

“the living dead” or “fight till the end”? – Metaphors of dementia in online health forums

Monika Pleyer

English Department, Universität Heidelberg

monika.pleyer@as.uni-heidelberg.de

Keywords: metaphor, e-health discourses, dementia, discourse analysis

Virtual health discourses are becoming increasingly important in the modern world. Persons living with dementia (PWDs) and their family care persons (FCPs), among other discourse groups, use e-health offers to gain information about illnesses and therapies, but also seek interpersonal connection in virtual health communities such as forums (e.g. Kleinke 2020). It is still relatively unexplored territory how exactly PWDs and FCPs use these virtual discourse spaces to conceptualize themselves as ‘ill’ or as ‘carers’, and which perspectives they take on the disease itself.

This talk will offer a concise, qualitative comparison of the specific perspectivation patterns of PWDs and FCPs, with a special focus on conceptual metaphors (see Lakoff & Johnson 1980; Kövecses 2010). Metaphors have been shown to have central importance in (health) discourses due to their perspectival and discourse-structuring functions (Charteris-Black 2004; Hart 2010). For instance, mass media discourses metaphorically construe dementia as a FLOOD, VIRUS, or ZOMBIE, thereby inducing fear and dehumanising PWDs (Behuniak 2011; Peel 2014; Hillman & Latimer 2017; Zeilig 2013). In medical discourses, metaphors are used to construe patient and caregiver roles, e.g. the patient as a WARRIOR (Sontag 1991), or the caregiver as a THEATRE DIRECTOR (Wilson et al. 2021).

The data for this talk stem from 300 posts each from specific threads in the FCP subforum “I have a partner with dementia” as well as the PWD subforum “I have dementia” on Dementia Talking Point (hosted by the Alzheimer’s Society UK). Established illness metaphors were identified with WordSmith concordance searches, and then analysed with a modified Metaphor Identification Procedure (MIP; see Semino et al. 2018); a close reading of each post was further conducted to identify novel, creative metaphors.

Results show that in online forums, discourses of fear and dehumanisation tend to be largely absent: FCPs do not conceptualise ‘their’ PWD as zombie-like, nor are such negative self-descriptors used by PWDs. While PWDs generally use less metaphorical conceptualisations, as well as less source domains overall, certain similarities between metaphor usage in PWDs and FCPs are apparent. For instance, both discourse groups make use of ‘classical’ illness metaphors of ILLNESS AS WAR and ILLNESS AS JOURNEY, and personify dementia as an intentional, malicious actor:

- 1) its a *evil disease* cruel and nasty (FCP_DJ#574)
- 2) they [the PWDs] may bite, scratch, nip punch, spit at you, kick out, or worse, please remember *it’s not them*, but *the disease*. (PWD_AYWTK#1)

Results also show that discourses of LOSS, DECLINE and DESCENT of the patient into dementia only occur in FCP posts. The metaphorical conceptualisations highlight the struggles and difficulties of being in a caregiving role. ‘Their’ PWD is conceptualised as absent as a partner, with memory loss being the key symptom of dementia that is discussed metaphorically. It is also only in the FCP data that we find rejections of metaphors (marked by quotation marks in (3)) that are felt to be unfit to conceptualise the FCP’s experiences:

- 3) I am almost 7 weeks into this phase of *the “dementia journey”* (FCP_DJ#473)

In sum, the talk highlights the unique, lived perspective of PWDs and FCPs, and gives insights into how metaphors are used in online health forum interactions to “reveal [the writers’] own specific and sometimes conflicting perceptions, views, attitudes and challenges” (Semino et al. 2018: 2) on dementia.

References

- Behuniak, S.M. 2011. "The living dead? The construction of people with Alzheimer's disease as zombies." *Ageing & Society* 31: 70-92.
- Charteris-Black, J. 2004. *Corpus approaches to critical metaphor analysis*. Basingstoke: Palgrave Macmillan.
- Hart, C. 2010. *Critical discourse analysis and cognitive science. New perspectives on immigration discourse*. Basingstoke: Palgrave Macmillan.
- Hillman, A., and J. Latimer. 2017. "Cultural representations of dementia." *PLoS Med* 14 (3): e1002274. <https://doi.org/10.1371/journal.pmed.1002274>.
- Kleinke, S. 2020. "Wissenskommunikation in Internetforen." In *Wissenskommunikation im Web: Sprachwissenschaftliche Perspektiven und Analysen*, ed. by K. Beckers & M. Wassermann, M., 85-102. Berlin et al.: Peter Lang.
- Kövecses, Z. 2010. *Metaphor. A practical introduction*. 2nd edn ed. Oxford: Oxford University Press.
- Lakoff, G., and M. Johnson. 1980. *Metaphors we live by*. Chicago; London: The University of Chicago Press.
- Peel, E. 2014. "'The living death of Alzheimer's' versus 'Take a walk to keep dementia at bay': representations of dementia in print media and carer discourse." *Sociology of Health & Illness* 36 (6): 885-901. <https://doi.org/10.1111/1467-9566.12122>.
- Semino, E., Z. Demjén, A. Hardie, S. Payne, and P. Rayson. 2018. *Metaphor, cancer and the end of life: A corpus-based study*. New York; London: Routledge.
- Sontag, Susan. 1991. *Illness as metaphor and AIDS and its metaphors*. London: Penguin.
- Wilson, C. B., J. Hinson, J. L. Wilson, S. Power, D. Hinson, and A. Petriwskyj. 2021. "Theatre production: a positive metaphor for dementia care-giving." *Ageing & Society*: 1-16. <https://doi.org/https://doi.org/10.1017/S0144686X21000428>.
- Zeilig, Hannah. 2013. "Dementia as a cultural metaphor." *The Gerontologist* 54 (2): 258-267. <https://doi.org/10.1093/geront/gns203>