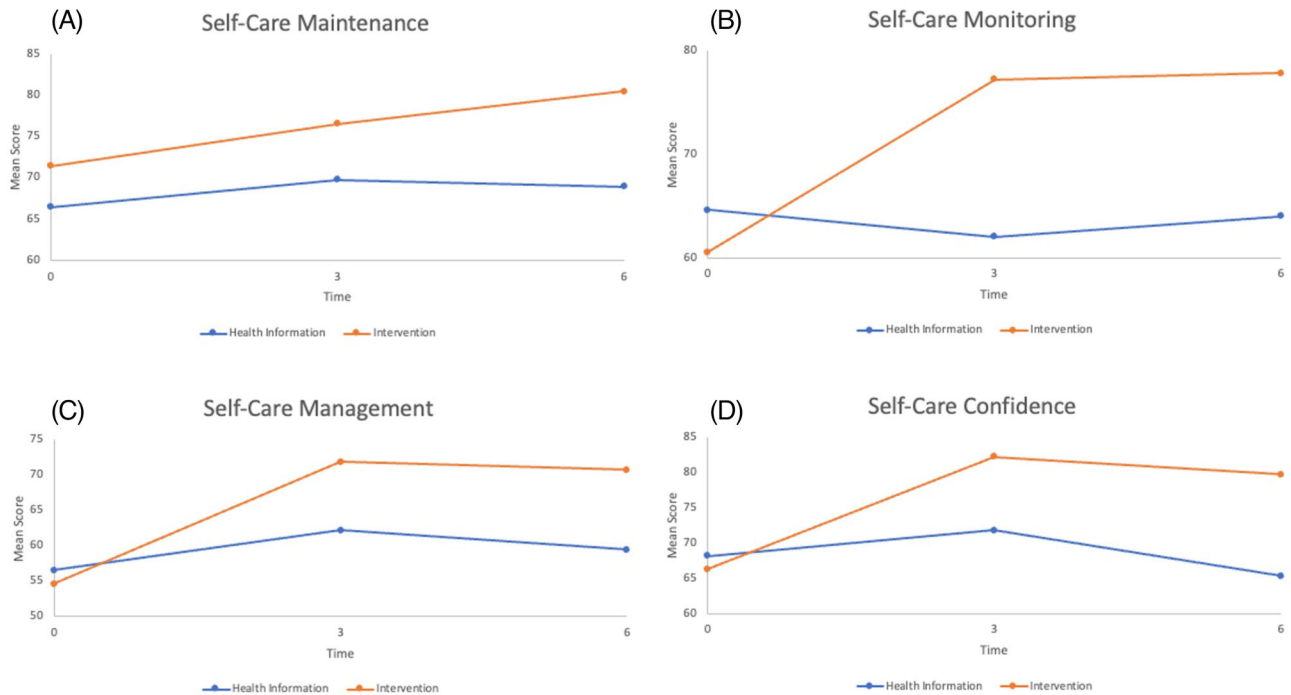


FIGURE 2 Self-Care Inventory (SCI) Results. Caregivers who received ViCCY improved their score on Self-Care Monitoring (Panel A; $p = 0.02$) and Self-Care Confidence (Panel D; $p = 0.02$) after 6 months (orange, intervention group; blue, control group).

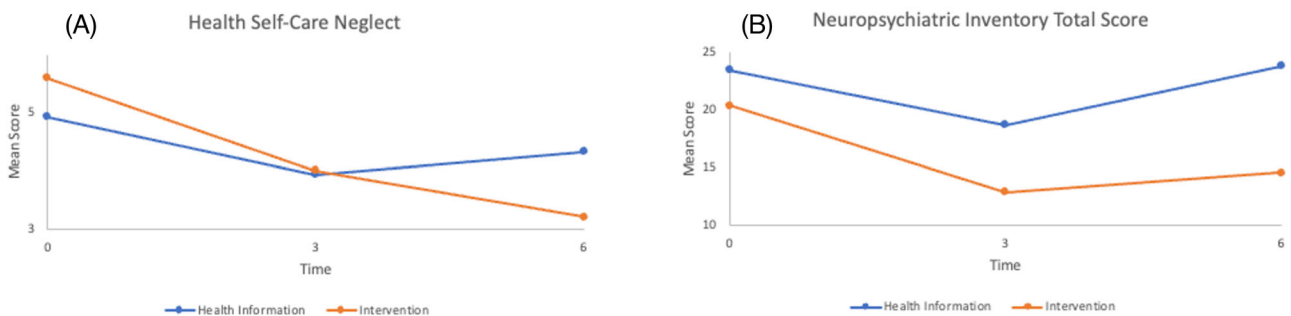


FIGURE 3 Health Self-Care Neglect (HSCN) and Neuropsychiatric Inventory (NPI) Results. Caregivers who received ViCCY improved their score on HSCN (Panel A; $p = 0.04$) and ratings of neuropsychiatric symptoms (NPI) in care recipients improved (Panel B; $p = 0.03$) after 6 months (orange, intervention group; blue, control group).

a reduction in neuropsychiatric symptoms measured by the NPI total score) compared to HI ($t_{54} = -2.15$, $p = 0.03$; Figure 3, Panel B). (See Figure S1 for individual NPI items for the ViCCY group. We did not observe significant group differences over time in the other four secondary outcome measures: stress (Perceived Stress Scale, $p = 0.66$), depression (CES-D, $p = 0.51$), coping (Ways of Coping Questionnaire, $p = 0.51$), or burden (Zarit Burden Interview, $p = 0.57$). (See Table 2 for outcome scores at baseline and 6 months.)

4 | DISCUSSION

This study addressed the body of evidence describing stress and poor self-care in FTD caregivers.^{2,39} Health coaching has been shown

to decrease stress and improve self-care in Alzheimer's dementia caregivers⁴⁰; however, bvFTD caregivers are a unique group who are most at-risk for poor self-care, stress, and depression. In this pilot RCT, we demonstrated that compared to an HI control group, caregivers who received ViCCY improved their self-care in the domains of monitoring and confidence. Furthermore, in addition to our primary aims, we also observed that caregivers who received ViCCY reported an improvement on behavioral scores on the NPI for their care recipients. These results provide preliminary support for health coaching as a promising intervention to improve health outcomes for caregivers of persons with bvFTD and their care recipients.

The personal and societal costs of FTD substantially exceed those of dementia in older adults,³⁹ yet supportive services that are available are designed for older persons and thus rarely meet the needs

TABLE 2 Outcomes at Baseline and 6 Months.

Outcome Measures	HI Control		ViCCY Intervention		Effect Size ^a /p
	Baseline	6 months follow-up	Baseline	6 months follow-up	
Self-Care Inventory (SCI)					
Maintenance	66.4 (18.3)	68.9 (14.7)	71.4 (14.1)	80.4 (12.0)	0.79
Management	56.5 (23.7)	59.4 (26.9)	54.6 (21.2)	70.7 (15.6)	0.46
Monitoring	64.6 (25.3)	64.0 (24.4)	60.5 (19.8)	77.8 (16.6)	0.62*
Confidence	68.1 (22.3)	65.3 (23.5)	66.3 (20.1)	79.6 (18.7)	0.65*
Perceived Stress Scale (PSS)	29.2 (8.7)	28.4 (8.3)	23.1 (10.0)	23.4 (12.4)	0.47
Center for Epidemiologic Studies Depression Scale (CES-D)	19.0 (12.8)	16.6 (10.4)	19.7 (15.1)	15.3 (11.3)	0.11
Zarit Burden Interview (ZBI)	43.6 (13.6)	46.3 (12.8)	38.4 (11.4)	39.3 (14.9)	0.50
Health Self-Care Neglect (HSCN)	4.9 (2.3)	4.3 (2.2)	5.6 (2.5)	3.2 (2.6)	0.45*
Ways of Coping	20.4 (15.0)	19.1 (14.6)	22.7 (16.0)	23.4 (15.9)	0.28
Neuropsychiatric Inventory (NPI) Total Score	23.4 (17.3)	23.8 (15.4)	20.4 (15.7)	14.6 (8.2)	0.76*

^aEffect size in units of Cohen *d* for 6 months follow-up between Control and Intervention.

**p* < 0.05.

of this group of caregivers. A scoping review found five small intervention studies directly targeting FTD caregiver stress.¹⁰ One of these included a 5-week pilot study utilizing positive emotion building for FTD caregivers. This study showed caregiver improvements in affect, stress, and burden in the intervention group compared to an attention control group.⁴¹ The remaining four studies were limited to small pilot studies exploring the use of support groups. To our knowledge, the present study is the first to specifically target and measure FTD caregiver self-care.

We observed a significant difference in self-care monitoring and self-care confidence, suggesting that health coaching may be an effective way to motivate caregivers to watch for changes in their symptoms and increase their confidence in their own self-care. Changes in self-care monitoring are clinically meaningful because people do not engage in self-care management unless they measure, detect, and interpret their physical and emotional changes. The observed change in self-care monitoring suggests that the caregivers who received the intervention may have begun paying attention to how they were feeling. Motivational health coaching has been used to increase self-care behaviors in persons with chronic conditions such as diabetes⁴² and chronic obstructive pulmonary disease (COPD).⁴³ The present study adds to this literature and suggests that health coaching may be a way to increase self-care in high-risk populations, such as FTD caregivers.

To our knowledge, the current study is the first FTD caregiver support intervention to demonstrate beneficial effects at the patient level. Previous work has pointed to the concept of expressed emotion to describe how much criticism, hostility, or emotional involvement the caregiver expresses in interactions with the person with dementia.^{44,45} It is possible that observed behavioral symptom

improvement occurred as a result of improved self-care in caregivers who received ViCCY; however, we acknowledge that the NPI, although reliable and valid, is subjective and relies on caregiver report of the patient's behavior. A critical question remains as to the mechanism by which ViCCY achieves positive effects on patient behavior.

The tremendous responsibilities of dementia caregiving coupled with distinct issues in FTD—such as young age and competing life demands such as work and raising children—greatly increase the demands on the FTD caregiver. Caregiving demand is a stressor that initiates a process of primary appraisal (e.g., perceived burden) and secondary appraisal (e.g., controllability) in caregivers. These appraisals lead to coping efforts which are supported by the ViCCY intervention. ViCCY is a multidimensional intervention based on the Transactional Model of Stress and Coping that addresses both appraisal and coping.⁴⁶ We used stress theory to address the caregivers' appraisal of events and coping responses. We anticipated that ViCCY would thus promote caregiver coping as a means to improve self-care; however, we did not observe a significant change in coping scores in the intervention group. Lack of findings here and in our other secondary measures could be due in part to insufficient sample size. Future well-powered studies are warranted to appropriately investigate the intervention mechanism.

Notable strengths of the study include the high recruitment rate (≈80% of bvFTD caregivers) and low drop-out rate (one participant in the control arm), indicating that the intervention was not only acceptable but that FTD caregivers recognized the need for the intervention. To evaluate whether the intervention can be delivered by different health coaches with the same effect, we compared primary and secondary outcomes from participants in each health coach group and observed no significant difference suggesting that the health coach

delivering the intervention did not affect the observed treatment effect.

A few study limitations should be noted. First, this was a pilot study and, therefore, it was not sufficiently powered to adjust the type I error rate for multiple comparison. We did not observe significant effects on our secondary outcome measures, such as perceived stress and depression, and it will be important to measure these and other psychological outcomes such as anxiety in a future well-powered study. The potential costs of intervention implementation include the length of intervention contacts, health coach time to deliver the intervention, and technology expenses (e.g., phones, tablets, or computers with video-conferencing ability and internet access). Although we believe that the cost of the intervention offsets the downstream costs related to poor physical and psychological health in FTD caregivers, to our knowledge no cost-effectiveness analyses of support interventions for FTD caregivers have been conducted and this would be an important area of future study.

We recruited our participants from a specialty dementia center. Research suggests that minority populations may be less likely to participate in neurodegenerative disease research because minorities are often diagnosed later and do not receive specialized neurodegenerative care relative to their White counterparts⁴⁷; therefore, future studies must increase recruitment of more diverse caregivers. Our caregivers were mostly White individuals with a high level of education, which is related to socioeconomic status, and it will be important for a future study to examine other social determinants of health and how that affects the delivery of a technology-based intervention. For example, internet access and financial limitations in obtaining technology as well as poor health literacy may be more common in racially minoritized populations.⁴⁸ The conceptualization of self-care is also important to consider from a sociocultural lens. Indeed, potential differences in health beliefs about self-care may require culturally relevant tailoring to enhance intervention efficacy.^{49,50}

With these caveats in mind, this randomized controlled pilot study showed preliminary evidence that bvFTD caregivers benefited from virtual health coaching. We also observed that the behavior of care recipients of caregivers who received health coaching improved over time. These results suggest that health coaching may have benefits for both the patient and caregiver over the course of the 6-month intervention period and it will be important for future work to measure outcomes over a longer period to determine if benefits are sustained. Future studies on a larger scale should incorporate testing of mechanisms of ViCCY to better understand the essential ingredients⁵¹ in an intervention designed to improve the well-being of FTD caregivers and the persons they care for.

ACKNOWLEDGMENTS

This work was supported by the National Institutes of Health (P01AG066597, R01NR018196-02S1).

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest. Author disclosures are available in the [supporting information](#).

CONSENT STATEMENT

All participants and/or legally responsible representatives participated in an informed consent procedure approved by an institutional review board convened at the University of Pennsylvania.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Massimo L, Hirschman KB, Aryal S, et al. iCare4Me for FTD: A pilot randomized study to improve self-care in caregivers of persons with frontotemporal degeneration. *Alzheimer's Dement.* 2023;9:e12381. <https://doi.org/10.1002/trc2.12381>