

Current Language Issues in Enhancing Dementia Discourse With Digital Caregiver Guides

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As the world's population ages, we see a commensurate increase in the cohort of adults in every country who are living with various dementias. After a brief definition of dementia, using the example of Alzheimer's disease, Section I draws on applied linguistics and pragmatics perspectives to illustrate features of dementia discourse as they occur in conversational narratives, particularly of reminiscence: represented speech of others and repetition. Section II describes the need for materials to introduce education about language, aging, and dementia to formal and informal caregivers, focusing on China and the USA. By formal caregiver, we mean clinical and other personnel in hospitals and a range of healthcare facilities for aging persons; informal caregivers are home care aides, direct care workers and family members. Section III discusses preliminary work with graphic medicine in the form of digital caregiver guides in four languages.

Keywords: dementia discourse, interpersonal pragmatics, cultural competence, caregiver guides

Introduction

Dementia of any kind occurs as a result of a number of injuries or diseases affecting the brain in some way, according to WHO (World Health Organization: www.who.int); it is not a normal part of the aging process. It includes "neurocognitive conditions in which there is a progressive, irreversible decrease in cognitive abilities" (Davis & Maclagan, 2021, p.1). On a worldwide basis, the millions of persons with dementia, who are typically over 60, result in a highly expensive burden on family

and formal caregivers estimated in the USA as 14 times the revenue of McDonald's (AD F&F [Alzheimer's Disease Facts and Figures] 2022, p. 39). The expense is physical, social, and possibly even moral as well as financial. Nor are medical establishments able to diagnose and treat dementia. Alzheimer's, for example, which represents nearly 70% of the conditions, can be confidently diagnosed by specialists and fully decided only at autopsy.

Wisdom tales from everywhere in the world feature the sayings of aged prophets while their audience laments the disintegration of usefulness, strength, and intelligence of ordinary people and the need to do something to care for them. The twentieth century found researchers beginning to examine the intersections of language aging, as summarized by Kemper and Anagnopoulos (1989). Some concern for investigating language disabilities had begun to surface in, for example, aphasia but only from the perspective of what Eling and Whitaker (2009) report as "word recognition and production; linguistic principles played no role"(p. 571). As fields in linguistics increased, so did the awareness of the need to study language production as it occurred across the life span. Emphasis grew on how language abilities and discourse practices might decline, improve, or be improved in old age given a

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sociolinguistic context (Coupland et al., 1991) or emphasis on stages in language production from psycholinguistics (Marini & Andreetta, 2016). By the midpoint of the nineteen-nineties, change in the speech or writing of people such as former President Reagan was an object of study. Researchers on acquired disorders such as dementia expanded their focus on medical diagnosis and potential alleviation and initiated an emphasis on social contexts (e.g., Hamilton, 1994; Ramanathan, 1997). By 2005 writers from thirteen different if related disciplines could write with confidence about transcripts and recordings from a corpus of recorded and transcribed spontaneous speech from persons with mild to moderate dementia (Davis, 2005).

Section I: Applied Linguistics and Dementia Discourse: Pragmatic Perspectives

Any of the areas of study in formal and in applied linguistics can be drawn upon to study language in dementia. The present study grows from findings from applied linguistics. It first draws on interpersonal pragmatics to examine repetition and represented speech in a conversational narrative both in person and online. It then moves to look at how linguistics findings support the development of a multilingual graphic intervention for communication in troublesome situations faced by dementia caregivers who may speak a language or variety other than that of the care recipient.

As Locher and Graham (2010) explain it, *interpersonal pragmatics* draws on a sociocultural perspective to look at how “social actors use language to shape and form relationships” (p. 1) with a focus on how the range of roles in those relationships affect the ways people choose their language. As Davis (2010) comments, interpersonal pragmatics is very like *interactional sociolinguistics* (p. 381), each of which is basically interdisciplinary. Either approach is useful for looking at language in health and medical contexts from any of four groups of researchers. These fall into “linguists who study health discourse, clinical linguists, health communications studies specialists, and clinicians” (Davis, 2010, p. 382). In their 2015 exploration of discourse and aging, Hamilton and Hamaguchi add to these groups depending on whether the researcher studies cognitive aging, or social identities, interactions across the life span, or public discourse about aging (2015, p. 706). That public discourse is increasingly likely to be digital and in more than just English. “Analyses of social media concerned with ADRD [Alzheimer’s Disease and Related Dementias] in languages other than English have not yet appeared in great number” (Davis et al., 2021, p. 186); however, discussions of twitter, support groups and video analyses by and of persons with dementia and

no longer only their caregivers are beginning to appear on the Internet.

Of increasing interest are stories that are either elicited or volunteered in spontaneous conversation. These stories generally fall into one of five types:

1. Stories in which the conversation partner (CP) provides minimal prompts so that the person with dementia is still able to tell a reasonably complete story;
2. Small stories which sound like everyday events and are usually ignored by the CP, very short stories told “in passing” (cf. studies and examples of small stories with full examples by Georgakopoulou, 2007; Georgakopoulou & Spilioti, 2016);
3. Shadow stories that remain “hidden” behind the conversation unless the CP probes;
4. Chunks of a story, usually the high point or evaluation, which appear without context or elaboration;
5. Chronicles or accounts that do not contain any narrative structure. (Davis & Maclagan, 2021, p. 6)

Any of the first four are likely to contain reminiscence, reported speech—either of oneself at an earlier time of life or of another person—or repetition of a word or story. The following (Table 1), taken from Davis (2020, p. 289) is a useful set of questions for learning about the conversation in dementia from an interpersonal pragmatics perspective before moving to look more closely first at several aspects of reminiscence, and then at repetition, which is a complex set of choices.

Table 1

Set of Questions for Learning About Conversation in Dementia

Impression/identity management	What kind of impression do participants seem to want to make? How are they doing this? Any specific language usage?
Discourse management	What words do people use in each conversation to introduce a story, to stall, to back up and start over? How does a person “keep the floor” or signal that the other person can change the subject?

In this example of reminiscence among “Glory Mason” (G), a person with Alzheimer’s disease, a caregiver, and a visitor, we see an interpersonal pragmatic device, repetition, used to support G as someone who is competent and happy. The repeats strengthen her sharing a reminiscence that displays her as strong (Davis, 2010, p. 394) and present the visitor and caregiver as showing positive affect in a social relationship. Numbers are taken from the original transcript; dots signal lengthy pauses.

Example 1

1. G: I just lived in a regular farm home. Farmed cotton, corn, eh-everything
2. you ... grow on a farm.
3. B: That's right.
4. G: I had a big ol' cotton bag tied around me, pickin' a hundred pounds of
5. cotton ... Uhhmm Hmm.
6. B: A hundred pounds? An' you so tiny!
7. G: Huh?
8. L: You're a tiny person to be carrying that much cotton
9. G: I decided one day I'd pick a hundred pounds. Guess how much!
10. L: How much?
11. G: A hundred and three.

Reminiscence therapy as a specific activity is typically undertaken in small groups of persons living with dementia either in a memory care facility or activity center (Moon & Park, 2020). Its impact is frequently measured by engagement scales such as the video-based analysis of Jones et al. (2015). Such group therapy has been shown to alleviate depression and increase quality of life (see literature review by Cuevas et al., 2020). However, one does not have to wait for scheduled groups. Conversation and reminiscence can be stimulated with a photo or video on a cell phone and a brief chat by an aide or direct care worker while making a bed or walking down the hall—this is task-plus communication defined by Lin and Hsueh (2022). Reminiscence does not have to be about self: in one study Davis & Shenk (2015) found conversation partners with dementia produced a wider range of conversational language topics and phrasal patterns with a generic video of objects, snapshots from previous decades, movie stars, posters, and fashions.

Reported or represented speech of selves or others is often used to build interest or establish relationships in conversational narratives, including stories told by persons living with dementia. A 2018 study of 80 conversations with five women in their eighties who were moving into moderate dementia showed how they were presenting social identities for themselves and others, and identified some remaining pragmatic skills in interaction. Represented speech was used in 56 of the conversations (Davis & Maclagan, 2018, p. 2). An example of unscaffolded conversational narrative from “Ms Tatter” shows her moving between her speech and her mother’s (italicized) speech in Tatter’s childhood, interspersed with a comment from the present day but looking back at that earlier time.

... Mother says, “Well, whenever you get me enough, I’ll make you some cookies” and I say, “Mama, no, don’t make cookies, make the rolls.” ... And they were so good, and she would, she would say, “Now, I don’t want you to chop them up in little pieces, I want big pieces in these rolls.” And that’s what we would do. And we had butternut trees, and we could, I don’t know how many we could get. She would say, “Now don’t give me too many.”

Repetition in dementia discourse is more complex than simply repeating a word. It may be keyed to the degree to which dementia is affecting a person’s memory and language, or to what is being repeated—a word, phrase or story—and we are just learning about language use in dementias other than Alzheimer’s, the most common form. The repetition may be a formulaic expression (FE): Van Lancker Sidits and Yang (2021) explain that “FEs, including conversational speech formulas, expletives, pause fillers, idioms, and proverbs known to a speaker of a language, may approach hundreds of thousands” (p. 310). Van Lancker Sidits (2012) adds that

production of formulaic expressions is significantly higher in left hemisphere than right hemisphere damage. Autistic and Alzheimer subjects produce an overabundance of formulaic expressions but show deficient ability to comprehend them or to utilize them according to pragmatic principles. (p. 357–358)

Tannen (1987) referred to repetition as “spontaneous formulaicity”, a “prepatternning”, adding that “by means of prepatternning and automaticity, speakers are highly interactive individuals for whom repetition enhances interpersonal rapport, creativity, and sense of self” (p. 215). This is not the same kind of repetition that is seen as bothersome as memory increasingly diminishes. Reeve et al. (2017, p. 959) explain that verbal repetition is seen more often with persons having probable Alzheimer’s disease as opposed to other dementias. By verbal repetition they mean repetitive questioning, as when a person asks repeatedly about an activity in the present or past, and repetitive stories or information recounted in the same conversation (p. 962). On the other hand, Wong (2000, p. 407) draws on conversation analysis to suggest that a first and second saying of a word (or more usually a phrase) in the same turn during a conversation, is really a storytelling technique.

We can see several types of repetition in the language of people with more than one kind of dementia: Ms Tatter, a woman in her eighties with probable Alzheimer’s disease,

repeats stories about her mom more than once in a single conversation with a partner and repeats them again in other conversations with other partners. Sometimes her repeated story tells us more about events and people of her childhood in the way it is contextualized, and other times, it tells us more about herself (Davis & Maclagan 2018, p. 5). Ms Tatter explains that she was called Penny as a child because she liked to pick up dropped pennies. In this example from a conversation in 2010, /I/ represents the conversation partner and /P/ represents Ms Tatter:

Example 2

I: And then that name just stuck, huh?

P: Uh hmm, yes.

I: (Chuckles).

P: I, uh, because I thought people were going to laugh at me. And Mama says well we won't, we won't say anything in front of people, and I said, "Oh, I want you to if you want to."

I: Yeah.

P: But it oh, I had a wonderful mother and uh I, I think that she thought more of doing for us than she did for herself. Always, always, well that's a good Mom. Yes, she was a good Mom. —And to this day she still is a good Mom.

Ms Tatter talks about her long-dead mother, using the same formulaic language, in nearly all her conversations. In contrast, examining repetition in the discourse of a man with frontotemporal dementia (FTD), Mikesell (2009) notes that in FTD, repetitional responses to questions are not necessarily answers to what is being asked. Instead, they may be portraying themselves as claiming knowledge even though the person with FTD may not understand what the question was. This causes caregivers and clinicians to need to change their questioning patterns or risk frustration and emotional outbursts from the person with FTD, and the caregiver may not know that this is typical FTD behavior. Kindell et al. (2013, p. 500) discuss how "Doug," who had semantic dementia, repeated other modes of communication in conversations: "he would regularly depict, or perform, his or others' talk or thoughts, using direct reported speech, prosody and body movement as a form of communication".

So far, examples have been from conversational interaction between two people, one of whom has dementia, in a face-to-face situation. Digital discourse in a variety of formats may be via simultaneous real-time two-party dialogue or multilogue with a group, with or without audio or video, and its usage

among caregivers as well as persons with dementia is growing rapidly. It may also occur as monologue, in blogs, forums of different kinds, and diaries. UK diarists with dementia can send their recording of a diary entry to www.dementiadiaries.org which then displays the audio recordings and transcripts online. It is hosted by DEEP, the UK Dementia Engagement and Empowerment Project. Stephen is among the diarists whose entries we studied (Davis et al., 2021). This spring we began expanding our previous work to start examining repetition in ten of Stephen's diary entries for 2021. A preliminary finding is that he demonstrates multiple types of repetition in every entry. Stephen has vascular dementia; we have italicized phrasal and content repetitions, some in the same turn, and regional formulaic expressions such as ending a sentence with *doesn't it* or *innit*. These are not questions expecting anything other than agreement from his audience and are moves for establishing or solidifying relationships. In February 2021, he offered a narrative of reminiscence to an online audience he could not see, but he presented his story as being in a conversation with friends he had made in his DEEP support group. He recorded it at home and he or his caregiver transmitted it to the support group and a volunteer transcriber.

Hi everybody. Welcome to my 139th video of living with vascular dementia. Voice is a bit croaky, just got up from lying down, little bit croaky but never mind. It's nice and sunny outside today, makes a change doesn't it... it's, you know. I was just thinking, going back, oh a long time, when I was a kid. Some of the things I can remember when I was a kid, like making dilly carts. We didn't have anything, internet, mobile phones or anything like that, X-boxes and all of that, and Wii games. We used to go out and make our own fun. Just playing with dilly carts and taking Mum's tin bath and sailing down the river with it. ... There are things I can remember back then, but what I done yesterday I can't imagine. That's what it's like, innit. That's what it's like, but there you go. I had to restart me computer just now, nothing working, so. There you go. They changed me settings here when I wasn't looking, that's what it was. Computers, eh? When they're sleeping who knows what they're up to. But there you go. Yeah, I'm a little bit croaky because my chest is a bit tight anyway...

Section II: Need for Materials Illustrating Language, Aging and Dementia

These examples of dementia discourse illustrate the point that caregiving for persons living with dementia (PLWD) means adjusting one's ideas about changes in speech over time for people in the specific situations of cognitive and linguistic impairment. Not all caregivers know that this adjustment is necessary or how to do it. An interpersonal pragmatic perspective for educating formal and informal caregivers facing this situation incorporates to some extent, "an expanded focus on emotions, relationships, rituals and social indexicality vis-à-vis stance and identities" (Haugh et al., 2013, p. 10). The caregiver of persons with dementia must call on, or very quickly learn to pay attention to, the components of what Celce-Murcia identified in 2008 as comprising what she called *communicative competence*. Those components are linguistic, strategic, sociolinguistic or socio-cultural, formulaic, interactional, and discourse competences. These are, of course, the components that change in different ways and at different rates as PLWDs' competence in interpersonal interaction deteriorates along with memory.

In a discussion of recent developments in intercultural pragmatics, Kecskes (2019) asks several probing questions which we believe are highly relevant to the situation of dementia caregiving, especially when the caregiver or assistant is an immigrant or from a highly different region of the PLWD's location:

- what happens when interlocutors can count only on limited support of actual situational context in interpreting and producing utterances?
- how will interlocutors compensate for limited access to formulaic and idiomatic language use? (p. 74)

We are suggesting, then, that we view caregiver-PLWD discourse as exemplified above from pragmatic perspectives that are both interpersonal and intercultural. Accordingly, we propose developing interventional strategies for explaining and illustrating components of communicative competence to formal and informal caregivers, especially if they are unfamiliar with the language variety spoken by the PLWD.

While people living with dementia usually undergo progressive deterioration in their language fluency, lexical memory, and familiarity with speech genres, it will be somewhat different for each person, just as the condition varies. They may have problems with starting, responding to, or ending a particular topic, and they may no longer know how to signal that another person can change the subject. They may not recognize a greeting or feel confident about where and how to start a story. Often narrative is how a person signals identity, which suggests that when a person with moderate dementia repeats a story with

only a few small changes, they may be using it to modify how they and their identity, or that of others in their story, are presented.

Medical preparation to give care or to educate formal and informal caregivers is uneven. In the USA, "50% of PCPs [Primary Care Physicians as opposed to specialists with additional psychological or geriatric training] reported that they do not feel adequately prepared to care for individuals with Alzheimer's and other dementias" (AD F&F, 2022, p. 53). There are insufficient geriatricians; family doctors, nurse practitioners and nurses report similar lack of training. An integrative review of nursing practices reminds us that culture of home and family affect nurse perceptions of dementia patients and that far too many nurses, regardless of country, were ill-equipped with knowledge about dementia care, leading to negative perceptions of patients and nurse burnout (Yaghmour, 2022; cf. Brooke et al., 2018). Roughly a quarter of the direct care workforce in the US—home health care, personal care aides and nursing assistants—are immigrants from 124 countries, with nearly 38% acting as home healthcare workers (PHI, 2018). PHI (2021) adds that almost a third of these workers speak English either poorly or not at all and over half are minimally educated. Similar situations exist across the world.

Medical researchers across China have been working hard to identify dementia prevalence (see Xu et al., 2018), to find resources to develop a continuum of care framework and to pinpoint needs (Wang et al., 2019). For example, Wang M. et al. (2020, p.1) found low dementia knowledge but positive attitudes among general practitioners in Beijing. Again in 2020, Wang Y. et al. (2020) found that nursing and medical students had poor knowledge and positive attitudes. Wang Y. et al. (2020, p. 199) note in their focused study of Tianjin, that based on Ministry reports, China had 30,000 long-term care facilities and Tianjin had 279 at the time of publication. These include nursing homes, community service centers, and retirement homes. In contrast to the US, China does not show a similar reliance on immigrants from "outside"; instead, many of the adults coming to urban from rural areas find employment in the growing number of nursing and community facilities. Their relocation adds to the growing concern about readiness to provide dementia care in facilities across China. Wang Y. et al. (2020) add that "most caregivers of long-term care institutions in China are laid-off workers, rural women and even the elderly; with limited educational level, they have a lot of misunderstandings in the process of care" (p. 199).

Offering training to formal and informal caregivers, or licensed nurses and direct care workers, especially those assisting in home care, means becoming aware of different intergenerational preferences and culture-based attitudes about

dementia and about ageing (Davis & Smith, 2013). Unfortunately,

No matter where you live, aging persons, many with various cognitive impairments such as dementia, are being cared for by those who do not speak their language, know little about their cultural preferences, and may not recognize when they are sad, ill, or lonely (Davis 2020, p. 282).

Only a few homebound dementia caregivers in any country can take time from work outside the home or in-home caregiving to participate in training courses, no matter how well-designed, or the technology to join e-learning or blended mini-courses. According to Gitlin et al. (2015, p. 10) only a few of the 200-plus excellent and approved interventions created for dementia caregiving in the US have gone past their original testing to become something readily available, reasonably familiar, and used frequently by caregivers themselves. Successful testing does not guarantee successful translation into something marketable, low cost (in terms of time or effort) or well known by a wide range of caregivers. Instead, those which have succeeded have been adapted to needs of specific populations from their initial funded trials (Cho et al., 2019).

Section III: Multilingual, Multicultural Digital Caregiver Guides

Influenced by the popular tastes of global citizens from 10 to 50, we have been working to design interventional materials that would offer dementia care information, illustrate training, and suggest supportive community outreach once the world pandemic had receded, but that could be both entertaining and available when wanted by the formal caregiver in a hospital or nursing home or the direct care worker /family caregiver for as long a time as they desired. We have turned to *Graphic Medicine* (<https://www.graphicmedicine.org>; see Wombles, 2021). Our team has chosen to create short graphics-based caregiver guides as a project to assist dementia care. We are aware of the increasing presence of im/migrants and people who seek relocation around the world as direct care workers who have immediate and hands-on care responsibilities and who typically receive minimal training other than physical, such as toileting or bathing.

To date, we have developed caregiver guides in English, Mandarin and Filipino, Vietnamese, and Latin American Spanish. These were selected to begin a collection of culture-specific graphic caregiver narratives because they are currently the

largest and most frequent migrant and relocating groups seeking direct caregiver employment outside of their home country. For example, over 35% of home health care aides in the US are migrants. However, in China, migrants from other countries are seldom hired to supplement family care or to work in long term care facilities. Instead, direct care workers are Chinese, typically relocating from rural to urban areas.

Because we are emphasizing situation-based communication that goes beyond completing tasks without any meaningful interpersonal interaction (Lin & Hsueh, 2022), we have created initial sets of 10 brief scenarios. Each of them is presented in different languages and different graphic styles. Constructed as a series of dialogues between a new formal or informal caregiver and a co-worker or friend with expertise, they are designed to attract and engage the reader and encourage their positive interaction with people living with dementia (PLWD). The initial scenarios focus on:

1. helping PLWD to talk—and avoid WH-questions (who/what/when/why/where/ and how);
2. helping PLWD to talk by co-creating stories;
3. helping PLWD to talk with feedback;
4. distracting PLWD from complaining, wanting to eat again, asking the same questions;
5. using arts and crafts with PLWD as distractors as well as enrichment;
6. helping PLWD who is wandering: trackers, GPS;
7. helping PLWD reduce anger and violence;
8. helping when PLWD doesn't recognize her/himself in the mirror;
9. finding ways to enter their reality;
10. finding ways to understand sundowning (agitation later in the day).

The scenarios, conducted as dialogues and including small stories, can be considered as narrative medicine. Small stories are “short narrative accounts embedded in everyday interactions, typically unnoticed by participants or researchers... With P[L]WD, however, they are frequently connected either to reminiscence or to events going on in the moment, and they do not carry the format for a conventional or canonical narrative” (Davis & Maclagan 2018, p. 84). Liao and Wang (2020, p. 1) describe how narrative medicine can work with sponsoring “interdisciplinary collaboration for healthcare education” which characterizes the way we have worked across linguistics, nursing, and gerontology to create these scenarios. Our scenario illustrations have come either from personal and free stock photographs or from student artists in various countries who have worked either with photographs we furnished or have

created cartoons and anime. They as well as the translators are being credited at the end of each Guide.

Figure 1 displays a single-section page from caregiver guides:

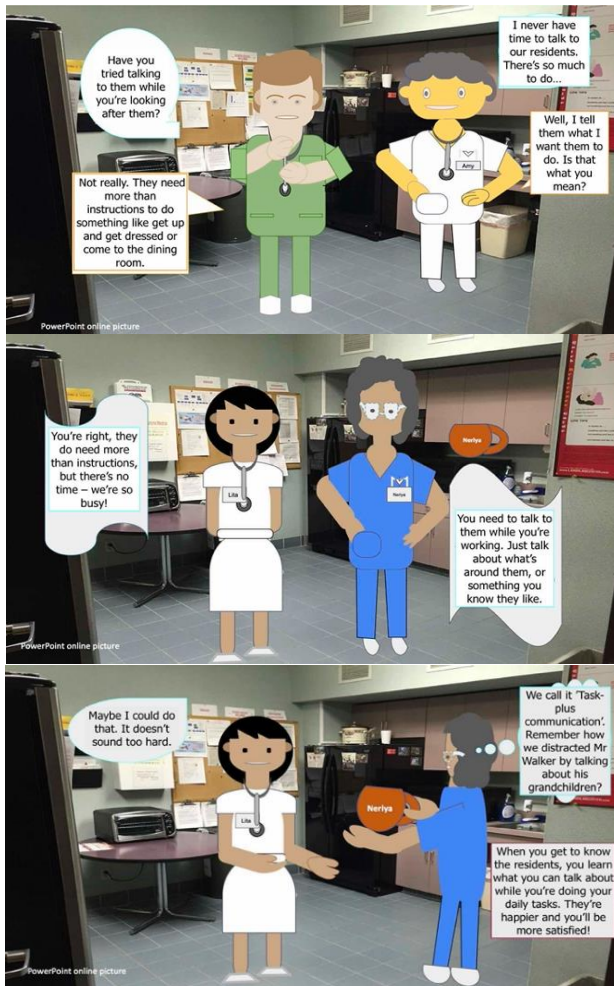


Figure 1. When you're so busy there's no time to talk to them...

To review American and New Zealand English Guides, we solicited opinions from family caregivers and nursing students in the US and palliative care nurses in NZ. For Mandarin Guides, feedback came from a small group of language and business professionals. Everyone was asked if they had had experience with someone living with dementia, which was roughly 90 per cent, and whether they thought the Guides were culturally appropriate. From those responses, which included 20% "maybe" or "not sure" (which are basically negative answers), we realized that we would also need to discover what people wanted to be changed or added to the Guide—and these responses pointed to a need for us to be far more culturally specific before enabling a second, more formal review with similar respondents across languages and cultural groupings, and similar numbers to enable statistical analysis. With shoes or

clothing, one size does not fit all, and this holds true for ways to show-and-tell about dementia discourse. For example, Mexican Spanish respondents wanted ID bracelets for people likely to wander to be engraved with name and emergency numbers; they also wanted backgrounds and clothing to be in different colors because they had found blues and greens to be hard to distinguish due to changes in vision of older adults who could be serving as caregivers. Some of the New Zealand English speakers wanted larger and bolder print and more relevant pictures. They also wanted a scenario keyed to the PLWD's frequent tiredness.

In addition to cultural features of country, locality, and situation, we find there is a need to consider preferences of generational cohorts and to consider literacy issues of im/migrant direct care workers. Although immigrants are often degree-holding doctors and nurses from their original countries, those who seek direct care work, particularly home health care, usually had less education originally, and a much lower chance at fluency in the language of the new host country. Looking at the impact of generational cohorts on anything—and especially on materials developed for dementia care—is complex. In this discussion, we mention three that should be considered. Cohort preferences by generation will undoubtedly affect perceptions of each other by both the caregiver and the care recipient, particularly if the caregiver is one or even two generations younger. In China, a family-centered cultural mandate stemming from Confucian thought has combined elders with the younger mothers who are expected to take care of them: they may be daughters or daughters-in-law, though this may be changing somewhat. A somewhat softer expectation in most of the ethnicities in the US will assume the daughter, daughter-in-law or female relative to be the unofficial caregiver. Third, migrant caregivers by necessity have split families for the period of migration, with children left at home often sharing eldercare responsibilities with another relative or the father, since most migrants seeking caregiving and home health care work are female.

In China, generations are often classified as Boomers, born between 1960–64; Generation X, born 1961/65 to 1979, and Generation Y, the single child in a family, born 1980 to 1998 (<https://hbr.org/2009/03/generations-in-china>). In the US and most of Europe, the dates are slightly different. Pew Research Center calls those born 1928–1945 the Silent Generation; Boomers (Baby Boom) born 1946–1964; Generation X 1965–1980; and Millennials, or Generation Y, born after 1980 to 1996. No one is quite sure what to call the next group, born since 1997, but they will probably be called Generation Z in the West. Li (2019) calls them Children of the Reform, noting that this group is stratified by educational differences between urban and rural

China. Indeed, Li (2017) comments that “children from poor rural families may fail the competition in the education system and become migrant workers at an early age” (p. 1). A recent study in China drew on the China Longitudinal Aging Social Survey conducted in 2014 (<http://class.ruc.edu.cn>), to find “a preference for the unmarried, the oldest or the youngest, and children who have provided them with support before. Coresident children are favored in rural but not urban China” (Hu & Chen, 2019, p. 390). For the US, Grigoryeva (2017) used the 2016 Health and Retirement Study (<https://hrs.isr.umich.edu/>) to find that daughters gave more support than their brothers, with daughters giving more care to mothers and sons to fathers. In addition, attention needs to be paid to the ethnicities that are portrayed.

In 2013, Davis and Smith identified “three cultural factors that underlie challenges for nursing educators and supervisors in dementia care who oversee direct care workers: (1) the effect of immigrant cultures and languages; (2) the effect of different intergenerational cultural constructs; and (3) the effect of culturally derived attitudes about aging and dementia” (p. 22). None of that has changed. To that, we now add the need to look at repertoires of languages within communities and situations and interpersonal relationships. In discussing globalization, the eminent Belgian linguist Blommaert follows the foundational ethnographer of communication, Dell Hymes, who focused not on country but on communities, which “differ significantly in the ways of speaking, in patterns of repertoire and switching, in the roles and meanings of speech. They indicate differences with regard to beliefs, values, reference groups, norms, and the like” (Hymes, 1972, p. 42). We cannot speak, says Blommaert (2010), only of “immobile languages” because

Our focus of analysis should be the actual linguistic, communicative, semiotic resources that people have, not abstracted and idealized (or ideologized) representations of such resources. Our focus should, therefore, be on repertoires, on the complexes of resources people actually possess and deploy. (2010, p. 102)

We take those statements to refer to the repertoires of each of two different persons in a situation of dementia discourse, the caregiver and the recipient of care. The person living with dementia retains a number of abilities and the caregiver—in whatever repertoire of, say, English or Mandarin they may normally use—can learn to identify and support those abilities. The materials developed for caregivers can work to facilitate both participants, particularly as each draw on interpersonal pragmatic devices (such as *um...ah...oh...eh...*) to assume the

role of competent communicator (Davis, 2010, p. 392; Song 2022 in preparation). In that way, they can negotiate their relationship in the sense developed by Haugh et al. (2013), cited above. In their review of the various debates in interpersonal pragmatics, Haugh et al. (2013) identify three areas of concern: “relational, attitudinal/emotive, and evaluative aspects of embodied language use... while attitudinal, emotive/affective or evaluative aspects of interpersonal pragmatics can be understood as conceptually distinct from relational aspects (and vice versa), they are nevertheless often intimately interlinked in situated interactions” (p. 4).

Thinking Toward Next Steps

By focusing on the sorts of language use that both formal and informal caregivers almost assuredly will encounter in conversing with relatives or patients with dementia, we have hoped to illustrate that not only is such conversation necessary for quality of life, it is also more complex than we often believe. Kindell et al. (2017, p. 402) reviewed studies of conversation and conversational language features in several types of dementias, finding that the delivery of any kind of communication training is challenging. What this means for the creation and dissemination of dementia care materials is first, that different sets need to be prepared in each language for at least two generations, certainly for Generation Y and probably for Generation X. And they need to show males as well as females talking about dementia care, as well as caregivers of different ages. We have learned there are technical details to consider when creating dementia care materials: viewers of the initial materials have already suggested that in addition to print versions, they should be available as apps, which means downloadable in multiple formats for tablets, cell phones, and watches. Audio and video versions—perhaps some individual scenarios in a format like *TikTok* and others as fuller videos—could solve issues in literacy for caregivers with weaker educational backgrounds. Text fonts and colors for text, backgrounds or clothing have cultural and generational implications: marketing and brand analysis companies can make us aware of some of them. For example, a 2010 study of Generation Y incorporating eye-tracking found this group “may prefer pages that include a main large image, images of celebrities, little text, and a search feature” (Djamasbi et al., 2010, p. 307); or see the review by Varzani et al. (2021) on text simplification and ages of readers. Online blogs from graphics and marketing companies have taken investigations further: for example, a Blog from color consultant AmyWax (amywax.com) suggests using bright yellow to attract GenZ, and soft colors such as dusty pink to make Millennials feel comfortable. Creating

multicultural, multilingual and multiformat materials for dementia caregivers is, as we have suggested, a bit like opening Pandora's box. Asking caregivers and care recipients for their participation has shown us first, that we need to learn more about the cultural competence they emphasize and value in whatever languages or language varieties they are using, and second, that these materials are far more needed for everyday situations in care than we had originally imagined.

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