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## Preliminary evaluation and implications of the SPECAL method as an intervention for informal dementia care partners

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### ABSTRACT

**Objective:** The degenerative nature of Alzheimer's disease and related dementias (ADRD) means that people diagnosed with ADRD often rely on friends and family to provide care as their cognitive and physical abilities decline. Caring for a person with dementia is complicated, in part because ADRD changes a person's ability to communicate and create memories. Practitioners have increasingly identified communication-centered interventions as one way to address care partner needs while also improving well-being for the person with dementia. In this study, we evaluated one program, the SPECAL<sup>®</sup> method.

**Method:** Using mixed-methods research, we assessed the effectiveness of a seven-week SPECAL course at facilitating positive outcomes for informal care partners. Participants completed pre- and post-program surveys ( $n = 17$ ) as well as post-program interviews ( $n = 20$ ).

**Results:** Results showed several positive changes from pre- to post-program. Participants also reported several key themes in their experiences and implementation of SPECAL, including many beneficial and some challenging outcomes.

**Conclusion:** Results from this study underscore the importance of communication as an intervention target for dementia care partners, identifying opportunities and challenges in working to help care partners communicate with people with ADRD in ways that sustain their relationship and foster mutual well-being.

### ARTICLE HISTORY

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Communication intervention; dementia; caregiving; mixed-methods research; SPECAL<sup>®</sup> method; Contented Dementia; person-centered care

Alzheimer's disease and related dementias (ADRD) are among the leading causes of death in the United States, and more than 6.2 million Americans live with ADRD (Alzheimer's Association, 2021a). ADRD are degenerative brain diseases that inhibit a person's cognition, memory, and language (Alzheimer's Association, 2021a, 2021b). As people living with dementia (PLWD) experience decreases in their capabilities, friends and family members often assume the role of informal ADRD care partners (CPs) to keep their loved one safe (Alzheimer's Association, 2021a). In 2020, an estimated 11.2 million individuals served as informal CPs for a PLWD, amounting to more than \$250 billion in unpaid caregiving (Alzheimer's Association, 2021a).

Providing care for PLWD involves numerous challenges. First, informal caregiving brings financial stress and physical demands, disrupting CPs' daily lives (Alzheimer's Association, 2021a). Additionally, CPs witness the decline of their loved one's capabilities daily and often over many years, an experience sometimes referred to as complicated grieving (Alzheimer's Association, 2021a; Blandin & Pepin, 2017). This creates emotional stress and is associated with an increased risk of depression and other health problems (Alzheimer's Association, 2021a). Third, ADRD impacts CPs' communication with their loved ones due, in part, to the PLWD's loss of memory and shared relational history (Bute et al., 2007; Polk, 2005). Additionally, ADRD often causes shifts in personality, mood, and difficulties with word-finding and language fluency, all of which can complicate the relationship between the CP and the PLWD (Bute et al., 2007; Eggenberger et al., 2013; National Institute on Aging, 2017). Moreover, CP stress, uncertainty, and communication challenges share a symbiotic relationship, as stress decreases

a CPs' ability and likelihood of engaging in beneficial communication with the PLWD (Petrovsky et al., 2020).

Given the prevalence of ADRD, the increasing demands for informal CPs, and the unique challenges facing ADRD CPs, researchers have increasingly focused on CP training programs targeting effective strategies for communicating with PLWD (Riachi, 2018; Watts & O'Connor, 2017). Polk (2005) argued that programs emphasizing communication and increasing CPs' understandings of dementia can address uncertainties and break negative communication cycles. Indeed, research demonstrates that these programs have the potential to produce immense benefits for PLWD and CPs alike (Nguyen et al., 2019; Watts & O'Connor, 2017). Multiple existing programs target effective CP communication (Nguyen et al., 2019) and encourage *person-centered care* (Kitwood, 1997; Weigel, 2017), which "values the individual and honors and facilitates expressions of his/her autonomy" (Weigel, 2017, p. 22). The present study explores CP experiences before and after participating in one person-centered caregiving program (the SPECAL method).

### The SPECAL method

The SPECAL method was created in the United Kingdom (UK) by Penelope Garner during the 1990s in response to providing care for her mother and participating in dementia care mapping research (Kitwood, 1997; Wray, 2020). The method aims to facilitate contentment in PLWD by "maintaining a person with dementia in a state of positive well-being as far as is possible" (Pritchard & Dewing, 2001, p. 64). The SPECAL method

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explains the experience of ADRD using the simple analogy of the SPECAL Photograph Album to help CPs understand what the experience of dementia is like from the perspective of the PLWD (Contented Dementia Trust, 2012). With this framework, the SPECAL approach equips CPs with communication-specific tools to help facilitate peaceful interactions and improved well-being (Contented Dementia Trust, 2012).

To help CPs understand ADRD, SPECAL compares dementia-influenced thinking to a photograph album (Contented Dementia Trust, 2012). In this analogy, each person's experiences are captured throughout their life like photographs in an album. Each photograph is stored with the facts of the event as well as its associated feelings (Contented Dementia Trust, 2012; James, 2008; Wray, 2020). According to SPECAL, in dementia, "memory impairment means that the facts can fail to be stored, while the emotional element is still recorded as a 'blank'" (Wray, 2020, p. 230). These blanks accumulate over time as PLWD fail to store factual memories but retain their feelings, so PLWD must look further into their past to match current events with photographs (memories) that explain their experiences (Contented Dementia Trust, 2012). As such, SPECAL emphasizes recognizing PLWDs' feelings and engaging with them around earlier memory experiences (James, 2008; Wray, 2020).

With knowledge of the photograph album approach, SPECAL encourages CPs to "take the general experience of dementia fully into account and then go forward with confidence to individualise the way they interact with their particular person" (Contented Dementia Trust, 2012, p. 5). SPECAL programming emphasizes three "Golden Rules": Do not ask direct questions of the PLWD (because the recent facts may not have been stored); listen to the PLWD as the "expert" (in knowing how to cope with a blanking album); and do not contradict the PLWD (or argue with whatever facts they need to use to make sense of what is happening in their life) (Contented Dementia Trust, 2012; Wray, 2020). By following these rules, SPECAL argues that CPs can restore and maintain a sense of agency and autonomy in the PLWD while also preventing the potential distress, anger, or humiliation that the PLWD is likely to experience when confronted with the reality of their memory loss (Wray, 2020).

To date, limited research has empirically evaluated SPECAL. One study examining SPECAL implementation among PLWD, their informal CPs, and the professional staff supporting their care revealed positive outcomes across all parties, with informal CPs specifically noting that SPECAL helped them feel empowered and allowed them to continue their relationship with the PLWD (Pritchard & Dewing, 2001). In another study, family CPs reported enhanced empathy for and harmony with the PLWD after completing SPECAL training (McCrae et al., 2020). Similar results have been found among formal CPs, who report improved well-being among PLWD as well as strengthened trust, communication, and relationship quality between CPs and care recipients (Riachi, 2018; Riachi & Markwell, 2020). This body of evidence suggests that SPECAL can produce positive outcomes for stakeholders invested in PLWD care, but continued evaluation of SPECAL is merited. Previous investigations have utilized qualitative evidence, with little examination of quantitative outcomes, and these studies have focused on capturing retrospective reports related to SPECAL outcomes rather than engaging with participants throughout the learning process.

To address to these gaps, this study used mixed methods (i.e. both qualitative and quantitative data) to explore how participation in a SPECAL program impacted well-being among informal CPs in the United States. Specifically, we explored how

SPECAL was related to CP outcomes (e.g. stress, feelings of social support, sense of loss, etc.). We also sought to identify the ways that CPs saw SPECAL as influencing their sense of caregiving identity as well as their relationship with the PLWD. With these goals in mind, we explore the following research questions:

RQ1: How do CPs experiences of stress, social support, and other outcomes change after SPECAL participation, and do they report changes in the PLWD?

RQ2: How does SPECAL influence CPs' understanding of their caregiving role?

RQ3: How does SPECAL affect CPs' interactions with the PLWD?

## Methods

### *SPECAL program description*

The present study features an evaluation of a SPECAL training implemented for dementia CPs during summer 2020. Given the prevalence of the COVID-19 pandemic at this time, all workshops were held virtually and lasted approximately 1.5 h. Participants were recruited using snowball sampling by a local dementia-focused nonprofit. The program included seven free workshops focusing on different SPECAL elements as well as opportunities for small-group interaction and social support. Each session was led by a certified SPECAL practitioner. In total, 28 participants completed the program, and all participants were invited to complete the study procedures. All study procedures received ethical approval by a university institutional review board (Colorado State University IRB#1915).

### *Quantitative methods*

#### *Participants*

Participants ( $n = 17$ ) completed both the pre- and post-test measures. The pre-test took place approximately one week before the SPECAL program began, and post-test surveys were completed within three weeks after the program ended. Participants were predominately female (82.4%,  $n = 16$ ), White (82.4%,  $n = 16$ ), and older ( $M = 67.69$ ,  $SD = 6.29$ ). Participants reported providing care for a spouse ( $n = 10$ ), parent ( $n = 6$ ), or sibling ( $n = 1$ ). When participants cared for more than one person, they responded about the person whose needs were most significant.

#### *Measures*

For descriptive statistics for all study measures, please see Table 1.

***Improvement in the person with dementia.*** Participants responded to four items assessing PLWD well-being. The first three items asked CPs how much they agreed with statements using a five-point scale: The person I care for feels like him/herself; feels safe; and feels relaxed. Participants also indicated how much anxiety the PLWD typically feels.

***Feelings about caregiving.*** Participants responded to four items measuring their feelings about caregiving using a "1—Hopeless" to "5—Content" scale: feelings of optimism about the PLWD's future; feelings of caregiving anxiety; the ability to create PLWD contentment; and the ability to foster PLWD well-being.

**Table 1.** Descriptive statistics and quantitative results for all outcome measures.

Variable	Range	Pre-test	Post-test
		Mean (SD)	Mean (SD)
Improvement in the PLWD			
Feels like him/herself	1–5, with higher scores indicating greater levels of agreement and/or higher levels of anxiety	3.44 (1.03)	3.38 (1.03)
Feels safe		4.44 (.89)	4.38 (.81)
Feels relaxed		3.25 (.68)	3.75 (.78)*
Feels anxious		2.44 (.63)	2.31 (.79)
Feelings about Caregiving			
Feels optimistic about PLWD's future	1–5, with higher scores indicating greater levels of contentment	2.35 (1.17)	3.71 (1.11)**
Feels anxious about caregiving		2.88 (1.11)	3.47 (.87)*
Feels confident in creating contentment for PLWD		3.29 (1.05)	3.76 (.90)
Feels confident in fostering well-being for PLWD		3.94 (.66)	4.12 (.78)
Perceived stress	1–5, with higher scores indicating greater levels of stress	2.89 (.56)	2.37 (.58)*
Perceived social support	1–7, with higher scores indicating greater levels of support	4.83 (1.32)	4.81 (1.70)
Positive aspects of caregiving	1–7, with higher scores indicating greater levels of positive aspects of caregiving	4.61 (.99)	4.98 (1.08)#
Feelings of loss	1–7, with higher scores indicating greater feelings of loss	5.19 (.91)	5.15 (.81)
Feelings of meaning	1–7, with higher scores indicating greater feelings of meaning	5.53 (.73)	5.63 (.64)

# $p < .10$ ; \* $p < .05$ ; \*\* $p < .01$ .

**Perceived stress.** CPs' stress was measured using the Perceived Stress Scale (Cohen et al., 1983). Participants responded to items regarding their sense of stress and control during the past month using a "1—never" to "5—very often" scale (e.g. "In the last month, how often have you felt nervous or stressed?").

**Perceived social support.** CPs' perceived social support was measured using the Multidimensional Perceived Social Support scale (MDPSS; Zimet et al., 1988). Using a "1—Strongly disagree" to "7—Strongly agree" scale, participants indicated how much they agreed with statements such as, "I have a special person in my life who cares about my feelings."

**Positive aspects of caregiving.** In the positive aspects of caregiving (PAC) measure (Tarlow et al., 2004), the first six items asked participants how much they agreed that providing care to their loved one made them feel certain ways (e.g. "useful," and "appreciated") using a "1—Strongly disagree" to "7—Strongly agree" scale. The last three items asked participants to indicate their level of agreement that providing help to their loved one enabled them to appreciate life more, to develop a more positive attitude, and strengthened their relationships with others. All items were combined into a single measure.

**Caregiving sense of loss and sense of meaning.** Participants completed two measures assessing CPs' sense of loss and meaning—Farran et al.'s (1999) sense of loss/hopelessness and sense of provisional meaning. For both measures, participants used a "1—Strongly disagree" to "7—Strongly agree" scale. The sense of loss measure included 19 items such as "I'm sad about losing the person I once knew." The sense of meaning measure included 11 items, with sample items stating, "I would not have chosen the situation I am in, but I get satisfaction out of providing care."

## Qualitative methods

### Participants

Twenty participants completed post-program, semi-structured interviews (see Table 2). All interviews took place four to six

weeks after the end of the last SPECAL class. Interviewed participants reported acting as CPs for between one and ten years, and they cared for their spouse ( $n = 11$ ), parent ( $n = 7$ ), more than one parent ( $n = 1$ ), and their parents and spouse ( $n = 1$ ).

### Procedures

After the program ended, participants were invited to participate in an interview. The semi-structured interviews lasted approximately 20 to 60 min and included questions like, "What does a typical day of providing care look like for you?" and "What were your overall impressions of the SPECAL program?" Upon completion, participants received a \$15 e-gift card.

Interview data were analyzed using an iterative approach to thematic analysis (Braun & Clarke, 2006; Tracy, 2018). The research team spent about 33 h creating, checking, and categorizing themes. Initial codes were generated by two researchers who engaged in code-checking and regular discussions about the themes and guiding research questions. At the end of open coding, thematic codes were identified through conversation and all transcripts were coded again, resulting in more than 300 instances of coded dialogue across all themes.

## Results

### Quantitative results (RQ1)

The first research question asked about changes in CP and PLWD outcomes after SPECAL program participation. Differences between pre- and post-test surveys were analyzed using paired samples  $t$ -tests. Analyses indicated statistically significant differences for four measures (see Table 1): CPs' perceived stress,  $t(15) = 2.56, p < .05$ ; CPs' feelings of optimism regarding the future of the PLWD,  $t(16) = 4.57, p < .01$ ; CPs' feelings of anxiety about providing care,  $t(16) = 2.16, p < .05$ ; and the PLWD's feelings of relaxation,  $t(15) = 2.24, p < .05$ . The positive aspects of caregiving measure approached significance,  $t(16) = 1.99, p = .06$ .

### Qualitative results

#### Care partners' understanding of their caregiving role (RQ2)

The second research question asked how SPECAL participation influenced participants' understanding of their caregiving role

**Table 2.** Profiles for interview participants.

Care partner pseudonyms	Person with dementia	Caregiving duration	Description of their caregiving role
Katherina	Parents (mother & father)	6 months	Katherina's parents moved into her home from a nursing home when the COVID-19 pandemic began. They require high levels of care.
Beatrice	Father-in-law	1 year	Beatrice's father-in-law is relatively independent. His main challenge is communication-based, as he struggles to converse with people and understand what's going on during conversations.
Ruth	Parents (mother & father); Spouse (husband)	1 year	Ruth sees herself as a secondary support for her parents with dementia. Her older sister provides more central support. Her husband has also begun showing signs of dementia, and she is increasingly stepping into a caregiving role for him.
Sylvia	Parent (mother)	1.5 years	Sylvia's father is the primary care partner for her mother. She entertains her mom for a few hours a day so her father can do other things.
Nora	Spouse (husband)	2 years	Nora's husband requires little assistance, as he spends most of his time sleeping, but she takes care of meals, household chores, and running errands.
Richard	Spouse (wife)	2 years	Richard's wife is fairly high functioning. They live together, and one of his biggest challenges involves managing her anxiety.
Dorothy	Spouse (husband)	3 years	Dorothy's husband struggles with tasks, as he can complete them but gets distracted or forgets to do things relatively quickly. She helps him with tasks, keeps him on schedule for his routine and his appointments, and spends time with him to keep him occupied.
Mark	Parent (father)	3 years	Mark's father recently moved out of their home and into an independent living center. He is at a point where he needs assisted living, but due to COVID-19 restrictions, Mark is unwilling to move him there.
Paul	Spouse (wife)	3 years	Paul's wife requires a fair amount of attention and assistance throughout the day, as she needs help with meals, getting dressed, showering, and taking medications.
Frank	Spouse (wife)	4 years	Frank has been caring for his wife with dementia, and he recently moved her into a memory care facility.
Gina	Mother/Daughter	4 years	Gina's mother lives in an assisted living facility. Because of COVID-19, Gina has only been allowed to see her mother once a week, and this has been incredibly difficult for them both.
Henriette	Parent (mother)	4 years	Henriette's mother with dementia lives independently in a separate house nearby.
Chloe	Parent (father)	5 years	Chloe shares the caregiving responsibilities with her sister. Her father is independent but likes routine and struggles to remember how to accomplish tasks.
Eve	Spouse (husband)	5 years	Eve lives with her husband who has dementia. He is still independent.
Irene	Spouse (husband)	5 years	Irene is a full-time care partner for her husband and lives with her daughter and son-in-law. She helps keep him on a routine, deals with his medications, and does activities with him throughout the day.
Victoria	Spouse (husband)	5 years	Victoria's husband requires assistance with hygiene and daily tasks. She recently hired another care partner to help her with her caregiving tasks.
John	Spouse (wife)	7 years	John's wife with dementia has been getting progressively worse. Though she still lives with him in their home, he is increasingly faced with the choice of moving her into some form of assisted living.
Leslie	Parent (mother)	8 years	Leslie's mother with dementia lives in an independent living community.
Annie	Spouse (husband)	9 years	Annie's husband with dementia is high functioning. He needs help getting started on tasks but can generally accomplish things on his own. She mainly focuses on keeping him entertained or occupied.
Maggie	Spouse (husband)	10 years	Maggie's husband with dementia lives with her. Her husband deals with dementia-related aphasia that is particularly challenging for her. He recently had major surgery that caused significant physical and cognitive challenges.

(see Table 3). Participant responses fell into three main themes: *caregiving as an identity*, *recognizing the role of support*, and *caregiver-as-educator*.

**Caregiving as an identity.** Several participants talked about how participating in SPECAL changed the way they thought about their role as CPs. For many CPs ( $n=9$ ), participating in SPECAL helped increase their acceptance of their role or situation. For example, Chloe recognized how SPECAL helped her experience more enjoyment when caring for her father with AD/DRD:

I kind of like figuring out the way he thinks. And that's what SPECAL's helped me with, too, is "How did you get to that point? Why are you asking a question?" And just trying to figure him out is actually enjoyable. I liked doing that.

Like Chloe, Gina experienced greater acceptance of her caregiving role because of SPECAL, empowering her to take greater ownership of her mother's medical care:

[People in SPECAL] said, "You need to command your authority as [her] power of attorney and tell [her medical team] you want this handled and this is how you want it handled." See, I never would've done that. I would've just kept, "You guys are the experts." [...] Instead of, "I'm the expert on my mom [...]"

Yet, for some participants ( $n=12$ ), SPECAL raised insecurities about truly adopting the title of "caregiver." For example, some seemed hesitant to call themselves caregivers because their PLWD lived outside of their home. Sylvia explained,

I feel like I'm not much help right now telling you things since I'm not the primary caregiver for my mom [...] I'm only there a couple of hours on average [...] like last week I went camping, so I do feel that I get to get out and get refreshed, and my mom is still lovely [...] I still can be on the sidelines and be the cheerleader.

Other participants were reluctant to label themselves as caregivers because they perceived their situation to be less extreme. Richard noted, "The other people [in the group] are a lot worse [in terms of their caregiving needs]." These sentiments reflected

**Table 3.** Research Question #1 Theme Exemplars: Caregiving role and identity.

Code/Theme	Speaker	Example quote
Caregiving as identity: Acceptance	Gina	[SPECAL] just helped, it helped me realize my role and how I could help from a distance. And so that was probably one of the best moments, to understand that my mom needs to have autonomy and she needs to feel like she's still part of society
Caregiving as identity: Uncertainty	Sylvia	She's my mom and father is the primary caregiver. [...] I'm really just supporting him, and you should know she is not that far progressed. She's in early stages of the dementia... I'm still on the sidelines a little bit, so hard for me to gauge... I feel like I'm not much help right now telling you things since I'm not the primary caregiver for my mom
Caregiving as identity: Shame/Guilt	Katherina	I think that [SPECAL] can be helpful. I think with me it was, "How do I really get this..." "What's the word I'm looking for?" "How do I put it into practice without feeling like a failure?" Because I'm scrambling just to take care of the basic needs for mom and dad. [...] So I realized that I had to have a little compassion for myself and realize that I couldn't do all this for both of them all at once.
Recognizing the role of support	Eve	[...] I enjoyed it the whole in general and getting to meet everybody and learn something different from everybody. We all, like you said, have different experiences and different journeys, but listening to everybody's and getting some positive feedback and things that you've done or giving positive feedback to the group as a whole, really helped.
	Leslie	[...] I have people who have gone. They're a step ahead of me in the care, so I'm not going in blind. It's like, "Oh, that's what's going to be next." I'm walking the journey with people who are where I am, and then I'm able to give support to the people coming up behind. So, it's a mentor-mentee the whole way. So, it's a head-heart connection with people that just helps along the journey.
Assuming education as part of caregiving role	Frank	The "questionless question" and the fact that this logic doesn't work despite how much I want it to and things like that that have helped me, but they have not been transmitted to the people who are now caring for [my wife]. And so, while they have good physical care, they would be better able to deal with these situations if they had information that [SPECAL] has [...] And so I'm kind of on my own as to how to get the SPECAL information to the people and as I was waiting for you to call, I put down the bullet points that I think are most important. And I'm going to take that down today and ask them if they can use that in one of their meetings or if they can hang it up on a prominent bulletin board at someplace [...]
	Henriette	But that alone could have been because you conflicted, you contradicted her, she comes away feeling like there was a conflict, can't put her fingers on what it was, but she thinks [her granddaughter is] upset. I tried to give my family this little, short version of "give up the right to be right." Don't ask direct questions. [...] And then I talked about the photo album. And so, I was trying to give them this crash course in dealing with grandma.

caregivers' hesitance about what counts as caregiving and when they have provided enough care to truly deserve that moniker.

Furthermore, after participating in SPECAL, several participants ( $n=6$ ) expressed negative reactions such as guilt or shame around their role. For example, Dorothy noted:

I never gained patience [as a caregiver]. I failed at that. And that's my fault. [...] I felt the program is wonderful if you are a kind, patient person who can set aside all of your needs to devote all of your time to your loved one. [...] I don't have a lot of patience.

Other CPs like Eve expressed similar frustrations when they failed to use SPECAL strategies flawlessly:

I've learned to... Instead of asking if he's hungry, saying "I'm going to fix me some dinner," and "I'm going to be in the dining room." [...] That's taken some getting used to doing] ... that takes practice because there's times when I'll be like, "Do you want something?" Then I'm like, "God, Eve, you did it again!" With practice, it's getting easier [...]

These findings highlight CPs' experiences in reckoning with their role after participating in SPECAL. Some expressed greater acceptance of and positivity about their role, whereas others experienced feelings of hesitancy, shame, or frustration.

**Recognizing the role of support.** After participating in SPECAL, many CPs ( $n=14$ ) described how the program helped them feel supported and connected to a broader network. For example, Henriette was relieved to find others in situations like her own:

[...] there was another woman in [SPECAL] whose mother also thinks she is fine. So she and I, it was like, "Oh my word, there's..." I just had never interacted with anybody else. [...] So just there being another person who totally gets what that is like was huge.

Leslie also expressed value in connecting with others during the program:

I was just so grateful to have direction and support to be able to move forward and not feel like I was doing it all alone. That was

key, too. I was all alone for all of these eight and a half years. And suddenly, I realized I didn't have to do this alone anymore.

These CPs appreciated the chance to meet with people who could truly empathize with their experiences and to learn from one another. In this way, SPECAL participants felt connected and encouraged through the program.

**Caregiver-as-educator.** After participating in SPECAL, some participants ( $n=9$ ) explained how their learning motivated them to share key SPECAL strategies with others. These CPs passed along techniques to people in their family and to other personnel, including medical staff. Eve explained how she shared SPECAL ideas with her husband's adult children (her stepchildren):

I even talked to his kids. I said, "Guys, don't contradict your dad." I said, "I'm learning this too. If you contradict him, then you're not going to get a full communication with him. You're going to make him feel like he's not being valued and listened to. [...] If you go along with whatever he says, trust me, the conversations will go much easier and better. Please don't contradict him."

Similarly, Maggie shared her SPECAL knowledge with hospital personnel, explaining:

[...] I wrote up a paper that [orderlies] pasted to [my husband's] closet in his hospital room, things that he likes to talk about, things he could identify with, and things that calm him down. I wouldn't have known to do that, but the nurses told me [...] they were able to calm him down with some of the things that I had written on his theme paper.

These participants felt empowered to use SPECAL techniques in their own caregiving and to educate others on interacting with their PLWD in accordance with SPECAL principles.

### **Care partners' interaction changes (RQ3)**

The third research question explored how SPECAL influenced CPs' relationships with their PLWD (see Table 4). Two key themes

**Table 4.** Research Question #2 theme exemplars: Relationship outcomes of SPECAL.

Code/Theme	Speaker	Example quote
Changes in perspective	Ruth	And then when mom goes to her ugly place, that's because the page she's dealing with, her picture's mostly lacking the facts and she's only dealing with the emotions. And so, what stands out the most to me is that because it helps me, it instantly helped me to understand how to better understand what my mom is dealing with. That she's still there. She just is not, doesn't have access to all of the facts that help her make everyday normal decisions.
	Irene	[At a group meet-up the other day my husband] gave an answer which wasn't true at all, about when he was a kid, what did he do? And he told a story. Well, what difference does it make? He was happy telling his story, being given the opportunity to say something. And I would have felt bad, if I hadn't gone to this class to understand that it really doesn't make that much difference if the facts... The feelings are far more important than the facts are. And I just feel so blessed to have learned that, that my job is to help him feel good, to make him still feel important that he's got a role in life, to feel comfortable.
Changes in communication	Eve	I gave him a space and then listened to what he said, and I didn't try to contradict him. I just listened because I think that's what he really wanted was somebody just to listen. Well then, maybe a week or so... Like I said a couple of days ago, [...] He said, "You know what Eve, I really think you and I are communicating a whole lot better. I enjoy spending time with you. I liked when you listen." I said, "You know what? You have a lot to say, and I will stop what I'm doing to hear you." One day he asked me "Hey, Eve..." He had an idea, so I put my book down and I looked at him. He goes "Well, I can wait until you are done reading." I said "No, if you have something to say, we need to just listen, and I don't want you to forget what you're going to say. So, I will take the time to hear you when you're ready to say it." He was like, "Oh my God, you're listening to me." I'm like, "Yeah, you have something to say." Learning to take the time to listen very carefully as to what he was saying and not contradicting him is actually making him, in my opinion, a much happier person.

emerged from the data: *changes in perspective* and *changes in communication*.

### **Changes in perspective**

Participants ( $n=12$ ) discussed how their perspective shifted throughout the SPECAL program, leading to a deeper understanding of the PLWD's experiences. These shifts helped participants feel better equipped to interact with their PLWD. For example, Gina explained:

As I started to recognize the—not just what's happening to [my mother's] brain, but that it's more feeling-based and not [facts] ... at first, I thought she was like a toddler that could be re-taught, but it's not like a toddler. It's like it's gone. It's gone, and all that she takes away is the feelings. So I say that's the biggest light bulb moment if you will.

For other participants, like Mark, a shift in understanding contributed to new communication patterns. As Mark noted:

What [my dad] can't handle is new things or things he doesn't do every day. Getting in touch with the emotions behind it, it became a lot easier to determine and assess when something was too much. My wife and I would just look at each other like, "Okay that's too much right now."

These new understandings helped participants reconsider their behaviors and sympathize with their PLWD, ultimately opening new ways of interacting with one another.

### **Changes in communication**

Almost all participants ( $n=19$ ) articulated ways their communication patterns changed after completing SPECAL. For example, Henriette described how she now approaches interactions with her mother:

So [my mother] and I had multiple conversations about the plans for [her husband's funeral] service [...] Then, at another time when she'd say, "So what are the plans?" And I would start to go through them, and she'd go, "Why, yes, nobody consults the widow." Which, of course, I would argue, like, "Mom, this is what you said. We talked about..." And I've learned that I should've just said, "I'm sorry you don't feel like you've been consulted. What would you like us to do?"

Ruth also noted how much more effective SPECAL strategies made her interactions with her mother with ADRD:

And within a week or 10 days of not asking questions, mom had almost become the person that we knew prior to her mind starting to slip. And because she was always angry at [my sister], and it's because [my sister] was always asking questions: "Well, have you done this, and have you done that, and are y'all doing this?" And mom wasn't having the answers [...] it's kind of like mom took a 90 degree turn all of a sudden [...] So amazingly impressed, hoping that it [would] kind of work only to have our socks blown off by how well it did work.

When reflecting on his experience, Richard observed that he had been using communication strategies that were frustrating for both him and his wife with ADRD. Through SPECAL, he changed his communication and dramatically improved his relationship with his wife:

[SPECAL] was magical to me because I didn't understand. It helped me understand what my wife was going through and where she was. And before I took that, we had a lot of [...] dissension sometimes, because I didn't realize really where she was and what I was doing to her [...] Basically I would say that the SPECAL program and the things that I learned there is saving our relationship.

As evidenced from these examples, many participants used their understanding of dementia and SPECAL strategies to adjust their communication and reported enhanced interactions with the PLWD and an ability to better connect in their relationship as a result.

## **Discussion**

Caregiving for a loved one with ADRD can be challenging, in part because ADRD changes a person's ability to communicate and draw upon shared history to make meaning. These changes often increase uncertainty in both the CP and the PLWD (Bute et al., 2007; Donovan-Kicken & Bute, 2008). The present study evaluated the SPECAL program (Contented Dementia Trust, 2012) and its associated outcomes for ADRD CPs. Quantitative results revealed that, after participation, CPs reported reduced stress and anxiety about caring for the PLWD as well as increased optimism about the PLWD's future. Additionally, qualitative analysis of follow-up interviews indicated that CPs reframed or renewed their identities, and many assumed a desire to educate others about SPECAL. They also reported changed understandings related to the experience of ADRD and positive communication changes with the PLWD.

### **Effectiveness of SPECAL programming for informal care partners**

This study's results echo previous findings that the SPECAL program can produce positive outcomes among ADRD CPs (McCrae et al., 2020; Pritchard & Dewing, 2001; Riachi, 2018; Riachi & Markwell, 2020) while taking the evaluation one step further by examining participants' experiences of SPECAL as they unfolded rather than solely through retrospective accounts. Additionally, this is the first effort to explore the effectiveness of SPECAL among CPs outside of the UK (Wray, 2020). While additional work needs to be done examining the effectiveness of SPECAL among more diverse CPs, this study provides evidence that SPECAL's methods can be successful at promoting positive outcomes for CPs and PLWD more broadly.

The successes of SPECAL also highlight its ability to transcend facilitation mediums. Previously, most SPECAL trainings took place via face-to-face settings (Pritchard & Dewing, 2001; Wray, 2020). Informal ADRD CPs, on average, provide 26.3 h of unpaid care each week, and finding alternative care arrangements is challenging, so it can be very difficult for CPs—especially those with disabilities or those in rural communities—to engage with programming outside the home (Alzheimer's Association, 2021a; Brodaty et al., 2005). Due to the COVID-19 pandemic, our participants completed their SPECAL program virtually, providing evidence that SPECAL still brings meaningful benefits when offered through a synchronous, virtual channel. Virtual programming can help practitioners address CP needs while offering greater flexibility, access, and equity (Astell et al., 2019).

Despite the largely positive experiences expressed by participants, some CPs noted that SPECAL made them feel like inferior CPs, lacking the patience or ability to incorporate SPECAL practices into their in-the-moment communication. CP guilt is associated with increased risk of depression (Martin et al., 2006) and other negative health outcomes (Prunty & Foli, 2019). Guilt and shame are also associated with negative communication patterns (Wiginton et al., 2004), which can, in turn, cause additional feelings of guilt or shame, creating a self-perpetuating cycle that can harm the CP as well as the PLWD. Future research should examine when/how trainings like SPECAL make specific people feel negative emotions around caregiving, and they should seek to establish program elements to respond to these realities, including increased CP validation and social support to facilitate reframing of these self-evaluations (Burlison & Goldsmith, 1998). Indeed, this recommendation (to create avenues for social support) is echoed in our findings related to participants' *recognizing the role of support*.

### **Value of communication interventions for dementia care partners**

In addition to highlighting the outcomes associated with SPECAL, this research also contributes to the burgeoning evidence indicating the importance of communication-specific interventions for ADRD caregiving. The nature of ADRD requires that CPs un-learn past modes of communication, uncovering new ways of connecting with PLWD (Bute et al., 2007). As one participant, Richard, explained:

[My wife and I have] been married over 60 years. Over 60 years, you learn a certain amount of communication, and all of a sudden that wasn't working anymore because she wasn't there. And I didn't understand. The tendency is to just keep doing the things that you've been doing all your life [...] And that really doesn't fit well.

Communication is at the heart of our ability to sustain meaningful relationships (Burlison et al., 2000). The "new normal" of ADRD can feel overwhelming for CPs, and they tend to experience increased stress because of communication challenges with the PLWD (Small et al., 2000).

Providing CPs with concrete, communication-centric strategies can help them more effectively cope with their experiences, create increased feelings of safety and contentment in their loved one (Nguyen et al., 2019), and help them enjoy their loved one's presence for as long as possible (McCrae et al., 2020). Indeed, participants in our study remarked on how the communication changes learned in SPECAL restored their connection with their loved one (as in the case of Ruth with her mother) and even "saved my marriage" (as in the case with Richard and his wife). The value of renewed communication among this population cannot be emphasized enough, and future research should continue to identify strategies that enable CPs to connect meaningfully with their loved ones with ADRD for as long as possible.

### **Limitations and directions for future research**

While this study provides preliminary evidence for SPECAL's effectiveness, it is not without limitations. First, the study sample is small for quantitative analyses; additionally, the sample is demographically homogenous, as most participants came from one community in the western United States. Future research should expand the diversity of participants, as research indicates that individuals from different backgrounds (including racial and ethnic minorities; Rote et al., 2019) uniquely experience ADRD caregiving. In addition, this study is limited in that it examined the experiences of single CPs. For PLWD, and as evidenced by our participants' adoption of education as part of their caregiving role, caregiving usually involves multiple people working in concert with the PLWD to facilitate quality care. Future research should examine the potential of SPECAL for caregiving teams. Finally, this study emphasized CPs' subjective experiences, leaving additional questions about how CPs actually enact SPECAL strategies in communication with PLWD. Future research should include an observational component, where researchers could observe if and how CPs enact SPECAL principles in their interaction with their loved ones and how those strategies influence outcomes with PLWD.

### **Conclusion**

ADRD produce multiple challenges for the person diagnosed as well as those who assume the role of informal CP (Alzheimer's Association, 2021a; Petrovsky et al., 2019; Polk, 2005). One of the biggest challenges inherent in ADRD is its impact on an individual's ability to maintain meaningful communication when factual memories are no longer storing efficiently. The present study examined how the SPECAL method introduces an understanding of the experience of dementia and explains why and how new norms of communication between CPs and PLWD promote enhanced well-being for CPs and care recipients alike. Results from our mixed method analysis indicate the potential and promise of the SPECAL method as one person-centered care approach. Scholars and practitioners should continue to explore the power of these interventions in promoting meaningful connection for families working to adjust to the new reality of dementia.



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## References

- Alzheimer's Association. (2021a). *Alzheimer's disease facts and figures*. <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>
- Alzheimer's Association. (2021b). *Dementia vs. Alzheimer's disease: What is the difference?* <https://www.alz.org/alzheimers-dementia/difference-between-dementia-and-alzheimer-s>
- Astell, A., Bouranis, N., Hoey, J., Lindauer, A., Mihailidis, A., Nugent, C., Robillard, J., & Technology and Dementia Professional Interest Area. (2019). Technology and dementia: The future is now. *Dementia and Geriatric Cognitive Disorders*, 47(3), 131–139. <https://doi.org/10.1159/000497800>
- Blandin, K., & Pepin, R. (2017). Dementia grief: A theoretical model of a unique grief experience. *Dementia (London, England)*, 16(1), 67–78. <https://doi.org/10.1177/1471301215581081>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp0630a>
- Brodsky, H., Thomson, C., Thompson, C., & Fine, M. (2005). Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry*, 20(6), 537–546. <https://doi.org/10.1002/gps.1322>
- Burleson, B. R., & Goldsmith, D. J. (1998). How the comforting process works: Alleviating emotional distress through conversationally induced reappraisals. In P. A. Andersen & L. K. Guerrero (Eds.), *Communication and emotion* (pp. 246–275). Academic Press.
- Burleson, B. R., Metts, S., & Kirsh, M. W. (2000). Communication in close relationships. In C. Hendrick & S. S. Hendrick (Eds.), *Close relationships: A sourcebook* (pp. 245–258). Sage.
- Bute, J. J., Donovan-Kicken, E., & Martins, N. (2007). Effects of communication-debilitating illnesses and injuries on close relationships: A relational maintenance perspective. *Health Communication*, 21(3), 235–246. <https://doi.org/10.1080/10410230701307675>
- Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24(4), 385–396.
- Contented Dementia Trust. (2012). *The SPECAL method*. <http://www.contented-dementiatrust.org/wp-content/uploads/2012/03/Contented-Dementia-Brochure-.pdf>
- Donovan-Kicken, E., & Bute, J. J. (2008). Uncertainty of social network members in the case of communication-debilitating illness or injury. *Qualitative Health Research*, 18(1), 5–18. <https://doi.org/10.1177/1047932307309005>
- Eggenberger, E., Heimerl, K., & Bennett, M. I. (2013). Communication skills training in dementia care: A systematic review of effectiveness, training content, and didactic methods in different care settings. *International Psychogeriatrics*, 25(3), 345–358. <https://doi.org/10.1017/s1041610212001664>
- Farran, C. J., Miller, B. H., Kaufman, J. E., Donner, E., & Fogg, L. (1999). Finding meaning through caregiving: Development of an instrument for family caregivers of persons with Alzheimer's disease. *Journal of Clinical Psychology*, 55(9), 1107–1125. [https://doi.org/10.1002/\(SICI\)1097-4679\(199909\)55:9<1107::AID-JCLP8>3.0.CO;2-V](https://doi.org/10.1002/(SICI)1097-4679(199909)55:9<1107::AID-JCLP8>3.0.CO;2-V)
- James, O. (2008). *Contented Dementia: 24-h wraparound care for lifelong well-being*. Vermilion.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Oxford University Press.
- Martin, Y., Gilbert, P., McEwan, K., & Irons, C. (2006). The relation of entrapment, shame and guilt to depression, in carers of people with dementia. *Aging & Mental Health*, 10(2), 101–106. <https://doi.org/10.1080/13607860500311953>
- McCrae, N., Penhallow, J., Rees, O., & Norman, I. (2020). The Specialized Early Care for Alzheimer's method of caring for people with dementia: An investigation of what works and how. *Scandinavian Journal of Caring Sciences*, 34(3), 736–744. <https://doi.org/10.1111/scs.12778>
- National Institute on Aging. (2017). *Symptoms and diagnosis of Alzheimer's disease. What are the signs of Alzheimer's disease?* <https://www.nia.nih.gov/health/what-are-signs-alzheimers-disease>
- Nguyen, H., Terry, D., Phan, H., Vickers, J., & McInerney, F. (2019). Communication training and its effects on carer and care-receiver outcomes in dementia settings: A systematic review. *Journal of Clinical Nursing*, 28(7–8), 1050–1069. <https://doi.org/10.1111/jocn.14697>
- Petrovsky, D., Sefcik, J., Hodgson, N., & Gitlin, L. (2020). Harsh communication: Characteristics of caregivers and persons with dementia. *Aging & Mental Health*, 24(10), 1709–1716. <https://doi.org/10.1080/13607863.2019.1667296>
- Polk, D. (2005). Communication and family caregiving for Alzheimer's dementia: Linking attributions and problematic integration. *Health Communication*, 18(3), 257–273. [https://doi.org/10.1207/s15327027hc1803\\_4](https://doi.org/10.1207/s15327027hc1803_4)
- Pritchard, E. J., & Dewing, J. (2001). A multi-method evaluation of an independent dementia care service and its approach. *Aging & Mental Health*, 5(1), 63–72.
- Prunty, M. M., & Foli, K. J. (2019). Guilt experienced by caregivers to individuals with dementia: A conceptual analysis. *International Journal of Older People Nursing*, 14(2), e12227–13. <https://doi.org/10.1111/opn.12227>
- Riachi, R. (2018). Person-centred communication in dementia care: A qualitative study of the use of the SPECAL method by care workers in the UK. *Journal of Social Work Practice*, 32, 1–321. <https://doi.org/10.1080/02650533.2017.1381948>
- Riachi, R., & Markwell, S. (2020). Improving well-being in dementia clients and carers. *Journal of Public Mental Health*, 19(4), 321–326. <https://doi.org/10.1108/JPMH-05-2020-0039>
- Rote, S., Angel, J., & Hinton, L. (2019). Characteristics and consequences of family support in Latino dementia care. *Journal of Cross-Cultural Gerontology*, 34(4), 337–354. <https://doi.org/10.1007/s10823-019-09378-4>
- Small, J., Geldart, K., & Gutman, G. (2000). Communication between individuals with dementia and their caregivers during activities of daily living. *American Journal of Alzheimer's Disease & Other Dementias*, 15(5), 291–302. <https://doi.org/10.1177/153331750001500511>
- Tarlow, B. J., Wisniewski, S. R., Belle, S. H., Rubert, M., Ory, M. G., & Gallagher-Thompson, D. (2004). Positive aspects of caregiving: Contributions of the REACH Project to the development of new measures for Alzheimer's caregiving. *Research on Aging*, 26(4), 429–453. <https://doi.org/10.1177/0164027504264493>
- Tracy, S. J. (2018). A phonetic iterative approach to data analysis in qualitative research. *Journal of Qualitative Research*, 19(2), 61–76. <https://doi.org/10.1002/9781118901731.iecrm0187>
- Watts, P., & O'Connor, S. J. (2017). Communication in dementia. In S. Schussler & C. Lohmann (Eds.), *Dementia in nursing homes* (1st ed., pp. 105–121). Springer International Publishing.
- Weigel, K. A. (2017). Patient-/Person-centered care. In S. Schussler & C. Lohmann (Eds.), *Dementia in nursing homes* (1st ed., pp. 21–27). Springer International Publishing.
- Wiginton, K., Rhea, D. J., & Oomen, J. (2004). Using the Anger Response Inventory to evaluate the effect of shame and guilt on interpersonal communication skills. *American Journal of Health Education*, 35(3), 152–157. <https://doi.org/10.1080/19325037.2004.10603631>
- Wray, A. (2020). *The dynamics of dementia communication*. Oxford University Press.
- Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The multidimensional scale of perceived social support. *Journal of Personality Assessment*, 52(1), 30–41. [https://doi.org/10.1207/s15327752jpa5201\\_2](https://doi.org/10.1207/s15327752jpa5201_2)