



Dementia, survival rates, and nursing home admissions

Predicting need for nursing home care remains complex

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For clinicians it is an important and demanding task to inform patients with dementia and their relatives about the prognosis. As with malignant diseases, discussing remaining life expectancy and time to death is a delicate matter. But it is even more challenging to provide information about the timeline for dependency and need for nursing home care because many factors are involved, not only the type of dementia, sex, and age of patients, but also comorbidities, lifestyle, and socioeconomic and cultural factors. Some patients seek all available information about their prognosis, whereas others prefer to know less, and the emotional response to information on the dementia diagnosis and prognosis varies substantially, from catastrophic to pragmatic. Additionally, a substantial discrepancy can exist between what patients and their relatives want in terms of information.

The previous reviews on dementia related survival^{1,2} and nursing home admission were published more than a decade ago,³ so the linked study by Brück and colleagues (doi:10.1136/bmj-2024-080636) is a welcomed update.⁴ Ninety per cent of the studies included in their systematic review were on survival, and as a result the knowledge base for survival has become solid. As in the previous reviews,^{1,2} Brück and colleagues found survival to be inversely associated with age, that type of dementia mattered (with highest survival in people with Alzheimer's disease), and survival was increased in clinic based versus community based studies, mostly attributed to the tendency for community dwelling participants to be older. Another factor that might matter is difference in referral due to socioeconomic status, as those referred to memory clinics tend to be of higher socioeconomic position and thereby better survival.⁵

Even with a solid knowledge base, differences in choice of survival measure could result in confusion about prognosis. Studies focusing on survival tend to highlight the better survival with early onset versus late onset dementia,² whereas studies focusing on loss in life expectancy emphasise the much higher loss associated with early onset dementia.¹ Brück and colleagues acknowledge this and report on both measures, with a reported median survival of 8.9 years for women with a dementia diagnosis at age 60 and 4.5 years at age 85, and with numbers for men slightly lower. The corresponding losses in life expectancy were 13 years at age 65, three to four years at 80, and two years at 85. With this information, clinicians could inform younger female patients that their expected survival would be a bit better than that for older peers but that compared with females without a dementia diagnosis, they could expect a shorter life, which might have implications for matters such as planning for the remaining years.

Brück and colleagues' estimates on time to nursing home admission were, however, less reliable and therefore less useful for informing patients and carers. This was due to both methodological challenges and multiple factors that affect nursing home admission. The pooled estimate in their study suggested that one third of remaining life expectancy after a dementia diagnosis was spent in a nursing home, with more than half of patients moving to this setting within five years of diagnosis. This is disheartening information to share with patients, and we believe these results may overestimate the risk of nursing home admission. Only 9% of the studies in nursing homes accounted for competing risk, so these estimates should be interpreted with caution. In the previous review, the authors concluded that research activities in this area lacked methodological strength,³ which is still true. Thus, we welcome more rigorous studies, taking competing risk of death into account. Furthermore, pooled averages might be of less relevance than country specific estimates, or more geographically finely granulated estimates.

Brück and colleagues suggest that multistate models that take mortality into account could shed light on transition probabilities to nursing homes. A Dutch study reporting on transition probabilities between no formal care, home care, institutional care, and death showed that older age was associated with higher probabilities of mortality and transitions to more care intensive states.⁶ Furthermore, men had a lower probability of transitioning from no formal care to nursing home care and a higher probability of mortality when receiving nursing home care or institutional care compared with women. Also, in a Norwegian multistate study of people with dementia,⁷ men had lower rates of nursing home admission owing to higher mortality, and cohabitating with a partner reduced the likelihood of admission.

Although the understanding of survival with dementia has advanced substantially, the complexities of predicting the timeline for nursing home admission persist. To enhance future healthcare services and optimise quality of life for people with dementia and their families, it is crucial that we continue to strive for more precise, context sensitive insights.

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- 1 Brodaty H, Seeher K, Gibson L. Dementia time to death: a systematic literature review on survival time and years of life lost in people with dementia. *Int Psychogeriatr* 2012;24:-45. doi: 10.1017/S1041610211002924. pmid: 22325331
- 2 Todd S, Barr S, Roberts M, Passmore AP. Survival in dementia and predictors of mortality: a review. *Int J Geriatr Psychiatry* 2013;28:-24. doi: 10.1002/gps.3946. pmid: 23526458
- 3 Lippa M, Luck T, Brähler E, König HH, Riedel-Heller SG. Prediction of institutionalisation in dementia. A systematic review. *Dement Geriatr Cogn Disord* 2008;26:-78. doi: 10.1159/000144027. pmid: 18617737
- 4 Brück CC, Mooldijk SS, Kuiper LM, et al. Time to nursing home admission and death in people with dementia: systematic review and meta-analysis. *BMJ* 2024;387:e080636.
- 5 Strand BH, Knapskog AB, Persson K, et al. The Loss in Expectation of Life due to Early-Onset Mild Cognitive Impairment and Early-Onset Dementia in Norway. *Dement Geriatr Cogn Disord* 2019;47:-65. doi: 10.1159/000501269. pmid: 31319412
- 6 Janssen O, Vos SJB, Handels R, et al. Duration of Care Trajectories in Persons With Dementia Differs According to Demographic and Clinical Characteristics. *J Am Med Dir Assoc* 2020;21:-1107.e6. doi: 10.1016/j.jamda.2020.01.008. pmid: 32113914
- 7 Mjørud M, Selbæk G, Bjertness E, et al. Time from dementia diagnosis to nursing-home admission and death among persons with dementia: A multistate survival analysis. *PLoS One* 2020;15:e0243513. doi: 10.1371/journal.pone.0243513. pmid: 33275638