A Follow-up Comparison of Study Participants and Refusers Within a Rural Elderly Population

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Background. Survey rates are known to decline with age. Survey results can be affected by response bias if nonresponders are more, or less, likely than participants to suffer from the condition being studied. For instance, it is possible that older adults with dementia would be less likely to participate in a study of dementing disorders.

Methods. A random sample of a rural U.S. population aged 65+ years yielded 1,422 participants and 912 refusers in addition to others who were ineligible, inaccessible, or untestable. Participants and refusers were compared on age, sex, 5-year mortality, and causes of death suggestive of dementia as listed on death certificates.

Results. Compared to participants, refusers were significantly older and more likely to be women, with mortality similar to that of participants at approximately 5-year follow-up. Death certificate data revealed no significant differences in reported causes of death indicating or suggesting dementia.

Conclusions. In this population, those who refused to participate in a dementia survey were not more likely to be ill or demented than those who did participate.

For the optimal interpretation and comparison of the results of research, potential sources of bias in the study populations should be known. Response rates in survey research decrease with age (1), potentially reducing generalizability and external validity of study results. Low response rates can lead to biased estimates of the frequencies of both diseases and exposures, and thus to errors in risk estimates (2). Prospective studies (1,3) can compare subjects who drop out during the follow-up period to those who remain in the cohort. In cross-sectional research, study participants who do not respond to certain questions can be compared with those who do (4). However, few data can generally be obtained from persons who do not consent to be studied or cannot be reached at all. The nature and degree of bias associated with such nonresponse are difficult to estimate.

We conducted a survey of elderly residents of a rural community to establish a population-based dementia registry (5) in the mid-Monongahela Valley of southwestern Pennsylvania. This article presents demographic and mortality data from participating and refusing subgroups of the age-stratified random sample selected for the survey.

Methods

Study site and population.—The 23 communities served by the Mon Valley Community Health Center were selected for the study. The population is largely blue-collar, of low income and education levels, of European descent, and has low rates of in- and outmigration.

Entry criteria.—Eligibility criteria for the study have been described and justified previously (5). Briefly, they included community residence (i.e., not already being in long-term care), age 65 years or older, fluency in English, and at least a sixth-grade education; the latter two criteria were intended to facilitate interpretation of the neuropsychological tests used to screen for dementia.

Sampling.—The sampling frame for the survey was the voter registration list for two counties. Given the stability of the local population, the electoral rolls were the most comprehensive lists available for our use. They include all individuals who have ever voted in the area, thus reducing systematic bias resulting from the aged and infirm not having voted in recent elections.

From the master sampling frame, a series of 1:13 random subsamples were drawn within each of the 65–74 and 75+ age strata. The sampled individuals were contacted to determine eligibility and to obtain consent to participate. Additional samples were then drawn to compensate for deceased, untraceable, untestable, and ineligible individuals, and for those who refused to participate.

General information about the study and its objectives was provided to the community through newspaper articles, flyers, talk radio, information booths at local fairs, and presentations to various religious and secular community groups. Selected subjects were mailed letters informing them that they had been randomly chosen to participate in the study. They were asked to mail back a form indicating the most convenient times for them to be contacted, and informed that they would receive a follow-up telephone call. Subjects who agreed to participate were scheduled for a home visit during which the study was explained in greater detail and informed consent was obtained.
Subjects who could not be contacted by letter or telephone were visited directly ("door-knocking") so that an effort could be made to recruit them in person. Sometimes, several calls and/or door-knocking visits were made before contact was made and consent to participate was either obtained or denied. Occasionally, positive word-of-mouth publicity from those who had entered the study was helpful in recruiting individuals who had initially refused to participate. After recruitment for the random sample was closed, a group of volunteers was also recruited from the same community. The volunteer group has been described elsewhere (6) and is not included in the analyses reported in this article.

Response.—Of a total of 3,073 individuals randomly selected, 2 had been listed twice, 241 were deceased, and 107 had moved out of the area; 86 who were untraceable may also have died or moved. Of those persons traced, 2,637 were found to still be living in the area. Of them, 63 were found to be younger than 65 years old; 21 were already in long-term care institutions, 53 had less than a sixth-grade education, and 59 were not fluent in English. Fifty-three persons were "too ill" to participate; 21 sampled persons were excluded because they had recently witnessed the cognitive screening of their spouses who were already enrolled in the survey. One person was excluded because he agreed to participate only after study recruitment was officially closed. Five persons were deemed cognitively untestable because of severe sensory impairment or aphasia. Those who consented to participate (participants), either immediately or after initially refusing, numbered 1,366. Those declining to participate (refusers) totaled 995. From a final random subsample, an additional 56 subjects consented in response to the initial recruiting letter; as these subjects have been previously shown (6) to resemble the rest of the random sample, they are included in these analyses for a total participating random sample of 1,422.

Age and gender information were initially obtained from the voter registration lists for the entire random sample. In all participants and some refusers, these data were confirmed in person; in other refusers, age and gender information was subsequently obtained from death certificates, as described below. In 96 refusers, we had no information except age as listed in the electoral rolls. Thus, it is not known what proportion of the refusers may have met the exclusion criteria (inadequate education and/or English fluency, living in long-term care, or age wrongly listed as 65+ years in the voter registration list). Therefore, we do not have a confirmed denominator that would allow us to calculate a refusal rate among those eligible to participate; if all refusers did in fact meet entry criteria, the refusal rate would have been approximately 40%. Of the refusers, 912 were age-confirmed and are included in the analyses reported here, along with 1,422 participants.

Recruitment of the random sample began on April 1, 1987, and closed on August 30, 1989. The midpoint of the recruitment period was June 15, 1988.

Mortality data.—The small towns and rural communities of the Monongahela Valley are known for their stability and low rates of in- and outmigration. Family and neighborhood networks are closely knit. Obituaries of area residents and former residents are published in local newspapers even if the decedent had moved away from the area. A "daily death index" was compiled from obituaries in six local newspapers; regular tracking of participants allowed us to become aware of deaths in this group. The vast majority (97.6%) of deaths (96.5% of participants and 99.5% of refusers) occurred either within the study area or in contiguous counties. Annually, with clearance from the Commonwealth of Pennsylvania Department of Health, death certificates issued during the previous year within Pennsylvania were abstracted to obtain date of death and listed causes of death for deceased participants and refusers; at this time age was also confirmed for refusers. Death certificates from other states were obtained to the extent possible.

Mortality data are reported as of December 31, 1993, 5.5 years after the recruiting midpoint, representing 6.75 years and 4.25 years of follow-up for the earliest and latest recruits, respectively. For convenience, we refer to "5-year mortality" in this article. Death certificates were examined for 341 deceased participants and 199 refusers for all-cause and cause-specific mortality with reference to disorders indicating or suggesting dementia (listed as immediate, underlying, or contributory causes of death). In doing so, we make no assumptions about the accuracy, sensitivity, or specificity of death certificate diagnoses of dementia. However, we do make the assumption that they should not be systematically different between participants and refusers.

Statistical analyses.—Descriptive statistics were calculated for age, gender, ethnicity (white vs nonwhite), and mortality data for participant and refuser groups. The Wilcoxon test was used to compare the ages of participants and refusers. Categorical data reflecting gender, ethnicity, and cause of death were compared using chi-square tests (exact tests being used where appropriate). A Cox proportional hazards survival analysis was performed with time to death as the dependent variable, and age, gender, and participant/refuser status as the independent variables.

RESULTS

Demographics.—Table 1 shows the age and gender distribution of participants and refusers within the original random sample. Refusers were significantly older (p = .0002) and more likely to be women (p = .001) than partici-
pants. Although ethnicity was only known for 592 of 912 refusers, the proportion of nonwhites in the two groups (3.2% of participants and 2.2% of refusers) was not significantly different (p = .21).

**Overall mortality rates.**—As of December 31, 1993 (“5-year follow-up”), similar proportions of refusers (21.8%) and participants (24.2%) were deceased (p = .186).

**Age- and gender-specific mortality rates.**—Mortality rates among men and women within the age intervals >69, 70–79, and 80+ years are shown in Table 2. Compared to participants, refusers had a significantly (p < .001) lower overall mortality rate among men, and a significantly (p < .001) lower mortality rate in women aged 85+ years.

Survival analyses were based on all 1,422 participants and the 912 age-confirmed refusers. In a Cox proportional hazards model including age (continuous variable), gender, and refusal/participant status, greater age (risk ratio = 1.09, 95% CI: 1.08–1.11) and male gender (risk ratio = 1.8, 95% CI: 1.5–2.2) were independently associated with increased mortality risk. Refusers had a lower risk ratio of .84 (95% CI: 0.7–0.997) of mortality compared to participants, but it should be noted that the upper confidence bound is close to 1 (i.e., this was marginally significant association).

**Causes of death.**—Cause-specific mortality between participants and refusers was compared with reference to the following conditions, whether they were listed as immediate, underlying, or contributory to death: (a) diagnoses indicating or suggesting dementia. These diagnoses included: Alzheimer’s disease, dementia, organic brain syndrome, senile dementia, senility, multi-infarct dementia, and Creutzfeldt-Jakob disease. In addition, we examined (b) causes of death related to central nervous system (CNS) disease and (c) nonspecific causes of death, which may have indicated dementia, including “old age” and “natural disease.” Frequencies of these conditions in the two groups are shown in Table 3. These causes of death were not mutually exclusive (i.e., deceased individuals may have had more than one of the conditions listed). Thus, these are not unduplicated counts except in the dementia categories. Two participants had both Alzheimer’s disease (AD) and organic brain syndrome (OBS) listed; only AD was counted. One participant had both senile dementia and OBS listed; only senile dementia was counted. One refuser had both dementia and AD listed; only AD was counted.

Causes of death indicating or suggesting dementia, as classified above, were found on the death certificates of 6.7% of deceased participants and 5.5% of deceased refusers; this difference was not statistically significant (p = .57). Causes of death indicating stroke (CVA, cerebral infarct, intracerebral hemorrhage) were found in 12.3% of participants and 11.1% of refusers; this difference was also not statistically significant (p = .66). Other dementia-related causes of death are listed but not compared because of their low frequency.

**DISCUSSION**

We selected a random sample of rural community-dwelling elders for a survey of dementing disorders. We were concerned that eligible participants and refusers may have had different distributions of dementia and/or potential risk factors for dementia. Such differences would have suggested the potential existence of nonresponse bias, which could have threatened the generalizability and external validity of results from the study.

Participants were older, more likely to be men, and slightly more likely to die within 5 years than refusers. Given the greater likelihood of refusers being lost to follow-up, the presence of even a small number of unreported deaths among them could alter this finding; thus, we conclude that participants and refusers had roughly similar survival rates. Of the deceased, there was no significant difference between the participants and refusers with regard to listings of dementia-like diagnoses on death certificates. These results provide our study with indirect evidence of external validity.

Most previous studies have also found women more likely to refuse to participate (7-10). Older women may under-
found that response rates decline with age (1,10,12,13). Between the groups (medians of 71 and 72 years) in our study was not large. The majority of previous reports have of gender in study participation appears to be complex. Depressed and men who were less depressed. Thus, the role panel study (3), men who were initially healthy were more among women. In a follow-up study of bereaved individuals who were randomly selected as described in this article. In a advertisements were more likely to be women than those who have found nonresponders to be healthier whereas others have found nonresponders to be healthier or no different. Although older age among refusers could be assumed to reflect poorer health or greater frailty, many individuals in our sample refused to participate, saying they were too busy—suggesting that they were active and perhaps healthy. Other studies have described refusers who claimed they were too busy or lacked the time to participate (8,9). Nonresponders appear to be a heterogeneous group. Those who are actually noncompliant appear to be different from those who are unreachable or inaccessible to recruiting efforts (18,19); in one study, the unreachable were found to be less healthy, whereas the refusers were more healthy than the responders (19). Among refusers, those who refuse because of “illness” may be different from those who do so out of “defensiveness,” with potentially different effects on prevalence estimates (20).

In a study of cardiovascular disease and risk factors, participants tended to be the “worried well” who had more risk factors (other than smoking), but less disease, than nonresponders (2). One study (21) found that “mental abnormality was rare and physical disability virtually absent” among refusers, even though the most important reason cited for refusal was “fear of the discovery of disease.” Some refusers in our sample did not understand or believe that they had refusal was “fear of the discovery of disease.” Other studies have described refusers who claimed they were too busy—suggesting that they were active and perhaps healthy. Other studies have described refusers who claimed they were too busy or lacked the time to participate (8,9). Nonresponders appear to be a heterogeneous group. Those who are actually noncompliant appear to be different from those who are unreachable or inaccessible to recruiting efforts (18,19); in one study, the unreachable were found to be less healthy, whereas the refusers were more healthy than the responders (19). Among refusers, those who refuse because of “illness” may be different from those who do so out of “defensiveness,” with potentially different effects on prevalence estimates (20).

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among men (11). Although we found refusers to be marginally less likely to have died after 5 years of follow-up, another group found no difference in mortality rates at 3-year follow-up (19), and yet another group found higher mortality rates among refusers at 10-year follow-up (27).

Other investigators have found that dementia was less common among refusers than among participants (28) and, contrastingly, that cognitive impairment was more common among initial refusers (29,30). Cognitive impairment and dementing illness have been shown to increase mortality (31,32). By comparing the survival rates of participant and refuser groups, we hoped to determine whether they had significantly different rates of mortality, and, by implication, morbidity. Our finding that refusers had similar or lower mortality rates than participants at approximately 5-year follow-up suggests that refusers were not, overall, a sicker group of individuals than participants. However, because our ability to track and monitor mortality is clearly more extensive among refusers escaped our attention. We do not believe this to be a major problem given the stable population of the mid-Monongahela Valley communities.

Although Alzheimer’s disease is often described as a leading cause of death in the elderly population, it is not often listed as a cause of death on death certificates (33,34). Thus, the prevalence of dementia among the deceased cannot be estimated from the frequency with which it is listed as a cause of death. Several factors may lead to dementia being listed in some demented cases and not in others. They may include the knowledge and interest of the physician with regard to dementia, the familiarity of the certifying physician with the individual patient, the manifestations and severity of the dementia (34), and whether the dementia is being listed to have caused or contributed to the death. It is also possible that the number of comorbid conditions contributes to whether or not dementia is listed; that is, if the patient was generally healthy except for the dementia, the dementia might be more likely to be listed as a cause of death. Although refusers in our sample had lower 5-year mortality than participants, and were therefore perhaps the healthier group, deceased subgroups of refusers and participants were, in a sense, “matched” on ill health, and thus equally likely or unlikely to have an existing dementia reported. Unless there is a systematic reason for dementia to be underreported on the death certificates of one group (participants or refusers) relative to the other, our findings suggest that refusers were not more likely to be recognizable demented than participants at the time of recruitment. Thus, dementia may not be substantially related to participation or refusal to participate in survey research.

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