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The Intricacy of the Ordinary

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Schizophrenia constitutes a lifelong vulnerability in relation to life stresses and the maintenance of social networks. Satisfactory quality of life – understood as subjective well-being in a lifetime perspective – is the ultimate treatment objective. This paper draws on research and clinical experience from Lofoten – the catchment area of a psychiatric out-patient clinic in Northern Norway. This work stresses the quality of life for the social network around the psychiatric patient as a consideration in its own right. The patient's coping resources and social network are regarded as a continuous professional concern.

In addition to the shame and stigma attached to psychiatric disorders, the very nature of the negative symptoms of schizophrenia – dysfunction of the ordinary, even banal, life activities involved – may contribute to the low status of long-term community treatment. This low status is not only attributed by community attitudes, but is also integrated into the hierarchy of psychiatric treatment modalities. To overcome this didactic problem at all levels, our scientific language and models must explicitly include these aspects of schizophrenia. The importance of social networks and coping resources needs to be emphasised as a continuous professional concern with respect to schizophrenia.

This paper considers community psychiatry from three points of view: total population responsibility; understanding the decisive social factors for aetiology, prognosis and help-seeking behaviour; and clinical and preventive praxis. The paper draws on experience from Lofoten, in North Norway, the catchment area for a psychiatric out-patient clinic, in which a number of surveys and clinical and preventive projects have taken place since 1983 (Sørgaard *et al*, 1991).

Decentralised psychiatry in Nordland county

Nordland county has 243 000 inhabitants. The many fjords and inhabited islands, and the very long distances within the county have been the basis for the most far-reaching development of decentralised psychiatry in Norway. However, this development has been gradual: the first psychiatric services were located in a neighbouring county – at Rønvik psychiatric hospital, established in Bodø in 1902; sectorisation of the hospital occurred in 1976, with the formation of three departments each responsible for a third of the county; teams from each sector department began travelling on a regular basis to the municipalities in their area; and from 1982 there was a gradual development of psychiatric out-patient clinics, located in relation to the existing seven local hospitals in the county. This linkage of the decentralised psychiatric service to the local hospitals results in small catchment areas, with an average of 20 000–30 000 inhabitants; teams for child and adolescent psychiatry are distributed in the same way. At a later stage, staff focusing on alcohol/drug abuse, planning for long-term patients, and rehabilitation of the mentally retarded have been attached to the same psychiatric teams. Usually there is co-operation with other departments, especially medicine, at the local hospital in the use of beds for acute cases. More recently, additional functions, including a 24-hour service and day care, have been provided in the local catchment areas. In Lofoten, most areas can be reached within one hour from Gravdal hospital. Table 1 shows information for Lofoten, the North region, and the county as a whole.

Table 1
Organisation of psychiatric services in Nordland county

Psychiatric hospital, Bodø

Three sectors:

- North region – three local hospitals
- Salten region – one local hospital (main hospital)
- South region – three local hospitals

North region:

- Ofoten (Narvik hospital)
- Vesterålen (Stokmarknes hospital)
- Lofoten (Gravdal hospital)

Lofoten:

- 24 000 inhabitants (18 000 aged 18 years or more)
- Four municipalities: Vågan, Vestvågøy, Flakstad, Moskenes (two of about 10 000 inhabitants, two of about 15 000 inhabitants)

Community psychiatric responsibility

In the Norwegian Mental Health Act, psychiatric treatment, care, prevention/identification, and

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after-care are described in terms indicating a system of community responsibility. From the 1970s, central plans for the sectorisation of the psychiatric system (Steenfeldt-Foss, 1973) have had strong roots in the ideas behind the American community mental health programme (Hume, 1974; Levenson, 1974). The service obligations in Lofoten are related to a geographically defined population, which includes everyone within the four municipalities making up the catchment area of Gravdal local hospital. This implies a responsibility exceeding that for people who themselves seek or are referred to the specialised psychiatric system. Those who are in contact only with the primary health or social services, and people not in contact with any professional helper, are included in the same way.

Since community psychiatry should also relate to potential future cases, primary, secondary, and tertiary prevention have to be an integrated part of the system. The treatment goals of such a service should not be limited to the reduction of symptoms. Our knowledge of the prolonged duration and frequent chronicity of psychiatric illnesses, both with regard to psychotic and many non-psychotic conditions, and their often extensive impact on most domains of life, make the inclusion of work with social networks and people's daily routines a professional concern. The ultimate objective of professional mental health concern must be the quality of life and general well-being of patients. Treatment should be routinely evaluated from this perspective, in both the short and the long run.

The psychiatric care system must have a proactive approach; for instance, with respect to long-term patients, there must be a proactive approach to the first signs of a schizophrenic illness and to people involved in serious accidents or stress situations. Those currently in treatment must be seen as a risk group both for the development of later psychiatric problems and for a strategic focus on prevention. For schizophrenic patients, there must be a continuous concern which goes beyond the mere reduction of symptoms in acute phases, and services must not just rely on the patients themselves or their close network having sufficient overt motivation for treatment to request help. The decision to offer qualified long-term psychotherapy, aiming at radical personality change, must be taken not only on the basis of the skills and engagement of the professionals in the region, but considering the whole group of schizophrenic patients, their social networks, other patients and possible preventive interventions. The mental health of the family and additional social network around defined psychiatric patients should be a concern in its own right; what risks exist for the burden of care and what resources are available in the network need to be determined.

Community psychiatry is concerned with promoting the welfare of the total patient population, and so attitudes toward the severely mentally ill in the catchment area form an important framework for our work. Professional staff may have to act as advocates for the acceptance of patients in defined social networks, in local organisations and at the political level; how to relate to newspapers and the other media can be important questions for them. The implications for these attitudes when dangerous or very disturbing behaviour is being treated in a local community also have to be considered. When should neuroleptic drugs, hospital care, or involuntary treatment be used so as to construct favourable conditions both for the patient involved and for the whole group?

How to develop knowledge and co-operation within this total mental health network, including the local health and social services, is a principal consideration in the Strategic Network Model (Sørensen & Sandanger, 1989). In this, a central consideration is how to establish priorities: who does which part of the work, at which time in the life of schizophrenic patients? How can continuity of care and cumulative knowledge of the individual patient be maintained? What proportion of total resources should be used on this group compared with other categories of patients? The consequences of schizophrenia – both in a social network and over a lifetime perspective – must be evaluated.

Community psychiatric understanding

An essential basis for the practice of community psychiatry is knowledge of the number of people suffering from psychiatric problems, their characteristics and the most important risk factors. In Lofoten, we have carried out population and patient surveys for this purpose. Representative samples of the general population were interviewed, both in 1983–1984 and in 1989–1990. The first survey showed that 15% (2700) of the adult population had recent symptoms which indicated definite need of professional help. Yet psychiatric attention on this scale cannot be delivered solely by psychiatric specialists. An additional survey (Sørgaard *et al*, 1991) based on the cumulative knowledge of primary care doctors, community nurses, social welfare officers, the local psychiatric out-patient clinic, and the psychiatric hospital, revealed the existence of about 300 people with long-term disorders in our catchment area, 40% of them with a psychosis diagnosis: a number well in reach for specialist attention. From a community psychiatric perspective,

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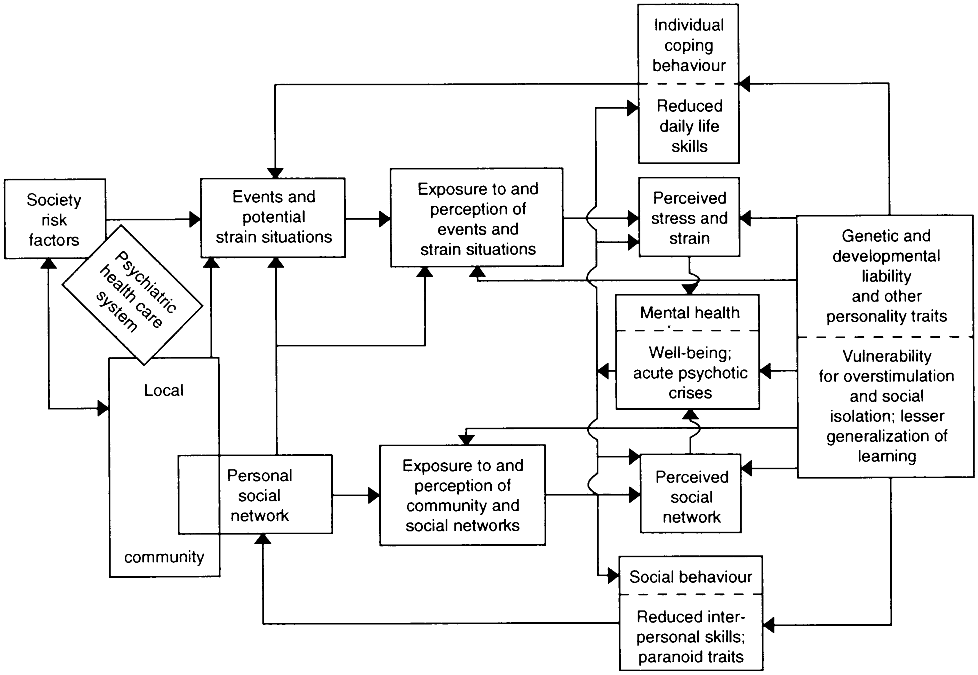

Fig. 1 Community psychiatric interaction model for schizophrenia.

mental health can be seen as an interplay between a stressful life situation, social supportive elements and more lasting personality characteristics. The model shown in Fig. 1 sets schizophrenia into such a community psychiatric perspective. This is a modified version of the Lofoten Comprehensive Model for Preventive Psychiatry (Sørensen, 1992), which relates to mental health in general.

The model draws attention to the way in which the environment – in the form of life events/life stresses, social networks, and personality factors – has an impact on mental health, while at the same time an individual's mental health influences the environment, which includes the socio-cultural integration of local communities. In schizophrenia, stressful life events may precede acute episodes (Dohrendwend & Dohrendwend, 1981), although, relatively, the additional risk represented by life events is limited. Studies of schizophrenic patients have found these individuals alone and isolated, even in well-integrated societies where they had been living all their life (Westmeyer & Pattison, 1981). Schizophrenia is a special case of vulnerability, with regard to both social networks and environmental stress, easily accessible supportive social networks having a positive influence. This was shown in a study of groups of 3–4 patients living in shared apartments in ordinary dwelling areas in Oslo, compared with groups living alone or at the hospital (Sørensen, 1988). Progress to higher subjective well-being seemed to derive from higher expectancy from the social network and greater satisfaction with leisure time, resulting in a diminished feeling of loneliness, higher sense of engagement and better self-expression. A shared apartment can provide the framework for an easily accessible and benign social network. In a controlled follow-up study in Oslo (Sørensen, 1985*b*), we found an increase in patients' well-being. Paid, supervised, non-professional enablers who worked with groups of patients were able to create new social networks as the basis for social support for their members. In the case of schizophrenia, the personality factor in the model is likely to have a relatively strong negative influence, but this does not mean that stress and social support are of lesser importance. On the contrary, to secure a satisfactory quality of life, a good deal of professional involvement is required in the day-to-day management of stress and in relation to social networks. Psychiatric patients who have spent many years in hospital, and even some who have been in intensive psychotherapy units, are in a particularly critical position with regard to social network factors. Six factors which contribute

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to a spiral of social-network reduction are listed below.

The first is the psychopathology itself. Schizophrenia is often characterised by problems – in close relationships – in finding the optimal balance between closeness and distance, and between dependency and isolation. Problems with family and friends lead to fewer persons being in the sufferer's social network, and no new foundation of an alternative network is possible. With the first episode being generally in early adult life, the process of change from dependency on the family of origin to a new adult social network tends to worsen such a crisis; the patient may never have experienced an adult role in relation to other people. Paranoid psychopathology, with fear, suspicion, and hostility, may cause further deterioration in important sectors of the social network. The nature of schizophrenia usually implies a burden on family and friends, and makes new friendly relations problematic through a lack of ability to relate flexibly in non-structured situations.

The second factor is the lack of social skills. Spending many years inside a psychiatric hospital may mean the loss of skills for daily living and interpersonal relationships in the general community, outside the parental home or other institutions. Patients with a tendency towards isolation are at particular risk both in total institutions and in indifferent and defensive communities. Since many have problems in generalising knowledge, practical and relational skills are optimally developed in the community setting they are going to live in afterwards, rather than by training within the hospital.

The third factor is lack of a basis for network development. Chronic psychiatric patients will often have ended their education early and are very often unemployed. For many, psychiatric institutions and related activities will be the only places where they meet people in a stable framework. When we ask a long-term patient to draw his/her network circle of close relationships, it is typical to find few people in it, and these are often other patients or psychiatric professionals.

The fourth factor is lack of material resources. Chronic psychiatric patients, even in our welfare states, mostly have a very limited budget. Disability pensions have made independent life outside hospital possible, but there is often not enough to join organisations or leisure activities. Network-promoting factors, such as a car and a telephone, are often lacking.

The fifth factor is distance to social network. In Norway, many psychiatric hospitals are still at a substantial distance from a patient's home milieu, resulting in declining visits from his/her social network and reduction in community participation if the stay in hospital is prolonged.

The sixth factor is stigma. There are often stereotyped attitudes towards psychiatric patients in general, e.g. fear that they may be unpredictable or even dangerous. People may also suffer from memories of problems that occurred during a patient's earlier psychotic episodes. These factors will tend to work against integration of the patient into the community as a valued member.

These factors may interact together, resulting either in social isolation within the community or life in an institution: to break such a vicious circle, social networks have to be developed and maintained. The patient's vulnerability and his/her difficulty in finding a balance between isolation and overwhelming closeness need to be matters of concern: the professional may be an important member of the patient's social network or he/she may supervise the activities of semi-professional enablers (Weinman & Kleiner, 1978), relatives, or others who are potentially part of the network. If the patient does not have social support, treatment modalities such as psychotherapy may have little or no long-term effect. Some of the structures in daily life which promote social support and quality of life must be actively supervised by the psychiatric care system and/or other organisations, particularly in the voluntary sector. In such work, the professional or semi-professional is a real member of the patient's social network, on a short- or long-term basis. Both a shared-apartment study (Sørensen, 1985*a*) and a social-network-stimulation study (Sørensen, 1985*b*; Dalgard *et al*, 1990) showed that a created network consisting of other patients and professionals will also stimulate ties to other networks. The vulnerability seen in schizophrenia makes stable social networks during rehabilitation programmes important, and may even require reduced mobility. A major problem in schizophrenia (Wing, 1977) is to find a balance between social withdrawal and excessive social stimulation, including the network stress described as 'expressed emotion' (Brown *et al*, 1972; Leff *et al*, 1985). For patients, their networks, and professionals, the crucial stage to play on in the treatment of schizophrenia is the intricacy of living an ordinary life.

Quality of life

Patients' subjective sense of well-being should be seen as the ultimate test of an adequate mental health system, but their quality of life must be seen in a cumulative, lifetime perspective. Psychiatric treatment will often involve the patient's whole life sphere,

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and the professional assessment will be of decisive consequence. Though therapeutic management may actively reduce the level of well-being for certain periods, it can still be right if it prepares the ground for a better life. The patient's well-being also has to be seen in relation to other peoples' quality of life, though where such conflicts arise the decisions involved may well be distressing to all concerned. In the shared-apartment study (Sørensen, 1985*a*), using a path analysis model, the patient's expectation of social support from his/her network acted as an explanatory variable between living situation and subjective well-being. On the other hand, we found small differences in psychiatric symptoms. In the network-stimulation study (Sørensen, 1985*b*) there was little correlation (0.11) between patients' subjective well-being, measured by ten items about life in general, and professionals' rating of global psychopathology, as measured by the Global Assessment Scale. The correlation between the single items of the Brief Psychiatric Rating Scale and the well-being index was relatively small in relation to core schizophrenic features (0.2 to 0.14); it was highest with the ratings of anxiety (0.34) and depression (0.44).

The lower level of well-being among patients of this kind may be explained by anxiety and depressed mood, either as part of a psychosis or secondary to disturbed social function and lack of social support, and so treatment directed at the main psychotic symptoms will not necessarily result in a higher quality of life. Only patients themselves have direct access to their emotions: complaints about side-effects of drugs or negative feelings about how their situation has been dealt with by the psychiatric services should be viewed in this light. Feelings of this kind, together with the way in which patients handle simple social interactions, may be the decisive factors producing a high or low quality of life. Compared with general populations, long-term psychiatric patients on the whole experience a lower quality of life – expressed as 'worse', 'more disappointing', 'unsatisfied' or 'unhappy' (Sørensen, 1989). However, some rate their life as 'good'; one important intervening factor seems to be a satisfactory experience of support from a social network.

Strategic Network Model

The model presented below has been a way of implementing decentralised psychiatry within a community psychiatric framework, with limited resources. From its start in 1983, the psychiatric team in Lofoten has combined an extremely decentralised framework of services with social psychiatric thinking. During this period the Strategic Network Model has emerged, which represents the catchment area as a series of interlinking social networks which are important for the mental health of the population. These networks consist of (a) professionals at all levels in the health and social field; (b) those who are encountered by people in crisis situations; (c) people who are of importance for the functioning of the local community, including its economic viability; (d) people who influence attitudes towards psychiatric patients and mental health in general; and (e) patients themselves and their close network. In addition to collaboration with the strategic networks in their normal occupation and role, one should also provide the professionals and persons with important influence on them, when needed, with crisis intervention or treatment for emotional problems. This may also enhance their instrumental and emotional skills.

A psychiatric team is a potentially important support structure in the community – a broker in relation to resources for help with mental health problems. The psychiatric specialist team has to find ways in which to reach and influence people and networks which have a major influence on mental health in different parts of the local community. In the Lofoten region, substantial effort has been invested in co-ordinating and increasing the competence of the professional networks. The psychiatric team do not act as consultants from outside, but rather promote collaboration and shared responsibility between professionals with different kinds of expertise. Our experience can be summed up in the following 15 recommendations:

(a) have small enough catchment areas with regard to population (20 000–30 000), travel distances, and administrative units (1–5 municipalities)
(b) have a psychiatric team small enough not to be self-sufficient and big enough to be stable (7–10 persons)
(c) co-ordinate different agencies so that they all give services within the same geographical boundaries
(d) obtain systematic information about both socially integrative structures and risk factors in the catchment area
(e) obtain systematic information about long-term psychiatric patients and their needs, as well as the resources available to them in the area
(f) learn to know and be known, and participate in person in all parts of the catchment area, on a continuous basis
(g) in conjunction with the primary health and social services, start with those patients who are felt to be the most burdensome

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(h) have a balanced division between direct consultations with patients and other activities (40–60% of each)
(i) have the courage to offer clinical and preventive services actively, even when not asked
(j) develop links between the specialist team and other elements of the strategic mental health network on a routine basis
(k) take the responsibility for improving knowledge of psychiatric disorders and their treatment among people in the catchment area, by seminars, lectures, newspaper articles, etc.
(l) take the responsibility to raise the general tolerance towards the mentally ill in the community; especially by active use of and cooperation with the local media
(m) maintain a continuous focus on cooperation with the political and administrative bodies of the county and municipalities
(n) collaborate with patients, their relatives and patients associations in relation to planning, resource allocation, and service development
(o) adapt the model to the present context.

The severely mentally ill in Lofoten

When a new psychiatric out-patient clinic is established, long-term psychiatric patients in the area to be served are not necessarily included in the treatment population. In Lofoten, though, priorities were not allowed to take that direction, and neither was a separate system wanted to take responsibility for chronically ill patients. The mutual personal knowledge and optimal collaboration between the psychiatric out-patient team and the primary health and social workers are at the core of the strategic network model; the psychiatric specialist service must not create new boundaries restraining the development of a shared mental health network. The regular work with the municipal health services does not aim to replace the primary health-care system but rather to increase the competence and total effort applied to psychiatry, and especially to the severely mentally ill. However, basic expectations were to have psychiatric specialists take over most aspects of psychiatric care. The 1989–1990 survey found that doctors were still the main professionals that people had used for emotional problems and expected to consult in future crises. More people than before said they had used a doctor for help with mental problems; the rise was greater than the increase in nervous symptoms, and may be interpreted as a greater willingness to talk about such problems. The 1983–1984 survey found three dimensions regarding attitudes towards the mentally ill in the community (Mastekaasa & Sørensen, 1991). One of these was that the population seemed to demand that patients had a certain level of functioning in daily living activities, to deal with the ordinary, if they were to be accepted in the community. In 1989–1990, slightly more tolerance was seen. It seems that even a community approach by psychiatric services has little influence on this type of attitude, and so more focused locally based efforts may have to be made, by means of the media, public campaigns and systematic educational programmes in schools and organisations, with patient participation.

At the very start of the service, a series of hearings with local politicians and administrators in each of the municipalities took place. Continuous efforts have been made to ensure that bodies which bear responsibility are included in committees and seminars concerned with psychiatry: there are now planning committees for psychiatry in each of the municipalities and an overall body for the catchment area. The responsibility for administering the planning committees has been assigned to the municipalities, but with representatives from the psychiatric out-patient clinic, the psychiatric hospital in Bodø, patients, and relatives. The team of professionals played an active part in establishing local groups of the main national patient organisation for mental health (NFMH), and has collaborated with this organisation to start and support a day-care centre. In the region, there has never been any sheltered accommodation for psychiatric patients; in 1986–1987 the professional agencies did not regard this as appropriate for more than a very few people. Activities and sheltered care were seen as a system operating throughout the region, rather than being concentrated in one 24-hour institution. A position was established in the team for a planner to promote activities, physical conditions, and networks for these patient groups in the community. One important result of this has been a project in collaboration with the Department of Health and Social Welfare (SME). One of its main objects has been to involve the patients themselves and their social network as responsible resources in treatment and activities influencing their quality of life. Together with professionals from the municipal services, they were invited to meetings to discuss ideas for new psychiatric provision in the area. These 'expectation conferences', in which patients and relatives formed a majority, were held in each of the municipalities. They were followed by an astonishing growth of activity and ideas, some in accordance with established plans, and others opening new avenues. As in the needs evaluations done by professionals, the importance is stressed of structures related to social networks

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and everyday human activities. In the 'expectation conferences', working groups on related ideas were established; later on, these groups involved relevant politicians and administrators. This working together has generated serious effective relations, and results have been incorporated directly into local public plans.

Needs uncovered in these discussions were for municipal services such as sheltered apartments, paid social-network organisers, day-care centres, sheltered work, education, transport, and informal network activities (contact telephone, a 'loneliness' cafeteria, keep-fit groups, self-confidence courses, interest groups for people using psychiatric services, and information aimed at attitudes toward psychiatric patients). Most of the topics relate to social support, tolerance, and decent treatment as a basis for reasonable quality of life. As a result, patients and relatives have changed their views of themselves, and this raised self-assertiveness leads to concrete demands, often followed by great improvement in their situation. Some of the informal network services, run by patients, have already come into existence; basic education, supervision and a professional back-up system have been provided. A Consumer Council for Psychiatric Health Care, with an advisory role, is in the process of being established. The 'expectation conferences' have brought about a fundamental new situation concerning the interplay with the most permanent users of the mental health services, and the mental health staff have been induced to rethink their professional role; patients are also responsible citizens and knowledgeable consumers. A willingness has developed to find solutions to needs that are not necessarily bound to an institutionalised system. Patients do not only ask for help and resources, but are engaged in taking control of their own lives. Attitudes towards municipal services have changed from accumulated frustration and resignation and moved towards understanding and a sharing of burdens.

Patients, relatives, municipal health and social services, and the specialised psychiatric services are making progress towards a shared mental health network. A main vehicle for this has been the Strategic Network Model. Regardless of perspective, psychopathology or quality of life, treatment of schizophrenia must deal with the intricacy of the ordinary. By giving understanding, legitimacy, and prestige to ordinary, banal problems, a necessary alliance of patients, relatives, professionals, administrators, politicians and the population in these local communities can be established. This is an essential condition for optimal treatment within the perspective of community psychiatric responsibility.

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