**Self-Reported Delays in Care Do not Predict Increased
Mortality in a Cohort of Community-Dwelling Elders.**

By

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Abstract

Background: Self-reporting of delayed care is a common measure of access to healthcare. The relationship of such reports to worsened health outcomes is often assumed, but few studies have tested this longitudinal connection.

Objective: To determine whether self-reports of delayed care predict increased mortality among community-dwelling elderly.

Design: 3-year longitudinal retrospective cohort study.

Setting: A five county area of North Carolina.

Participants: 4,162 randomly sampled individuals age 65 and older.

Measurements: The outcome was the proportional hazard ratio (HR) for death stratified by the factor of interest, baseline self-reports of delayed or foregone care. Control variables included predisposing, enabling, and need factors influencing care seeking and/or mortality.

Results: Of 3,964 eligible participants reporting, 61% never, 27% once in awhile, and 12% quite often delayed care. 13% of participants died during the study period. Older age, male gender, lower income, less education, lack of supplemental insurance, less social support, more depression, more severe chronic disease, smoking, and worse self-rated health predict increased mortality (p-values<.01). Of these, age, lower income, less education, lack of supplemental insurance, less social support, worse self-rated health, and more depression were

significantly associated with more self-reported delays in care. In both an unadjusted and fully adjusted survival model, 3-year mortality rates did not differ among cohorts reporting varying degrees of delayed care.

Conclusion: Among community dwelling elders, self-reports of delayed care did not predict increased 3-year mortality rates. These results raise questions about self-reporting of delayed or foregone care as a measure of access to the healthcare system.

Background

Differential access to health care persists as a national concern for the public, lawmakers, and health care professionals[1-4]. Quantifying and tracking access over time requires a measurable definition of access. Given the complexity of health care access, its measurement is methodologically challenging[5]. Appreciating this difficulty, the Institute of Medicine (IOM) recommended the development of measures of health care access that can be easily understood and widely applied. In a major report on this subject, the IOM defined access to medical care as "the timely use of personal health services to achieve the best possible health outcomes[3]." Conceptually, this definition suggests that barriers to access cause delays in seeking appropriate medical attention, and that these delays lead to worse health outcomes. The definition also implies that establishing the validity of measures of access requires longitudinal study[6].

One common measure of access involves asking survey participants directly to report whether they have delayed necessary medical care. This question is contained in some form in nearly every major survey about access[7]. While this direct questioning has face validity, few studies have explored the association between self-reported delays in care and undesirable health outcomes. Results of these studies have varied by setting. Delays in care as assessed at the time of hospitalization increase the length of hospital stays[8]. However, a community based sample of adults age 25-64 failed to demonstrate any difference in mortality among those participants who reported foregone care[9]. Due to the higher disease

burden, delays in care among the elderly may be especially problematic[10].

Elderly non-users of health care services have been shown to have higher

mortality as compared to low-volume elderly health care users[11]. However, we

are unaware of any previous longitudinal study that tests the association between

self-reports of delayed or foregone care and mortality rates among the elderly. To

answer this question, we used data collected prospectively from a cohort of

community-dwelling elders. We hypothesized that reports of delay by these

participants would be associated with an increased rate of mortality in the

subsequent 3-year period.

Methods

Study population.

This study uses data from The Established Populations for Epidemiologic Studies

of the Elderly (EPESE), a multi-site project initiated in the 1980s by the National

Institute on Aging[12-14]. We used the North Carolina sample, which included

participants from five contiguous counties in the northern portion of the state, and

which intentionally over-sampled African-Americans. The initial sample

consisted of 4,162 people, age 65 and older, who participated in surveys

conducted by trained interviewers in 1986 and 1987 at the residences of the

participants. We excluded 162 participants who were unable to self-report and

thus had only proxy information, as well as 12 subjects who did not respond to the

question about delaying or foregoing care. We also excluded 24 participants who

listed their race as neither black nor white, due to lack of power for independent analysis.

Variables

In conceptualizing the potential role of independent variables, we followed the Anderson and Aday model of access, in which variables are categorized as being predisposing, enabling, or describing need for care[15, 16]. Variables were chosen because of their known relationship with mortality rate and/or their previous utility in examining access, particularly in the elderly.

Factor of interest

Our factor of interest, self-reported delayed or foregone care, was defined in three categories based on the response to a single survey question, "How often do you put off or neglect going to the doctor when you feel that you really should go—never, once in awhile, or quite often?"

Outcome

The outcome variable, death at three years, was confirmed with a family member or a reliable respondent at the scheduled three-year follow-up interval. Death certificates obtained from state records were used to verify date of death. Verification with the National Death Index through the year 2001 was also performed, and this information provided the source of mortality information for participants otherwise lost to follow-up.

Predisposing variables

Demographic information obtained at the time of the baseline interview included age, gender, race, marital status, and education (dichotomized at the median between the eighth and ninth grade).

Enabling variables

Annual income divided at $10,000 dollars, the presence or absence of supplemental insurance to Medicare, a reported usual site of health care (excluding emergency or urgent care clinics), and urban versus rural county residence were included as dichotomous variables. Social support was defined as having family or friends that the respondents could "count on in times of trouble" and with whom they could discuss their "deepest problems" as described in previous EPESE studies[17]. Satisfaction with care was included as a dichotomous variable "very satisfied"/"satisfied" versus "very dissatisfied"/"dissatisfied."

Need-for-care variables

Self-reported health was included as a categorical variable consisting of poor, fair, and a combined good and excellent category. An internally validated chronic disease index, developed by the EPESE study team, has been reported on previously[18, 19]. This index creates a three level variable of chronic disease severity based on history, current medications, physical measurements, and laboratory findings, for the following categories: Heart condition, Hypertension,

Diabetes, Stroke, and Cancer. A depression score was calculated using a modified version of the Center for Epidemiologic Studies-Depression scale (CES-D)[17], and was included as a continuous variable. Current smoking was included as a dichotomous variable.

Analysis

The descriptive analysis and initial model development were performed using Stata v7.0 software (Stata Corporation, College Station, TX). However, given the complex sampling strategy, SUDAAN v8.0 software (Research Triangle Institute International, Research Triangle, NC) was used to incorporate sample weights in all Cox regression models.

Following a descriptive analysis of all of the variables, Cox proportional hazard models were fit to assess the mortality rate over a 3 year period due to self-reported delays, as well as to other risk factors. We then explored the potential for confounding by the predisposing, enabling, or need-for-care variables by examining the relationships between them and self-reports of delay using chi-square tests for categorical variables, and analysis of variance for continuous variables.

Following this analysis, we developed a Cox model to examine the relationship between delay and mortality adjusted for potential confounders. Dummy variables were constructed to represent categorical variables in the model. The

proportional hazards assumption was tested for all variables, both individually and as a group, that were included in the full model. In addition, we examined interaction terms between delay and the other independent variables in the full model. Likelihood ratio tests were used to assess the significance of the interaction terms. Variables were eliminated from the full model if their elimination had only minimal effect on the hazard ratio associated with the delay variable and mortality rate. Adjusted Kaplan-Meier curves were plotted to assess the persistence of any noted associations over time.

The Committee on the Protection of the Rights of Human Subjects at the University of North Carolina School of Medicine exempted this study from review because none of the individual participants were identifiable in the available data.

Results

Of the 4,162 participants in the baseline survey, 3,964 were eligible for analysis. The mean age of the participants was 73.3 years, and they were predominantly female (Table 1). The sampling strategy yielded relatively equal numbers of blacks and whites, as well as urban and rural participants. Notably, the average education level for participants was only eighth grade.

The unadjusted hazard ratio between self-reports of delayed care and mortality rate over a 3 year period was not significant (Table 2). Male gender, older age,

lower income, less education, lack of insurance (supplemental to Medicare), smoking and worse self-rated health were significantly associated with increased mortality. Higher scores on the depression scale, less reported social support, and more severe chronic disease were also significantly associated with increased mortality. Race was not associated with increased mortality, consistent with past findings demonstrating a "mortality cross-over" between blacks and whites that occurs at advanced age[20].

Younger age, lower income, less education, no supplemental insurance, less support, and higher depression scores were associated with reports of more delay (Table 3). A particularly strong association exists between self-rated health and self-reports of delay. Three times as many participants rating their health as poor report delaying care quite often as compared to those participants who rate their health as good or excellent. Among variables not associated with mortality, dissatisfaction with medical care, rural residence, and lack of a usual site of care were significantly associated with self-reported delays. The chronic disease index, gender, and smoking (all of which were related to mortality) had no significant relationship with reports of delay.

Based on our conceptual model and our preliminary analysis, we developed a Cox proportional hazards model adjusting for age, gender, education, lack of supplemental insurance, social support, depression score, chronic disease category, and self-rated health. Because a substantial number of individuals did

not report their annual income, and because prior modeling in the subset of participants with income data demonstrated minimal effect of income on the HRs for mortality associated with reports of delay, income was not included in this full model. All models used the cohort reporting quite often delaying care as the referent group (Table 4). In the full model, the HR for the cohort reporting never delaying care was 1.4 (CI 0.95-2.1), while the HR for the cohort reporting once in a while delaying was 1.1 (CI 0.7-1.7). The full model can be reduced to a slightly more precise model adjusting only for the key confounder, self-rated health. In this reduced model the HR for the cohort reporting never delaying care was 1.5 (CI 1.0-2.2), with a HR of 1.2 (CI 0.8-1.7) for those once in a while delaying care.

Using the National Death Index, we extended the mortality information for the cohorts through 2001. By then, over 80% of the population was deceased. Given the long-time frame and high mortality rate, violation of the assumption of proportional hazards precludes Cox modeling over the entire period. Nevertheless, a Kaplan-Meier plot (Figure 1) graphically illustrates the persistence of the 3-year trends over time.

Discussion

Barriers that limit an individual's access to medical care are often believed to cause adverse health outcomes because they delay the timely receipt of appropriate care. Viewed from this conceptual framework, the appeal of asking survey participants directly about delayed or foregone care is obvious. However,

the connection between self-reported delays in care, and higher mortality rates has not been established. In a well-done study of community dwelling adults age 25 to 64, no association was found between mortality rates and self-reported foregone care[9]. In this study, we examine the relationship between mortality and self-reported delayed or foregone care in a population of community-dwelling participants age 65 and over. In this population, the lack of an unadjusted or fully-adjusted mortality association is punctuated by the surprising finding that in a reduced model adjusting for self-rated health, those participants who report never delaying or foregoing care die at a slightly, but significantly higher rate over the next three years when compared with those participants who report quite often delaying or foregoing care.

The reasons that self-reported delays in care fail to predict subsequent mortality are not obvious. One explanation may involve the respondent's interpretation of the question about access. Specifically, the single question about delaying care, implicitly requires a survey participant to answer at least two questions: 1) "Did you need care?" 2) "Did you get care?" Only an affirmative answer to the first question can lead to the conclusion that care was needed but not obtained. This disadvantaged elderly population may have found the assessment of medical need difficult. Ultimately, participants may have had better outcomes if they recognized their unmet needs, as compared to those participants in whom medical need went unrecognized. We are unable to distinguish such subgroups based on the available data.

Alternatively, the perception of need may not be equivalent to a physiologic presence of need. We note that while both self-rated health and the chronic disease index strongly predict mortality, self-rated health has an important association with self-reports of delay while the chronic disease index does not. These data may be a reflection of the lack of symptoms associated with many predictors of increased mortality in the elderly, such as hypertension or occult gastrointestinal bleeding.

Finally, we point out that resource use in our health care system continues to have a heavy concentration at the end of life[21]. This heightened care may lead the sickest elders to answer that all of their medical needs are being met, but have questionable impact on their mortality. Although our study occurred in a community setting and attempted to adjust for health status, we cannot exclude this possibility.

This study was conducted in a fixed geographical area in North Carolina. As compared with the general population, this population of elders is relatively uneducated and impoverished. Although potentially affecting generalizability, we believe that the demographics of this study population amplify the results, since it is precisely in vulnerable populations that we would hope that questions about access would perform well.

This study does not measure any intermediate adverse outcomes that might be significantly associated with self-reported delays in care over the study period. These intermediate adverse outcomes could potentially provide early indicators of decline that would cause mortality differences to emerge over time. However, the Kaplan-Meier plot extends the mortality data for these cohorts for an additional 12 years beyond the initial study period. It does not suggest that additional time improves the capacity of self-reports of delayed care to predict mortality.

The percentage of people who respond that they lack access to care in cross-sectional studies is sensitive to survey methodology and question placement and phrasing[5]. The question about delayed or foregone care used in our study allowed for three levels of response, and did not confine participants to a specific time frame. In addition to the geographic and demographic issues noted above, the lack of a uniform methodology in measuring access, including measuring delays in care, limits our ability to extrapolate findings from this study to other cross-sectional studies that measure delays in care in different ways.

Nonetheless, the percentage of people who report delays in obtaining needed care in large, cross-sectional surveys continues to be reported as a measure of access to the healthcare system. We do not discount the importance of perceived delays in care in the lives of individuals, nor do we imply that self-reports of delay do not serve as a valuable measure of consumer confidence in the healthcare system. On the contrary, particularly at this time when consumers are faced with increasing

financial burdens when they choose to seek care[22], this study demonstrates the necessity of further studies that examine how people determine what their medical needs are and whether those needs are being met, and whether educational or other interventions can improve the ability of individuals to correctly perceive and act on their medical needs.

However, in conjunction with the work of others, this study calls into question the use of self-reports of delayed care or foregone care as a surrogate for measuring actual delays in care that lead to adverse health outcomes. These results demonstrate the continued need for longitudinal research exploring the complex causal connections between lack of access and poor health outcomes in vulnerable populations. This study also highlights the continued need to develop improved measures of access as called for by the IOM almost a decade ago.

Acknowledgment

Table 1. Characteristics of the Study Population. (n=3,964)

Variable	Mean (s.d) or % Reporting
Age (years)	73.3 (6.5)
Female	65
Black	54
Currently married	41
Income <$10,000	71
Dissatisfied with care	9
Education (years)	8.6 (4.1)
No supplemental insurance	46
No usual source of care	5
Support scale†	5.5 (.92)
Rural county	44
Chronic disease index	
Low	46
Moderate	29
High	25
Current smoking	17
Depression score‡	3.2 (3.4)
Self-rated health	
Excellent/Good	53
Fair	33
Poor	14
Delay or Forego Care	
Quite often	12
Once in awhile	27
Never	61

† Support Scale ranges from 2 to 6 with higher numbers indicating more support
‡ Depression score ranges from 0 to 18 with higher numbers indication more depression

Table 2. Unadjusted Cox proportional hazard ratios for 3-year mortality rates.

Variable	HR	95% CIs
Delay/Forego Care		
Quite often	1.0	
Once in awhile	0.99	0.7-1.9
Never	1.2	0.8-1.7
Age (3 year increase)	1.2	1.1-1.3
Male	1.9	1.6-2.4
Black	1.1	0.9-1.3
Married	0.87	0.7-1.1
Income <$10,000	1.7	1.3-2.2
Dissatisfied with care	1.2	0.8-1.7
Education <9th grade	1.5	1.2-1.8
No supplemental insurance	1.4	1.1-1.7
No usual source of care	1.3	0.7-2.3
Low social support	1.5	1.2-1.8
Rural	1.1	.85-1.3
Chronic disease index		
Low	1.0	
Medium	1.5	1.1-2.0
High	2.7	2.1-3.6
Current smoking	1.3	1.0-1.7
Self-rated health		
Good/Excellent	1.0	
Fair	1.5	1.2-1.9
Poor	2.7	2.0-3.5
Depression (3 point increase)	1.2	1.2-1.3

Table 3. Association of self-reported delays in care with other factors.

Variable		mean or % delaying		p-value
	Never	once in awhile	quite often	
Age	73.6	73.0	72.6	<.01
Gender				
Female	60	28	13	
Male	63	26	11	.10
Race				
Black	62	27	11	
White	60	27	13	.11
Married				
Yes	61	26	12	
No	60	28	12	.64
Income				
<$10,000	58	28	14	
>$10,000	66	27	8	<.01
Satisfied with care				
Dissatisfied	52	27	20	
Satisfied	62	27	11	<.01
Education				
<9th grade	58	28	14	
>8th grade	64	26	10	<.01
Supplemental Insurance				
Yes	64	26	10	
No	58	28	14	<.01
Usual Source of Care				
Yes	61	27	12	
No	59	23	18	.04
Support Scale	5.5	5.5	5.3	<.01
Rural Residence				
Yes	56	30	15	
No	65	25	10	<.01

Table 3 (cont.). Association of self-reported delays in care with other factors.

Chronic Disease				
Low	61	27	12	
Moderate	61	26	12	
High	59	28	12	.79
Smoking				
Yes	59	27	14	
No	61	27	12	.10
Self-rated health				
Good/Excellent	70	22	8	
Fair	53	34	13	
Poor	47	29	24	<.01
Depression Score	2.7	3.9	4.7	<.01

Table 4. Cox proportional hazard ratios with 95% Confidence Intervals stratified by self-reports of delayed or foregone care. The group that reports delaying quite often was used as the referent.

Model	Never delay	Once in awhile
Unadjusted	1.2 (0.8-1.7)	0.99 (0.7 -1.5)
Adjusted for all potential confounders†	1.4 (0.95-2.1)	1.1 (0.7-1.7)
Adjusted for self-rated health only	1.5 (1.0-2.2)	1.2 (0.8-1.7)

†Potential confounders include age, gender, education, supplemental insurance, social support, depression score, chronic disease index, and self-rated health.

Figure 1. Kaplan-Meier plot showing 15 year survival curves stratified by self-reports of delay adjusted for self-rated health.
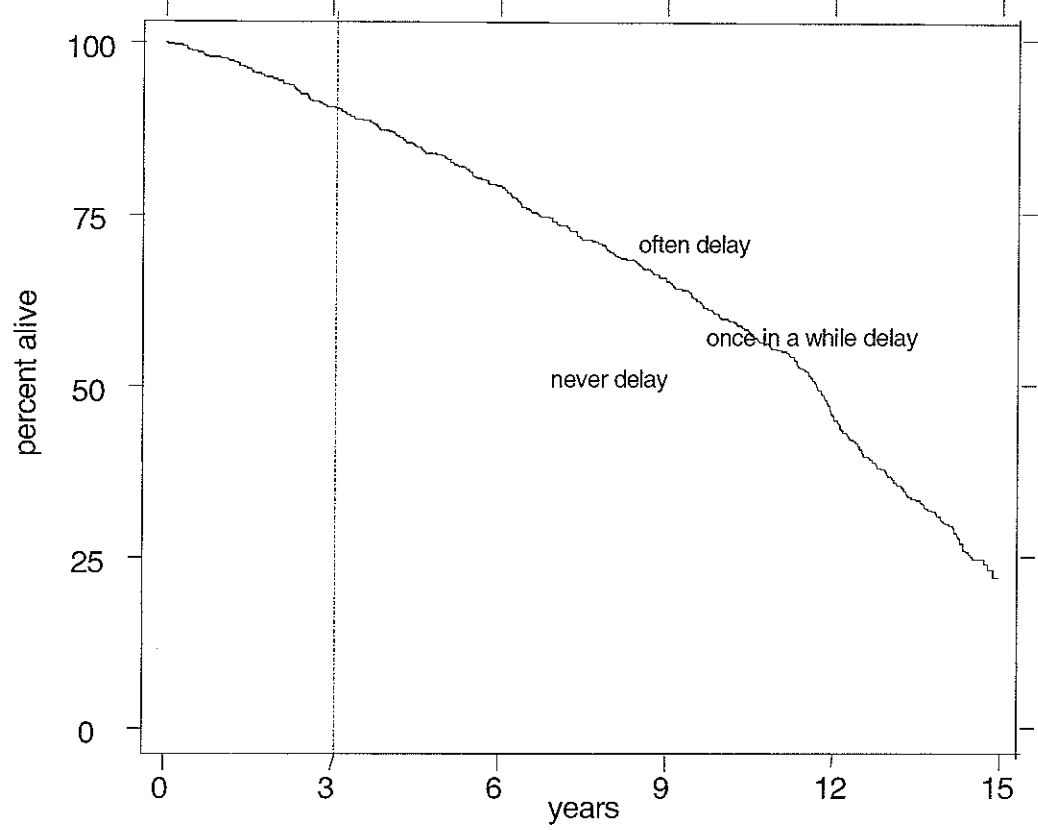
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