



Minimizing confusion and disorientation: Cognitive support work in informal dementia caregiving[☆]



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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 work as a concept within dementia caregiving.

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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 (Anthony-Bergstone, Zarit, & Gatz, 1988; Donaldson, Tarrier, & Burns, 1997; Hersch & Falzgraf, 2007; Lu et al., 2007; Pruchno & Resch, 1989; Schulz, O'Brien,

Bookwala, & Fleissner, 1995; Teri, 1997; Wilks, Little, Gough, & Spurlock, 2011). While a steady stream of research has tested the effectiveness of both pharmacological and non-pharmacological approaches to managing these behaviors (see Algase et al., 1996; Arcona, Hatoum, Thomas, Lin, et al., 2004; Cohen-Mansfield, 2001; Devanand, Marder, Michaels, Sackeim, et al., 1998; Livingston, Johnston, Katona, Paton, & Lyketsos, 2005; Rowe & Glover, 2001; Yuhas, McGowan, Fontaine, Czech, & Gambrell-Jones, 2006), 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

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¹ By 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.

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 (Carpentier, Bernard, Grenier, & Guberman, 2010; Crisp, Thomas, Goddard, & Owens, 2011; Clark et al., 2005; Hinton, Franz, & Friend, 2004; Knopman, Donohue, & Guterman, 2000; Krull, 2005). 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, 2004; Beard, Knauss, & Moyer, 2009; 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 (Fontana & Smith, 1989; Perry & O'Connor, 2002). Perry and O'Connor (2002), for instance, explain how caregivers protect their spouse with dementia from distressing moments of “incompetence” by lessening the 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 (Beard, 2004; Blum, 1991; Perry & O'Connor, 2002; Werner, Mittelman, Goldstein, & Heinik, 2012). Drawing from Erving Goffman (1959, 1963), 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 charts 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

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