

Empirical correction of seven myths about schizophrenia with implications for treatment

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This paper presents empirical evidence accumulated across the last two decades to challenge seven long-held myths in psychiatry about schizophrenia which impinge upon the perception and thus the treatment of patients. Such myths have been perpetuated across generations of trainees in each of the mental health disciplines. These myths limit the scope and effectiveness of treatments offered. These myths maintain the pessimism about outcome for these patients thus significantly reducing their opportunities for improvement and/or recovery. Counter evidence is provided with implications for new treatment strategies.

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There are at least seven prevalent myths about schizophrenia which often discourage clinicians, significantly impact the view of the patient, and thus his or her treatment. All of these myths have been challenged by research data, yet they persist in training and practice across mental health disciplines. This paper endeavors to contribute a more balanced and contemporary view of the person with schizophrenia in order to re-energize clinicians and revitalize treatment approaches.

**1. Myth: Once a schizophrenic always a schizophrenic.
Reality: Ever widening heterogeneity of outcome across time**

Kraepelin (1) initiated the myth by categorically splitting mental illness into either good outcome (manic depression) or poor outcome (dementia praecox). Diagnosis was verified or invalidated by the outcome. Even Eugen Bleuler (2), who was originally more optimistic about the outcome of schizophrenia, later decided that there was never "full *restitutio ad integrum*". Harding et al. (3, 4) have explained that these two pivotal investigators suffered from "the clinician's illusion" (5). The "illusion" occurs when clinicians repeatedly see the few most severely ill in their caseloads as "typical" when, in fact, such patients represent a small proportion of the actual possible spectrum. The Scandinavians have generally held a broader view as

evidenced by their use of the category "reactive psychosis" (6). However, even in Scandinavia, pessimism has remained about patients who were unable to fit these criteria or patients who fit these criteria, but failed to improve quickly.

Evidence: Recent worldwide studies have investigated the assumption of downward course and all have found wide heterogeneity in the very long-term outcome (over 2 decades) for schizophrenia, despite differences in diagnostic criteria used (e.g. 7-14). The European studies have often been dismissed in the U.S. because of the perception that their criteria were not equivalent and because of sheer ethnocentricity. However, notwithstanding the criticisms of diagnostic differences (valid or not), all of these studies have come to the same conclusions. The longer investigators followed an identified intact cohort (whether probands were in or out of treatment), the more pronounced the picture of increasing heterogeneity and improvement in function. These studies have consistently found that half to two thirds of patients significantly improved or recovered, including some cohorts of very chronic cases. The universal criteria for recovery have been defined as no current signs and symptoms of any mental illness, no current medications, working, relating well to family and friends, integrated into the community, and behaving in such a way as to not being able to detect having ever been hospitalized for any kind of psychiatric problems. All of these investigators of

long-term studies were trained in the older, more pessimistic conceptual models and were surprised by their own findings. Because the myths have been repeated so often, they had become reified. The strong belief systems and resistance, encountered by these investigators, were caused by many factors and were not easily altered by one study (3, 4). However, there is now a confluence of results.

Suggested treatment strategies: Slowly, these investigators have all persisted. The beliefs about course and outcome are changing. Clinical practices and programs are being restructured (e.g. 15-19). The mental health disciplines are getting the message. Given the evidence, it is suggested that treatment programs be constructed "as if" everyone will turn the corner toward significant improvement and/or recovery. This suggestion is made because the state of the art does *not* permit clinicians to triage patients on the basis of prognostic factors. In schizophrenia, particularly the multiple episodic types, the display of early symptom severity and dysfunction in illness trajectories may persist for many years. Then, as the illness lifts, the patient's energy returns, thinking clears, coping strategies for stressors improves, and he or she inches the way toward improvement in both function and symptom reduction. This is the opposite picture of a relentless downhill course for most patients as described by Kraepelin. This long process of recovery implies a revision of what the clinician tells patients and their families about prognosis ("You have a very serious illness which takes some time to work itself through. However, worldwide data shows over more than 50 percent of patients significantly improve or even recover. We will be there to walk with you on this journey toward recovery"). This new message keeps a small spark of hope alive. Hope promotes the self-healing capacity inherent in any recovery process for any illness (e.g. 20-22). Treatment also means a cohesive, comprehensive biopsychosocial approach to the whole person (23-24), and a collaborative effort between the patient, the family, the clinical team, other community agencies, and natural networks. Treatment means celebrating the small moves forward and learning from the steps backward in a manner which does not blame the patient, the team, or the family. Treatment means environmental engineering to reduce the stressors. Important to remember is the need to re-evaluate repeatedly because the same structured environment which enables a patient to organize a disorganized brain can become psychotogenic later when a now organized brain faces a much too organized environment (25).

2. Myth: A schizophrenic is a schizophrenic is a schizophrenic. Reality: Wide individual heterogeneity within the diagnostic category

Paraphrasing "Rose is a rose is a rose" (26), there is a tendency in the field to lump everyone with the same diagnosis together for treatment and research.

Evidence: In reality, every group of patients has substantial heterogeneity. In addition to the major impact of gender (27), there are considerable differences in age, developmental tasks, education levels, job histories, symptom presentation, coping skills and other personality strengths and weaknesses, meaning systems, response to stress in general and to stress of particular situations (28). Further, it should be noted that the field has forgotten the heterogeneity of schizophrenia, itself. When E. Bleuler renamed dementia praecox, he called it "the group of schizophrenias" (29). Recently, Kendler (30) has developed several models of genetic-environmental interaction and weighting in the etiology of schizophrenia. His models make a great deal of sense given the wide heterogeneity of our patients.

Suggested treatment strategies: The heterogeneity, described above, requires a comprehensive, biopsychosocial assessment of each patient's unique status, the place in his or her own course trajectory, and ecological niche. Individual differences require individualized treatment planning, an appreciation of developmental achievements or strivings, and a recognition of the "person behind the disorder" (10). In order for clinicians to achieve this level of understanding, they must consider the task as a genuinely collaborative enterprise with both the patient and others who know him or her well. Continued assessment of changing, ongoing status is especially important after years of severe psychopathology and dysfunction, given the longitudinal nature of these disorders. The use of "timelines" or "life charts" is recommended in this endeavor by collecting data in a chronological comprehensive life history as well for setting a collaborative tone for treatment (31-32). Attention to individual differences, life histories, and developmental steps, will encourage patients to perceive themselves, *not* as "schizophrenics", but rather as people, who happen to have schizophrenia. Consumers repeatedly note that this recognition of their "personhood" plays a critical role in their recovery and re-acquisition of their sense of well being (33-34).

3. Myth: Rehabilitation can be provided only after stabilization. Reality: Rehabilitation should begin on day 1

This myth has been deeply embedded within a narrow but popular version of the medical model. "Real treatment" in today's managed care climate consists of assessment, diagnosis and medication. Anything else, such as rehabilitation, must wait until stabilization and is often considered to be an ancillary service. But stabilization usually leads just to "maintenance" and not to rehabilitation.

Evidence: "Real treatment" has been only modestly successful in reducing symptoms, and in helping the patient by increasing the levels of functioning in self care, work, interpersonal relationships, and integration back to the community. However, there is a burgeoning field of psychiatric rehabilitation which combines with medical treatments to significantly improve the patient's level of functioning (35, 36). The problem has been a paucity of integrated models proposed to incorporate all of these facets of care. The notable exceptions have been Engel's "biopsychosocial model" (24) and Adler et al's paper (35) which set forth an expanded medical model as a task for psychiatry. Adler's model delineates the tasks for psychiatry to be legal, societal-rehabilitative, educative-developmental, as well as medical. Anthony (36) has proposed a rehabilitation model but left out most of the illness factors.

Suggested treatment strategies: Rehabilitation is accruing an honored place in the treatment of patients as a key modality in partnership with psychopharmacology. Skill building (e.g. how to manage one's symptoms, managing one's medication, learning how to manage a budget, acquiring a job skill, conducting social conversation). All raise a patient's self-esteem and lower symptoms. Anything which lowers symptoms and improves function deserves to be called and reimbursed as "treatment" (17, 36-38).

4. Myth: Why bother with psychotherapy for schizophrenia? Reality: Supportive psychotherapy is crucial for integrating the experience and enhancing continued adult development

Research findings, regarding the ineffectiveness of psychotherapy in curing schizophrenia, have led to widespread discouragement in this area and to a relative lack of innovation and research. Heinrichs (39) concluded from his review that "The kindest interpretation of controlled studies to date is that the benefit of psychotherapy with schizophrenia

has not yet been demonstrated." However, instead of abandoning psychotherapy altogether, the challenge is for clinicians to use psychotherapy appropriately for maximum benefit.

Evidence: Two main lines of evidence support the judicious use of psychotherapy. First, surveys and personal accounts of consumers have indicated that they value psychotherapy and find it to be beneficial in various ways (40-43). Second, several different types of psychosocial interventions have demonstrated positive impact on the lives of persons with schizophrenia including family interventions (see below), group therapies tailored to the needs of persons with schizophrenia (44-45), and very specific, targeted cognitive remediation (46-47).

Suggested treatment strategies: To accept that psychotherapy cannot help persons with schizophrenia reinforces the dangerous and erroneous message that such persons are separate, distinct, and deficient relative to others. On the other hand, a realistic and appropriate approach to the use of psychotherapy in the overall treatment plan can facilitate patients' recovery by integrating their experiences of a life interrupted by severe illness and by helping them learn coping strategies. Coursey (48) clarified the basis of a sound psychotherapy for persons suffering from schizophrenia: 1) psychotherapy should not be seen as competing with medication but, rather, as complementary to it; 2) psychotherapy can and should address the personal, human issues raised by having a serious mental illness; 3) psychotherapy must be practical, thus making use of educational as well as experiential approaches to help individuals learn to manage the disorder; and 4) psychotherapy should address the "normal problems of living that people with schizophrenia have to deal with just as anyone else does" (p. 351).

Neligh and Kinzie (49) have identified ten practical approaches to accomplish the goals mentioned above. These authors suggest the following: 1) accepting the current level of functioning without pressure to change, 2) determining the appropriate frequency of contact for each patient, 3) selecting a comfortable style of relating, 4) modeling desirable social attitudes, 5) facilitating problem-solving skills, 6) providing a safe place for patients to express emotions, 7) managing dependence, 8) effecting changes in the patient's environment, 9) setting limits and discussing consequences of actions, as well as 10) establishing rules for confidentiality and the need to share information across systems of care. These authors propose a respectful, humane approach which emphasizes positive social

behaviors, upbeat emotional tone, the provision of advice, information sharing, compliments, jokes, companionship, as well as sharing in the triumphs and tragedies of life. Such supportive psychotherapy may increase self-esteem, facilitate awareness of limitations, avoid deterioration and /or hospitalization, prevent undue dependence, and improve levels of function.

5. Myth: Patients must be on medication all their lives. Reality: It may be a small percentage who need medication indefinitely

This myth has been generated by physicians for a wide variety of reasons. First, it is an attempt to underscore the importance of taking medication in a power struggle with the patient. Secondly, if a physician believes in Myth #1 "once a schizophrenic always a schizophrenic" or its corollary "once a broken brain always a broken brain", then the physician believes that medication is the key to maintenance of lifelong stabilization.

Evidence: There are no data existing which support this myth. When analyzing the results from the long term studies, it was clear that a surprising number (at least 25% -50%), were completely off their medications, suffered no further signs and symptoms of schizophrenia, and were functioning well. Over time, most patients altered their dosages and schedules. These behaviors often resulted in relapses early on in their illness trajectories when the illness was raging. The physicians in charge often felt justified and the patients felt defeated. Part of the trouble lay in human nature since there is usually only a 40-50% compliance rate for any kind of prescription taking in the U.S. by any kind of patient (38). Other problems involved: 1) the patient's lack of understanding about having an illness, 2) in becoming disoriented enough not to manage taking medication, 3) in the lack of clear knowledge about the reasons for and the skills needed in taking medication, 5) in the frequent increase of covert and overt side effects which are unpleasant or undesirable (e.g. dyskinesia, dystonia, akinesia, akathisia, obesity, impotence, dry mouth, weight gain), and 6) in the lack of engineering to reduce environmental stressors. Such high stressors have been shown to increase relapse rates in some patients even if medicated intramuscularly. However, even though patients experimented with their medications and learned to use them more regularly, the long-term studies found that more subjects than not, eventually discovered through trial, error, and time, that they were able to function without medication later on in their illness trajectories.

Suggested treatment strategies: Most successful approaches involve the following: a strong patient-physician collaboration (49), targeted psychoeducational and skill building strategies aimed at prodromal and chronic symptom recognition and medication management (17) as well as built-in re-assessment strategies and standardized side effects monitoring techniques (49).

6. Myth: People with schizophrenia cannot do anything except low-level job. Reality: People with schizophrenia can and do perform at every level of work

The idea that persons with schizophrenia are unable to work or can only achieve a low level of function because of their illness has had long standing credence especially in the U.S.. Anthony et al. (50) reported in their review of the literature that only 10-30 percent of patients worked full time throughout a year or at follow-up. This finding has reinforced this perception.

Evidence: The early vocational approach consisted primarily of sheltered workshops designed originally for the developmentally disabled (51). Until recently, little thought was given about whether or not these workshops were appropriate settings for these patients or for those with serious mental illnesses. In addition, there has been minimal appreciation about the power of stigma, the low priority in the vocational rehabilitation ladder, distinct systems problems at the interface (such as rigidity, isolation, compensatory ad hoc operations, and narrow frames of reference [28, 50]). However, in their 1974 follow-up study, Strauss and Carpenter (52) found that symptoms and levels of functioning, such as work, were only loosely related to one another in an "open-linked" fashion. The Vermont Longitudinal Research Project (12) also found that, in their "improved but not recovered group", wide heterogeneity existed within the same person with some cohort members working well despite ongoing and persistent hallucinations and/or delusions. These patients had learned not to tell anyone because it "upset" others. For other patients, work became the primary treatment strategy to reduce symptomatology (25, 37, 53).

Across time, clinicians have appreciated the interactive therapeutic effects of work on illness (e.g. Galen [172 AD] "Employment is nature's best physician and is essential to human happiness" [see 54 p. 663]). Harding (28) discovered that "Despite this basic understanding of human functioning, the integration of work into systems that treat severe mental illness is limited, sporadic, and inadequately addressed." When a rehabilitation pro-

gram has a strong emphasis and a cohesive approach for clients, the long-term trajectory is significantly enhanced and the work histories greatly altered (12, 14).

Suggested treatment strategies: At the current time, vocational and other forms of rehabilitation are accomplished by "persistent, energetic personnel inventing ingenious solutions to the roadblocks set up at the system interfaces" (28). To treat the patient first means to "treat" the system of care in order to encourage flexibility, collaboration, data-based training, and a unified theoretical framework. Other approaches have been laid out such as the vocational strategies of "choose, get, keep" job model from the Boston group headed by Anthony et al. (50). They formulate a rehabilitation diagnosis, develop a rehabilitation plan, (which incorporates resources available and needed), and devise individually constructed interventions. This collaboration involves career counseling, skills training, placement, and work training to keep the job once the person has one (such as getting to work on time and dressing neatly and maintaining appropriate social interaction [50]).

7. Myth: Families are the etiological agents. Reality: Families as collaborators can provide critical information and provide environments to lower a relative's vulnerability to episodes

The myth, that families cause schizophrenia, flourished prior to the most recent biological revolution in psychiatry. Proponents of this myth targeted the family's severe dysfunctions, especially in the area of communication, as the cause of schizophrenia. For example, after observing communication difficulties in persons with schizophrenia, many theorists (55-57) reasoned that the dysfunctions were learned through interaction with disturbed family members. Although many investigators have since discarded this myth, it has survived even in the current biological era, such that numbers of clinicians and academics, who train students in the different mental health disciplines, still believe it (58).

Evidence: Although family researchers have demonstrated that the emotional and interactional climate of families can help precipitate relapses in their relatives (e.g., 59) as well as the efficacy of enhanced family communication in lowering vulnerability to relapse (60), they have failed to show that family factors are necessary and sufficient causes of schizophrenia (61-62). No evidence exists that a family's psychosocial climate, communication patterns, or parenting practices are

primary causes of schizophrenia. In fact, despite the finding that vulnerable individuals from families high in expressed emotion are more likely to relapse, the majority of families are not rated high on this factor (58). Many families, who are low in EE, may very well represent a biologic protective factor (61). Family researchers now recognize that it is the co-occurrence of an ill individual's behaviors and the various emotional/interactional characteristics of a family's response which often precipitates symptoms. The available evidence suggests that schizophrenia is an episodic disorder which, not unlike many other episodic disorders (e.g., asthma, Crohn's Disease, arthritis), is often vulnerable to environmental stresses and triggers. Stressors, such as family environment, are now not considered to be sufficient in and of themselves to be considered etiological agents of the underlying disorder.

Suggested treatment strategies: The optimal roles of families in treatment, and the appropriate relationships between clinicians and families are now well established, if not widely realized. Families need, and want, education, information, coping and communication skills, emotional support, and to be treated as collaborators (63). As many authors have noted (e.g., 64), scientific theories of family causation contributed to the alienation between professionals and families, as well as to the guilt and burden that families feel. For this reason, clinicians need to make a special effort to solicit the collaboration and involvement of family members. In some cases it may even be necessary to entice families into collaboration by acknowledging the difficulties they have experienced and apologizing for the way they have been treated by the mental health system. Once a relationship is established, clinician, patient, and family can work together to identify needs and appropriate interventions. Many families benefit from communication training, psychoeducation about the illness and coping strategies. Fortunately, several effective models exist (e.g. 66-67; see also 68). In addition to assisting families in the acquisition of skills and knowledge, it is important for the clinician to encourage families to develop realistic, yet optimistic expectations about their relatives' chances for improvement (see above discussion of Myth #1), and about their own ability to contribute to the recovery process, thus helping to relieve family burden.

Conclusion

This paper has reviewed 7 prevailing myths about the group of schizophrenias. The authors have proposed counter-evidence to each myth. Some

treatment strategies were suggested to enhance the possibility of improvement and recovery through reduction of symptoms and the increase of levels of functioning for patients. It is hoped that this paper will encourage clinicians, program designers, policy makers, patients and their families to deal more effectively with these difficult and often prolonged disorders. A longitudinal perspective about schizophrenia should imbue everyone with a renewed sense of hope and optimism. After studying 508 patients across 22 years, Huber and colleagues (68) stated that "...schizophrenia does not seem to be a disease of slow, progressive deterioration. Even in the second and third decades of illness, there is still potential for full or partial recovery." All of the recent long-term follow-up investigators have recorded the same findings (7-14).

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