

University of Nevada, Reno

**Helping Those Who Cannot Help Themselves:
Enhancing Collaborations in Dementia Care
Through Individualized Assessment and Training**

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in
Psychology

by

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Abstract

Enhancing Collaborations in Dementia Care

From the contextual perspective of dementia care, affective or behavioral changes associated with degenerative dementias can be prevented or reduced by a) orienting caregivers to the care recipients' performance deficits, b) training individually tailored strategies for effective communication, and c) promoting caregivers' understanding of the functions of the care recipients' behaviors. This study examined the contextual model. Phase 1 compared the performance predictions of 12 caregivers with actual care recipient performance and assistance provided by the caregiver. Phase 2 implemented a brief, three-session intervention on caregiver-reported behavioral problems within a multiple baseline design with three caregiver-care recipient dyads. In addition to the effects of the intervention on the target behaviors, potentially correlated changes in the quality of caregiver-care recipient interactions and in the degree of assistance provided were also monitored. The results of this study suggest that caregivers tend to overestimate the care recipients' performance and that, when caregivers contact the care recipients' deficits, caregivers provide more assistance than needed. The ratios of positive-to-negative dyadic interactions in the task demand situation were similar to those found with highly distressed couples in the couples therapy literature. In Phase 2, the contextual interventions implemented by the caregivers decreased the targeted behaviors (arguing, spending time unsupervised, and driving). Over the course of the study, caregivers adjusted their expectations of the care recipients' abilities to be more congruent with actual performance; however, more accurate expectations were not accompanied by more effective helping in a task demand situation. Although the ratio of positive-to-negative

interactions increased for all participants, it remained low. Results are discussed in terms of the heterogeneity of this community-dwelling sample, attrition related to undetected medical illness, the benefits of individualized assessment and intervention, and domain-specificity of treatment effects. While targeted interventions on problematic behaviors are effective, the results point out a need for specialized caregiver training with guided practice in compensatory and relationship-maintaining strategies, to generally promote more positive interactions, decrease ongoing interpersonal strain, and address caregivers' idiosyncratic thoughts, emotions, and behaviors in response to the care recipients' progressive loss of repertoires as potential barriers to effective care.

Dedication

At the Alzheimer's Center¹

Tim Myers (2009)

He's just dropped her off,
 his wife of thirty-seven years.
 For him, this is what mornings are now:
 this gray midwinter heaviness of sky,
 this thing he must keep doing.
 Their conversations are oddly casual
 but with a strange circularity:
 "Here we are, Martha," he'll say flatly;
 "Oh? What is it?" she'll ask.
 Sometimes he answers with a quiet smile,
 but even when grief lurches through him
 he's always tender.
 "The Center, honey. It's time to go to the Center."
 If you saw him later, in the aisles at Wal-Mart
 or watching TV in his reclining chair,
 you wouldn't know:
 just an old blue-collar guy like a million others,
 ball cap, graying mustache, bit of a swag-belly.
 old wolf in the lean deeps of winter,
 he fights an inextinguishable hunger
 hour after snow-muffled solitary hour –
 fights even now, as he pulls up to the hardware store,
 not to glimpse in memory
 the woman she was.

To the families.

¹ From *Beyond Forgetting: Poetry and Prose About Alzheimer's Disease* (p. 90), edited by H. Hughes and T. Gallagher, 2009, Kent, OH: The Kent State University Press. Copyright by Tim Myers. Reprinted with permission.

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CHAPTER 1

Introduction

Approximately 75% of individuals with dementia diagnoses live at home and rely on the help of spouses, children, and friends (Schulz & Martire, 2004). Epidemiologists forecast the number of persons with dementia in North America will double to 9.2 million by 2040 (Ferri et al., 2005). Interpolating from these data, within the next decades the number of people with dementia who receive assistance in their homes will rise from more than three million today to almost six and-a-half million. If individuals with mild cognitive impairment are taken into account, home-based assistance will be provided to 9.8 million people (Ferri, et al., 2005).

Since the 1970s, there has been a growing awareness of the medical, psychological, and economic consequences of home care: Family caregivers of persons with dementia are at higher risk of cardiovascular and coronary disease and may have a depressed immune response (Damjanovic et al., 2007; Känel et al., 2008; Mausbach et al., 2007; Schulz & Beach, 1999). In response to the demands of their role, family caregivers tend to increasingly restrict their activities to caregiving, withdraw from other aspects of their lives, and become depressed (Mausbach, Patterson, & Grant, 2008). Caregivers also commonly change their work schedules or their jobs and, consequently, incur financial losses to maintain home care. Thus, millions of individuals bear the physical and mental health as well as the economic tolls of assisting family members as their cognitive abilities wane (Schulz & Martire, 2004).

Despite its personal costs, most caregivers – if asked to choose again – would maintain their decision to provide in-home help for the person with dementia, whether

out of love, reciprocity, civic or religious duty, or personal obligation (Ablitt, Jones, & Muers, 2009). While research on psychosocial interventions for caregivers has almost exclusively focused on reducing anxiety and depression, most caregivers accept anxious and depressed feelings as an inevitable part of caring for a loved one with an incurable disease (Gottlieb, Thompson, & Bourgeois, 2003). Moreover, many caregivers, valuing their relationship with the person with dementia, are reluctant to characterize home care for a loved one as a “burden.” Only lately have researchers begun to ask whether changes on anxiety, depression, or burden measures—constructs thought to be related to education and skills training—appropriately reflect caregiver needs and are of clinical significance (for a detailed discussion, see Gottlieb, et al., 2003).

While there are thousands of descriptive accounts of caregiver burden within the research literature, interventions for caregivers are still in search of clinical significance (Schulz et al., 2002; Zarit & Toseland, 1989). As the review by Schulz and colleagues (2002) points out, interventions and their outcomes are domain-specific: If depressed behavior is targeted by an intervention, samples limited to individuals with higher depression scores are most likely to yield changes in scores of clinical and/or statistical significance. The same holds for anxiety or burden, such that enhanced research strategies would call for an even more careful choice of research participants (Schulz, et al., 2002). However, as others have noted (e.g., Logsdon, McCurry, & Teri, 2005), the stringent inclusion criteria of research studies and their treatment protocols often result in the perception of less relevance of these studies to “real-world” clinical settings. Thus, there has been a continuous tension between researchers doing what they know to do best—that is, employing widely studied measures of psychopathology to assess the

results of interventions targeting caregiver education and skills—and ignoring the relevance of their findings for the study participants themselves as well as for community practitioners.

A solution to this tension has been proposed (Burgio et al., 2001): Rather than defining participant samples more exclusively, researchers are increasingly focusing on defining a comprehensive theoretical and practical approach that allows the tailoring of individualized interventions for a heterogeneous population of caregivers and care recipients, without losing the link between intervention and outcome. Treatment is consequently standardized, yet flexible and adaptable. Interventions that allow a multi-faceted approach to caregiver and care recipient needs—stepped care options with global dementia education and concurrent training in behavioral management techniques according to an A • B • C antecedent-behavior-consequence model (Kanfer & Saslow, 1969)—are known to hold the most promise (SAMHSA, 2009). This A • B • C-model forms the core of the Project REACH protocols promoted by the National Institute on Aging and the U.S. Center for Mental Health Services (Gallagher-Thompson & DeVries, 1994; Schulz et al., 2003; Teri, 1990) and also has been termed the “contextual model” of dementia care (Fisher & Carstensen, 1990; Fisher, Drossel, Yury, & Cherup, 2007; Fisher & Swingen, 1997). The study proposed here will be a replication and extension of existing applications of this A • B • C, or contextual, model focusing on the effects of training on care recipient behaviors perceived as problematic by the caregiver, and on caregiver-care recipient interactions.

Background and Aims

A brief introduction to dementia.

“Dementia” is an umbrella term for a heterogeneous array of diseases, including Alzheimer’s, cardiovascular, and Parkinson’s diseases. While laypeople tend to equate “dementia” with forgetting, research within the last decade has shown that many neurodegenerative diseases are marked by impairment of planning and problem-solving abilities (also termed “executive functioning”), sparing a person’s ability to remember. Diagnostic criteria are currently debated (see for example, Reisberg, 2006), for the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association, 1994) still requires a clinically significant memory deficit (criterion A) for diagnosis. In practice, however, fronto-temporal and other vascular dementias with relatively intact memory function are being diagnosed based upon neurological and neuropsychological evidence. “Forgetting” is thus a small fraction of the possible presenting problems (for cognitive-behavioral profiles of dementias, see Levy & Chelune, 2007). Changes appear in

- Perception, particularly visual disturbances and diminished olfaction; current theories propose that changes in cognition follow heretofore undetected and significant perceptual disturbances (for a review, see Rizzo, Anderson, Dawson, & Nawrot, 2000)
- Communication (Bourgeois, 2002; Killick & Allan, 2001; Lubinski, 1995)
- Performance of previously learned tasks with intact motor ability and sensory acuity (Gross & Grossman, 2008)
- Recognition of objects and people

- Executive functioning (planning, organizing)
- Spatial and temporal orientation (Buonomano & Karmarkar, 2002; Geldmacher, 2003) (Buonomano & Karmarkar, 2002; Geldmacher, 2003)
- Attention/concentration
- Motor skills and coordination
- Motivation

Family caregivers of persons with neurodegenerative diseases often have difficulties understanding the level of functioning of a person with a neurodegenerative disease for two reasons: First, repertoires disappear selectively. For example, a person who is not able to name or recognize a watch (“anomia” or “agnosia”), may be able to play the piano, sing songs from his childhood, or unhesitatingly recite her social security number when asked. Even when other repertoires, such as naming and recognizing, have faded, rote-learned (“intraverbal” (Skinner, 1957/1992)) repertoires may persist. Similarly, a person may emit all the behaviors associated with “reading” (moving eyes to follow lines word-by-word, going from the top to the bottom of the page and onto the next page, turning pages), yet may not be able to describe or recall anything she has read. Speech production (fluency, grammar, syntax, phonologic accuracy, and proper articulation) may be preserved, but comprehension may have decreased. Moreover, even when expressive and receptive speech have deteriorated (e.g., the content of speech may not fit the current context; a person may not be able to follow or produce a logical argument), the behavior of many individuals with dementia remains extraordinarily sensitive to social cues. Some research has suggested that this sensitivity tends to increase as language skills wane (Hubbard, Cook, Tester, & Downs, 2002).

Secondly, in neurodegenerative diseases, repertoires fade away insidiously. They do not disappear in an all-or-none fashion, unless delirium or some other co-morbidity is present, or the person had another cerebrovascular event (Hussian, 1981, p. 72). Consequently, a person unable to use the microwave on Monday may be able to do so on the Friday of the same week, yet not on Saturday. As repertoires decrease in frequency over time rather than disappear all at once, the complexity of dementia presentations results in caregivers overestimating their family members' abilities, particularly when verbal fluency is still relatively spared and impairment is in the mild to moderate range (Cotter, Burgio, Roth, Gerstle, & Richardson, 2008; Folstein, Folstein, & McHugh, 1975).

The consequences of caregiver judgment errors.

Caregivers, whose histories with the care recipient span many decades, may rely on care recipients' verbal report, which tends to lead to an overestimation of their abilities. Accordingly, 60% of caregivers who participated in an intervention aimed at aligning caregiver expectations with actual care recipients' functioning were "surprised" by the level of the care recipient's deficits revealed through objective measures (Martin-Cook, Davis, Hynan, & Weiner, 2005, p. 208). This prevalent overestimation of abilities raises safety concerns for both the caregiver and the care recipient. Ala and colleagues (Ala, Berck, & Popovich, 2005b) found that 31% of family caregivers were not aware that the person with dementia had lost the ability to dial a telephone or call 911 in case of an emergency. Correspondingly, 37% of the caregivers overestimated the care recipients' ability to state their home address or the name of their caregiver (Ala, Berck, & Popovich, 2005a). When caregivers have health problems or are frail, such an

overestimation may put the dyad at especially high risk, for the caregiver may still rely on the care recipient to summon assistance in case of an emergency. In addition, caregivers often overestimate their family members' abilities to complete instrumental activities of daily living, such as identifying currency or giving the correct change (Argüelles, Loewenstein, Eisdorfer, & Argüelles, 2001), thus putting the person with dementia at risk of financial exploitation.

Underestimations, in contrast, may produce inappropriate helping, which either fosters premature dependence on the caregiver for tasks the person with dementia would have been able to complete, or the person's refusal of assistance that, if disregarded, may spur arguments. Perhaps not surprisingly then, underestimations of family members' abilities have been found to correlate with higher scores on caregiver measures of depression and caregiver burden (Argüelles, et al., 2001; Zanetti, Geroldi, Frisoni, Bianchetti, & Trabucchi, 1999).

Caregivers tend to be more accurate in their judgments when their family member's functioning is either intact or severely impaired (Cotter, et al., 2008; Loewenstein et al., 2001) but tend to overestimate the time they spend on providing assistance with activities of daily living (Cotter, Burgio, Stevens, Roth, & Gitlin, 2002). However, no data are available that directly assess whether the assistance that is actually provided exceeds or matches actual need.

The Contextual Model of Dementia Care

When caregivers seek out behavioral health services and are permitted to select the targets for intervention themselves, they tend to choose areas where the collaboration

with the care recipient breaks down (Teri, McCurry, Logsdon, & Gibbons, 2005), including:

- 1) General refusal by the care recipient to participate: Refusal to follow any directions or attend day programs;
- 2) Care recipient refusal to engage in activities of daily living: refusal to dress, eat, shave, shower, bathe, take medications, use a walker;
- 3) Care recipient refusal to stop driving;
- 4) Care recipient refusal to stop drinking alcohol;
- 5) Frequent complaints by the care recipient.

Note that many of these behaviors can be summarized as “maintaining autonomy.” At the same time and more often than not, many of these behaviors receive pathological categorizations as care recipient “agitation” or “aggression.” The terms “agitation” and “aggression” clearly denote the stressful the impact of these care recipient behaviors on the caregiver. Yet, these terms do not take reflect whether requests were made and assistance was offered in a manner appropriate to the strengths and weaknesses of the person with dementia, in a tone and with a rationale that respected the care recipients’ dignity and the history of the relationship (e.g., spousal traditional division of labor, parent-child asymmetry); or whether the interaction was coercive (for example, the caregiver used terms like “should,” “must,” “ought to”).

It is remarkable that refusing care and failing to comply are behaviors that are routinely analyzed within dyadic caregiving interactions of parental caregivers and children (Patterson, 1982), yet by default are ascribed to pathology in the case of dementia. This is not to suggest that individuals with dementia resemble children in any

way. Rather, this ascription is surprising considering that research has found the majority of family caregivers endorse using coercive means, such as loudness, threats and intimidation, as well as general criticism and hostility to produce care recipient behavior change (Cooper et al., 2009). The degree to which hostility and criticism are directed at the care recipient predicts the emergence of care recipient affective and behavioral disturbances 15 to 18 months later (Vitaliano, Young, Russo, Romano, & Magana-Amato, 1993). Further suggesting that caregiver skills and care recipient behavioral patterns are related, caregiver characteristics, such as young age, little education, high self-reported depression and burden, predict care recipient affective and behavioral changes (Sink, Covinsky, Barnes, Newcomer, & Yaffe, 2006). Caregivers' avoidant coping style has been linked not only to an increased expression of hostility and criticism (Vitaliano, et al., 1993), but also to shorter care recipient survival time (McClendon, Smyth, & Neundorfer, 2004), suggesting that many care recipients live in conditions that hasten decline and potentially fail to deliver necessary assistance and advocacy.

While family caregivers play a crucial role in the provision of care and, quite literally, become the voice of the person with dementia, aside from distal constructs such as caregiver burden, depression, and expressed emotion – all assessed in isolation from the care recipient and correlated with care recipient affective and behavioral status – little is known about actual caregiver/care recipient interactions.

Brief description of the contextual model.

The contextual model of dementia care treats caregiver/care recipient interactions as essential to caregiver and care recipient wellbeing. In general, it assumes that a person who is experiencing progressive cognitive impairment will develop strategies to

compensate for such impairment (Hussian, 1981), and that affective and behavior changes can be understood within the biopsychosocial context in which they occur. References to “context” thus include consideration of the degenerative brain disease, the person’s current circumstances, the person’s history, and broader socio-cultural factors. Note that family caregivers, as well as professional dementia care providers, are part of the person’s context. Rather than viewing individuals with dementia as “withdrawing from the world” or “encapsulated,” the model emphasizes the reciprocity between the person, albeit with the brain disease, and his or her psychosocial environment. The model assumes that persons with progressive cognitive impairment continue to value human connection and intimacy, regardless of the degree to which they are able to engage in factual verbal-vocal communication. Even the behavior of people with severe dementia is sensitive to its context (Buchanan & Fisher, 2002).

Of all the aspects of “context,” only a few are amenable to change: Dementia care providers are not able to alter a person’s history, cultural background, or features of the brain disease itself. Thus, for practical reasons, the contextual model slices up the context into alterable psychosocial antecedents and consequences, formulates hypotheses about the relationship among antecedents, consequences, and behavior, and then implements interventions based upon these hypotheses. Table 1 provides definitions and summaries of the relationships among these different aspects of one analytical unit (see also McCurry & Drossel, 2011).

Table 1

Relationship of Antecedents, Behavior, and Consequences

Antecedents	Behavior	Consequences
1. Proximal: All features of the situation, e.g., when did the behavior occur? Who was present? What did the other person do or say?	3. Any human activity, specified in gerund form: thinking, remembering, problem-solving, crying, laughing	4. Proximal: What occurred right after the target behavior happened? Who was present? What changed? What did others do?
2. Distal: Cultural background, social role identity, expectations		5. Distal: What happened to the behavior over time? Did its rate increase or decrease?

The relationship between cells 3 and 5 (behavior and its long-term consequences) is important, for it reveals the function of the behavior. If the behavior increases in rate, it is – by definition – said to have produced reinforcement, if it decreases in rate, it is – by definition – producing punishment as illustrated in Table 2 below.

Table 2

The Relationship Between Behavior and Its Consequences

		1. Following behavior, events are:	
		accessed, presented	prevented, terminated, postponed, or reduced
2. Over time, the frequency of behavior	increases	positive reinforcement	negative reinforcement (avoidance, escape)
	decreases	positive punishment	negative punishment (timeout, penalty)

Note. Read table cells in numeric order (from Drossel, Rummel, & Fisher, 2009).

Importantly, the functional relations defined above are distinct from the terms as used in the vernacular: In everyday language, “reinforcement” may be equivalent to “reward,” “punishment” with vengeance or retribution. This is not the case here: Reinforcement and punishment are simply summary terms for increases (reinforcement) and decreases (punishment) in the frequency of behavior as a result of its outcome. The circumstance that behavior and consequences are reciprocal is denoted by $B \cdot C$: Behavior produces an outcome and is changed by it in return (Skinner, 1957/1992). It follows that reinforcement and punishment are highly idiosyncratic terms: What reinforces one person’s behavior may be punishing another person’s.

Disappearance of functional repertoires.

While the degenerative brain changes per se predispose a person’s repertoires to easy disruption, additional degenerative behavioral processes further may impact the

degree to which function is maintained: (1) punishment, as mentioned above, and (2) extinction. Extinction denotes the circumstance that reinforcement increases and maintains behavior; when it is withdrawn, the previously reinforced behavior will slowly fade away over time (“extinction”). Side effects of extinction are emotional behaviors as well as so-called extinction bursts, in which the behavior increases in frequency or intensity even though it does not produce the desired consequences anymore. Both punishment and extinction of previously reinforced behavior lead to the disappearance of repertoires, and both tend to characterize the experience of people with dementia.

Extinction of previously reinforced behavior.

When repertoires, such as completing stepwise tasks or problem-solving, fall apart due to the degenerative progressive brain disease, previously enjoyed activities suddenly become menacing. Engagement with solitary hobbies – whether repairing antique clocks, tinkering with cars, gardening, or building model airplanes – is not met by its usual reinforcing consequences. More and more situations will be encountered that seem strange; problem-solving hits a wall, and tasks need to be adjusted to the lower skill level.

Social hobbies and social engagement often have a different fate: The person with dementia tends to make more factual errors, have more word-finding difficulty, or use unusual circumlocutions or neologisms. For example, the person with dementia says to a provider: “You’re a barrican. You don’t know what that is? I’ll tell you. It’s something that you don’t expect to be good but that turns out better than expected. That’s you” (Killick & Allan, 2001, p. 75). As a result of deteriorating expressive and receptive skills more acquaintances and friends end conversations more quickly.

Correspondingly, higher educational levels correlate with an initially steeper decline (Scarmeas, Albert, Manly, & Stern, 2006; Unverzagt, Hui, Farlow, Hall, & Hendrie, 1998) and, controversially, higher mortality (Stern, Tang, Denaro, & Mayeux, 1995). Current thinking holds that higher education initially masks mild cognitive decline (“cognitive reserve”), that is, individuals with known neuropathology are asymptomatic. When the deficits cannot be masked any longer, performance decrements become apparent, as measured by rapid decline on cognitive measures. At this point, one may hypothesize that a person known for his or her verbal brilliance or problem-solving ability may rapidly lose social opportunities for reinforcement. Such loss of opportunities for both the caregiver and the care recipient is associated with higher depression scores on standardized measures (Mausbach, et al., 2008).

Extinction also plays a significant role when considering the caregiver’s behavior. While reinforcement erosion – the slow fading of frequency of reinforcement in close relationships – is common to all relationships as novelty wears off and routine sets in (Jacobson & Christensen, 1996, pp. 153-155), its progression is rapid in dyads with one member who may not be able to engage in those day-to-day activities that can be considered relationship-maintaining. Whether adult children depended on their parent’s consult, problem-solving skills, and emotional or instrumental – and even financial – help, or whether one spouse depended on the other in a traditional division of labor, caregivers as well as care recipients experience discontinuation of reinforcement in day-to-day interactions.

As mentioned above, research has shown that extinction of behavior usually results in an increase in frequency, intensity, and variability. In laypeople’s terms, people

try more, harder, and more flexibly. Accordingly, speech pathologists studying communication patterns in dementia found that spouses asked their loved one with dementia three times as many questions about recent than about remote events – although memory for recent events is typically most impaired, and these questions consistently led to communication breakdowns (Small & Perry, 2005). While Small and colleagues (2005) interpreted the caregivers' behavior as intentional probes of the spouses' short-term memory capacity, it is more likely that “w”-questions (who, when, where, why, etc.) make up a large part of typical daily discourse; that these questions persist because the person with dementia may be intermittently able to provide an at least plausible, if not factually accurate, answer; and that extinction conditions (the person with dementia does not answer as expected) result in more intense, frequent, and variable questioning. Thus, given the long history of reinforcement, often spanning over half a century, the extinction of communicative patterns will be slow, even if these patterns do not work anymore.

Caregivers usually experience this slow extinction process as pain- and stressful. Not having learned about their loved ones' particular deficits or about dementia generally as a probabilistic fading of repertoires – increasingly sensitive to disruption – many caregivers find themselves alone, unsure how to gauge their loved ones' abilities, and subjected to history effects, which support erring on the side of autonomy rather than safety. As a consequence, many care recipients incur avoidable risks, and many caregivers engage in ruminative self-blame for dyadic processes that are as predictable as water flowing downhill, such as becoming angry and demanding when the care recipient does not follow through with a task or cannot remember a conversation.

Punishment of behavior.

The behavior of individuals with dementia is often inadvertently punished. Good examples are terms of endearment used by strangers, waiters, or long-term care staff: One resident may ask upon seeing a staff member, “Can I have a glass of water, please,” (B). Staff may respond, “Sure, sweetie, I’ll get it for you right away” (C). The resident’s behavior may increase in rate – she may ask that particular staff member more frequently in the future. Another resident, asking the same question (B) and producing the same outcome (C), may refrain from approaching the staff member again. For her, the term “sweetie” may signify an inappropriate term of endearment and function as a punisher. Consequently, Salari and Rich (2001) found that clients of adult day programs engaged in fewer peer interactions if staff used elderspeak, provided activities fit for children rather than adults, and did not respect individuals’ autonomy and privacy. From a functional perspective, staff inadvertently punished social interactions, and this punishment may have affected social interactions within the setting in general. Even well-intentioned correcting or filling-in may function as punishers (Gentry & Fisher, 2007) and decrease the person’s engagement in social interaction over time.

Escape and avoidance behavior.

From a contextual perspective, many of the behaviors of individuals with dementia are maintained by escape from or avoidance of a demanding or overwhelming situation (see for example Fisher & Swingen, 1997, for aggressive behavior). The ability to report on one’s own physiological or psychological status as well as the skill to describe the relationship between events and one’s own feelings, are complex repertoires (Bandler, Mauaras, & Bem, 1968; Bem, 1972; Skinner, 1957/1992), and many dementias

result in an early breakdown of these complex self-reporting repertoires, possibly because self-perception is distorted. While syntax and grammar are still intact and overall speech and word-finding difficulties rare, the person with dementia might not be able to characterize his or her own affect or behavior in relation to the current situation, e.g., by saying, “I feel overwhelmed” or “I feel scared.” This detrimental lack of self-descriptive ability can be tragic when illness, infection, and potentially life-threatening conditions are resulting in rapid cognitive decline accompanied by emotional and disruptive behaviors, for the caregiver may call for mental health interventions rather than ascertain the direly needed medical assistance. Caregivers, who have been able to rely on their loved one’s descriptions for decades, thus have to learn to search for converging evidence and not trust verbal self-statements, which may have an escape or avoidance function (for example, “I am fine and do not need to see a doctor.”). Gitlin and colleagues (2010) found that 37% of their sample of individuals with dementia suffered from undetected illnesses (mostly bacteriuria, anemia, and hyperglycemia). The possibility of undetected illness is exacerbated by preexisting DSM-IV diagnoses, which generally place older individuals at risk of inappropriate admission to a psychiatric institution for undetected delirium due to medical conditions (Reeves, Parker, Burke, & Hart, 2010).

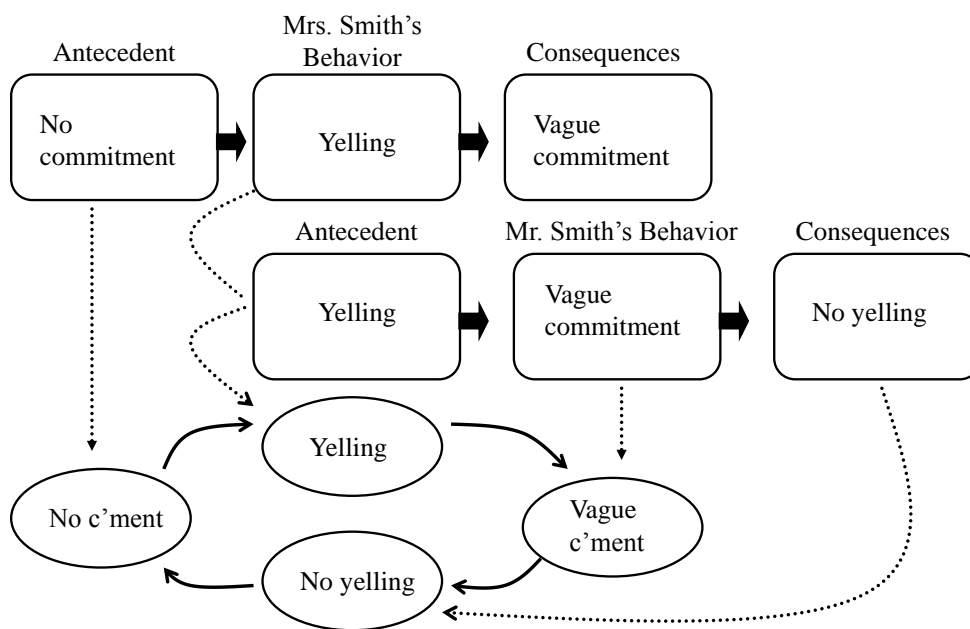
Neurodegenerative processes break down not only the correspondence between what we feel and what we say we feel, but also between what we actually can do and what we say we can do. Our very human tendency to escape from demand situations may result in verbal agreement. A person with dementia may, for example, agree to undertake tasks that – in actuality – have become too difficult, such as setting up the sprinkler system, repairing a tile, changing the oil in the car, or fetching milk at the

corner store. Subsequently the person, despite verbal agreement, will not complete the task. As in our previous example of extinction, the caregiver may escalate demands as a result – and the person with dementia may again verbally comply (“Quit nagging me. I’ll do it later”). These escalating demands are at the heart of Patterson’s (1982) coercive family model, later applied to couples interactions (Jacobson & Christensen, 1996) .

Figure 1 illustrates the mutual trap that caregiver and care recipient enter when the care recipient’s, Mr. Smith’s, verbal agreement is reinforced by avoidance of the caregiver’s yelling, yet Mrs. Smith’s loud demands are reinforced by Mr. Smith’s agreement. Under these circumstances, with repeated cycles, Mrs. Smith’s behavior may escalate from yelling to physical prodding and, finally, hitting or shoving. At the same time, Mr. Smith’s behavior may also escalate – from simple agreement to accusations of nagging, saying “yes” followed by refusing to further talk with Mrs. Smith or by leaving.

Figure 1

Escalation of Behavior as a Function of the Mutual Trap



Note. Adapted from Malott, Malott, & Trojan (2000).

Mr. Smith's yelling can be interpreted as self-protective behavior – escaping from Mrs. Smith's demands, given that he is not able to forecast his inability to initiate and complete the task. In line with the coercive family process model, it has been shown that community-dwelling care recipients are more anxious in relationships involving negative communication (Orrell & Bebbington, 1996). However, the prevalence of coercive interactions within these dyads is not known. Providing some additional support, however, are correlational data gathered in skilled nursing facilities, where researchers have demonstrated a link between staff communication patterns and the behavior of persons with dementia in personal care situations. Studies concluded that “refusal” of care, and “aggression” and “resistance” in personal care situations are better interpreted as self-protective behaviors that function to avoid socially inappropriate situations (e.g., infantilization and elderspeak) or to escape from perceived violations of privacy or personal boundaries (Burgio et al., 2000; Cunningham & Williams, 2007; Talerico, Evans, & Strumpf, 2002) .

Implications of the contextual model for dementia care.

Individuals with brain diseases in general and progressive dementias in particular are stigmatized. In addition to encountering provider prejudice, such as, “They’re just going to get worse anyway” (Hopper, 2003), people with brain diseases are perceived as unpredictable, possibly dangerous, and in need of intensive and harsher treatment than gentle psychosocial interactions (Mehta & Farina, 1997). To emphasize, even family members may hold such views and interpret their loved one’s affective and behavior

changes as “out of the blue” and attributable to changes in the brain, rather than alterable psychosocial circumstances. The contextual model explicitly contradicts this view.

While the repertoire of individuals with dementia slowly narrows, the contextual model assumes that dyadic processes, characterized by evidence-based behavioral principles, such as reinforcement, punishment, and extinction, also apply to caregiver-care recipient interactions. Affect and behavior of the person with dementia remain sensitive to aspects of the context, even if the person is severely impaired (Buchanan & Fisher, 2002). Consequently, providers of caregiver skills training in dementia care can learn from well-established interventions based upon contextual (antecedent-behavior-consequence) processes, such as cognitive-behavioral interventions for lacking compliance (Gardner, Burton, & Klimes, 2006; Webster-Stratton, 1998) or integrative behavioral couple therapy (Jacobson & Christensen, 1996).

A stated goal of the contextual approach to dementia care is to generate a general understanding of affective and behavioral processes within their context to enhance predictability in the service of preserving relationships and maintaining social engagement, in light of progressively waning repertoires. Teaching family caregivers about reinforcement erosion and the “mutual trap” (Jacobson & Christensen, 1996); taking blame out of the situation; conducting functional A • B • C analyses in collaboration with the caregiver, and designing and implementing interventions based upon these analyses is at the heart of the contextual approach to dementia care. A contextual intervention:

- Tailors dementia education to the care recipient’s diagnosis and skill level;
- Reduces problem behaviors;

- Enhances collaborative interactions by reducing harsh, negative, or coercive care strategies.

The current study addresses behavioral disturbances in dementia from a contextual perspective. Phase 1 consists of baseline assessments of caregiver and care recipient status, including care recipient functional abilities and caregiver knowledge thereof. While previous studies have examined the congruence between caregiver predictions of functional ability and care recipient need for assistance, the relationship between the assistance provided and the assistance actually needed to maximize care recipient independence has not been investigated. This study is the first to look at all three aspects of care recipient functioning: Caregiver prediction of independence, assistance rendered by the caregiver when the situation arises, and actual care recipient need.

Phase 2 of this study consists of a contextual dementia care intervention on caregiver-identified behavioral problems within a multiple baseline design. Also explored are the effects of that intervention on the caregivers' predictions, the degree of assistance rendered, and the quality of caregiver-care recipient interactions in task-demand situations, including potential coercive aspects.

CHAPTER 2

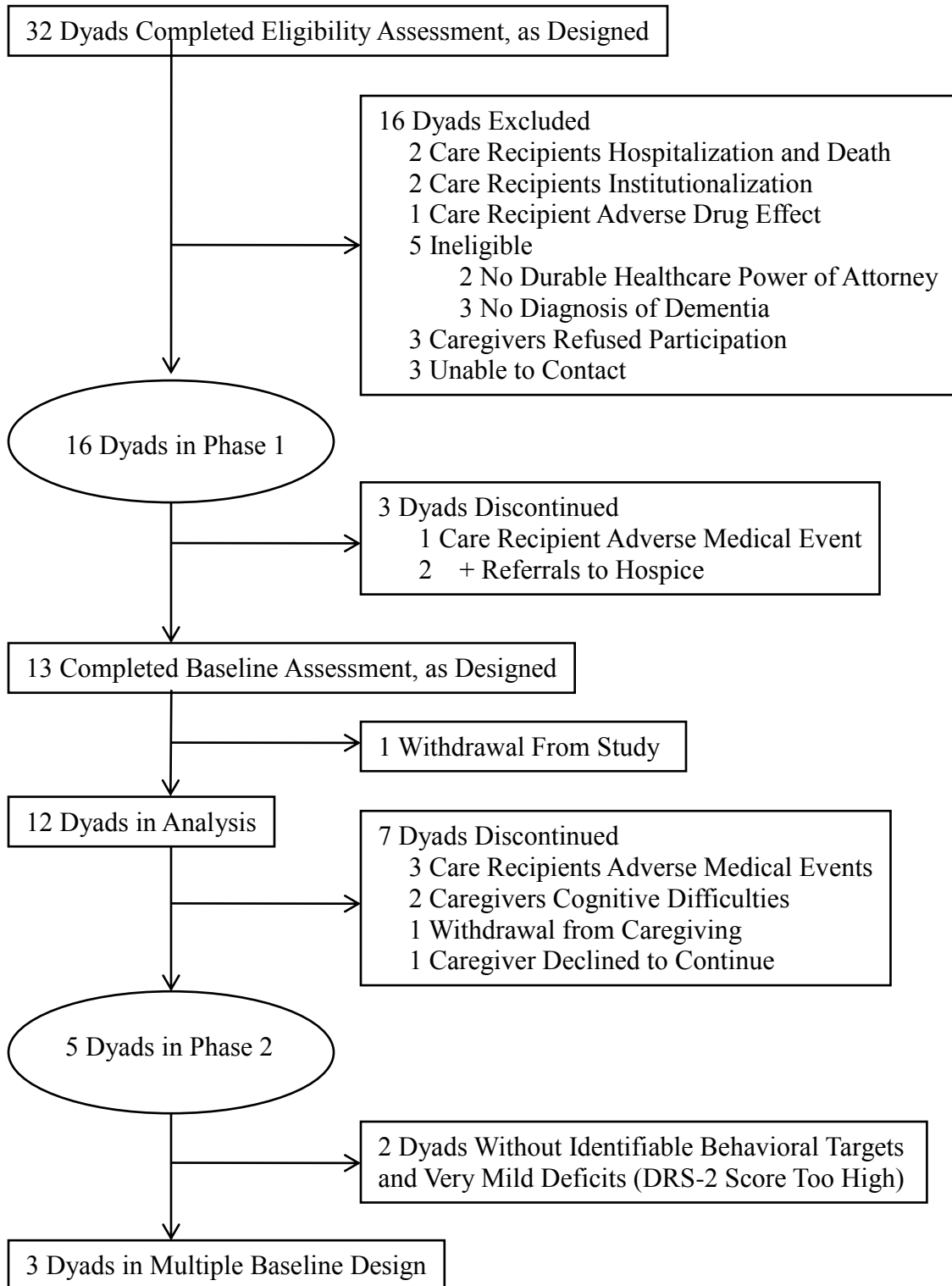
General Methods

Participants

Dyads were recruited through in-services at the Alzheimer's Association caregiver support groups (Reno, Carson City) and at adult day services (Washoe County Senior Services Daybreak; Continuum). Advertisements ran in print matter for two months (monthly Senior Spectrum Newsletter, the Sparks Tribune, and the Reno Gazette), and the study was announced on the radio (KUNR) for one week. One thousand business cards were printed with the name of the study and the author's contact information. All neurology and psychiatry practices in the greater Reno-Sparks-Carson City area received announcement letters, personal visits, and business cards for referral to the study. Study information was also available at the Nevada Caregiver Support Center, on the Center's web site, and at Washoe County Senior Centers.

Enrollment duration was four months (February through May of 2010). A total of 32 caregiver care-recipient dyads were assessed for eligibility, and 16 dyads entered the study. The study was approved by the institutional review board of the University of Nevada, Reno. Figure 2 shows the flow of recruitment, participation, and attrition for the six-month period of the study duration.

Figure 2

Flow of Participants in the Study

Care recipient participants had a medically confirmed diagnosis of dementia, were at least 60 years of age, resided at home, and had a primary caregiver who provided minimally 20 hours of care or supervision per week and was willing to participate in assessment and training sessions. Care recipients were excluded from the study if there had been an abrupt decrease of functioning within the last two weeks, indicative of conditions necessitating immediate medical care, such as delirium. Two prospective participants were referred for immediate medical attention and died within a two-week period. One participant was unresponsive due to adverse medication effects at the time of eligibility assessment and was referred to a geriatric pharmacist for medication reconciliation. Five of the ineligible dyads chose to receive behavioral health care services through the Nevada Caregiver Support Center by the author of this study and her colleagues. Other ineligible dyads were referred to appropriate community agencies for continuity of care, according to their presenting problems.

General Procedure

Consent

Interested caregivers received home visits or, if they preferred, traveled to the Nevada Caregiver Support Center to discuss the study and verify their status as the care recipient's designated attorney-in-fact. After brief rapport-building, persons with dementia participated in a Mini-Mental State Examination (MMSE; Folstein, et al., 1975). Caregiver and care recipient then completed the informed consent process. If a care recipient's MMSE score was below 19, the attorney-in-fact holding a durable healthcare power of attorney provided consent on behalf of the care recipient, and the care recipient gave written assent to participation. Also, if behavioral observations while

discussing aspects of the study with the care recipient led the author of this study to question capacity (for practical clinical guidelines, see Grisso & Applebaum, 1998), the caregiver consented on behalf of the care recipient. Depending on whether care recipients gave consent or assent, caregivers and/or care recipients signed releases for the exchange of information with medical providers to gather details about the care recipients' diagnoses and medication status. Caregivers and care recipients filled out baseline paper-and-pencil measures and set a date and time for the following assessments and the associated digital recording.

Safety monitoring.

Given that the vulnerable population participating in this study was community-dwelling, the author implemented the data and safety monitoring strategies recommended by Czaja, et al. (2006), who identified the following adverse events and appropriate response strategies for healthcare providers of individuals with dementia: Family caregiver death, hospitalization, institutionalization, emergency room visit; care recipient death, hospitalization, institutionalization, emergency room visit. Adverse event data and changes in medication status were reviewed weekly. Additionally, a caregiver's report of a care recipient experiencing abrupt changes in functioning or any observation thereof led to an immediate referral for medical care to rule out infection, illness, or pain.

This study also applied Czaja, et al.'s (2006) baseline risk assessment to detect and generate safety alerts if the caregiver had severe medical problems; the caregiver's response on a depression screen indicated depression scores higher than those in the general population; there was suspicion of caregiver abuse; the care recipient had severe medical problems; the care recipient engaged in threats of self-harm more frequently than

three times per week; the care recipient had access to a gun; the care recipient drove; or there was suspicion of care recipient abuse. In addition, substance use by the caregiver and the care recipient was assessed. Dyads flagged for increased safety risks were monitored closely and received telephone checks between weekly sessions.

Before mandated reports for suspected elder abuse, neglect, or exploitation were made, the author discussed the grounds for the report and the report itself with the respective caregiver. In collaboration with Elder Protective Services, State of Nevada Aging and Disability Services Division, the caregiver and the author worked to resolve the problem; if appropriate or necessary, the caregiver received referrals for additional behavioral health, medical, or social services.

Session outline and continuity of care.

Participants who completed the study received seven individual one to two-hour sessions described in Table 3.

Table 3

Outline of Sessions

Phase	Description
Phase 1	<ol style="list-style-type: none"> 1. Introduction; Consent; Paper-and-Pencil Measures, including Caregiver Completion of Performance Rating Scale (Appendix 1) 2. Direct Assessment of Functioning Tasks (Appendices 2-4) with Author of Study (“Clinician”) 3. Direct Assessment of Functioning Tasks (Appendices 2-4) with Caregiver

- Phase 2
4. Intervention 1: Dementia Overview Tailored to Care Recipients' Strengths and Weaknesses, Review of Video Recordings of Direct Assessment of Functioning Tasks (Appendices 2-4) with Clinician and Caregiver
 5. Intervention 2: Effective Communication (Appendices 5a-c), A • B • C Contextual Model,
 6. Intervention 3: A • B • C Contextual Model, Effective Communication (Appendices 5a-c)
 7. Paper-and-Pencil Measures, including Caregiver Completion of Performance Rating Scale (Appendix 1); Direct Assessment of Functioning with Caregiver (Appendices 2-4); Debriefing and Referral for Continuity of Care
-

Participants who discontinued participation after Phase 1 as well as participants who completed Phase 2 of this study (see Figure 2, Flow of Participants) received referrals to the Nevada Caregiver Support Center and other community agencies for continuity of behavioral healthcare. All participants were offered and most accepted a DVD of the video-recorded direct assessment of functioning tasks (Phases 1 and 2).

Assessment, intervention, and respite personnel.

The author of this study conducted all assessment sessions in Phases 1 and 2. Undergraduate or continuing education students assisted with transporting or setting up equipment for the direct assessment of functioning tasks and remained in the area, that is, at the person's home or at the Nevada Caregiver Support Center, during assessment. The

author of this study also conducted all intervention sessions in Phase 2. During that time, undergraduate or continuing education students provided respite services in English or Spanish, depending on the care recipients' preferences. These students were enrolled in a gero-psychology field course (PSY 375 or PSY 448) that took place at UNR's Gerontology Center and the Nevada Caregiver Support Center. They had received six to seven weeks of dementia-specific didactic training, followed by in-the-room supervised field training in respite services and companionship. One respite session was provided by a graduate student, a master's-level trainee of the University of Nevada, Reno's Clinical Psychology Program, trained in clinical psychology within a cognitive-behavioral perspective with two years of experience working with individuals with cognitive impairment and their families. Jane Fisher, Ph.D., the principal investigator of the study, provided weekly clinical supervision and was immediately available for questions or concerns.

Video-recording and coding.

The direct assessment of care recipient functioning by this author and/or the caregiver was digitally recorded. All video-records were transcribed into a spreadsheet format (see Appendix 6, Coding Rules). Two graduate students served as blinded, independent raters of recordings pertaining to the direct functional performance assessments and the interactional observations (Phases 1 and 2). The raters watched each interaction before coding it and followed the interaction on the transcript. Coding occurred in three steps: First, raters coded each subcomponent of the direct assessment of functioning using "pass/fail" criteria (see Appendices 2-3 for task analyses). The story retelling task (Appendix 4) was coded according to its manual, allowing only

predetermined utterances to be scored. Independence on subcomponents of tasks resulted in a code of 1 and any assistance or dependence on these subcomponents was denoted with 0. Secondly, the number of independently performed subcomponents divided by all subcomponents for one task (e.g., mailing a letter) rendered a percentage (e.g., the care recipient performed 50% of the task independently). Guided by these percentages (see Appendix 1), raters then selected a code to rate independence from 1 (total assistance) to 7 (total independence). Thirdly, raters coded the quality of caregiver-care recipient interactions into three codes, positive, negative, or neutral. When raters used “positive” or “negative” as a code, they were asked to justify their decision by selecting subcategories of positive or negative caregiver behaviors listed in Appendix 6. Intervention sessions in Phase 2 were randomly voice-recorded for treatment fidelity.

CHAPTER 3

Study Phase 1

Introduction

Phase 1 of this study focused solely on caregiver prediction of care recipient abilities and their assessment. As described earlier, failure to accurately characterize a person's functional deficits may expose persons with dementia to preventable risk. While the literature repeatedly has shown incongruence between caregiver and care recipient reports (Argüelles, et al., 2001; Loewenstein, et al., 2001), or incongruence between caregiver report of duration of assistance with basic activities of daily living and actual time spent (Cotter, et al., 2002), no data are available that would shed light on the relationship between care recipients' ability to perform instrumental activities of daily living, caregivers' predictions, and caregiving behaviors.

Of particular interest were predictors of incongruence, such as severity of dementia or caregiver-specific factors, and the relationship between incongruence and caregiver-reported behavioral disturbances. We hypothesized that caregivers would have more difficulty accurately predicting care recipients' abilities when they were mildly to moderately impaired, producing both underestimation and overestimation according to the literature described earlier. Higher depression and anxiety scores, decreased scores on a caregiver competence measure, younger age and less education were hypothesized to correlate with incongruence. Additionally, it was hypothesized that the intensity of reported behavioral disturbances would correlate with greater incongruence between prediction and actual performance.

Next, this study examined the hypothesis that overestimations of the care recipients' performance would not predict the caregivers' actual helping behavior (e.g., even upon predicting autonomous task completion, the caregiver would assist the care recipient when difficulties are observed) and that helping more than necessary would result in lower performance scores in the caregivers' presence than in the trained personnel's presence.

Methods

Participants

As shown earlier (Figure 2), 16 dyads participated in Phase 1 of the study. The data of one dyad were excluded subsequent to withdrawal from the study. Complete data sets consisting of cognitive measures, paper-and-pencil measures, and direct assessment of functioning were obtained for 12 of the remaining 15 dyads.

Caregiver Characteristics.

Participant characteristics are outlined in the following tables (4 and 5).

Table 4

Caregiver Characteristics

Demographic and Relationship Information (n = 15)	
Mean Age (SD)	60.53 (15.40)
Gender	14 Females, 1 Male
Race (Ethnicity)	15 White (3 Hispanic)
Relationship	2 Children, 11 Spouses, 1 Relative, 1 Other
Employment	11 None, 1 Part-time, 3 Fulltime

Education	1 Grade School, 3 High School, 5 Some College, 1 Associate's, 5 Bachelor's
Current Quality of Relationship (Past, Premorbid Quality)	4 Difficult, 4 Average, 7 Good (3 Average, 11 Good, 1 N/A)
Mean Length of Relationship Years (SD)	35.07 (18.03)
Mean Care Duration in Months (SD)	33.67 (35.39)

Two of the caregivers who worked fulltime were daughters who had arranged within the past year for their mothers to live with them. These households consisted of the caregiver and her family, including teenage children. Two caregivers had prematurely retired from their jobs to provide 24/7 supervision to their spouse; one caregiver had been able to arrange part-time work from home with his employer. One caregiver was a live-in carer for the person with dementia.

Caregiver baseline risk assessment.

There were guns in five of the households. One caregiver-care recipient dyad had a history of domestic violence as well as a history of an accidental shooting of the care recipient by the caregiver, and guns had been removed subsequently. Five caregivers drank alcohol once or twice per week. One caregiver had taken a position as a live-in carer upon recent successful completion of a one-year-long drug rehabilitation program for methamphetamine abuse. Five caregivers screened positive for depression, eight caregivers for elevated anxiety scores. Three caregivers had a history of cancer, one of myocardial infarction. One caregiver endorsed current physical limitations. All

caregivers reported complete independence in their own basic and instrumental activities of daily living.

Care recipient characteristics.

Care recipient characteristics are outlined in Table 5. All care recipients read English at a 6th grade level. When care recipients preferred speaking Spanish, translators were available.

Table 5

Care Recipient Characteristics

Demographic and Health Information (n = 15)	
Mean Age (SD)	77.93 (7.33)
Gender	5 Females, 10 Males
Race (Ethnicity)	14 White (2 Hispanic), 1 African American
Education	3 Grade School, 3 High School, 3 Some College, 3 Associate's, 3 Bachelor's
Dementia Type	6 Alzheimer's disease, 4 vascular, 2 Parkinson's, 1 Lewy Bodies, 1 Meningioma, 1 Cardiogenic Dementia, 1 Anoxia
Mean Years Since Diagnosis (Mode)	2.9 (< 1)
Drug Regimen	
For Mood, Affect, Behavior	11 Individuals Total: 9 Antidepressants, 2 Antipsychotics, 3 Benzodiazepines
For Pain	3 Individuals Total: 3 Narcotics, 2 OTC

For Cognition	7 Individuals Total; 7 Cholinesterase Inhibitors; 2 Memantine; 1 Dimabon
Referrals for Medication Reconciliation	10
Co-Morbidities	Mode = 5, Range 1-10

Care recipient baseline risk assessment.

One care recipient lived alone. This person's caregiver, her granddaughter, reported taking her to work and providing care at least four hours per day. Five care recipients had fallen within the last month before entering the study, three had required emergency care. Seven care recipients drank alcohol once or twice per week. Two care recipients drove daily.

A report was made to Elder Protective Services regarding one care recipient in the study, who was perceived at risk of financial exploitation by his family (ex-wife, adult children, and grandchildren). The author of this study, the caregiver, and the state agency's social worker collaborated to resolve the problem, and the caregiver and his spouse subsequently moved into an assisted living facility.

Procedure

In Session 1, caregivers indicated how much assistance they thought the care recipient required for designated tasks of daily living (Appendices 2 through 4; Ala et al., 2005a; Bayles & Tomoeda, 1993; Loewenstein et al., 1989) using the Performance Rating Scale (Appendix 1). Tasks received ratings from 1 (total assistance) to 7 (total independence). The corresponding actual, direct assessment of the abilities of the person with dementia occurred in Session 2, in the absence of the caregiver with one exception:

One caregiver insisted on being present and sat in a location that was not in the care recipient's direct line of vision, yet could be recorded by the camera.

While assessing functioning, the author of this study described each task to the care recipient and provided instructions to engage in the task as usual. If the person with dementia failed to initiate any action or asked for assistance, semantic and phonemic verbal cues were delivered and followed by modeling or physical prompts as necessary. The purpose of the prompts was to protect the person from the effects of extinction, determine the optimal degree of support to maintain engagement, and to provide the person with dementia with the experience of task completion and success, regardless of correctness or whether the whole task or a component thereof was completed. In past studies (e.g., Martin-Cook, et al., 2005), people with dementia self-reported an increase in self-esteem as a result of such efforts. Task completion was digitally recorded.

In Session 3, caregivers and care recipients performed these same tasks together. At the beginning of the session, the author of this study provided to the caregiver a script outlining each task. She then explained each task and associated props (e.g., clock, groceries). Caregivers were instructed to "have fun," "to play a game," and that they as well as the care recipient could "take a break or stop at any time." Caregivers were told they did not need to track the care recipients' abilities, for the session was video-recorded, and that they could help the care recipient as they deemed necessary. At the beginning of the session, caregivers were asked to convey the following script to the care recipient (either verbatim or ad lib, with emphasis on the ability to ask for assistance or to discontinue at any time): "I am going to give you some tasks. Do the best you can. You can ask me for help, or for a prompt, at any time. If you want to stop or take a break, you

can do so at any time.” During the caregiver-care recipient sessions, this author and other study personnel left the room or the house and returned per caregiver’s telephonic request. The caregiver called the study author’s cell phone number. One couple had a remote history of domestic violence. In this case, the author of this study only left the room for brief periods of time and monitored caregiver-care recipient interactions closely.

Measures

All measures for care recipient functioning were available in English and Spanish versions (Arnold, Cuellar, & Guzman, 1998; Beaman et al., 2004).

Direct assessment of care recipient function.

1) Assessment of knowledge of personal and emergency information (Ala, et al., 2005a, 2005b); administration time: 5 minutes (Appendix 2). The care recipient was asked to state his or her name and to spell it. This information was followed by requests for the address, telephone number, caregiver’s name, and the name of the primary care physician. In accordance with the Performance Rating Scale (Appendix 1), 7 points were assigned if the care recipient answered the questions without assistance ($7 \times 6 = 42$ points total independence), 1 point for completion of each request by the caregiver or the clinician ($7 \times 1 = 7$ points total assistance), and 6 to 2 points were assigned dependent on the percentage of subtasks performed independently and the assistance rendered (e.g., if the care recipient took out his or her business card to provide the requested information versus use of the business card prompted by the caregiver). Test-retest reliability was not known.

2) Direct Assessment of Functional Status Scale (DAFS; Loewenstein et al., 1989); administration time: 35 minutes (Appendix 3). The DAFS was specifically

designed to assess the functioning of community-dwelling older adults. Each task is broken down into discrete steps, and points are awarded for their completion. Note that dialing the operator and a number from the phonebook were eliminated as subtasks, as many households did not have a phonebook. Individuals with dementia also used their own cell phones if the household did not have a landline. The maximum score of 76 is indicative of normal functional ability (Kane & Kane, 2000). Test-retest reliability after four to seven weeks is high, with Cohen's kappa = 0.71 to 0.91 on summary scores of the functional tasks (Loewenstein, et al., 1989). The items from the DAFS provided the majority of structured opportunities for caregiver-care recipient interactions in this study. In addition to the normed DAFS score (maximum score = 76), each of the eleven subtasks also received the rating with the Performance Rating Scale (Appendix 1).

3) Standardized story retelling; Arizona Battery for Communication in Dementia (Bayles & Tomoeda, 1993); administration time: 10 minutes (Appendix 4). The immediate story-retelling tasks correlates with MMSE scores (see "Mini-Mental State Examination" below), and there is a learning effect after one week ($r^2 = 0.5$). Test-retest reliability assessment was conducted with moderately to severely impaired Alzheimer's disease participants only, who scored 0 at both test and retest (Bayles & Tomoeda, 1993). While the retelling of this narrative has been used for approximately 30 years to distinguish typical from impaired functioning, its main purpose in this study was to provide a neutral occasion for the caregiver and the care recipient to engage in collective recall. Here also, care recipient performance was rated with the Performance Rating Scale (Appendix 1).

4) Performance Rating Scale (Appendix 1) to be completed by caregivers and independent raters. This Performance Rating Scale is based upon studies by Cotter and colleagues (Cotter, et al., 2008; Cotter, et al., 2002) who used a similar Functional Independence Measure (Granger, Hamilton, Keith, Zielezny, & Sherwin, 1986) to rate the ability to perform basic activities of daily living (Cohen's kappa = 0.67 to 0.88 for second-by-second comparisons of observers per categories). This study constituted the Performance Rating Scale's first application to care recipient instrumental activities of daily living. It employed global summary ratings per task (described in Appendices 2-4) rather than the second-by-second ratings of caregiver behavior used by Cotter and colleagues (2002; 2008). After caregivers had prejudged the care recipients' abilities by completing the Performance Rating Scale, it was then applied to rate the video-records of each of the preceding measures (Assessment of Knowledge and Emergency Information, DAFS, and the Standardized Story-Retelling Task) to produce a quantitative measure of actual assistance rendered ("Performance Rating") for comparison purposes.

Assessment of care recipient affect, behavior, and cognition.

1) Revised Memory and Behavior Problems Checklist (RMBPC; Teri et al., 1992). The RMBPC assesses behavioral and affective changes common in dementia in terms of frequency and caregiver bother (reaction ratings). Teri and colleagues (1992) reported good validity and reliability (alphas of 0.84 for the ratings of affective and behavioral changes, 0.9 for caregiver reactions to these changes). Following Ferretti and colleague's (2001) study of anxiety in dementia, five anxiety items (appears anxious/worried, expresses fearfulness/worry, nightmares/fear on waking, constantly

restless, and fidgets/unable to sit still/paces) were included to generate an anxiety scale (subscale Cronbach's alpha = 0.81).

2) Identifying and monitoring target behaviors via A • B • C checklist (Bourgeois, Schulz, Burgio, & Beach, 2002; Teri et al., 2005).

3) Mini-Mental State Examination (MMSE; Folstein, et al., 1975); administration time of 5 to 10 min. The MMSE is a brief screening instrument for dementia, most effective in discerning moderate to severe impairment (score < 15) and routinely used to select participants in dementia trials (Lezak, Howieson, & Loring, 2004).

4) Mattis Dementia Rating Scale-2 (DRS-2; Jurica, Leitten, & Mattis, 2002); administration time: 20-40 minutes. The DRS-2 samples from five different performance areas (attention, initiation and perseveration, construction, conceptual ability, and memory). It is sensitive to fronto-temporal dementia, affecting mainly the performance on the Initiation and Perseveration subscale. Items are structured such the most difficult items are given first, ending with simple tasks and perceived success. The scale has excellent test-retest reliability for homogeneous diagnostic samples (.97 for the total score); when samples are heterogeneous, test-retest reliability is somewhat lower (coefficient alpha = 0.82). A drop of 10 points or more on the scale is rare and alerts to the possibility of an adverse event, such as illness (Lezak et al., 2004). Recently, a high correlation between DRS-2 scores and informant-based ratings of activities of daily living has been demonstrated (Fields et al., 2010).

Indirect assessment of caregiver functioning.

1) Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977). The CES-D is a 20-item self-report measure with a maximum score of 60 and a designated cutoff score of 16 to differentiate depressed from non-depressed population samples. Reported test-retest correlations were .51 to .67 after 2, 4, 6, or 8 weeks, and the scale was sensitive to treatment effects (Nezu, Ronon, Meadows, & McClure, 2000).

2) Beck Anxiety Inventory (BAI; Beck, Epstein, Brown, & Steer, 1988). The BAI is a 21-item self-report scale with a maximum score of 63 (8 to 15 indicate mild, 16 and above moderate to severe anxiety). The BAI was chosen because it correlates more strongly with anxiety than depression measures. Test-retest reliability is high, $r = .75$ after one week and .83 after five weeks (Antony, Orsillo, & Roemer, 2001).

3) Short Sense of Competence Questionnaire (SSC; Vernooij-Dassen et al., 1999) is a 7-item scale that assesses the degree to which a caregiver is able to effectively manage care for the person with dementia. All items require caregivers to disagree or strongly disagree to demonstrate advocacy, as common behavioral and affective changes related to dementia are attributed to willfulness or intention. The highest score is obtained by strongly disagreeing with every statement (SSC=35). Test-retest reliability was satisfactory ($\alpha = .68$ to $.87$).

Data analysis.

The small sample size prohibited the use of inferential statistics. Consequently, data were organized via descriptive statistics and graphical analysis.

As described earlier (General Method, Video-Records and Coding), to answer the question whether individuals could perform tasks independently, performance was scored

in a dichotomized manner, and any assisted task completion did not contribute to the score. Secondly, to answer how much assistance a person required, task performance was coded with the Performance Rating Scale (Appendix 1). Caregiver predictions of care recipient functioning then could be analyzed with regard to the number of tasks completed independently as well as the degree of assistance rendered for recalling emergency information, performing instrumental activities of daily living from the DAFS, and retelling a story. Care recipients' performances with the caregiver and with the clinician were compared, to arrive at a closer approximation of assistance rendered and actual care recipient needs.

Results

Care recipient scores on standardized measures.

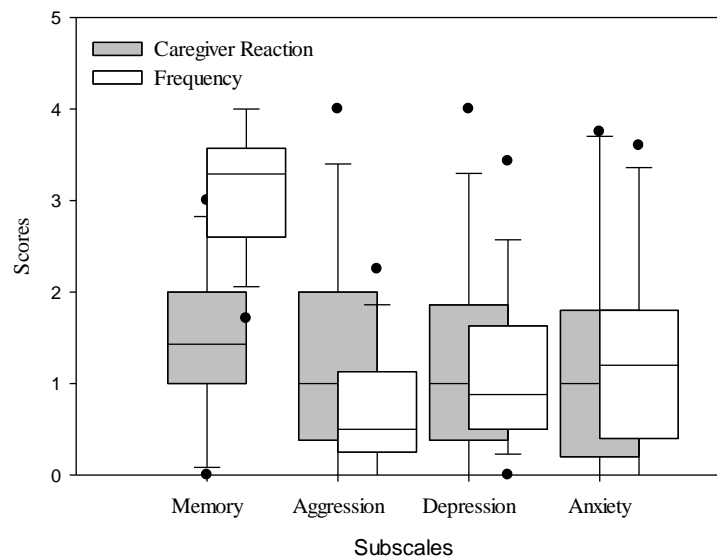
Care recipients had a mean MMSE score of 17.33 (SD = 8.18), with a range from 5 to 27. Scores on the DRS-2 suggested that the cognitive performance of three individuals were in the mildly impaired to intact range (>126), while the performance of all other care recipients showed significant impairment across cognitive domains. The mean DRS-2 score was 102.46 (SD = 25.04), with a range from 65 to 139 (suggested cut-off = 124). The delayed recall of a short story evidenced the severe deficits, with only 22% of the story being recalled on average (range 0 -76%, mode = 0), and on average only 45% of the previously recalled information retained over an interval (range 0-125%, mode = 0).

Caregiver-reported problematic affect, behavior, and cognition are shown in Figure 3. According to their caregivers, care recipients had almost daily difficulties with remembering, while aggressive, depressed, or anxious behaviors were rarer. Caregivers

described themselves as relatively unbothered by memory problems and having relatively greater reactions to aggressive, depressed, or anxious behaviors.

Figure 3

Revised Memory and Behavior Checklist Scores



Note. “Reaction” denotes the degree to which caregivers consider themselves bothered by the observed changes in affect, cognition, and behavior (0 = not at all, 4 = extremely), while “Frequency” indicates caregivers’ estimates of occurrence (0 = not at all, 1 = not in the past week, 2 = 1-2 times in the past week, 3 = 3-6 times in the past week, 4 = daily or more often). Horizontal lines denote medians, filled dots are outliers. Whiskers show the 10th and 90th percentiles, box bottom and tops are at the 25th and 75th percentiles, respectively.

Twenty-five percent of the caregivers were able to pinpoint specific problem behaviors.

Care recipient task performance.

Two independent observers rated 20% of the video-recorded sessions, sampling each task at least twice. Cohen’s kappa, a measure of interrater agreement, was computed per task (emergency information, temporal orientation, using the telephone, preparing mail, identifying currency, counting out change, balancing a checkbook,

shopping, making change, and retelling a short story) and ranged from 0.80 to 1.0, indicating excellent agreement.

Only half of the individuals with dementia were able to provide the personal information that would be required in case of an emergency (that is, address, phone number, or doctor's name). Two of the care recipients were unable to recall their caregivers' names. Table 6 shows these results (Emergency Information). Tasks 2 through 11 detail the care recipients' DAFS performance. Most individuals with dementia were unable to perform the instrumental activities of daily living contained in the DAFS without help. Likewise, only one individual was able to retell all pertinent details of a short story after a delay. Performances are shown with the author of this study ("Clinician Condition") and the caregiver ("Caregiver Condition").

Table 6

Percentage of Individuals with Independent Performance

Task	% Individuals who Performed Task Independently (n = 12)	
	Clinician Condition	Caregiver Condition
1. Emergency Information		
Name	100	92
Spelling Name	92	83
Caregiver's Name	83	83
Address	50	58

Phone Number	42	42
Doctor's Name	50	50
2. Reading a Clock	42	33
3. Using the Telephone	8	8
4. Preparing Mail	8	0
5. Identifying Currency	58	17
6. Counting out Change	17	17
7. Writing a Check	25	0
8. Balancing a Checkbook	8	17
9. Shopping	0	0
10. Making Change	50	33
11. Eating	58	58
12. Recalling a Short Story	8	0

Except for two tasks (giving an address and balancing a checkbook), the percentage of care recipients who accomplished tasks independently was the same or greater when the clinician assessed functioning than when the caregiver did so.

There was a high correlation between the obtained DRS-2 score and the number of tasks an individual completed independently with the clinician. This correlation was lower for the MMSE (Figure 4).

Figure 4

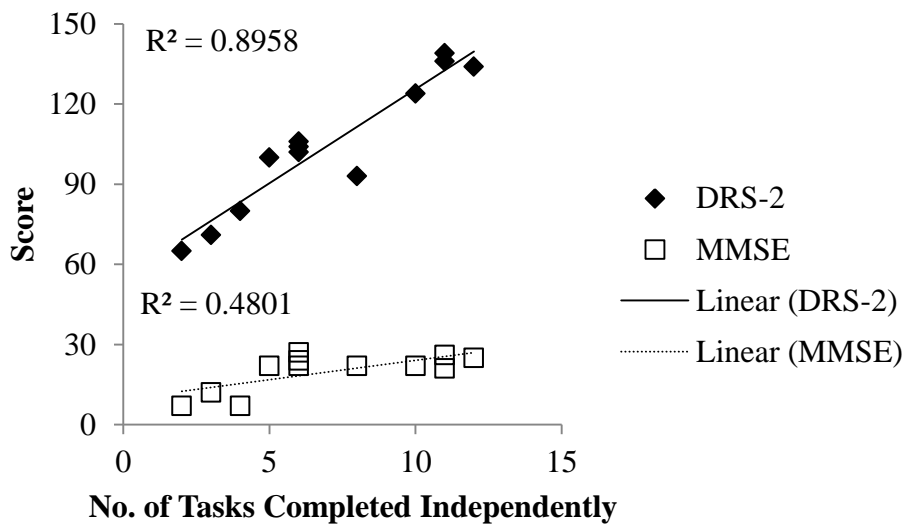
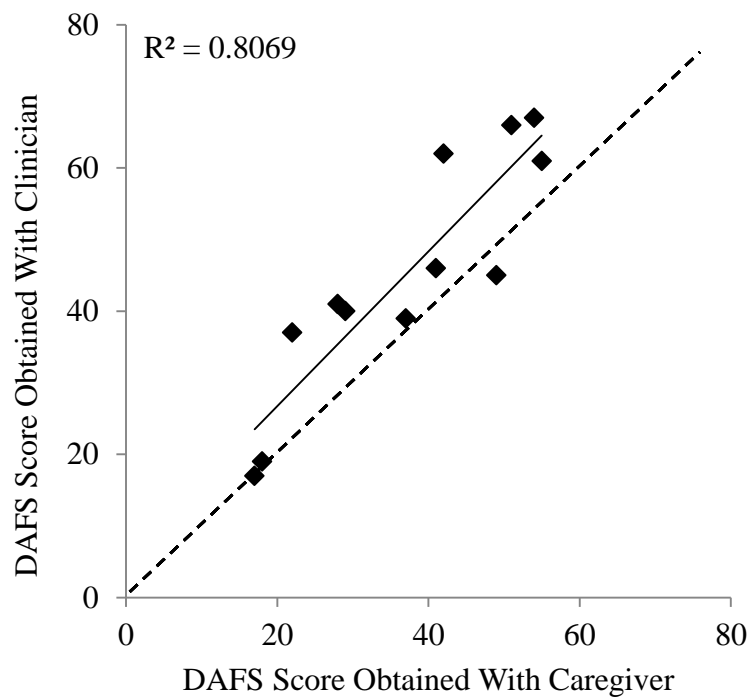
Relationships Between Cognitive Measures and Functioning

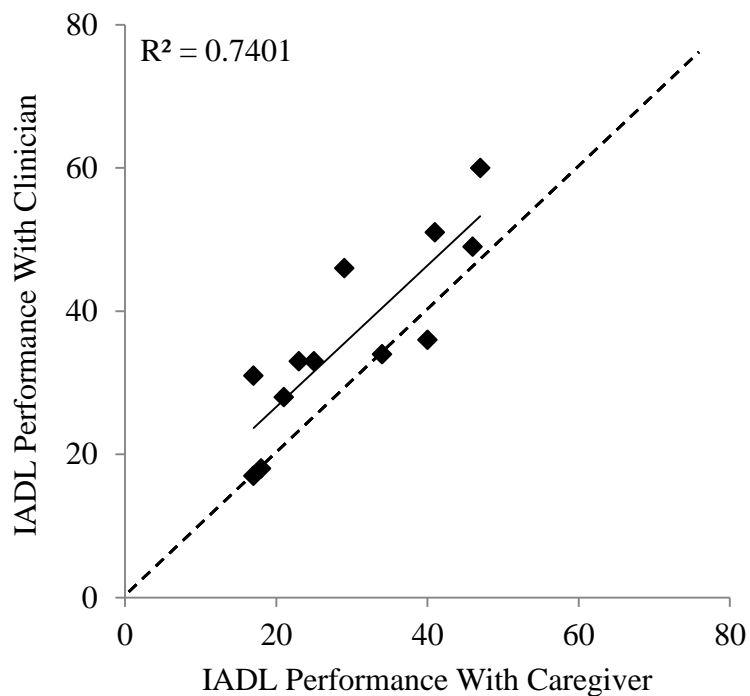
Figure 5 demonstrates a high correlation between the Direct Assessment of Functional Status Scale (DAFS) scores obtained by the care recipient with the clinician and the caregiver as well as higher scores in the clinician condition.

Figure 5

DAFS Scores in the Clinician and Caregiver Conditions

Accordingly, the degree of assistance with which care recipients completed the instrumental activities of daily living contained in the DAFS was observed to be mostly lower in the clinician than in the caregiver condition (Figure 6).

Figure 6

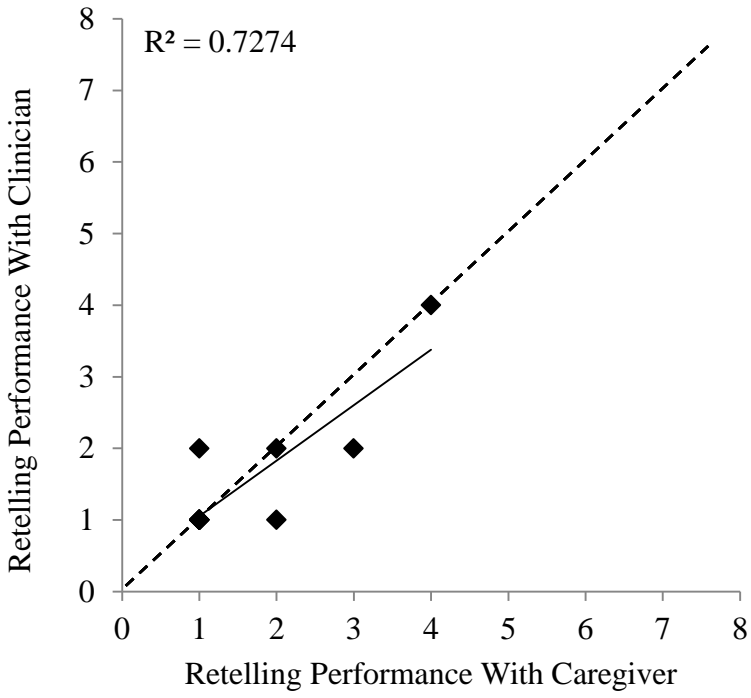
Performance Ratings on IADLs in the Clinician and Caregiver Condition

Note. Higher scores reflect a greater degree of independence during instrumental activities of daily living. Lower scores indicate more reliance on assistance.

The care recipients' tendency to demonstrate less independence with the caregiver than with the clinician did not emerge in the emergency information and the story-retelling tasks (Appendices 2 and 4). Here, performance was similar in both conditions (Figures 7 and 8).

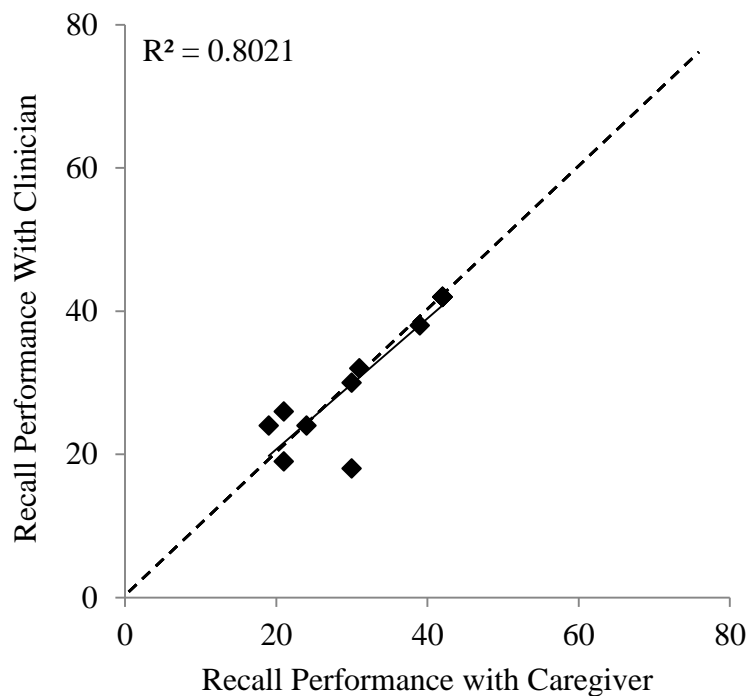
Figure 7

Performance Ratings of Delayed Recall in Clinician and Caregiver Conditions



Note. Higher scores reflect a greater degree of independence while recalling a short story. Lower scores indicate more reliance on assistance. Data point (1,1) consists of six overlapping rating pairs.

Figure 8

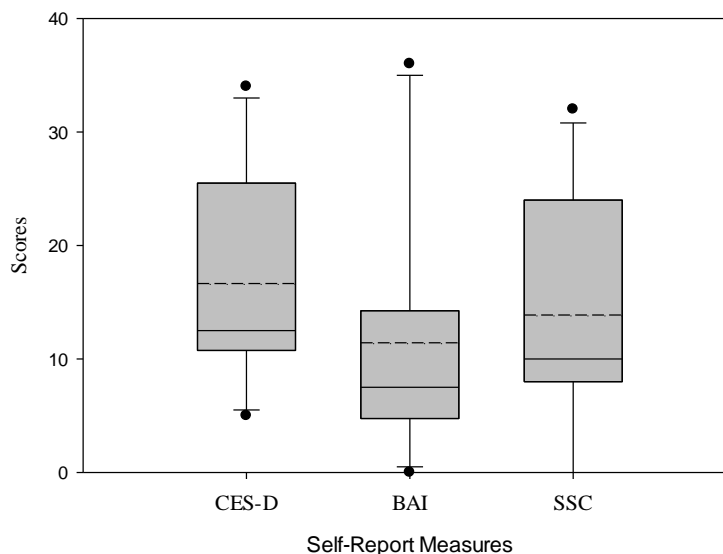
Performance Ratings on Recall of Emergency Information

One data point (30,18) shows the performance of an individual with Parkinson's disease-related dementia who benefited from cueing by the clinician and used a taught strategy in the caregiver condition one week later, leading to more independence.

Caregiver scores on standardized measures.

On average, caregivers reported elevated depression and anxiety scores, and a diminished sense of caregiver competence (Figure 9). On the Short Sense of Competence Questionnaire (SSC), nine out of 15 caregivers attributed the care recipients' affective and behavioral patterns to willfulness ("I feel that (s)he behaves the way (s)he does to have his/her own way"), and four out of 15 caregivers attributed these patterns to intention ("I feel that (s)he behaves this way to annoy me").

Figure 9

Caregivers' Depression, Anxiety, and Competence Scores

Note. Horizontal lines denote medians, dashed lines the means. Filled dots are outliers. Whiskers show the 10th and 90th percentiles, box bottom and tops are at the 25th and 75th percentiles, respectively. The CES-D's suggested cut-off score is 16, the BAI's 8, where higher scores are associated with greater psychological distress. Higher scores on the SSC indicate greater competence.

Caregiver judgment.

When caregivers were asked to predict the degree to which the care recipient required assistance with a task (complete independence, varying degrees of assistance, and total assistance), caregivers' judgments were largely incongruent with actual care recipient performance (n=12). The percentage of predictions that matched the care recipients' performance is listed in Table 7.

Table 7

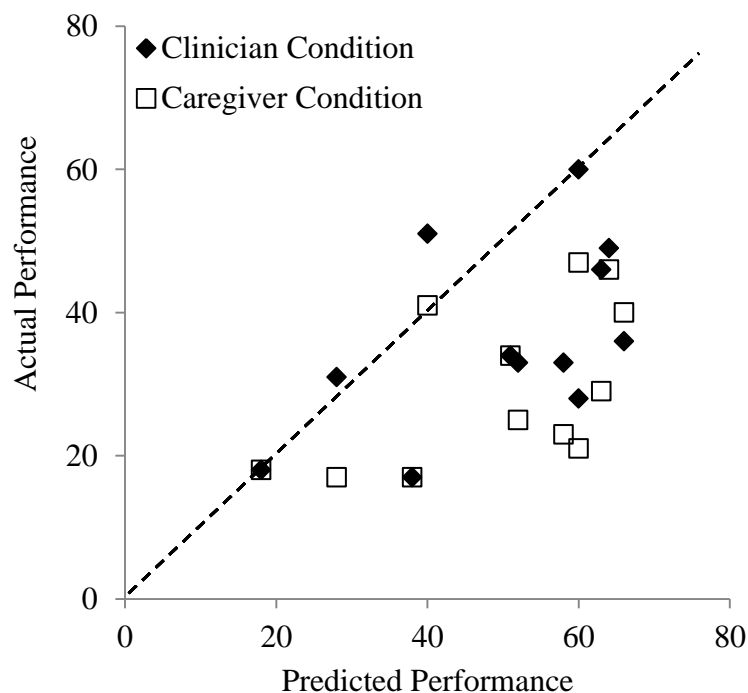
Percentage of Congruent Predictions of No, Some, or Total Assistance Needed

Task	Percentage of Congruent Predictions
<hr/>	
Emergency Information	
Name	100
Spelling Name	75
Caregiver's Name	58
Address	75
Phone Number	33
Doctor's Name	67
Reading a Clock	50
Using the Telephone	25
Preparing Mail	33
Identifying Currency	58
Counting out Change	25
Writing a Check	58
Balancing a Checkbook	42
Shopping	17
Making Change	42
Eating	67
Recalling a Short Story	33

Concerning instrumental activities of daily living (reading a clock, using a phone, preparing a letter for mailing, identifying currency, counting out or making change, signing a check, balancing a checkbook, shopping, eating) caregivers (n=12) tended to overestimate the care recipients' functional independence (Figure 10).

Figure 10

Caregivers' Predictions of Care Recipients' Functional Independence



Note. Filled diamond represent care recipients' performance with the clinician, open squares that with caregivers. If caregivers' predictions aligned with actual performance, all symbols would fall on or close to the dotted reference line. Symbols under the reference line show actual performance lower than prediction.

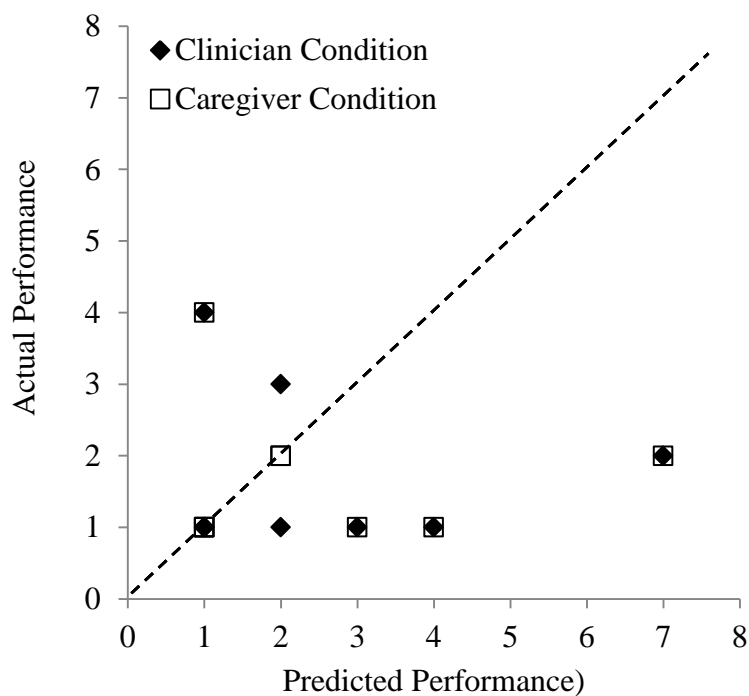
Caregivers' predictions were generally higher than actual performance, with one exception: The diamond at (40, 51) shows one care recipient who significantly

underestimated her spouse's performance with staff; her prediction reflects the care recipient's performance with her, as shown by the open square at (40, 40).

Caregivers (n = 11) also estimated the degree to which a respective care recipient could retell a short story as depicted in Figure 11.

Figure 11

Caregivers' Predictions of Care Recipients' Delayed Recall of a Short Story



Note. Filled diamond represent care recipients' performance with the clinician, open squares that with caregivers. If caregivers' predictions aligned with actual performance, they would all fall on the dotted reference line. Overestimates are found below this line.

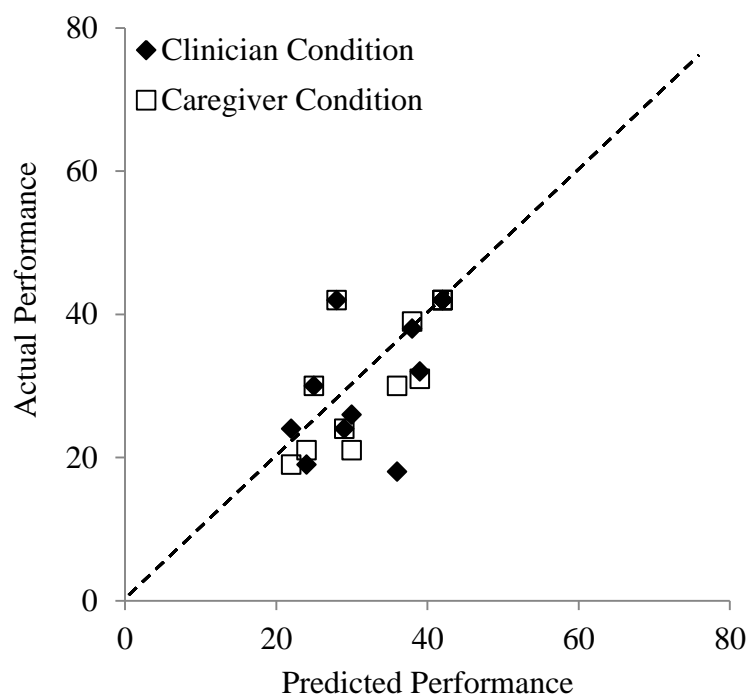
Four caregivers made correct predictions for the care recipients' performance with the clinician and the caregiver. These correct predictions occupy the (1,1) data point on the reference line. Four caregivers' predictions of the care recipients' ability to retell a story after a considerable delay were overestimates. Two exceptions are the diamond at

(1,4), which shows one care recipient who significantly underestimated her spouse's performance with the clinician and the caregiver, and the diamond at (2,3), which depicts an underestimate of performance with the clinician and a correct prediction (2,2) in the caregiver condition.

Caregivers' predictions of the care recipient's ability to provide important emergency information (name, address, telephone number, caregiver's name, doctor) and their relationship to care recipient performance are shown in Figure 12.

Figure 12

Caregivers' Prediction of Care Recipients' Recall of Emergency Information



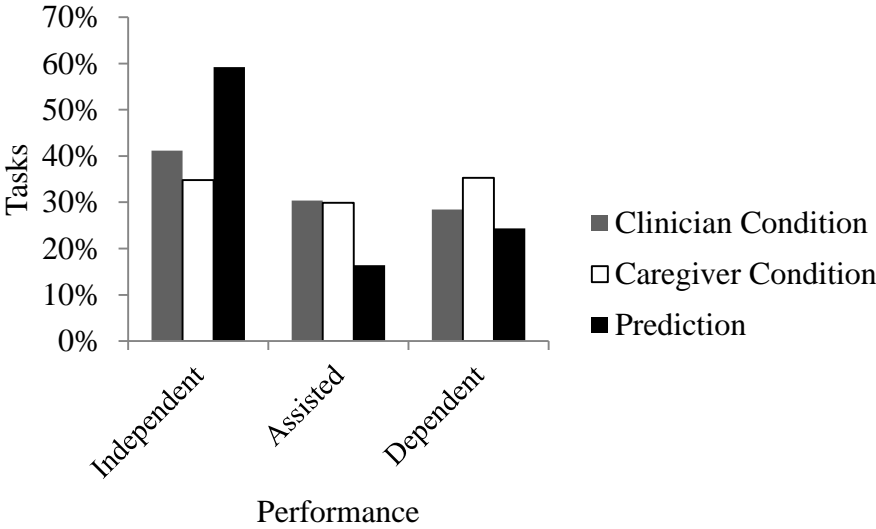
Note. Filled diamond represent care recipients' performance with the clinician, open squares that with caregivers. If caregivers' predictions aligned with actual performance, they would all fall on the dotted reference line. Overestimates are found below this line.

When comparing predictions to care recipient performance with the clinician, five caregivers predicted performance within a range of 0 to 2 points from actual performance, four caregivers within five points of actual performance, two caregivers overestimated performance (difference scores = -7, -18), and one caregiver underestimated her spouse’s ability to give emergency information.

An analysis of the predictions showed that the discrepancies between performance with the caregiver and the clinician, as well as actual performance and predictions were related to independence. Figure 13 illustrates that caregivers predicted independent performance for 59% of all tasks. Individuals with dementia achieved such independence on 41% of the tasks with the clinician and 35% of all tasks with the caregiver. Similarly, caregivers predicted complete dependence on their help on only 24% of the tasks but rendered total assistance on 35% of all tasks (versus 28% in the clinician condition).

Figure 13

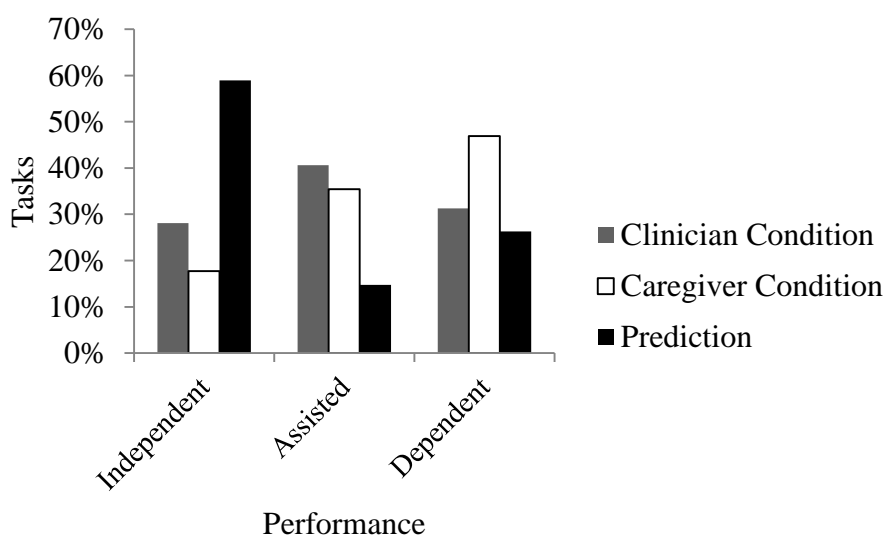
Percentage of Tasks Performed Independently, Assisted, or With Complete Dependence



Separating care recipients' performance on tasks that heavily relied on stepwise progression and sequencing (activities of daily living contained in the DAFS) from those tasks that required punctate recall of bits of information (Assessment of Personal Knowledge and Emergency Information; Story Retelling), caregivers were more accurate in predicting verbal recall. Figures 14 and 15 show the relationship between prediction and actual performances for the instrumental activities of daily living of the DAFS and the verbal recall tasks, respectively.

Figure 14

Percentage of IADLs Performed Independently, Assisted, or With Complete Dependence

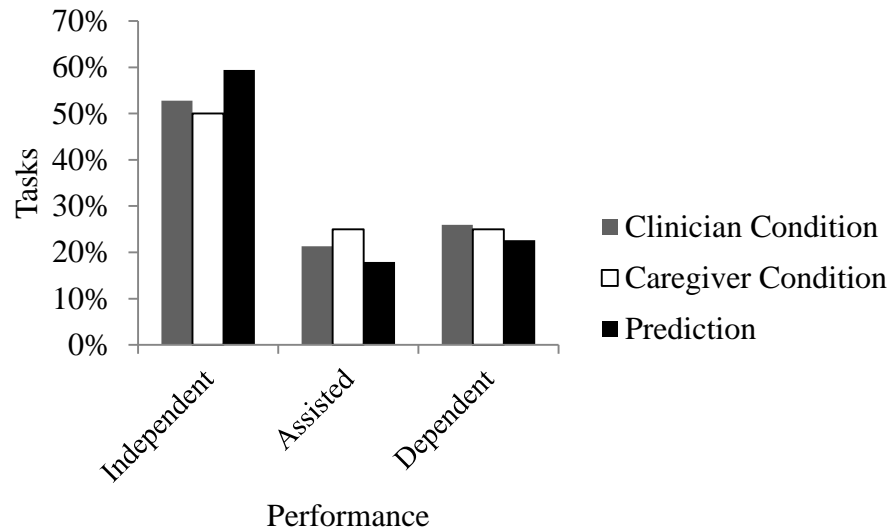


Caregivers predicted independence on 59% of the tasks that involved stepwise progression and sequencing. Care recipients performed with independence on 28% of the tasks in the clinician condition and 18% of the tasks in the caregiver condition.

Predictions were more accurate when tasks were limited to verbal recall (Figure 15).

Figure 15

Percentage of Recall Tasks with Independence, Assistance, or Complete Dependence

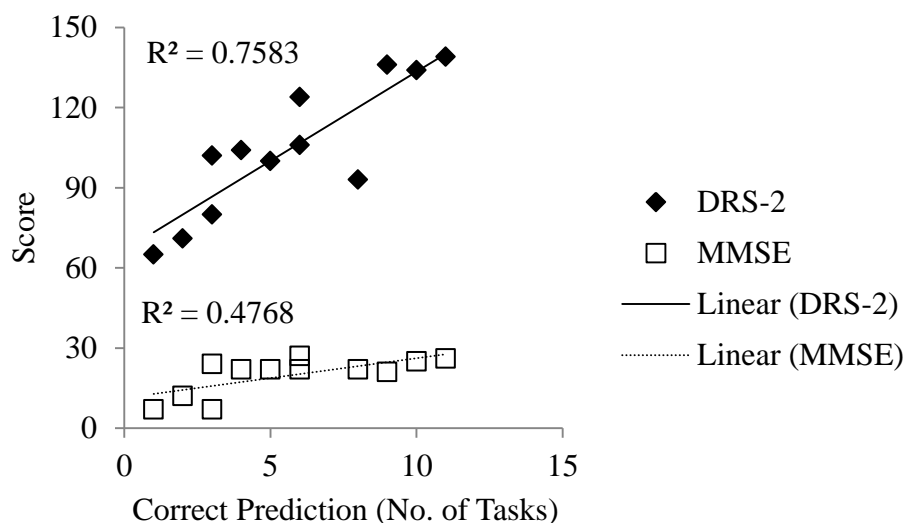


When tasks consisted of recalling bits of information or retelling a story, caregivers predicted independence on 59% of the tasks. Care recipients performed with independence on 53% of the tasks in the clinician condition and 50% of the tasks in the caregiver condition.

While there was a relationship between the type of task and incongruent predictions of performance by the caregiver, there was no correlation between the degree to which caregivers had overestimated the care recipient's performance and caregiver depression, anxiety, or sense of competence. Similarly, care recipient cognitive impairment level, as measured by MMSE or DRS-2, did not predict the degree to which caregivers had overestimated performance. When focusing solely on the prediction of task independence, however, caregiver judgment highly correlated with DRS-2 scores ($n = 12$). The higher the DRS-2 score, the larger the number of task performances correctly predicted as independent (Figure 16).

Figure 16

Relationship Between Correct Prediction of Independent Task Completion and DRS-2



In addition to the correlation between incongruence of prediction and type of task as well as level of cognitive functioning, there was a negative correlation between the number of years that the care recipient and caregiver had known each other and overestimation of abilities ($r^2 = 0.37$), such that briefer relationships corresponded to greater overestimation.

Discussion

While the number of participating dyads was small, Phase 1 of the study replicated and extended findings regarding incongruent care recipient functioning and caregiver predictions. The caregiver participants generally erred on the side of predicting independence. Consequently, the frequency of accurate predictions of independence increased as care recipient functioning increased (Figure 16), an artifact of caregiver bias. Considering degree of assistance needed rather than independence, caregivers had difficulties characterizing how much assistance the person in their care actually needed

or, said differently, how much assistance a caregiver would have to provide in the actual situation. This is in line with the findings of Cotter et al. (2002) that caregivers could not correctly pinpoint the time they spent helping a person with dementia with personal care and basic activities of daily living.

Correspondingly, Phase 1 of this study showed that caregivers' predictions of IADL functioning did not match what caregivers actually did in the hands-on helping situation. While IADL independence was overestimated, caregivers tended to provide more assistance than the care recipient with dementia would have needed. These findings suggest that the situation of community-dwelling adults with dementia resembles that of individuals in nursing homes, where the trend is for staff to provide either no assistance at all or total assistance. Studies, such as those by Engelman and colleagues (Engelman, Altus, Mosier, & Mathews, 2003), have demonstrated that staff training in task analyses and prompting hierarchies decreases care recipients' dependence and improves their engagement in activities of daily living.

Phase 1 of this study also indicates that caregivers – rather than attending to stepwise task performance and potential breakdowns of behavioral chains – are focusing on the care recipients' verbal behavior and may infer abilities based on verbal information obtained. Accordingly, caregiver prediction of verbal recall in the personal knowledge/emergency information or the story-retelling tasks was closer to actual functioning, as shown by the number of points that fell on or around the dashed reference lines of Figures 11 and 12 compared to those on Figure 10.

Caregiver behavior thus may be mainly influenced by verbal interactions with the care recipient and not by observations of what the care recipient does in the actual

situation. As described in the introduction to this paper, individuals with dementia commonly have strong social and interpersonal repertoires and are able to give good reasons for performance failures or for reluctance to engage in a task. The following were common comments of care recipients in this study: “I didn’t pay attention;” “if you had taught me how to use this phone, I’d be able to use it;” “can I dial this number? Sure, but not with this phone;” “I never had to do this.” Phase 1 of this study may be indicative of the circumstance that care recipient verbal behavior, particularly reasoning, prevents caregivers from contacting the actual performance contingencies. This possibility is ever more likely given that caregivers seemed surprised or even startled during the video-recorded interactions (see also Martin-Cook, et al., 2005) and seemed at a loss as to how to provide effective assistance in the form of a prompt hierarchy.

In contrast, when care recipients were asked to recall information, such as personal information or a short story, their performances with the caregiver and the clinician were much more similar. Caregivers were more skilled in providing phonemic or semantic verbal cues than organizing the hands-on task for a person with dementia. Video-records showed that giving hands-on, instrumental tasks, caregivers tended to repeat task instructions (as often as ten times) rather than breaking up the task into manageable components. Repeating or varying the request for information may work when cueing verbal recall or when instructions are not understood, but this strategy does not work when addressing complex tasks with a person with dementia for whom a larger number of instructions might be confusing. Thus, extinction conditions for the caregiver, when the care recipient could not meet the task demand, may have produced caregiver behavior (that is, intensely repeated and elaborated requests) that decreased the

probability of the care recipient's response even more. Alternatively, caregivers' surprise about care recipients' performance failure may have led to a premature take-over of the task to escape from the situation.

While strong relationships were found with types of tasks (sequential and procedural versus verbal recall), Phase 1 of this study could not provide support for the hypotheses that higher depression and anxiety scores, decreased scores on the caregiver sense of competence measure, younger age, and less education correlate with incongruent predictions. Only length of the relationship negatively correlated with the overestimation of care recipient abilities, albeit weakly.

There was also no detectable relationship between reported care recipient behavioral disturbances as measured by the RMBPC and incongruent judgments, possibly due to small sample size and floor effects on the RMBPC. Indeed, about 75% of all caregivers were not able to pinpoint any specific, observable, and frequent problem behaviors other than memory loss. When problematic and potentially dangerous episodes had occurred (for example, one care recipient had raised his hand toward the caregiver's face in a threatening manner; another care recipient had struggled with the caregiver while trying to gain control over a moving vehicle), these episodes had been singular. One caregiver characterized her reactions to the care recipient's general difficulties by saying, "I am simply overwhelmed with grief for the person who used to help me with the grief." All outliers on the RMBPC were produced by one caregiver, who was very distressed about the care recipient's physical decline and repeated hospitalizations. This care recipient completed the intake and the MMSE, but subsequently was too frail to complete the DRS-2 and began hospice services within the next week.

One unanticipated difficulty incurred in this study was that two of the caregivers could not perform the DAFS tasks themselves. Specifically, they had trouble setting a clock and performing financial operations (e.g., subtraction, counting out change). These caregivers were the ones who underestimated the care recipients' performance. While conclusions cannot be drawn as formal testing of caregiver ability was not included in the protocol and the sample size was too small, further studies should determine whether underestimating a care recipients' level of functioning is more likely when the caregivers' cognitive skills have been compromised. Within the contextual model, underestimation could fulfill two concurrent social functions: (1) Masking one's own deficits while (2) asking for help and services. As moderately to severely depressed behaviors can be accompanied by neurocognitive deficits (Clark, Chamberlain, & Sahakian, 2009), Phase 1 of this study would also predict that a long-term diagnosis of clinical depression or other conditions interfering with caregiver functioning (e.g., substance use, chemotherapy) would positively correlate with underestimates of care recipient abilities. Confirmatory evidence is emerging: Given that deficits in executive functioning (that is, organizing, planning, sequencing, self-monitoring) correlate with impaired practical judgment (Rabin et al., 2007), one study examined the relationship between executive dysfunction of otherwise cognitively intact caregivers and their predictions of care recipient abilities. This study found that caregiver impairment correlated with underestimations of care recipient abilities (Dassel & Schmitt, 2008). The subjective impact of care recipient disability on the caregiver has tended to be a better predictor of caregiver distress than a care recipient's actual daily functional abilities (Razani et al., 2007). Again, underestimation would fulfill the social function of expressing heightened

distress over care recipient deficits, due to lack of problem-solving skills, and of requests for help without drawing attention to one's deficits.

The limitations of Phase 1 of the study are its small sample size as well as floor effects on some of the measures (e.g., RMBPC). Regardless of the small sample size, Phase 1 suggests that caregivers tend to overestimate the abilities of the person for whom they care. These history effects, that is, the long-term personal experience with the care recipient as competent, may be all caregivers' default *modus operandi*. As most caregivers complain about care recipients' lack of motivation and apathy in the course of the dementia progression, it is intriguing to speculate that caregivers accept reports of "I don't want to," "I didn't feel like it," as plausible reasons for not engaging in everyday tasks – surmising controllability of initiative and performance as a function of history – and are not privy to the care recipients' instrumental decline unless given the opportunity to directly assess functioning, as in this study. These preliminary findings suggest to clinicians that the taking of unnecessary risks and the rendering of inefficient assistance can only be prevented if caregivers get an opportunity to directly contact the care recipients' decline and learn effective helping strategies.

CHAPTER 4

Study Phase 2

Introduction

Phase 2 of this study addressed the effects of caregiver training within the contextual dementia care model on care recipient problem behavior. Phase 2 also examined correlated dyadic interactions and care recipients' post-intervention performance of tasks that had been presented in Phase 1.

Behavioral principles within an A • B • C framework have previously shown to be effective in the management of affective and behavioral disturbances in dementia (see McCurry & Drossel, 2011). However, any potentially correlated effects on caregiver-care recipient relationships are not known. As relationships commonly deteriorate with the progression of dementia and the erosion of mutual reinforcement (see Table 4, Caregiver Characteristics, for the quality of relationship before dementia diagnosis and currently), not only the management of behavioral disturbances but also the preservation of a workable relationship is a concern. Gottman and colleagues' (Gottman, 1993; Gottman & Levenson, 1992) empirical data suggest, for example, that not the occurrence of interactions with negative valence eventually erodes couples' relationships, but the overall relative ratio of positive to negative interactions. They have pointed out that relationships are sustained and characterized as satisfactory when the overall ratio of positive to negative interactions approaches 5:1.

Applying the contextual perspective described earlier to these findings, it follows that the incremental cognitive decline inevitably produces a very quick erosion of reinforcement of the caregiver's behavior, followed by inadvertent extinction and

punishment of the care recipient's behavior. As the care recipients' growing skills deficits become barriers to the initiation of positive interactions or problem-solving in socially difficult interactions, one might anticipate a decrease in the ratio of positive to negative interactions over time, with positive interactions becoming less frequent (reinforcement erosion) and negative interactions increasing in rate (behavioral effects of extinction and punishment of both the caregiver and the care recipients' behavior). Literature of how marital distress in cognitively intact couples older than 60 years of age affects physical functioning (e.g., Kiecolt-Glaser et al., 1997) may be extended to the caregiving population, in that the deterioration of the long-term relationship may be one of the main contributors to the negative health effects of caregiving, particularly decreased immune system functioning.

It has been long known that individuals with dementia are more likely to be institutionalized upon caregiver reports of behavioral and affective changes, rather than the cognitive decline per se. However, Phase 1 of this study showed that most caregivers had diffuse rather than specific complaints, suggesting that the interpersonally struggling quality of daily interactions as well as insurmountable feelings of loss may grind down the tolerability of the home care. If interventions for behavioral and affective disturbances in dementia target a long-term prevention of institutionalization, they also must shift the interactional patterns to decrease interpersonal strain – particularly deriving from coercive interactions as described earlier – and its associated potentially detrimental health effects (see Kiecolt-Glaser & Newton, 2001, for a review).

Because of attrition from the study (see Figure 2), Phase 2 programmed a contextual intervention for care recipient problem behavior in a multiple baseline design.

This contextual intervention consisted of standard components described in McCurry (2006) and McCurry and Drossel (2011). In addition to monitoring the effects of the intervention on care recipient behavior, a treatment check examined the dyad's positive-to-negative interaction ratio.

Methods

Participants

As shown earlier (Figure 2), five dyads initially expressed interest in Phase 2 of the study, with data from three of these dyads in the final analysis. Care recipients' cognitive (attending, remembering, planning, constructional and conceptual) abilities varied widely: Two care recipients – one male, one female—had DRS-2 scores of 134 and 139 (well above the suggested cut-off of 124), one female care recipient had a DRS-2 score of 106, and the other two care recipients had scores of 65 and 71. Only the latter three care recipients engaged in behaviors that the caregivers had identified as problematic in Phase 1: (1) provoking arguments; (2) refusing to spend time with anyone but the caregiver; and (3) refusing to cease driving.

The other two care recipients did not engage in any behavior the caregivers perceived as difficult to manage. Intermittent inability to remember (e.g., where items were; what one had said at the last community meeting) was the main presenting problem. One of the high-functioning care recipients recently had received a diagnosis of Alzheimer's disease, upon which the couple had moved from their large home into an apartment and made substantial lifestyle changes that had generated difficulties adjusting and some depressed behavior of both the caregiver (who had lost her art studio) and the care recipient (who had built the home). This person also had peripheral neuropathy

related to Agent Orange exposure in Vietnam and was having difficulties holding objects (such as books) for long periods of time. Difficulties with instrumental activities of daily living were physical (e.g., holding a pen) rather than cognitive at this point. The other person had a diagnosis of cardiogenic dementia related to anoxia, secondary to resuscitation after myocardial infarction, and had gradually regained her abilities within the past one-and-a-half years since the event (e.g., she had relearned to walk, speak, reason, and problem-solve). It was not clear whether residual deficits (e.g., some short-term memory deficits requiring repetitions and mnemonic strategies) would completely resolve over time. The caregiver had provided 24/7 supervision during the recovery process; as the care recipient regained her skills, the task for her husband was to provide opportunities for growing autonomy in the face of his fear of another heart attack in the future.

Both care recipients were oriented to person, place, time (using electronic or traditional calendars), purpose, and could complete instrumental activities of daily living with only minor difficulty. They had insight into their respective conditions and deficits, were able to program and use prosthetic devices (e.g., cell phones, computers including tablets), compensated for their deficits with prosthetics and cueing, and could potentially benefit from further rehabilitative/compensatory interventions that also included the prevention of depressed or anxious behavior, commonly seen with chronic illnesses. Services outside the scope of this study were necessary and offered to both dyads.

Caregiver characteristics.

The remaining participants' characteristics are outlined in the following tables (8 and 9).

Table 8

Caregiver Characteristics

Demographic and Relationship Information (n = 3)	
Ages	48, 61, 65
Gender	3 Females
Race (Ethnicity)	3 White (1 Hispanic)
Relationship	1 Child; 2 Spouses
Employment	2 None; 1 Fulltime
Education	1 Some College, 2 Bachelor's
Current Quality of Relationship (Past, Premorbid Quality)	1 Average (Average); 1 Difficult (Good); 1 Good (Good)
Length of Relationship Years	25, 36, 48
Care Duration in Months	7, 24, 24

Caregiver baseline risk assessment.

There were guns in two of the households. One caregiver had a history of cancer. One caregiver drank alcohol more frequently than twice a week. In Phase 1, all three caregivers had been able to complete the activities of daily living from the DAFS. Their answers on the depression measure (CES-D) in Phase 1 suggested no behavioral or affective patterns similar to those individuals with depression diagnoses (cutoff > 15). The Pleasant Event Schedule (see Measures below) confirmed this finding, with overall activity level, potential for pleasurable experiences, and satisfaction derived from activity

engagement within normal limits. One caregiver's answers on an anxiety measure (BAI) indicated mild anxiety (cutoff > 8).

Care recipient characteristics.

Care recipient characteristics are summarized in Table 9.

Table 9

Care Recipient Characteristics

Demographic and Health Information (n = 3)

Ages	79, 82, 87
Gender	1 Female; 2 Male
Race (Ethnicity)	3 White (1 Hispanic)
Education	2 Grade School; 1 Bachelor's
Dementia Type	2 Vascular Dementia; 1 Alzheimer's Disease
Years Since Diagnosis	0.5; 2; 3
MMSE	7; 12; 27
DRS-2	65; 71; 106
Drug Regimen	
For Mood, Affect, Behavior	1 Antidepressant
For Pain	1 OCT
For Cognition	2 Individuals Total: 1 + memantine + dimabon
Referrals for Medication Reconciliation	1
Number of Co-Morbidities	4; 6; 10

Care recipient baseline risk assessment.

Of the three care recipients who participated in this study, one drove on a daily basis. One care recipient spent up to 8 hours per day unsupervised, including unsupervised walks. One care recipient had fallen within the last month but had not visited an emergency room in the same timeframe. One care recipient drank alcohol more often than twice a week.

Procedure

Following Phase 1, Phase 2 consisted of three individually tailored intervention sessions, which integrated the video-records and the DRS-2 results from Phase 1, as well as a post-intervention assessment. Start and end times of the multiple baseline design were not concurrent. Dyads 2 and 3 entered the study 16 and 21 days after intake of Dyad 1. Sessions were scheduled in accordance with the strategies of a non-concurrent multiple baseline design. Each baseline condition was in effect until the following stability criteria were reached: The mean number of responses was calculated in three blocks of three days; consequently, nine was the minimum number of days per baseline condition; conditions were only changed if the means could not be rank-ordered in an ascending or a descending manner. Conditions were also changed if there had been no new high or low scores (Sidman, 1960).

Ninety-minute to two-hour sessions occurred in the families' homes or at the Nevada Caregiver Support Center, dependent on caregiver or care recipient preference. Intervention sessions, all conducted by the author of this study, were randomly audio-recorded (randomness was determined by Office Excel random number generator); the

post-intervention direct assessment of care recipient functioning with the caregiver was video-recorded with a digital camera.

Between sessions, the author of this study was available via a 1-800 number 24/7 per day to assist the caregiver with the implementation of behavioral strategies and to collect reports on care recipient behaviors. Staff of the Nevada Caregiver Support Center provided companionship and activities to the person with dementia when the caregiver was in session.

The three intervention sessions were structured as follows:

Session 1: Individualized dementia education / feedback 1. From Phase 1, two video records (one of the care recipient completing tasks with the author of this study, one with the caregiver) were available for review in addition to the results of the DRS-2. Caregivers shared their reactions to completing the direct assessment of functioning tasks with the person with dementia. The discussion of reactions was tied to an overview of dementia that integrated the care recipient's presentation (e.g., Alzheimer's disease, vascular dementia) and associated strengths and weaknesses. Thus, the author of this study assisted caregivers in making sense of what they had observed during the direct assessment of functioning tasks and linked their observations to more general conclusions and characteristics of dementia. During the session, the care recipients' need for self-protection and the maintenance of dignity and role-identity was stressed. "Exit with dignity" was introduced as an escape/avoidance strategy.

Caregivers had monitored potential target behaviors (Bourgeois, Schulz, Burgio, & Beach, 2002; Teri et al., 2005) in Phase 1 and then settled on the most frequently

occurring behavior for intervention in Phase 2. For homework, caregivers were instructed to begin practicing effective communication (Appendix 5).

The following target behaviors and interventions were selected:

Dyad 1: Arguing (defined as emotional discussion of whether care recipient could return to living independently, could travel independently, had been robbed by her children, or faced limitations and restrictions in the caregiver's home). The tone of the conversation was angry, included yelling and cursing, and usually ended in silence by both parties. Arguments most frequently occurred on weekdays in the car, to and from the adult day center and sometimes on weekends at home. Provoking was defined as non-reciprocation of care recipient remarks such as, "How much is a plane ticket to Southern California," "Your brother stole my house," "May I come out of my room?"

Intervention Dyad 1: A brief social acknowledgment of care recipient utterance (e.g., "We can check prices on the computer once we're home," "Did you still have the big tree in the front yard?," "We're planting flowers."), differential reinforcement of other verbal behavior (changing topics to a preferred and fluent conversational item) or contextual (antecedent) manipulation for response prevention (such as putting on a preferred radio station on rides to and from the adult day center). In terms of A • B • C analyses, baseline data collection showed that provoking comments were frequently related to confusion (e.g., inability to buckle the safety belt or undo it) and temporal and spatial disorientation. The goal was for the caregiver to understand the comments as avoidance or escape behaviors ("exit with dignity").

Dyad 2: Spending time alone (defined as refusing companionship or respite during caregiver absences, leaving the house alone, or any time care recipient would

have to manage without in-home or close-by supervision in case of an emergency).

Respite hours were third-party supervision hours arranged by the caregiver. Arguing was defined as care recipient anger at the caregiver, which included yelling at her, pointing his finger into her face, making threatening gestures (e.g., raising his hand as if to hit her in the face), and the consequence was usually escape from third-party contact.

Arguments were a rare, albeit great self-reported stressor in the caregiver's life.

Intervention Dyad 2: Caregiver was to refrain from explaining, convincing, or reasoning with care recipient (generating potential social punishment contingencies). She was instructed not to dispute care recipient's narrative of independence and autonomy while hiring a third-party caregiver trained in dementia care. This person was introduced as somebody who "cleaned the house and needed to be supervised" and "needed to learn about dogs" (the care recipient had two). Thus, the caregiver manipulated the context of third-party presence and provided antecedents for two historically strong care recipient repertoires (supervising and teaching) that were incompatible with being alone. In terms of A • B • C analyses, data collection showed that escape from third-party respite was related to overstimulation (too much talking and social demand). The goal was for the caregiver to understand the care recipient's refusal as avoidance or escape behaviors ("exit with dignity").

Dyad 3: Daily driving to and from a local coffee shop (approximately 3 miles) to meet with acquaintances. Arguing was defined as care recipient anger at the caregiver. It included yelling and cursing at the caregiver for restricting his movement, initiating a role reversal ("becoming the boss") and disrespecting the care recipient.

Intervention Dyad 3: Caregiver was to refrain from explaining, convincing, or reasoning with care recipient (generating potential social punishment contingencies). She was instructed not to dispute care recipient's narrative of independence and autonomy while arranging for care recipient's friend to pick him up in the morning ("I was in the neighborhood, would you like to ride with me, now that I'm already here?"), thus maintaining access to care recipient's social reinforcers (meeting people at the local coffee shop). This intervention could also be conceptualized as a contextual (antecedent) manipulation with response prevention.

Sessions 2 and 3: Individualized dementia education / feedback 2. Video-records of care recipient-caregiver or clinician-care recipient interactions were available to illustrate points. These intervention sessions reviewed homework, the effectiveness of the behavioral strategies to reduce problem behaviors, and related barriers and difficulties. In addition to P.O.L.I.T.E. (McCurry, 2006), exit with dignity, and compassionate misinformation, the A • B • C framework to address problems behaviors was introduced (McCurry & Drossel, 2011). The same framework also was used to emphasize pleasant events and engagement in self-care (Lewinsohn, Muñoz, Youngren, & Zeiss, 1992).

Session 4: Post-assessments (direct assessment of functioning tasks with the caregiver; paper-and-pencil questionnaires), debriefing, and referral to Nevada Caregiver Support Center or other community agencies for continuity of care.

Measures

Direct assessment of intervention effects on caregiver and care recipient.

The contextual model of dementia care relies on caregivers to conduct an assessment and implement the intervention on care recipient target behaviors. Caregivers recorded the frequency of target behaviors on a printed weekly outlook calendar sheet provided to them. They also reported the frequency during phone calls with the study author and in weekly sessions with her.

In addition to monitoring effects on target behaviors, the direct assessment of functioning with the caregiver of Phase 1 was repeated (Appendices 2 through 4). This interaction was video-recorded and coded using the procedure of Phase 1 (Appendix 1). The caregiver-care recipient interactional patterns were also coded to derive a positive-to-negative interaction ratio (Appendix 6).

Indirect assessment of care recipient outcomes.

1) Revised Memory and Behavior Problems Checklist (RMBPC, Teri et al., 1992), described in Phase 1.

2) A • B • C checklist (Bourgeois, Schulz, Burgio, & Beach, 2002; Teri, et al., 2005). Behaviors identified and monitored in Phase 1 were intervened upon in Phase 2.

Indirect assessment of caregiver outcomes.

1) Center for Epidemiologic Studies Depression Scale (Radloff, 1977), described in Phase 1.

2) Beck Anxiety Inventory (Beck et al., 1988), described in Phase 1.

3) Short Sense of Competence Questionnaire (SSC; Vernooij-Dassen et al., 1999), described in Phase 1.

4) Miller Social Intimacy Scale (MSIS; Miller & Lefcourt, 1982). The MSIS is a 17-item scale designed to assess social intimacy regardless of relationship type. Its test-retest reliability in a college student sample was $r = .84$ over a one-month interval.

5) Boundary Ambiguity Scale (BAS; Boss, Caron, Horbal, & Mortimer, 1990). Five boundary ambiguity scales were designed to assess the degree of continuity within the family unit and to determine whether a person is perceived as being outside the family unit. Caregivers answer on a five-point Likert scale (1=strongly disagree; 2=disagree; 3=agree; 4=strongly agree; and 5=I am not sure). Scores of 1 and 2 show less ambiguity about the role of the person with dementia in the household as well as one's own role as a caregiver. Higher scores indicate psychological distress, not being sure of one's own and the care recipient's role in the household, and feeling unable to reconcile self-care and caregiving duties. Thus, higher scores have correlated with higher caregiver depression scores and a decreased sense of competence. Reliability and validity data are available for a number of Boundary Ambiguity Scales but not for the dementia-specific one (Fischer & Corcoran, 2007).

5) Pleasant Events Schedule (PES; Lewinsohn, et al., 1992). The PES is a 320-item scale assessing behavioral activity and pleasantness within the last 30 days. While completion of the PES was labor-intensive, it provided a teaching aid for the intervention, illustrating activity restriction of the caregiver, one of the main sources of caregiver depression.

Data analysis and coding.

The small sample size prohibited the use of inferential statistics and, as in Phase 1, data were organized via descriptive statistics and graphical analysis. Coding occurred as described earlier (see General Methods).

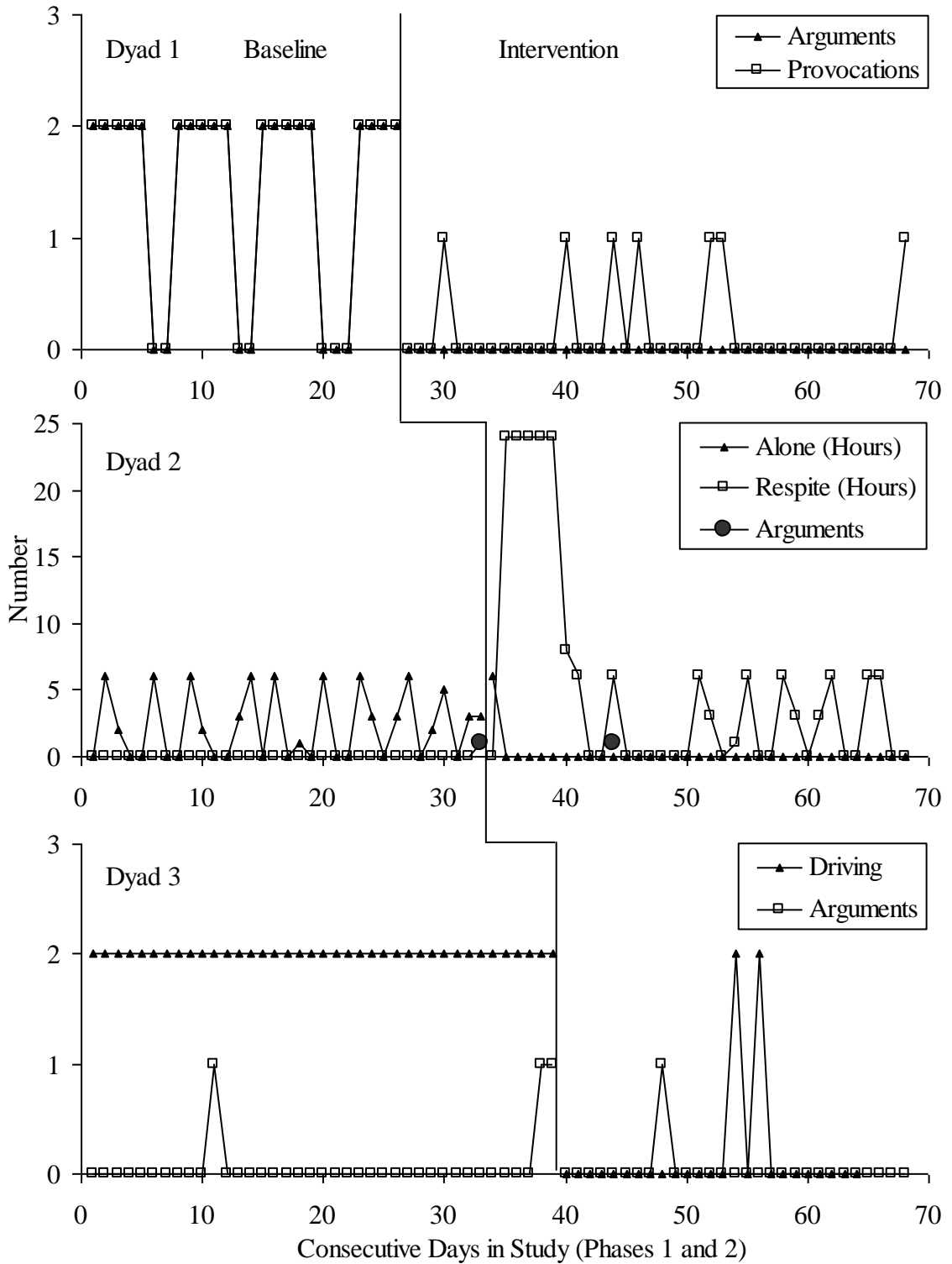
Results

Effects on target behaviors.

Target behaviors decreased to zero within one or two days of the first intervention session. Figure 17 shows the behavioral effects of the intervention within the multiple baseline design.

Figure 17

Multiple Baseline Design Across Three Caregiver-Care Recipient Dyads

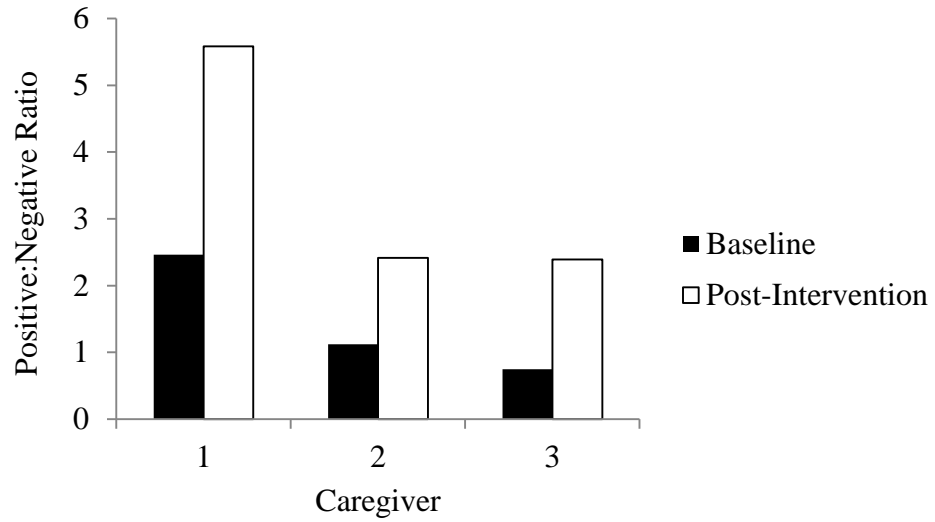


Vertical lines within each graph denote the change from baseline to intervention conditions and are placed between the day of the first intervention session and the next day. For Dyad 1, arguments ceased but provocations continued to occur intermittently. The care recipient of Dyad 2 was alone for six hours on the day following the first intervention session. Then he stayed at his daughter's house for five days until a professional caregiver was available at home. The care recipient of Dyad 3 stopped driving immediately after the session and never asked to drive again. He drove again on days 54 and 56.

Direct assessment of caregiver-care recipient interactions.

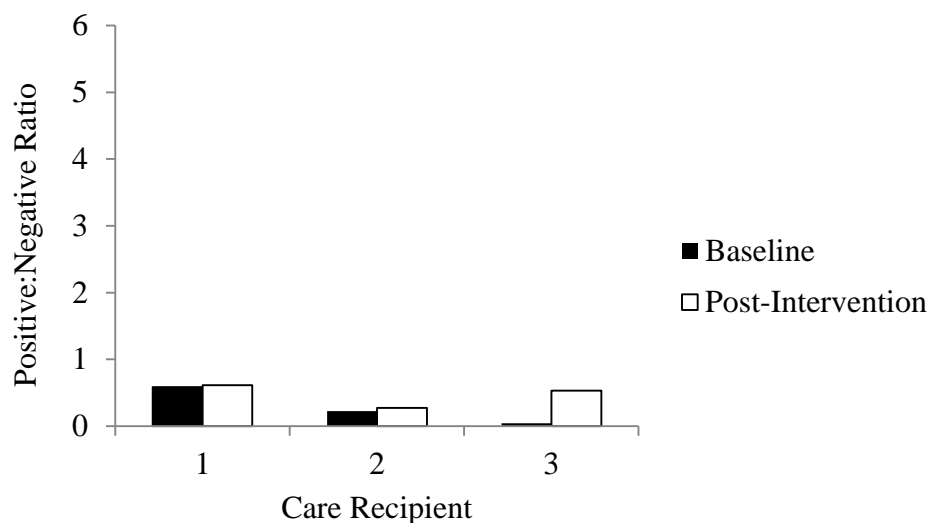
Codes were positive, negative, and neutral interactions (simple counts per person). Two independent raters, blinded to the conditions, rated 28% of all turns (see Appendix 6). For caregiver behavioral ratings, point-by-point agreement was moderate for the three codes (positive, negative, and neutral) ($\kappa = 0.59$) and substantially higher ($\kappa = 0.81$) when only two codes, positive and negative interactions (70% of the coded turns), were considered. Point-by-point agreement for care recipient behaviors was high ($\kappa = 0.96$). At baseline, the positive-to-negative interaction ratio was well below 5 (2.46, 1.12, and 0.75 for caregivers of Dyads 1, 2, and 3, respectively). There was an increase in the ratio of positive to negative interactions for both caregivers and care recipients after the intervention. In general, negative interactions decreased by half. Positive interactions increased for Dyads 2 and 3 and stayed about the same for Dyad 1. Figure 18 shows these changes in caregiver positive-to-negative interactions that occurred while caregivers engaged the care recipients in structured tasks (recall of emergency information, activities of daily living from the DAFS, and story-retelling).

Figure 18

Caregiver Behavior and Ratio of Positive to Negative Interactions

Corresponding data for the care recipients are illustrated in Figure 19, with care recipients initiating very few positive interactions (positive-to-negative interaction ratios of 0.58, 0.22, and 0.04).

Figure 19

Care Recipient Behavior and Ratio of Positive to Negative Interactions

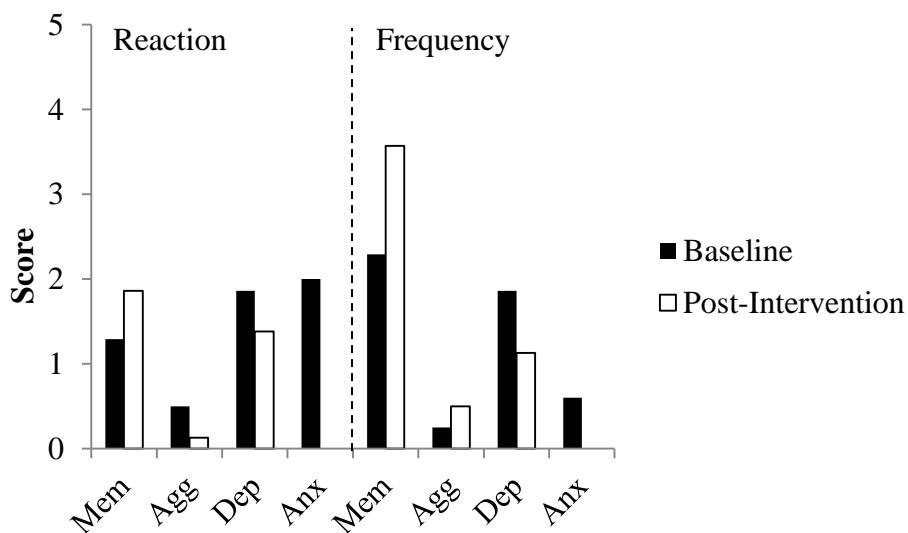
The ratio of positive-to-negative interactions increased slightly. There were no discernible changes in care recipient mean length utterance (words per turn), speech rate (words per minute), or rate with which turns were taken (turns per minute).

Indirect assessment of care recipient functioning.

Regarding care recipients' affective or behavioral disturbances, results were inconsistent. Changes of RMBPC scores are shown separately for each dyad (Figures 20 through 22). Two of the caregivers (Dyads 1 and 2) reported lower reaction as well as frequency scores on the RMBPC (Figures 20 and 21).

Figure 20

Dyad 1: Revised Memory and Behavior Checklist at Baseline and Post-Intervention



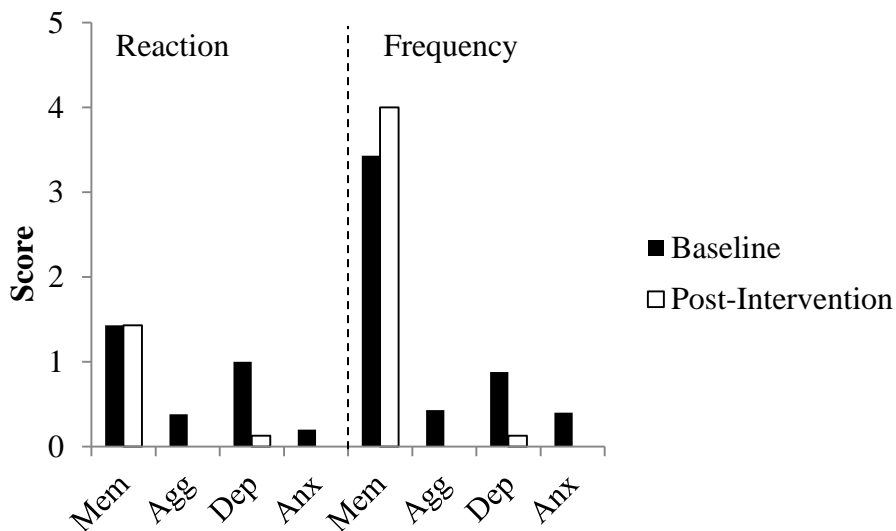
Note. Mem=Memory, Agg=Aggression, Dep=Depression, Anx=Anxiety Subscales.

The caregiver of Dyad 1 reported being more bothered by the care recipient's memory difficulties and less by aggressive, depressed, or anxious behaviors. She also reported that memory problems and aggressive behavior increased while depression and anxiety decreased (Figure 20).

The caregiver of Dyad 2 reported still being bothered by the care recipient's memory problems, but having no or decreased reactions to aggressive, depressed, or anxious behaviors. She reported memory problems with greater frequency than at baseline (Figure 21).

Figure 21

Dyad 2: Revised Memory and Behavior Checklist at Baseline and Post-Intervention

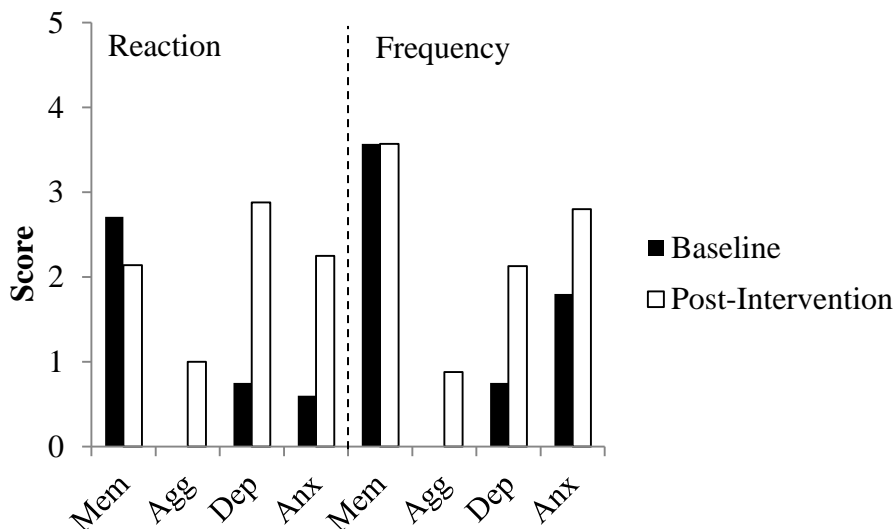


Note. Mem=Memory, Agg=Aggression, Dep=Depression, Anx=Anxiety Subscales.

In contrast to the preceding two dyads, the caregiver of Dyad 3 endorsed more frequent affective and behavioral disturbances (but not memory problems) as well as increased reactions to them (Figure 22).

Figure 22

Dyad 3: Revised Memory and Behavior Checklist at Baseline and Post-Intervention



Note. Mem=Memory, Agg=Aggression, Dep=Depression, Anx=Anxiety Subscales.

Indirect assessment of caregiver functioning.

Changes in paper-and-pencil measures are listed in Table 10 in the order of the Dyads (1, 2, 3). Two caregivers reported lower depression scores. All three caregivers had slightly higher anxiety scores post-intervention than at baseline. Two caregivers disagreed with more of the items listed on the Short Sense of Competence Questionnaire (SSC), indicating increased advocacy for the person with dementia and fewer attributions of problematic behavior to intention. For one caregiver, scores on the SSC decreased (she did not endorse, “I wish that the care recipient and I had a better relationship”) post-intervention. Relating to social intimacy, reported scores on the MSIS decreased for two of the caregivers (Dyads 1 and 2) and stayed the same for one (Dyad 3). Two caregivers (Dyads 2 and 3) reported decreased scores on the BAS, measuring psychological distress

due to ambivalence about the degree to which the care recipient is part of the family system; for one caregiver (Dyad 1), the score was unchanged.

Table 10

Paper-and-Pencil Measures

Standardized Measure	Post-Intervention Score (Baseline)
CES-D	17 (11); 8 (14); 8 (10)
BAI	6 (4); 8 (5); 17 (14)
SSC	8 (0); 12 (8); 20 (30)
MSIS	4 (5); 3 (5); 7 (7)
BAS	3 (3); 2 (3); 2 (3)

Note. CES-D = Center for Epidemiological Studies Depression Scale (range 0-60, cutoff > 15); BAI = Beck Anxiety Inventory (range 0-63, cutoff>7); SSC = Short Sense of Competence Questionnaire (range 0-35, with higher scores indicating greater competence); MSIS = Miller Social Intimacy Scale (range 1-10, with higher scores indicating more intimacy); BAS = Boundary Ambiguity Scale (range 1-5, with higher scores indicative of more psychological distress due to shifts in roles).

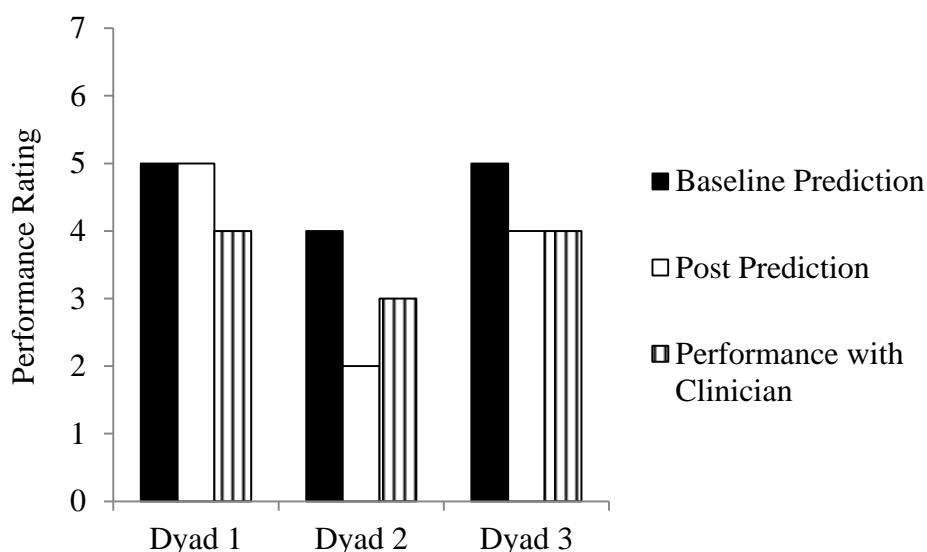
Caregiver judgment and care recipient performance.

Caregivers' ratings of care recipient independence or need for assistance shifted from baseline to post-intervention. At baseline, caregivers overestimated the care recipient's functioning. When caregivers were asked during the final debriefing session to indicate the care recipients' functioning on the Performance Rating Scale, the caregivers' answers reflected a lowering of their expectations toward matching the care recipients' actual performance. Figures 23 through 25 show this trend for each of the

direct assessment of functioning tasks (recall of emergency information, activities of daily living from the DAFS, and story retelling).

Figure 23

Predictions and Actual Recall of Emergency Information



Note. The Performance Rating Scale has seven rankings: 7 = independence; 6 = modified independence; 5 = supervision; 4 = minimum assistance; 3 = moderate assistance; 2 = maximum assistance; and 1 = total assistance. Compare solidly colored bars (predictions) with striped bar (performance with clinician).

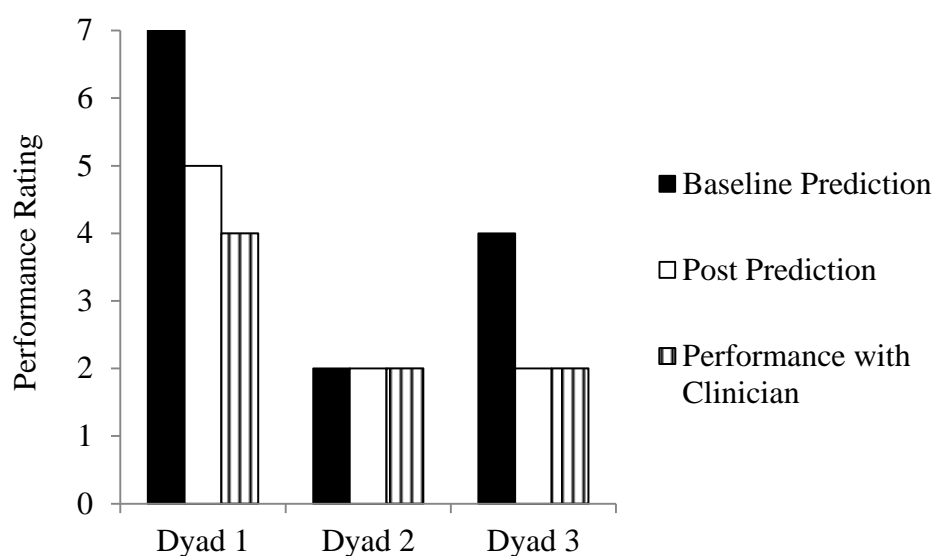
Figure 23 illustrates that the caregiver of Dyad 1 overestimated her mother’s recall of emergency information at baseline (“Baseline Prediction”) and after the intervention (“Post Intervention”). The care recipient needed minimum assistance while recalling the information (i.e., she answered between 75 and 100% of the questions spontaneously and without caregiver taking over the task), while her daughter predicted that the care recipient could come up with all information if given enough time to think and semantic cues. The caregiver of Dyad 2 overestimated the care recipient’s functioning at baseline (“Baseline Prediction”) to be at minimum assistance and underestimated the care

recipient's abilities with a prediction of maximum assistance later. The caregiver of Dyad 3 predicted correctly after the intervention.

Figure 24 shows that, in addition to lowering expectations for the recall of emergency information, caregivers also lowered their expectations of care recipients' abilities concerning the IADLs contained in the Direct Assessment of Functioning Scale.

Figure 24

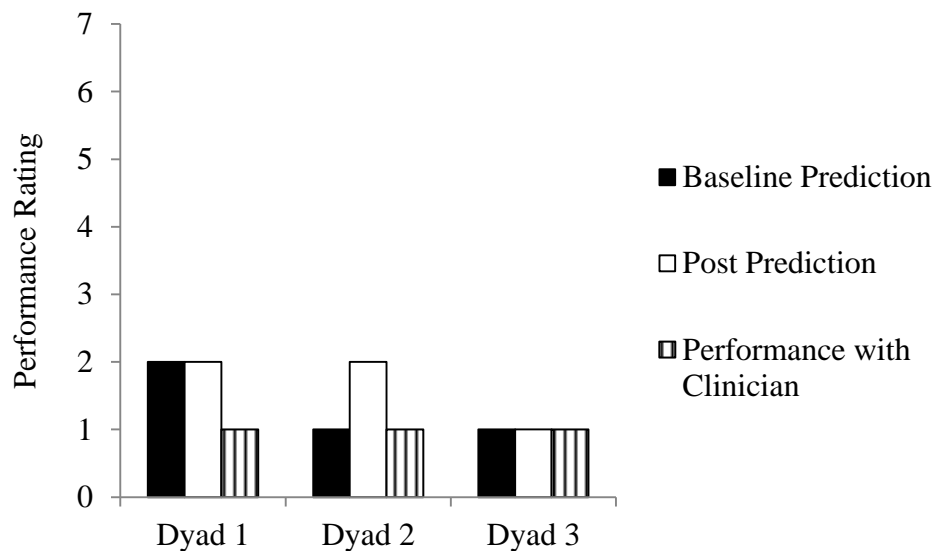
Predictions and Actual Performance of IADLs



Note. The Performance Rating Scale has seven rankings: 7 = independence; 6 = modified independence; 5 = supervision; 4 = minimum assistance; 3 = moderate assistance; 2 = maximum assistance; and 1 = total assistance.

After the intervention ("Post Prediction"), two out of three caregivers' predictions matched the respective care recipient's actual performance with the clinician. Figure 25 shows predictions and actual ability to retell a short story.

Figure 25

Predictions and Actual Ability to Retell a Short Story

Note. The Performance Rating Scale has seven rankings: 7 = independence; 6 = modified independence; 5 = supervision; 4 = minimum assistance; 3 = moderate assistance; 2 = maximum assistance; and 1 = total assistance.

All care recipients only retold between 0 and 25% of a short story after a delay (“total assistance”). The caregivers of Dyads 1 and 2 overestimated the care recipients’ abilities (the former at baseline and after the intervention, the latter only after the intervention). The caregiver of Dyad 3 predicted the care recipient’s abilities correctly at baseline and after the intervention.

As indicated by the results of Phase 1 of this study, caregivers did not necessarily emit helping behavior that corresponded to their predictions. Table 11 shows how caregivers adjusted their predictions from baseline to post-intervention. Predictions that matched caregivers’ experiences are marked with an asterisk.

Table 11

Predictions and Performance at Baseline and Post-Intervention

Dyad	Task	Caregiver Prediction		Care Recipient Performance with Caregiver	
		Baseline	Post	Baseline	Post
1	Recall	5	5	1	2
	DAFS	7	5	3	3
	Retelling	2*	2	2	3
2	Recall	4	2	1	1
	DAFS	2	2	1	1
	Retelling	1*	2	1	1
3	Recall	5	4	1	1
	DAFS	4	2	1	1
	Retelling	1*	1*	1	1

Note. Recall = Recall of Emergency Information; DAFS = Direct Assessment of Functioning Scale; Retelling = Retelling a Short Story after a delay; the Performance Rating Scale has seven rankings: 7 = independence; 6 = modified independence; 5 = supervision; 4 = minimum assistance; 3 = moderate assistance; 2 = maximum assistance; and 1 = total assistance; * = prediction matches performance.

Thus, for these particular caregivers, most predictions – other than those concerning story retelling – remained incongruent with their own experience.

Discussion

Phase 2 of this study demonstrates that the common affective and behavioral changes in dementia, usually related to refusals to participate in activities, accept respite, stop driving, or to complaints and utterances perceived as provocative, can be effectively managed with brief individually tailored, non-pharmacological interventions. The multiple baseline design generated reasonable certainty that observed changes in the frequency of problematic behaviors could be attributed to Session 1 of the intervention.

It is important to note, however, that after Phase 1 of this study, involving the direct assessment of care recipient functioning, caregivers appeared for the first intervention session prepared for change. In particular, the caregivers of Dyads 2 and 3, who both had attempted to address safety issues unsuccessfully in the past, came to session with ideas on who could provide supervision (Dyad 2) and who could take over driving (Dyad 3). They needed assistance to translate their ideas into solutions that would be accepted by the care recipient (e.g., for Dyad 2 family support was solicited immediately before transitioning to strangers in the home; for Dyad 3, care was taken not to inform the care recipient of the caregiver's plans to keep him from driving). Thus, Phase 1 may have served as an establishing operation for caregiver behavior, building motivation and reducing hesitation to try out new techniques. Caregivers of Dyads 2 and 3 were ready and eager to receive a plan for intervention, in the service of care recipient safety.

A similar change occurred for Dyad 1: Mother and daughter had a history of conflict spanning decades; topographically, the ongoing and almost daily arguments did not look much different from those of a lifetime, although they fulfilled different

functions for the care recipient, such as escape from task demand. During the direct assessment of functioning in Phase 1, the care recipient also made nonfactual remarks with the putative function of escaping from the situation (for example, when the caregiver asked to whom the care recipient wanted to address a letter, the care recipient answered, “my boyfriend”; when the author of the study left the room, the care recipient asked, “Does she leave us alone so we can fight?”). In this case also, the caregiver’s contacting the care recipient’s deficits may have served as a significant motivator to address and forgo long-standing interactional patterns consisting of the proverbial “swallowing of the bait” and starting to engage in an argument with mother.

The identification of changes in dyadic or individual care recipient and caregiver functioning is much more complex. Phase 2 of this study is the first of its kind suggesting that the positive-to-negative ratio of dyadic interactions can improve. Caregiver-recipient dyads in task demand situations present similarly to highly distressed couples with the ratio of positive-to-negative interactions as low as 0.75 (3 positive interactions to 4 negative ones) and far from the five-to-one ratio recommended for sustaining relationships (Gottman, 1993; Gottman & Levenson, 1992). The lack of experimental control, however, prohibits a definite attribution of this improvement to the intervention of Phase 2.

Similarly, changes in self-reported caregiver emotional functioning (as measured by the CES-D and BAI), competence, dyadic intimacy and boundary ambiguity cannot be attributed to the intervention alone. In addition to the effects of Phase 1 of this study, further confounding events (such as the caregiver of Dyad 1 separating from her husband and moving to a new location with her teenage daughter and the care recipient) affected

the self-report scores. The same can be said for the caregivers' reactions to care recipient problem behaviors and the reports of frequency, especially as both Phase 1 and Phase 2 of this study forced the participating caregivers to pay attention to their parent's or spouses' deficits and interpret behavior in the context of cognitive decline. It would be plausible for the progressive realization of deficits to be accompanied by at least temporarily increased anxious behavior, decreased ambiguity about roles, increased advocacy for the person with dementia, and lower social intimacy scores as one relies less on the person with dementia as an emotional and instrumental resource. These patterns did not clearly emerge here.

Caregivers generally decreased the expectations of independent functioning they had held at baseline. This finding is of social significance, as accurate judgment of impairment may prevent caregivers from exposing care recipients to dangerous situations (such as driving or taking walks alone). However, Phase 2 of this study suggests that knowing about the significance of impairment does not necessarily lead to knowing how to engage the care recipient more effectively in tasks. Only one caregiver provided more effective assistance (Dyad 1) post-intervention, and only in the verbal tasks (recall of emergency information and retelling a story). The other two caregivers, whose spouses had ceased to benefit from verbal instructions as well as semantic or phonemic cues and needed modeling and physical prompting, continued to give total assistance and thereby limited care recipients' opportunity to engage in the tasks.

Given that any intervention in dementia care is implemented against the backdrop of decades of history, it is not surprising that the rules of conduct (POLITE, exit with dignity, compassionate information) and problem-solving techniques (A • B • C analyses

of problematic behaviors) were not implemented consistently or in novel situations. The caregiver of Dyad 3, for example, called the telephone helpline during an argument (see Figure 17, panel 3, intervention condition, symbol for arguments on Day 48). As the care recipient was not driving anymore, she had suggested to him to sell his automobile, a proposal that spurred confusion (“I need my car”) and defensiveness (“You’re trying to rule my life”). This caregiver also did not expect that on two days during which she was ill and remained in bed in the morning (see Figure 17, panel 3, intervention condition, symbols for driving on Days 54 and 56), the care recipient would revert to his usual routine, grab his car keys, and drive to the coffee shop. The caregiver was not able to conceptualize that “waiting for the friend to show up” was a temporally extended repertoire outside of the care recipient’s abilities, and that prior to becoming ill she had inadvertently but effectively distracted the care recipient each morning until the friend picked him up.

Similarly illustrating this lack of generalization, the caregiver of Dyad 2 left the care recipient with the new third-party respite provider and was called home in an emergency after one of the care recipient’s dogs had been bitten by the other dog. The caregiver had not anticipated that the care recipient did not have the skills to let the provider know that the dogs needed to be separated during feeding times. The caregiver addressed the incident with the care recipient, which resulted in care recipient refusal of third-party presence and an argument (see Figure 17, panel 2, intervention condition, symbol for argument on Day 44).

Phase 2 of this study suggests that, while non-pharmacological interventions are effective and the positive-to-negative ratio during task demand situations can be

increased, the effects of caregiver interventions are domain-specific and do not easily generalize without multiple exemplar training across situations, behaviors, and levels of deficits. In other words, caregiving for an individual with dementia is a very complex repertoire that people do not acquire without specialized training of a long-term nature, taking into account that progressive decline brings about novel challenges.

CHAPTER 5

General Discussion

Important implications arise from the current study: First, the attrition and mortality rates that were observed in this study suggest that most caregivers who seek services have failed to consider undetected illnesses underlying the affective and behavioral changes in dementia. Thirty-seven percent of the participating dyads (and 28% of all dyads considering participation) incurred undetected medical illnesses and medication effects. Some presentations were sufficiently severe to warrant hospice services. This number corresponds to the percentage detected by Gitlin and colleagues (2010) in their recent study of undetected illness within a population of community-dwelling individuals with dementia.

While some referrals to immediate medical care were based upon caregiver report of the abrupt nature of the affective, behavioral, or cognitive changes, the video-recorded assessments in Phases 1 and 2 were also useful for the detection of adverse events. In Phase 1, one care recipient, for example, complained about a “hurting arm,” and groaned as he got up from the table. While the caregiver noticed the pain and briefly inquired about it, she dismissed it when the care recipient did not elaborate on his physiological status. Upon watching the video-recorded interaction, the author of this study referred the care recipient for medical examination, which revealed gastric bleeding requiring a blood transfusion. Similarly, in Phase 2, the care recipient of Dyad 1 complained in the last video-recorded caregiver-care recipient interaction about a rumbling stomach that would not settle. A referral for medical examination resulted in a diagnosis of bacteriuria, which otherwise likely would have remained untreated since urinary tract

infections occurring in verbally impaired care recipients are commonly detected only after intense pain produces behavioral disturbances. These episodes suggest that care recipients often indirectly mention pain but are not able to properly locate it or to stay on the conversation long enough to give the social cues necessary to communicate intense discomfort. In the current study, caregivers were astounded to review the video-record and see how cues had been presented, but not with sufficient intensity, frequency, or duration to result in follow-up. Given the large number of co-morbidities in the population of community-dwelling individuals with dementia, honing techniques to train family caregivers in the detection of illnesses and pain may prevent emergency room visits, unnecessary psychiatric hospitalizations, and inappropriate behavioral interventions for affective and behavioral changes related to undetected medical problems.

Adverse events were not limited to care recipients. In the current study, the caregiver of the person who had the aforementioned adverse medical event (gastric bleeding) suffered a stroke which ultimately led to the care recipient's institutionalization. In addition, one caregiver was undergoing an oncology workup while enrolled in Phase 1 of the study, and another caregiver revealed in Phase 2 that she and her husband were separating. These descriptions underscore the complex situations (including physical and cognitive decline, but also concurrent employment, care for underage children, or marital conflict) of caregiver participants.

When contemplating a behavioral intervention for affective or behavioral disturbances in a degenerative dementia, undetected illness must be ruled out and the caregiver's biopsychosocial situation must be examined. In addition, the caregiver's

level of cognitive functioning should be ascertained. Here, two out of 15 caregivers were functionally impaired (13%) and unable to complete some activities of daily living from the DAFS. Phase 1 of the study found a high correlation between individuals' scores on the DRS-2 and the number of tasks a person could complete independently. For this reason, Phase 1 suggests a routine assessment of caregiver as well as care recipient functioning with the DRS-2 at intake, before designing or implementing any behavioral interventions. Note that the current study employed an intake questionnaire that asked caregivers about their own deficits in basic and instrumental activities of daily living. None of the 15 caregiver participants self-reported functional deficits. To protect both caregivers and care recipients, cognitive screenings with high correlation to functioning, such as the DRS-2, should be conducted.

The direct assessment of functioning, in concert with DRS-2 scores, was also useful in determining whether care recipients would directly benefit from intervention (rather than indirectly, through caregiver coaching). In this study, two of the care recipients were able to complete the activities of daily living tasks with only minor difficulty and had DRS-2 scores well above the suggested cut-off for dementia. These individuals with confirmed diagnoses of incipient Alzheimer's disease and cardiogenic dementia were able to implement prosthetic and compensatory strategies and to insightfully address their own deficits, in collaboration with their spouses. They did not have affective or behavioral changes, other than an occasional memory lapse. Thorough assessment facilitates the detection of these individuals and their referral to appropriate services.

This study also suggests that a direct assessment of care recipient functioning by the caregiver is a useful intake strategy to reveal a potentially dangerous overestimation of abilities that puts the dyad at avoidable risk. In addition, the detection of underestimation may be a clinical warning sign for caregiver functional deficits, as described above (Dassel & Schmitt, 2008). Clinically, underestimation of care recipient functioning co-occurring with reports of significant distress and demands for services may indicate both caregiver and care recipient deficits, particularly if a care recipient filled the caregiver role in the past and his or her growing decline led to increased demand on the other member of the dyad, who now starts functioning in the caregiver role. This was the case in one of the dyads.

However, most commonly in clinical practice as well as in Phase 1 of this study, caregivers tend to overestimate functioning and tend not to implement behavioral strategies designed to keep the care recipient safe and supervised. It is likely that retained social and verbal skills mask severe deficits and mislead caregivers (and healthcare providers) to believe that the care recipient's behavior is intentional, willful, and reasonable. Stepping up to safety issues and providing 24/7 care involves significant response costs both in terms of traditional aspects like time and money, but also in the acknowledgment of the loss of autonomous functioning that sometimes seems too hard to bear for caregiver and care recipient alike. Barriers can be addressed more effectively if decisions related to the balance of autonomy and safety can be brought back to the caregiver's own experience with care recipient functioning. Rather than being prescribed by a provider, the direct assessment of functioning by the caregiver allows him or her to come to own conclusions and to generate proactive responses. Interestingly, even if only

the recall of emergency information and story retelling were implemented as a routine direct assessment tool in medical practice, many care recipients would be protected from receiving discharge instructions without proxy present or medical treatments based on the delivery of false information to physicians (e.g., receiving prescriptions for Viagra without involvement in romantic relationships). In a society that relies on and values *logos* – the written and spoken word – professional and family care and healthcare providers have to contact performance deficits to be able to respond appropriately.

The complexity and heterogeneity of this population, evidenced in this small study, calls into question the plethora of internet-based advice and generic helplines for affective and behavioral disturbances in the degenerative dementias (e.g., the Alzheimer’s Association’s helpline) that do not require face-to-face contact and thorough assessment. They put caregivers and care recipients at risk of undetected care recipient illness; caregiver cognitive impairment, illness, or social distress; oversight of appropriate rehabilitative treatment; and potentially harmful mischaracterization of care recipient functioning.

The interventions, tailored to the specific caregiver-care recipient dyad, were effective in decreasing problematic behaviors, such as arguing, spending time unsupervised, and continuing to drive. In all three cases, reasoning with the care recipient about the behaviors had not resolved the problems but exacerbated them: telling the care recipient of Dyad 1 that she now resided with her daughter and could not return to her own house, informing the care recipient of Dyad 2 he needed continuous supervision and was not safe alone, and asking the care recipient of Dyad 3 not to drive were strategies that only served to elicit the care recipients’ utter incredulity and

subsequent suspicion and anger. After a long history of attempting to orient these care recipients to reality and to generate insight, strategies that surely worked in the past, caregivers abandoned these efforts and implemented contextual changes that prevented the behavioral problems or differentially reinforced alternative behaviors. Caregivers effectively stopped correcting and thereby inadvertently punishing care recipient behavior. The focus of these kinds of interventions is on preserving the caregiver-care recipient relationship by doing what works, rather than continuing to rupture the relationship with arguments that, due to one party's memory loss, could be replayed every single day or even multiple times per day.

The current study suggests that caregiver-care recipient dyads resembled highly distressed couples in their positive-to-negative interaction ratios, although it is not clear whether this semblance holds for task demand situations only. Couples research (Gottman, 1998) proposes multiple ways to improve conflicted interactions, namely using positive affect to deescalate the situation; accepting influence from one's partner; avoiding the partner's defensiveness; and decreasing physiological arousal. It is an experimental question whether caregiver-care recipient relationships characterized as "resilient" contain these repair patterns, which may be implicitly incorporated in all caregiver coaching materials.

One fundamental difference between couples interactions and caregiver-care recipient interactions is that the caregiver implements strategies in isolation rather than in dyadic collaboration. Video records of the caregiver-care recipient interactions revealed how difficult the experience of care recipient loss of skills was for caregivers. The camera captured the startle that occurred when a caregiver discovered that the care

recipient could not recall vital emergency information, especially the caregiver's name. Videos documented the many futile attempts to elicit the information (usually by repeating the request) and, finally, extinction of the request. Caregivers did not change these behavioral patterns as a function of the intervention in Phase 2: While the tone of the interaction became less negative and the ratio of positive-to-negative interactions increased, the helping strategies remained futile, especially in the case of those care recipients who did not benefit from instructions (Dyads 2 and 3). To the study author's surprise, the post-intervention records were very much a repeat of the video-recorded sessions in Phase 1, without the harsh overtones ("You don't!"), overcorrections ("No, no, no, no, no!"), or infantilizing comments ("Poor baby").

In contrast to the controversial literature on anticipatory grief or emotional reactions to prospective loss (Fulton & Gottesman, 1980), these video-recorded interactions suggest that the spouses' or parents' experience of loss of ability in the moment is difficult for the caregiver (Monin & Schulz, 2009; Schulz et al., 2006). For example, when the caregiver asks the care recipient a question that the latter cannot answer, the caregiver's behavior is not reinforced and, by definition, begins to extinguish. As extinction is accompanied by emotional responding and diffuse physiological arousal, these nonverbal cues may be sufficient to set into motion a cycle of negative affect involving both caregiver and care recipient. Caregiver physical and emotional cues may be more salient contexts for care recipients than any spoken word, and for individuals with memory loss these emotions can linger on – even if the situation in which they arose cannot be recalled (Feinstein, Duff, & Tranela, 2010). Caregiver emotional responding may also compete with emitting more effective helping responses, particularly when the

care recipient gets defensive or withdraws. To break through this cycle, caregivers may have to learn to manage their reactions to care recipient loss of functioning, by noticing their emotions, normalizing them within the context of loss, taking time to reconcile the old with the new status quo, and orienting to it. McCurry (2006) used the term “caring detachment” to illustrate the stance from which family caregivers could become non-entangled in the actual interaction and thereby effective. Viewing the video-records with the author of this study put the participants into such an observer role and seemed to have generated readiness for the subsequent interventions. However, caring detachment creates an intentional lopsidedness in the relationship, in that the caregiver always acts with an eye to the long-term benefit of the care recipient and forgoes behaviors (e.g., discussing financial worries; sharing upsetting information) that would have a negative impact on the relationship by expecting the care recipient to problem-solve or emit instrumental or emotional support. Sheltering the care recipient and creating a “safety bubble” (McCurry & Drossel, 2011) for shared dementia-appropriate activities during which the care recipient is not confronted with his or her deficits are relationship-maintaining behaviors, yet they paradoxically require distancing and a shift in the relationship. Some caregivers may be especially opposed to the notion of “detaching” or “distancing,” as they may feel that the stance itself compromises their relationship with the care recipient. In this context, it is noteworthy that caregivers liked learning the POLITE acronym, exit with dignity, and compassionate information, with their experience-near language, better than considering behavior in terms of A • B • C analyses using a spreadsheet and experience-distant language, although the latter may be more

useful when analyzing a care recipient's remaining skills or seemingly intractable behavioral problems.

While problem behaviors decreased and positive-to-negative ratios increased, the care recipients' lack of initiation of positive interactions is worrisome in the long-term, for it raises the suspicion that caregivers' efforts will not produce clinically significant change sufficient to maintain the caregiver's positive behaviors. The care recipients who participated in Phase 2 of this study seemed to cope with adversity by exemplifying that "offense is the best defense," and challenged caregivers repeatedly in confusing or uncertain situations, initiating negative interactions more often than positive ones during baseline and post-intervention. If care recipients are unable to maintain the caregivers' repertoire over time, this repertoire is likely rule-governed (doing what is "right," no matter what) and supported by social demand (e.g., participating in solution-focused caregiver groups). Again, research on the interactions of "resilient" caregiver-care recipient dyads versus dyads plagued by conflict and strain could shed some light on the contingencies of reinforcement maintaining the caregivers' behavior.

Like all caregiver interventions, the current interventions were domain-specific. They produced clear effects on the target behaviors, as caregivers quickly implemented strategies arrived at collaboratively with the author of this study. However, generalization to other situations or novel behaviors was not observed, and it is not clear whether the shift in the ratio of positive to negative interactions was maintained, whether it has clinical significance, or whether the ratio itself holds in non-task demand situations. In light of the relationship literature and the need for shared pleasant activities and positive emotionality, it is important to note that domain-specificity also constrained the

helping behavior, which did not change much despite adjustment in caregiver judgment of care recipient abilities.

After interacting with the care recipient in Phase 1, caregivers knew that the care recipient needed more assistance than predicted, but this knowledge did not translate into knowing how to help or engage the person with dementia in the task. While effective for pinpointed problem behaviors, the intervention of Phase 2 repeated the mistake of educational approaches by assuming that “knowing *that*” the person needed assistance would lead to “knowing *how*” to translate the recognition of need into effective behavior. As the professional caregiver literature has demonstrated, care recipients’ independence and task engagement increases when professional staff learn to conduct task analyses and design the appropriate prompting hierarchies and procedures (Engelman, et al., 2003). The teaching of A • B • C’s for problem behaviors in Phase 2 and watching brief video snippets with the author of this study modeling a different task approach were not sufficient for a conceptualization of task performance in these terms, suggesting that specialized training, including guided practice, is necessary.

As implied earlier, teaching and implementing task analyses and prompting procedures furthering care recipient task engagement and caregiver mastery may be a more fruitful point of intervention than only teaching rules of conduct (as in the POLITE acronym). Knowing how to perform task analyses and prompt care recipient engagement may allow caregivers and care recipients to discover shared meaningful activities. Activity engagement is an important part of high-quality dementia care and serves to improve quality of life as well as to prevent behavioral and affective changes (Teri et al., 2003; Teri, Logsdon, Uomoto, & McCurry, 1997). Further research should teach task

analyses and prompting hierarchies in a fourth intervention session, and then follow up across multiple exemplars to program for generalization and long-lasting intervention effects, while addressing caregiver emotional responses to loss, negative-affect reciprocity, and the caregiver-care recipient relationship history as potential barriers to caregiver training.

In summary, while political and fiscal demands combined with an aging population call for “one-size-fits-all” interventions that can be quickly – and without cumbersome assessments – delivered to caregivers of individuals with dementia for the management of affective and behavioral changes, the current study underlines the complexity of the endeavor. Samples are heterogeneous, the presenting problems are often not well characterized (e.g., caregiver deficits), undetected illness and adverse medication effects commonly underlie the perceived affective and behavioral changes, contextual factors generate additional demands on the dyad (e.g., financial strain, caregiver health problems, marital conflict while caregiving for a parent), caregivers may exacerbate situations by overestimating the care recipients’ deficits, and interventions are domain-specific. Furthermore, dyadic factors, such as caregiver-specific reactions to loss and relationship history, must be addressed if caregivers are to encounter the challenges of living with somebody with dementia with generosity, flexibility, and resilience.

If task analyses prove too cost and labor intensive to teach to caregivers, it may well be the case that care recipients who are inactive and completely dependent at home may benefit from transitioning to a specialized dementia facility where experienced staff can engage them (see Appendix 7 for remarks on functioning by caregivers and care recipients throughout the study). While limited in its scope with only twelve dyads in

Phase 1 and three dyads in Phase 2, this study demonstrated that the technology for quick and effective individualized non-pharmacological interventions on behavioral and affective disturbances exists; now the challenge is to hone and expand the technology and make interventions more user-friendly as well as clinically relevant and interpersonally meaningful to the dyad's needs, to increase quality of life of both caregivers and care recipients.

CHAPTER 6

References

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Appendices

1. Performance Rating Scale (Granger et al., 1986; from Cotter et al., 2002)

Rank	Description
7	Independence (no supervision, prompting, touching, cueing, sequencing; setup of materials limited to what is described in respective protocols)
6	Modified independence (assistive devices used; person problem-solves independently, takes three times as long as normal to perform activity)
5	Supervision (specific verbal direction to materials exceeding initial setup; verbal encouragement; no sequencing, touching, or taking over parts of the task; takes 3 x as long to complete task)
	Assistance (setting up materials plus sequencing, touching (e.g., pointing to line on check, moving money) or taking over parts of the tasks):
4	Minimum (at least 75% of steps or subtasks accomplished independently)
3	Moderate (50-75% of steps or subtasks accomplished independently)
2	Maximum (25-50% of steps or subtasks accomplished independently)
1	Total (less than 25% of steps or subtasks accomplished independently)

Applying this Performance Rating System to the standardized tests used produced 42 points total when rating independent recall of emergency information (Appendix 2), 77 points total when rating independent performance of the task DAFS (Appendix 3), and 7 points total for independent recall of a short story (Appendix 4).

Direct Assessments of Function

After caregivers have prejudged care recipients' abilities via the Performance Rating Scale, participants with dementia are asked to complete the following tasks:

2. Assessment of knowledge of personal/emergency information

- a) Please tell me your name.
- b) Could you spell your name for me, please?
- c) What is your address (Providing street name, city, state, zip code)?
- d) What is your telephone number?
- e) What is your spouse's/daughter's/son's/family member's name?
- f) What is the name of your doctor?

Protocol in Ala et al., 2005 (11 points total).

3. Direct Assessment of Functioning Scale (from Loewenstein et al., 1989; 2005)

- (a) Reading a clock (4 items, 8 points total), progressive difficulty. Material: A clock with hands. Question to caregiver: "Can the person tell time on a clock with hands?"
- (b) Temporal orientation (4 items, 8 points total). Not prejudged by caregivers.
- (c) Using the telephone (6 items, 6 points total). Question to caregiver: "Can the person use a phone to make a call?"
- (d) Preparing a letter for mailing (6 items, 6 points total). Materials: A piece of paper, an envelope, a stamp, a written name and address. Question to caregiver: "Can the person prepare a letter for mailing?"

- (e) Identifying currency (7 items, 7 points total). Materials: A penny, nickel, dime, quarter, one-dollar bill, five-dollar bill, and ten-dollar bill. Question to caregiver: “Can the person identify currency?”
- (f) Counting currency (4 items, 4 points total). Care recipient is asked to count change and paper currency on four different trials, increasing in difficulty. Question to caregiver: “Can the person count currency?”
- (g) Writing a check (5 items, 5 points total). Material: Actual check, to be written in the amount of \$400. Criteria: 1) correct payee; 2) correct written amount; 3) correct numeric amount; 4) date; 5) signature in appropriate place. Question to caregiver: “Can the person write a check?”
- (h) Balancing a checkbook (4 items, 4 points total). Care recipient is asked to balance a checkbook at four different levels of difficulty. Question to caregiver: “Can the person balance a checkbook?”
- (i) Simulated shopping (8 items, total 16 points). Care recipient is told four grocery items (orange juice, soup, cereal, tuna fish) and asked to remember them. Ten minutes later, the grocery items are picked out from among 20 items. Selection is repeated with a written list and four new items (milk, crackers, eggs, laundry detergent).
- (j) Making change for a purchase (1 item, 2 points total). Care recipient is asked to count out the correct change that should be received from a purchase. Question to caregiver: “Can the person make change for a purchase at a cash register?”

(k) Eating skills (5 items, 10 points). Materials: Eating utensils, water glass. Tasks: pouring water into a glass, drinking from a cup, and using a fork, a spoon, and a knife.

Question to caregiver: “Can the person use eating utensils?”

(l) Ability to fetch things in the house (for replacement of simulated shopping if the person has no history of cooking or grocery shopping).

Protocol in Loewenstein et al., 2005 (76 points total)

4. Story Retelling (from Bayles & Tomoeda, 1993)

Purpose: To evaluate the ability to recall verbal information in the form of a story.

Materials: Response Record Form (1 point for each unit of information recounted; 17 total points at each recall).

Instructions: *I am going to tell you a short story. When I am done, I want you to tell it back to me.*

While a lady was shopping, her wallet fell out of her purse, but she did not see it fall.

When she got to the check-out counter, she had no way to pay for her groceries. So she put her groceries away and went home. Just as she opened the door to her house, the phone rang and a little girl told her that she had found her wallet. The lady was very relieved.

Now, you tell me the story.

Final instruction: *Remember the story because I will ask you to tell it again later.*

Earlier, I told you a short story and you told it back to me. Can you tell it to me again now? Discontinue if, after 20 s, the examinee recalls nothing.

Protocol from the Arizona Battery for Communication in Dementia (17 points)

Quality of Caregiver-Care Recipient Interactions

5. Effective Communication

(a) P.O.L.I.T.E. (from McCurry, 2006, p. 42).

Caregivers were instructed to approach care recipients in an unhurried manner (P = patience), break down tasks into manageable parts (O = organize and observe), use humor (L = laughter), let slips, mishaps, or mistakes not harmful to care recipients or caregivers go without commenting (I = ignore what you can), be gentle and provide choices (T = tone of voice), and to orient the care recipient toward the interaction (E = eye contact).

(b) Exit with dignity (McCurry & Drossel, 2011).

Caregiver and author of this study developed multiple examples for respective care recipient's escape responding, showing how he or she could terminate task demands by engaging in provocation, changing the topic, or other distracting behaviors.

(c) Compassionate misinformation (McCurry, 2006).

Author of this study solicited examples from caregiver when information, correction, persuasion, etc., have not worked. If there were clear situations in which factual information did not seem to change care recipient's narrative (e.g., "I lost my child" when she indeed had given up a daughter for adoption), caregiver was encouraged to respond to the tone and function of the statement rather than its content or topography.

Multiple examples were introduced that illustrated the difference between topography and function of verbal behavior. The goal of compassionate misinformation is the prevention of confrontations, with caregiver or care recipient on different sides of the argument.

6. Coding of Interactions

The coding of caregiver-care recipient interactions aimed at capturing the main strategies taught within the A•B•C Model (McCurry, 2006; McCurry & Drossel, 2011). The coding system (rules and code descriptions below) integrated material from Hahlweg (1997/1999), Malik (2000), McCurry (2006), and Patterson (1982), some of it verbatim. Every session was transcribed. The spreadsheet delineated turn number, caregiver utterances, care recipient utterances, followed by the next turn number. Each interaction was watched at least twice by at least two different study personnel to verify the number of turns.

Blank columns allowed for coding of each turn in terms of quality (positive, negative, or neutral) and rationale (see description of positive and negative behaviors below). The total time of the session was also recorded.

Coding rules (adapted from Hahlweg (1997/1999)).

- (a) The complete video-record was watched by each coder before starting to code.
- (b) Unit of analysis: The coding unit was one turn, which did not have any time limitations. If there was no interruption of the speaker by a functional utterance (including listener's vocal acknowledgments like "ahem" or requests for clarification, such as, "What?" or "Huh?"), then one code was used even if content shifted. When one

turn contained neutral plus positive or neutral plus negative codes, the neutral code was not recorded. When one turn contained a positive plus a negative code, only the last one was coded regardless whether it was positive or negative.

(c) Each turn had four components: Caregiver utterance; care recipient utterance; caregiver physical cues (facial expressions, tone of voice, body language); care recipient physical cues (facial expressions, tone of voice, body language).

(d) Each turn was coded twice, once for the caregiver, then for the care recipient.

(e) Maintaining the alternating sequence: Two codes by the same speaker never followed each other. After each caregiver code, there was a care recipient code. If one of the partners remained silent, the other partner's turn continued even if the content shifted.

(f) There could not be two codes for one person at the same time.

Positive caregiver behaviors.

“Patience” (adapted from McCurry, 2006, p. 42). Caregiver waits, so the care recipient is given time to think, contemplate, problem-solve, or has a chance to complete sentences or tasks without being cut off or rushed. Within the interaction, caregiver instruction or clarification is followed by a long pause and the next turn by the care recipient. Caregiver does not withdraw, get up, drum fingers on the table, shake leg, or shows signs of boredom but remains engaged with care recipient.

“Organization” (adapted from McCurry, 2006, p. 42). Caregiver sets up materials, eliminates distractions, verbally breaks down tasks into smaller steps, provides semantic or phonemic cues or physical prompts, uses strategies to enhance or facilitate

task. Caregiver does not modify the task itself, only the steps within it. Caregiver does not provide the answer or take over parts of the task. Examples: Instructing care recipient to give 100 cents and then 2 cents, rather than 102 cents. Sequencing tasks into small pieces.

“Loving” (adapted from Malik, 2000; McCurry, 2006). Caregiver uses appropriate and affectionate humor and laughter. Positive affect may be expressed through behaviors such as affection, laughter, smiling, or making jokes. A positive tone of voice can be happy, relaxed, cheerful, or satisfied. Positive facial expressions include smiles and looking relaxed and happy. Positive body language can include being relaxed, holding the other’s hand, light touching on the leg or shoulder. Caregiver does not use humor that belittles or implicitly criticizes the care recipient.

“Ignore what you can” (adapted from McCurry, 2006). Caregiver does not show knee-jerk reactions when care recipient is factually mistaken or demonstrates memory deficits. Caregiver changes topic, does not dig for a correct answer and lets the care recipient off the hook. When care recipient is frustrated with a task, caregiver does not automatically defend but distracts.

“Tone of voice” (adapted from McCurry, 2006). Caregiver is respectful and asks for permission before helping care recipient. Caregiver checks in with care recipient to see if (s)he needs help. Caregiver gives choices.

Examples: “Ready?” “Would you like to show me how to ...?” “Could you please ...?”
 “To whom would you like to make the check out?”

“Exit with dignity.” Care recipient is already engaged in task when caregiver notices that care recipient won’t be able to accomplish task. Caregiver lets care recipient

escape from task by telling a white lie that preserves care recipient's dignity. Caregiver modifies the task to suit care recipient's needs. Caregiver takes the blame. Caregiver goes along with care recipient's defensive story.

Examples: "Take a guess – it's a guessing game." "Yes, I'm sorry – I didn't notice that you were not paying attention. I should have waited to tell you the story." "I must have been unclear."

"Compassionate misinformation" (adapted from McCurry, 2006). Knowing that care recipient does not benefit from reality orientation, caregiver tells white lie designed to protect care recipient from discomfort. Caregiver normalizes memory loss and other difficulties, e.g., by telling anecdotes of somebody forgetting things. Caregiver uses praise effectively when it is not indicated.

Examples: "This story about forgetting the wallet could have been about me." "You are retired and don't need to worry about financial information anymore."

Positive care recipient behaviors (adapted from Malik, 2000).

"Affection." Care recipient uses appropriate and affectionate humor and laughter. Positive affect may be expressed through behaviors such as affection, laughter, smiling, or making jokes. A positive tone of voice can be happy, cheerful, or satisfied. Positive facial expressions include smiling and looking relaxed and happy. Positive body language can include being relaxed, holding the other's hand, touching on the leg or shoulder; expressing explicit appreciation for the caregiver role, for assistance received, or for time spent together. Making positive comments about the relationship.

Negative caregiver and care recipient behaviors (adapted from Malik, 2000).

“Educating.” Any attempt to educate the care recipient: Contradicting, correcting, reasoning, explaining, persuading, convincing, saying “no,” – with the goal to have care recipient learn the correct or right answer or to have care recipient do the task correctly. Care recipient’s attempts to educate the caregiver. Either caregiver or care recipient takes a one-up or expert position when “educating” occurs.

“Berating the person.” Any utterance that may make the conversational partner feel defective, diseased, stupid, or childlike.

- (1) Jarring and forceful tone, tones of disgust, condescension, mockery, spite, cruelty, or significant, hurtful hostility.
- (2) Name-calling, cursing, swearing.
- (3) Insults, put-downs.
- (4) Patronizing, bossy tone of voice or content.
- (5) Infantilizing or treating with pity.
- (6) Critical comments.

Examples: “Poor baby.” “I don’t care what you feel, you need help.” “Spending money has never been your problem.” “If you’d been listening you would have known.” “It doesn’t make sense to tell you anything – you have Alzheimer’s disease.”

“Menacing.” Any utterance or gesture that threatens the person: Menacing or frightening tone of voice; invading the person’s personal space; intimidating the person through posturing; pointing into someone’s face; gesturing, poking, inadvertently hitting the person with movement.

Examples: “If you don’t stop acting that way, you’ll have to go to a nursing home.” “If you’re not willing to work on this, I won’t either.”

“Defensive.” Person uses underhanded, insensitive, unfair, shrewd, devious, or calculating tactics to blame the other person. Care recipient finds an excuse for why (s)he could not do the task. When help is offered, care recipient says, “I know,” and shuts down attempts to assist him or her.

Examples: “I’m doing the best I can, so you have no right to complain.” “Because you didn’t teach me, that’s why I don’t know how to ...” “I thought these would be our golden years; if it weren’t for you, we wouldn’t be here.”

“Ruling the other person’s thoughts, feelings, or actions.” Person conveys that he or she decides and lays down the law. Statements are in present tense and often include “ought,” “must,” “should,” or “need.”

Examples: “You need to get over that.” “You can’t feel that way.” “Don’t worry so much.” “You are wrong to feel that way.” “The fact is that you have a memory problem and you need to realize that.” “You must give me ten dollars.”

“Withdrawing.” Caregiver or care recipients disengages from the interaction, retreats into a shell, becomes detached, backs off, shuts down. Withdrawal can occur physically or emotionally (body language, tone of voice, and/or attitude). Person can be flat, bored, disinterested, defeated, tired, or distracted when speaking. Caregiver or care recipient may avoid eye contact, turn body away, slouch in his or her chair, change body position to create more distance, stare at the wall or the ceiling, cross arms, fidget with hair, clothing, glasses, or nails. He or she may become indifferent, nonchalant, disinterested, or unresponsive and try to terminate the ongoing interaction.

Example: “I don’t care, do whatever you want.” “Just shoot me and get it over with.” “I’m tired of talking.” “I’m finished and have nothing left to say.” “I have a headache.”

“Negative self-talk.” Care recipient or caregiver makes generalized statements about low level of functioning.

Examples: “ I can’t do anything right.” “I am horrible.”

Typical extinction sequence: Giving an instruction (neutral), organizing task (positive = O), correcting/explaining task more (negative = X), insisting on correct behavior (negative = R), becoming irritable with care recipient (negative = B).

7. Memorable and Instructional Quotes

- Care Recipient (debriefing after shopping task, first recalling items from memory then recognizing them with a list in hand): “It’s interesting how it went from a feeling of despair to recognition of some of these things.”

- Caregiver (after completing the first direct assessment of functioning with Care Recipient and noticing more engagement than usual by Care Recipient): “I notice that [Joe], when he’s here, really, he tries harder ... and accomplishes more. And so that ... That means ... I don’t know what it means ... Perhaps he doesn’t have confidence in himself anymore.” Joe answers: “I have never had confidence in myself.”

- Care Recipient (using cell phone successfully with author of this study): “Claudia, I was able to call you today but I wished there were not all these ornaments on the phone.”

- Care Recipient (discussing his reactions to assessment and intervention): “You are a light at the end of the tunnel, a 60-Watt bulb so-to-speak.”

- Care Recipient (to a surprised spouse when he was able to use the landline phone with author of the study with prompting procedure): “I believe I can use this and use it well. I have to get the basic information to do that. It seemed to me you have avoided doing that.”

- Caregiver to Care Recipient: “These are all these short-term little things. They’re little things. They’re little things, baby. You gotta remember the important things. Big things. You know. How to take care of me ... just don’t forget me, that’s all I ask. You can forget everything else, but don’t forget me. Okay?”