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Running head: Language and dementia science

The Language of Dementia Science and the Science of Dementia Language: Linguistic Interpretations of an Interdisciplinary Research Field

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The Language of Dementia Science and the Science of Dementia Language: Linguistic Interpretations of an Interdisciplinary Research Field

Abstract

Language is a balance of precision and flexibility, and scientific dialogue across disciplines faces challenges in how terms are used and how phenomena, including language itself, are described and explained. Taking dementia as its focus, this paper offers linguistic perspectives on causes of inherent difficulty with terminological exactness. Attention is paid to the interface between the positivist imperatives of clinical evaluation and the relativist interpretations that help make sense of uses of terms across contexts. Two types of reason are examined for why the language produced by people with dementia is sometimes hard to characterize and predict: the theoretical challenges inherent in analyzing the language of dementia, and the social variables that affect how that language is manifested. The paper concludes with the vision of linguistic research using corpus-based discourse analysis to underpin and catalyze communication-bridging activities in interdisciplinary projects, within and beyond the dementia context.

Keywords

dementia; interdisciplinarity; terminology; language; communication

This paper explores how linguistics can support research across interdisciplinary boundaries in the dementia context. Linguistic research gets ‘beneath the skin’ of language, uncovering tacit assumptions and interrogating the relationship between *how* something is said and what a hearer or reader infers. Both individual words and combinations of them encode layers of meaning, well beyond what dictionary definitions can capture. Scientists are acculturated into discipline-specific uses of words and phrases, as shortcuts for complex ideas understood and accepted within that community of practice but not necessarily beyond it. When scientists collaborate across disciplines, miscommunication is a significant risk. Linguistic science is equipped to assist interdisciplinary researchers with understanding why apparently simple conversations about shared information and objectives do not always go smoothly.

Dementia attracts researchers from the medical, biological, environmental and social sciences, as well as the humanities. Their joint aim is to further knowledge about causes, characteristics and potential future cures for dementia, and ways of accurately diagnosing it and treating and caring for people who develop it. But different conceptualizations of the knowledge underpinning these activities generate an uneven surface on which to kick the elliptical terminological ball. *Dementia*, *Alzheimer’s disease* and *Mild Cognitive Impairment* are shown below to have less than clear-cut meanings, once considered in their contexts of use. Ways are needed for navigating these ambiguities.

The situation is further complicated by the fact that in dementia, language itself is a variable. Patterns in the language produced by people with dementia (PwDs) contribute to understanding the underlying phenomenon. Two aspects of the interface between the language about dementia and the language observed in the dementia context will be considered: (1) the role played by linguistic evidence in diagnosing and predicting the risk of dementia; (2) how society’s ways of talking about dementia shape the contexts in which PwDs generate language. Linguistic theory provides mechanisms for tracking the relationship

between what someone says or writes and its cognitive and social *motivation* on the one hand, and *impact* on the other. Thus, it is shown how the language *of* dementia cannot be fully separated from the language used to talk *about* dementia. The final discussion confronts the implications of these complexities and offers an innovative way for linguists to contribute to improving interdisciplinary communication.

Terminological Ambiguity

Knowledge about dementia encompasses genetics and biomarkers, neurological evidence of the triggers and trajectories of physiological changes, clinical approaches to diagnosis and treatment, healthcare protocols, and studies of the behavior of people with dementia and those they interact with. In all of these domains language is the main medium for sharing knowledge. Compared with other knowledge-sharing mediums such as mathematical expressions, diagrams and images, language is the most flexible but, by the same token, potentially the least exact. It is also the most localized. Whereas there is universal agreement about the meaning of 4 and $<$, interpretations of words, even between speakers of one language, can vary on a geographical, temporal and disciplinary basis.

Terminology is a particular type of vocabulary, intended to behave more like a mathematical symbol and thus support effective understanding. Formal definitions and careful delineation should establish and sustain clarity so that, ideally, there is a shared understanding of what a term means by virtue of a single point of reference and consistent use. Terminology should enable readers either directly to understand a text, or to recognize the limitations of their understanding.

In practice, however, terminology can also be an insidious barrier to understanding. There are two main reasons. One is that in a scientific account not every term is defined, because assumptions are made about the existing knowledge of the reader. The other is that

language has a life of its own, and a term, however clearly defined, picks up connotations from its uses, that gradually separate its fine-grained meaning into potentially incompatible sub-meanings.

Why Terminology is Not Always Defined

The decision on the part of an author not to define a term is a largely pragmatic one. Definitions are cumbersome and can be distracting if the text has a different purpose. For example, we will see later how linguists debate what the *word* is. Yet, other than in discussions about that issue, linguists will not expect to define *word* before they use the term. It will be left implicit that everyone knows enough about what a word is, at a general level, for the author's meaning to be clear. Vagueness is sometimes sufficient and even preferable (Wray, 2015).

Yet if a term is used without a definition, it creates the risk of misunderstanding. When one is familiar with a particular definition of a term, one may not be alert to the possibility that the author meant something else.¹ Thus, perversely, it can be quite helpful when terminology tips into jargon—terms that one does *not* understand—because one does at least know that a definition should be sought.

Fluidity in Terminology

The second potential barrier to understanding is that terminology is not static. A basic definition of the meanings of *dementia* and *Alzheimer's disease* is found in the medical section of the online Freedictionary:²

Dementia is a group of symptoms caused by gradual death of brain cells. The loss of cognitive abilities that occurs with dementia leads to impairments in memory,

reasoning, planning, and behavior. While the overwhelming number of PwDs are elderly, dementia is not an inevitable part of aging; instead, dementia is caused by specific brain diseases. Alzheimer's disease (AD) is the most common cause, followed by vascular or multi-infarct dementia.

Yet specialist definitions are more complicated. The most authoritative source relating to dementia is the *Diagnostic and Statistical Manual of Mental Disorders* (APA, 2013). This 5th edition (DSM-5) introduces new terminology that downgrades *dementia* as an independent term (though retaining it as a qualifier in sub-types, such as *vascular dementia*) in favor of the broader *major neurocognitive disorder* (p. 816). The rationale for the change is the increased capacity to diagnose the specific locus of the brain disease causing the cognitive changes (p. xlii). DSM-5 manages the transition by juxtaposing the old and new terms in a quite cumbersome and not always unequivocal way—*dementia* is frequently mentioned in brackets when the new term is used, even though they are not synonymous. DSM-5 also makes concessions to established practice, e.g., “The term *dementia* is retained in DSM-5 for continuity and may be used in settings where physicians and patients are accustomed to this term” (p. 591).

DSM-5's handling of the “major neurocognitive disorder due to Alzheimer's disease” (e.g., p.23) implies that it is a well-defined, unitary, diagnosable condition. However, this position contrasts with the assertion made in a 2012 radio interview by Sir John Bell, President of the UK Academy of Medical Sciences. Commenting on the reasons why drug treatments for AD are not yet all that effective, he said: “It's not clear that Alzheimer's disease is a single disease. If you try to develop a drug to a disease that is just a name and is an assortment of different disorders, then the likelihood of failing is quite high” (BBC, 2012). If it is vital that pharmacology deconstruct the concept of Alzheimer's disease, then a more

fine-grained diagnosis of sub-types is presumably desirable. The cases of *dementia* in DSM-5 and Bell's claim about AD show how terminological uses risk impeding alertness to important new information.

A further type of definition of AD is associated with directly observed neurophysiological characteristics, such as reduced hippocampal and cortical volume, beta-amyloid plaques and tangles of tau (e.g., Förstl, 2010; APA, 2013). The brain disease and the symptoms of AD do not always coincide, for the symptoms of other diseases can mimic those of AD, and some people with plaques and tangles have no symptoms (Beach et al., 2012; Iacono et al., 2009; Kempler and Goral, 2008). It is the job of research to understand why the mapping of a phenomenon across domains is not exact. To do that, scientists must understand the potential of definitions to entail different information in different contexts.

The term *Mild Cognitive Impairment* (MCI), which DSM-5 (APA 2013) defines as “substantially congruent with mild NCD [Neurocognitive Disorder]” (p. 608), has been on a particularly interesting trajectory. MCI is a recognized precursor of AD, but, as DSM-5 notes, only a “substantial fraction” of those with MCI go on to develop AD (APA, 2013, p. 612). A decade and a half ago, Milwain (2000) pointed out how the term was accumulating associations through its use as a euphemistic entry point for discussions about AD with patients and their families. This meant that the subset of people with mild memory loss as a natural function of ageing were being equated with those whose mild memory loss was a precursor of AD. In short, the term *MCI* has been in shift towards meaning “early AD”. Interventions suitable for those who do have early AD might not be desirable for those who do not (Petersen et al., 1999; Selnes et al., 2012), and serious social, psychological and economic risks could ensue. Paralleling Bell's observation, above, initiatives to pinpoint the observable differences between these two types of MCI might be undermined by the use of the single term.

Meanwhile, terms also cross the divide into general usage, adopting loose, even inaccurate, connotations, partly because accuracy is a less powerful driver than attitudes and emotions. For example, the husband of “Joan”, a singing teacher with symptoms consistent with Alzheimer’s, confirmed her dementia diagnosis, but insisted it was not Alzheimer’s “because if it was, she’d be talking to you one minute, then she’d turn to talk to someone else, and then turn back to you and not remember she’d been talking to you before” (Wray, 2010, p. 519). His lay definition of Alzheimer’s was seemingly shaped by more than just limited knowledge. He did not *want* Joan to have something called “Alzheimer’s” because of its profound social and personal implications. So he characterized it in a manner that excluded her from its domain (see also Schrauf & Iris, 2014).

Terms like *dementia* and *Alzheimer’s disease* may also be used inaccurately by care professionals—not because they lack access to formal definitions and to individuals’ diagnoses, but because of the embodied reality of these conditions in their work. A resident might be labelled as having dementia as a shorthand for “challenging behavior” such as aggression, even though “aggressive behavior is not unique to people with dementia” (Alzheimer’s Society, 2013).

Insights into Terminology from Linguistics

How can confronting issues with terminology help our understanding of dementia and associated phenomena across disciplines? Linguistics offers a means of coping with the complexity, rather than just seeing it. Driving the science of dementia are strong positivist traditions that offer hope of finally having a clear, delineated understanding of the phenomenon. Implicit is that language behavior is also clear-cut. Linguists, however, generally conceptualize language in relativist terms. Language shapes how we think, while our beliefs, assumptions and usages determine what words mean for us and others. A

relativist position tolerates ambiguities in language use and exploits the breadth of language meaning, as constituted through the context and cotext (the other words used around a term), to examine phenomena in new ways.

Linguistics shows us how denotation (e.g., Alzheimer's is a disease that affects memory) is supplemented by layers of connotation (e.g., people with Alzheimer's are typically old, may need assistance in their daily lives). Fine-grained information about a word's meaning is inferred from other words typically associated with it. These *collocates* color a term's interpretation in a manner that is typically culturally-determined rather than absolute. For instance, *dementia* co-occurs with words and phrases like *ravaged by*, *start a war on*, *beating*, *fear*, *dreaded*, *vigilant*, *lapses*, *bad news*,³ indicating that the dominant narrative is one of conflict (Lakoff & Johnson, 2003). Once in the mindset of conflict, one's perception of what dementia is like, and how it can be responded to, will tend to be contained within that frame.

Recognizing the power of metaphorical associations can be productive for challenging and extending understanding. In a study by Vittoria (1999), changing how AD was talked about reframed speakers' negative stereotypes, to present people with AD as "socially responsive actor[s] with a surviving self that is to be treated with respect" (p. 361). Meanwhile, the terminology used in other languages can raise our awareness of how some characteristics of a complex phenomenon are cast into shade by a cultural focus on others, when all require recognition (Berrios, 2010, pp. 5-6). For example, *dimāg*, "hot brain", used in part of India to describe PwDs, emphasizes "anger rather than memory as a fundamental index of senile difference" (Cohen, 1995: 314).

The Analysis of Language as a Marker of Dementia

We turn now to the language that PwDs use. First we consider how the language of PwDs is talked about, both as object and medium. Then we explore the parameters for making sense of language patterns, and how they interface with linguistic theory.

Talking About the Language of Dementia

Language is a variable that pervades our understandings of and engagement with dementia well beyond the issues with labelling already discussed. It is a complex phenomenon, the different facets of which can seem quasi-autonomous, though in fact they are not. It is a basic human cognitive capacity in its own right, but also makes visible other capacities and functions. It conveys information about what we see, hear, feel, want, and remember. It helps us organize our thoughts and plans, and is the medium for learning and for passing information to others. Choices in how we use language signal our beliefs, attitudes and allegiances, marking our social identity. As a result, what PwDs say, and how, offers a window on their capabilities, perceptions and experiences.

Meanwhile, how we talk about language is a window on what we construe it to be, how we understand it to work, and what we believe to be possible for it to do. These factors influence what we look for and expect, what we measure, and how we reconcile the pieces of the language jigsaw as a whole—from formal test behavior to informal conversation.

- Figure 1 around here -

Figure 1 maps out part of the field of play for interdisciplinary understandings of language in the dementia context (a further part is presented as Figure 2 later). Central are the two main sources of information about the language of a PwD: day-to-day communication and tests. Judgements about a person's underlying linguistic capacity based on how they manage everyday interaction are vulnerable to a range of variables that are difficult to recognize, let alone control. Consequently, tests are the preferred route to a clearer and

replicable snapshot of ability, even though they do not cover the full gamut of uses of language. Such tests can reveal striking patterns, some offering direct insights into problems that might be encountered in everyday talk, such as having more difficulty naming animals, fruit and vegetables than tools, clothing and furniture (Whatmough et al., 2003).

As Figure 1 shows, test design is iteratively informed both by previous performance and by theoretical models, so as to hone the accurate mapping of performance onto an understanding of the individual's underlying capacities. Diagnosis also aims to take account of the individual's performance outside a formal test situation. However, truly informal interaction is sometimes difficult to achieve in an assessment setting and, consequently, decisions about a person's future, from diagnosis onwards, should depend on more than test results (Asp and De Villiers, 2010). A person's capacity to compensate for problems plays a major role in how well they, and others, can cope with the interaction (see later discussion).

Conceptualizing Language Units

Figure 1 indicates how our inferences about an individual's linguistic capacity are drawn from what we observe, and how what we observe is shaped by what we believe it is possible to see. It behooves us to recognize how easily our understandings can be colored by implicit assumptions about the nature of language as a system. The point can be illustrated through a consideration of the "word" as the dominant unit for measuring language performance.

Balota and Yap (2006, p. 649) express the status quo for most researchers of language both within and beyond linguistics: "Research at the word level is particularly tractable and revealing, as words are well-defined units that can be analyzed and processed at various levels." Clinical and psychological testing, along with quantitative studies using linguistic corpora (large, representative collections of texts), converge on the assumption that the word is a reliable unit of measurement. The word is easy to find and is a strongly intuitive concept.

Yet the different fundamental properties of “wordness”—as a unit of meaning, pronunciation and grammar—fail fully to coincide with either each other or the written form (letters with a space either side) (Trask, 2004; Lucy, 2010; Wray, 2015):

lexical items⁴ may be bigger or smaller than grammatical words⁵; not all grammatical words are lexical items; more controversially, there are rather complex lexical items that contain no phonological material (Jackendoff 2000, p. 30).

There are two important reasons why this issue should resonate beyond the boundaries of linguistics. Both relate to the risk of perceiving precision in scientific measurement where in fact there is not precision. Firstly, any measure of dementia behavior that relies on counting words will not be replicable unless there is agreement about their enumeration. Chand et al. (2012), seeking a definitive word count to calculate idea density, report four different values for the same text, according to which software program was used. Idea density, the number of ideas per ten words, has been found to vary according to both the stage of Alzheimer’s (e.g., Le et al., 2011) and future risk of it (e.g., Engelmann et al., 2010; Iacono et al., 2009; Snowden et al., 1996). Different methods for counting words (and also ideas) could certainly impact on whether impaired and unimpaired language are accurately contrasted (Chand et al., 2012).

Secondly, although the archetypical unit of meaning (the *lexical item*) maps onto a single written word, usually a noun, it is far from the case that all the lexical items we use to construct linguistic output are single words. For example, in *the President of the United States*, the entire form is stored in memory as the representation of that idea, and it can be retrieved as a single unit. Such expressions, termed *formulaic language*, have been the focus of considerable research in recent years, with evidence of their importance emerging from

computational linguistics (e.g., Biber et al., 2004; Sinclair, 1991), psychology and second language learning (e.g., Segalowitz, 2010), phonology (e.g., Lin 2010); neurolinguistics (e.g., Tremblay & Baayen, 2010) and linguistic theory (e.g., Wray, 2002; 2008; Wray & Grace, 2007).

Because formulaic expressions make cognitively low demands, using them offers a significant social payoff to a person who might not otherwise be able to engage in conversation (Wray, 2011, 2016). “Maureen” (Davis et al., 2013) delivers a small repertoire of story fragments about her childhood with an engaging impression of freshness that could fool a stranger into believing she had no impairment. Expressions behaving like single words probably do not require any grammatical processing to put together or understand, even though they do contain grammar. Consequently, they may muddy the waters regarding the grammatical capacity of a PwD. In examining dementia language, some accommodation, in terms of grammatical theory, is therefore needed for the likelihood that the output is simpler to produce than it looks (e.g., Bates et al., 1995; Trousdale & Hoffman, 2012).

How Dementia Language is Shaped and Interpreted by Society

- *Figure 2 around here* -

Figure 2 shows how professional and lay perceptions of the nature of dementia communication help generate societal representations of what a PwD can say and do. According to Ballenger (2006), during the 20th Century there was a shift in the default interpretation of the term *senile*, from “old” to “mentally infirm”, part of a social trend towards pathologizing previously unstigmatized aspects of ageing. Such changes often mark more general social preoccupations. Post (2000) and Ballenger (2006) argue that dementia is socially demonized in Western society because it “violates the spirit...of self-control, independence, economic productivity, and cognitive enhancement that defines our [current,

western] dominant image of human fulfilment” (Post, 2000, p. 245). Smith (1996) challenges the assumption that there is “a universal neuropathology [for AD]” (p. 267) and argues for greater awareness of cross-cultural differences in how conditions like dementia are perceived.

These powerful social positions color how information is interpreted for mass consumption by the print and broadcast media, and what individuals and organizations take as their starting point when judging what is appropriate and desirable (e.g., what sorts of changes to communicative practice will constitute being “dementia friendly”). Consequently, the way society presents dementia communication has significant capacity to affect the communicative contexts to which PwDs have access (Wray, 2011). In turn, that impacts on the observations that researchers across disciplines can make (Figure 2).

When social expectations of the capabilities of PwDs are low, little is asked of them, but when they are given more responsibility, more capability is stimulated (Sabat, 2001).⁶ “Joan” (Wray, 2010) is a case in point. This experienced singing teacher with Alzheimer’s symptoms could share her knowledge and advise on singers’ performances during a workshop weekend because she was in a social situation where such behavior was expected of her. The context gave her license to produce authoritative and incisive information forged from a strong sense of self-identity (c.f. Small et al., 1998), even though she had only limited linguistic capabilities. All too often, however, the prevailing assumption is that PwDs can’t understand anything, and don’t have anything interesting to say (Lloyd et al., 2006; Polk, 2005). The opportunities for interaction may become so restricted as to fulfil the prophecy.⁷

Figure 2 also highlights how the patterns observed in the linguistic output of PwDs shape professional and lay perceptions of what dementia communication is like. We already saw in Figure 1 that these patterns are interpreted through the receiver’s models of how processing, grammar and function work. The calibrations of those models help determine the prevailing social representations of dementia communication. For example, filler words and

expressions like “thing”, “you know” and “and things like that” tend to be viewed as indicative of vagueness or sloppiness. Heard to excess in PwDs, it is easy to assume that they are a marker of deficit. However, that might not always be so.

Formulaic expressions like this may also be a tool for patching up fluency under cognitive pressure, so that the turn can be completed (Wray, 2010, 2016), and so control can be maintained of the content and direction of a conversation (Davis et al., 2013). They can thus represent a valid and effective adjustment to the changes in communicative capacity caused by dementia, drawing on compensatory strategies developed through a lifetime of managing occasional lapses in concentration, embarrassing linguistic incidents and breakdowns in communication. PwDs bring with them a sophisticated lifelong portfolio of communicative skills, interactional agendas and personal priorities. But these attributes can be difficult to recognize, if one is looking for something else.

Interdisciplinary researchers need to be aware of the multiple influences on language behavior. If a PwD does not come up with an anticipated word, word-finding difficulties may be only part of the story. One must also ask how (un)important it might be, in the current context, to strive to find the word, and also what other tactics are employed to resolve their communicative problem. Joan used mime and quotations from songs to fill gaps in her word-finding, as well as deferring to the piano accompanist, who articulated ideas for her to reclaim (Wray, 2010). MB, a PwD described by Davis and Maclagan (2010) used “you tell her” to pass responsibility for answering a question to her daughter. Since medical history was being sought, it was pragmatic of MB to hand the job over to someone likely to remember and express herself better.

In sum, Figure 2 shows how the terms used to talk about dementia can all too easily shape the world in which PwDs live, while the world they live in shapes the opportunities they have for expressing themselves. We need to be alert to the fact that dementia behaviors

do not occur in a vacuum. More than that, researchers and clinicians must be vigilant about how their use of language might influence what they seek to observe. Interdisciplinary dialogue about the impact of the social aspects of language behavior is vital.

New Approaches to Interdisciplinary Understandings of Language in the Dementia

Context

Managing an Inherently Complex Phenomenon

Language, as an object of study, a conduit of expression and the medium for sharing research and clinical knowledge, is unavoidably complex. We have seen that terminology is difficult to keep under control, and an important take-home message from linguistics is that meaning drift is not an aberration but a reflection of what language needs to be like. It is how we sustain flexibility in both thought and expression. Language, as an integrated system of cognitive, social and structural variables, offers no simple solutions to the problem of terminological drift. However, there are opportunities within linguistics to help navigate the challenges.

Being Pragmatic About Interdisciplinarity—the Role of “Interpretivist”

The generally relativist stance taken in linguistics accommodates the need to resist looking for simple answers in complex systems (e.g., De Bot, Lowie & Verspoor, 2007; Larsen-Freeman & Cameron, 2008; Lowie, 2013). On the other hand, it is difficult to make progress at the practical level, if one can only acknowledge that things are complicated. Rather, linguists need to deploy their insights and skills to make a difference to how science is practiced.

Linguists are well-placed to help scientists navigate the linguistic map imposed by their respective disciplines and develop awareness that the maps of others are not the same (Wray

& Wallace, 2014, 2015). For interdisciplinary scientific communication to be effective, all parties need to recognize that their thinking is shaped by tacit connotations, beliefs and assumptions disguised by an apparently common language. The membrane between disciplines is not porous, and osmosis will not naturally result from juxtaposing research activities. A stable middle ground of shared knowledge must be deliberately created.

The linguist, then, can act as an interpreter of the language of science. The role is in some ways similar to that of a knowledge broker for the translation of research findings into practice (e.g., Glegg & Hoens, 2016; Strekalova et al., this issue), because it entails an intervention with specialist skills to release untapped potential. However, the linguist as interdisciplinary ‘interpretivist’⁸ (cf. Wray & Wallace, 2015) is different in one important respect: the intervention must be introspective first, before the science can hope to reach out effectively to lay audiences. The aim is to facilitate effective communication within the research group, as a means of ensuring that any external benefits are founded on a robust and holistic scientific understanding of the phenomena.

Carefully examining how phenomena are discussed, the interpretivist will take responsibility for establishing where the collaborating disciplines most risk being confounded by under-exposed differences in apparently common terminological language, or overlooking compatible findings because of different ways of talking about them. One particularly flexible method for doing so is corpus-informed discourse analysis. Quantitative computational methods first analyze collections of texts for discipline-specific uses of terms, before interview and observational methods contribute qualitative insights into the subtle decisions that term-users make (e.g., Baker, 2006; Baker et al., 2008; Handford, 2014; Partington et al., 2004; Potts & Semino, 2017; Zhu et al., 2016). The computational analyses can highlight spikes and troughs not visible to the naked eye. That information is used to direct precise questions that tease out fine-grained meaning.

Given the centrality of language to the pursuance of science, it is perhaps surprising that interdisciplinary research does not already typically feature regular sessions in which contributors consider just what they mean when they use a given term, and what assumptions they bring to discussions about a given phenomenon. Were the interpretivist role to be recognized as beneficial, then future interdisciplinary research projects might include in the team a linguist whose first job was to carry out a risk assessment of the potential for miscommunication during the project. Subsequently, observational and interview sessions with the disciplinary specialists, along with discourse analyses of team meetings, could surface linguistic sources of miscommunication and rectify them.

Conclusion

In keeping with the special issue theme, this paper has explored how language, a primary resource for scientific communication, can impede as well as facilitate understanding. Although the solutions offered are much more broadly applicable, dementia is a particularly challenging case. Firstly, its research, diagnosis and care require the involvement of experts of many types, each bringing linguistic usages with their own manifold connotations. Secondly, language variation is a manifestation of dementia itself, which demands adequate language for talking about language. Finally, the science of dementia is fundamentally grounded in the actions and experiences of the general public, who also need, and have, a language for talking about the phenomenon. Linguistics engages with how, at all these levels, the patterns in what we say are sensitive not only to cognitive but also social variables, which affect the scientists as well as people with dementia.

The linguist as an “interpretivist” can use sophisticated research methods to identify and help mitigate the risks of miscommunication, both between the investigators and between scientists and the general public. The essentially relativist stance of the linguist will

encourage acceptance of the inherent complexity of language, challenging uncritical positivism. This is a vital component of a holistic approach to care, where the relationship between general, scientifically verified patterns and the particular experience of the individual can be bewildering. Creative responses both to scientific challenges and those of daily life come from recognising that everyone brings their own portfolio of experience, knowledge and skills to a situation, including the PwD.

Meanwhile, unbridled pluralism is kept in check by the necessary pragmatism of prioritising workable practices for effective dementia diagnosis, treatment and care. Consideration of the daily experiences of people with dementia, their family, and caregivers must remain central to how the science progresses. And the scientists must ensure they are adequately equipped to communicate effectively with their stakeholders and with each other.

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Notes

1. Wray & Wallace (2014, 2015) interviewed top international researchers about their interdisciplinary collaborations. One said, “I’ve discovered that we use [some words] in the social sciences in an entirely different way to computer science and so you just have to get down to real basics and pin down what your assumptions are” (2014, p. 43). Several informants mentioned the need to have sufficient “interactional expertise” (Collins, 2007) to know where issues of misunderstandings might arise.

2. <http://medical-dictionary.thefreedictionary.com/dementia>

3. Examples drawn from the first 20 entries listed for *Alzheimer’s* in the Corpus of Contemporary American English, using the Brigham Young tool, corpus.byu.edu.

4. Word-like units of meaning.

5. Units with a grammatical role.

6. See Ryan et al (1986:, p.16) for a similar model of the social determinants of language production in dementia.

7. “[A caregiver] was holding the pegs up to her face and saying, ‘Did you ever have pegs Mary? Did you have pegs like these? Do you like pegs? Look at the pegs’.” David Clegg (personal communication, August 2011).

8. The term *interpretivist* is used here in order to keep it distinct from *translational science*, the bridging of pure and applied science to find real world applications for research discoveries.

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Author Biography

Alison Wray is a Research Professor in the Centre for Language and Communication Research, Cardiff University, UK. Her main contributions to research have been in the conceptualization of the cognitive and social role played by 'formulaic language' – lexical units composed of more than one word that seem to be processed like a single word. This discussion has ranged across first and second language acquisition, communication aids for the disabled, the evolutionary origins of language, and the language of people with dementia.

Figures

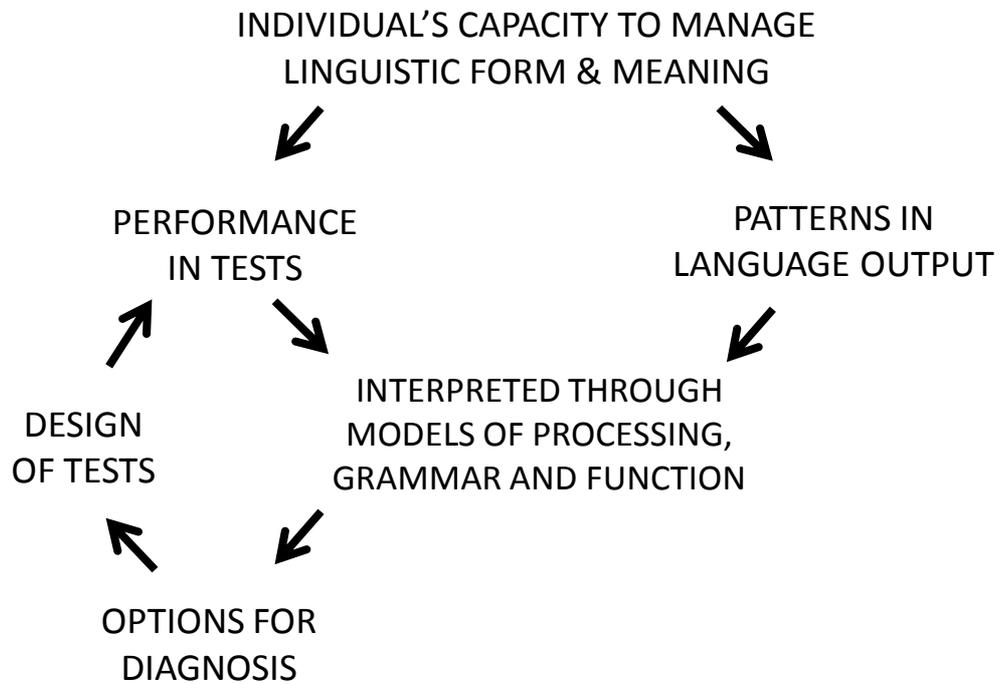


Figure 1: Relationship between linguistic capability, performance and interpretation

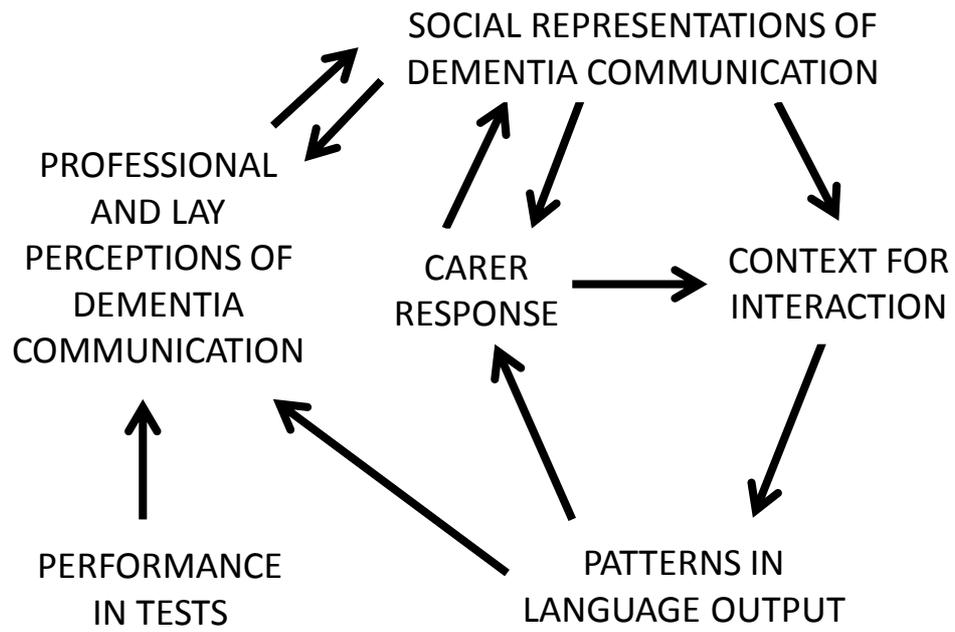


Figure 2: The impact of social perceptions on dementia language