

Recovering and Recovery in Schizophrenia

*Improving
the long-term
outcome
of patients
with serious
mental
disorders*

A new perspective on the course of schizophrenia has emerged that offers a source of hope for persons with schizophrenia. New pharmacologic and psychosocial treatments along with a better understanding of the heterogeneity in course and outcomes in schizophrenia, are leading both clinicians and researchers to achieve goals beyond just the reduction of symptoms. An emphasis on positive outcomes and recovery has replaced the old notion that the diagnosis of schizophrenia meant that at best, a person would be chronically ill and disabled, or at worst, would have a deteriorating course resulting in institutionalization. This new point of view has been quickly adopted with such enthusiasm by consumers, family members, and advocates that policymakers have begun to envision a transformed mental health care system that promotes recovery. The publication of documents, such as the President's New Freedom Commission and the VA companion document, the VA Action Agenda, have outlined this vision and set specific goals. Along these lines, the Substance Abuse and Mental Health Services Administration (SAMHSA) issued a consensus statement outlining principles necessary to achieve mental health recovery (see box; a complete version can be viewed at: http://www.samhsa.gov/Pubs/MHC/MHC_NCrecovery.htm).

"We envision a future when everyone with a mental illness will recover,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."

*President's New Freedom Commission,
2003*

"Individuals also identify recovery as being an ongoing journey and an end result as well as an overall paradigm for achieving wellness and optimal mental health."

SAMHSA, 2006

This revised view of the course of schizophrenia was prompted by two significant, yet different sources. Results of long-term outcomes studies in schizophrenia showed that many people have good outcomes thus challenging the traditional notion of a chronic, and possibly deteriorating, course of this illness. At the same time, a grass roots movement, begun by consumers and advocates to improve care for and reduce stigma toward those with schizophrenia gained momentum. Through their educational efforts, groups such as the National Alliance on Mental Illness and the National Empowerment Center publicized the fact that many persons with schizophrenia live productive and meaningful lives.

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Recovery and Evidenced-based Practices in the Desert Pacific MIRECC

At first glance, it may appear as though the goals of recovery and the use of evidence-based practices are at odds. Person-centeredness is central to the notion of recovery and recovering, focusing on the personal objective goals and the subjective experiences of the consumer. In contrast, evidence-based practices are determined by examining data on groups of people and by using objective definitions of outcomes. Emerging research in several areas should narrow the gap between recovery and evidence-based practices. The Desert Pacific MIRECC (VISN-22) is involved in many efforts at the local, regional, and national level to promote recovery- and evidence-based practices throughout the VA.

The VISN-22 MIRECC is helping to promote recovery both as a process and as an outcome in several ways. The MIRECC has organized conferences for providers and administrators to

publicize established and innovative psychosocial interventions to improve social and vocational functioning in persons with schizophrenia (give url for Recovery Conference). We are also participating in the national effort to expand and modify My HealthVet to include information about mental health. In response to input from veterans and family members, the My HealthVet team plans to develop a web-based format for each veteran to have an individualized Recovery Plan that can be accessed by approved healthcare providers in order to increase continuity of services. Finally, MIRECC members are involved with a national group that is spearheading the measurement of recovery.

Many MIRECC investigators have developed and tested treatments that incorporate a recovery perspective. There are current research activities in all of the rec- *Continued on Page 3*

Stephen R. Marder, MD

Recovery in Schizophrenia



This issue describes recovery, an important focus of our MIRECC. There is an increasing awareness that clinicians who treat individuals with schizophrenia and other serious psychiatric illnesses may be failing to understand the goals of many patients. For example, psychiatrists believe that most patients with schizophrenia are disinterested in work. Actually, more than 60% would be willing to work. It is interesting to speculate on why there is this disconnect between patients and their providers. One possible reason is that the providers are focused on reducing psychotic symptoms and may fail to ask the patient about his or her priorities and goals. Moreover, the patient with schizophrenia may not raise the issue since the clinician may seem disinterested in this aspect of their life.

This dilemma emphasizes important aspects of a recovery

orientation toward treating schizophrenia and other serious psychiatric illnesses. That is, care should be patient-centered. The goals of treatment should emerge from a dialogue that includes discussions that go well beyond symptoms and considers the patient's vocational, social and other interests.

The MIRECC research program is addressing some of the important issues that support patient-centered care. For example, our participation in My HealthVet will help to create an environment within the VA that will permit patients to play a larger role in managing their own illnesses. Research programs that focus on methods for helping patients to succeed in the workplace or in their social environment have the potential for enriching the lives of individuals even when they need to live with symptoms that resist drug treatment. A new research initiative will focus on patients who have managed to succeed in meeting their personal goals despite suffering from schizophrenia. We will study how these people manage to cope with their illness and still manage to work and function in their families and communities. Hopefully, these successful individuals have learned strategies for managing their illnesses that can be helpful to others. ♦

Recovering and Recovery *(Continued from page 1)*

Definitions of Recovery

Despite the consensus regarding a more positive view of the course and outcome of schizophrenia, the definition of recovery is still unclear. In part, this lack of clarity is the result of the multifaceted nature of the concept of recovery and the many definitions of recovery that exist.

As an example, in medicine the basic concept of recovery is a "cure"; a disease is treated and health and functioning are restored, like the treatment of a bacterial infection with antibiotics. Other chronic diseases, such as cancer, coronary artery disease, and asthma, occur in episodes in which there may be relapses and remission of symptoms. After a certain period of symptom remission, the person returns to previous levels of functioning and is considered recovered. Similarly, recovery from an addiction is characterized by periods of abstinence and relapses until the person achieves sobriety for a long enough period, has returned to a normal lifestyle and is considered recovered. Some diseases, such as the neurological disorder multiple sclerosis (MS), are variable in their courses and outcomes. In some individuals, MS symptoms and levels of functioning get progressively worse. In others however, symptoms wax and wane with near normal levels of functioning in between periods of illness. There is also a group of persons with MS who experience periodic worsening of symptoms that eventually remit, but they never quite return to their previous level of functioning. Nonetheless these individuals learn to cope with and compensate for their residual disabilities and are able to lead fulfilling lives.

Since there is not yet a cure for schizophrenia, recovery usu-

ally involves eliminating or reducing symptoms and restoring social and vocational functioning and community participation. Like cancer and addictions, schizophrenia is episodic; and like MS, the course and outcome of schizophrenia is variable. Because of this variability, recovery goals are different from person to person. To some, the process of recovering is even more important than the actual recovery outcomes. Viewing recovery as a process, often called "recovering", as well as understanding recovery as several different outcomes, further adds to the confusion to the concept of recovery.

Recovery or Recovering

Consumers and advocates often view recovery as a personal journey to overcome a psychiatric disability and lead a successful and meaningful life. Important in this conceptualization is the fact that recovering is highly personal. It is a non-linear process with symptoms re-emerging and levels of functioning at times changing, sometimes to previous levels and sometimes to higher or lower levels. One of the important issues in the process of recovering is not so much the absolute level of symptoms and functioning, but rather the subjective meaning the individual attributes to the changes. This subjective nature of recovery, however, makes it difficult to assess.

While consumers and advocates view recovering as a personal journey, most researchers tend to view recovery as an outcome. Several definitions of recovery have been proposed including specific criteria for symptom severity and level of functioning. Recovered usually means mild or no symptoms and no interference with an individual's community, social and vocational functioning. Although many

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ognized evidence-based practices (skills training, cognitive behavioral therapy, family psychoeducation, behavioral management, and supported employment), as well as in testing promising new interventions such as peer support. For example, Tom Patterson, Ph.D., has created and tested an intervention to help people with schizophrenia learn skills to improve their daily functioning. Eric Granholm, Ph.D. has developed a program to change cognition and behavior to reduce psychotic symptoms. Shirley Glynn, Ph.D. is examining a new approach for helping persons with schizophrenia succeed in the workplace.

Yet another way that the MIRECC is supporting the partnership between recovery and evidence-based practices is through evaluating innovative methods for disseminating already established interventions. Drs. Alex Young, Amy Cohen, and Matt Chinman are conducting a study using the collaborative care model to implement a wellness program and supportive employment. This project is studying the collaboration among the psychiatrist, nurse case manager, and the consumer to improve health and vocational outcomes.

The goal of the VISN-22 MIRECC is to improve functioning and quality of life and to promote recovery for persons with schizophrenia through educational efforts and clinical research programs that develop and disseminate recovery- and evidence-based practices. ♦



Rehabilitation and Recovery of the Client with Psychosis: Evidence-based Practice

Conference lectures available online at:
www.desertpacific.mirecc.va.gov/conferences/rehab-and-recovery/

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people can be classified as having recovered from schizophrenia using these criteria, most would agree that important aspects of recovery are still missing from these definitions. For example, the subjective experience of the individual needs to be considered. Since each person has unique goals, there is no gold

Components of Recovery

- Self direction
- Individualized and Person-Centered
- Empowerment
- Holistic
- Non-linear
- Strengths-Based
- Peer support
- Respect
- Responsibility
- Hope

SAMHSA, 2006

The MIRECC Website gets a makeover and a new home

Yes, you are in the right place -all VA websites now look alike!



Yet, you will still find our familiar features... and some new ones too.

The Veterans Administration (VA) has mandated several changes for all VA supported websites. They include residing on a VA server and using a VA standard design. We recently completed our “rennovations” to comply with the new mandates and have also changed our web address to:

WWW.DESERTPACIFIC.MIRECC.VA.GOV

MIRECC featured content can be accessed by using the menu items just below the “MIRECC LINKS” section on the left side menu. VA content and services are accessed from the top banner menu and the first 3 links on the left.

Let us know what you think by filling out our Guestbook form at www.desertpacific.mirecc.va.gov/guestbook.shtml

standard with which to measure recovery.

More recently, researchers have begun to further expand the concept of "recovering". One new view is that recovery is a life orientation or attitude that can be measured. Using subjective information gathered from the PORT study (Patient Outcomes Research Team), the largest systematic survey on the treatment of schizophrenia, investigators found that the recovery attitude consisted of four factors-1. self-perceptions about knowledge about mental illness and available treatments, 2. capacity to feel empowered in one's life, 3. hope and optimism for the future, and 4. satisfaction with quality of life. Further research on measuring recovery attitudes and combining them with objective measures of functioning in areas chosen by the consumer should help consumers, family members, providers, advocates, and policy makers evaluate both the effectiveness of treatments for schizophrenia and the quality of the systems that provide these services. ♦

THE FACES OF MIRECC

David Braff, M.D.



David Braff, M.D. is a Professor of Psychiatry, and the Director of the Schizophrenia Program at the UC San Diego School of Medicine. He is Director of Clinical Neurosciences Unit at the VA VISN 22 Mental Illness, Research and Clinical Center (MIRECC) program. He trained at the University of Pennsylvania, Yale University, and the University of California, San Francisco.

Dr. Braff has published over 200 articles, related reviews and book chapters and is among the top 1/2 of 1% of most highly cited psychiatric researchers. Dr. Braff has

been dedicated to mentoring young scientists and understanding and treating schizophrenia patients and their families for over 30 years and says "They are about the most courageous people I've ever met".

David Braff is married and has two grown children. When not working he enjoys walks through the Torrey Pines nature preserve, spending time with his family, jazz, and watching his favorite films over and over again.

How long have you been studying schizophrenia?

My interest in schizophrenia began in the late 1970's when I started treating patients and studied prepulse inhibition (PPI) deficits in schizophrenia patients in my mentor's (Dr. Noch Callaway) laboratory at UCSF. This work showed that persons with schizophrenia did not "gate" or process sensory information normally. I continued my research in the identification of neural substrate and neural circuit deficits in various psychiatric disorders with an emphasis on schizophrenia using neurocognitive, neurophysiological and imaging methods.

When did you become interested in the genetics of schizophrenia?

My research focusing on attentional dysregulation as an endophenotype in family/genetic studies led me to investigate the specific genetic architecture and it's deficits in schizophrenia patients.

What are "endophenotypes"?

Endophenotypes are laboratory based measurable variations underlying the presentation of a disease or disorder and they are present in patients and their clinically unaffected relatives, reflecting the genetic burden of schizophrenia, hypertension, diabetes and other complex, genetic human disorders. The variations could be neurophysiological, biochemical, neurodevelopmental, neuroanatomical, cognitive, or neuropsychological in nature. Scientists compare endophenotypes to gain an understanding of the genes that contribute to the disorder.

How can the study of genetics lead to improved treatment for schizophrenia?

My colleagues and I have used translational human and model organism and genomic research to identify new antipsychotic compound targets and to assess the efficacy of antipsychotic medications that can improve the real world functional outcome of schizophrenia patients.

What is COGS?

COGS stands for the "Consortium on the Genetics of Schizophrenia" which is funded by the National Institute of Mental health (NIMH) to explore the genetic architecture of schizophrenia through the use of endophenotypes. Through the efforts of the COGS we hope to understand the genetics of schizophrenia and be able to foster the development of new, third generation medications that are selected for their molecular level "restorative" and therapeutic properties. These compounds can then be used early in the course of the disorder (even for prevention), hopefully with minimal side effects ♦

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