

1 The rights of a powerless legion

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Introduction

The most frequent contact the general public has with mental illness is through the media or by direct observation in the busy streets of large cities of derelicts, most of whom are mentally ill. Unfortunately, media portrayals of mental patients usually relate to them as unpredictable, violent and dangerous. The association between mental illness and violence is only one of the many negative stereotypes and prejudicial attitudes held by the public about persons with a mental illness. Direct observation of mentally ill persons in the streets further cements the stereotype that mental illness causes an inevitable downward spiral for those who are affected. These impressions help to perpetuate stigmatizing attitudes against mental conditions and discriminatory practices against mental patients.

Findings of the landmark psychiatric epidemiological study of Stirling County in Nova Scotia, Canada, are described in a classic book entitled *My Name is Legion* [1].¹ This biblical quote [2] is used by many writers and, as used in the Stirling County study, it conveys the large number of those affected. Years after this study and on observing how mental patients are treated, managed or disposed of in many countries, it is obvious that their numbers do not change their plight in society. Despite their numbers, mental patients do not count politically, they are powerless. It is the thrust of this chapter that whereas attitudes such as stigma might be endured, discrimination has to be counteracted; rights have to be fought for.

This chapter contains a historical overview on matters of stigma and includes a review of theoretical elements that lie at the foundations of stigma as a social construct and its negative impacts on patients and their families as well as a dissection of common elements of programmes aimed at combating the stigma of mental illness. The chapter also contains a review on the matter of discrimination which is considered to be the most pernicious aspect of stigma as it impacts on the political and civil rights of mental patients.

Historical elements

Stigma, a tattoo or brand in Greek (from the verb *stizein*), was a distinguishing mark burned or cut into the flesh of slaves or criminals by the Ancient Greeks so that others would know

¹ This is a quote from the Bible relating how Jesus is said to have cast the demons out of a possessed individual. Pigs ate the demons and proceeded to drown themselves in the Sea of Galilee.

who they were and that they were less valued members of society. Although the Greeks did not use the term 'stigma' in relation to mental illness, stigmatizing attitudes about the illnesses were already apparent in the sense that mental illness was associated with concepts of shame, loss of face, and humiliation [3], as in Sophocles' *Ajax* or in Euripides' *The Madness of Heracles*.

Later, and throughout the Christian world, the word *stigmata* became associated with peculiar marks on individuals re-presenting the wounds of Christ on their bodies, mostly on their palms and soles [4]. This religious connotation is not the same as the other derivative of the Greek word *stigma*, which is a form of social construction to indicate a distinguishing mark of social disgrace that, at the same time, conveys a social identity. The inquisitorial attitude toward witches, as dictated in the *Malleus Maleficarum* (*The Witches' Hammer*) [5], apart from being highly misogynous, also represents a negative and condemning attitude toward mental illness. This attitude might have been the origin of the stigmatizing attitudes held toward persons with mental illness from the rise of rationalism in the 17th century to the present day in Christian cultures [6]. 'Madness' has long been held among Christians as being a form of punishment inflicted by God on sinners [7].

Recent movements to advance the human rights of mentally ill persons have their genesis in the appalling abuses suffered by generations of mental patients, both before and after the birth of the asylum. Paradoxically, however, the birth of the asylum was in many respects the product of compassion: although the story may be apocryphal, the establishment of the first European asylum for the insane in Valencia in 1409 by Father Gilabert Jofré is said to have been motivated by Jofré's witnessing of the abuse suffered by a mental patient [8]. However, what began as a refuge quickly developed into a prison, and resulted in what Luis Vives in the 16th century was already describing as institutionalized social exclusion [9]. But, as Sebastian Brant pointed out [10], banishment through institutionalization was just a continuation of a more pernicious model of social management prevalent before the advent of the asylum in Valencia. In his *Stultifera Navis* (*Ship of Fools*) Brant tells us how, before the *Narrenhaus* (madhouse), mental patients were condemned to navigate the waters of the rivers of Europe in *Narrenschiffes* that never found a port as they were banished from town to town.

Socio-politically, the asylums replaced the leprosariums. But whereas the latter were exclusively for lepers, asylums became places for all sorts of undesirables, not just those affected by mental conditions: institutions made for their time and aptly described as the 'great confinement' [11]. In fact, the *lettres de cachet* contemplated in the French *Loi sur les aliénés* of 1838 [12] gave the 'hospital archers' (*gardiens de l'Hôpital*) authority to round up and lock up, among others, 'beggars, vagabonds, the chronically unemployed, criminals, rebel politicians, heretics, prostitutes, syphilitics, alcoholics, madmen and idiots'. These orders became the blueprint for similar institutions all over the Western world [13]. The characterization of the mentally ill as 'wild beasts' left no alternative but to put them away [14].

It has been a long struggle for the mentally ill to return from their banishment. Even gestures such as that of Pinel who, imbued with the libertarian ideals of the French Revolution, publicly cut the chains that held the mentally ill to their posts at La Salpêtrière in 1795, have been insufficient, as old and decrepit mental hospitals are still the preferred, and often only, model of care in many countries [15]. And yet, the opposite, allowing patients to return to their communities, has not resulted in meaningful liberation for most persons with mental disabilities. In most countries, even the most advanced and prosperous, mental patients are no longer in asylums, but in prisons, which have become veritable mental

hospitals [16]. Criminalization of persons with mental disorders is regulated and overseen by courts of law and forensic psychiatrists who, in concert, have become the gatekeepers, or modern-day superintendents [17]. The process of forensic evaluations has become another filter for treatment that keeps mentally ill persons in limbo, ensconced among three seemingly inimical systems – health care, justice and corrections. In the end, the impacts of many forensic evaluations amount to the same reality – loss of liberty in a hospital for the criminally insane or deprivation of liberty in a jail pending legal dispositions. As asked by one commentator, what have the mental patients gained? [18].

Theoretical considerations

Stigma has been thought of as an attribute that is ‘deeply discrediting’ so that stigmatized persons are regarded as being of less value and ‘spoiled’ by three different kinds of stigmatizing conditions: ‘abominations’ of the body, such as physical deformities, ‘tribal identities’ such as race, sex or religion, and ‘blemishes of individual character’, such as mental disorders or unemployment [19]. *Stigma*, however, is not a static concept, but a social construction that is linked to values placed on social identities, a process consisting of two fundamental components: the recognition of the differentiating ‘mark’, and the subsequent devaluation of the bearer [20]. Thus, stigma could be conceived of as a relational construct that is based on attributes, which may change with time and from one culture to another. Stigma develops within a social matrix of relationships and interactions so that new conditions could become stigmatizing and conditions that may be stigmatizing at one time or within a given culture could come to be accepted later so that their bearers stop being stigmatized.

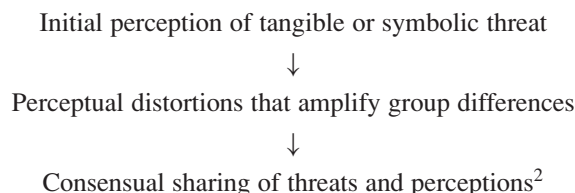
Furthermore, stigma can be understood within a three-dimensional axis involving perspective, identity and reactions. *Perspectives* pertain to the way the stigma is perceived. Stigma is different, whether it be perceived by the person who does the stigmatizing (perceiver) or by the person who is being stigmatized (target). *Identities* relate to group belongingness, and they lie in a continuum from entirely personal to group-based identifications. *Reactions* are the ways the stigmatizer and the stigmatized react to the stigma and its consequences; reactions could be measured at the cognitive (knowledge), affective (feelings, tones and attitudes), and behavioural levels.

Along with these three dimensions it is also important to distinguish three major characteristics of the stigmatizing mark: ‘visibility’, or how obvious the mark is, ‘controllability’, which relates to the origin or reason for the mark and whether it is under the control of the bearer, and ‘impact’ or how much those who do the stigmatizing fear the stigmatized [21]. The more visible the mark, the more it might be perceived to be under the control of the bearer, and the more feared the impact, such as conveying an element of danger, the more pronounced the stigma.

Mental patients who show visible signs of their conditions because their symptoms or the side effects of medications make them appear abnormal, who are socially construed as being weak of character or lazy, and who display threatening behaviours, usually score high on any of these three dimensions. By a process of association and class identity, all mental patients are equally stigmatized; individual patients, regardless of level of impairment or disability, are lumped together into a class; class belongingness reinforces the stigma against the individual.

Unfortunately, a definition of stigma, what it is and how it develops, still leaves unanswered the question of *why* it develops. However, a theory has been advanced although little

is known about this, that three major components are required – function, perception and social sharing [22]. An original ‘functional impetus’ would be accentuated through ‘perception’, and subsequently consolidated through social ‘sharing’ of information. The sharing of stigma becomes part of a society that creates, condones and maintains the stigmatizing attitudes and behaviours. These authors further indicate that the most likely candidate for the initial ‘functional impetus’ is the goal of avoiding threat to the self.



Tangible threats are ‘instrumental’ in the sense that they threaten a material or concrete good, while those that are symbolic threaten beliefs, values, ideology or the way in which the group ordains its social, political or spiritual domains.

Cultural perceptions of mental illness consider it as posing a tangible threat to the health of society because it engenders two kinds of fear: the fear of potential immediate physical threat of attack and the fear that we may all share in losing our own sanity. Furthermore, to the extent that mentally ill persons are stereotyped, conceptualized and labelled [23] as lazy, unable to contribute, and hence, a burden to the system, mental illness may also be perceived as posing a symbolic threat to the beliefs and value system shared by members of the group. At a more practical level, the stigma associated with mental illness can also be attributed to the traditionally different venue for treatment for the mentally ill. For whereas persons affected by a physical condition, with the exception of leprosy and tuberculosis, have always been cared for and treated in general hospitals in their own communities, mental patients were for centuries sent away to mental institutions or asylums that were usually situated far away from their communities. The decision to send persons with mental illness to far-away mental hospitals, although well intentioned in its origins, contributed to their dislocation from their communities, and the loss of their community ties, friendships and families. At an academic level, the segregation between the two systems of health also meant the banishment of mental illness and of psychiatry from the general stream of medicine. Psychiatry had no cures to offer and, being away from academic centres led it to stagnation in research and development. The few therapeutic successes, such as the cures for pellagra and for syphilis, were accomplished out of the mental hospitals. Worse, as those conditions ceased to be reasons for mental hospitalization, the idea was reinforced that the patients that remained in the mental hospitals suffering from other mental illnesses were incurable. The lack of effective therapies that influenced most of psychiatric work for centuries not only contributed to the asylum mentality, but was also a result of the academic banishment of psychiatry.

Myths and stigma

Stigma is a negative differentiation attached to some members of society who are affected by some particular condition or state. This negative *attitude* that dictates that those members

² Adapted from Stangor and Crandall [22], p. 73

be maintained at a distance is related to negative stereotyping and *prejudicial* attitudes that, in turn, lead to *discriminatory* practices. Thus, whereas stigma is an attitude, *discrimination* is behaviour aimed at depriving the stigmatized person of legal rights and legally recognized entitlements. Stigma, prejudice and discrimination are, therefore, inextricably related. Unlike prejudice, however, stigma involves definitions of character and class identification, so it has larger implications and impacts.

Prejudice most often stems from ignorance, or unwillingness to find the truth. For example, a study conducted by the Canadian Mental Health Association [24] found that the most prevalent misconceptions about mental illness included that mental patients were dangerous and violent (88%), that they had a low IQ or were developmentally handicapped (40%), that they could not function, hold a job, or have anything to contribute (32%), that they lacked will power or were weak or lazy (24%), that they were unpredictable (20%), and, finally, that they were to be blamed for their own condition and should just shape up (20%). In a survey among first-year university students in the United States, it was found that almost two-thirds believed that 'multiple personalities' were a common symptom of schizophrenia, and on a different poll conducted among the general public 55% of respondents did not believe that mental illness existed and only 1% acknowledged that mental illness was a major health problem [24]. Some of these myths also surfaced in a study conducted in Calgary, Alberta, Canada, during the pilot study for the World Psychiatric Association (WPA) programme '*Open the Doors*'. In this study [25], it was found that respondents believed that persons with schizophrenia could not work in regular jobs (72%), had a split personality (47%), or were dangerous to the public because of violent behaviour (14%). In Africa, conceptions of mental illness are strongly influenced by traditional beliefs in supernatural causes and remedies. Even policy makers frequently hold the opinion that mental illness is often incurable and unresponsive to accepted medical practices [26]. Thus, high levels of knowledge could coexist with high levels of prejudice and negative stereotypes. For while most of the myths about mental illness could be traced down to prejudice and ignorance of these conditions, enlightened knowledge does not necessarily translate into less stigma unless the tangible and symbolic threats that it poses are also eradicated.

Violence and mental illness

An association between mental illness and violence, specifically schizophrenia, although confirmed epidemiologically, remains unclear and seems to flow not so much through direct links of causality, but through a series of confounders and covariates [27]. These facts, however, do not deter the media from their penchant to portray mental patients as unpredictable, violent and dangerous [28, 29]. This portrayal is reinforced by movies in which a popular plot, long exploited by the cinematographic industry, is that of the 'psycho-killer' [30]. Movies about 'mentally ill killers' have been identified by 85.6% of relatives of persons with mental illness as the most important contributor to the stigma of the illness [31]. Movies have not only stigmatized those with mental illness, their negative stereotypes have extended also to psychiatrists who are often portrayed as libidinous lechers, eccentric buffoons, vindictive, repressive agents of society, or evil minded; and in the case of female psychiatrists, as loveless, sexually frustrated and unfulfilled [32]. In fact, the media and movies may just be reflecting on what the public feels and believes about mental illness. This would be hardly surprising when the public is bombarded with factual information of mayhem and gore in horrendous crime committed by an alleged mental patient. At times, the story also mentions that the culprit is suspected to be 'psycho', 'paranoid', 'depressed'

or 'schizophrenic'. This type of news, even when reported conscientiously and accurately, arouses fear and apprehension and pushes the public to demand measures to prevent further crimes. Fear is the primary impulse to the development of stigma. The fear of mental illness, and the subsequent stigmatization of those with mental illness, is largely based on fears that they are unpredictable and dangerous. One single case of violence is usually sufficient to counteract whatever gains mental patients have made to be accepted back into the community. Persons with mental illness in general bear the brunt of impact because of the actions of the few. Unfortunately, the media do not inform the public that only a very small minority of mental patients commits serious crimes, or that the percentage of violence that could be attributed to mental illness as a portion of the general violence in the community is also small [33].

Human rights infringements

Outright discriminatory policies ending in abuses of human rights and denial of legal entitlements can often be traced to stigmatizing attitudes, plain ignorance about the facts of mental illness, or lack of appreciation of the needs of persons with mental illness. These policies and abuses are not the preserve of any country in particular.

Modern mental health systems do not depend on mental hospitals, but on psychiatric units in general hospitals and on an array of community mental health agencies. These systems need a different level of discourse on human rights from the discourse attached to institutions. Economic discrimination and the disparities in access to care as well as the systemic, structural violence to which mental patients are subjected in the community are the major issues in modern mental health systems. The human rights discourse has to evolve from over-preoccupation with basic rights to freedom and autonomy to protection of citizen entitlements denied to the mentally ill as a class within the larger social system. The struggle for those who care about them is to gain for them the same rights and entitlements that other citizens enjoy [34].

A distinction must be drawn between negative rights and positive rights or entitlements. International sources of human rights recognize both negative and positive rights. Negative or 'first-generation' rights include those which preclude interference with a protected freedom, and prevent the state from certain proscribed action. Positive or 'second-generation' rights impose mandatory obligations upon states. Although the national systems of many countries, especially democratic ones, provide significant civil and constitutional protections with respect to the negative rights of its citizens, including those who suffer from mental disorders, the same cannot be said with respect to entitlements to the provision of social services [35]. Legal activism in mental health should aim at remedying these shortcomings.

Most legislation that deals with the mentally ill reflects the realities of the past when they were forced to remain in institutions; thus, it focuses on traditional political rights such as liberty, due process, protection against abuses and the authoritarian imposition of treatment [36]. While it is very important to keep these protections in place, in the majority of countries where deinstitutionalization policies have been implemented mental patients are no longer in mental hospitals, but in the community. Most of them do not have access to a bed in any type of hospital. The challenge facing many mental patients is the obverse of what preceded the current model; where systemic abuse and deprivation of freedom constituted the greatest weakness under prior regimes, mental patients in modern models of care face structural and systemic neglect. This neglect has had a profound impact on all

mental patients, as an unprotected social underclass. In this regard, the question whether mental patients have gained anything may appear to be rhetorical, but looking at the plight of the mentally ill in the mental health ghettos of any large city, or in the prisons, makes the question practical, obligatory and immediate and one that demands answers from legislators and policy makers and from society in general.

High levels of stigmatizing attitudes among the general public and even among clinicians may be at the base of what Kelly calls 'structural violence', a pernicious and insidious form of discrimination and abuse, the resolution of which is translated into a deprivation of rights [37]. In fact, mental patients seem to have obtained the 'anti-right' to remain homeless on the streets where they might freeze to death on winter nights, to be unemployed, or to be confined to a permanent existence of poverty and charity. On the basis that an existence on the street for lack of proper accommodation increases the risk of victimization, it may be that mental patients are disproportionately robbed, mugged, raped, beaten up or murdered in the streets where they sleep. Should they react violently, many times in self-defence, they are labelled dangerous and sent to prison. Mental patients have in effect been granted the anti-right to be criminalized and to receive treatment, if any, in prisons and penitentiaries, as opposed to hospitals, where most citizens expect to go if they fall ill [38]. The facile manner in which mental patients have been criminalized reinforces the stigmatizing attitudes in society. This has fuelled further fears that they are dangerous and unpredictable, and has led to further calls for expansion of controls via commitment legislation [39, 40]. In turn, the harshness of their existence has a negative impact on their illness as biological, psychological and social elements are in close interplay to reinforce aetiological factors and to maintain disease status.

Unfortunately, mental patients are caught in a tetrad of misfortunes – poverty, disenfranchisement, powerlessness and championlessness – that conspire to make impossible any improvement of their situation.

Mental patients are usually found on the lowest rungs of the socio-economic scale. Mental illness seems practically a synonym for *poverty*. Their illness impacts heavily on their employability as it attacks before many of them achieve their developmental potential, thereby truncating their education and reducing their marketability. To complicate matters, accessing prompt treatment is difficult for young persons. Poor knowledge of the nature and presentation of mental conditions, confusion as to the nature of the symptoms, fear of stigma among family members, lack of financial resources, and a health system that does not provide sufficient treatment options for the young unnecessarily prolong the period between the appearance of the illness and the first opportunity for treatment. For others who become ill later in life, the illness often leads to unemployment and catastrophic loss of income with a rapid fall in the socio-economic scale. Oftentimes, even claiming disability insurance, which has been paid for eventualities of this nature, becomes a nightmare. Insurance companies tend to regard mental health claims suspiciously, curtailing treatment options, and causing the person to incur unnecessary legal costs for experts to redress the injustice.

Politically, mental patients are *disenfranchised*. They have no voice. In some countries, they have no right to vote and in those where they can, because of their mental condition, they find it difficult to enter the electoral registries; many simply have no address and, having no home address, they cannot vote. In comparison with other patient groups, such as those for breast cancer, prostate cancer, AIDS, heart disease, chronic obstructive pulmonary disease (COPD), which are capable of mounting lobbies and carrying out political activism in order to improve their access to better health care, lobbying and political mobilization are hard to

organize among the mentally ill. The families of mental patients are themselves affected. Many live in poverty, so that they too have little political influence. *Disenfranchisement* and lack of voice render social problems invisible so that the plight of the mentally ill or their families seldom enters the sphere of political debate. This results in neglect of mental health systems, poor budgetary allocations, inadequate facilities and utter disregard for their social situation.

Powerlessness of the mentally ill often stems from the nature of the symptoms that consume their energies and compromise their ability to participate in social and political activities. Seriously ill mental patients are too preoccupied with their delusions and hallucinations, may be too paranoid to even consider trusting others in any form of group action, too disordered because of manic behaviour, or too depressed to even care, and the chronically ill are too preoccupied with their own conditions and about surviving to be able to mount any concerted political action. Serious mental conditions are incapacitating and disturb the appropriate modulation of affects and behavioural controls. These conditions also alter cognitive processes that are necessary to make sense of complex issues and to express opinions in a coherent fashion, especially if speaking in public, as most political actions require. The mentally ill are not just disenfranchised, they are totally alienated from the political system; they are powerless.

Finally, *championlessness* completes the misfortunes, for besides lacking a political voice of their own, the mentally ill also lack political champions. Even when a leader or advocate surfaces and argues for the mentally ill, the motivating force is not infrequently outrage stemming from a personal situation, for example – oftentimes a close relative has succumbed to mental illness and the champion politician has to face the reality of inadequate services. Unfortunately, fear of negative repercussions in political capital has led politicians to hide the mental illness of their relatives or among themselves. A history of mental illness is a major roadblock to seeking or remaining in public office. In regard to clinicians who often feel that they have to confront the social reality of their patients and who have a duty to advocate for them, if they do, they are seen as self-serving. If they gain political office, they move on to other issues as they do not wish to be type-cast as a single-issue politician hammering at something for which there is no political resonance.

Over the past several years, however, states have come to realize the depth and cost of mental health conditions within their populations; this awareness has accelerated the momentum for mental health law reform. Such reforms, however, ought not to be restricted to operational questions on the adequate level of services, nor to the problem of financing, but should include a review of the human rights dimension of such systems. For, while the protection of the human rights of mental patients seems to have become a priority in the international arena, as evinced from the growing body of international law in this area, the actual plight of mental patients does not seem to have improved, and in fact, seems to be getting worse, largely as a result of neglect at the national level

In her 15 January 2005 statement to the Open-Ended Working Group of the UN Commission on Human Rights, the UN High Commissioner for Human Rights underscored the importance of expanding our vision, both nationally and internationally, of the scope of fundamental human rights:

Recognizing the status of economic, social and cultural rights as justifiable entitlements is crucial to honouring the political, moral and legal commitments undertaken by States when the international bill of rights was adopted [41].

Her comments reaffirmed the conception of positive social entitlements as justiciable human rights under international law (as enshrined in such conventions as the *International Convention on Social, Economic and Cultural Rights*) [42] and underscored the failure of states to give meaningful effect to ‘second-generation’ rights. International law has, in many respects, led the way in advancing the rights of mentally ill persons. This advancement has taken the form of both binding and non-binding international norms, as well as proposals for domestic legislative reform. International law finds its expression in either treaties or customary norms. It is under these treaties that human rights, including a right to health and social services, have figured prominently under international law.

Human rights under international law, however, have made the furthest progress with respect to negative rights (that is, relative to states) than to citizens’ entitlements. Thus, the *International Covenant on Civil and Political Rights* (ICCPR) [43] has had a great impact on the promotion of negative rights with respect to persons with disabilities. This covenant, which has been ratified by 151 countries, is among the most important multilateral treaties advancing first-generation human rights. The covenant extends a number of protections to the individual that are particularly relevant to mentally ill persons, in particular, Article 9 which extends rights to individuals with respect to liberty and security of the person, and prohibits state action which arbitrarily restricts those rights [44].

On matters of secondary rights, Article 12 of the *International Covenant on Economic, Social and Cultural Rights* (ICESCR) is perhaps the most significant international source of a ‘right to health care’ as it enjoins the *States parties to the present Covenant* (to) *recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health* (see [43]). Unfortunately, this covenant is subject to the limitation that, in order to be effective for any citizen worldwide, its principles have to be given expression and individually enacted by each country in its national legislation.

Another significant development with respect to the development of positive rights to health care is UN Resolution 46/119, the *Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care* (the ‘MI Principles’) [45]. These Principles specifically recognize the positive right of persons with mental illnesses to treatment. For example, Principle 1.1 specifies that “[a]ll persons have the right to the best available mental health care, which shall be part of the health and social care system’. Although it may be true that Principle 1.1, and the *MI Principles* generally, may be incapable of grounding any positive rights claim against an individual state, it is nevertheless expressive of a growing international recognition of the importance of positive rights, particularly where the rights of the mentally disabled are concerned.

Notwithstanding the existence of a growing body of international law both prohibiting discrimination and limiting state interference with respect to people with disabilities, as well as positive entitlements with respect to the provision of medical services, it is unclear what practical impact these resolutions have in the domestic sphere. As indicated, implementing negative rights is, in general, not too difficult as derelict states that do not comply are usually identified and even sanctioned, but not so in regard to positive rights whose absence is the most appalling in regard to mental patients. For example, in countries with established economies, health insurance companies openly discriminate against persons who acknowledge that they have had a mental problem [46]. Life insurance companies, as well as income protection insurance policies make a veritable ordeal out of collecting payments due to temporary disability caused by mental conditions such as anxiety or depression. Many patients see their payments denied or their policies discontinued. Government policies sometimes demand that mental patients be registered in special files before pharmacies could dispense

needed psychiatric medications. At a larger level, many countries dedicate only a pittance of their health budgets to mental health and most developed countries provide only a modicum of funds from their national research budgets for research into mental conditions [47].

In developing countries, beliefs about the nature of mental conditions, sometimes enmeshed with religious beliefs and cultural determinants, tend to delay needed treatment by penalizing and stigmatizing not only the patients, but also their families, even when they are entitled to access treatment opportunities [26]. Within the Chinese culture, mental illness is highly stigmatizing for the whole family, not just the individual afflicted. The emphasis on collective responsibility leads to the belief that mental illness is a family problem. Thus, Chinese care givers may prefer to cope with mental illness within the context of the family as long as possible. The downside to this approach is unnecessary delays in treatment and worsening of the mental condition [48].

In general, illness and disability due to mental disorders have received little attention from governments in developing countries. Mental health services have been poorly funded and most countries lack formal mental health policies, programmes and action plans. In 1988 and 1990 two resolutions designed to improve mental health were adopted among African countries. However, a survey conducted two years later to follow up on what progress had resulted from these resolutions unfortunately showed disappointing findings [26].

In Uganda, per capita yearly expenditure for mental illness is only US \$ 4.00, well below the US \$10.00 recommended by the World Bank [49]. In Nigeria, excessive workloads, frequent transfers, responsibility without authority, and other inherently poor management practices are blamed for the poor mental health conditions of employees and the consequences if they happened to complain about their difficulties [50]. In the words of the World Health Organization, mental patients are 'denied citizens' [51].

Three levels of social interaction – stigmatizing attitudes, lack of or failure to implement positive rights, and the tetrad of poverty, disenfranchisement, powerlessness and champi-onlessness – are essential to understand the vacuum that exists between official documents and good intentions of the law against discrimination and the realities in the lives of mentally ill persons in modern-day society.

Consequences of stigma

The stigma of mental illness affects the requirements for care of good quality in mental health, compromising access to care through perceptions among policy makers and the public that persons with mental illness are dangerous, lazy, unreliable and unemployable. Eventually, these attitudes impact on the willingness of authorities to provide proper financial resources for their care so that a vicious circle forms, entrapping the mentally ill person and the family [52].

There may be some controversy about whether what is stigmatized is not the mental condition as such or the mental patient, but the behaviours that they tend to display [53]. On the assumption that objectionable behaviours are part and parcel of the mental condition, this controversy appears Byzantine. Real-life perceptions and patients' estimonials tell a different story about how it feels to have a mental illness.

Michelle, a vivacious 25-year-old office worker, tells about her major disappointment with her family and family friends who simply expected her to have an abortion when she announced that she was pregnant. They assumed that her schizophrenia would incapacitate her to deliver and to care for her baby. They were also afraid that her

medications could have teratogenic effects on the baby. She carried her baby to term and is taking care of it despite the opposition of family and friends.

Michelle's experience is not uncommon. For many persons with mental illness, the stigma of their illness is worse than the disease and it spreads a cloud over every aspect of their lives and further on the lives of other members of the family.

John, a 19-year-old university student, had to accept the termination of a relationship he had just started with a girl from his neighbourhood. Her parents objected to the relationship and decided to send her to another city for her education, in part in an attempt to break up the relationship, once they knew that John's mother's frequent hospitalizations for the past several years were not due to 'diabetes', but to a manic depressive illness. John described the experience with some resignation, 'it seems as if I have to carry the sins of my parents'.

In the study by the Canadian Mental Health Association quoted above [23], mental patients felt that social and family life (84%), along with employment (78%) and housing (48%), were the areas most commonly affected by stigma. In that survey respondents also felt excluded from the community (22%) and complained that stigma has a negative impact on their self-esteem (20%).

In a survey conducted among members of their own support organization by 'survivors'³ of mental illness in Thunder Bay, Ontario, Canada [54], housing, employment, and transportation in public buses were described as degrading and outright discriminatory.

'I have to lie to my landlord to get a place to live, like tell him you are on disability, if it is not visible or physical, they don't take you. Even slumlords won't take you because they don't want psychiatrically ill people living in their buildings.'

In this Report, 'survivors' found that 'mental health barriers' among the public often led to stigmatization, prejudice and stereotyping and that they were not listened to, or understood. They also felt ignored, avoided or treated without respect and sensitivity. They reported that these attitudes could also be found during their interactions with social assistance personnel and with clinical staff.

'At the agency the staff talk about patients and how crazy they are. No wonder there is such stigma in the community.'

And another patient commented poignantly about health personnel:

'At the hospital, they take your clothes away. They put you in pyjamas . . . it strips away your identity. You know, we are not all crazy. We don't all see the boogiemán around the corner. Some of us have legitimate complaints. But if you are always told "oh, you are just overreacting, you know, you don't know what you are talking about" or stuff like that, after a while you start to believe that yeah, maybe I am. And you know, there

³ Some mental patients' self-help support groups in Canada and in other countries have used this term to bring attention to their struggle for a more compassionate mental health system and better social acceptance.

are some doctors who don't know anything about mental illness and who cannot tell an oesophagus from an asshole.'

One newspaperman [55] describes his feelings after a bout of major depression:

Stigma was, for me, the most agonizing aspect of my disorder. It cost friendships, career opportunities, and – most importantly – my self-esteem. It wasn't long before I began internalizing the attitudes of others, viewing myself as a lesser person. Many of those long days in bed during the depression were spent thinking, 'I'm mentally ill. I'm a manic-depressive. I'm not the same anymore'. I wondered, desperately, if I would ever again work, ever again be 'normal'. It was a godawful feeling that contributed immensely to the suicidal yearnings that invaded my thoughts.

Strategies to combat the stigma of mental illness

Four strategies have been identified as appropriate to combating stigma and discrimination: stigma-busting, education, contact and political activism to diminish or stop abuse of civil and human rights of mental patients.

- *Stigma-busting activities* are usually undertaken by mental patient lobby groups or support family groups and aim at identifying and denouncing negative and highly stigmatizing portrayals of mental patients in movies and the media. Often, letters are written to the media or producers and, on occasions, rallies are mounted in front of movie houses to protest. These groups, therefore, should remain vigilant and be ready to denounce local or national news, advertisements or movies that stigmatize, ridicule or demonize people with mental illness as violent, unpredictable or dangerous. No evaluations have been conducted about the effectiveness of these confrontational activities, but from the point of view of lending a voice and undertaking political action they can be seen as serving a major need for mental patients themselves to let their voices be heard.
- *Educational activities* usually take the form of massive national campaigns aimed at increasing knowledge in the general population about mental illness, its treatment and the prospects for recovery. They can also be aimed at smaller audiences of identified stakeholders or groups with influence via pamphlets, conferences, presentations, and so on, on the nature of mental illness and the treatments available. National and international organizations and associations as well as national and local governments have come to appreciate the need to change attitudes toward persons with mental illness and to sensitize the public to the notion that mental conditions are no different than other conditions in their origin and that diagnosis and treatments are available and effective.

Campaigns like *Changing Minds*, organized by the Royal College of Psychiatrists in the UK [56], are based on providing information to the public so as to dispel myths and stereotypes about those with mental illness. This campaign has used leaflets, pamphlets, films and other ways of mass communication.

In one well-known film, *I in 4*, the message is direct and pithy; it emphasizes that mental health problems can touch anyone, proclaiming that '*1 in 4 could be your Brother, your Sister. Could be your Wife, your Girlfriend... 1 in 4 could be your Daughter... 1 in 4 could be me... it could be you!*'

Pamphlets produced for this campaign emphasize messages indicating that social despair and isolation have replaced old methods of physical isolation:

For centuries people with mental illness were kept away from the rest of society, sometimes locked up, often in poor conditions, with little or no say in running their lives. Today, negative attitudes lock them out of society more subtly but just as effectively.

Similarly, a campaign in Australia by the National Mental Health Promotion and Prevention Action Plan [57] through the *Community Awareness Program* (CAP) and the Australasian *Psychiatric Stigma Group* aimed at improving mental health literacy in the population. CAP was a four-year programme liberally funded to increase community awareness of all mental conditions. Specifically, it had three goals: to position mental health on the public agenda, to promote a greater understanding and acceptance of those experiencing mental illness, and to dispel myths and misconceptions about mental illness. The programme had a built-in evaluation based on a benchmark survey and pre-/post-test tracking design. The most significant results include the fact that while tolerant attitudes were consolidated, they did not increase; that there was a slight increase in the awareness of services; and that there was no clear evidence of behaviour change [58]. The Australasian Psychiatric Stigma Group has more modest goals, mostly by linking consumers, providers, and many other interested groups in a public evaluation of the impact of stereotyping and stigma on the lives of psychiatric service-users, their carers, and the lives of providers [59].

SANE Australia is a national charity that helps people affected by mental conditions. One major and famous feature of this group is the popular TV soap opera *Home and Away* in which one storyline is about a young character who develops schizophrenia [60]. SANE has a function similar to NAMI (National Alliance for the Mentally Ill) in the United States [61] and CAMIMH (Canadian Alliance on Mental Illness and Mental Health) [47]. They are all umbrella family groups that lobby for better education, more research funding, and more accessible treatment opportunities for persons with mental illness.

Similar programmes and groups can be found in other countries such as Germany [62], the United States [61] and most recently, in Canada a newly established Mental Health Commission [64] has announced the possibility of mounting a major national campaign and programmes to combat stigma and discrimination. Two international programmes are those of the World Health Organization [65] and the World Psychiatric Association [66].

- *Contact* refers to increased visibility of mental patients among particular audiences in order to convey a sense that they are not always deranged, psychotic or seriously depressed and suicidal, and that they can act as normally as anybody else. Contact and educational strategies are found in the two international programmes. The WHO programme '*Stop exclusion. Dare to care*' follows mostly an educational strategy with elements of legal activism, at local levels and through local organizations. This programme aims at combating stigma and at rallying support for more enlightened and equitable structures for the care of those with mental illness and the acceptance of mental health as a major topic of concern among member states. This programme brings timely information to correct the myths surrounding mental conditions such as the beliefs that they affect only adults in rich countries, that they are not real illnesses but

incurable blemishes of character, or that the only alternative would be to lock mental patients in institutions. The programme also invites individuals, families, communities, professionals, scientists, policy makers, the media and NGOs to join forces and to share a vision where individuals recognize the importance of their own mental health; where patients, families and communities will feel sufficiently empowered to act on their own mental health needs; where professionals will not only treat those with mental illness, but will also engage actively in mental health promotion and preventative activities; and where policy makers will plan and devise policies that are more responsive to the needs of the entire population. Methodologies of this programme include the distribution of pamphlets, posters, booklets and stickers, and through the many collateral organizations and distribution channels open to WHO contact with patients and their families.

On its part, the WPA initiated in 1998 its Global Programme against Stigma and Discrimination because of Schizophrenia. Full information on this programme including training modules, and a full annotated bibliography can be found at the site *Open the Doors* (www.openthedoors.com) some attached as appendix to this book. Although circumscribed to schizophrenia, the results of the programme in the different countries where it has been implemented are equally applicable to any other mental condition. The programme was first pilot-tested in Calgary and Alberta, Canada, in 1998, and has now been established in over 27 countries in all continents. This programme targets different audiences according to location, but depends heavily on local action groups that organize themselves to plan and initiate projects that mobilize local resources into action to combat the stigma associated with this disease. Education at a local level is a major element of this programme, but it is possible that contact is its main characteristic as patients and their families are co-participants and active players in all activities. Contact is also encouraged through special programmes such as *Partnership* where mental patients are coached to go to schools or to businesses to speak about their conditions or theatre activities where again mental patients are the actors and perform in front of live audiences.

- *Political activism* includes a systemic and concerted effort to bring to the attention of society and various levels of government the plight of mental patients and to lobby for better access to care and other services while promoting changes in practices, laws or regulations considered discriminatory against mental patients. Political activism forms part of the two international programmes. The WHO programme *Stop exclusion. Dare to care* aims at providing incentives to national governments and health care organizations to change policies and to become actively involved in the reorganization of services and in the development of appropriate mental health policies. The WPA programme *Open the Doors* also has a major political activism component. The programme in Calgary lobbied the National Hospital Accreditation agency to change its best practices requirements regarding management of mental patients at Emergency Departments in general hospitals and has managed through presentations of its members to be active in the Federal Government lobbying for a National Commission on Mental Health.

Conclusions

Empowerment is intrinsic to the mental health of communities. The support and involvement of communities in the development, implementation and organization of their own health structures and programmes has led to the realization at the community level of the impact

and the ramifications to health of social scourges such as drug and alcohol abuse, family and social violence, suicide and homicide, and mental illness.

Centuries of prejudice, discrimination and stigma, however, cannot be changed solely through government pronouncements and legislative fiats, important as they are. The successful treatment and community management of mental illness relies heavily on the involvement of many levels of government, social institutions, clinicians, care givers, the public at large, the patients or 'consumers' and their families. Successful community reintegration of mental patients and the acceptance of mental illness as an inescapable fact of our social fabrics can only be achieved when communities take control and become masters of their own mental health structures, programmes, services and organizational arrangements.

There is a need, therefore, to engage the public in a dialogue about the true nature of mental illnesses, their devastating effects on individuals, their families and society in general, and the promises of better treatment and rehabilitation alternatives. An enlightened public working in unison with professional associations and with lobby groups on behalf of persons with mental illness can put pressure on national governments and health care organizations to provide equitable access to treatment and to develop legislation against discrimination. With these tools, communities could then enter into a candid exchange of ideas about what causes stigma and what are the consequences of stigmatizing attitudes in their midst. Only these concerted efforts will, eventually, dispel the indelible mark, the stigma caused by mental illness and the associated discrimination that is the basis for the denial of rights and entitlements to mental patients.

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