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MADNESS: Schizophrenia, Then and Now

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MADNESS

Schizophrenia, then and now

A senior thesis submitted to the faculty of the Dominican University of California in partial fulfillment of the requirements of the Bachelors of Arts in Humanities

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ABSTRACT

In examining the subject of mental illness, it is clear that diseases and disorders of the

brain have not received the same degree of attention in the United States, over the

years, as have acute and infectious diseases of the body.   This thesis discusses the

history of research and treatment of brain disorders, generally, with particular

emphasis on schizophrenia, the most serious of mental disorders. The narrative

includes the story of my aunt, who was schizophrenic. The objective of this thesis

is to add another voice to the many who have asked that the bar on mental health

research and treatment be raised significantly. A secondary objective is to include this paper as

a chapter in the family memoir I hope to write.

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MADNESS: Schizophrenia, then and now

Introduction

All of our lives changed the day Aunt Dagmar came home from the mental hospital to live with her family. I was only fourteen years old, and was stunned and a little horrified by the sight of this gaunt, hollow-eyed, and vacant woman. Was she really related to us? I had no previous memory of her, having been only two years old when schizophrenia claimed her mind. Dagmar, or Dinty as she was known to her family, was then thirty-four, and had spent twelve years (from 1942 to 1954) in a mental hospital in southern Saskatchewan, Canada.   On that day, I became painfully aware of mental illness–not only the illness, but the stigma it carries with it– and I have been painfully aware of it ever since. In the days, weeks, months and years that followed, it became obvious to me that mental patients have been generally considered freaks of nature and, correspondingly, they have been treated with a lack of compassion. I also came to understand another painful truth, that only someone who is related to a mentally ill person can fully appreciate the condition, and how little has really been known about it.

As I grew older, I intuitively sensed a vast difference in the way mental patients were treated compared to patients with diseases of the body, and of the lack of resources being directed toward research of disorders of the brain. My research on the subject shows that my perceptions were correct, although I must admit that I am more hopeful today.

In those early days following her release from the hospital, Dinty was still showing many of the symptoms of her disorder, although they were not nearly as severe as when she was initially incarcerated. Her two sisters who lived in the same small town in the neighboring Province of Alberta shared the burden of her care for a long time. She would live with one family until either she or they tired of the situation, then she would move to the other family. So it went, for years. When she was living with my family, I shared a bedroom with her, and I was able to observe her strange behavior, such as: In response to suggestions from the voices only she could hear, she would wear several sets of underwear at one time, or she would strip her bed of all bedding and sleep naked on the bare mattress. On top of that, she would chain-smoke all night long, and sometimes respond to the voices in her head.

Before she came home, I had already seen the 1948 Academy Award-winning film *The Snake Pit,* based on the novel by Mary Jane Ward, and I was very curious to find out how her experiences compared with what I had seen in the film. They matched in so many ways. She described what it was like to live day-to-day with other patients suffering from varying degrees of madness: being forced to eat food that resembled pig-slop (her description); receiving rough, uncaring handling by overworked nurses and staff; enduring various means of restraint, be it handcuffs, a straitjacket or medicinal; and, worst of all, experiencing horrific electric shock treatments. Shock treatments sound harsh, to be sure, but consider that "long ago insane people were lowered into snake pits, the thought being that what might drive a sane person out of his wits might send an insane person back into sanity" (Ward 217*).*

The medicinal shock treatment was Chlorpromazine, a drug used to quiet disruptive patients and reduce them to childlike behavior. It was described as a medicinal lobotomy. This drug was introduced at a time when there were more than a half million people in public mental

hospitals. States were then spending two dollars per day per patient, less than one-seventh the amount spent in general hospitals (Whitaker 146-7).

Eventually, with appropriate medication, Dinty would appear to function normally, albeit with a few obvious quirks. However, there were always periodic lapses when she would discontinue her medication, believing herself to be normal again. Of course, she wasn't well, and it was a long and painful process to get her back on medication and back on track.

Blessedly, there were endearing aspects to living with Dinty. Many people who suffer from brain disorders have talents that belie their conditions. Some display extraordinary musical talent, mathematical skills or superhuman memories. Dinty had an innate sense of humor combined with a down-home practicality. She was witty without even knowing it. Her descriptions of just ordinary things would often send us all into hysterics. For example, she could say the word *shit* in such a way that one could almost taste it. She had no sense of delicacy when dealing with sensitive issues, describing exactly what she was seeing whether or not it hurt someone's feelings. That meant that if one had gained weight, one could be sure she would mention it, saying something like, "Diane, I think you are beginning to look a little matronly."

Fortunately, I was too young to be concerned about how our small community reacted towards Dinty or the rest of us. She was family, and that was that! Thirty years and many false starts later, at the age of 64, Dinty was able to successfully live semi-independently. However, she was never able to hold a job. "As far as we have progressed in research and treatment, recent statistics indicate that only one in five people can ever be expected to live independently and hold a job" (Saks 288). Dinty eventually moved to a beautiful resort area in the Province of British Columbia where she lived for a time close to two older sisters.   She died at the age of eighty.

What is Schizophrenia?

According to The American Psychiatric Association, mental health disorders fall roughly into two categories: disorders of thought and disorders of mood. Schizophrenia is a chronic, severe, and disabling thought disorder characterized by psychosis. Bipolar disorder (a condition that used to be called manic depression) is an example of a mood disorder (Saks 54).

Many people who suffer from bipolar disorder or clinical depression lead full and rich lives--journalists Mike Wallace, Jane Pauley, and the author William Styron are a few prominent examples. Historical figures include Abraham Lincoln, Vincent Van Gogh, Virginia Woolf and Samuel Johnson (Saks 327).

The story is not the same for people with thought disorders. Comparatively few schizophrenics lead happy and productive lives. The psychosis that accompanies schizophrenia generally means being out of touch with reality. Schizophrenia is considered the most severe of the psychotic disorders, and seems to affect one in every hundred people. "Some researchers think that it may actually be a whole set of diseases, not just a single disease, which would explain why people with the same diagnosis can be so different from each other" (Saks 328). Most patients with schizophrenia are not wildly psychotic all the time. Rather, they are symptomatic, sometimes suffering from delusions, hallucinations, or confused thinking. Other symptoms include apathy, withdrawal, and diminished emotional expression (Saks 329). Dinty's symptoms included all of the above, although they weren't always displayed at the same time. Patients can be quick to display depression, anxiety or anger, and at times suffer from disturbed sleep patterns and a lack of interest in eating, or food refusal. As previously mentioned, schizophrenics have difficulty holding a job or caring for themselves, causing them to rely on others. Some people cope with this disorder all of their lives (Saks 329)**,** as did Dinty**.**

Other mental health disorders besides depression include anxiety, obsessive-compulsive behavior, addictive behaviors, and eating disorders such as bulimia and anorexia. Today, "mental and behavioral disorders account for approximately seven percent of the global burden of disease and represent the leading cause of disability worldwide. Nonetheless, they have been largely disregarded within the global health agenda" (Pike et al. 2).

"To complicate things, further, schizophrenia, bipolar disease and multiple personality disorder are often clinically confused. Since treatments for these disorders range widely, the potential for no diagnosis at all–or the wrong one–is vast" (Saks 171.)

Features of schizophrenia typically emerge between the late teens and mid-30s. In the early stages of my aunt's illness, before being hospitalized at age twenty-two, she began hearing voices that instructed her to do strange and sometimes destructive things. At one point, she cut up all of her clothes and photographs. During another phase, she went to great lengths to repay every outstanding debt she could remember, down to pennies she had been given as a child. As time went by, Dinty became more and more withdrawn, showing signs of increased anxiety. Then, one day, someone found a suicide note she had written on the back of a photograph. At this point, she was taken to a doctor, who confirmed she was suffering from schizophrenia, and she was confined to the mental hospital.

Approximately five to six percent of people with schizophrenia die by suicide, and about twenty percent attempt suicide on one or more occasions (Whitaker xiii). Ninety percent of suicides are related to mental and behavioral disorders (Pike, et al. 4).

Schizophrenia shares symptoms with *parkinsonism,* and a neurological disorder of the brain known as *encephalitis lethargica*. This latter disorder was first described by Hippocrates,

and named by the clinician von Economo in 1931 (Whitaker 162-166). In 2007, another similar condition was discovered known as *anti-NMDA-receptor auto immune-encephalitis.* This auto-immune disorder was first identified by Dr. Josep Dalmau in 2007. In her 2012 book, *Brain on Fire*, Susannah Cahalan described her experience with this condition and the lifesaving diagnosis that would not have happened if Dr. Souhel Najjar, now a celebrated neurologist, hadn't joined her team of doctors. Dr. Najjar had remembered reading about Dr. Dalmau's discovery two years earlier, and applied to Susannah what had been learned. Dr. Najjar estimates that ninety percent of people suffering from encephalitis lethargica in 2009 were misdiagnosed.

> Also, some forms of schizophrenia, bipolar disorder, obsessive-compulsive disorder, and depression are actually caused by inflammatory conditions in the brain. One to wonders how many misdiagnosed people currently are in psychiatric wards and nursing homes denied the simple cure of steroids, plasma exchange, Intravenous Immunoglobulin (IVIG) treatment and, in the worst cases, more intense immunotherapy? How many children throughout history have been exorcised and left to die when they did not improve? (223)

How Genes Contribute to Schizophrenia

There seems to be no doubt that there is a strong genetic component to schizophrenia. However, there is an indication of complexity of genetics and the environment that is not yet well understood:

> Experts now say that schizophrenia (and all other mental illness) is caused by a combination of biological, psychological and social factors. Further, that schizophrenia develops as a result of interplay between one's genes and the environment a person is exposed to during pregnancy or in early childhood. Environmental factors include everything from the social, nutritional, hormonal and chemical environment in the womb of the mother during pregnancy, up to the social dynamics and stress a person experiences in adolescence or early adulthood such as street drug use, virus exposure, vitamin use, etc. A child born in the winter months (January through March/April in the Northern hemisphere) has a ten percent higher risk of schizophrenia than average. The molecular mechanism by which a mother's or father's behavior reaches down to influence the expression of a gene is not known. Shyness or social anxiety, and also aggression, are linked to genetics, both of which can be exacerbated by neglect or abuse. (Schizophrenia 1-3)

The problem is that there is no specified amount of input, genetic or environmental, to determine that someone will or will not develop the disorder. Having the genes associated with schizophrenia is just a starting point. However, if one has the gene and is exposed to certain environmental factors, then the risks of developing the disorder are increased. "It is becoming increasingly clear that a gene contributes zero percent of what one becomes if one doesn't grow up in an environment that turns it on. Likewise, the environment contributes zero percent if one

lacks the gene it acts on. However, if both the gene and the environment are present, it's as if each contributes one hundred percent" (Schizophrenia 3).

In analyzing my aunt's case, I found the following: Dinty was the fifth child born in 1918, during World War I, into an immigrant farm family under very poor circumstances. She was born in the month of February. No doubt there was a lot of stress in the family during a time of food rationing while living on the remote and, at times, climatically formidable prairies of Saskatchewan. I understand that Dinty was always very shy as a youngster. In her teens, she would never attend country dances with her sisters, nor participate in social outings at the country school. I was also told that she was raped in her late teens while doing domestic work on a ranch. A traumatic experience such as rape could severely affect a vulnerable brain. "Research has now shown that children's and teen's brains are very sensitive to stress, up to five to ten times more sensitive than adult brains" (Schizophrenia 2).

During the past five years, some of the genetic factors being researched are how multiple genes contribute to the disease. There are about a dozen genes that are leading candidates. Also being investigated and receiving considerable research support is the possibility of epigenetic interactions--certain genes and other biological molecules that determine whether and when certain genes present in the body are turned off and on (Schizophrenia 4).

History of Mental Health in America

For severely mentally ill patients, "medical treatments reflected (and continue to reflect) the societal and philosophical values of the day" (Whitaker xv).

In the 1700s, European societies conceived of the mentally ill as beings that had descended to the level of animals, and they developed harsh methods in able to subdue them (Whitaker 6). America, generally, looked upon the mentally ill as hereditary defectives without the rights of normal citizens, setting the stage for therapeutics designed to alter their states of mind even over their protests (Saks 329).

During the 1800s, treatment of patients with mental disorders in the United States was reasonably compassionate, as practiced by the Pennsylvania Quakers, who viewed them as brethren–fellow human beings worthy of their empathy--and developed methods that emphasized kindness and the comforts of a good home (Whitaker 23). However, the picture was entirely different if one was a slave during the Civil War years, when one was considered crazy if one had black skin. Institutionalizing the mentally ill in state psychiatric hospitals became common practice in the 1840s. "At that time the activist, Dorothy Dix, lobbied for better living conditions for the mentally ill after witnessing the dangerous and unhealthy conditions in which many patients lived. Over a period of forty years, Dix persuaded the U.S. government to fund the building of thirty-two psychiatric hospitals" (Module 2-1). Inpatient care provided increased access to mental health services and seemed the most effective and cost-efficient way to care for these patients. As time went by, however, the hospitals were often underfunded and understaffed. Ultimately, the system received harsh criticism following a number of high-profile reports of poor living conditions and human rights violations (Module 2-2).

At the turn of the century, there was a positive movement when Clifford W. Beers published his autobiography in 1908, *A Mind That Found Itself*.   This book chronicled his struggle with mental illness and his three years of institutionalization being treated for manic depressive disorder. Beers exposed the shameful conditions he and millions of others endured in such institutions throughout the country--he was placed in a straitjacket for twenty-one consecutive nights--and set a reform movement into motion. Beers, along with philosopher, William James and psychiatrist, Adolf Meyer created what ultimately became Mental Health America (History 1).

Then, early in the 20th century, the science of eugenics–improving the population by controlled breeding to increase the occurrence of desirable heritable characteristics–was coming into favor, in combination with the practice of sterilization of the mentally defective and genetically unfit, i.e., Negroes, criminals, and other perceived misfits of society. The selling of eugenics began in 1921 at a conference hosted by the American Museum of Natural History, attended by the country's wealthy elites and Ivy League universities. "Papers were presented on the financial costs incurred by caring for defectives whose birth rates were rising compared to the low birth rate of the elite in America. This meeting stirred the New York Times to editorialize that life, indeed, was becoming ever more unfair to the well-to-do" (Whitaker 55). California led all other states in performing sterilizations of the mentally ill. By 1935, eighty-three per cent of Californians favored eugenic sterilization, which was then considered a humanitarian therapy (Whitaker 62).

Eugenics, which originated in America, was a precursor to the Nazi philosophy under Hitler. Only after the Holocaust did it fall out of favor when Americans viewed the photographs

of the prisoners of Auschwitz, and then were horrified to view similar photographs of the guiltless patient prisoners of their own mental institutions (Whitaker 67).

In the 1930s, eugenics and asylum medicine influenced the experimental medical therapeutic practices that were adopted for psychotic disorders – insulin coma, metrazol convulsive therapy, electroshock, and prefrontal lobotomy, all of which damage the brain (Whitaker 73).

By 1943, state hospitals averaged one doctor for every 277 patients, and one nurse for every 144 patients. In some cases, a patient might not see a doctor for a year (Whitaker 69). Furthermore, if a patient was institutionalized in a remote, regional hospital not easily visited by family members, as in Aunt Dinty's case, there was little or no patient advocacy. The Weyburn, Saskatchewan, mental hospital was a long distance from family members who lived in neighboring provinces that were long distances away. That meant she may have had one or two visits from family members in a year while institutionalized. The family relied on doctors to keep them advised of her progress or lack of same.

At about this time, a number of government initiatives helped improve the U.S. mental healthcare system. President Truman passed the National Mental Healthcare Act, which created the National Institute of Mental Health, and allocated funds toward research into the causes and treatments for mental illness. In 1963, Congress passed legislation to benefit those with mental retardation and provided funding for the development for community-based mental health care services. Another positive step occurred following the establishment of Medicare 1965, when *Mental Health America* was successful in advocating for inclusion of mandated mental health services in Medicare (Module 2-1). Further, the National Alliance for the Mentally Ill was

founded in 1979 to provide "support, education, advocacy and research services for people with serious psychiatric illnesses" (Module 2-2).

As previously mentioned: historically, schizophrenia was considered an affliction of the *lower man* (Whitaker 6). As late as 1950, very little was known in the field of psychiatry about the cause of the condition, and a sense of futility hung over the field (Fullenwider 170). At that time, in an effort to show progress in this field, a new mechanism was introduced known as *systems theory:* The matter of mental illness became a question of whether or not a person was programmable. If so, a behaviorist would be called in to develop a program; if not, meaning the person was hostile, aggressive, or generally unmanageable, it became a medical matter and a psychiatrist or neurologist would be brought in armed with a variety of chemical substances to hopefully restore programmability (Fullenwider 170-1). What wasn't apparent was that although brain chemistry was stabilized by these drugs, brain function was not. Schizophrenia is usually combined with comorbidity (one or more disabling disorders accompanying the prime disorder), which makes it more complicated to treat. Cognitive Behavior Therapy has been shown to work for patients with mood disorders. However, as of 2009, according to the online journal *Psychiatry (Edgmont)*, improvement in overall function of patients with thought disorders has not occurred. It is hoped that the use of CBT in rehabilitation settings may lead to improvement (Morrison 10).

In 1963, it was determined that neuroleptic drugs inhibit the chemical messenger in the brain, dopamine, which is so important to normal brain activity (Whitaker 168). Another study, by Stanford University psychology professor David Rosenhan, provided evidence "that American psychiatry was diagnosing schizophrenia in a willy-nilly manner. Not only could patients be misdiagnosed, they could be treated with the wrong antipsychotic drugs, as occurred

in the 1960s. Rosenhan's study coincided with a number of studies that showed American doctors were preferentially applying the label to people with black skin, the poor, and beatniks or non-conformists " (Whitaker 168-170). Scenes come to mind from the 1962 novel and subsequent movie, *One Flew over the Cuckoo's Nest.* Rosenhan wrote further: 'We now know that we cannot distinguish between sanity and insanity' (168). If this situation wasn't bad enough, in 1982, a researcher who reviewed Manhattan State Hospital's case records from the sixties determined that eighty percent of the schizophrenics there had never exhibited the symptoms necessary to support such a diagnosis. On top of all that, Rosenhan also revealed the cold and disinterested treatment of hospitalized patients by doctors and nurses (168-170).

Whitaker comments further about the use of wonder drugs, and how the popular press had been manipulated by the pharmaceutical companies: magazines were promised advertising revenues for mentioning a company's drug in a positive light; writers were bribed with extra fees and other perks. In the 1950s, what doctors and the general public learned about new drugs came from the pharmaceutical industry's marketing efforts. The neuroleptic drug, Chlorpromazine, recast as Thorazine, was approved by the FDA in 1954, after administering it to fewer than 150 psychiatric patients. The American public had been told it had been rigorously tested. Next, Smith, Kline produced a national television show entitled *The March of Medicine*, featuring Thorazine in a piece about dutiful science at work. Failures were not featured. Instead, a story of lives being wondrously restored would be told. In 1958, *Fortune* magazine ranked Smith, Kline and French second among five hundred American corporations in terms of 'highest net profit after taxes on invested capital.' Federal spending on mental-health research rose from $10.9 million in 1953, to $100.9 million in 1961. Completing the delusion, President John F. Kennedy unveiled his plan for reforming the nation's care of the mentally ill in 1963 by stating

that 'the new drugs made it possible for most of the mentally ill to be treated quickly and successfully in their own communities' (Whitaker 150-163). Since then, there have been scores of new antipsychotic medicines and antidepressants marketed, each all trumpeted to be better than the last one, and all with varying results.

The reform movement toward deinstitutionalization--outpatient, community-oriented care--was based not only on the scandalous condition of the hospitals but also the belief that psychiatric patients would have a higher quality of life with their families in a community setting rather than in isolated mental hospitals. Strict standards were passed in the United States and Canada so that only individuals who posed an imminent danger to themselves or someone else could be committed to state psychiatric hospitals. By the mid-1960s the most severe cases had been moved to local facilities (Module 2).

Where We Are Today

By 2000, mental patients were being treated in smaller residential homes and by community-based psychiatric teams. However, the reality of deinstitutionalization continues to be a very controversial. According to health care workers, law enforcement and parents of mentally ill adults, this reaction was too extreme. Although the impulse might have come from the heart, it didn't take into account the unintended consequences of mass deinstitutionalization (Edwards 57). For the many positive reports about community-based programs, there are just as many negative reports. Loneliness, poverty, bad living conditions and poor physical health are prevalent among mental health patients living in communities. Some studies argue that community-based programs that have proper management and sufficient funding may deliver better patient outcomes than institutions, and are not inherently more costly. The key is management and funding.

Many people believe the state psychiatric hospitals and the criminal justice system have become inter-dependent. According to this theory, deinstitutionalization, combined with inadequate and under-funded community-based mental health care programs has forced the criminal justice system to provide the highly structured and supervised environment required by a minority of the severely mentally ill population.   Government records show that people with serious mental illness make up fifteen percent of state prisoners and twenty-four percent of jail inmates. "Three times as many people with a serious mental illness are incarcerated as are in psychiatric hospitals, according to a 2010 report co-authored by the National Sheriff's Association (Edwards 57). Some studies have found that it costs roughly twice as much to incarcerate an inmate with a mental illness, and can run states up to one hundred thousand

dollars per inmate per year. Multiply that by the estimated three hundred fifty-six mentally ill inmates (Edwards 58).

People with mental illness symptoms account for as much as thirty percent of the chronically homeless population" (Edwards 57).   Studies have suggested that it costs federal, state and local governments forty thousand to sixty thousand dollars to care for a single homeless person with a serious mental illness, and multiply that by the estimated two hundred fifty thousand mentally ill homeless people. "Thomas Insel, director of the National Institute of Mental Health has said the total cost to government--including things like Medicare, Medicaid, disability support and lost productivity--is as much as three hundred seventeen billion dollars per year" (Edwards 58).

 Health professionals, families and advocates for the mentally ill are now calling for a combination of high-quality community treatment programs, and increased availability of intermediate and long-term psychiatric inpatient care for patients in need of a more structured care environment. Experts hope this combination will achieve improved outcomes (Module 2).

In 2002, according to Robert Whitaker: "Outcomes for people in the United States and other developed countries with schizophrenia have worsened over the past twenty-five years. It is as much of a health challenge as it was a century ago. Furthermore, schizophrenia outcomes are worse in this country than in poorer countries of the world" (xiii). He goes on to offer his candid view that little is known about what causes schizophrenia. Further, antipsychotic drugs do not fix any known brain abnormality, nor do they put brain chemistry back into balance. What they do is alter brain function in a manner that diminishes certain characteristic symptoms (291). It is also known that they cause an increase in dopamine receptors, and an increased

biological vulnerability to psychosis. Lastly, long-term outcomes are much better in countries where such medications are less frequently used (291).

Insel and Scolnick of the NIMH state: this disease "remains a chronic, disabling disorder, belonging to a group of serious illnesses such as heart disease, cancer and diabetes" (6).

The authors of *Towards a Healthier 2020: Advancing Mental Health as a Global Health Priority* confirm the views of Whitaker and the NIMH, adding "mental and behavioral disorders now represent the leading cause of disability worldwide, but are largely disregarded within the global health agenda. Disability associated with these disorders exceeds the burden associated with non-communicable diseases such as cancer, diabetes and cardiovascular disease, as well as HIV/AIDS, neurological diseases, war and injuries. Furthermore, unipolar depressive disorder is on track to be the leading cause of total disease burden by 2030 throughout the world, regardless of country income-level" (Pike et al. 3).

Obviously, we have yet to realize the results of the rapidly spreading hemorrhagic Ebola virus now occurring in Western Africa. Nor do we know the toll that mental disorders will have on a progressively ageing and urban population. The global ageing demographic is growing rapidly, and far exceeds the number of trained mental health specialists, particularly psychiatrists, needed to manage the complex mental health issues of a geriatric population. Today there are about nine and a half million adults with a serious mental illness living in the United States, but fewer than one hundred fifty thousand psychiatric beds available for them (Edwards 57). It is estimated that by 2030, in the United States, there will be ten to fourteen million adults aged sixty-five and older needing help for mental health or substance abuse disorders. However, there will only be an estimated sixteen hundred fifty geriatric psychiatrists

practicing in this country, fewer than one per six thousand older adults with mental health and substance abuse issues (Pike et. al 15).

To improve outcomes related to mental health and behavioral disorders will require global leadership, conviction and hard work on many levels. The World Health Organization Comprehensive Mental Health Action Plan recommends a coordinated approach with four major objectives: 1) strengthen effective and governance for mental health; 2) provide comprehensive, integrated and responsive mental health and social care services in community-based settings; 3) implement strategies for mental health promotion and prevention; 4) strengthen information systems, evidence and research for mental health (Pike et al. 10).

In addition, addressing global mental health requires a unifying language--internationally standardized and clinically useful--that speaks to the universality of mental illness and the common threads of human experience (Pike et al. 10).

Also required is the development of a system that maximizes clinical utility and feasibility across cultures and health care settings based on an existing knowledge base but is sufficiently agile such that it can evolve in tandem with emerging science. Networks are also required for collaboration among health sites around the world, together with comprehensive and coordinated policy, training and systems initiatives that prioritize and rethink strategies for treating mental disorders (Pike, et al. 11).

In contrast to the seeming lack of progress in mental health, there has been much progress on the infectious disease front. "Health care one hundred years ago was dominated by acute, infectious diseases. Chronic infectious and non-infectious diseases such as tuberculosis, syphilis, leprosy and the mental illnesses were frequently confined to large public institutions," where

patients could be monitored for a given period of time.   Today, most acute, infectious diseases

are preventable or curable, and, as such, are categorized as *chronic*. We have been living in this

new era of chronic illnesses since 2005. Many of the so-named chronic illnesses of 1905 are

now almost unknown to young physicians (Insel and Scolnick 3).

Recent New Initiatives

Considering the enormous challenges, it is good to note that there have been new initiatives regarding mental health within the past decade or so:

- President's New Freedom Commission on Mental Health

A press release from The National Alliance on Mental Health (NAMI) announced President George W. Bush's establishment of this new commission on April 2002 as part of his commitment to eliminate inequality for Americans with disabilities. In May 2003, the commission submitted its final report, *Achieving the Promise,* which recommended a fundamental transformation of the nation's approach to mental health, emphasizing how we are to consider and treat patients going forward:

1. Americans understand mental health is essential to overall health

2. Mental health care is consumer and family driven

3. Disparities in mental health services are eliminated

4. Early mental health screening, assessment and referral to services are considered common practice

5. Excellent mental health care is delivered and research accelerated

6. Technology is used to access mental health care and information. (President's New Freedom Commission)

One can only hope this report marks the beginning of a new chapter in the saga of mental health treatment and research, and that this report does not become another dust collector on a bookshelf in the Library of Congress.

- <u>United Nations' Millennium Development Goals</u>

In its press release of September 16, 2010, United Nations Enable announced the collaboration of The United Nations Department of Economic and Social Affairs with the World Health Organization in addressing and including mental health initiatives as necessary to achieving its Millennium Development Goals. The recommendations resulted from a panel discussion on the *Emerging Development Issue: Integrating Mental Health into Efforts to Realize Millennium Development Goals and beyond.* The panel recognizes that mental health walks hand-in-hand with poverty.

- <u>World Health Organization's Quality Rights Tool Kit</u>

In its Note for the Media of June 15, 2012, WHO urged all countries to protect the rights and dignity of people with mental health conditions. Its aims are to ensure that quality of care and human rights standards are put in place in mental health and social care facilities around the world. Key quality standards to be met are as follows:

- Living conditions to be safe and hygienic and the social environment to be conducive to recovery;

- The provision of evidence-based care for their mental and physical health condition, on the basis of free and informed consent;

- Gearing services towards enhancing people's autonomy enabling them to engage in their own recovery plans;

- Reporting and halting all inhuman treatment; and

- Linking health services with employment, education, social and housing services in order to promote independent living in the community for mental health service users. (WHO)

- <u>President Obama's Brain Commission</u>

In a press release on April 2, 2013, President Obama announced plans for a long-term project to map the human brain at all levels, from individual neurons to complex circuits, proposing to devote one hundred million dollars to start the initiative as part of his 2014 budget. Francis Collins, Director of the National Institutes of Health and well known for his work on human genomics, was present for the President's announcement. Collins acknowledges this project is ambitious: "To understand how the human brain works is about the most audacious scientific project you could imagine; it's the most complicated structure in the known universe." (BRAIN Initiative)

- <u>Charlie Rose's Public Television series</u>

Charlie Rose introduced his thirteen-part Brain Series in a press release on October 12, 2013. "This series focuses, once-a-month, on a new subject of the brain, including perception, social interaction, aging and creativity. In addition, it features scientific discoveries and advances in technology, with the hope that someday terrible illnesses such as depression, schizophrenia and alzheimer's will be history. Involved is Dr. Eric Kandel, psychiatrist, neuroscientist and professor at Columbia University, as well as recipient of the Nobel Prize in physiology or medicine in 2000 for his research into the biological mechanisms of learning and memory (Kandel).

- <u>National Institute of Mental Health/National Institute of Health</u>

On October 14, 2013 the NIMH/NIH proposed re-engineering clinical research by testing new compounds in clinical trials, trials that can move quickly and may increasingly be public rather than private. Also, to develop a strategy for pre-emption and treatment that could have a greater impact than heretofore experienced (Insel and Scolnick 8-9).

Studies have also shown that "The burden of mental and behavioral disorders is remarkably comparable across countries from the lowest to the highest income brackets" (Pike et al. 4). Despite the clear need, disproportionately few resources, both in research and in service provision, are dedicated to mental health. More than seventy-five percent of people with severe mental disorders live in low and middle-income countries and receive no treatment for their disorders. Even in high-income countries, thirty-five to fifty percent of such people never receive care. Even if these gaps could be addressed, the mental health workforce is woefully unprepared in terms of sheer number and quality of training.   "In fact, WHO estimates that we have a current shortage of almost four and a half million health care providers globally, mostly concentrated in fifty-seven of the world's poorest countries" (Pike et al. 16).   This data underscores an urgent need to scale up resources within countries in order to meet the need presented by mental disorders.

Not to be ignored are the needs of the nation's returning veterans who suffer brain injuries and posttraumatic stress disorder (PTSD). According to a recent Time Magazine article *The Workshop on the Fourteenth Floor,* the scientific establishment has failed to move fast enough. "Perhaps a third of returning fighters struggle with PTSD in some form, the same proportion as in World War II, and the stigma persists. We have state of the art prosthetics, but

when it comes to treating veterans for traumatic brain injury or posttraumatic stress, they have to go back to the thirties" (Waxman 49).

What More Should be Done?

The National Institute of Mental Health (NIMH) believes the following approaches can lead to cures and strategies for prevention of schizophrenia and mood disorders:

Redefining the Goal: The goal needs to be redefined from a goal of recovery to a goal of recovery defined by a complete and permanent remission. Policies should aim to ensure that mental health care is cost-effective, affordable and feasible (Insel and Scolnick 5).

Treatments: Some conditions simply lack biomedical treatments for core symptoms. For others, such as schizophrenia, current treatments target only select symptoms. Neuroleptics and other antipsychotic drugs reduce psychotic symptoms but may not treat the cognitive deficits or negative symptoms of schizophrenia. Five decades of research have shown that the effectiveness of antipsychotics in treating hallucinations and delusions in schizophrenia remains disappointing. In a five year follow-up study of one hundred and eighteen schizophrenic patients after their first episode of psychotics, only about fourteen percent met criteria for full remission lasting two years or more. Available medications are insufficient for treating the disorders (5).

Research: As stated earlier, scores of new antipsychotics and antidepressants have been introduced over the past three decades to reduce side effects and improve quality of life. We have all seen the television ads for the likes of Prozac, Zoloft, etc., for treating anxiety and depression. Also, broad-spectrum micronutrient formulas for the treatment of psychiatric symptoms have been introduced recently. However, "despite positive preliminary findings, there

are less data available to support the use of these formulas and no clinical trials have yet been done" (Ruckledge and Kaplan).   Unfortunately, there have been few new medications for the treatment of schizophrenia. What is needed is to identify the pathophysiology--processes or mechanisms--of mental disorders. According to NIMH, there are three key steps to be taken:

1.   Comprehensive studies of people with these disorders using genomic variations to identify cellular pathways that are affected. This search is just beginning and rapid progress is expected.

2.   The use of in vitro screening will be critical for identifying new compounds. The recent creation of molecular library screening centers network in universities has encouraged academic investigators to engage in the early phase of identifying small molecules for influencing specific cellular pathways. Rapid development of new compounds for cell biology may graduate to medications with new mechanisms of action.

3.   New compounds can then be tested in clinical trials. The NIH Roadmap as part of its effort to re-engineer clinical research has proposed the development of a national network of clinical trials that can move quickly to test the effectiveness of new treatments (Insel and Scolnick 5-9).

Prevention**:** Psychiatry needs to develop strategies for prevention to reduce morbidity and mortality of schizophrenia, mood disorders, and autism, where no efforts currently exist. There are two possible approaches:

1. Studies of the prodome, an early symptom that may identify those who will go on to have a psychotic break with 86% sensitivity and 91% specificity. In schizophrenia, biomarkers and imaging have not yet been developed for clinical use.

2.   It is not known if either medication or psychosocial interventions will pre-empt a psychotic break. Now is the time to develop such a strategy. In any case, identifying risk comes first. As in the rest of medicine, genomics will be essential, but there will be a need for epidemiology and developmental neuroscience to understand how these diseases develop if they are to be pre-empted (Insel and Scolnick 8-9).

New Approaches: The next era must address not only mental disorders but also fashion an agenda that strives to create and sustain overall good health and well-being (Pike et al. 9). Also, given that people with severe and persistent mental illness will continue to need specialty mental health care, an effort should be made to integrate primary, preventive and wellness care into the specialty health care settings where appropriate and feasible (Pike et al. 16). Initiatives currently underway in some middle-income countries in Latin America include extending the number of mental health clinics, strengthening their ties to primary care, and emphasizing truly community based care (Pike et al. 17).

Addressing Myths and Stigma: There should be an ongoing effort educate the public about mental disorders and the myths associated with them in order to reduce the stigma associated with these conditions. The sad truth is that a significant percentage of the public considers mental health sufferers as unpredictable and threatening. As outlined by John Grohol (1-2), the following facts need to be impressed upon the public:

1) It is not true that mental health problems are uncommon. In fact, nearly one out of every five Americans will have a diagnosable mental disorder within their lifetime.

2) It is not true that mental health problems are caused by the person suffering from them. People suffering from a mental disorder are no different than people suffering from a physical illness.

3) The belief that mental health problems are purely biological or genetic in nature is a mistruth. Mental problems are not caused solely by bad genes. They may be caused by a biological chemical disorder.

4)   It is not true that all mental health disorders are considered life-long and difficult to treat. This statement relates to bipolar disorder and schizophrenia. Anxiety disorders and depression are treated with short-term psychotherapy, in some cases, and medications should be taken for short-term symptom relief.

5) Some people who suffer from mental health problems sometimes don't seek help because they may be considered weak. No one considers a person weak who seeks help for an illness or an injury such as a sprain or fracture. Mental health disorders are no different. It is well to recognize when something might become a permanent disability if left untreated.

6) Having a mental disorder doesn't mean one is crazy and needs to be hospitalized. It simply means a person has a problem similar to a medical disease. Like any other problem, hospitalization is used only in extreme cases. In the Emergency Room, a person will be assessed, treated and released when he or she is feeling better.

7) Similarly, suicidal feelings must be recognized as symptoms of depression or a related mood disorder. Such feelings usually go away when one receives adequate care. It is important to seek help to prevent the tragedy of suicide.

8) Mental disorders should be taken seriously and should be treated by a qualified and trained specialist. One's primary care doctor may be consulted, initially, and should be able to refer a patient to a psychiatrist, psychologist or clinical technician. The least effective treatment approach is a psychopharmacological medication prescribed by someone who is not a specialist in the field of mental health.

7) At one time in the not too distant past, it was true that mental health professionals made a ton of money off of people suffering mental health disorders. However, that is not true any longer. Over the past six to seven years, there has been a vast expansion of managed care into the mental health field. It is well-documented that psychiatrists are often the lowest-paid physicians in the specialty field.

Stigmatizing beliefs are held by a wide range of individuals within society, whether or not they know someone with mental problems, have a family member with a mental problem, or are also complicit in perpetuating mental health stereotypes in passing along misinformation about symptoms, causes and treatment (Davey 1).

> Not only does stigma surrounding mental illness fuel ignorance and prejudice towards individuals with mental disorders, which in turn can foster social isolation and poor self-esteem, but it is also associated with reduced allocation of financial resources for mental health research and treatment. Stigma also has a negative effect on treatment outcomes, and hinders efficient and effective recovery impacting quality of life and life expectancy. (Pike et al. 18)

Until recently, some major donors and foundations have been reluctant to be named as

supporting mental health needs (unless a family member or close associate was afflicted)

because of the associated stigma.

Considering the efforts that were made to educate the public on the benefits of new drug

therapies–largely beneficial to the pharmaceutical companies–surely there could be a campaign

of similar strength to benefit patients!?!

Because stigmatizing beliefs are so entrenched, campaigns to change them will have to

be multi-faceted, including the press and entertainment media. Besides being informational, they

will have to challenge negative stereotypes. The United Kingdom's *Time to Change* campaign is

an attempt to address this problem, and is supported by charities and mental health service

providers. Promotional events encouraging mass participation social contact are held to facilitate

intergroup contact (Davey 2).

Graham Davey, in *Psychology Today,* describes mental health stigma as distinct types:

Social stigma, characterized by prejudicial attitudes and discrimination directed towards people

suffering a mental disorder; and *self-stigma,* characterized by the mental health sufferer

internalizing over their perceptions which can affect feelings of shame and lead to poorer

treatment outcomes.

"In 1971, Mental Health America did produce and distribute a film *Only Human,* which

aired on one hundred and fifty television stations, to improve public understanding of mental

illness and public acceptance of patients with mental illnesses" (History 2). As recently as the

late 1980s, if a person sought help for clinical depression by way of therapy and medication,

before treatment, the psychiatrist or psychologist would counsel the patient about the possible

ramifications of having the treatment on his or her medical record, a situation I experienced, personally.

"In 1998, Mental Health America released a nation-wide study that revealed the top reasons individuals refused to seek help for anxiety disorders, the most common mental illnesses, which included shame, fear, and embarrassment" (History 3). I can remember the case of Tom Eagleton, who was chosen by Presidential hopeful, Walter Mondale, as his running mate. Eagleton had to publicly withdraw his name because he had once sought the counsel of psychiatrist for help with depression.

The aspect of violence perpetrated by mentally ill people also needs to be addressed as it relates to the policy of deinstitutionalization. This issue is also very controversial. Do we compel adults with a serious mental illness to receive involuntary psychiatric treatment, many of whom are not capable of making the decision, nor are they able to follow through with the treatment program? Some argue that doing so will only destroy patients' civil rights, discourage them from seeking help voluntarily, and further stigmatize mental illness. Others say that society has a moral obligation to help people receive treatment. Complicating things further is the fact that the medical community categorizes psychiatric disorders under "behavioral" illnesses rather than physical ones, limiting health care providers' ability to treat patients without their consent. On the other hand, law requires people with Alzheimer's or autism to be treated. "Whichever side prevails in this battle will shape the publicly funded health system going forward." (Edwards 57-58)

Currently, there are laws in forty-five states giving judges the power to order an adult with a serious mental illness into assisted outpatient treatment (AOT), if the person has been recently and repeatedly hospitalized or arrested as a result of his/her illness, or have committed a

serious act of violence on himself/herself or others. Under AOT, a patient can't be forced to take

medication. However, if treatment is refused, a team of health care workers are tasked with

monitoring the patient to ensure stability.   AOT is expensive at the state and local levels; only

New York has funded it at the local level. AOT laws are also considered very controversial by

human rights activists. Other programs like mental-health courts, which allow mentally ill

people to choose inpatient care over prison, offer more effective alternatives. (Edwards 57-58)

Conclusion

Of course, I applaud all of the new initiatives, especially the suggested new strategies and approaches.   It was great to hear about the new pace-maker for the brain that is now available-- as announced earlier this year. Progress!!   I also believe the public needs to be educated to recognize the relationship between mental health disorders and other health conditions. For example, depression can adversely affect treatment of and recovery from another health problem and, likewise, a serious problem affecting the body can trigger depression. Major depression and psychological stress are associated with reduced cell immunity and increased inflammatory processes.   People may not die of depression, unless by suicide, but depression plays a huge role in whether a patient has the will to think positively and fight the affliction.

One cannot help but consider the plight of the poor and homeless surviving out there on the streets, thirty percent of whom are suffering from one mental disorder or another (Edwards 58). Anyone who has lived in or visited a major city, and taken public transportation, has seen the homeless sleeping in doorways, begging on streets, or camping under bridges or freeway on-ramps. They are just struggling to survive the elements. The California advocacy group Right2Treatment considers it "a moral catastrophe" for people to be left to sleep on sidewalks and freeze, or to spend their lives in jail (Edwards 57).   Likewise, I'm sure, the families of the victims of shooting and stabbing rampages in Tucson, Arizona; Aurora, Colorado; Newtown, Connecticut; and Isla Vista, California would like to see the mentally ill treated to preempt such tragedies.

As a lay person who has witnessed and experienced mental health problems up close, I have often thought that annual medical examinations should include some brief but pointed questions designed to identify potential mental disorders and possibly preempt the onset of a serious problem, so I am heartened to see this idea is included in the suggested new approaches.

I wholeheartedly agree with the NIMH suggestion that the goal of mental health care should be recovery defined by a complete and permanent remission.

Finally, when I decided to research this subject, I was fairly confident about my intuitive feelings regarding the dismal failure of treatment and research of mental health disorders to-date. I now must admit that as a result of looking into the matter, I am feeling much more hopeful about the future for people suffering from these disabilities.

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