The Contribution of European Case Registers to Research on Schizophrenia

by Heinz Häfner and Wolfram an der Heiden

Abstract

Psychiatric case registers have become important instruments for epidemiological research and for the evaluation of care provided for persons suffering from schizophrenia. Under the condition of a sufficient provision of care, case registers permit relatively reliable estimates of "treated" incidence and prevalence, and enable the investigation of associations between morbidity risks, disease courses, and variables such as ecological, social, and occupational factors. The linkage with twin, adoption, and birth registers provides new opportunities for the investigation of the impact of genetic versus environmental factors on the probability of becoming ill with schizophrenia. On the basis of long-term utilization figures, case registers enable a valid measure for controlling utilization, effectiveness, quality, and costs of care. Because case registers take demographic and regional factors into account, they enable better planning of mental health services—a task that grows more important with the shift from hospital-based to community-based treatment, especially for the chronic patients.

Cumulative Psychiatric Case Registers: Composition and Organization

Cumulative psychiatric case registers are health information systems of a geographically delimited region. They register all contacts of their population with psychiatric services over long periods of time. Case registers were preceded by hospital statistics, which in general are based on aggregate data and therefore are of minor value to research. They were also preceded by disease registers to which hospitals and physicians reported all cases of a certain diagnosis. Disease registers were mostly used to collect large enough numbers of cases with rare diseases to enable clinical and genetic studies to be carried out. Only relatively recently have more and more disease registers, such as cancer registers, been run as population-related case registers, so that findings can be generalized, and changes in morbidity and environmental impact can be assessed. Cumulative psychiatric case registers collect and compile their data in relation to cases and exclude multiple counting. Contrary to disease registers, they cover the entire spectrum of diagnoses given to inhabitants of the catchment area when they contact a psychiatric service.

The functions of psychiatric case registers are determined by the extent to which they can be used. According to Wing, Wing, and Hailey (1970), there are four possible uses, namely correlation and comparison with other population-related registers and statistics, follow-up of utilization cohorts and of long-term utilization trends in an entire health care region, and finally drawing of defined, representative patient samples.

Case Identification. The procedure of case identification leading to registration in a case register is based on a diagnosis given by a psychiatrist who contributes to the provision of mental health care. Therefore, case registers could only be started in those areas where all psychiatrists had learned to diagnose according to common, sufficiently precise definitions—for example, in Norway after Reprint requests should be sent to Prof. Dr. H. Häfner, Zentralinstitut für Seelische Gesundheit, J5, D-6800 Mannheim, Federal Republic of Germany.
the adoption of Kraepelin’s scheme of diagnoses in 1926 (Ødegård 1971b) or after the introduction of the ICD in various European countries about 1960 (Kendell 1975). The use of case registers for epidemiological research depends on the reliability of diagnoses and on the proportion of cases recorded in the register in relation to the total number of individuals of a population who suffer from the same disease.

The possibilities of epidemiological and service-related evaluation improve when, in addition to the main diagnosis, secondary diagnoses are also registered (e.g., three additional diagnoses are recorded in the Danish register (Dupont 1979)) or when diagnoses are based on a multi-axial classification.

In diseases that have a long course, the reliability of attribution to a diagnostic category is increased in a case register, because successive diagnoses by several services, as well as observation of the course, can be used to validate the first diagnostic judgment. Because the reliability of the diagnosis of schizophrenia has been satisfactory since the 7th and 8th revisions of the ICD (Klug 1983), the course of schizophrenia proves to be long term in about 70 percent of first onsets, and nearly all schizophrenics contact a psychiatric service in their lifetimes (Ødegård 1971b; Nielsen and Nielsen 1977). Case registers are important instruments of research on schizophrenia. For psychiatric disturbances which have low diagnostic reliability, or of which only a minor proportion receive care from psychiatric services—for instance, neuroses—the use of psychiatric case registers is rather limited. Because of the increasing period over which disease courses can be observed and the growing amount of information to be evaluated, the scientific value of a case register increases with the length of its existence (Baldwin 1970; Helgason 1979).

Size of Catchment Area and Population. Registers are either run on a national level, as is done in Norway and Denmark (Ødegård 1952, 1971a, 1971b; Kiselev 1972; Dupont, Videbech, and Weeke 1974; Weeke, Kastrup, and Dupont 1979), or on a regional or local basis.

National registers cover large population figures (about 5 million in Denmark, about 250 million in the U.S.S.R.). Thus, they comprise relatively large case figures of a specific diagnosis. National registers allow epidemiologists to investigate the relation of morbidity risk and course of schizophrenia to factors showing an uneven regional distribution, such as occupational status or ecological variables.

Regional or local registers usually comprise the catchment area of a community mental health service. Therefore, the population at risk included in these registers is comparatively small: Lomest, Italy—88,000 (Torre, Marioni, and Allegri 1982); Salford, U.K.—130,000–140,000 (Wing and Fyers 1976); Iceland—about 110,000 (Helgason 1977); Mannheim, F.R.G.—about 300,000 (Hafner and Klug 1982). The non-European case registers are organized on a regional level, but most of them cover a larger population; e.g., Maryland, U.S.A.—about 3.5 million; Monroe County, U.S.A.—about 700,000; Victoria, Australia—about 3.5 million.

Since their catchment areas are easy to survey, most of the regional case registers cover all contacts with psychiatric services. They are able to furnish additional information about services and context variables of utilization or course of illness. Also, on the basis of regional registers, it is convenient to carry out followup studies in neighboring medical or social facilities. Regional case registers can contribute to research on schizophrenia, especially in the evaluation of mental health care systems and services, and in the investigation of epidemiological samples—for instance, prospective cohorts which allow the analysis of changes over long periods of time.

Information systems based on individual data—similar to case registers—originated in centralized national health care systems (e.g., in Finland). These information systems have the advantage of compiling utilization data from all branches of the health care system. Even though this approach reduces the reliability of relevant psychiatric data, general health registers can be used for making important epidemiological evaluations.

Services and Facilities Affiliated with a Register. When interpreting epidemiological data from case registers, one should take into consideration how extensive the network of services providing data is. The Norwegian register records admissions to all psychiatric hospitals and departments run in Norway (Ødegård 1971a, 1971b). The Danish register additionally includes data on all admissions to psychotherapeutic sanatoriums and psychiatric day and night clinics. In general, regional registers also receive information about contacts with psychiatric outpatient services; this information is nearly complete in centralized health care systems (e.g., the United Kingdom and the U.S.S.R.). In countries where a larger proportion of outpatient care is provided by psychiatrists in private practice (Federal Republic of Germany, Netherlands, Italy), outpa-
tient utilization is often registered incompletely.

If a register also covers neighboring fields of the social or health care system, it improves the possibilities of evaluating interdisciplinary care provided to some patient groups. Thus, the Camberwell Register also includes data on homeless persons who contact a psychiatric service or are provided social care in homes of the catchment area (Wing and Hailey 1972; Wing and Fryers 1976). While the majority of the registers compile only data on mentally ill adults, a few are affiliated with mental health services for children and adolescents and with facilities for the mentally retarded (e.g., the Camberwell Register of Psychiatric Illness and Mental Retardation and the Register of Essex Hospital Region in the United Kingdom). The Mannheim Register comprises a subregister recording all parasuicidal acts seen in general hospitals of the region. The inclusion of these acts, which can be identified rather reliably, makes possible epidemiological studies on the risk of suicide and attempted suicide. Furthermore, the Mannheim Register comprises all psychiatric homes, sheltered apartments, and sheltered workshops. Case identification is made by a consultant psychiatrist. The inclusion of these facilities allows studies to be carried out of the utilization of alternative and complementary services by schizophrenic patients, and changes in the mental health care system to be evaluated (Hafner and an der Heiden 1982, 1983).

Diagnostic Groups Recorded. The Norwegian Case Register records only psychoses (ICD no. 295-299), whereas the majority of case registers cover all psychiatric diagnoses and contacts with mental health services.

Number of Items Registered. The number of registered items varies between 12 in the U.S.S.R. (Kiselev 1972) and a maximum of 126 in Aberdeen, Scotland (Baldwin 1971). Mean values are between 20 and 40 items (Camberwell, 20; Denmark, 26; Iceland, 29; Mannheim, 42). The restriction to a smaller number of items is generally dictated by the need to keep the proportion of missing information as small as possible. Although detailed social, health, and treatment data are of value to epidemiological research, a register that provides a minimum of information about each patient in a community is more important than one that provides more detailed information only from specific facilities, as pointed out by Murphy (1975).

Different levels of information—e.g., between inpatient and outpatient facilities—are bridged by block systems of data registration (Jakubasch et al. 1978).

One exception is the Icelandic Case Register. Since 1960, it has registered only first contacts of all persons who utilize a psychiatric service, a general hospital, or a nursing home and receive a psychiatric diagnosis. This register is therefore exclusively used for epidemiological research (Mazer 1966; Helgason 1975, 1979) (see table 1).

Access to and Crossing With Public Statistics. In principle, disease registers need aggregate data from population statistics in order to get population-related, age-corrected rates and to be able to compute on the basis of parallelized control groups. Additionally, the local authorities (register's offices, public health offices, residents' registration offices) transmit case-related information about social and demographic indicators, deaths and causes of death, to most of the registers. This makes it possible to undertake investigations on mortality (e.g., the mortality of suicide) and to eliminate the deceased. But it also improves the completeness and quality of the registered items.

The crossing of psychiatric case registers with population registers, such as twin and adoption registers, is of great importance to epidemiology, especially for hypothesis testing. The best prerequisites for crossing registers are to be found in the Northern countries, which have relatively stable populations, excellent population registers, and psychiatric registers containing large case numbers without essential regional distortions.

Epidemiological Data

Indicators of True Morbidity. Under the conditions of a sufficient provision of care for the population and high utilization rates for the investigated disease group, as apply in schizophrenia, first contacts compiled by a case register can be regarded as indicators of true morbidity. Investigating the relations among morbidity risks, disease courses, and environmental variables is only appropriate if a diagnostic group is sufficiently large and representative. The analysis of such relations or trends over longer periods of time on the basis of case register cohorts is more valid than cross-sectional comparisons or longitudinal studies among hospital populations. Besides, long-term collection of data on representative patient groups—starting with first admissions—is an excellent instrument for observing the manifestation of diseases over a long period and for assessing changes that may occur due to therapeutic measures.
Table 1. Some psychiatric case registers in Europe

<table>
<thead>
<tr>
<th>Registers</th>
<th>Year of starting</th>
<th>Information going back to</th>
<th>Catchment area</th>
<th>Population at risk (approximate)</th>
<th>Registered population (case definition and affiliated services)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Norway/Oslo</td>
<td>1936</td>
<td>1916</td>
<td>National</td>
<td>8 million</td>
<td>Psychoses; psychiatric inpatient services</td>
</tr>
<tr>
<td>Denmark/Aarhus</td>
<td>1937</td>
<td>1905</td>
<td>National</td>
<td>5 million</td>
<td>All mental disorders; psychiatric inpatient services &amp; partial hospitalization</td>
</tr>
<tr>
<td>Iceland/Reykjavic(^1)</td>
<td>1968</td>
<td>1908</td>
<td>Regional</td>
<td>40,000</td>
<td>All mental disorders; psychiatric inpatients &amp; outpatients; general hospitals</td>
</tr>
<tr>
<td>U.S.S.R./Moscow</td>
<td>1968</td>
<td>1968</td>
<td>National</td>
<td>250 million</td>
<td>All mental disorders; mental hospitals &amp; mental health dispensaries</td>
</tr>
<tr>
<td>U.K./Nottingham</td>
<td>1958</td>
<td>1958</td>
<td>Regional/local</td>
<td>390,000</td>
<td>All mental disorders; mental health services</td>
</tr>
<tr>
<td>U.K./Salford</td>
<td>1959</td>
<td>1959</td>
<td>Regional/local</td>
<td>135,000</td>
<td>All mental disorders; mental health services</td>
</tr>
<tr>
<td>U.K./Aberdeen</td>
<td>1962</td>
<td>1962</td>
<td>Regional/local</td>
<td>200,000</td>
<td>All mental disorders; mental health services</td>
</tr>
<tr>
<td>U.K./Camberwell</td>
<td>1964</td>
<td>1964</td>
<td>Regional/local</td>
<td>155,000</td>
<td>All mental disorders; mental retardation; mental health services; homeless people</td>
</tr>
<tr>
<td>F.R.G./Mannheim</td>
<td>1973</td>
<td>1973</td>
<td>Regional/local</td>
<td>300,000</td>
<td>All mental disorders; mental health services &amp; psychiatric components of social services</td>
</tr>
<tr>
<td>Netherlands/Groningen</td>
<td>1973</td>
<td>1973</td>
<td>Regional/local</td>
<td>43,000</td>
<td>All mental disorders; mental health services</td>
</tr>
<tr>
<td>Ireland/Three County Psychiatric Case Register</td>
<td>1973</td>
<td>1973</td>
<td>Regional</td>
<td>150,000</td>
<td>All mental disorders; mental health services</td>
</tr>
<tr>
<td>Italy/Lomest</td>
<td>1975</td>
<td>1975</td>
<td>Regional/local</td>
<td>81,000</td>
<td>All mental disorders; mental health services</td>
</tr>
<tr>
<td>West Dublin County Register</td>
<td>1973</td>
<td>1973</td>
<td>Regional</td>
<td>230,500</td>
<td>Inpatient &amp; outpatient services; public &amp; private</td>
</tr>
</tbody>
</table>

Note. — Further psychiatric case registers are run in the Netherlands on a national level and in Maastricht, in Geneva (Switzerland), Cardiff, Oxford, Southampton, Worcester (U.K.), Verona (Italy), and Basque Country (Spain).

\(^1\) Not cumulative; first ever contacts only.

and health care provisions. The investigation of groups at high risk and the comparison with the rest of the population with regard to morbidity patterns, environmental conditions, and long-term changes may provide information about distribution processes of morbidity risks, connections with possible stress factors, and special needs for care.

Exact comparisons of "administrative" annual incidence rates for schizophrenia from several case registers cannot be made because of differences in definitions (e.g., diagnosis, first contact with a certain facility or with the register) and in denominators (e.g., total population or population aged 15 and over). The influence of differing denominators (total population versus population aged 15 and over) is shown by a comparison of incidence rates from the Mannheim Case Register calcu-
Table 2. Annual incidence rates for schizophrenia in Mannheim—1974–80

<table>
<thead>
<tr>
<th>Year</th>
<th>First onsets (n)</th>
<th>Total population per 1,000</th>
<th>Population aged &gt; 15 per 1,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>1974</td>
<td>159</td>
<td>.48</td>
<td>.58</td>
</tr>
<tr>
<td>1975</td>
<td>176</td>
<td>.56</td>
<td>.67</td>
</tr>
<tr>
<td>1976</td>
<td>210</td>
<td>.67</td>
<td>.81</td>
</tr>
<tr>
<td>1977</td>
<td>195</td>
<td>.63</td>
<td>.75</td>
</tr>
<tr>
<td>1978</td>
<td>193</td>
<td>.63</td>
<td>.75</td>
</tr>
<tr>
<td>1979</td>
<td>174</td>
<td>.57</td>
<td>.67</td>
</tr>
<tr>
<td>1980</td>
<td>190</td>
<td>.62</td>
<td>.72</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Rate of first onsets related to Population aged &gt; 15 per 1,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>.59</td>
</tr>
</tbody>
</table>

Source: Psychiatric Case Register, Mannheim.

lated according to both methods for the period 1974–1980 (see table 2).

In spite of these differences, the incidence rates of various case registers range rather precisely about two mean values: the rates from British registers are about a mean of 15–20/100,000/year; those from the U.S.A., Ireland, and the F.R.G. amount to 50–60/100,000/year (see table 3). With respect to confidence intervals, this is a minor difference, but it is impossible to conclude whether it reflects a true difference in morbidity. It might stem, for example, from a wide or narrow definition of schizophrenia, the proportion of age groups at risk (especially the proportion of persons aged 20–40 years) in the total population, and the density of mental health services affiliated to a case register.

The point or period prevalence, i.e., the rate of manifestly ill persons in a population who are in contact with mental health services, has a greater probability of being complete and consistent. However, these rates are influenced by regional differences in morbidity (e.g., higher prevalence of chronically ill in large cities or in populations with a higher life expectancy in general). Furthermore, with long-lasting diseases in particular, they are also influenced by the care system, and by high proportions of long-term hospital patients (e.g., in Ireland) (Hafner and Klug 1982; Hafner and an der Heiden 1983) (see table 4).

Long-term Epidemiology. The Scandinavian case registers collect large numbers of first admissions over long periods, and thus may serve as a basis for investigating correlations and differential processes of distribution for relevant social variables. While first admission rates remained stable over several decades in Iceland (Helgason 1975), in Denmark (Dupont and Weeke 1977; Weeke and Strømøren 1978), and in Norway (Ødegård 1971b) (the same is true for the admission rates of persons aged up to 35 (Weeke and Strømøren 1978) and of persons up to 30 years (Ugelstad 1978)), point prevalence rates and length of hospital stays of schizophrenic patients varied greatly. In Norway, the sharpest decline took place in the period 1936–59 (Ødegård 1964). In Denmark, the number of schizophrenic patients in mental hospitals dramatically decreased by about 30 percent between 1957 and 1962 (Dupont and Weeke 1977; Weeke and Strømøren 1978). By 1971, there had been only a slight further reduction, which has remained constant since then. Preceded by a steady increase, in England and Wales, the number of hospitalized schizophrenics continuously declined by over 50 percent in the period 1956–73. These trends reflect systematic efforts to curtail the length of hospital stays of the chronically mentally ill and to accommodate them in complementary facilities.

Following Ødegård’s model, Astrup (1982) studied first admissions for schizophrenia recorded in the Norwegian Register from 1926 to 1978. He calculated the lifetime risk of ten 5-year cohorts and one 3-year cohort in a period of investigation covering 53 years. He took the life expectancy of the same age classes of the total population as a basis (timetable method). The lifetime risk for schizophrenia declined in males from 194/100,000 in 1926–30 to 42/100,000 in 1977–78; in females it decreased from 179/100,000 in 1926–30 to 35/100,000 in 1977–78.

To the same extent, the “lifetime risk for the diagnostic group of reactive psychoses and paranoid syndromes” increased from 43/100,000 to 167/100,000 in males and from 52/100,000 to 220/100,000 in females. In the more comprehensive diagnostic category of “functional psychoses,” the lifetime risk corrected for age and age group remained stable over a period of 53 years. According to Astrup (1982), the decrease in first admission rates for schizophrenia can be explained by the increasing tendency of Norwegian psychiatrists to diagnose schizophrenic disorders that are precipitated by life events, and show severe
Table 3. Incidence rates for schizophrenia from psychiatric case registers

<table>
<thead>
<tr>
<th>Place</th>
<th>Author</th>
<th>Year</th>
<th>Rate/1,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Norway</td>
<td>Astrup (1982)</td>
<td>1926-30</td>
<td>.23</td>
</tr>
<tr>
<td>Iceland</td>
<td>Helgason (1977)</td>
<td>1966/67</td>
<td>.27</td>
</tr>
<tr>
<td>Denmark</td>
<td>Dupont and Weeke (1977)</td>
<td>1972/73</td>
<td>.12</td>
</tr>
<tr>
<td>Victoria, Australia</td>
<td>Krupinski (1984)</td>
<td>1978</td>
<td>.16</td>
</tr>
<tr>
<td>Netherlands</td>
<td>Giel et al. (1980)</td>
<td>1978/79</td>
<td>.11</td>
</tr>
<tr>
<td>South-Verona, Italy</td>
<td>Tansella et al. (1985)</td>
<td>1983</td>
<td>.08</td>
</tr>
<tr>
<td>Maryland, U.S.A.</td>
<td>Warthen et al. (1967)</td>
<td>1963</td>
<td>.50</td>
</tr>
<tr>
<td>Rochester, U.S.A.</td>
<td>Babigian (1975)</td>
<td>1970</td>
<td>.69</td>
</tr>
<tr>
<td>Oberbayern, F.R.G.</td>
<td>Dilling and Weyerer (1975)</td>
<td>1974/75</td>
<td>.48</td>
</tr>
</tbody>
</table>

Note — Includes data from case registers in Europe, United States (survey based on comparable sources of data collection), and Australia. Incidence rate = first contacts with a psychiatric case register per year and per 1,000 total population.

1 "Lifetime expectancy rate," hospitalized cases only, schizophrenia, and "reactive psychoses.
2 Rate separately for men (hospitalized cases of schizophrenia without "reactive psychoses").
3 Rate separately for women (hospitalized cases of schizophrenia without "reactive psychoses").
4 Including ICD 297.0-297.9; 298.3-298.9.
5 Rate for first-ever contacts.
6 Rate for schizophrenia and other functional psychoses.
7 Survey based on comparable sources of data collection.
8 Rate for first contacts with mental health services for schizophrenia when three periods were compared: 1926-27, 1946-47, and 1966-67. In the registers of Camberwell and Salford, Wing and Fryers (1976) found stable rates of first contacts with mental health services for schizophrenia when three periods were compared: 1926-27, 1946-47, and 1966-67. The fact that the admission rate for schizophrenic patients aged under 30 years had remained stable in the Danish Case Register from 1957 to 1976 (Ugelstad 1978) also supported Ødegård's assumption: The astonishing stability of first admission rates over half a century indicates that in the countries investigated the true incidence of schizophrenia remained essentially unchanged. The findings also tallied with Goldhamer and Marshall's (1953) studies in Massachusetts. Due to non-age-corrected data from the Norwegian register, Astrup had assumed in 1956 that the frequency of schizophrenia would particularly increase in the period of rapid industrialization as a consequence of the capitalist society. However, Astrup corrected his results and their interpretation in his 1982 publication. As Astrup (1982) stated, his data are consistent with the hypothesis that functional psychoses are biological reaction types that are relatively independent of the social environment.
Ecological Factors. In the industrial City of Mannheim, which then counted 300,000 inhabitants, Häfner and Reimann (1970) once again found a concentric distribution pattern of first admission for schizophrenia, similar to the one found in Chicago by Faris and Dunham (1939). The analysis of deviating accumulation—e.g., in subcenters on the outskirts of the city—indicated that mobility steered by sociopolitical measures (such as housing projects) influences the distribution of morbidity. Ødegård (1972) could not furnish proof of a concentric distribution pattern of first admissions in Norwegian towns, although the first admission rates in the City of Oslo, like those from Copenhagen (Dupont and Weeke 1977), were higher than the national average. Levy and Rowitz (1970, 1973), in their replication of the study by Faris and Dunham (1939), were able to demonstrate in Chicago a zonal distribution pattern of the origin of patients readmitted for schizophrenia, but not of first admissions. Ødegård took this finding to be a confirmation of his assumption: Within the complex structure of modern cities, the migration processes of individuals at risk for schizophrenia cannot be described by unidimensional ecological models. Although the greatest concentration of domiciles of persons already suffering from schizophrenia is in cheap dwelling areas as a consequence of downward mobility, Ødegård’s findings based on case register data were confirmed by Hare (1956) in Bristol and Stein (1957) in London. They showed that first onsets have a stronger connection with social isolation than with poverty.

Civil Status. At the time of first admission, schizophrenics are significantly more often unmarried than the population of the same age (Ødegård 1946; Dupont and Weeke 1977). A comparison of two time periods (1931-45 and 1956-65) showed that in Norway the proportion of unmarried males among first admissions for schizophrenia rose from 4.3 to 7.7 and that of unmarried females from 3.7 to 4.5 times the amount of the same age group in the general population. Ødegård attributed these differences to prepsychotic character traits. Social disability preceding the psychosis affects men more strongly than women, since in European culture men have to play a more active role in matchmaking. It is true that the rate of unmarried persons among schizophrenics rose in a period in which the frequency of marriage declined and the average age at marriage increased (1931–65). But the disproportionately higher increase in unmarried schizophrenic males reflects their disproportionately larger difficulties in active matchmaking due to prepsychotic disturbances in the ability to establish interpersonal relationships (Ødegård 1971a). Widowed persons have a considerably higher first admission rate compared to married ones, but a lower rate than unmarried persons. Ødegård (1971a) attributes this to the missing protective factor of matrimony, which at least in cases of less severe illness, diminishes the probability of hospital admission.

Social Class. The uneven distribution of schizophrenia over social classes or socioeconomic strata, being maximal in the lower class, is a consistent finding over nations and continents, with rare exceptions. Because schizophrenia frequently entails social disability, the uneven distribution of prevalence rates over social classes is much more obvious than the inequality of first admission or true incidence rates (Adelson et al. 1968; Goldberg and Morrison 1963). However, the construct of “socioeconomic class” is too imprecise to be used to assess detailed hypotheses proposed to account for the distribution processes of individuals at risk for schizophrenia (Ødegård 1975).

Employment. Various factors unevenly distributed over time may have contributed to the long-term trend toward shorter hospital stays and extramural care of schizophrenic patients in industrial countries (Brown 1960; Häfner and Klug 1982). At first, the decrease in hospitalized schizophrenic patients resulted exclusively from the decline of long-term hospitalized patients (Wing and Fryers 1976; Fryers 1979; Häfner and Klug 1982; Häfner and an der Heiden 1983). As was earlier stated by Brenner (1967) in his study covering a 60-year period of hospitalization in New York (1900–60), Ødegård (1971) and Astrup (1982) pointed to the correlation of time between changes in the length of hospital stays of schizophrenic patients and the employment situation. The reversed trend observed by Fryers in Salford since 1973 and by Weeke and Stromgren on the basis of the Danish Case Register since 1971—a new increase in the accumulation rate for long-term hospitalized schizophrenic patients—is clearly connected with declining economic activity and increased unemployment in both countries. In the Federal Republic of Germany, where unemployment increased more recently, the proportion of long-term hospitalized patients decreased until 1980. In principle, the entry of psychosocially disabled persons into the free labor
market must be understood as a threshold phenomenon: Whenever unemployment rates and demands on the applicants for a position are high, the number of schizophrenics who, due to their psychosocial disability, cannot find employment on the free labor market grows disproportionately in relation to the total population.

**Therapeutic Measures.** Ødegård attached only partial importance to the introduction of psychotropic drugs, since in Norway the greatest changes had already occurred in the 1936–50 period following the introduction of electroshock therapy. In some European countries, the provision of complementary services and their influence on the length of hospital stays of schizophrenic patients came to the forefront between 1960 and 1980 (Wing and Fryers 1976; Weeke and Stromgren 1978; Fryers 1979; Hafner and an der Heiden 1982, 1983), but this influence was counterbalanced by the unfavorable effects of the high unemployment rate (Wing and Fryers 1976; Weeke and Stromgren 1978; Weeke, Kastrup, and Dupont 1979; Dupont 1979). An increased provision of complementary services, especially of sheltered homes, apartments, and workshops, can keep the proportion of schizophrenic long-stay patients low even in times of economic recession and make it possible for the majority (about 75 percent) of schizophrenic patients needing care for over 1 year to live in the community (Hafner and an der Heiden 1983).

**Occupation and Social Mobility.** From an analysis of the age-corrected distribution of first admissions for schizophrenia over various occupational groups in the period 1926–65, Ødegård (1971a, 1971b) deduced that the largest proportion was to be found in occupational groups with little practical and theoretical training and low social prestige. He found high rates in sailors and farm laborers, and considerably lower rates in first mates of the merchant marine and farmers, although their situation in life and work is comparable. Since the morbidity risk of Norwegian seamen was about twice as high as that of industrial workers belonging to the same social class, Ødegård concluded that the economic status had no direct effect on the morbidity risk.

Long-term changes in the characteristic features of occupational groups gave further opportunities to compare two competing hypotheses. The "selection" hypothesis attributes the low socioeconomic status of schizophrenics to their preexisting disorder or to their predisposition to develop disorder. By contrast, the sociogenetic or "breeder" hypothesis links the development of schizophrenia to preexisting social precipitants or stressors. In Norway, the occupational groups with unusually high first admission rates for schizophrenia (seamen and farm workers), which continued to increase in the period of observation, showed a sharp decline in employment. Ødegård demonstrated this process by the example of female domestic servants, an occupation that nowadays has almost died out in Norway: The exceptionally high first admission rates for schizophrenia in this occupational group contrasted with significantly lower rates for single housewives without occupation, a group which differed very little from the domestics with respect to their life and work situation. From this, Ødegård concluded that occupations which are dying out and offer little chance of success are the domain of individuals who, because of their social disability, avoid changing to more promising occupations. They are joined by newly disabled individuals from other occupational groups, for whom the lower threshold of qualification makes it possible to find employment. These data do not support the sociogenetic hypothesis that schizophrenia is caused or precipitated by social strain.

However, the selection hypothesis is supported by the substance and dimension of the described processes of distribution over social situations. Thus, Ødegård's findings in case register studies point in the same direction as the findings of Goldberg and Morrison (1963) on intragenerational mobility of individuals suffering from schizophrenia. Eaton (1980) recently used a stochastic model to demonstrate that social intergenerational and intragenerational mobility in male schizophrenics, compared to normal males, fully explains the quantitative differences in social class distribution.

**Selective Effects of Premorbid Behavioral Patterns.** Since the processes leading to uneven distribution in marriage, in the choice of an occupation, and in migration were in effect before first admission, they must have been determined by premorbid traits of those who later would develop schizophrenia. Noreik and Ødegård (1966) retrospectively examined the school files of a sample of schizophrenic patients and compared them with a matched control group. They found that those pupils who later developed schizophrenia, on the average, had obtained lower grades and had had fewer social relations than their classmates. These findings, which have since been verified by prospective studies of individuals at high risk for schizophrenia (Garmezy 1981).
support Ødegård’s (1972) and Astrup’s (1982) assumption that the social processes which lead to an uneven distribution of the morbidity risk are initiated by the preexisting personality traits of individuals who later develop schizophrenia.

Schizothymic personality traits, lack of social contact, rigidity, and lack of self-assertiveness can also be found more frequently in the lower classes (Ødegård 1975). From this apparent evidence of social selection, Ødegård (1975) deduced that schizophrenia is deeply rooted in the patient’s past and that its causes should be sought, not at the time of onset, but in the premorbid period. Ødegård considers it possible that the earliest manifested disturbances are not character traits, but initial symptoms of a psychosis that is taking a very slow course. At this early stage, the personality change can barely be recognized as pathological. Ødegård’s conclusion has implications for theories about the productive (positive) symptoms that characterize schizophrenia. The fact that the productive symptoms are not powerful predictors of long-term outcome (Strauss and Carpenter 1977; Tsuang, Woolson, and Fleming 1979; Schubart et al. 1982) could be explained as follows: The real process of schizophrenia, which is accompanied by the development of social disability and is of greatest prognostic value, in general precedes and is largely independent of, episodes of productive symptoms, which may be precipitated by additional factors.

Geographic Mobility (Migration). The first comprehensive empirical study of the relation between morbidity rates for schizophrenia and migration was published by Ødegård in 1932. It was based on data from the Norwegian Case Register and on hospital admission data from Minnesota. The studies demonstrated elevated first admission rates in Norwegians who had emigrated to the United States in comparison to the native population in the United States and in Norway. Even in Norwegians who had emigrated from the United States, the first admission rates for schizophrenia were elevated (Ødegård 1973).

Malzberg (1969) demonstrated that the differences diminished when analyses controlled for the variables of age and sex. The tendency, however, remained. Jointly with members of his staff, Ødegård then carried out several systematic studies on the influence of migration processes on the morbidity rate for schizophrenia. Within the country, Dalgaard (1971), Astrup and Ødegård (1960), and Ødegård (1975) found significantly lower first admission rates for schizophrenia in migrants from rural to urban areas and from large cities to suburbs. However, the frequency of first admission was increased in migrants from urban to rural areas. In connection with his findings on processes of labor migration, Ødegård favored an explanation suggested by the selective hypothesis: Premorbid personality traits, especially the lack of social relationships and occupational success, make it easier to decide to leave home and occupation. This explains the fact that in migration streams connected with social ascent there are relatively few, whereas in migration streams of individuals with little social success there are relatively many, individuals with a disposition to schizophrenia.

The morbidity rate for schizophrenia in Hungarian emigrants to Norway, who had left their home country mainly for political reasons, was investigated by Eiting and Grünfeld (1966) on the basis of the Norwegian register. In the period from 1956 to 1963, hospital admission rates for schizophrenia were slightly elevated in emigrants compared with the Norwegian population and showed a trend to assimilate after a longer stay in Norway.

On the basis of hospital statistics for England and Wales, Cochrane (1977, 1979) found significantly higher first admission rates for schizophrenia in Irish women (but not men) and in immigrants from the West Indies and Pakistan.

Bebbington et al. (1981) compared the morbidity rates of West Indian immigrants with those of Irish immigrants and of the native population. Their study used data from the Camberwell Register and from an additional population study covering the catchment area of the register. The purpose of the study was to test the following three alternative hypotheses: (1) The morbidity hypothesis—the morbidity of schizophrenia is dependent on racial or national differences. (2) The selection hypothesis—previous abnormalities reflecting a predisposition to schizophrenia influence the decision to emigrate. (3) The stress hypothesis—stress due to emigration and confrontation with a foreign culture increases morbidity.

A comparison between immigrants and the population born in England corrected for age showed significantly higher true incidence rates for schizophrenia in immigrants from the West Indies, in females more markedly than in males. Admission rates and rates for treated prevalence were also elevated in this group. In immigrants born in Ireland, Bebbington et al. (1981) could only partially verify Cochrane’s findings, which had not been corrected for age: Incidence rates for schizophrenia were clearly lower in Irish men and
clearly, although not considerably, higher in Irish women than in the local population. Bebbington et al. points out that the three hypotheses are not exclusive, but they attribute the greatest importance to the selection hypothesis.

The case register study on psychiatric morbidity of foreign workers in Mannheim done by Hafner (1980) underlines the extraordinary importance of the selection hypothesis. In the period of investigation—1974–78—about 13 percent of the Mannheim population were foreigners. The age composition of foreign workers showed an overrepresentation of younger age groups and thus differed markedly from the German population. Consequently, the rates of psychiatric morbidity among foreign workers were correspondingly lower. When corrected for age, the rates of treated schizophrenic episodes (a comparison of first admission rates was not appropriate because of the low number) were still significantly lower than those of the German population. The lowest rates were found among Turks and slightly reduced rates were found among Italians, whereas Yugoslavs and the group of other foreigners in which refugees prevailed did not differ significantly from the native population. The distribution of the rates for alcohol-related diseases and organic brain syndromes was analogous; however, the rates for affective psychoses and for neurotic and psychosomatic disorders showed no marked differences between the foreign groups and the German population. Hafner (1980) assumed that both the decision to go abroad to work and the chances of passing a medical screening before emigration are influenced by an early onset of chronic disease courses and by premorbid abnormalities of personality. Medical examination by the German labor administration is most severe for Turkish workers. Higher morbidity rates among women of migratory workers may be explained by the fact that they contribute less to the decision to emigrate and are examined less thoroughly. In contrast to the earlier mentioned emigrant groups, in Germany foreign workers represent an example of positive selection (reduced disposition to schizophrenia and other long-term mental disorders). As a consequence, in comparably poorer regions in which large proportions of the healthy population emigrate, the remaining individuals tend to be those who are old and at risk for chronic mental disorders. This may result not only in an unhealthy population structure, but also in a relative increase in the morbidity rates for schizophrenia, as was found in Istria, a region in Yugoslavia that was affected by several waves of emigration (Lemkau et al. 1980), and in Ireland (Scheper-Hughes 1979).

Morbidity Risk for Schizophrenia After Extreme Stress. In several studies, Eitinger (1959, 1960, 1967) used data from the Norwegian Case Register to investigate the morbidity rate for schizophrenia in individuals who had spent several years in German displaced persons (DP) and concentration camps by means of data from the Norwegian Case Register. In a first study, he found 14 persons suffering from schizophrenia among a total of 19,000 persons returned from German concentration and DP camps. Thus, in this group, the rate for the lifetime risk is markedly higher than in Norwegians. However, the group could not be compared for age, social class, or other factors. In a later study, Eitinger and Ström (1973) compared a total of 4,447 Norwegians who had returned from German concentration camps with a control group matched for age, sex, and socioeconomic status. The investigators aimed at a more precise determination of mortality and morbidity following severe stress. A representative sample of 480 males and 18 females out of this group were interviewed. The prevalence rate for schizophrenia among survivors of concentration camps was identical with that found in the control group of the Norwegian population. In each of the two interview samples, three cases of schizophrenia had occurred since the war. In contradiction to his former assumption and to the assumption of other authors (e.g., Baeyer and Binder 1982), which were not based on epidemiological results, Eitinger thus could not find any indication that the risk of schizophrenia increases after the severe stress of a stay in a concentration camp. These findings, as well as the unchanged incidence rates for schizophrenia in belligerent countries, are of importance for the hypothesis that any sort of mental stress precipitates psychoses.

Risk for Subgroups of Schizophrenia. As long as clinical diagnosis is not based on standardized diagnostic instruments and as long as detailed findings are not recorded, case register data do not allow inferences to be drawn about changes in the incidence of certain symptoms, syndromes, or subgroups of schizophrenia. Only syndromes that are reliably identified, such as febrile catatonia, are an exception. On the basis of hospital statistics and catamnestic samples, Paulikoff (1969), Huber (1969) and M. Bleuler (1972) had assumed that the syndrome of febrile catatonia had ceased to occur since 1960 as a result
of improved therapy. By means of case register data and data on the utilization of a unit for intensive psychiatric care in Mannheim, Hafner and Kasper (1982) showed that in the period 1974–81, acute life-threatening catatonia occurred with an almost unchanged frequency of episodes per year, about 1/300,000 total population.

The fact that this syndrome disappeared from the psychiatric hospitals in the F.R.G. may be explained by changes in the system of medical care: After the opening of intensive care units at hospitals or departments for internal medicine, neurology, and anesthesiology from about 1960 on, the treatment of life-threatening syndromes was shifted from the psychiatric hospitals, most of which are insufficiently equipped, to these units.

Special Population Groups at Risk for Schizophrenia. Noreik and Ødegård (1966) compared the admission rates of a cohort consisting of about 13,000 Norwegians who in the period 1916 to 1925 had finished secondary education, with those of Gypsies and homeless persons and those of neglected and criminal adolescents in Norway. While the academic cohort showed a slightly lower prevalence rate for schizophrenia in both sexes compared to the total population corrected for age, the rate of schizophrenia was significantly higher than expected among individuals without fixed abode and dissocial adolescents. Ødegård’s cohort studies allow statements on the morbidity risk of the investigated population group, whereas the increased prevalence rates for schizophrenics among homeless persons found in Camberwell (Wing et al. 1972) point to an augmented risk of social deterioration and social disintegration in persons suffering from schizophrenia. The followup investigation of representative samples, drawn from the Camberwell Case Register, in the community (Wing and Olsen 1979) confirmed this tendency: Many of them lived in poor circumstances, were out of work, and not able to accomplish their tasks at home. Nevertheless, few members of this socially neglected group wanted to accept offers made by mental health or welfare services. Apparently in contradiction to this, Wing and Brown (1970) had found that most schizophrenic patients who had been living in mental hospitals for many years preferred to stay there. Chronic schizophrenic patients seem to be more afraid of a change in their present circumstances than of the low quality of life often characterizing conditions in the hospital or in the community.

Genetic Studies. After Luxenburger (1936) had used twin registers to get undistorted concordance rates for schizophrenia, Tienari first examined a larger series in 1963: 903 out of 1,053 pairs of male twins from the Finnish Twin Register. Among 15 monozygotic pairs with a clearly schizophrenic index twin, he found no cotwin who met strict criteria for schizophrenia. When a wider definition was applied, three cotwins could be identified as cases: one as reactive psychosis and two as borderline schizophrenia. Later, Tienari (1975) crossed the original twin population with the register of all psychiatric hospitals and psychiatric outpatient departments in Finland. The result was essentially unchanged. Only the cotwin first diagnosed with a reactive psychosis later received a diagnosis of schizophrenia.

The most important study is the one carried out by Kringlen (1964). For the period 1901–30, he drew a total of 25,588 twin pairs out of the Norwegian national birth statistics and matched them with the Central Register of Psychoses. The concordance rate of monozygotic twins was 25 percent when narrow, and 38 percent when broad, definitions of schizophrenia were applied. The corresponding rates for dizygotic twins were 4 percent and 10 percent, respectively. Kringlen also found that 38 percent of monozygotic cotwins having schizophrenic partners were given the diagnosis of neurosis or “borderline” disease and that about 30 percent were clinically healthy. Similar to Slater (1953) and Tienari (1963), Kringlen showed that the more dependent, submissive twin is at greater risk to develop schizophrenia in the course of his life than the dominant one.

Fischer, Harvald, and Hauge (1969) and Fischer (1973) crossed all same-sexed twin pairs listed in the Danish Twin Register as being born in the period 1870–1920 with the National Psychiatric Register in Aarhus. Among the 21 monozygotic and 41 dizygotic twins of the same sex who had a schizophrenic partner, they found concordance rates of schizophrenia of 24 percent in monozygotic and 10 percent in dizygotic twins. Furthermore, Fischer examined the children of healthy monozygotic cotwins. The morbidity rate of these children almost equals the rate of monozygotic partners of schizophrenic twins. The number is still too small, however, for these findings to be generalized.

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1 E. Kringlen (1980) described most of the results of the epidemiological studies carried out among twins and adopted persons in his report on the contribution of the Scandinavian countries to research on schizophrenia. We therefore confine ourselves to a short survey.
difference between the consistently lower concordance rates from studies using case register data and the mostly much higher and more strongly varying risk figures from nonrepresentative twin populations is mainly due to different sampling methods. The introduction of register strategies greatly contributed to progress in psychiatric genetics (Rosenthal 1962; Kringlen 1967; Shields 1975).

The Danish adoption studies were designed to test the alternative hypotheses of a genetic transmission of schizophrenia versus a family/environmental transmission of schizophrenia. They were based on crossing an adoption register with the Danish Case Register. A sample of 5,483 children from the Province of Copenhagen who had been legally adopted by nonrelatives in the period 1924–47 formed the basis of a two-part investigation: (1) a comparison between adopted-away children of schizophrenic parents and adopted children of nonschizophrenic parents (Rosenthal et al. 1968) and (2) a comparison between the biological and adoptive relatives of schizophrenic adoptees and those of nonschizophrenic control adoptees. For case identification in the parents, the register data were supplemented by reports on the parents taken from the adoption files (Kety et al. 1968).

The adopted-away children of schizophrenic and control parents underwent a blind interview and a large battery of tests. Three out of 76 index cases were given a diagnosis of schizophrenia by at least one rater, whereas none of the control cases had developed schizophrenia. As the findings were not significant because of the small sample size, the investigators extended the case definition to the so-called “schizophrenia spectrum disorder,” a rather imprecise diagnostic group. They then found 24 (31.6 percent) positive cases among 76 index cases and 12 (17.9 percent) among 67 control cases, a difference that was significant on the 0.5 percent level. The same case definition and the same method of data collection were applied in the second phase of the study, which took as its point of departure adopted persons who developed schizophrenia. In this phase, the biological parents were compared with the adoptive parents.

Meanwhile repeated secondary analyses were made on the basis of these data (Haier, Rosenthal, and Wender 1978; Kendler, Gruenberg, and Strauss 1981a, 1981b, 1981c; Lidz, Blatt, and Cook 1981). The findings, partially processed according to the criteria of DSM-III (Kendler, Gruenberg, and Strauss 1981a, 1981b, 1981c), generally affirmed that neither the number of biological relatives who received a reliable diagnosis of schizophrenia nor the number of index cases among the adoptees were sufficiently large for definite conclusions to be drawn. There remains a clear trend toward a greater probability of developing schizophrenia in genetic as compared to adoptive parent and child relationships. This trend needs to be confirmed on the basis of larger case numbers and of precise criteria of case definition and identification. As a next step, the adoption registers could be crossed with a psychiatric case register on a national level.

Quite a few of the Scandinavian register studies were carried out in populations at risk. Mednick and Schulsinger (1971) undertook a prospective longitudinal study among children of schizophrenic mothers in Denmark. Out of 173 children, who were re-examined at an average age of 28, eight (4.6 percent) compared to one (1.1 percent) out of 91 controls had developed schizophrenia. Tienari et al. (1979) identified all females who had been given the diagnosis of schizophrenia and had been recorded in the Finnish Case Register between 1960 and 1970. By crossing these data with the birth register, he formed a sample of those 120 children who had been separated from their genetic mothers by adoption. Kringlen (1978) investigated a sample of 48 married couples in which both partners had a functional psychosis recorded in the Norwegian Register and had been hospitalized. The average age of the parents was 38 years. Five out of 25 children (20 percent) developed schizophrenia; seven (28 percent) developed a reactive psychosis. When corrected for age, the lifetime expectancy rate of schizophrenia was relatively low, at 29 percent. Kringlen emphasized that 28 percent of the children of two schizophrenic parents had remained clinically normal.

**Evaluative and Services Research**

Assessment of Needs, Planning, and Evaluation of Services. Case registers cover only treated morbidity. A precise assessment of changes in morbidity, especially in the morbidity of those mental disorders in which only a minority receive mental health services, requires additional field studies or data collection in primary health services, particularly in general practice (Ödegård 1972; Fryers 1979). A large amount of work is required in such studies. L. Wing et al. (1968) pointed out that about 100,000 persons would have to be examined per year in order to find 15 new (first onset) cases of schizophrenia. Therefore, field studies are carried out only in rare cases in needs assessment and, if
so, with a precise formulation of the research questions to be addressed.

Although they cannot contribute much to the direct assessment of unserved needs of a population, registers are of great importance in evaluating the adequacy of services and care systems. They allow us to ascertain which group of patients utilized which elements of available services at what time and to what extent. They enable us to identify patients who do not utilize offers of care recommended to them, and facilitate the assessment of specific needs of patient groups, e.g., for alternative offers of care, which are still uncovered (Fryers 1979). This presupposes the use of existing knowledge of specific needs of certain patient groups, which—in case they are not covered—lead to misplacement or lack of care.

Demand and Utilization. The utilization of mental health services cannot be equated with a region's actual needs. Data on utilization also do not permit direct conclusions on the effectiveness of services to be drawn. To determine the uncovered proportion of need (see Matthew 1971; Alderson 1976; Hafner 1979; Jakubasch et al. 1978; Klug, an der Heiden, and Scheel 1980), it would be necessary to do field studies as described above. The field studies would include persons who reject psychiatric care although it is clearly indicated or turn to other medical disciplines (see Weyerer et al. 1982). With only a few exceptions, psychiatric case registers are restricted to utilization data from psychiatric services. The amount of missing information resulting from this restriction lessens the generalizability of findings, but this problem applies much less to the group of schizophrenic patients than to those with milder conditions. When data are also collected from alternative and complementary services, as is done by the Mannheim Case Register (Hafner and Klug 1980, 1981, 1982), changes of care provided to chronic schizophrenic patients—following the recommendations laid down under the concept of "comprehensive community mental health care" (World Health Organization 1973)—can be described continuously.

A crude comparison of census data on treated prevalence collected by eight case registers for all diagnostic groups shows considerable differences at the first glance (see table 5). The data partially reflect different stages of the development of outpatient and complementary services in the respective regions. Besides, they reveal differences in the proportion of long-term hospitalized patients and the completeness of data collection by the institutions contributing to mental health care (see, also, Walsh et al. 1980).

Planning. In the past, changes in the field of mental health care were often made without taking into consideration the scientific knowledge about factors that influence the extent of disease and impairment in a population and also the provision of optimal care (Wing and Hailey 1972). For this reason—often to an unusual degree and unacceptable to the persons affected—political ideologies found expression in laws or measures alleged to improve mental health care.

The prediction of future need on the basis of utilization trends, and demographic and social developments, is important for planning services. Its reliability increases when the factors influencing a large part of the variation are analyzed and the trends are observed over a longer period of time (Ødegård 1972).

There are numerous examples of valuable contributions by case registers to the planning of psychiatric services. Thus, in 1976, the need for psychiatric hospital beds in the Danish provinces was assessed on the basis of the Danish Case Register following a request of the government. The findings were used to prepare the transfer of responsibility for psychiatric hospitals from the state government to the provincial governments (Strømgren et al. 1979). In the United Kingdom, case register studies have long been used to interpret the misleading

Table 5. Point prevalence rates of some European case registers ¹

<table>
<thead>
<tr>
<th>Register</th>
<th>Rate</th>
<th>Point prevalence</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Randers, Denmark</td>
<td>822</td>
<td>March 1, 1977</td>
<td>Kastrup &amp; Bille (1980)</td>
</tr>
<tr>
<td>Three County, Ireland</td>
<td>1770</td>
<td>March 31, 1973</td>
<td>Walsh et al. (1980)</td>
</tr>
<tr>
<td>Lomest, Italy</td>
<td>268</td>
<td>Dec. 31, 1975</td>
<td>Marinoni et al. (1983)</td>
</tr>
</tbody>
</table>

¹ Inpatient and outpatient care; rates per 100,000 total population.
² Census data added.
aggregate data of hospital statistics and of the National Health Service, and also to correct prognoses of need for hospital beds and alternative facilities (Department of Health and Social Security 1975).

Evaluation of Utilization. In the last decades, a transition from hospital-centered to community mental health care, including outpatient and complementary services, took place in many European countries (World Health Organization 1973; Department of Health and Social Security 1975; Report of the Expert Commission on Psychiatry, F.R.G., 1975). This process of marked change in the system of care, which was accompanied by a considerable increase in treatment prevalence, has been evaluated in various countries on the basis of case register data (Wing and Bransby 1970; Wing and Fryers 1976; Hafner and Klug 1980, 1981, 1982; Giel and ten Horn 1982).

It appears that the different levels of psychiatric care have contributed to the increase in treatment prevalence to a varying extent. The rate for contacts with complementary and outpatient services rose drastically, whereas the population-related rate of occupied beds declined in the regions analyzed or, in case of lower initial values, remained stable (Wing and Fryers 1976; Hafner and Klug 1982; Hafner and an der Heiden 1983).

In Mannheim, for example, the total number of treated episodes per year of schizophrenic patients increased from 485 to 756 in the period 1974–79; in the same period, the number of occupied beds decreased from 243 to 209 (Hafner and Klug 1981). There are two reasons for this trend: (1) the increased provision of outpatient and complementary services, accompanied by changes in the help-seeking behavior of schizophrenic patients (an der Heiden and Klug 1980; Hafner and an der Heiden 1982); (2) the drastic shortening of stays in inpatient services, as reported from other case registers (Gam 1980; Wing and Bransby 1970; Fryers 1974). The reduction of long-term hospital stays (over 1 year) is followed by a rise in short- and medium-term stays so that in spite of unchanged or decreasing rates of occupied beds, an equal number of schizophrenic patients has to be cared for at more frequent intervals during the same period of time.

This historical trend in the care of schizophrenic patients is clarified when the respective rates for the years 1974–79 from the Mannheim Case Register (Hafner and an der Heiden 1982) are added to a review of eight studies on discharge rates for schizophrenic patients 1–5 years after their first admission carried out between 1900 and 1950 (Brown 1960). The proportion of schizophrenics who, after first admission, stay in the hospital for more than 1 year has consistently declined since the turn of the century, from about 70 percent to about 5 percent in 1980 (see figure 1).

Simultaneously with the reduction of the average length of stay, the case/episode ratio has increased. In 1974, one hospitalized schizophrenic patient in Mannheim accounted for 1.16 inpatient treatment episodes per year, but this value increased to 1.28 by 1979 (Hafner and an der Heiden 1982), including long-term patients.

Long-term Patients. In the past, schizophrenics constituted by far the largest proportion of long-term hospitalized patients. On December 31, 1972, for example, 60.3 percent of all long-term hospital patients in Camberwell had been given a diagnosis of schizophrenia; in Salford they amounted to 66.8 percent in the same period (Wing and Fryers 1976). A 1-day census carried out in Mannheim on May 30, 1973, ascertained a proportion of 53 percent (Hafner and Klug 1982).

When the composition of inpatients over several census days is examined on the basis of case register data, the following trend can be discerned: In all diagnostic groups, the proportion of long-term patients in the total number of occupied beds is continuously diminishing; however, the rate of decrease greatly differs in the various areas of care (Wing and Bransby 1970; Wing and Fryers 1976; Hafner and Klug 1980, 1981, 1982; Giel and ten Horn 1982). An example from England and Wales reported by Wing and Fryers (1976) may illustrate this: In the period 1964–74, the rate of schizophrenic patients fell from 72.9 percent to 59.9 percent in Camberwell, whereas in Salford it remained stable between 1967 and 1973 at a high mean of 82 percent.

Comparison of “Old” and “New” Long-stay Cohorts. To show the changes in the need for long-term hospital admission in the context of a community mental health service, the total cohort of long-term patients can be divided into the following two subcohorts: (1) Patients who on a given census day had been hospitalized for over 1 year; to a large part, these are the inheritance of a past hospital policy. (2) Patients who from this census day on become new long-stay patients under the conditions afforded by modern treatment.

In all case register areas, a corresponding accumulation of “new” long-stay patients can be observed, and does not seem to have yet reached its peak (Wing and Bransby 1970; Hailey 1971, 1973, 1974; Wing...
Figure 1. Percentage of schizophrenic patients discharged within 5 years after admission—1900-1950

Note.—Studies included seven from the United States, one study from the United Kingdom, and one study from Mannheim.

1 From Cumulative Psychiatric Case Register, Central Institute of Mental Health, Mannheim.
2 From Brown (1960).


In several publications, Hailey (1971, 1973, 1974) thoroughly dealt with the problem of long-stay hospital patients living in the catchment area of the Camberwell Register. In 1964, 54 percent of the patients with schizophrenia had been hospitalized for more than 20 years. Out of 95 male patients who had stayed in the hospital for more than 15 years, 83 were diagnosed schizophrenic. In Camberwell the rate for all long-stay patients per 100,000 population calculated on 5 census days between 1964 and 1969 consistently fell from 240.5 to 209.9: Out of 410 patients who on the census day of December 31, 1964, had been admitted for over 1 year, 60.9 percent were still provided inpatient treatment on December 31, 1969.

The reduction of the group of "old" long-stay patients and the accumulation of "new" ones proceeded markedly faster in Camberwell than in Salford. In addition to the differences in the structure of the care system, the different age composition of long-term patients (on December 31, 1972, about 60 percent of all patients recorded in the Camberwell Register were aged 65 and over, whereas this age group accounted for only about 43 percent in the Salford Register) played a role (Wing and Fryers 1976).

A comparison between both cohorts ("old" versus "new" long-
term patients) made in Mannheim (census day: May 30, 1973; Häfner and Klug 1982) showed that, under a community mental health service, fewer schizophrenics needed long-term hospitalization than before; their rate decreased from 53 percent of the old to 35 percent of the new long-stay patients (Häfner and Klug 1982). Moreover, schizophrenics became long-stay patients at a considerably later time—mostly only after several preceding hospital stays. Parallels to the findings from Mannheim are to be found in the United Kingdom (Fryers 1979).

Beds Needed for Long-stay Patients. Before case register data were available, estimations of future needs for hospital beds were based on extrapolations from the change in bed occupancy over a defined period (e.g., Tooth and Brooke 1961) or on a retrospective analysis of the probability of discharge in relation to different lengths of stay in psychiatric hospitals (e.g., Baldwin and Hall 1967). Only the case-related inclusion of accumulating new long-stay patients in case registers allowed planners to make a differentiated analysis of changes in bed needs and residential placements resulting from changes in the mental health care system (Eason and Grimes 1977; Weeke, Kastrup, and Dupont 1979; Fryers 1974, 1979; Häfner and Klug 1982). Thus, case register data also permit a better interpretation of the trends observed in hospital statistics.

Complementary Services for Schizophrenics in the Community. Many chronically ill patients, who formerly would have been consigned to long-term residence in a psychiatric hospital, can now live in the community due to the extensive network of complementary services available. Studies carried out in the United Kingdom (Mann and Sproule 1972; Mann and Cree 1976; Magnus 1967) showed that, according to clinical judgment, even a large percentage of the new long-term hospitalized patients did not require treatment in a psychiatric hospital.

Wing (1982) investigated the specific needs of patients from the Camberwell Register who on June 30, 1979, had had contact with a halfway or complementary facility for at least 1 year. The study comprised institutions providing 24-hour care (hospital departments, homes) and also day clinics, day centers, and sheltered workshops. Patients with one episode of treatment of less than 1 year and patients who had been hospitalized for more than 1 year at the census day were excluded. Out of the 181 patients aged over 18—corresponding to a rate of 139 per 100,000 population—who met the criteria, almost half had received a diagnosis of schizophrenia. Regarding the distribution of sociodemographic variables, the composition was similar to that found in long-term hospital patients. In three quarters of the patients, the first contact with a psychiatric institution was more than 10 years in the past; only four of them had never been hospitalized before. Although the findings of this investigation primarily reflect the specific aspects of the mental health service in Camberwell, some general statements can be formulated. Thus, Wing (1982) emphasizes the need to examine each patient regularly in order to adjust the patient's placement to his needs and to improve his abilities in an environment that optimally encourages his independence.

The provision of support and advice to relatives as part of complementary health care for schizophrenic patients is of special importance. Over 40 percent of the sample drawn from the Camberwell Register had relatives who more or less regularly looked after them. The relatives often had to meet the same requirements as the staff of homes and nursing homes without being provided comparable institutional support.

A study based on data from the Mannheim Case Register (Häfner and an der Heiden 1983) showed to what extent the focus of care for chronic schizophrenic patients can be transferred from the psychiatric hospital to alternative services. In the period between the two census days, December 15, 1974, and December 15, 1979, the proportion of patients who remained in the hospital for more than 1 year among the total number of schizophrenic patients treated in psychiatric hospitals and homes (about 200–220) decreased from 85 percent (= 164) to 68 percent (= 148). In the same period, admissions of "new" long-stay patients from Mannheim, a city of about 310,000 inhabitants, to psychiatric homes increased from 7 in 1974 to 30 in 1979. Thus, in 1979, about three quarters of the annual admissions of all new long-stay patients with schizophrenia were made to psychiatric homes, whereas only about one quarter went to psychiatric hospitals. This distribution has remained stable to date.

Further Research on the Basis of Case Register Data. The necessity of continuous psychiatric treatment and of comprehensive care for chronic schizophrenic patients, including the fields of housing, occupation, leisure time, and social contacts, led to the implementation of a network of services. The evaluation of these complex patterns of care, their effectiveness, and the functions of every single service therefore gained significance (see Wing and Bransby 1970;
Research on utilization of the network of community mental health services. Ten Horn (1980) demonstrated the multiple utilizations of outpatient facilities by 1,594 patients with different diagnoses who had been recorded in the Groningen Case Register (Netherlands) in 1974–75. The complex pattern of use of various services was even more striking in a cohort of 148 schizophrenic patients from Mannheim who had been admitted to inpatient services between October 1, 1977, and September 30, 1978 (Häfner and an der Heiden 1982, 1983). After hospital discharge, 116 (78.4 percent) patients contacted three to seven facilities of extramural care either simultaneously or successively. In most of the patients, it was a suitable combination of visits to a physician, home care, and attendance at a sheltered workshop and/or patients’ club. These results demonstrate the interrelatedness of components of comprehensive community mental health care, a factor that should be considered in planning, coordinating, and analyzing the costs of such an extensive service. The effectiveness of intensive extramural care was demonstrated by the fact that the intensity of utilization considerably reduced the probability of rehospitalization.

Leff and Vaughn (1972) explored disease variables and social indicators that differentiated patients who used extramural care facilities from those who did not. A comparison between two samples of schizophrenic or manic-depressive patients drawn from the Camberwell Register (50 patients “in contact” and 40 patients “out of contact”) revealed the following: Patients “in contact” had more frequently been treated in a hospital and to a larger extent received medication. This may indicate that the extent of care is flexibly adapted to the severity of the disease. Patients with more severe disabilities are provided more frequent and more intensive care. An investigation by Häfner and an der Heiden (1982) also showed a significant relation between the number of preceding hospital admissions and the intensity of use of outpatient and complementary services. In the study by Leff and Vaughn (1972), patients “in contact” had more frequent and also a larger number of symptoms, as reported by their relatives, and both family and occupational ties were less stable. Furthermore, the study indicated that among the patients who had no outpatient contacts, those receiving medication showed a better social adjustment (see Leff and Wing 1971).

Experimental research on the basis of case register data. Methodological problems in the retrospective analysis and interpretation of changes and of factors influencing them often reduce the generalizability of epidemiological research findings. This also applies to intervention studies carried out in a nonrepresentative utilization population, such as patients of a specific hospital. It is an inherent deficiency of many clinical and treatment studies. The combination of epidemiological and experimental designs is an excellent way of solving this problem.

Wing et al. (1972) made an interesting attempt to combine an epidemiological with a quasi-experimental approach. Out of a group of 380 schizophrenic patients recorded in the Camberwell Register in 1968, 75 were found who had been living at home for at least 1 year without occupation. Twenty-eight of these patients were divided into two equal groups. In order to evaluate the effectiveness of preparatory training for occupational rehabilitation, the experimental group was assigned to a day clinic program. All of the patients had severe secondary handicaps. Even though a followup examination after 2 years indicated no differences between the groups with respect to occupational reintegration (four patients from each group were employed) or social adjustment, the study nevertheless had some intriguing results: Observations during the phase of social activation indicated, for example, that intensive methods of social treatment, as well as pressure by the family, may lead to deterioration or acute relapses (Vaughn and Leff 1976). In addition, five patients from the original group were found to have committed suicide. So the suicide rate was 11 times as high (132/100,000) as that of the Camberwell population (12/100,000). From this study, it was concluded that the appropriate accommodation for the majority of chronic schizophrenics would be an environment in which permanent handicaps are accepted and excessive activation is avoided.

Methodology

Stability of Diagnoses. The cumulative case-related registration of successive contacts drew attention to the diagnoses attributed to a patient who had been repeatedly recorded in the register. Quite a few publications deal with the search for explanations of changes in the diagnoses recorded. In addition to the possibility of a patient’s developing two independent psychiatric disorders, or expressing different states characteristic of the same basic disorder over the course of time, the influence of external, disease-related variables was
examined. In one of the first studies based on case register data, Babigian et al. (1965) investigated the stability of diagnoses in 1,215 patients in the Monroe County Psychiatric Case Register who had contacted a psychiatric institution at least twice during 1961-62. When patients were assigned to four diagnostic categories (schizophrenia, affective psychoses, organic brain syndromes, and miscellaneous), the concordance of first and second diagnoses varied between 69 percent and 88 percent. The patient's setting and social class had no discernible influence, but the institution giving a first diagnosis seemed to play an important role, especially with respect to a change in diagnosis: In three quarters of all cases, the diagnosis "worsened," in the direction of a psychosis, if the first contact was with a physician in practice.

In the study of Babigian et al. the period between each contact did not influence diagnostic consistency, but Jakubasch and Hurry (1977), using data from the Camberwell Register, found that concordance diminished in parallel with the length of the interval between two diagnoses. Concordance was assessed with respect to the 13 diagnostic categories of the register (not identical with the ICD classification) in a random sample of 144 patients entered in 1970 who had had at least one subsequent contact. In 50.5 percent of the cases, the diagnoses given at the first and last contact were identical; there was no significant connection between diagnostic changes and changes of the attending physicians or the institution.

A central register containing all data on admissions to and discharges from psychiatric hospitals in England and Wales was used by Cooper (1967) to investigate the reliability and quality of the recorded diagnoses. In a sample of 293 patients who were registered as first admissions in the second half of 1955 and had three readmissions in the following 2 years, the diagnoses were identical (four-figure ICD classification) in only 20 percent of cases. Unlike Jakubasch and Hurry (1977), Cooper found an important connection between change of physician and change of diagnosis: A change of physician increased the probability of being given a different diagnosis. Cooper concluded that most diagnostic changes are not based on changes in the clinical picture, but on inadequate diagnostic criteria and classificatory systems.

In a study using the Mannheim Psychiatric Case Register, Klug (1983) included data for 2,028 persons who had had 2-12 contacts with psychiatric facilities between May 31, 1973, and July 31, 1976. For the 17 diagnostic categories investigated (ICD, 8th revision), diagnostic concordance between the first two dates of utilization was about 67 percent when both primary and secondary diagnoses were taken into account. The average time difference between the two diagnoses was 244 days. The comparatively high level of diagnostic agreement found by Klug (1983) may reflect improvements in the classificatory system and effects of training among the diagnosing psychiatrists. Among individual diagnostic groups, lifelong disturbances (chronic and recurrent diseases such as mental retardation and schizophrenia) showed the highest levels of stability.

In Klug's study, the interval between two treated episodes had an unexpected influence: If time differences were small, concordance rates were much lower than with larger differences of time. This result may reflect a tendency to stabilize a diagnosis when the amount of information, particularly on indicators of course, is growing. A further aspect points into the same direction: In case of a change of institution, the stability of diagnoses grew continuously, from 55 percent to 63 percent, between the first and the third change.

Although their findings on the effects of a change of physician and institution or on diagnostic habits differ, all investigators concluded that the type of psychiatric disorder is an important factor. The concordance rate for schizophrenia was about 70 percent throughout (see, also, Kaebling and Volpe, 1963) and was relatively insensitive to influences of time and institution. The effects of external factors, particularly of multimorbidity, on the stability of diagnoses may be diminished by giving primary and secondary diagnoses and by attaching different weights to them (Dupont, 1980). The reduction and standardization of diagnostic categories (Babigian et al. 1965; Cooper 1967; Jakubasch and Hurry 1977; Klug 1983) may also lead to an increase in stability, albeit at the price of a loss of information. The introduction of a multi-axial classification makes it possible to classify important variables on different levels of stability. Diagnostic reliability can be improved if standardized diagnoses are made by specially trained staff of the case register (Cooper 1967; see, also, Walsh et al. 1980).

Data Processing and Evaluation. The amount and quality (in the sense of measurement theory) of information delivered to a case register require increasingly differentiated methods of data processing and analysis. By developing a special documentation system, an der Heiden and Klug...
(1980) illustrated the use of intramural and extramural institutions by schizophrenic patients in Mannheim over an 18-month period on the basis of 14-day intervals. The system made it possible to calculate the probability of transition between various stages of care over the course of time. With a time series analysis (Markov chain), they showed that after about 6 months, roughly 63 percent of a cohort utilized aftercare services, 17 percent got inpatient care, and 20 percent were not provided any care. These proportions remained stable at every further cross-section within the 18-month period (Hafner and an der Heiden 1982). This method could also be useful in cost-effectiveness analyses.

**Summary**

Because schizophrenia often takes a long-term course and is linked with socially conspicuous disturbances, the probability that a schizophrenic will contact a mental health service at least once in his lifetime approximates 100 percent if a sufficiently developed network of care is provided. Case registers therefore are important instruments of research on schizophrenia. In particular, their value to epidemiological and services research increases with the length of period they cover.

The first cumulative psychiatric case register was established in Oslo in 1936. The data of this national register of psychoses go back to 1916. Most local and regional registers in European countries were started in the 1960's in connection with the introduction of the ICD classification. These registers cover smaller populations, but record all contacts with psychiatric inpatient services, and a portion of contacts with complementary and outpatient facilities, irrespective of the diagnosis given.

The validity of cross-sectional comparisons of rates for first admissions and treated prevalence is limited because of the varying registration-density, differing definitions, and—reflecting the age-dependent morbidity risk—different denominators. The development of first admission rates, which can be observed over a period of 53 years in the Norwegian register and over 30 years in the Icelandic and Danish registers, proved to be an indicator of the long-term trend in morbidity: In schizophrenia, the morbidity risk, controlled for age, seems not to have changed in these countries for about half a century. The correlations between the rates for first admissions and demographic, ecological, and social factors—primarily investigated by Ødegård et al. on the basis of the Norwegian Case Register—strongly suggest the validity of selection hypotheses.

In investigations of the frequency of schizophrenia among migrating population groups, the results were inconsistent: In Norwegian immigrants to the United States and in Southeast Asian immigrants to Great Britain, the frequency of schizophrenia was higher, whereas the age-corrected rates for foreign workers in the F.R.G. were lower. These findings can be interpreted on the basis of different selective processes: Those selective factors leading to an unequal distribution at the onset of the disease seem to reflect certain traits of the premorbid personality of preschizophrenic patterns of social behavior. Long-term epidemiology and the analysis of geographic migration and social mobility could not verify the hypothesis that environmental factors—such as social systems, social context variables, or severe stress—might heighten the risk of becoming schizophrenic. Some of the findings tend to refute the assumption that the risk of illness is causally dependent on environmental factors.

By crossing data from twin and case registers, genetic research on schizophrenia for the first time obtained valid empirical data on hereditary factors in schizophrenia. The hypothesis of a genetic transmission of the predisposition to develop schizophrenia was confirmed, although some portion of the risk appeared to depend on environmental factors. Adoption studies based on Danish population registers have made an important contribution to the assessment of genetic versus familial/environmental factors in the transmission of schizophrenia. However, the results of the adoption studies need to be confirmed in larger samples.

Long-term trends in utilization of mental health services can be discerned in analyses of case register data, which permit relatively reliable determinations of future needs. Because they take demographic and regional factors into account, case registers contribute to a better interpretation of aggregate data from hospital statistics and to more valid planning of mental health services. The evaluation of mental health care systems and services on the basis of case registers has enhanced significance because of recent fundamental changes in mental health care.

Schizophrenics are the main target group of the reform in the mental health care system, and they also provide the largest group of patients for whom care has been transferred from hospital to complementary services. In this context, case registers are an indispensable instrument for assessing utilization,
effectiveness, quality, and costs of interrelated components of an increasingly complex system of care. In addition, case registers have been used as a basis for combining epidemiological and quasi-experimental methods of research on schizophrenia. This approach has contributed findings (e.g., on the specific vulnerability of chronic schizophrenics) that can be generalized. The possibilities of using case register data to follow the course of a disease and its dependence on intervening variables, to study the stability of syndromes and diagnoses, and to develop new methodologies have not yet been fully exhausted.

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