EXPERIENCE AND PHILOSOPHY WITH REGARD TO CASE REGISTERS IN HEALTH AND WELFARE

ANITA K. BAHN, Sc.D.*

For planning and evaluation, community mental health programs require better systematic data than has been previously available on the persons who are served by these programs and their fate in terms of subsequent need for additional services and eventual outcome. Case registers or similar types of longitudinal records offer a possible solution. However, registers are difficult and costly to maintain and therefore should be established only after careful study.

A case register may be defined generally as a roster of cases meeting specified criteria of disease or disturbance, identified or reported by a specified set of facilities, and on which follow-up information is systematically obtained. Continuous addition of new cases to the register distinguishes it from a cohort study. The purposeful collection of follow-up data and deletions from the register due to death or from other causes distinguish the case

A well designed and executed case register for mental illness or other conditions can provide information not readily obtainable by any other method. This includes unduplicated counts of diagnosed cases of the disease and longitudinal information such as changes in diagnosis, outcome, and survival information. Registers often are the only way in which "new" cases can be identified with any certainty. Also, the register can serve as a sampling frame for more intensive studies of services and of prevalence of the disease in the community, genetic studies, studies of the cost of treating various types of patients, "before" and "after" comparisons, and many other sociological and epidemiologic investigations. At the same time, there are many problems and pitfalls to case registers. This paper outlines some of these difficulties and suggests that registers be established only after careful planning and preparation.

*Dr. Bahn, a Statistician, is Chief, Outpatient Studies Section, Office of Biometry, National Institute of Mental Health, Bethesda, Md.; and Lecturer in Epidemiology, Johns Hopkins University School of Hygiene and Public Health, Baltimore, Md. This paper is based on a presentation for a Workshop on Case Registers, American Orthopsychiatric Association Meeting, Chicago, Illinois, March 20, 1964. An extended bibliography on case registers is available from the author.
register from the case index. A case register provides for the prospective collection of longitudinal information on individuals, thereby avoiding certain biases which may be associated with retrospectively collected data.

Case registers have been used for some time as an administrative and epidemiologic tool in various fields of public health, particularly for welfare and for chronic diseases where follow-up over a long period of time is required to determine exacerbations or survival. Since registers are not easy to establish and maintain at a high level of accuracy, usefulness for epidemiologic study is therefore often limited. As a result, their value has been a controversial issue.

In view of the widespread interest in establishing psychiatric case registers or broader psychosocial registers, a brief review of registry experience may be useful for suggesting conditions under which a register can take root and flourish. Registers in various fields of chronic disease and social welfare will be discussed with regard to (a) the characteristics of the disease or social condition, such as whether communicable, chronic, treated in special facilities, etc.; (b) intended uses for case management or for research; and (c) the location and scope of the register—that is whether for a specific facility or for a population or community.

EXPERIENCES FROM PUBLIC HEALTH

It is probable that case registers have been developed earliest and most extensively in tuberculosis. Because tuberculosis is a communicable chronic disease, it is reportable by law, and control has been largely a public health responsibility. Tuberculosis registers have been established in the local health department for case management and follow-up of disease contacts, and in the state health department for program administration and service statistics. For these purposes, the register has been an excellent administrative tool. The current therapeutic procedure of maintaining patients on chemotherapy in the community has enhanced the value of the register. Because of poor reporting by private physicians, however, tuberculosis registers have been in the past too incomplete for studies of incidence. Today, because of special reporting efforts, relatively few newly active cases are first reported at death. Preventive and follow-up data still are generally inadequate, however, and limited use has been made of these registers for epidemiologic purposes.

Registers of cancer cases have less value for case management since cancer is noncommunicable and the follow-up benefits are less clearly demonstrable. Also, since cancer incidence does not vary markedly by geographic area, there is usually less motivation to establish a local register except for determining the stage of disease at which cases are discovered.

Tumor clinic registers have been encouraged by the American College of Surgeons primarily to assist in evaluating success of treatment and to stimulate patient follow-up. A large cooperative hospital-based register study sponsored by the National Cancer Institute has investigated trends in survival as related to stage of disease and to treatment. This study has provided valuable leads for therapeutic trials and has assisted in improving prognostic methods. However, since the cases are limited to those seen at the 100 reporting hospitals, principally in California, Connecticut, and Massachusetts, the findings are somewhat selective for survival information and cannot be related to a population base.

In contrast, population-based cancer registers attempt to identify and follow all cases of cancer in the community for the purpose of obtaining unselected morbidity and survival data, as well as for local educational programs. However, such registers require special reporting from all medical facilities serving a population at "risk," which adds considerably to the difficulties. Only a few cancer registers of this type (for example, those in New York and Connecticut) have survived long enough and