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

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Commentary for “A thematic analysis of psychotic symptoms in Young Onset Dementia”
by Borelli-Millot et al

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Young-onset dementia (YOD) can affect approximately 5-10 percent of all people with dementia (55 million people worldwide) (WHO, 2022), 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 (Giebel et al., 2014; Geraudine et al., 2021; Matar et al., 2020). In general, living with YOD brings additional barriers to living well with the diagnosis and 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 behaviours 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-Millott 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-categorised 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. Whilst 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. Whilst as Borelli-Millott (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.

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