

Stability of Diagnoses in a Cohort of Long-Term Mentally Ill Patients in Sweden

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ABSTRACT *The aim of this study was to investigate diagnostic stability in a cohort of patients in Sweden over a 15-year follow-up period and to study the associations between diagnostic mobility and the patients' utilization of care, their age, duration of their illness and factors related to the reorganization of psychiatric care. Information about psychiatric diagnoses was collected from medical records in all care settings utilized by the patients. There was a high level of instability. Fifty-five percent of the patients had a change of diagnosis. Age and duration of illness were the most important factors related to diagnostic stability/instability. Since the diagnosis constitutes the basis of prediction of course and outcome of the disease as well as of choice of treatment, these results indicate that the current diagnostic system may have considerable limitations with regard to the clinical need for a holistic approach.*

In recent decades, most Western countries have carried through major changes in the provision of psychiatric care. The number of beds in large institutions has been heavily reduced and smaller community-based open units have been set up. Both humanitarian and financial principals have guided these changes (Sytema & Oldehinkel 1996). This change, often referred to as a process of deinstitutionalization, has had a major impact on psychiatric treatment and services available to people with severe mental illnesses. It has also involved a challenge to psychiatric professionals, administrators and politicians to rethink the provision of psychiatric care and services. In the wake of the deinstitutionalization process access to psychiatric care and social service, in and by the community, has become a lawful right for people with severe mental illness in many countries.

In Sweden, the right to community-based care, service, and support was legally stated by the *Swedish Social Service Act* of 1982. However, since people with mental disturbances to a large extent had difficulty gaining access to these services, the municipal responsibilities were clarified by the Mental Health Reform, which came into effect in January 1995. Who should be

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entitled to these rights was vaguely defined in the 1995 reform, but the target group was people who suffered from severe psychiatric illnesses of long duration. The terms “severe mental illness”, and “psychiatric disability”, frequently occur in policy and service planning documents, but they are not well defined. In Sweden this has generated problems in the drawing-up of boundaries and distribution of responsibilities between psychiatry, primary healthcare and municipal social services when it comes to the provision of care and service. The lack of a clear definition also entails uncertainties concerning on what grounds clients can legitimately demand access to the services (National Board of Health and Welfare 1998).

The transfer of locus of care from hospitals to community-based settings has made the relationships between patients, psychiatrists and society more complicated. Earlier, when all forms of care and service were provided in psychiatric hospitals, decisions concerning the patient’s hospital-stay and post-hospital future had the character of a one-way communication in which there was no need to involve persons outside the hospital in the decision process. Today, psychiatrists have to consider the points of view of other parties. Decisions have to be made in agreement with, among others, community nurses, social workers, insurance officials, members of the family and the patients themselves. The decisions have become more a matter of either/or, that is, either admission or not; medication or not; discharge or not; receipt of social support or not; entitlement to financial support or not. These decisions have increasingly been grounded in psychiatric diagnoses in societies that seem to have been increasingly medicalized (Rogler 1997).

The interest in psychiatric classification has increased rather dramatically since the beginning of the 1970s (Kendler 1990) and, as suggested above, the psychiatric diagnoses have come to play a more important part in the decision-making process. This rather recently-occurring interest has resulted in rapid revisions during the 1980s and 1990s of earlier editions of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) in the USA. However, the DSM has not been uncontroversial. Diagnostic categories have appeared and disappeared and fundamental changes of criteria have been made between the different editions. The most famous example on this account is homosexuality, which was removed as a diagnostic category after continual pressure from the gay liberation movement (Kutchins & Kirk 1997). These frequently-occurring changes call into question the scientific claims made by the American Psychiatric Association and, as Manning (2001:79) states, “Rapid changes in the classifications themselves are difficult to reconcile with stable underlying states”. The latest editions of WHO’s international classification system, the *International Statistical Classification of Diseases and Related Health Problems*, tenth revision (ICD-10 1997), has mainly the same structure and theoretical approach as DSM-IV (1994), although without the DSM-IV’s multi-axial assessment.

Stable and reliable diagnoses are of fundamental importance to the psychiatric enterprise, from both a clinical and a scientific point of view. From the scientific point of view stable diagnoses could be argued to be an important measure of psychiatry’s credibility as a scientific discipline, since

diagnoses with a high degree of stability increase the probability of there being definite psychopathological processes that the diagnoses reflect (Fennig et al. 1994). Diagnostic stability is of great importance for establishing diagnostic validity in the absence of aetiological psychopathology. It is one of the five suggested criteria, presented by Robins and Guze (1970) in their influential article, to verify the validity of a diagnostic construction. Stable and correctly determined diagnoses are of decisive importance to research into the proper ways of classifying psychopathological phenomena (Carson 1991), to pharmacological research, to the interpretation of epidemiological studies (Pichot 1994) and to evaluations of medical interventions (Blacker & Tsuang 1992).

Unstable diagnoses have obvious clinical consequences for the proper choice of treatment and to make predictions of course and outcome. Incorrect and unstable diagnoses also have consequences for patients who partake in psycho-educative groups for first episode psychosis. There is an impending risk of iatrogenic effects for patients who by way of mistaken diagnoses become members of groups with a gloomy prognosis (McGorry 1994).

Psychiatric diagnoses are also of fundamental importance to the welfare of people with mental disturbances, since financial support and social services are related to applications of diagnostic categories.

Studies of diagnostic stability have been carried out with a clinical focus on selected diagnostic disorders (Amin et al. 1999, Chen, Swann & Burt 1996, Chen, Swann & Johnson 1998, Deister & Marneros 1993, Ferro et al. 1998, Kendell, Malcolm & Adams 1993). More rare are studies that focus on overall changes of diagnoses in a clinical practice (Daradkeh 1996). Most studies of diagnoses are made using in-patient care occasions and there are, to our knowledge, no studies that have followed the development of diagnoses with a longitudinal model after the patients have been discharged from hospital and receive continued care and support at nursing homes, treatment homes, or in out-patient or community-based care facilities.

The aim of this study was to make a detailed inquiry into the diagnostic stability over a 15-year period (1984–98) in a cohort that was hospital-based at the start of the period. This period is characterized by a major organizational change. The basis of psychiatric care has been shifted from the hospital to the community. The specific questions addressed are the following:

- How stable are the diagnoses of the patients in the cohort over the 15-year period?
- What relations are there between diagnostic stability and sex, age, utilization of care, illness duration and some factors (housing, relations, work, substance abuse, criminality) that can be related to the consequences of the deinstitutionalization process and the reformation of psychiatric care?
- How can the changes in the diagnostic pattern in the cohort over time be described? Which diagnostic categories increase, and which decrease, in the cohort over the period studied?

Material and Methods

The cohort that was followed retrospectively over the period 1984–98 comprised all the 138 patients who received in-patient care during 1984 at a psychiatric rehabilitation clinic in Jönköping, Sweden. The group was characterized by all patients having severe symptoms and/or severe behavioural disturbances and substantial functional reductions, and they could all be designated “severely mentally ill”. The average time from the patients’ first contact with psychiatry to the end of the investigation period in 1998 was 26.3 years (range 15–57 years). Nine of the patients had their first contact with psychiatric in-patient care at the start of the investigation period in 1984. The average number of hospital admissions among the patients for the period 1984–98 was 15.5 (range 1–123).

All of the patients have been followed up for the whole 15-year period. One of the patients moved abroad in 1993, 2 had no contact with psychiatry since 1984, 1 not since 1990 and 36 patients have died. These 40 are excluded from the analysis. The remaining number of patients is thus 98.

During the period, the patients have been classified according to three editions of the ICD classification system: ICD-8 (1965) up to and including 1986, ICD-9 (1987) 1987–96, and ICD-10 from 1997 (the Swedish version went into effect in January that year). This creates problems for the analysis, since the dividing-lines between and the designations of, categories have been partly changed across the editions. Verbal designations are therefore used throughout this article for the categories instead of classification codes (e.g. “schizophrenia” instead of “295” or “F. 20”).

During the period investigated, some patients have moved to other parts of Sweden, mostly to the south. In 1998 approximately 50% of the patients were still living in, or nearby, the town of Jönköping. This means that the patients in the cohort have been treated in different care settings and different psychiatrists have been involved in the diagnostic procedure. Information about diagnoses has been collected by one of the authors from medical records in psychiatric hospitals, out-patient care units, treatment homes and nursing homes, as well as from community-based psychosis teams, treatment units and day care units. By this procedure all psychiatric diagnoses, whenever a change occurred, in any settings, have been collected for all patients over the 15-year period. There was, however, no information in the records on diagnostics reasoning or whether or not any structured interview schedules were used. The empirical data consists of the ICD-codes of principal and subsidiary diagnoses established by psychiatrists in different settings over the studied 15-year period.

In the results section a comparison is also made regarding diagnostic stability for an earlier time period, 1969–83. Thirty of the patients in the cohort had contacts with psychiatry, which led to psychiatric diagnoses, during that 15-year period. The procedure for collecting those psychiatric diagnoses parallels the one described above.

The incidence of co-morbidity across different categories has reached a level that causes problems in longitudinal studies. This phenomenon has

become increasingly common after the introduction of DSM-III (1980) as hierarchical exclusion criteria were reduced and it became feasible to give a patient several contemporaneous diagnoses (McGlashan et al. 2000). According to the instructions in ICD-10 (as in ICD-9), when a patient has more than one diagnosis, one of them should be entered into the patient's medical record as the principal diagnosis and the other/s as subsidiary diagnosis/es. The principal diagnosis is defined as the one referring to the condition for which the patient has mainly been examined and treated and which has demanded the greater part of the healthcare resources utilized. Other significant pathological conditions should be noted as subsidiary diagnoses (ICD-10). Co-morbidity has consequences for analyses and interpretations of diagnostic statistics. There is a risk of the patient being mistakenly apprehended as having one disease at one point in time and another disease at a later point in time, when the fact of the matter is that he or she has got two, or more, diseases simultaneously, that vary in severity over time. An example of this would be a patient that has the simultaneous diagnoses of schizophrenia and alcohol addiction. On some occasions, the alcohol addiction might be the main reason for the patient's being admitted to hospital, and on those occasions that condition would be entered as the principal diagnosis, with schizophrenia as a subsidiary diagnosis. The patient will, however, all along be treated for his/her schizophrenia, that is clinically highly significant. By studying only principal diagnoses one would, in such a case, get a misleading notion of the patient's diagnosed mental disturbances.

To avoid that dual psychiatric diagnoses, merely shifting between principal- and subsidiary diagnosis (as described above), should indicate instability it has been stipulated that the diagnosis most frequently documented as principal diagnosis should be regarded as the principal diagnosis throughout the period of shifting diagnoses. This should make the assessments in the study stricter and they will describe real differences in the interpretations of the clinical manifestations of the patients' problems, translated into diagnostic disease categories, rather than judgements on degrees of severity among simultaneous mental disturbances. By this procedure, it is avoided that the diagnoses will appear less stable than they really are.

A diagnosis is defined as stable when a patient has a diagnosis within the same diagnostic group, but not necessarily within the same diagnostic subcategory, over the 15-year period. Stability regarding diagnostic subcategories will be examined under a separate heading (see below).

In order to calculate the relationship between diagnostic stability, demographic variables, utilization of care and factors related to the reformation of psychiatric care, the χ^2 test was used. In Table 3, the four last variables were calculated by the χ^2 test for trends. The level of significance was set at $p < 0.05$.

Results

All of the patients were subject to psychiatric diagnoses (that is, they received medical care or some kind of support on account of their mental problems)

during the whole investigation period, 1984–98. Fifty-five percent of the patients had unstable diagnoses. There are substantial differences between diagnostic groups, when it comes to instability, as shown in Table 1.

There are also substantial differences regarding frequency of shifts from index to subsequent diagnoses (Table 2). Patients with the index diagnosis unspecified psychosis had the highest frequency of changes. This group of 17 patients had their main diagnosis changed 39 times. The most common subsequent diagnosis was schizophrenia and the diagnosis appeared on 38 occasions. For a majority, i.e. 25 patients, the diagnosis shifted once. Nine patients had their diagnoses shifted twice, 11 patients three times, 5 patients four times, 2 patients five times and the remaining 2 patients had their diagnoses changed six and nine times, respectively. There was no sharp dividing-line between shifts from psychotic to non-psychotic disorders or vice versa. Of the 54 patients who had unstable diagnosis a number of 18 patients shifted between psychotic and non-psychotic disorders. As Table 2 indicates, for some of the patients, the index diagnosis reappeared as a subsequent diagnosis after having had other subsequent diagnoses.

Factors Associated With Unstable Diagnoses

Changes of symptoms, as a factor in the explanation of unstable diagnoses, cannot be determined retrospectively, since the medical records do not provide data of a quality sufficient for reasonable interpretations in that respect. However, the possible existence of associations between diagnostic instability and the utilization of care, sex, age and duration of illness among the patients was investigated. A study was also made of possible

Table 1. Changes in index diagnosis (%)

Diagnoses	Index diagnoses (1984) <i>n</i>	Changes in % 1984–98		
		Men	Women	Total
Schizophrenia	37	24	33	27
Other psychoses				
psychosis NOS	17	100	100	100
affective psychoses	9	33	67	44
organic psychoses	3	100	100	100
reactive psychoses	3	100	100	100
Personality disorders	11	75	100	82
Neurotic disorders	6	100	67	83
Substance-relates disorders	4	33	0	25
Mental retardation*	6	33	–	33
Other*	2	0	–	0
Total	98	51	63	55

*There were no women in these categories.

Table 2. Frequency of shifts from index to subsequent diagnosis

Index diagnosis	Index diagnoses <i>n</i>	SCH	USP	AFP	ORG	REA	PER	NEU	SRD	MER	OTH	Changes <i>n</i>
Schizophrenia (SCH)	37	7	1	7	–	3	4	–	–	1	–	23
Unspecified psychoses (USP)	17	19	2	5	1	4	4	3	–	–	1	39
Affective psychoses (AFP)	9	3	–	1	–	–	–	1	–	–	–	5
Organic psychoses (ORG)	3	2	–	–	1	–	1	–	–	1	1	6
Reactive psychoses (REA)	3	3	1	3	1	3	–	1	–	–	–	12
Personality disorders (PER)	11	1	1	2	–	–	2	2	3	2	1	14
Neurotic disorders (NEU)	6	1	–	2	–	–	2	4	5	–	–	14
Substance-related disorders (SRD)	4	1	–	–	–	–	–	–	–	–	–	1
Mental retardation (MER)	6	1	–	1	–	–	–	–	3	2	–	7
Other (OTH)	2	–	–	–	–	–	–	–	–	–	–	–
Total	98	38	5	21	3	10	13	11	11	6	3	121

associations between diagnostic instability and some factors closely related to the efforts in recent decades to reform psychiatric care and to enhance the quality of life of mentally ill people by increasing their participation in society and by providing a supply of care better adjusted to their needs (Table 3).

A higher level of diagnostic instability in the cohort can be noted for the patients who received care from general psychiatric teams, the patients who had substance abuse as a subsidiary diagnosis and the patients who committed crimes. Advanced age and long-term mental illness of the patients is strongly related to stability of diagnosis.

Diagnostic Stability/Instability Across Diagnostic Subcategories

The changes in diagnosis presented involve changes between disease groups, which is the most basic level in studies of changes in diagnosis or reliability (Sartorius et al. 1995). If you move up one level of specification and study changes between specific subcategories the stability of diagnosis is even lower. At this level 71% of the patients investigated have unstable diagnoses. The 29% ($n = 28$) whose specific diagnosis subcategories are stable constitute a group who in 1998 had received medical care and treatment for, on average, 31.5 years (range 16–55 years). Twenty of these had diagnoses within the schizophrenia spectrum: 12 had the diagnosis undifferentiated schizophrenia, 4 hebephrenic schizophrenia, 2 simple schizophrenia and 2 unspecified schizoaffective disorder. Two had unspecified mental and behavioural disorder due to use of alcohol, 2 had late effects of injury or inflammatory diseases of the brain, 2 Down's syndrome and 2 intellectual disability.

Comparison with the Period 1969–83

Before the start of the reduction in number of in-patient care facilities in Sweden at the beginning of the 1980s, to fall ill with a psychosis meant, in a majority of cases, that the patient was separated from society and would come to spend long periods in a mental hospital. It is, on that account, interesting to compare the results from the investigation period 1984–98 with the period covering the 15 years preceding 1984. During this period, 1969–83, there was no change in the classification system. ICD-8 was used consistently. Thirty of the patients in the cohort also received psychiatric care during this earlier period. Eighteen of them had stable diagnoses. Fifteen of these had schizophrenia diagnoses, 2 affective psychosis diagnoses and 1 a diagnosis of organic psychosis. This means that 40% of the patients had unstable diagnoses over the period 1969–83, which should be compared with the period 1984–98 for the same 30 patients when the instability had decreased and 27% of them had their diagnoses changed.

Table 3. Relationship between diagnostic stability, sex, demographic variables, care utilization and factors related to the consequences of the reformation of psychiatric care. The figures reflect the facts in 1998

Variable	Total (<i>n</i> = 98)	Changes <i>n</i>	Changes %	<i>p</i> -value
Sex				NS
Women	30	19	63	
Men	68	35	51	
Housing conditions				NS
Independent housing	50	28	56	
Other housing	48	26	54	
Living with someone				NS
Yes	10	7	70	
No	88	47	53	
Sees relatives/friends				NS
Yes	76	44	58	
No	22	10	46	
Work/occupation				NS
Yes	34	19	56	
No	64	35	55	
Substance abuse (dual diagnosis)				<0.05
Yes	34	24	71	
No	64	30	47	
Criminality				<0.05
Yes	38	28	74	
No	60	26	43	
Out-patient care				NS
Yes	60	37	62	
No	38	17	45	
Type of out-patient care (60 patients)				NS
Specialist teams	12	7	58.3	
Psychosis teams	21	10	47.6	
General teams	18	14	77.8	
Teams in the community	9	6	66.7	
Care in the community				NS
Yes	53	26	49	
No	45	28	62	
Number of admissions				NS
1	9	5	56	
2–5	26	7	27	
6–10	23	17	74	
11–20	16	11	69	
21–50	19	11	58	
≥51	5	3	60	
Total time of in-patient care (days)				NS
≤200	15	8	53	
201–550	17	10	59	
551–750	17	10	59	
751–1400	16	8	50	

Table 3 (Continued)

Variable	Total (n = 98)	Changes n	Changes %	p-value
1401–2500	17	12	69	
≥2501	16	6	38	
Age				<0.001
30–39	20	16	80	
40–49	40	25	63	
50–59	23	10	44	
60–69	9	2	22	
≥70	6	1	17	
Duration of illness (years)				<0.001
≤16	12	10	83	
17–20	25	18	72	
21–25	18	11	61	
26–30	15	8	53	
31–40	19	6	31	
≥41	9	1	11	

Changes of Diagnostic Patterns in the Period 1984–98

The most stable diagnosis groups were substance-related disorders (75%), schizophrenia (73%) and intellectual disability (66%). The stability percentage for affective psychoses was 55%, for personality disorder 18% and for neurotic disorders 16%. Unspecified psychoses, organic psychoses and reactive psychoses all had 0% stability. Schizophrenia, substance-related disorders and affective psychoses are diagnostic groups that increase in number over the studied period. The schizophrenia group consisted of 37 patients at the start of the period and 32 of these had the same diagnosis in 1998, 27 of these diagnosis having been stable during the whole period. An additional 21 patients with other index diagnoses had the diagnosis schizophrenia in 1998, which makes a total of 53 patients. The period from each of these 21 additional patient's first diagnosis to his or her diagnosis of schizophrenia varies from 1 to 38 years, with an average of 14.0 years. In the group of affective psychoses, the number increased from 9 to 15 patients. Six had the same diagnosis in 1998, 5 of these diagnoses having been stable during the whole period. Nine patients with other index diagnoses were given affective psychosis diagnoses and the period from their first diagnosis to the affective psychosis diagnosis varies from 4 to 26 years, with an average of 14.1 years. The diagnosis group of substance-related disorders had also grown in number, from 4 to 9 patients. Three of these had stable diagnoses. The average time from the additional 6 patients' first diagnosis to substance-related diagnosis was 11.5 years. Finally, it should be mentioned that a new diagnosis group was added during the period, that of Tourette's syndrome. Two patients had this diagnosis in 1998. The distribution of the diagnoses and the number of changes for each year are presented in Table 4.

Stability of Diagnosis Measured in Alternative Ways

There are different ways of studying patterns in changes of diagnoses and of calculating the stability/instability of diagnoses over a period of time, depending on whether the starting point of the calculations is index diagnoses, latest diagnosis or diagnoses that have appeared at least once (Munk-Jørgensen & Mortensen 1992). In this study the index diagnoses were taken as the point of departure; if a different starting point had been taken the results would have been different. If the study had started from the latest diagnosis, that is, the diagnosis that each patient had at the end of the investigation period in 1998, the stability calculated as a percentage would be substantially lower. For the diagnosis group schizophrenia, where 53 patients had this diagnosis in 1998 and 27 of these patients having stable diagnosis, the stability will amount to 51%. For intellectual disability it will be 50%, for affective psychoses 47%, for substance-related disorders 33%, for personality disorder 33% and for neurotic disorders 33%. For the remaining diagnosis groups (reactive psychoses, organic psychoses and unspecified psychoses) the corresponding figure is 0.

With the third method of calculation, the point of departure is diagnoses that have appeared at least once during the period. This approach will result in stability figures that are even smaller. Sixty-one of the patients had at least at one point an episode with the diagnosis schizophrenia. Since 27 of these had a stable schizophrenia diagnosis over the whole period the calculation will be $27/61 \times 100 = 44\%$. For intellectual disability the figure will be 50%, for substance-related disorders 23%, for affective psychoses 21%, for personality disorders 13% and for neurotic disorders 10%.

Discussion

As severe mental disorders are frequently viewed as having life-long endurance, and because psychiatric classification is a controversial issue that is the subject of constant debate (Jablensky 1999, Wakefield 1992), it is of considerable interest to follow the diagnostic development of a group of patients over a long period.

The period studied 1984–98 is, in Sweden, characterized by a fundamental disruption of a more than 200-year period of institutional care and ideology. In the same period diagnostic decision-making, guided by diagnostic criteria regulated by sets of rules, through DSM-III-R and ICD-10, has become of professional interest in Sweden. The deinstitutional process, with a change of locus of care, and a renewed interest in classification matters has altered the significance and power of the diagnostic endeavour. It is therefore of interest, both from a clinical and a theoretical point of view, to make a close investigation of the mobility between different psychiatric diagnoses.

The group under investigation for this study is relatively small, 98 persons, and some of the diagnostic groups are represented by only a few patients, which should be taken into account when interpreting the results. This limits the possibility to make generalized conclusions to other populations. Since

the purpose was to study changes over the whole 15-year period, 40 patients were excluded, in most cases on account of death. The exclusion has probably increased the diagnostic instability due to advanced age and long periods of disease and inpatient care among the excluded patients. The results, however, indicate that there are shortcomings in the prevailing diagnostic systems, and they call for further investigation and replication in other clinical settings.

Forty-five percent of the patients in the study had stable diagnoses. Correlations between stability and studied factors show no clear pattern when it comes to number of in-patient care occasions or length of in-patient care periods. There is an indication of differences in stability of diagnosis between, on the one hand, patients cared for by psychosis and specialist teams and, on the other hand, those cared for by general psychiatric and community-based teams. One explanation of this could be that the patients that are referred to the former teams have had longer periods of disease and therefore more stable diagnoses. Another explanation could be that the specialist teams make more intensive follow-up efforts and have different treatment strategies, compared with the general psychiatric teams, which would contribute to a more stable course of development of symptoms and make diagnoses more stable.

The patients who had substance-related disorders, as subsidiary diagnosis, had less stable diagnoses than the group with no substance abuse problems. This finding is in line with Chen et al. (1998), who propose that substance abuse triggers affective disorder and changes the symptom picture in such patients. That patients who were registered criminals also had more unstable diagnoses could be attributed to the fact that 75% of those in the cohort who committed crimes also had substance abuse problems.

The results agree in some respects with those of some other studies. It should be taken into account, however, that direct comparisons are difficult, due to variations in lengths of period studied, and in investigation populations. The diagnosis group of schizophrenia is, in most studies, shown to be the most stable (Amin et al. 1999, Chen et al. 1996, Daradkeh 1996, Jørgensen & Mortensen 1988, Marneros, Deister & Rodhe 1991, Vetter & Köller 1993). The results concerning other diagnosis groups vary a great deal. The stability for manic disorders, for instance, varies from 14% (25-year observation period) in the study by Marneros et al. (1991) to 91% (3-year observation period) in the study by Amin et al. (1999). Substance-related disorders are excluded from most studies, but was studied by Daradkeh (1996), who reported 71% stability (5-year observation period), and by Amin et al. (1999), who estimated the stability to be 69% (3-year observation period).

The diagnoses in this study thus showed considerable instability and there was frequent mobility between the various diagnostic groups. There is no consensus as to what should be regarded as a "normal" or acceptable degree of mobility. The mobility, however, causes problems when it comes to describing a cohort studied over a long period. Kendell et al. (1993) suggest that all one can do is to arbitrarily choose to start from (i) the first diagnosis given to the patient, (ii) the most frequent diagnosis, or (iii) the latest diagnosis. To start from the first diagnosis has, in recent years, been given

status of being the most reliable and the most scientifically sound approach (Kirch, Keith & Matthews 1992, Preti & Miotto 2000), but the results from this study show that this is not unproblematic. Following the three suggestions given by Kendell et al. (1993) the percentage of, for example, patients with schizophrenia in this study would be either 28 (first diagnosis), or 45 (most frequent diagnosis) or 54 (latest diagnosis).

The introduction of ICD-9 in 1987 had a major impact on the measuring of changes in the group called unspecified psychoses in this study, since this category thereby disappeared. This has above all affected the number of schizophrenia diagnoses. Eleven of the persons had a diagnosis of schizophrenia in 1998. Unspecified psychosis, however, is primarily an interim or "residual" category and it can only be speculated as to how these changes would have appeared if the category had still been there in ICD-9. When ICD-10 was introduced in 1997 the category reappeared and one of the patients under investigation got this diagnosis in 1998, without, however, having had it before. In general, we would make the judgement that ICD-9 and ICD-10 have only had a marginal effect on diagnostic changes.

Time is the factor that can be most closely associated with changes in diagnosis in this study. Long periods of disease and old age are significantly related to more stable diagnoses. It is difficult to determine the correct diagnosis for patients who have recently fallen ill with psychoses, and for a majority of cases there is a failure to fit the symptoms into the categories of the classification systems (Strauss et al. 1979). That diagnoses become more stable in older patients could be attributed to the phenomenon that patients in the course of time learn how to handle their psychotic experiences and that secondary psychological and behavioural reactions decline or the multitude of symptoms decreases as a disease process becomes more uniform. All disease phenomena are integrated parts of a social context, and an often overlooked circumstance is that the patient will eventually adapt to the social construction of the disease and will accept and adapt to the system of care that he or she is involved in. Some classical studies in the 1960s show that the more closed a care environment is, the greater is the compliance with expected behaviour (Goffman 1961). Primary psychopathology, secondary psychological reactions and the social construction of the disorder interact in a complex way and the importance of different specific factors to the course and outcome is difficult to determine. McGorry (1994) reports that the time from first contact with psychiatry till the determining of the schizophrenia diagnosis is 2–3 years in most studies, in some cases up to 5 years. This should be compared with this study where the diagnoses of schizophrenia were determined, for the 21 patients who did not have schizophrenia as index diagnosis, after on average 14.0 years. The corresponding figures were, for affective psychoses 14.1 years and for substance-related disorders 11.5 years.

Since this study is retrospective and the information on changes in symptoms and on what grounds psychiatrists have determined diagnoses is scarce, no certain answers can be given to the question of why diagnoses in a cohort selected from a clinical practice are so unstable. The findings, however, provoke several questions, where answers can be sought on various levels of

explanation. Firstly, answers can be searched for in the complexity of mental disorders, where experiences of mental symptoms find expression in varying ways. Patients recently taken ill often display co-morbid disease pictures, disease courses vary in degree of severity and early symptoms are difficult to detect. Psychiatrists are also often reluctant to make early determinations of diagnoses that have a stigmatizing effect. It can also not be ruled out that spontaneous changes in psychiatric disorders occur. Secondly, explanations could be searched for in the system of classification in itself, where psychiatric disorders often do not represent discrete entities with clear dividing lines between them and where most disorders have symptoms in common. This problem is reflected in the incessant reconsidering of dividing lines and defining of new disease classes (Kendler, Karkowski & Walsh 1998, Kirkpatrick, Buchanan, Ross & Carpenter Jr 2001). The mobility across diagnostic groups also raises theoretical issues as to whether psychoses should be seen as qualitatively separated or as a homogeneous disorder with varying degrees of severity along a continuum (Crow 1995). Thirdly, explanations of the instability could be looked for in problems with regard to classifying mental disorders according to a medical model at all. All models, including the medical model, are abstractions constructed to bring some measure of order and intelligibility to complex realities, and are on that account not necessarily true or false (Lemma 1996). The issue of the applicability of the medical model touches on difficult problems that involve, for instance, providing terms such as “mental health” and “mental disorder” with clear meanings and making assessments of dysfunctions in mental processes on the basis of an often sparse knowledge of the functions of these processes. There is no satisfactory definition of mental disorder and Allen Francis, chairman of the task force of DSM-IV, writes that “it is by no means clear what is mental disorder and whether one can develop a set of definitional criteria to guide inclusionary and exclusionary decisions for the manual” (Francis 1994).

One should have in mind that the classification systems of today (ICD-10 and DSM-IV) have their origin in the asylum era from the end of the 19th and the beginning of the 20th centuries. The knowledge, and classification, of psychiatric disorders are the result of a gradual accumulation of clinical experience made by clinicians, who were also researchers, such as Kraepelin, who in the 1890s coined the concept of dementia praecox, a forerunner to schizophrenia. The categories in DSM and ICD, based on clinical wisdom, are thus founded in clinical observations of recurrent behaviour and emotional manifestations displayed by people in large institutions (Millon 1991).

It is suggested that the transformation of care of patients with psychiatric disorders, from hospitals to community-based alternatives, has implications for the usefulness of current diagnostic practice (Jenkins & Singh 2001). When people with psychiatric disorders largely live their lives in the community, the consequences of the disorders, in the form of social and functional disability, become apparent. The prevailing systems of classification, DSM and ICD, with a focus on symptomatology, have shortcomings when it comes to taking into account the level and distribution of disability in

various populations. Another basis for classifications, that involves the psychological, social and physical environments as well as the person, is *the WHO International Classification of Functioning, Disability and Health* (ICF 2001). This classification manual was published in 2001 and consists of three dimensions grounded in the biopsychosocial model. The dimensions are impairment, activity limitations and participation restrictions and they are conceptualized as an interaction between intrinsic characteristics and the person's social and physical surroundings. This classification manual may have relevance for a classification better adjusted to the demands of community-based psychiatric care.

To sum up: since most of the diagnostic categories are represented by only a few patients the value of making interpretations for each category should not be overestimated. The overall instability of the psychiatric diagnoses is the main finding of the study. The results from this study indicate that the current classification system has obvious shortcomings from an everyday clinical point of view and raise the question of a better adjustment of the system to the various needs of different clinical enterprises. Diagnostic systems that aim at well-defined dividing lines and strict criteria are primarily constructed to underpin reliable diagnoses that suit the requirements of psychiatric research and the development of psychopharmacological drugs. They are far less useful when psychiatric care today is largely provided in smaller community-based settings and the patients need of care and support is formulated in terms of consequences of psychiatric disorders. The boundaries between primary symptoms, secondary psychological reactions, functional reductions and disabilities are not distinct. The information about symptoms become of secondary importance when there is an urgent need for information about impairment, capability to handle everyday living and to participate in social life.

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