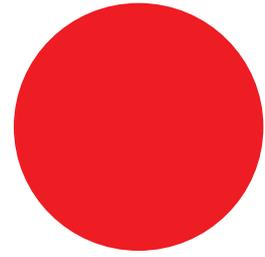


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January-February 2015

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### Power to Label: The Social Construction of Madness

-Prateeksha Sharma\*

My entry into mental illness has been an accident. But as a result I have had the occasion to witness the field of mental health, from many different positions. I experienced the pharmacological, social, health and spiritual consequences of bipolar disorder for a good part of two decades, entered into (non-university based) research<sup>1</sup> in social psychology, started analysis of illness narratives<sup>2</sup> from interdisciplinary perspectives. However I also 'recovered', using the many possibilities that life offers<sup>3</sup> to anyone. Thanks to research and a lived experience, when I entered into the realm of counseling my whole attitude toward people was different from the attitude of those who come from university based knowledge of mental distress, relying on ideas from abnormal psychology or clinical psychology courses

In many ways I find that when I talk to anyone given a serious mental illness label, the sort of

communications that happen are unlike most communications they have had with another. Of course I lay aside their labels and heard their stories-as their constructions of reality. For someone who had experienced the entire range of psychiatric medication<sup>4</sup> and seen their effects in all possible ways, another's label did not frighten me, nor gives me a starting point to look at people's life stories. People like me, understand that a label will least serve the person who suffers, nor bring any change in their condition. No matter what you give by way of medicine you cannot heal the injured spirit, in a chemical way. It just asks for communication, prays to be heard, and weeps when no one pays heed.

Jung (2002) reminds us that the predominance of one or the other point of view depends less upon the objective behavior of things than upon the psychological attitude of the investigator and thinker (p.5). When one enters into a therapeutic alliance as a superior 'knower', as someone who can lead another or who knows 'better', that (superior) position robs the other of their autonomy, selfhood, and sovereignty as humans with an ability to create a life of their own sensibilities. Gergen (1997) is of the view that since the mental health professions are allied with science, and science is socially represented as a progressive or problem-solving activity, scientific labeling also invites a hopeful attitude toward the future. (p.148). Is it not about time we inquire into the outcomes of the hope reposed in psychiatric diagnostic classification?

#### Positivist Tradition

The positivist paradigm asserts that real events can

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<sup>1</sup>Downloadable from  
<https://independent.academia.edu/PrateekshaSharma>

<sup>2</sup>It started with the illness narrative of a classical musician, Pt. Kumar Gandharva and then my own, and thereafter scores of others- also via counseling.

<sup>3</sup>Some of which include family support of an extraordinary nature, classical music, dogs, homeopathy, my own temperament for research and analysis, poetry, gardening, writing and ability to look at the suffering of others around me; which pushed me to go beyond my own. I must mention that living alone was one of the biggest reasons for my recovery, which taught me how in the presence of others we become pathological and also something different from what we can be by ourselves.

<sup>4</sup>This included psychiatric and somatic co-morbidities, ECTs and most antidepressants, antipsychotics and mood stabilizers.

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be observed empirically and explained with logical analysis. Positivism as a philosophy adheres to the view that only “factual” knowledge gained through observation (the senses), including measurement, is trustworthy. In positivism, the role of the researcher is limited to data collection and interpretation through objective approach and the research findings are usually observable and quantifiable.<sup>5</sup> In its attempt to look scientific and objective, psychology also entered the realm of positivism. Human behavior was seen as an extension of animal behavior, which was observable in the laboratory, based on which theories of development: personality, ab/normal, learning, anger, aggression and so forth were put forward.

Positivism also became the basis to decide what sort of behavior one could expect in a situation, from a human (recall the famous ‘conditioned reflexes’ study by Pavlov). If someone were to behave any different from that ‘expected’ behavior s/he would be treated as ‘not normal’. Psychology, in its zeal to position itself as a scientific discipline opted for positivism since the early decades of the 20<sup>th</sup> century. Psychoanalytic theory remained dominant for decades and served as the theoretical basis for both DSM I and II (Lafrance and McKenzie-Mohr, 2013). Gergen (1997) reminds that during the greater part of this period, a certain cluster of behaviourist theories dominated the scientific landscape. Now those perspectives have withered substantially, succeeded by a cluster of cognitive theories (p.15). ‘With its symptom-based orientation, the DSM-III contributed significantly to a biological vision of mental health, which stresses the neurosciences, brain chemistry and, medications’ (Mayes and Horowitz, 2005, p.258). In other words, there is a transformation of what holds center-stage in terms of significance. The psychiatric explanations of delusional formations are expressions of the empiricist and rationalist paradigms upon which modern science is based (Gergen, 1985). However, this cognitive basis is what social constructionism challenges.

### **Social Constructionism**

Social constructionism is an epistemological approach that conceives of social and psychological

phenomena as constituted through interpersonal and wider social processes (Georgaca, 2012). The human is a social entity, and the psyche of a person is created in a social milieu. To understand the construction of a person’s mind, we need to also examine the role played by their milieu. A child growing up in India is not the same as a child growing up in Africa, Denmark, Australia and Venezuela. Each child’s mind will be shaped by its environment, and scores of other social and cultural variables, in addition to a web of relationships around. So on what basis can we say that behaviours observed and established as ‘normal’ are indeed so, or the same as that of a child growing up in the US? Each of the child’s experience would be a function of their sociocultural milieu and an outcome of their own social attributes.

Social constructionism is a philosophical position that challenges all the previously held positions of reality as the basis of human action. According to earlier ideas, since the individual is a rational person s/he would act in his/her best interests at every level- sociopolitical, economic, financial, and more and by default this would bring about the best outcomes for the whole society. The cumulative outcomes in society, in which every individual behaves individualistically, as a result of ‘rationality’ does not produce social outcomes that were foreseen at the time of the birth of the idea of individual rationality. As a result human society itself did not proceed on a predictable path of growth and universal good, but in a haphazard, lopsided and detrimental manner. Neither was human behavior predictable, nor every person in society equally empowered to make choices.

One of the key pillars of social construction lies in relationships - in particular in the dialogues that happen between people as part of a relational engagement. Nothing in the world is outside of a dialogic context - neither in education, family relationships, social norms, therapy, business, organizational work nor governmental policy. However, even though people may have the ability for dialogue, their voices are not equally heard in any dialogue for that depends upon who holds the ‘power’ in the relationship. Power is unevenly distributed among the various groups of people in society and that reflects in every relationship across

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<sup>5</sup>See <http://research-methodology.net/research-philosophy/positivism/>

human social systems- including therapeutic ones. 'Psychiatrists, although they constitute a minority of mental health workers, literally "own" the contemporary meaning of madness. That ownership is the cornerstone of their profession: its area of responsibility and control. As such, psychiatry must maintain firm control over the meaning of madness and ensure that it is shared among experts who recognize it as legitimate and that it remains accepted by the public.' (Kirk, S.A., Gomory, T., & Cohen, D. 2013, p.122)

In a certain part of the world (US), psychiatry based on an empiricist/rational worldview creates categories of illness, discussed and consolidated within a group of people - the American Psychiatric Association (APA). The US being in a position of economic, social, financial and global power, commands a pride of place in every aspect of life, around the globe and whatever 'knowledge' is created in that group is diffused to the rest of the world, via the Diagnostic and Statistical Manual (the DSM). That knowledge, a linguistic agreement between the people participating, to classify clusters of behaviours as 'symptoms' is systematically and thoroughly diffused to the rest of the world - via media, conferences, internet, books and you name it devices. People, institutions and libraries in faraway countries buy the DSM for their (medical) education and believe every word written there and make it a part of their own vocabulary - the ideas become reified! When men of education and 'authority' propagate those ideas further, nobody can dare to think alternatively, let alone question. This is the milieu in which we live right now. Do you think if we were to create any system of diagnosis or recovery (apart from yoga, ayurveda), it would be accepted by any part of the Western industrialized society?

We need to think again, whether we can go with the Western model of illness labels and question, if we have the courage, what purpose it serves. Does it help anyone to be called as schizophrenic, and not as showing symptoms of schizophrenia? Or bipolar in disorder? Or having multiple personality disorder or any other disorder? By giving medicines to each one of these groups of people, do we consolidate

their illness as a category or do we help them recover and reclaim their fractured lives and narratives?

### Constructing an Alternative

Via this sort of a representation, I not only represent myself as a 'recovered' person, but also another whose story I (share and) construct briefly, to shed light on those realities which would not reach most ears. I want to hear the echoes, and resonances that come back to me, from among those who engage with these ideas. Ultimately the purpose for any 'democratic' discourse is to produce a meaningful understanding with and for the largest social good. I will encapsulate all my ideas for committed health activists, doctors, academics, and people with various other degrees of engagement with the field of medicine, with the following queries, that I invite you all to consider.

1. Is it correct to assume that a diagnostic system developed in a Western industrialized nation, whatever its basis, can be unequivocally imposed on the rest of the world? If we assume even hypothetically that the diagnostic system is foolproof, then is it able to diminish human suffering even in the country of its own origin? If it cannot do it in its own country, from what are we deriving this comfort and following, of its values and basis?
2. On whose shoulders should lie the responsibility for leadership in mental health? The psychiatrists<sup>6</sup> whose bread and butter is tied to medicating more people, toward never-to-recover futures, while they themselves stand to gain from making those medical prescriptions? On care-givers who are lead by the awe and terminology of psychiatry, who face the unenviable prospect of lifelong responsibilities of those rendered completely dysfunctional due to psychiatric medication, yet who are also the chief instrument for carrying out psychiatry's prescriptions? By those who are fighting for the rights of the 'mentally ill' and representing their suffering as any other human's and the right to lives of dignity? By those who are looking at recovery options via various alternatives? By those who

*<sup>6</sup>I would like to draw attention to the fact that most research in mental health is funded by pharmaceutical industry and if one were to just read how clinical trials are done and how they are interpreted, it may shed more light on a subject which is rarely scrutinized. I recommend Kirk, Gomory and Cohen's book cited in the bibliography to anyone who would like to investigate further.*

have recovered themselves? Whose role is the most promising if we really want to create more wellness, mid this ocean of ignorance and suffering?

3. Bombs were not what Einstein had in mind when he discovered the equation,  $E=mc^2$ . So though scientists work toward many useful outcomes, not all of their science is ethically employed. Should we not ask collectively whether the dominant discourse in mental health, even if it wears the garb of medical science, really the most ethical that science could get to diminish the suffering human spirit? Is science value neutral here, or subservient to other interests, whose amplitude is so big that every other voice is marginalized, if not silenced, in their presence? Is there a science that is truly value neutral? Do we ignore the ethics behind transforming language of distress to an illness category, yet not be able to 'cure' it by any stretch of imagination, despite decades of medications?

4. Are we, as a 'poor' nation, only going to live by ideas handed down on us by the West, and accept them irrespective of our sociocultural realities, where something as simple as malnutrition or female foeticide could be leading women to depressions?

### Conclusion

Anyone who seeks to create new outcomes, and not just rhetoric, may have to consider the various challenges we face in the task of finding solutions for millions of people in poorer nations. We need to gather courage to look beyond the dominant model offered to us from the richer West, in hegemonic ways. We in developing nation, not only suffer the consequences of 'knowledge' (even psychiatric knowledge) handed down to us from the rich West, but also a lack of self-worth and inferiority in bargaining about the validity of our perspectives. Most research, even about our society, is done by Western scholars and the research in medical humanities, within India, is at an infancy. Even if our psychiatrists were to challenge the ideas coming from the West their voices would be rendered insignificant in a pharma-driven enterprise. However, many people around the world, including psychiatrists are rejecting the authority of the DSM as the sole arbitrator of psychological suffering.

It is about time, we in India, also understand the various points of view and not be blindly led by the lack of diffusion of knowledge, another attribute of poorer nations and continue the cycle of spiritual enslavement that we are accustomed to.

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## The Discriminatory Standards of Constructing 'Patienthood' of the 'Mentally Ill' within Public Health

-Bhargavi V Davar\*  
Bapu Trust, Pune

There has been a spate of literature in the last two decades, struggling to make a public health subject out of 'mental disorder'. To become a public health subject, a variety of other scientific cognitions and proofs about constructing a 'disorder' have to be fulfilled: 'Prevalence', 'evidence base', 'validity', 'effectiveness', 'universal coverage', 'life course approach', etc. This construction of theory, proof and practice of 'No health without mental health' has filled several thousands of pages of publications since the 1990s. An alien reading the medical and medical social science journals today may be convinced that mental health is indeed a public health subject.

Going against the WHO findings of the late 1970s, which provided global evidence base for better outcomes for mental distress and disturbance in low income countries including India, the data of this century predicted, if not actually made manifest, an 'epidemic' of mental disorders in Low and Middle Income Countries (LMICs). This century has also witnessed the rise of the human rights movement for 'persons with psychosocial disabilities' and 'users and survivors of psychiatry' in the Asian region, including India: Their advocacy has been, in the main, for inclusive communities where people with psychosocial disabilities can fully and effectively participate and contribute to all aspects of life with autonomy and dignity on equal basis with others, in the face of severe social adversity and inequity. This advocacy has been inspired by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).<sup>1,2</sup>

Arguing that 'mental disorder' scoped by psychiatry sits awkwardly within the frame of 'public health', causing various degrees of harm to its subjects, this paper draws from human rights movements and critical psychiatry. The paper throws light upon what constitutes the awkwardness, even 'dis-ease', having the effect of a disparity within medical disciplines. People diagnosed with 'mental illness' seem to be a different and lesser species of a 'public health patient', vulnerable to lowered standards of care; degrading, inhuman and torturous 'treatments'; and a nonexistent medical ethics. We clarify that, we are not considering here the 'reform' of 'bad practice', but rather the very genealogy, design and practice of the discipline of psychiatry; Neither are we asking

whether 'psychiatrists are bad', but rather, 'Why and how did psychiatry and psychiatrists arise (the past); What spaces do they occupy (the present)? And, perhaps, being aspirational, what is their future role, in human development (the future)?' This raises questions about the possibilities of responses of public health theorists and practitioners when it comes to the field of 'mental disorder', and also the psychiatrists, what is the history of their practices, the present nature of their relationship with human society and future engagements with health and disability.

Psychiatric diagnosis like no other medical diagnosis Unlike other public health topics, there is a vast number and diversity of disciplines engaging critically on 'mental illness': Is it a social construct (medicalization of deviance); a legal construct (criminalization of difference); a historical construct (imperialistic approach to socially excluded constituencies); or a personal construct (experience of personal distress with associated embodied and mental phenomena)? Is it a construct upholding capital markets, if necessary by applying the rule of the gun, is also another question, that we raise, later in the paper. Such questions do not plague a disease, such as, say, 'malaria', 'pneumonia' or even to a certain extent, 'leprosy'. We just find the bug and contain or kill it.

Is 'mental illness' an 'illness'? As a stream of recent critiques of psychiatry, often by psychiatrists or ex-psychiatrists, has argued, unlike other medical conditions, there are no biological markers for a finding of an object like 'depression' or even a 'schizophrenia'.<sup>3,4,5,6,7</sup> 'Mental disorder' is not a natural kind of illness the same way as a physical disease. Finding the biological and cellular cause of 'mental disease' remains an *Aspiration* of a discipline desiring to be medical; somewhat akin to the Aspiration to *Nirvana* of practising Buddhists; but, alas, without the 'Cause No Harm' principle nor the necessary detachment required for the exercise of clarity and compassion, which are values central to any healing science, and particularly a *mental healing science*.

Researchers from low and middle income countries in the late 1990s and this century have published comprehensive data bases on the rising tsunami of mental disorders in low and middle income countries<sup>8</sup>. Data on 'psychiatric morbidity' had existed since the

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1960s, generated using Diagnostic and Statistical Manual, III.<sup>9</sup> While socio economic features of those studies included basic socio demographics, the literature of the 1990s and later, presented the mental health sequelae of ushering in of the new economic order in emergent capitalist countries, including India. Poverty, gender, migration, displacement, disaster, HIV, conflict, violence and trafficking were linked to the meteoric rise of ‘mental disorders’ and the advocacy for ‘treatments’, rather than advocacy for a profound reform of how we live as a human society.

By 2000, the WHO set the policy ball rolling with comprehensive reports, talking about epidemiological explosion of mental disorders, and advocating governments to develop policies on ‘daring to care’.<sup>10-16</sup> The ‘social determinants and risk’ approach (in the case of women, for example), led, not so much to integration of psychosocial health and wellbeing in empowerment processes; But rather to alarming findings of ‘Common Mental Disorders’<sup>17</sup>. 11% of DALYs and 27% of YLDs were attributed to ‘neuropsychiatric’ disorders. Risk was magnified in primary health care, and 26% - 46% of primary health care patients were said to suffer from CMDs, with predictions and findings of ‘chronicity’ within a 12 month period. Several women’s ailments considered hitherto as public health failures by women’s health activists, now became elevated to primary health care topics, redefined as ‘mental disorder’ requiring psychiatric treatment. For example, ‘chronic fatigue’, ‘vaginal discharge’, ‘genital complaints’ and ‘medically unexplained’ pain were analyzed as masked depression in large sample point prevalence studies conducted in India on women. Such findings led to the development and validation of psychiatric diagnostic tools that can be easily administered at the PHC level, and to advocacy for anti-depressant medications being made available in primary health care.<sup>18</sup>

Such findings led to moral indignation of neglect of an emerging public health topic, by researchers and policy makers, and then to a call for globalizing psychiatry:

*“Borrowing from the lessons of our colleagues in other areas of public health, such an initiative could take the form of a Global Alliance for Mental Health, under the umbrella of the World Health Organization, in which mental health professionals work alongside patients, families, and public health groups. The practical design of policies, programs, and interventions is most likely to be effective when articulated with a moral orientation toward sufferers of mental illnesses. The Alliance’s primary goal*

*would be to spearhead a movement to increase access to evidence-based care, perhaps a 5×10 program to get 5 million untreated patients into treatment and rehabilitation programs by 2010.*<sup>19”</sup>

By the year 2000, in India and in the wake of the Erwadi tragedy (2001), several researchers, policy makers and global bodies advocated ‘filling the treatment gap’ and scaling up ‘mental health treatment’<sup>20</sup> in LMICs.

Global Mental Health Movement writings were based on a moral revulsion concerning those many millions of untreated public health patients in the low and middle income countries and outrage concerning those projected in the media and in field experience of people chained in communities or at traditional healing centers. In a recent significant intervention to the United Nations,<sup>21</sup> the GMHM leaders recommend a target of “service coverage for severe mental disorders will have increased by 20% by 2020 and the rate of suicide will be reduced by 10% by 2020”.

This moral outrage masked some important political economic factors: The social determinants studies which indicated psychosocial stress, distress and disturbance required *psychosocial, social economic and justice* interventions. As the world changed very fast, especially in low and middle income countries, social systems crumbled, equality and justice safeguards disappeared and more war zones appeared on the map. Public health systems failed, a generalization which is a truism in this group. Yet, in the new psychiatric parlance, social, economic, justice and public health failures got algorithmically converted into psychiatric disorder. It is a brand new challenge and a finding that people who are without money, homes, food, education, steady employment, belonging or social status will feel sad; and GMHM is heralding the ‘good news’ that *evidence-based treatment is available*. For an informed and intensely argued critique of ‘Evidence base in psychiatry’, see David Ingleby (2014).<sup>22</sup>

Noting that mental health law in the US (*and also elsewhere in the world*) uses circular or tautological definitions,<sup>23</sup> Summerfield has been a very strong western psychiatric voice against psychiatric diagnoses<sup>24,25</sup> arguing that it is a renewed western cultural oppression. For him, the question, whether we see a social disadvantage as new psychiatric business or as requiring humane social policies and interventions has receded, in the alarmist way in which disadvantaged communities are being psychiatrized. Further, Derek Summerfield (2012) challenges the (RCP, UK) based claim for the World, that 1 out of 4 people in the general population will suffer a mental disorder:

“These claims surely amount to disease-mongering, highlighting an urgent need to deconstruct a naive

reliance on the capacity of screening instruments to generate hard data on population prevalences. Such instruments, with their demand characteristics and tendency to reify subjective consciousness through a mechanistic focus on “symptoms”, produce estimates that insult our common sense and everyday social experience. Structurally unable to assess a whole person immersed in the dynamic complexity of a life and situation, they tend to recast the physiology of normal distress as pathology. We face an epidemic of false positive diagnoses of mental disorder promoted by a mental health industry in which pharmaceutical companies are significant actors”. (p. 520)

The heated critiques of (DSM-5) contest the ‘diagnosis inflation’ and ‘diagnostic exuberance’, leading to the ‘pathologisation of the normal’.<sup>26, 27</sup> Unlike ‘treatment for malaria’, treatment for ‘mental illness’ touches something very personal in its entirety. If markets saw a huge potential in harvesting persons as a whole, then why would they not do so, especially against the context of ‘evidence base’ of an ‘epidemic’? Values of autonomy, identity, individuality, liberty and choice, or ‘selfhood’, are held as core within the ‘psy’ disciplines in ‘inventing our selves’ in new ways through modernity.<sup>28</sup> Achieving a ‘modern self’ is fuelled by modern political economies, which are acted upon not only by doctors and therapists, but also by scientists, politicians, managers, families, lawyers, media, and a plethora of other authorities. In reference to the making of the DSM Hacking (1998) has also referred to the ‘invention’ of the individual self in categorical and pathological terms, as having ‘looping effects’, i.e., ‘providing actionable DSM self identifications for the people taking up such self descriptions’ (Strong 2012): Thus, according to some, we become that which is projected on us, through the DSM, and there is the incredible rise of ‘mental disorder’.

Is this alarmist prediction of mental disorder (and the tools used for those predictions) itself a result of the capitalist order? Many have argued so, in the context of the presently adopted Diagnostic and Statistical Manual, Version 5. Public health diseases, with support of diagnostic, lab, radio, pathology testing, etc., are not so easily subject to the vagaries of market forces as are the psychiatric diagnoses, and once a pathogen is identified, there is usually diagnostic clarity. Absent a pathogen, the process by which little over half a dozen categories of ‘mental illness’ found in early DSM precedents, has now burgeoned into well over 300 diagnoses will remain a ‘public health’ puzzle, only if you neglect the market factor. Well, if there is no biological marker for a particular nominated ‘disease’, it is logical that 2000 diagnoses

is as acceptable as 1; Further, free market enterprise will focus on the 2000 rather than the 1! This kind of mindless medicalization of the human condition has brought dishonour to the American Psychiatric Association, the promoter of the business of the Emperor’s New Clothes for the Millennium.

While the British Society of Humanistic Psychology has issued an open letter to APA, condemning the DSM 5, the American Psychological Association has been more tempered in their critique, reserving its comment to better transparency and imploring APA for keeping ‘best treatment outcomes’ in mind.<sup>29</sup> See, also, NIMH dissociating itself from DSM and DSM based clinical research, but pursuing the super-dream of finding the Mental Disorder Bug<sup>30</sup>, which seems supremely vain and recalcitrant, and indeed, omnipresent and indestructible to any and all psychotropic cure, thereby ensuring evergreen business profits. Following humungous payouts to communities in successful class action suits, psychopharmaceuticals are in ‘crisis’<sup>31</sup>, and do not want to take a market risk, slowly withdrawing from drug research for ‘mental disorder’. See also Das and Rao (2012)<sup>32</sup> and Mills (2013)<sup>33</sup>, among others in the Indian context, for a critique of the creation of psychiatric diagnoses using the business opportunities of globalization. Also see the collection of articles in a recent volume of *Transcultural Psychiatry*<sup>34</sup> where writers have critiqued the psychiatrization of communities, ignoring culturally available supports and resources and creating cultures of sick people, against rising social and economic disadvantage and deprivation, especially for children and the young.

Why something that has never been supported by material evidence, was upgraded to ‘disease’ is a primordial puzzle since many decades. Several other puzzles plague the canvas of ‘mental health as public health’, and I enlist a few of them below. Robert Whitaker<sup>35</sup> has articulated what is by now a classic puzzle in critical psychiatry: If mental health is a disease, and there are good medicines for it, how is it that psychiatric disorder has escalated phenomenally in the last 20 years? In a recent Bapu Trust evaluation, the senior psychiatrist who led the team noted that we should be ‘smoking them out from their dens’ (*referring to people with psychosocial disabilities*); adding that mental illness can only increase and we are not expecting it to go down in communities. But with a public health topic, is this the expected trend, that a public health intervention will actually result in an escalation of the problem and not its containment? As Summerfield has written, “As more resources are provided for mental health services, more are perceived to be needed – an apparently

circular process. Has the mental health industry in the West become as much a part of the problem as of the solution?" Several critical drug reviews in recent times suggest that indeed, psychiatric internment and drug treatment add layers of dis-ease and disability to the original 'finding' of mental disorder<sup>36</sup>. Philip Thomas, a Canadian psychiatrist, reviews psycho-tropics and a variety of clinical studies on effectiveness, placebos, etc. concluding that, while some of the drugs may work in the short term, long term effects are seriously hazardous and life threatening<sup>37</sup>.

Another puzzle, relevant to postcolonial situations (India and some other commonwealth nations), is, If health care and mental health care patients are all patients, why is it that the former have the right to legally consent to treatment, while the latter cannot? While earlier literature in public health had been silent on the role of mental asylums and forced treatment in mental health care, more recent policy papers advocated in low and middle income countries talked about the need to, if necessary, enforce treatment by using a penal law.<sup>38</sup> Within the public health system, people don't charge or accuse each other of being 'diabetic' or 'cancerous'; and surely there exists no 'special protection' health care law which specifically codifies the nullification of the patient's right to consent or their right to live freely in the community. The court of justice issues comes much later in the health system, when maltreatment happens. In mental health, the very 'finding' of 'mental illness' sets up a close medico-legal environment for that person, where justice and care get mixed up.<sup>39</sup> The mental hospital system, which, in the 200 years of its existence, never ascended to the status of 'public health hospital', but have remained 'asylums' (National Human Rights Commission Report, 1999). As described in other papers,<sup>40,41</sup> this is a peculiar situation where in the case of some health care subjects, viz., the 'mentally ill', the authorities first have to arrest them, strip them of all subjecthood and citizenship, and then bring them into an asylum/custodial treatment setting. In the health system, nuanced debates on proof of disease and effectiveness of treatment are possible and do happen, and cases of human rights violations may reach the consumer courts usually with petitions against the doctor. In mental health, the judicial contest begins with the very assertion of a finding of 'mental illness', and it is the patient who goes before the court, not the doctor. This 'Guns and Pills' situation is a very peculiar public health anomaly, defying all medical ethics.

In conclusion, there are huge anomalies in the 'patienthood' of the 'mentally ill' patients which the advocates of the position that mental illness is an illness, like diabetes, must contend with. The larger

medical fraternity have a hugely critical role in this debate, especially in codifying an ethics that will hopefully bridge the anomalies and restore the dignity of persons with psychosocial disabilities.

### References and Notes

<sup>1</sup>NAAJMI and Bapu Trust (2010). *Bill of Rights: Insights from a Mad Pride Campaign, 2005-2010*. Published by National Alliance on Access to Justice for persons living with a Mental Illness and Bapu Trust, Pune.

<sup>2</sup>Report on "Transforming Communities for Inclusion of People with Psychosocial Disabilities: A Trans-Asia initiative", Holiday Inn, Pune, April 30 - May 4, 2013, Pune. Supported by Open Society Foundation, NY. Organized by the Bapu Trust for Research on Mind & Discourse, Pune.

<sup>3</sup>Summerfield, D. (2012). 'Afterword: Against 'global mental health'', *Transcultural Psychiatry*, Special Issue. 49(3-4), pp. 519-530.

<sup>4</sup>Whitaker, R. (2010). *Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs, and the Astonishing Rise of Mental Illness in America*. New York: Broadway Paperbacks.

<sup>5</sup>Fernando, S. (2014). *Culture, Globalization and Mental Health*. London: Palgrave MacMillan.

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## Mental Health, Human Rights and Law

-Amita Dhanda\*

### I. The Central Question

What should the role of law be in the contentious field of mental health and human rights? This paper is an effort to answer this question. The paper looks at the question in terms of the future and examines the past and the present laws only insofar as they are relevant to answering this central concern.

The deliberation on the role of law in the field of mental health and human rights has primarily revolved around the issues of compulsion and choice. Can a person who is perceived to be in mental distress or diagnosed to be mentally ill be compelled by law to obtain treatment? If yes, then can the law privilege one form of treatment over another? Is the sanctioning of forced treatment in accordance with human rights and mental health?

### II. History of Mental Health Laws

Since the middle of the nineteenth century this question has been answered in the affirmative by lunacy legislations which primarily addressed the law and order dimension of mental aberration. This endorsement of force was not dislodged by legislations which adopted a more therapeutic approach, though here, compulsion was sought to make interventions that would alleviate and cure. The lunacy legislations were prompted by the legal need to protect society from the alleged dangerousness of "lunatics". Mental health legislations on the other hand, added to the obligations of social protection, the paternalistic duty of providing care and treatment to persons with mental illness in their own best interest. The argument for force was primarily built around the fact that the affected person by reason of his or her condition was unable to seek the required help. The refusal stemmed from the diseased will of the person and hence need not be deferred to. Compulsion was then advocated in the best interest of the affected person.

Though the motivations of the two kinds of legislations differed, both kinds of statutes attributed certain qualities to persons of unsound

mind, hence the use of force was viewed as unproblematic in both kinds of statutes. Since a link was established between mental state and force, it was important that the process of compulsion should only come into play, if the afflicted person had a mental condition, which was in accord with the statutory definition. Since compulsion should not be used against a person not covered by the definition, hence the other role accorded to law and adjudicators was to monitor the utilization of force and to ensure that such force was not used against persons of sound mind. This role was performed by making legislations which provided for hearings, lawyers, reasons and the entire gamut of fair procedure safeguards before permitting compulsory mental health intervention. These legislations varied on the intensity of fair procedure safeguards; the role that they accorded to mental health professionals; and the manner in which they defined unsoundness of mind. However there was unanimity on using compulsion against persons of unsound mind. **Force was only problematic if it was used against a non-mentally ill person.**

### III. Use of Force in other Areas of Law

The use of force against the non-mentally ill has been delegitimized across sectors. Thus the rule against self-incrimination and the prohibition of torture to extract confessions demonstrate this normative disapproval. On similar reasoning, the provision of treatment to an individual for physical illness without their consent and against their will has been categorized as assault. The quarantine for communicable illnesses is justified on the grounds that it causes the danger it causes to others; and the compulsory administration of any immunization program also stems from the danger an individual person can cause to the health of all. More importantly the universality of the immunization programs accords some acceptance to their compulsion. Even so, particular religious groups or communities have resisted (sometimes even successfully) the administration of certain kinds of medical interventions.

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The above narrative underscores two major points: one, that the use of force against persons with mental illness has been long used and till very recently only, efforts to curb misuse have been made. On the other hand, use of force against non-mentally ill is generally impermissible and whenever used is easily categorized as a breach of human rights. And yet this paper is being written to ask whether the use of compulsion in mental health care and treatment accords in accord with human rights?

#### **IV. Questioning the Use of Force in Mental Health**

There are several developments which make it appropriate to ask this question today. Persons with psychosocial disabilities have initiated a movement-level discourse whereby they have questioned the use of compulsory treatment and care for their psychosocial conditions. Such treatment, they contend, is only informed by prejudice and hence is in breach of their right to equality and non-discrimination.

This challenge substantially influenced the normative content of the Convention on the Rights of Persons with Disabilities (CRPD). The Convention brings persons with mental disabilities within its purview and recognizes that persons with disabilities are entitled to all rights on an equal basis with others. Along with this cross-cutting right the Convention recognizes that persons with disabilities have a right to legal capacity on in all aspects of life on an equal basis with others. It also recognizes their right to liberty, mental and physical integrity on an equal basis with others. The right to informed consent for treatment has to be extended to persons with disabilities on an equal basis with others. The CRPD does not expressly prohibit the use of force in treatment, but such prohibition is a logical deduction if the other rights guaranteed by the Convention are to be duly implemented.

In earlier paragraphs of this paper, it was recounted that compulsion was used to force people to obtain psychiatric treatment. A number of countries have enacted legislations whereby persons with psychosocial disabilities may/could be discharged from hospitals only if they entered bonds whereby they committed to seek outpatient treatment or stay on a particular

drug regime. Failure to fulfil the conditions could result in re-institutionalization. Such like laws did not just compel treatment; they compelled a particular kind of treatment that is western psychiatric treatment or administration of psychotropic medication. Persons with psychosocial disabilities have always accessed or referred to alternative forms of treatment be it of faith healers; temple healing or other culturally grounded interventions. In more recent times, persons with psychosocial disabilities have spoken of the therapeutic power of music, croquet, art and peer to peer interventions. Yet state legislations, even if they acknowledge alternatives (such as the Indian Mental Health Care and Treatment Bill of 2014), they tend to limit themselves to other institutionalized systems of medicine. The non-medicalized interventions, even if they have been documented to help and heal people, are accorded no recognition. Significantly, these alternatives are only accessed voluntarily. People access such care even when no law is compelling them to seek resort to it. If an alternative is assisting an individual to obtain personal resolution, would it be in accord not be a violation of with human rights to dismiss such intervention as charlatanism and force the person to seek institutional psychiatry?

The point being made is that compulsion in the law would not be restricted to seeking treatment, but would also extend to providing a particular kind of treatment. As once the law rules that an individual is a danger to self or others and incompetent to decide, then the incompetence would then extends to both the fact of obtaining help and the kind of help. The law would thus be privileging one kind of treatment over another, without any evidence or basis for doing so. If there is evidence of psychotropic medication and western psychiatric interventions helping people, there is as much testimony in favour of alternative interventions. In making the case for compulsion, continuous reference is made of the to tragedies which occur when compulsory treatment was not offered. However a scientific understanding would require to us to also also refer to the tragedies which occur due to the use of force, often conveyed through . The first-person stories emanating directly from persons with psychosocial disabilities refer to

these tragedies. A history of forced psychiatric interventions from lobotomy, to insulin coma and to electro-convulsive therapy, demonstrates the experimental nature of such treatments. The point is not about the efficacy or otherwise of these treatments; the point is about their forcible administration of these treatments.

#### **V. Human Rights Consonant Mental Health Law**

To return to the question, with which I started this paper. Would legislatively compelled mental health interventions be in accord with human rights? The above brief description of the CRPD, the opinions of persons with psychosocial disabilities and the various alternatives to mental health care would answer this query in the negative. Insofar as law has been resorted to either detain or compel treatment of persons with psychosocial disabilities, does this negative response imply that there is no role for law in the realm of mental health care?.

It is my submission that considering there has been a long history of mental health laws being used to rob persons with psychosocial disabilities of their will and preference, a legal recognition of their autonomy and choice would provide the much-needed protection needed by a to a disenfranchised population. Besides, such a law would be in accord concord with the CRPD and the aspirations of the disability movement. This response would also be supported by the fact that the Special Rapporteur on Torture has sought for special scrutiny of psychiatric detention centers as places of torture due to the force accompanying them. The General Comment on Article issued by the UN Treaty Body on Article 12 expressly includes care and treatment as an aspects of life on which determinations should be made by persons with disabilities on an equal basis with others.

The ouster of force is often put forth as an onset of neglect. To this it may be said that it is not force which provides care, but rather services. In fact, the legislative permission to use force allows governors decision-makers to squeeze the service budget son development of services. The paper is not contending that there is no need for a large bouquet of mental health services. It is also accepting that both mainstream and alternative services have their proponents

and evidently different kind of services have benefitted different kinds of people. If both kinds of services have helped, then there is no case for the legal privileging of any one kind. The law should play a regulatory role by setting the standards by which various kinds of intervention should be provided. The standards should be set in consultation with the practitioners of the intervention and not by its opponents. The presence of these interventions could be declared by the law; however the making of choice should be left to the individual person. A range of mental health interventions, provided as a menu of choices for people who need them, would be in accord with human autonomy and dignity. And alternatives would not be developed if governments can legitimately keep using force. To speak about the inevitability of force for some persons with psychosocial disability is to allow governments a cheap let off.

To conclude, the law has been used till date to permit the use of force in mental health care. Such legal permission was seen as legitimate because persons with psychosocial disabilities were put outside the pale of human rights. The Convention on the Rights of Persons with Disabilities has ended this human rights exile of persons with psychosocial disabilities. This normative change in the CRPD was largely prompted by disability rights activism. The jurisprudence of the CRPD Treaty Body and the UN Special Rapporteurs on Disability and Torture have started to render these norms real in International Human Rights Law. The change in international human rights law would reach the bearer of the rights only if it is duly incorporated in mental health legislations. Thus, existing compulsions permitting mental health laws need a makeover. Just a repeal of existing mental health laws would not be sufficient to usher in a the culture of human rights-consonant mental health practices. To inaugurate such a culture, it is necessary to enact mental health legislations, which recognize the autonomy and choice of persons with psychosocial disabilities;,, oust abjure the use of force; mandate a bouquet of services; and regulate their provision. By enacting such like humane legislations, there is a greater probability of reversing our legacy of force-prompted jurisprudence.

## Coping and Recovery from a Community Perspective

-Tasneem Raja\*

### Stress Coping and its Cultural Influencers

Emotional pain and suffering are a universal experience; how this has been understood has changed over time and is still an evolving process. The expression of emotion is also influenced by myriad factors bringing into play the individual's personality and experience, the context in which the expression occurs and the cultural and normative understanding around expression.

The word 'stress' meaning hardship or adversity seems to have first appeared in the 14<sup>th</sup> Century though without programmatic focus (Lumsden 1981<sup>1</sup>). It was the famous physicist-biologist, Robert Hooke<sup>2</sup>, who in the 17<sup>th</sup> century described stress in a technical manner. He described stress as the area over which load impinged and caused strain. Load was considered as weight on a structure, though this understanding changed as it transitioned to other disciplines, it did influence thinking in conceptualization of physiological and psychological stress and the resonance of this remains in how stress is understood today. Systematic interest in emotional stress seems to have begun around World War II and was referred to as 'battle fatigue'. It was later understood that many other life situations like high performance expectations, transitioning into new roles, loss and bereavement, etc., could produce similar conditions. This was an era dominated by the Behaviorist School of Thought, and empirical evidence was sought largely through Laboratory-based experiments. Understanding of human emotionality has come a long way from a stimulus-response framework and there is indeed a great emphasis on studying the

variables that promote health and coping.

Stress and coping are a complex interplay of an Individual's skill sets, social support and temperament, and the organization of societies and cultures and how it impacts the nature and type of stressors individuals tend to face, and the resources that they can draw upon to cope with these stressors. As communities undergo change, individuals may face newer stressors, and coping will often be influenced by the community's ability to adapt or develop appropriate resources to combat these stressors.

The anthropologist A.F.C. Wallace (1966)<sup>3</sup> defined culture in terms of 'mazeways' that consists of patterns of beliefs, values, and commitments, as well as expected behaviors and resources that shape individual behavior. The pathways within this mazeway may not be the same for different individuals or subgroups and may pan out differently influenced by factors such as gender or caste or class. Add to this other more nuanced conditions such as that of illness and the disability arising out of it. In such a scenario there is interplay of a variety of factors that influences the stressors, the resources available and an individual's capability of drawing upon them in the course of healing and restoring function. Thus, the types of stressors that an individual encounters, and the range of acceptable coping strategies, are determined in large part by an individual's position in the mazeway. A woman from a Dalit family in Eastern UP with a mental illness may have a completely different pathway compared to a man from the same milieu which in turn would differ from the experience of a woman with mental illness from a city like Mumbai. The role that gender, class and caste, plays in determining the course of illness and subsequent recovery are at best poorly understood.

However coping is an iterative process that not only changes over time and through an

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interface of the various factors that impact it. It also modifies the cultural maze way influencing the availability of resources and formation of newer institutional mechanisms for addressing problems of a group or subgroup.

There exists a dynamic balance between the types of stressors typically faced by individuals in a culture and the culturally-sanctioned means of coping with them. Severe stress arises when there is a mismatch between culturally patterned stressors and coping responses. At that point, it is upon individuals within a culture to derive new patterns of problem solving. This often occurs through what Wallace termed 'revitalization movements'.

Human development is replete with such examples some of which have taken the shape of 'movements' that have made a marked shift in the socio-cultural maze way. Women's movement across the world stands out as an eloquent example of how pathways have been reshaped over time. The consumer survivor movement or the 'mad pride movement' is yet another attempt at reshaping pathways for people living with debilitating mental illness and disability.

#### **Non-Formal Healing Practices**

Rituals of various sorts may also be viewed as cultural mechanisms that aid individuals in both emotion- and problem-focused coping. Through their symbolic ability to transform personal and situational states, rituals provide an opportunity for individuals and social networks to cope with various stresses. Funeral rituals help to serve these functions for the bereaved, marriage rituals for newly-weds and rites of passage for individuals undergoing status transitions. Among other things, rituals focus social support on individuals who are undergoing a transition. In general, they provide a sense of closure for one part of an individual's life, allowing him or her to make the transition to a new life. However, resources available in a particular socio-cultural context often tend to get institutionalized over time. While this might ensure a sustained presence

of the resource, it often tends to lose the original thought process on which it was based. Thereby, it runs the risk of turning into a dogma – and takes away the space for individual differences in coping to find the same support within the cultural environ. This may often turn into an additional stressor.

A plethora of practices exist within the non-formal realm in any given culture, some of these traditional practices are deeply entrenched in folk wisdom and in sound theories of mind. These practices provide practical solutions to personal, familial and social problems, and have been integrated into communal life. Despite their popular mass base, there is not enough work to test the premises of traditional practices on the scientific crucible. There is a crying need to decipher this folk wisdom and traditional knowledge, and examine it to augment our limited tool box of therapeutic services. In a highly unregulated environment, just as psychiatric casualties occur so do ones on this front. The Erwadi incident of 2001 only brought into public consciousness the tip of the iceberg of violation and abuse that happens with people with severe disability.

#### **Understanding, Coping and Healing in the Context of Mental Illness**

References of recovery have been noted very early on. One such reference can be traced to the 1830s in Perceval's Experience;<sup>4</sup> however it was only much later that an attempt to define recovery was made.

Recovery from mental illness has been defined as 'a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles - a way of living a satisfying, hopeful and contributing life even with the limitations caused by illness.'<sup>5</sup>

This definition resonates with early descriptions of the process by Emil Kraepelin who in his famous phrase described the recovery process as 'healing with scarring' or 'cure with defect' - such people could get on in the world even if they appeared 'eccentric' and this they did by renegotiating their place

in the world often lowering their aspirations and expecting less from themselves and those around them. (Hopper 2007)<sup>6</sup>

Social recovery is known to be common enough in a variety of settings. Recovery does occur even in very difficult circumstances like large government mental hospitals. Anyone who has worked in a mental hospital in India will know that people in various stages of recovery constitute a part of the extended work force within such institutions and often carry out the responsibility without supervision for years on end. It is difficult to comment if a return of functionality, however compromised it may be, brings about any change in the power equation of the 'patient' and the service providers or care givers.

#### **Facilitating the Recovery Process**

It is important to look at how social framework facilitates recovery of the returning 'patient'. As any debilitating condition, a severe mental disorder, a drug or alcohol addiction, progresses, an individual slowly gives up function across various roles he/she played within the rubric of family and society - yet life carries on - others in the rubric take over this function. There is no automated process that changes this rubric to reintegrate this individual as wellness returns. Experience of people who have worked with families of persons with severe mental illness and chemical dependency conditions indicates that the micro system of the individual readapts to the 'sick role' and intensive work is needed in reshaping the system to the 'new' role of returning functionality. This however may not be an easily accomplished process. In low resource settings there is not enough work even with the 'identified patient' and scarce work exists around micro systems such as families, care givers and employers.

For a vast majority of people living with a mental illness, the illness phase is not a constant and is interspersed with phases of wellness - at least from the stand point of the illness. However does this allow an automatic restoration of social status and decision making functions that are normally accorded to any adult? Mental illness alters

the dynamic in a variety of relationship, often leaving behind traces of the 'caregiver' and 'patient' roles that linger on even after years in recovery. Most people in recovery from addiction will narrate experiences of their significant others 'suspecting' a relapse at the slightest change in a behavior pattern

In the context of the larger socio-economic framework, it appears that the rural milieu with its traditional agrarian economy is better able to accommodate a returning wellness role than is a more tightly controlled labor market. It stands to reason to assume that chronically sick roles perpetuated by a micro system interplay with the large social and economic reintegration of an individual in recovery. So is reintegration a simple function driven by economics? Yet again there is a great deal of the unknown around the variables that promote the process.

#### **Recovery and the User/Survivor Movement**

The Mad Pride Movement<sup>7</sup> towards the end of the 20<sup>th</sup> century brought the concept of recovery from a mental illness to the forefront and marked a change in the articulation of the concept and organization of services. This movement arose out of the civil rights ferment of the 1960s and 70s and the personal histories of psychiatric abuse experienced by some ex-patients. The subtext from this vantage point largely seems to echo the rhetoric that patients are good, doctors are bad, family members - however well-intentioned - botch it up and become accomplices to the physician. This movement geared itself to support each other and grip on to a range of alternative means of promoting wellness.

The fellowship and support provided by this movement marks a very important milestone in reshaping the pathway for people living with an illness. Closer examination, especially in the Indian context, reveals that we are perhaps yet at the stage of concept and tends to have a tokenistic inclusion of people. A systematic approach is needed to ensure that the most vulnerable do not slip through the cracks and the movement of the

masses does not turn into a representation of the advantaged and the elite. Though the movement and collectivization of people living with HIV and AIDS emerged at about the same time, its reach and vibrancy has a lot of lessons to draw upon.

The user survivor movement is of course not a single voiced entity and this reflects in part, its ability to accommodate different opinions. It would be important to study and document how the movement retains space for individual well-informed choices and how those choices influence the pecking order within its members.

### **From a Movement to Operationalization of Recovery**

The recovery movement managed to establish the need to relook at power equations and pathways that will alter the trajectory of experience of a person with severe mental illness and disability. However, translating this into an operational model brings into question aspects that a movement need not answer. What are the standards and specifications of a recovery-oriented model? How does one address fidelity to these standards? What is the regulation required and finally how does it measure up on costs. Even prototypes based on this are few and far between and there is a diverse opinion on moving from prototype to scale. In this, user/survivor and caregiver involvement, remains an ideology at best.

One of the most plausible goals spoken about in the recovery movement is the engagement of the person living with a mental illness in charting his or her own care - this seems eminently possible to do specially during the phases of wellness that the person has. The individual has a choice to make. It is this space that really needs to be respected. Taking away any workable option from the person or applying an option that may not have enough evidence around it is not just unfair but unethical as well.

### **Concluding Comments**

Building healing and recovery for the most marginalized calls for very hard repair work

on a social fabric that remains tattered. Bringing in the four base requirements of connectedness, hope, identity and empowerment that hallmark recovery, calls for widening our horizons and being inclusive to development arenas that may have traditionally been outside the care provision spectrum. A varied set of skills will need to be harnessed to build a recovery-centric approach. Further work is needed in taking a critical look at the recently launched Mental Health Policy announced by the Government of India, and in using the opportunity to truly build a movement of people living with a mental illness, that is inclusive and representative. Work is also needed with care givers who remain a largely unattended entity from the healing standpoint. Yet there has never been as much interest in mental health before as today. The coming years will only witness a sharper implementation of policies and programs scrutinized and modified by an increasing pool of actors.

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### **Endnotes**

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<sup>7</sup>Mad Pride is a mass movement of the users of mental health services, former users, and their allies.

## Does Community Mental Health Really Engage the Community?

*Critical Perspectives from Local Healing Practices*

*-Shubha Ranganathan\**

### Introduction and Background

The paper seeks to understand the complex connections between different actors concerned with mental health care in India, by exploring transactions between local healing practices and global discourses of mental health. More recently, religious shrines in India have come under scathing criticism from various quarters for their 'superstitious' and 'regressive' practices, particularly following the Ervadi accident in 2001, when a fire broke out in a mental asylum affiliated to the Ervadi dargah (in the South Indian state of Tamil Nadu), killing several mentally ill inmates who were chained to their beds. The ensuing public outrage over the incident resulted in both state surveillance over healing shrines, as well as pressure on the state to step-up public mental health facilities (Davar and Lohokare 2009). Healing shrines were now at this point considered 'unlicensed' mental asylums, and pilgrims residing in them were labeled 'mentally ill,' ignorant villagers in need of 'awareness' and (medical) intervention. Accordingly, they were transferred to the 'appropriate' venue for mental distress, namely, state mental hospitals.

Thus, the state response to healing shrines has largely been that of delegitimation. In general, mainstream psychiatry in India is characterized by a strongly medicalized approach, where alternative rationalities and 'unscientific' local healing practices are dismissed as 'superstitious'. At the same time, at the international level, global mental health discourses are now considering healing shrines as potential sites for implementation of low-cost community mental health initiatives. Given its current focus in scaling up mental health services in low and middle income countries, the availability of large number of 'mentally disturbed' individuals in residential healing shrines makes them ideal locations for

community-based approaches. Thus, a report by the World Psychiatric Association describes psychiatrists and traditional healers as 'unwitting partners in global mental health' (Inciyawar, Wintrob, Bouchard & Bartocci, 2009). Along the lines of community-based approaches that advocate the integration of mental health services in primary care settings, advocates of the Movement for Global Mental Health speak of integrating mental health with indigenous healing practices.

It was against this background that one such community mental health program was initiated within a popular healing shrine in India, following the Ervadi incident. Through the establishment of a modern medical clinic with the shrine, the state endeavored to 'modernize' and 'sanitize' these 'irrational' spaces, which could not be shut down due to religious beliefs. In the clinic, psychiatric treatment is provided to pilgrims residing in or visiting the shrine. The clinic is run by an NGO in collaboration with the state mental hospital. This paper presents illustrative examples of the pattern of diagnostic consultations and treatment approaches within the clinic in order to question the celebrated approach of blending modern medicine and traditional healing, and to raise questions about the increasing medicalization of distress and over-reliance on pharmacological solutions for suffering.

### Snapshots from Community Psychiatry

The following cases reflect the widespread prevalence of a medicalized perspective of mental illness in the community psychiatric clinic, where mental health care becomes reduced to an administrative exercise of distributing medicines. The routinized pattern of conversations between the psychiatrist and patient, where a list of six to ten questions were asked by the psychiatrist in a diagnostic interview that typically lasted a couple of minutes, reflects the emphasis on symptom identification and medication management. An

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affirmative response to any of these questions was considered sufficient grounds for prescribing a cocktail of anti-depressants, anti-psychotics, and anxiolytics.

**Case 1: Gita's 'headaches' as a Psychiatric Problem**

Gita's case illustrates how ambiguous symptoms such as 'headaches' were transformed into psychiatric symptoms that warranted pharmacological intervention. It was her first visit to the clinic.

Psychiatrist: What is the problem?

Gita: I get headaches.

Psychiatrist: Since how long (have you been having them)?

Gita: One month.

Psychiatrist: Does it hurt more in the morning or evening?

Gita: Evening.

Psychiatrist: Are they accompanied by nausea or vomiting?

Gita: Yes, nausea.

Psychiatrist: How is your sleep?

Gita: I cannot sleep when I have a headache.

Psychiatrist: Do you have any thoughts/worries (vichaar)?

Gita: Yes.

Psychiatrist: What kinds of thoughts?

Gita: I have worries (chinta) – (leaves off midway)

Psychiatrist: Do you feel sad?

Gita: Yes.

Psychiatrist: (looking up) What do you feel sad about?

Gita: (Smiling, hesitating) Nothing – about the pain . . . (leaves off)

Psychiatrist: About anything else?

Gita: (Smiling) No.

Psychiatrist: No? You have no tension?

Gita: (Smiling) No.

Psychiatrist: Okay. Don't worry too much.

Based on the above conversation, Gita was diagnosed with migraine + major depressive disorder. (Major depressive disorder is the technical term for clinical depression.) She was prescribed an anti-migraine drug (flunarizine) and an anti-depressant (amitriptyline).

Two features stand out in the above conversation. The first is the brusque nature of consultations which is by no means unusual and a standard feature of psychiatric practice in India (Halliburton, 2009). But more pertinently, Gita's case shows how common experiences such as 'headaches' and 'sadness' become reframed as indications of psychiatric distress ('major depression').

**Case 2: Parveen's 'Somatization'**

Parveen also complained of headaches, which she had had since four years. The phrase she used was "dimaag dukhta hai". She also complained of accompanying nausea and neck pain. When asked if she had difficulties with her vision, she responded that at times she found she could not see anything – everything would black out in front of her. When does it hurt more? The psychiatrist asked. "It hurts more when I have fights", she answered. "So, I try not to fight." She also said it increased when she was worried (*vichaar karna*).

Although I do not have a verbatim record of the psychiatric consultation, I noticed that Parveen appeared to answer with a yes to any question put to her. As new symptoms were posed to her, her list of complaints accordingly increased. Thus, when asked if she had any other pains, she complained of pain in the limbs. When asked if she had any memory problems, she said: "Sometimes I can't remember what I ate in the morning or the (previous) night. Sometimes I can't even remember my name!"

Confused by her vague assortment of symptoms, the psychiatrist eventually gave a diagnosis of 'somatization', a term that refers to the expression of psychological distress in the form of physical complaints. (Although not a legitimate psychiatric diagnosis, 'somatization' is often used in India as if it were one.) He reasoned that her headaches must be psychological in nature, and that therefore

she would benefit from mild anti-depressants. He elaborated:

*“She is a middle-aged woman from a minority community (Muslim). They usually show somatization at this age. We regularly see women from this community present themselves with the same symptoms. Half of these patients have depression.”*

When I wondered aloud about the connections postulated between ethnicity and symptomatology, he explained that her symptoms were “culture-specific” adding:

*“One’s (psychiatric) practice depends on the region. If we practice in metro cities, patients will present only those symptoms which are required to make a diagnosis. As their education level increases, patients become more aware about diseases. But in rural areas, there are issues of literacy and minority communities.”*

What he meant was that Parveen’s vague and nebulous symptom picture was a reflection of her lack of psychological literacy, and not the absence of psychiatric distress. It almost appeared as if the onus was on the *patient* to offer only the ‘relevant’ complaints that would enable the psychiatrist to arrive at a diagnosis!

Parveen’s case illustrates the process by which physical complaints were fitted neatly within psychiatric diagnoses, through the category of ‘somatization’. Although theories about somatization have a long history in psychological and psychoanalytic thought, they have also been criticized for their ethnocentric assumption that people in ‘non-western’ cultures are more likely to ‘somatize’ their distress, due to their poor language sophistication and inability to articulate emotions in psychological idioms (e.g. Scheper-Hughes, 1992). Yet, what is often ignored is the very real physical problems that the poor in India often have to contend with, such as malnutrition, anaemia, overwork, and fatigue, to name a few, which very likely give rise to long-term somatic stress. In the case of Parveen, although the psychiatrist conceded that her headaches could be due to anaemia, since “70-80% of women from this class and community

are anaemic”, he still maintained that she would benefit from a dose of mild anti-depressants. Clearly, for him, Parveen’s somatic complaints were undisputed indications of underlying psychopathology, which, according to him, she was almost destined to suffer from, given her religious background and gender. Unfortunately, the permeation of such ethnocentric and sexist assumptions in expert speak is all too common in psychiatric practice (Addlakha, 2008).

### **Case 3: Abdul’s ‘abnormal’ Sleep Pattern**

One of the most common complaints in the clinic was sleep difficulties and it was customary for almost all patients to be prescribed medications of sleep, regardless of the nature of their problem. Thus, when Abdul, who worked at the shrine as a healer, presented himself at the clinic complaining that he “could not sleep”, he was instantly put on sleep medication. On further probing, he explained that he would be up all night attending to work-related international calls, going to bed at dawn and sleeping through the day. He explained: “This is a question of my livelihood. My clients are all either in America or London. I cannot afford to call them, but I have to be prepared to receive their phone calls.” Clearly, Abdul’s sleep routine was a matter of choice. Yet, the clinic staff insisted that medication was required to alter his sleep cycle, and Abdul dutifully arrived at the clinic to pick up his monthly supply of sleep medicines.

Similarly, Roopvati, when asked about her experience of the clinic, explained that the medication essentially enabled her to sleep:

*What is there to say? Here, they make our case papers, give us medicines – that is all. They have not told us what the problem is. They just give us medicines. We can sleep at night with those medicines. We have no tension, we are able to eat. That is all.*

For patients, the clinic served as a ‘medicine pick-up point’ that disbursed free ‘sleep medicines’. In fact, clinic staff were often willing to ‘hand over’ the medicines to relatives and friends who came in lieu of the patient, reasoning that most psychiatric problems were long-term in nature, requiring

maintenance on the same drugs. They were even willing to post medicines for a few months to patients who lived far away. One senior official justified this practice saying:

*If patients have symptoms of paranoia, their insight will be impaired and they may not turn up for consultations. It is particularly important to continue psychiatric medication since if they are discontinued, relapses may occur and patients would become difficult to manage at home; they may become violent and even self-harm.*

Similarly, another official overseeing the project explained:

*If a mentally ill person becomes violent, it is easier to give medicines and make them sleep. You cannot tie them up because that is a violation of their human rights. But you can give them medicines.*

Despite these assumptions about the inherent dangers posed by violent psychiatric patients, what the officials failed to recognize was that most cases at the clinic were related to everyday problems such as vague physical complaints, sleep difficulties, and abnormal 'thoughts' and not dramatic violent behavior. Yet, for the NGO, these practices of reaching medicines to patients through whatever means possible were presented as evidence of the humanity of the staff in the clinic. Drawing on a narrow conceptualization of 'human rights' which fuelled the discourse of 'care',<sup>1</sup> the NGO maintained meticulous records of the number of clients serviced by the clinic, which were displayed in impressive bar diagrams in the office. It did not matter that most of these patients were maintained on the same drugs for years. Clearly, in this case, the concept of 'community' is understood merely in a statistical sense to refer to a collection of individuals.

### **User/Survivor Critiques of Mental Health Practice in India**

One of the most distinctive features about mental health services in India is the heterogeneity of approaches and wide range of models employed. In this very conference as well, many examples will be presented, illustrating the plurality of

approaches. Given this diversity, any easy generalizations about 'community mental health' in India are virtually impossible. The increasing involvement of NGOs in implementation of state and local mental health programs (Padmavati 2005; Patel and Thara 2003) further adds to this heterogeneity. Often, however, their role remains limited to that of inculcating 'awareness' about mental disorders and emphasizing the importance of 'compliance' with the treatment regimen (Chatterjee, Patel, Chatterjee and Weiss 2003). Although the community mental health movement originally sought to deinstitutionalize mental health care and extend the reach of services to the wider community,<sup>2</sup> at the level of implementation, state-led community programs tend to focus largely on the provision of essential psychotropic medicines in primary health care institutions (Isaac 2012). This is reflected in the vision of the National Mental Health Programme (NMHP), described in one policy document as ensuring "the availability and accessibility of minimum mental healthcare for all", where 'minimum mental healthcare' is typically understood in terms of the availability of essential psychotropic drugs.<sup>3</sup> Thus, a narrow understanding of mental health care prevails, based on a medicalized understanding of distress and suffering.

Accordingly, user/survivor perspectives have called for a paradigm shift in community mental health, so that non-pharmacological and psychosocial interventions are incorporated (Davar, 2012). Although the community mental health movement was imagined as a decentralized alternative to the clinic approach, with the potential for heightened community participation, in actual practice, community mental health programs have often achieved nothing more than a shift in the location of drug delivery. Davar has therefore argued, "[w]hat happened in the hospital now happened outside the hospital", exemplified in the 'visit-camp-prescribe' model that became widespread (Davar 2002, 21). Similarly, Jain and Jadhav (2009) found that the community mental health program run by the District Mental Health Program (DMHP) in Uttar Pradesh became reduced to an administrative

exercise of procuring and disbursing psychotropic medicines despite ambitious goals of ‘community participation’ and ‘decentralization’.

Finally, user/survivor perspectives have questioned the medical model of mental illness, which frames psychosocial distress as a disease that falls within the domain of psychiatry. Taking inspiration from the disability movement in India which has moved from a medical model of disability to a social paradigm of distress (Addlakha, 2013; Mehrotra, 2013), user/survivor researchers have sought to reframe psychiatric distress as ‘psychosocial disabilities’ (Davar, 2008). Such a perspective recognizes the disabled as not just passive victims but experts who can contribute to new knowledge.

In the Indian context however, the field of mental health has seen little mobilization from users of mental health services, unlike the disability movement, which has made a concerted effort to include the perspectives of those who are directly affected by national and state-level health policies and programs. As Davar (2002) alerts, the lack of people-based movements in mental health carries the danger of leading to even more psychiatrization of distress and discounting of personal experience on the grounds that psychiatric patients are of ‘unsound mind’.

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### Notes

<sup>1</sup>Much more can be said about whether this ‘right to care’ for mental illness overrules the question of informed consent and justifies forced institutionalization and treatment. For a sample of the debate, see the articles on the Mental Healthcare Bill of 2010 in the *Economic & Political Weekly* by Davar (2012), Gopikumar and Parasuraman (2013), and Patel (2013).

<sup>2</sup>While the goal was to shift mental health care from the clinic to the community, this was only possible due to advances in psychotropic drugs that dramatically reduced in-patient stays and allowed for treatment of psychiatric distress on an out-patient basis.

<sup>3</sup>This is available on <http://mohfw.nic.in/WriteReadData/1892s/9903463892NMHP%20detail.pdf>.

## Mental illness: Diverse Perspectives, Partial Truths and Imperfect Solutions

-K. S. Jacob\*

I must admit that I was surprised when the Organizing Committee of the MFC Annual Conference 2015 asked me to write a background paper on mental illness based on my experience and practice. Writing for the Bulletin with its nuanced debates, diverse readership, varied disciplinary backgrounds and divergent perspectives is a challenge.

### Biomedical Perspectives

It has been over thirty years since I joined the department of psychiatry, at the Christian Medical College Vellore, after completing my training in medicine. The early 1980s were an exciting time for psychiatry. The Diagnostic and Statistical Manual (DSM) III, with its operational criteria for diagnosis, had revolutionized the discipline.<sup>1</sup> Its focus on inter-rater reliability and its promise of valid biological categories in the future were enticing for young psychiatrists attempting to understand mental illness. Diligent students began to study the diagnostic scheme, memorizing criteria and many new labels.

A few years later, the journal *Nature* had published articles, which identified and described specific genes for bipolar disorders and for schizophrenia, which run in certain families and communities.<sup>2</sup> We believed that such recognition of etiology would soon lead to specific therapy, which would reverse pathology and cure disease.

The explosion in newer antidepressants and antipsychotic medication added to the anticipation of therapeutic success.<sup>3</sup> No longer would people with mental illness have to cope with treatment-resistant symptoms and distressing adverse effects of medication. We even swallowed the pharmaceutical industry's public relations line about monoamine deficiency for depression and dopamine hyper function in schizophrenia and justified our indiscriminate use of psychotropic medication. We adopted physical illness models for mental illness and distress and were comfortable with our refuge in scientific psychiatry and medicine. Conflicts over gold standards, validity of diagnoses, syndrome thresholds, heterogeneity within categories and the variability of treatment response were all swept under the carpet.<sup>3</sup> The role of stress and coping styles were discounted. DSM firmly placed many unresolved issues on the backburner - it became the new standard.

Newer psychotropics soon flooded the market. They did not have troublesome side effects. Antidepressants became the treatment of choice for all types of depression. There was neither the need to speculate on the role of the precipitating stress and coping strategies nor the requirement to manage them with psychotherapy.<sup>3</sup> The ease of prescribing medication and the investment of time and effort required for cognitive

therapy meant that psychological interventions were often praised but seldom practiced. Fluoxetine became the panacea for loneliness, relationship difficulties, interpersonal conflicts, inability to cope with day-to-day stress, and the like. Why would anybody spend time on psychotherapy when these wonder drugs were said to elevate the patient's mood irrespective of its cause and context?

The pre-liberalization 1980's in India posed many challenges to young psychiatrists who were studying possible career options. Should one choose biological over social psychiatry? However, how could one settle for second-rate biological research, which essentially replicated western evidence? Alternatively, should one follow the many academics who passionately argued for biological solutions while writing prescriptions was their only claim to such nirvana? Was pursuing social approaches to mental illness and its treatment, considered an inferior option, going to pay rich dividends in the long term?

After much soul searching, I decided to pursue a career in epidemiology, which allowed for an academic focus, while continuing clinical practice. It allowed for the study of psychosocial risk factors and approaches to mental illness. Complex study designs and convoluted statistical modeling allowed one to believe that I was still within scientific medicine. I then applied for a doctorate in epidemiology at the Institute of Psychiatry, London (The Maudsley). Two years and two PhD proposals later my supervisor suggested that I also study anthropology as it would be easier to get funding for cultural studies and that it would justify my training and return to India.

### Population and Primary Care Perceptions

The three years in London raised more questions than answers. My work in primary care showed me clearly that tertiary care concepts did not fit primary care practice.<sup>3</sup> Surveys of public attitudes suggested that social adversity was seen as the cause, people were reluctant to consult their General Practitioners (GPs), counseling was the preferred treatment and antidepressants were viewed with suspicion as they were considered addictive. GPs who believed in psychological therapies for depression tended to prescribe lower doses of antidepressants for shorter periods, or not at all. Marked variability of counseling in busy GP settings meant limited availability of psychological intervention for emotional distress. The few antidepressant trials in primary care were done on subjects with severe depression, while many patients seen by GPs had mild forms of the condition. Most physicians working in primary care while accepting the medical model of depression during discussions, employed psychosocial models in their practice.<sup>3</sup>

The long journeys on the London Underground from the general practice in Ealing to the Institute of

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Psychiatry at Denmark Hill were a time for reflection. My experience differed from the views I heard from academic psychiatrists. They emphasized medical models of depression and found it difficult to understand why GPs could not recognize and treat depression. I buried my conflicts and completed the doctoral thesis employing standard psychiatric perspectives and arguments.

I returned to Vellore and started liaison work in primary care. Weekly clinics, regular lectures and several research projects led to much interaction with physicians. My unresolved conflicts resurfaced. Majority of physicians subscribed to non-medical perspectives.<sup>4</sup> Physicians see milder and mixed presentations and short duration illnesses, often associated with psychosocial adversity. Such conditions often respond to placebos or commonly remit spontaneously. Consequently, physicians refuse to count symptoms, sans context, or employ labels with disorder suffixes as these emotional states reflect distress rather than disease.<sup>5</sup> The psychiatric classifications recommended for primary care were unheard of in medical settings. There was no escaping the conclusion that the reality in primary care differed considerably from that found in psychiatric facilities. There was no option for primary care physicians but to reject tertiary care perspectives about mental illness or at least not apply them in their practice. The cross-cultural divide was between primary and tertiary settings rather than between geographical regions and cultures.<sup>6</sup>

### Psychiatric Classifications

The past three decades saw many revisions of the DSM (III, IIIR, IV, IV-TR, 5 and IV for Primary Care) and the International Classification of Diseases (ICD 9, 10 and 10 for Primary Health Care). However, the passion for diagnostic criteria in tertiary care had waned. Many questioned the wisdom of these frequent and minor changes that were often not based on hard evidence.<sup>7</sup>

Classifications are not absolutes and are constructs that mirror the understanding of the period.<sup>8</sup> They help mental health professionals communicate and are useful tools for statisticians and public health administrators. They aid in reimbursement for insurance companies. They provide pharmaceutical companies who need "homogeneous populations" on whom to carry out drug trials. They also help individuals find terms to communicate their distress, seek support and treatment. Categorizations, which employ symptom counts, use day-to-day phenomena and discount context also tend to medicalize normality.<sup>9,10</sup> The realization of the complexity and multiple dimensions of mental illness also meant that the dream of finding valid psychiatric categories receded into the distant future.

### Public Mental Health

My work in primary care led me to examine issues related to public health policies for India. Even the most ardent public/community health specialists tended to concentrate on curative medicine albeit through outreach clinics. They employ emergency driven curative strategies rather than focus on long-

term public health solutions.<sup>11</sup> While medicine had appropriated the public health goal, which it cannot deliver, politics and finance, which have the ability to provide for such approaches, pay lip service to these aims while keeping them on their back burners.<sup>12</sup>

### Community Care

India accepted the plans of the World Health Organization and aimed to incorporate mental health components into primary care. Despite 40 years of effort and the current Mental Health Gap Action Program (mhGAP campaign),<sup>13</sup> the country is nowhere near providing for such care in the community. Physical health priorities, poor infrastructure, overburdened health systems, inappropriate training of personnel, professional apathy, and limited finances markedly limit efforts to provide mental health treatments in primary care.<sup>14</sup> The lack of ability to restructure medical and nursing education, revamp psychiatric training, revitalize primary care and renew political pressure means that new programs, which sleekly package failed approaches, are also doomed to failure.

My stints at the different committees of the World Health Organization, the Planning Commission of India, National Rural Health Mission and the Central Council for Health were revelations. "Experts" are nominated to these supposedly elite panels only to be silenced by their co-option to these committees. Finance and politics trump medicine and public health every time.

### Evidence-based Medicine

Nevertheless, mhGAP is very sophisticated compared to past approaches. It employs research evidence of proven successes in low and middle-income countries. However, a closer look at evidence-based medicine suggests that the evidence fades over time and is not generalizable.<sup>15</sup> For example, established evidence that the newer antipsychotic medication is superior to conventional drugs took over a decade to disprove. The questions of efficacy ("Can it work?"), effectiveness ("Does it work in my practice?") and efficiency ("Is it worth it?") are often not clearly elicited.<sup>15</sup> The prohibitive cost of generating evidence gives the pharmaceutical industry monopoly over evidence-based medicine. The industry softens the Indian market by sponsoring physician education, advertising and selling newer drugs without doing effectiveness or efficiency trials in India.

My slow disillusionment with pure biological approaches to mental illness coincided with my association with the CMC-Anveshi Collective. The discussions and meetings, which resulted in the book,<sup>16</sup> allowed me to see the world through the humanities and social science frameworks. Issues related to politics, power and economic systems and their distortion of democracies and their impact on science and on evidence base became much clearer. It allowed me to see clearly the politics behind PTSD and encouraged me to forcefully argue the need to reclaim primary care from tertiary perspectives.<sup>17,18</sup> It also brought into focus user points of view. It allowed me to see

the complexity of mental illness and the impact of disciplinary backgrounds on understanding.

### Culture and Mental Illness

I had done a series of investigations into explanatory models (EMs) (defined as "... the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process.") of diverse kinds of mental illnesses over the past two decades. While the investigations were originally designed from the standard psychiatric perspective, they did contain anthropological approaches, which documented patient beliefs about illness and its treatment. Our data suggested that people hold multiple and contradictory models for their illness (e.g. disease, degeneration, deficiency, sin, punishment from God, karma, black magic, etc.).<sup>19</sup> These conflicting beliefs are held simultaneously and people concurrently and sequentially seek biomedical and non-medical treatments. They visit hospitals and use modern medicine and also visit temples/mosques/churches and seek healing from traditional and faith healers. For example, while they may believe in black magic as the cause of their illness, they are also prepared to take medication to reduce symptoms and distress.

I was also looking for alternative perspectives to the medical model of insight in people with psychosis. The traditional view within psychiatry is that insight predicts the course and outcome of psychosis. It argues that congruence with the biomedical model of psychosis results in compliance with medication and consequently produces better outcomes. However, our data documents that illness variables (e.g. severity, functioning) rather than insight at baseline predicted longer-term outcomes.<sup>20</sup> We have argued that good insight (i.e. congruence with biomedical model) suggests milder disease while severe disease by definition precludes the acceptance of the disease model.<sup>21</sup> People with disabling symptoms and distress and who did not respond to treatment tended to hold non-medical explanations, while those who improve with medication tend to accept biomedical models of illness. We have postulated that "insight" is secondary to interaction between course and progression of illness on one hand and local culture and social environment on the other.

Most societies are pluralistic and offer multiple, divergent and contradictory explanations for illnesses. These beliefs systems interact with the trajectory of the person's illness to produce a unique personal understanding, often based on a set of complex and contradictory EMs. Like all EMs, insight provides meaning to explain and overcome challenges including disabling symptoms, persistent deficits, impaired social relations and difficult livelihood issues.<sup>21</sup> The persistence of distress, impairment, disability and handicap, despite regular and optimal treatment, call for explanations, which go beyond the simplistic concept of disease. People tend to choose EMs, which are non-stigmatizing and which seem to help explain and rationalize their individual concerns. The frequent presence of multiple and often contradictory EMs, held simultaneously, suggest that they are pragmatic responses at coping.

The results advocate a non-judgmental approach and broad based assessment of EMs of illness and their comparison with culturally appropriate beliefs, attributions and actions. The biomedical model of illness should be presented without dismissing patient beliefs or belittling local cultural explanations for illness.<sup>21</sup> Clinical practice demands a negotiation of shared model of care and treatment plan between patient/user and physician perspectives.<sup>22</sup> The diversity of patients, problems, beliefs and cultures mandates the need to educate, match, negotiate and integrate psychiatric and psychological frameworks and interventions.<sup>22</sup> It calls for multifaceted and nuanced understanding of "insight" and explanatory models of illness.

### Recovery Model

These findings tie in well with the "recovery model" of mental illness.<sup>23</sup> The concept of recovery is about staying in control of life rather than the elusive state of return to premorbid level of functioning. It does not focus on full symptom resolution but emphasizes resilience and control over problems and life.

While there is no single definition of the concept of recovery for people with mental health problems, there are guiding principles, which emphasize hope and a strong belief that it is possible for people with mental illness can regain a meaningful life, despite persistent symptoms. Recovery is often referred to as a process, an outlook, a vision, a conceptual framework or a guiding principle. There is evidence to suggest that self-management strategies based on the recovery model may have more value than models based on physical health.

The recovery process provides a holistic view of people with mental illness that focuses on the person, not just their symptoms.<sup>23</sup> The process calls for optimism and commitment from people with mental illness, their families, mental health professionals, public health teams, social services and the community. The recovery process is profoundly influenced by people's expectations and attitudes and requires a well-organized system of support from family, friends or professionals. It also requires the mental health system, primary care, public health and social services to embrace new and innovative ways of working.

### Shared and Negotiated Approaches

The universal models employed by psychiatry deemphasise the role of context and culture. Despite highlighting the impact of culture on psychiatric diagnosis and management in the DSM-5, most of the changes suggested remain in the introduction and appendices of the manual.<sup>22</sup> Nevertheless, clinical and biological heterogeneity within phenomenological categories mandates the need to individualise care. Despite its attempts at "patient-centered" medicine, psychiatry continues to be undergirded by the "doctor-centered" biomedical model. Social and cultural issues are often on the back burner. In fact, many issues related to patient beliefs about causation, impact, treatment and outcome expectations are never systematically elicited, as they are not essential to diagnosis and classification. This results in a neglect of

large swathes of information about the patient's background, concepts, culture, and local reality.

Patient experience and narratives are trivialised and the biomedical model is considered universal and transcendental.<sup>24</sup> The need to elicit patient perspectives, evaluate local reality, assess culture, educate patients about possible interventions, and negotiate a shared plan of management between patient/user and clinician is cardinal for success.<sup>22</sup> The biopsychosocial model, which operates within a paternalistic physician-patient relationship, needs to move towards a shared approach, within a more equal patient-clinician partnership. Respect for diverse points of view and informed consent are essential to success of such partnerships.

Psychiatry, when divorced from the cultural and psychosocial context, with the naïve use of universal DSM categories and criteria, reflects poor clinical practice. Similarly, the unsophisticated use of these categories in biological research has also proven to be unproductive. The heterogeneity within diagnostic groups and within cultures, regions and populations demands that clinicians understand local and individual reality, match strategies, and choose the best treatment options from a diverse therapeutic armamentarium.<sup>22</sup> There is a need to bridge the disease-illness divide.<sup>25</sup> The inadequacy of individual and disciplinary systems of beliefs about mental illness suggests that there is a need for new synthesis, albeit eclectic, embracing the essence of contemporary biology and humanism.

### Conclusions

The divergence of perspectives, disciplinary straightjackets, partial comprehension of issues and the incomplete and imperfect solutions on offer all demand humility from all those involved in the care of people with mental illness. It calls for a shared perspective, which should be negotiated with people with mental illness and their families.

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## Mental Health Budgets – a Brief Note

- Ravi Duggal\*

Mental healthcare related budgetary allocations are not separate line items in the public budget and hence are difficult to compile. What we get in budgets is direct allocations to mental health institutions and this we see is about 1% of the Centre's budget on health and about 1.25% in a state like Maharashtra (Table 1).

**Table 1: Allocations to Mental Health in Union and State Budgets in Crores INR (% to health budget)**

|                                       | 2012-13 A/C     | 2013-14 RE      | 2014-15 BE      |
|---------------------------------------|-----------------|-----------------|-----------------|
| Union Budget                          | 251.31 (0.99%)  | 310.61 (1.13%)  | 317.80 (0.90)   |
| Maharashtra Budget                    | 77.94 (1.31%)   | 77.77 (1.10%)   | 93.49 (1.28%)   |
| National Estimate direct allocations  | 1114.60 (1.23%) | 1118.45 (1.11%) | 1405.80 (1.17%) |
| National estimate direct and indirect | 2120 (2.36%)    | 2200 (2.2%)     | 2500 (2.08%)    |

Source: 2014-15 Expenditure Budgets of Union Government and Maharashtra state

Using the Union and Maharashtra budget allocations we arrive at a rough national estimate of about 1400 crores INR being spent directly on mental health by the public exchequer. Apart from this we see that in teaching hospitals psychiatry departments account for about 2% of the hospital budgets. At the national level this would be another about 400 crores INR and extrapolating this ratio to non-teaching hospitals perhaps another 700 crores INR (these estimates have been derived from Maharashtra's selected teaching and non-teaching hospitals – further a 4 country study which included Kerala from India revealed that Kerala was also spending 2% of its health budget on mental health<sup>1</sup>). So roughly the national public health expenditure on mental health is estimated to be around 2500 crores INR or 2.08% of the health budget or a mere 0.02% of GDP.

For an estimated burden of 70 million prevalence for all minor and major mental health cases this works out to 350 INR per case, a very small amount considering the high cost of psychiatric medicines, interventions and consultations. What is also clear is that an overwhelming proportion of this, perhaps more than 80%, is spent on psychiatric hospitals/departments. In the last couple of decades at least

<sup>1</sup>Shoba Raja, Sarah K Wood, Victoria de Menil and Saju C Manarath: Mapping mental health finances in Ghana, Uganda, Sri Lanka, India and Lao PDR, International Journal of Mental Health Systems 2010, 4:11

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in a few states some investments have also been made into supporting community mental health programs but such health spending is difficult to track as non-hospital budgets are not well structured and standardized and there is much less transparency at sub-state levels. Further, there is no significant evidence available on estimates

of household spending for mental healthcare. What we can derive is that given the very low investment for mental health by the state, the out of pocket burden is likely to be much higher than for general healthcare. So clearly finding larger resource allocations for mental healthcare is a major challenge and concern in the quest for strengthening mental healthcare in India.

To conclude some suggestions for incorporating key concerns for our discussion and debate on mental health and budgets for mental healthcare:

- Greater transparency of what the public health system is spending at each level of health care from the mental health institutions and hospitals to primary healthcare levels
- Compiling costs for different mental healthcare interventions
- Breaking down of the mental health spending by different interventions – medicines, diagnostics, counseling, community and patient education, training and capacity building, institutional care etc..
- Getting NSSO and other research/data agencies to research on household burden for mental healthcare
- Steering the national mental health policy to discuss financing and budget issues so that an appropriate financial memoranda for the mental health policy is also put in place
- Understanding civil society initiatives on mental health care and support, estimating the costs thereof, and also state support to such initiatives

## Childhood Sexual Abuse and its Relation to Mental Illness

- *Sathyasree Goswami\**

Sexual violence against children, can take the form of harassment, touching, incest, rape or exploitation in prostitution or pornography. It happens in the home, schools, care and justice institutions, the workplace and within communities at large.<sup>1</sup> Evidence shows that sexual violence can have serious short- and long-term physical, psychological and social consequences not only for girls or boys, but also for their families and communities.<sup>2</sup> The objective of writing this paper as a survivor of childhood sexual abuse is to point out the silent shame that causes enormous amount of psychological distress sometimes leading to psychiatric conditions, but most often not correlated and/or recognised in clinical settings.

In a study conducted by an NGO RAHI it was found that 76% out of 600 adult women from 5 Indian cities reported that they were sexually abused as a child or adolescent.<sup>3</sup> The current study is a compilation of the authors work over the last ten years when she met various persons seeking counselling in formal and informal settings to overcome the trauma of child sexual abuse. All the participants of the study approached the author when she disclosed that she was a victim of child sexual abuse. Most often victims of child sexual abuse lose trust in the familiarity around them; it is often shrouded in silence, which contributes to lack of service-seeking among children. Sexual violence experienced as a child can have a profound impact on core aspects of emotional, behavioural and physical health and social development throughout life.

In-depth case study methodology was used for this study; the participants currently reside in Bangalore, Mumbai and Delhi. There were 15 participants of this study, all of them who had voluntarily disclosed that they were sexually abused as a child; All the participants are between 25 and 45 years of age, have a university degree and come from an economically stable background; it is interesting to note that all the participants felt parental neglect and lack of protection within the family.

Except one male participant who was abused by a much older woman, all the other fourteen were abused by men. Many of the participants especially boys have responded that they “felt” this happens to everyone and that they are supposed to enjoy it. While in case of girls who did tell the parents/guardians, they were also told that this happens to many girls and that they have to learn how to protect themselves. As a child, it is confusing and therefore most of the victims of child sexual abuse grow up with enormous amount of guilt for having not being able to protect themselves

and later this guilt transforms into anger against the people who were supposed to protect them.

Two participants (one male and one female) of this study they abused drugs as the confusion, shame and guilt found refuge in the use of substance and it took them over ten to twelve years to get de-addicted. In cases where there is acknowledgement from close family members, it is to ensure protection from this and other such perpetrators in a hush-hush manner so the child feels as if s/he is constantly living “undercover” worsening the guilt and inducing a sense of shame.

In case of boys, they carry a further layer as they are “supposed” to be able to protect themselves. In case of NJ the male participant who was abused by a woman had to live as neighbours with the perpetrators’ family even during his adult life, until he decided to move to another city; when he visits his parents he sees the woman and has extremely stomach aches and sometimes experiences blackouts. He is 44 now and has not been able to have any sexual relationships, nor marry anyone. He is apprehensive about acknowledging that the various physical ailments he suffers from (that have unexplained symptoms) might have a link to the trauma of sexual abuse. It is interesting to note that amongst the 15 participants only 3 went for a complete medical diagnosis of how some of the psychological illnesses like bipolar disorder, post traumatic stress disorder and in certain cases dissociative disorders could be associated with childhood abuse and neglect. In most cases it was understood that the physicians were unable to relate the two very well.

It was also observed that though all the participants suffered from some form of depression, most of them were never clinically diagnosed. One of the major reasons being the participant has seldom told anyone other than a close friend/relative about the childhood abuse added with a taboo of going for clinical psychological interventions for childhood sexual abuse. In a study conducted in Ontario Canada in 2003 it was found that consistent across all analyses, was a marked association between early sexual abuse and co-morbid depression and anxiety but not the “pure” disorders. The overall pattern of results suggests that particular manifestations of depression and anxiety disorders later in life are found. A particularly strong association between early sexual abuse and co-morbid depression/anxiety was found.<sup>4</sup>

Although in case of the fifteen participants there are three participants who were addicted to substances other than tobacco and alcohol. In a study conducted in USA interviews of 34 young people was carried

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out who had been sexually abused as children, 6 or 8 years after the abuse had occurred and compared them with 34 control subjects who had not been abused. The findings suggest a link between childhood sexual abuse and later drug abuse, juvenile delinquency, and criminal behaviour.<sup>5</sup>

Interestingly it was found that all the participants had an eating disorder and experienced obesity which could not be controlled. The long-term psychological sequelae of childhood sexual abuse have been pursued in clinical and nonclinical samples. Although linked with a plethora of psychological, emotional, and physical disturbances in adulthood, childhood sexual abuse appears most distinctively overrepresented in subjects with depressive, anxiety, personality, and eating disorders; in those who display self-destructiveness and in those with low self-esteem and high interpersonal sensitivity.<sup>6</sup>

One of the participants of the study has been diagnosed with Fibromyalgia and it has been directly related to a childhood of neglect and sexual abuse. The issue of neglect however has been pointed out in various studies conducted globally and it has been seen that there might be a direct relation between childhood sexual abuse and post traumatic stress disorder (PTSD). It was found that the odds of an abused and neglected child developing PTSD were 1.75 times higher than the odds for a matched comparison subject. Increased risk for lifetime PTSD was also manifest for subjects who experienced the three specific types of abuse and neglect: any physical abuse, any sexual abuse and any neglect.<sup>7</sup>

Given that neglected children are also at increased risk for violent criminal behaviour, multiple pathways to PTSD.<sup>8,9</sup> The participants of this study were not able to identify any signs of PTSD as they were not aware that disturbing recurring flashbacks, avoidance or numbing of memories of the event etc were signs of PTSD.

It is interesting to find that out of the fifteen participants, 3 women had divorced/separated and five out of the six men could not hold any committed relationships. Results from the DSM-IV field trial for posttraumatic stress disorder shows that sexually abused women, especially those who also experienced physical abuse, had a higher risk of developing complex PTSD (CP), although CP symptoms occurred at a high base rate among physically abused women.<sup>10</sup>

In 2007 Friedman and Tin<sup>11</sup> argue that there are a large number of studies looking at the rates of childhood sexual abuse in various psychiatric conditions (in the United States of America). There is recognition of the fact that childhood sexual abuse is a common factor in people with schizophrenia. The current level of research does not allow us to be confident in reaching conclusion that CSA is a causal factor in schizophrenia, but neither does it allow us to rule out the possibility that it might be.<sup>11</sup>

In Pinki Virani's words, patriarchy, power, penetration- these are all the factors that allow the child to be sexually and physically abused.<sup>12</sup> It is therefore imperative for all stakeholders to understand that it is this power relation they hold with children, that does not allow children to be able to seek protection. The hurt child continues to live as a "child" in the grown-up body and has difficulty in seeking assistance even as grown-ups.

It is the duty of the society as an institution to provide protection to children from all forms of oppression however taboo and difficult the subject might be to the adult mind. In growing up with trauma that translates into physical ailments and mental agony that gives rise to psychiatric conditions either full blown or borderline, there is a need to recognise the demon of child sexual abuse that lurks in every corner of the society by the medical fraternity and the common people amongst whom children live and adult survivors of childhood sexual abuse silently suffer.

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## Personal Resilience: The Missing Link in Improving Well-being among Youth

- Gracy Andrew\*

### Adolescent Mental Health: An Overview

Adolescents aged 10-19 constitute about one fifth of India's population and young people aged 10-24 about one third. This large and increasing share can translate into a demographic dividend only if policies and programmes focus on the health and well-being of this 243 million strong, yet very vulnerable cohort (22, 31, 32). Adolescents are generally considered to be healthy yet there is a paucity of reliable and/or generalizable data about this age group, compared to any other age groups (16, 17). The most common causes for adolescent deaths, worldwide, have been found to include communicable diseases such as HIV/AIDS, tuberculosis, and respiratory tract infections, and non-communicable diseases such as road accidents, self-harm, violence, substance abuse and early pregnancies (17). Young people in India are considerably healthier, as compared to earlier generations, yet one sees a number of worrying trends. Over 35% of all HIV infections occur among young people 15-24 years of age and a large proportion of young women - around 16% of 15 to 19 year olds - have experienced pregnancy or childbirth (18). Fifteen percent of all deaths among rural women ages 15-24 years can be attributed to maternal mortality and morbidity. The early onset of sexual activity and the pressure on young married women to prove their fertility soon after marriage results in high rates of adolescent fertility (18, 23, 24). Young people as emerging adults have to deal with a number of transitions – in relationships, in educational domains, in the early stages of their careers which makes them vulnerable to depression and anxiety and at risk to substance abuse and sexual risk behaviour (19, 20, 21, 23, 25).

On the global stage, most mental disorders are first detected or begin during adolescence. An

estimated 10-20% of young people worldwide experience mental health problems, leading to related health and social problems such as adverse school performance, delinquency, risky sexual behaviour and substance abuse with suicide being the third leading cause of death among young people (28, 29, 34). The suicide death rate in India is among the highest in the world with 40% of Indian suicide deaths among men and 56% among women occurring in the age group 15-29 years (1). Substance abuse is also a serious problem with its roots in adolescence: 40% of adolescents start taking drugs between ages 15-20 (2, 19).

Given this, effective preventive interventions targeting youth becomes imperative. Large body of evidence, mostly from High Income Countries (HICs), indicates how preventive interventions targeting promotion of mental health among young people results in advancement not just in their mental health but also in other health behaviours and their social functioning (26, 27, 29). However mental health of young people is a neglected public health issue in Low and Middle Income Countries (LMICs) (21, 29). Preventive programs can be universal or that are targeted at young people at risk or show early signs/ symptoms (27). A WHO-UNICEF study that mapped actions in the area of adolescent mental health by international NGOs and research organizations, mostly in LMICs, shown that 96% of the organizations directly targeted young people who were exposed to risk while only 39% took up universal programs that focussed on young people's mental health, in a 10-year span from 2000 (28).

In a more recent review, 22 studies evaluated and 20 mental health promoting interventions for young people in LMICs were identified. Most of the interventions targeted at children at risk such as those affected by armed conflicts or

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AIDS orphaned children. All the universal life skills and resilience school based interventions reported positive effects on student's mental health and well-being. Of the community-based interventions multi-component interventions showed promising results though the number of interventions were limited (29). Important to note herethat, from 22 studies with strong evidence base that were identified, only one community based intervention was identified from India. This was a multi-component intervention done through peer educators, teacher training and professional psychologists and social workers. Though showed significant effects, they were not found sustainable and scalable.

### **CorStone and its Resilience-based Work in India**

CorStone is a non-profit organization with the mission to provide evidence-based personal resilience programs to improve mental and physical health and increase academic achievement among marginalized youth. Resilience has been defined as the ability to achieve positive life outcomes despite significant stress, challenge, or adversity (35). Resilience theory refers to the fact that although people may face adversity in many aspects of their live such as threats to their emotional health, physical health, or educational or career-related well-being, they are often able to overcome or successfully 'bounce back' from such challenges in one or more areas of their lives (37). Research shows that resilience can be developed or 'built' through interventions, and interest in such interventions for youth is growing worldwide (38). Research in HICs confirms that improving personal resilience consistently predicts positive mental and physical health and education outcomes for youth facing significant risks. Specifically, cognitive, emotional and social factors such as positive emotions, gratitude, hope, goal-setting, and character strengths have been increasingly associated with well-being among youth (5, 7-11). Moreover, interventions which successfully promote these factors can advance subjective well-being as well as decrease

psychiatric symptoms in the general population. Such programs have been incorporated into schools in several countries (5,8,38).

After conducting two successful pilots among marginalized adolescent girl groups in India, CorStone launched its first 4-arm Randomized Controlled Trial (RCT) in 2012, in rural Bihar and in Surat urban areas of Gujarat. The aim was to investigate whether 'Youth First, a holistic adolescent health program that integrated emotional resilience with physical health training, could significantly impact adolescent health as compared to the impact achieved by its components alone. Consequently a small pilot of the resilience program was implemented with 250 boys from 4 schools. Preliminary results including demographic covariates in Bihar indicate improved gender equality attitudes over 2.3 times more and improved school performance nearly 2.7 times more among girls receiving the resilience program, versus girls who received an adolescent health programme alone without a resilience component. Similar results emerged in the Gujarat study as well. In the boys' cohort, we found that boys improved their emotional resilience, self-efficacy, school performance, and social well-being to the level of statistical significance. Other indicators such as gender attitudes, psychological well-being, social-emotional assets, health knowledge and physical well-being showed positive changes, though not to the level of statistical significance, amongst boys.

Qualitative data from both trials have shown how girls were using the skills taught in the resilience curriculum alongside their knowledge gained in the health curriculum. They improved their relationship with family members and peers, were able to set goals for themselves and became more aware of their health needs. For example, girls were able to communicate and advocate to parents to stop their own as well as others' early marriages, using their persistence, emotional awareness, and assertive communication skills they gained through the resilience curriculum.

While building evidence through these trials, CorStone also reviewed around 33 policies for youth to assess how much the mental health needs of young people have been addressed in them. The review revealed that the primary focus of most policies has been on reproductive and sexual health. Additionally, though mental health has been included in some recent policies, it has neither received the amount or type of attention required to achieve positive change among youth through universal mental health promotion based interventions. In the latest Rashtriya Kishor Swasthya Karyakram (RKSK), a flagship program being launched by Government of India, mental health outcomes have been included but the emphases is limited to early detection and referral of depression and/or anxiety, and to building capacities of primary health workers, ASHA's and peer educators on this. Similarly a literature review revealed that, though there are a number of life skills based interventions being implemented for youth in various parts of the country, their effectiveness is not known.

### Conclusion

Mental health needs of young people have been a neglected area within public health work in India. In recent years there have been some attempts by government as well civil society organizations to include a few mental health promotion interventions within broader health promotion programs for eg. the Adolescent Education Program in schools. The RKSK also addresses common mental disorders among youth. However, these attempts need to be reviewed and there is a need to build evidence on their effectiveness.

Mental health promotion with a focus on building personal resilience among youth may be one key missing link in youth programs in India. We must consider strength-based mental health work as a core program that can lead to better outcomes not only in overall well-being, but also in specific but related areas as in the field of health, education, and livelihoods.

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## Unmodified ECT:

*Challenging the Call to Continue an Inhumane Practice*

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Electroconvulsive therapy (ECT) or ‘shock treatment’ is one of the most controversial treatments in the history of psychiatry. The treatment has been controversial for several reasons, with proponents and opponents discussing its efficacy and practice, and issues relating to human rights and agency of those subjected to it. In its over 75 years of history, several attempts have been made through research and evidence gathering to pinpoint how ECT works, what benefits, if any, it brings to people experiencing mental health problems, and its role in an ethical and humane methodology and practice of treating mental health problems.

Despite this long history, the evidence on the efficacy of all ECT is yet to be proven beyond reasonable doubt (Andre 2008; Breggin 2008; Ross 2006; Read and Bentall 2010). The use of unmodified ECT (use of ECT without anaesthesia) is banned in several countries. The World Health Organisation’s Quality Rights Toolkit specifies that “Electroconvulsive therapy is never used in its unmodified form (i.e. without an anaesthetic and a muscle relaxant)”<sup>1</sup>. This standard is set in line with Articles 15 (‘Freedom from torture or cruel, inhuman or degrading treatment or punishment’) and 16 (‘Freedom from exploitation, violence and abuse’) of the UN Convention on the Rights of Persons with Disabilities.<sup>2</sup>

In India, however, there has been a call to continue the use of unmodified ECT, especially against the proposal to legally prohibit the use of unmodified ECT in the Mental Health Care Bill. This call has been put forth in an article commissioned by the Indian Association of Private Psychiatry (IAPP) and endorsed by itself, the Indian Psychiatric Society (IPS) and the Indian Association of Biological Psychiatry (IABP) (Andrade et. al. 2012). This paper seeks to refute the claims made by these professional

bodies for the continuing use of unmodified ECT and calls on the MFC to consider issuing a statement against this inhumane practice.

### Unmodified ECT: Questioning the IAPP Premises

IAPP justifies its call to continue the use of unmodified ECT based on three main principles:

1) Unmodified ECT is currently practiced widely: The article calls our attention to the widespread use of unmodified ECT in India and in other countries.<sup>3</sup> The reasons for the continuing use of unmodified ECT is summarised as follows: lack of anaesthesiological support (including lack of facilities and resources), inability to administer anaesthesia (for example, not being able to find a vein), contraindications for the use of anaesthesia or succinylcholine, lack of adequate guidance from professional bodies, and ease of use (‘takes less time to administer’). The argument is that given these constraints that support widespread practice, it is unlikely to stop.

What the article does not do is to call attention to the fact that, in many countries, even *modified* ECT is minimally used. In England, for example, ECT for consenting patients has decreased by 80 per cent in the last 30 years, although there is an increase in involuntary use in recent years.<sup>4</sup> In countries such as the Netherlands, use of all ECT is being phased out, while Slovenia is the first country to ban ECT entirely.<sup>5</sup>

Significantly, the article does not raise the ethical question about allowing an inhumane practice to continue simply because of extraneous factors such as availability of resources for anaesthesia (Rajkumar 2014). There are no discussions about what alternatives might be made available, instead discusses the issue as if ECT is the only and viable option and must be practiced despite ethical problems.

2) Benefits outweigh risks: The article addresses the disadvantages and risks of using unmodified ECT. These include: pre-treatment anxiety, risk of bleeding, risk of physical injuries such as broken bones, joint dislocation and spinal fracture, risk of death, feelings of restlessness and confusion post-ECT, and so on. The methodological problems associated with some of the studies analysed have been discussed fully elsewhere (Rajkumar, 2014). It is significant that the writers do not feel that any of these risks are important enough to warrant not using unmodified ECT. Unmodified ECT is beneficial, according to the

<sup>4</sup><http://ectstatistics.wordpress.com/2014/01/29/ect-without-consent-in-england-201213/>

<sup>5</sup>For current statistics and debates around ECT, see <http://ectstatistics.wordpress.com/category/ect-worldwide/>

<sup>1</sup>Standard 4.3, criteria 4.3.3. World Health Organisation (2012). *WHO QualityRights Tool Kit: Assessing and improving quality and human rights in mental health and social care facilities*. P83. [http://whqlibdoc.who.int/publications/2012/9789241548410\\_eng.pdf](http://whqlibdoc.who.int/publications/2012/9789241548410_eng.pdf)

<sup>2</sup><http://www.un.org/disabilities/documents/convention/convopt-prot-e.pdf>

<sup>3</sup>Some of the information given here is misleading. For example, UK is said to be a country where unmodified ECT is practiced and reference is to an article from 1980. UK has since had several reforms and guidelines prohibiting the use of unmodified ECT and modified ECT without consent (although there are still some continuing issues around consent and capacity).

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article, because they do not have the risks associated with anaesthesia and succinylcholine. The writers also refer to clinical claims that unmodified ECT is more effective than modified ECT, although they admit that there is no real evidence to support these claims.

The literature analysed to reach these conclusions is unilaterally clinical and based within a bio-medical understanding of mental distress and its treatment. Over the last decades, there has been a vast literature that has looked at mental health problems and its care from social models of understanding distress.<sup>6</sup> Prominent among these are evidence presented from experiential and user/consumer/survivor research. A review of consumer perspectives on ECT, conducted by the Service User Research Enterprise at the Institute of Psychiatry in London, found that clinical studies that sought consumer perspectives immediately after administering ECT tended to over-estimate the extent of satisfaction with ECT and its efficacy (Rose et. al 2002). Testimonies of those who have undergone ECT, analysed as part of this study, showed further that the 'perceived benefit' from ECT may be both discrepant from and much more complex than clinical concepts of symptom improvement. Memory loss and its personal/autobiographical significance was found to be more important a factor than the reduction of symptoms of psychiatric illness in how people decide on the benefits and risks of ECT. The implications of these experiential views about ECT on consent and coercion are discussed later.

3) There are no measures prohibiting unmodified ECT in place: The writers point out that the guidelines from the American Psychiatric Association and the Royal College of Psychiatrists make no comments about unmodified ECT, assuming all ECT to be modified. They do not connect this assumption to the practice on the ground, instead presents outdated data to argue that unmodified ECT is widely practiced in the US and UK. The WHO's directive to never use unmodified ECT (quoted above) is dismissed as being not based on "scientific discussion" or "empirical data". No reference is made to the fact that the WHO directive squarely addresses the UNCRPD (Convention on the Rights of Persons with Disabilities) Articles which were developed based on widespread consultations and involvement of people with psycho-social disabilities and their allies. It is also significant that the call now to continue the use of unmodified ECT is being made when India has finally made an attempt to legally curtail its use.

### Consent and Ethics

The IAPP and its allies, the IPS and IABP, call for the continued use of unmodified ECT based on these arguments and offer recommendations. These recommendations, the authors say, are "based on the review of literature presented

<sup>6</sup>See <http://camhjournal.com/2012/04/24/2004-a-campaign-against-direct-ect/> for a succinct analysis.

in this document, on general prudence, on consensus amongst the authors of this document, and on consensus during the participatory process involved during the preparation and approval of this document" (Andrade et. al. 2012: 128). Several further problems arise in terms of what is included in the review and what is left out in this consensus formation and how the recommendations are arrived at.

4) As we have seen, the literature reviewed does not include evidence that has come from experiential perspectives outside of bio-medical psychiatry. A fundamental problem here is the fact that mental health or ill-health is understood as a 'medical' problem with no other explanations or understandings outside of this model taken into consideration. It is pertinent that on the occasion of 75 years of ECT, an editorial in the British Journal of Psychiatry acknowledged how ECT "powerfully reinforced the belief in somatic treatment in psychiatry" and "stimulated the development of biological psychiatry" (Gazdag et al. 2009: 388).

This narrow definition allows for the prevalence of the idea that mental health problems are curable only within bio-medical psychiatry and that ECT is "a last stop treatment", much like chemotherapy to cure cancer. While the perspective that socio-cultural understandings of mental distress held by people may have a role in therapeutic relationships (Jacob, 2014), it is unclear, still, how many psychiatrists consider social, cultural, community-based models of healing and recovery before accepting ECT as the final weapon in their psychiatric arsenal. The literature on the efficacy of these other models of healing and recovery is vast and it is unacceptable that discussions about the need for ECT and its efficacy are undertaken without proper engagement with this literature.

5) The focus of the article on the validity of unmodified ECT, its risks and benefits and its cost efficiency allows the writers to disregard the painful and sometimes violent history of ECT, and its misuse historically, both in India and elsewhere. The use of ECT as a form of torture is prohibited under international laws, while as a treatment it continues to be accepted. But this contradiction has not gone unnoticed even within psychiatric circles and the potential for ECT to be misused is very much in discussion.<sup>7</sup> Survivor/consumer perspectives have also addressed this issue and talked about the use of ECT within psychiatric settings as punishment for "unmanageable" patients and as treatment for behaviours seen as "not normal", ranging from homosexuality (Smith et. al. 2004) to engaging in Naxal politics (Ramaswamy 2001). So it is unsettling to see that the IAPP position statement not only ignores this history, but advocates further relaxing of the parameters of ECT use.

6) The recommendations suggest that unmodified ECT should be given only when "strongly indicated" and that

<sup>7</sup>For an analysis of these discussions, see <http://camhjournal.com/2012/04/24/2004-a-campaign-against-direct-ect/>

legally valid “informed consent” should be obtained from the patient after giving information about why unmodified ECT is being used and its risks and benefits. The recommendation that unmodified ECT will be given to people only when “strongly indicated” is as vague as a previous qualification of people needing ECT as “highly disturbed” (Andrade 2003). The question to ask is whether “informed consent” is possible at all when a person has already been characterised as so ill that they need unmodified ECT and is presented with a benefit-risk analysis that clearly favours the benefits. Or would any person refusing consent be easily seen as “lacking the capacity to consent” and subjected to ECT anyway?

Consent is based on a rational, liberal view of an individual calmly making a choice through careful consideration of all information with ultimate liberty. This is, however, not the case in practice. In a study on consumer perspectives on ECT, approximately a third of the people did not feel they had consented to ECT even when they had signed a consent form (Rose et al. 2005). The study also found that clinician-led research evaluated these findings to mean that patients trust their doctors, while service user-led evaluations see these as showing inadequacies in informed consent.

Further, the question of consent and how it might be achieved is a complex issue in the context of mental health, especially in patriarchal societies where treatment decisions are routinely taken by families, professionals and the legal machinery which has control over a person deemed “of unsound mind”. No recommendation has been made on how informed consent might be achieved in a complex situation where a person is at once deemed in need of a most aggressive procedure and capable of making non-coercive, informed decision.

7) Finally, what are the ethical implications for a doctor/psychiatrist who consents to administering unmodified ECT? Much of the discussion on the need for the continued use of unmodified ECT in the IAPP article is based on the argument that the risks were not dissimilar to the risks associated with modified ECT. Not only does this argument fly against the face of the lack of evidence on long-term efficacy of ECT in general (Andre, 2008; Breggin, 2008; Ross, 2006; Read and Bentall, 2010), it amounts to disregarding the therapeutic and experiential effects of a proposed treatment in favour of economic and logistic concerns. The ethical implications of a professional body such as the IPS, which claims to “promote ethical standards in the practice of psychiatry in India,” supporting a discredited treatment with high risks for people subjected to it needs to be discussed. Not doing so will amount to injustice (Rajkumar 2014) and violate the provisions of the UNCRPD which India has ratified.

### Appeal to MFC

The above analysis of the IAPP position statement is submitted before the MFC as a discussion paper. There is

much here that needs careful expansion and further debate. I hope the mid-annual meeting participants will consider this statement and work together towards generating a public debate and ending cruel and inhuman treatment of those who experience mental distress and are subject to psychiatry.

In a previous campaign, spearheaded by the Centre for Advocacy for Mental Health (Bapu Trust), the need to ban unmodified ECT was made in no uncertain terms:

*“Because of the physical and mental trauma caused by the procedure, patients given direct ECT must be considered as victims of torture and the perpetrators of this form of torture must be brought within human rights jurisprudence. Direct ECT research should not be allowed to happen in future, as this would be a clear human rights violation. Statutory authorities, institutional ethics committees and consumer bodies must ask explanations regarding the recent highly objectionable research done on direct ECT.”*<sup>8</sup>

Clearly, this is not the first time there has been a call for the ban from those who are concerned about the human rights, safety and self-determination of people with psychosocial disabilities or those who experience mental distress. It is time, in 2014, that we make this call a reality.

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## Response to Bagchi and Chaudhuri – Suicide and the Law in India

(Source: [www.bmj.com/content/347/bmj.f6975/rapid-responses](http://www.bmj.com/content/347/bmj.f6975/rapid-responses))

Bagchi and Chaudhuri take an equivocal stance about the Mental Health Bill's article 124 that recommends presuming suicide as an act of a person with 'mental illness'. This response has been written to provide a critical perspective on the issue.

The current discussion of suicide in India arises amidst extensive social churning. These developments are of varied origin and come together in a period of rapid change. For example: a) An increasing number of dalit (formerly untouchable castes) and tribal students enter apex universities each year and face hostility and alienation in the classroom, with the administration and in social life on campus; b) In agriculture, increasing capital intensive cash-crop farming is leading to debt-traps and unprecedented levels of farmer suicides; and c) Reduced acceptance of violence against women in and out of marriage leading to confrontation, intolerance and finally murder or suicide. Thus: in two Hyderabad universities with a student population of under 3000, there have been 7 suicides of dalit students over the past two years.

Farmer suicides in Andhra Pradesh in the period 1999-2012 have been recorded at 35898.<sup>1</sup> A total of 135,445 persons committed suicide all over India in 2012.<sup>2</sup> In these varied contexts, the understanding of suicide as an individual's failure to cope has been challenged by

<sup>1</sup>Reply to question filed under the Right to Information Act, filed from PIO, CID, AP Dt:06-08-2013 C. No 7421/

<sup>2</sup>The Hindu, June 25, 2013. Kollam edition. Accessed at <http://www.thehindu.com/news/national/india-saw135445-suicides-last-year/article4849710.ece> on 10 December 2013.

the women's movement, the farmers' movement, the dalit movement, and also the movement of users and survivors of psychiatry. Today, suicide is understood to be a response of protest and desperation against violence (familial, sexual, social or institutional); loss of respect and social discrimination; and falling prey to a debt trap. Pressing charges against a survivor of suicide is almost unheard of. But criminal investigations are often launched to probe the much more serious crime of abetment to suicide by those in social and familial relationships with the deceased (or survivor). When the bill, in its eagerness to ameliorate the patent injustice of charging a survivor with crime categorizes suicide as an act of a 'mentally ill' person, it undercuts the concrete social gains made by these movements. Here are some examples of what the presumption of mental illness will entail in concrete situations:

1. When a beaten and harassed housewife who tries to commit suicide and survives the attempt, is presumed mentally ill, her testimony against the husband and family in a case of abetment to suicide will be weakened. It will be open to charges of incompetence and will be exploited by the husband's defense. Her potential future claim to property share or child custody will also be questioned on grounds of mental incompetence. This weakness will be exploited in other familial circumstances too.

2. In many parts of India, it is still taboo to marry outside one's caste. Many youth today who defy convention and marry those they love from another caste are hounded by family and community members. They are in many cases, either murdered and described as, or forced into, suicides to save family honour. Police standing orders, which are operational guidelines in procedures like filing first information

reports of such crimes, will broadly reflect the mental illness presumption in this as in other cases, resulting in a softening of the police approach to investigating abetment.

3. Dalit students commit suicide in prestigious higher institutions of learning such as universities at an alarming frequency. Recent events suggest that there are extensive structural lacunae in administrative procedures that require interpretative judgment of the teacher or administrator. Unfortunately in several known cases, these lacunae have permitted inhuman discrimination through acts of commission and omission on the part of specific biased individuals. The suicide which results is an ultimate act of resignation and protest against an outrageous situation. Labeling this the result of 'mental illness' will exonerate the context and causes of the suicide. It will handicap crucial struggles against institutional and social bias.

4. When a farmer in a debt-trap commits suicide, as often occurs, in response to financial pressure,

extortion or coercion, labeling him mentally ill will make unnecessary any investigation into the kinds of financial pressure being exerted on him by moneylenders, suppliers, etc. The understanding of the socioeconomic context of suicide will be de-emphasized, leading to an individualization of the flaw in the deceased or survivor.

5. A blanket presumption of mental illness on suicide attempts will implicitly influence unreported cases of attempted but

failed suicide, which may be 20 times the number of reported cases. In many cases familial and social relations that lead to the unbearable tension realign themselves to correct the situation and relieve the pressure. If social attitude follows the law, this will result in the suicide survivor being taken for psychiatric treatment and medication. On the one hand, the normal corrective process will be abandoned and the distress individualized as 'mental illness'. On the other hand, this is a market for anti-depressants tailor-made for pharma.

It is important to understand these extremely hard consequences so that the section 124 of the bill is expunged when the bill is enacted.

We conclude this response by simply pointing to the other side of the picture in jails, police and judicial custody, and unfortunately in mental health institutions too. There is a violation of the rights of inmates in cases where suspicious deaths are passed off as suicides. These institutional environments are sometimes known to drive inmates to suicide through physical torture, humiliation and loss of self esteem, as a result of taunting, heckling, and inhuman treatment by other inmates or people in authority. Thus far these have been seen as a human rights violation, but they will become invisible if the law looks at all suicide as driven by mental illness.

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### Special Issue of the Bulletin

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- Editor

## Pebbles from a Lonely Beach

- Jagannath Chatterjee\*

I am here to try and write about my experience with the fond hope that it will help parents, doctors and caregivers understand what their loved ones, patients or wards are going through. It will not be a pretty picture. What people with health issues go through has never been fully described in any medical textbook, cannot be mapped through clinical tests, is not subject to rational thinking, and does not limit itself to the label flung at the patient in the form of a diagnosis.

Health depends upon how the authorities or experts understand it. If the understanding is correct, it culminates in health and happiness. If the understanding is partial or improper, suffering spreads like the plague. If the understanding is shaped by forces that have no intention to ensure health, suffering becomes the norm. If the intention is to profit, suffering is eulogized and people feel proud to be classified on the basis and extent of their suffering.

Can we separate health issues on the basis of which part of the body is affected? If a patient has cirrhosis of the liver can we say that only the liver is sick and the rest of the body and mind continues to be in an optimal state? To understand this, one needs to look at the patient as a whole and develop interest in what s/he narrates in the consulting room. "Oh I feel so depressed doctor. I am so anxious about what the future holds for me. Can you cure me?" Not one word about the liver. The patient is more interested in the 'me'.

A psychiatrist once told me when I had gone to him un-chaperoned and narrated to him my problems. "Who is it that is telling me that 'I have lost my mental balance'? Is it the mind itself or is it something behind it?" He went along to tell me that this was often a discussion in psychiatric circles.

I used to be normal. I was quiet and observant as a child. I had a sense of humour and friends would be wary of my pranks. I could also withdraw from the world as I dipped into books I loved to read. Even as I was growing up I noticed qualities in persons that I did not approve of. I hated selfishness, greed, meanness, cruelty, disrespect for elders, and the lack of fellow feeling towards living beings. Negativity repelled me and I remember being protective towards people subject to it. Physically I used to suffer from bronchial asthma which confined me to the local library in winter months. I had a tendency to catch a cold.

My parents tell me I was extremely healthy at birth. My favourite sport was rolling off the bed and playing on the floor. Even putting pillows all around me did not help and no one had ever heard me cry from the fall. I continued to be healthy till I suffered a severe bout of green diarrhoea. My health deteriorated after that. If you read the DPT vaccine package insert green diarrhoea stands out as a side effect. So does bronchial asthma.

As my father was a central government employee, medical care was not a problem. I was medicated with whatever the doctor suggested. I was protected against small pox, polio, typhoid, cholera and tuberculosis either in hospitals or during vaccination drives in my school. My health did not improve despite the costly tonics I consumed regularly. My immune system was weak, the doctors said and I had developed asthma probably because I was afraid of school. What a load of crap, I remember thinking and gave Ghosh Uncle a piece of my mind. He was taken aback and never raised the subject again. Later I used to guide the doctors of the Air Force Hospital in the base my father was posted in on exactly what I was going through and they developed respect for me. They used to encourage me to take up medicine.

My vaccine injury just as I was readying myself for a career in medicine plunged me into a crisis from which I can never recover completely. I was affected at all levels possible. Normally when you fall sick you strengthen your mind and resolve to get well. In my case the mind itself had gone haywire.

I have written 'affected at all levels'. How do I describe it? I was sick from the night I was given the shot which I later learnt was the Measles Mumps Rubella (MMR). I tossed and turned in bed, had disturbed dreams and woke up into a new world. Everything seemed strange around me. The sunlight looked surreal, the sounds seemed to come through a medium that twisted them, time seemed to have lost meaning, and the only thing that was real was the thought that something was terribly wrong with me. My skin became overtly sensitive and I avoided all touch. I developed headaches so severe I got relief only from banging my head on the wall. My eyes ached as I looked at the light and I developed the habit of looking sideways at things. My eyesight deteriorated rapidly. I faced body coordination problems and felt tremors all over causing me to contort my body for relief. My intestines acted strange as if a constant churning was going on in it.

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This was just the beginning. I started experiencing memory problems. Nervousness and panic attacks followed. Public speaking was my forte but I stopped, as I started breaking into cold sweats whenever I attempted it. I used to stop midway if I pushed myself, losing the thread of what I was saying. I felt extremely tired all the time, as if I had just run a marathon. One night I awoke with a start to find that my legs had gone cold. What was creepy was that the coldness started progressing upwards. When it reached my heart I sprang up from the bed and screamed. My worried parents did not know what to do. I was taken to a doctor who told them it was just an allergy and gave me an antihistamine. I slept and when I woke up in the morning I was again cold all over and thinking about suicide. This became a regular phenomenon.

I developed nightly diarrhoea. It was profuse and exhausting. I started dreading the nights even more than the days. I had turned into a recluse -my friends were full of questions to which I had no answer. I lost weight rapidly and soon I was a skeleton. I could sense a throbbing sensation in my chest as if someone was squeezing a gland there and it was getting smaller by the day. Doctors said that was the region of the thymus gland but not to worry because it was important only for children. Later I learnt that the thymus was a very important part of the immune system and that it shrunk only in populations that had embraced the modern civilization. In tribal and others who stayed away it retained its size even in old age.

I developed a pain in the region of the spleen that made me bend double and roll on the ground screaming. I had a peculiar cold accompanied with violent sneezing. I used to sit beside a pan with my hands on the head to ease the pain as a steady stream flowed from my nose. The doctors tried to help but held back whenever I uttered that dirty word, 'vaccine'. They said it had nothing to do with any vaccine I was given. When I persisted I was told that I was suffering from Obsessive Compulsive Disorder. They said if I persisted with the 'vaccination theory' I would go to a mental institution. I knew that I was being threatened.

My descent into hell continued. My memory problems and panic attacks became worse by the day. I developed a fear of travelling as I would have memory lapses. My mother always slipped a note containing my name, address and contact numbers into my pocket if I had to travel. When I travelled by train, the sound of the train's whistle seemed to enter my innards and I used to panic with a great menacing emptiness descending into me. When I used to get down at my destination I often could not even remember my name, let alone know why I was there in the first place. I used to sit down somewhere with

my luggage and instinctively rummage through my pockets for the note. Often before I could get to that the person assigned to receive me would have arrived. Nearer home I would wander and then suddenly find myself in a place without any idea about how I got there.

What troubled me the most was the way my thoughts betrayed the strong value system that has been the back bone of my life. I hated negativity and here I was full of it. I would shake my head vigorously to throw away the thoughts that assaulted me. I would visit temples during my wandering phases and lie prostrate before the idol begging to be rid of them. Had I not read in homoeopathic literature that toxins and heavy metals corrode the mind as well I would have either given in to them or built a fire and cremated myself to escape the trauma and humiliation.

I lived from day to day. My body seemed hell bent on destroying itself. A severe burning sensation all over the body made my life miserable. I was attracted by fire and had the impulse of jumping into it. When I rode my moped I used to look at the vehicles rushing towards me and fight off the impulse to crash into them. The all pervading pain that persisted relentlessly made me scream and throw furniture around. My parents told me I groaned and sobbed all through the night. I had nightmares about being pushed into a coffin like room from which there was no escape. Every night I would go to bed hoping that the morning would not come.

I was a lunatic, yes, but could I be compared to the system that pushed me into the state? Even as I was going through such a terrible experience my whole effort was directed towards warning others about the procedure that was causing harm. My heart ached for the children who were experiencing what I, as an adult, was unable to tolerate. Can we say the same thing for those who push such procedures for the sake of profit? What kind of a mentality, what kind of a heart, and what kind of an upbringing do these people have? Are they fit to be members of any civilized society? Do they deserve an iota of the respect they demand? Surrounded by sycophants these maggots feed upon suffering. They are the ones who are insane, not I.

We talk of the increasing incidence of mental illnesses and the need for infrastructure, trained manpower and policies to attend to those who are affected or who will be affected in future. My insane advice would be to consider the many factors lying in plain sight that are causing the spurt in cases and try to stem them so that people are spared the 'benefits of care and treatment'. That is the best pebble I can offer from the lonely beach that I am stranded in.

## Healing as the Archaeology of the Self<sup>1</sup>

-AA\*

*[Dear Friends! I feel the need to state in the beginning that the following autobiographical psychical account has been written with all due sincerity in order to share with you some of the inner experiences that proved to my reason over time that the key to someone's 'psychotic experience' and 'healing' could be found within the [creative] process of 'psychosis' itself. I found it most difficult to talk about this in a public forum - not because I'm ashamed or secretive, but have never been able to come to a story of my experiences that would fit everywhere; also, each time I spoke about it, different impressions appeared. Now, by presenting my story publicly, I would like to say that 'psychosis' can very much be a transformative and empowering experience, provided the right kind of guidance and care could be found. I am going to present it from the standpoint of what is being called today as 'traditional healing'. Healing here could be understood as the removal or the process of removal of the root cause of suffering.]*

In the year 2012, some events of extraordinary importance to my life took place. In Other words, it was the very first time in my life that I had gone nuts. 'Going Nuts' is not really just a metaphor. This was the first time I encountered the form of the seed. I saw myself in this form. As Two, joined together to make one new Whole - the endless chain within itself. I instinctively started collecting seeds from under the trees of our University space. I had a vision of my body splitting into two parts. My left half was feminine and my right half masculine. And they would appear to dance together along with the sounds of my environment. This was the time when somewhere deep inside, I was always in a state of bliss, but on another layer outside this bliss, a great drama was going on. Most amazing things were taking place in this drama, leaving me bewildered. This was the time I was literally taking birth. As a

<sup>1</sup>*I wish to dedicate this essay to the brave spirit of Clifford Whittingham Beers, the author of A Mind that Found Itself, who inspired in me a faith to reclaim the truth of my own experience and at the same time a zeal to judge everything under the light of reason including even the latter's very absence.*

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person awakening from a deep slumber, I found my Self. And I had not the slightest of an idea whether other people around me were aware of this process of sprouting that I was going through. In my mind then, Everyone and Everything around me seemed to be constantly aware of my state of mind. In fact I could not distinguish between my environment and me. Sitting near a dog, I felt like a dog. Seeing an insect, I became one. And in every little corner of the world, I had visions of divinities - some sprouting life in everything and some guarding the secret gates.

My crying and laughing, and all my other emotions left my side and joined a different family. *Vibhishan* left me and went across the Great Ocean to join the army of my enemy. All my ten heads took separate masters and started ruling the lands of my body making me do things according to their whims and fancy. *Kumbhakaran* left me. I became hungerless and sleepless. When my father came to Hyderabad to take me home, I became Hanuman. I blackened my face and put a tail behind myself. This was the time when Hanuman was facing *Ravan* in his *Darbar* but in his self-bound form. For just some time he opened his chains and came face to face with *Ravan* at equal height and gave him a vision of his grace and told him to surrender. Both *Ravan* and *Hanuman* faced each other - and you yourself being both of them experience both at the same time. In this way the entire gamut of a mythology known as well as unknown to me before, appeared in front of me, bringing forth great gushes of emotion. This force was irresistible and brought great pleasure in destructing all my things in the room. One night I stood inside my room and took each thing in my room in my hands one by one, and weighed it, looked at it, measured its worth and gave it a worthy treatment- which was usually its destruction on the ground if it did not touch my heart. I broke so many things in my room and by the morning, when my father came to see me, there was a pile of broken things in my room. That day I was Hanuman in the *Vatika* searching with all his heart for my Master's soul. I found it in Blue colour. Everything blue at this time was dear to my heart. I wrote verses in honour of the

Blue Lotus.

The armies of *Ravan*, in the form of my parents and friends came to the crime scene. First they were scared to see me in this form. They saw their son or friend with his face painted black and with a false tail hanging behind him. And he was simply acting crazy and breaking everything and acting like a monkey. It brought a lot of anguish and pain to

them as I seemed completely separated from their world. I lived in my enchanted garden of life for about six months in mortal time. After that there was a sudden realization of separation. I felt now separated from that resplendent energy that had been taking care of me. The magic that I was witnessing everywhere left me. What remained with me were nervous ticks throughout my body, and weakness



'all my Ten  
Heads  
have  
been  
arranged  
in this picture  
Strictly for  
illustration purpose  
Only...

and depression- just the opposite of what had been happening till then. I lost hunger completely, I was extremely angry at myself. I fell down so low in my own eyes that I did not want to wake up from bed. I dreaded having to do anything except smoking cigarettes. This was the first time I went to the psychiatrist myself. Before this I was taken to the Psychiatrist and most often I wasn't even aware of her being a psychiatrist. The first time I was taken to her clinic for example, in my world I was there for my wedding. I'll spare you with the details of the dramas that took place there. Anyhow, this third or fourth time was different. I went there as a man confused about everything. Whereas till then whatever was being witnessed by my eyes was magical and amazing, now seemed dull and lifeless- and in fact harmful even. So till then the antenna tower over my room which was functioning as the tower that connected me live to the pulse of the entire universe became the tower that was radiating such harmful rays that it had messed up with my mind. I became so distressed over this. I shifted my house and called my mother to stay with me. After that it was her patience that kept the seedling of my heart alive and she nurtured it with her tears. This was the time when a part of me as *Laxman* had fallen down during the fight and I had left my weapons in pain. My mother became my healer and brought me back to life.

I took medication for two months and then stopped taking it. Other than that I have not taken any psychotropic medication for finding relief in distress or managing my several pseudo selves. My motto now is - '*why take medication if you can do some meditation*'.

All in all the first episode of my epic scale mental illness ran for a year or so and slowly found relief in the company of a few rabbits and a freelance work which was quite suitable for me. I lived normally during this time. I tried many things to put a stop to my nightmares which were frequent at that time. By this time I had come to terms with my condition. I knew I was severely damaged and broken inside. I spent my time reading and informing myself about various themes on the subject of madness and religious experience. I travelled to many places that were known as healing centres and after these visits had a brief novella size episode of disbalance and

epiphany- a time after which I devoted great time and energy in thinking, dreaming and being possessed by ghosts and other spiritual beings - having visions of clarity, insight or fear and anguish.

In this manner I spent almost 2 years roaming about, looking for an ideal place to conduct formal research, and searching for healing of my soul that would have monthly periods of pain. I found great hope and relief through some meditation practices prescribed to me by *Sri KS* - a great practitioner, lineage holder and scholar of *Vajrayana Buddhism*. In the beginning they seemed to me like ordinary relaxation techniques. But slowly they took a life of their own and became the vehicle through which it seemed to me that the ocean of life and its various facets could be measured and crossed. The seed form of humankind, ever potent with creative energy, eager to create by merging with the nearby energies and manifesting in various forms, became apparent again and the entire "First Episode" started to finally make clear sense to me as a whole. The body, soul and the universe are always a fertile ground for seeds and weeds to grow as they please. In order to be a happy soul, one has to turn to a Constant Gardener, nurturing the seeds that are needed and removing the unwanted ones. Over a period of a few months I found great healing and deep fulfilment. My work became effortless and I gained a relative control over my emotional states. I realized that it was possible to ride the mad horse instead of being driven over by it. Meditation, as I'm describing it here is a process of looking within, to realize the one-ness of the two parts of the seed form. By constant practice of this realization, day and night, one starts to see in the world living and live everywhere, the nurturing aspect of the *mOther* element and the growing aspect of the *Other element* in the Great Divide which itself is also the *Union* of these two. The world of the Psychotic is sometimes a dream of fairy tales and myths and sometimes a nightmare in a locked castle. Through meditation it is turned into a game of musical chairs, slowly cutting off the number of chairs like the different heads of *Ravan* and giving the throne to *Vibishan* - the guy who had in the beginning fled from the field leaving the entire *Lanka Nagari* in Psychotic Chaos.

## A Dalit Poet and Death<sup>1</sup>

- Gogu Shyamala\*

Among the writers in Telugu literature, and in the stream of dalit writing that has influenced Telugu literature, Kalekuri Prasad is a significant poet. Personally speaking, he is my favourite. In the nineties, the whole of Andhra Pradesh was drawn to his song

*O flower blossoming on sacred ground  
Smiling shyly as a bud in bloom  
Your dreams dissolve in your tears  
Have you yet charred in the dowry's blaze?  
[...]*

Whoever sang this song was noticed. Sung in a college programme, it would win a prize. It was written in the context of a dowry death at Ongole - everybody knew this. It was also included in the Telugu film *Sriramulayya*. I feel that this song found such significance because there were so many dowry deaths in the country. I have, as one of the editors, included it in a forthcoming OUP volume of translated Telugu dalit writing.

In the decade of the 1990s, Kalekuri Prasad appears to us as a poet and activist who took part in various streams of literary and political movements. His pen name 'Yuvaka' gained much recognition. In my opinion, these streams are dalit literature, feminist literature, and before these, revolutionary literature. Kalekuri worked as a revolutionary writer and activist, then a dalit writer and activist, and as a friend of feminism. During his higher studies he worked as a leader of the Revolutionary Writers' Association.

In 1969 kamma landlords burnt alive a dalit boy, Kotesu, in Kanchikacherla village of Krishna district. In response to this atrocity, Kalekuri Prasad wrote his agonistic response in *A Fistful of Self Respect*:

*I do not know when I was born  
but I was killed on this very land thousands of  
years ago*

<sup>1</sup>This essay sketches the sociopolitical dimension in which the spectre of alcoholism appears beyond individual pathology.

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'The endless cycle of birth and death'

*I do not know the theory of karma,  
but I am being born, again and again, in the very  
place I died.*

*My land melted into this country  
and became the plain between the Ganga and the  
Sindhu.*

*My eyeballs dissolved into tears, and  
this country's perennial rivers flowed.*

*When lifeblood oozed from my veins,  
Riches rained down and the land turned verdant.*

*I was Shambuka in the Treta yuga.*

*Twenty years ago I was Kanchikacherla Kotesu  
My birthplace is Kilvenmani, Karamchedu,  
Neerukonda.*

*Now, Chundururu is the name the cold-blooded  
cruelty of landlords*

*has tattooed on my heart with their ploughs.*

(Borrowed with gratitude from K Satyanarayana and Susie Tharu. *steel nibs are sprouting*. Noida: Harper Collins 2013: p 602)

After the Chundururu massacre, during the political response of the dalits, there was a call to bury the dead in the middle of the village. The police, landlords, political leaders and culprits all opposed the move with their combined might. Kalekuri wrote in this context

*I am a flag flying high against oppression*

*Do not shed tears for me.*

*Inter me in the town's navel*

*I will flourish as a bamboo grove that hums life's  
melody.*

*Stamp my body as the portrait of this nation*

*I will return from the leaves of history as the beauty  
to come.*

*Take me to your hearts*

*I will be born again and again in this country as a roaring blaze.*

Kalekuri would often lament the wide gap between the literary movement and the political movement in the dalit context. He would describe his predicament as being hunted by the devil of dissatisfaction. For this reason, some say that he did not find attachment in any aspect of his life. He never preserved or promoted any of his poems, essays, stories, plays or scripts. Just as he did not preserve his literary work, he neglected his own life and body. People called him a mendicant. There are different kinds of mendicant: literary, musical, mendicants who roamed without home, hearth, wife or children; with all these elements in him, Kalekuri also appeared as a drunkard mendicant. There is a jocular criticism regarding poets that they were drunkards...

“No, no - mala/madiga poets are drunkards!”

“No, no, not all mala/madiga poets, are drunks, only some like Kalekuri were drunkard mendicant poets!”

This description was actually applicable to revolutionary writers. In the association of revolutionary writers, there are in addition to mala and madiga poets, revolutionary poets of all hues. In one discussion however, the following question came up: why, when the brahmin poet who drank liquor (like Sri Sri) became a great poet (maha kavi), the mala-madiga poet who drank liquor was described as simply a drunkard? The opposing point of view adopted by the democratic section was that a drunkard was a drunkard – it made no difference whether he was a brahmin or a mala-madiga. There was only one difference: only those who ripped Manuvada apart and opposed its oppression were maha kavis. Thus, even though he was a drunkard, only Kalekuri Prasad who questioned Manuvada was a maha kavi.

After his exit from the Revolutionary Writers Association, we need to look specifically at Kalekuri work with the dalit organizations. He left the revolutionary association because of its faulty class analysis of the caste atrocities at Kanchikacherla and Karamchedu (where 6 madiga men were slaughtered in an attack on the

madigawada by a horde of kamma landlords). The Marxist class framework did not permit the revolutionaries to see the kmmas as perpetrators of a caste atrocity. Disillusioned, he moved into the Dalit Mahasabha which was founded by dalits in response to Karamchedu. He worked actively here and wrote a ballet on the incident.

However, in this work context, the strong concept of family and community among the mala-madigas ran against Kalekuri's own life and practice. In my opinion and analysis as a dalit feminist, I believe dalits generally give primary importance to their family and community and take their support against a dominant caste society that is hostile to them. Kalekuri did not pay attention to this issue. For example, the Dalit Mahasabha had the wife of a man who was killed in the massacre remarried in order to restore her family life. Kalekuri, while participating in this event, did not care too much for his own marriage. A few times, dalit women barged into public meetings with 'his' children and insisted aloud that he acknowledge being the father. He refused, saying he had no connection with these women. The activists, attendees, participants, poets and leaders were thrown in a dilemma between their sympathy for the women and the respect he commanded. In addition to being an alcoholic, he was now being criticized for rejecting the women who were with him. He also rejected advice that he would ultimately need a family and that he should get married. Kalekuri had married a kamma woman member of the revolutionary writers association, and the marriage had failed. Why was it that he was against marrying these women? It seemed as if Kalekuri, working in a dalit organization on dalit issues for the dalit community, never adopted the dalit culture of family life. Another opinion expressed then, and which caused pain to the community was that Kalekuri was not against marriage, or against a wife, but he was against formally recognizing a dalit woman as his wife.

As he lost his wife, he rejected family life completely and applied all his skills to drinking. It was said that a bottle of liquor would suffice to have him translate a book (he was a prolific writer and translator). Towards the end of his life Kalekuri was paralyzed below the hips and had drag himself on his hands. Even in this situation, he refused to

go to a doctor to get treated. In the last stages he lived on the streets often being carried from the bus stops where he was found, to the bungalow he owned in his village. Some poets and members of his community fed him and kept him alive for another six months. Even at this time, he continued to drink without taking care to eat. He died on May 17, 2013, in Ambedkar Bhavan, Ongole. How do we understand his death? Rather than argue that he drank to death because of the failure of his marriage, or that it was a pathology of alcoholism, I will suggest in the following paragraphs, that we need to look at the fact that he was a dalit poet and activist who was fighting battles against caste oppressors through literature, and at the same time facing insurmountable contradictions with left theoretical frameworks.

A brief account of the failure of his marriage is available in *steel nibs are sprouting* (op.cit.). Some more information is available in a video interview on the Dalit Camera website. In addition, there is memory of much oral discussion on the failure of that marriage.

It is necessary here to say that in *steel nibs are sprouting* only one aspect of the failure of that marriage is written about. That too, it was written from a view (Kalekuri's own) that was sympathetic to the woman. Thus, in my opinion, this can be seen as a version that is from the perspective of the woman. In the Dalit Camera video interview, Kalekuri gives another version. If we examine this, it is difficult say clearly whether he saying that the marriage failed due to the woman's errors or his own. However, he narrated the circumstances that led to the separation very clearly, described how and in what specific contexts others (and he named them) interfered in the problems between him and his wife, making the situation worse. At the time the marriage failed, Kalekuri did not have a dalit perspective. However, when he spoke to Dalit Camera, it seems to me that he did to an extent provide an analysis from a dalit perspective of how caste politics in the Revolutionary Writers Association made the problem worse. In not so many words, he narrated how the disputes were fuelled by dominant caste politics, how a key factor in the failure of his marriage was the sustained interference and denigration of his

leadership by individuals from the brahmin/karnam caste background. This was because his wife belonged to the kamma community, and the caste polarization within the dominant castes in the association expressed itself as personal disputes between a mala husband and a kamma wife.

In the oral discussions about him, those who had worked with and observed Kalekuri closely felt that though he had married a kamma woman, "... it was all right. When problems arose between them, they could have divorced and lived independent lives couldn't they? Both had a right to their lives." Since people working in movements knew about rights, this was clear to everybody. Why was it so problematic for this husband and wife to separate in a legally valid manner? I think this was because Kalekuri and his wife did not subscribe to the legal framework of rights within the state. They didn't accept themselves a common couple under state law, they felt superior to ordinary law and this made the problem immensely more complex. On the other hand, it seems to me as if Kalekuri did not take the hazards of caste and community politics seriously. Therefore when Kalekuri married a kamma woman, he was carried away by the ideology of patriarchal arrogance that suggested he had conquered a kamma woman. It is also likely that he was swept away by the notion that having conquered a kamma woman, he had conquered the kamma caste itself.

As I have already narrated, he could not marry any other woman after this. He chose to live alone. The dalit community had hoped that he would lead a more disciplined life and take care of his food and health. Normally, dalits in agricultural families of the Telugu states, whether men or women, accept a family life as a means to ensure health and food security. Despite his refusal to do so, many felt that Kalekuri's thoughts, poetry and vision were the living pulse of the community. Kalekuri rejected family, food and health and chose liquor as his path. He drowned in excess and at the end it seems as if he took support of drink to seek out death.

*Translated by R Srivatsan*

## Critical Perspectives on the NIMH Initiative

“Grand Challenges to Global Mental Health”\*

In July 2011, *Nature* carried a Comment titled “Grand Challenges to Global Mental Health”[1] announcing research priorities to benefit people with mental illness around the world. The essay called for urgent action and investment. However, many professionals, academics, and service user advocate organisations were concerned about the assumptions embedded in the approaches advocated and the potential for the project to do more harm than good as a result. *Nature* refused to print a letter (sent on 20th August 2011) protesting against the issue citing ‘lack of space’ as the reason.

This letter is an effort to critique the initiative through wide participation and consensus.

### Background

The largest international Delphi panel ever was assembled in a project starting March 2010 to formulate the ‘Grand’ Challenges to Global Mental Health project. The panel consisted of a scientific advisory board from the US National Institute of Mental Health who “nominated 594 researchers, advocates, programme implementers, and clinicians... researchers in genetics and genomics, neuroscience, basic behavioural science and neurodevelopment made up just over one-third of the panel. Mental health services researchers consisted another quarter, and a further third were clinical researchers and epidemiologists” (p 28).

The panel listed 25 grand challenges including biological, social and genetic factors that needed to be identified and tackled.

While environmental influences and community care were mentioned, the main framework for the project utilized a narrow ‘medical’ model for understanding mental distress that emphasized treating mental, neurological and substance-use (MNS) disorders through improved understanding of the brain, its cellular and molecular mechanisms. Fourteen MNS disorders were listed including unipolar depressive disorders, alcohol-use, schizophrenia, bipolar affective-disorders, epilepsy, panic disorder,

migraine, insomnia, PTSD, and Parkinson’s disease. The fact that disorders likely to be linked to adverse experiences (such as depression) were put alongside known organic pathologies (such as epilepsy) illustrated the lack of inclusion of lived social and political realities in the models for causation and manifestation of mental distress. In addition, while the authors proposed ‘understanding root causes, risk and protective factors’ including poverty, violence, war, migration and disaster, the essay largely advocated biomedical, clinical or ‘social services’ oriented measures to alleviate the distress, with no protest, voice or opinion against the root causes listed. They argued that MNS disorders constituted 14% of the global burden of disease surpassing cancer and cardiovascular diseases with a global loss of DALYs at 148.8 million. This programme is now growing in strength as it is being rolled out internationally [2].

### Problems with the Grand Challenges Project

The following are some of the main problems with adhering to the ‘Grand Challenges’ proposal:

- a) We agree about the need to improve mental health in non-western countries, but are concerned about the approach of the ‘Delphi panel’ as developing appropriate frameworks for mental health requires active collaboration with local communities and with those with personal experience of mental health problems. The Delphi panel was not representative of these stakeholders. The data on which the Delphi panel bases its recommendations is also questionable and could grossly exaggerate the global burden of mental disorders.
- b) The focus on ‘molecular and cellular mechanisms’ in the brain for the complex problems of living ignores the experiences of ordinary people and the different settings in which mental health problems manifest.
- c) The recommendations overlook indigenous healing, social support networks, rights-based organizations and family support.
- d) The assumption of a global norm for mental health and the idea that deviations can be subsumed within a simplistic biomedical framework is restrictive

\*A briefer version was published in *EPW*, Oct 20, 2012.

and disconnected from the real lived experiences of potential service users.

e) Mental health services should not be dependent on funds driven by pharmaceutical, insurance and other industries with potential conflicts of interest.

f) The picture of a black girl chained to a tree on the front page of their paper in Nature suggests that rights violations are a more prevalent issue in non-western countries. Mental health service delivery has involved rights violations across the globe (e.g. use of seclusion, restraint, high dose medication).

Instead we propose that protections, in line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), should be at the centre of developing mental health programmes. These programmes should also be developed in a way that reflects the experience of local communities. A framework that emphasizes respect for persons requiring services would result in approaches that are interactive and not imposed (as is the case in most Western countries).

If the US-NIMH is concerned about the lives of people in LMI countries it should be in dialogue with representative stakeholders, and not impose solutions identified by non-representative experts.

We the undersigned are concerned activists and practitioners who come from different representative organizations like MFC, Anveshi and CAMH in India, and Survivor Research, ICPN, the UK.

Abhay Shukla, Anand Philip, Anand Zachariah, Anant Phadke, A Suneetha, Bhargavi Davar, CEHAT, Chinu Srinivasan, Dhruv Mankad, Imrana Qadeer, Jayasree Kalathil, K Lalita, K Sajaya, KS Jacob, Kamayani Balimahabal, Manisha Gupte, Mohan Rao, Moosa Salie, Padma Prakash, Prabir Chatterjee, Rama Baru, Rama Melkote, Rajan Shukla, Rakhil Gaitonde, Ramila Bisht, Ravi Duggal, Renu Kanna, Ritu Priya, R Srivatsan Sami Timimi, Sarojini NB, Sathyamala, Shyam Ashtekar, Suman Fernando, Susie Tharu, Veena Shatrugna

[1] Collins, P.Y., Patel, V., Joestl, S.S., March, D., Insel, T.R., Daar, A.S., "Grand Challenges to Global Mental Health" *Nature* Vol 475, pp 27-30

[2] See the Grand Challenges to Global Mental Health Website at: <http://grandchallengesgmh.nih.gov/> accessed on September 28, 2012.

## Ignoring for Bliss

-Adithya Pradyumna\*

*The phone rang again.*

*I ignored it.*

*And then again.*

*"Why won't he give up?"*

*I thought to myself.*

*Why should I pick up?*

*To put myself through all that pain?*

*He had fallen ill.*

*My friend from childhood.*

*He was on many a pill.*

*Like a silent pole he stood*

*When we had met last time.*

*It had unsettled me.*

*Was it a crime?*

*Plus, I wasn't free!*

*Wasn't there the other thing*

*That I had to do?*

*Why meet this bloke who was cuckoo!*

*And I wasn't his only friend...*

*There were quite a few!*

*Why not trouble them?*

*They too may not have a clue*

*Of how to react to this situation.*

*A medical education*

*Hadn't prepared me for this.*

*How are we to understand*

*this life of his?*

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