Characteristics of non-responders and the impact of non-response on prevalence estimates of dementia
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During the last decade much attention has been paid to methodological differences as an important source of variability in the results of prevalence studies of dementia. Application of internationally accepted criteria for dementia and standardized diagnostic procedures have indeed been effective in diminishing the variation in prevalence rates of studies conducted recently. Based on meta-analysis of such studies the prevalence of dementia among the Dutch population age 65 and over can be estimated to range from 5.1% to 6.7%.

However, the issue of non-response, a potentially important source of variation, has attracted relatively little attention. Most studies show that non-responders do not differ from responders in terms of sociodemographic characteristics. However, a similar distribution of demographic variables in responders and non-responders may result in a biased prevalence estimate of dementia based on responders only. Methods. Responders \((n = 2191)\) to a cross-sectional, two-stage community study were compared with regard to sociodemographic characteristics and cognition with three subgroups of non-responders: \((A)\) subjects who refused to participate \((n = 369)\), \((B)\) subjects who were too ill or who had died prior to the screening \((n = 72)\) and \((C)\) subjects who had moved out of the study region or were not traceable \((n = 23)\). Prevalence estimates specific for age and housing situation in responders and physicians’ ratings of cognitive impairment were used to estimate the prevalence of dementia among non-responders.

Results. Group A differed from responders in age and housing situation, group B in age, housing and cognition, and group C only in age. Separate prevalence estimates of dementia based on age, housing and cognition yielded figures for group A between 4.9% and 7.2%, for group B between 13.1% and 19.1%, and for group C between 2.6% and 4.2%. Joined with the prevalence rate among responders \((6.5\%)\) the best possible point estimate of the prevalence of dementia in the target population lies between 6.4% and 6.9%, i.e. within the 95% confidence interval \((CI)\) of the prevalence among responders \((5.4–7.5\%)\).

Conclusions. Although in this study non-response had no important influence on the overall prevalence, the findings among the distinct non-response subgroups point to the importance of describing non-response sociodemographically as well as in terms of the study objective. The authors recommend that non-responders are categorized into distinct groups based on the reason for non-response.

Keywords: attrition, non-response, prevalence, dementia, bias
The objectives of the present study are (1) to investigate factors associated with different types of non-response and (2) to study the effect of non-response on prevalence estimates of dementia.

MATERIALS AND METHODS

Population

The target population was derived from eight general practices in a well-defined rural area near Zwolle, a city in the centre of the Netherlands. In the Netherlands, the general practitioner (GP) acts as a gatekeeper to other medical services. Nearly all inhabitants—except those living in long-term care institutions—are registered with a general practice. All people aged 65 and over on 1 March 1991 and who were currently registered in these practices, and those who were formerly registered but had left because of ill-health, were included in the study. The latter group covers people admitted to institutions for long-term care such as specialized nursing homes or psychiatric hospitals. People living in homes for the aged generally remain registered with their general practice.

It should be noted that in the Netherlands two institutions for long-term care of the elderly can be distinguished: the specialized nursing home and the home for the aged. The former is an institution with somatic and psychogeriatric wards, and nearly 120 specialized nursing, medical and paramedical staff per 100 beds. Homes for the aged, by contrast, have smaller nursing staffs (40 people per 100 residents) and their residents remain registered with GP practices and live in one- or two-room apartments.13

Study Design

In order to meet the objectives of the study, data from the prevalence study among participants and from the study of GPs’ diagnostic accuracy among participants were used as basic material for the analysis of non-response. These studies are briefly described as follows.

Prevalence study among participants. In order to estimate the prevalence of dementia a two-stage design was applied which is described in detail elsewhere.14 Over a period of one year (1 March 1991 until 1 March 1992), the GPs invited their patients aged 65 and over to participate in the study. For residents of long-term care institutions, this was done by their attending physician. After informed consent was given, interviewers were assigned randomly to conduct the first stage interview.

In this stage, participating subjects were screened for cognitive disorders. The interview included the Mini-Mental-State-Examination (MMSE)15 and questions regarding sociodemographic factors. In order to obtain a sample with an over-representation of cases, a non-proportional, stratified random sample was drawn based on the MMSE-scores. Subjects scoring 17 or below, together with a random two-in-three sample of those scoring between 18 and 23, and a random one-in-three sample of those scoring between 24 and 27, were invited to the second, diagnostic stage (Table 1). The diagnostic examination included the Dutch translation of the Cambridge examination for mental disorders of the elderly (CAMDEX).16,17 Diagnosis was based on information gathered during administration of the CAMDEX. For every subject diagnostic classification according to DSM-III-R diagnostic criteria18 was applied. The age-specific prevalence and prevalence for different housing situations used in the present study was estimated by weighting according to different sampling fractions.

Physicians’ ratings. The GP was asked to judge the cognitive state of all members of the target population (responders and non-responders) registered in the GP practice in order to obtain information regarding cognitive functioning of non-responders as well as to determine diagnostic accuracy of this judgement.14 Prior to the invitation of subjects for the study, the GP had to indicate for each subject (1) acquaintance, (2) number of consultations in the past year and (3) cognitive state. For this latter judgement GPs were given a forced choice between DSM-III-R dementia, cognitive impairment or no cognitive impairment. A GP diagnosis of cognitive impairment refers to the situation where the GP has noted the presence of signs and symptoms indicative of the diagnosis dementia without being certain whether the patient meets all the necessary DSM-III-R criteria.
For that diagnosis. Diagnostic accuracy of GPs’ judgement of cognitive functioning (cognitive impairment or dementia contrasted to no cognitive impairment) was studied by means of comparing this item with the DSM-III-R diagnosis dementia in participants, resulting in a sensitivity of 0.69, a specificity of 0.94 and 84% agreement.14

For non-responding residents of specialized nursing homes without a GP’s rating, presence or absence of dementia was recorded by attending specialized nursing home physicians.

Non-response analysis. Subjects not participating in the above described first study stage were studied indirectly, through their attending physician, in order to examine potential non-response bias. These physicians recorded sociodemographic characteristics and cognitive functioning of the non-responders and they determined the reason for non-response, distinguishing three subgroups:

(A) refusers,

(B) subjects who were too ill or died before screening took place, and

(C) subjects who moved out of the region or could not be traced.

Factors associated with non-response. Responders and subgroups of non-responders to the first study stage were compared with regard to age, (subdivided into groups aged 65–74 years, 75–84 years, 85 and older), housing situation (at home versus institutionalized in homes for the aged/specialized nursing homes), marital status (married versus widowed, divorced or never married), gender and GP’s judgement regarding cognitive state. Each non-response subgroup was compared with the total group of responders univariately and multivariately to study possible differential distributions not apparent in univariate analysis. However, the GP’s judgement variable was excluded from multivariate analysis because this variable was missing for most residents of specialized nursing homes, whereas these residents were unequally distributed among responder and non-respondent subgroups. In the multivariate analysis logistic regression modelling was used with the response state as the dependent variable.

Effects of non-response. In case the comparisons indicated differences in distribution of theoretically important confounders, i.e. age, housing situation and cognitive functioning according to the attending physician, data derived from study participants were used to estimate the prevalence of dementia among non-responders. Separate weighted-average-prevalence figures were computed based on each of these variables. Thus, when a non-responding subgroup differed in age distribution from the participants, the prevalence estimates for each age category of the participants was applied to the age distribution of the non-responding subgroup. For housing the same method to estimate prevalence among non-responders—based on housing situation—was used.

Prevalence among non-responders based on attending physician’s judgement regarding cognitive functioning was estimated using the predictive values of GP’s judgement for different housing situations and the records of specialized nursing home physicians to calculate the number of demented subjects. This number was divided by the total number of non-responders for whom physicians’ ratings were available, yielding a weighted-average-prevalence estimate based on physicians’ ratings.

It should be noted that the above calculations are only valid assuming that the age-specific prevalence rates, the prevalences in different housing situations and the validity of physicians’ ratings are the same for responders and non-responders.

The complex sampling method used for the prevalence study among respondents—in which the first-stage MMSE-score had a central role—hampered the possibility of studying the joint influence of variables on prevalence among non-responders.

All analyses were performed using the software packages SPSS-PC19 and Epi Info.20 Results were considered significant if $P < 0.05$.

RESULTS

In the target population of 2655 people aged 65 and over the mean age was nearly 74 years, 92% were living at home, 58% were married and 44% were male (Table 2). Of the 2655 invited subjects 2191 were screened, yielding a response rate of 82.5%. Representativeness of the target population for the Dutch elderly population was indicated by the absence of significant differences in age-distribution by gender.

The overall prevalence of DSM-III-R dementia was 6.5% (95% CI: 5.4–7.5%).14 ranging from 1.1% for those in the age-category 65–69 to 32.7% for those age 90 years and over (Table 3).

Predictive values of GPs’ judgement ‘cognitive impairment/dementia’ were based on housing-specific prevalence estimates (Table 3)21 and sensitivity and specificity figures of GPs’ judgement regarding cognitive functioning.22 Positive predictive values of GPs’ judgement ‘cognitive impairment/dementia’ were 0.32, 0.75 and 0.92 respectively for those living at home, in
homes for the aged and in specialized nursing homes; negative predictive values were 0.99, 0.92 and 0.50 respectively.

The non-responders (n = 464) were divided into the three subgroups as follows: (A) refusers (n = 369), (B) patients with a serious illness or subjects who died before the interview took place (n = 72) and (C) subjects who moved away or who could not be traced (n = 23).

**Refusers (A), n = 369**

Univariate as well as multivariate analysis revealed that age and institutionalization were significantly associated with refusal: older subjects were more likely to refuse, whereas institutionalized subjects were less likely (Table 4).

The differential distribution of the variables age and housing among refusers and responders may have consequences for the prevalence in spite of the rather low refusal rate. Based on the age-specific prevalence among responders, the estimated prevalence among refusers was 7.2% (Table 5). However, because of differential distribution of the housing situation, with a smaller proportion of refusers in housing arrangements associated with higher prevalences, it can be assumed that this figure of 7.2% is an overestimate of the actual prevalence. On the other hand, the prevalence based on housing situation, 4.9%, can be assumed to be an underestimate, because this figure is not adjusted for the higher age

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**Table 2** Distribution of sociodemographic and cognition characteristics in distinct groups of non-responders compared with the responders to the screening stage (%)

<table>
<thead>
<tr>
<th>Type of non-response</th>
<th>Total</th>
<th>Responders</th>
<th>Target population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Refusal (A)</td>
<td>116 (31)</td>
<td>13 (18)</td>
<td>12 (52)</td>
</tr>
<tr>
<td>Ill/death (B)</td>
<td>105 (28)</td>
<td>9 (13)</td>
<td>7 (30)</td>
</tr>
<tr>
<td>Moved /not traced (C)</td>
<td>59 (16)</td>
<td>13 (18)</td>
<td>2 (9)</td>
</tr>
</tbody>
</table>

**Table 3** Prevalence of DSM-III-R dementia according to age (5-year groups) and living situation

<table>
<thead>
<tr>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall 6.5%</td>
</tr>
<tr>
<td>Age group</td>
</tr>
<tr>
<td>65–69 1.1%</td>
</tr>
<tr>
<td>70–74 3.3%</td>
</tr>
<tr>
<td>75–79 5.2%</td>
</tr>
<tr>
<td>80–84 16.1%</td>
</tr>
<tr>
<td>85–89 25.7%</td>
</tr>
<tr>
<td>90 32.7%</td>
</tr>
<tr>
<td>Housing situation:</td>
</tr>
<tr>
<td>At home 4%</td>
</tr>
<tr>
<td>Homes for the aged 21%</td>
</tr>
<tr>
<td>Specialized nursing homes 71%</td>
</tr>
</tbody>
</table>

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The non-responders (n = 464) were divided into the three subgroups as follows: (A) refusers (n = 369), (B)
among refusers. Based on physicians’ rating, which was not significantly associated with refusal, the prevalence among refusers would be 4.9%.

Thus, based on the available information, the prevalence of dementia among refusers is presumably between 4.9% and 7.2%.

Non-Response due to Death or Illness (B), n = 72

Univariate as well as multivariate analysis revealed that this type of non-response was associated with higher age, male gender, living in institutions, and cognitive impairment according to the GP (Table 4). Prevalence estimates, calculated using data of responders, yielded rates based on age and housing of 13.1% and 18.5% respectively. For the prevalence based on physicians’ judgement, the predictive value of GPs’ judgement in different living situations and ratings of specialized nursing home physicians were used, yielding a figure of 19.1% (Table 5). Thus we conclude that in this non-response subgroup prevalence is at least 13.1% and 19.1% at most.

Non-Response due to Moving from the Region and Untraceable Subjects (C), n = 23

Because of small numbers, only univariate analysis was considered and the intermediate and highest age group were combined. Those age 75 and over were less likely to belong to this non-response subgroup (Table 4). Prevalence figures based on age, housing, and GPs’ ratings were 4.2%, 4.0% and 2.6% respectively (Table 5).
Table 6: Estimates of prevalence of dementia in responders and non-responders to the screening stage and minimum and maximum final prevalence estimates in the target population (responders and non-responders)

<table>
<thead>
<tr>
<th>Response group</th>
<th>Number in response group</th>
<th>Estimated prevalence (%)</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-responders:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refuse</td>
<td>369 (13.9%)</td>
<td>4.9</td>
<td>7.2</td>
<td></td>
</tr>
<tr>
<td>Ill/death</td>
<td>72 (2.7%)</td>
<td>13.1</td>
<td>19.1</td>
<td></td>
</tr>
<tr>
<td>Moved</td>
<td>23 (0.9%)</td>
<td>4.2</td>
<td>4.2</td>
<td></td>
</tr>
<tr>
<td>Subtotal non-responders</td>
<td>464 (17.5%)</td>
<td>6.1&lt;sup&gt;a&lt;/sup&gt;</td>
<td>8.9&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>Responders</td>
<td>2191 (82.4%)</td>
<td>6.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total population</td>
<td>2655 (100%)</td>
<td>6.4&lt;sup&gt;c&lt;/sup&gt;</td>
<td>6.9&lt;sup&gt;d&lt;/sup&gt;</td>
<td></td>
</tr>
</tbody>
</table>

<sup>a,b,c,d</sup>: Prevalence estimates calculations:

\[
\begin{align*}
a &= \frac{(369 \times 4.9) + (72 \times 13.1) + (23 \times 4.2)}{464} = 6.1 \\
b &= \frac{(369 \times 7.2) + (72 \times 19.1) + (23 \times 4.2)}{464} = 8.9 \\
c &= \frac{(464 \times 6.1) + (2191 \times 6.5)}{2655} = 6.4 \\
d &= \frac{(464 \times 8.9) + (2191 \times 6.5)}{2655} = 6.9
\end{align*}
\]

Final Prevalence Estimate

The prevalence of dementia among the target population was estimated using both the overall prevalence estimate among responders (6.5%)<sup>14</sup> and the overall prevalence estimate among non-responders which was derived from the figures of the distinct non-responders’ groups. In view of the results of the comparisons between responders and non-responders who had left the region or were not traced, regarding the latter group only the prevalence estimate based on age distribution was used for calculations. However, due to the small number, using 2.6% as the minimum estimate would not alter the results. Calculated prevalence among non-responders ranges from 6.1% to a maximum of 8.9% (Table 6).

The best possible point estimate of the prevalence of dementia in the target population is between 6.4% and 6.9%, which is well within the 95% CI (5.4%–7.5%) of the prevalence based on responders only.

DISCUSSION

In this study, subjects not participating in a population-based cross-sectional prevalence study of dementia did not constitute a homogeneous group with regard to sociodemographic characteristics as well as cognitive functioning. Compared with responders, refusers were older and less often institutionalized, whereas migrated or not traced subjects were younger. Non-response due to death or illness was more likely to occur in men, older and institutionalized subjects and among those cognitively impaired according to the judgement of attending physicians.

Prevalence of dementia among non-responders differed between subgroups of non-responders in opposite directions from the prevalence among responders, with the final effect that non-response had no important influence on the overall prevalence. However with higher non-response rates, a substantial bias is not imaginary, especially when a considerable proportion of non-response is due to death or illness. In this study non-response for this reason can be considered the most important source of bias, despite the fact that it only concerned 2.7% of the target population. Unfortunately, data on such subjects are usually not easy to access. In several studies, information regarding these subjects is missing,<sup>23</sup> and often response rates are calculated after subtracting those not participating for reasons other than refusal,<sup>24–26</sup> thus possibly yielding an underestimation of the true prevalence. In fact, higher mortality rates are reported among cognitively impaired<sup>27–29</sup> or demented subjects.<sup>30–33</sup>

The described target population is relatively stable. Less than 1% had moved away or could not be traced. As migration patterns and demographic characteristics of populations can vary considerably, the results regarding those who had moved or could not be traced can only serve as an illustration of the importance of distinguishing non-response groups.

No attention was paid to non-response in the second stage of the prevalence study (response rate 84.9%).<sup>14</sup> Prevalence was estimated applying a weighting procedure in which the MMSE-score of the diagnosed cases and the sampling fraction for the second stage—based on MMSE score—was used. Available MMSE scores thus preclude bias of the prevalence estimate by non-responders of the second study stage.

Prevalence estimates of dementia among non-responders were computed using the best available information. Of the variables available for non-responders housing situation, age and physicians’ ratings of cognitive functioning were considered the theoretically most important predictors of dementia based on former studies and the cross-sectional prevalence study which is the base for the present study. Because of the design of the prevalence study it was not possible to adjust for the joint effects of the three mentioned...
variables. The necessary assumptions of comparability between responders and non-responders of age-specific prevalence rates, housing-specific prevalence rates, and the validity of GPs’ judgement could not be tested. Thus, the computations regarding non-responders result from indirect, and possibly slightly unstable, measures of prevalence.

In planning an epidemiological study, magnitude and impact of sample attrition cannot be predicted, but it can seriously threaten the validity of the results. Therefore, it is important to consider incorporating in the study design procedures to describe non-response sociodemographically, as well as in terms related to the study objective. Moreover, we recommend, especially in studies with substantial non-response rates, categorizing non-responders into distinct groups depending on the reason for non-response.

ACKNOWLEDGEMENTS

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*(Revised version received February 1997)*