

## NONRESPONSE BIAS IN DATA REPORTED BY NURSING HOME RESIDENT'S NEXT OF KIN

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### I. Introduction

The National Nursing Home Survey (NNHS) is a nationwide sample survey of nursing homes, their residents, discharges, and staff. A unique feature of the most recent survey is the inclusion of a patient followup study called the Next of Kin (NOK) Survey. The NOK was designed to supplement information collected from the nursing home about sample residents (both current and discharged) by interviewing the residents' next of kin. The NOK questionnaire collected information about the residents' demographics characteristics, living arrangements, functional status in activities of daily living, and history of nursing home use prior to entering the nursing home. This paper will estimate nonresponse rates and investigate correlates of nonresponse to the Next of Kin Survey by comparing data obtained about residents with completed next of kin interviews and for those without completed interviews. The data was obtained from the sampled nursing homes.

### II. Source of Data

The NNHS is cross-sectional sample survey of nursing homes conducted periodically by the National Center for Health Statistics. The most recent survey was conducted from August 1985 through January 1986. The scope of the survey included all nursing and related-care homes in the conterminous United States with three or more beds and that routinely provided nursing and personal care services.

The survey was designed as a stratified two-stage probability design. The first stage was a selection of 1,220 nursing homes. The second stage was a selection of residents, discharges, and staff. Data were obtained for 5,243 current residents, and 6,023 discharged residents in 1,079 participating nursing homes. Current residents included in the survey were all persons on the facility's roster as of the night before the survey. Discharged residents included in the survey were all persons discharged dead or alive during the 12 months preceding the survey date. In general the current resident sample tends to be more representative of residents with long nursing home stays (average stay of 2.9 years), while the discharged resident sample is more representative of residents with short nursing home stays (average stay of 1.1 years). Because of this and other differences between the two samples, this paper will examine NOK response rates separately for each sample. Major emphasis, however, will be placed on NOK response within the discharged resident sample.

In this paper, baseline data will refer to data collected in personal interviews with nursing home staff, who referred to the sample resident's medical records when necessary. Data on residents currently in the nursing home were collected using the Current Resident Questionnaire (CRQ); data on residents who were discharged during the 12 months preceding the interview date were collected using the Discharged Resident Questionnaire (DRQ). These baseline questionnaires collected information on the residents' demographic characteristics, their health and functional status, prior living arrangements, history of nursing home utilization, and sources of payment for care, as well as the information on the names of the residents' next of kin. Final statistics from these questionnaires have already been published in several reports (1-6).

Table 1 shows that baseline data were obtained for 5,243 current residents and 6,023 discharged residents or a total of 11,266 current and discharged residents. The total number of cases in the two samples, however, includes multiple cases for the same individual. This occurred because the discharged resident sample represented discharge events and therefore, some residents were included in the sample multiple times. For example, some current residents were

included in both the current and discharged resident samples because they were discharged in the previous calendar year and were later readmitted to the same nursing home. After excluding multiple cases from the two samples, 11,181 individuals were included in the current and discharged resident samples and were, therefore, eligible for the NOK followup.

The NOK was conducted about 3 months after the initial facility contact, or from October 1985 through October 1986. It was conducted by Computer-Assisted Telephone Interview (CATI) with a contact identified during the baseline interview. Residents for whom NOK interviews were fielded were those for whom names of next of kin were identified and sufficient information about these individuals was collected to obtain a telephone number. Overall, the percent of cases eligible for the NOK was similar in the current resident (91 percent) and discharged resident sample (90 percent). Persons not fielded in the NOK follow-up were those for whom insufficient information was available to conduct a telephone interview. The most frequent reason for sample residents not being fielded for the NOK was that the facility refused to give the name of the sample resident. This occurred in 6 and 5 percent of cases in the current and discharged resident sample, respectively. The next most frequent reason for not fielding the NOK was that the facility refused to disclose any information about the name of the resident's next of kin. The third most frequent reason was that the NOK respondents did not have telephones (Table 1).

Table 2 shows the response status of the NOK interview by sample. For the purposes of this paper, cases with only facility respondents were treated as nonresponse to the NOK because the only information provided by these respondents was followup information such as the patient's vital status (dead or alive) and whether the patient had been readmitted to the nursing home since the first contact. Facility respondents provided such information more often for discharged residents (82 cases) than current residents (4 cases). Fielded cases in the current resident sample had a slightly better response rate (91 percent) than did those in the discharged resident sample (88 percent). The reasons for non-interviews among fielded NOK cases in each sample, however, were similar. The most frequent reason for a non-interview was that the interviewer was unable to locate or contact the respondent named by the nursing home staff. Refusal or breakoff was the next most common reason.

The preferred respondent for the NOK interview was the resident's next of kin. Eighty four percent of NOK respondents for the sample discharged residents respondents were relatives. Friends (4 percent), lawyers and legal guardians (2 percent) were also contacted in the NOK.

In this paper, differences in characteristics of discharged residents fielded in the NOK will be compared with those of not fielded discharges to check the representativeness of the NOK sample. This is the first level of nonresponse. In addition, differences in characteristics of fielded discharges will be examined by their response status to the NOK and will be referred to as "responding" or "nonresponding". Although both samples were analyzed, this paper will focus on response to the NOK among discharges.

Both univariate analysis and multivariate logistic regression analyses were used to assess determinants of nonresponse to the NOK questionnaire. Univariate analyses were used to assess statistical significance for individual characteristics. Standard errors were approximated using the balanced repeated replication procedure (7-8). Z-tests were used to assess statistically significant differences between population proportions at the  $\alpha = .05$  level.

Variables found to be significant in the univariate analysis

were included in the saturated backward stepwise logistic regression analysis. The logistic regression model, in the form of:

$$\log \frac{p}{1-p} = B_0 + B_1 x_1 + \dots + B_k x_k$$

was used to assess the simultaneous effects of these significant variables (9-10). A final model was run using WESLOG, a logistic regression procedure designed for complex survey data. Sampling errors of model parameters in this program were estimated by using the balance repeated replication method (11).

### III. Comparison of Discharged Resident Characteristics

Table 4 profiles the population characteristics of discharged residents by their NOK field status. In general, discharged residents fielded in the NOK were fairly similar to not fielded discharged residents; there were no statistically significant differences by sex, race, hispanic origin, primary diagnosis at admission, mobility and continence status, bedsize, census region, or metropolitan status between the fielded and not fielded cases. There were differences, however, by age, marital status, prior living arrangements, payment source at admission, and type of facility resided in. Discharges not fielded in the NOK were more likely to be have unknown marital status (10 percent compared with 3 percent of NOK fielded discharges), and to have been admitted primarily from an unknown location or from a location other than a private residence or a health facility (10 percent compared with 2 percent of NOK fielded discharges). In contrast, fielded NOK were more likely to be 75 years or older (71 percent compared with 65 percent of not fielded NOK), to use Medicare as their primary source of payment at admission (18 percent compared with 10 percent of not fielded NOK), and were more likely to reside in a facility certified as a skilled nursing facility (28 percent compared with 17 percent of not fielded NOK). Thus, it appears that discharges not fielded for the NOK may have had less information available about them because of the type of home they resided in. Homes certified as a skilled nursing facility (SNF) are certified by either Medicare or Medicaid. Because Medicare has many requirements for certification, Medicare certified SNFs are more likely to have complete patient records than homes not participating in Medicare. A similar difference may also occur among Medicaid certified SNFs and homes not certified as a Medicaid SNF.

Table 5 shows that the population characteristics of fielded NOK discharges differed according to their response status. Discharged residents with NOK responders were generally typical of all nursing home patients (1). Compared to discharges with NOK nonrespondents, discharges with NOK responders were more likely to be over 85 years of age at admission, female, white, widowed, and admitted with a primary diagnosis involving diseases of the circulatory system. Discharged residents with NOK responders were also more likely to use Medicare, or their own income or family support to pay for their care at the time of admission, stay in a nursing home certified by Medicare or Medicaid, and stay in homes located in the Midwest.

Discharged residents with NOK nonresponders, on the other hand, were more likely to be under 65 years of age at admission; male; black; divorced, separated, never married, or have unknown marital status; and admitted from health facilities other than a nursing home or short-stay hospital. This category included primarily mental facilities and Veterans hospitals. Residents with NOK nonresponders were also more likely to have a primary diagnosis at admission of mental disorders other than senile dementia and organic brain syndrome, and to have used sources other than Medicare or own income or family support to pay for their care at the time of admission. Residents with NOK nonresponders were more likely to stay in homes not certified by Medicare or Medicaid than were NOK nonresponders.

### IV. Models to Predict Response

In order to assess the independent effects of variables on response status, logistic regression was performed to control simultaneously for all variables in the model. Two models were estimated: one comparing cases fielded in the NOK with those not fielded and one comparing NOK responders with nonresponders. The final logistic regression models for predicting response to the NOK interview are shown in Tables 6 and 7. Limiting analysis to NOK fielded discharges with cases not fielded shows that the only statistically significant variables differentiating these two groups was their marital status and their living arrangement prior to admission. Being divorced, separated, never married, or having unknown marital status was associated with a greater likelihood of having no NOK named by the nursing home; persons with these marital statuses were 38 percent less likely to be fielded for the NOK after controlling for other factors than were fielded discharges. Similarly, residents admitted from other or unknown prior living arrangements were 81 percent more likely not to be fielded in the NOK after controlling for other factors. These data suggest that persons not eligible for NOK fielding were basically unlocateable. They were often without spouses or their marital status was unknown from the records. They were most often admitted from an unknown location.

Limiting analysis to the NOK respondents and nonrespondents shows that only race, marital status, admission diagnosis, prior living arrangements, primary payment source, and certification were significant when included in the model. In this model, response to the NOK Questionnaire was associated with residents in homes certified by either Medicare or Medicaid, and with residents living in the Midwest. On the other hand, lack of response to the NOK Questionnaire was associated with discharged residents of black or other race; with divorced, separated, never married or unknown marital status; with discharged residents admitted with a primary diagnosis of mental disorders other than senile dementia or organic brain syndrome; and with residents using Medicaid and other sources to pay for care at admission. The profile of discharges with NOK nonresponders suggests that many of them may have been mentally ill patients deinstitutionalized into nursing homes because of their primary diagnosis. They were also more likely to be single and of minority race. According to a study on the deinstitutionalization of the chronically mentally ill (CMI), the CMI population in nursing homes was younger, had a greater number of minorities, and a higher percentage of never married (12).

### V. Discussion

This study has profiled nursing home discharges fielded in the NOK survey, and compared it with those not fielded. In addition, this study has profiled discharged residents with responding and nonresponding next of kin. The major finding of this study is that there is little difference between discharges fielded for the NOK and discharges not fielded other than in their marital status and admitting location. Basically these persons were not fielded because their NOK were not locateable. Discharges who had nonresponding NOK, on the other hand, had a profile that suggests many were deinstitutionalized mental hospital patients. Compared with discharges with responding NOK, they tended to be younger (under 65 years), male, never married, and had primary diagnoses involving mental disorders. If this interpretation is correct, it is perhaps to be expected that these patients would have nonresponding NOK, since there is probably a stigma associated with mental illness. Thus, NOK data for discharges is biased by the lack of these types of patients.

In general, these findings replicate those of Potter's study of nursing home residents' next of kin (13) from the 1987 National Medical Expenditures Survey Institutional Population Component (NMES IPC). For example, Potter's final nonresponse (refusal) model found that residents with NOK nonrespondents were more likely to be of black or other

race, never married, in homes not certified by Medicare or Medicaid, and in homes outside the Midwest Census region. Lower response by persons of black or other race has also been reported by Shapiro and Kosanich (14).

When analysis was limited to NOK fielded and not fielded discharges, it was found that the not fielded NOK discharges were more similar to the fielded NOK population in the present study than in the 1987 NMES IPC. However, differences that were found to be significant in the Potter study but not in the 1985 NOK study were in the same direction as was found in the 1987 NMES IPC. For example, patients living in more rural metropolitan areas in the 1987 NMES IPC were significantly more likely to be fielded than those in metropolitan areas. The findings for this variable in the 1985 NOK study had a similar direction as in the 1987 NMES IPC, but was not statistically significant.

That this study would have similar results to Potter's was expected; in many respects the design of the 1985 NNHS and 1987 NMES IPC are similar. Both had national probability samples of nursing homes and sample patients. Both were designed to yield unbiased National and regional estimates of nursing homes and their patients. In both studies, certification and bedsize were identified a priori and used as weighting class variables in nonresponse adjustments for next of kin.

The two studies, however, differed in their definitions of the patient population sampled. These differences may be important in explaining some of the differences in findings on NOK nonresponse from these two surveys. This paper was based on a sample of patients discharged alive or dead during the 12 months prior to the nursing home interview (a discharge sample), while the 1987 NMES IPC sample included all persons who spent one or more nights in a nursing home during 1987 (an admissions sample). Previous research has shown that admissions to nursing homes share characteristics with both discharged residents and current residents (15). Parallel analysis of NOK response rates and NOK eligibility characteristics among the current resident sample replicate some of Potter's findings that were not replicated in the discharged resident sample. For example, the final logistic regression model for NOK nonresponse among NOK fielded current residents found age at admission, bed size, independence in mobility and continence, location of the nursing home in the Midwest, and location outside of a metropolitan statistical area was associated with NOK response in the same direction as was reported in the Potter study (Table 8). This implies that similar results might have been attained if the NNHS NOK survey had used an admissions sample similar to that used in the 1987 NMES IPC.

The findings of this study has implications for long-term care researchers attempting similar follow-up studies of the institutionalized long-term care population, and in particular for the continuing follow-up of the 1985 NNHS patient sample. In addition to the NOK study on which this paper was based, there have been three additional telephone follow-ups of patients included in the 1985 NNHS; these were conducted in 1987, 1988, and 1990.

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Table 1. Field status of Next of kin (NOK) for current and discharged residents included in the 1985 National Nursing Home Survey.

Eligibility status	Current resident sample		Discharged resident sample	
	Number	Percent distribution	Number	Percent distribution
Total residents 1/	5200	100.0	5981	100.0
Total fielded	4720	90.8	5389	90.1
Facility refused NOK name	122	2.3	157	2.6
No NOK phone	63	1.2	96	1.6
Facility refused name of subject	286	5.5	307	5.1
Other	9	0.2	32	0.5

1/ Excludes multiple cases for sample residents.

Table 2. Field results from the Next of kin Questionnaire by sample and response status.

Field status	Current resident sample		Discharged resident sample	
	Number	Percent distribution	Number	Percent distribution
All cases	4720	100.0	5389	100.0
Data complete	4275	90.6	4723	87.6
Refused/Breakoff	120	2.5	164	3.0
Unable to locate or contact any respondent	250	5.3	288	5.3
Language barrier	5	0.1	6	0.1
Physically or mentally incompetent	4	0.1	12	0.2
Facility only available respondent	4	0.1	82	1.5
Other	47	1.0	114	2.1

Table 4. Comparison of discharged resident characteristics by field status.

Characteristic	Total eligible	Field status				
		Not fielded		Fielded		
	Percent (SE)	Percent (SE)	Percent (SE)	Percent (SE)	Percent (SE)	
Unweighted totals	5981	592	5389			
Age at admission	100.0	-	100.0	-	100.0	
Under 65 years	11.6	1.04	14.0	1.99	11.4	1.17
65-74 years	18.1	0.90	21.3	1.91	17.8	1.09
75-84 years	40.1	0.66	38.5	2.74	40.3	0.57
85 years and over	30.2	0.93	26.2	2.46	30.6	0.97
Marital status at admission						
Married	23.9	1.53	19.3	2.71	24.4	1.53
Widowed	53.3	1.10	48.2	4.13	53.8	1.07
Divorced or separated	6.9	0.57	8.6	1.08	6.7	0.55
Never married	12.5	0.68	13.8	1.81	12.4	0.67
Unknown	3.4	0.51	10.1	2.89	2.7	0.392
Living arrangements prior to admission						
Private or semi-private residence	27.9	1.09	29.2	3.67	27.7	1.02
Nursing home	6.8	0.43	5.2	1.36	7.0	0.49
Short-stay hospital	55.0	1.25	47.9	3.68	55.8	1.2
All other types of health facilities	7.5	0.47	7.9	1.24	7.5	0.53
Other or unknown arrangement	2.8	0.32	10.0	2.83	2.1	0.279
Primary source of payment at admission						
Own income/family support	42.1	1.49	46.1	3.78	41.7	1.47
Medicare	17.5	1.47	10.0	1.97	18.2	1.619
All other sources	40.4	1.25	43.9	3.40	40.1	1.2
Certification						
SNF only	27.0	2.18	17.0	3.84	28.0	2.448
SNF and ICF	48.7	2.51	51.6	5.35	48.4	2.59
ICF only	18.3	1.32	20.3	4.28	18.1	1.44
Not certified	6.0	0.76	11.1	2.87	5.5	0.81

Indicates statistically significant difference between NOK fielded and not fielded cases.

Table 3. Next of kin respondent types for discharged residents.

Type of respondent	Discharged resident sample	
	Number	Percent distribution
All respondents	4723	100.0
Sample resident	183	3.9
Proxy respondent	4540	96.1
Next of kin	3958	83.8
Friend	198	4.2
Case or social worker	10	0.2
Lawyer or legal guardian	69	1.5
Entries not covered above	33	0.7
Unknown relationship	272	5.8

Table 5. Comparison of fielded BSK discharged resident characteristics by response status.

Characteristic	Total eligible	Response status				
		Responding		Nonresponding		
	Percent	(SE)	Percent	(SE)	Percent	(SE)
Unweighted totals	5901		4723		666	
Age at admission	100.0	-	100.0	-	100.0	-
Under 65 years	11.6	1.04	10.0	1.14	20.6	2.41*
65-74 years	18.1	0.90	17.6	1.25	18.6	1.92
75-84 years	40.1	0.66	40.5	0.42	38.6	2.00
85 years and over	30.2	0.93	31.8	1.03	22.2	2.35*
Sex						
Male	37.0	1.00	36.2	1.09	43.6	2.81*
Female	63.0	1.00	63.8	1.09	56.4	2.81*
Race						
White	92.9	0.40	95.8	0.56	86.9	2.11*
Black	6.7	0.56	5.7	0.52	12.8	2.00*
Other	0.5	0.14	0.5	0.14	0.3	0.24
Marital status at admission						
Married	23.9	1.53	24.8	1.55	21.1	2.52
Widowed	53.3	1.10	55.1	1.08	44.8	2.38*
Divorced or separated	6.9	0.57	6.2	0.50	10.1	1.57*
Never married	12.5	0.48	11.9	0.48	15.8	1.80*
Unknown	3.4	0.51	1.9	0.29	8.1	1.92*
Living arrangements prior to admission						
Private or semi-private residence	27.9	1.09	28.3	1.02	23.9	1.97
Nursing home	6.8	0.43	7.0	0.55	7.0	1.52
Short-stay hospital	55.0	1.25	55.9	1.32	55.0	2.42
All other types of health facilities	7.5	0.47	7.1	0.54	10.4	1.30*
Other or unknown arrangement	2.8	0.32	1.8	0.26	3.8	1.82
Primary diagnosis at admission						
Senile dementia and organic brain syndrome	8.2	0.48	8.4	0.55	6.9	0.96
Other mental disorders	5.9	0.52	5.0	0.50	11.4	1.66*
Diseases of the circulatory system	30.9	0.80	31.7	1.02	25.8	1.48*
All other diagnoses	55.0	1.04	54.7	1.11	56.6	1.92
Primary source of payment at admission						
Own income/family support	42.1	1.49	42.6	1.58	35.7	2.52*
Medicare	17.5	1.47	19.2	1.75	11.3	2.43*
All other sources	40.4	1.25	38.2	1.16	52.9	2.65*
Certification						
SNF only	27.0	2.18	27.7	2.36	30.2	3.98
SNF and ICF	48.7	2.51	49.2	2.62	42.8	3.11
ICF only	18.3	1.32	18.2	1.53	17.1	2.17
Not certified	6.0	0.76	4.8	0.82	9.9	2.16*
Geographic region						
Northeast	19.3	1.39	19.2	1.47	25.0	3.36
Midwest	31.3	1.47	32.5	1.38	26.4	2.89*
South	28.4	1.71	28.9	1.79	25.7	3.45
West	21.0	1.22	20.4	1.37	24.9	2.97

\*Indicates statistically significant difference between responding and nonresponding categories.

Table 6. Logistic regression model to predict field status to the Next of Kin Questionnaire.

Variable	Beta	Standard error	T-Statistic	Odds Ratio
Age at admission				
Under 75 years	-0.1401	0.1203	-1.16	0.87
Marital status				
Divorced, separate, never married or unknown	-0.4127	0.1353	-3.05*	0.66
Prior living arrangement				
Not admitted from a health facility, private or semi-private residence	-1.5802	0.3871	-4.06*	0.21
Certification status				
SNF only	0.6029	0.3391	1.78	1.83
Not certified by either Medicare or Medicaid	-0.4781	0.3386	-1.41	0.62
Constant	2.4060	0.1501	16.03	

\*Indicates individual coefficient is statistically significant at the  $\alpha=0.05$  level.

Table 7. Logistic regression model to predict response to the Next of Kin Questionnaire; nonresponse model for discharged residents.

Variable	Beta	Standard error	T-Statistic	Odds Ratio
Age at admission				
Under 75 years	-0.1869	0.1566	-1.19	0.83
Race				
Black or other	-0.6406	0.2028	-3.16*	0.53
Marital status				
Divorced, separate, never married or unknown	-0.4467	0.1189	-3.76*	0.64
Prior living arrangement				
Admitted from a mental health facility, Veteran's or long-term care hospital, other or unknown arrangement	-0.0610	0.1784	-0.34	0.94
Primary admission diagnosis				
Other mental disorders 1/	-0.4004	0.1571	-2.55*	0.67
Primary admission payment source				
Medicaid and other sources	-0.4571	0.1175	-3.89*	0.63
Certified by Medicare or Medicaid				
Yes	0.6891	0.275	2.51*	1.99
Census region				
Midwest	0.3624	0.1287	2.82*	1.44
Constant	1.6570	0.2677	6.19*	

1/ Includes psychoses other than senile dementia, neurotic or other personality disorders, mental retardation, and other mental disorders.

\*Indicates individual coefficient is statistically significant at the  $\alpha=0.05$  level.

Table 8. Logistic regression model to predict response to the Next of Kin Questionnaire; nonresponse model for current residents.

Variable	Beta	Standard error	T-Statistic	Odds Ratio
Age at admission				
Under 75 years	-0.4055	0.1079	-3.76+	0.67
Hispanic origin				
No	0.4331	0.2094	2.07	1.54
Marital status				
Divorced, separated, never married or unknown	-0.3406	0.1643	2.07	0.71
Prior living arrangement				
Admitted from a private or semiprivate residence	0.2780	0.1385	2.01	1.32
Primary admission diagnosis				
Other mental disorders 1/	0.0534	0.2139	0.25	1.05
Mobility and continence status				
Independent in both	-0.3064	0.1066	-2.87+	0.74
Dependent in both	0.2662	0.1576	1.69	1.30
Primary admission payment source				
Medicaid and other sources	-0.2706	0.1208	-2.24+	0.76
Certification				
Medicare or Medicaid certified SNF	0.2313	0.1253	1.85	1.26
Not Medicare or Medicaid certified	0.3933	0.2554	1.54	1.48
Bed size				
50-199 beds	0.2953	0.1203	2.45+	1.34
Census region				
Midwest	0.4345	0.1403	3.10+	1.54
South	0.4187	0.1377	3.04+	1.52
Metropolitan Statistical Area (MSA) status				
Yes	-0.6165	0.2002	-3.08+	0.54
Constant	1.6912	0.3231	5.23+	

1/ Includes psychoses other than senile dementia, neurotic or other personality disorders, mental retardation, and other mental disorders.

+Indicates individual coefficient is statistically significant at the  $\alpha = .05$  level.