

Dementia Sufferer and Person Living with a Diagnosis of Dementia: Naming Practices in Academia

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The language used to describe people is an important means of categorization that has a powerful role in constructing the identities of the social actors being labelled. This forum entry focuses on the responsibilities of researchers in the field of dementia studies in this regard. Since their research output helps shape public discourse, the way scholars choose to refer to the people informing their research, in this case the linguistic labels they use in reference to those living with a form of dementia, has a societal impact that should not be underestimated. This is why academic referencing practices require careful (re-)consideration.

Using labels like *demented/dementia sufferer* is problematic in various respects. The noun *sufferer* positions the person as a passive victim. Modified by *demented/dementia*, this form of reference furthermore draws on the strategy of somatization, foregrounding a deficient state of health, body, and mind (Reisigl and Wodak 48). In addition, particularly the adjective *demented* is fraught with multifaceted meanings. Its first attestations in the *Oxford English Dictionary* date from the mid-seventeenth century and refer to a meaning still quite common today: “Mentally unbalanced, esp. through intense emotion; behaving irrationally; beside oneself with anger, grief, anxiety, excitement, infatuation, etc.; (in weaker sense) extremely worried, annoyed, irritated, etc.” (*OED*, s.v. *demented*, sense 1.a). The related noun *dementia* has increasingly shed this original meaning derived from the Latin root. It has come to be used mainly as a medical term and is still widely common in health care disciplines, though it was actually replaced as a technical term by the more comprehensive term *major neurocognitive disorder* in the *DSM-5* (2013). However, the adjective *demented* has retained a semantic ambiguity, which makes it problematic when used for a person.

It is, therefore, not surprising that these forms of reference have been increasingly viewed from a critical standpoint, and there has been a rising

demand for non-stigmatizing labels, especially by people living with dementia themselves (e.g., Swaffer). Indeed, referencing practices in academic discourse on dementia have changed quite substantially over the past 20 years, as our diachronic study of more than 300 articles from the journal *Aging & Society* (1981–2021) has shown. Ranking second after *patient*, the label *sufferer* featured prominently in the dataset, predominantly in the collocation *dementia sufferer*. Its usage peaked in the 1990s and then decreased substantially, coinciding with the trend towards person-first language, as reflected in the label *person with* [*dementia, the disease, etc.*], which is the third-most frequent term in the dataset.

However, what deserves closer scrutiny is the fact that the label *dementia sufferer* is still found today (though in comparatively small numbers). The usage of this label in recent publications is related to the referencing of work from the 1990s, where *dementia sufferer* was used in a cluster of articles by highly influential scholars including Kitwood (and colleagues) and Sabat and Harré. These authors made abundant use of the term, which was, of course, not problematized at the time. A closer investigation reveals that other 1990s studies also used the term *dementia sufferer*, particularly, but not exclusively, when paraphrasing and relating to the work of Kitwood, Sabat, and Harré. Thus, such high impact studies strongly contribute to setting the tone in the referencing practices of (more or less contemporary) publications.

In recent work that paraphrases Kitwood's and Sabat and Harré's 1990s work, the authors sometimes continue to use the label *dementia sufferer* elsewhere in their text. Although the term is sometimes marked by single quotation marks, this attempt at distancing can easily escape the reader, particularly when employed inconsistently. Other authors differentiate between the use of the original label *dementia sufferer* when drawing on the 1990s studies and their own labelling practices. Still, we argue that reciting quotes from undoubtedly important studies containing now-problematized labels, again and again over decades, perpetuates outdated terminology. Scholars should, therefore, reconsider their citation practices and avoid contested language by using strategies such as paraphrasing, or indirect or embedded quotations.

What are the alternatives, then? As mentioned, *patient* is by far the most frequent label and its use has remained stable over the decades. Use of this term, however, has the potential to be problematic as well. It is a label that certainly lends itself to clinical contexts, referring to predefined roles in institutional healthcare settings, such as, for example, in the standardized relational pair

doctor-patient. Our dataset indicates that *patient* is also used in reference to people living with dementia in informal contexts. The relational pair established in this way is imbalanced with regard to the ascribed informal role of *family member* vs the institutionally defined role *patient*.

Going beyond the choice of individual labels, further insights can be drawn from their co-occurrence patterns. In the 1990s, *person with dementia* started to co-occur with *demented* and *sufferer*, indicating a transition phase of parallel usage of now-problematized labels and person-first labels. In more recent publications, *person with dementia* often alternates with *subjects* and *patients*. The latter two are the terms that are most frequently used together, which can be related to referencing practices in clinical studies. In health care contexts, *demented* and *dementing* still find ample use in relation to medical conditions, despite the problematizing discussions surrounding the terms. Also, *patient* often appears together with *sufferer*.

The use of *person living with* is a more recent development, appearing more regularly in the 2010s. The related acronyms *PWD* and *PLWD* were observed only in the past five years. Young et al. point out that the construction *person living with dementia* is particularly preferred by those living with the condition themselves, as it is

felt to more accurately capture their experience of the condition, and to be more positive, person-centred and life-affirming than the alternatives ‘people with dementia’ (which they felt over-emphasised the condition at the expense of their individuality), and ‘people with dementing illnesses’ (which did the same, to an even greater extent, sounding in the words of one PLWD ‘cold and medical’). (1014)

The abbreviations *PWD* and *PLWD*, also employed here by Young et al., are certainly economic and hence often favoured in academic writing. However, positive language guides published by non-profit health organisations have pointed out that people become invisible behind such abbreviations (e.g., alzheimers.org.uk 5). Alternatively, the label *person living with a diagnosis* has been promoted more recently; it is a term not (yet) found in academic papers. One of the reasons might be that the costly medical tests required before a conclusive diagnosis is made are not accessible in large parts of the world. Also, the diagnosis itself is controversial. Another term that might gain some traction in the future, but was not documented in the dataset, is *person with a lived experience of dementia*.

The prevailing usage of problematized labels in some academic domains significantly impacts discourse practices more generally. For example, clinicians and physicians do not just communicate in the academic sphere but are also in personal contact with people living with dementia and their inner circles, acting as public spokespeople, communicating with news media, public organizations, hospital donors, and so on. Additionally, other members of society, including people living with dementia and their families, engage with academic research findings which brings them into close proximity with the labels used and the respective constructions of their ascribed roles. Language practices used in the dissemination of academic studies are also, potentially, communicated to broader audiences via mainstream media. Scholars therefore need to embrace their position as role models; they must help to shape the public discourse about dementia in a way that gives visibility to people experiencing a form of dementia, acknowledging their multifaceted identities and their status as experts by experience.

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