

COMMENTARY

Can psychotic symptom identification help to improve young-onset dementia care?

Commentary on “A thematic analysis of psychotic symptoms in young-onset dementia” by Borelli-Millot *et al.*

Clarissa Giebel^{1,2} 

¹Department of Primary Care & Mental Health, University of Liverpool, Liverpool, UK

²NIHR Applied Research Collaboration North West Coast, Liverpool, UK

E-mail: clarissa.giebel@liverpool.ac.uk

Young-onset dementia (YOD) can affect approximately 5–10 percent of all people with dementia (55 million people worldwide) (WHO, 2023) and can be more difficult to diagnose. It brings with it a set of often different challenges than late-onset dementia (LOD), which is diagnosed from the age of 65 onwards. People with YOD, and their families, can face additional challenges due to their age, including employment and potential double caring duties (including for children and parents) (Greenwood & Smith, 2016). This is in addition to the various levels of cognitive, motor, neuropsychiatric, and everyday functioning changes experienced in different subtypes of dementia at large, and YOD (Geraudine *et al.*, 2021; Giebel *et al.*, 2014; Matar *et al.*, 2020). In general, living with YOD brings additional barriers to living well with the diagnosis, receiving adequate care and receiving a diagnosis in the first place (Giebel *et al.*, 2023; Perry *et al.*, 2024). Thus, people with YOD require special attention to overcome these age-related inequalities.

With cognitive deteriorations in dementia influencing many aspects of the person’s and their carer’s lives, non-cognitive concerns in dementia research primarily focus on adequate care and how people with dementia’s needs are met, the importance of social connectivity, and general physical health, including frailty (i.e. Joranson *et al.*, 2021; Wallace *et al.*, 2021). Neuropsychiatric symptoms receive particular attention in care home residents with dementia, with research focusing often on an inclusive and broad approach of various neuropsychiatric symptoms (such as agitation, hallucinations, sleep, irritability, disinhibition, and changes in appetite) (Appelhof *et al.*, 2019; Bauhuis *et al.*, 2020). By comparing care home residents with YOD and LOD, Appelhof *et al.* (2019) showed for example that people with YOD experienced higher

levels of apathy and lower levels of verbally agitated behaviors than people with LOD. With research on neuropsychiatric symptoms in dementia primarily relying on quantitative data and frequencies and levels of symptoms (i.e. Vik-Mo *et al.*, 2020), providing a qualitative insight into a specific form of symptom can shed interesting light into the evidence base.

To understand particular experiences of psychotic symptoms in people with YOD, Borelli-Millot *et al.* (2024) went through discharge summaries from the Royal Melbourne Hospital in Australia and looked for qualitative descriptions of psychotic symptoms. Using thematic analysis, the authors coded and grouped these experiences broadly into delusions and auditory/visual hallucinations for 23 patients with YOD. Delusions were sub-categorized into paranoid/suspicious, harm/abuse, loss, romantic/sexual, grandiose, and somatic. Hallucinations were themed into danger, paranoid/suspicious, non-specific/unintelligible, harm/abuse, and religious/mystical for auditory, and people/faces and objects/shapes for visual. While the authors explored diagnostic subtype of YOD and time from diagnosis, there was no apparent link or cluster of psychotic symptom themes with either subtype or time from diagnosis. This suggests that themes may relate to other factors, with other underpinning reasons of experiences of for example grandiose or romantic delusions, or religious or paranoid hallucinations. However, a larger sample of people with YOD is required to establish relationships between these factors.

Overall, it is interesting to see the variation of psychotic symptoms in some people with YOD, especially the qualitative richness of the quotes which paint a clearer picture of the types of symptoms. The patients seen were assessed in a neuropsychiatry unit, and not in a generic memory

clinic for dementia. Thus, all included participants were selected from a database of patients who were seen by neuropsychiatry. It would thus be of value to assess in future database research the frequency of psychotic symptoms in all people with YOD, and how certain subtypes of dementia, such as Lewy Body, may and are more likely to be prone to specific themes of delusions and hallucinations. While Borelli-Millott *et al.* (2024) evidence no apparent linkage between subtypes and psychotic symptom themes, a greater focus on those subtypes who experience hallucinations and delusions may be a suitable next research avenue. In addition, this study provides knowledge that can be important for unpaid carers of people with YOD, to understand that psychotic symptoms, and which, may be affecting their relative with the dementia. Further research is required, which has clear applications for the lives of people living with dementia and their carers.

Conflicts of interest

None.

Funding statement

CG is funded by the National Institute for Health and Care Research Applied Research Collaboration North West Coast (ARC NWC). The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health and Care Research or the Department of Health and Social Care.

Acknowledgements

None.

References

Appelhof, B., Bakker, C., Van Duinen-van Den IJssel, J. C. L., Zwijsen, S. A., Smalbrugge, M., Verhey, F. R. J., de Vugt, M. E., Zuidema, S. U., & Koopmans, R. T. C. M. (2019). Differences in neuropsychiatric symptoms between nursing home residents with young-onset dementia and late-onset dementia. *Aging & Mental Health*, 23(5), 581–586.

- Bauhuis, R., Mulders, A. J. M. J., & Koopmans, R. T. C. M. (2020). The course of neuropsychiatric symptoms in institutionalized patients with young onset dementia. *Aging & Mental Health*, 24(3), 439–444.
- Borelli-Millott, L. F., Loi, S. M., Velakoulis, D., & Goh, A. M. Y. (2024). A thematic analysis of psychotic symptoms in young onset dementia. *International Psychogeriatrics*, 1–9.
- Geraudine, A., Battista, P., & Garcia, A. M. (2021). Speech and language impairments in behavioral variant frontotemporal dementia: A systematic review. *Neuroscience & Biobehavioral Reviews*, 131, 1076–1095.
- Giebel, C., Cations, M., Draper, B., & Komuravelli, A. (2023). Ethnic disparities in the uptake of anti-dementia medication in young and late-onset dementia. *International Psychogeriatrics*, 35(7), 381–390.
- Giebel, C. M., Sutcliffe, C., Stolt, M., Karlsson, S., Renom-Guiteras, A., Soto, M., Verbeek, H., Zabalegui, A., & Challis, D. (2014). Deterioration of basic activities of daily living and their impact on quality of life across different cognitive stages of dementia: A European study. *International Psychogeriatrics*, 26(8), 1283–1293.
- Greenwood, N., & Smith, R. (2016). The experiences of people with young-onset dementia: A meta-ethnographic review of the qualitative literature. *Maturitas*, 92, 102–109.
- Jøranson, N., Olsen, C., Calogiuri, G., Ihlebæk, C., & Pedersen, I. (2021). Effects on sleep from group activity with a robotic seal for nursing home residents with dementia: A cluster randomized controlled trial. *International Psychogeriatrics*, 33(10), 1045–1056.
- Matar, E., Ehgoetz Martens, K. A., Halliday, G. M., & Lewis, S. J. G. (2020). Clinical features of Lewy body dementia: Insights into diagnosis and pathophysiology. *Journal of Neurology*, 267(2), 380–389.
- Perry, M., Michgelsen, J., Timmers, R., Peetoom, K., Koopmans, R., & Bakker, C. (2024). Perceived barriers and solutions by generalist physicians to work towards timely young-onset dementia diagnosis. *Aging & Mental Health*, 28(2), 262–267.
- Vik-Mo, A. O., Gil, L. M., Borda, M. G.án, Ballard, C., & Aarsland, D. (2020). The individual course of neuropsychiatric symptoms in people with Alzheimer's and Lewy Body dementia: 12-year longitudinal cohort study. *The British Journal of Psychiatry*, 216(1), 43–48.
- Wallace, L., Hunter, S., Theou, O., Fleming, J., Rockwood, K., & Brayne, C. (2021). Frailty and neuropathology in relation to dementia status: The Cambridge City over-75s Cohort study. *International Psychogeriatrics*, 33(10), 1035–1043.
- World Health Organisation. *Dementia Factsheet*. World Health Organisation 2023. Accessed February 1, 2024. <https://www.who.int/news-room/fact-sheets/detail/dementia#:~:text=Currently more than 55 million,injuries that affect the brain.>