STUDIES OF LONG-TERM FUNCTIONAL PSYCHOSIS
IN THREE DIFFERENT AREAS OF STOCKHOLM COUNTY

Per Borgå
Studies of long-term functional psychosis in three different areas of Stockholm County

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Per Borgå, med lic

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ABSTRACT

The object of these studies was to delimit those amongst the total population (18-64 years) suffering from a long-term functional psychosis and to examine their social conditions and care utilisation. Three different but adjacent areas were chosen; rural, suburban and urban with a total of 89,414 inhabitants of whom 57,035 were within the target age group. Few such studies focus upon an almost entire population.

Cases were identified by screening in- and out-patient psychiatric records for the period 10 years prior to and 5 years after the index year (1984). A case register was also used. GPs and social workers were asked to add hitherto undetected cases.

By means of a new diagnostic definition - Long-term Functional Psychosis (LFP) - aimed at identifying people with a history of at least 6 months' psychotic illness and with psychotic or residual symptoms present during the index year, a target population of 341 individuals was identified. This group was mainly suffering from schizophrenia (N=237) as defined by DSM-III but also included bordering conditions (N=104) such as paranoia, affective psychosis and psychotic disorder not elsewhere classified.

Prevalences recorded for both LFP and schizophrenia showed a gradient from the rural to the urban area, the figures being 4.0, 6.2 and 7.9 per 1000 inhabitants for LFP and 3.0, 4.1 and 6.0 for schizophrenia. The prevalence of schizophrenia was higher amongst males whilst the prevalence of paranoia and affective psychosis was higher amongst females.

Living conditions were reasonable regarding economy and housing, 76% having their own flat, but most LFP individuals were unemployed (69%) and over half received disability pension. They were mostly unmarried (57%) and living alone (64%). Nearly half spent time as in-patients during the year and then for such long periods as 5 months on average.

There were increasing levels of hospital care and antipsychotic medication with proximity to city centre. Also duration of illness was correlated to increasing medication.

Outcome, measured both in terms of social conditions and in-patient care, was worse for individuals with schizophrenia compared to other diagnoses, for early age at onset compared to late age at onset and for males compared to females. Males spent twice as long as in-patients as females.

Social outcome was related to all three background variables each per se: gender, age at onset and diagnosis (schizophrenia vs bordering conditions) whilst for length of in-patient care, gender alone was predictive amongst the background variables.
STUDIES OF LONG-TERM FUNCTIONAL PSYCHOSIS
IN THREE DIFFERENT AREAS OF STOCKHOLM COUNTY

Per Borgå
To Suad
Carpe diem (seize the day)

Horatius, 65-8 B.C.
LIST OF PAPERS

This thesis is based on the following five papers which will be referred to in the text by their Roman numerals:


Papers I, III and IV are photocopied by permission of Munksgaard International Publishers, Copenhagen.
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- Summary of paper II - Approaching the true prevalence of long-term functional psychosis
- Summary of paper III - Patterns of care among people with long-term functional psychosis in three different areas of Stockholm County
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INTRODUCTION

The Nacka-Värmdö psychiatric sector, well-known for its innovative development of out-patient services in the 70's (1), in 1984 after a decade of experience, focused its attention on long-term psychotics as a major target group. This was partly a reflection of the planning for deinstitutionalisation, which had started to dominate the psychiatric agenda in Sweden as well as in other Western European Countries. It was also a self-critical acknowledgement, that the out-patient services developed so far poorly met the needs of long-term psychotic patients (2).

Long-term psychotics were clearly at a disadvantage in society. Only exceptions were members of organisations like RSMH\(^1\) which were able to articulate their social and political needs and demands. Organisations for schizophrenics or relatives of schizophrenics, which later grew in number, were at this time only embryonic.

At the Research and Evaluation Unit, originally part of the Nacka-Värmdö Psychiatric Sector and later becoming the independent Psychosocial Research Unit, we saw the need to "give this group a profile" and accordingly planned a survey, intended to be an initial mapping of all long-term psychotics in the catchment area. For the sake of comparison, an inner city working class dominated parish was added to the two municipalities - one rural and one suburban - which formed the catchment area.

With a leaning towards social antropology I was personally opposed to the idea of making a specific diagnosis - schizophrenia - the basis of the study. My notion was that psychiatric diagnoses, bound to western scientific culture, had little relevance as to how people in general perceive their illness or how it is regarded by society. My preconception was that society noted psychotic behaviour, but did little to differentiate between diagnoses. In all societies I was aware of including peasant cultures, there were names for psychotic behaviour. Whilst I believed our society to have a similar overall concept of "mental disease" I doubted the social validity of schizophrenia. Contributing to this view was the sometimes low interrater reliability for schizophrenia even within the scientific community (3).

Another preconception was that it was the duration of the illness rather than the specific psychotic manifestations which shaped the patient's self perception and also society's reaction. It was on this basis that schizophrenia was singled out as the gravest of the functional psychoses. My personal experience was also that quite a few

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1 Swedish National Association for Social and Mental Health.
of the patients at nursing homes, where I had been employed as a consultant for Stockholm County Council, did not have the diagnosis of schizophrenia but rather of affective psychosis, thus contradicting both the view of Kraepelin (4) and of somewhat more modern text-books in psychiatry (5), that the prognosis of affective disorders is generally good with no residual state after the affective episode.

My view was that there was an active interaction between the ill individual and society, including its care organisation, where not even diagnoses could be taken at face value. This interaction could apparently influence the course of illness (6) to the extent that the best prognosis was to be found in developing countries with very tiny psychiatric resources of the same kind as Tanzania, where I had worked earlier.

By making an epidemiologically thorough survey with wide inclusion criteria aiming at the long-term psychotic patients we hoped to get some of these still vaguely formulated questions illuminated. Moreover, such a study would form the basis of further qualitative studies.
BACKGROUND

Schizophrenia and contiguous long-term functional psychoses represent a human suffering of great magnitude. With a lifetime risk of about 1% for schizophrenia (7) and 0.5% at a rough estimate for other long-term functional psychoses, these conditions cannot be said to be rare.

From a personal and family perspective, onset of functional psychosis often means the destruction of a potentially rich life for a young individual and a painful and desperate witnessing of the deterioration by family members. From a care perspective these conditions often lead to numerous years in hospital. From a medical perspective schizophrenia and bordering conditions pose a challenge to the practising psychiatrist with their frequently, but not invariably poor outcome.

**Schizophrenia** has often been singled out for research because it constitutes the most prominent component of long-term functional psychosis and at the same time affects the youngest age group.

**Other functional psychoses** have more rarely been the subject of epidemiological studies. This is mainly due to the low prevalence of these conditions in the population. They have sometimes been included in studies of schizophrenia, often without stating so very openly. They have then been regarded as a "borderline group" and less often studied in their own right. One exception from this general trend is found in the studies emanating from the Camberwell Register 1964-1971 (8) where treated one-year-prevalence of schizophrenia as well as affective psychosis is given as 0.3%. These studies are built on cases recorded by the psychiatric services. Another exception is the Nottingham study (9) also including both schizophrenia and affective psychosis but with a focus on incidence.

Studies attempting to include an *entire population* of schizophrenic or psychotic individuals are rare, most studies being based on admitted cases only. McCreadie (10) in the Nithsdale survey attempted to achieve a better coverage of schizophrenic individuals by including psychiatric out-patient as well as GP services. This rendered a point prevalence of 0.24% and 0.17% when Feighner criteria were applied.

Clear definitions of disorders form the basis of all epidemiological studies. A definition which included other long-term functional psychoses than schizophrenia seemed to be lacking. The terms "long-term" or "chronic" were sometimes used in literature in combination with the term functional psychosis, but without a standardized meaning. These terms often reflected the utilisation of in-patient care (11,12), thus
including an outcome variable in the definition. They were therefore not suitable for use as an instrument apt to follow the process of deinstitutionalisation or to use for comparisons between different societies, as admission praxis could vary with time and geographically.

Studies of *incidence*, the rate with which people fall ill, can spawn further research in etiology. Studies of *prevalence*, the number of ill people in a population during a given time period, are more interesting to health planners but can at the same time reflect how psychiatric care as well as different social conditions influence the course and outcome of the disease.

Questions posed regarding schizophrenia have addressed whether or not the epidemiology is similar in different societies (6,13,14,15), whether it is similar in urban and rural areas (16,17,18) and whether the incidence and prevalence is the same for males as for females (7,18,19).

Whilst Torrey (15) claims differences in prevalence between countries to be significant, Strömgren and the authors of the WHO comparative studies (6,13,14) argue that the focus on incidence reveals that schizophrenia occurs with comparable frequency in different countries. This should be the case especially for schizophrenia with "core symptoms" (6), which is a somewhat restricted definition of schizophrenia. Disparities in prevalence could then result from differences in life expectancy, outcome and other factors.

Studies in the USA and Europe have for a long time indicated higher prevalence of schizophrenia in urban as compared to rural areas. This has been the case especially in slum areas of the big cities and is believed to be connected with a selective migration of healthy individuals from these areas, leaving behind a "residual population" (16,17).

Whilst Lehtinen (7) and Jablensky (18) have argued that there are no gender differences in the prevalence of schizophrenia, Strömgren (19) has claimed that such a difference exists and added that it results from a recent decline in the incidence of female but not male schizophrenia.

*Outcome studies* have used social indicators in combination with care utilization (6,20) or only one of the indicators (21). In comparisons of schizophrenia, schizoaffective psychosis and affective psychosis, schizophrenia has been found to have the gravest outcome and affective psychosis the most favourable whilst schizoaffective
psychosis was said to take an intermediate position (22). In other comparisons (23) paranoia was found to have a more favourable outcome than schizophrenia.

Some studies had pointed to the differences between males and females in the length of hospital stay with males spending longer periods as in-patients (20,21,24), whilst most studies of gender differences in social outcome appeared later, around 1990 or even more recently (25). The worse social outcome for males has often been linked to the earlier age at onset for male schizophrenics, regarded as a globally homogenous trait of the diagnostic entity of schizophrenia (26,27).

The question as to whether duration has an impact on outcome has been a subject for debate. Whilst Kraepelin viewed schizophrenia as a continuously downhill process Manfred Bleuler (28) has pointed to the natural healing process leading to a relatively positive outcome for a considerable proportion of individuals with a schizophrenic disorder. Kolakowska et al (29) found that poor outcome was not associated with duration but with early age at onset. Later contributions to the debate have been made by among others Courtenay Harding et al (30) who showed in the studies of the Vermont area that a majority of people with schizophrenic diagnosis may lead a "full life" after a long illness duration, at least when out-patient support has been adequate.

When planning our research we found no studies comparing outcome of total, discrete geographical populations of schizophrenics or other long-term psychotics as most studies relied solely upon hospital material. In 1989 Davies (31) pointed at the less severe psychopathology among schizophrenic patients in rurally situated nursing homes compared to urban ones and McGlashan (32) in a review of North American long-term follow-up studies had in 1988 concluded that outcome is more favourable in rural settings than in urban ones.
AIMS OF THE STUDIES

The aims were

* to test a new diagnostic concept for long-term functional psychosis (LFP) designed to include individuals with schizophrenia and bordering functional psychoses and exclude organic psychosis

* to study the one-year total prevalence of LFP (18-64 years) and its constituent diagnoses in three different types of geographical area; one rural, one suburban and one urban

* to study outcome and its predictors among LFPs as reflected by social conditions and in-patient care
MATERIAL AND METHODS

Study areas

By choosing three different areas for the studies, we aimed to compare conditions for LFPs in one rural, one suburban and one urban area. As the psychiatric services of the rural and suburban areas were run by one out-patient oriented organisation and the psychiatric services of the urban area by another more traditionally in-patient oriented organisation, there would be also a possibility of comparing the two organisations and their possible influence on LFPs' conditions.

The three areas are rather distinct in character and may well be described as rural, suburban and urban. They border each other, stretching from the outer archipelago to the southern city centre of Stockholm. The total population in 1984 was 89,414 inhabitants (33). In the studied age group 18-64 years the number was 57,035. Population distribution according to area type and gender is shown in table 1.

Table 1. The population of the catchment areas aged 18-64 years according to gender and area type.

<table>
<thead>
<tr>
<th></th>
<th>Rural</th>
<th>Suburban</th>
<th>Urban</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>5.676</td>
<td>18.781</td>
<td>4.015</td>
<td>28.472</td>
</tr>
<tr>
<td>Total</td>
<td>11.869</td>
<td>37.202</td>
<td>7.964</td>
<td>57.035</td>
</tr>
</tbody>
</table>

The majority of the people in the rural municipality live on a few large islands in the Stockholm archipelago but the area also includes smaller, more distant islands. Whilst the municipal centre with about half of the population is only a half-hour car or bus journey from Stockholm, reaching the smaller islands may take several hours. In winter time some of the islands are only accessible by helicopter. Some of the residents of the municipality are employed in the city of Stockholm, whilst others work for local companies, the largest of which is a china factory. Employees of social services and local government, self-employed craftsmen and fishermen make up the rest of the working population.

The suburban municipality is to a greater extent part of the greater Stockholm area (Storstockholm) regarding communications and economy. All the parts of the municipality are within a half-hour journey of the city centre of Stockholm. Residential
areas consist partly of low status blocks of flats and partly of areas dominated by detached houses. Some areas are characterized by old buildings, others by new developments.

Psychiatric services for the rural and the suburban municipality are part of the same organisation, and are characterized by an emphasis on out-patient services and a low hospital bed/population ratio. This clinic has been a strong advocate of community psychiatry since its start in 1974.

The *urban parish* is a low status, former working-class residential area consisting of blocks of flats. Although parts of it had started to be rebuilt at the time of this study, in 1984 43% of the flats consisted of only one room and kitchen. The psychiatric services of this parish belonged to a more "traditionally" oriented organisation with a high hospital bed/population ratio. In-patient wards were located both at a general hospital in the southern city centre and at a somewhat more distant mental hospital.

Some sociodemographic characteristics of the three areas are summarized in table 2 (33,34).

**Table 2. Sociodemographic conditions amongst the general population in the three different subareas of the study (1984)**

<table>
<thead>
<tr>
<th></th>
<th>Rural</th>
<th>Suburban</th>
<th>Urban</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median age (years)</td>
<td>35</td>
<td>33</td>
<td>37</td>
</tr>
<tr>
<td>Marital status %</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unmarried</td>
<td>31</td>
<td>33</td>
<td>50</td>
</tr>
<tr>
<td>Married</td>
<td>56</td>
<td>53</td>
<td>28</td>
</tr>
<tr>
<td>Divorced</td>
<td>11</td>
<td>12</td>
<td>14</td>
</tr>
<tr>
<td>Widowed</td>
<td>2</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Living alone %</td>
<td>14</td>
<td>16</td>
<td>42</td>
</tr>
<tr>
<td>Unemployed %</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16-24 years</td>
<td>6</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>25-64 years</td>
<td>2</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Immigrant background %</td>
<td>13</td>
<td>15</td>
<td>11</td>
</tr>
<tr>
<td>Migration in/year %</td>
<td>9</td>
<td>11</td>
<td>23</td>
</tr>
<tr>
<td>Migration out/year %</td>
<td>9</td>
<td>11</td>
<td>16</td>
</tr>
<tr>
<td>Mean income SEK</td>
<td>78.700</td>
<td>90.800</td>
<td>83.900</td>
</tr>
<tr>
<td>Sick leave (mean days/year)</td>
<td>19</td>
<td>18</td>
<td>20</td>
</tr>
<tr>
<td>Disability pension %</td>
<td>4.5</td>
<td>4.6</td>
<td>6.5</td>
</tr>
</tbody>
</table>
Identifying the LFP population

Psychiatric in- and out-patient services of all kinds were screened and patients included irrespective of whether or not there was a current psychiatric contact during the index year. For the psychiatric service organisation covering the rural and suburban sector a psychiatric register had been maintained (35). This covered a period of 10 years prior to the index year with 5,313 patients registered. In 1984, chosen as the index year, this register covered 6,227 medical records as it also included those visits to psychiatric clinics outside the psychiatric sector (but only within Stockholm county council). Each case registration included a diagnostic assessment by the clinician in charge.

The medical records of all those with psychotic or affective disorders and those diagnosed as borderline personality disorders were rediagnosed according to the LFP concept and later according to DSM-III, as were all those where an admission had been necessitated.

As no case register existed for the psychiatric sector covering the urban area all medical records here (approximately 750) had to be screened manually. In addition, enquiries were made regarding the whole of the catchment area with the following organisations/institutions serving Stockholm county council:
- Nursing homes
- Foster homes
- Special psychiatric clinics for criminal offenders
- A private psychiatric clinic run by the diocese
- A specialist clinic for alcohol and drug abusers.

Whenever there was a suspicion that LFP-criteria might be fulfilled a newly constructed register form was completed. This demanded that some background information be collected from the patient's record before an assessment was made as to the LFP diagnosis. The identification of the target population is illustrated in figure 1.

The original study carried out in 1985-86 was complemented by a study in 1989-90, reflecting on conditions in 1984. This study used as informants GPs, district nurses at primary health-care centres and social workers active in the catchment area. As these had already been interviewed in the original study regarding identified cases they were aware of the target population. They were now asked to add cases they knew of and to render information about these individuals. Whenever there was a suspicion that the individual might fulfill LFP criteria the interview was recorded in writing. A
retrospective screening was carried out taking account of the observation made by Ödegaard (36) that not all schizophrenic patients will immediately - but after various time lapses - report to psychiatric services. This aimed at including cases who had got into contact with psychiatric services after 1984 although according to history they fulfilled criteria for inclusion at the end of 1984.

**Definition of long-term functional psychosis (LFP)**

For the articles on which this thesis has been based long-term functional psychosis has been defined as

- having been affected by a psychosis not caused by organic disease for a continuous period of at least 6 months at some time during the person's lifetime

- having shown psychotic features or residual symptoms during the index year (1984).

As "residual" is defined in DSM-III only in connection with schizophrenia, while in major affective disorder a condition with some signs of the disorder that do not meet the full criteria is considered as being "in remission", a diagnosis neutral definition of "residual" covering different psychotic conditions in a similar way was created.

"Residual" is thus used if there is

- at least one previous episode fulfilling the criteria for LFP

- a clinical picture without any prominent psychotic symptoms that occasioned evaluation or admission to clinical care; and

- continuing socially significant evidence of the (psychotic) illness.

The assessment was normally made from medical records and case register information. The persistence of psychotic or residual symptoms was crucial to inclusion. If only affective symptoms were present in 1984 the individual would not be regarded an LFP even if he fulfilled the criteria of having had a previous history of psychotic illness of 6 months' duration.

If deemed necessary the psychiatrist responsible, or other psychiatric staff, was interviewed. Clinical diagnoses were never taken at face value. The LFP-diagnosis was made on a 5-point probability scale answering the question whether the individual fulfilled the LFP criteria in 1984. The answers "yes" and "probably" led to inclusion whilst the other three options were excluded. (Prior to this, the option "don't know" led to further collecting of information to enable - if possible - a more securely anchored answer.) When no medical records were available, as with some cases in the
complementary study, the written interview with social workers formed the basis of the evaluation.

**Reliability of LFP concept**

Separate reliability tests were made for the original study and the complementary study. In the first case a weighted but randomised sample of 30 was selected with 20 cases belonging to the LFP-group and 10 not belonging. The composition of the sample reflected both the diagnostic difficulty on the probability scale and the prevalent diagnoses.

The original diagnosis was made by P.B. The co-rater was an independent expert on the DSM-III classification.

The reliability test for the complementary study was performed in a similar way with 15 cases belonging to the LFP group and 5 not belonging, drawn at random.

The proportion of the LFP to the non-LFP group was unknown to the co-rater.

The interrater reliability was assessed by kappa ($\kappa$) which measures the proportion of concordance between two independent raters when the concordance by chance is subtracted (37). In the first test the interrater reliability was $\kappa=0.93$ and in the second $\kappa=0.88$ for LFP diagnosis. In each test there was only a one case discrepancy.

**Table 3. The 'total' LFP population in three different areas according to gender and area type**

<table>
<thead>
<tr>
<th></th>
<th>Rural</th>
<th>Suburban</th>
<th>Urban</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>31</td>
<td>112</td>
<td>30</td>
<td>173</td>
</tr>
<tr>
<td>Females</td>
<td>17</td>
<td>118</td>
<td>33</td>
<td>168</td>
</tr>
<tr>
<td>Total</td>
<td>48</td>
<td>230</td>
<td>63</td>
<td>341</td>
</tr>
</tbody>
</table>
DSM-III diagnosis

The DSM-III manual was applied in diagnosing the LFP individuals in a second step. Taking into account the duration of 6 months and that organic psychosis was excluded, possible diagnostic categories for the LFP group were: schizophrenic disorder, paranoia, affective psychosis and psychotic disorder not elsewhere classified (PNEC). There was a small discrepancy in our judgements as compared to DSM-III as 'residual' cases could theoretically be considered for the diagnosis of affective psychosis (or paranoia) whereas they might have been judged as "in remission" according to DSM-III. The concept "residual", however, was only used in relation to a psychotic illness, and not in relation to an affective disorder without psychotic symptoms. When different diagnoses of psychosis could be made during the index year the latest one was chosen. Interrater reliability assessments were performed in connection with the LFP interrater test referred to above. Interrater reliability figures were $\kappa=0.74$ for the original study and $\kappa=0.66$ for the complementary study respectively.

Data collection

The sources of information for social and care variables were
- Case register form - (rural and suburban only)
- Psychiatric records - (in- and out-patient services)
- The parish office - national registration data
- General insurance system - information on sick leave and disability pension
- Municipality, social workers
- Primary health care, general practitioners, district nurses
- Stockholm County Council - computerized care data from in-patient services.

A form was constructed for manually recording the information (figure 2). In order to attain uniformity of data a manual was written to facilitate the completion of the register form. A manual was also devised for "translating" daily dosages of different antipsychotic drugs into the equivalent amount of chlorpromazine on the basis of studies by Axelsson & Öhman (38) and Wyatt & Torgow (39).
Quality of data

Three pilot studies were carried out prior to deciding the design of the register form to find out which data was readily available.

Some data is unequivocal whilst some is the result of assessments. The reliability of the latter is more open to debate. As this was basically an epidemiological study, it seemed important to adhere to diagnostic criteria and a strict definition of residency.

Neither the LFP nor the DSM-III diagnosis is based on the researchers interviewing the patients but rather on medical records or on an interview about the patient.
Figure 2. Two pages of the register form.
However, symptoms regarding possible psychosis belong to the kind of data regularly noted in psychiatric records. Exceptions were to some extent patients who had a long illness duration where psychiatric records sometimes were very meagre. In these cases, surrounding conditions gave an indication as to the state of the patient; changes in prescribed medication, ability to work etc. Informants were often well acquainted with the patients. At the same time they were not specialists in assessing psychiatric conditions. Information by non-professionals ought probably to be viewed with somewhat more caution than psychiatric records. The results of reliability tests were however high for the LFP diagnosis in both the original and complementary study and satisfactory for the DSM-III diagnosis.

The Axis II diagnosis of personality disorder was difficult to attain on psychiatric record data alone. Although originally included in the form it was henceforth deleted.

In the complementary study there were some quite diverging views regarding residency. In the urban subarea there seems to be a group of people with substance abuse problems and occasional psychotic symptoms, who have an affiliation to the area without being registered there. They were thus reported by social workers to be living in the area whilst they were in fact registered at an address in another part of the county. One reason for this may be the character of the area, whilst another factor that they might have been attracted to the specialist group of social workers working there. In order to avoid counting people twice it was decided that legal registration would be the criterion for deciding residency. This afforded a good level of reliability. If individuals were actually living in the urban area although registered somewhere else, the validity could be said to be low.

The completeness of the target population is probably higher in the rural and suburban areas as we had the benefit of a case register for these areas. The drop-out percentage for this case register has been calculated to be between 3-5% (1). To estimate the drop-out rate for the urban area is more difficult, as the method here was less standardised (collecting all available patient files).

In the area covered by the case register as well as in the urban area, it is more difficult to estimate the number of omitted cases who have not been in contact with psychiatric services although fulfilling LFP criteria in 1984. As such cases were actively sought after and added to over a period of several years, personal experience was gained of the diminishing speed with which hitherto unknown cases were detected. Ways to prevent leakage are described in paper II. A rough guess is that probably 10 and maximally 30 cases have remained undetected.
Data in psychiatric records was sometimes judged not to render sufficient information. This was the case in the earlier mentioned Axis II diagnosis. Also, side effects of drugs were noted in the records showing a much lower frequency (17%) than would normally be expected. It was thus not believed to reflect the real prevalence and therefore not used in the study.

If information in medical records sometimes was questionable, official register data in Sweden generally has a high reliability. The two examples given below contradict this general picture: severe abuse of alcohol and narcotics seems to be recorded in the psychiatric records with high accuracy for this patient group. When screening the files of the special clinic for treatment of abusers, only one case was detected where the abuse was not already noted in psychiatric records.

In the complementary study, made in 1989, it was difficult to obtain reliable sick leave figures for 1984. As the system was not computerised, figures had to be looked for manually by the employees at each office. There was no way of checking on the reliability, but the figures given were astonishingly low. In table 4 some examples are given of good and poor (or questionable) reliability.

Table 4. Examples of variables of presumed high and low reliability respectively

<table>
<thead>
<tr>
<th>Presumed or confirmed high reliability</th>
<th>Questionable or low reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td>LFP diagnosis</td>
<td>Axis II-diagnosis</td>
</tr>
<tr>
<td>Axis I diagnosis</td>
<td>Side effects of drugs</td>
</tr>
<tr>
<td>Age</td>
<td>Sick days (complementary study)</td>
</tr>
<tr>
<td>Area of living</td>
<td>Receiving home care</td>
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<tr>
<td>Marital status</td>
<td></td>
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<tr>
<td>Co-habitation</td>
<td></td>
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<tr>
<td>In-patient care</td>
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<tr>
<td>Disability pension</td>
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<tr>
<td>Prescribed medication</td>
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<tr>
<td>Taxated income</td>
<td></td>
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<tr>
<td>Contacts with GP</td>
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<tr>
<td>Contacts with social welfare office</td>
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</table>

The frequency of missing data was generally very low, especially with regard to essential variables (0-5%).

The analysis of the results brought the background variables diagnosis, sex and age at onset into focus as they all have a strong influence on outcome. Whilst the diagnosis
arrived at has been subject to a reliability test and sex could be taken at face value, one would have wished that some more time had been devoted in planning how to record age at onset. In the present study age at onset is linked to an established diagnosis of psychosis. This moment is later in the career of developing a LFP than the first appearance of symptoms and often later than the first admission. It would have been desirable to have tested different ways of recording onset and made the method chosen subject to a reliability test. However, there are no indications that the later onset indicator (diagnosis of psychosis) used in our study is less reliable or is correlated in a systematic way with other significant variables investigated.

**Statistical methods**

Prevalence figures were calculated on the basis of official census records of the population of each subarea for 1984 (33). Wherever the data fulfilled statistical assumptions, pairwise double-sided tests for proportional differences were carried out (Paper I and II). For the LFP and DSM-III diagnoses interrater reliability tests were performed using kappa (37). (See Reliability of LFP concept, page 22.).

The study population (N=302 or N=341) was divided into subgroups according to sex, diagnosis, living area, age at onset of illness, illness duration, presence of substance abuse during the index year and presence of psychiatric in- or out-patient treatment during the index year. Care variables (Paper III) and social variables (Paper IV) were tested using statistical analysis of the SAS computer programme (40) consisting of chisquare, correlation analysis, non-parametric oneway analysis of variance and the Wilcoxon rank sum test. P-values less than 0.05 were considered statistically significant.

A social disability index (SDI) was constructed on six different social outcome variables according to $\text{SDI} = \sum \frac{\text{yes}}{6} \times 100$ and tested according to the background variables sex, age at onset and diagnosis (Paper V).

Possible confounding effects were simultaneously controlled for, using Cochran-Mantel-Haenszel statistics or multivariate analysis of variance (Paper IV and V).
REVIEW OF PAPERS

Summary of paper I - Epidemiology of long-term functional psychosis in three different areas in Stockholm County

The aims of this paper were to
- introduce and test a new diagnostic concept, long-term functional psychosis (LFP), in epidemiological studies of psychosis.
- study the one-year prevalence of LFP in one rural, one suburban and one urban area in Stockholm county.
- illucidate differences in one-year prevalence according to subdiagnosis, gender and age in the three areas.

By screening all individuals in the population who had been in contact with the psychiatric care organisation, including all kinds of in- and out-patient services, during a 10 year period prior to the study, 302 individuals were identified as fulfilling the LFP criteria.

The LFP concept proved reliable, interrater reliability being \( \kappa = 0.93 \).

One year prevalence of LFP showed a gradient from the rural to the urban area with 3.4, 5.6 and 6.6 individuals per 1000 inhabitants in the studied age group, as did the one year prevalence of schizophrenia, with 2.6, 3.8 and 5.0 per 1000 inhabitants respectively.

Further analysis showed that the rural-urban gradient was more pronounced amongst females in the population, whilst for males differences did not reach the level of statistical significance. The high prevalence in the oldest age group in the urban area indicates a possibility of the existence of a "residual population" of ill individuals whilst there has been a selective migration of healthy individuals.
Summary of paper II - Approaching the true prevalence of long-term functional psychosis

By availing itself of information from the social institutions most likely to be in contact with psychotics, this study aimed at identifying all LFP 18-64 years, irrespective of their contact with psychiatric services in the three study areas. Thereby cases less known to psychiatric services would be given a profile and the 'true' one-year prevalence of LFP would be approached.

The aim was also to use the epidemiologically defined population to answer the question as to whether schizophrenia is more prevalent amongst males than females and to study the prevalence of other diagnoses covered by the LFP concept according to gender.

The methodology used was case finding through
(a) interviewing GPs and social workers at all GP clinics and social welfare offices
(b) screening psychiatric institutions five years after the initial study with the view of detecting cases, which fulfilled LFP criteria in 1984, although they at that time had not established a psychiatric contact.

In addition to the LFP population identified in the study referred to in Paper I, 39 new cases were found, adding on average 0.7 cases per 1000 inhabitants to the recorded one-year prevalence. Reasons as to why they had not been included in the original study which screened psychiatric services varied, but 27 out of the 39 cases had had no psychiatric contact during the index year. It was judged that a few cases remain undetected even in a thorough screening. However, the recorded figures were considered to be a good approximation of "true prevalence".

The study shed light upon the fact that some LFP individuals actively avoid contact with psychiatric services, and the ways in which they do this.

An even steeper gradient of one year LFP prevalence as compared to the results in paper I was recorded in the rural, suburban and urban areas: 4.0, 6.2 and 7.9 cases per 1000 inhabitants. Corresponding figures for schizophrenia were 3.0, 4.1 and 6.0.

Schizophrenia was more prevalent amongst males in all three regions and to a significant level in the total population. Paranoia and affective psychosis within the LFP concept was significantly more prevalent among females.
Summary of paper III - Patterns of care among people with long-term functional psychosis in three different areas of Stockholm County

This study aimed at
- comprehensively describing all care given to an epidemiologically defined population (N=302) of LFP individuals
- comparing care utilisation in subgroups according to gender, diagnosis, type of housing area, illness duration and age at onset.

Information about the care situation and social welfare contacts during the year of investigation was recorded from psychiatric patient files, official municipal records and computerized data on in-patient care from Stockholm County. Social workers were interviewed about the extent of contact with identified LFP individuals as were GPs. Medical records at primary health care departments were screened and all out-patient visits recorded. Psychiatric patient records were screened and types of psychopharmacai prescribed were recorded. Medication with antipsychotic drugs were recalculated into equivalent daily dosages of Chlorpromazine.

**In-patient care and out-patient contacts**

Nearly half (48%) of LFP individuals were admitted to psychiatric care during the index year. Admitted patients spent an average of 5 months as in-patients. Mean number of in-patient days for all LFP was 75. 21% experienced some form of involuntary inpatient treatment. 2/3 had a psychiatric out-patient contact, 1/3 had a social welfare contact. Levels of somatic out- and in-patient care were low. There was a gradient with increasing levels of in-patient care towards the urban area. This may be a reflection of the type of care organisation as well as of the area type, the psychiatric organisation serving the suburban and rural area being more out-patient oriented.

Comparisons were made between sexes, diagnoses, type of living area and illness duration categories. Men spent twice as long on average as in-patients compared to women in spite of a similar admission rate. LFP with a diagnosis of schizophrenia were hospitalised for a longer time on average than paranoid and affectively psychotic patients and those with early age at onset spent more time as in-patients than those with later onset.

**Medication**

75% received various forms of antipsychotic medication with a median daily dosage of Chlorpromazine 273 mg. Levels of antipsychotic drugs were higher in the urban area. Individuals had increasing levels of antipsychotic drugs with illness duration and increasing probability of being on depot medication.
Summary of paper IV - Social conditions in a total population with long-term functional psychosis in three different areas of Stockholm County

The aim of this study was to
- describe social conditions as reflected by marital status, cohabitation, housing, income, employment, sick leave and disability pension for an epidemiologically defined 'total' population of LFP (N=341).
- to compare social conditions in subgroups according to gender, diagnosis, type of housing area, age at onset, illness duration, presence of substance abuse and presence of psychiatric treatment contact.

Available register data, from the case register, patient records, municipality, parish and General insurance system as described in 'Material and methods' was used to reflect social conditions.

LFP individuals were mostly unmarried (57%) and living alone (64%). Most were unemployed (69%) and over half received a disability pension. Declared income was on average low, 54,000 SEK (9,000 USD). 76% however, had their own flat.

Social conditions varied considerably according to the mentioned subgroups as summarised in table 5, where + indicates a statistically significant difference in relation to the variable mentioned.

Table 5. Significant differences of social conditions according to sex, diagnosis, area type, age at onset, duration, presence of substance abuse and presence of treatment contact during index year. (Controlled for confounding factors.)

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Diagnosis</th>
<th>Area type</th>
<th>Age at onset</th>
<th>Duration</th>
<th>Abuse</th>
<th>Treatment contact</th>
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<td>+</td>
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<tr>
<th>Cohabitation</th>
<th>Diagnosis</th>
<th>Area type</th>
<th>Age at onset</th>
<th>Duration</th>
<th>Abuse</th>
<th>Treatment contact</th>
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<tr>
<th>Housing</th>
<th>Diagnosis</th>
<th>Area type</th>
<th>Age at onset</th>
<th>Duration</th>
<th>Abuse</th>
<th>Treatment contact</th>
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<th>Diagnosis</th>
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<th>Age at onset</th>
<th>Duration</th>
<th>Abuse</th>
<th>Treatment contact</th>
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<th>Income</th>
<th>Diagnosis</th>
<th>Area type</th>
<th>Age at onset</th>
<th>Duration</th>
<th>Abuse</th>
<th>Treatment contact</th>
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<tr>
<th>Disability pension</th>
<th>Diagnosis</th>
<th>Area type</th>
<th>Age at onset</th>
<th>Duration</th>
<th>Abuse</th>
<th>Treatment contact</th>
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<tr>
<th>Sickdays/year</th>
<th>Diagnosis</th>
<th>Area type</th>
<th>Age at onset</th>
<th>Duration</th>
<th>Abuse</th>
<th>Treatment contact</th>
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Sex
Females enjoyed in all respects significantly better social conditions compared to males except regarding sick leave (where there was no difference) and income where men had a significantly higher income, if controlled for diagnosis as a confounding factor (more men being schizophrenic).

Diagnosis
In all respects the diagnosis of schizophrenia predicted a significantly worse social condition than paranoia and affective psychosis, except regarding housing, income and sick-leave where primarily recorded significance was at least partly due to an uneven distribution of age at onset or sex categories across diagnostic groups. There are no marked differences between paranoid and affectively ill.

Area type
It is more common to live with a relative in the rural municipality and in an institution in the urban one. Unemployment is higher in the urban area whilst employment on the open market is relatively more common in the two other areas.

Age at onset
Later onset as measured by first psychosis diagnosis indicates a more favourable outcome in areas of matrimony, cohabitation, housing and disability pension.

Illness duration
With increased illness duration unemployment increases as does disability pension.

Substance abuse
Alcohol and narcotic abuse in the LFP population increases the likelihood of being unmarried, unemployed and not having one's own housing.

Psychiatric treatment contact
20% had no psychiatric contact during the year of investigation. The lack of a psychiatric treatment contact during the index year not surprisingly indicates a higher likelihood of having one's own housing (institutionalised individuals being in the other group). No psychiatric treatment contact also decreases the likelihood of disability pension and number of days on sick leave.

To summarise the results point to the strong influence on social outcome of sex and age at onset not disregarding the influence of diagnosis. (Other background factors have a more restricted influence on certain areas of social life.)
Summary of paper V - The effect of gender and age at onset on outcome in an epidemiologically based population with schizophrenic and non-schizophrenia long-term functional psychosis

It has been argued that the poorer outcome for male schizophrenia as compared to female should be viewed in the light of earlier onset of male schizophrenia.

The aims of this study were
- to study outcome - as measured by social variables and degree of in-patient care - in an epidemiologically based 'total' population of long-term functional psychotics
- to test how differences in outcome could be accounted for by gender, age at onset and diagnosis.

To evaluate a possible link between the diagnosis of schizophrenia and gender differences, the material supplied a study population of 237 schizophrenics as well as a control group (N=104) of individuals with other long-term functional psychoses.

There was a gender difference in age at onset both for schizophrenic LFP (27 years for males versus 28 years for females) and for non-schizophrenic LFP (31 years for males versus 35 years for females), but a statistical significance was only reached for the total LFP population (p=.004). The age for first diagnosis of psychosis was chosen as age at onset.

Six different social conditions indicating poor outcome; never married, living alone, lack of housing, unemployed, income below median, disability pension were used in a dichotomized way (1=yes, 0=no) as outcome variables. On the basis of these six factors a social disability index ranging from 0 to 100 was constructed. A further outcome factor was in-patient days during the index year.

Results show a nearly uniform pattern with females faring better than males. The pattern is not specific to schizophrenia but on the contrary applies also to non-schizophrenic LFP.

Non-schizophrenic LFP generally fare better than schizophrenics and those with late age at onset fare better than those with early age at onset. This is specially pronounced with age at onset after 30 years.

An examination of a conceivable interaction between gender, diagnosis and age at onset, shows that each of these variables - independent of each other - has a
significant relation to social outcome. The pattern does not change when controlled for confounding effects from present age, type of housing area, illness duration and alcohol or drug abuse.

*In-patient* care is significantly related to gender. Differences between diagnostic groups and age at onset groups are at least partly an effect of an uneven gender distribution in age at onset and diagnostic categories, i.e. more males belong to the early age at onset and schizophrenic categories. A positive correlation exists between poor social outcome and level of in-patient care when the three background variables (gender, age at onset and diagnosis) are controlled for.
GENERAL DISCUSSION

The overall aims of the studies were to test the new diagnostic concept of long-term functional psychosis (LFP), to study its prevalence and the prevalence of DSM-III diagnoses covered by the concept. Furthermore the aims were to study social and care conditions as well as predictors of outcome (see Aims of the studies, page 16).

The LFP concept and the 'group of schizophrenias'

The LFP concept was designed to correspond, in a scientifically defined way, to a popular concept of "mental disorder". It was hoped that, by being less detailed in symptomatological description, it would be a more robust instrument and easier to handle in the process of deinstitutionalisation, where the involvement of non-psychiatric staff would be essential. There was of course also an interest in seeing how the new concept related to clinically established diagnoses.

The reliability of the LFP concept was high both when applied to psychiatric records (Paper I) or when applied to more mixed material including second hand descriptions by social workers (Paper II). Reliability was found to be higher than for the DSM-III diagnoses. The concept's borders are evidently well defined and demarcated. It was easy to describe in contacts with social workers, who were in fairly good agreement regarding the evaluation of their clients (Paper I), better in fact than the GP:s.

Jablensky (18) criticized the fact that in European studies, schizophrenia has been conceptualized as a nosologic entity and has as a rule in epidemiological studies been limited by too narrow margins, thereby excluding cases "which, in the light of more recent genetic studies, belong to the wider spectrum of schizophrenic disease". He points out that Eugen Bleuler already viewed schizophrenia as a group of disorders, "die Gruppe der Schizophrenien" (41). In our study, by applying the LFP concept in a first step and the DSM-III diagnosis in a second, schizophrenia has been delineated with a broad margin (figure 3).

The same interest has been directed to the margin as to the centre of this concept, thereby diminishing the risk of omitting false negatives. This procedure is likely to give a more accurate (and higher) prevalence of DSM-III schizophrenia.
It is obvious to any clinician, that a patient first diagnosed as paranoid can later fulfill the criteria of schizophrenia. Paranoia can then be viewed as an early stage in an illness course sometimes leading to schizophrenia. According to Strömgren (19) the male-female difference in schizophrenia incidence is due to decreasing rates for females. Females, having a later onset, are more likely to be diagnosed as paranoid. Der et al (42) show a decrease in both male and female incidence of schizophrenia and paranoia grouped together by analysing admission figures from 1970 and onwards, but more pronounced for females. Their material ought to be reanalysed with the diagnoses separated to reveal if they to some extent are communicating vessels. There is so far no clear explanation as to a possible recent decline in incidence, although different suggestions have been made. Strömgren takes up a dynamic aspect in the fulfillment of different diagnostic criteria. According to this view, if diagnostic criteria for schizophrenia are not at once fulfilled in a psychotic process, paranoia can be viewed as a diagnosis en route or as a more favourable outcome of a LFP-disorder than schizophrenia (figure 4). This is also in accordance with viewing schizophrenia as a stress-diathesis vulnerability disorder.
Figure 4. More favourable (a) and less favourable (b) course of a LFP disorder.

The diagnosis in itself would then be one aspect of outcome.

Whether it is possible to view long-term *affective psychosis* in the same way, as a more favourable stage or outcome than schizophrenia, but belonging to the same spectrum, is more debatable but should not be ruled out. As Strauss states (43) in a recent issue of British Journal of Psychiatry: "...structured approaches demonstrated how poorly real people often fit our categories." In the same issue Zubin et al (44) indicate a possible connection between relapse in schizophrenia and affective disorder.

In social and care outcome variables there are no marked differences between paranoid and affectively ill LFP. Before the introduction of DSM-III with its more restricted criteria for schizoaffective psychosis, many of these cases would have been given that diagnosis. The 6 months criterium obviously delimits the most severe part of the affective psychosis. In our studies no analysis is made of all affective psychoses, including those outside the LFP criteria. Such data, however, is available from the Camberwell studies (8). Our prevalence figures compared with the Camberwell ones indicate that the whole group with affective psychosis is approximately 7 times larger than the group delimited by the LFP criteria calculated on one-year prevalence. Less than 10% of those with affective psychosis in Camberwell belonged to the "new long-stay" (treated for more than 12 months) patients admitted between 1965-70 to the Camberwell in-patient services. In fact for patients over 45 the typical "new long-stay" patient was a woman with affective psychosis. This shows that in spite of optimistic textbook views on the prognosis of affective disorder, in clinical practice there has long been an awareness that some
affectively ill patients do not recover swiftly and without sequelae. Probably the old text-book view is still influencing DSM-III in not acknowledging "residual" cases for affective disorder as for schizophrenia.

The heterogenous group of *Psychotic disorder not elsewhere classified* has seldom been included in studies of this kind, although a few of the cases fulfill criteria for schizoaffective disorder (DSM-III). Care and social outcome clearly indicate that there are reasons for including these 2-3 cases per 10,000 in a diagnostic concept intended to define those patients most in need of our attention.

Apart from the advantages of the LFP concept pointed out above, its usefulness can also be seen in providing a psychotic reference group for the DSM-III schizophrenics, using the same time criterion as for schizophrenia itself (Paper V), but allowing a different psychotic symptomatology.

**Epidemiology**

One criticism that can be voiced against the presented method is that the diagnostic evaluation has been based on second-hand material and not on clinical interviews. The drop-out rate from clinical interviews would however have been considerable in a population of LFP, many of whom have chosen not to have contact with psychiatric services. The disadvantages of screening total and unselected general populations through clinical interviews have been discussed in Paper II. It is therefore believed that a better coverage of the LFP population of a geographical area is achieved by using institutions and informants from different social services, including social workers and that fairly reliable diagnostic assessments can be made on this basis.

The prevalence figures reached at in our studies confirm that different societies have different prevalences of schizophrenia and bordering conditions (45), and that inner city areas have a higher prevalence than the surrounding districts (16,17,18).

In our studies a two-step gradient is observable from the rural to the suburban area and from the suburban to the urban area (Paper II), significant differences being recorded alternately for total LFP and for schizophrenia. The non-schizophrenic LFP only contributes to the first (rural-suburban) but not to the second (suburban-urban) step of this gradient, the explanation being that paranoid cases are most prevalent in the suburban area and not in the city centre.

The casual mechanisms behind the findings of increasing LFP and schizophrenia prevalence towards the city centre have not been addressed by our studies. Migration
of sick individuals to the city centre and selective migration of healthy individuals from the city centre has been suggested as explanations for similar findings (17). The urban area in the present studies is of a similar character to that of Freeman and Alpert referred to above; a low status working class area with small flats and high migration in and out of the area. Our finding that LFPs are most prevalent in the highest age group speaks in favour of a "residual population" of ill individuals remaining in the area, when more healthy individuals move out. Until recently the effects of migration have dominated the discussion and less interest has been directed towards etiological factors in the urban environment, although Wing (46) has pointed out that overstimulation may provoke psychotic episodes in schizophrenics and McGlashan (32) in a review of North American follow-up studies has concluded a better prognosis in rural than in urban areas. If, as suggested above, the diagnosis is seen as an outcome measure, it would not be hard to imagine that more vulnerable persons could end up as schizophrenics in the more stressful urban environment. Supporting this view are the findings that other outcome measures are worse than in rural areas. Lewis et al (47) have shown recently, by using a register of Swedish conscripts, that the risk of developing schizophrenia is increased for those living in city areas during their childhood and teenage years.

How complete a population has been attained? How do the present studies relate to earlier ones?
The Camberwell studies (8) are based on a psychiatric case register, but use broad inclusion criteria covering schizophrenia as well as affective psychosis. Evidently paranoid conditions have been included in the diagnosis of schizophrenia. The recorded prevalence of schizophrenia is however only 2.8/1.000 in the Camberwell studies whilst the corresponding figure in the present studies is 4.2/1.000 inhabitants.

The Nithsdale studies (10) looked for cases from not only within the psychiatric services but also those known to GPs. Regarding these studies the criticism of Jablensky concerning too narrow inclusion criteria for schizophrenia is justified (18). The recorded prevalence in the rural area of those studies is given as approximately 2.0/1.000 inhabitants, with a certain variation depending on the strictness of the inclusion criteria. In our studies the corresponding prevalence for DSM-III schizophrenia in the rural area is 3.0/1.000.

The Nottingham studies (9,48) are more recent but as they are focused on incidence rather than prevalence, the figures are difficult to compare with ours. In the Nottingham studies, as in the present ones, there are great variations in rates in different areas.
The Salford studies (49) also covering a low status area in a city shows a comparably high prevalence for schizophrenia: 6.26/1.000 adult population for ICD-9 schizophrenia as compared to 6.0 for DSM-III schizophrenia and 7.9 for LFP in the inner city area in the present survey.

Hence, the levels of prevalence in our studies generally show higher rates compared to those which has been recorded for comparable areas in other studies. This is also true when strict DSM-III criteria for schizophrenia have been applied. If not an indicator of completeness, the recorded prevalence at least does not indicate an incomplete coverage. Our complementary study (figure 1) has served as a "leakage" study. Different methods to prevent leakage have been applied (Paper II) where the retrospective search for "patients to be" in 1984 as well as the use of social workers as informants, are innovations as far as we know. In Paper I it is stated that "private psychiatric resources available to these LFP patients were negligible in all three areas". In the complementary study (Paper II) no attempt was made to check with private psychiatrists possibly receiving patients from these three areas. Such a check was however carried out in the Nottingham studies (48), where "no previously missed patients were found as a result of checks done by the local psychiatrists, who accepted private patients....".

From an epidemiological point of view the studies have a value in that they focus upon an approximately total, epidemiologically defined population of individuals with schizophrenia and bordering conditions. The representativeness of a sample will always be at stake when used to describe the qualities of schizophrenia or differences between subgroups according to sex, age at onset etc. Not only is this an approximately total population (N=341) but it has also been drawn from three various types of housing area, the total population of which represents a little more than 1% of that of Sweden. This thereby increases the representativeness of the study population.

Only Papers II, IV and V are based on the total population of 341 individuals. The results of Paper I and III could therefore justifiably be criticized for being less complete. The epidemiological differences between the original and the total population have been shown in Paper II. In order to test what differences in care utilisation would be the result if the N=341 population had formed the basis of Paper III, figures were recalculated based on the total population (Table 6).
Table 6. Care utilisation in the N=341 population compared to the N=302 population of Paper III.

<table>
<thead>
<tr>
<th></th>
<th>N=302-population</th>
<th>N=341-population</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>In-patient care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proportion in in-patient care %</td>
<td>48</td>
<td>44</td>
</tr>
<tr>
<td>Mean number of in-patient days (all LFP)</td>
<td>75</td>
<td>67</td>
</tr>
<tr>
<td>Mean number of in-patient days (only those admitted)</td>
<td>155</td>
<td>152</td>
</tr>
<tr>
<td><strong>Medication</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proportion on antipsychotic medication %</td>
<td>75</td>
<td>70</td>
</tr>
<tr>
<td>Median daily dosage Cpz</td>
<td>175</td>
<td>160</td>
</tr>
</tbody>
</table>

In table 6 there are no significant shifts in care utilisation variables due to the inclusion of new cases.

The differences are marginal due to the fact that the originally defined population had already been identified via out-patient and in-patient services and contained a group of individuals (N=40) who had had no contact with psychiatric services during the year of investigation. Although in the 'total population', cases were also defined via GP:s and social welfare employees and the figure of individuals with no psychiatric contact rose from 40 to 67, the differences are not outstanding.

This is not to say that focusing on the patients less known to psychiatric services is not of interest. Paper II has shown, that the less known population, contributed significantly to prevalence and Paper IV has shown that as many as 20% avoided contact with psychiatric services during the year whilst still maintaining reasonable social conditions. The process by which LFP individuals make these choices would be worthwhile describing in a qualitative study.

Articles aimed at describing conditions for schizophrenic individuals are frequently based entirely on admitted cases (SO ), sometimes also allowing a high drop-out frequency (SO ). Some of the main findings in the Papers II-V have been recalculated on the assumption that a sample of convenience had been used, namely those patients who were in-patients during the index year. Table 7 compares the results of the present studies with the results of such a selected sample constituting those LFPs (left
column) and schizophrenics only (right column) out of the total sample, who were admitted during the year.

Differences are striking especially regarding prevalence and care utilisation. Social conditions would also have shown a considerably darker picture had such a selected sample been used. One interesting effect of having an unselected sample is that age at onset seems to increase (table 7). The relatively high age at onset recorded in our study as compared to the mean age at onset recorded at different centres of the WHO collaborative study (51) is then at least in part an effect of having included non-admitted cases.

In order to be able to draw more general conclusions regarding epidemiology, care outcome and social outcome, it is thus essential to include those cases which have not been in-patients during the investigation year.
Table 7. Epidemiology, care utilisation and social conditions according to the selection of the sample

<table>
<thead>
<tr>
<th>Out-come variables</th>
<th>All diagnoses - LFP</th>
<th>Schizophrenics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total (N=341)</td>
<td>Total (N=237)</td>
</tr>
<tr>
<td></td>
<td>Inpatients only (N=151)</td>
<td>Inpatients only (N=111)</td>
</tr>
<tr>
<td><strong>Epidemiology</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prevalence</td>
<td>6.0</td>
<td>4.2</td>
</tr>
<tr>
<td>Prevalence ratio</td>
<td>2.0</td>
<td>2.0</td>
</tr>
<tr>
<td>urban/rural</td>
<td>3.3</td>
<td>3.1</td>
</tr>
<tr>
<td>Prevalence ratio</td>
<td>1.03</td>
<td>1.42</td>
</tr>
<tr>
<td>male/female</td>
<td>1.12</td>
<td>1.46</td>
</tr>
<tr>
<td>Age at onset</td>
<td>29.5</td>
<td>27.6</td>
</tr>
<tr>
<td>Male-female diff</td>
<td>-3.0</td>
<td>-0.8</td>
</tr>
<tr>
<td>in age at onset</td>
<td>-3.1</td>
<td>-0.9</td>
</tr>
<tr>
<td><strong>Care utilisation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care out-come</td>
<td>67</td>
<td>79</td>
</tr>
<tr>
<td>days/year in</td>
<td>152</td>
<td>169</td>
</tr>
<tr>
<td>in-patient care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>On antipsychotic</td>
<td>70</td>
<td>73</td>
</tr>
<tr>
<td>medication %</td>
<td>86</td>
<td>91</td>
</tr>
<tr>
<td>Median daily dosage</td>
<td>295</td>
<td>367</td>
</tr>
<tr>
<td>Cpz</td>
<td>461</td>
<td>557</td>
</tr>
<tr>
<td><strong>Social conditions</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>57</td>
<td>69</td>
</tr>
<tr>
<td>Living alone</td>
<td>62</td>
<td>68</td>
</tr>
<tr>
<td>No own housing</td>
<td>26</td>
<td>33</td>
</tr>
<tr>
<td>Income below</td>
<td>50</td>
<td>57</td>
</tr>
<tr>
<td>median for LFP</td>
<td>56</td>
<td>65</td>
</tr>
<tr>
<td>Not employed</td>
<td>66</td>
<td>71</td>
</tr>
<tr>
<td>Sick pension</td>
<td>45</td>
<td>51</td>
</tr>
<tr>
<td>Social disability</td>
<td>51</td>
<td>58</td>
</tr>
<tr>
<td>index (SDI)</td>
<td>60</td>
<td>67</td>
</tr>
<tr>
<td>Male-female diff</td>
<td>14</td>
<td>34</td>
</tr>
<tr>
<td>in SDI</td>
<td>20</td>
<td>47</td>
</tr>
</tbody>
</table>
Some questions such as the one regarding gender differences in schizophrenia are also best answered by studies of unselected populations (50). It has been claimed by Strömgren (19) and Ring et al (52) that schizophrenia has a higher prevalence among males than females. According to Lehtinen and Jablensky (7,18) there is no valid evidence for such a statement. The present studies (Paper II) show gender differences regarding prevalence in all three areas studied, for DSM-III schizophrenia and to significant levels in one of the subareas and in the total population. At the same time there is an equal prevalence amongst males and females regarding LFP as a whole. Non-schizophrenic LFP are significantly more prevalent amongst females (figure 5).

![Diagram of prevalence ratios for schizophrenia and non-schizophrenic LFP](image_url)

**Figure 5.** Male/female prevalence ratios for schizophrenia and non-schizophrenic LFP.

Hence the significance of making a distinction between schizophrenia and non-schizophrenic LFP, even the two may be conceptualised as different prognostic outcomes of similar processes as indicated under the heading *The LFP concept and the 'group of schizophrenias'* (page 36). The question as to whether DSM-III schizophrenia is more prevalent amongst males has been answered in the affirmative by the present studies.

**Social conditions and care utilisation**

The LFP population, often considered by the media as having been deinstitutionalised, is still very dependent on in-patient care. Nearly half of them spend time as in-patients during the year and then on average for such long periods as 5 months. 69% have an out-patient contact with the psychiatric services most of them
with regular visits approximately once a month. This creates a feeling of "belonging" to the psychiatric services and is described in other studies (53). This feeling is often reinforced by the dependency on drugs, 71% being on antipsychotic medication. Individuals in this group often differentiate between those who are either "within psychiatry" or "in society" (53).

Most of them have never married (57%) and 64% live alone. The majority is unemployed (69%) and after some time lag receive their disability pension. Whereas most people in our society face a shortage of time, this group has a surplus, and do not always know how to spend it.

Regarding material living conditions, our studies, somewhat discrepant from The Parliamentary Investigation of Mental Services in Sweden (54) which describe the material conditions as deplorable, show that long-term mentally handicapped have, or at least in 1984 had, a reasonable standard of living. Table 8 shows their annual income in relation to the general population of the three areas. Incomes are about 60% of the average for the total population. 76% also had their own flat. The figures for declared income do not include municipal rent contributions or financial support from the social welfare office. The Swedish social security system must be said to function reasonably well for this group especially when comparing with international studies. Economically this is achieved mainly through transfers by the General Insurance system.

**Table 8. Income of LFP related to that of the general population 1984 of the respective areas.**

<table>
<thead>
<tr>
<th></th>
<th>Rural</th>
<th>Suburban</th>
<th>Urban</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=48</td>
<td>N=230</td>
<td>N=63</td>
</tr>
<tr>
<td>Income difference (SEK)</td>
<td>-29.700</td>
<td>-32.800</td>
<td>-40.900</td>
</tr>
</tbody>
</table>
| Proportion of average income % | 62 | 64 | 51

However, it is not difficult to imagine that many individuals in the group have difficulties in making ends meet. Those who have received disability pension are, however, sometimes hesitant in trying for a job on the open market, as this would risk their relative security and would in fact mean a lowering of economic standard (55) due to the construction of the insurance system.
The most striking finding is that these individuals constitute a very lonely group in society, to a large extent outside the networks of family and work. They evidently depend on psychiatric services not only for psychiatric, but also for emotional needs. In this respect women fare better than men, being able to maintain their social contacts longer and being less dependent on in-patient care. The situation for people in the rural area is more like that of the general population as compared to other areas. The income gap is smaller, they are more often employed on the open market, they are more often living with relatives and less frequently hospitalized. When admitted, however, care periods tend to be as long as for the urban LFP.

**Predictors of outcome**

My preconception that duration would have an impact on outcome was not verified. The picture given is not one of a continuously downhill course as described by Kraepelin.

The only outcome measures found which are significantly influenced by duration are medication (Paper III) on the one hand and expulsion from the labour market (Paper IV) on the other.

Both these factors can be seen as reflecting reactions from the environment rather than being a direct reflection of the state of the LFP individual due to duration. In the first case increasing dosages are related to polypharmacy. Regarding increasing unemployment and disability pension, the number of days on sick leave is very high in the group still in employment. It is reasonable to speculate that duration of illness takes its toll on the tolerance of the environment, resulting in unemployment, after which disability pension will follow.

Although duration after the initial phase has little influence, the time criterion of the LFP diagnosis - a minimum of 6 months' of illness duration - seems to have singled out the fraction amongst those with affective psychosis, which has most similar outcome to schizophrenia; 60% being on antipsychotic medication, 57% being admitted for in-patient treatment during the year and then for nearly 3 months on average.

The design of outcome studies has often been to follow a cohort of patients for many years from their first admission (30). It might therefore seem strange to base a paper focusing on outcome (Paper V) on this mixed, but 'total' material. It is however possible to do so as the duration of illness can be controlled for statistically (Paper V) together with other background factors such as age. Moreover, one
result of these studies is that duration does not play a significant role for most outcome factors. Outcome must then be viewed as being on the one hand related to background factors or factors in the early course of illness (gender, age at onset, diagnostic severity and unknown factors) and on the other to the interaction with society including its psychiatric services.

The diagnosis of schizophrenia has been believed to embody a poor outcome, in fact it "was validated by a uniformly bad outcome" (43). This picture has been somewhat modified by the present studies. Although the diagnosis of schizophrenia amongst the LFP has shown to encompass a poor outcome, two other factors, male gender and early age at onset, have proved to be as powerful as the diagnosis itself in predicting a poor outcome.

These two factors are often concealed by the diagnosis of schizophrenia as there is an overrepresentation of males and those with early age at onset in the schizophrenic diagnostic group.

When confounding factors were controlled for in a systematic way (Paper IV and Paper V) all three background variables - schizophrenia, male gender and early age at onset - were shown to lead to poor social outcome whilst male gender was the factor found to be related to length of in-patient care.

It is worthwhile mentioning two other background factors:
Alcohol and drug abuse is associated with negative outcome regarding marital status, housing and employment.
Rural living seems to imply a greater involvement of the social network in areas of housing and employment. Higher levels of medication and in-patient care in the urban area may indicate a more severe psychopathology for individuals living there, although it might also reflect the policy of the care organisation.

Implications for further studies and for social policies

One surprising finding of the thorough case finding studies, which formed the basis of this thesis, was that 20% of the group which, from a purely psychiatric perspective, could be described as the most mentally handicapped in society, did not use the psychiatric services which were readily available to them in their area. It is not feasible to answer the question as to why they did not from the material we have collated. The clinicians in contact with this group of individuals are unlikely to be sure of the reasons.

It seems that another perspective has to be applied in order to fathom what it means to be a mental patient. It encompasses sharing a "part culture" (53,58) with other
patients, who have experienced similar attitudes and reactions from society. Obviously there are personal choices to be made whether to accept this "part culture", which once you are in it may not be easy to reject. Some individuals are evidently unwilling to accept it (Paper II). Anthropological or ethnological perspectives may help us to see this "part culture", to be able to formulate the questions about the personal choices. It seems that these perspectives, as shown by one of the above cited studies (53) have a lot to contribute to the description of the lives of LFPs in general.

Possibly we could be helped by viewing similar conditions in quite another culture. This approach has been tested in a small pilot study about LFP in Tanzania (56).

Quite contrary, but notwithstanding the above finding, are the results that the LFP group in general is very much dependent on hospital care. There seems to be a need of some basic mapping of reality so as not to get carried away by massmedia pictures of the dehospitalisation process or expressions of political intentions.

A thorough mapping of different areas with respect to LFP may also be most helpful in the process of deinstitutionalisation. If the main responsibility of long-term mentally handicapped is going to shift from the county councils to the municipalities as indicated by The Parliamentary Investigation of Mental Services in Sweden, it is essential to facilitate a transfer of resources. The presented material may provide a basis for health economics studies. The shifting prevalences found in different municipalities as well as the different weight of care utilisation may place quite different financial demands on different municipalities.

Health economics studies would also reveal the size of resources allotted to different groups of LFP. If the strong prediction an early age at onset has on outcome is accepted, it seems imperative to intervene early in the psychosis process with prevention in mind. From a lifetime perspective resources spent on this group will probably be vast. There is presently a long delay between "real onset" and first admission (26,27). It seems that this time lag could be used in a more fruitful way than for expectancy.

The present epidemiologically based population can be used to answer other questions e.g regarding the size of subgroups. As pointed out earlier comorbidity of substance abuse led to poorer social outcome (Paper IV). 76 individuals or 22% of the population have a recorded substance abuse. The information on abuse has been assessed to be reliable. It would therefore be justified to make a separate study of the LFP with substance abuse.
Schizophrenia has been mentioned as a "life-shortening disease" (57) not only due to suicide but also neglected physical health. The high rate of in-patient care to date has probably to some extent met physical needs (Paper III). In the process of deinstitutionalisation the physical health of LFP must be guarded and planned for.

The Parliamentary Investigation of Mental Services in Sweden (Psykiatriutredningen) has stated that the most severely mentally handicapped in society will need personal representatives to give them access to society and support their need of contact and meaningful activities. It has been anticipated that this group will be covered legally by the handicap legislation. There has been some uncertainty as to the size of this group in society. Calculating on the basis of the hypothetical assumption that the general population of the present studies is a representative sample of 1.03% of the present one of Sweden, the number of LFPs would be 33,000. Out of this number a substantial proportion would have reasonable social conditions, e.g. would 24% be employed on the open market (Paper IV). Using the social indicators and social disability index of Paper V it can be calculated that 20,650 individuals in Sweden would have a social disability index above 50 which means that they would score on 3 or more of the following indicators: never married, living alone, no own housing, income below median for the LFP group, unemployed, disability pension.

However, LFP is not a comprehensive description for all mentally handicapped, as it leaves out organic psychoses and some other grave handicaps of a non-psychotic nature. A certain, but yet unknown, number of individuals will have to be added to obtain the target group aimed at by the mentioned proposals.
CONCLUSIONS

The main results of this thesis can be summarised as follows:

The LFP concept covering schizophrenia and bordering conditions has proved reliable and useful in defining the part of the general population most in need of psychiatric attention showing a similar prevalence amongst males and females.

There is a gradient of LFP prevalence and its main constituent diagnosis, schizophrenia, with twice as high ratio in the city centre as in the rural area. Schizophrenia is significantly more prevalent among males while paranoia and affective psychosis within the LFP concept is significantly more prevalent amongst females.

The group of LFP individuals, contrary to the general view of an active deinstitutionalisation, still very much depend on in-patient care; nearly half of them spent time as in-patients during the year of investigation and then on average for such long periods as 5 months. Females, although admitted with a similar frequency only spent half as long in hospital as males.

Levels of in-patient care as well as levels of antipsychotic medication increase with proximity to the city centre.

Part of the group of LFP (20%) manage with no psychiatric attention at all, either in-patient or out-patient.

The material standard is much below average for the general population but still reasonable and not deteriorating with illness duration.

The social picture given of the LFP individuals is one of loneliness; they are for the most part unmarried, living alone and gradually being ousted from the labour market.

Social outcome is more favourable for females than for males amongst both schizophrenic and non-schizophrenic LFP. Early age at onset, male gender and a diagnosis of schizophrenia are the three factors, which each per se predict poor outcome.
ACKNOWLEDGEMENTS

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