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The Validity of Self-reported and Surrogate-reported Cataract and Age-related Macular Degeneration in the Beaver Dam Eye Study

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The validity of reported ocular disease was investigated in a population-based epidemiologic study of persons aged 43–86 years residing in Beaver Dam, Wisconsin. In a telephone survey conducted from September 1987 through May 1988, histories of cataract and age-related macular degeneration were obtained from the subject for 2,155 cases and from a surrogate for 1,433 cases. Within 2 years, these persons underwent a complete ocular examination. At that time, an "in-person" self-reported history of eye disease was obtained and disease presence was determined based on ocular photographs. The reporting methods, telephone versus in-person and surrogate versus subject, were compared and the validity of each assessed. Reporting methods were in agreement in better than 90% of all cases. Reporting of cataract showed a sensitivity of 20.4 for surrogate by telephone, 30.2 for self-report by telephone, and 37.8 for self-report at the examination. Sensitivity of reported age-related macular degeneration was poorer, with the highest rate of 17.9 for the "in-person" self-report. Specificity was better than 90.0 for all reporting methods for both cataract and age-related macular degeneration. These data suggest that estimates of prevalence of ocular disease should not be based solely on reported histories, and that clinical determinations are necessary. *Am J Epidemiol* 1991;134:1438–46.

aging; eye diseases; questionnaires; reproducibility of results

Cataract and age-related macular degeneration are leading causes of blindness in the United States (1, 2). Yet, many persons are unaware that they have a vision-threatening disease. As part of the Beaver Dam Eye Study, a population-based study of prevalence and severity of eye disease, we attempted to evaluate the validity of surrogate-reported and self-reported eye disease, namely cataract and age-related macular degeneration. We also investigated the factors which may contribute to reporting error in this population.

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Abbreviation: CI, confidence interval.

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MATERIALS AND METHODS

Beaver Dam, Wisconsin is located 63 km northeast of Madison, Wisconsin. It is a well-defined community consisting of approximately 17,000 persons, who are primarily white. There is a low out-migration of the older persons in this community. The estimated 5,910 persons aged 43–84 years who reside in Beaver Dam provide adequate power for addressing the specific aims of the study, namely determining disease prevalence and examining the associations of eye disease with potential risk factors.

A complete census of the city and township of Beaver Dam, Wisconsin was conducted by the University of Wisconsin-Extension's Wisconsin Survey Research Laboratory. By survey research procedures described elsewhere (3), the Wisconsin Survey Research Laboratory furnished information on 6,654 Beaver Dam households.

Of these, 42 households were determined to have duplicate information and the second set of data was omitted. A small percentage (1.3 percent) of the 6,612 unique households failed to complete the survey, either because they were unreachable (0.4 percent) or they refused (0.9 percent).

Of the 6,612 households identified by the Wisconsin Survey Research Laboratory, 3,715 contained at least one person who satisfied the age criteria. These households reported a total of 5,833 individuals aged between 43 and 84 years. Since the census, 76 additional households have been included in the population. Nine were originally labeled as unreachable by the Wisconsin Survey Research Laboratory and four were early refusals.

In addition to enumeration of the population, the census accumulated data concerning visual impairment and ocular disease (see Appendix). Any member of the household 18 years of age or older was allowed to answer these questions for the persons over 40 years of age living in the household. The majority of the respondents (71 percent) were female and 96 percent were aged between 35 and 85 years.

Persons aged 43–84 years were then contacted by telephone and invited to participate in the examination phase of the study. At this time, the participant underwent a complete ocular examination and a personal history questionnaire that included questions about cataract and age-related macular degeneration history (see Appendix) was administered.

Included in the examination were slitlamp and red reflex photography of the lens of the eyes and stereoscopic fundus photography of the macula. From the resultant photographs, lesions typical of cataract and age-related macular degeneration were graded by trained photograders. Presence of cataract and age-related macular degeneration was determined based on the photogradings and is represented by lesions that are typical of a progressed disease state. A person was identified as having a cataract if at least one lens showed nuclear sclerosis worse than Beaver Dam Standard 3 and/or if cortical opacities covered more that 25 percent of a lens and/or if a posterior subcapsular cataract covered an area of at least 5 percent of the center circle in a standard grid or 3 percent of any other portion of the lens. Details of this lens opacity grading scheme have been reported elsewhere (4). Diagnosis of age-related macular degeneration required the presence of any of the following: drusen in the presence of retinal pigment epithelial degeneration; retinal pigment epithelial or sensory serous retinal detachment; subretinal hemorrhage; disciform scar; or geographic atrophy.

Given the response to the telephone survey questionnaire, the response to the "in-person" questionnaire at the time of the examination, and the clinical determination of disease presence, we obtained several responses of reported disease presence. We then calculated and compared prevalence estimates. Reliability estimates, including concordance rates and Kappa statistics, are presented for those persons who responded to both surveys. The Kappa statistic adjusts for agreement that may be attributed to chance. Fleiss (5) recommends the following guidelines for evaluation of the Kappa statistic: $\kappa < 0.40$ represents poor agreement; $0.40 \leq \kappa \leq 0.75$ represents fair to good agreement; and $\kappa > 0.75$ represents excellent agreement. The validity of the reporting methods was evaluated using measures of sensitivity and specificity. Odds ratios were computed to test for univariate associations with reporting error. Multiple logistic regression was used to identify factors which might be associated with reporting error after adjusting for other significant factors.

We base this report on the first 3,588 persons examined. Of these, 2,155 responded personally to the telephone survey; for 1,433, another family member answered the questions.

RESULTS

The mean age of these subjects is 60.9 years, with the highest frequency of individuals between ages 45 and 49 years and the lowest frequency in the 80–86 years age

group. Two thousand fifty (57 percent) of the subjects are female. They are, on the average, older than the males (63.5 vs. 61.6 years of age).

Demographic and visual impairment information obtained at the time of the census is shown in table 1. Seventy-eight percent of the individuals had seen an eye doctor within the past 2 years and 62 (1.7 percent) had never seen an optometrist or an ophthalmologist at the time of the survey.

Age-specific prevalence rates of cataract, based on the surrogate-report by telephone, the self-report by telephone, the self-report at the examination, and the clinical determinations, are shown in figure 1. All three reporting methods underestimate the examination or "true" prevalence ($p < 0.001$). In addition, a stepwise discrepancy is indicated with the surrogate-report by telephone showing the most severe underestimation and the self-report at examination being the least discrepant.

For age-related macular degeneration, the reporting methods also underestimate ($p < 0.001$) the "true" age-specific prevalence of disease (see figure 2).

Given the disparity in these prevalence estimates, we looked at where the discrep-

TABLE 1. Demographic characteristics based on survey data of the first 3,588 persons examined in the Beaver Dam Eye Study, Wisconsin, 1988–1990*

No. of persons	3,588
Mean age (years)	60.9
% male	43.0
Report that they wear corrective lenses for distance vision (%)	72.9
History of "good" distance vision (%)	96.5
History of "good" near vision (%)	94.4
History of hearing loss (%)	23.3
History of diabetes (%)	6.7
History of hypertension (%)	37.8
Have ever seen an eye doctor (%)	97.9
Report having seen an eye doctor within 2 years of the survey (%)	78.4
Have a regular medical physician (%)	90.9

* See Appendix for specific questions

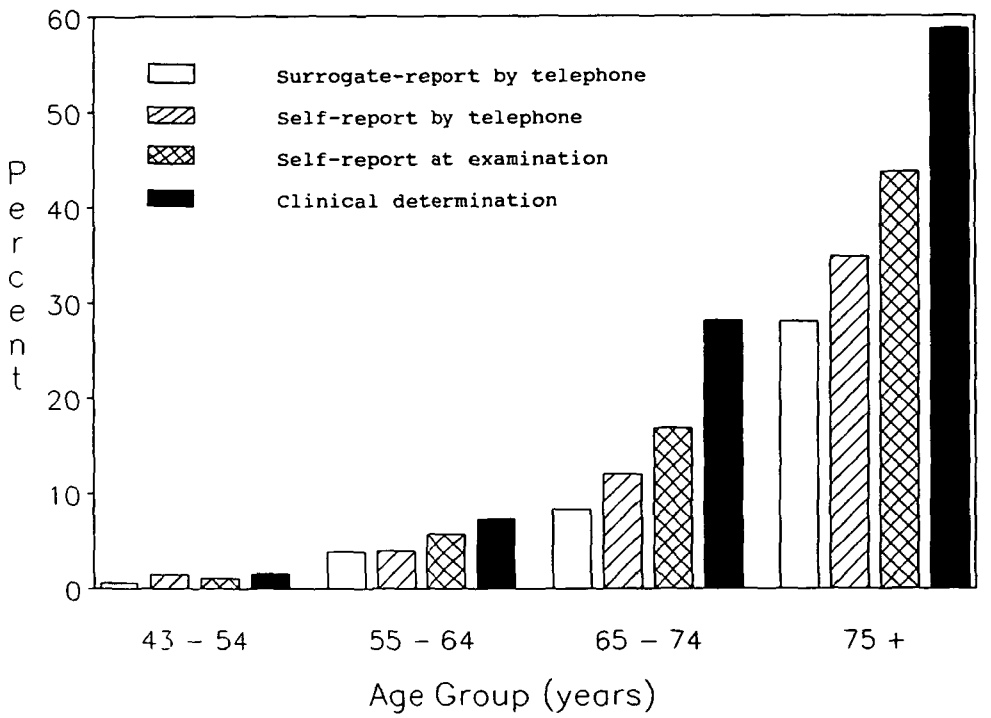

FIGURE 1. Age-specific rates of cataract in the Beaver Dam Eye Study, Wisconsin, 1987–1988.

ancies occur. A comparison of the reporting methods is shown in table 2. Surrogate-report by telephone agrees with self-report at examination in 96 percent of the cases of cataract and 97.5 percent of cases of age-related macular degeneration. The unweighted Kappa statistics for these comparisons are 0.75 and 0.49 for cataract and age-related macular degeneration, respectively.

Reliability measures obtained by comparing self-report by telephone to self-report at the examination show agreement similar to that exhibited when comparing surrogate-report versus self-report (table 3). Exact agreement is 94.4 percent for cataract and 96.2 percent for age-related macular degeneration. The respective Kappa statistics are 0.78 and 0.50.

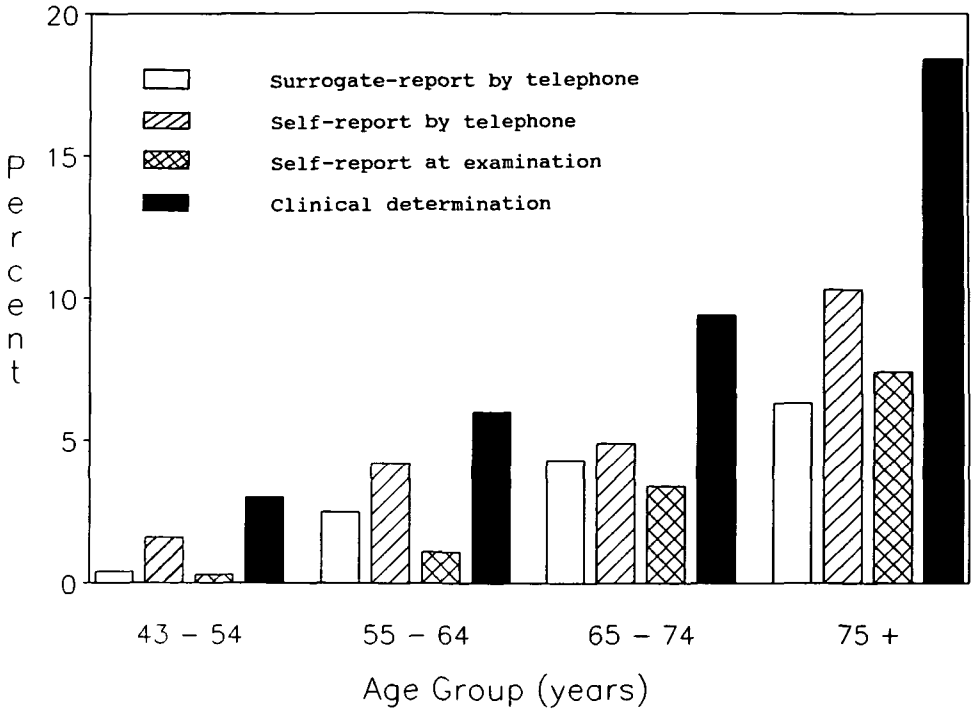

FIGURE 2. Age-specific rates of macular degeneration in the Beaver Dam Eye Study, Wisconsin, 1987–1988.

TABLE 2. Comparison of surrogate-reported and self-reported history of cataract and age-related macular degeneration in Beaver Dam, Wisconsin, 1988–1990

		History of					
		Cataract			Age-related macular degeneration		
		Self-report at examination			Self-report at examination		
		No	Yes	Total	No	Yes	Total
Surrogate-report by telephone	No	1,265	46	1,311	1,314	12	1,326
	Yes	10	93	103	22	17	39
	Total	1,275	139	1,414*	1,336	29	1,365†
		Agreement = 96.0%			Agreement = 97.5%		
		Kappa = 0.75			Kappa = 0.49		
		(95% CI‡ 0.70–0.80)			(95% CI 0.44–0.54)		

* 18 "don't know" and 1 "refused" excluded.
† 67 "don't know" and 1 "refused" excluded.
‡ CI, confidence interval.

TABLE 3. Reliability of reported history of cataract and age-related macular degeneration in Beaver Dam, Wisconsin, 1988–1990

		History of					
		Cataract			Age-related macular degeneration		
		Self-report at examination			Self-report at examination		
		No	Yes	Total	No	Yes	Total
Self-report by telephone	No	1,753	104	1,857	1,988	19	2,007
	Yes	15	250	265	62	44	106
	Total	1,768	354	2,122*	2,050	63	2,113†
		Agreement = 94.4%			Agreement = 96.2%		
		Kappa = 0.78			Kappa = 0.50		
		(95% CI‡ 0.74–0.82)			(95% CI 0.46–0.54)		

* 33 "don't know" excluded.
† 42 "don't know" excluded.
‡ CI, confidence interval

TABLE 4. Validity of surrogate-reported and self-reported history of cataract and age-related macular degeneration in Beaver Dam, Wisconsin, 1988–1990

		Clinical definition					
		Cataract			Age-related macular degeneration		
		No	Yes	Total	No	Yes	Total
Surrogate-report by telephone	No	1,116	198	1,314	1,247	83	1,330
	Yes	14	89	103	26	14	40
	Total	1,130	287	1,417*	1,273	97	1,370†
		Agreement = 85.0%			Agreement = 92.0%		
		Sensitivity = 31.0			Sensitivity = 14.4		
		Specificity = 98.8			Specificity = 98.0		
Self-report by telephone	No	1,505	357	1,862	1,853	158	2,011
	Yes	42	223	265	76	33	109
	Total	1,547	580	2,127‡	1,929	191	2,120§
		Agreement = 81.2%			Agreement = 89.0%		
		Sensitivity = 38.4			Sensitivity = 17.3		
		Specificity = 97.3			Specificity = 96.1		
Self-report at examination	No	2,590	473	3,063	3,235	243	3,478
	Yes	109	408	517	44	53	97
	Total	2,699	881	3,580‖	3,279	296	3,575¶
		Agreement = 83.6%			Agreement = 92.0%		
		Sensitivity = 46.3			Sensitivity = 17.9		
		Specificity = 96.0			Specificity = 98.7		

* 15 "don't know" and 1 "refused" excluded.
† 62 "don't know" and 1 "refused" excluded.
‡ 28 "don't know" excluded
§ 35 "don't know" excluded.
‖ 8 "don't know" excluded
¶ 13 "don't know" excluded.

Measures of validity obtained by comparing these reporting methods to the clinical determinations are displayed in table 4. For cataract, agreement with clinical determination is 85.0 percent for surrogate-report by telephone, 81.2 percent for self-report by telephone, and 83.6 percent for self-report at examination. Sensitivity measures increased in a stepwise manner from 31.0 for surrogate-report to 38.4 for self-report by telephone and 46.3 for self-report at examination. Specificity of all three methods is

quite high (>90.0) due to the large number of persons with no disease. Similarly, for age-related macular degeneration, high measures of agreement are obtained for surrogate-report by telephone (92.0 percent), self-report by telephone (89.0 percent), and self-report at examination (92.0 percent). Yet, the sensitivities of these reporting methods are quite poor, ranging from 14.4 for surrogate-report by telephone to 17.1 for self-report by telephone to 17.3 for self-report at examination. Thus, 83 percent of those persons clinically diagnosed as having age-related macular degeneration do not report a history of this condition.

The relation of reporting error to the following factors was examined: age of subject, age of respondent, sex of subject, time since last visit to eye doctor (either ophthalmologist or optometrist), whether the subject has a regular physician, visual acuity of subject, history of hypertension, and history of diabetes. In general, reporting error is positively associated with the age of the participant, age of the respondent, sex of the participant, and poor visual acuity. However, when a multiple logistic model is used, only age of subject provides a consistently significant association with reporting error regardless of method. After adjusting for age, few other factors are significantly associated with reporting error. These are summarized in tables 5 and 6.

DISCUSSION

In this population, over 75 percent of the persons have some level of lens opacity or cataract. We chose to use a definition of late lens change for cataract due to the fact that many doctors are unlikely to inform a patient of a lens opacity that is of a level commonly seen in persons of this age group and that is not likely to cause visual dysfunction. Though age-related maculopathy, a possible precursor to age-related macular degeneration, is more common in the population (prevalence = 28 percent) than age-related macular degeneration, it is a difficult disease to diagnose and many persons have mild forms of age-related maculopathy that are not vision threatening and are often attributed to the aging process. Therefore, we chose to inquire about history of age-related macular degeneration rather than age-related maculopathy.

Numerous studies comparing interview techniques have been conducted previously.

TABLE 5. Factors associated with reporting error of cataract history in the Beaver Dam Eye Study, Wisconsin, 1988–1990

Reporting method	Significant factor	Odds ratio (95% CI*)
	False positives	
Surrogate-report	Age of subject	1.07 (1.03–1.12)
Self-report by telephone	Age of subject	1.06 (1.03–1.08)
Self-report at examination	Age of subject	1.06 (1.04–1.08)
	False negatives	
Surrogate-report	Age of subject	1.07 (1.03–1.12)
Self-report by telephone	Age of subject	1.06 (1.03–1.08)
Self-report at examination	Age of subject	1.06 (1.04–1.08)
	Any error	
Surrogate-report	Age of subject	1.07 (1.03–1.12)
Self-report by telephone	Age of subject	1.06 (1.03–1.08)
Self-report at examination	Age of subject	1.06 (1.04–1.08)

* CI, confidence interval.

TABLE 6. Factors associated with reporting error of age-related macular degeneration history in the Beaver Dam Eye Study, Wisconsin, 1988–1990

Reporting method	Significant factor	Odds ratio (95% CI*)
	False positives	
Surrogate-report	Age of subject	1.07 (1.03–1.12)
Self-report by telephone	Age of subject	1.04 (1.01–1.06)
	Years since last saw eye doctor	3.50 (1.28–9.57)
	Visual acuity	1.57 (1.01–2.43)
Self-report at examination	Age of subject	1.09 (1.05–1.12)
	Sex of subject (F)	2.26 (1.06–4.78)
	False negatives	
Surrogate-report	Age of subject	1.06 (1.03–1.08)
Self-report by telephone	Age of subject	1.06 (1.04–1.07)
Self-report at examination	Age of subject	1.06 (1.04–1.07)
	Any error	
Surrogate-report	Age of subject	1.06 (1.04–1.08)
Self-report by telephone	Age of subject	1.05 (1.04–1.07)
Self-report at examination	Age of subject	1.06 (1.05–1.07)

* CI, confidence interval.

In a study on smoking, the US Department of Health and Human Services found that telephone surveys tend to provide lower estimates than in-person surveys (6). The prevalence estimates presented here agree with this finding.

It has been suggested that in nutrition interviews the agreement between proxy and index interview may be high in aggregate measures, but in individual levels the proxy is often a crude substitute for index with Kappas generally less than 0.5 (7).

Though cataract and age-related macular degeneration can lead to severe visual loss, it is not surprising that the validity of the reported disease histories is not as high as that reported for chronic conditions requiring constant medical attention. In fact, there are several criteria that must be met before a person will accurately report history of eye disease. He/she must see a doctor; the doctor must diagnose the disease; the doctor must inform the subject of the condition; the subject must remember that he/she has the condition (often unlikely if no treatment is required and disease is asymptomatic); in the case of the surrogate-report, the subject must have told the respondent; the respondent must then tell the interviewer. False positives are likely for those suffering visual impairment due to other factors. False negatives may be due to asymptomatic disease or absence of any of the steps above.

Few other studies have attempted to validate questionnaires relating to ocular conditions. However, it has been suggested that the reliability of survey data varies across the range of disease outcomes, with the acuteness of the disease, and with the complexity of the diagnosis (8–12). A study by Krueger (11), similar to this one in that data were obtained from one respondent per household, found a large percent of agreement between interview and clinical diagnoses for impaired vision (although the number of cases was small), but the agreement of reported non-blinding cataract with clinical diagnosis was at most 20 percent.

Constraints of large-scale epidemiologic studies often force the use of questionnaire response rather than clinical determinations to estimate disease prevalence. Yet, one must be aware of the limited validity of such surveys. The results of this study suggest that

any type of reporting procedure will underestimate the true prevalence of cataract and age-related macular degeneration. This is an important fact to consider when planning for health care needs and for other studies. In addition, the poor validity of these reporting methods suggests that in epidemiologic studies, significant associations may not be detected (or erroneous associations concluded) based on reported histories that are themselves in error. Analytic methods which attempt to account for misclassification error may be necessary.

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APPENDIX

1. Survey Research Questions

Use of corrective lenses:

(Do you/Does (NAME)) wear either glasses or contact lenses for distance vision?

Distance visual ability:

(Do you/Does (NAME)) see well enough (with glasses or contact lenses) to recognize a friend across the street?

Near visual ability:

(Do you/Does (NAME)) see well enough with or without glasses to recognize letters in newspaper stories?

History of cataract:

(Have you/Has (NAME)) ever been told that (you/he/she) had a cataract—that is, clouding of the lens of the eye?

History of age-related macular degeneration:

(Have you/Has (NAME)) ever been told that (you/he/she) had an aging change or degeneration of the back of the eyes? (MACULAR DEGENERATION or SENILE MACULAR DEGENERATION is "YES")

History of diabetes:

(Have you/Has (NAME)) ever been told that (you/he/she) had diabetes?

History of high blood pressure:
(Have you/Has (NAME)) ever been told that (you/he/she) had hypertension or high blood pressure?
Hearing loss:
(Do you/Does (NAME)) has a hearing loss?
Eye doctor:
(Have you/Has (NAME)) ever seen an eye doctor—that is an optometrist or ophthalmologist?
Year last saw eye doctor:
In what year did (you/(NAME)) last see an eye doctor?

2. Questions Pertaining to Cataract and Age-related Macular Degeneration from the Examination Questionnaire

Cataract history:
Have you ever been told by a doctor that you have a cataract in either eye?
Age-related macular degeneration history:
Have you ever had macular degeneration, sometimes called hardening of the arteries in the back of the eye (damage to the back part of your eye, the retina: senile macular degeneration)?