

# Towards a more complete picture of discourse in dementia studies

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**Abstract.** Although research at the intersection of language and dementia has matured over the past several decades, much still needs to be accomplished in the quest to understand how discourse relates to the quality of everyday life for individuals living with dementia. Toward this goal, this essay proposes four concrete steps that scholars can take in the design and execution of their studies to move collectively and incrementally toward a more complete picture of discourse in dementia: (1) move beyond interviews and casual conversations as primary sources of data; (2) video record activities to allow for multimodal analyses; (3) develop sustained collaborative relationships with families, institutions, and/or individuals with dementia; and (4) seek out partners in other disciplines.

**Keywords.** dementia; interactional sociolinguistics; multimodal analysis; aging; communication

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Over the course of my career as an interactional sociolinguist I have enjoyed the great privilege of learning from and collaborating with scholars and professionals who have also devoted their lives to exploring issues grounded in the lived experience of dementia (see for example Hamilton 1994 and Hamilton 2019). Based on these many interactions I am pleased to add my thoughts to those of my colleagues in this inaugural issue of the *Journal of Language and Aging Research*. As I enter into the first years of my retirement, it is in the spirit of a figurative passing of the baton that I offer these recommendations to guide those at the outset of their careers in this fascinating and consequential area of study.

Thirty-five years ago, when work at the intersection of language and dementia was in its relative infancy, Bayles and Kaszniak recommended that scholars systematically investigate conversational abilities of individuals with dementia to supplement traditional research focused on standardized testing within experimental and clinical paradigms—not

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only because decline in conversational abilities was thought to be an early marker of dementia, but also because discovering how such individuals navigate conversational interactions could shed light on important and varied dimensions of their everyday lives (Bayles and Kasniak 1987, 175). Since then, linguists have responded with great energy and creativity (for useful reviews see Kindell et al. 2017 and Hamilton 2020) to highlight critical connections between language use and quality of life in dementia, although significant gaps remain. With an eye towards advancing the insights of this foundational research, I urge scholars to consider the following points as they design their studies, collect and analyze their data, make theoretical contributions, and translate their findings into practice. In this way, we will move collectively and incrementally towards a more complete picture of discourse in dementia.

**1. Move beyond interviews and casual conversations to illuminate a more expansive landscape of social life involving individuals with dementia.** Most research to date has focused on multiple dyadic or triadic interactions that involve individuals with dementia communicating with researchers, family members, and/or healthcare professionals. In order to learn more about relative communicative strengths and weaknesses of those with dementia, as well as how others in their social worlds may help or hinder this communication, we need to study interactions that involve such individuals engaging with a variety (in number and type) of interlocutors in a range of public and private situations, including the following:

- everyday routines (e.g., getting dressed; taking medication; mealtimes; moving around one's residence)
- social events (e.g., coffee breaks; parties; movies; concerts; sporting events)
- talk-based activities (e.g., reminiscing; support groups; news discussions)
- physical activities that can be supported by talk but do not require it (e.g., cooking; gardening; armchair exercise; dancing; arts and crafts; creating music)
- engaging with professionals (e.g., bankers, physicians; attorneys; spiritual advisers)

Given the multifaceted nature of social life, there are no limits to this exploration as long as care is taken to identify relevant dimensions of selected activities that allow for systematic comparison with findings of previous investigations. For example, when selecting activities, consider how language relates to the ongoing activity (e.g., whether it plays a central, supportive, or minimal role); how the physical surroundings (including the presence of objects) shape the interaction; and how the activity draws on various domains of knowledge, engenders positive and/or negative emotions, and offers individuals opportunities to demonstrate personal agency.

**2. Video record activities to allow for subsequent multimodal analysis.** The decision to move beyond interviews and casual conversations to study the wider range of activities outlined above requires an associated move away from audio recordings that capture only the sounds (linguistic and paralinguistic) of language to audio-video recordings that also capture non-vocal (gestures, eye gaze, facial expressions) aspects of communication, physical alignments between and across participants, and the use of and reference

to objects (e.g., cooking utensils; gardening tools; art supplies) within the physical environment. This shift becomes critically important in studies that include individuals with advanced stages of dementia, as audio-only recordings are inadequate to capture the communication beyond words that characterizes many in this population.

**3. Develop sustained collaborative relationships with families, institutions, and/or individuals with dementia at the heart of the investigations.** Researchers' significant investments of time and energy into building such relationships will undoubtedly lead to valuable ethnographic insights that help situate research findings. The associated time-won trust of those involved may allow interested scholars to launch the kinds of time-intensive longitudinal studies necessary to follow individuals' changes in language and communication over time.

**4. Seek out partners in other disciplines.** Being part of the fascinating and important study of language and dementia is as exhilarating as it is overwhelming. The sheer numbers of interactions to be collected and analyzed present a daunting challenge; the complexity and dire nature of the issues can lead some scholars to feel too small for the job. Recognizing one's limits of time, energy, and scope can be instructive if this recognition leads one to reach out to researchers and practitioners in other disciplines. Such interdisciplinary teamwork can offer welcome relief and creative solutions as the work is shared and the issues come to be viewed through different eyes (see Goodwin 1994 on 'professional vision').

In closing, the future of research into the interrelationships between language and dementia looks bright if scholars continue to reach out to collaborators within linguistics and elevate their intellectual gaze to include partners in other disciplines, as well as those whose lives are affected by dementia. Mounting evidence from multiple well-defined studies will help us attain our goal: to understand how the biological, cognitive, psychological and social changes that individuals identify as the experience of dementia influence the way these individuals use language and, conversely, how individuals' use of language may influence the biological, cognitive, psychological and social changes that they and others perceive and identify as dementia.

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