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BEYOND DEMENTIA PRAECOX: FINDINGS FROM LONG-TERM FOLLOW-UP STUDIES OF SCHIZOPHRENIA

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With his characterization of schizophrenia as *dementia praecox* (an early-onset form of dementia), Emil Kraepelin (1902), the father of modern psychiatric nosology, set a pessimistic tone for understandings of the course and outcome of schizophrenia for the century to follow. The term *dementia praecox* implies a progressively degenerative course, leading the individual from initial onset toward increasing impairment in social and cognitive functioning. Kraepelin arrived at this diagnostic construct through a categorical division of severe mental illness into conditions with a good prognosis (manic depression) or a poor prognosis (*dementia praecox*). Those classified in the latter group were doomed to a symptom-ridden, disability-dominated future. However, several lines of research have arisen to challenge these views.

In this chapter we review the long-term follow-up studies that have tested Kraepelin's assumptions about the course and outcome of schizophrenia. These studies provide support for a more positive prognosis than is

typically assumed for people with this illness. In reviewing these findings, we discuss criteria for recovery, contrasting symptom-based criteria and criteria based on functionality. We also discuss the effect of diverse diagnostic criteria on the research findings and the question of whether medications and rehabilitative treatment play a significant role in recovery or whether recovery occurs spontaneously regardless of treatment. Finally, we argue for a greater understanding of the role of sociocultural factors as they influence the course and outcome of schizophrenia.

ONWARD FROM KRAEPELIN

Eugen Bleuler (1911) renamed Kraepelin's dementia praecox as a "group of schizophrenias," giving greater emphasis to the heterogeneity of the diagnostic category and shifting the focus from the course of the disorder to its symptomatology. Bleuler's new term literally means a "splitting in the mind" and is derived from his view that the disorder reflects a loss of integration between mental functions, especially emotional and cognitive functions. However, Bleuler's view of the prognosis of people diagnosed with the disorder ultimately left Kraepelin's theory of an unrelenting downward course unchanged.

Today, many still share the pessimistic views of schizophrenia held by Kraepelin and E. Bleuler. This has not only reinforced a view of schizophrenia as a catastrophe for people who have the illness, it has also limited treatment options. If schizophrenia is seen as a lost cause, clinicians are likely to limit their time and effort on these cases, leaving people with schizophrenia with the lowest common denominator of treatment (Lieberman, Kopelowicz, Ventura, & Gutkind, 2002). If schizophrenia is seen in the same way by the people who have it, they will not be encouraged to work toward recovery, but will instead feel stigmatized and afraid. A pessimistic view of the disorder may thus become a self-fulfilling prophecy for many.

The lasting influence of Kraepelin's emphasis on progressively deteriorating course as a diagnostic feature can be seen in the diagnostic criteria set forth by the American Psychiatric Association's *Diagnostic and Statistical Manuals (DSM)*. Beginning in 1952, the American Psychiatric Association (APA) has included in its description of schizophrenia statements that reflect the expectation of many mental health professionals that the disease's course will include a progressive increase in symptom severity (APA, 1952). Echoing Kraepelin, the authors of *DSM-III* (APA, 1980) added that remission of symptoms or return to premorbid functioning is so rare that it would likely result in the clinician questioning the original diagnosis. Even in the recent *DSM-IV* (APA, 1994), authors stated that for those diagnosed with this disorder, a return to premorbid functioning "is probably not common" (p. 232).

Long-term follow-up research, however, beginning with a study by Eugen Bleuler's son Manfred, has challenged the diagnostic legacy of Kraepelin and his followers. These studies present evidence that suggests heterogeneity in the outcomes of schizophrenia, with significant improvement or recovery typically occurring in more than half of the participants (Bleuler, 1968, 1978; Ciompi, 1980; DeSisto, Harding, McCormick, Ashikaga, & Brooks, 1995; Harding, Brooks, Ashikaga, Strauss, & Breier, 1987; Huber, Gross, Schuttler, & Linz, 1980). Given these findings, it has been suggested that the dementia praecox view may have been an artifact of "the clinician's illusion," in which clinicians view their patients who are the most severely ill as typical of the illness when they are not (Cromwell, 1993; Harding, Zubin, & Strauss, 1987). Both Kraepelin and E. Bleuler worked exclusively with patients with chronic schizophrenia who remained in contact with their hospitals; this, no doubt, biased their views on the prognosis of schizophrenia. As Manfred Bleuler himself wrote, Eugen Bleuler visited his former patients at the psychiatric clinic of Rheinau each summer and was depressed to note that those people with schizophrenia who greeted him appeared to have deteriorated. However, "E. Bleuler did not know how many improved patients were out for their Sunday walks during his visits, and certainly not how many had been released and were living at home, recovered" (Bleuler, 1978). In addition, it is possible that Kraepelin's sample included people with organic disorders such as tertiary syphilis for which diagnostic tests were not yet available (Davidson & Bagley, 1969; Harding, Zubin, & Strauss, 1992). It was left for Manfred Bleuler to initiate follow-up studies on people who were no longer in touch with the hospital, many of whom had gone on to recover from their illness. Note that in addition to the clinician's illusion, an epoch effect is likely at play. Some part of the findings of improved outcomes over time is likely a result of the historical development of new psychopharmacological and therapeutic/rehabilitative treatments.

In addition to these long-term studies, investigations of schizophrenia outside industrialized Europe and North America also support the view that the course of the illness is much more heterogeneous than was once thought. The World Health Organization (WHO) has completed the most important of these studies, beginning with the 9-country International Pilot Study of Schizophrenia (WHO, 1973, 1979), and continuing through the 10-country Determinants of Outcome Study (Jablensky, Sartorius, Ernberg, Ankar, Korten, et al., 1992) and the International Study of Schizophrenia (Harrison, et al., 2001; Sartorius, Gulbinat, Harrison, Laska, & Siegel, 1996), a study that unites the cross-cultural and long-term research literature. All of these studies had the same startling and controversial finding. The course and outcome of schizophrenia were better for people in developing societies than they were for people in developed societies. Though the categorical distinction between developing and developed societies is too

simplistic to capture the complexity of world cultures, these findings from the WHO studies strongly suggest that we must view schizophrenia in its various sociocultural contexts.

THE LONG-TERM FOLLOW-UP STUDIES OF SCHIZOPHRENIA

We were able to identify 10 long-term follow-up studies of schizophrenia that had average follow-up periods of 15 years or more. In this section, we briefly summarize the findings of each study and the various criteria for improvement and recovery used in each.

The Burgholzli Hospital Study (Switzerland)

In the first of the long-term follow-up studies, Manfred Bleuler (1978), who succeeded his father as director of the Burgholzli clinic in Zurich, Switzerland, followed a cohort of 208 patients for an average of 23 years. This cohort included both first admissions and readmissions to the hospital during 1942 and 1943. Bleuler's diagnostic criteria emphasized psychotic symptoms and excluded people who had never had a severe psychotic episode. Outcome assessment was based on clinical interviews conducted by Manfred Bleuler and was based on end-state criteria he defined as stable functioning for at least 5 years prior to assessment. According to these criteria, 53% of research participants overall and 66% of the first-admission group were judged to have recovered or significantly improved. Twenty-three percent of the first-admission group and 20% of all research participants were considered to have fully recovered.

The Iowa 500 Study (United States)

The Iowa 500 study (Tsuang & Winokur, 1975) assessed 186 people with schizophrenia for an average of 35 years. One important aspect of this study was the inclusion of individuals with a diagnosis of affective disorder, as well as a control group of 160 surgical patients. People with mental illness were selected on the basis of operationalized criteria (Feighner, et al., 1972) that required 6 months of illness without prominent affective symptoms; presence of delusions, hallucinations, or disorganized communication; and presence of various psychosocial status factors. Outcome was assessed by rating marital, residential, occupational, and psychiatric status on a three-point scale representing good, fair, or poor outcome in each area. Compared to people from other psychiatric groups in the study (i.e., people diagnosed with affective and schizoaffective disorders), those diagnosed with schizophrenia were reported to have not fared as well. However, 46% of the participants diagnosed with schizophrenia had either improved or recovered.

The Bonn Hospital Study (Germany)

The Bonn Hospital study (Huber et al., 1980; Huber, Gross, & Schuttler, 1975) followed 502 people with schizophrenia for an average of 22.4 years. Follow-up exams, which focused on psychopathology and social functioning, indicated that 22% of research participants had complete psychopathological remission, 43% had noncharacteristic types of remission, and 35% experienced characteristic schizophrenia residual syndromes. *Noncharacteristic remission* was described as involving nonpsychotic symptomatology such as cognitive disturbances, lack of energy, sleep disturbances, and hypersensitivity (a more favorable outcome than characteristic schizophrenia residual syndromes such as persisting psychosis). Thus, 65% had a more favorable outcome than would have been expected with schizophrenia. With regard to social functioning, 56% of all participants were judged to have "socially recovered," which was defined as full-time employment. At the last follow-up, 86.7% were living at home and 13.3% were permanently hospitalized.

The Lausanne Study (Switzerland)

The Lausanne study (Ciompi, 1980; Ciompi & Mueller, 1976) reported the longest term follow-up of the major long-term studies. In this study, 289 research participants (92 men and 197 women with an average age of 75) were followed for an average of 37 years and up to a total of 64 years. The criterion for inclusion of research participants in the study was a clinical diagnosis of schizophrenia at first hospitalization. Diagnostic criteria at the Lausanne hospital initially followed Kraepelin's standards and later those of E. Bleuler and M. Bleuler. Outcome was measured using M. Bleuler's (1978) 5-year end-state criteria. The results indicated that 27% reached a stabilized 5-year end state of "recovery," 22% reached an end state described as "mild," 24% were "moderately severe," and 18% were "severe" (Ciompi, 1980). Nearly half of the interview participants (47%) had been hospitalized only once during their lives. However, 14% of probands remained hospitalized "almost constantly" (i.e., for 80% to 100% of the observation period), indicating that many people with schizophrenia remained chronically disabled.

The Chestnut Lodge Study (United States)

In the Chestnut Lodge Study (McGlashan, 1984a, 1984b), 446 (72%) of the people treated between 1950 and 1975 at Chestnut Lodge, a private psychiatric hospital in Rockville, Maryland, were followed for an average of 15 years. This site specialized in psychotherapy-oriented long-term residential treatment. Psychopharmacological medication was not a standard

element of treatment until the late 1960s. Research participants in this study were described as chronic and largely treatment resistant. These participants were re-diagnosed using current operational criteria, including *DSM-III*. Multiple outcome criteria (hospitalization, employment, social activity, and psychopathology) were combined into a global assessment in an effort to achieve a comprehensive picture of outcome. The ratings were on a five-point scale with the following rather restrictive definition of normality: "Take as 'normal' someone fully employed, experiencing no symptoms or need for treatment, and engaged meaningfully in family and social relationships" (McGlashan, 1984b, p. 587). This study found that two thirds (64%) of people with schizophrenia were chronically ill or marginally functional at follow-up and one third (36%) were recovered or functioning adequately. The author points out that recoveries included people who had been "the most chronic and 'hopeless' cases in the hospital" (p. 600).

The Japanese Long-Term Study (Japan)

This study took place at Gumma University Hospital in Japan (Ogawa et al., 1987). Follow-up evaluations were conducted for 105 people with diagnoses of schizophrenia who had been discharged between 1958 and 1962. Follow-up periods were 21 to 27 years. Results on psychopathological outcomes indicated that 31% were "recovered," 46% improved, and 23% unimproved. Results on social outcome indicated that 47% were fully or partially self-supportive (i.e., were productive, had a home, and were often married) and 31% were hospitalized. Early stages of illness course were typically found to fluctuate with regard to social functioning, whereas later stages stabilized to either a stable, self-supportive state or a chronic, institutionalized state.

The Vermont Longitudinal Research Project (United States)

The Vermont Longitudinal Research Project (Harding, et al., 1987) was a study of 269 people who were followed for an average of 32 years. At the time of selection for the study, the cohort had been ill for an average of 16 years, totally disabled for 10 years, and hospitalized on the back wards of the Vermont State Hospital for 6 years. This study is also unique in that the patients participated in an innovative rehabilitation program and were released with community supports already in place.

Participants were re-diagnosed using *DSM-III* criteria. At follow-up, one half to two thirds of all participants (including both living and deceased participants) were considered to have improved or recovered. Of the living participants who met *DSM-III* schizophrenia criteria, 68% did not display further signs or symptoms of schizophrenia at follow-up. Almost one half (45%) of participants displayed no psychiatric symptoms at all. More than

two thirds (68%) of participants were rated as having good functioning on the Global Assessment Scale, which provides a global measure combining psychological and social functioning.

The Maine-Vermont Comparison Study (United States)

The Maine-Vermont Comparison Study (DeSisto et al., 1995) used a group-matching design, comparing the outcomes of 269 people with schizophrenia in Maine with the outcomes of the 269 research participants in the Vermont Longitudinal Study. The average length of follow-up was 32 years for the Vermont participants and 36 years for the Maine participants. The Vermont participants participated in a model rehabilitation program organized around the goal of self-sufficiency, immediate residential and vocational placements in the community, and long-term continuity of care. The Maine group received standard inpatient treatment and aftercare. Results showed that the Vermont participants alive at follow-up ($n = 180$) were more productive ($P < 0.0009$) and had fewer symptoms ($P < 0.002$), better community adjustment ($P < 0.001$), and global functioning ($P < 0.0001$) than Maine participants ($n = 119$). Roughly one half (49%) of the Maine participants were rated as having good functioning on the Global Assessment Scale, the main global measure used for both the Maine and Vermont studies. The authors suggest that the model rehabilitation program utilized in the Vermont study, which gave Vermont participants an earlier opportunity to adapt to life in the community, may explain the better outcomes for these participants.

The Cologne Long-Term Study (Germany)

The Cologne Long-Term Study (Marneros, Deister, Rohde, Steinmeyer, & Junemann, 1989; Steinmeyer, Marneros, Deister, Rohde, & Junemann, 1989) followed 148 people with *DSM-III* schizophrenia and 101 people with schizoaffective disorder for an average of 25 years. Outcome was established using the Global Assessment Scale, the Disability Assessment Schedule, the Psychological Impairment Rating Schedule, and the global categorization of psychopathological outcome used by Huber and colleagues (1975, 1980), which divided participants into full remission, noncharacteristic remission, and characteristic schizophrenia deficiency syndrome. On the Global Assessment Scale, 30.5% were found to have moderate, slight, or no difficulties. On the Disability Assessment Schedule, 36% of those with schizophrenia achieved good to excellent adjustment. Of people with schizophrenia, 6.8% had full psychopathological remission and 51.4% had noncharacteristic residua. Thus, 58.2% had a more favorable outcome than would have been expected with schizophrenia. Comparing their findings to the more favorable outcomes described by Huber et al. (1975, 1980), the authors suggested that the Cologne modified *DSM-III* criteria are narrower

than Huber's, and the narrower the criteria for schizophrenia, the less favorable the outcomes will be.

The World Health Organization International Study of Schizophrenia

The WHO International Study of Schizophrenia is a long-term follow-up study of 14 culturally diverse, treated incidence cohorts and 4 prevalence cohorts totaling 1,633 people diagnosed with schizophrenia and other psychotic illnesses. Global outcomes at 15 and 25 years were judged favorable for more than half of all people followed. This study found that 56% of the entire incidence cohort and 60% of the prevalence cohort were rated "recovered" using a four-point scale based on Bleuler's criteria applied to the past month only. This global assessment took into account all information related to course, symptoms, and functioning. Nearly half had not experienced psychotic episodes in the past 2 years (Harrison et al., 2001). Those participants with a specific diagnosis of schizophrenia had slightly lower recovery rates (48% for the incidence cohort and 53% for the prevalence), though these are still close to 50%.

The authors suggested, however, that a stricter operationalization of recovery may be more meaningful. If recovery is operationalized as a Bleuler rating of "recovered" and a Global Assessment of Functioning (GAF) disability rating greater than 60, then only 37% of people with schizophrenia can be considered recovered. The authors also cautioned that these figures are based on the living cohort of participants and that many cases lost to follow-up may have fallen into poor outcome categories. However, the authors cite a study by Drake, Levine, and Laska (2001) that found the biasing effects of basing analysis on the living cohort alone were negligible. This study reported striking heterogeneity across the different dimensions of outcome. This is illustrated by the finding that 20% or more of the cohort managed to sustain employment despite persisting symptoms or disability.

The short-term course of psychosis, specifically the percentage of time spent experiencing psychotic symptoms in the 2 years following onset, was the best predictor of all long-term outcome measures. Interestingly, however, this study found that 15.7% of people with schizophrenia in the incident cohort and 18.4% in the prevalence cohort showed late improvements, rating "recovered" at long-term follow-up after a period of continuous symptoms. Living in certain sociocultural contexts also appears to have had a significant role in determining both symptoms and social disability. Certain research locations were associated with improved chances of recovery, even for participants with unfavorable early-illness courses. The authors state that the precise nature of these setting- or culture-specific effects "remains to be unravelled" (Harrison et al., 2001, p. 515). A comprehensive report of the findings, including more information on cross-cultural findings, had not yet been published at the time of this review (Hopper, Harrison, Janca, & Sartorius, in press).

HETEROGENEITY AND HOPE IN THE LONG-TERM COURSE OF SCHIZOPHRENIA

Table 3.1 summarizes the findings of improvement or recovery in the long-term studies reviewed in this chapter and lists the criteria used by each study to determine outcome. In this table, noncharacteristic remissions without psychosis (as described in the Bonn and Cologne studies) were counted as improvements. Each of these studies found that, rather than having a progressively deteriorating course, schizophrenia has a heterogeneous range of courses from severe cases requiring repeated or continuous hospitalization to cases in which a single illness episode is followed by complete remission of symptoms. The findings reported in these studies as a whole indicate that roughly half of the participants recovered or significantly improved over the long-term, suggesting that remission or recovery is much more common than originally thought.

Diagnostic Criteria and Sample Characteristics

Cultural differences in diagnostic criteria for schizophrenia complicate the findings of these studies and lead some scholars to discount them, arguing that the resulting samples studied are so different that they cannot be meaningfully compared. In discussing these differences, Angst (1998) points out that the Swiss and German criteria of M. Bleuler, Ciompi and Muller, and Huber are broad and inclusive, including conditions that in other classificatory systems would be called affective psychoses, reactive psychoses, and schizophreniform psychoses. In contrast to the Swiss and German criteria, Scandinavian diagnostic approaches separate "true schizophrenia" from reactive psychoses and schizophreniform psychoses that have a comparatively better prognosis. The United States seems to fall between these two approaches. American diagnosis of schizophrenia using operationalized

TABLE 3.1
Results of Long-Term Follow-Up Studies

Name of Study	% Recovered or Improved	Average Follow-Up (Years)	Recovery/Improvement Criteria
Burgholzli study (M. Bleuler, 1974)	53 (66 1st adm)	23	5-year end state determined through clinical interview by M. Bleuler
Iowa 500 study (Tsuang & Winokur, 1975)	46	35	Marital, residential, occupational, and symptom status rated on three-point scales and combined into a global measure

(continues)

TABLE 3.1 (Continued)
Results of Long-Term Follow-Up Studies

Name of Study	% Recovered or Improved	Average Follow-Up (Years)	Recovery/Improvement Criteria
Bonn Hospital (Huber et al., 1975)	65	22	Symptoms and social functioning assessed by examination; social recovery was defined as full-time employment
Lausanne study (Ciompi, 1980)	49	37	M. Bleuler's 5-year end-state criteria
Chestnut Lodge (McGlashan, 1984a, 1984b)	36	15	Personal interview in which examiner rated subject on hospitalization, employment, social activity, psychopathology, and a global functioning score that combined these
Japanese study (Ogawa et al., 1987)	77	21–27	Follow-up interviews on psychopathology, social relationships, and residential status
Vermont study (Harding et al., 1987)	68	32	Interviews using structured instruments (Harding et al., 1987) for the collection of data on social functioning, hospital records, various symptom-based measures summarized with the Global Assessment Scale
Maine sample (DeSisto et al., 1995)	49	36	Criteria replicated the Vermont Study; (DeSisto et al., 1995) Global Assessment Scale provided a global measure of psychological and social status
Cologne study (Marneros et al., 1989)	58	25	Interviews using Global Assessment Scale, Disability Assessment Scale (Marneros et al., 1989), Psychological Impairment Rating Schedule, and Bonn criteria for categorization of psychopathological outcome
WHO International Study of Schizophrenia (Harrison et al., 2001)	48–53	15 and 25	Bleuler global assessment based on all information on course, symptoms, and functioning (Harrison et al., 2001)

criteria (Feighner et al., 1972), research diagnostic criteria (Spitzer, Endicott, & Robins, 1978), or the *DSM-III* (APA, 1980) is narrower than the Swiss and German concepts but does not place as much emphasis as Scandinavian diagnosis does on separating out reactive and schizophreniform psychoses. However, these differences do not invalidate the finding that outcomes for people with schizophrenia (variously defined) are much more varied and, on the whole, better than the Kraepelinian view would hold.

Criteria for Recovery

Different dimensions of outcome, such as symptom levels and psychosocial functioning, have generally been found to intercorrelate only to a modest degree (Harding et al., 1987; Strauss & Carpenter, 1972, 1974, 1977). For this reason, the choice of which dimensions are used as criteria for recovery is important. Some investigators (e.g., McGlashan, 1984a) believe that a study must use multiple dimensions to provide a comprehensive and valid picture. However, one could also argue that the presence of symptoms within an otherwise functional life should not disqualify an individual from being judged "recovered." Psychosocial functioning is arguably a more important criterion of recovery than being symptom free, and an overreliance on symptom-based criteria, together with the false assumption that symptoms and functioning are strongly correlated, may partially explain why the pessimistic Kraepelinian view of schizophrenia has persisted. Reliance on global ratings of outcome collapses these differences, making the exact nature of outcome unclear.

In many cases, people with schizophrenia have learned ways to cope with and manage symptoms when they arise. In cautioning against the criterion of presence versus absence of symptoms, Liberman et al. (2002) write that in many cases, "positive symptoms experienced during a given follow-up period may be brief, lasting days or weeks, and may have a minimal impact on social or occupational functioning" (p. 258). In addition, the International Study of Schizophrenia (Harrison et al., 2001) found that 20% of participants maintained employment despite persisting symptoms or disability.

Treatment Outcome or Spontaneous Recovery?

Some researchers have raised the question of whether treatment played a necessary role in favorable outcomes or whether a naturally occurring "burnout" process accompanies schizophrenia that involves disappearance of positive symptoms as the person ages. This view is supported by the neurobiological changes that accompany aging, including reduction in dopamine activity (Arranz, et al., 1996). However, several lines of evidence suggest that the burnout hypothesis cannot completely account for the improvements documented in the follow-up studies.

First, studies have found that a majority of older people with schizophrenia continue to have both positive and negative symptoms (Jeste, et al., 1997; Palmer, Heaton, & Jeste, 1999). In addition, the WHO International Study of Schizophrenia (Harrison et al., 2001) found that the greatest predictor of a negative long-term outcome is a prolonged psychosis within the first 2 years following onset. When we combine these findings with the many studies that indicate that early, assertive intervention is very effective in achieving remission of psychotic symptoms (Gitlin, et al., 2001; Lieberman, et al., 1993), treatment appears to play an obvious role in long-term outcome.

Furthermore, it seems that the type of treatment employed also makes a difference in outcomes. This is convincingly demonstrated in the Maine-Vermont Comparison Study (DeSisto, et al., 1995). Even though Vermont participants were very chronic patients from the "back wards" of the Vermont State Hospital, they had significantly better outcomes than the matched cohort from Maine and the highest recovery/improvement rate of all the follow-up studies we reviewed. The most likely explanation for this is the innovative rehabilitation/community integration program that was made available to the participants. In short, recovery can be facilitated by treatment in two ways: assertive treatment early in the course of the disorder and comprehensive, well-coordinated services when the disorder is more chronic (Lieberman et al., 2002).

The Role of Medication

There is some disagreement in the literature on the role of antipsychotic medication on long-term outcome of schizophrenia. Judicious use of antipsychotic medications definitely has an important role in treatment of acute psychotic disturbance. But do people with remitted symptoms have to stay on these medications for long periods? Manfred Bleuler (1974) wrote that, of all his patients who had long-standing remissions or a stable recovery, not a single one had been on long-standing neuroleptic medication. Rather, many were given neuroleptics only during active phases of psychosis and never for longer than a few weeks after they had recovered. In their assessment of the long-term follow-up literature, Harding and Zahniser (1994) found that at least 25% to 50% of participants were completely off medications, experienced no further symptoms of schizophrenia, and were functioning well.

However, many clinicians feel that continuous maintenance medication is necessary for continued remission of symptoms. Further research is required to determine if there is a period of symptom remission after which medications can be safely discontinued or if medications should be continued indefinitely. Another possibility is suggested by Lieberman (2002): that there may be an "exchangeable protection against relapse" (p. 339) between

antipsychotic drugs and certain psychosocial treatments that may reduce the amount of medication that people with schizophrenia require.

THE IMPORTANCE OF SOCIOCULTURAL CONTEXT

A corollary of the Kraepelinian assumption that schizophrenia has a progressively deteriorating course is the assumption that schizophrenia is a universal human biological phenomenon that runs its course unaffected by aspects of the social and environmental surround. However, studies reviewed in this chapter indicate that the course of schizophrenia varies with sociocultural context and appears to be influenced by environmental factors. As Harding, Zubin, and Strauss (1987) concluded, the development of chronic illness "may be viewed as having less to do with any inherent natural outcome of the disorder and more to do with a myriad of environmental and other psychosocial factors interacting with the person and the illness" (p. 483). In this section, we discuss what some of these factors might be as we review evidence that suggests the need for a greater understanding of the sociocultural context of recovery from schizophrenia.

Sociocultural/Regional Differences

Beginning in the late 1960s, the WHO has conducted important cross-cultural research on schizophrenia. The first of these studies, the International Pilot Study of Schizophrenia (IPSS; WHO, 1973, 1979), examined 1,202 cases of schizophrenia at sites in nine countries. This study resulted in a surprising and controversial finding: The course and outcome of schizophrenia was better for people in the developing societies (Columbia, India, and Nigeria) than it was for people in developed societies in North America and Europe (represented in this study by Washington, London, Moscow, Prague, and Aarhus, Denmark). Overall, 52% of those in the developing countries were rated in the "best" category of outcome (defined as initial episode only, followed by full or partial remission) compared with 39% in the developed countries (Sartorius, et al., 1996). This finding was also reported in a 5-year follow-up study (Leff, Sartorius, Jablensky, Korten, et al., 1992). In this study, 73% of those in the developing countries were in the best outcome category compared with 52% in the developed countries (Sartorius, et al., 1996).

Many clinical researchers found it hard to believe that the modern health care systems of rich, industrialized societies did worse than those of the poorer, less developed countries. As with the long-term studies within Europe and North America, methodological critiques focused on the comparability of samples selected at the different sites and the adequacy of diagnostic criteria. To address these and other critiques, the WHO undertook a

second study called the Determinants of Outcome of Severe Mental Disorder (DOSMD; Jablensky, et al., 1992) that used more rigorous criteria and treated incidence cohorts, defined as "cases in the early stages of the illness, evaluated as closely as possible to the point of their first contact with any service or helping agency" (p. 6). This study examined more than 1,300 cases in 10 countries and, like the IPSS, found that the highest rates of recovery occurred in the developing countries. DOSMD findings at 2-year follow-up indicated that 56% of those in the developing countries were in the best outcome category compared to 39% in the developed countries (Sartorius, et al., 1996). The finding of better outcomes in the developing countries remained whether illness onset was acute or gradual.

This study also found differences between societies in which subtypes of schizophrenia predominated. Paranoid schizophrenia (marked by delusions of persecution, grandiosity, and jealousy) was the most commonly diagnosed subtype in the study overall. However, in developing countries, the acute subtype was found twice as often (40% of all cases) as the paranoid subtype. In addition, catatonic schizophrenia (marked by motoric abnormalities such as immobility or posturing) and hebephrenic schizophrenia (marked by disorganized speech and behavior) were found much more frequently in the developing countries than in the developed countries. The investigators identified culture as an important determinant of outcome, though the precise mechanism of influence was not understood.

These findings by the WHO have been critiqued on the basis of differences in follow-up, arbitrary grouping of centers into developed and developing, diagnostic ambiguities (e.g., narrow vs. broad definition of schizophrenia), selective outcome measures, gender-related factors, and age. Recent reanalysis of the data by Hopper and Wanderling (2000) convincingly demonstrates that none of these potential areas of bias is sufficient to explain away the findings of differential course and outcome. The finding of better outcomes in developing countries is surprisingly robust.

Even in the Western studies, sociocultural environment seems to matter. Researchers have commented on the possible role of the Swiss social system or the rural environment of Vermont in the high recovery rates found in these contexts. What explains these differences? What aspects of modern industrialized Western societies may exacerbate the course of schizophrenia, blocking recovery? The remainder of this section looks at several possibilities.

Family Environment and Expressed Emotion

Researchers have suggested that variation in family systems may account for many of the differences in outcomes across cultures for people with schizophrenia. In the West, the nuclearization of the family with its associated neolocal residence pattern (pressure for children to move away and live inde-

pendently) and abrogation of obligations toward family members seems crucial. This pattern, which involves the breakup of the extended family characteristic of more traditional cultures, may leave relatives with mental illness without support and socially isolated (Lin & Kleinman, 1988). Another aspect of family systems that has been found to influence the course of schizophrenia is *expressed emotion* (EE). EE is a measure of family environment that is sensitive to critical comments, hostility, and emotional overinvolvement of family members. Research suggests that people with schizophrenia who return to households with high EE are more likely to relapse than people who return to households with low EE (Bebbington & Kuipers, 1994; Brown, Birley, & Wing, 1972; Leff & Vaughn, 1985). Cross-cultural studies have found EE to be higher in Euro-American families than in Indian, British, and Mexican families (Jenkins & Karno, 1992).

Many studies of expressed emotion focus on negative family functioning that predicts relapse. Another way to understand expressed emotion is to focus on supportive aspects of family functioning that can prevent relapse (Lopez, Nelson, Snyder, & Mintz, 1999). Lopez and colleagues found that a lack of family warmth predicted relapse for Mexican Americans, whereas criticism predicted relapse for Anglo Americans. Warmth was unrelated to relapse in the Anglo American sample. However operationalized, EE has been found to vary across countries and cultures and it constitutes one possible explanation for the low relapse rate found in the developing world as compared to more industrialized societies (Jenkins & Karno, 1992; Kuipers & Bebbington, 1988).

Social Role Expectations

Another obvious difference between the developed and the developing world is the complexity and pace of modern industrialized society. One reason why criticism and other aspects of expressed emotion may be more salient for Western societies is the pressure involved in simply meeting the basic expectations of life in one of these competitive societies. For example, Jablensky and Sartorius (1988) suggest that industrialized societies impose on their members "complex and potentially conflicting cognitive tasks." Consider the increasingly complex expectations involved in modern living: operating a large motor vehicle on a busy highway, mastering the use of a computer, interacting with a diverse array of cultural groups, excelling in higher education, fitting into the expectations of the workplace, and so on. Combined with the fast pace of many industrialized societies, these complex demands may result in people who experience episodes of severe mental illness coming to perceive themselves as increasingly "off time" in comparison to role expectations for people of their age (Cohler & Ferrono, 1987). In a less culturally and technologically complex society (one that is based on agricultural work, for example), life may be much more flexible and forgiving,

with less opportunity to fall behind expectations (Cooper & Sartorius, 1977). In contrast to the intimidating prospect of entering a competitive and impersonal job market accompanied by a history of psychiatric treatment, jobs in traditional village or tribal settings are more often assigned than won in competition and one's coworkers are likely to be one's relatives and friends (Lin & Kleinman, 1988).

Stigma and Discrimination

The failure of some people with schizophrenia to meet criteria for recovery is likely a result not only of the illness itself, but also the stigma associated with the illness, which results in discrimination against people with schizophrenia (Corrigan & Calabrese, in press; Corrigan & Penn, 1997). The societal stigma is also likely to exacerbate critical comments and expressed emotion in family relationships and social interactions generally. North American studies find that people are less likely to hire a person who is labeled mentally ill (Bordieri & Drehmer, 1986; Farina & Felner, 1973; Link, 1987) or to lease the person an apartment (Page, 1977, 1983, 1995). One study found that 75% of family members of a child with mental illness believed that stigmatizing attitudes decreased their child's self-esteem, ability to make friends, and ability to gain employment (Wahl & Harman, 1989). These studies illustrate some of the ways in which stigma and discrimination can limit a person's options and increase social isolation.

Research also suggests that stigmas about mental illness are widely held in the general population (Link, 1987; Phelan, Link, Stueve, & Pescosolido, 1999; Roman & Floyd, 1981) and even among mental health professionals (Heresco-Levy et al., 1999; Keane, 1990; Lyons & Ziviani, 1995; Mirabi, Weinman, Magnetti, & Keppler, 1985). Two independent factor analyses of survey results of more than 2,000 American and British citizens (Brockington, Hall, Levings, & Murphy, 1993; Taylor & Dear, 1980) yielded three stigma factors: (a) fear of people with mental illness because they are dangerous and a desire to exclude them from one's community, (b) authoritarian emphasis on controlling people who are viewed as irresponsible, and (c) benevolent desire to care for people who are seen as childlike. The social impact of these stigmatizing attitudes has been documented.

More research needs to be done to increase our understanding of cross-cultural differences in mental illness stigma and the role of these differences in recovery from schizophrenia. Several ethnographers have argued that mental illness stigma is much less prominent in traditional, nonindustrialized societies. Waxler (1977, 1979) reported that, in Sri Lanka, schizophrenia is viewed and reacted to like any other acute illness. However, the reality is probably a much more complex one than can be captured in a simple dichotomy such as "developed versus developing" or "Western versus non-Western." China, for example, is a non-Western society with a relatively

high level of mental illness stigma (Lin & Kleinman, 1988). These simple dichotomies should be replaced with detailed analyses and comparisons of individual cultures as cognitive and behavioral totalities.

SUMMARY

This chapter has discussed two of the most important findings in contemporary research on schizophrenia that relate to recovery. First, long-term follow-up studies of schizophrenia have revealed more varied and positive outcomes than are typically expected by clinicians. In addition, cross-cultural studies have indicated that the course and outcome of schizophrenia varies with sociocultural context and is significantly better in developing countries than in developed countries. Each of these findings suggests that recovery is a real possibility for people with a severe mental illness such as schizophrenia. Research now needs to change its course in this area. Instead of testing the hypothesis of whether people recover, research needs to continue to look at what it means to recover and what conditions foster it. We began a discussion of the latter issue in this chapter. Clear candidates for mediators and moderators of recovery include appropriate antipsychotic medication regimens and community-based services and support. An equally important goal for research is to develop our understanding of the role of sociocultural factors in recovery. Combining these various constructs in future research will help us better understand what recovery is and how it is facilitated.

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