

## Incidence of Dementia in a Representative British Sample

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In a four-year follow-up study of 1042 elderly people (aged 65 years or older), randomly sampled from the community, levels of dementia were assessed using a two-phase case-finding procedure (screening followed by clinical interview) among survivors. Clinical information on those not reinterviewed was provided by death certificates, hospital case notes, or postal questionnaires. The weighted four-year cumulative incidence of dementia was 3.7% (95% confidence intervals: 2.4%–5.0%), with age-specific rates of 0.9%, 2.8%, 5.2%, 9.0%, and 8.7% for the age groups 65–69, 70–74, 75–79, 80–84, and 85–89 years respectively. While consistent with data from other British regions, it remains likely that these rates underestimate true incidence.

The prevalence of dementia in Britain has been examined in a number of recent studies (Copeland *et al*, 1987; Morgan *et al*, 1987; Brayne & Calloway, 1989; O'Connor *et al*, 1989; Livingston *et al*, 1990). All confirm that levels of dementing illness increase with age, and most report higher levels of dementia among women (Copeland *et al*, 1987; Morgan *et al*, 1987; Livingston *et al*, 1990) and among institution-alised populations (O'Connor *et al*, 1989; Livingston *et al*, 1990). Nevertheless, the overall rates do show considerable variations, attributable, at least in part, to the different sampling procedures, case definitions, and instruments employed (see Black *et al*, 1990).

The extent to which these variations are mediated by genuine differences in survival or incidence remains unknown. Most reports are based on cross-sectional data, and longitudinal follow-ups of known cases or populations at risk are rare, and currently show widely varying estimates. Among survivors of a non-urban population, for example, Jagger *et al* (1989) report a five-year cumulative incidence of cognitive impairment of 7% (average annual incidence = 1.4%). Given that no attempt was made to classify respondents who had died, or to validate scale ratings of 'impairment', this rate is of limited value in predicting the true incidence of dementing illness.

More recently, Copeland *et al* (1992), in a six-year follow-up of people living in the community in urban Liverpool, reported an overall incidence of dementia among 690 survivors of 9.2 per 1000 per year (0.92%). The present study examines the four-year incidence of dementia in a representative British sample using a two-phase case-finding procedure, backed-up by classification procedures (dementia/no dementia) for non-responders and non-survivors.

### Method

The Nottingham Longitudinal Study of Activity and Ageing (NLSAA) was set up in 1983 to assess the role of lifestyle and customary physical activity in promoting and maintaining mental health and psychological well-being in later life. The first population survey was conducted between May and September 1985, during which time 1042 people, randomly sampled from Family Practitioner Committee lists, and demographically representative of the British elderly population, were interviewed in their own homes. Within the survey sample, those aged 75 years or older were intentionally over-represented in order to admit sufficient numbers for subsequent longitudinal analyses. Thus, while the ratio of 'old' (65–74 years) to 'very old' (75+ years) people in the British population was, in 1985, approximately 1.62:1 (Office of Population Censuses and Surveys (OPCS), 1983), a baseline ratio of 1:1 was aimed for in this study. In estimating incidence for the whole sample, therefore, the over-represented 75+ group was appropriately weighted (by a factor of 0.6) so that the age structure of the combined subsamples approximated that of a true random sample.

Cognitive status was assessed using the 12-item Information/Orientation (I/O) subscale from the Clifton Assessment Procedures for the Elderly (CAPE; Pattie & Gilleard, 1979). The score ranges 0–7, 8–9, and 10–12 were used to classify respondents as impaired, borderline impaired, and unimpaired, respectively. This classification was then validated against clinical diagnostic ratings in subgroups randomly selected from all three classes ( $n = 20$ , 'impaired';  $n = 14$ , 'borderline'; and  $n = 20$ , 'non-impaired'). This validation procedure was conducted within 12 weeks of the original interview and showed 92% agreement between survey and clinician's ratings ( $\kappa = 0.83$ ,  $P < 0.001$ ). Using the cut-off score of  $\leq 7$  on the CAPE I/O scale, the overall prevalence of cognitive impairment consistent with a diagnosis of dementia was 3.2%. Further information on age-specific rates, together with details of the validation procedure, can be found in Morgan *et al* (1987).

Table 1  
NLSAA attrition from original sample

Sample details	<i>n</i>
Number of respondents interviewed in 1985	1042
Successful interviews in 1989	690
Losses between 1985 & 1989	
Deaths	261
Untraceable	25
Refusals	63
Emigration	3
Total	352

The first complete follow-up of survivors was conducted between May and September 1989. All respondents who had participated in 1985, and who were still living in Nottingham, were invited to participate in the follow-up study. Attrition from the originally interviewed sample is shown in Table 1. Overall, 781 people from the original sample were available for follow-up interviews and, of these, 690 agreed to be reinterviewed (a follow-up response rate of 88%). Information on respondents who had died since 1985 was provided by the National Health Service (NHS) central register, general practitioners' records, and hospital case notes. Information on respondents who had moved within, or migrated out of the study area was provided by general practitioners, the Family Health Services Authority (formerly the Family Practitioner Committee), the NHS central register, the local authority and, where appropriate, local social networks.

For the purposes of the dementia incidence study, the population at risk comprised all respondents for whom there existed clear evidence of non-impairment in 1985 ( $n = 970$ ). Specifically excluded from the original sample of 1042 cases were those with I/O scores  $\leq 9$  ( $n = 53$ ), and those with incomplete I/O scores ( $n = 19$ ). If, during the validation procedure in 1985, a respondent with a score  $\leq 9$  was subsequently clinically rated as unimpaired, then that subject was included in the population at risk.

The questionnaire used in the follow-up was similar to that employed in 1985, and covered aspects of health, lifestyle, and physical activity. As in 1985, cognitive status was assessed using the 12-item CAPE I/O Scale. All respondents with an I/O score of  $\leq 9$  were selected for clinical diagnostic assessments conducted 4–12 weeks after

Table 2  
Age-specific incidence of dementia

Age: years	<i>n</i> at risk	<i>n</i> of cases	Four-year incidence (%)	Average annual incidence (%)
65–69	211	2	0.9	0.23
70–74	282	8	2.8	0.70
75–79	252	13	5.2	1.30
80–84	166	15	9.0	2.25
85–89	46	4	8.7	2.18
90+	13	0	0.0	0.0
All ages	970	42	4.3 3.7 <sup>1</sup>	1.10 0.93 <sup>1</sup>

1. Weighted.

the screening interview. These assessments were undertaken by experienced psychogeriatricians using DSM-III-R criteria (American Psychiatric Association, 1987). In the findings reported here, clinician-rated dementia refers to undifferentiated dementing illness of at least moderate severity. Respondents who had died since the 1985 interview were classified demented/non-demented on the basis of death certificate information or, where available, hospital case notes.

## Results

Overall, 50 'at risk' respondents scored  $\leq 9$  on the CAPE I/O scale and 37 of these were clinically assessed. Of the remaining 13, eight had died, and one had moved out of the area between the screening and assessment phases of the study. A further four extant cases were unavailable for clinical interview, and were therefore classified on the basis of hospital records. Clinical assessment found evidence of dementia, consistent with DSM-III-R criteria, in 30 cases. Information from hospital case notes (where available) confirmed a diagnosis of dementia in three of the 13 respondents eligible for assessment, but not clinically assessed.

For those respondents who had died before the 1989 survey, a diagnosis of dementia was recorded in hospital notes in one case, and on NHS death certificates in eight cases. Overall, therefore, 42 cases of dementia were

Table 3  
Four-year age-specific incidence of dementia

Age: years	Women			Men		
	<i>n</i> at risk	<i>n</i> of cases	Four-year incidence	<i>n</i> at risk	<i>n</i> of cases	Four-year incidence
65–69	113	2	1.8	98	0	0.0
70–74	163	3	1.8	119	5	4.2
75–79	153	8	5.2	99	5	5.1
80–84	116	14	12.1	50	1	2.0
85–89	36	4	11.1	10	0	0.0
90+	10	0	0.0	3	0	0.0
All ages	591	31	5.2	379	11	2.9

identified within the population at risk, corresponding to a cumulative weighted incidence of 3.7% (4.3% in the non-weighted sample), and an average annual weighted incidence of 0.93% (1.1% in the non-weighted sample; see Table 2). The age-specific rates for both sexes combined are also shown in Table 2, and for men and women separately in Table 3.

### Discussion

Given the representativeness of the survey sample, the response rates obtained at both original and follow-up interviews, and the conservative cut-off point employed for the screening instrument, it is unlikely that the present study overestimates the incidence of dementing illness in Britain. Three factors, however, would suggest that the rates reported here are an underestimate of true incidence. Firstly, it is known that death certificates often fail to record dementia as a cause (or contributory cause) of death (Burns *et al*, 1990). Secondly, it is of course possible that some of those respondents categorised as 'refused' or 'untraceable' may have included cases of dementing illness. Thirdly, it is possible that the incidence of dementing illness may be higher among the institutionalised elderly people excluded from the baseline (1985) survey. To some extent, the likely impact of the first two possibilities can be estimated.

Examining the recorded causes of death among 84 known dementia sufferers, Burns *et al* (1990) found that, in 30% of cases, no mention of dementia syndrome was made on the death certificate. In the present study, only 48% of those respondents for whom there was evidence of dementia in 1985, and who had subsequently died, had this information recorded on their death certificates. It is reasonable to suggest, therefore, that the death certificate data reported here underestimate cases of dementia by approximately 30–48%, equivalent, in the present study, to between three and seven cases. This would place our unweighted cumulative incidence rate in the range 4.6–5.1%.

Few inferences can be drawn from those respondents untraceable in 1989. However, of those who refused, 41% returned postal questionnaires explaining their reasons for not wishing to participate, which varied from "No reason. I just don't want to bother" to "I'm in good health. There's no need to." Interestingly, the age distribution of refusers did not indicate a bias towards older respondents, among whom dementia shows both a higher incidence and prevalence. On this basis, therefore, there is little evidence that undetected cases of dementia were significantly over-represented among the non-responders.

In view of the sampling procedure used, the present findings have both national and local significance. At a national level, these rates contribute to the emerging geography of dementing illness in Britain. It is particularly noteworthy that the estimated annual incidence rate from the present study (0.93%) is within 0.01 percentage points of that reported by Copeland *et al* (1992) for a similarly representative urban/suburban sample in Britain.

Locally, these provide a research-based guide to service planning. At the present time it is reasonable to suggest that, within the Nottingham Health District which has a population aged 65 years or older of 95 510, approximately 860 new cases of dementing illness will arise each year (based on a population at risk of 95 510 minus 3056 existing cases). This number will, of course, increase as the older population continues to age into the next century. In the Nottingham Health District, the number of women aged 85 years and over is expected to increase by 37% over the next ten years, while the number of men will increase by 70% (Nottingham Health Authority, 1991, p. 6).

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