MENTAL HEALTH IN NEW ZEALAND FROM A PUBLIC HEALTH PERSPECTIVE

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The views expressed in this report are those of the authors and they do not necessarily represent the views of the Ministry of Health.
Schizophrenia is a heterogeneous disorder, characterised by abnormalities in mental and cognitive functioning, and impairment in social, academic, occupational and personal arenas. To meet current criteria for diagnosis (APA 1994), characteristic symptoms (including delusions, hallucinations, disorganised speech, grossly disorganised behaviour or negative symptoms) must be present for at least one month. In addition, there must be continuous signs of disturbance in one or more major areas of functioning for at least six months, which may include periods of prodromal or residual symptoms; and substance abuse or a medical condition must be excluded as a primary cause.

The characteristic symptoms are classically grouped into two domains, called positive symptoms (eg, delusions, hallucinations) and primary negative symptoms (eg, emotional flatness, withdrawal). A third domain is of disorganisation typified in speech pattern and behaviour. It has been postulated that these three domains may have different natural histories, different patterns of heritability, and different treatment responses. Risk factors and precipitating factors may also vary according to the type of disorder. Further elucidation requires increasing sophistication in the studies of schizophrenia.

Schizophrenia is a major mental illness. It usually begins in late adolescence (peak age about 20–24 years for males, and 25–29 years for females), but prodromal symptoms may be present for about two years prior to this. Follow-up studies show the course of the illness to be diverse – a quarter of those affected will make a full, or nearly full recovery but it is seriously disabling for up to a third of sufferers. The course of the illness depends on the quality and quantity of available treatment and rehabilitation (Harding 1988). Studies of early intervention suggest that delay before treatment may significantly impair full recovery, and worsen prognosis (McGorry 1992). Standardised mortality rates are 2.5 times those of the rest of the population, and 10–15 percent of the people who develop the disorder will eventually commit suicide (Black and Fisher 1992).

Comorbidity with other mental illnesses is well documented, including substance abuse in over 50 percent of cases (Shaner et al 1993), affective disorders (60 percent) and anxiety disorders (60 percent) (Epidemiologic Catchment Area data (Robins and Regier 1991)).

The cost of schizophrenia can be measured as the costs of health care (including acute care, through to continuous long-term support); residential care; individual loss of earnings; individual loss of quality of life; the financial and emotional burden of care to families and informal carers; and an increased risk of mental disorders in parents, siblings and carers (Fadden et al 1987).
**International Data**

A number of international studies indicate that the lifetime prevalence for schizophrenia is approximately 1 percent. At any point in time, approximately 3–4 per 1000 people will be experiencing problems associated with schizophrenia. An estimate for New Zealand would therefore be about 10,500–14,000 people actively unwell at any point in time (Oakley-Browne et al 1989).

**New Zealand Data**

There has been only one study that provides information on prevalence of specific disorders for New Zealand – the Christchurch Psychiatric Epidemiology Study (CPES) (Wells et al 1989; Oakley-Browne et al 1989). The results for schizophrenia are listed in Table 18.1.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>One year (%)</th>
<th>Lifetime (%)</th>
<th>One-year recovery (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schizophrenia/schizophreniform disorders</td>
<td>0.2</td>
<td>0.4</td>
<td>50.0</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>0.2</td>
<td>0.3</td>
<td>33.3</td>
</tr>
</tbody>
</table>

(Total sample period prevalence rates (%) of *DSM-III* disorders)

*Sources: Wells et al 1989; Oakley-Browne et al 1989*

These results are the lowest rates among recent similar studies conducted in the United States, Puerto Rico and Canada (Oakley-Browne et al 1989). The authors suggest the lower rates in New Zealand may reflect a lower response rate for people with schizophrenia, as the study did not sample institutions, and Christchurch may be more likely to have people in institutional care compared with other sites.

The CPES shows no significant sex differences for schizophrenia. It does not provide information on ethnicity.

The annual New Zealand Mental Health Dataset provides information on first admission rates and readmission rates to hospitals according to diagnostic groups (Ministry of Health 1993). Admission rates have limitations as a means of determining the occurrence of schizophrenia but there are no other studies at a national level. They are influenced by patterns of service delivery and do not reflect services provided by voluntary or trust agencies, or day or out-patient services. For one-third of those initially diagnosed as suffering from schizophrenia in New Zealand, the initial diagnosis may prove incorrect over the following five years. Age has an effect on the stability of diagnosis. Fourteen percent of the younger age group initially diagnosed with schizophrenia were reclassified to bipolar disorder, and 15 percent of those diagnosed as suffering bipolar disorder were diagnosed as having schizophrenia (Stanton and Joyce 1993).
In 1992 schizophrenic disorders were the most common cause of mental health readmissions (92 per 100,000 age-standardised readmission rate) and the fourth most common cause of mental health first admissions (11.5 per 100,000 age-standardised) to New Zealand hospitals (Ministry of Health 1993). The trend over the past 20 years has been for first admission rates to decrease (Joyce 1987), but this may reflect the effect of change in service delivery and the narrowing of diagnosis in clinical practice, rather than a true decline. Readmission rates have risen dramatically (eg, the male readmission rate in 1974 was 72 per 100,000, compared with 112 per 100,000 in 1992).

The trend to increasing readmission rates and increasing disparity between first admission rates and readmission rates is also seen for affective psychoses, paranoid states and other psychoses. The pattern therefore may reflect changes in service delivery as patients are admitted with greater frequency for shorter periods of time. Length of stay for schizophrenic disorders in 1992 was an average of 204 days (median 19 days).

MĀORI AND SCHIZOPHRENIA

No particular study has addressed rates of mental illness in the Māori population. The CPES was not sampled for ethnicity and the data obtained were insufficient for analysis. Therefore no extrapolations can be made to minority groups.

The only source of information about Māori and schizophrenia is the New Zealand Mental Health Dataset. An analysis of the data is presented in Ngā ia o te Oranga Hinengaro Māori: Trends in Māori Mental Health (Te Puni Kōkiri 1993). This document looks at mental health trends for Māori, Pākehā and Pacific people.

First admission data indicate that Māori are diagnosed with schizophrenia about twice as often as non-Māori. The readmission rates for Māori are 7.8 times higher than first admission rates (compared with 5.6 times for non-Māori). Schizophrenia accounts for a higher proportion of admissions for Māori: 37 percent of all male admissions and 32 percent of all female admissions (compared with 22 percent and 16 percent for Pākehā males and females). Māori are more likely to become seriously ill before help is sought, and admission is more likely to be through law enforcement agencies or welfare services.

The Te Puni Kōkiri report raises three key issues regarding schizophrenia and Māori:

• **aetiology:**
  – what is the role of cultural alienation, and socioeconomic factors?

• **diagnosis:**
  – are current criteria sensitive to and accurate for diagnosis in Māori?
  – are Māori misdiagnosed by health professionals?

• **service delivery:**
  – is there a lack of culturally appropriate early detection and support systems?
  – are services acceptable and accessible for Māori?
  – are methods of treatment appropriate for Māori?
PACIFIC PEOPLE AND SCHIZOPHRENIA

The information is again limited to the New Zealand Mental Health Dataset (Ministry of Health 1993). These data suggest that Pacific people have lower first admission and readmission rates for all disorders compared with Māori or Pākehā. Specific age-standardised rates for schizophrenia are not available for comparison.

RECOMMENDATIONS

As noted, there is only limited information available that addresses the epidemiology of schizophrenia in New Zealand, and less documenting the long-term course of the illness for the New Zealand population. Research must involve interdisciplinary collaboration, to encompass the heterogeneity of the disorder, and must consider both biological and psychosocial factors. Ethnic identity with particular reference to Māori and Pacific people must be considered, and data gathered on differences between population groups, including inception rates and service utilisation. Studies that sample appropriately for schizophrenia are required to validate or reject the findings of the CPES in order for service development plans to have a sound base.

RISK FACTORS

Evidence is mounting with regard to a variety of factors that increase the risk for development of schizophrenia. It is important to emphasise, however, that the risk of an individual developing schizophrenia remains largely unpredictable.

GENETIC RISK

The most prominent biological risk factor is heredity. The lifetime risk for schizophrenia with one affected parent is 10–12 percent (ie, 10 times the population risk), and if both parents have schizophrenia the risk for the offspring is 35–45 percent. However most people with schizophrenia do not have parents with schizophrenia (eg, 95 percent of people with schizophrenia do not have a mother with the illness). Also 36 percent of identical twins are discordant for schizophrenia (Kendler 1988) demonstrating the importance of non-genetic factors.

The role of genetic vulnerability and non-genetic factors interacting is further highlighted by Gottesman and Bertelsen (1989) in which the risk to offspring of discordant monozygotic twins was shown to be similar (ie, the illness ‘skipped a generation’).

PRENATAL RISK FACTORS

Observation of excess late winter and spring births of individuals who develop schizophrenia has led to a focus on prenatal events. In the last decade, the effect of viral exposure has been investigated and an association reported between prenatal exposure to influenza during the second trimester of gestation and subsequent schizophrenia. An Australian study has replicated the northern hemisphere observations (McGrath et al 1994) but it has been concluded that on the basis of current studies ‘overall . . . viral exposure cannot be considered a documented risk factor’ (Mrazek and Haggerty 1994).
Research has also documented increased risk with Rhesus incompatibility (Hollister et al 1996), extreme starvation in the first trimester (Susser and Lin 1992), and severe maternal distress especially during the third to fifth and ninth gestational months (Huttunen and Niskanen 1978).

**BIRTH COMPLICATIONS AND BIRTHWEIGHT**

A consistent finding in studies of prenatal events for those affected by schizophrenia has been an excess of obstetric complications (perinatal difficulties) which is more marked in those without a family history of the disorder. The mechanism for this is postulated to be infant anoxia during birth. Low birthweight has also been reported (reviewed McNeil 1995). Rifkin and colleagues (1994) reported that a birthweight below 2500 grams is more common in adults with schizophrenia than in patients with affective psychosis, and that a lower birthweight correlated significantly with impaired premorbid social adjustment and poor cognitive performance in adulthood.

A recent investigation of maternal influenza and obstetric complications suggests a link between maternal influenza during the second trimester, at least one definite obstetric complication and lower birthweight (Wright et al 1995). The authors conclude that maternal influenza may impair foetal growth and predispose to obstetric complications. The model suggests that obstetric complications may be the result of prenatal insult. However, this is a small retrospective study which requires replication.

McNeil (1995) reviews current research regarding obstetric complications, and addresses methodological concerns, highlighting the importance of studying the gestational timing of the insult to the foetus and risk for schizophrenia.

**NEUROINTEGRATIVE DEFECTS**

Subtle deficits in sensorimotor functioning (eg, fine motor co-ordination, visual motor functioning), together with 'soft' neurological signs have been described in infancy and early childhood in prospective studies of individuals at risk for schizophrenia. There is little specificity for these clinical signs, except when combined with other risk factors, namely a parent with schizophrenia and poor parenting (Marcus et al 1987; Jones et al 1994). The children with a parent with schizophrenia and neurointegrative deficits who had positive parental experiences did not develop schizophrenia (Marcus et al 1987).

**LOW SOCIOECONOMIC STATUS**

There is increased prevalence of schizophrenia in the lower socioeconomic classes. One explanation is that of downward social drift as a consequence of the illness. A UK study found there was an association between incidence of schizophrenia and social deprivation, and that this relationship existed early on in the lives of patients prior to the prodromal phase of the disorder (Dauncey et al 1993).

**FAMILY ENVIRONMENT**

Family discord and communication disturbances have been cautiously raised again in recent years as having a role in the onset of schizophrenia (Tienari 1992). In a retrospective adoption study, ‘severely disturbed households with disrupted communication’ was a risk factor predicting onset of psychopathology. This study does not adequately address the role of vulnerable children in causing disruptions to the family and communication styles. The evidence from expressed emotion research supports the role of environmental emotional milieu as a critical factor in the risk of relapse but has not shown it to be a contributor to the initial development of schizophrenia.
BEHAVIOURAL AND EMOTIONAL PROBLEMS IN CHILDHOOD

Precursor patterns of behavioural problems in childhood have been described. One is poor impulse control and aggression in children who have earlier exhibited neurointegrative defects and attentional impairment. A second is social withdrawal, awkwardness in interpersonal relations, diminished emotional expressiveness and lack of feeling during childhood and adolescence. These patterns define a population at risk for schizophrenia, but with little specificity. However if there is also a family history of schizophrenia then the risk is increased (Mednick and Silverton 1988).

SOCIAL FUNCTIONING

The premorbid level of social functioning is predictive of outcome in schizophrenia, with competency in areas such as friendships, intimate relationships, and occupation strongly correlating with good prognosis. Social impairment may itself be an expression of an inherited genetic personality pattern within the schizophrenia spectrum (eg, schizoid personality), rather than a separate risk factor for the onset of the disorder.

EFFECTS OF SEX

There are significant differences in the age of onset of schizophrenia between males and females, with male onset occurring about three years earlier. Males have a poorer prognosis than females, which may be related to the effect of sex itself, the younger age of onset, or poorer premorbid social functioning. Studies have not addressed the interactions between these variables to determine the potential role of each risk factor.

SUBSTANCE ABUSE

The role of substance abuse as a risk factor for the development of schizophrenia remains unclear and studies have generated conflicting findings as to whether it is a direct aetiological cause or enhances risk in a vulnerable individual. A body of evidence suggests that schizophrenia-like illnesses may be precipitated by heavy drug use. There is evidence that the use of cannabis is related to increased severity of symptoms and increased likelihood of relapse in people who have received a diagnosis of schizophrenia (Linszen et al 1994). The effect of heavier drug use can operate in the absence of a family history of schizophrenia (Bowers 1987).

SUMMARY

Genetic vulnerability predisposes to schizophrenia, but by itself does not account for the illness. There is mounting consistent evidence that a broad range of toxic prenatal and perinatal factors occurs more frequently in individuals with schizophrenia. The variation in timing of specific factors suggests that influences in different phases of early brain development are related to the subsequent development of schizophrenia. This is known as the neurodevelopmental hypothesis (Murray et al 1992).

The role of experiences and environmental factors in early childhood, including parenting, emotional development and socioeconomic status, are poorly understood. In later childhood and adolescence, social competency and substance abuse are examples of factors shown to be related to the outcome of schizophrenia, but relation to onset remains unclear.
PROTECTIVE FACTORS

The role of protective factors in prevention of the onset of schizophrenia has received little direct study. Protection has been inferred from studies identifying individuals with lower risk. The absence of perinatal complications, a sociable and easygoing temperament, and being of average intellectual ability are associated with lower risk. For children with a parent with schizophrenia, the experience of receiving adequate parenting is protective, even when other risk factors are present (Marcus et al 1987). If the parent is ill, having input from a stable non-psychotic adult is also protective (Garmezy 1988).

PREVENTION

Effective programmes for primary prevention will result in a decrease in the incidence of schizophrenia over a defined period of time, while secondary prevention will lower the rate of established cases of the disorder in the population. Optimal secondary prevention programmes could be expected to have an effect on one or more of the following: decreasing the duration of schizophrenia; halting the severity; halting recurrences; decreasing the time between episodes; or decreasing comorbidity. Secondary prevention in schizophrenia is commonly referred to as early intervention, and analysis of current literature and programmes is discussed later in Part I of this chapter, while primary prevention is discussed next.

PRIMARY PREVENTION

Primary prevention can be considered under three categories: universal, selective and indicated (Mrazek and Haggerty 1994). Recent articles written in Australia (NHMRC 1993), the US (Institute of Medicine (Mrazek and Haggerty 1994)) and Canada (Beiser and Iacono 1990) have reviewed the literature.

Universal preventive interventions are targeted to the general public, or to all members of a specific group not identified by individual risk. The intervention has advantage when the benefits outweigh the costs for everyone. There is little evidence to propose such interventions for the prevention of schizophrenia. For example, in an evaluation of the evidence for influenza causing schizophrenia, McGrath and Castle (1995) conclude that there is not sufficient evidence to start planning public health interventions (eg, vaccination, or education about infections in pregnancy). They highlight that ‘even if an association is present, the mechanisms are unknown. If the teratogenic element is the maternal antibody reaction rather than a direct effect of the virus, then vaccination may be detrimental.’

Selective preventive interventions are those interventions targeted to subgroups of the population whose risk of becoming ill is above average, and where the balance of benefit against risks and costs of the intervention can be justified. There is little documentation of intervention programmes in high-risk groups (eg, lessening risk through lessening obstetric complications).

The provision of optimal antenatal and obstetric care particularly for people with schizophrenia should be combined with programmes assisting these families during infancy and childhood. The children of parent/s with schizophrenia, particularly those with behavioural and emotional problems, need to be identified and involved in programmes designed to enhance resilience and lessen vulnerability (eg, social competency programmes), particularly when they reach adolescence. Such programmes need to be provided in a setting acceptable to and easily accessed by adolescents.
Indicated preventive interventions are those targeted to high-risk individuals who are identified as either having markers indicating predisposition for a disorder but being asymptomatic, or having detectable signs foreshadowing a mental illness but not reaching severity for diagnosis. The Institute of Medicine report concludes that at present the best hope for prevention of schizophrenia lies with interventions that target individuals exhibiting precursor symptoms and signs and that intervene early with pharmacological and psychosocial strategies to prevent the ‘full-blown disorder’. The high-risk precursor stage will overlap clinically with the prodromal period. In New Zealand, according high priority to the development of services that provide accessible early intervention is crucial, as is evaluation of such services.

Prevention programmes need to be developed by Māori, and provide cultural understanding of vulnerability and resilience in this population.

**EARLY INTERVENTION IN SCHIZOPHRENIA**

**First Episode Psychosis Studies**

The relationship between duration of illness, treatment response, recovery and outcome for first episode psychosis/schizophrenia has been the focus of an increasing number of studies that have produced compelling evidence of the cost of delay in detection and treatment.

The longer the duration of psychotic symptoms before treatment, the longer the time to remission, and the more likely there will be residual symptoms (Loebel et al 1992). Those who had taken longer than one year to access services had three times the relapse rate over two years (Johnstone et al 1986). The delay was associated with increased severe disturbed behaviour and family difficulties (Humphreys et al 1992). This ‘treatment lag’ has been measured: in North American studies there is an average duration of untreated psychosis of about one year for schizophrenia (Loebel et al 1992; Beiser et al 1993). In Australia, a similar delay has been found (McGorry et al 1994). A New Zealand survey of families found an average of three years from first signs of illness to diagnosis and intervention (Leafberg 1994).

Delay leads to increased economic cost of illness (Moscarelli et al 1991). If the duration between onset of psychotic symptoms and first contact is less than six months, total costs of the subsequent three years are US$5,606, but if the delay is greater than six months the total economic cost rises to US$12,283.

**Prodrome and Critical Period**

The prodrome period is a period of disturbance preceding the first psychotic symptoms, which is usually seen as representing a change from a stable premorbid mode. The prodrome may be thought of as an ‘at-risk mental state’. The symptoms of this state can be identified retrospectively, but are not specific in predicting the onset of schizophrenia. There are no data on the relative risk of transition to psychosis of people with at-risk mental states.

The deterioration in functioning classically described with the syndrome of schizophrenia appears to occur early in the course of the illness, and plateaus within the first five years (Carpenter and Strauss 1991). This period has been termed the ‘critical period’ (Birchwood and MacMillan 1993).
Early Intervention Studies

Using the classification developed by the Institute of Medicine report (Mrazek and Haggerty 1994), early intervention programmes encompass indicated prevention and treatment (ie, the traditional primary–secondary prevention classification). As noted, ‘the optimal treatment protocol aims to reduce the length of time the disorder exists, halt progression of severity, and halt the recurrence of the original disorder’.

The Early Psychosis Prevention and Intervention Centre (EPPIC) in Melbourne, Australia, is an internationally renowned centre that has developed a comprehensive service, which combines early detection (indicated prevention) with optimal early treatments. Community education and training, targeting those services and people likely to encounter young people with first episode psychosis (eg, general practitioners (GPs) and school counsellors), combined with easy access to initial assessment has reduced the treatment lag by more than a third (approximately 7 months to 4 months). Treatment results include reduction in length of hospital stay (an average 24 percent reduction), a 66 percent reduction in the amount of medication needed, improved compliance rates, and improved quality of life for individuals and families (McGorry 1994).

Falloon (1992) describes an intervention that targeted early detection of prodromal symptoms of schizophrenia (primarily through GPs), and referral without delay to the specialised mental health team. The provided interventions included education, home-based stress management, and targeted low-dose antipsychotic medication, and then continued monitoring and stress management for 24 months after resolution of the ‘prodromal state’. Case detection rates for schizophrenia over the four-year study period represented an annual incidence rate of 0.75 per 100 000 total population. Expected incidence was 7.4 cases per 100 000.

Recommendations

Research documenting basic epidemiological information regarding schizophrenia and the course of the illness in the New Zealand population is crucial, and must address the issues for the Māori and Pacific people.

‘Prevention efforts can be undertaken prior to the elucidation of aetiology’ (Mrazek and Haggerty 1994). In the absence of biological or psychosocial markers capable of predicting who is likely to develop schizophrenia, the intervention aim must be to accurately identify the earliest manifestations of psychosis, and provide interventions to the population at risk. These services need to be accessible, proactive and involve targeted community health worker training in the recognition of early psychosis. They must be appropriate to the culture of the individual and their relatives/whānau.

The first psychotic episode offers a ‘watershed in the course of a psychotic disorder. . . . (to) strongly influence the medium term pattern of illness and mode of recovery’ (McGorry et al 1994). Early intervention treatment programmes need to address key issues including relapse prevention, optimal medication strategies, and specific psychological therapies. Evaluation including outcome monitoring of New Zealand programmes will provide local information regarding efficacy of the programmes.
REFERENCES


CHAPTER 18: PART II
SCHIZOPHRENIA: THE NEEDS OF INDIVIDUALS AND FAMILIES

SUSAN NOSEWORTHY

THE NEEDS OF INDIVIDUALS AFFECTED BY SCHIZOPHRENIA AND RELATED DISORDERS

CONSUMER PARTICIPATION IN MENTAL HEALTH SERVICES

Since the early 1980s, there has been a trend, internationally and in New Zealand, for users of mental health services to participate in the planning and delivery of mental health programmes. A survey of Quebec out-patient service users found that consumers’ satisfaction with services was higher when patients and therapists agreed on treatment objectives. The survey also revealed that people with schizophrenia were less satisfied with their treatment than were people with affective and anxiety disorders (Perreault et al 1996).

The New Zealand Ministry of Health, in an attempt to increase consumer satisfaction, has issued *A Guide to Effective Consumer Participation in Mental Health Services*, in which strategies are presented to expand consumer participation (Ministry of Health 1995). Use of these strategies would benefit the delivery of all services – medical, social support, accommodation, vocational – and allow the services to meet consumer needs more effectively, empower the service users, and decrease the attitude of ‘benevolent paternalism’ which has been predominant in some mental health services over the past decades.

EARLY AND ONGOING MEDICAL SUPPORT

Overseas consumers and families often experience difficulties with crisis services, access to ordinary medical care, and lack of availability of hospital care when it is needed (Pulice et al 1995). In New Zealand, early intervention for treatment of psychotic symptoms is often not possible, because there are too few resources to accommodate those who are ‘becoming unwell’. Only the acutely ill person is able to access treatment (Schizophrenia Fellowship 1995).

There is a high incidence of untreated medical problems among people with schizophrenia, for a variety of reasons: difficulties in communicating with physicians, neglect of symptoms, and delayed diagnoses. There may be no follow-up care or treatment, and antipsychotic medications may confuse the clinical picture (Torrey 1995). Untreated physical illnesses and substance abuse, in addition to a high suicide rate, result in people with schizophrenia experiencing a mortality rate of up to five times that of the general population (Corten et al 1991).
The prevalence of substance abuse among people with schizophrenia has been estimated at between 34 and 48 percent, and this further complicates aspects of medical care. In New Zealand, the drugs most commonly abused are alcohol and cannabis. Young Māori men and women are much more likely to be admitted to a psychiatric hospital for treatment for drug-induced psychosis than are other New Zealanders (Te Puni Kōkiri 1993). Drugs may be abused in an attempt to self-treat the symptoms of psychosis, or to relieve side-effects of medications. People with schizophrenia give a variety of reasons for using and abusing alcohol: it decreases anxiety in social situations, it relieves depression (but only in the short term), and it combats sleep problems. However, some alcohol abusers also report that alcohol exacerbates symptoms such as hallucinations and paranoia (Pristach and Smith 1996).

It has been suggested that traditional drug treatment programmes are not suitable for people with mental illness (Hatfield 1994). Instead specialised treatment that is neither confrontational nor moralistic, but takes into account the special needs of the person with a dual diagnosis, is recommended.

Side-effects of antipsychotic medication may be serious and interfere with daily living, and ongoing medical assistance is necessary to ensure that extrapyramidal symptoms are kept to a minimum. The Transitional Health Authority is moving towards subsidisation of the new atypical antipsychotic drugs, which cause fewer Parkinson-like side-effects, and which may in some cases relieve the negative symptoms of schizophrenia. However, the medications are not yet used regularly as front-line drugs, and are not freely available to everyone who might benefit from them.

**SUPPORT FOR SUCCESSFUL LIVING IN THE COMMUNITY**

Psychosocial rehabilitation attempts the practical resolution of social and psychological difficulties faced by many people with schizophrenia. It may encompass such services as education for the individual and family to help them learn about the illness, cope with stress, set treatment goals, and develop coping strategies for all the issues that may confront the person and the family. Psychosocial rehabilitation may also include social and occupational skills provided in day centres; lessons in daily living skills such as cooking, shopping and cleaning; vocational skills; and supported employment. Programmes that have been designed in consultation with the consumers of mental health services, and which employ consumers as staff, are often more successful in helping people find meaningful employment and satisfactory accommodation (Silvestri 1994).

**Completion of Interrupted Education**

The age of onset of schizophrenia is strikingly narrow: 75 percent of those who get schizophrenia do so between the ages of 17 and 25 (Torrey 1995). A large number of young people have their formal education interrupted by early and subsequent acute symptoms of schizophrenia.

Completion of interrupted education is essential if a person is to fit back into community life, get a job, and maintain social contacts. Education programmes that are supported by the students, families, mental health workers, teachers, and educational institutions have the best chance of success. An example of a successful programme is that offered at Boston University in the late 1980s, which was developed to prepare young adults with long-term mental illness to get on with their lives (Unger et al 1991). The university campus was a normal, non-stigmatising environment for young adults. The curriculum was designed to teach the skills needed to choose, develop, and implement a career plan, and support was offered both inside and outside the classroom. Upon completing the four-semester course, the students either went on to other secondary courses or training programmes, or found a job.

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The number of hospitalisations experienced by the students decreased significantly, and their self-esteem increased significantly. There are no such specialised programmes in New Zealand at present.

**Skills Training, Social Networks, and Vocational Opportunities**

Finding and maintaining meaningful employment is a goal of most adults in Western society, and this is no less true for people with schizophrenia and related disorders. Vocational support must be considered an integral part of any rehabilitation–recovery programme for people with schizophrenia, despite the inherent difficulties presented by both the person with the illness and the community in which he or she wishes to work.

Extensive support is often needed for people with psychiatric disabilities to maintain employment. A client may need advocacy assistance to get along with supervisors and co-workers, help with symptom management, and access to peer support. The types of work support particularly important to people with psychiatric illness are natural co-worker supports; peer and family supports; training supports; and organisational support from the employer (Marrone et al 1995).

Activity-based rehabilitation services are available to some extent in New Zealand, but are not universally accessible to people with serious psychiatric disorders. People do not usually have the opportunity to relearn skills, learn a trade, or participate in the workforce (Schizophrenia Fellowship 1995). The recent surveys of users of mental health services in Auckland and Christchurch showed that around 75 percent of the respondents did not have paying jobs, even though one-third of the people were looking for paid work (Dimensions 1995a, 1995b).

Social, vocational, and housing programmes for people with serious mental illness are blended together in the ‘clubhouse’ model, of which Fountain House in New York is probably the best-known example (Peterson 1982). The Framework Trust in Auckland is based on this model, and offers social and development clubs, activity centres, work skill centres, work co-operatives, needs assessment, employment and training support, and accommodation and community support services. The Framework Trust has twice won a gold medal for innovation and excellence from the Australia–New Zealand Mental Health Services. Its service is based on the premise that mental health consumers choose opportunities according to their changing and individual needs (Loates 1995).

**Accommodation and Financial Support**

Recovery from serious mental illness is intimately tied up with consumers earning a fair wage for work and living in decent accommodation of their own choosing. An example of a service using this philosophy is Monadnock Family Services in Keene, New Hampshire, in the US. In this work co-operative and housing trust, individual clients work in consumer co-operatives and in the community. People live in their own flats, or with other people. With help from key workers, people with psychiatric illnesses who previously spent months on end in hospital are now keeping jobs and living independently (Silvestri 1994). Social support from friends is also crucial (Kearns et al 1993).

In New Zealand there is a variety of ‘supported housing’ available to people who are in contact with mental health services. Such accommodation provides varying degrees of support from paid workers, and involves living in group homes with other consumers. Most people with a mental illness would prefer to live in their own flats or houses with a spouse, partner, or friends. Individuals also generally prefer not to live with other mental health consumers, which may reflect a reaction against the practices of traditional residential services which tend to offer people too little choice in decisions about where and with whom they will live (Tanzman 1993).
Consumers and families advocate choice in accommodation, but this can only occur if options are available at prices people can afford. A 1993 survey of members about accommodation in New Zealand for people with schizophrenia showed that 46 percent of the respondents lived with their families, and 38 percent in their own or rented flats. The remainder lived in hostels or boarding-houses, but the actual numbers of people who live in boarding-houses or hostels was under-represented in this survey (Schizophrenia Fellowship 1993).

In 1989, users of psychiatric services in Auckland and Christchurch were surveyed about their accommodation (Kearns et al 1993). For many people, serious problems resulted from insufficient living space, lack of maintenance of the dwelling, and inability to afford adequate heating in the winter. It was clear from the survey that mentally ill people, dependent on welfare benefits, were living in substandard dwellings. Those who have little or no contact with mental health services may be more at risk in this respect.

A 1995 survey of consumers in the same two cities showed that living in one’s own house or flat, with a partner or friends, was by far the most popular accommodation option (Dimensions 1995a, 1995b). Living in a group home, boarding-house, or rehabilitation programme was not seen to be desirable in the long term.

However, data from the 1989 Auckland–Christchurch survey have been used to show that support from friends appears to mitigate the distress experienced by the mentally ill living in the community, even those who are encountering housing stressors (Smith et al 1994). Supporting interventions that help to foster healthy social structures and increase development of the community itself, as opposed to simply a greater proliferation of services in the community, may be an effective policy and planning strategy.

THE NEEDS OF FAMILIES AND CAREGIVERS OF PEOPLE WITH SCHIZOPHRENIA AND RELATED DISORDERS

THE BURDEN OF CARE

The onset of illness often produces a state of crisis in the family, as familiar reality gives way to a new kind of existence imposed by an unforeseen and uncontrollable event. The life that the family is accustomed to must change to one that is affected by the rapidly changing demands of mental illness, and this disruption in existence causes psychological and physical stress.

Families experience a range of emotions when schizophrenia strikes one of their members. They feel the loss of the person who is ill, who may become a ‘different person’. Families empathise with the illness, mourn the loss of a young person’s potential, and often have intense grief reactions, which may manifest themselves in physical symptoms. Siblings are often greatly affected.

The self-image of parents whose children have schizophrenia suffers a severe blow. Families usually feel embarrassment and shame, have feelings of guilt and blame, and may be stigmatised by the community. There is the worry about the dangerousness of the unwell relative, both to family members and to the wider community, and family members may be anxious about their own loss of control in the face of constant stress (Hatfield 1990). These reactions are often not recognised by mental health professionals, despite the increasing body of literature by family workers (Hatfield and Lefley 1987; Alexander 1991; Backlar 1994; Torrey 1995). The psychological ill health in family carers is around twice that expected in the general population, and is a function of objective and subjective burdens, as well as patient symptoms (Oldridge and Hughes 1992).
RELATIONSHIPS WITH HEALTH PROFESSIONALS

Families must learn to relate to mental health professionals as well as learning how to cope with their ill family member (Spaniol et al 1987). Families require supportive and understanding help from mental health workers but frequently report that they do not receive this. Both historical studies and recent surveys report that families feel that they are not given adequate information about mental illness, that they are not advised on how to take care of themselves, and that they are not actively involved in their family member’s treatment. The need for more communication with the mental health staff is the biggest perceived need by family caregivers (Fadden et al 1987; Biegel et al 1995).

Health professionals should understand not only the huge emotional burden on families, but also the financial burden incurred when caring for relatives who are not employed, who may not be able to manage money efficiently, and who may occasionally run up alarming expenses due to impulsive spending or misplaced generosity. Difficulties may arise because caring for a relative limits opportunities for an adequate income, or if the ill person was formerly the main income-earner (Fadden et al 1987). There are no New Zealand figures available, but it has been estimated that in the US, the aggregate cost of family caregiving for schizophrenia (time and money) is US$2 billion per year (Rice and Miller 1992). The extent to which families are impoverished should not be underestimated.

The idea of a ‘therapeutic partnership’ in the treatment of schizophrenia, involving the individual, health professionals, and family or caregivers, is slowly gaining ground among mental health workers. It is a difficult goal, but one worth striving for, given the improved outcomes for patients and families, and the reduction in costs to the state of acute and long-term care. Advances in the treatment of schizophrenia will not occur simply as a result of implementing isolated therapeutic strategies. Such interventions need to be synthesised into a comprehensive approach to management of the illness (Boker 1992).

WHOLE-FAMILY INVOLVEMENT AND PSYCHOEDUCATION PROGRAMMES

Families are a key resource in the care and treatment of their mentally ill relatives. The older hypotheses that families were to blame for causing mental illness were abandoned by the 1970s. The 1980s saw the development of a number of psychoeducational programmes where families were seen as allies of the treatment team. In general, research on family psychoeducation has reported success for both patients and family members, especially when continued over several months or years.

There is a variety of effective family intervention approaches that share the following features (Bellack and Mueser 1993):

- a positive approach and genuine working relationship between health professionals and families
- the provision of psychoeducation in a stable, structured format
- a focus on improving stress and coping in the ‘here and now’ rather than focusing on the past
- encouragement of respect for interpersonal boundaries within the family
- provision of information about the biological nature of schizophrenia so as to reduce blaming the patient and family guilt
- the use of behavioural techniques, such as breaking down goals into manageable steps
- improving communication between family members.
Further important characteristics include: de-emphasis on family systemic change as a therapeutic goal, and a strong emphasis placed on the individuals’ and relatives’ realistic expectations for recovery (Vaccaro et al 1993).

All family models are labour-intensive packages. Families and individuals are accorded far more therapeutic input and contact with health professionals than would be the case in ‘routine’ care, and the result is often a greater understanding of the nature of the illness, the rationale of treatment, and a greater commitment from the family to ensure compliance with the programme. This formation of an alliance between professional workers, individuals, and families or carers is vital, and the resulting benefits include a reduction in the number of major episodes of psychotic disorder, and reductions in social disability and household stress (Hatfield 1990).

In New Zealand, a number of centres are assisting families using methods based on Falloon’s model of Integrated Mental Health Care (IMHC) (Falloon and Fadden 1993). IMHC is a standardised method that emphasises education about schizophrenia for the whole family unit, communication skills training, problem-solving training, and advance planning for special situations. This is combined with medication, intensive crisis intervention, and specific strategies for dealing with persistent symptoms and social disabilities. The approach has been shown to markedly reduce relapse and hospitalisation rates, improve the social functioning of the person with the mental disorder, and decrease the family’s level of burden and distress (Falloon et al 1987).

The success of family models of care in reducing relapse rate and improving quality of life depends upon the other existing health services. The availability of income support, alternative housing, and respite care are all likely to influence the ability of families to support family members with schizophrenia (Halford 1994). To date, research has not accounted for the relationship between available resources and the success of family support models.

**FAMILIES’ COPING MECHANISMS**

Families develop a variety of coping mechanisms to deal with the effects of a relative’s illness on the family. Even without professional help, they are able to distinguish between effective and ineffective strategies, reduce their emotional stress, identify their relative’s behaviours that will lead to family stress, take advantage of natural family support systems to ease their responsibilities, and become more knowledgeable about schizophrenia. Using these mechanisms, a substantial percentage of family carers manage to cope with the difficulties without suffering psychologically (Oldridge and Hughes 1992). However, more assistance from mental health professionals would help immensely, especially in alleviating anxiety, minimising adversarial situations with the relative, and relieving forebodings about ‘what will happen to my relative when I am gone?’ (Lefley 1987).

The development of self-help and advocacy groups is another family coping mechanism that helps families ‘mobilise their energies for advocacy rather than invest them in futile despair’ (Lefley 1987). Self-help groups for families, such as the Schizophrenia Fellowship in New Zealand, the National Alliance for the Mentally Ill in the US, the National Schizophrenia Fellowship in Britain, the Schizophrenia Association of Ireland, and the Association of Relatives and Friends of the Mentally Ill in Australia, are oriented towards providing emotional support to families and empowering them through education and mutual strength. Such self-help groups act as a referral service to sympathetic health and welfare professionals, teach advocacy skills, provide education materials, and effect change.
COMMUNITY EDUCATION AND UNDERSTANDING

The community in general knows very little about mental illness. A recent survey of Dunedin residents revealed that fewer than 20 percent of the sample felt that their knowledge of mental illness was adequate. Fewer than half the respondents knew that mental illness could be inherited, and there was great confusion about the terms ‘mental illness’, and ‘mental disorder’. Ninety-five percent of the residents knew that schizophrenia is a mental illness, but 24 percent were uncertain about the status of alcoholism, dementia, and child molestation (Ng et al 1995). Another New Zealand survey found that stress is widely seen as being the main cause of mental illness (Patten 1992), followed by heredity, substance abuse, and organic causes or accidents.

Similar results have been reported from the UK where schizophrenia was by far the most commonly known type of mental illness among residents of several London suburbs (Wolff et al 1996b). In the same neighbourhoods, people from lower socioeconomic groups, the least educated, and people with children had the most negative attitudes towards the mentally ill (Wolff et al 1996a).

A 1992 series of ‘focus group’ discussions in the Wellington area was designed to investigate the attitudes and views of the general public about mental illness (Patten 1992). Group members recognised that stigma was a problem, but felt that fear of violence and fear of unpredictable behaviour were the reasons that many people distanced themselves from people with mental illness. Several groups thought that community attitudes could be improved by education programmes about mental illness. They cited television and radio programmes about AIDS, heart disease, and intellectual handicap as examples of public education efforts that made a difference in their own attitudes and understanding.

If people with major psychiatric disorders are to live and work successfully in the community, there must be a greater degree of community education and tolerance than exists at the present time. Education must be offered in an accessible and ongoing fashion to employers, police, community groups, schools, and service organisations, so that the disabilities associated with mental illness come to be understood and accepted in the same way that people are beginning to understand physical and intellectual disabilities.

REFERENCES


