Editorial review

Mental illness and human rights

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For the past two decades there has been a growing realization of the extent and costs of mental conditions worldwide that has led to much debate about the best ways to fund and to organize mental health services. Similarly, alerts have been made and strategies have been devised to counteract even veritable mental health epidemics such as drug abuse, violence and posttraumatic stress disorders resulting from multiple conflicts and wars around the world. These developments have accelerated a momentum for reform of mental health systems in many countries. Debate on the nature of such reform, however, should not be kept just at the level of services and better financing, but should include an exhaustive review of the human rights of persons with mental conditions. While protection of human rights has become priority, as observed from the multiple documents of international agencies and in legislative decisions, the plight of mental patients in the community has not improved, and, in fact, seems to be getting worse as a result of neglect of national mental health systems. This editorial aims to contribute to the debate by reviewing general issues on the matter of human rights of mental patients.

Mental health reform

Human rights are inextricably linked to the degree of development of mental health systems. Each system, however, seems to have seeds of abuse that range from complete denial of such basic rights as liberty of the person in the custodial model to the loss of entitlements of citizenship in the deinstitutionalization model [1].

A distinction must be made between negative or 'first-generation rights' and positive or 'second-generation' rights. The former include those rights which preclude interference with a protected freedom and that prevent the state from certain proscribed action. Positive or 'second-generation' rights are those that impose mandatory obligations upon states. Although countries with advanced mental health systems may provide significant civil and constitutional protections with respect to the positive 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 that are considered subsumed within the scope of positive rights.

In a number of modules on mental health reform, the WHO spearheaded a multicountry mental health system reform project along different lines of action. One of those lines pertains to the promotion of human rights standards and principles in mental health legislation, as emphasized in one of the modules of this initiative [2]:

> All people with mental disorders have the right to receive high quality treatment and care delivered through responsive healthcare services. They should be protected against any form of inhuman treatment and discrimination.

The WHO emphasizes the need for protection of mentally ill persons when their mental conditions impact on their decision-making capacities and when they are in need of hospitalization against their will. In its approach, the WHO articulates 10 principles that are considered basic to proper mental health systems and for the protection of the rights of the mentally ill:

(1) promotion of mental health and prevention of mental disorders;
(2) access to basic mental healthcare;
(3) mental health assessment in accordance with internationally accepted principles;
(4) provision of the least restrictive type of mental healthcare;
(5) self-determination;
(6) right to be assisted in the exercise of self-determination;
(7) availability of review procedures;
(8) automatic period review mechanisms;
(9) qualified decision-makers;
(10) respect for the rule of law.

In the module on mental health legislation and human rights, the WHO endorses the 25 principles contained in the United Nations Resolution 46/119 [3] that covers a gamut of areas that impact on the rights and care of the mentally ill, such as the following:

(1) protection of confidentiality;

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(2) standards of care and treatment including involuntary admission and consent to treatment;
(3) rights of persons with mental disorders in mental health facilities;
(4) protection of minors;
(5) provision of resources for mental health facilities;
(6) role of community and culture;
(7) review mechanisms providing for the protection of the rights of offenders with mental disorders;
(8) procedural safeguards to protect the rights of persons with mental disorders;
(9) obligatory notification of rights.

The principles endorsed by the WHO and declarations by scientific organizations such as the Declaration of Madrid of the World Psychiatric Association (WPA) are framed with a sense of urgency and concern. The WPA document [4], for example, specifically reminds psychiatrists that

> The patient should be accepted as a partner by right in the therapeutic relationship to allow the patient to make free and informed decisions.

More to the point, on the matter of rights, in paragraph 4 of the Madrid Declaration, the WPA alerts psychiatrists that

> When the patient is incapacitated and/or unable to exercise proper judgment because of a mental disorder, or gravely disabled or incompetent, the psychiatrists should consult with the family and, if appropriate, seek legal counsel, to safeguard the human dignity and the legal rights of the patient.

Finally, on the matter of systems, the Declaration of Madrid [5] emphasizes that

> As members of society, psychiatrists must advocate for fair and equal treatment of the mentally ill, for social justice and equity for all.

These concerns underline the close relationship between the quality of mental health systems and treatment for mentally ill persons and the impact that systems and treatments could have on the human rights of mental patients. Oftentimes, however, legal protections do not translate into actual enforcement of the rights of individuals. This is more so when violations are entrenched in social beliefs about mentally ill persons; those beliefs conspire to deny rights and citizen entitlements to mental patients that many other persons take for granted.

Such entitlements were highlighted in the 15 January 2005 statement to the Open-Ended Working Group of the UN Commission on Human Rights by Louise Arbour, UN High Commissioner for Human Rights. In her statement the Commissioner emphasizes the importance of expanding our vision of the scope of fundamental human rights [6••]:

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

Commissioner Arbour's comments, while reaffirming 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* [7]) underscore the failure of states to give meaningful effect to positive or 'second-generation' rights.

Arbour has also applied her concerns for human rights of vulnerable populations in Canada. As a Justice of the Supreme Court of Canada, and a frequent dissenter with respect to the ambit of social rights under the *Canadian Charter of Rights and Freedoms* [8], she has gauged the shortcomings of national legal systems in this respect. Her observations are particularly apposite with respect to the human rights of persons with mental disorders, for while there have been significant advances with respect to the 'negative' or first-generation rights of such persons over the last 50 years, 'positive' or second-generation social rights have not fared so well.

Historical legacy

The entrenchment of protections and rights of mental patients in many declarations and official documents is an attempt to rectify the harm committed on them ever since asylums were developed, and even before. Historically, it has been described that it was since observing the abuse that one mental patient was subjected to in the street that a monk, Father Gilabert Jofré, was moved to develop the, possibly, first European asylum for the insane in Valencia in 1409 [9]. While well motivated, this invention was later taken to the extreme in a wholesale locking up of mental patients that Luis Vives [10] describes as social exclusion, many times for life. Yet, banishment via institutionalization was only a continuation of a more pernicious social management style prevalent before the asylum in Valencia – the *Narrenschiff* or *Stultifera Navis*. These ships of fools, if they ever existed, were, according to Sebastian Brant [11], supposed to carry the mentally ill condemned to navigate the waters of the rivers of Europe never finding a port, but always banished from place to place. Socio-politically, the asylums replaced the leprosariums. Whereas the latter were exclusive for lepers, however, the asylums became the place for the 'great confinement' [12], places used to

banish all sorts of undesirables, especially persons affected by mental conditions. In fact, the *lettres de cachet* contemplated in the 1838 *Act on the Insane* in France that gave the 'hospital archers' authority to round up and lock up, among others, 'beggars, vagabonds, the chronically unemployed, criminals, rebel politicians, heretics, prostitutes, syphilitics, alcoholics, madmen and idiots' [13] became the blueprint for similar institutions all over the western world. The characterization of the mentally ill as 'wild beasts' left no other alternative, but to put them away [14].

It has been a long struggle for the mentally ill to recover from their banishment. Even gestures such as Pinel's, who imbued with the libertarian ideals of the French Revolution publicly cut the chains that, like prisoners, held the mentally ill to their posts at la Saltpêtrière in 1795 [15], have not been enough as old and decrepit mental hospitals are still the preferred, and only, model of care in many countries. Yet, removing the chains and allowing mental patients to return to the community has not liberated them from the yoke of yesteryears – 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]. At present, in order to protect their basic right to freedom, the tortuous path into criminalization is overregulated and overseen by courts of law and by forensic psychiatrists [17] who have become gatekeepers, or modern day superintendents. The process of forensic evaluations has become another filter for treatment that keeps mentally ill persons in a limbo ensconced among three seemingly inimical systems – the healthcare system, the justice system and the correctional system. At the end, however, the effect of a forensic evaluation may be the same – loss of liberty in a hospital for the criminally insane or deprivation of liberty in a jail pending legal dispositions. At this point, therefore, it would be appropriate to ask, what have the mental patients gained [18]?

From protection of negative rights to social neglect

Most documents, legislation and declarations regarding protection of the rights of the mentally ill tend to deal with individual protection of basic rights to liberty, protection against lack of process, protection against abuses from the psychiatric establishment [19] and protection against authoritarian impositions on the mentally ill. While it is very important to keep these policies in place, the fact is that these documents are plagued with the rhetoric of anti-institutionalism and are enmeshed in a preoccupation for protection of freedom and personal autonomy while failing to recognize that realities have changed and that, in many countries, most mental patients are no longer in mental hospitals, but in the community, and that many of them do not even have access to any bed in any type of hospital. Challenges currently facing mental patients in many countries are not individual abuses of freedom or autonomy, but structural and systematic neglect that covers all mental patients as an unprotected social underclass. Thus, the question of 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. Furthermore, it is a question that demands answers not only from legislators and policymakers, but also from society in general so that they can comprehend the negative attitudes and lack of understanding of the powerlessness of the mentally ill to change their lot in life.

Three levels of social interaction – discrimination, 'antirights' and powerlessness – are considered 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.

Discrimination

Stigma, prejudice and discrimination have been identified as the reasons for most of the difficulties mental patients face when they are clinically ready to reintegrate into society [20]. While stigma and prejudice are attitudes, discrimination is the active denial of entitlements and rights that are ordinarily enjoyed by most citizens. Stigma, prejudice and discrimination are closely related and tightly interwoven social constructs that are observed across all classes and social groups. Stigma develops within a social matrix of relationships and interactions and has to be understood within a three-dimensional axis [21] – perspective, identity and reaction. Perspective is the way stigma is perceived by the person who does the stigmatizing (perceiver) or by the person who is being stigmatized (target); identity entirely engulfs personal perceptions of being mentally ill and involves group-based identifications and group belongingness; and reaction, or the way the stigmatizing person and the stigmatized react to the stigma and how its consequences play on each other and perpetuate stigma transgenerationally.

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

reinforces the stigma against the individual. This process of lumping everybody together extends to the perception of all mentally ill persons as unpredictable and violent because, unfortunately, the general public's perceptions of the mentally ill are shaped by images in the media or the movies. The media often depicts patients as dangerous [22] and movies usually follow the popular 'psycho-killer' [23] plot, long exploited in the cinematographic industry. The association between mental illness and violence helps to perpetuate stigmatizing and discriminatory practices against mentally ill persons and is only one of the many negative stereotypes and prejudicial attitudes held by the public about them [24].

To the extent that many mental conditions are chronic and incapacitating, mentally ill persons can hardly migrate out of the grip caused by negative social attitudes. The result is social annihilation, a constriction in the lives of the mentally ill that prevents them from full re-engagement into their communities and from participating in the social activities of their groups of reference.

Fear of stigmatization prevents many affected persons from seeking opportune treatment or adhering to treatment regimes. Fear of stigmatization at work and of losing their job keeps many persons within an internal prison of despair until it becomes too late, often with serious consequences to the person and to others.

Antirights

High levels of stigmatizing attitudes among the general public and even among clinicians may be the basis of 'structural violence' [25]. This is a pernicious and insidious way of discrimination and abuse that is translated into a social situation whereby some people are nonpersons and are 'allowed' to gravitate to nonright zones at the fringes of society where they can enjoy their 'antirights'. Thus, mental patients have the right to remain homeless in the streets where they could freeze to death on winter nights, to be unemployed, to be confined to a permanent existence of poverty and to live on handouts. They have the right not to have the financial means or places where they can enjoy some sense of privacy conducive to the development of intimate and emotionally rewarding relationships. They have the right to be robbed, mugged, raped, beaten up or murdered on the streets where they sleep due to lack of proper accommodation. Should they react violently, many times in self-defense, they are then labeled dangerous and sent to prison. Thus, mental patients also have the 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. The easy way in which mental patients are criminalized reinforces the stigmatizing attitudes in society as it fuels further fears that they are dangerous and unpredictable. This leads to further calls for expansion of controls via commitment legislation and a yearning for the good old mental institutions. In turn, the harshness of the existence that mental patients are condemned to has negative impacts on their illness as biological, psychological and social elements are in close interplay to reinforce etiological factors and to maintain disease status.

Powerlessness

Unfortunately, mental patients are powerless to modify their plight [26]. Poverty, disenfranchisement, disability and championlessness are all partly to be blamed for this situation, forming a circle from where there is practically no escape.

Poverty

Mental patients are usually at the lowest socioeconomical levels and many live in abject poverty. Their socioeconomic status is related to impacts of illness that attacks before many of them achieve their development potential, so their education is truncated and their marketability is reduced. Many persons who develop mental illness when young cannot access prompt treatment to help stem the disease and mitigate the impacts. Poor knowledge of the nature and presentation of mental conditions, fear of stigma among the family members, lack of financial resources and a healthcare system that does not provide treatment facilities for the young prolong the period between appearance of the illness and the first opportunity for treatment. For others who became ill later in life the problem is unemployment caused by the illness. This leads to a catastrophic loss of income and a rapid fall on the socioeconomic ladder. Oftentimes, even claiming disability insurance, which had been paid for eventualities of this nature, becomes a nightmare for many. Insurance companies tend to view any claims for mental disability with suspicion, curtailing treatment options, and causing the affected person to spend unnecessarily on legal costs and experts to redress the injustice.

Disenfranchisement

Mental patients have no political voice and many cannot even enter the electoral registries because they have no address, so they cannot vote. Lobbying and political activism, as exercised by many other patient groups to improve their access to better healthcare, including facilities and treatment options, are hard to organize among the mentally ill. Oftentimes, the families of mental patients are themselves affected and many live in poverty so they do not have any political clout either. Politicians do not give talks at mental hospitals or seek out the dispossessed mental patient in the street to hand leaflets. Disenfranchisement and lack of voice render social problems invisible so that the plight of the mentally ill or their families seldom enters the radar of politicians. This results in neglect of mental health systems, poor

budgetary allocations, inadequate facilities and utter disregard for their social situation. The mentally ill are not just disenfranchised, they are totally alienated from the political system.

Disability

The powerlessness of the mentally ill stems from their own mental difficulties that often consume their energies at the expense of not being able to pay due consideration to the realities of the world past their immediate survival. Seriously ill mental patients are preoccupied with their delusions and hallucinations; many are too paranoid to even consider trusting others in communal action and some are too disordered because of manic behavior or too depressed to even care. Serious mental conditions are incapacitating and disturb the appropriate modulation of affects and behavioral 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.

Championlessness

Powerless individuals who are unable to coalesce into social forces where numbers create political realities also lack political champions. Even when a champion surfaces and argues for the mentally ill, the reason is often because of outrage due to a personal situation – usually a close relative has succumbed to mental illness and the champion politician has to face the reality of inadequate services. More often, however, fear of negative repercussions leads politicians to hide the mental illness among their relatives or among themselves. A history of mental illness is a major barrier to seeking public office and a drawback when seeking reelection. Clinicians who feel that they have to confront the social reality of their patients and who have a duty to advocate for them are often seen as self-serving. If they gain political office they move on to other issues as they do not wish to be typecast as single issue politicians hammering at something for which there is no political resonance.

Lack of voice, lack of social recognition and lack of political power have condemned mental patients to migrate to prisons or to live their lives in mental health ghettos, jobless and dispossessed on the streets in utter poverty while enjoying their antirights of being systematically abused, stigmatized and discriminated against. This is how the mentally ill have been celebrating their hard gained freedom out of asylums and mental institutions.

Conclusion

Mere rhetoric about protection of basic rights to freedom and personal autonomy rings hollow and is as an empty exercise that harks back to old arguments appropriate to previous levels of development of mental health systems. 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 that addresses the political powerlessness, the economical discrimination and the disparities in access to health systems as well as the systemic, structural violence to which mental patients are subjected to in the community. The human rights discourse has to evolve from over-preoccupation on 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 the mentally ill is to gain for them the same rights and entitlements that other citizens enjoy.

References and recommended reading

Papers of particular interest, published within the annual period of review, have been highlighted as:

- • of special interest
- •• of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (p. 522).

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This is a seminal work to understand the importance of 'positive rights' for the mentally ill.

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