

Blindness Register as a Research Tool

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ALTHOUGH blindness (including severe vision impairment) is an impairment as old as history and although the determination of visual acuity is relatively objective and easy to make, little is known about the number of blind persons, their demographic characteristics, and the causes of their blindness. Briefly, severe vision impairments which, depending on the criteria for inclusion, appear to affect from some 385,000 (1) to almost 1 million persons (2) in the United States, have not been subjected to rigorous epidemiologic investigation to arrive at causal or associational clues on the basis of the distribution of such persons by cause, age, sex, race, and other characteristics.

That the extent of blindness will probably increase is mutely attested to by estimates of the blind population which showed an increase of some 67 percent (1, 3) during the period 1940 to 1960, compared with an increase of 36 percent in the general population. Although these estimates are not precise, they do indicate crudely the trend in prevalence of blindness. Much of the increase in blindness may be attributed to aging in the general population.

Blindness Surveys

Theoretically, information dealing with blindness could be collected by periodic surveys or through the operation of a routine reporting system. A number of surveys have attempted to achieve national estimates of

blindness. In 11 decennial censuses, the Bureau of the Census tried vainly to estimate the magnitude of blindness on the basis of house-to-house enumerations. However, after the 1930 census it concluded that "enumeration of the blind—has doubtless always been more or less inaccurate and incomplete" (4). This was, no doubt, caused by the lack of definition of blindness, personal judgment of the enumerators, and the tendency of respondents to conceal the presence of blindness in their relatives.

The U.S. National Health Survey of 1935–36 attempted to arrive at a national estimate of blindness, but it too suffered from some of the same difficulties encountered in the census enumerations. The National Health Survey during the period July 1957 through June 1958 defined blindness as the "inability to read ordinary newsprint with glasses," and arrived at an estimated prevalence of blindness in 960,000 persons or a rate of 5.7 per thousand population (5). The rate was far greater than rates produced by any census or by the 1935–36 National Health Survey. This estimate of blindness prevalence, as defined in the 1957–58 National Health Survey, is generally thought to exceed the number determined by the definition of economic blindness; that is, 20/200 visual acuity in the better eye with best correction (or an equally disabling loss of the visual field). Such overestimation may largely be due to reliance on respondents' replies to a question embodying a rather crude definition of blindness.

The latest National Health Survey probably achieves a reasonable estimate of severe visual impairments rather than blindness as such. In fact, Survey officials no longer refer to the definition as pertaining to "blindness" but rather to "severe visual impairments." The latest estimates (July 1959 through June 1961) of the National Health Survey indicate that approxi-

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mately 988,000 persons in the United States suffer from severe visual impairments (2).

Periodic surveys of a representative sample of a population attempt to obtain information concerning the conditions, characteristics, or opinions of the population at specific points in time. Such a survey may entail interviews with specific households or respondents, selected in advance by a sampling procedure adequate to the purposes of the survey. If medical conditions are being measured, the survey may, but often does not, include medical or ophthalmological examination of a specified sub-sample. With a scientifically drawn sample, the estimate of prevalence or incidence derived from the survey is qualified by the error inherent in drawing a sample to represent that total population or universe. Thus, by adequate survey of a sample, it is possible to state that the true prevalence or incidence for the universe falls within a given range based on the degree of confidence attached to the estimate.

The difficulties in deriving an estimate of the prevalence of disease or impairment states in the community relate to (a) drawing an appropriate sample, (b) actual finding and interviewing of such sample, making provision for the substitution of households or persons that fall into the sample but cannot be located, and (c) elicitation of cooperation and reliable information from respondents. It is certain that, in conditions such as legal blindness, the respondent may not know that his condition falls within this category, or if he knows, may not be willing to admit it even to himself, much less to others.

A survey which uses inability to read newspaper print even with the aid of eyeglasses as a criterion for blindness is likely to omit a severely impaired person who is able to read only with low vision aids. To the extent that such omissions occur, prevalence of blindness is understated. To the extent that the survey picks up as severely impaired those persons who are not blind or severely impaired but cannot read newspaper print with the aid of eyeglasses for reasons other than visual impairment, the prevalence of blindness is overstated. It would appear unlikely that the extent of understatement balances that of overstatement.

Obviously, the factors of memory loss, distortion, or changing conditions must be consid-

ered where the data are not based on recent examination. Also, in the ordinary house-to-house survey, questions relating to impairment cannot be answered definitively in the absence of examination. Further, where a sample of respondents is called for examination, the bedridden, infirm, and institutionalized may be among the missing unless the survey design provides in advance for inclusion of such persons. Finally, surveys by their nature are time consuming and expensive. At best, they allow estimates that may be valid only for a particular time, place, and population.

Blindness Registers

Routine reporting of all known cases of a given disease or impairment in a community to a register is another way of developing methods of prevention and control. Such reporting is usually mandatory. In the case of specified acute communicable diseases, the register makes action possible toward prevention of the spread of disease. Where the register deals with chronic diseases, such as cancer, the reporting process may serve not only to insure the provision of services by the register agency to the patient but also to provide necessary statistics needed to plan and develop programs of prevention and control (6).

Thirty-eight States have registers of the blind, and each of these registers is maintained by a single State agency for the blind. Although the names and organizational structures of such agencies differ from State to State, their functions are similar. The registers are maintained by statute in 28 of these States, of which 8 also have another statute which makes the reporting of blindness mandatory. However, there are not sufficient data to determine whether mandatory reporting of blindness does in fact increase the completeness of reporting. The best possible approach, therefore, is to maintain good liaison with professional reporting sources.

Registers Versus Surveys

What are the advantages and disadvantages of the register over the survey? A routine reporting system which constitutes the backbone

of every register is an intricate part of a service program. Various records, kept in connection with every service program, are generally intended to facilitate service and facilitate program planning and evaluation. A case register is one record system which readily lends itself to dual use, as an administrative tool in a service program and as a source of morbidity data (6).

A person's eligibility for admission to a blindness register usually depends on the results of an ophthalmological examination, which provides the history, visual measurements, cause of blindness, prognosis, and recommendations. This constitutes an official document that, when approved by the State supervising ophthalmologist, makes services available to the blind person. (Validation by professional examination of the visual status is rarely, if ever, present in survey procedures.) Services include aid to the blind, vocational rehabilitation, talking books, and home teaching. There is no compulsion to accept service when it is not desired.

Uses of the blindness register as an administrative tool have been detailed elsewhere (7). A register is a continuing mechanism and, theoretically, should reflect not only persons with legal blindness newly added to the register during a given period of time in the community, but also the number of legally blind in a community at a given time. If the assumption is made that new registrants are the newly blind, that reporting is fairly complete, and that the cause of blindness data are reliable, then the register is extremely important in detecting rapid changes in incidence of blindness due to specific causes, such as the chronic and degenerative diseases of old age—a consequence of our aging population. The newly blind person becomes newly registered ideally when blindness has been determined by ophthalmological examination and only when the patient has been promptly referred to the State register agency. The register also reflects changes in prevalence that may occur as a result of improvement in methods of sight restoration for specific causes of blindness and severe vision impairment.

The register is flexible in terms of the information requested for each new registrant. As the need arises for certain kinds of information, not originally present on the eye report form,

such information may be added to the printed form. Conversely, as the need for other kinds of information decreases, such information may be modified or dropped from the form. Finally, maintenance of the register is relatively inexpensive considering the uses that the register serves.

The possible disadvantage of a register relates mainly to the fact that individual State registers may not be geared to the production of uniform statistics from State to State. This is not really a disadvantage except where it is desired to compare data from State to State or to pool such data in order to arrive at national estimates. It is obvious that where States differ in the definition of blindness used for eligibility for admission to the register, in the kinds of data they request, and in the use of different classifications of causes of blindness and severe vision impairment (some States use no classification), their register incidence and prevalence data are not comparable. Furthermore, when they differ in the extent of their updating and in whether or not they remove promptly from the register persons who have died, who have had vision restored, who have moved out of State, or who cannot be located, there is no possibility of obtaining uniform statistics on register prevalence.

Finally, there is no comparability among registers and their data when one State includes in its register only eligible persons that need or want services and another includes all eligibles whether or not service is to be provided. Service records alone cannot ordinarily be used as a source of information concerning the magnitude and nature of disease or impairment in a community (6).

The register of known blind persons is a valuable potential source of statistics of blindness in 38 States. "But in only several of these States is the cooperation of physicians and of agencies serving the blind sufficient or the procedure of maintaining the register adequate, to give assurance that the count of names on the register does not give a quite misleading indication of the actual prevalence of the handicap" (1). In this kind of operation, the only way to determine the error of under-reporting is by house-to-house surveys, using a valid, portable optical screener. Those suspected of meeting

the legal definition of blindness, or a random sample thereof, are called in for ophthalmological examination.

Comparison of results of such surveys with register data may give some indication of the number and characteristics of the legally blind who may be missing from the register. Thus, it may be possible to pick up persons who are legally blind but who have not been so diagnosed as well as those who, having been so diagnosed, are not referred to the register agency. Again, however, the bedridden and institutionalized may be among the missing. On the other hand, unless a sample of those whom the optical screener indicates are not legally blind are also examined ophthalmologically, it will not be possible to determine how many the screener itself misses.

Therefore, the only practical solution is to continue efforts to get all reporting sources to register those that may be eligible for registration. It is unlikely, because of the nature of the registration process, that non-blind persons are registered as blind except, of course, in error. Thus, it seems that prevalence of blindness is most often understated and rarely, if ever, overstated, unless updating of the register has been neglected.

Research Value of Register

The research value of a register is limited by the adequacy of the information it contains. There are some inherent problems in getting adequate cause-of-blindness data. In most cases a thorough ophthalmological examination together with a satisfactory history would be the best way to assign a reliable diagnostic classification. In the event that the ophthalmologist is unable to perform an examination until the patient has been blind for a number of years, examination alone, without a satisfactory history, may not lead to the determination of the initiating cause or mechanism.

Because the eye is limited in the number of ways it can respond to insult, many visual disorders converge along the same final common pathway toward blindness and, thus, the accuracy of etiologic diagnosis is sometimes limited. If histories were more reliable, some of this difficulty might be resolved but, unfortunately, such is not the case. Relief for such

problems must lie in more effective education of the public toward reducing the interval between onset of the severe vision impairment and the time of diagnosis.

Delay in diagnosis is, of course, intimately related to delay in treatment. With ophthalmic disorders particularly, severe vision impairment or blindness, or both, may often be a direct (and sometimes abrupt) result of delayed treatment. It thus becomes evident that in areas where ophthalmological diagnostic and treatment resources are sparse, blindness might be more prevalent. These are also the locations where reporting of blindness may be incomplete and where the ophthalmologist eventually observes the blind patient, long post-facto, with an inadequate supporting history. Thus, the circumstances conducive to missed cases of blindness are also instrumental in the inadequate reporting of those that are encountered. Perhaps an increase in the number of ophthalmologists and eye-ear-nose-and-throat specialists in certain areas of the country is one possible solution. Even on a nationwide basis, as of August 1963 there were approximately only 6.5 physicians with a specialty in ophthalmology per 100,000 population (personal communication from the American Medical Association's library at Washington, D.C.).

The Model Reporting Area for Blindness Statistics developed under the sponsorship of the Biometrics Branch, National Institute of Neurological Diseases and Blindness, Public Health Service, with the support of the American Foundation for the Blind, the National Society for the Prevention of Blindness, and the Division of Chronic Diseases, Public Health Service, constitutes at present a group of nine States with blindness registers. These States, having 14 percent of the U.S. population, have agreed to adopt certain standards that would improve the possibility of getting uniform, comparable data and that would permit interstate comparison of prevalence and incidence of blindness. In addition, the standards would enhance the possibility of arriving at national estimates of these magnitudes, and, hopefully, would stimulate the conduct of much-needed blindness research (7).

By adopting as a common definition of blindness the definition which has usually been ac-

cepted to denote economic blindness, the States have agreed to use a uniform common denominator of the impairment being considered. Incidence and prevalence reflected by the register will be more accurate when: (a) complete reporting of the blind is achieved; (b) all persons meeting the definition of blindness are included on the register regardless of age, race, need for service, or any other factor outside the definition; and (c) the status of, and information on, all registrants is brought up to date annually.

States in the Model Reporting Area have determined that longevity of the blind must be assured by some means other than by getting on a register that is never updated. By standardizing and classifying uniformly the recording of essential information on each new addition to the register, data on the causes of blindness and characteristics of the blind from different States can be more meaningfully compared or pooled.

The data considered essential by the Model Reporting Area are relatively few and simple, yet they represent a good deal more than many States now routinely collect and tabulate. The National Society for the Prevention of Blindness has given considerable aid to this objective by developing a uniform eye report form, a Standard Classification of Causes of Blindness and Severe Vision Impairment, and by training supervising ophthalmologists and their coding personnel in the use of this classification. Finally, Area States have agreed to prepare specified tabulations annually, and this will facilitate the production of Model Reporting Area tabulations as well as estimates for the country as a whole. These tabulations will be made available in published form. Clearly, the States in the Model Reporting Area, by agreeing to common standards, have made possible not only the reality of comparability of data from State to State, but also that of comparability and replication of research based on register data.

All Model Reporting Area States seek the fullest cooperation from ophthalmologists in order to get as complete reporting as possible. The complete, adequate, and routine reporting of all cases of blindness and severe vision impairment will not only greatly advance the cause of good statistics on blindness and severe vision impairment, but will be of great help in stimu-

lating research studies. The data will be valuable in planning more intelligently programs of service as well as those of prevention and control, and will, of course, result in better and more accurate feedback of statistical data and explanatory text to the practicing ophthalmologist.

It is of interest to know in what way adherence to the standards of the Model Reporting Area can promote the possibility of undertaking meaningful research studies of register data. With the establishment of a common definition of blindness, comparable age-sex-race-standardized incidence and prevalence rates for each State, by cause and visual acuity as well as other characteristics, are possible. Of course, age-sex-race-specific rates also become available. Furthermore, similar rates may be computed by community and census tract, using population data published by the U.S. Census Bureau for the decennial census. Information on trends becomes more meaningful because it is based on common fundamental definitions which remain unchanged and on statistics which become comparable due to standardization procedures. For example, accurate registers would lend themselves to studies of trends in incidence of blindness due to diabetic retinopathy and the epidemiology of such incidence in relation to age, sex, and race, as well as to the age at onset of diabetes and type of treatment. The comparison between trends in age-sex-race-standardized incidence rates for diabetic retinopathy and for diabetes might provide clues for more definitive, controlled studies of the determinants of diabetic retinopathy.

Although blindness statistics, classified by cause, seem of great importance in assisting the allocation of research resources, as well as in planning prevention programs, blindness itself is not a disease but an end result or terminal stage of severe ocular disease processes or of injury. Although a given disease may or may not result in blindness, the figures on the prevalence of blindness due to that disease do not reveal the prevalence of the disease in the population. Thus, the prevalence of blindness gives no measure of the prevalence of less severe ocular diseases which might nevertheless be sufficiently prevalent and morbid to warrant serious research attention.

Because the blindness registers are on punch-cards in the majority of Area States, they become a universe of the blind from which random samples of cases and controls, on a stratified or other basis, may be drawn for research studies. Studies to test the effects of visual acuity, age, and other factors, such as motivation and intelligence, on visual performance may thus be encouraged. Hopefully, it may become possible to stimulate programs to measure not only visual acuity but also what has been designated as visual versatility and visual capacity (8) so that research on the relationship between visual efficiency and performance may be more readily undertaken. It also becomes possible to easily select appropriate subjects for studies of the effectiveness of low vision aids and studies of difficulties the blind encounter in adapting to and using sensory devices utilizing hearing or touch (9).

The register is a most flexible medium for the collection and study of data for specific or for indefinite periods of time, as the number of items on a register card may be expanded or contracted. Hopefully, in the near future it may be possible to include among the uniformly collected items recorded on each new addition to a Model Reporting Area register, those items pertaining to hearing loss and other handicaps, as well as to psycho-social characteristics, such as occupation, education, and marital status. Although some of the Area States routinely collect some or all of these items, they have not yet concurred on the need for reporting them for Model Reporting Area statistics.

Because the Model Reporting Area standards require the annual updating of each registrant's status, it becomes somewhat easier to conduct cohort studies over time; that is, to follow cohorts or groups of visually impaired persons stratified by such characteristics as age group, race, sex, visual acuity, and cause of blindness, in order to note their disposition, such as recovery of vision or death. This information and the resultant recovery and death rates that are computed may be of interest to the ophthalmological profession.

When register records are matched with death certificates in prospective or followup record-linked studies, it is possible to obtain data on life expectancy and causes of death for

groups of blind persons by cause of blindness, visual acuity, age, sex, and race. Such a study is underway cooperatively between the Massachusetts Division of the Blind, Massachusetts Office of Vital Statistics, and the Biometrics Branch, National Institute of Neurological Diseases and Blindness. In similar fashion, retrospective or follow-back record-linked studies may be made where register records of blind children are matched with birth certificates. Such matching will reveal data that may be of value in, for example, determining the relationship between the occurrence of blindness in children, of which the cause is diagnosed as hereditary, genetic, prenatal, or unknown, and specific complications in pregnancy, labor, and delivery. At present such a study is underway on a cooperative basis between the New York State Commission for the Blind, New York State Health Department, New York City Health Department, and the Biometrics Branch, National Institute of Neurological Diseases and Blindness.

Followup studies of blind populations can supply information that is urgently needed, namely, the incidence of acute and chronic disease states and of impairment of other sensory channels in a blind population. Information is not available at present concerning the risk of acquiring disease or additional impairment by such a population. Blindness agencies do not routinely receive or record on register cards information dealing with new disease or impairment beyond that recorded at the time of the original registration. Thus, special studies are needed.

The research needs of States will be better served when register studies using uniformly collected data make possible replication as well as comparability of research efforts from State to State. When the membership in the Area appears to have greater representativeness of the country as a whole, geographically and demographically, it will be possible and desirable to make estimates of blindness nationally within the limits of error inherent in such procedure.

Unquestionably, difficulties such as attaining uniformity in reporting and obtaining professional cooperation in the community will continue for States in the Model Reporting Area

as they do for any group of political bodies that agree to relinquish some sovereignty in order to gain the benefits of union for a common cause. However, there is rarely a problem in such endeavor that cannot be solved by true dedication to its solution.

The value and meaningfulness of a blindness register depends largely on the completeness, accuracy, and reliability of its data, particularly those dealing with cause of blindness and visual acuity. In this connection, the cooperation of the ophthalmologist is essential. Such data are of value not only in planning programs for clients needing service, but also in supplying the administrator with information on all the legally blind, whether or not service is indicated, that is needed for policy planning. The scientist must have access to these data to conduct research designed to elucidate meaningful relationships pertaining to etiology and prevention. Obviously, however, confidentiality of the data must not be violated. The causes of administration and of science can and must be served without infringing on the client's privacy.

The administrator of a program for vision conservation must use any and all reliable data to arrive at a proper balance of resources and needs. The blindness register supplies information that may assist him in setting up and evaluating certain kinds of prevention and control programs. In this respect, the blindness register may serve as an invaluable research tool.

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Action on Smoking Report

The Public Health Service has announced its full acceptance of the principal findings and conclusions of the report of the Surgeon General's Advisory Committee on "Smoking and Health."

Surgeon General Luther L. Terry said the Service is developing programs covering education, public information, and research in light of the findings and conclusions.

Among the early actions has been notification to the medical officers in charge of the 16 Public Health Service Hospitals and 50 Indian Hospitals that:

1. Acceptance of free cigarettes for distribution to patients will be discontinued immediately.
2. Medical officers in charge are urged to conduct educational programs for patients on the harmful effects of smoking.
3. Physicians are urged to counsel individual patients on the dangers of smoking.

Legal Note . . . Public Health Nuisance Abatement

In prosecution under statute authorizing municipal directors of health to examine into and cause abatement of nuisances and sources of filth injurious to public health, court held "nuisance" involved must be one injurious to public health and failure of trial court to so instruct jury or to define injury to public health was error. *State v. Cooney*, 24 Conn. Supp. 242, 189A 2d 511 (1962).

As the result of a complaint, a town health officer inspected the premises of the defendant and found an accumulation of stable manure; manure in pens; and boxes, crates, lumber, tree branches, tin cans, paper, and other debris about the yard and out-buildings. The town director of health acting under authority of Connecticut statutes directed the defendant to abate the above described condition. Upon inspection of the premises about 1 month later, it was found that the condition remained substantially unchanged.

The State then brought action against the defendant under Connecticut Statute 19-79 which provides in part as follows:

Town, city and borough directors of health shall within their respective jurisdictions, examine into all nuisances and sources of filth injurious to the public health, cause such nuisances to be abated and cause to be removed all filth which in their judgment may endanger the health of the inhabitants.

In a trial, the defendant offered evidence to the jury to show that the only condition affecting the neighborhood was odor from the manure. The defendant was found guilty of the crime of failure to abate a nuisance injurious to the public health.

From this conviction the defendant appealed to the Connecticut Supreme Court claiming that the trial court erred in instructing the jury. In the instructions to the jury the trial court had defined "nuisance" as: "That which annoys or causes trouble or vexation or which is offensive or obnoxious or which works hurt, inconvenience or damage. A common or public nuisance is a condition of things which is prejudicial to the health, comfort, safety, property, sense of decency or morals of the citizens at large . . ." The court did not provide the jury with a definition of "injury to the public health."

Defendant claimed that the nuisances with which

the statute is concerned are only those which are "injurious to the public health," and therefore, the trial court's broad definition failed erroneously to so qualify "nuisance."

The State contended that since the statute authorized the health authority to "cause such nuisances to be abated and cause to be removed all filth which in their judgment may endanger the health of the inhabitants," a distinction was made between "nuisances" and "filth." They argued that the endangering of health qualified filth but not nuisance, so that the public health authority had the power to abate any nuisance.

The Connecticut Supreme Court held that the phrase "injurious to the public health" modified both filth and nuisances, and therefore the town health authority was empowered to abate only those nuisances which were injurious to the public health.

The court based its view on the history of the statute, which initially appeared in 1808 under the title "Sickness." That title dealt with protection of the public health and the control of contagious diseases. That statute remained substantially unchanged through the various revisions of the statutes. The court viewed this as evidence that the original purpose of the statute remained the protection of the public health.

It was the court's conclusion that since the instructions to the jury did not properly define the nature of the nuisance involved the judgment must be set aside and a new trial ordered.

Comment: This decision exemplifies the difficulties faced by public health officers whose authority is based on ancient statutes which have not been updated to meet the needs of our changing environment.—DAVID A. SCHUENKE, *Public Health Division, Office of the General Counsel, Department of Health, Education, and Welfare.*