

Part I

Recovery in Historical Context

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Introduction: Recovery from Schizophrenia

Overview

In this chapter, schizophrenia serves as an exemplar of a most serious form of mental illness, which historically has been difficult to understand, classify or treat. As such, it has been widely researched over many years, generating a large body of empirical research into recovery. Much of the consumer-oriented qualitative research into recovery, however, includes other mental illnesses. Therefore, we have utilized the empirical research into schizophrenia to provide 'hard evidence' for recovery from mental illness before expanding our work to incorporate the consumer-oriented literature.

Here we put into historical perspective how the idea that there was no hope of recovery from schizophrenia became entrenched within the mental health profession. First we present an historical overview of concepts of schizophrenia, and how these influenced diagnostic systems and prognosis. Next, we present findings from longitudinal and cross-cultural research that show that recovery, in the medical sense – that is, freedom from signs and symptoms of mental illness – occurs more frequently than once believed, and discuss why the rate of recovery went unrecognized for most of the twentieth century.

We then look at how the consumer recovery movement grew from diverse ideological standpoints, and how the consumer movement describes a form of recovery in addition to the traditional medical meaning of the term. Finally we conclude that there is a need for consensus on the consumer definition of recovery, which can be operationalized, in order to meet demands for evidence-based practice with a recovery orientation.

Early Conceptualizations of Schizophrenia

A diagnosis of schizophrenia has traditionally been considered tantamount to a 'prognosis of doom' (Deegan, 1997, p.16), which denied all hope of recovery or even of a reasonably satisfying life. Mental health professionals, in particular medical professionals, have a pessimistic outlook regarding the prognosis for schizophrenia (Hugo, 2001; Jorm *et al.*, 1999). The idea that schizophrenia had an inevitable deteriorating course culminating in a life which revolved around stabilization, medication management and survival, has its roots in early descriptions, in which chronicity was considered a criterion for schizophrenia. The earliest description of schizophrenia was that of Emil Kraepelin, who, over many years of clinical observation, asserted that the diseases then known as hebephrenia, catatonia, and paranoia were all characterized by commencement in adolescence followed by a progressively deteriorating course culminating in dementia (1913, cited in Weiner, 1966/1997; Turner, 1999). Kraepelin believed that these diseases all had a common aetiology, course and outcome, and should be identified as forms of a single disorder, *dementia praecox*, the fundamental criterion for which was its outcome, dementia (Turner, 1999; Pull, 2002). Kraepelin considered the illness to be an irreversible disease of the brain, probably caused by autointoxication – toxicity due to metabolic or other bodily processes (Turner, 1999) – and was not open to the idea that any symptoms of the illness could have psychological underpinnings (Weiner, 1966/1997). Although 12% of Kraepelin's patients made a complete, or almost-complete, recovery (Warner, 2004), he felt that those who recovered had been incorrectly diagnosed, as an outcome of dementia was fundamental to the disease (Weiner, 1966/1997; Read, Mosher and Bentall, 2004).

Eugen Bleuler, on the other hand, did not think that dementia was an essential aspect of the disease, and he noted that the illness did not always commence in adolescence (E. Bleuler, 1911/1950). He asserted that the fundamental symptom of schizophrenia was a 'splitting' of the various psychic functions – a loosening of associations between ideas and incongruous emotional responses. Bleuler coined the term *schizophrenia*, which comes from the Greek for 'to split' (schizin) and 'mind' (phren), and advocated the use of this term to replace *dementia praecox* (E. Bleuler, 1911/1950). Bleuler elaborated on Kraepelin's formulation of *dementia praecox* with a number of new concepts. First, he argued that symptoms could range over a continuum from the almost unnoticeable to the most florid; second, he claimed that the label schizophrenia could apply to people who are making reasonable life adjustments in the community, with no psychotic symptoms; and third, he asserted that, although a person may be socially reinstated after an acute episode, residual symptoms were always present (Weiner, 1966/1997). Bleuler also argued that schizophrenia was not one single illness, but rather a group of several diseases with different aetiologies, courses and outcomes (Pull, 2002). He added two new subgroups: *simple schizophrenia*, which broadened the concept of schizophrenia considerably (to apparently include those who hold menial jobs and bad housewives

who are nagging shrews); and *latent schizophrenia*, which parallels later concepts of schizoid and schizotypal personality (Wing, 1999). Bleuler's conceptualization of schizophrenia was much more psychodynamic than was Kraepelin's, and he believed that there was a link between symptoms of schizophrenia and psychological processes (Weiner, 1966/1997). Bleuler posited that the symptoms of schizophrenia may be the result of psychological factors, but was unsure as to the underlying cause of the disease. He concluded that schizophrenia was a group of disorders, some endogenous (and therefore organic), and some reactive (and therefore psychological) (E. Bleuler, 1911/1950; Clare, 1980). The organic form carried a worse prognosis than the reactive form.

In contrast to those of Kraepelin, 60% of Bleuler's patients recovered well enough to work and support themselves outside hospital. There are a number of possible explanations for this difference in outcome. First, Bleuler broadened the definition of schizophrenia to include those with a better prognosis; and second, Kraepelin would have defined recovery as freedom from symptoms, rather than social functioning (Warner, 2004). However, we cannot overlook the effects of Bleuler's more psychodynamic perspective, and his belief that there were psychogenic causes for much of the observed symptomatology (Warner, 2004). This point of view resulted in a more therapeutic approach to treatment, in which great importance was placed on minimizing hospital-based care, on the quality of the person's environment, and on providing opportunities for work (Warner, 2004). Although Bleuler did not agree that schizophrenia necessarily resulted in dementia, neither did he believe that people ever fully recovered: 'Personally I have never treated a patient who has proved on close examination to be entirely free from signs of the illness' (E. Bleuler, 1911/1950, p. 256).

These early formulations of Kraepelin and Bleuler have had long-reaching effects. With no firm evidence of its aetiology, schizophrenia has continued to be conceptualized and classified in terms of its clinical manifestations. Theorists have classified the symptoms of schizophrenia on a number of dimensions, in attempts to improve diagnosis and prognosis. In terms of diagnosing schizophrenia, the formulations of Bleuler (1911/1950) and Schneider (cited in Pull, 2002) have been widely influential. Bleuler differentiated *fundamental* symptoms from *accessory* symptoms. The fundamental symptoms – disturbances in association and affect, ambivalence and autism – were always present in schizophrenia, while the accessory symptoms – including hallucinations and delusions – may or may not be present, and may also be present in other illnesses. The fundamental symptoms were direct manifestations of the disorder, and therefore necessary for a diagnosis of schizophrenia, whereas the accessory symptoms were psychological reactions to the illness, and were not required for a diagnosis (E. Bleuler, 1911/1950; Pull, 2002). In contrast to Bleuler, Schneider (1950, cited in Pull, 2002) held that such symptoms as hallucinations and delusions were pathognomonic of schizophrenia. That is, these symptoms alone were sufficient to give a diagnosis of schizophrenia. Schneider differentiated between abnormal *experiences* and abnormal *expressions* (1950, cited in Pull, 2002). He identified 11

first-rank symptoms, which can be grouped into three categories: passivity experiences, in which thoughts, emotions and actions are felt to be externally controlled; auditory hallucinations in the third person; and primary delusions, which arise suddenly and without explanation from a normal perception (Clare, 1980). These abnormal experiences he called 'first-rank' symptoms, and the presence of any one of these was sufficient for a diagnosis of schizophrenia. 'Second-rank' symptoms included disturbances in language, writing and movement, affective symptoms and emotional blunting, all of which could occur in other illnesses (Clare, 1980). A diagnosis of schizophrenia could also be given when only second-rank symptoms were present (Schneider, 1950, cited in Pull, 2002).

Whereas Kraepelin's definition of schizophrenia was based on onset, course and prognosis, Bleuler focused on the dissociative symptoms and Schneider emphasized the importance of the psychotic symptoms such as hallucinations and delusions. All three formulations have been influential to varying degrees in different diagnostic systems until the present day, including the *Diagnostic and Statistical Manual of Mental Disorders* (4th Edition) (DSM-IV; American Psychiatric Association, 1994), the tenth revision of the *International Classification of Diseases and Related Health Problems* (ICD-10; World Health Organization, 1992) and Present State Examination (PSE; Wing, Cooper and Sartorius, 1974).

Diagnostic Systems and Prognostic Pessimism

For the first half of the twentieth century, there was no universal or even widespread definition of schizophrenia. In the United States, the strong psychoanalytic tradition led to a leaning towards Bleuler's broader definition, while in the United Kingdom, Schneider's first-rank symptoms were dominant, and in Europe diagnosis was largely based on Kraepelin's prognostic approach (Clare, 1980). Different countries, even different schools within a country, had widely differing conceptualizations of schizophrenia (Leff, 1988). The first classification systems for mental disorders were published in the mid-twentieth century. The World Health Organization (WHO) included mental disorders in the sixth edition of the *International Classification of Diseases, Injuries and Causes of Death* (ICD-6; WHO, 1948) and the American Psychiatric Association (APA) published the first edition of the *Diagnostic and Statistical Manual* in 1952 (DSM I; APA, 1952). However, diagnosis of schizophrenia was much more frequent in the United States than it was in the United Kingdom or Europe. Two major research programmes highlighted this problem. The United States–United Kingdom Diagnostic Project (Cooper *et al.*, 1972) found that there were almost twice as many people admitted to hospital with a diagnosis of schizophrenia in the USA than in the UK. In addition, when UK psychiatrists diagnosed the USA schizophrenia patients, only approximately 50% were given the same diagnosis (Cooper *et al.*, 1972). The WHO then conducted the International Pilot Study of Schizophrenia (IPSS), a transcultural research project that compared diagnostic practices across nine countries (WHO, 1973). Again it was found that

many patients diagnosed with schizophrenia in the United States would have been given a diagnosis of neurosis in other centres.

Following from these studies, the DSM-III (APA, 1980) represented a major change in official diagnostic procedures, advocating the use of operationally defined phenomenological criteria based on Schneider's (1957, cited in Leff, 1988) first-rank symptoms, and specifying a minimum duration of illness of six months (Leff, 1988). As a consequence, the DSM-III diagnostic criteria were much narrower than those of its predecessors, or even the ICD criteria (Leff, 1988), which still retains simple schizophrenia, a diagnosis not requiring any psychotic symptoms (Bertelsen, 2002). The DSM-III took an atheoretical approach to classification which avoided descriptions based on an assumed aetiology, although a chronic course was still emphasized (Carpenter and Buchanan, 1994). It was not until work began on the tenth edition of the ICD (ICD-10; WHO, 1992) that international efforts were made to coordinate diagnostic criteria, mainly for the purposes of research. As a result, diagnostic criteria for schizophrenia in the fourth edition of the DSM (DSM-IV; APA, 1994) and the ICD-10 are much more closely aligned than previous systems. The ICD-10 continues to give diagnostic importance to Schneider's first-rank symptoms, and, although the DSM-IV states that no single symptom is pathognomonic for schizophrenia, the presence of 'bizarre' delusions, or auditory hallucinations consisting of a voice giving a running commentary on the person's behaviour, or two voices conversing, are sufficient to meet the psychosis criterion for schizophrenia.

Kraepelin's belief that all mental illnesses arise from biological causes has tended to dominate psychiatric classification systems. It was not until the DSM-IV that any remaining distinction between organic and psychological disorders was eliminated (Barlow and Durand, 1995). In practice, Bleuler's broad definitions of 'simple' and 'latent' schizophrenia became coupled to Kraepelin's organic formulation, giving a wide range of disagreeable behaviour the weight of a medical diagnosis (Wing, 1999). Thus the pessimistic prognosis inherent in Kraepelin's early formulation became incorporated into the expectations of those professionals who were using Bleuler's more inclusive definition, with the result that people who were diagnosed with schizophrenia on even the most loosely-defined criteria were not expected to recover.

Empirical Evidence for Recovery

Despite the pessimistic culture within psychiatry which flowed on to inform societal expectations and ultimately those of the afflicted individual and his or her family, there is a growing literature surrounding the notion of recovery from schizophrenia. The concept of recovery started gaining momentum in the 1980s, when people with schizophrenia began publishing accounts of their recovery. These accounts revealed that many had managed to overcome the problems imposed by the illness and went on to enjoy a full and meaningful life. Influential consumer advocates have been

working towards breaking down the notion that schizophrenia necessarily has a long-term deteriorating course, for example, Curtis (2000), Deegan (1997), Fisher (1994), Frese (2000) and Schmook (1996). Autobiographical evidence of a more positive outlook for schizophrenia is supported by a number of quantitative studies, including longitudinal and cross-cultural studies of outcome.

Longitudinal studies of outcome

The Vermont longitudinal study was a landmark study of long-term outcomes of schizophrenia (Harding *et al.*, 1987a, 1987b). This research involved 269 of the most disabled, long-stay patients who had been ill for an average of 16 years, had been totally disabled for 10 years and hospitalized continuously for six years. During the era of deinstitutionalization in the mid-1950s, these patients, who had not responded well to modern drug therapy, took part in a comprehensive rehabilitation programme. Ten years after their release from hospital, 70% remained out of hospital. The study used blind raters and comprehensive, reliable, structured protocols, including the Global Assessment Scale (Endicott, Spitzer and Fliess, 1976), the Strauss–Carpenter Levels of Functioning Scale (Hawk, Carpenter and Strauss, 1975) and 13 other well-established measures. It was found at follow-up 20 to 25 years later, that 68% were functioning at a level most people would consider ‘normal’ (Harding *et al.*, 1987a). When restricting the cohort to those who retrospectively met the DSM-III criteria for schizophrenia, 34% were found to have achieved full recovery, and a further 34% to have achieved significant improvement in both psychiatric status and social functioning. The criteria were strict and included: living in the community, being employed, not using psychiatric medications, being free of symptoms, not having behaviours that would be considered those of a ‘mental patient’, and having good relationships with others (Harding *et al.*, 1987b). Harding and colleagues have championed the cause of heterogeneous outcome expectations for schizophrenia. In a review of longitudinal studies, Harding, Zubin and Strauss (1987) noted a number of methodological problems with earlier studies that had produced contradictory results. They therefore proceeded to review the more recent, methodologically sound studies of the time and found that poor outcomes were much less common than had been previously assumed.

The Harding, Zubin and Strauss, (1987) review included the Vermont study and four other long-term studies: M. Bleuler (1972/1978), Tsuang, Woolson and Fleming (1979), Huber *et al.* (1980) and Ciompi and Muller (1976). Combining the results of the five studies, Harding, Zubin and Strauss (1987) found that, of over 1300 ex-patients, one-half to two-thirds had recovered or significantly improved. A number of more recent studies have lent further support to these findings. For example, in a five-year follow up study of a cohort of 70 schizophrenia patients, good social functioning was recorded in 62% of the entire cohort, and a good outcome in terms of combined symptoms and hospital admissions for 58% of the

first-admission cohort (Shepherd *et al.*, 1989). Harrison *et al.* (1993) explored 15- and 25-year follow-up outcomes of 644 subjects from the WHO International Study of Schizophrenia (ISoS; Sartorius *et al.*, 1996). Using Bleuler's (1972/1978) scale, 48% of the 15-year incidence cohort and 54% of the 25-year prevalence cohort were rated as recovered, meaning 'he could be fully employed in meaningful work and resume his former role in society' (Bleuler, 1972/1978, p. 191). Furthermore, 42% of the total cohort had not experienced a psychotic episode in the past two years. Mason *et al.* (1995) conducted a 13-year follow-up study on an incidence cohort of 67 patients. Using measures including positive and negative symptoms, social disability, functioning and treatment status, they found that 44% achieved a 'mild' or 'recovered-treated' outcome. Using a definition of 'complete recovery' as no symptoms, no disability and no treatment, 17% of the sample were completely recovered at follow-up, while using Bleuler's criteria, approximately 57% were recovered. Harrow *et al.* (2005) conducted a prospective 15-year follow-up study. Recovery was defined as status over the follow-up year based on the following criteria: absence of psychotic or negative symptoms, adequate psychosocial functioning including at least half-time employment (not necessarily paid), absence of poor social activity level, and no psychiatric hospitalizations. Harrow *et al.* found that at 15 years, 19% of the schizophrenia cohort were in recovery. In addition, they found that, over the course of 15 years, 41% of patients had been in recovery at some point, demonstrating that schizophrenia was not necessarily chronic and continuous, but episodic in nature. It is worth noting that the criteria for recovery in some of these studies perhaps describe a higher level of functioning than would be met by many people who do not have a mental illness or other disability.

Cross-cultural studies

In addition to the longitudinal studies conducted in the United States, United Kingdom and Europe, cross-cultural studies have found sociocultural differences in outcome. A number of studies have found that outcome from schizophrenia is better in developing than in developed countries.¹ Warner (2004) reviewed follow-up studies conducted in Third World countries. Warner's review included a number of studies from India, as well as studies in China, Mauritius, Sri Lanka, Hong Kong, Singapore, Nigeria and Bali that were published between 1971 and 2001. The follow-up intervals for these studies varied from one to 15 years. The majority of the studies found better outcomes than would be expected in Western countries, with two exceptions: Chandigarh, India and Sichuan, China. These two centres did not return substantially better outcomes than achieved in Western countries. However,

¹ There has been some criticism of the dichotomy 'developed/developing', as some centres, although non-Western, are nonetheless developed (e.g. Hong Kong). Other terminology used is 'industrialized/non-industrialized', 'Western/Non-Western' and 'Third World'. We use terminology consistent with that of the author cited.

the Indian study can be faulted by the high percentage of subjects lost to follow-up. Only 57% of the original Indian sample could be traced for follow-up, a group that included those who had remained in hospital, but did not include those who had moved on (Warner, 2004). The Sichuan results can perhaps be explained by the fact that the sample was a point prevalence cohort, which, since it includes those who have already demonstrated a long-term course, will be biased towards poorer outcomes (Warner, 2004).

Comparing findings of studies conducted in various countries may be limited by the method of identification of subjects, differences in diagnostic practices and in measurement of outcome. To address these issues, the WHO conducted two standardized international follow-up studies into schizophrenia (WHO, 1979; Jablensky *et al.*, 1992). The IPSS research project, described earlier, compared outcomes from nine centres: Aarhus, Denmark; Agra, India; Cali, Colombia; Ibadan, Nigeria; London, Moscow, Prague, Taipei and Washington, DC; representing both developed and developing centres (WHO, 1973). Patients were evaluated using a standardized system, the PSE, enabling comparison of similar subjects across developed and developing centres. Five outcome categories were devised from the results of a two-year follow-up. The best outcome was described as full symptom remission, no social impairment and less than four months of psychosis during the two-year follow-up period (WHO, 1979). An unexpected finding from this study was that 35% of patients from developing countries fell in the best recovery category, compared with only 15% of patients from the developed centres.

One possible explanation for these results is that of selection bias in developing countries. Leff (1988) posited that those people who are violent or disruptive to the community may be more likely to be referred for treatment in developing countries, and at the same time, may have a better prognosis than others (Leff, 1988). However, in a review, Leff (1988), found that these characteristics were not associated with better prognosis, nor were they a source of selection bias. The possibility of selection bias was minimized in a second international WHO study, the Determinants of Outcome of Severe Mental Disorders (DOSMeD; Jablensky *et al.*, 1992). In this study, care was taken – including contacting traditional healers – to locate all patients at centres in 10 countries who had made their initial contact with help services during the study period. The study encompassed 12 centres across 10 countries: Aarhus, Denmark; Agra and Chandigarh, India; Cali, Colombia; Dublin, Ireland; Honolulu and Rochester, United States; Ibadan, Nigeria; Moscow, Russia; Nagasaki, Japan; Nottingham, United Kingdom; and Prague, Czechoslovakia (Jablensky *et al.*, 1992).

One- and two-year follow-up data confirmed the findings of earlier studies, with a more benign course and better outcome in developing countries. Sixty-three per cent of cases in developing countries were in the best outcome group, compared with 37% of those in developed countries. In contrast, 16% of patients in developing countries were in the worst outcome group – impairment in functioning throughout the follow-up period – compared with 42% of cases in developed countries (Jablensky *et al.*, 1992). Interestingly, the two strongest predictors of two-year course and outcome were found to be type of onset and setting (developed versus

developing country; Jablensky *et al.*, 1992). Using an alternative analytic procedure on the data, Craig *et al.* (1997) found that the strongest predictor of course was 'centre', but with two developed centres grouping with the developing centres, and one developing centre grouping with the developed centres. Hopper and Wanderling (Hopper, 2004; Hopper and Wanderling, 2000) further explored these outcome differences in a 15-year follow-up study of only the incidence cohort of the WHO ISoS studies. They found that a more favourable outcome for developing centres was consistent on all outcome measures, even when different diagnostic groupings were used (ICD-10 schizophrenia, broad-spectrum schizophrenia and all psychoses). As well, a 15-year follow-up study of the DOSMeD incidence cohort also found that 'centre' was the second strongest predictor of outcome after 'short-term course' (Harrison *et al.*, 2001).

Why should it be that developing countries, which often lack the facilities and resources of the West, consistently show better outcomes for schizophrenia? These studies suggested that environmental factors had a profound impact on the course and outcome of schizophrenia, although some researchers have questioned the validity of this conclusion.

Explanations for cross-cultural differences

Some explanations for the observed cross-cultural differences in outcomes for schizophrenia question the methodology of the studies, while others describe cultural factors that may affect outcome. If the differences can be explained by poor methodology, then we can retain the assumption that the natural course of schizophrenia ends in a poor outcome. However, if methodological problems can be ruled out, we need to examine cultural factors that may explain the better outcomes in non-Western countries, in an effort to understand the processes of recovery.

Methodological sources of bias. The WHO studies were designed to minimize diagnostic artefact, with clinicians undergoing training in the use of the PSE, and having to demonstrate reliability during the study both within and across centres. In addition, in the DOSMeD study, diagnoses were reviewed by WHO experts. Nonetheless, Hopper and colleagues discussed several sources of potential bias and offered evidence to counter each of these issues (Hopper and Wanderling, 2000; Hopper, 2004).

- *Attrition pattern.* Although efforts were made to reduce selection bias, Hopper and Wanderling (2000) explored the possibility of systematic bias in attrition rates. They found that the rates of loss to follow-up were comparable across centres. Furthermore, it was found that in developed countries, the subjects with a more favourable early course of illness were more likely to be traced for follow-up. Therefore the data would more likely be skewed in favour of developed countries (Hopper and Wanderling, 2000).

- *Arbitrary grouping.* The ‘developing/developed’ dichotomy used in the WHO studies has been criticized. One centre that stands out is Hong Kong, which was categorized as ‘developing’ (Hopper, 2004). However, when reanalysed with Hong Kong in the ‘developed’ group, differences in symptoms were reduced, but differences in functioning became greater. The overall change in results was small. So although the terminology may be inappropriate, there are unidentified differences between the groups that affect outcome (Hopper and Wanderling, 2000).
- *Diagnostic ambiguities.* Although the WHO studies were designed to minimize potential differences in diagnostic practices, there was a possibility that a higher percentage of ‘non-acute remitting psychosis’ (NARP) in the developing countries may bias the results. When the results were reanalysed excluding these subjects, recovery rates remained significantly better in developing countries (Hopper and Wanderling, 2000). Even when all single-episode cases were excluded from the analysis, recovery rates favoured developing countries (Hopper, 2004).
- *Gender or age bias.* Since female gender has been found to predict better outcome, Hopper and Wanderling (2000) compared gender differences in the initial cohort, the follow-up group, and in recovery rates. No significant differences were found. Older subjects also had better prospects of recovery. However, the developing centres had proportionally more young subjects, so age was not a source of bias favouring developing countries.

If the results of the cross-cultural studies are indeed veritable, then we must consider the properties of non-Western cultures that distinguish them from Western cultures and may be conducive to better outcomes.

Sociocultural factors. Leff (1988) identified two main classes of social factors that may influence the differences in outcomes: the attitude of the patient’s family, and the ease with which the person can be reintegrated into society. However, both these factors are likely to be influenced by community attitudes towards mental illness generally, as demonstrated by the degree of stigma attached to the illness.

- *Labelling and stigma.* There are differences between industrialized and traditional cultures in labelling and in opportunities to integrate into the community. Warner (2004) provides many examples of Third World countries in which mental illness is considered the work of spirits. The afflicted person bears no blame for their condition, as the cause is from outside the person. Furthermore, in some cultures a person may actually gain increased status from treatment rituals (Warner, 2004). In contrast, in Western nations, the label ‘schizophrenia’ comes with a constellation of blame, fear and discrimination, affecting every aspect of life (e.g. Kruger, 2000; Warner, 2004).
- *Family relationships.* Relapse rates have been found to be higher for people who live with family who are very critical or emotionally overinvolved compared with

those who live with less emotional relatives (Leff, 1988). The typical Western family is nuclear, with more emotional investment between individual family members, whereas people in developing countries tend to live in extended families. Leff suggests that the resultant lower emotional involvement may be a positive factor in recovery. The degree of emotional involvement across countries has been found to be related to the degree of Westernization, and one of the factors posited for this was the degree to which a person was held responsible for his or her symptoms (Leff, 1988).

- *Care within the community.* In developing countries there is less likelihood of the hospitalization and segregation from the family and community typical of Western styles of treatment (Bresnahan *et al.*, 2003). In some countries, such as India, the person stays within the home, and the family is closely involved in treatment and support (Bresnahan *et al.*, 2003). As well, communities themselves in developing countries may be more cohesive and conducive to recovery than industrialized centres (Bresnahan *et al.*, 2003), and community involvement in care can reduce family tensions (Warner, 2004).
- *Informal economies.* It has been shown that employment is beneficial to recovery (e.g. Bell, Lysaker and Milstein, 1996). Warner (2004) argues that there may be greater opportunity to carry out meaningful work roles in developing countries. Non-competitive subsistence economies provide a natural gradation of work (Kruger, 2000). The person can work at his or her current ability levels and their contribution is valued, whereas in a wage-based economy, the mentally ill are the lowest on the employment hierarchy, often considered less employable than ex-convicts (Warner, 2004).

These features of non-Western cultures may promote recovery from mental illnesses. With so much evidence for the possibility of recovery from schizophrenia, the reason for the pervasiveness of pessimistic expectations and the prevalence of poor outcomes in the West must be explored.

The Persistence of a Pessimistic Prognosis

Although there is a body of literature describing and attempting to explain a more benign course of schizophrenia in the latter half of the twentieth century (e.g. Harrison and Mason, 1993; Zubin, Magaziner and Steinhauer, 1983), this notion has been disputed by a number of researchers. Meta-analyses conducted by Hegarty *et al.* (1994) and Warner (2004) failed to find unequivocal improvements in outcome between early and late twentieth century studies. Although there was an improvement in outcomes around mid-twentieth century, this was followed by a decline from the 1970s, with the percentage of good outcomes at the end of the century comparable to that at the beginning (Hegarty *et al.*, 1994). The most surprising finding was from Warner's (2004) meta-analysis, which focused solely on

developed countries. No improvement in outcomes was found in Western countries in the periods before and after the introduction of antipsychotic medications (Warner, 2004). Moreover, although a decrease in hospital use between 1945 and 1955 was associated with an improvement in recovery rates, the later introduction of antipsychotics brought no further improvement in symptoms or social functioning (Warner, 2004). Why do poor outcomes persist in the West? A number of explanations have been put forward.

Sampling bias and the ‘clinician’s illusion’

Kraepelin’s conviction that schizophrenia had a deteriorating course culminating in dementia was most likely a result of sampling bias. Kraepelin’s patients may well have been ill for some time before entering hospital and, once admitted, were likely to remain in hospital for custodial care (Harding, Zubin and Strauss, 1987). The effects of institutionalization are discussed below. M. Bleuler (1972/1978) pointed out that his father’s (E. Bleuler) initially quite optimistic prognosis for schizophrenia gradually became more pessimistic during his yearly visits to his former clinic after the First World War. He found that most of the patients seemed to have deteriorated. However, in E. Bleuler’s facility, there was an emphasis on early release and finding patients placements in the community (Warner, 2004). E. Bleuler was therefore seeing only the more unwell patients (M. Bleuler, 1972/1978). Therefore, both of these early psychiatrists were observing only the most severely ill patients (Harding, Zubin and Strauss, 1992).

In the day-to-day work of the clinician, a similar effect is known as the ‘clinician’s illusion’ (Harding, Zubin and Strauss, 1987). The clinician sees only a cross-section of people who have been diagnosed with schizophrenia, which is biased towards those who need long-term care (Harding, Zubin and Strauss, 1987). They are denied feedback from clients who never used the service, or who no longer need the service, and therefore gain a distorted impression of the course and outcome of the illness, leading to an expectation amongst professionals of poor outcome (Harding, Zubin and Strauss, 1987; Kruger, 2000).

Circularity in diagnosis

Kraepelin’s original prognosis, which was influenced by the clinician’s illusion and sampling bias, became intertwined with the diagnosis of schizophrenia. When one of Kraepelin’s patients improved, he assumed that there had been an error in diagnosis (Harding, Zubin and Strauss, 1987). In attempting to increase reliability of diagnosis internationally, the DSM-III introduced a narrower definition of schizophrenia, which incorporated prognosis in the diagnosis, with the criterion that the symptoms should have been present for at least six months (APA, 1980). Therefore, people who otherwise meet all the criteria for schizophrenia are diagnosed

differently if they improve. Thus, the classification of schizophrenia *excludes* people who recover (Kruger, 2000).

The DSM-III (APA, 1980), which was current until 1994, included the statements: 'The most common course is one of acute exacerbation with increasing residual impairments between episodes' (p. 185), and 'A complete return to premorbid functioning is . . . so rare . . . that some clinicians would question the diagnosis' (p. 185). The current DSM-IV (APA, 1994) continues to encourage pessimism, stating that a return to premorbid functioning is 'probably not common' (p. 282).

Sensitive to the stigma and negative prognosis attached to schizophrenia, some clinicians may withhold diagnosis of schizophrenia until a chronic course has been established (Weiner, 1966/1997). A paradoxical consequence of this is that the belief in a poor outcome for schizophrenia is reinforced. In addition, treatment may not be timely, further jeopardizing optimal outcome (Weiner, 1966/1997).

Treatment effects

Medication effects. First, conventional medications have been shown to cause some of the 'negative symptoms' and cognitive deficits that are attributed to the illness itself (Gerlach and Larsen, 1999; Velligan and Miller, 1999). The neuroleptic-induced deficit syndrome (NIDS), which includes anhedonia, apathy, feelings of emptiness and slowing of thought processes, can be misinterpreted as disease symptoms. In addition, the benefits of antipsychotics are equivocal (Warner, 2004). Long-term use can cause a dependency in which withdrawal could exacerbate symptoms. This effect has been interpreted by some researchers as a demonstration of the success of the medication in controlling symptoms. However, a number of studies have demonstrated that, for patients who enter treatment with a good prognosis, antipsychotics can, by this action, bring about a poorer course of illness (Warner, 2004). Ironically, this may be one reason for the more benign course in developing countries, where there is likely to be less access to medications than in the West.

The newer 'atypical' antipsychotics have been shown to have fewer extrapyramidal side-effects, reduce secondary negative symptoms (Kopelowicz *et al.*, 2000) and improve cognitive functioning (Manschreck *et al.*, 1999; McGurk, 1999), thereby increasing the possibility of successful rehabilitation (Noordsy and O'Keefe, 1999). Whether or not the newer antipsychotics will have the same detrimental effects on outcome as the conventional medications has yet to be shown (Warner, 2004).

Institutionalization. Findings of earlier studies, and research that included patients who experienced long-term hospitalization before the deinstitutionalization period which began in the mid-twentieth century, would have been confounded by the effects of institutionalization. Goffman (1968) described the processes by which patients in asylums were denied their personal history and encouraged to take on the life of a mental patient. If a person resisted the patient identity, 'Consequently he

may avoid talking to anyone . . . so as to avoid ratifying any interaction that presses a politely reciprocal role upon him and opens him up to what he has become in the eyes of others' (Goffman, 1968, p. 146). Of course this would only serve to 'confirm' his or her illness to others. First-person experience of the dehumanizing and depersonalizing effects of institutionalization, the 'breaking of the spirit' and helplessness have been described eloquently by Deegan (1990). Long-term patients later released into the community have difficulty overcoming the helplessness and dependence that they have learned (Chovil, 2005).

Psychological effects of the diagnosis

The pessimistic expectations brought on by the factors discussed in the foregoing sections lead to a self-fulfilling prophecy of poor outcome. As a result, psychological responses to the diagnosis itself, which are not an essential part of the illness, can lead to poor outcomes.

- *The patient role.* Even without long-term institutionalization, chronicity may be exacerbated by engulfment in the 'patient role', in which the person becomes resigned to being a passive recipient of care (Lally, 1989). Estroff (1989) asserts that 'becoming a schizophrenic' (p. 194) is essentially a social and interpersonal process, not an inevitable consequence of primary symptoms and neurochemical abnormality. The patient role is one of the few remaining open to the person, and although negative, it serves to organize the person's experience better than no identity at all (Rosenberg, 1993).
- *Self-stigma.* The label of schizophrenia carries with it status loss and discrimination (Link and Phelan, 2001), and delivers 'a judgment on that person's whole history, prospects, and indeed basic worth as a citizen' (Summerfield, 2001, p. 148). Self-stigma occurs when the expectation of social rejection by people with a mental illness brings about self-defeating styles of coping, such as social withdrawal and helplessness (Gray, 2002; Fekete, 2004), affecting their self-esteem, social relationships and employment prospects, thus leading to depressive symptoms and poor quality of life (Link and Phelan, 2001). A consequence of stigma is that people who have received a diagnosis of schizophrenia, but go on to lead a normal life, do not wish their diagnosis to be known, ironically increasing the pessimistic expectations for others with the diagnosis (Leete, 1989; Frese, 1997).
- *Motivated withdrawal.* Consumers have described withdrawal as a strategy for self-protection from the 'numerous . . . psychological assaults inflicted by the disorder, by society and even by oneself' (Strauss, 1989, p. 184). In a first-person account of recovery, Deegan described apathy and indifference to others as 'a strategy that desperate people, who are at the brink of losing hope, adopt in order to remain alive' (Deegan, 1996b, p. 93). Therefore, rather than resulting from a lack of volition, withdrawal can be very much goal-directed (Strauss, 1989). Indeed, early last century, E. Bleuler (1911/1950) showed insight into this

response: 'Of course, *conscious withdrawal* from the surroundings may easily be mistaken for lack of interest' (p. 332; italics added).

These secondary bases for apparent negative symptoms and poor course and outcome stand in contrast to the purported cultural benefits to outcome offered in developing nations. Warner (2004) pointed out that many features of chronic schizophrenia – for example, apathy, negativity, social withdrawal, isolation and loneliness – are mirrored in the psychological sequelae of long-term unemployment in otherwise mentally healthy people. It is clear that the iatrogenic effects of treatment as well as the psychological consequences of the label could easily be misinterpreted as signs of the illness itself. That these same psychological reactions would be exceptionally detrimental to recovery serves to highlight the self-fulfilling prophecy that is inherent in the diagnosis of schizophrenia. When the diagnosis of schizophrenia is '... synonymous with "chronically mentally ill" ... this pessimistic outlook pervades verbal and nonverbal clinical interaction as well as programs and policies that aim only for stabilization and maintenance' (Harding, 1987, p. 1227).

The Real Possibility of Recovery

We have reviewed research that shows recovery from schizophrenia is more prevalent than traditionally recognized, and that the course and outcome of schizophrenia is more benign in developing countries, with fewer financial resources, than Western countries. Then we looked at some possible sources of bias that may account for the differential outcomes found in research, and found them unsupported. We have also considered cultural differences that may have some bearing on the superior outcomes observed in developing countries, including less stigma and better integration into society. And finally, we have discussed some iatrogenic effects of treatment and the psychological sequelae of the diagnosis which may contribute to poor outcomes, and that stand in contrast to treatment in some developing countries.

That environmental factors favourable to recovery can improve outcomes in the West was made evident in the differential outcomes obtained in a comparison study involving the patients of the Vermont longitudinal study (Harding *et al.*, 1987a). DeSisto *et al.* (1995a, 1995b) compared long-term outcomes for matched groups of patients from Maine and Vermont. Patients in Maine received traditional services, consisting of drug treatment and aftercare, while those from Vermont took part in a comprehensive rehabilitation programme. The Vermont programme had as its overarching goal the self-sufficiency of the patients. In hospital, the rehabilitation programme strengthened relationships between staff and patients, and included home-like wards, group therapy, vocational therapy and counselling, and self-help groups. After discharge, community care included halfway houses, community clinics, job placements and the establishment of links to natural support networks (Harding *et al.*, 1987a). Even though the Vermont subjects

were those patients who had not responded well to drug treatment, they had a better course and long-term outcome than the Maine cohort. This study demonstrated the importance of environment in the outcomes of schizophrenia and the role social and psychological factors play in the chronic course prevalent in the West (DeSisto *et al.*, 1995a, 1995b).

[The Vermont] legacy is the values and principles that guided it. Perhaps the most important value was that the program has a pervasive attitude of hope and optimism about human potential. . . . (DeSisto *et al.*, 1995b, p. 340)

Kleinmann (1988) has stated that ‘the forms and functions of mental illness are not “givens” in the natural world. They emerge from a dialectic connecting – and changing – social structure and personal experience’ (p. 3). The importance of social consensus as a factor in recovery has been highlighted by Warner (2004), who maintained that the beliefs of society as a whole can be a powerful factor in the outcomes of treatment.

It is accepted that people with schizophrenia have no hope of recovery and always deteriorate, and so the subjective experience of a catastrophic illness is worsened by the very psychiatric establishment that should be involved in the succour and healing of people. (Kruger, 2000, p. 30)

The discussion thus far has illuminated the real possibility of better outcomes for people in Western cultures by the adoption of practices more conducive to recovery, beginning with optimism among mental health professionals. The consumer recovery movement has now thrown down the gauntlet to clinicians, researchers and policy makers, demanding that services and systems become recovery-oriented.

The Emergence of the ‘Recovery’ Movement

In response to the mounting evidence that people with schizophrenia could go on to live a normal and meaningful life, the recovery movement emerged. The recovery movement grew out of the mental health consumer movement. The contemporary consumer movement began as the ‘ex-patients’ movement, which arose in the 1970s as a result of deinstitutionalization policies that led to many ex-patients being released from hospitals to no viable alternative care (Everett, 1994). Initially, the ex-patients’ movement was focused on the human and legal rights of people with psychiatric disabilities (Chamberlin, 1990), and worked to improve conditions in hospitals and community treatment centres (Kaufmann, 1999). By the 1980s the consumer movement was largely an advocacy and self-help movement, focusing on fighting for the legal and human rights of patients, and forming mutual support and self-help groups in the community (Chamberlin, 1990). However, the consumer movement is not a single unified organization, but a diverse collection of groups

(Epstein and Olsen, 1998). Following the publication of the abuses and degradation of hospital patients and the iatrogenic effects of hospitalization, the anti-psychiatry movement arose, which rejects the concept of mental illness as a disease, and coined the term 'psychiatric survivors' (Kaufmann, 1999). A guiding principle of the 'ex-patients' movement is the exclusion of non-patients from their organizations (Chamberlin, 1990). However, many people accept a medical model of mental illness, while supporting the need for social change and the importance of psychological factors to recovery. Therefore, the major thrust of the consumer movement was towards a more coherent community health system for people with a mental illness (Kaufmann, 1999). Reflecting this direction, the term 'consumer' has become the preferred term for most mental health advocates, signifying a degree of power and freedom of choice, while accepting the existence of mental illness (Kaufmann, 1999). It is recognized that this is not the preferred term for everybody, as not all agree that they have choice or power, preferring 'ex-patients' (Chamberlin and Rogers, 1990), or, more militantly, 'psychiatric survivors' (Kaufmann, 1999). In addition, not all people with mental illness use mental health services.

Notwithstanding these differences, the consumer movement can be conceptualized as a movement with common aims (Epstein and Olsen, 1998). Epstein and Olsen listed these aims as: (i) the right to be recognized as human beings, rather than diagnoses; (ii) the right to accurate information and input regarding their treatment; (iii) the need for changes in community attitudes; and (iv) the need for consumer-run support and advocacy groups. More recently, consumer advocates have fought for consumer involvement in all aspects of personal treatment, service provision and policy-making (e.g. Chamberlin, 1990; Fisher, 1994; McLean, 1995; Epstein and Olsen, 1998; Deegan, 1997; Tenney, 2000; Frese *et al.*, 2001).

In parallel with the mounting evidence for recovery provided by longitudinal studies, people had begun writing and publishing first-person accounts of their own recovery experiences (e.g. Deegan, 1988; Leete, 1989; Armstrong, 1994; John, 1994; Koehler, 1994; Mary, 1994; McDermott, 1994; Roman, 1994; Schmook, 1994; Unzicker, 1994; Watson, 1994; Wentworth, 1994). With the networking occurring in the consumer movement, awareness of recovery from mental illnesses became more widespread and became the goal of self-help and community organizations (Schmook, 1996; Chadwick, 1997; Bassman, 2000; Tenney, 2000), although the term recovery may not always have been used (Turner-Crowson and Wallcraft, 2002). Thus the recovery movement emerged to advocate for public mental health and rehabilitation services to become recovery-oriented: operating on the assumption of the possibility of recovery, rather than on the entrenched objectives of medication management and coping (e.g. Anthony, 1993; Crowley, 1997; Frese, 1997; Acuff, 2000; Glass and Arnkoff, 2000; Jacobson and Curtis, 2000; Curtis, 2001). 'Recovery is no longer the exception. Recovery is the expectation' (Tenney, 2000, p. 1439). Consequently, recovery has been adopted in policy as the goal of mental health services in many English-speaking countries, for example, Australia (Australian Health Ministers, 2003), Canada (Pape and Galipeault, 2002), Ireland (Mental Health Commission, 2009), Israel (see Roe *et al.*, 2007), the United Kingdom

(Department of Health, 2001), New Zealand (Mental Health Commission, 1998) the United States (New Freedom Commission on Mental Health, 2003b) and Scotland (Scottish Government, 2009). The non-English-speaking world is also becoming aware of and researching the concept, for example, Japan (Chiba *et al.*, 2009), Taiwan (Song and Shih, 2009) and continental Europe (see Slade, Amering and Oades, 2008). However, the meaning of 'recovery' is not always clear (Davidson *et al.*, 2006; Meehan *et al.*, 2008; Onken *et al.*, 2007; Silverstein and Bellack, 2008; Slade and Hayward, 2007).

What Do We Mean by 'Recovery'?

Consensus on a definition and a way of measuring, recovery is a prerequisite for the development of recovery-oriented services. Davidson and McGlashan (1997) and Harrison *et al.* (2001) pointed out the lack of consensus of a definition of recovery across longitudinal studies of outcome, and called for careful operationalization of the concept.

An even more fundamental problem is that the word 'recovery' has been used in the literature with different meanings. The traditional meaning is based on the medical model of illness. There are two main medical definitions of recovery: the first describes complete cure, the second refers to recovery from a discrete episode. The medical meaning of recovery from schizophrenia is synonymous with 'cure'. In studies of the course and outcomes of schizophrenia, recovery has traditionally been assessed with objective measures such as symptomatology, hospitalization history and functioning (Harrison *et al.*, 2001). That is, all signs and symptoms of the illness have disappeared, and the person returns to his or her former level of functioning. These measures of outcome, based on the medical model, have been the most frequently used definition of recovery.

Another use of the term recovery is in describing the end of a discrete episode of schizophrenia. This meaning is also based on the medical model, and refers to the end of the psychotic phase of an episode. Phases of an episode have been outlined by Keshavan (2005) as:

[A] premorbid phase (characterized by subtle cognitive and social difficulties), a prodromal phase (gradual beginning of subtle psychotic-like symptoms, social withdrawal and functional decline), the psychotic phase (with florid symptoms such as hallucinations and delusions), the transitional or recovery phase (a return to functioning but with increased proneness to relapses and comorbid difficulties), and the stable or residual phase (with persistent cognitive and social deficits) (p. 22).

This description seems to beg the question of whether full recovery is even possible, implying that one is never completely free of the illness. Recovery from an episode is usually operationalized in terms of the abatement of symptoms. In proposing consensus criteria for assessing clinical outcomes, Andreasen *et al.* (2005)

distinguished symptom abatement from complete recovery by adopting the term 'remission' to describe a level of symptomatic recovery in which symptoms do not influence behaviour. In their formulation, remission is necessary, but not sufficient for recovery (Andreasen *et al.*, 2005), which should also be assessed in terms of cognitive or psychosocial functioning. Liberman and Kopelowicz (2005) suggest that recovery from an episode for a prerequisite period is equivalent to recovery from schizophrenia itself. They agree that, although remission of symptoms is a key dimension, it is inadequate as a definition of recovery, and improvements in psychosocial functioning must also be taken into account.

Given that schizophrenia is characterized by an episodic course, with recurrent exacerbations of symptoms followed by periods of remission, neither of these medical definitions describe recovery as it is described by consumers. Consumers do not see psychiatric symptoms as incompatible with recovery (e.g. Anthony, 1993; Fekete, 2004) even if these require hospitalization (Deegan, 1997). This claim is supported by the finding of a discrepancy between outcomes assessed by clinical measures and outcomes in social functioning (Shepherd *et al.*, 1989). Shepherd *et al.* pointed out that, as long ago as early last century, E. Bleuler discriminated between a medical definition of recovery based on symptoms, and social recovery, where a person can support him- or herself outside hospital. Shepherd *et al.* (1989) assessed both clinical and social outcomes, and found that a high level of social functioning was often achieved despite persistent clinical symptoms. Conversely, Liberman and Kopelowicz (2005) argue that even with complete symptom remission, psychosocial functioning may still be impaired in psychiatric disorders. Liberman and Kopelowicz (2005) assert that a definition of recovery should also include participation in work or study, and social, family and recreational activities. So, for the purpose of studying the course and outcomes of schizophrenia, there is a need for consensus on a comprehensive measurement protocol that is broader than typical clinical measures. Regrettably, over the years, the drive towards objective measures of pathology and physiology led researchers to neglect the measurement of psychological and social aspects of mental health (Anthony, 2001). Nevertheless, most of the longitudinal studies supporting the notion of recovery described earlier used strict definitions that included both symptomatic and psychosocial dimensions.

However, with empirical evidence for recovery over the long term well documented, the main concern for consumers is not with demonstrating that recovery is possible, but with the adoption of the recovery vision in mental health services. Moreover, people who have experienced serious mental illness speak of recovery in terms that are at odds with traditional measures, even the more comprehensive definitions that include psychosocial functioning as well as symptoms. Consumers have argued that the medical model is not appropriate to recovery from mental illness (Fisher, 1994; Crowley, 1997; Bassman, 2000; Tenney, 2000). Rather, the recovery vision is one of attaining a productive and fulfilling life regardless of the presence of recurring symptoms (Crowley, 1997). The person recovers from the 'psychological catastrophe' of the illness (Anthony, 1993). Consumers urge us to abandon the 'pathology model' which binds us to pessimism and denies hope

(Frese, 2000; Tenney, 2000) and instead to look at a person's strengths and abilities and to explore the possibilities for transformation and growth (Fisher, 1994; Bassman, 2000). As Schmook (1996) asserts, 'The process of recovery then moves from survival to realizing individual potential with its transforming power of personal growth' (p. 13). The consequence of this alternative view of recovery is that, in addition to the underestimation of the recovery rate using conventional definitions, many more people consider themselves recovered, or recovering, by their *own* definitions.

Conclusion

In an era calling for evidence-based best practice internationally, for example, in Australia (Australian Health Ministers, 2003), New Zealand (Mental Health Commission, 1998), the United Kingdom (Department of Health, 1999), Ireland (Mental Health Commission, 2009), Scotland (Scottish Government, 2009), Canada (Clarke Institute of Psychiatry, 1998) and the United States (New Freedom Commission on Mental Health, 2003a), there is no universally accepted criterion for defining and operationalizing the concept of recovery (Silverstein and Bellack, 2008; Warner, 2009). Therefore, in view of the large and growing consumer literature on recovery, we should strive to conceptualize recovery in the terms of those who have experienced it (Lehman, 2000; Frese *et al.*, 2001; Fisher and Ahern, 2002; Anthony, Rogers and Farkas, 2003; Solomon and Stanhope, 2004; Farkas *et al.*, 2005). A model of recovery that honours consumers' experience can be the only valid basis on which to advance research into the processes of recovery, and to develop and evaluate recovery-oriented programmes. In the following chapter we describe a conceptual model and definition of recovery based on consumers' accounts of their experiences.

Summary

- Historical diagnostic practices led to pessimism regarding the outcome of schizophrenia.
- Longitudinal and cross-cultural studies provide evidence of clinical recovery from schizophrenia.
- Sources of continued pessimism include the 'clinician's illusion' and circularity in diagnosis.
- Some 'negative symptoms' of schizophrenia can be attributed to the effects of medication and treatment.
- Social and psychological repercussions of the diagnosis also play a role in course and outcome.
- Consumers claim that clinical definitions of recovery are too narrow, and that recovery can occur in the presence of recurring symptoms.
- Consumer-oriented models and measures are needed for the development and evaluation of programmes.