

Dementia may affect 18 319 people under the age of 65 in the UK

Harvey RJ, Skelton-Robinson M, Rossor MN. The prevalence and causes of dementia in people under the age of 65 years. *J Neurol Neurosurg Psychiatry* 2003;**74**:1206–9.

Q What is the prevalence of dementia in people under 65 years old in the UK?

METHODS

 **Design:** Cross sectional study.

 **Setting:** Three boroughs in London; time period of survey not specified.

 **People:** 567 500 residents of the catchment area.

 **Analysis:** Medical and care professionals were contacted and asked to report confirmed and suspected cases of early onset dementia under their care on a given “census” day. Databases and registers from the four main hospitals were searched for relevant cases with appropriate ICD-9/10 diagnoses. All available hospital and general practitioner notes for reported cases were obtained and reviewed. Where possible, cause of dementia was ascertained from genetic diagnosis, neuropathology, or using recognised validated diagnostic criteria. Age at onset was taken as the age at which first definitive dementia symptom was recorded. Detailed clinical assessment during a home visit by the study author was made of 47% of cases to confirm diagnosis.

 **Outcomes:** Incidence and aetiology of dementia in people under 65 years old.

MAIN RESULTS

In people aged 30–64 years the prevalence of dementia was 54.0 per 100 000 people (95% CI 45.1 to 64.1 per 100 000). The main causes of dementia onset before age 65 years were: Alzheimer’s disease (34%), vascular dementia (18%), frontotemporal dementia (12%), alcohol related dementia (10%), and dementia with Lewy bodies (7%). Using data from the 2001 UK census, extrapolation of the findings gives an estimate of 18 319 people (95% CI 15 296 to 21 758) in the UK with dementia under the age of 65.

CONCLUSIONS

The results of the study are similar to previous estimates of the prevalence of young onset dementia in the UK. Aetiology of dementia is different in younger people than the elderly; for example, Alzheimer’s is a more common cause of dementia in the elderly (up to 80% of cases).

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Commentary

This is an informative article conducted using multiple data sources which provide better case ascertainment than single sources, but less complete ascertainment than community based surveys with cognitive screening.^{1 2} Although studies of young onset dementia differ in methodology and may be based on small numbers which produce less stable estimates, a community based survey in Finland² that included only cases of severe dementia and excluded associated depression reported 4.8 times higher prevalence for all cause dementias in people aged 30–64 years than Harvey *et al.* In the Finnish population surveyed, 11% of all cause dementia occurred in people aged 30–64 years.² One possibly significant correction is that the Kokmen investigation,³ which reportedly found dementia prevalence similar to Harvey *et al.*, is not from the community based Framingham study as stated in this paper, but is methodologically more similar to Harvey *et al.* in that it is also based largely on health records. Thus, despite consistency with other studies assessing dementia prevalence in younger populations,⁴ it is likely that investigations conducted without community screening and neuropsychological testing produce underestimates of dementia. Partial support for this premise is found in the Finnish study² and in a community based study of elderly with US Medicare insurance coverage, where multiple health data sources failed to identify large numbers of demented people.¹

The clinical significance of under or delayed diagnosis lies in the potentially modifiable component of some young onset dementias. Unlike older populations where Alzheimer’s dementia predominates, only 34% of diagnosed dementia in this younger population was Alzheimer’s. To the extent that dementias and related complications in younger populations are modifiable, increased awareness by clinical practitioners may lead to earlier disease identification, treatment of vascular risk factors, improved HIV treatment, earlier alcohol interventions, treatment with neuroprotective drugs as they become available, and preventive measures for injury, including head trauma.

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- 2 Sulkava R, Wikstrom J, Aromaa A, *et al.* Prevalence of severe dementia in Finland. *Neurol* 1985;**35**:1025–9.
- 3 Kokmen E, Beard CM, Offord KP, *et al.* Prevalence of medically diagnosed dementia in a defined United States population. Rochester, Minnesota, January 1, 1975. *Neurol* 1989;**39**:773–6.
- 4 Newens AJ, Forster DP, Kay DW, *et al.* Clinically diagnosed presenile dementia of the Alzheimer type in the Northern Health Region: Ascertainment, prevalence, incidence and survival. *Psychol Med* 1993;**23**:631–44.