



Practice of Epidemiology

Linking the Iowa Women's Health Study Cohort to Medicare Data: Linkage Results and Application to Hip Fracture

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This study linked the Iowa Women's Health Study cohort to Medicare administrative data and assessed the value of using Medicare and survey-based sources to study hip fracture incidence. The authors used Social Security number to combine the Iowa Women's Health Study cohort Medicare enrollment and claims data for 1986–2004. Hip fractures were identified from Medicare and follow-up-mail, survey-based sources. Estimates of hip fracture incidence after age 65 years and postfracture mortality were compared. The authors were able to match to Medicare 99.2% of the 40,978 Iowa Women's Health Study participants who survived to age 65 years. Although both Medicare and survey-based hip fracture incidence showed the expected positive association with age and negative association with body mass index, hip fracture incidence was considerably underestimated by self-report (2.61 per 1,000 person-years of observation vs. 4.20 per 1,000 person-years of observation from Medicare-based estimates). Similarly, 1-year postfracture mortality was significantly underestimated by survey-based measures (1% vs. 14% for Medicare-based estimates). Medicare data are an outstanding source of health care information to supplement for older cohorts that have identifiers such as Social Security numbers. These data are useful for studying clinically unambiguous and high morbidity and mortality conditions. They enable less-biased collection of health data.

cohort studies; data collection; hip fractures; Medicare

Abbreviation: IWHS, Iowa Women's Health Study.

Since the mid-1970s, the National Institutes of Health has sponsored many large, population-based cohort studies that examine the relation between baseline risk factors and development of acute and chronic diseases. With growing knowledge of risk-factor/disease associations, interest in expanding the scientific uses of the cohorts is increasing. At the same time, the challenges and costs of direct follow-up continue to rise over time. Identifying efficient follow-up mechanisms for established cohorts will expand their scientific utility.

The Iowa Women's Health Study (IWHS) is a prospective cohort of 41,836 postmenopausal women. At baseline in 1986, the women were aged 55–69 years; by 1996, all surviving women had become eligible for Medicare (age 65 years). The baseline mailed questionnaire assessed diet, lifestyle, anthropometrics, family and personal medical history, and reproductive history (1), and 5 mailed follow-up ques-

tionnaires over 18 years built on these baseline data. Linking the IWHS cohort with Medicare enrollment and claims data offers an important opportunity to study many more health outcomes without increasing the survey response burden. Medicare provides electronic records of payments for a wide range of inpatient (since 1986) and outpatient (since 1991) health care, with the notable exceptions of prescription drugs (a benefit available in 2006) and long-term care. The data are an established population-based source of detailed health information on the elderly (2–5). The combination of the Medicare data and the population-based Surveillance, Epidemiology, and End Results (SEER) Program cancer registries' data is the basis for many seminal papers on cancer outcomes (6–9).

Linking cohorts to administrative data is particularly valuable for studies of endpoints associated with high levels

of morbidity or mortality because the completeness of the administrative data reduces loss to follow-up. Likewise, as cohorts age, challenges associated with response burden, cognitive decline, and institutionalization limit the completeness of survey-based follow-up measures. In such cases, external measures, such as health care claims, provide opportunities for validation or direct measurement of these endpoints. Finally, without alternate sources to measure endpoints, it may not be possible to evaluate new risk factor–outcome associations because of the increased recall bias that would result from survey-based assessments of long-prior events.

In this paper, we evaluate the success of linking the IWHS cohort with Medicare data and demonstrate the potential of these linked data. We use hip fractures to illustrate the value of the linkage and the issues that may pose challenges to using linked data. Hip fractures are relatively common among older persons, at 9.2 hospitalizations per 1,000 women in 2006 (10). In 1994, Baron et al. (11) reported that hip fracture claims had a high degree of internal consistency between hospital and physician reports. Hip fractures are also associated with high (more than 20%) 1-year mortality in the elderly (12), making survey-based assessments of hip fracture incidence challenging.

MATERIALS AND METHODS

Data sources

The IWHS comprises a prospective cohort of women aged 55–69 years in 1986 randomly selected from the Iowa driver's license list. Of the 99,826 potentially eligible women, 41,836 responded to a mailed questionnaire (1). There have been 5 follow-up mail surveys since baseline: 1987, 1989, 1992, 1997, and 2004.

We obtained Medicare enrollment data for the IWHS cohort for the period 1986–2004. Medicare hospitalization data (MedPAR file) were obtained for the same period. Hospital outpatient, carrier (physicians and other suppliers), home health, hospice, and durable medical equipment claims are available for services between 1991 and 2004.

Linkage

The IWHS cohort was matched to Medicare records by using the same algorithm that links Surveillance, Epidemiology, and End Results Program and Medicare data (13). Each study participant's Social Security number, name, sex, and date of birth were submitted for linkage. Matches were determined based on combinations of these identifiers. Data for only 11 of those who were matched by this algorithm were discarded after further comparison of matching variables. Most of the mismatches were associated with children who were receiving benefits through the participant's Social Security number and a respondent was mistakenly linked to the child's Medicare records.

We identified those women whose Medicare claims were most likely to represent their complete health care experience. We selected women who had both Medicare part A (hospitalization) and Medicare part B (physician and other

services) coverage and were not enrolled in a Medicare managed care plan (i.e., fee-for-service enrollees).

Assessment of hip fractures from self-report and Medicare data

Self-reported hip fractures were assessed on each of the 5 IWHS follow-up surveys. Respondents were asked to indicate whether a hip fracture had occurred since (the date of the last survey) but were not asked to report the exact date of the hip fracture. The baseline mail survey did not collect information specific to hip fractures but rather asked whether the subject had a history of any fracture after age 35 years. Hip fractures were identified from Medicare data by using *International Classification of Diseases*, Ninth Revision, code 820.XX from an inpatient hospital (MedPAR) claim (14, 15). Although some women had multiple incident hip fractures, only the first hip fracture identified from each source was included in the analysis.

Statistical analysis

To assess the additional information provided by the linkage, we calculated the percentage of claims-based hip fractures also identified on a follow-up mail survey for women aged 65 years or older. Date of hospital admission was used as the date of hip fracture for those fractures identified from Medicare sources. Date of fracture for the self-report-only group was imputed as the halfway point between the date indicated on the survey (e.g., “Since July 1989, have you suffered a hip fracture . . .”) and the date on which the survey was mailed (16). Date of death was obtained from the linkage to Iowa vital records and the National Death Index for both IWHS and Centers for Medicare & Medicaid Services survival analyses.

Age-specific hip fracture incidence was calculated by using person-years of observation after age 65 years as the denominator and incident fractures as the numerator. Survey-based estimates censored subjects at their last survey response. Medicare-based estimates included only person-years of observation for periods with both Medicare part A and part B coverage and no managed care enrollment. We evaluated 1-year survival (days) after fracture using the Kaplan-Meier method.

RESULTS

Overall linkage results

Figure 1 illustrates the timing of the IWHS baseline and mailed surveys with the gradual aging of the IWHS cohort into the Medicare program at age 65 years, along with the varying availability of Medicare data. As shown, while some IWHS participants were eligible for Medicare at baseline (1986), the entire cohort was not enrolled in the program until 1996.

Ninety-eight percent of the IWHS cohort survived to age 65 years (typical Medicare eligibility). We were able to successfully match 99.2%, or all but 93 of these women. Of the 858 who did not survive to age 65 years, 216 were

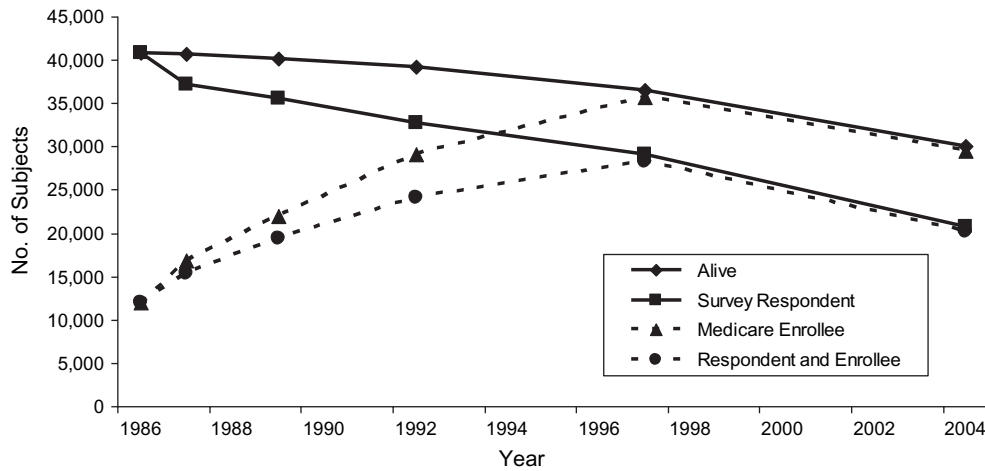


Figure 1. Availability of Iowa Women's Health Study survey and Medicare data over time. Medicare hospitalization data became available in 1986, and Medicare outpatient data became available in 1991.

linked to the Centers for Medicare & Medicaid Services data (25%). This enrollment prior to age 65 years included a mix of beneficiaries who qualified because of disability or end-stage renal disease (71%) and people who died close enough to their 65th birthday that their Medicare enrollment had been automatically initiated (29%).

All but 87 of the IWHS participants who survived to age 65 years and were linked to Medicare data had been, for at least some period of time, enrolled in the Medicare fee-for-service program. Table 1 shows the number of IWHS participants who survived to age 65 years, enrolled in Medicare, and did or did not use health care, by calendar year.

Variability in maintaining both part A and part B coverage was a source of loss of Medicare-based information. Eight percent of the cohort had only part A coverage for some period of time after age 65 years, indicating the likelihood of a primary payer other than Medicare. Incomplete Medicare coverage impacted only 3% of the total potential person-years of observation for the cohort (546,083 of 560,131 possible person-years of observation).

Ascertainment of hip fractures

Overall, 1,195 women reported a hip fracture on a follow-up mail survey, and 2,246 women had a Medicare hospitalization for hip fracture. We found 781 women who had hip fractures according to both data sources (Table 2). Only 35% of women with Medicare-identified hip fractures were also identified as having a hip fracture by using the survey data. On the other hand, 65% of women with a survey-reported hip fracture also had a Medicare-identified hip fracture. Failure to be enrolled in Medicare at the time of fracture was the explanation for approximately one-third of the 414 women who reported a hip fracture and for whom we could not find a corresponding hip fracture recorded in the hospitalization data. There was no clear explanation for the discrepancy for the remaining women.

The majority of the 2,246 women whose fractures were identified by using Medicare claims (74%) survived to the next follow-up survey (Table 3). Of these survivors, 907

Table 1. Availability of Medicare Data for IWHS Participants by Year, 1986–2004

Year	No. of Surviving IWHS Members	Aged ≥65 Years and Enrolled in Parts A and B Fee-for-Service Medicare		No. of Parts A and B Fee-for-Service Medicare Enrollees With Hospitalizations	No. of Parts A and B Fee-for-Service Medicare Enrollees With Outpatient or Physician Services Claims
		No.	%		
1986	41,836	11,977	29	1,417	N/A
1987	41,650	14,642	35	1,806	N/A
1988	41,355	17,114	41	2,260	N/A
1989	41,009	19,516	48	2,505	N/A
1990	40,649	22,157	55	2,902	N/A
1991	40,279	24,852	62	3,353	23,543
1992	39,870	27,391	69	3,723	25,991
1993	39,459	29,994	76	4,224	28,798
1994	38,960	32,280	83	4,653	31,175
1995	38,422	34,622	90	5,051	33,532
1996	37,820	36,552	97	5,462	35,559
1997	37,170	36,034	97	5,672	35,223
1998	36,511	35,386	97	6,030	34,733
1999	35,743	34,670	97	6,175	34,016
2000	34,926	33,958	97	6,374	33,345
2001	34,072	33,179	97	6,567	32,708
2002	33,178	32,343	97	6,712	31,909
2003	32,104	31,354	98	6,627	30,953
2004	31,006	30,211	97	6,589	29,788

Abbreviations: IWHS, Iowa Women's Health Study; N/A, not available.

Table 2. Identification of Hip Fractures From Medicare and Self-report, IWHS, 1986–2004

Hip Fracture Reported on Follow-up Mail Survey ^a	Hip Fracture Found on Medicare Claims		
	Yes	No	Total
Yes	781	414	1,195
No	1,465		
Total	2,246		

Abbreviation: IWHS, Iowa Women's Health Study.

^a Limited to those eligible for Medicare during at least part of the follow-up period.

women, representing 40% of all Medicare-identified fractures and 55% of survivors, responded to the first possible follow-up survey after hip fracture. The majority of these respondents (83%) reported having suffered a hip fracture. The percentage of hip fractures identified by Medicare that were also identified by self-report decreased dramatically across IWHS surveys. Loss to follow-up because of mortality increased over the study period. Only 68% of the Medicare-identified hip fracture patients between 1997 and 2004 were alive at follow-up 5 compared with 95% of those with hip fractures between 1986 and 1989 who survived to follow-up 2. This trend of increasing loss to mortality was influenced by both the aging of the IWHS cohort and the increasing time between follow-up surveys. In addition, the rate of survey response among hip fracture survivors decreased over time. Ninety-two percent of survivors who had a hip fracture between 1986 and 1989 responded to the next follow-up survey (1 or 2), but only 46% of survivors who had a hip fracture between 1997 and 2004 responded to follow-up 5.

Overall estimates of hip fracture incidence were lower when the survey-based measure compared with the Medicare-based measure was used (2.61 vs. 4.20 hip fractures per 1,000 person-years, respectively). The difference

between survey and Medicare-based estimates of hip fracture incidence was minimal at younger ages but dramatically increased at older ages. In addition, the differences between survey and Medicare-based measures were maintained for all body mass index groups (Table 4). Both approaches showed the expected positive association of hip fracture with age and negative association with body mass index. However, the gradient in risk ratios for the survey-based measure of hip fracture was less prominent than for those based on Medicare data.

Comparing the characteristics of the IWHS participants whose Medicare-identified hip fractures were not found in the survey data with those whose hip fractures were also reported on a follow-up survey provides important insight into the role of nonresponse bias in this population. Those whose hip fractures were also reported on a follow-up survey were younger at hip fracture than those with Medicare-only identified hip fractures (median age, 75.1 years vs. 77.6 years). The 2 groups did not differ on several other baseline risk factors for hip fracture: body mass index or waist-to-hip ratio (Table 5).

There were, however, substantial differences in estimated age-specific post-hip-fracture mortality. One-year mortality among those with Medicare-identified hip fractures was 14% compared with just 1% among the subset also identified on a survey. Mortality in the overall Medicare group increased with age, while mortality for women whose fractures were also identified by survey response was stable across age categories. It was not possible to calculate true 1-year mortality for those women whose self-reported fractures were not also found in Medicare data.

DISCUSSION

In cohorts such as the IWHS with high-quality identifiers, linkage with Medicare administrative data is feasible and technically straightforward. The linkage is particularly valuable for studying endpoints associated with high levels of

Table 3. Reporting of Medicare-identified Hip Fractures on IWHS Follow-up Surveys

	No. of Hip Fracture Hospitalizations During the Survey Period	Hip Fracture Hospitalization During the Survey Period and Alive at the Follow-up Survey		Hip Fracture Hospitalization During the Survey Period, Alive at the Follow-up Survey, and Responded to the Survey		Hip Fracture Hospitalization During the Survey Period, Alive at the Follow-up Survey, Responded to the Survey, and Reported Hip Fracture on the Survey	
		No.	% of Total Fractures	No.	% of Total Survivors	No.	% of Total Respondents
		Follow-up 1 and 2 ^a (1986–1989)	91	86	95	79	92
Follow-up 3 (1989–1992)	153	138	90	107	76	87	81
Follow-up 4 (1992–1997)	538	433	80	264	61	227	86
Follow-up 5 (1997–2004)	1,464	994	68	457	46	376	82
Overall	2,246	1,651	74	907	55	755	83

Abbreviation: IWHS, Iowa Women's Health Study.

^a Time period for follow-up 1 overlaps with that for follow-up 2; survey results were combined.

Table 4. Comparison of Hip Fracture Rates and Rate Ratios for IWHS Participants Aged 65 Years or Older, 1986–2004

	Hip Fractures Ascertained From the IWHS Survey		Hip Fractures Ascertained From CMS Hospitalization Records	
	Rate per 1,000 Person-Years	RR	Rate per 1,000 Person-Years	RR
Age, years				
65–69	1.42	Ref.	1.19	Ref.
70–74	2.70	1.90	2.86	2.40
75–79	3.71	2.61	6.08	5.11
≥80	6.33	4.46	13.42	11.28
Body mass index				
Low	6.92	2.27	11.41	2.25
Normal	3.05	Ref.	5.06	Ref.
Overweight	2.38	0.78	3.81	0.75
Obese	2.07	0.68	3.14	0.62

Abbreviations: CMS, Centers for Medicare & Medicaid Services; IWHS, Iowa Women’s Health Study; Ref., referent; RR, rate ratio.

morbidity or mortality since they will be more subject to loss to follow-up bias than outcomes with low levels of morbidity or mortality. Medicare also offers opportunities to more validly assess the population impact of high morbidity and mortality conditions, to measure the mortality associated with acute and chronic conditions, and to link that mortality to pre-event risk factors. With Medicare data, exact event dates are available, which offers increased precision for assessing both short- and long-term survival, costs, and associated health care use.

Furthering the value of Medicare linkage are the detrimental effects of aging on the quality and availability of survey-based data. With age, challenges associated with mortality, response burden, cognitive decline, and institutionalization limit the value of survey-based measures. In such cases, external measures such as those from health care claims provide opportunities for direct measurement of disease incidence as well as external validation of responses. Conditions such as hip fracture that are unambiguous in their diagnosis and that require health care are ideally suited for analysis with Medicare claims data. The claims-based literature has grown considerably in recent years, and algorithms are available for a wide range of acute and chronic conditions such as stroke, small bowel obstruction, diabetes, congestive heart failure, and arthritis (17).

Likewise, claims can be used to identify and quantify the receipt of health care, including influenza vaccination, elective joint repair, mammography use, and rehabilitation. Beyond using claims to assess risk factor associations, the data can also be used to estimate economic costs of disease, treatment patterns, and outcomes following diagnosis. All extend the value of baseline and follow-up data for these cohorts.

Some of the apparent mismatches between Medicare-reported and survey-reported hip fractures represent self-report errors. An earlier IWHS study of hip fractures (18) found that data on 12% of hip fractures reported on the

Table 5. Comparison of Fracture Risk Factors and Mortality Between All Hospitalizations for Hip Fracture and the Subset Reported on a Survey, IWHS, 1986–2004

	Hip Fracture Hospitalization From Medicare Data During the Survey Period (n = 2,266), %	Reported Hip Fracture on the Survey (n = 733), %	P Value
Age at fracture, years			<0.001
65–69	11	17	
70–74	22	29	
75–79	39	35	
80–84	21	14	
85–89	7	5	
Body mass index, kg/m ²			0.299
<18.5	2	2	
18.5–24.9	46	49	
25–29.9	34	34	
>30	17	15	
Waist-to-hip ratio			0.219
<0.78	23	25	
0.78–0.82	23	26	
0.83–0.89	23	23	
>0.89	30	26	
1-Year mortality after hip fracture			<0.001
Overall	16	1	
Age 65–69 years	13	1	
Age 70–74 years	12	0	
Age 75–79 years	15	1	
Age 80–84 years	18	1	
Age 85–89 years	26	0	

Abbreviation: IWHS, Iowa Women’s Health Study.

survey could not be found in medical records. These mismatches were later confirmed by the respondent to have been erroneously reported on the survey. The Women’s Health Initiative was able to confirm 78.2% of self-reported hip fractures with medical records (19). These estimates are consistent with our findings that a measurable percentage of self-reported hip fractures may represent survey error.

In this example, we illustrated the value of Medicare claims for studying hip fractures in older women. We demonstrated that an analysis based on self-report would underestimate both the incidence of and mortality after hip fracture. The mortality effects, as we illustrated, are considerable. People rarely die directly from hip fractures; rather, fractures can start a cascade of disability that leads to complications such as pneumonia, sepsis, or the deconditioning resulting from the fall and associated immobility.

A key advantage to linkage with Medicare data is that they are available from a single source in standard formats, which results in considerable efficiency compared with

other electronic or secondary data, particularly when studying geographically dispersed populations. Linkage is facilitated by the program's ability to match records on the basis of each beneficiary's own Social Security number. This advantage allows individuals to be identified even if they claim their Medicare benefits under another person's work history (most often a spouse). The ability to link medical claims longitudinally and nationally is particularly useful for tracking health events for IWHS participants who move out of state or become institutionalized.

There are attributes of the IWHS cohort that are unique and may contribute to the high level of success of this linkage process. Most importantly, the cohort had extremely complete and high-quality identifiers. We were able to link 99.2% of the IWHS women who survived to age 65 years. Second, there was relatively little Medicare managed care in Iowa. In the IWHS cohort, only 1% of the total possible person-years of observation after age 65 years was lost to managed care enrollment. The rest of the 3% loss was due to incomplete part A and/or part B enrollment. Managed care exceeds 30% in other areas of the United States (e.g., California) (20); linkages to populations in high-managed-care areas would observe significant loss. It is important to note that managed care enrollment varies over both geography and time. Thus, the loss due to managed care may change over time and differently across regions of the United States. Although managed care enrollees represent a source of missing utilization data, these enrollees will link to Medicare enrollment records, so the amount of missing data can be quantified.

Our high linkage rate is consistent with the experience of the Surveillance, Epidemiology, and End Results Program/Medicare project. Medicare linkages do not reflect the experiences of the small percentage of people older than age 65 years who are not covered by Medicare—largely persons who never participated in the Social Security or Railroad Board Retirement programs. Others who may be underrepresented in Medicare populations include civil servants who, in the 1960s and 1970s, were allowed to opt out of Medicare, and a small group of elderly who have Medicare part A coverage (i.e., hospitalization) but not Medicare part B coverage (i.e., other services). Reasons for waiving part B coverage include having other (primary) insurance such as from an employer and relying on another system such as the Veterans Administration or Indian Health Service for primary care. In our study, we found that approximately 7% of IWHS participants spent some period of time without part B coverage. Overall, however, the impact on person-years of observation was minimal: we found complete part A plus part B fee-for-service enrollment for 97% of the potential person-years of observation for our cohort.

With expanded use of Medicare data for cohort follow-up, methodological advances will likely follow. One challenge is how to appropriately study a cohort with a large percentage of left truncation. That is, there are gaps between date of a survey and date of Medicare enrollment when it is unknown whether the outcome of interest was experienced. For 65% of the cohort, there was a gap between baseline survey and Medicare enrollment at age 65 years. Current Medicare data users often adopt approaches such as using

the first year of Medicare enrollment to confirm that elderly are disease free or to identify comorbidities. With linked cohorts, the surveys themselves offer this opportunity, but the challenge of left truncation remains.

In conclusion, the linkage experience of the IWHS cohort illustrates the value of using Medicare administrative data to extend the utility of established cohorts for identifying additional endpoints, particularly those associated with considerable morbidity and mortality. Even when the condition of interest may not be associated with survival or response, administrative data may offer a means to reduce response burden and enable surveys to focus on topics such as quality of life and risk factor changes not measurable by using external data sources.

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