Published in final edited form as:

J Aging Stud. 2014 August ; 30: 121–130. doi:10.1016/j.jaging.2014.05.001.

Minimizing Confusion and Disorientation: Cognitive Support Work in Informal Dementia Caregiving

Brandon Berry, PhD

Duke University, Center for the Study of Aging and Human Development, Duke University Medical Center, 201 Trent Drive, DUMC 3003, 3502 Blue Zone, Durham, North Carolina 27710

Abstract

Drawing from ethnographic fieldwork and in-depth interviews, I explain how informal dementia caregivers attempt to reduce the affected individual's moments of confusion and disorientation through cognitive support work. I identify three stages through which such support takes shape and then gradually declines in usage. In a first stage, family members collaborate with affected individuals to first identify and then to avoid "triggers" that elicit sudden bouts of confusion. In a second stage, caregivers lose the effective collaboration of the affected individual and begin unilateral attempts to minimize confused states through pre-emptive conversational techniques, third-party interactional support, and social-environment shifts. In a third stage, caregivers learn that the affected individual has reached a level of impairment that does not respond well to efforts at reduction and begin abandoning strategies. I identify the motivations driving cognitive support work and discuss the role of lay health knowledge in dementia caregiving. I conclude by considering the utility of cognitive support as a concept within dementia caregiving.

Keywords

Alzheimer's Disease/Dementia; Caregiving; Chronic Illness; Cognitive Support; Confusion/Disorientation; Symptom Management

Studies of Alzheimer's disease and related dementias identify the disease's behavioral symptoms as a subject of significant concern. Routine occurrences of confused and disoriented behaviors, such as delusion, agitation, hallucination, and wandering are associated with a diminished quality of life for affected individuals and an increased likelihood of severe stress and depression for caregivers (Wilks et al., 2011; Hersch & Falzgraf, 2007; Lu et al., 2007; Donaldson et al., 1997; Schulz et al., 1995; Teri, 1997; Pruchno & Resch, 1989; Anthony-Bergstone et al., 1988). While a steady stream of research has tested the effectiveness of both pharmacological and nonpharmacological approaches to

© 2014 Elsevier Inc. All rights reserved.

¹Current Affiliation: University of California, Davis, Medical Center, 2315 Stockton Blvd, Sacramento, CA 95817, brandonberry@gmail.com, Phone: 310-736-5163

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

managing these behaviors (see Yuhas et al., 2006; Livingston et al., 2005; Arcona et al., 2004; Cohen-Mansfield, 2001; Rowe & Glover, 2001; Devanand et al., 1998; Algase et al., 1996), far fewer studies have examined how family caregivers respond to confused behaviors in their own households and on their own terms.

Among these studies, many effectively describe cognitive support techniques, but few if any describe how family members first encounter instances of confusion,¹ learn to provide support, and adapt to the disease's progression. Prior approaches tend to de-emphasize social process and imply that family members naturally and inevitably undertake the work without difficulty. The current study contributes to the literature on dementia caregiving by offering a process model of cognitive support work, elucidating the set of steps that caregivers take and challenges they overcome to provide this form of support.

Prior research examining pre-diagnostic uncertainty around dementia symptoms lays the foundation for a process model of cognitive support work. This line of research identifies a key early phase in the cognitive support process, showing how family members collaborate with the affected individual to identify and define uncharacteristic behaviors as symptomatic of dementia or discount them as signs of normal age-related decline (Chrisp et al., 2011; Carpentier et al., 2010; Clark et al., 2005; Krull, 2005; Hinton et al., 2004; Knopman et al., 2000). These studies tend to highlight the fluctuating and contested meanings attributed to behaviors by kin that later may or may not become defined as symptomatic by healthcare professionals. Krull (2005), for instance, explains how caregivers play a key role in the process by identifying moments of confusion and disorientation as "first signs" of the illness. She shows that these impaired states precipitate formal help-seeking when caregivers are no longer able to "normalize" them.

Moving beyond the initial stage of pre-diagnostic definitional work around confused states, studies investigating the post-diagnosis period explain how affected individuals and their caregivers try to lessen the negative impact of confusion and disorientation on their everyday lives. One line of inquiry documents how affected individuals draw on their spouses and other kin for targeted support around these troubling moments (Beard, Knauss, & Moyer, 2009; Beard, 2004; Pearce, Clare, & Pistrang, 2002). Beard (2004), for instance, describes how individuals with Alzheimer's sought guidance from others by regularly asking if they were "on the right track" while engaged in interactions with them (424). Pearce, Clare, and Pistrang (2002) explain how men with Alzheimer's protected their sense of self and minimized reappraisals of their abilities by relying upon their wives for strategically sought memory support.

In a second line of inquiry targeting caregiver-initiated support work, studies document how individuals try to preserve the affected individual's personhood by protecting remaining competencies and reinforcing autonomy in various ways (Perry & O'Connor, 2002; Fontana & Smith, 1989). Perry and O'Connor (2002), for instance, explain how caregivers protect their spouse with dementia from distressing moments of "incompetence" by lessening the

¹By confusion, I mean its various observable manifestations identified by caregivers such as nonsensical talk, confabulation, vocally trailing off mid-sentence, mistaking another's identity, getting lost, losing objects, and so on.

difficulty of old tasks. Fontana and Smith (1989) illustrate how caregivers “protect and speak” for affected individuals and use many devices to “defuse” their challenges (42–43).

In a complementary line of research, studies show how caregivers engage in a form of support meant to reduce the threat of embarrassment and courtesy stigma around moments of confusion when in co-presence with others (Werner et al., 2012; Beard, 2004; Perry & O’Connor, 2002; Blum, 1991). Drawing from Erving Goffman (1959, 1963, 1967), this body of research describes how caregivers and care recipients engage in impression management work to maintain an image of competency or lucidity when moments of confusion unexpectedly arise. Blum (1991), for instance, explains that early on in the illness trajectory the caregiver colludes with the affected individual to avoid discrediting displays and then as the illness progresses the caregiver colludes with others around the individual to excuse these displays. In this way, the work transforms from “information control” to “social control” (265).

This research is noteworthy because it takes a longitudinal view, illustrating how caregivers shift in the way they manage impressions as cognitive impairment advances and the affected individuals become less able to engage in teamwork. With its primary focus on managing impressions however, it leaves out caregiver concerns with reducing actual moments of confusion rather than just the appearance of confusion. The current study will show that caregivers typically want the affected individual not merely to *appear* lucid, but rather to *be* lucid to the extent that it is still possible at the current phase of the disease.

Collectively, these works indicate the deep concern and innovative responses that both caregivers and affected individuals develop around moments of confusion and disorientation. Past research has largely cast the work of managing such behaviors in an atemporal light, implicitly denying that cognitive support work goes through a process of change over time. To advance this area of research, the current study seeks to chart how caregivers learn to provide cognitive support and adapt the work across the disease trajectory.

Methodology

This study is based on five months of multi-sited fieldwork and in-depth interviewing in North Carolina. My initial entrance into the dementia community developed from my participation in two dementia support groups as a self-identified researcher from a nearby university investigating social support related to dementia. Meetings for both groups were loosely facilitated by a licensed social worker or a volunteer from the community and would typically last two hours. One group was integrated with caregivers and care recipients and drew 14 individuals on average. The other group was attended by caregivers only and drew 10 individuals on average. Care recipients, either present or about whom we spoke, were predominantly college-educated white men over 65 years of age diagnosed with Alzheimer’s. The caregivers were typically wives of the care recipients, predominantly college-educated white women, and over 65 years of age. I estimate that one-fifth of support group regulars and visitors did not have a formal diagnosis, but suspected a subtype of dementia.

I attended 9 meetings total. In both groups, there were regulars, occasional visitors, and a flow of newcomers who social workers described as “support group shopping.” Facilitators of both groups conducted meetings in a relaxed format that usually began with each attendee’s self-introduction. The social worker typically had a few activities planned but left space for ample ambling and digressions. Many of the meetings appeared like what social scientists know as focus groups. Members, including myself, introduced topics for conversation, such as how to deal with certain challenges of caregiving. Many attendees routinely offered personal reflections and descriptions of relevant experiences from their lives. Commonly, attendees shared stories of their day-to-day lives and special family events with their affected family member. In the integrated group, these conversations were always punctuated by a variety of symptomatic behaviors typical of individuals with dementia. Many tried to engage in the conversation but ran into problems expressing themselves; some occasionally broke out in song; a number stared vacantly; several sat pleasantly smiling.

I conducted twenty-seven open-ended, semi-structured interviews with caregivers attending the support group meetings or other kin (such as a sibling, an adult-child, or a friend) regarding twenty individuals with a self-reported subtype of dementia. This sample included five caregivers who did not attend the support group meetings that I recruited through snowball sampling among support group attendees. Of the total interviews, seven were conducted through a series of emails with individuals who were unable to meet or speak on the phone within the data collection period. Face-to-face interviews lasted 60 to 90 minutes and were digitally-recorded and transcribed verbatim.

In each interview, I collected retrospective accounts. I asked individuals to describe especially meaningful or vivid moments around symptomatic behaviors (such as forgetfulness, stray phrases, mistaken identity, disinhibited acts, frequent possession losses, etc.) and their own responses to these behaviors, including supportive acts. I supplemented these formal interviews with informal conversations with caregivers and affected individuals in and outside of support group meetings. I visited some of their homes, went to lunches with them, and played racquetball with one man with Alzheimer’s while his wife watched through the glass partition. I talked on the phone and emailed occasionally with several others.

Participant-observation within support group meetings and other settings began before and then occurred concurrently with the interview process. During support group meetings or immediately after, I took observational notes in a small notebook that I expanded into fieldnotes upon returning to my office after each meeting (Emerson, Fretz, & Shaw, 1995). I generated coding categories using a modified grounded theory procedure (Timmermans & Tavory, 2007). The theme of cognitive support work as a caregiving activity emerged during an early phase of open coding. Through subsequent phases of focused coding, I identified variations of cognitive support techniques. All caregivers that I interviewed engaged in some form of cognitive support prior to the affected individual entering the most severe phase of the illness. In analyzing retrospective reports from caregivers and other kin in combination with my current day observations, I identified stage transitions in the development of and then discontinued use of cognitive support techniques. All of the caregivers that I interviewed who had transitioned through the first stage conformed to the trajectory of the

stage model, though only approximately 25% of observed or interviewed caregivers had entered the third and final support stage that I identify. This analytic work occurred simultaneously with and often directed subsequent data collection efforts (Charmaz, 1983).

I employ a double layer of confidentiality in this study. All the names are pseudonyms, but in addition several members of extended networks did not want their words to be linked back to the person about whom they were speaking. As a safeguard, I disguise familial and friendship affiliation in several cases.

Findings

This study reports that a key feature of dementia caregiving is the caregiver's concern with lessening the affected individual's level of confusion and disorientation to the extent that it is possible. This effort involves *cognitive support work*, or strategic practices designed to promote comprehension and reduce confusion and disorientation. These findings indicate that caregivers become adept at cognitive support work through a process of learning and adapting idiosyncratic techniques of support across three stages. Caregivers engage in an effort to minimize the affected individual's level of confusion for several reasons, including: 1) they believe it may slow the progression of the disease and 2) they believe that it limits the level of distress experienced by affected individuals and co-present others.

Early-Stage Cognitive Support

Overcoming Early Interpretive Trouble

Among the participants in this sample, the self-conscious effort to provide cognitive support to a family member with confirmed or suspected dementia began after resolving a recurring form of interpretive trouble. Many reported initially seeing the affected individual's behavior as occasionally "strange" or "puzzling" and were unsure how they should respond to the individual during these moments. Many sought to work out these interpretive challenges with the affected individual him or herself or others familiar with the affected individual.

Family members spoke about these early interpretive troubles as "learning experiences," or experiences in which they had to learn what dementia behaviors look like. These participants reported finding themselves at a loss around early displays of confusion. Helen, a caregiver, recalled that her husband, who would shortly later seek a neuropsychiatric evaluation, asked her if she ever had the experience of "driving on the [local highway] and not knowing which way she was going, north or south?" That was her "first sign that something was wrong." But she conceded not knowing what it meant about his health.

In another instance, members of a family first attributed a man's episodic confusion and trouble managing personal belongings to a state of depression. "We thought perhaps he was depressed. ... [H]e got on medication that perked him up a bit, but not for long," the daughter-in-law recalled. Several months later they would learn that they were seeing the early signs of frontotemporal dementia.

Caregivers identified the intermittence of such displays of confusion as another common source of early interpretive trouble. In some cases, caregivers identified the appraisals of acquaintances as causing them to reconsider their own early appraisals. Susan, the caregiver-spouse of a former history professor with Lewy body dementia, described an event in which they visited a museum with a group of others. “I remember we went ... to the National Museum and he started talking about a painting and everyone gathered around him ... and people said, ‘he doesn’t have dementia.’”

These alternating displays of lucidity and confusion sometimes put friends and family members at interpretive odds with one another. Barbara, the wife of a man with Alzheimer’s, recalled that no one believed her at first. “Everyone said he’s fine, I’m just being hypersensitive or something like that. But he didn’t go into it [confusion] very badly when they were around. So how would they know?”

Affected individuals themselves sometimes provided the source of interpretive difficulty as they resisted the early definitional efforts made by others. A caregiver noted that her husband “wouldn’t admit that something was wrong at first. He said it’s just normal aging and that I wouldn’t know because I’m 12 years younger.” Another man started taking Aricept [a widely-used dementia medication] “as a compromise.” His wife recalled that, “till this day he still hasn’t admitted that something is wrong.”

Negotiating the Caregiver’s Role around Confused States

After concluding that a family member’s cognitive health was the source of the problems through either professional or informal means, caregivers commonly worked collaboratively with the affected individuals to determine how to reduce these occurrences. Laura recalled asking her husband what gives him “the most trouble with his memory.” She noted that his response, that he was having a “hard time remembering people,” gave her a better “idea of how to help him.”

Caregivers sometimes experienced ambivalence about the level of help they should provide the affected individual around a bout of confusion in the early stage. Janine, the wife of a man who had received a diagnosis of Alzheimer’s three months prior, explained: “I don’t know, maybe I help him too much. Maybe he needs to do the work to keep exercising his brain. ... But I don’t want to see him struggling to remember if he’s already checked the mail when I know he did. I can just so easily tell him what he’s struggling with.” For some, attempts to help were met with resistance. One caregiver, noted, “He didn’t like it when I filled in the word for him...”

Many affected individuals and caregivers spoke of the causes of sudden confusion or disorientation as “triggers” and sought ways to limit them in their lives. Caregivers commonly worked with the affected individual to discourage them from certain activities that could “trigger” confusion or disorientation. Some reported “negotiating” with their spouse or parent to restrict their involvement in certain activities requiring “quick decision making” or careful planning, such as driving, cooking, home repairs, and grocery shopping. Many caregivers described taking over primary driving duties because it lessened the likelihood that the affected individual would enter into a confused state. One caregiver-wife

of a man with Alzheimer's mentioned in a conversation with another caregiver that she "took over driving because he got too confused and it flustered him."

In sum, early on in the illness trajectory, affected individuals entered into bouts of confusion and disorientation in intermittent fashion. First, before trying to suppress or avoid these bouts, they along with friends and family engaged in definitional work to understand what was causing them. In a second stage, having established a progressive dementia as cause, caregivers attempted to define their role around bouts of confusion when they suddenly appeared. The process shifted from trying to define the problem to trying to determine what to do about occurrences of sudden impairment on a practical level.

From Collaborative to Unilateral Cognitive Support

As the disease progressed, affected individuals gradually disengaged from collaborative work seeking to reduce or avoid confused states with caregivers. From the caregiver point of view, the work shifted from trying to preserve states of lucidity or periods of clarity in concert with the affected individual to trying to minimize and control bouts of heightened impairment without their help. In this unilateral support stage, caregivers attempted to keep affected individuals from going into prolonged periods of deep confusion and disorientation, or what some described as "bouts," "spells," "fits," or "states" of greater "confusion," "disorientation," or less commonly, "delusion" and "hallucination." From the caregiver's perspective, the affected individual displayed a baseline state of impairment that was gradually worsening across the months or years and episodes of heightened confusion or disorientation intermittently-occurring across the day or week. I describe three forms of unilateral cognitive support approaches: pre-emptive conversational techniques, third-party interactional support, social-environment shifts.

Pre-emptive Conversational Techniques

Caregivers and kin relied upon conversational devices for increasing comprehension and avoiding a confused state in the affected individual. The sister of a man with Alzheimer's described her technique of contextualizing the statements she makes to her brother with extra contextual clues. "I try to be more specific to hopefully help him make connections when relaying information. Instead of just saying 'Dan,' I'll say, 'your brother Rick's son Dan,' in the hopes that he can follow me. If he says 'now who am I talking to,' I'll say 'your favorite baby sister Joan.'"

A psychologist and friend of a man with frontotemporal dementia described his technique of setting up their conversations in a strategic way to increase the likelihood of meaningful exchange. He noted, "[I] give clear preparatory clues about what I'm going to say. For example, 'Ed, we were talking about bicycles. I remember when we used to ride our bikes on the beach. Boy was that fun.' Notice that I didn't ask him if he remembered riding the bikes but I told him I remembered riding with him, which he may be able to enjoy even if doesn't explicitly remember it ... Also, by getting his head into the world of bicycles before telling my story he's more likely to process my story about riding bikes with him."

Eileen, the wife of a man with unspecified dementia, explained that she primarily “sticks to the here and now” when trying to involve her husband in conversation. Similarly, the psychologist introduced above noted that he carefully chooses conversational topics with his friend. When the impairment first set in, he recalled only soliciting information about his friend’s distant past rather than recent days or weeks. He explained, “He could go on and on about ice skating in Central Park and about the food at Coney Island growing up when he couldn’t talk about more recent weekends trips to the beach when we’d been together.” As the impairment deepened, he limited his choice of topics to more concrete subjects. “I never ... ask him about things not in our field of vision. I’ll more often comment on something I see and can point out to him or that I hear, thinking, perhaps wrongly, that these are more likely to be accessible to his awareness.”

In addition to these techniques, caregivers noticed that presenting the affected individual with too many options during personal care tasks, such as those related to eating and dressing, could cause states of confusion. As a pre-emptive technique, they avoided presenting multiple options about which individuals must deliberate. Sandra, the daughter of a woman with Alzheimer’s explained a common strategy among caregivers: “I used to ask her what she wants to eat or what she wants to wear ... [S]he would look in the closet with me and soon her head was swimming [she laughed]. I mean, you should see her closet. It’s a walk-in and it’s full ... I just assumed because she used to love clothes that it’d make her happy to choose something. But I guess it was too much. Now I just tell her ... Okay mom, you’re wearing this top and these pants.... That works better. It’s less confusing.”

Third-party Interactional Support

Caregivers and other kin engaged in a set of extemporaneous or situationally-emergent practices designed to help the individual with dementia maintain relative clarity in conversational exchanges with others. Individuals performing this role routinely intervene at the first sign of confusion, such as nonsensical statements, missed cues to speak, vocal trail-offs, etc., to guide the affected individual toward competent social exchange. Certain individuals, especially familial caregivers, claim special privileges to engage in this work because it commonly requires a more intimate knowledge of the affected individual’s mind. They must be able to anticipate what the dementia sufferer is trying to say or do when the expression comes out cryptically or the behavior seems confused. Caregivers took up the privileged position to explain the affected individual’s ambiguous displays in public interactions with strangers such as restaurant servers, but also at gatherings with close family members such as daughters and sons.

Ellen explained how she saw her role when her husband was socializing with others. “You just got to keep him straight in his facts or he’ll go off the deep end. They’ll just make things up sometimes and they’re not even trying to. They’re not lying, you know ... [T]hey just forgot the story.” Ellen and other caregivers saw themselves as operating as a form of surrogate memory for their spouses.

The first step in performing this work is identifying when impaired behavior has occurred. Identifying distortions of the past sometimes posed a challenge for spousal or other caregivers. Discussing this matter in an interview, Lorraine, the wife of a man with an

unspecified dementia, noted that sometimes she has to do a “bit of digging” to determine if he is distorting a memory from his past. “I can’t remember everything that’s ever happened to him ... Sometimes I’m wondering, did he really have a dog as a kid, ‘cause I can’t remember if he mentioned it [before] or not.”

A very common form of impromptu modification is editing. Editing is the process by which a caregiver or ally makes a meaningful change to the dementia sufferer’s statement in order to reign the mistaken individual back in and promote comprehension for a third party. Some edits are crucial for the conversation to proceed. Others reflect a concern with being historically or biographically accurate and would not cause a breakdown in the conversation if not performed. The following fieldnote provides an instance in which a caregiver’s edit helped sustain a conversation.

I had been visiting the home of Jerry [a man in his mid-seventies with Alzheimer’s] and Martha for several hours. We are standing and looking through a very large window at their backyard bird feeders while Martha tells me about the family of squirrels who steal from it. With a break in the conversation, Jerry turns to me and asks if I want to see a photo. “Absolutely,” I say. He walks over to a desk, opens a drawer, and retrieves a manila envelope. He carefully pulls out a 5×7 photograph, holding it out for both of us to examine.

“What is this?” I ask.

“This is the atom bomb... I helped work on it,” he replies. “See these?” he points to the stream of vapor trailing what seem to be missiles flying through the sky, “these are atoms.” His tone is matter of fact.

“Wow,” I respond. I study the photograph closer. I’m perplexed and not sure if I can really trust his description of it. I quickly try to decide if this man, who is in his mid-70s, is old enough to have worked on the Manhattan project. As I am thinking this through, his wife suddenly appears behind me, glancing at the photo from over my shoulder.

“He means the cruise missile,” she quickly adds. I look at Jerry who nods in agreement. Other than this factual distortion, Jerry seems lucid and personable.

With Martha’s editing of Jerry’s statement, we continue the conversation and I am able to formulate a meaningful response to his photograph that sustains the interaction for a few conversational turns.

In another instance, the facilitator at a support group meeting asked a man with dementia how he and his wife met. In a back and forth exchange, he offered short, but apparently accurate answers, until the final question.

She asks him how long he and his wife have been together. “We met in ’73,” he quickly offers with a closed mouth smile and nod. His wife immediately glances at her husband and then back at the facilitator, “We met in 1991.” He doesn’t show any reaction to the correction, looking pleasantly toward the facilitator as if his statement had not been corrected.

Caregivers also perform the task of contextualizing the affected individual's statement or providing further contextual clues to keep the individual on track and to facilitate understanding for others. The following occurrence at a support group meeting illustrated this technique:

The facilitator had asked for people to describe something they are looking forward to in the future. The wife of a man with an unspecified dementia begins to explain that she and her husband are getting ready for their son's wedding. She turns to her husband.

He begins to speak: "I'm going to be involved, standing up there... [2 second pause] with everyone."

Looking at her husband, his wife quickly adds, "He'll be the best man."

Several people quickly respond with, "Ohh."

Her husband repeats, "Best man."

Lastly, caregivers provide turn-taking prompts, or cues that it is the affected individual's turn to participate in a turn-taking sequence. In support group meetings for instance, the facilitator or other members routinely try to engage individuals with dementia in conversational exchanges. Frequently, affected individuals fail to pick up on the cue that someone is trying to speak to them or fail to notice that it is their turn to speak. Caregivers routinely prompt their loved one that it is their turn with a nudge or by turning to them and repeating the question that has been addressed to them.

Social-Environment Shifts

In addition to pre-emptive techniques and impromptu behavioral modifications, caregivers developed an understanding of the kinds of social environments that could elicit heightened states of confusion. They attempted to control with whom the affected individual spent time and in which activities they engaged. Barbara decided to reduce the amount of time her husband spent with one of his old friends because "[the friend] doesn't get it." "He argues with him when he starts getting the facts wrong. ... [T]he way he does it ... only agitates him.

Some caregivers spoke of reluctantly ending their social relationships with certain individuals because of the style and logistics of social activities that these individuals engaged in, such as the time of day that they were available for get-togethers. One caregiver noted, "I can't take him over to Jim and Dorothy's [their friends] anymore. It's the same thing every time. They want to get together late and I tell them that Arnold gets sundowners ... [I]t's too difficult to keep him calm and relaxed." Lorraine explained why she had lost contact with a couple who they had been friends with for twenty-five years. "I can't take him over there anymore. It gets too loud and confusing for him."

In sum, caregivers began adjusting to a baseline level of impairment and began working mostly unilaterally to minimize exacerbations of it. They engaged in several kinds of cognitive support techniques meant to sidestep or minimize states of impairment that could suddenly engulf the affected individual.

Cognitive Support Work Declines in Effectiveness

As the disease progressed and impairment deepened, caregivers discovered that affected individuals became less responsive to their techniques of support. Some reported gradually acquiescing to heightened moments of confusion, as they observed their once useful techniques declining in effectiveness. Norma described how her attempts to reduce confusion became less effective over time. “I don’t do half the things I used to. I used to stop him and say, ‘Honey, that’s not right, we never lived in [a local neighborhood].’ Now I don’t really say anything. He doesn’t really understand when I try [to correct him].”

The daughter-in-law of a man with frontotemporal dementia introduced earlier, echoed Norma’s experience. She reflected on her increasing difficulty connecting with him and offering support, “My husband, my 10-year old daughter, and I no longer feel we can connect with him. We often wonder if he’s still in there and just can’t communicate out or if he’s gone. It’s strange and awkward and at moments even creepy to have his body here, but not his personality ...”

As caregivers experienced a growing difficulty connecting with the affected individual and minimizing his or her heightened bouts of confusion, they began working on the individual less and more carefully choosing his or her social environments. Caregiver spouses sometimes found it difficult to maintain their old peer groups at this stage in the disease trajectory because the confused behaviors upset old friends who knew the individual with dementia before his or her more advanced decline. Caregivers spoke about re-engineering the affected individual’s social life so that disorientation, confusion, nonsensical talk, and similar displays would not upset or alienate others. Some began to favor support group friends over others. Barbara, the wife of a man with Alzheimer’s explained, “There’s an incredible burden with old friends for him to be who he used to be. I feel it and he feels it. With new groups, they don’t have the old Tom to compare him to and that’s actually nice.”

Seeking out environments that allowed for the affected individual’s displays of confusion and disorientation without causing a major disturbance, some caregivers developed folk understandings of the kind of people for whom the affected individual’s deepening impairment would not be upsetting. Martha, the wife of a man with Alzheimer’s, noted, “You begin to notice who will be fine with it and who won’t ... I’ve noticed, now I’m not sure if this is true everywhere, that African-Americans and other ethnic groups like Asians are more at ease with [impaired behaviors]. I think it’s because they don’t send their old folks off to nursing homes as much.”

The Motivations Behind Cognitive Support

Caregivers commonly treated moments of confusion as bi-directional threats. They could undermine both the well-being of the confused individual and the well-being of co-present others, including the caregiver, family members, and friends. Hence, caregiver attempts to reduce confused states commonly served the dual function of reducing the potential distress it could cause both the affected individual and others.

Preventing Distress in the Affected Individual

For caregivers, cognitive support was thought to provide benefits to the affected individual in two linked ways. First, caregivers generally believed that reducing confusion and disorientation would keep individuals with dementia in more calm and contented states. Second, such composed states, they believed, allowed affected individuals to maintain social relationships that they deemed beneficial to the affected individual's well-being more generally and disease prognosis in particular.

Caregivers expressed concern that if they allowed confused states to occur too frequently, they would alienate friends and family and effectively cut off their spouse's opportunities for meaningful interpersonal relationships. They attributed a tangible benefit to their loved one's mood and general well-being to social stimulation of various sorts. Helen was adamant about the benefits of social interactions for her husband. She noted, "Oh I know that it perks him up. As far as I can tell, it's the only thing that seems to help him. I don't think Aricept or Namenda [two common dementia medications] does it."

Beyond improvements in mood and well-being, many caregivers believed that the social stimulation of interpersonal relationships could delay the progression of the disease. The general sentiment was that the more they could keep the affected individual socially engaged, the longer he or she would be able to delay becoming fully subsumed by the impaired states. A friend of a man with Alzheimer's, for instance, used this therapeutic reasoning to explain his motivation to escort his friend to academic conferences on their shared substantive interests. "I had thought that the stimulation would help slow the decline of mental function and maybe it did for a while ..."

Within this therapeutic discourse, moments of confusion appeared as threats to social relationships and any cognitive benefits that could be derived from them. Cathy, the wife and caregiver of a man with Alzheimer's, put the matter in stark terms. "If he gets out of hand, I know the risks ... boom, we're out of the loop... we're not getting invited to things and pretty soon we're alone and who knows, he goes downhill faster."

After inquiring about the potential benefits of social interaction in a casual conversation with a caregiver after a support group meeting, she sent me several internet links touting the potential for regular social interaction to delay the progression of Alzheimer's. One link read: "A growing body of research indicates that stimulating the brain has the power to slow the progress of Alzheimer's, particularly in the early stages. ... Some research suggests that activities are especially protective when they involve interacting with others."²

Preventing Distress in Self and/or Others

From the perspective of caregivers, states of confusion and disorientation could also present threats to their own well-being and the well-being of others. While many caregivers treated these occurrences as obstacles to their personal care duties—they believed that it was less challenging to help someone through everyday personal care tasks like bathing, dressing, eating, etc., with less confusion and disorientation complicating their work—their concerns

²Retrieved on 3.10.13 from <http://www.caring.com/articles/slowing-alzheimers-progress>

to minimize confused states went beyond their desire to keep personal care challenges to a minimum.

Caregivers and other family members reported that displays of impairment were emotionally difficult to watch and often tried to minimize them to avoid upsetting themselves. They conveyed two logics behind this explanation: incomprehensible speech or other disoriented behavior could indicate that their loved one is suffering or these states could transform their loved one into someone whom they did not recognize. One member of the group noted, “To be honest, I can’t take it. It’s upsetting to see the smartest person you know unable to count out change or tell time ... I do whatever I can to keep him relatively clear. Really, it’s upsetting.”

Displays of impairment were emotionally difficult for friends and family who were still coming to terms with the extent of the decline or were too young to understand it fully. Caregivers sometimes tried to reduce this potentially upsetting behavior in the presence of vulnerable others to avoid upsetting them. Helen, a spouse-caregiver, described her strategic efforts to limit displays of impairment in front of her grand-daughters. “I run an extra tight ship when Lily and Erica visit ... I don’t want them to be afraid of their grandpa ... I think they would get pretty upset if he started calling them by the wrong names or whatever...”

The inability to recognize close friends and family members can be distressing to the unrecognized individuals. Lydia, the wife and caregiver of a man with an unspecified dementia, recalled a poignant incident: “His sister came to visit and he hadn’t seen her in over a year. He was doing really good that day. ... But when she came he didn’t know who she was and that devastated her. ... She excused herself to the bathroom at one point and I went back to talk to her. She was pretty torn up. ... [That] was her big brother.”

Confused states also posed situational threats from the perspective of caregivers. Caregivers routinely expressed concern that the affected individual might disturb others through ‘strange’ behavior, such as making statements that do not fit a conversation, spontaneously singing, not responding in conversation when addressed, and similar behaviors. At a support group meeting, for instance, Janice, a caregiver, began sharing a story of a recent family reunion when Edna, a woman in her mid-nineties with Alzheimer’s began singing loudly.

“Laa-dahhh-dahhh-dEE [raising in volume on the last note] ...” Her caregiver-son, Ron, smiles and looks around at the rest of the group sheepishly. Janice stops her story when the singing grows so loudly that few people seem able to hear what she is saying. Ron whispers something to his mother and she stops. Janice starts to tell her story again and Edna once again begins to sing. Several people sigh audibly and shake their heads in a display of frustration. The group facilitator seems intent on ignoring the disturbance.

These instances generally posed a challenge to the immediate conversation or social engagement and caregivers commonly described them as “unpleasant” or “stressful.”

Caregivers spoke of managing the affected individual’s interactions with others to prevent such situational sources of distress. For instance, Arlene saw the work of minimizing confused states as a straightforward procedure of “trying not to ruffle any feathers.” She

continued, “They’ve forgotten the rules of normal social intercourse. You’ve just gotta remind them ... usually over and over again [she laughed].” Similarly, Ellen noted, “Mostly I’m just his ambassador trying to keep him out of trouble ... [I’m] making sure he doesn’t drink someone else’s coffee at [the café].”

Discussion

This study documents a three-stage process through which informal caregivers provide cognitive support for a family member with dementia. In a first stage, caregivers attempted to interpret the meaning of puzzling cognitive disturbances and determine their role in managing them in collaboration with the affected individual. In a second stage, caregivers began taking over most of the work of managing these behaviors as their loved one became less able to assist them due to the advancement of the disease. In this stage, caregivers developed and deployed various unilateral techniques designed to minimize confused states. In a third stage, caregivers began utilizing these practices less frequently as they noticed their declining effectiveness. While prior research describes various caregiver techniques for lessening occurrences of confusion and disorientation and promoting autonomy, few if any studies describe the process by which caregivers take on the role of cognitive support practitioner. It is by describing how individuals transition into this role and struggle to do the work effectively that research begins unearthing some of the distinct challenges of providing this form of care.

A more comprehensive perspective on cognitive support work must take into consideration the larger medical-cultural context in which it develops. While families in this study routinely sought out and relied upon medical expertise for diagnostic purposes early on, granting medical doctors the final explanatory authority over “strange” cognitive behaviors, in the post-diagnostic period many discovered that medical expertise was only modestly effective for managing moments of confusion and disorientation. Caregivers responded to the dearth of effective medical options by developing their own highly idiosyncratic techniques for reducing various behavioral manifestations of confusion and disorientation. While they gradually developed a lay expertise that some felt exceeded the effectiveness of commonly prescribed symptom management medications like Aricept and Namenda, many nonetheless proceeded with a patchwork of lay and professional approaches to symptom management in order to ensure that they were providing optimal caregiving. When lay care declined in effectiveness in the third stage of cognitive support work, they entered into a symptom management gap in which they found little expertise, lay or professional, on which to rely.

Evidence from this study suggests that there may be limits to how widely cognitive support work is practiced across care settings. Several factors may discourage formal caregivers, for instance, from using these or similar cognitive support techniques in long-term care facilities. First, there is indication that many individuals who enter long-term care facilities do so because they have reached a phase of the disease that does not respond well to informal care (such as cognitive support techniques) by family members (Caron et al., 2006; Cohen et al., 1993), reducing the likelihood that formal caregivers will find such techniques to be compelling options. Second, formal caregivers must be motivated to reduce confused

states when doing so is not formally specified in their job description. For informal caregivers, such as spouses, episodes of confusion motivate them to reduce such displays because they are commonly distressing to them, even when they do not act as obstacles to daily caregiving tasks, like bathing and dressing. In contrast, signs of decline from the perspective of a formal caregiver may appear less distressing and elicit less effort to minimize them, unless the confused states are acting as obstacles to daily caregiving duties. Third, some techniques of cognitive support, such as editing the affected individual's statements in an effort to curb an episode of confabulation, require the caregiver's familiarity with the care recipient's biography. As a segment of the care industry plagued by high turnover and understaffing (Castle, 2006), the typical level of familiarity between staff and care recipients may be insufficient for much of the cognitive support work that spousal caregivers readily provide.

Prior research indicates that formal caregivers do not typically engage in the subtle work of helping individuals find clarity during bouts of heightened confusion, relying on what some describe as harmful shortcuts in behavioral interpretation instead (see Dupuis et al., 2012; Downs et al., 2006; Lyman, 1988; Gubrium & Lynott, 1987). Downs et al. (2006), for instance, introduce the concept of 'diagnostic overshadowing' to describe the practice in which care staff members tend to see the entirety of the affected individual's behavior as "attributed to the labeled condition" (240). Drawing on this concept, Dupuis et al. (2012) document how staff members in a long-term care facility see the behaviors of affected individuals through a "lens of pathology" rather than as meaningful efforts to achieve some desired end. These practices appear antithetical to the work of cognitive support practitioners who seek to minimize confusion so that affected individuals may maintain self-directed behavior. Assuming that all of an individual's behavior is a meaningless muddle of pathology is not a productive vantage point from which to support cognition. If the interpretive approaches described by Downs et al. (2006) and Dupuis et al. (2012) are common in care facilities, cognitive support work is likely infrequently practiced.

Documenting the process by which caregivers undertake the work of cognitive support may improve the effectiveness of interventions designed to help caregivers. Citing only modest effectiveness of pharmacological approaches along with worrisome side-effects, today many studies urge nonpharmacological approaches for managing the symptoms of dementia (see Gitlin et al., 2012). While these recommendations generally seem wise, most studies make them without appreciating that informal caregivers may have successfully managed many symptoms on their own for many years using informal cognitive support techniques before seeking support from health care professionals. When caregivers do seek formal help, they are likely doing so after their own indigenous techniques have declined in effectiveness and they need further support. At this point, they have entered the third stage of cognitive support work, or a stage in which their efforts have become less effective and they have begun to look for new ways to manage the affected individual's symptoms. Attempts to support caregivers in managing symptoms should begin from an understanding of where caregivers are in the trajectory of cognitive support work and the kinds of practices that they still deem effective. Professional support that builds from existing lay understandings promises more effectively to bridge the lay/professional divide and achieve greater adherence to the interventions they propose.

The study's contributions must be tempered by important limitations regarding its generalizability. A majority of the study's participants were well-educated, white middle-class individuals over the age of 65 who regularly participated in dementia support groups. While the basic practices of cognitive support were present across this sample, it is difficult to say to what extent the practice is culturally peculiar to them. Research now strongly suggests many important variations in dementia caregiving practices across racial-ethnic lines (see Lee & Diwan, 2010; Jett, 2006; Jones et al., 2006; Ortiz & Fitten, 2000). Future research can determine to what extent cognitive support is a product of the socio-cultural context of the current study's participants or a form of work that transcends racial, ethnic, and cultural lines.

In a second issue regarding generalizability, the study relied on a mixed sample of dementia subtypes, including Alzheimer's disease, frontotemporal dementia, and Lewy body dementia. While there is utility in grouping subtypes together because of their overlapping behavioral symptoms of confusion and disorientation, research indicates that certain cognitive symptoms tend to cluster with certain dementia subtypes (Chiu et al. 2006). Future research could increase in precision by investigating the ways in which cognitive support practices vary by subtype.

In closing, it is important to note that the practices of cognitive support are not exclusive to dementia caregiving. Providing assistance to others in maintaining clear or unconfused thinking is a dimension of work familiar to those who care for individuals with intellectual disabilities and a dimension of work normal-functioning peers do for one another when, for instance, a name or location is forgotten or misremembered in routine social encounters due to normal oversight. Within spousal dyads, dementia disrupts the reciprocal exchange of cognitive support that many individuals provide for one another. Through the dementing process, affected individuals involuntarily lose legitimacy to help others while simultaneously drawing on these others for greater assistance. Hence, cognitive support in dementia caregiving constitutes an asymmetrical version of a normally-occurring process of reciprocal cognitive support in everyday interpersonal relationships.

Acknowledgements

Research reported in this publication was supported by the National Institute on Aging of the National Institutes of Health under Award Number T32AG000029. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. I would like to express my gratitude to all of the caregivers and care recipients who participated in this research. I thank Alice Goffman, Alexandra Murphy, Forrest Stuart, Lydia Manning, Carolina Apesoa-Varano, and Robert Emerson for useful comments on an earlier version.

References

- Anthony-Bergstone CR, Zarit SH, Gatz M. Symptoms of psychological distress among caregivers of dementia patients. *Psychology and Aging*. 1988; 3(3):245–248. [PubMed: 3268265]
- Arcona S, Hatoum H, Thomas S, Lin S, et al. Effect of Rivastigmine on the Disruptive Behavior of Nursing Home Residents with Alzheimer's Disease. *The Gerontologist*. 2004; 44(1):255.
- Beard RL. In their voices: Identity preservation and experiences of alzheimer's disease. *Journal of Aging Studies*. 2004; 18(4):415–428.

- Beard RL, Knauss J, Moyer D. Managing disability and enjoying life: How we reframe dementia through personal narratives. *Journal of Aging Studies*. 2009; 23(4):227–235.
- Blum NS. The management of stigma by alzheimer family caregivers. *Journal of Contemporary Ethnography*. 1991; 20(3):263–284.
- Bradshaw J, Saling M, M Hopwood M, Anderson V, Brodtmann A. Fluctuating cognition in dementia with lewy bodies and alzheimer's disease is qualitatively distinct. *J Neurol Neurosurg Psychiatry*. 2004; 75:382–387. [PubMed: 14966152]
- Caron CD, Ducharme F, Griffith J. Deciding on institutionalization for a relative with dementia: The most difficult decision for caregivers. *Canadian Journal on Aging*. 2006; 25(2):193–205. [PubMed: 16821201]
- Carpentier N, Bernard P, Grenier A, Guberman N. Using the life course perspective to study the entry into the illness trajectory: The perspective of caregivers of people with alzheimer's disease. *Social Science & Medicine*. 2010; 70(10):1501–1508. [PubMed: 20207459]
- Castle NG. Measuring staff turnover in nursing homes. *The Gerontologist*. 2006; 46(2):210–219. [PubMed: 16581885]
- Charmaz, K. The grounded theory method: An explication and interpretation. In: Emerson, R., editor. *Contemporary field research: A collection of readings*. Prospect Heights, IL: Waveland; 1983. p. 109-126.
- Chiu MJ, Chen TF, Yip PK, Hua MS, Tang LY. Behavioral and psychologic symptoms in different types of dementia. *Journal of formosan medical association*. 2006; 105(7):556–562.
- Chrisp TAC, Thomas BD, Goddard WA, Owens A. Dementia timeline: Journeys, delays and decisions on the pathway to an early diagnosis. *Dementia*. 2011; 10(4):555–570.
- Clare L, Rowlands J, Bruce E, Surr C, Downs M. 'I don't do like I used to do': A grounded theory approach to conceptualising awareness in people with moderate to severe dementia living in long-term care. *Social Science & Medicine*. 2008; 66(11):2366–2377. [PubMed: 18325650]
- Clark PC, Kutner NG, Goldstein FC, Peterson-Hazen SM, Garner VB, Zhang RM, Bowles T. Impediments to timely diagnosis of alzheimer's disease in african americans. *Journal of the American Geriatrics Society*. 2005; 53(11):2012–2017. [PubMed: 16274388]
- Cohen-Mansfield J. Nonpharmacologic interventions for inappropriate behaviors in dementia: A review, summary, and critique. *The American Journal of Geriatric Psychiatry*. 2001; 9(4):361–381. [PubMed: 11739063]
- Cohen CA, Gold DP, Shulman KI, Wargon M. Factors determining the decision to institutionalize dementing individuals: A prospective study. *The Gerontologist*. 1993; 33(6):714–720. [PubMed: 8314097]
- Devanand DP, Marder K, Michaels KS, Sackeim HA, et al. A randomized, placebo-controlled dose-comparison trial of haloperidol for psychosis and disruptive behaviors in alzheimer's disease. *The American Journal of Psychiatry*. 1998; 155(11):1512–1520. [PubMed: 9812111]
- Donaldson C, Tarrier N, Burns A. The impact of the symptoms of dementia on caregivers. *British Journal of Psychiatry*. 1997; 170:62–68. [PubMed: 9068778]
- Doody RS, Stevens JC, Beck C, Dubinsky RM, Kaye JA, Gwyther L, Mohs RC, Thal LJ, Whitehouse PJ, DeKosky ST, Cummings JL. Practice parameter: Management of dementia (an evidence-based review). Report of the quality standards subcommittee of the american academy of neurology. *Neurology*. 2001; 56(9):1154–1166. [PubMed: 11342679]
- Downs, M.; Clare, L.; Mackenzie, J. Understandings of dementia: Explanatory models and their implications for the person with dementia and therapeutic effort. In: Hughes, JC.; Louw, SJ.; Sabat, SR., editors. *Dementia: Mind, meaning and the person*. Oxford, UK: Oxford University Press; 2006. p. 235-258.
- Emerson, R.; Fretz, R.; Shaw, L. *Writing ethnographic fieldnotes*. Chicago: University of Chicago Press; 1995.
- Fontana A, Smith RW. Alzheimer's disease victims: The "unbecoming" of self and the normalization of competence. *Sociological Perspectives*. 1989; 32(1):35–46.
- Gitlin LN PhD, Kales HC MD, Lyketsos Constantine G MD, MHS. Nonpharmacologic management of behavioral symptoms in dementia. *JAMA*. 2012; 308(19):2020–2029. [PubMed: 23168825]
- Goffman, E. *Presentation of self in everyday life*. New York: Anchor; 1959.

- Goffman, E. *Asylums*. New York: Anchor; 1961.
- Goffman, E. *Stigma: notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice Hall; 1963.
- Gubrium J, Lynott R. Measurement and interpretation of burden in the alzheimer's disease process. *Journal of Aging Studies*. 1987; 1(3):265–285. [PubMed: 25195724]
- Hinton L, Franz C, Friend J. Pathways to dementia diagnosis: Evidence for cross ethnic differences. *Alzheimer Disease & Associated Disorders*. 2004; 18(3):134–144. [PubMed: 15494619]
- Hersch EC, Falzgraf S. Management of the behavioral and psychological symptoms of dementia. *Clinical Interventions in Aging*. 2007; 2(4):611–621. [PubMed: 18225462]
- Jett KF. Mind-loss in the african american community: Dementia as a normal part of aging. *Journal of Aging Studies*. 2006; 20(1):1–10.
- Jones RS, Chow TW, Gatz M. Asian americans and alzheimer's disease: Assimilation, culture, and beliefs. *Journal of Aging Studies*. 2006; 20(1):11–25.
- Knopman D, Donohue JA, Guterman EM. Patterns of care in the early stages of alzheimer's disease: Impediments to timely diagnosis. *Journal of the American Geriatrics Society*. 2000; 48(3):300–304. [PubMed: 10733057]
- Krull, Amy C. First signs and normalizations: Caregiver routes to the diagnosis of Alzheimer's disease. *Journal of Aging Studies*. 2005; 19(4):407–417.
- Lee SE, Sathna D. What do korean american immigrants know about alzheimer's disease (AD)? The impact of acculturation and exposure to the disease on AD knowledge. *International Journal of Geriatric Psychiatry*. 2010; 25(1):66–73. [PubMed: 19551701]
- Livingston G, Johnston K, Katona C, Paton J, Lyketsos CG. Systematic review of psychological approaches to the management of neuropsychiatric symptoms of dementia. *The American Journal of Psychiatry*. 2005; 162(11):1996–2021. [PubMed: 16263837]
- Lu YY, Austrom MG, Perkins SM, Bakas T, Farlow MR, He F, Jin S, Gamst A. Depressed mood in informal caregivers of individuals with mild cognitive impairment. *American Journal of Alzheimer's Disease and Other Dementias*. 2007; 22(4):273–285.
- Lyman, K. Infantilization of elders: Day care for alzheimer's disease victims. In: Wertz, D., editor. *Research in the Sociology of Health Care*. Greenwich, CT: JAI Press; 1988. p. 71-103.
- Nalbantian, S.; Matthews, PM.; McClelland, JL., editors. *The memory process: Neuroscientific and humanistic perspectives*. Cambridge, Mass.: MIT Press; 2010.
- Ortiz F, Fitten LJ. Barriers to healthcare access for cognitively impaired older Hispanics. *Alzheimer Disease & Associated Disorders*. 2000; 14(3):141–150. [PubMed: 10994655]
- Perry J, O'Connor D. Preserving personhood: (Re)membering the spouse with dementia. *Family Relations*. 2002; 51(1):55–62.
- Pruchno RA, Resch NL. Aberrant behaviors and alzheimer's disease: Mental health effects on spouse caregivers. *Journal of Gerontology*. 1989; 44(5):S177–S182. [PubMed: 2768777]
- Rowe MA, Glover JC. Antecedents, descriptions and consequences of wandering in cognitively-impaired adults and the safe return (sr) program. *American Journal of Alzheimer's Disease and Other Dementias*. 2001; 16(6):344–352.
- Schulz R, O'Brien AT, Bookwala J, Fleissner K. Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist*. 1995; 35(6):771–791. [PubMed: 8557205]
- Teri L. Behavior and caregiver burden: Behavioral problems in patients with alzheimer's disease and its association with caregiver distress. *Alzheimer's Disease and Associated Disorders*. 1997; 11(4):S35–S38.
- Timmermans, S.; Tavory, I. Advancing ethnographic research through grounded theory practice. In: Bryant, A.; Charmaz, K., editors. *Handbook of grounded theory*. London: Sage; 2007. p. 493-513.
- Werner P, Mittelman MS, Goldstein D, Heinik J. Family stigma and caregiver burden in alzheimer's disease. *The Gerontologist*. 2012; 52(1):89–97. [PubMed: 22048807]
- Wilks SE, Little KG, Gough HR, Spurlock WJ. Alzheimer's aggression: Influences on caregiver coping and resilience. *Journal of Gerontological Social Work*. 2011; 54(3):260–275. [PubMed: 21462058]

Yuhas N, McGowan B, Fontaine T, Czech J, Gambrell-Jones J. Psychosocial interventions for disruptive symptoms of dementia. *Journal of Psychosocial Nursing & Mental Health Services*. 2006; 44(11):34–42. [PubMed: 17128678]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Highlights

- Cognitive support work is a dimension of dementia caregiving
- Cognitive support work involves using techniques for trying to minimize various manifestations of confusion
- Individuals transition into and then out of cognitive support work in three stages
- In a first stage, caregiver and affected individual collaborate to preserve lucidity
- In a second stage, caregivers begin unilateral efforts to minimize confusion
- In a third stage, caregivers discover that their techniques decline in effectiveness as the disease advances

Table 1

Characteristics of care recipients discussed by caregivers and other kin in interviews

Characteristic	Care Recipients	
	N	Pct.
<i>Sex</i>		
Female	4	20
Male	16	80
<i>Age</i>		
35–54	0	0
55–64	5	25
65–99	15	75
<i>Race/Ethnicity</i>		
African-American	3	15
White	17	85
<i>Highest Education Level</i>		
High School	4	20
College or above	15	75
Unknown	1	5
<i>Marital Status</i>		
Married	14	70
Single/Divorced	1	5
Widowed	5	25
<i>Dementia Subtype</i>		
Alzheimer's	9	45
Frontotemporal	2	10
Lewy body Dementia	2	10
Unknown Subtype	7	35
<i>Primary Caregiver</i>		
Spouse	15	75
Adult-Child	3	15
Other	2	10