

Scientific and Consumer Models of Recovery in Schizophrenia: Concordance, Contrasts, and Implications

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Schizophrenia has traditionally been viewed as a chronic condition with a very pessimistic outlook, but that assumption may not be valid. There has been a growing consumer movement among people with schizophrenia that has challenged both the traditional perspective on the course of illness and the associated assumptions about the possibility of people with the illness living a productive and satisfying life. This new conception of the illness is supported by long-term studies that suggest that as much as 50% of people with the illness have good outcomes. There has also been a change in political and public health perspectives of the illness, stimulated in part by the President's New Freedom Commission on Mental Health. The purpose of this article is to provide an overview of some key themes about the recovery concept, as applied to schizophrenia. The article will address 3 questions: (1) What is recovery? (2) Is recovery possible? and (3) What are the implications of a recovery model for a scientific approach to treatment (ie, the use of evidence-based practices)? Scientific and consumer models of recovery are described, and commonalities and differences are discussed. Priorities for future research are suggested.

Key words: outcomes/course of illness/treatment/evidence-based practice

Schizophrenia has traditionally been viewed as a chronic condition with a very pessimistic outlook. It has generally been assumed that at best 20% of people who meet the diagnostic criteria for the disorder have a benign form of the illness, with a substantial return to premorbid levels of functioning after an early period of acute illness. Another 20% or so have been thought to have a continually declining course, the true Kraepelinian form of the disorder. The remaining approximately 60% have been

believed to have a more variable but chronic course, with neither a continuing decline nor a return to premorbid levels of functioning. Corollaries of this perspective are that most people with the illness need to be maintained on antipsychotic medication throughout their lives and that patients and family members should be given guarded expectations about restoration of a premorbid level of functioning.¹ Beginning (at least) in the late 1980s, this pessimistic view has begun to change, as a series of long-term outcome studies have demonstrated that the course is more variable both across and within individuals and that many people who meet strict diagnostic criteria have very good outcomes, often without maintenance medication. At the same time, there has been a growing consumer movement among people with schizophrenia that has challenged both the traditional perspective on course of illness and the associated assumptions about the possibility of people with the illness living a productive and satisfying life.

These 2 forces—new data and consumer voices—have contributed to a political change that has begun to have an impact on public attitudes, patterns of service delivery, including criteria for reimbursement, and relationships between providers and consumers. A central focus in this evolution is the concept of recovery. This term, which would have been considered something of an oxymoron in the literature a generation ago, is now the subject of considerable interest among professionals, consumers and their families, and health administrators at the local, state, and national levels. There is increasing recognition that recovery is not only possible, but that it may even be common. Moreover, there is increasing consumer and political pressure to ensure that mental health services are recovery-oriented. At the same time, there is considerable confusion and disagreement about the definition of recovery and the implications of a recovery model for science and practice. The purpose of this article is to provide an overview of some key themes about the recovery concept as applied to schizophrenia. The article will address three questions: (1) What is recovery? (2) Is recovery possible? and (3) What are the implications of a recovery model for a scientific approach to treatment (ie, the use of evidence-based practices)?

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What Is Recovery?

Scientific Definitions

The scientific and consumer literatures have very different conceptualizations of what the term ‘recovery’ encompasses. In the scientific literature recovery is generally considered from the perspective of the definition of the disease and involves the elimination or reduction of symptoms and return to premorbid levels of function. In its most casual use the term recovery implies the absence of disease, or cure.² This conceptualization may be adequate in the case of acute medical conditions, such as influenza or a broken bone, but it does not fit well for chronic conditions such as diabetes, asthma, or schizophrenia. First, it fails to account for cases in which there is substantial symptom remission, but the disease process still exists. Second, it does not allow for cases in which the illness has produced an enduring change from premorbid status but still allows for a substantial return of function. This would be the case, for example, when a broken bone has healed, but the bone is weakened. Schizophrenia has a profound impact on the person above and beyond symptoms, including a loss of self-esteem, alienation from friends and family, interruption of school and career, and the experience of social stigma. The longer and more severe the course of illness, the greater the impact these changes are likely to have on the person’s life and how he or she views himself in the world. These experiences cannot be reversed or forgotten, regardless of symptom status or disease process. Third, this conceptualization of recovery as cure is relatively vague and does not lend itself to empirical study. For example, how much symptom remission is required for how long, and how does one determine what premorbid functioning was? Given that the disease is often associated with a gradual period of behavioral and cognitive disruption before the first exacerbation, the person may never have experienced an unaffected period of adult life that could serve as a standard of restored function.

In light of these problems, there has been considerable effort to develop standard, operational definitions of recovery that reflect the course and consequences of the illness and lend themselves to use in research. Studies on short-term outcomes in schizophrenia have generally focused on remission and relapse rather than on recovery. The Remission in Schizophrenia Working Group defined remission “as a state in which patients have experienced improvements in core signs and symptoms to the extent that any remaining symptoms are of such low intensity that they no longer interfere significantly with behavior and are below the threshold typically utilized in justifying an initial diagnosis of schizophrenia.”^{3p442} They contrasted remission with recovery, which they described as the ability to function in the community, socially and vocationally, as well as being relatively free of psychopathology. According to the working group,

remission is a necessary but not sufficient step toward recovery.

Research definitions of recovery vary on a number of dimensions, but a commonality is that recovery is considered to be an ‘outcome’: an endpoint or level of functioning that one achieves and maintains for some period of time (eg, 2 years). As such, recovery is a cross-sectional reflection of functional status and may alternate with periods of relapse. Given that recovery is not a permanent state, Torgalsbøen and Rund⁴ suggest the term ‘full remission’ may more accurately characterize these asymptomatic phases of the illness. However, the term ‘remission’ fails to address the positive changes and accomplishments associated with recovery in most scientific definitions and all consumer definitions.

Studies on long-term outcomes of schizophrenia have employed a diverse set of criteria for assessing current level of functioning, with or without an operational definition of recovery. Several examples are illustrative. The Vermont Longitudinal Study,⁵ one of the earliest and most influential studies to challenge the pessimistic view of outcome, relied primarily on the Global Assessment Scale (GAS) and the Strauss-Carpenter Levels of Functioning Scales to assess outcomes. Their primary criterion for good outcome was a GAS score above 61: “some mild symptoms ... or some difficulties in several areas of functioning, but generally functioning pretty well ... and most untrained people would not consider him sick.” Harrow and colleagues⁶ have been conducting a follow-up trial for 15 years. They have developed a more detailed operational definition that requires a 1-year period of (a) the absence of psychotic and negative symptoms, (b) adequate psychosocial functioning, including paid work half-time or more and the absence of a very poor social activity level, and (c) no psychiatric hospitalizations. Torgalsbøen and Rund⁴ included a similar set of dimensions but over a period of 5 years. They defined recovery as a reliable diagnosis of schizophrenia at an earlier time but not at present, no psychiatric hospitalizations for at least 5 years, and present psychosocial functioning within the ‘normal’ range (ie, above 65 on the Global Assessment of Functioning Scale).

In an effort to advance the state of the science, several groups have proposed standardized operational definitions. One of the most widely cited sets of criteria was developed by Liberman and colleagues.^{1,7} They proposed using a 2-year period in which the person is functioning within normal limits in the domains of symptomatology, participating in work or school, living independently, and maintaining social relationships. The symptom criterion is a Brief Psychiatric Rating Score (BPRS) score of 4 (moderate) or less on the psychotic symptom items (grandiosity, suspiciousness, unusual thought content, hallucinations), on cognitive and behavioral disruption (conceptual disorganization, bizarre behavior, and self-neglect), and on the negative symptom items (blunted

affect and emotional withdrawal). The work criterion requires full- or part-time participation in an age and culturally appropriate instrumental activity (worker, student, volunteer). The person must also be living independently and have primary responsibility for activities of daily living (money management, self-medication). Finally, the person should have friends and/or otherwise participate in age-appropriate social activities that do not require professional supervision.

Several aspects of this definition warrant comment. First, a key feature of these criteria is that in order to be considered recovered the person must sustain adequate functioning for an extended period of time, in this case 2 years. The definition assumes that some people with the illness will have brief periods of good functioning interspersed with a more chronic course or intermittent exacerbations. As evidenced by the Harrow et al.⁶ and Torgalsbøen and Rund⁴ definitions (1 year and 5 years, respectively), 2 years is an intermediate criterion that appears to be reasonable, albeit arbitrary. A second important assumption is that recovery does not require total symptom remission, but it can be achieved in the presence of mild to moderate symptoms. Third, the definition specifies that recovery entails a normative level of functioning in a variety of important life activities including work and social relationships, along with the ability to live independently and be responsible for oneself. This criterion underscores that recovery entails more than symptom remission and that it is marked by minimal or no continuing disability. One notable limitation of these criteria is that they do not address the person's subjective appraisal of functioning or the extent to which he or she is satisfied with life. This omission would allow the untenable circumstance of a person being judged recovered by a professional interviewer yet feeling distressed by residual symptoms (albeit scored low on the BPRS), stigmatized by the illness, frustrated by an inability to achieve one's ambitions, and hopeless about the future.

An alternative set of criteria was developed by Nasrallah, Targum, Tandon, McCombs, and Ross.⁸ They conducted a roundtable of experts to develop criteria for clinical effectiveness of treatments, but the domains they addressed were parallel to what Liberman et al. and others referred to as recovery.^{1,7} They proposed the following definition: "A clinically effective treatment is characterized by sustained adherence by the patient to the prescribed treatment regimen; long-term reduction in symptoms of disease, treatment burden (side effects), and impact of the disease on the patient and members of his or her social circle; and long-term increase in healthy behaviors and restoration of wellness."^{8p274} One limitation of this definition is that it assumes that ongoing pharmacotherapy is required for good outcome. This is a reasonable expectation for patients in treatment trials (the primary focus of this def-

inition), but it is not applicable when considering course of illness and recovery in general. Long-term follow-up trials (eg, Harrow et al.⁶) have demonstrated that recovery can be achieved by some patients without maintenance pharmacotherapy. A positive feature of this definition is that it addresses burden on families. Given that a large proportion of people with schizophrenia present a continuing financial and psychological burden on family members, this is an important consideration. Another positive feature of this definition is the focus on health and wellness, which includes physical health and quality of life, as well as the ability to live independently and function adequately in work or school and in social relationships. Although this does not encompass the full range of phenomenological and personal elements included in consumer definitions (see below), it is an important addition to the narrower clinical perspective provided by Liberman et al.,⁷ Harrow et al.,⁶ and Torgalsbøen and Rund.⁴

All extant scientific definitions are limited in that they have been determined consensually, rather than empirically. Issues such as the requisite duration of recovery, residual symptom levels that are acceptable, and the level of role functioning that must be achieved have not been analyzed to determine concurrent or predictive validity: eg, does current recovery status predict future status or need for treatment? does it relate to family satisfaction or the consumer's satisfaction with self? Similarly, the diverse perspectives of professionals, family members, and consumers have not been systematically integrated. These diverse views are reflected in the Nasrallah et al.⁸ definition, but specific guidance for measurement and how the different scores should be combined or weighted is not provided. A related problem is that the field lacks well-validated measures of key elements, such as role functioning and productive activity. For example, work would appear to be a straightforward dimension to measure (eg, hours worked per month, income), but there are a number of complexities in the context of recovery: eg, part-time work at a low-skilled job by a former college student might be considered a failure in that it fails to reflect premorbid promise, but it might be a notable improvement for someone who had been homeless and unemployed for 10 years. Finally, recovery is better conceptualized as a multidimensional construct rather than as an objective status or level of functioning. There is no gold standard against which to evaluate definitions and measures. Consequently, it should be evaluated in the context of utility and convergent and discriminant validity. Path analysis and structural equation modeling may be more appropriate analytic strategies than correlations (or regressions) with concurrent and predictive criteria.

Consumer-Oriented Definitions

In comparing consumer-oriented and scientific definitions of recovery, it is important to recognize that they

have evolved from very different perspectives, different historical contexts, and with different goals. As indicated above, scientific definitions evolved from a clinical/disease orientation with the goal of advancing research on the course of schizophrenia and treatment outcomes. In contrast, consumer definitions have evolved from something akin to a civil rights movement among consumers and a sociopolitical change in public attitudes about mental illness. The goals of consumer-oriented definitions include consciousness raising among consumers and family members and changes in mental health policies and practices, not comparative evaluation of treatments or analysis of disease process. The target audience is consumers, family members, politicians, policymakers, and clinicians, not clinical scientists.

Beginning (at least) in the late 1980s, a growing group of consumers and professionals have been expressing increased dissatisfaction with what has been seen as a paternalistic and unresponsive mental health system. As with many social movements, there is a continuum of views about mental health services among consumers. At its most extreme, the consumer movement has vilified professionals and seen traditional mental health services as iatrogenic, generating feelings of hopelessness and helplessness, promoting dependence, and fostering stigma. Some consumers identify themselves as survivors not of mental illness but of the mental health system.⁹ They contend that the system should be supplemented, if not replaced, by peer-based services.¹⁰ The more moderate view is that mental health professionals have often failed to promote a sense of hope and optimism, failed to give consumers choices, and failed to include consumers and family members as partners in the treatment process.

There is no precise history to account for the changes in attitudes and the consumer movement, but several factors have contributed. Advocacy organizations, such as the National Alliance for the Mentally Ill (NAMI) and the National Empowerment Center, have engaged in extensive public education and political lobbying. A growing cadre of individuals, including mental health professionals, have publicly identified themselves as mental health consumers and become very effective spokespersons for the consumer community. They have not only advocated for changes in the service delivery system but have also very effectively illustrated the fact that recovery from severe mental illness is possible. In addition, they have effectively argued that recovery may be something very different from the disease-oriented, scientific-clinical concept. Two important reports from the US federal government provided considerable momentum to the recovery movement. First, the surgeon general's report on mental health¹¹ concluded that all mental health care should be consumer- and family-oriented and have the promotion of recovery as its primary aim. While this report did not have the force of law to produce changes, it served as a focal point for change among

many state and municipal mental health systems, and it stimulated discussion among advocacy organizations and the professional community.

This position was echoed more forcefully in the report of the President's New Freedom Commission, *Achieving the Promise: Transforming Mental Health Care in America*.¹² The report opened with a powerful vision statement: "We envision a future when everyone with a mental illness will recover, a future when mental illnesses can be prevented or cured, a future when mental illnesses are detected early, and a future when everyone with a mental illness at any stage of life has access to effective treatment and supports—essentials for living, working, learning, and participating fully in the community."^{12p1} It went on to specify that transforming the mental health system depended on 2 principles, the second of which is, "care must focus on increasing consumers' ability to successfully cope with life's challenges, on facilitating recovery, and on building resilience, not just on managing symptoms."^{12p5}

The principles enunciated in the surgeon general's report and the New Freedom Commission report have been adopted by several state mental health systems, including Connecticut, Ohio, Wisconsin, and New Mexico. More recently, they were adopted by the Veterans Administration (VA) as part of the Undersecretary's Action Agenda, "Achieving the Promise, Transforming Mental Health Care in VA." This plan committed the VA system to adopt a recovery model in VA mental health programs nationwide, including educating all VA staff about recovery and requiring the inclusion of consumers and families as partners in treatment planning. VA is the largest health care system in the United States, and adoption of a recovery model in VA will undoubtedly serve as a model and stimulus for action by other governmental agencies at the national and state levels.

In the context of the consumer movement and these policy statements, the recovery concept represents a model of care, as well as a conceptualization of possible outcomes.^{13,14} According to Jacobson and Greenley,¹⁴ the recovery model involves both internal conditions and external conditions. Internal conditions include the attitudes and processes that lead to change, including (a) hope that recovery is possible; (b) healing, which entails developing a sense of self separate from illness and the ability to cope with symptoms; (c) empowerment, which corrects for a sense of powerlessness and dependence that results from traditional mental health care; and (d) connection, which entails reestablishing social connections with others. External conditions are the experiences, policies, and practices that lead to recovery: (a) human rights, including combating stigma and discrimination against people with mental illness; (b) a positive value of healing, which involves a culture that fosters growth, respect, and hope; and (c) recovery-oriented services, which are services that foster hope and empowerment and include

the consumer as a partner in a relationship of mutual respect.

The scientific definitions view recovery as an outcome. In contrast, consumer definitions consider it to be a process that occurs over time, in a nonlinear fashion. In one of the earliest and most influential papers on recovery, Anthony^{13p527} described it “as a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness.” More recently, in a report on the New Freedom Commission, Hogan^{15p1469} described recovery “as a process of positive adaptation to illness and disability, linked strongly to self-awareness and a sense of empowerment.” The key elements of these 2 statements, recovery as a process in which the individual strives to overcome the fact of mental illness and its impact on one’s sense of self, have been echoed in many other definitions.¹⁶ They stand in clear contrast to scientific definitions, which emphasize the manifestations of illness: symptoms and functional disability. In an attempt to bridge this distinction, Liberman and Kopelowicz^{17p735} refer to recovery as “an outcome of the process of recovering.” However, this is a tautological solution that defines away the consumer perspective that recovery is a process, not an outcome. It fails to address the fact that the scientific and consumer communities have distinctly different conceptions of what recovery means, each of which may be valid for different purposes.

Although most consumer-oriented definitions of recovery and the recovery model convey a clear and powerful message, they are relatively nonspecific and are markedly limited as criteria for research, for evaluating the effectiveness of clinical programs, or for developing public policy. For example, the VA’s Action Agenda mandated 82 systemwide changes based closely on the New Freedom Commission report but appointed a series of workgroups to develop detailed implementation plans. Similarly, in late 2004 the Substance Abuse and Mental Health Services Administration (SAMHSA) held a 2-day National Consensus Conference on Mental Health Recovery and Transformation to develop a definition of recovery, reach a consensus on its key principles and elements, and identify essential characteristics of effective recovery-oriented services, as a first step in transforming the mental health system nationally. Sponsored by the federal agency charged with developing and implementing national health policies, the product of this workshop will likely have important implications for clinical practice and reimbursement in the United States.

The following draft definition was developed: “Mental health recovery is a journey of healing and transformation for a person with a mental health disability to be able to live a meaningful life in communities of his or

her choice while striving to achieve full human potential or ‘personhood.’”¹⁸

Ten characteristics of effective recovery-oriented services were identified:

Self-Direction: Consumers lead, control, exercise choice over, and determine their own path of recovery.

Individualized and Person-Centered: There are multiple pathways to recovery based on the individual person’s unique needs, preferences, and experiences.

Empowerment: Consumers have the authority to exercise choices and make decisions that impact their lives and are educated and supported in so doing.

Holistic: Recovery encompasses the varied aspects of an individual’s life including mind, body, spirit, and community.

Nonlinear: Recovery is not a step-by-step process but one based on continual growth with occasional setbacks.

Strengths-Based: Recovery focuses on valuing and building on the multiple strengths, resiliency, coping abilities, inherent worth, and capabilities of the individual.

Peer Support: The invaluable role of mutual support in which consumers encourage one another in recovery is recognized and promoted.

Respect: Community, systems, and societal acceptance and appreciation of consumers—including the protection of consumer rights and the elimination of discrimination and stigma—are crucial in achieving recovery.

Responsibility: Consumers have personal responsibility for their own self-care and journeys of recovery.

Hope: Recovery provides the essential and motivating message that people can and do overcome the barriers and obstacles that confront them.

A complete discussion of these parameters and the implications for research and treatment services is beyond the scope of this article, but several points warrant mention. There is a clear emphasis on treatment as a partnership between clinician, consumer, and family when family members are involved. The traditional top-down, clinician-driven approach is seen as unhelpful at best and harmful at worst. Similarly, there is an emphasis on empowerment: helping the consumer develop a sense of control in his or her life, beginning with control and choice over treatment (both what type of treatment and whether to participate), but extending to control over the illness (eg, ability to cope with symptoms) and other aspects of life as well.^{14,19} There is a clear recognition of the value of peer support in learning how to cope with mental illness and move beyond it. In that regard, both the VA Action Agenda and the National Health Service in the United Kingdom²⁰ have actively promoted the recruitment of peers as service providers.

Finally, the SAMHSA report¹⁸ emphasized that the key element in defining recovery was hope. This point

is poignantly made in a paper by Patricia Deegan, a consumer-survivor:

when those of us with psychiatric disabilities come to believe that all of our efforts are futile; when we experience that we have no control over our environment; when nothing we do seems to matter or to make the situation better; when we follow the treatment teams' instructions and achieve their treatment goals for us and still no placement opens up in the community for us; when we try one medication after another after another and none of them seem to be of any help; when we find that staff do not listen to us and they make all of the major decisions for us; when staff decide where we will live, with whom we will live; under what rules we will live, how we will spend our money, if we will be allowed to spend our money, when we will have to leave the group home, and at what time we will be allowed back into it, etc. etc., then a deep sense of hopelessness, of despair begins to settle over the human heart. And in an effort to avoid the biologically disastrous effects of profound hopelessness, people with psychiatric disabilities do what other people do. We grow hard of heart and attempt to stop caring. It is safer to become helpless than [sic] to become hopeless.^{21p93}

Is Recovery Possible?

In light of the momentum behind the recovery model, it is reasonable to ask whether, in fact, recovery is a reasonable goal. It certainly stands in contrast to the traditional view of schizophrenia as a chronic, possibly deteriorating condition. Not surprisingly, concerns have been raised that the model is little more than old wine in new bottles and that it offers false hopes to consumers and their families.^{16,22,23} From the perspective of consumers there is no question that recovery is not only possible but that it might be relatively common. First-person accounts published in the scientific literature for more than 25 years (eg, in *Schizophrenia Bulletin*), as well as numerous survey papers,²⁴ conceptual papers,^{21,25,26} and public addresses by consumers provide ample, albeit not scientifically controlled, evidence to that effect. Of course, just as one can define recovery in such a stringent way as to make it an impossible goal, it can also be defined so broadly as to make its achievement unimportant. However, even the most optimistic views differentiate recovery from cure and/or a return to normality,^{14,21} and the consumer literature underscores that the path to recovery is a struggle, often marked by relapses and ongoing adjustments to residual symptoms, functional difficulties, and altered life goals.

Perhaps more important from the perspective of most readers of *Schizophrenia Bulletin*, there is now a growing scientific literature demonstrating a more optimistic picture of the course of illness. A full explication of this literature is beyond the scope of this article, and the reader is referred to a recent book by Davidson, Harding, and Spaniol,²⁷ along with other reviews that provide extensive discussions of the literature. Beginning with the Vermont

Longitudinal Study,^{5,28} there are now upwards of 20 contemporary trials of the long-term outcome of schizophrenia.^{17,29,30} Studies vary in specific criteria, measures, samples, and time frame, but overall 20–70% of people with careful research diagnoses appear to have a good outcome, with substantial reduction of symptoms and good quality of life and role function over extended periods of time. The modal percentage with good outcomes is in the range of 50%.^{6,31} Improvement varies across domains of functioning (eg, symptoms and role performance), and aside from deficit symptoms there are few reliable predictors of outcome.^{1,30,32} There is wide variability in course of illness between individuals and geographic regions (eg, outcome tends to be somewhat better in less developed regions of the world).³³ Both empirical data and anecdotal reports suggest that much of the pernicious effect of schizophrenia is manifested early in the course of illness, followed by a plateau, and then gradual improvement for many patients.^{24,30}

Two recent examples of long-term outcomes are illustrative. The International Study of Schizophrenia³¹ conducted 15- and 25-year follow-ups of subjects originally recruited for earlier international trials. In this study 48.1% of patients with schizophrenia were rated as recovered (by M. Bleuler's criteria: employed and resumed former role functioning, not seen as mentally ill by family, and no overt psychotic symptoms); 37.8% were rated recovered using a more stringent criterion (Bleuler criteria plus Global Assessment of Functioning > 60). The Chicago Follow-up Study⁶ has followed a cohort of patients for 15 years, conducting assessments at 5 occasions. Based on their recovery criteria (discussed above), 41% of subjects with schizophrenia and 55% of those with schizophreniform disorder were in recovery on at least 1 follow-up. However, relatively few patients were in continuous recovery: most had episodic courses. Of note, 40% of each diagnostic group who were in recovery at the 15-year follow-up were not taking antipsychotics. These data suggest some patients who do well may not need to take maintenance medications. However, this is a complex issue. Some of these patients may have done better if they were maintained on medication. There are also data to suggest that duration of untreated psychosis is a strong predictor of subsequent course of illness,³¹ and a growing literature on first-episode cases suggest that early treatment can play a substantial role in improving outcomes.³⁴ This is an important issue that warrants further study, as it has major implications for treatment recommendations provided to consumers and their families.

The long-term outcome data can be interpreted as a glass half full or half empty. There is little evidence that a large proportion of patients have a benign course of illness with substantial symptom remission and return of function after a brief period of acute dysfunction. The majority of people with schizophrenia have a long period of intermittent or continuous disability. Conversely, it

appears as if many, if not most, people with the illness have periods of relatively good functioning, which increase in frequency and duration as they pass through middle age. At least half of the population can be expected to achieve and maintain scientific criteria for recovery for extended periods of time during their lives. Moreover, the empirical data may actually underestimate the actual prevalence of good outcomes. It is widely assumed that there is a population of good outcome patients who are not treated in public mental health systems and therefore are less likely to be recruited into studies than patients who are doing poorly.

No systematic data are available on rates of recovery as defined from the consumer perspective (eg, SAMHSA or the New Freedom Commission definitions). Anecdotal data and commentary by the many impressive consumer spokespersons for the recovery model are informative, but it is difficult to extrapolate from these sources of information. It is clear that the professional and scientific communities have not sufficiently appreciated the subjective experiences of people with schizophrenia and their ability to recover from the debilitating effects of the illness. Similarly, there has not always been adequate consideration of the value of engaging the consumer as a partner with decision-making authority in the treatment process. Conversely, it is not clear if the experiences of consumer-professionals are characteristic of the broader population of people with schizophrenia or if they represent a distinct good-outcome subgroup.

Controlled trials are required to understand factors that contribute to consumer-defined recovery and to determine its course and prevalence. An essential step to accomplish that goal is development of psychometrically sound measures of the subjective dimensions of recovery, such as empowerment and hope. A number of measures have been developed to date,³⁵ but none have yet been shown to have adequate psychometric characteristics. One major problem in developing recovery scales concerns the content to be included and scope. Instruments designed to assess change or stage of recovery in more disabled persons need to address relatively basic aspects of functioning (eg, ability to perform activities of daily living [ADLs]). These instruments may not have adequate ceiling to effectively assess persons who are functioning very well, such as the professionals who self-identify as consumers. Conversely, an instrument designed to have adequate ceiling for these exceptional individuals may not have sufficient floor to capture the functioning of more disabled consumers. The assessment of subjective experiences and attitudes of people with schizophrenia, such as quality of life or satisfaction with life, has proven to be quite problematic.³⁶ There are consistent differences in ratings of objective and subjective quality of life, as well as between ratings provided by consumers and other informants. Assessing subjective experiences is especially problematic in persons with sig-

nificant cognitive impairment. While some consumers would argue that self-appraisal is always valid, that viewpoint is difficult to reconcile with observed reality distortion and impaired reasoning. Given that recovery is (at least partially) a subjective experience and is self-defined, some determination will need to be made of when and to what extent a person with schizophrenia can provide an accurate and reliable self-appraisal.

The Recovery Model and Evidence-Based Practices

The President's New Freedom Commission strongly advocated for the role of science in guiding mental health practice. The report specified, "The Nation must have a more effective system to identify, disseminate, and apply proven treatments or evidence-based practices (EBPs) to mental health care. Systematic approaches to bring scientific discovery to service providers, consumers, and families must be emphasized."^{12p72} At one level this mandate provides a clear endorsement of the recent trend within the scientific community to define and disseminate EBPs.³⁷⁻³⁹ While there is not unanimity on how to define EBPs or the relative weight that should be accorded to clinical judgment versus clinical trial evidence, there is considerable agreement on what treatments currently merit the EBP designation (eg, the Schizophrenia Patient Outcomes Research Team [PORT]³⁹), including acute antipsychotic treatment, maintenance pharmacotherapy, family intervention, skills training, supported employment, cognitive behaviorally oriented psychotherapy, assertive community treatment, and token economic interventions.³⁹

However, consistent with the recovery model, the New Freedom Commission report also stated, "First, services and treatments must be consumer and family centered, geared to give consumers real and meaningful choices about treatment options and providers."^{12p5} The report goes on to say, "Consumers, along with service providers, will actively participate in designing and developing the systems of care in which they are involved.... In partnership with their health care providers, consumers and their families will play a larger role in managing the funding for their services."^{12p8} The mandates for EBPs and consumer choice are likely to be entirely consonant in many cases, when, for example, EBPs are seen as desirable to consumers and their families. However, there is a potential for considerable tension when the consumer and/or family do not accept the need for or desirability of EBPs.

It is well known that many, if not most, consumers do not take antipsychotic medication as prescribed. For example, the CATIE (Clinical Antipsychotic Trials in Intervention Effectiveness)⁴⁰ study reported that more than 74% of subjects discontinued study medication during the initial randomized treatment phase. Patient preference was the most frequent reason cited for discontinuation (around 30%), and it may actually have accounted for more than half of all cases. This phenomenon has typically

been viewed by providers as noncompliance or, more recently, nonadherence. Regardless of which term is used, it is generally assumed that failure to take medication as prescribed represents poor judgment by the patient and is something that needs to be fixed, whether through education, persuasion, or use of a medication with a different side-effect profile. While the evidence of nonadherence with psychosocial treatments is not as clear, a high rate of attrition and inconsistent attendance is commonplace in both psychosocial treatment trials and clinical programs, and the onus is similarly placed on the consumer. Discontinuation or self-determined medication dosage schedules are rarely assumed to be a reasoned decision by the consumer that should be respected.

To be sure, there is a legitimate argument that consumers with significant cognitive impairment may have poor judgment and that the clinician should be in a position to protect the person and impose EBPs at those times. Writing from a consumer perspective, Frese, Stanley, Kress, and Vogel-Scibilia²⁵ cogently argue for a tiered strategy of provider control or decision making, in which the consumer gradually assumes more control and decision making as he or she recovers decisional capacity. Conversely, there is a legitimate argument championed by some members of the consumer community that refusing treatment can be a reasoned decision even when the person is acutely ill and should rarely, if ever, be ignored. For example, Fisher and Ahern⁴¹ have argued that the application of the recovery model, with its emphasis on hope, responsibility, and self-control, is particularly important during the most distressing periods of illness. It should also be noted that professionals, family members, and consumers often assign different priorities to the goals of treatment, suggesting that the issue is not who is right and who is wrong so much as legitimately different values based on different perspectives.^{42,43}

Are Current Evidence-Based Practices Consistent with a Recovery Model?

If there is a mandate to combine evidence-based practices with a recovery model, a logical question concerns the extent to which current EBPs are compatible with the model. The recovery model refers to how treatment is delivered, as well as to what treatment is delivered. Given the structured nature of evidence-based pharmacotherapy, the primary issue in the use of medication pertains to the way the clinician interacts with the consumer: is treatment approached as a partnership that encourages the consumer's participation in decision making, and does the clinician foster a sense of hope? The one contentious issue concerns how the clinician deals with a person who elects not to take medication. The recovery model would lead to education and ongoing discussion, rather than a more paternalistic decision-making strategy. This approach represents positive clinical values that should

guide practice, aside from the fact that it is consistent with a recovery model.³⁷

There is much more variability in the goals and content of psychosocial treatments. Consequently, psychosocial EBPs can be evaluated in terms of both how they are implemented and what they are designed to do. In fact, each of the treatments determined to be evidence-based in the PORT review are consistent with a recovery model:

1. Recommendation 15 is that persons who have ongoing contact with their families should be offered a family intervention. The goals of the intervention are to reduce stress and burden on family members and to develop a collaborative relationship between the family and treatment team, as well as to have clinical benefits for consumers.⁴⁴ This approach is clearly consistent with the New Freedom Commission recommendation that interventions be family-centered and engage families as partners.
2. Recommendation 16 endorses "supported employment," an innovative strategy to increase the ability of consumers to work. In contrast to traditional vocational rehabilitation programs, which typically involve low-level activities in sheltered workshops, supported employment programs help the consumer to find a real job in the competitive marketplace and provide ongoing supports in the workplace.⁴⁵ Notably, the job counselor works with the consumer to identify the type of work he or she wants to do, at a level of intensity with which he or she is comfortable. The program is, thus, very much a partnership and serves to enhance feelings of accomplishment and self-worth.
3. Recommendation 18 is for skills training. This recommendation is based on the extensive literature on social skills training, one type of skills training.^{46,47} Skills training programs use a well-established teaching technology to help the consumer develop skills that can enhance community functioning and reduce stress. Skills training is administered in a classroom format, and the curricula are selected so as to have current relevance for the participants. Critics of social skills training sometimes view it as formulaic and unresponsive to consumer needs. To the contrary, consumers are invited to participate in classes (groups) of interest, analogous to a student choosing elective courses. The training itself is closely tailored to each participant's needs and level of skill. As with supported employment, the program is designed to foster feelings of self-efficacy and to provide supports that enhance the person's ability to achieve his or her personal goals. Skills training also assumes that failures are based on the environment and/or faulty teaching, not symptoms or negative consumer characteristics such as low motivation.
4. Recommendation 19 is for cognitive behaviorally oriented psychotherapy (CBT). Based on the work of Beck and colleagues,⁴⁸ CBT for people with schizophrenia

is designed to help the person cope more effectively with psychotic symptoms and dysphoric feelings. A significant part of the intervention is devoted to developing a trusting relationship in which the clinician and consumer develop a shared perspective of the illness. CBT is conducted as a partnership between clinician and consumer. As in skills training, there is an emphasis on skill building and enabling the consumer to feel more in control of themselves and their experiences.^{46,49} Symptoms are viewed as impediments that the person can learn to cope with or control, rather than as handicaps that must be eliminated.

5. Recommendations 17 (assertive community treatment [ACT]) and 20 (token economy interventions) are, perhaps, the most controversial in the context of a recovery model. Each of these approaches is designed to work with the most impaired consumers who are not helped by less intrusive interventions. In the context of ACT, a treatment team provides 24-hour coverage in the community, making it difficult for the consumer to refuse or avoid treatment.^{50,51} However, consumers assigned to ACT teams are generally at grave risk for harm from self, others, or the environment. The goal is to help improve level of functioning and reduce risk so a less intensive and intrusive level of care can be provided. Token economies and related social learning interventions are designed for long-term inpatient units in which many residents are unable to perform activities of daily living or actively participate in the social milieu.⁵² While they are often imposed on residents without their active permission, the programs are designed to reduce the possibility of harm from self or others, increase the extent to which the person can make proactive choices (eg, elect whether to engage in reinforced activities, select reinforcers) and provide the least restrictive level of care possible under the circumstances. For example, social learning programs are very effective in reducing rates of seclusion, restraint, and prn medications. They also teach behaviors that are required for community placement and thereby facilitate discharge. Both ACT and social learning programs are consistent with the arguments made by Frese et al.²⁵ to the effect that more control is justified for persons with very severe illness and that programs should be designed to increase the amount of choice and self-control as illness is brought under control.

Summary and Conclusions

Mental health care in the United States and western Europe is undergoing a seismic shift in values. The paternalistic, medical model of care that has dominated practice for more than 75 years is being challenged by an activist group of consumer-survivors, with the support of public officials and an increasing number of profes-

sionals. The shift in values is likely to be accompanied by a significant shift in patterns of reimbursement and the structure of public health systems. The centerpiece of this shift is the recovery model. In contrast to earlier views of schizophrenia as a chronic, debilitating condition with a very poor prognosis, the recovery model assumes that all consumers have the capacity to improve and develop a life distinct from their illness. In that sense, schizophrenia is seen as more akin to chronic medical conditions like diabetes or heart disease, which may interfere with functioning but which do not define the person in his or her own eyes or in the eyes of society. The consumer model of recovery involves a nonlinear process in which the consumer gradually adapts to and moves beyond the illness. It is an individualized, personal journey with bumps along the way. This model stands in contrast to scientific and clinical models, which view recovery as an outcome, primarily involving reduced symptoms and improved functional capacity. Scientific-professional views also place considerable emphasis on the role of treatment, especially including maintenance pharmacotherapy. In contrast, the consumer model places greater emphasis on peer support and personal experience. Treatment is seen as potentially helpful, but it is not an invariant requirement.

The 2 different conceptions of recovery should be viewed as complementary rather than right or wrong. They reflect different consequences of the illness and important criteria on which to judge disability and improvement. From the perspective of scientists, clinicians, society, and families, it would be untenable to ignore the continued presence of psychotic symptoms or functional disability and inability of the person to resume expected social roles. Conversely, the consumer movement has made it clear that hopelessness, dependence, absence of a feeling of control over one's life, and loss of a sense of self have a profound impact that can be more painful than symptoms and objective manifestations of role functioning.

The scientific literature suggests that around 50% of people with the illness meet objective criteria for recovery for periods of time during their lives, with the periods increasing in frequency and duration once past middle age. There is, as yet, no scientific literature on the prevalence of recovery as defined by consumers or on the factors that contribute to it. Consumer definitions, including recent definitions developed by the President's New Freedom Commission and SAMHSA, involve poorly defined, subjective terms (eg, empowerment, hope, respect). To date they have not been operationally defined in a way that would lend itself to careful study, and no psychometrically sound assessment instruments have been developed. It is essential that the consumer model of recovery be subjected to empirical evaluation if it is to have a meaningful and lasting impact on systems and patterns of care. Self-report of recovery status and consensual validation by

other consumers is necessary but not sufficient. Reliable and valid assessment instruments are required. Empirical study is also needed to examine the elements of recovery, such as the 10 characteristics of recovery identified by SAMHSA. Questions to be examined include the magnitude and nature of the relationships among the elements; the extent to which they are each necessary conditions for recovery (versus being correlates or consequence of recovery); and how they can best be achieved (eg, to what extent can they be fostered by professionals, peers, and families?). Similarly, if the consumer treatment model is to be promulgated, it will be important to determine that recovery-oriented treatment produces better outcomes as seen by clinicians and families, as well as consumers.

The President's New Freedom Commission report placed great emphasis on the role of evidence-based practices and consumer choice. These 2 mandates may sometimes be incompatible, as when a consumer declines to take medication or participate in evidence-based psychosocial treatments. For the most part, established EBPs are consistent with the recovery model and will ordinarily be administered in the context of a partnership. However, the balance of power may need to shift toward the professional when the consumer is highly impaired and has diminished decisional capacity. It will be important to study this issue objectively so decisions about decisional capacity and level of control required can be made empirically.

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