

What Is a Nonresponder? A Qualitative Analysis of Nonresponse to a Behavioral Intervention

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This study used qualitative methods to understand reasons for treatment nonresponse following a behavioral intervention for family caregivers of people with dementia. Caregivers and interventionists completed semistructured interviews about their experience of the treatment after completing a course of Resources for Enhancing Alzheimer's Caregiver Health in VA (REACH VA). Treatment response from the 22 caregivers who completed the 12-session treatment was assessed using pre- to posttreatment change scores on measures of depression and caregiver burden. Interviews from the 14 nonresponder caregiver/interventionist dyads (28 total) were analyzed qualitatively to identify caregiver factors that negatively impacted improvement in depression and caregiver burden, such as emotional processing difficulties, wanting more support than structure, and limited support/difficulty asking for help. Ways nonresponders benefited from REACH VA beyond improvement on self-report symptom measures were also identified and included learning to problem solve more effectively, feeling understood and supported by another, and taking a different perspective on caregiving. The benefits of using qualitative methods to assess the experience of treatment nonresponders and identify individuals who may benefit from additional treatment or a different approach are discussed.

IN THE UNITED STATES, family caregivers provide the majority of care to the 15 million individuals with dementia. They often experience significant depression, burden, anxiety, and physical health issues in response to the strains of their role (Alzheimer's Association, 2014; Chattillion et al., 2012; Schulz & Williamson, 1991; Takai, Takahashi, Iwamitsu, Oishi, & Miyaoka, 2011). Caregivers of people with dementia (PWD) suffer from rates of psychiatric symptomatology as high as 48% (Draper, Poulos, Cole, Poulos, & Ehrlich, 1992; Pinquart & Sørensen, 2003). Additionally, caregivers experience significant health problems including lower rates of preventive health behaviors, decrements in immunity, greater cardiovascular reactivity, and increased risk of illness and mortality compared to noncaregivers (Schulz & Martire, 2004).

In the Veterans Health Administration (VA), the dissemination of Resources for Enhancing Alzheimer's Caregiver Health in VA (REACH VA), a behavioral intervention that includes psychoeducation, behavioral and problem-solving strategies, and relaxation tech-

niques, was implemented to support caregivers of PWD. The REACH VA intervention study was conducted across 24 VA facilities in the United States (Nichols, Martindale-Adams, Burns, Graney, & Zuber, 2011). Consistent with common elements of behavioral interventions, REACH VA provides education on issues related to caring for PWD, skills building designed to help caregivers better manage their stress, and behavioral strategies to address difficult patient behaviors (e.g., wandering, agitation). REACH VA represents the first national clinical translation of an empirically supported behavioral intervention for caregivers in the United States and one of the few behavioral interventions to demonstrate statistically significant change in outcomes such as depression and burden (Belle et al., 2006; Cooke, McNally, Mulligan, Harrison, & Newman, 2001; Nichols et al., 2011).

The REACH VA Clinical Translation Study examined the effect of REACH VA on 127 caregivers across 24 VA sites in the United States (Nichols et al., 2011). In this study, caregivers showed significant improvements in depression (mean Patient Health Questionnaire [PHQ-9] at baseline = 7.8, $SD = 5.9$ with estimated improvement of 1.49, $SE = 0.55$) and burden (mean Zarit Burden Score [Zarit] at baseline = 17.6, $SD = 9.7$ with estimated improvement of 2.88, $SE = 0.86$). Some subjective responses regarding the REACH VA intervention have been published and indicate that caregivers experience benefits beyond those assessed by self-report measures, including

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feeling reassured that they are “doing the right thing” and that they are not alone, learning how to ask for help, and taking a different approach to caregiving (Nichols, Martindale-Adams, Burns, Zuber, & Graney, 2014).

Despite these significant changes, effect sizes were small to medium (Cohen’s $d = 0.26$ and 0.33 , respectively). Follow-up studies have found similar results for a modified version of REACH VA comprising four to five sessions (Nichols et al., 2014). Furthermore, results of the REACH II randomized control trial indicated that 40% of caregivers assigned to the intervention did not complete the 12-session treatment and that, of those who completed, Hispanic/Latino(a) and Caucasian caregivers demonstrated significant improvements, whereas African American caregivers did not. Further examination of the data showed significant improvements among African American spouses of the care recipient but not among other caregiver relationships (Belle et al., 2006). Researchers investigating a modified version of REACH (REACH OUT) that combined home visits and phone sessions found several moderating factors on level of subjective burden following REACH interventions, including race, caregiver relationship to PWD and rurality with Caucasian, nonspousal, urban caregivers showing greater improvements than African American, spousal, and rural caregivers (Burgio et al., 2009). More generally, a meta-analysis comparing the outcomes of 78 caregiver interventions similarly reported that demographic variables such as caregiver age, gender, type of caregiver–care recipient relationship (spouse vs. adult child), and initial burden moderated treatment response (Sörensen, Pinquart, & Duberstein, 2002). However, none of these variables are mutable and appropriate targets of an intervention for nonresponders.

While no data have been published on nonresponse rates to REACH VA, findings from similar interventions indicate that the average caregiver remained moderately depressed posttreatment (Gallagher-Thompson et al., 2003) and another indicated that rates of clinically significant depression and anxiety postintervention were nearly 50% (Andrén & Elmståhl, 2008). Beyond treatments targeting caregiver issues, review of cognitive-behavioral therapy (CBT) treatment outcomes for older adults with late-life depression indicate that one third to one half do not appear to experience significant symptom relief from either antidepressant medication or psychosocial treatments (Steffens & Blazer, 2012). A range of variables such as poor social support (Bosworth, Hays, George, & Steffens, 2002), external locus of control (Marquett et al., 2013), high neuroticism (Bagby et al., 2008; Quilty et al., 2008), and personality pathology (Levenson, Wallace, Fournier, Rucci, & Frank, 2012; Mulder, 2002) have been found to be predictive of treatment nonresponse for CBT for depression. A review of treatment outcomes for anxiety disorders (Taylor, Abramowitz, & McKay, 2012) indicated

that a third of treatment completers are classified as nonresponders. Poor homework adherence, living in an environment with high expressed emotion (e.g., hostile, critical), and greater severity of the disorder were all found to be predictive of nonresponse.

While nonresponders make up a substantial percentage of treatment completers, little has been written on understanding their experience. This is unfortunate because it is nonresponders from whom we can learn the most about how a treatment could be improved (Steinert, Kruse, & Leichsenring, 2016). The majority of prior research on treatment nonresponse has utilized self-report measures that can provide some information regarding predictors of treatment response but limited to no information on ways the treatment can be improved to address the needs of nonresponders. Qualitative data can provide useful information about a client’s experience of “nonresponse” not otherwise assessed by outcome measures, including symptom areas that were not adequately addressed as well as benefits of treatment beyond symptom reduction.

We hypothesize that there are multiple reasons for nonresponse within and between caregivers and, further, that some caregivers who receive REACH VA may experience meaningful changes not captured by quantitative outcome measures. This study utilizes qualitative methods to identify themes associated with variability in reasons for nonresponse and changes articulated by caregivers receiving REACH VA that may not be captured by outcome measures focused on symptom assessment.

Method

The current study represents an independent investigation of REACH VA at a VA Medical Center (VAMC) that was not involved in the national study. The primary investigator of the project was a clinician in the national study and all interventionists were trained and certified in REACH VA by the VA National Caregiver Center at Memphis VA by the developers of REACH VA.

Participants

Participants were referred by VA staff in the geriatric, mental health, and primary care clinics, as well as by other participants and self-referral from flyers posted throughout the VAMC. Participants were romantic partners, adult children, and other family members of PWD, in which one member of the caregiving dyad was a veteran. Caregivers who reported an average of at least 4 hours per day devoted to caregiving and were experiencing elevated burden or depressive symptoms, as defined by a 12-item Zarit score greater than or equal to 9 and a PHQ-9 score greater than or equal to 5, were offered the REACH VA intervention.

These analyses focused on 14 caregivers who completed treatment and were designated to be nonresponders and their interventionists. A total of 10 interventionists, certified in REACH VA, provided treatment to the 14 caregivers included in this study. Demographic distributions for these 14 caregivers and the larger REACH study are presented in Table 2.

Procedure

Caregivers completed the 12-session REACH VA behavioral intervention (see Table 1 for session content). REACH VA focuses on psychoeducation, strategies for problem solving typical challenges faced by caregivers, and stress management strategies. Caregivers were seen at the VAMC with the option of completing occasional (one to two) sessions over the phone if they were unable to come to the VAMC. Following the intervention, all caregivers and their interventionists who completed the 12-session REACH VA protocol independently completed semistructured qualitative interviews conducted by trained nonclinical research staff not involved in the intervention arm or data analysis. Caregivers and their interventionists were asked what they found most helpful and what could be changed to improve REACH VA or make a new intervention for nonresponders. They were also asked about caregiver factors that impacted the ease

Table 1
Content of 12 Individual Sessions of REACH VA (Based on REACH VA Intervention Manual)

Session	Description
1	Introduction to REACH VA and review of caregiver notebook
2	Psychoeducation about Alzheimer's disease, safety, health, and stress
3	Identifying treatment goals, establishing behavior plan, stress management skills
4	Review status of treatment goal, stress management skills
5	Review status of treatment goal, identify additional treatment goal, stress management skills
6	Review status of treatment goal, stress management skills
7	Review status of treatment goal, stress management skills
8	Review status of treatment goals, identify additional treatment goal, stress management skills
9	Review status of treatment goal, stress management skills
10	Review status of treatment goal, stress management skills
11	Review status of treatment goal, stress management skills
12	Review of treatment

Table 2
Nonresponder Caregiver Demographics

	Mean	
Age	63.93	
	Min–Max	48–85
Gender	Female	64.28%
Racial identification	White	78.57%
	Black	14.28%
Highest education level	Some college	35.71%
	College graduate	28.57%
	Postgraduate	14.28%
Veteran status	Caregiver	21.4%
	Care recipient	78.6%
Relationship to care recipient	Romantic partner	57.14%
	Adult children	35.71%
	Niece/nephew	7.14%

of the intervention's implementation. Interviews lasted between 20 and 60 minutes, were electronically recorded, and transcribed verbatim by research assistants not involved in the intervention or data analysis. Interventionists and caregivers were not aware of their status as responder or nonresponder at the time of the interview.

Depression and caregiver burden were measured pre- and postintervention using the PHQ-9 and the Zarit, respectively. These measures were used to determine responsiveness to intervention. Caregivers were divided into nonresponders ($\Delta < 50\%$ on PHQ-9 and Zarit) and responders ($\Delta \geq 50\%$ on PHQ-9 and/or Zarit). While nonresponders may have shown substantial improvement on one measure, significant symptoms persist in at least one of the two measured areas suggesting that additional treatment is indicated. We found significant effects of REACH VA in our sample for depression ($p < .05$) and burden ($p < .001$) with effect sizes (Cohen's d) of 0.45 and 0.70, respectively. However, over 50% of the caregivers in our sample did not show a $>50\%$ change in their depression or burden scores following treatment, represented by the 14 caregivers that are the focus of this study. The average pretreatment Zarit score for this group is 26.50 and posttreatment is 24.35. The average pretreatment PHQ-9 score for this group is 10.50 and posttreatment is 9.71.

Measures

Patient Health Questionnaire (PHQ-9; Spitzer, Kroenke, Williams, & Patient Health Questionnaire Primary Care Study Group, 1999)

The PHQ-9 consists of nine questions based on DSM-IV criteria for depression rating the presence and severity of depression on a scale ranging from 0 (*not at all*) to 3 (*every day*). The validity of the PHQ-9 depression severity has been shown to correlate with the scores of the short version of BDI ($r = .73, p < .0001$; Martin, Rief, Klaiberg, & Braehler, 2006). In the current sample it demonstrated acceptable reliability ($\alpha = .74$).

Zarit Burden Interview (O'Rourke & Tuokko, 2003; Zarit, Reeve, & Bach-Peterson, 1980)

The Zarit Burden Interview is a unidimensional scale of caregiver strain. Caregivers rate the amount to which they experience a statement such as "Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?" on a scale ranging from 0 (*never*) to 4 (*nearly always*). This measure has been shown to have good internal validity ($\alpha = .85$) and predicts depression scores among caregivers (O'Rourke & Tuokko, 2003). In the current sample it demonstrated acceptable reliability ($\alpha = .75$).

Qualitative Analysis

Transcribed semistructured interviews of caregiver-interventionist dyads (28 total) were initially analyzed in two phases using thematic analysis as outlined by Braun and Clarke (2006). Codes were compiled and organized manually. In the first phase, line-by-line coding of each transcript was completed by two senior authors and all potentially meaningful responses were noted that related to benefits of REACH VA, ways the protocol could be improved to address the caregivers' needs, and caregiver factors that made the treatment easier/harder to implement. These meaningful responses consisted of a phrase or sentence that maintained, as closely as possible, the words of the caregiver or interventionist. Once all initial codes were compiled, one author reviewed each transcript to ensure that codes were evenly applied. In the second phase, initial codes were organized into specific categories that were discussed and agreed upon by three authors. Categories were organized into broader conceptual themes by two of these authors and were then discussed with a third author to reach agreement. In some cases, categories were reorganized and renamed to ensure that conceptual themes, categories, and codes were coherent and accurately represented the data. Finally, four authors identified and then discussed all reasons for nonresponse from the meaningful responses identified and collapsed them into themes related to nonresponse. Two authors then reread all transcripts for reasons related to nonresponse in order to understand which reasons were relevant for each caregiver. In rare cases of disagreement between the two authors, two additional authors were consulted and the question was discussed until consensus between the four authors was reached. These nonresponse themes were used to organize the data for each caregiver in order to understand ways in which caregivers with particular reasons for nonresponse benefited from REACH VA and aspects of a treatment that might improve response.

Results

Reasons for Nonresponse

Initially, 14 reasons for nonresponse were identified that comprehensively accounted for all reported caregiver

issues that may have adversely impacted treatment. The following five reasons were not used as primary themes to organize data because they pertained only to a couple of caregivers who also had other reasons for nonresponse that were more commonly noted: mental health diagnoses, cognitive difficulties, personality difficulties, resistant to treatment, and environmental stressors. Due to substantial overlap in concept and patient distribution, some reasons were combined: "limited social support" with "difficulty asking for help," "structure is not what they wanted" with "wanted more general support," and "interpersonal difficulties beyond treatment relationship" with "interpersonal difficulties within treatment relationship." The following six reasons were included in the analyses and discussion below: emotional processing difficulties, limited support/difficulty asking for help, caregiver not implementing plans/techniques, wanted more support than structure, interpersonal difficulties, and caregiver already knew what REACH VA had to offer. Multiple reasons were relevant to each caregiver (range = 2–5, mean = 3.86).

Data from interventionists and caregivers were analyzed together in order to gain a richer picture of the experience and impact of treatment by using multiple perspectives. Interventionists were most likely to discuss caregiver factors that were relevant to determining reasons for nonresponse. Caregivers were more likely to either attribute their remaining symptoms to aspects of the treatment they did not like and/or view themselves as having had a successful outcome. There was considerable overlap between caregiver and interventionist perspectives on the benefits of treatment suggesting that these were likely discussed during the intervention.

Limited Support/Difficulty Asking for Help

For the majority of caregivers ($n = 12$) long-standing interpersonal difficulties and resulting social isolation was related to being accustomed to the caregiving role and doing everything oneself, or wishing to avoid "burdening" others with their problems. Several interventionists described their caregivers as having difficulty asking for help and only wanting help if others offered. These caregivers appeared to minimize their needs and their care-recipients' difficulties, making others unlikely to volunteer support. Some caregivers described finding the support they've received in the past to be unhelpful, which has taught them to not ask for help. As one caregiver explained, "I don't go around asking for help because I know from experience people will not help me. Family will interfere and make things worse . . . and then I'll just abandon my father and say, 'you take care of him . . . I don't need this.'"

Emotional Processing Difficulties

In many cases ($n = 11$), interventionists discussed their sense that the caregiver needed help processing his or her

emotions surrounding the loss of his or her loved one to dementia and the challenges of taking on the caregiver role. The REACH VA protocol provides tools to manage stress and the caregivers' mood and includes possible target problems to address caregiver grief and depression. However, the intervention can be largely structured around addressing problem behaviors in the care recipient. Several interventionists pointed out that the protocol can allow for avoidance of the caregiver's emotional difficulties, such as one who described a caregiver who "always downplayed the deterioration of her husband . . . and was able to hide behind the 'alright, let's talk about making his hygiene better. . . .'" The structure and skills-based approach of REACH VA may send a message to some caregivers that it is not the place to talk about their feelings. One interventionist noted, "She would often stop herself (because) she didn't really want to express (her emotions), or think it was an appropriate place to express them because she viewed it as more like a classroom." A couple of interventionists sensed that their caregivers were "in denial" of their care-recipients' dementia and their emotional response to that loss, which contributed to their depression and emotional and social isolation. While some discussed the caregivers' active avoidance of their emotional experience, others wished there was more time within REACH VA to help the caregiver access and process his or her emotional experience in the efforts of alleviating his or her depression and burden.

Caregiver Not Implementing Plans/Techniques

Many nonresponder caregivers ($n = 9$) seemed uninterested in referencing the caregiver notebook, practicing skills, or implementing the strategies discussed in sessions. In many of these cases, interventionists described caregivers who had been caregiving for a while and had developed a system that they were reluctant to disrupt by trying strategies offered by the protocol. One interventionist stated, "He had a lot of this knowledge already and had tried these things so it was really hard to get him to try them again or try new things because he had already figured out his own way." In some cases, caregivers felt they weren't getting enough practice or support in the sessions to implement the plans and skills at home. A few interventionists described some of the caregivers in this category as "help rejecting," wishing to avoid the therapeutic work and making positive changes. For others, it seemed that the caregivers were less interested in practical solutions and were seeking more general support so did not take to the more solution-focused aspects of the intervention.

Wanted More Support Than Structure

While these caregivers ($n = 8$) still found useful information in the protocol, they often expressed things

like "having a regular outlet to say what's been going on," was the most helpful aspect of REACH VA. These caregivers wished for more time to "vent" or talk more generally about their challenges as caregivers than the structure of the protocol allowed. One caregiver said, "There was a timeline and structure to the program . . . I felt like it wasn't necessarily about me and it was about that," and suggested adding "a bit of space where there's time to talk about whatever it is the person wants to talk about." One interventionist said, "I think he struggled when he realized that REACH VA was going to be more educational, problem-solving based, not a place he could just come and vent." Interventionists reported feeling "stuck" in their work with these caregivers because they had difficulty identifying a clear target behavior and appeared to resist the structure of the protocol (e.g., disinterest in educational materials, caregiver notebook, practical skills). In several cases, interventionists felt that the caregiver's wish for support over structure was related to deeper interpersonal (e.g., having a complicated history with the care recipient) and emotional problems (e.g., emotionally overwhelmed or avoidant).

Interpersonal Difficulties

While some caregivers ($n = 8$) reported difficult relationships with family members and/or their care recipient, interventionists often added that these caregivers had not processed the effects of these negative relationships and were generally unaware of their contributions to interpersonal difficulties. Therefore, data for this category largely came from interventionists' interviews, which provided insight into the impact of these issues on the course and outcome of treatment, rather than from caregiver interviews. Interventionists discussed how interpersonal difficulties often affected caregivers' relationships to their care recipients, access to social support, and the therapeutic relationship. Common difficulties included not knowing how to appropriately ask for support (e.g., used subtle hinting or demanding), help rejecting (e.g., believing no one can care for the care recipient as well as themselves, criticizing others' efforts to help), and being inflexible regarding their approach to caregiving. One interventionist described a caregiver in this way: "She's . . . aggressive, lacks warmth, and gets rejected by others and then feels abandoned . . . She isolates herself because of the way she behaves." A few caregivers appeared to minimize the role of the interventionist. One caregiver suggested that REACH VA would have been just as effective if the information was delivered via e-mail and another stated that he would have benefited more if the interventionist had had a Ph.D. rather than an M.A. In these cases interventionists described a difficult therapeutic relationship in which they often felt devalued or alternately pushed away and pulled close.

Caregiver Already Knew What REACH VA Had to Offer

These individuals ($n = 5$) had often been caregivers for a long time, believed they had tried most of what REACH VA had to offer, and had sought out other forms of caregiver support (e.g., support groups). They often reported that the treatment was beneficial inasmuch as it provided a different perspective, “fine-tuned things (they) already knew about,” and compiled information in one place for easy reference or to give to others. However, they were hoping for information beyond what was already known. Some were looking for specific help on such things as financial or legal matters, while others were hoping to discover some new approach to caregiving or wishing for more general support. Being too educated prior to treatment often resulted in the caregiver not implementing plans and techniques offered by the protocol. Nonetheless, most reported taking away something new from the intervention but appeared to minimize the benefits of treatment compared to the interventionists’ reports that often highlighted aspects of change that went beyond the techniques taught in REACH VA, such as opening up more to the therapist, seeking support from friends, and benefiting from self-care suggestions.

Ways Nonresponders Benefited From REACH VA Beyond Symptom Reduction

Nonresponder caregivers reported benefiting from the treatment in many ways that may not have been directly reflected in their symptom reduction scores on the outcome measures used. These benefits are represented by the following themes.

Learning Skills to Manage Stress

The majority of nonresponder caregivers and/or interventionists ($n = 9$) discussed the benefits of the stress management skills taught within the REACH VA protocol. One caregiver broadly stated that REACH VA “helped me realize that the problem is not the care recipient but how I manage stress.” Caregivers reported particular benefits from signal breath. One caregiver said, “[the interventionist] taught me how to relax when I’m feeling stressed, especially . . . the breathing, which I have been using.” Several caregivers reported incorporating these skills into their lives with plans to continue them in the future. A couple of interventionists reported noticeable decreases in caregivers’ anxiety as a result of using the stress management tools.

Feeling Understood and Supported by Another: Someone Else “Bearing Witness”

Many nonresponder caregivers and/or interventionists ($n = 6$) discussed the importance of having someone to talk to who understands and cares about their experience. An

interventionist explained, “To have someone to understand what he was going through . . . was helpful.” While some caregivers reported more generally benefiting from speaking to an objective person about things that are important to them, others described a more personal connection. One caregiver reported, “I was able to talk to her and not really hold back anything. We developed a trust after a couple of visits and I was able to really talk.” Others discussed feeling supported and motivated by their interventionist and being able to cry and complain without feeling like they’re burdening another—not having to do it all on their own.

Learning to Take a Different Perspective on Caregiving Situation and Change Self in Order to Approach Caregiving in a New Way

Many nonresponder caregivers ($n = 6$) reported that a benefit of REACH VA was helping them recognize that while they cannot always change the care recipient, they can alter their approach to their caregiving situation. Broadly speaking, one caregiver said, “Do I have more awareness of Alzheimer’s? Perhaps. But I’m much more aware of my inner strength and that’s really more effective than knowing the facts.” Others discussed learning to have a more positive outlook and put things in perspective. More specifically, a couple of caregivers recognized that the problem is often not the care recipient but how they manage stress or anger that they can more effectively manage their response to a situation regardless of the actual outcome with the care recipient. One caregiver reported being able to shift her anger to compassion during difficult interactions with her care recipient. Another shared that REACH VA helped her step back during moments of anger, stating, “If I still have a bad temper, at least I know there’s things I could be doing, and I’ve actually been able to stop some of those episodes myself.” A couple of caregivers and interventionists reported that the caregiver recognized the need to approach communication with others differently and learned communication skills to more effectively interact with family members around caregiving issues.

Focusing More on Self-Care

Some nonresponder caregivers ($n = 5$) discussed an increased focus on their own health and self-care as a result of REACH VA. A few caregivers reported that they considered REACH VA sessions as self-care because, as one caregiver put it, “dedicated time to concentrate on my situation forced introspection once a week.” One interventionist noted, “I know one of her problems is taking care of herself and making time for herself so having a weekly intervention where she comes for an hour and can just be by herself was really important.” A couple of interventionists and caregivers reported that the psychoeducation on the physical and emotional effects of stress helped motivate

caregivers to engage in self-care activities and take care of their health. One caregiver explained, “[the interventionist] taught me to keep lists of things I need to do for my own health and follow through on them which I found very helpful because I was not eating properly or taking my medicine properly, so she brought that to my attention . . . [which] was great.” Some caregivers were motivated to reengage in more pleasurable activities for themselves. As one interventionist described, “He figured out more of a balance between caregiving and his own duties, moving forward with pleasure and goals he had for his own life.”

Learning to Problem Solve More Effectively

Some nonresponder caregivers or interventionists ($n=4$) described improvements in problem solving as a result of REACH VA. A couple of caregivers reported benefiting from finding specific solutions to current problems. One caregiver explained, “Every time I came in with a problem, [the interventionist] was able to help me see options that I hadn’t noticed before so that I could apply them to the situation.” Another caregiver took a prospective approach reporting benefits in “recognizing what is coming and how to start preparing and problem-solving to potentially avoid problems.” A couple of others felt they were able to be more effective generally because they had been armed with resources to problem solve on their own.

Case Studies

“Rose” (Age 70, Caring for Husband)¹

Rose fell into five nonresponder themes: limited social support/difficulty asking for help, wanted more support than structure, caregiver not implementing plans/techniques, interpersonal difficulties, and emotional processing difficulties. She experienced role reversal as a caregiver since she had been cared for throughout her marriage by her significantly older husband who now has dementia. Her interventionist described her as “emotionally avoidant and overwhelmed.” She appeared to be in denial of her husband’s illness and avoided talking about him, preferring to “vent” about issues in her life unrelated to caregiving. She avoided asking for help, believing that if people wanted to help, they’d offer. She disliked the materials on caregiving and did not implement new techniques or practice skills at home. She appeared “paralyzed” by caregiving and financial responsibilities and unable to access the resources that were available to her. Following the treatment, she reported that the most helpful aspect was that the therapist allowed her the space to “complain, cry, laugh,” and she didn’t want it to end. The interventionist noted that Rose appeared to need emotional support and a place to accept her husband’s decline and process her grief.

¹Names were changed and identities disguised by altering nonessential details.

“Alice” (Age 82, Caring for Domestic Partner)¹

Alice fell into two nonresponder themes: emotional processing difficulties and caregiver already knew what REACH VA had to offer. She had worked as a teacher and responded well to the structure and didactic approach. She described herself as a “proactive person,” able to look at her situation “less emotionally and more rationally.” She reported that she liked having the manual as a tangible resource to share with others, particularly members of her caregiver support group. She wished the protocol had more interaction, such as role-playing, and the flexibility to target the specific needs of the caregiver and not “waste” time reviewing areas that were already working well. She appeared to have difficulty being in the role of “student” taking suggestions from the interventionist. Her interventionist experienced her as the “perfect” patient for REACH VA, reporting that she was motivated and had a lot of positive social support. She “really bought into the stress management techniques . . . and would modify them to what worked for her.” She could have completed the protocol in a quicker time frame because she had already implemented a lot of the strategies taught by REACH VA and didn’t seem interested in having open space to talk. However, the interventionist noted that she minimized the extent of her partner’s decline and “used the structure and the tasks to almost protect her . . . from going to a certain emotional place.” The interventionist felt that that emotional exploration was an important missing element from the work with this caregiver and would have needed to be built into the protocol to alert her to the importance of engaging in this process.

Discussion

The study of treatment nonresponse is a neglected area in psychotherapy outcomes research. Understanding the experience of nonresponse from caregiver and interventionist perspectives can help improve treatment and/or provide direction for follow-up interventions posttreatment. This is of critical importance as over half of our sample were classified as nonresponders based on less than 50% change in their depression or burden scores following treatment. This study addressed potential reasons for nonresponse REACH VA, as well as ways nonresponders benefited from the intervention beyond symptom reduction.

The reasons for caregivers’ nonresponse appear to be most often related to a mismatch between what the patient wanted or what the interventionist deemed the caregiver as needing from the treatment and what REACH VA had to offer. In many cases it seemed that these caregivers wanted more general support or were looking to address a specific problem not included in the REACH VA protocol. Interventionists most commonly

noted caregivers' need for help processing their emotions surrounding their loss and interpersonal difficulties that stood in the way of accessing the support they needed. For some, the caregiver's apparent lack of motivation to implement the problem-solving skills and stress management techniques provided by the REACH VA protocol may be explained by these factors.

The varying needs of caregivers indicate the need for a flexible approach to treating caregivers of PWD who are experiencing depression and caregiver burden. A behavioral intervention's pragmatic approach and concrete strategies for addressing issues faced by caregivers, while helpful for many, may not appeal to all. Additionally, some caregivers present with difficulties beyond the scope of a behavioral intervention focused on caregiving (e.g., psychiatric diagnoses, difficulties with acceptance and grief, complex family dynamics, or long-standing interpersonal difficulties that negatively impact access to support). While many reported benefits from the problem-solving, self-care, and stress management skills taught in REACH VA, nonresponders appeared to require additional support and areas of focus such as emotional processing, interpersonal skill building, support, and connection, likely better suited for a longer-term treatment. These findings are consistent with other research on nonresponse that suggest poor follow-through on homework/implementation outside of treatment, greater severity of disorder, and living in high-expressed emotional environments (likely leading to difficult interpersonal interactions) are predictors of nonresponse (Taylor et al., 2012).

The accessibility of behavioral interventions, such as REACH VA for caregivers, is critical as most benefit in some way—however, for many caregivers additional approaches may be necessary to address unique issues and complex experiences evoked by caregiving. A stepped-care model of treatment may be indicated in which a short-term, skill-based intervention may be the most economical first-line treatment. If indicated, alternative treatments or resources, tailored to the caregiver's specific needs beyond what REACH VA provides, can be offered. For many of the nonresponders studied here, a longer-term treatment targeting caregivers' emotional and interpersonal difficulties would be indicated. For a few nonresponders, additional work with social workers, estate planners, or lawyers with expertise in elder care issues could provide them with the specific information they are seeking (e.g., managing financial and legal issues). Alternatively, in addition to the standard assessment currently conducted in REACH VA, additional evaluation of areas such as emotional regulation skills, ability to effectively navigate their interpersonal sphere, interest in general support versus specific skills and

problem-solving strategies, and long-standing psychiatric diagnoses may help to identify those who are likely to show nonresponse to this particular intervention.

An important finding of this study is that, despite demonstrating nonresponse on symptom measures, these caregivers generally reported a very positive experience of the intervention and appeared to benefit from it in a number of meaningful ways, including feeling supported, learning to manage stress and problem solve more effectively, and taking a different approach to caregiving. The majority reported improvement in their lives as caregivers akin to qualitative results from previous studies of REACH VA (Nichols et al., 2014). It is critical for researchers and clinicians to keep in mind the many different ways individuals' lives can improve as a result of therapy, even if they do not achieve the desired symptom reduction by the end of a brief intervention. Qualitative methods are useful for discovering such factors that are likely not assessed for by traditional outcome measures focused on symptom relief. Uncovering these meaningful changes can inform new areas of change to assess for following treatment.

Limitations and Future Directions

These are preliminary findings and data collection is ongoing. The sample size was insufficient to compare findings across types of caregiving relationships, and the treatment needs of partners versus children versus extended family of PWD may differ. Similarly, cohort effects may play a role as engagement in psychotherapy is generally more acceptable among younger generations. Additionally, racial/cultural identification might impact beliefs about caregiving, emotional expression, and expectations of social support. A larger sample size would allow for clarification of these issues and could determine the robustness of the findings presented here. It would also be useful to investigate such between-group differences in a larger-scale study to further inform the treatment needs of individuals. Furthermore, while the original REACH VA treatment was delivered by licensed doctoral-level psychologists, the majority of interventionists in the current study were doctoral students in clinical and counseling psychology programs who were supervised by licensed psychologists. Additional data on interventionist characteristics were not gathered, thus generalizability of these findings across interventionists with different levels of training is unclear. It is possible that the skills learned in REACH VA will continue to benefit these nonresponders and over time impact their levels of depression and caregiver burden. Due to the number of caregivers who reported learning skills to decrease stress, an outcome measure related to stress management could provide additional information about

treatment response. The long-term effects of this treatment merit additional study.

The findings reported here are based on therapist and patient perceptions of what occurred during treatment. Responses during the qualitative interviews could be biased by such factors as caregivers' social desirability, particularly in discussing treatment benefits, as well as interventionists' blindspots that could cause them to miss personal factors impacting their delivery of the intervention. More objective measures, such as coding video of the sessions for data on what actually transpired, could yield additional data pertaining to reasons for nonresponse and treatment benefits. Collateral information could also be obtained from family members and/or other treatment providers to determine whether the caregiver demonstrated meaningful changes in his or her mood, stress management, communication style, and daily functioning.

Finally, this study shows that alternative assessment strategies for treatment response that include qualitative analysis and/or clinician-rated functioning can be beneficial in understanding the many ways that patients experience and benefit from a treatment. Future research on psychotherapy outcomes could be further enhanced by mixed-method approaches.

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