

# DISEASE AND DISCRIMINATION: TWO PARADIGMS THAT DESCRIBE SEVERE MENTAL ILLNESS

## Abstract

Disease and discrimination are two different paradigms that describe severe psychiatric disorders. Divergent views about mental illness have practical implications; people with severe mental illness may be exposed to conflicting paradigms and thus confused about appropriate intervention. The purpose of this paper is to highlight differences between the two paradigms. In particular, important differences exist in the fundamental assumptions about severe psychiatric disorders and in the epistemology that examines these assumptions. Practical differences that result from these fundamental assumptions are also discussed including divergent views about the nature of care, venues of care, and prognosis.

Frank Smith was admitted to the inpatient psychiatric unit at General Hospital in acute distress, hearing voices, and reporting paranoid delusions. After a comprehensive diagnostic work-up, the treatment team prescribed several medications to control his symptoms. The patient was referred to a psychosocial rehabilitation program upon discharge to learn independent living skills that will help him cope with stress. He was also referred to a case manager to provide ongoing community support.

Frank Smith has been attending the Consumer Empowerment Project in his neighborhood so that he could gain greater control over his life. Frank admits that he obtained symptom relief with the help of medication provided by his treatment team. Unfortunately, he also experienced a keensense of loss of control because he depended on counselors and case managers too much. Frank sought an intervention program that was operated by consumers where he could learn to accept the disorder.

## Introduction

Several paradigms govern the way in which severe and persistent psychiatric disorders are understood, two of which are the focus of this paper: Disease and discrimination. The impact of a severe mental illness such as schizophrenia is described very differently depending on the paradigm. The disease paradigm views severe psychiatric illness as an external agent that must be identified and overcome. The discrimination paradigm acknowledges the intrusive nature of the illness. However, stigma and social prejudice exacerbate the impact of psychiatric symptoms exponentially. The discrimination that results is as disabling as the illness itself.

Paradigms govern the way in which we understand phenomena; extreme components of a disease model may suggest ways to control severe mental illness in a manner that diverges significantly from the discrimination view. Moreover, extreme differences between models may obscure commonalities and undermine communication across perspectives. For example, psychiatrists who ascribe to the disease perspective may view consumer empowerment as irrelevant. Consumers who embrace the discrimination model may suggest that treatment by medical professionals is harmful. People with severe mental illness are caught between the two perspectives and conflicted about appropriate directions for intervention. The purpose of this paper is to compare and contrast the disease and discrimination perspectives to increase the awareness of people with severe mental illness, family members, and professionals. This awareness

will assist interested parties in avoiding internecine battles about the best way to address the needs of persons with mental illness.

## Scientific paradigms

Kuhn (1970) noted that revolutions occurred in science when the natural evolution of knowledge resulted in changes in the paradigms that defined the object of study. Paradigms comprise the basic assumptions and epistemology that define an object of study. For example, classical physicists (e.g. Archimedes, Galileo, Newton, and Faraday) studied relatively molar, slow-moving phenomena using the rules of algebra and calculus. A revolution in physics occurred when modern physicists (e.g. Einstein, Bohr, Heisenberg and Schroedinger) broadened their mathematical assumptions to include stochastic models that address the relative uncertainty of very small (e.g. atomic and subatomic particles) and very fast (approaching the speed of light) objects (Einstein, 1905; Heisenberg, 1966). A new paradigm was needed as a result.

Rychlak (1993) discussed the influence of divergent paradigms on psychology. He argued that the breadth of study on human behavior could be described by four paradigms: (1) *Physikos*, understanding behavior in terms of physical and chemical laws; (2) *Bios*, behavior based on physiological processes and anatomical structures; (3) *Socius*, behavior based on socialisation, historicism, and political collectivism; and (4) *Logos*, behavior according to processes such as personal construing or mental acts. These assumptive frameworks are not necessarily orthogonal, in part because there is no absolute evidence to which adherents of any paradigm might base their perspective. Nevertheless, problems in theory development and collegial communication have arisen in psychology because of significant splits between paradigms.

There is a sociology to scientific paradigms; these paradigms are affected by the social forces of the time (Merton, 1973). For example, paradigm shifts from mentalism to behaviorism moved practical concerns from inferring psychological constructs to observing discrete behaviors. The influence of disease and discrimination paradigms is not limited to fundamental assumptions about mental illness and epistemological models to study these illnesses. These paradigms also affect such practical concerns as the nature of care, roles in treatment, responsibility for care, and venues of interventions.

Kuhn (1970) perceived paradigms as constructs that distinguished intellectual movements over the evolution of history. Hence, classical physics as framed by Newton, and the fundamental assumptions and epistemology it entails, can be distinguished paradigmatically from Einstein's modern physics. Such neat categories are difficult to discern when looking within any single epoch. The community of physicists could not easily be divided into modernists and classicists at the end of the nineteenth century. Similarly, paradigms that describe severe mental illness are not mutually exclusive in present-day practice. Many of the assumptions that comprise disease and discrimination models overlap. This overlap generates common elements which affect the fundamental assumptions, epistemology and practical concerns that define severe mental illness. However, there are also distinct components of each paradigm that independently affect severe mental illness. It is these distinct components, and rigid advocates for these distinct components, which lead to clashes.

## **The disease paradigm**

The disease paradigm has evolved, for the most part, out of the field of psychiatry and clinical psychology. The standards of the field (i.e. The International Classification of Diseases and Related Disorders, tenth revision (World Health Organisation, 1992) and the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (American Psychiatric Association, 1994)) view the process of defining mental illnesses as fundamentally one of classification; i.e., describing disorders in terms of meaningful clusters of symptoms and dysfunctions. Severe mental illnesses, for example, are defined in terms of the composite symptoms that distinguish these disorders from other, less dysfunctional syndromes.

Symptoms affect people in several ways; perhaps most prominent is the effect on social functioning. People with severe mental illness have diminished interpersonal skills (Corrigan, Schade & Liberman, 1992). People with fewer social skills will likely alienate family members and friends. Research suggests that this group has a smaller and less satisfactory support network (Holmes-Eber & Riger, 1990; Meeks & Murrell, 1994). People who lack social skills and interpersonal supports are less able to avail themselves of social opportunities that are presented to adults. Hence, people with severe mental illness are less likely to obtain competitive jobs, satisfactory housing, and engaging recreation.

Current research is focused on biological and environmental factors that account for the etiology or maintenance of severe mental illnesses (Birchwood, Hallett & Preston, 1989; Hirsch & Weinberger, 1995). Etiological models include both ultimate and proximal causes of symptoms. For example, the stress-diathesis model of schizophrenia describes ultimate causes of schizophrenia in terms of early biological agents that generate subtle cognitive and autonomic vulnerabilities (Nuechterlein et al, 1992; Zubin & Spring, 1977). These vulnerabilities may then interact with proximal environmental stressors so that the person with severe and persistent disorders experiences either the onset of the disorder in young adulthood or relapses during the subsequent course.

Description of the causes of symptom clusters suggests specific interventions that may remediate these causes. Interventions have been clustered in a manner that corresponds with causes; i.e. biological and environmental methods. Psychopharmacological strategies seek to ameliorate the effects of biological agents producing various symptoms (Gratz & Simpson, 1992). Rehabilitation strategies seek to enhance the behavioral repertoire so that the person is better prepared to address environmental precipitants of the illness (Liberman, 1992). The effects of medication and rehabilitative therapies are maintained in the community through the efforts of assertive case managers (Baker & Intagliata, 1982).

## **The discrimination paradigm**

Proponents of a discrimination paradigm believe the loss of social opportunity - diminished work, housing and recreation - is not attributable to the disease alone. People with severe mental illness may be viewed as an under-privileged minority who suffer discrimination by the majority (Hahn, 1985; Nagler, 1994; Vash, 1981). Like ethnic minorities and people with physical disabilities, people with severe mental illness endure stigmata that lead to significant social and economic disadvantages (Fisher, 1994; Penn et al., 1994; Riger, 1994; Link et al., 1989). These stigma are manifest in disrespectful images portrayed in movies, television, cartoons, news stories and advertising (Wahl, 1995).

Stigma in ethnic groups derives from skin color. Stigma experienced by people with physical disability stems from their wheelchairs and other prostheses. Stigma in people with severe mental illness is a function of their distinct (or what the majority might call 'abnormal') behaviors in the community. Proponents of the discrimination paradigm do not deny that psychiatric symptoms lead to a loss of social opportunities. However, the impact of these symptoms on social opportunity is far greater than symptoms alone suggest; societal prejudices exacerbate this impact significantly. Because the public has misconceptions about severe mental illness, members of society withhold opportunities (Link, 1982; Monahan, 1992; Nagler, 1994; Riger, 1994; Stephens & Belisle, 1993). The loss of opportunity that accompanies severe mental illness is due as much to the injustices of societal stigma as the effects of biology.

A primary way to address such injustice is for persons with severe mental illness to obtain power over their life in their community. Empowerment has been described as a process of increasing interpersonal and political power so that individuals can take action to meet their life goals (Fisher, 1994; Anthony, 1991; Deegan, 1992; Unzicker, 1989). People with severe mental illness expect society to recognise their rights to economic opportunity; that means political and cultural changes so that these fights are guaranteed. Individuals have sought power in several ways including fostering advocacy groups (Chamberlin, 1984) and promoting rehabilitation programs that are developed and operated by people with severe mental illness (Chamberlin, Rogers, & Sneed, 1989).

Proponents of a discrimination model propose an additional way to address stigma. People with severe mental illness need to recognize that many of the psychiatric symptoms and social deficits (e.g. hallucinations that do not diminish with medication, recurring social awkwardness) do not remit. In similar fashion, the losses in movement due to paraplegia are never regained (Fisher, 1994). People with schizophrenia should not be compelled to hide the behavioral aspects of their disorder just as people with paraplegia should not hide their difficulty walking. People with schizophrenia should accept these limitations and learn to build an independent and quality life accordingly. This kind of task is achieved, in part, by client-centered psychotherapies where values such as unconditional positive regard, warmth and congruence provide an atmosphere for the person to rediscover him- or herself (Carkhuff, 1972; Mosher & Burti, 1992).

### **Differences between paradigms**

Paradigms need not be mutually exclusive nor must proponents be in active opposition to each other (Rychlak, 1993). Disease and discrimination paradigms overlap in many areas including a priority for individualised treatment and a goal of independence through active intervention (Bachrach, 1992). Many of the differences between disease and discrimination actually represent distinct points on the same continuum rather than qualitatively disparate categories. Nevertheless, there are distinct components of disease and discrimination models which promote different perspectives about severe mental illness. These perspectives may affect the person's experience with mental illness as well as his or her experience with treatment.

### **Differences in fundamental assumptions and epistemology**

Elements of the disease paradigm imply a normative, almost ethical, view towards understanding and acting on human behavior. There are ways of acting that are appropriate (i.e. functional and asymptomatic) and behaviors that are inappropriate (dysfunctional and symptomatic). Inappropriate behavior is the target of psychiatric care and may be defined in terms of statistical average, societal norms, or established codes of behavior. These behaviors suggest psychiatric symptoms that represent some malevolent disease agent. The goal of psychiatry is to identify these agents and develop strategies that eradicate them.

The normative and moral basis of the disease model is most apparent when compared to the assumptions of discrimination which are fundamentally existential. According to this view, psychiatric disability is one of many components of the whole person; disability is defined as a typically unremitting impairment in functioning that results from the biological disorder (Anthony & Liberman, 1992; Vash, 1981). Proponents of this paradigm might acknowledge that an aggressive intervention is essential for addressing the sequelae of the biological disorder. However, these proponents do not recognise a moral imperative suggesting that disability is worse than other parts of the person. On the contrary, eradicating some aspects of the disability may diminish the wholeness of the person.

This does not mean that, according to the discrimination paradigm, people with severe mental illness ignore psychotropic medication or rehabilitation strategies that might better their quality of life. However, some 'abnormal' behaviors may remain immutable. The disabled individual's task is to acknowledge and accept these parts of themselves.

The potential for clashes between paradigms might occur when proponents of disease and discrimination paradigms target disabilities. The aggressive disease practitioner attempts to identify and eradicate pathogens. The practitioner tells patients to reject their disability and learn alternative behaviors; 'Let's help you to stop hallucinations by prescribing medication and learning relevant coping strategies.' Discrimination proponents may not only find this view unhelpful, but believe it may ultimately exacerbate the existential confusion of the person with severe mental illness. To deny part of who one is only further separates one's experience from his or her essential character. Hallucinations may never remit in some persons. Therefore, these people cannot deny their hallucinations. The person should acknowledge the pains and difficulties commensurate with their disability and move on from there towards a quality life.

Epistemological differences. Paradigmatic differences also lead to distinctions in epistemologies; in particular, differences in the ways in which models are studied and evaluated. Proponents of the disease model view themselves principally as scientists. The various manifestations and causes of disease are best known via the laws of science (Hirsch & Weinberger, 1995; Hsu & Hersen, 1992). In this vein, objective observation of patients and their problems is the first rule of psychiatry and clinical psychology. Reliable and valid observation is only assured when scientist-practitioners act as aloof students of human behavior.

Advocates of the discrimination model support a more phenomenological approach to knowing mental illness (Rogers & Palmer-Erbs, 1994; Rapp, Shera & Kisthardt, 1993). People with severe mental illness have special insights based on their unique experiences, insights which are essential to a full

understanding of their disorder and themselves; e.g. the terror of unremitting voices or the pleasure of manic episodes. Much of their insight is relatively private, such that excluding their perspective would omit a large and essential body of information. Because of their experiences, people with severe mental illness share a kindred sense of the strengths and limitations with others who have similar disabilities.

Psychology and psychiatry have struggled with the split between the objective and empirical, versus the phenomenological and private, for almost the length of its history (Fearon, 1937; Fernberger, 1935; Frankl, 1983). Some theorists believe that the two ways of knowing need not be diametrically opposed (Giorgi, 1970; Merleau-Ponty, 1963). For example, people with severe mental illness who participate in disease-related research are privy to experiences that are not manifest behaviorally; examiners are unaware of a person's auditory hallucinations unless that person reports them. Therefore, self-report strategies are used to elicit this information. However, disease scientists do not grant the person with severe mental illness any special understanding about their private experience. The person who hallucinates is not better able to explain these experiences than behavioral scientists studying the phenomenon. The methodological and statistical techniques of science are needed to make theoretical sense of private experience.

Empirical research also suggests that an individual's ability to report private information may be limited by his or her self-awareness of the disorder (Amador et al., 1991; Cuesta & Peralta, 1992). Many people with severe mental illness are relatively unaware of the extent of their disorder and the subsequent limitations. Therefore, some disease proponents argue that the nature of severe mental illness per se may hamper participation in more phenomenologically-focused investigation. Researchers with a more discrimination view believe that people with severe mental illness not only have access to this private experience, but also have unique understanding of the experiences because they have lived them. To avail this perspective, some discrimination researchers have joined with people with severe mental illness as co-investigators (Rogers & Palmer-Erbs, 1994; Sofaer, 1993).

Discrimination researchers also believe that the disease perspective misdirects the focus of investigation. Rapp and colleagues (1993) describe a 'blame the victim' mentality that permeates disease research. People with severe mental illness lack skills, lack work histories, lack motivation, lack family ties, etc. It is these person-centered deficiencies that account for the disorder. Discrimination researchers counter that the focus on individual limitations misses the cultural, economic, and environmental forces that lead to the difficulties associated with severe mental illness. People who are socially disadvantaged themselves are more invested in understanding these forces and more likely to investigate external issues that influence severe mental illness.

### **Some practical differences**

Differences in paradigms not only affect relatively esoteric concerns such as metaphysical assumptions, extreme elements of these paradigms frame some practical concerns as well.

Differences in the nature of care. Many proponents of the disease model view persons with severe mental illness as patients and treatment providers as experts (Corrigan, Liberman, & Engel, 1990; Meichenbaum & Turk, 1987). Although most adherents to the disease model are concerned with the

individual's experience of his or her disorder, they view the professional's understanding of the illness as primary. The product of professional training and experience is an educated view of the various manifestations of mental illness, a view which uneducated persons do not share. Psychiatrists, psychologists, and other professionals know best how to treat the problems associated with severe mental illness.

The nature of treatment from the disease paradigm can be characterised as assertive. Disease professionals diagnose and treat pathogens in a systematic manner, whether the disease is schizophrenia or cancer. Psychotropic medications provide relief from many symptoms. Rehabilitative treatments developed by proponents of the disease model include various behavioral programs that target specific behaviors (Lieberman, 1992; 1988). Collaboration with the person is most important to facilitate compliance to the treatment regimen (Axelrod & Wetzler, 1989; Boczowski, Zeichner & DeSanto, 1985; Kane & Borenstein, 1985).

Proponents of the discrimination model believe that people with severe mental illness are consumers of care (Fisher, 1994; Deegan, 1992). As consumers, people with severe mental illness have primary responsibility for decision making. Consumers may survey professionals regarding available services and select those that best meet their needs. Therefore, caregivers must assess the needs of consumers and develop programs that meet those needs best (Brewin et al., 1987; Corrigan, Buican & McCracken, 1995). Caregivers serve the consumer's perspective of the disorder.

Sometimes, the best way to meet consumer needs is for consumers to operate the program themselves. Some proponents of the discrimination paradigm describe effective intervention programs operated jointly by consumers and professionals (Chamberlin, Rogers & Sneed, 1989). Others believe that only consumers can understand the difficulties of severe mental illness, so only consumers should operate these programs (Chamberlin, 1984). Professional credentials are viewed negatively when hiring staff for these programs (Hopkin, 1985). The strongest reactionaries to the disease paradigm go so far as to assert that medication and behavior therapy have no role in the rehabilitation of the person with severe mental illness (Chamberlin, 1984).

The greatest tension in providing care occurs when the professional (adhering to the disease paradigm) disagrees with the consumer (adhering to the discrimination paradigm) about an individual treatment program. Conceivably, professional and consumer might 'agree to disagree', requiring the consumer to look elsewhere for care. However, such a solution is unfeasible for many economically disadvantaged consumers who have few options to seek treatment in other settings (Lewis & Lurigio, 1994). This economic disadvantage limits choices about care, a point frequently made by proponents of the discrimination paradigm. They argue that people with severe mental illness have a right to an array of services from which they might select an appropriate match just as people confined to a wheelchair have a right to ramps into public buildings.

The tension caused by differences in views about treatment is even greater in in-patient settings, which seem to be dominated by the disease paradigm. Most regions in the world have laws which permit involuntary hospitalisation when the person is viewed as dangerous to self or others (Mills, 1986; Tardiff,

1992). Some states have proposed expanding the criteria for involuntary commitment to include the likelihood of suffering 'substantial mental or physical deterioration' (Lamb, 1984). Many places also permit forced administration of antipsychotic medication or seclusion and restraints when deemed to be necessary by the psychiatrist (Fisher, 1994). Although both sets of laws require due process and court involvement (reflecting the discrimination view about equal rights), the actual use of these restrictions tends to reflect the disease perspective and its concern for control and safety (Reed & Lewis, 1991).

Some proponents of the discrimination paradigm believe there is a fundamental error in characterising involuntary commitment and forced medication as treatment (Fisher, 1994). They do not dismiss the need for involuntary interventions for dangerous individuals. Discrimination proponents believe, however, that these forms of intervention are needed for all dangerous people - mentally ill or not - and should, therefore, be administered by police and other public safety experts in accordance with normal concerns regarding civil liberties. In this way, the collaborative nature of treatment remains sacrosanct.

Venues of care. Perspectives about treatment settings also differ across paradigms. Interventions consistent with the disease paradigm are typically conducted in clinics. Clinics are designed to provide services efficiently to a large number of persons with severe mental illness. They tend to be operated by professionals who are expert in clinical and administrative matters. Cost effectiveness should not be dismissed as merely the concern of accountants and administrators. Research repeatedly suggests that insufficient funds are available to provide effective care for most people with severe mental illness, the majority of whom are poor. Cost effectiveness is an important factor in policy planners' decisions about monetary allocations (Andrews, 1991; McGuire, 1991).

The venue of treatment for proponents of the discrimination model is very different. Some have described psychosocial clubhouses where consumers run the enterprise (Beard, Propst & Malamud, 1982; Dincin, 1981). Perhaps best known of these are Fountain House in New York City and Thresholds in Chicago. The clubhouse evolved from consumers' dissatisfaction with the lack of control they experienced in typical institutional settings. Alternatively, Fairweather designed a lodge program where residents with severe mental illness gained support and learned to cope from the peers with whom they reside (Fairweather et al., 1969). The power and control that these settings offer consumers seems to outweigh the decrement in treatment prowess that occurs when professionals do not have central roles.

Differences in prognosis. Some proponents of the disease paradigm tend to view the prognosis of severe mental illnesses such as schizophrenia poorly. Poor prognosis stems from a Kraepelinian (1971) notion that schizophrenia is a progressively dementing disorder. This view is still evident in DSM-IV, albeit in muted form (American Psychiatric Association, 1994). The current DSM definition of schizophrenia includes a marked reduction in social or occupational functioning after the onset of the disorder. Recent findings from long term follow-up studies of people with schizophrenia suggested a somewhat brighter outlook (Harding, 1988). A progressively degenerative course is not necessarily characteristic of the disorder. Nevertheless, many people with schizophrenia show residual social dysfunctions that require continued care. From the disease perspective, the prognosis of persons with severe mental illness remains guarded.



This view is markedly different from the discrimination model; this model speaks about recovery from the disorder rather than a progressively downhill course (Anthony, 1991; Spaniol et al., 1992). Proponents of this view have published testimonials by persons with severe mental illness who are no longer disturbed by the symptoms of their disorder and who have achieved most of their interpersonal goals. Prognosis for those holding a discrimination view is fundamentally hopeful and optimistic (Anthony, Cohen & Farkas, 1990; Watts & Bennett, 1983).

Differences in prognosis recapitulate fundamental differences between paradigms. Note the two parts of the definition of recovery: (1) 'No longer disturbed by symptoms'; people with severe mental illness who have learned to accept their symptoms are no longer bothered by them; and (2) 'Achieved most of their interpersonal goals'; people who set up goals that represent a true reflection of their possibilities and limitations will be able to attain them. The existential nature of the discrimination view likely leads to a more positive prognosis.

### **Unanswered differences and a rapprochement of paradigms**

Recognition of differences between disease and discrimination leads to unanswered questions that need to be addressed for improved quality of care. These questions will be answered in future research examining the outcome of various intervention efforts. What, however, is the final arbiter of a successful outcome: symptom-free community living or a sense of self-determination and empowerment? Various conceptual arguments and research protocols might tackle this query. Unfortunately, the varied strategies to resolve this question result in a second problem. What is the best process for testing alternative perspectives on treatment outcome? Scientists are methodologically well equipped to understand complex patterns of evidence. However, consumers are more vested in implications of research efforts.

Intellectual quagmires about research design are the stuff of philosophers and thinkers. Issues about treatment and self-determination are more basic and of greater concern to most consumers, family members and front-line clinicians. These differences can be especially poignant when the person with severe mental illness is caught between individuals who represent both paradigms. Note the contrasting experiences of Frank Smith in the vignettes that began this paper. The first step in resolving this predicament is educating all concerned parties about the divergence of perspectives.

Perhaps most foreign to the disease perspective is the notion introduced by the discrimination model regarding political and economic forces affecting the course and outcome of severe mental illness. The disease adherent strongly believes that severe mental illness is a biologically caused and environmentally exacerbated disorder. Like other diseases, the appropriate arena for wrestling with various definitions and treatments of severe mental illness is the academic classroom and research laboratory. Thus, disease proponents are often poorly prepared for the demands of the political arena. Nevertheless, as consumers and family members assume greater power, disease professionals must be better prepared to bare their treatment practices to public scrutiny. Demands and accountability are only likely to grow as consumer groups dictate their preferences in interventions.

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