Disability Legislation and Mental Illness: What the stakes are

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Are we ‘the mentally ill’, ‘persons with mental illness’, ‘the mentally disabled’, ‘persons with mental disabilities’ or ‘persons with psychosocial disabilities’? Whether we think of how we should name ourselves as a significant matter or a silly issue, we may be named by our laws and may have to make negotiable peace with these names. The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, is a law that lists ‘mental illness’ as one of the meanings of the term ‘disability’ for the purposes of the act. The other categories of disabilities include blindness, low vision, leprosy-cured, hearing impairment, locomotor disability and mental retardation. This brief essay is an attempt to understand mental illness in the context of the PWD Act and an appeal to mental health interest groups in the country to become more involved in the mobilizations around the new law that will repeal the PWD Act. The new law currently known as the ‘RPD Bill’ or the Rights of Persons with Disabilities Bill 2014 has been prepared in accordance with the United Nations Convention on the Rights of People with Disabilities (UNCRPD) to which India was one of the earliest signatories. The essay will, however, begin by reflecting on the term ‘disability’ and explore whether the use of this terminology has caused discomfort among mental health interest groups and why it is perhaps time to displace that discomfort.

The MFC mid-annual meeting held in October 2014 in Hyderabad made me wonder if the concept ‘disability’ meant anything at all to the mental health interest group that was gathered there. Except for two people who work in the NGO sector, none of the other service providers, health-care practitioners used the word disability. How much does this have to do with the sense that ‘disability’, the term itself is structured with a negative prefix and two with how the category disability is more often than not visually represented in signs and signage as a physical one? The problem could be that the physical nature in which the category disability is rendered obscures invisible disabilities such as mental illness, hearing impairment and mental retardation. It’s intriguing then that popular media chooses to use physical markers to depict mental illness or ‘madness’ on stage and in cinema – wild eyes and flailing hair, unkempt clothing and at times nudity are all repeatedly used to make visible an invisible category. The invisibility of mental illness seems to be the cause for great anxiety and a category that when identified visually has only caused harm. The present is a good time in which to impress the larger disability movement to take up more strongly the differences of people with invisible disabilities and bring greater recognition to such groups, one being people with mental illnesses.

Disability, a category that includes a wide variety of conditions, diagnoses and categories, is now reclaimed as a category of identity and not just a descriptive label. Disability has come to connote diversity and difference. Making disability a value-free category has been a signal accomplishment of the disability rights movement and one that could well imbue the mental health movement with a similar force. The framing of disability as an aspect of humanity that is worth reclaiming may facilitate more beneficial give and take between the disability rights activists and the mental health interest groups, one instance of which is the group that came together for the MFC annual meeting.

Another reason why mental health practitioners and activists have distanced themselves from the category disability was that the PWD Act (1995) that explicitly frames mental illness as disability has done some disservice to this group of stakeholders. Perhaps mental health interest groups have used it and given up on it, because, after all the PWD Act is also known as a legislation that failed people with mental illnesses. While there are critiques of this law and strong arguments for its including mental illness “more by default rather than by intent”, this is the one law we have, at the moment, that emerged within the human rights paradigm and discourse and therefore distinct from the more one colonial and archaic Mental Health Act of 1987. The PWD Act,

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in spirit at least, argues for equal opportunity and full participation. What’s more important is that, the PWD Act and critiques of it have paved the way for the new bill that has been identified from its earliest draft as one that would ensure legal capacity and independent living to all persons with disabilities. Nevertheless, let’s take a look at how and why the PWD Act has failed in ensuring even basic entitlements of ‘equal opportunity’ and ‘full participation’ to people with mental illnesses.

The PWD Act provides that a person “suffering from 40 percent or more disability” can be defined as a disabled person. Such measuring of mental illness raises a major problem as it is difficult to demarcate such a percentage for people with mental illness. One of the reasons is that there is difficulty in computing the total duration of the illness in the context of episodic illnesses. Certification of disability is also a complex matter in the case of mental illness when compared with the other disabilities listed in the PWD Act because many mental health professions refuse to certify people with substance dependence syndrome. Suresh Bada Math and Marina Christine Nirmala, researching in psychiatry, argue that mental health professionals don’t realize, when asked to certify, that what they are engaging with is not the person’s diagnosis but the disabling situations they may face on a day to day basis.

Shampa Sengupta who is involved with Sruti Disability Rights Centre in Kolkata, and an advocate of the disability rights of people with mental illness, speaks movingly about this problem of defining what ‘home’ is for persons with mental illness or psychosocial disabilities. In her experience of working with such persons in the hope that they obtain disability identity cards, Shampa found that one of the major hurdles was that a lot of people, especially women, had no place they could call home. Not having a home meant not being able to apply for the ID cards as that requires proof of residence. Since a lot of the women had been displaced from their homes and were either in institutions or between these two places, they had no address to supply.

Though there are provisions for reservation in education and employment sectors according to the PWD Act, this does not include reservations for persons with mental illnesses. One of the major hindrances in the PWD Acts inability to ensure equal opportunity and full participation for people with mental illness is the presence of regressive clauses in other laws. Many other laws use the category of ‘unsound mind’ or ‘unsoundness of mind’ to disqualify people with mental illness from a variety of contractual and political activities.

Unsoundness of mind is grounds for divorce according to section 13 of the Hindu Marriage Act. This brings us to the question of whether persons with mental illness could every identify themselves as and reclaim the categories “person with mental illness”, “person with mental disability” “person with psychosocial disability” when mental illness as “unsoundness of mind” is discredited by other existing laws. This is likely to make the person in question hide their ‘diagnosis’, their ‘condition’, their ‘disability’ or their ‘disease’ and not embrace what disability as an identity has offered to persons with other kinds of disabilities, more visible or more physical ones like blindness and locomotor disability. Secondly, having to hide one’s diagnostic category or having to hide even a visit to a counsellor or psychiatrist is likely to increase distress. Persons with mental illness then fall between the cracks of these various laws.

Shampa Sengupta writes that in her experience in West Bengal, mental illness seems to have fallen between the cracks between different ministries as well. The ministry of social welfare thinks it is the task of the ministry of health to take care of mentally ill persons and their concerns and the latter thinks it is the work of the former. Since marriage is often considered such an important part of the making of womanhood or of being a woman in the Indian context, the discreditation of mentally ill persons as per the Hindu Marriage Act impacts more severely women with mental illnesses than men, according to Shampa.

It is not surprising to hear that “40 percent of divorce cases before the Chennai court involved allegations of unsoundness of mind”. It is for these reasons that there is a greater need for mental health practitioners, activists and survivor groups to come together in the making of stronger disability legislation that will overwrite other detrimental laws. The UNCRPD (United Nations Convention on the Rights of Persons with Disabilities, 2007) and India’s commitment to shape its future disability laws on the basis of the CRPD’s framework has brought some hope to this particular group that Shampa speaks of, women with disabilities. The new bill, the RPD Bill has been forwarded to the Standing Committee for further changes is one of the several drafts that have been prepared since 2011. The issue of full legal capacity has been a major part of the UNCRPD and has offered a new lease of life for persons with psychosocial disabilities the world over. Legal capacity means recognizing the legal status of a person before the law and is a significant move if adopted into the RPD Bill because that will then challenge the unsoundness of mind clause in all other legislations that has been detrimental to persons with psychosocial disabilities attaining personhood status before the law and rights to citizenship. Amita Dhanda sees legal capacity as not just a right of persons with psychosocial disabilities and intellectual disabilities but “as a duty of the appropriate government”. The first draft of the RPD Bill had expressly asked for the repeal of all other laws that obstruct the rights of persons with mental illnesses but the final one that was placed before the parliament nods in the direction of the Mental Health Care Bill of 2013, thus entrusting the concerns of the persons with mental illnesses to the MHC and detracting from the fundamental ideas of the CRPD. The MHC Bill makes a push for institutionalization as well as plenary guardianship and in doing so returns persons with psychosocial disabilities to the
medical model or the individual model that the CRPD denounces in its robust focus on the social context of the disablement.

It is important that mental health interest groups in India become actively involved in the discussion and debates on the RPD Bill because there is much to gain. According to Gabor Gambos, a disability rights activist and member of, the UNCRPD from 2011 to 2013, the UNCRPD has deemed that “treatment with neuroleptic medications without free and informed consent in psychiatric hospital as violation of the right to be free from torture” 14. Considering that treatments that amount to torture such as Electro-Convulsive Therap (ECT) 13 are an important focus of this year’s annual meeting of the MFC, it would be useful to mobilize for the ban of unmodified ECT as a standard treatment method, through the new disability legislation. Detention in psychiatric facilities without the consent of the individual with psychosocial disability would also be a breach of the CRPD. The UNCRPD strongly holds that discrimination on the basis of one’s disability is violation of human rights. The CRPD also emphasizes independent living and full inclusion in society thereby enabling persons with psychosocial disabilities to claim rights of living without the restrictions of institutions or the paternalism of family-oriented coercive care. Bhargavi Davar refers to the independent living clause as a “foundational right on which to pitch all advocacy efforts” 19. The ‘reasonable accommodation’ clause of the CRPD could mean that persons with mental illnesses be provided certain accommodations in their professional lives.

This essay, to conclude, serves as an appeal to mental health care practitioners and survivor groups to actively participate in discussions around the RPD Bill to motivate law makers to ensure that all the provisions in the CRPD be incorporated into the new disability legislation, especially those that people with psychosocial disabilities would most benefit from. A CRPD-compliant legislation would then have the strength to implement such demands as the removal of unmodified ECT from everyday mental health care practice, which was an important focus of the MFC annual meeting in 2015.

References
1 Jayna Kothari, in her book on the future of disability law in India states that the presence of ‘mental illness’ in the Persons With Disabilities Act of 1995 is “more by default rather than by intent” (Pg 45). She discusses the ambiguity in defining mental illness in that legislation and how the absence of an exact definition has led to much confusion in the understanding and implementation of the act.

2 In their letter published as ‘Stigma Haunts Persons with Mental Illness Who Seek Relief as per Disability Act 1995’, in the Indian Journal of Medical Research in July 2011, Suresh Bada Math and Maria Christine Nirmala survey a range of reasons that instantiate their claim.


4 Shampa Sengupta speaking at National Seminar ‘Perspectives on Mental Illness in India’ held from 1 - 3 July 2010 by The Banyan Academy of Leadership in Mental Health (BALM) in Chennai https://www.youtube.com/watch?v=SwY86vnmRyw

5 Both Bhargavi Davar and Amita Dhanda have argued for a long time for the removal of these regressive clauses in their academic writings as well as in their media activism. Their works that engage with this issue include Legal Order and Metal Disorder (Amita Dhanda, Sage Publications, 2000) and Bhargavi Davar’s article in the Economic and Political Weekly titled ‘Legal Frameworks for and against People with Psychosocial Disabilities’ (29 December 2012).

6 Shampa Sengupta ‘No Rights for the Mentally Disabled’, 2008, infochangeindia.org


8 The Café Dissensus issue of August 2014 (http://cafedissensus.com/2014/08/15/contents-debating-the-disability-law-in-india-issue-10/) brings together reviews and critiques of the various drafts of the RPD Bill. Of particular interest may be there articles by AmbaSalelkar, ‘Between a Rock and a Hard Place: Dilemmas and disability rights’ and Jayna Kothari, ‘The RPD Bill 2014: New frontiers for disability rights or repackaging the old?’ which outlined the watered down nature of the Bill that was finally passed by the Parliament. The collection of articles also reflects the different voices of disability interest groups as well as the split between those who think the Bill in its current form should be passed as it would benefit groups of disabled people that are being brought under the category legally for the first time and those who are demanding for a comprehensive overhaul of this Bill with the aim of making it fully compliant with the UNCRPD.


10 Bhargavi Davar in her article in Café Dissensus titled ‘What Changed for Persons with Psychosocial Disabilities in the making of the RPD Bill?’ http://cafedissensus.com/2014/08/15/what-changed-for-persons-with-psychosocial-disabilities-in-the-making-of-the-rpd-bill/ traces the changes in the various drafts of the RPD Bill and how the clauses on full legal capacity, plenary guardianship and supported decision making have transformed between these drafts leaving people with mental illness at the mercy of the Mental Health Care Bill of 2013 that has provisions for creation of mental institutions as well as the application of plenary guardianship.

11 The Mental Health Care Bill was introduced in the Parliament in August 2013 and on becoming an Act will repeal the Mental Health Act of 1987.


13 See Jayashree Kalathil’s background paper, ‘Unmodified ECT: Challenging the Call to Continue an Inhumane Practice’.

14 Bhargavi Davar in her EPW article ‘Legal Frameworks for and Against People with Psychosocial Disabilities’ (2012) examines the differences between the presently operational Mental Health Act of 1987 and the proposed Mental Health Care Bill and critiques the latter as being non-compliant with the CRPD. http://www.epw.in/special-articles/legal-frameworks-and-against-people-psychosocial-disabilities.html
Mental health – both illness and wellness are too entangled and complex, to be tidily described in neat packages. There is an urgent need for countries like India to continue to develop and disseminate models of mental health care that are centred in communities, appropriate to cultural contexts, work actively to address mental health determinants such as employment and social inclusion, and emphasise psycho-social interventions which are more durable and have few side effects than drug therapy (Drake, Binagwaho, Martell, & Mulley, 2014).

At the same time, perhaps 90% of people in India with mental illness do not have any option of access to allopathic (bio-medical) care (World Health Organisation, 2011). The described prevalence of mental illness in India varies depending on the framework for definition and the instruments used for identification. There are crores of people in India disabled by mental symptoms and with little access to care regardless of whether they are categorised as distressed, despairing or disordered (Tawar, Bhatia, & Ilankumaran, 2014).

The Indian context also provides unique opportunities. The vast huge majority of PWMD in India are cared for by family members, and people with severe and common mental disorders are often well integrated in their communities with opportunity to participate in community functions. Some PWMD find social sanction, initiate further help-seeking and find support and healing in a supportive and non-threatening environment of some traditional healers (Padmavati, Thara, & Corin, 2005; Raguram, Venkateswaran, Ramakrishna, & Weiss, 2002).

Emmanuel Hospital Association (www.eha-health.org) is one of the largest non-profit providers of health services in North India, primarily working in the most deprived districts with 20 community hospitals providing clinical services and over 40 community health projects. In this paper I describe the context and learnings we have encountered in four locations where we are implementing community mental health programmes, and present possible models for moving forward.

**Setting**

The four project locations are in Saharanpur and Bijnor districts in western Uttar Pradesh (UP), Dehradun district, Uttarakhand and a fourth project in East Champaran district, Bihar, India. The national District Mental Health Plan (DMHP) had not been implemented in any of these locations and for the majority the nearest Government provider was 3 – 6 hours travel away.

**Context Analysis**

In all our projects we spent the initial months seeking to understand the realities of life, health and ill-health for PWMD. This included baseline surveys of knowledge, attitudes and practices, a prevalence survey of help-seeking, and depression, in-depth interviews with PWMD and caregivers and focus group discussions. Salient points are listed below:

1. Help-seeking efforts are monumental - Most of the families we visit spend high resources of time and money seeking help. This includes travelling long distances, selling land and spending months at healing shrines

2. PWMD and their families are particularly vulnerable to the very worst of the Indian private medical system. We read the outpatient cards and heard stories of many PWMD attending private psychiatrists and neurologists who were required to undergo multiple expensive MRI and CAT scans. Access to private care often means impoverishment.

3. There are varied knowledges about mental illness. E.g post-partum psychosis may be understood by some as contagious and people with a seizure disorder are regarded as having an evil spirit

4. PWMD have a dominant experience of social exclusion which ranges from more subtle distancing and negative judgements to verbal violence (public ridicule and taunting), economic violence (disinheritance) and physical violence (Mathias, Kermode, San Sebastian, Korschorke, & Goicolea, 2015)
5. PWMD have a hugely increased premature and preventable mortality versus a mentally well population. This includes young people with untreated seizure disorders dying in accidents as well as mortality related to neglect and lack of access to care.

6. The sparse human resources for mental health described for India above are actually even worse in rural areas and in northern States e.g. in Uttar Pradesh with over 200 million people there are 10 government psychiatrists (State nodal officer for mental health, 2013).

Programme Objectives and Learnings

Each of our community mental health projects have 5 – 8 staff and teams of community workers/ volunteers who are based in the communities where they work. Broadly shared objectives are:

1. Build mental health/ resilience knowledge and skills among community members
2. Build knowledge and skills in mental health of ASHA, AWW and ANM government workers
3. Identify people with mental distress and offer both community based support and care, and facilitate access to care (primarily through advocacy for provision of government services)
4. Support PWMD to access relevant Government entitlements such as disability pensions and also link to form Disabled People’s Groups (DPGs) and Federations
5. Advocate for access to primary mental health services and essential medicines for mental disorders by Government services working towards community monitoring of health services
6. Describe and disseminate resources, learnings and models of care including development of alternative cadres of mental health providers

We have developed further a framework of community mental health competency (Campbell & Burgess, 2012) schematically represented in Figure 1.

Key learnings from our first three years working in community mental health:

1. In a context of almost non-existent mental health services advocacy was ineffective without the voice of PWMD to demand a right to care. Mental health services (clinical and community-based) support PWMD to take further steps for recovery and bring healing.
2. Government services are stretched with very high out-patient loads, and are highly variably in quality.
3. Addressing proximal and distal mental health determinants such as employment, stigma and discrimination and social inclusion seems critical but much more difficult than
providing allopathic care. (The number of PWMD identified in our four mental health projects are summarised in Table 1)

4. Building capacity of project team and community members and developing resources to support this has been the largest commitment in time in the initial years.

5. Building knowledge and awareness on mental health among community and health providers, has lead to many community members self-identifying with mental distress and requesting support and help.

6. Even sub-optimal bio-medical care can make a difference to individual people and families. When PWMD visit Bareilly Mental Hospital, new patients get a 10 minute consultation (personal communication, SHARE project staff, 2014) yet even so, the treatment provided here means over 200 people with seizure disorders have been able to return to school, employment and other responsibilities. Similarly people significantly disabled with psychosis, depression, anxiety have a much higher level of function than previously.

**EHA - Model of Care for People with Mental Distress**

We schematically represent our three step model of care in Figure 2 below.

- **Step One** - All people need support and capacity building to build their own skills at remaining mentally well.
- **Step Two** - In addition to this some people with mental distress can benefit significantly through talking therapies.
- **Step Three** - Adding further to personal skills and talking therapies, for some PWMD, there is significant benefit from short or long term use of psychotropic drugs. Ensuring that all PWMD have the opportunity to access mental health services and specialists is also key for all of our programmes.

We have adapted a simple Five Step approach to Well-being developed in New Zealand (Mental health foundation of New Zealand, 2012) as a resource for

**Table 1: Overview of PWMD Identified in past 18 months in EHA Community Mental Health Projects**

<table>
<thead>
<tr>
<th>LOCATION</th>
<th>TOTAL PWMD</th>
<th>NUMBER CMD</th>
<th>NUMBER SMD</th>
<th>NUMBER EPILEPSY</th>
<th>NUMBER OTHER EG INTELLECTUAL IMPAIRMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>SAHARANPUR, UP</td>
<td>228</td>
<td>35</td>
<td>148</td>
<td>35</td>
<td>13</td>
</tr>
<tr>
<td>BIJNOR, UP</td>
<td>1016</td>
<td>390</td>
<td>201</td>
<td>344</td>
<td>81</td>
</tr>
<tr>
<td>DEHRADUN, UTTARAKHAND</td>
<td>251</td>
<td>135</td>
<td>60</td>
<td>34</td>
<td>22</td>
</tr>
<tr>
<td>EAST CHAMPARAN, BIHAR</td>
<td>103</td>
<td>56</td>
<td>47</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>1598</strong></td>
<td><strong>616</strong></td>
<td><strong>456</strong></td>
<td><strong>414</strong></td>
<td><strong>114</strong></td>
</tr>
</tbody>
</table>

We schematically represent our three step model of care in Figure 2 below.
building resiliency. English and Hindi understandings of this are shown in Figures 3 and 4 below:

**Summary**

Working in community mental health in rural North India is both exciting and overwhelming. There is huge capacity to bring healing and transformation for many thousands of PWMD and families who are currently isolated without care or support. There are also significant risks of doing harm if we use models of care that do not acknowledge the cultural context and promote mental health care exclusively dependent on pharmacology and Western biomedicine. These models of care are working drafts and continue to be developed iteratively. Documenting and writing about what we are learning is morally required in a context where there is very little written about effective community based mental health programmes in North India. We journey on with small steps.

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LGBTQIA & Mental Health

Navadeep*

As I sit in Hyderabad, Telangana and start working on this piece of paper about Lesbian, Gay, Bisexual Transgender (LGBT) groups and mental health from a lay gay person’s perspective with no scientific knowledge of mental health there in western India, Goa’s Sports and Youth affairs minister Mr. Ramesh Tawadkar makes an announcement on setting up centers LGBT youth to “cure” them.

Mr. Tawadkar said, “We will make them (LGBT youth) normal. We will have a centre for them. Like Alcoholic Anonymous centres, we will have centres. We will train them and give them medicines too…”. I initially thought that I would try to present here a picture of mental trauma that LGBT people go through in their lifetime and how it is mostly left unnoticed and unaddressed. But this new unpleasant incident reminded me that we still live in the times where the whole debate of looking down upon the sexuality of LGBT people as a mental disorder is very much unsettled. Saying so I would now like to project on two major aspects in this paper, one being “Homosexuality and gender identity as a mental health issue” and the other on “Mental health issues of LGBT people.”

Ideas and observations presented in this paper are not based on any specific research, they are purely based on my individual reading/experiences as an open-and-out-queer person and also from the learnings I had from my other queer friends.

The idea of homosexuality as a deviant nature emerged out of religious moralistic understanding which eventually paved its way into the field of medical sciences, got categorised as a disease (one that could be and must be treated and cured), without any proper scientific evidence. This shows the extent to which moral and ethical beliefs of religion had penetrated into the field of science. With the passage of time, there was a shift in the arguments of pathologising of homosexuality. For a good long time it was believed that children with single parents and children with troubled and abusive childhoods tend to have these perverse homosexual tendencies. The works of people like Alfred Kinsey and Evelyn Hooker during 1940’s to 1960’s challenged the notion of considering homosexuality a disorder. In 1973, the American Psychiatric Association called for voting among the board of directors to remove homosexuality from the list of Diagnostic and Statistical Manual of Mental Disorders (DSM), which was passed by members vote in 1974. Though this was a welcoming move, it did not completely end the debate of treating homosexuality. Further it resulted in creation of two categories of homosexuality, ego-syntonic homosexuality and ego-dystonic homosexuality.

**Ego-dystonic sexual orientation** is a mental disorder where the individual has a great discomfort with his/her sexual orientation and feels/expresses a strong desire to change. In contrast to this **Ego-syntonic homosexuality** is a state where the give individual is absolutely comfortable with his/her sexual orientation. Though the ‘homosexuality’ diagnosis has been completely removed from the DSM, this classification has been adopted by Indian Psychiatric Association and Medical Council of India.

This classification is a big laugh at the lives of homosexual people: given the kind of stigma, hatred and taboo a queer person often lives with, would he/she be in a situation of making an independent choice of living life as a happy queer person without a conflict of thought? With scarce support and inadequate information, most queer people would be in a state of confusion and dilemma in the initial days after realising the difference of their sexuality from that of the so called normal heterosexual crowd, would this be considered ego-dystonic homosexuality?

Adding to this, the normative and legal framework of child rights in this country is still evolving and being discussed at different levels. When a child comes out to his/her parents as gay or lesbian or if parents happen to find out about their child’s homosexuality, who decides whether a child’s homosexuality is ego-dystonic or ego-syntonic?

All these questions would project how this classification has only tried to maintain the existing anti-gay and homophobic status. To illustrate this further, following is an account is that of a trans-woman in Hyderabad who has lived through this psychiatric abuse and violence during her adolescence in late 1990’s:

“That I have been open and out as a queer person living in Hyderabad. Since my early childhood, I always knew that I was sexually attracted to men unlike others around me. I was never attracted to the opposite sex. I am the only child of my parents. I told my parents about my sexuality when I was 20 and they could never understand it. They thought that I had made a choice to be homosexual. In the past my parents put me through a battery of very traumatic and unscientific therapies (called conversion or reparative therapies) to try to change my sexual orientation.

That at the age of twenty and soon after my graduation exams, I was admitted to a psychiatric home for 8 months and was put through anti-psychotic drugs and Electroconvulsive Therapy (ECT). As these treatments didn’t seem to work to my father’s satisfaction, he forcibly took me off them very abruptly without allowing time for a reduction of dosage. I suffered two months of severe withdrawal symptoms ranging from intense fear, anxiety, fear of death and trauma.”

This particular individual’s story is just one among many such LGBTQ people who has survived inhuman
reparative and electro convulsive therapies. Although the LGBT rights movement in India has come a long way, unfortunately the medical fraternity, especially the psychiatric stream, has more or less remained in the same state of offering treatment and cure to homosexuality. Most of the people I meet in the community have been taken to psychiatrists after coming out to their parents about their homosexuality.

The fact that should be surprising is not that the parents take their gay children to the psychiatrist, but the assurance that these medical professionals offer about straightening their sexuality. The frequency at which I happen to meet people in the LGBT community who express their distress of being taken to a doctor and being prescribed anti-psychotic drugs deeply worries me. Some people go to their psychiatrists to keep their parents content and to avoid taking the prescribed drugs; whereas most of the others are forced to the clinic and are carefully monitored to ensure that they take the drugs, which in turn have various adverse effects.

Along with all this another issue, which I find difficult to digest, is how psychiatry has an absolute say about a transgender person’s gender identity. I still fail to understand how science (Psychiatry) has a final say about an individuals gender dysphoria. Instead of addressing issues such as stress, anxiety, and depression that go along with gender dysphoria how psychiatry takes the charge of deciding whether a person is having gender dysphoria or not whether they can go through hormonal therapy, sexual reassignment surgery or not leaves me perplexed.

Despite the clear stand of World Health Organization, the American Psychiatric Association, and many other international bodies that homosexuality is a normal and healthy variant of human sexuality, sadly, the state of affairs in this regard has remained regressive in India. It’s time for the mental health fraternity and set-ups such as Medical Council of India to take a progressive stand and ensure a healthy and safe living to the LGBT people in the country.

Till now I have described the still existing notion of homosexuality as a mental disorder, now let’s see where the mental health of LGBT people stands amidst a situation like this. From the studies of Evelyn Hooker in 1950’s till present-day studies, many have asserted that there is no psychological difference between heterosexual and homosexual individuals. All people – including homosexuals - go through stages of distress, depressions, anxiety disorder and also suicidal tendencies. Most of these are regarded as symptoms of homosexuality itself, and ignored as being caused by the stigma, exclusion and rejection of being a homosexual.

The roots of mental distress and depression among LGBT people can be found from their childhood itself. A majority of the LGBT individuals report being bullied and harassed as kids in school. Most of this bullying goes unnoticed both by teachers and parents. In some cases, adults hold the opinion that it’s okay to be bullied as this might cause a child to conform and behave more like a boy and more like a girl.

Constant efforts by peers, parents and teachers to correct children and make them fit into dysphoric roles of being a boy and girl causes LGBT people to develop internal homophobia. This continues further as they grow into adults; they are taught about the gender appropriate skills/manner, walk, talk, mannerism, compelling them fit into socially sanctioned, heterosexual behavior. Also, a homosexual person then needs to put a great deal of effort, continuously conscious among their peers and family, hiding their true sexual identity. This makes life no easier.

A large part of this is very much unaddressed, resulting in a great level of depression and anxiety disorder among LGBT people. Depression of an LGBT individual is very much correlated with social and personal acceptance of the individual about his/her sexuality and gender identity. By now there is lot of research which states that suicidal tendencies among LGBT youth are relatively higher than those among heterosexual youth. The responsibility of assuring an LGBT person with safe and healthy environment lies not only with family and peers but also with the mental health fraternity. As medical professionals, they play a huge role in providing society with the correct scientific information about sexuality and gender related issues. Being Lesbian, Gay, Bisexual, Transgender, Asexual and Queer is not a mental health problem. Anyone falling in these categories does not deserve to be subjected to a life which in turn affects his/her mental health adversely. As Marmor put it: The basic issue ... is not whether some or many homosexuals can be found to be neurotically disturbed. In a society like ours where homosexuals are uniformly treated with disparagement or contempt—to say nothing about outright hostility—it would be surprising indeed if substantial numbers of them did not suffer from an impaired self-image and some degree of unhappiness with their stigmatized status. ... It is manifestly unwarranted and inaccurate, however, to attribute such neuroticism, when it exists, to intrinsic aspects of homosexuality itself.

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**References**


College Mental Health: the ‘Disha’ Experience  
Sadhana Natu

Introduction

College Mental Health is a world unto itself. The world of students in terms of its cultural, ethnic, racial, sexual orientation and age diversity has to be understood. The presenting concerns, developmental issues of their stage of life and readiness for treatment have to be understood too. Every day is a new challenge. Treating a college student on campus is quite different from seeing the same student in private practice. Developmental stage challenges, stressors for the college experience, social life, self-care, change, diversity, sexual orientation academic performance disturbances, crises are some of the issues that need to be tackled (Grayson, 2007). Taking this into consideration, most of the Colleges and Universities in Europe and USA have strengthened Counselling Services in Higher Education Institutions over the last few decades.

The situation in India is a far cry from this. The University Grants Commission (UGC) 2002-03 estimates state that there are 92, 27, 833 enrollments in various Universities & Colleges. These students are facing several mental health issues on a day to day basis and a lot of them cannot afford to go to private practitioners. In 2000, the University Grants Commission made it mandatory for colleges and Universities to have Counselling Centres on the campuses, but most of these have remained either on paper or are not functional. The causes are evident: students are unwilling to access these centres due to lack of rapport with the practitioner or the stigma of seeking help.

The poorly developed Mental Health Services on College campuses are certainly a cause for concern. The concern is further augmented, since the WHO report 2014 titled Preventing Suicide: a Global Imperative has been published, which predicts that the highest Youth Suicides in the world will be from India. Earlier, according to a Lancet study, India has the highest suicide rates in the world with maximum number of young people on the brink, worse it may soon turn out to be the biggest killer in the country (Patel, 2012). Mathew Varghese, Professor and Head of Psychiatry, NIMHANS, says though there are many impulsive suicidal attempts, not all are due to depression. “Suicides in teenagers and young adults are possibly due to change in the social fabric of our society and much more complex in causation. For example, causes may vary from performance expectations, loss of family support and communication, urbanization, poverty, loss of desired objects and so on. (DNA, June, 2013). This corroborates the fact that many of the suicides amongst Youth, both in urban and rural are caused by psycho social factors.

The demographic profile of students in College campuses has changed in the last ten years. Gone are the days of the homogenous classroom and campus, with middle, upper middle class and upper class students (especially in the elite and ivy-league institutions). The campuses are full of a lot of urban and rural poor and marginalized students, students from various parts of the home state, from various states in India and from foreign countries.

Most of the Counsellors and Psychologists are not equipped to deal with this diversity and myriad aspirational dreams of this wonderfully heterogeneous group of youngsters. Neither their University training in etiology, diagnosis, psychometrics and therapy nor their superior position of a ‘healer’ has prepared them to engage with the ‘lived realities’ of these multitudes of youngsters so diverse, different and unique, who bring their own ethos and phenomenological self into the picture. Students who have already visited Psychiatrists (with venerable exceptions) are often wary of seeking help. It is against this backdrop that I wish to share the ‘Disha’ (the Psychology Study Circle) Experience.

‘Disha’ - the Background

It is both a Speak Out group as well as a Peer Support group, run and managed by the students in my college for the last 20 years. There are six coordinators and fifty regular members, a floating population of around eighty to one hundred others (apart from the fifty members) participate in all the activities organized by the group. The members are from Pune, other parts of Maharashtra, other states in India as well as those from other countries. There are first and second generation learners as well as well to do students. It is a truly inclusive group. This aspect is both a challenge and the strength of the group.

‘Disha’ - the Philosophy

A gender-just, secular, non-discriminating (on the basis of language, religion, caste and class) humane platform (these are the specificities that most mainstream psychologists and psychiatrists rarely go into) that allows dialogue, debate and dissent. It also creates a space for friendships, bonding and nurture. The commonalities and differences help to embrace ‘multiple realities’ which in turn help to look at life, issues and conflicts in a new light.

‘Disha’ - the Module

Group Discussions on topics ranging from:

• Battling with science (a huge cross that those who opt for science since it is the smartest stream and not because they like it, carry)
• Changing the stream (from science to commerce, humanities, arts, social science etc.) and dealing with

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educational hierarchies (self-esteem is affected by what stream you are studying in)
- Diversity, Inclusion and Exclusion
- Relationship issues - love, living in, marriage, one-sided attraction, rejection in love (also how these issues are complicated by caste, class and gender intersections)
- Academic pressure, Competition
- Cultural adjustment (students from other countries, states, rural areas, urban poor)
- Dealing with hierarchies - parents, teachers, ragging, sexual harassment

**Workshops on topics like:**
- Gender and Sexuality
- Gender sensitization
- Stigma of Mental disorders
- Study visits to CBOs working on mental health issues and social issues, volunteering with them, watching films and short films on psycho social issues (followed by a discussion) and a lot of other interactive activities.

‘Disha’ - the Model

**Peer Support:** The free flowing discussions help the youngsters that to realize that they are not alone (others are facing similar problems too) and also to validate their experiences. The atmosphere is non-threatening, especially when we have just the members, and most of them speak up.

**Peer Learning:** a lot of them learn by listening to the experiences of others (their age and their kind) both present members and a lot of our Alumni whose life stories are full of resilience and triumph.

**Resilience by experiential learning:** For example, the visits to organizations like SWACH where interaction with the feisty ‘rag pickers’ (the real role models) left an indelible impression on their minds. These visits are meant for interaction and are not just a mechanical exercise.

Feminist counseling and empathetic listening: Learning in grass root level organizations and engagement with feminist counseling allowed me to take a ‘hands off’ approach, of intervening only for those who come for one-on-one counseling after attending a ‘Disha’ meeting, on their own. This is based on my belief that counseling is not the only option, nor is the counselor/clinical psychologist a pre-ordained healer; and that my role as ‘Disha’ facilitator has far more learning and enjoyment than that of a ‘so called practitioner’.

During the counselling session the principles practiced are - validating experiences of the counselees; making a connection between their problems and larger social contexts; respecting their resilience and agency (Vindhya, 2013)

**‘Kaleidoscope’ - the student journal**

Students write on psychological and psycho social themes giving expression to their thoughts, emotions and angst. It is therapeutic for them and an eye opener for others. Four such stories are reproduced here.

Four Stories, Sourced from Previous Volumes of Kaleidoscope

1. Finding Myself

“I would like to share the reason I’m here as a first year arts student rather than walking around in some hospital in white coat, as was planned by me and well everyone. I’m sorry if I bore you to tears. Please bear with me for the new few minutes. I passed my high school as a science student and spent two years in medical coaching classes before I decided to be a psychologist. This change of mind is something quite consistent with my history. At age ten I was adamant on being a doctor. Then I decided to be an archeologist before I was sure I would be seeing the gates of NASA one day. No small dreams, you see. I was the golden child – the shining star of the family, made hide and seek almost impossible after dark. Then I passed tenth, all grown up, set to break records. One month in, with both mathematics and biology on my back I was sure I was meant to be a psychiatrist. Couldn’t put two concepts by Einstein together but I was probably going to Stanford for my masters. I got these weird spinning feelings when I used to look at the board for more than ten minutes. I was creating fictional characters in my head while my biology teacher was telling us how many type of leaf arrangement we can find in plants. I loved studying brain and it’s function, knew that adding something to alcohol gives you aldehyde and that every action has equal and opposite reaction – that’s about the total of what I got in the two years. I then spent two months on anti-depressants before I could give my board finals. This summer I finally put my foot down – I was done with science.

So how does it feel to attend classes these days? – Like I finally belong somewhere. Science was not Chinese for me but rather Hindi – a subject that I could read as long as I’m not asked to write it down. I am finally reading and writing the same language. And “Disha” is a big part of this new niche. When I started my classes I was content and had a plan that didn’t leave me with dread. Then I attended Disha, I realized that I was happy too, that even though I did not have many friends. I wasn’t an outsider. It is a group where every word that you say matters and you learn the value of words off stage. The group being bilingual did make me feel like banging my head against the wall sometimes but then you can’t have dishes on a platter all the time. To add to the inside joke a big thanks to our senior coordinators who never made us feel little in any form. The funniest part is how people react when I tell them what I’m studying – I mean the people who know me from...
When I embarked on a MSW course I had a tough time emotionally, mentally and financially. I was really depressed. But thank God, I could not afford the fees of a professional- I survived! My friends from Disha and my MSW course and my mentor helped to come to grips with the situation and also to deal with my problems. This journey has made me stronger and happier than I ever was. I share my story with younger group in Disha every year.”

2. Peeking into lives

“I am from FYBA and I’d like to tell you about my experience in Disha. But first, I probably should tell you a little about myself. I spent the first 15 years of my life in a Hindu household, in a Christian school and in an Islamic country. My class was always a mixture of people from different religious beliefs. My mom is a commerce graduate, my father is an engineer and I’ve been exposed to different perspectives and have been able to form my own. However, when I moved to India almost 3 years back, I felt very restricted and didn’t bother to put my point across. I didn’t want to deal with the criticism and then there were the people who didn’t listen anyway.

However, with Disha, I got a platform where I could air my thoughts without being scared of being judged. Disha helped me learn new perspectives, think more broadly and peek into lives so different from mine. It instilled a new enthusiasm in me. Here, so many people come together and share experiences which are very personal but still inspire and help us be more empathetic human beings. We visited a wonderfully enthusiastic woman named Saraswati Waghmare who is, what we would say, a rag-picker, but she is so much more beyond that. She left us all motivated, inspired and refreshed with a new spirit for life. Disha has given me a new family and a new respect for my friends and all human beings in general. Kaleidoscope is the work of months of love and interest and I hope you thoroughly enjoy reading it.”

3. I am a Role Model too!

“For the rest of the college, I did not exist. Why? I am dark, I come from a poor background, do not wear fancy clothes and I am certainly not attractive! It does not amount to much that I topped the college every year, am sincere, kind hearted. That does not matter. You have to have ‘attitude’ and you have to impress and you must be able to speak English. The only place where what I said mattered, where I mattered was Disha! It is a platform for the intellect, the mind and also emotions. Nobody judges you. Your background does not matter. In fact after I did my MSW overcoming all odds, I have been invited several times to interact with the present members and actually hailed as a role model of sorts!

When I embarked on a MSW course I had a tough
My friend Albert, social activist, was visiting a coastal village in Orissa post Super-cyclone in 1999. He saw a man staring at a human body floating, right in front of his house. He was with a blank distant stare without any visible expression of emotions or body response to an approaching visitor. Only upon repeated questioning about whose body it was, he gave a terse answer—“my wife.” He had a tired look on his face and no tears in his eyes. For the previous two days he could not get over the shock of losing everything in life, including his dear wife in the fast approaching high waves of sea water. And that dear wife’s body was decomposing right in front of him and he had not got up to give a decent burial and the last rites due to her.

Well, that is the level of depression any victim of natural disasters can go into. Often it is unrecognized and not acted upon as part of the relief operations. During the same post Super-cyclone period I have heard of children attending schools from relief camps having symptoms of deafness and blindness—manifestations as a psychological reaction to the shock of a deep trauma. These children were repeatedly experiencing the howling and whistling of high velocity wind and the sight of approaching deadly high waves swallowing their siblings and parents—probably a hysterical escape mechanism for a traumatised mind. Similar anecdotes were heard from coastal Andhra, Tamil Nadu and Andaman islands as well, during post-tsunami period.

Acute Post Traumatic Stress Syndrome is a clinical entity well recognized in the aftermath of Natural disasters. Justifiably, during any natural disaster the first concern of relief workers is to save lives and rescue all those who are still alive and limit further loss of lives and physical damage.

Relief Commissioners and their government staff as well as voluntary organizations get busy with setting up relief camps, telecommunication networks, power supply, approach roads, shelter camps, community kitchen and toilets. Provision of drinking water, food, medical aid and prevention of communicable diseases all get priority, but not mental health needs of the survivors and victims of disaster.

Many of the states do not have even absolute minimum number of psychiatrists and clinical psychologists in government services. Most medical colleges also do not have enough persons on pay rolls to satisfy even the MCI Inspection teams. No wonder mental health needs of displaced communities are ignored or kept as last priority.

In such severe shortage of required expertise, managers of disaster relief operations are compelled to provide immediate Psychological First Aid (PFA) through volunteers and paramedical staff. They may be coached to use simple psychological techniques to relieve anguish or panic and possibly prevent any need of psychiatric intervention for majority of trauma victims. However, the fundamental Principles of PFA are mostly not adhered to. These principles (Reyes and Jacobs, 2006) are:

**Protection:** Damage control or stabilization to prevent worsening further from existing level. Gain survivors attention and cooperation to move to safer places. Despondent and persons not cooperating to move can endanger themselves and others, who may benefit from moving location.

**Social Support:** Boosting the inherent coping mechanism—every individual or community has some endurance for hardships without external assistance. There are 3 categories of social support—(1) **Tangible (material) support**—Food, shelter, financial aid etc. (2) **Emotional support**—anything someone says or does that helps another person to bear up, even a caring and attentive companionship is an emotional support (3) **Informational support**—sharing some valuable bit of knowledge or information that solves their problem or gain access to resources that can reduce their misery or hardship. Volunteers for PFA require good interpersonal skills—with active yet calming, comforting, confident presence, listening more than talking, offering unreserved compassion without judgement or prejudice.

**Arousal Reduction:** Any life threatening situation like disasters can arouse fear and self protective emotions and stimulate nervous system response for survival—the “flight /fight response”. The consequent thinking abilities and emotional functioning of victims during disaster may be altered and is a ‘necessity’ for a short period but debilitating in the long run. PFA volunteer should soothe and reduce this “arousal phenomena” so that the survivor is calm and mentally at rest; able to function at a higher level and even sleep well. Loss of or separation from near and dear ones also stimulates “arousal”. Hope of reunion and frantic search for the loved ones also increase mental

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Often humanitarian and requiring referral for psychiatric treatment. Those attending schools, then paramedical workers can be trained to screen at home or neighbourhood. Survivors should be treated with respect and encouragement for their resilience, competence and dignity. They must not be clinging on to the aid workers with a dependency feeling. People tend to cope either by confronting directly, or by enduring a problem, or by managing their thoughts in minimising the emotional impact of the problem. Assisted coping is facilitating the selection of best option among these three, to solve their problem.

Supervision: There is a limit to the resourcefulness or abilities of a PFA volunteer. At times they become helpless and timid in confronting the field level issues. Supportive supervision by experienced PFA experts or mentors can solve this limitation.

Helping the Helper: Often humanitarian and philanthropic workers are very good, sensitive and idealistic personalities. They are particularly vulnerable to daily exposure to traumatic experiences of fellow human beings who for no fault of theirs have had to undergo such misery and hardships. Occupational hazards they face may include a sense of helplessness, obsessive thoughts coming up repeatedly of suffering of your clients and difficulty managing the level of involvement in the lives of others. In their enthusiasm they may feel they are not getting enough back up and the organization they represent is inefficient, inadequate, insensitive and even corrupt. Practitioners need themselves compassionate ‘self care’ to withstand ‘burn out’ syndrome. They must be encouraged to avoid long shifts, take mandatory breaks during duty hours and compulsory home leave after continuous working weeks for recuperation.

Screening and Detection of those who need Psychiatric Help

Once the relief camps are established, certain group therapy and counselling services could be undertaken by the deputed clinical psychologists or the paramedical workers trained specifically in management of grief. If families are already disbursed from the camps and they are back at home or children are attending schools, then paramedical workers can be trained to screen at home or neighbourhood, those requiring referral for psychiatric treatment.

Psychiatric Help through Primary Physicians

If the ground reality is such that no psychiatrist is deputed or available for daily duty in relief camps or in the vicinity of affected villages, a team of MBBS doctors can be trained on how to treat acute post trauma stress syndrome. Algorithms of management of locally prevalent most common diagnosis, based on situation specific signs and symptoms can be taught to those MBBS doctors. The options of medications like anxiolytics (Diazepam, Alprazolam, Lorazepam) antidepressants (Imipramine, Fluoxetine) should be limited to absolute minimum for common disorders. Those with severe breakdown may be psychotic and need antipsychotic medication, which must be made available in full at each camp site. Those prescribing and dispensing the medicines must emphasize the need for intake of correct and regular dosage, with information that many medicines take time even up to two weeks to start producing the desired results. The psychiatrist who volunteers or is deputed to train these primary care physicians should take “vicarious responsibility” and must be available for clarifications or consultation over phone or internet or for videoconferencing. Ready-reckoners and handbooks for case management should be prepared and made available adequately.

Conclusion

Psychological needs of displaced communities in transient shelters and victims and survivors of natural calamities living in their homes are seldom addressed systematically by government or international donors. Often it gets no deserving priority and attention by relief workers or civil society organizations as well. Training in mental health given to undergraduates in the Indian medical curriculum is also extremely inadequate. Professional organizations of Psychologists and Psychiatrists must come forward to address this situation. Protocols and handbooks for management and training modules for health staff should be designed, in addition to drafting policy guidelines. One such manual was created after the Bhopal Gas Leak disaster in the early 1980s but this may need updating. National Disaster Management Agency must show stewardship to issue clear-cut directions to states to include this critical aspect in their Disaster Preparedness Plans.

Author acknowledges inputs from his former classmate Dr. Ajit Bhide, Psychiatrist, St. Martha’s Hospital, Bangalore.

References

One and half decades of Basic Needs India’s Community Based Mental Health and Development Program: An Analytical Overview

Mani Kalliath, Vandana Bedi and Guru Raghavendra*

1. The Background

During later part of 1990’s, in absence of a reliable District Mental Health Programme, poor Persons With Mental Illnesses (PMMI) and their family carers faced the reality of only care option being informal and traditional care associated with certain religious centres. The voluntary agencies (NGOs) involved in Community Based Rehabilitation (CBR) of disabled persons or in Community Health did not enter into mental illness issues, though it was confronting them in the field situation. This was considered a complicated medical problem requiring specialized psychiatric intervention and hence beyond their purview. The pioneers involved in promoting CBR were faced with the challenge that community based rehabilitation interventions were conspicuous by the absence of mental illness rehabilitation, despite the Disability Act, 1995 defined severe and chronic mental illness as one of the 8 disabilities.

Sensing the potential opportunity for promoting CBR in mental illness after the World Health Report 2001 and subsequently launched Global Action Program on Mental health, a farsighted social entrepreneur in the rehabilitation sector, Mr. Chris Underhill, teamed up with his long-time associate Mr. D.M. Naidu, initiated a non-institutional approach to mental illness rehabilitation. Mr Naidu spent a year visiting and studying the then existing community extension efforts towards mental illness in the country, and interacting with the various stakeholders of this issue- this lead to the registration of ‘Basic Needs India (BNI) Trust’ in 2001, and subsequent registration of Basic Needs U.K Trust, both meant to systematize and structure this effort. Consultations with relevant stakeholders from the local community brought to light and articulated the ‘felt needs’. These consultations contributed to the development of a conceptual frame for a community based approach. The large list of needs identified were subsequently strategized into intervention modules. The initial conceptual frame was also influenced by the learnings in CBR sector, particularly regarding the importance of realizing productivity by the affected individual. Economic productivity (earning money) or at the least contributing to the family chores, was recognized as an important contributor to ‘self-respect and self-image’ of the affected individual.

2. The Evolution of the Intervention Modules of Community Based Mental Health and Development (CMHD)

The excitement of the early stages of the development of this community based approach is captured in the early writings of the BNI. We are trying to capture the essence of those early documents in this section:-

A series of consultations took place in the field with mentally ill people, their caregivers and staff of CBOs, with the participants divided into these three groups that discussed and depicted the world of people with mental illness. The carers expressed their apprehensions about mentally ill people discussing about themselves, however, the presentations revealed that mentally ill people shared nothing but the truth and that other presentations were coloured by their own misconceptions and intentions- which was a revelation. This exercise was followed by ‘needs’ and ‘what next’. The ‘voices’ of the participants were the potential seeds initiating the programme. It dispelled the myths and laid a solid foundation for inclusion of people with mental illness into the development process. The need for both mentally ill and carers to meet often on a common platform was conspicuous and they all wanted access to treatment, enhanced family incomes, social integration, training and other capacity building. All the stakeholders sitting in a circle expressed their determination to take the cause further. At the end of the day debriefing sessions contributed to the depths of understandings.

Consultations were held with the NGO project heads and staff to give meaning to bottom up approach… The exercise was guided by the previous field consultations ‘needs’ and ‘what next’. The needs list was classified broadly into - appropriate treatment at local level and follow-up; economic independence; and social integration. Training and skill development needs from the staff were also incorporated. Heads of the organisation expressed need for strong administration and management support, to make these happen. Need of the whole process to be converted to modules emerged, as this was such an important work for the neediest people. The work under each module was discussed and agreed upon. Further discussions defined the roles and responsibilities of the participants in implementing the model. This model was accepted and agreed to be implemented by all other partners who joined later. To ensure effective implementation of this model, a MoU was signed with each partner incorporating the expected outcomes under each module. The implementation structures developed for the partnership included:

• At the BNI level a Program Manager was responsible for certain number of partner organisations located in
particular states.

- Each of the partner NGO had a staff person designated for the mental health work, namely, the Mental Health Coordinator
- The cross disability program of the NGO now included the mental illness rehabilitation, and the field staff for this reported to the Mental Health Coordinator

How does this work?

At the beginning, community consultation earlier mentioned is repeated in each partner location, starting with the work plan with each of the PWMIs and their family carers. The ongoing consultation process ensures that the primary stakeholder’s participation is strengthened and the roles of the different groups are made mutually clear, setting the tone for the long term relationships and guarding against dependency relationship setting in.

Community Mental Health

The coordinators and field staff of the partner NGOs gets trained in identifying, screening, referring to treatment and very importantly following up regular treatment and addressing side effects. These barefoot workers become the turning point in giving meaning to the community mental health module. With the diagnosis and treatment varies from place to place, approaches include, camps organized by Partners (and Government agencies); and people going to district hospitals, mental health institutes, and private psychiatrists- including access to alternative treatments like Homeopathy and Ayurveda by some. Majority of those who are regular get stabilized and very few relapses are noticed. People with Severe Mental Illness- who are highly symptomatic, whose behaviour was seen as major problem and their family members would have given up hopes- show dramatic and magical changes for the better in fairly short time. Concerns about dropouts, drug regime and other physical ailments associated with mental illness are discussed with family carers.

Sustainable Livelihoods

One of the main reasons for people not to accept mentally ill people as equal members of communities is that they are not seen as capable of contributing to the community or to the income and livelihood of the household. Thus, the programme ensured that after stabilisation, consultations take place regarding some gainful occupation for the affected people. Planning done after taking all illness related issues of the PWMI into consideration, giving first preference to ‘going back to the previous work’. Whereever previous work does not suit, new enterprise developed assessing the skills, market, financial viability and coping abilities. Here, family is seen as one unit hence the entire family’s needs and current income patterns considered. Joining the self-help groups, micro credit groups, accessing loans and accessing money from government schemes and other financial institutions were also seen as important. This followed with necessary preparation and training to all concerned i.e. mentally ill person, caregiver and field worker.

Lakshmana, a person with mental illness from SACRED project area, was denied opportunities to learn his family trade of weaving and he openly confronted his mother in the very first consultation meeting. The same Lakshmana today is weaving, earning around Rs.2,000 a month and is married.

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**Figure 1. BNI Approach/Model - at a Glance**

*The Community Mental Health and Development (CMHD) Model*

- **Community Mental Health:** To bring easy to access and cost effective treatment to people, especially from the public health systems.
- **Capacity Building:** To sensitize and develop the ability of health personnel, communities, family members and persons with mental illness themselves, to deliver comprehensive support to the lives of persons with mental illness.
- **Sustainable Livelihood:** To enable persons with mental illness and their family members to get involved in economically viable activities, including returning to their earlier occupation.
- **Research, policy and advocacy:** To generate data and evidences from programmes; to influence change in policies and procedures; and to support advocacy work.
- **Administration & Management:** To Develop systems in the organization, to ensure the quality of programmes and optimum use of resources.

These components aimed to strengthen persons with mental illness and their families to be self-reliant, free of stigma and to facilitate access to public provisioning systems, namely health care and social security entitlements.
Capacity Building
This has clear focus on the different levels, i.e. person with mental illness, family members, community, organization involved and others. The techniques used are animation and facilitation either in a meeting or in workshop. It has always been drawing from people and not preachy. Therefore, the building of capabilities at all levels takes place in a planned way, meaning through home visits, group meetings, staff meetings, workshops for caregivers, staff, local communities, review meetings, plans and budgets, etc. Awareness building on existing laws, government schemes and entitlements and preparing them to lobby for their rights and networking among partners is an important aspect of capacity building. Partners are involved in annual reviews and preparation of plans and budgets.

Evaluators from Big Lottery Fund recorded their experience of seeing a street theatre performance related to the programme, raising awareness on major mental health issues. The performance largely engaged the community, and the audience approached BNI staff with questions after the play. However, part of the play appeared to ‘preach’ to the audience. This was noted by BNI staff and was taken up with the project manager. According to the evaluators, this emphasised the importance of BNI staff observing project staff undertaking activities during visits on a regular basis. -- The need to take a critical look at awareness materials and cultural programmes was noted as a key issue at the partner review meeting during the end of the year.

Research and Policy Advocacy
Training is imparted to field staff to gather data and to record the same in a manner that helps the worker, organization and to disseminate such information for the good of the users of service. The outcome of the training was the format for individual files. Jointly with partners a format has been devised for sending quarterly reports, which captures both qualitative and quantitative information, using which the partners track changes in each individual case. Life story writing is also an intense process by which mentally ill people begin to narrate their experiences, situation in their own ‘Voice’. These stories have been followed up regularly, and have been edited and used for advocacy, later. The analysed data are being used by the partners in advocacy with the district administration for better provisioning of services and policy changes where possible.

A powerful example of this is the achievement of a partner, with the support of a disability advocacy resource, in AP. Through their efforts the policy for participation of disabled persons in the MNREGA program was expanded to accommodate and include PWMIs, opening the gates for stabilized PWMI to gain regular wage income up to 150 days a year, under the MNREGA.

Evaluators from Big Lottery Fund, after meetings with panchayat members and community leaders, noted that mental health issues were clearly being discussed at panchayat and Gram Sabha meetings. The individuals that they met were clearly engaged in the work of the project, and had a number of ideas about how to undertake further awareness building and improving service delivery in the community. Project staff, according to evaluators, recognised that they need to engage more with these influential members of the community, utilising them more strategically in advocacy work.

Management & Administration
BNI team closely work with the partners, right from the preparation of plans and budgets through the mental health coordinator. The management responsibilities include arranging required training for all the modules, monitoring the progress, getting quarterly reports and financial statements and analysing them. Conducting annual reviews and evaluations and taking mid-

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course corrections, supervising and ensuring proper implementation of research module, disseminating all the necessary information, arranging visits with prior intimation, getting audited financial statement of annual accounts form the important elements of management.

3. The Second Phase of Rapid Expansion - through Partnerships

During the ‘start-up period’ of the initial 2-3 years, the BNI was intensively engaged with the affected groups and the ‘primary NGO partners’ and in the development and the evolution of the CMHD model. This was facilitated by several positive factors, including flexibility offered by start-up funding; relative geographical access to the initial ‘primary partners’ i.e. within 4-5 hours by road; and intense interest and involvement of the BNI team and trustees. The outcomes were rewarding and affirming the relevance and usefulness of this comprehensive approach.

The start-up phase of CMHD approach led to its second phase, marking a radical expansion, both in terms of locations and partners. Two types of partnership came into being - one termed ‘primary partners’ with whom the first phase was launched, who were small organisations working in CBR; the Secondary partners with whom partnership developed in the 2nd phase were ‘nodal NGOs’ i.e. large NGOs supporting several partner NGOs themselves. As a result the CMHD work got initiated in pockets of 38 districts in 6 states (22 in the southern states and 16 in the states of Bihar and Jharkhand), securing a 4 year funding. The targets were identified and listed, for the numbers of PWMIs to be identified and supported through the five modules. The project was designed to keep with the ‘sustainability principle’, with a reducing funding for the year 3 (50%) and year 4 (25%).

The role of the BNI also got changed - decision making related to engagement with the affected people, the immediate responses made and the strategic directions taken were moved to the partner locations and the BNI role was become that of a supporter’s – around routing timely resources; assisting in monitoring and meeting of agreed targets; consolidating data for reporting as well as for analysing trends; and providing technical support wherever needed.

Put together, the community mental health programme promoted by BasicNeeds India through 6 partners in southern India had covered 6448 people affected by mental illness by December 2007. Overall outputs of the partnership programs and outcomes during this phase were large, as excerpted below from various reports.

The Impact Seen/Experienced/Voiced
- Early identification and access to treatment locally
- Reunion of families where the couples got separated due to mental illness
- Partner organizations have been invited by district authorities to be the NGO representative for various committees
- Association of care givers was formed in the project area, they are meeting regularly to discuss mental health programme.
- Marked increase in identification of women with mental illness
- Women with mental illness actively participated in all the events organised on behalf of world women’s day and represent federations as executive members
- Increase in self-esteem among people with mental illness.
- People with mental illness are having confidence that they can raise their economic status.

(Annual Report, 2004)

“The most impressive aspect of the project is its success in mainstreaming the issue of mental illness into existing development organisations. This has enabled mental illness to be dealt with holistically, addressing the three areas of concern identified by people with mental illness; treatment and stabilization of their condition, income generation, and social integration... A number of partners have already met their targets for identification and treatment of people with mental illness, even before the half way stage of the project. The project has been very successful in raising awareness of mental illness in the community, and reducing stigma experienced by people with mental illness. Community involvement in raising awareness and promoting the project has been strong. The project has excellent links with government at all levels, and in some states has had great success in lobbying for changes in policy and practice”

(International Grants Officer, Big Lottery Fund: from the mid-term review, Annual Report, 2005)

Further Outcomes
- Treatment and medicines available in 23 of the 38 districts
- Medicines made available at block level hospitals in Karnataka
- Partner organizations succeeded in activating the DMHP in Kanyakumari district in the South. There was collaboration and activation in Dumka and Godda districts in Jharkhand
- General Practitioners got trained in mental health issues in Karnataka and Andhra Pradesh
- Prisoners with mental illness accessed treatment regularly in Hazaribagh Central Jail
- Persons with mental illness and families got 90% concession in train and bus fares to attend mental
health camps in Jharkhand
- Housing schemes were accessed by the homeless
- 75 people got work under the National Rural Employment Guarantee schemes
- 2680 people with mental illness have been integrated into self-help groups
- 1158 people were given loans by financial institutions, government schemes and BNI for their livelihood
- A few eligible people got identity cards
- Understanding and support from the police and the judiciary

(Annual Report, 2006)

Extract from Evaluation Report
- The most significant outcome of the BasicNeeds India programme is the establishment of the community mental health programme for poor people from rural areas, who otherwise would not have been able to access the needed treatment. The programme has been very successful in activating and building capacity of the government health system and other local government institutions to respond to the needs. Generating awareness in the rural communities that mental illness is treatable has significantly reduced the stigma and superstitions associated with this illness, leading to increased voluntary reporting, identification and referrals by the community.

- The second major outcome is the participation and inclusion of people with mental illness in their families and communities. People with mental illness have had their self-worth restored, are involved in productive activities, and their human rights are protected. Alongside, their care givers’ capacity and awareness is raised.

- The third significant outcome is the capacity of community level groups such as self-help groups and federations of people with disabilities to deal with the issue of mental health in the community, using a rights based approach.

- Another outcome is the internalisation of mental health and development policies and practice by the NGOs and CBOs who are BasicNeeds partners, and their capacity to deal with this issue, which has led to improved public profiles for these organisations’.

(Evaluation of BNI CMHID Programme, 2008)

An Urban Intervention
During this period an urban CMHD initiative was also started in the Bangalore city through partnership, which eventually covered a population of 2 lakhs slum dwellers. About 1,000 PWMIs and families were enrolled into this program, majority of whom made significant improvements and recovery. Two ‘work therapy’ units were initiated in the slum areas which were helpful for very chronic PWMIs. Earning a small income for the first time (in their recent memory) did much to improve their self-image and also families’ perception of them. A counselling / therapy centre was initiated and the ‘more difficult families’ were referred, supported by City Corporation, a CSR group, and a Counselling resource group. Remarkable changes were noticed in those limited PWMIs and carers, who attended a minimum of three sessions. An important change observed was related to ‘insight development’ in several chronic PWMIs and hence lasting improvements in their relationship skills. In the latter part of this program a federation of ‘Carers, stabilized persons and supporters’ was formed. With the strong support of the state level cross disability federation KARO, they succeeded in advocating and realizing access to medical care. Their sustained advocacy resulted in the appointments of psychiatrists in the three district level hospitals in the city and availability of psychiatric medications in these centres. This program gave the opportunity for the newer team members of the BNI to engage directly with the affected groups, also to explore innovations. Though an important step, this could not be sustained as the intensive resource requirements for could not be managed.

(Voices Uniting for change, BNI Sep 2011)

4. Some Learnings from Critical Reflections of the Experiences

During the second (expansion) phase the data from the field showed two sets of contradictory trends:
One was the continued attribution to medicines for the gains made, by the affected groups. This was in contradiction to the fact that only one of the five CMHD intervention modules relates to treatment. A field based research study was initiated on the ‘roles of caregivers’ in mental illness rehabilitation’.
The study found that family care givers contributed significantly and played multiple roles in the total rehabilitation load, at great personal cost and sacrifice to themselves. However they themselves as well as other stakeholders were undervaluing their contributions. There is need to acknowledge this invaluable contribution institutionally by the program and at the public policy level.

A second contradiction that emerged from the data sets is related to the gender imbalance of the program in the project areas of northern states as compared to the southern states (the ratio of men and women in the project area varied from 90: 10 to 52:48). Another field based research study was undertaken, while simultaneously steps for gender sensitization were undertaken. The gender sensitization efforts were addressed at the partnership teams at all levels as also in some refinements in the intervention strategies. The study brought out that the factors of gender discrimination existing in the general society were
responsibility for the gender imbalance observed in the CMHD program. The proactive steps undertaken gradually helped to change this situation, especially in the northern states where the situation was acute.

In the southern states the partnership field programs have been followed up by the BNI periodically after the end of the 2nd phase (though there was no funding relationship). Though several of the NGOs managed to integrate the MI concerns into their priority of focus, there were severe constraints for funds experienced by several partners leading to re-allocation of the CMHD staff to their other programs and decreased intensity of focus on this program. At the end of 3 years of ‘non-funded activity’ a consolidation study was carried out in 2011 to understand the ground situation in the southern states. The data collected brought out some impressive achievements especially from the point of view of sustainability. In general it was observed that majority of the gains of the active period were sustained and that community level stakeholders were actively involved in sustaining these gains. It is important to say here that an ongoing hurdle in promoting sustained community based rehabilitation in mental health is the dependency on external funding, and the fact that there are very limited funders interested in community mental health. The funder perspectives and policies are guided by the mainstream understanding of Mental Illness rehabilitation i.e., disease oriented approach or the ‘medical model’. The ‘CBR or empowerment model’ is yet to gain currency. As a result there is the potential for ongoing tension between the implementing group and the funder and efforts at influencing funder perspectives from the CBR perspectives is urgent.

Finally, an important skill transfer which could not be brought into the earlier phase was the ‘psychosocial rehabilitation skill transfer’ to the families and supporters. Some families had expressed this need at the very beginning, through their unmet expectations and frustrations with the PWMI, around their economic contributions. As ability to transfer such skills is a rare competency even among MH professionals- further rare in the rural context - this area needs more innovative efforts.

Developments during this period demonstrated the enhanced role and potential of primary stakeholder organisations promoted by the partner NGOs. They had become effective players in MI rehabilitation through demand raising and accessing needed resources both within the community and from the state services. The story of Narendra Foundation in the Pavagada Taluka of Karnataka is a powerful example. The NGO partner had a long term vision and built up empowered grassroots stakeholders over the ten years of its implementation work. The cross disability federation gradually grew in strength and autonomy, integrated mental health concerns into its priorities. The founding NGO completely withdrew from the scene at the end of the planned period. The taluka level cross disability federation (Swami Vivekananda Federation) has successfully engaged with taluka and the district administration, for the mandated entitlements of the 3% reservation of Plan Funds as well as for medical services. The grassroots activists of the federation influenced the Karnataka state policy to promote a cadre of disability workers at the panchayat level – The Village Rehab Worker (VRW). Many of the federation members function in this capacity and sustain their activism.

Observing the new directions being charted out by few effective partners through building up and empowerment of the primary stakeholder groups, the BNI was challenged to build upon the learnings emerging and build capabilities across the partnership. One initiative started on a pilot basis was ‘Fellowship in Community’s Leadership for Mental Health’, to build the grass-roots stakeholders to become community’s resources in mental health.

5. The Third Phase – Post Expansion

The holistic CMHD approach was established as suitable to meet the quality of life needs of PWMI s and families as a result of the successful scaled up phase of intervention. The model had been replicated successfully by several development organisations in the north and south of the country. These organisations, none of them specialized psychiatric care groups, agreed to sustain their involvements in this issue at the end of the partnership phase. The ‘Consolidation Study’ confirmed that by and large the gains made were sustained (without depending on direct funding mobilized by the BNI). The BNI had discontinued dependence only on one foreign source for its funding (channelised through BN U/K). However alternate sources of funding in mental health were difficult to access, especially for southern states. Despite this, this phase has the maximum involvement of PWMI s in the program, touching the figure of 20,000- an equal numbers of family carers were also involved. During this phase, intense reflections at the BNI level were more focused on future strategic direction. Three strategic directions developed over this period and are still going on:

1. The learning of CMHD implementation were consolidated into trainings in partnership with TISS and several such trainings were offered to senior functionaries in the development sector and a few in the governmental sector. A trainer’s manual ‘People in our world, Community Mental Health and Development, The Practices’, Nov. 2009, has been jointly developed with TISS and is available.

2. The BNI has become technical resource agency
for larger CBR networks and organisations, for integrating CMHD into their larger CBR programs. Presently 4 medium term district level CBR programs are getting implemented, integrating CMHD in the southern states of AP, Karnataka and TN. The sub-partners of these CBR networks and organisations are effectively supporting empowerment of large numbers of PWMI and families. Through support of an Indian Foundation, new CMHD project was initiated in the states of Orissa and Maharashtra. This program is presently working through 11 partners in parts of 9 districts in these two states. The learnings from the decade long implementation experience is adding value to this program and the innovations tested are getting integrated.

3. A Fellowship program was initiated and tested to develop and promote grass root activists leadership in ‘Community’s leadership for Mental Health’ in partnership with several people’s organisations in Karnataka. Three batches of grassroots activists were intensively trained for one year each (totalling roughly 70 members). Most of these Fellows have continued being active in their local communities, finding meaning in their involvements and facilitating ‘communities’ leadership in mental health’.

Conclusion

Basic Needs India and partnership’s one and a half decades of interventions in the community mental health sector have demonstrated the effective roles of development agencies in mental illness rehabilitation. Partner organizations from the north, south, east and west of the country have intervened in a holistic manner, in support of PWMI and family carers, for meeting their own needs. In these locations mental illness rehabilitation is no more a complex and unsolved issue, hidden in stigma, superstition and neglect. Through this process these primary stakeholders have also become empowered to varying extents, to become agents of change for mental health concerns in their communities. One more significant result is that the public care system have started delivering services, though within existing provisions, in a sustained manner. The affected people and families are experiencing a better quality of life too.

Community health movement ushered in from the 60s through pioneering community health programs, established the roles and responsibilities and empowered individuals and communities for their own health. Some niche areas within the broader health sector, such as mental health, continue to remain an island of bio-medical domination, with limited variety of resources available to the affected. It is necessary for empowered individuals, people’s organizations and communities, to claim back ownership of mental health concerns. The roles and responsibilities of multiple sectors and actors (both state and community) need to get established and result in multiple resources available for mental illness rehabilitation, as also mental health promotion. This process would hopefully result in psychiatric resources playing their important role, yet not be the dominant role player in mental health sector. However, the CMHD model continues to evolve to become more and more rights based, locally relevant and effective.

Three macro level developments add further hopes to this:

- UNCRPD (United Nations Convention on Rights of persons with Disabilities, 2007 signed and ratified by India), that ensures equal human rights including equal recognition before the law (Article 12) to persons with mental illness.
- WHO promoting community based rehabilitation even for persons with mental illness (WHO CBR Guidelines, 2010). The CMHD model aligns with basic principles of UNCRPD and WHO’s CBR approach. Hopefully a great potential exists, for adoption of such a model at a macro level in India, especially when the model has been successfully replicated in different States.
- District Mental Health Programs are proposed to be universalised to all districts as part of the 12th five year plan in India. Effectively implemented CMHD has potential to educate the affected groups and their community on the needs and rights of PWMI as well as the scope for mental illness rehabilitation approaches, which could help to raise community’s demand for mental health services and entitlements. Envisaged universalisation of DMHP would be effectively complimented by this multi-sectoral and empowerment oriented approach of CMHD.

Endnotes

i. Process documents from exploratory meetings conducted by Basic Needs with People with Mental Health Problems, their careers, and supporting Community Based Organisations, by Sonykuty George, Oct 2000.

ii. These are mainly from the Baseline Document March 2003 by Naidu D M, during the 3rd year of the startup work. The various older internal documents were also referred to, from the period 2000 to 2003 March. Process documents of Mitra Jyothi, SACRED and Narendra Foundation were referred too.

iii. From Partners’ Reports (CMH module)


v. From the process documentation - figure represents the earning in the year 2003.


vii. Based on Report on training


ix. BNI & NBJK. Gender Perceptions of Families and Communities, in Community Mental health and Development Programs, a Report, 2012
Mental Health Policy in India: Unpacking the ‘Right to Mental Health Care’

This paper is an attempt to foreground the contradictions inherent in different policies related to mental health and promotion viz., the NMHP, the UNCRPD, the proposed National Health Policy (NHP) and the Mental Health Care Bill (2013). The paper is a call to shake this status quo by examining critically the continuing ‘medicalisation’ and ‘individualization’ of mental illness whereby ‘distress’ is being continuously diagnosed as ‘illness’ stripping the ‘agency’ of suffering individuals.

National-Level Policies in India: ‘Right to Mental Health’ or ‘Right to Mental Health Services’?

National Mental Health Programme (NMHP)

There have been various policies formulated at national and international levels with regard to mental health and disability. The first one to be rolled out in India was the National Mental Health Programme (NMHP) in the year 1982 with particular emphasis on community participation in the mental health service development and to stimulate efforts towards self-help in the community. The policy objectives of the NMHP have not been met because in practice it has become an administrative affair of distributing medicines quite divorced from the community it is supposed to shake hands with by nurturing collective adaptation and building social support systems. The NMHP has failed to address the social determinants of mental health and illness through inter-sectoral engagements. There is little data on community mental health from a community or developmental perspective. While ‘prevention and promotion’ of mental health has always been a policy objective through the National Mental Health Programme 1982, ground level practice has focused on mental illness and tertiary care treatments (Jain & Jadhav, 2009).

United Nations Convention on Rights of Persons with Disabilities (UNCRPD)

The UNCRPD adopted on 13 December 2006 at the United Nations is intended as human rights instrument with the aim of changing attitudes and approaches to the persons with disabilities. The UNCRPD which was ratified by India in the year 2007 has been progressive in including psychosocial disabilities under its umbrella. Article 26 of the UNCRPD states that,

“States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services”.

Further, Article 28 states,

“States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability”.

UNCRPD has thus brought about a social perspective about mental health replacing ‘mental illness’ with a forward looking term of ‘psychosocial disability’ drifting away from the earlier biomedical model of mental illness. Yet, how far it would be implemented in letter and spirit in India remains to be seen.

Mental Health Care Bill (2013)

The Mental Health Care Bill, 2013 piloted by the Ministry of Health and Family Welfare, Government of India is intended to replace the Mental Health Act, 1987 to push forward reforms in the mental health sector. Unfortunately, however, the Bill has narrowed down the scope of mental health care to merely increasing access and availability of psychiatric facilities and medicines free of cost. This is far from what is envisaged in the UNCRPD which exhorts mental health professionals to recognize and

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address the social barriers to wellbeing and to design disability-sensitive mental health programs.

The clause of Right to Mental Health mentioned in the bill defines the right as access to mental health services by integrating mental health services at all the levels of health care, namely, PHC and CHC close to the residence and scaling up access to psychiatric drugs free of cost at the nearest vicinity. It reads as follows: “Every person shall have a right to access mental health care and treatment from mental health services run or funded by the appropriate Government. Nowhere is it mentioned that right to mental health would go hand in hand in securing rights for the deprived sections of the society and improving their quality of life.

The Bill further states that “Mental illness of a person shall not be determined on the basis of,

(a) Political, economic or social status or membership of a cultural, racial or religious group, or for any other reason not directly relevant to mental health status of the person;

(b) Non-conformity with moral, social, cultural, work or political values or religious beliefs prevailing in a person’s community.”

Yet, it well-known that non-conformity to certain social norms (e.g. alternate sexuality) is often pathologised and treated with anti-anxiety and anti-depressant drugs, without exploration of the social cause of the anxiety/depression.

Draft National Health Policy (2015)

The draft National Health Policy, 2015 which is placed in public domain by the Ministry of Health for feedback, comments and suggestions aims to improve performance of the health systems. A preliminary survey of the proposed National Health Policy reveals that it has also not been able to conceptualize mental health in its psychosocial aspects; it is silent about addressing the root problems of social inequality, injustice and other deprivations that give rise to distress. The focus has been on telemedicine linkages, integration with primary health care, easy access to follow-up medications and increasing access to mental health care services by increasing the number of mental health professionals to fill the gap. In a nutshell, there is a quest to equate mental health with that of physical health in every respect.

Medicalisation and Individualisation of Distress

One of the awareness campaigns published in a national daily by the Ministry of Health and Family Welfare, Government of India on World Mental Health Day a few years back read as follows: “Mental illness is a brain disorder” which is an explicit recognition by the state that mental health care is nothing but treatment of the brain and this would naturally entail extending and scaling up of medical services for mental health problems.

At the same time, scholars have pointed out the limitations of the biomedical model with regard to explaining historical and intergenerational trauma (Yankovsky, 2014). Even if a patient’s distress is rooted in extreme poverty that he doesn’t have money for a square meal, the tendency among the psychiatrists is to individualize the problem and term their distress as illness and treat with pharmacological agents.

The disadvantaged people’s attention is deflected from the deprived socio-politico-situation in which they are in, towards their supposedly compromised brains. Thus, for example, the governments of many states in India had sent a team of psychiatrists to prevent farmer suicides-a knee-jerk response-without paying attention to the macro level agrarian crisis and consequent widening of social inequalities (Mills, 2014). This exemplifies what Rose (2013) refers to as expansion of the scope of psychiatric treatment to treat social problems and social deviance by posing that psychiatrists can identify and ameliorate the miseries that plague society in various forms by drugs. Every distress arising out of a person’s compromised social environment is termed as illness and treated with psychotropic drugs reinforcing the false notion that pills can cure life’s ills.

Disability scholars like Mehrotra (2013) have drawn attention to the need for a social paradigm of mental health that frames distress as not just rooted in one individual but as affected by the micro and macro forces surrounding the person. Giving a diagnosis to a person beset by social problems would be akin to symbolic violence which then legitimizes social order based on inequality. Reddy et al. (2013) state that most strongly associated factors with mental disorders are deprivation and poverty. Reducing discrimination against sex, caste, disability and socioeconomic status is an important aspect to reduce
mental disorders (Reddy, 2013). They further state that national mental health policies should not be solely concerned with mental disorders, but should also recognize and address the broader issues which promote mental health which includes education, labour, justice, transport, environment, housing, and health sector.

Rose (2014) has drawn attention to the expansion of psychiatric gaze which medicalises even common life problems that are encountered by everyone on earth. As a trainee clinical psychologist in LGBRIMH, Tezpur, I was a witness to such psychiatrization of social distress. Half of the patients who thronged the OPD were migrant Muslim women from Bangladesh’s Sylhet district. Many of them experienced constant, chronic trauma in multitude forms of illiteracy, poor nutrition and poor sanitation. Most of them were daily wage labourers engaged in manual work. These women often presented themselves in the OPD with physical complaints such as aches. I was always struck when they were prescribed with a bunch of antidepressants and anxiolytics (under the diagnosis of mixed anxiety and depressive disorder, somatisation disorder, conversion disorder etc.) by the psychiatrists. They were also advised to come for follow-up every month to replenish the supply of medicines handed out free of cost by the Government. Talking to these women revealed many stories of resistance and struggles. But for the psychiatrists, they were merely ‘Sylheti psychosomatic’ women to be prescribed with medications. Their social problems became essentialized as problems within themselves, within their brains, consequently depriving them of agency to act against injustices or improve their conditions by other means. This has been referred to as the creation of “somatic individuality” by Rose (2006) whereby we are disguised to think that all our states of mind are invariably caused by neuro-chemical imbalances and can be rectified through medicine. Poverty and unemployment are both causes and effects of disability. Pharmaceutical companies add to this by employing disease awareness programmes.

In fact, the diagnostic category of ‘psychosomatic disorders’ has become so common that it subsumes every individual who seeks mental health care with presenting complaints of physical complaints without a known physical etiology. Even I was a victim of this extreme form of psychiatrization when I was diagnosed as homesick (‘adjustment disorder’) as a student of clinical psychology when suffering from high fever and weakness. Since the medical investigations turned out to be negative for TB, even though my symptoms were indicative of TB, I was given a psychosomatic label by psychiatrists, who commented on my introverted and withdrawn nature. I was later found to have Extrapulmonary TB at an advanced stage.

Recent research has found that more and more people in India are on mood stabilizers. Ecks’ (2005) research in Kolkata found that India is one of the world’s biggest producers of pharmaceuticals. The spiraling of events stemming from social demarginalisation to accessing of psychiatric medications is explained in the article with a broader worldview based on the ‘global monoculture of happiness’ and how the psychiatric medications travel to reach the marginalised citizens who yearn to make both ends meet toiling hard with poverty and other social disadvantages.

All these studies draw attention to the need for a holistic approach which is rights based. For this to materialize there is a dire need to shift the lens to asocial model of distress and to redefine mental health as entirely different from physical health which cannot be simply reduced to the brain.

References

How to Think about Chronic Diseases for the Mid-Annual?

A Summary of Email Exchanges in the mfc e-group

What are the different ways in which to approach the chronic diseases question based on different conversations with Anand, Yogesh, Malini, Sathya and Anurag? Some discussion on these aspects would help us understand the problem in the Mid-Annual 2015. Please feel free to add...

1. Clinical questions -- the specificity of the disease, regional variations in presentation and disease progress, prognosis, etiology.
2. Epidemiological questions -- projections, accuracy, ‘disease mongering?’ How do these connect with the clinical ones, what are the links between the rural and urban in the patterns of the disease? How do we think of urbanization in relation to NCDs?
3. Public health questions -- existing PH initiatives for NCDs in India, structural questions on Public Health capability to work with NCDs, what are examples and models of successful handling of PHs in the third world and the rest.
4. Patient experiences -- what do patients face with chronic diseases, how to think about the change in life experience of the patient with the progression or efforts to stall the progress of the disease, difficulties with diet, medication, life practices.

Srivats
--
Shall I also add recording and reporting of chronic diseases? Urban vs Rural?
Dhruv
--
Would be useful to look at how caste, gender and poverty influence experience of and access to treatment of chronic disease, especially the life style modification component.
Subha Sri
--

You have brought in the regional variation angle. Do existing manner of collecting data on chronic diseases enable us to detect variation by gender?

Padmini
--
I have a basic question - in the description below chronic diseases and NCDs are used interchangeably. Is our focus going to be on NCDs (in which case I suggest we stick to NCDs) or on chronic diseases (in which case TB, HIV etc will fall in the ambit)?

Also, important are the nutrition questions, the questions of linkage to mental health (esp. depression). And appropriateness of treatment options (one sees both over-treatment and mis-treatment in NCDs -- especially a choice for more costlier options when cheaper options would suffice).

Anant (B)
--
Basic question first, Anant: I used the term chronic diseases and then didn’t want to shorten it to CD because it could mean communicable diseases! That is why NCDs. When we first thought of the question, we thought of excluding TB and cancers, because each of those topics could take a full session in themselves, and TB has been discussed in the past. I would say HIV too should be excluded, not because it is unimportant but because it is a full and complex field in itself deserving a full annual discussion. But it is open to discussion to fix the ambit of the theme.

May be we want to limit the discussion to those theorized by the epidemiological transition -- heart diseases, strokes and diabetes, specifically?

Treatment options are crucial aspects of the discussion -- especially in relation to heart diseases.

Nutrition would be extremely important no doubt and

A Note from the Editors about this Issue
The first part of this issue contains articles on the theme of Mental Health - articles which we could not carry for various reasons in the special issue brought out for the Annual Meeting in February 2015.

The second half of this issue carries articles written for the mid annual meet at Hyderabad in August 2015 where issues related to chronic and non-communicable diseases, and urban health were discussed. We also carry a long report of the exchange on the issue in the eforum.

The tail piece is a concept note on vaccines that started a preliminary discussion on immunisation at the Mid-Annual - Devaki Nambiar, R.Srivatsan, V.R.Raman and Chinu, for the Bulletin Editorial Committee.
would deserve a full exploration in this context, both in relation to heart diseases and diabetes and their interrelation.

Also Padmini, questions of gender are not too often probed in the Indian context, though I did see a small study in Bangalore which did comment on the problems the poor and women faced in relation to medication.

Yes Subha -- caste and gender are important dimensions. Also Dhruv -- recording, reporting of chronic diseases, the difficulties of recording and reporting the complexities of practice, etc.

And also, please anyone who is interested in offering to be part of the organizing theme to decide content, authors, presentations, etc., please feel free to volunteer.

Srivats

Sickle Cell Disease would count as a chronic disease I believe. The situation of a community practitioner and of the patient is the same for any disease for which medicine is needed lifelong. So Diabetes and AIDS face the same problems of long term treatment, repeated testing, medicines running out, etc. In this they differ from malaria and leprosy which need medicines for less time - but still needs a long time follow up. In that sense it behaves like a post operation malignant tumour from the point of view of a patient or the family practitioner.

Prabir

I do not know if it fits within one of these or as a separate theme but I think one could add: Children and youth - how does it need to fit into policies/ preventive measures for the future generations (what exists and what needs to be done).

Gracy Andrew.

There are certain neglected chronic diseases that need attention:

- Mental Health issues addressing the chronic aspects to ensure continuity of engagement of MH group and addressing of issues that need to be addressed in terms of long term care.
- I would personally like the inclusion of corporate junk food industry and their role in contributing to NCDs or chronic health problems Diabetes, Hypertension/CVDs, etc.
- Dealing with Diabetes in all its dimension as Anand Zach can do will be great.
- Asthma, Chronic Obstructive Lung/Pulmonary disease doe need addressing, association with pollution, allergies, toxic polluting cooking fuels, occupational health hazards associated with silicosis pneumoconiosis (continuation of earlier meets), Parthenium, etc. Availability of affordable essential medicines and their rational use. Role of other systems of medicines.

Mira


The Burden of Disease and the Changing Task of Medicine David S. Jones, M.D., Ph.D., Scott H. Podolsky, M.D., and Jeremy A. Greene, M.D., Ph.D.

Thanks and regards

Dhruv

Your second article has an extremely interesting analysis, which is verging on accuracy, but fails at the attempt to provide a synthesis of what needs to be done. Perhaps this is inevitable given the complexity and intractability of modern life.

The first article link is too glib and very thankful to god that we are so much better off -- am much less impressed!

Srivats

Re gender in/ and medicine ...resource: www.gme-cehat.org

Padma Deosthali

Not many of us would like a philosophical perspective in response to your correct comment about ‘need for synthesis about what to do. Anant’s response in the vaccine and its -ation debate had a strong philosophical/ideological viewpoint. Even,
the analysis in NEJM’s article isolates ‘medical interventions or causes’ without looking upon factors which lead to such causes and lifestyles. Because they are considered as given, essential or inevitable existing factors.

Dhruv
--

For Mental health- can we focus on “Addressing the treatment gap”

For Tuberculosis - community health initiatives in improving access and adherence, along with the other topics already mentioned.

I do not know if it fits within one of these or as a separate theme but I think one could add.

Tasneem
--

In fact if MFC is discussing TB at all, it should discuss its relation with occupational hazards and/or pneumoconiosis. We see huge numbers of pneumoconiosis patients being treated as TB patients, even if smear is negative they are put on AKT. Pneumoconiosis is NCD and that must be included in the list of the topics.

Jagdish
--

The commonest risk factors for TB are smoking, malnutrition and diabetes. The vulnerability factors of barriers to access to health services, poverty, delay in diagnosis and lack of airborne infection control can also be included. Satyameva jayate was a landmark advocacy in breaking the ice on the commonly neglected disease - TB, and we need to take the dialogue forward in our agenda.

Mira
--

In addition to the points that are emerging, we may like to think of the following:

● The ‘up-stream factors’ or societal determinants of chronic diseases. For instance, this would include the food industry and the marketing of high sugar/salt/fat content foods that result in obesity hypertension, etc. The shift from ‘agriculture’ to ‘agribusiness’ also has a role to play. These factors are more complex such that health workers/doctors and the health system feel helpless and unable to influence them, even if the role is understood. The food industry however has no such difficulty and works with professionals and international bodies including the WHO to change recommended daily requirements, norms to diagnose hypertension, etc.

● A community health approach to chronic diseases wherein health promotion and life skills education play an important role to increase health literacy, followed by measures to enhance the autonomy of patients, families and communities when the disease process has commenced; and a role for inter-disciplinary teams and community health workers to support lifestyle changes. This may sound very idealistic but is work in progress in many countries and in pockets here.

Thelma
--

What is presented here appears to be a nice framework which would allow us to cover a lot of ground in the annual meet on NCD. I also agree with the suggestions by Thelma and Jagdish. I would like to suggest two sub-topics for considerations – you and the group that would be coordinating the thematic content of the meet.

1. I came across a paper (see below the abstract I have pasted. I have sent the said paper to Srivats for uploading in Drop Box) which speaks of adverse consequences of public health interventions and the need to respond to this issue at the intervention design level as an ethical imperative. This, to the best of my knowledge, is rather less talked about. It is a cause of concerns especially given the growing trend of using RCTs for testing various public health interventions. (Poverty Action Lab/MIT is an example). It would be relevant to include this sub-topic in the annual meet in the context of NCD. If we decide in favour of its inclusion, I would like to do a small paper on this sub-theme.


ABSTRACT

Although it might be assumed that most public health programmes involving social or behavioural rather than clinical interventions are unlikely to be iatrogenic, it is well established that they can sometimes cause serious harms. However, the assessment of adverse effects remains a neglected topic in evaluations of public health interventions. In this paper, we first argue for the importance of evaluations of public health interventions not only aiming to examine potential harms but also the mechanisms that might underlie these harms so that they might be avoided in the future. Second, we examine empirically whether protocols for the evaluation of public health interventions do examine harmful outcomes and underlying mechanisms and, if so, how. Third, we suggest a new process by which evaluators might develop ‘dark logic models’ to guide the evaluation of potential harms and underlying mechanisms, which includes: theorisation of agency structure.
interactions; building comparative understanding across similar interventions via reciprocal and refutational translation; and consultation with local actors to identify how mechanisms might be derailed, leading to harmful consequences. We refer to the evaluation of a youth work intervention which unexpectedly appeared to increase the rate of teenage pregnancy it was aiming to reduce, and apply our proposed process retrospectively to see how this might have strengthened the evaluation. We conclude that the theorisation of dark logic models is critical to prevent replication of harms. It is not intended to replace but rather to inform empirical evaluation.

2. It appears health of migrants is also somewhat less studied. The ever stronger forces that push more and more workers into un-organised sector possibly also have been impacting the incidence and prevalence of NCDs. This may be covered under the framework you present. I just wanted to mention this point so that if there is work in this area it will be worthwhile for the group to learn more about it.

Sunita
--

Somewhere, we had mentioned NCD and development including urbanization to be included.

Dhruv
--

That’s right Dhruv. The second sub-topic I mentioned might be covered under urbanization. However, this leaves out issues of workers and labour force in rural, and smaller townships. While sugarcane labour issue has been looked into extensively I am uncertain if farm labourers, labour in horticulture and allied industries have studied adequately for their health. They might have been which I am not aware of.

Sunita
--

Well agriculture labourers itself is somewhat unorganized sector. Many agriculturalists themselves are labourers.

Dhruv
--

We can add brick kiln workers to the list that Sunita presents.

Jagdish
--

I have uploaded Sunita’s paper into the MFC dropbox see link:
https://www.dropbox.com/s/8517oiyoj53syyp8/Bonell%20on%20dark%20logic%202014.pdf?dl=0

Srivats
--

Forwarding a mail conversation between Anurag and Srivats on the subject of chronic diseases:

Dear Srivats,

I saw your mail about the MAM and I had thought about responding in some way, but find it increasingly difficult abstracting from my daily experience with people and their illnesses into words and issues for discussion. After more than 25 years as a practising doctor I can say that diseases no longer interest me primarily, although they continue to perplex me. I am more interested in people and am saddened by the constant visitation of disease on a poor population (much of which is avoidable) and the destruction that follows. Differences between acute and chronic diseases, communicable and non-communicable diseases, under nutrition/tuberculosis/diabetes/hypertension/mental health are in a sense specious and artificial as they are all linked in ways that we either deny or perhaps do not recognise, and which most often affect the same groups of people in terms of frequency or impact. In India acute illnesses in family members have long-lasting and devastating impact which is no less than the effect of chronic diseases, while chronic diseases like diabetes present with acute complications - thousands in India lose their limbs to diabetes or develop TB due to uncontrolled diabetes. In terms of some risk factors for diseases, should we assess the effect of smoking in terms of heart attacks (an acute disease) or chronic lung disease or cancer, or the effect of alcohol on road accidents (acute effect), or liver disease (chronic effect)? We can safely say that for a large proportion of our population with the state of public health and healthcare in India, there are preventable diseases which are not prevented and treatable diseases which are not treated.

I am offering some narratives related to patients that I am seeing currently as an illustration of linkages between social conditions and diseases, some provocative comments on diabetes, and some thoughts on collective action.

● A 44-year old non-hypertensive, non-smoking, non-alcohol consuming small time property dealer who was intensely worried about repayments collapsed suddenly. Our evaluation showed a large brain hemorrhage on one side that compressed brain tissue enough to result in brain death. He was also found to have a blood sugar of 420 mg/dl for the first time in his life. No hypertension could be recorded. CT angiography did not reveal any reason for the bleeding in the brain. He leaves behind three daughters and a son.

● A 28-year old woman from the hills developed a psychotic illness after delivery. Inspite of being on psychotropic medication she did not improve and tried to hang herself. She survived but developed a
stroke on one side because of possible injury to her carotid artery. Now she has both kinds of disabilities. There are 2 children under five and a devoted husband who await her recovery.

I have seen people with TB develop permanent disability of the lungs, permanent blindness as a complication of meningitis, and have 2 patients with their intestines opened onto their abdominal walls because of intestinal TB - communicable disease leading to non-communicable sequelae of a horrific nature.

Diabetes is not a disease but a syndrome. There is a diabetes of the rich and a diabetes of the poor. The latter is possibly not linked to obesity directly, but to maternal undernutrition, low weight at birth and lifelong intake of a diet which does not result in normal growth, but which can lead to abdominal adiposity with urbanisation or its equivalents.

We may discuss themes for an annual meet, and I know that MFC acts like a thought current rather than a collective for action, but the situation on the ground with a non-existent public health system and a rapacious private sector is intolerable. A very frequent event in my own experience is of people breaking down saying they have nothing left, of families taking away very sick patients home to die. Only God knows how many never approach a hospital.

I think somewhere and somehow we have to rekindle our original vision of ensuring health for all as well as relaunch a struggle for universal access to healthcare. How do we connect with people and their issues and make them politically sensitive? Jan Sunwais were tried in the past but failed possibly because they were held in the wrong location. The proper place for them would be our hospitals who are full of patients with tales of neglect and negligence and of exploitation of misery, which are an inherent feature of our healthcare system.

Anurag

I am able to follow theoretically and conceptually your argument about the fluidity and un-pin-downability of disease category boundaries - which perplex you, though you are interested in people, as you say. Without offending your sense of sympathy and humanity as a doctor, let me try to raise the question of categories in two or three philosophical registers. To clarify, my questions are not intended to criticize you, but to see what can be added to what you say in whatever small way my perspective allows.

First, at the level of the disease category itself -- your observation and cutting argument is that it is very difficult to differentiate at a deep level, the difference in categories, and I quote Differences between acute and chronic diseases, communicable and non-communicable diseases, undernutrition/tuberculosis/diabetes/hypertension/mental health are in a sense specious and artificial as they are all linked in ways that we either deny or perhaps do not recognise.

While I can sense what you are saying to a degree, I have a different intellectual problem. Disease categories are ways of determining in detail differences in the pathology -- this is a part of medical science’s effort to actually differentiate diseases. These differences in pathology presumably contribute to the success of modern medicine. If we refuse these differentiations or categorizations we go back to undifferentiated illnesses -- how do you propose this will be a step forward to meet our condition? What is the further differentiation that is necessary to mark out these historical problems of illness in India?

On the other hand, I understand you also saying that for the purposes of treatment or prevention, there are indications that the long term embodied historical, epigenetic, etc., determinants of disease are so similar and that therefore the curative (to a degree) and the preventive measures may actually coincide. That is though there are differences in medical categories, the long term treatment may well be very similar -- enough to ask questions whether these are actually different ailments.

On the other hand, your brilliant, because in hindsight so obvious, point about the lack of a boundary between chronic and acute diseases, manifestations, effects, iatrogenic consequences, economic catastrophes, etc. These observations and their consequences really need to be followed.

It may well be that a lay person (in ‘modern’ medical terms -- a believer in homeopathy, a health activist who isn’t a doctor, a medical philosopher) would push to actually soften the boundaries of disease categories. How would the category difference of being a doctor be different from being a non-medical person? In other words, what torsion or twist or dynamic are you as a doctor adding to the problem as seen by a lay person? How would your call for health for all differ from mine?

The hard question I am posing to you is, how are you going to move away from the despair of your practice to think productively about what to do?

One of the difficulties I have seen with very good doctor thinkers is that they tend to give primacy to their practice to a degree that they don’t spend enough time actually thinking about their work seriously, consistently and with stamina. I am sure you don’t fall in this category, because your questions have remarkable sharpness indicating a great deal of
thought. However, I do see some giving in to despair, which I despair of! Also I see that you are posing a quite original crisis of categories, and then moving back, away from it to softer solutions that may or may not be practical in the large scale in which you present them.

Srivats
--

Then later on the phone this morning, Anurag repeated that it is very difficult to move back when you see absolutely intractable cases every day. He also said that he was part of so many committees which were geared to public health and targeted disease prevention, which had solutions that were piecemeal and destined to fail. So in effect, he was criticizing my somewhat “presumptuous” (my self-criticism, not his words) suggestion that he find ways to move back from despair and irresolution and think productively about the problem. I other words, he feels that there seems to be no easy solution to the complex problems of health in India.

--

Thanks for your reply to my mail. Let me think about the points you raised. I realise that I have to strive for greater clarity and coherence in the points I raised. But for example, there is nothing unifying in the term non-communicable diseases into which are lumped hypertension, diabetes, mental health or cancer and injuries, or communicable diseases with different pathways of acquisition like HIV and Kala azar. Some conditions which impact on both of these categories like under nutrition figure in neither. I feel that the categories are more like maps which create faulty boundaries. Witness the commitment to provide life long ART to the HIV positives which is considered a human right and the neglect of the rights of all other people who suffer life-threatening illnesses.

The point about primacy to your own practice is well taken, but it probably has to be so. If I encounter again and again on a daily basis, poor people driven to the edge by illnesses, a thin short woman wailing outside the operation theater about her young daughter being operated for abdominal TB (she had not eaten for 3 days, and her bills were paid by a collection), a young man of 28 with TB meningitis ready to be taken home without treatment by his father and brother whose cumulative weight might be less than my own, despair seems logical.

Anurag
--

That’s a good suggestion from Anurag.
--

I can fully understand what Anurag feels because he is dealing with human beings in despair & being a sensitive person he has subconsciously internalized their pain, suffering & sense of hopelessness. I think we can collectively decide to modify the topic to something which is much more geared at possible action for change. The existing situation cannot and should not be tolerated.

20% Budget cut in Health, 50% cut in ICDS, significant budget cut in Mid-Day Meal. This will worsen the existing malnutrition scenario. At the one-year new Govt’s performance Assessment, the fact that in many states Ashas and AWWs have not been paid for several months was shared. This will dismantle the existing asphyxiated Health System. Shortage of doctors, nurses, medicines, etc., is really too serious. We can link this to addressing health problems - acute going on chronic spectrum with complications and sequelae.

CII, FICCI have come up with their market friendly solutions in partnership with Pharma, Vaccine, Diagnostic Instruments and Medical Devices Industry and Corporates, with IPR issue linked to all, with the Trade Agreements in the process of being signed.

Deaths from cold and heat which are preventable and are a matter of concern. Over 500 deaths from heat, most are of elderly, laborers, homeless, street persons, et al. A large number are from Telangana and AP. Most have already forgotten the prevention and treatment of heat strokes and heat exhaustion. There is so much more that needs urgent response from all of us, from addressing health problems to constitution violations. Each one of us tries to do the best we can, where ever we are, in spite of all the various constraints. This is not enough; collective response is needed at critical times. The Public Health crisis, the Agrarian crisis and as Prabhat Patnaik put the extremely rapidly increasing inequities and as Jayati Gosh shared that the rural economy is suffering deeply and apparently global economy too is not great. If as a nation we can be totally blind to over 300,000 suicides of farmers, deaths obviously doesn’t seem to move the powers that be.

It is definitely not a very inspiring time for most and I think a look at what is doable with all our constraints is not a bad idea.

Mira
--

The hospital and community visit will be easy at Raipur or Bilaspur.
Maybe try at Hyderabad too?
Prabir
-If we are to do it at Hyderabad, we will need access to a hospital that is democratically oriented, with low fee or free patients from impoverished (majority) backgrounds, and willing to have us milling around, perhaps looking in on case analyses, etc. We would also need a sympathetic medical practitioner/hospital administrator/head who will understand the questions we are trying to address and keep them on some sort of standby from his inpatient population. Others from Hyderabad must respond here, but I don’t see too many candidates of this kind, with doctors of this kind.

Srivats

--

Thanks.

I think there is no problem about hospital visit which Srivats says is in 2016 linked with GB in Chattisgarh, or Hyderabad or anywhere. Objective of the visits have to be clear. I am sure between Anurag and Prabir this can be worked out. It must be in a resource poor situation to show the links of the socio economic reality and the disease patterns, as well as access to health care. I was thinking of Shahid Hospital, if it is possible…

Mira

--

I was trying to imagine myself in the position Anurag was describing -- as a doctor faced with a stream of patients who come in -- each with some intractable, chronic/acute serious ailment. Each of which require, at the level of treatment or cure, extensive and expensive strategies well beyond the capacities of impoverished families. To the practitioner these diseases are clearly avoidable with measures of prevention. It would seem as if, given the constraints of having to charge money and the inability to pay, many or most of these patients could only undergo palliative care under these circumstances -- no cure, only delay, deferral of death and a degree of alleviation of suffering. What would I understand as a doctor, who was trained to differentiate diseases, categorize them, treat them effectively, efficiently and humanely? How would my training help me understand the situation? Where would all my categories and diagnoses lead? More food, less hunger, earlier access to treatment meaning more cheap, effective, early and easier to access health care. All of which seem to be unachievable, even given the fact that India is growing, shining, and ballooning in its ego as a world player. Perhaps at the cost of these poor. That is where his despair stems from.

Doctors usually dull their emotional response in order to be able to treat the patient who comes with a serious ailment. Many doctors, focusing on the case, wouldn’t normally think of the circumstance, context, determinants and larger possibilities of ensuring health. But what if you do? How do you deal with that larger, more reflective, despair that comes from a wider understanding of a situation.

So in answer to my somewhat unintelligent (at any rate, less than insightful) question how did Anurag’s position and call for ‘health for all’ differ from mine, he says, “Come to the hospital and see for yourselves. My despair is every day, heightened by the paralysis I feel between my extensive knowledge and practical impotence in relation to what I see each moment.”

Srivats

--

Like Anurag, and working in the same district of the country which is certainly not the most deprived by any stretch, I have recently been feeling overwhelmed by the grim, complex, sad, tangled lives of people in our work - mostly with mental disorder, intellectual disability, stifling poverty and pushed down by exploitation and lack of access to sensible compassionate health care. Our efforts to engage with community based support feel inept and presumptuous and insiginificant.

Like Mira, I also feel genuinely alarmed by this highly dysfunctional health system of India that is degenerating and unravelling further in front of our eyes - and so incisively summarised in the Lancet editorial on Modi health policy last week.

I feel particularly gutted by the cut in ICDS budget - under 5 nutrition and pre-school education are surely one of the most critical factors for life long health. For me MFC is a beacon of encouragement, hope and activism in the face of such despair and degeneration and I think its important to really dig into the complexity of chronic diseases and ill health… and move past trite vertical solutions and also believe we must give some time on ways to move forward and seek change in the current policy environment…so we can all chase away the black darkness and light our small candles. And encourage each other with sparks of hope.

Kaaren
CVD Risk Factor Trends in India

Kavita Singh, Prabhakaran Dorairaj and K Srinath Reddy*

Our serial cross sectional surveys (Survey 1 during 1991-1994 and Survey 2 during 2010-2012) on community prevalence of CVD risk factors in Delhi - NCR demonstrated a marked rise in burden of most conventional CVD risk factors over the last two decades. Urban and rural prevalence of alcohol use, hypertension and diabetes increased with increases in age-standardized mean systolic blood pressure ([urban 124.3 to 132.2 mm Hg and rural 116.8 to 124.6 mmHg], diastolic blood pressure (urban 74.9 to 84.1 mm Hg and rural 73.5 to 82.5 mmHg] and fasting glucose (urban 102.3 to 117.0 mg % and rural 83.9 to 105.0 mg %). The smoking prevalence increased in rural male population and remained unchanged among others. However, raised total cholesterol declined in urban population (details are given in tables 1&2).

Disparity in Cardiovascular Disease Risk Factors and Socioeconomic Gradient in India

The relationship between cardiovascular (CV) risk factors and socio-economic status (SES) is complex and different CV risk factors show apparently disparate relationship with SES. This could be due to the fact that In India the epidemiological transition (transition from the ‘age of pestilence and famine’ to the ‘age of degenerative and man-made diseases’) has occurred rapidly, so much so that both pre- and post-transitional conditions can co-exist in several communities.

Table 1: CVD Risk Factor Trend (Urban)

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Total (Men)</th>
<th>Total (Women)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td>23.3 (21.2, 25.4)</td>
<td>43.3 (40.1, 46.6)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>12.7 (11.0, 14.4)</td>
<td>23.3</td>
</tr>
<tr>
<td>Raised total Cholesterol (≥200mg/dl)</td>
<td>36.0 (33.4, 38.5)</td>
<td>30.5 (27.0, 34.0)</td>
</tr>
<tr>
<td>Smoking</td>
<td>29.3 (26.7, 31.5)</td>
<td>29.8</td>
</tr>
<tr>
<td>Alcohol use</td>
<td>30.5 (28.0, 32.9)</td>
<td>50.1 (46.8, 53.4)</td>
</tr>
</tbody>
</table>

Table 2: CVD Risk Factor Trend (Rural)

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Total (Men)</th>
<th>Total (Women)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td>12.8 (10.6, 14.6)</td>
<td>32.2 (29.1, 35.1)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>2.6 (1.6, 3.9)</td>
<td>12.3 (9.4, 14.9)</td>
</tr>
<tr>
<td>Raised total Cholesterol (≥200mg/dl)</td>
<td>16.7 (13.5, 19.8)</td>
<td>37.6 (33.5, 41.7)</td>
</tr>
<tr>
<td>Smoking</td>
<td>54.4 (51.3, 57.5)</td>
<td>66.7 (63.7, 69.8)</td>
</tr>
<tr>
<td>Alcohol use</td>
<td>15.0 (12.5, 17.5)</td>
<td>65.1 (62.0, 68.1)</td>
</tr>
</tbody>
</table>

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the well-accepted global cardiovascular risk assessment approach, was elevated in individuals in the low SES group\(^1\)\(^2\). Furthermore, the proportion of individuals with optimal CV risk factors was lowest in individuals in the low education group\(^1\)\(^0\). The Sentinel Surveillance in Industrial Population (SSIP) study\(^1\)\(^1\), carried out in industrial settings, involving nearly 20,000 adults (both industrial employees and their family members), across 10 different sites demonstrated reversal of social gradient, which is also confirmed in community-based studies conducted in 11 different regions in India\(^1\)\(^2\).

A study conducted in the urban areas of Chennai during 2000\(^1\)\(^3\) (age group >=40) reported a higher prevalence of hypertension (54%) among low income group (monthly income < Rs 30000/annum and 40% prevalence among high-income group (monthly income >=Rs 60000/annum).

Furthermore, as seen in the CREATE registry\(^1\)\(^4\) from India, poor people who were admitted with an acute coronary syndromes (ACS) episode frequently miss out on evidence-based treatments because neither the individual nor the public can pay for it, and they experience higher death rates within the first year or two after the attack. Available evidence indicates that both acute myocardial infarction (AMI) and stroke are more often seen in individuals from relatively poor SES. In a separate analysis of the INTERHEART South Asian population published by Joshi et al. in JAMA in 2007\(^1\)\(^5\), low educational level was strongly associated with increased risk of AMI in native South Asians. If, in Pendekar et al.’s study\(^1\)\(^6\), we combine the groups of those with lower than secondary school education and compare with those of higher levels of education, the inverse relationship of SES with CVD death becomes apparent. In fact, the stroke mortality trend does show a negative gradient in this population. We also know from the INTERHEART study that tobacco use, low fruits and vegetables intake and history of hypertension together contribute to nearly two-thirds of the population attributable risk for AMI\(^1\)\(^7\). This is also consistent with the GBD study which shows that the above-mentioned risk factors are among the top five risk factors for mortality as they lead to adult chronic diseases and contribute significantly to ischaemic heart diseases\(^1\)\(^8\). Therefore, it is biologically plausible that individuals from low SES are vulnerable to IHDs and stroke despite having normal body mass index (BMI).

References


My Perspective on the Chronic Disease Epidemic in India

Anand Zachariah*

The chronic disease epidemic as I am seeing it in my clinical setting is the large number of patients in the OPD who have been screened and detected to have diabetes, hypertension, dyslipidemia and obesity. Some of them are symptomatic and some asymptomatic. And the wards are filled with a range of complications of these, strokes, heart attacks, chronic kidney disease, severe infections with pyelonephritis, cellulitis and pneumonias. This is affecting the whole range of socioeconomic conditions.

Medicine deals with diseases as discrete, watertight categories. But we know that these conditions - altered glycemia, blood pressure, cholesterol and weight are closely overlapping profiles which occur together. They are a set of modernising conditions. What is this set of modernising conditions as they are affecting the human body?

Essentially all these conditions - glycemia, blood pressure, cholesterol and weight are themselves are not diseases (conditions which have invariably have symptoms, pathology). They are derangements of physiology which predict future complications. On the one hand, the modern trend of screening large samples of individuals in whole populations for chronic disease is creating epidemics (50% of adult population having prediabetes and 20% having diabetes, 20% having hypertension) - suggesting an overmedicalisation. On the other hand- many patients are falling ill with life threatening conditions which are expensive to treat. Thus, the epidemiological techniques of modern medicine are leading to overmedicalisation- stating that a large proportion of the normal population is diseased. However, there is also a true epidemic of people falling sick and dying due to these changes in modern life. How do we understand this dichotomy?

The epidemiological way to think about these risk factors in chronic disease is at the level of individual causation of morbidity. This approach asks the question: what are the risk factors causing the disease in the individual- in relation to diabetes, dyslipidemia or heart attacks, and then designs ways to focus on modifications of these. But the other way to think about it is that the human being (as an evolutionary species, as a human anatomy, physiology and biochemistry) is adapting to rapidly urbanising conditions, consisting of changes in physical activity, diet, stress and social relations, developing new physiological norms to cope with these changes. What else could it mean if a large majority of a species had a disease which largely causes no symptoms and this disease was less important several decades before? These changes in glycemia, blood pressure, cholesterol and weight could be regarded as adaptations or maladaptations. Modern medicine has only one way to deal with this epidemic, i.e. to medicalise it. To regard each of these abnormalities as diseases, which have a specific drug for treatment. So this drug based therapeutic drive of modern medicine, based on its own logic of treatment and the pharmaceutical companies’ imperative to generate profits is governing our approach to deal with this chronic disease epidemic. But if these derangements in physiology (which we call diseases), reflect a change in the modern human condition (the way we live our lives) and our (the human) maladaptation to these, then how do we redefine our approach to deal with these maladaptations? The medical approach will always be a drug based therapeutic approach based on the individual- individualised risk factor modification, individual drug treatment and entering the medical system (the regime of hospitals, laboratory, pharma with ceaseless drug ingestion and monitoring till the day one dies).

One is not saying here that the human species has to go back to the villages, to traditional life, to the forests, to growing one’s own food and stitching one’s own clothes. Given that urbanisation is going to take greater hold of us as the 100 mega cities take off and 50% of the population becomes urban, life in the rural areas will become increasingly unsustainable. What communitarian approach can we take to deal with the pervasive changes in modern life?

How do we as a species- human beings living on this planet earth in the 21st century- understanding what we are doing to the environment and to other species, and to each other (inequality, social relations), and to ourselves (changes in the nature of human existence)- respond to the chronic disease epidemic? Approaches that can lead to more sustainable ways of living—not in terms of living longer, but giving value to each other and human life.

How will such a way of thinking lead to a restatement of the problem- disease definitions, the individual clinical approach, the public health perspective?

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The advent of drug therapy was fundamental in defining individual risk categories for coronary artery disease, diabetes, hypertension and dyslipidemia. The discovery of hydrochlorothiazide, clinical trials and marketing of this drug by Merck Sharpe and Dohme were fundamental in defining the risk category of hypertension. The discovery of statins and sulfonyl ureas and marketing of these drugs had a similar parallel history and were again critical in defining hypercholesterolemia and diabetes mellitus Type II as disease categories.

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Till the early 1950’s epidemiology was focussed on study of infectious disease. In the two decades that followed with the recognition of the importance of cardiovascular deaths, and presidential heart attacks such as that of Eisenhower, there was governmental focus on the epidemiological investigation of chronic disease. The first large scale long term study of cardiovascular disease - the Framingham study — published in the early 1970s played a defining role in the conceptual framework of chronic vascular disease. It also defined the epidemiological method of investigation of chronic diseases and public health both in America and across the world. The Framingham study demonstrated the statistical association of diabetes, hypertension and hypercholesterolemia as risk factors for coronary artery disease. Randomised controlled trials of interventions such as hydrochlorothiazide for hypertension reduced heart attacks and deaths. The statistical association of risk factors with the occurrence of heart attacks and the efficacy of interventions such as aspirin, statins and antihypertensive in preventing heart attacks are together what sustains the logical framework of risk factors as causative agents and disease categories. Exactly how these risk factors lead to atherosclerosis, heart attacks and strokes is not clear. Studies of tight diabetes control have not shown that it prevents heart attacks and strokes, although it may prevent diabetic retinopathy. The point being made here is that the edifice of chronic vascular disease is based on the epidemiological framework set in place by the Framingham study. The earlier German model of a primary health care approach to addressing the cardiovascular disease epidemic that was functional up to the 1970s, was quickly overturned by the impact of screening and drug based approach to treatment developed in America.

The origins of conceptual framework of cardiovascular disease has a local history in the United States, of the Framingham trial, the VA trial on hypertension, the efforts of MSD to promote Diuril as the first specific anti-hypertensive drug, the JNC guidelines. Does vascular disease behave differently in India? Is there another way of conceptualizing chronic vascular disease which is cognizant of the realities of the Indian scenario? It is necessary to critically examine the Framingham study and its impact on the conceptual framework of cardiovascular medicine. We also need to do a study of how hypertension, diabetes and hypercholesterolemia became disease categories with the aim of uncovering the assumptions regarding causation, treatment and the ecology of these disease categories themselves. We also need careful examination of epidemiological risk factor studies of vascular disease in India and how they fit the risk factor model developed in the west.

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The studies of urban diabetes in Chennai and other urban centres across the country show an increasing prevalence of diabetes up to 18% and of prediabetes up to 50%. Longitudinal studies seem to suggest a gradually increasing epidemic. Based on these data, we usually assume that the entire population of the country is undergoing large scale developmental change in the form of urbanisation, lack of physical activity and calorie and fat rich diet. Is this actually true?

Our studies in Gudalur seem to suggest that the scale of diabetes mellitus Type II is of a much smaller scale compared to the urban epidemic. The adult prevalence of diabetes in three tribes, Panniyas, Bettakurumbas and Kattunayakans in Gudalur valley is < 1% and one tribe the Mullukurumbas who are more modernised is around 3%. The Gudalur tribes are exposed to major developmental stress, change from a varied food basket to a carbohydrate diet constituted by PDS rice, displacement from the forest and decreased access to forest resources and increasing use of motorised transport. What is protecting these tribes from diabetes? The three tribes with low prevalence of diabetes have high rates of undernutrition, with >40% of adult population with BMI < 18.5. Is it undernutrition, or high physical activity, or access to some fruits, vegetables from the land that is protecting them? These tribes are clearly not displaying the predisposition to diabetes that has been demonstrated in Pima Indians, aboriginal communities in United States, Canada, Australia and Pacific Islands. However all the tribes of Gudalur have rates of hypertension above 10%. Although diabetes prevalence is low, community mortality statistics over 1 year showed that of 181 adult deaths (>15 years), vascular causes of death were the most common 22.1% (14.9 % due to strokes and 7.2 % deaths due to heart attacks) followed by suicides 11.5%. Therefore although the diabetes is of low prevalence, deaths were predominantly cardiovascular though due to different epidemiological risk factor profile dominated by hypertension.

Is urban and rural India, one homogenous matrix with high rates of diabetes, hypertension and dyslipidemia and increased mortality due to heart attacks and strokes? The Gudalur epidemiological study seems to suggest that the epidemiology of vascular disease is different. Anecdotal data from Bissam Cuttack and Sittilingi seem to suggest that the communities in these locations have low rates of diabetes. More careful local epidemiological studies are required to trace the risk factor profiles and rate of myocardial infarctions and strokes.

What are the implications for prevention? Our model of cardiovascular medicine is based on pharmacological approach to prevention based on therapy of the individual. When working with traditional local communities, is there a more democratic model of prevention that addresses the underlying developmental changes that are precipitating the epidemic?
Deconstructing Chronic Diseases

Yogesh Jain*

My point of reference as I approach the problem of chronic diseases is first of a rural physician observing the vast spectrum of ill health that people present with at the clinic. Second, it is of one trying to determine a technological solution to these illnesses based on a good understanding of the biology and the sociology. Third, it is of someone trying to understand the social determinants of ill health. And finally, of one interested in the politics of ill health as it plays at the local and the global level.

I must share another aspect of my development: the growing necessity to free myself of the presumptions and ‘knowledge’ acquired prior to actually working in rural areas. For example, I grew up with the idea that the most important health problems were due to childhood illnesses, obstetric problems, followed by falciparum malaria and tuberculosis - all problems conventionally associated with deprivation. This, I am afraid coloured my observation too, for a long time.

I found dogmas that dominate the discourse around certain illnesses, which tend to exclude views that are at variance. For example, I saw the tuberculosis debate being dominated by practitioners of adult medicine and that tuberculosis was assumed to be predominantly pulmonary. Extra-pulmonary and childhood TB were not as important to the epidemiology, many felt. Excessive stress was given to sputum positive tuberculosis, as if rest was not so important. And then much focus was on the bacteria, its drug sensitivity pattern in specific, with little attention to the host. I found the same repeating in chronic diseases.

A turning point in my understanding: At a late evening camp to investigate and treat falciparum malaria clustering in a single village, we were shouted at for not responding to the felt problem of large numbers of people with stroke in the village.

And from there, I was forced to open my eyes to a wider spectrum of problems,

My first response to the world of chronic diseases was a traditional dichotomy – Communicable Disease v/s Non Communicable Disease.

Figure 1: Illness Profile for New Patients over one Calendar Month at JSS Clinics (November 2010)

![Diagnosis Graph]

Since most communicable diseases were acute - measles, malaria, ARI, gastroenteritis, typhoid and newborn infections (except for tuberculosis and leprosy) and most NCDs often presented with slow symptoms, the terms were loosely transferred to acute v/s chronic illnesses. Anurag vividly brings out the irrationality of this in his note — NCDs present acutely as well as chronically.

The next myth was broken when I saw NCDs among the desperately poor. Till then I had grown with myths NCDs were more common among the non-poor and even if they occurred among the poor, the numbers were small. Also that the solutions necessary for them were expensive, and thus it was not cost effective to try to look after them when faced with mountainous problems of infectious illnesses and hunger. I would thus not be prepared to pay them the same attention as I was more interested in the diseases of the poor - a bit of reverse arrogance.

I also grew up with the idea that injuries or illnesses that require surgery were not major public health problems, that they did not deserve a position of priority in the pecking order of human ailments and diseases. I would attribute the large numbers that thronged our modest clinic, to the offer of cheap and competent surgical services. But soon I realized that surgical problems and injuries were a large unmet need - surgery has been a step-child of public health.

Slowly, my world view evolved to the present.

Picture: This woman weighing all of 39 kg could have either tuberculosis, cancer cervix or diabetes mellitus. Same poverty, same social group, working condition, as far as I could see...

And over time, I have the following observations and questions regarding this problem.

1. The Chronic Illnesses are diverse, and I think, they are increasing in number

Understandably the interest in chronic illnesses started with vascular diseases and diabetes and their understood risk factors such as hypertension, dyslipidemia and obesity. But the primacy given to these select illnesses due either to what was observed in the west, or in urban India, or perhaps because of their unduly high projected prevalence of over 5%, is not justified. This seems to have been unfair to the other chronic illnesses even though they may not reach such proportions.

So we see cancers in huge numbers, chronic kidney disease, non-obese or lean diabetes, mental health problems, surgical problems, chronic lung illnesses such as bronchiectasis and fibrothorax, burns and many more.

The NCD Alliance among the Poor - a new outfit focusing on Africa, Latin America and South Asia has called this as the long tail of other NCDs.

And I feel that the numbers are not as small as believed by many.

We need to define and quantify the burden (existing,

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1Eds. The note referred to is in the email conversation on NCDs reproduced in this issue of the MFC bulletin.
projected, and avertable) of chronic diseases and their risk factors in populations living in extreme poverty.

2. The importance of the host/ deprivation

In the entire discussion on the epidemiology of these illnesses, the overwhelming stress is on the environment or the agent and not so much on the host. Is it due to tobacco, is it bad lifestyle related dyslipidemia, etc. By host, I don’t mean genetics here. I am talking about the embodiment of deprivation of various types impacting on the host – deprivation of income, of food, of access to health services, of their spirit, or deprivation inside their mothers’ womb as well as mental stress. There is a need to investigate this.

To paraphrase Louis Pasteur for what he said for infections then, now for the chronic illnesses: The (onco)gene or the environmental agent or toxin is nothing, the terrain everything.

3. The hidden chronic diseases

These are large neglected problems: Alcohol use dependence, untreated epilepsy, chronic arthritis, RHD, mental health problems including suicides, chronic skin disorders, which don’t find space in the discourse on chronic diseases. It seems that the competition between illnesses makes these get neglected. There is an overemphasis on vascular diseases and diabetes as well as urbanization and whatever it stands for. The nature of the chronic disease burden among the poorest may be misunderstood.

4. Risk factor versus illness management

The emphasis on Risk factor management is certainly important for prevention of these chronic illnesses. But an equal emphasis on management strategies for coping with them when they actually occur is needed.

Drugs and hospitals are important components of management at an individual level, particular if someone presents with a complication.

We are aware that for acute and /or severe presentations of any illnesses, communicable or non communicable: a hospital is justifiably important, and if the management strategy could be communitized, it could go to a health worker too outside of a hospital. For example, for an acute illness like falciparum malaria, we are looking towards an ASHA to perform a rapid kit test and administer prompt treatment, or to prevent serious haemorrhage after birth, she is being expected to offer the woman 3 tablets of misoprostol. Other examples are of home based care of a newborn, or Integrated Management of Childhood Illnesses.

But for chronic/continuous illnesses, there are no models available. Hospitals are inadequate for their optimal care. City NCD clinics are an option only for cities. The usual duration of dispensing of medicines in rural public health facilities in Chhattisgarh, till recently was 3-7 days. Very reluctantly, they are allowing 15 days of refills. How can that work? How do you keep people motivated to continue medications for years?

What then works? Frankly there are no good answers. We believe that here we have to learn from the models of disease based patient groups, like the way PLHIV have done or AA have done. We have attempted some such work for the last two years, and our early results are promising. But a lot more needs to be done. The point is – we badly need effective models of effectively managing chronic diseases, not just preventive strategies.

5. Do the traditional risk factors adequately account for all common chronic diseases?

What proportion of adverse cardiovascular events is accountable by conventional risk factors such as dyslipidemia, hypertension, diabetes, strong family history and smoking? The ‘Interheart’ study tried to answer part of the question by saying that traditional risk factors accounted for approximately 90% of MI risk. However a closer look suggest that psychosocial factors (stress? poverty?) accounted for an Odds Ratio of 2.67 and a Population Attributable Risk of 32.3%, almost the same as that of smoking.

I would also like to ask how we limit potential risk factors such as those I mention above as the only cardiovascular risk factors to be considered. How does one start increasing the pool of risk factors such as say poverty, or lower birth weights, or not having enough food, or just extreme sadness due to an event (sadmaa in a different context)? I wonder whether people have proved that oral tobacco use is NOT a CV risk factor. I think we need to unbundle the word ‘chronic stress’, but under no circumstances should we dismiss it as being unimportant.

The link of chronic illnesses to deprivation should be explored more seriously. Paul Farmer calls diseases as biological embodiments of deprivation—and thus I am not comfortable with the postulation that chronic illnesses are more common in the non-poor than among the poor.

We are stricken by the paucity of social category disaggregated data on any illnesses, including chronic diseases. And in the absence of this, how can good planning or resource allocation happen?

Finally, we all like homogenous, common and minimum principles explaining diseases, especially causation (but also of cures and prevention). But is this a correct way to think about the problem?

Since recently, a category ‘NCDs among the poor’ had come up and is trying to carve a space for itself. It is now supported by ‘The Lancet’. The Global Framework for NCDs has not so far been designed specifically for low-Income countries or for the Poor in Middle Income countries.

6. Politics of chronic diseases

Where do you put your money? Which chronic diseases should be supported?

Several disease manifestations that happen among the poor have been poorly studied. For example, thin diabetes as a disease is poorly worked up. The role of stress in heart diseases, or in cancers has not been explored well. So how do these illnesses among the poor get their rightful due?

Next, in acute care, you can get away with hospitals or with selective/vertical programmes. But in chronic care you need very robust and well-functioning community health programmes too, or else you are done for. Are we ready to invest in them for the large and still predominantly rural population?

7. There seems to be an ideological warfare between the MCH/infectious diseases and the NCD lobby internationally vying for funds and pre-eminence. Are there different determinants for them? Do we require fundamentally different strategies for them?

So at Ganiyari when we see a wasted or consumed adult, man or woman who is very poor, we think of tuberculosis, food starvation, diabetes, HIV and an advanced cancer all as equal possibilities; and depression and hyperthyroidism as further possibilities...
Chronic Diseases: Some Reflections

C. Sathyamala*

Following the thought provoking, sensitively written papers by Anand Zachariah, Yogesh Jain and the long mail from Anurag Bhargava here are some reflections of mine on chronic diseases.

1. On “Disease” Classification

How is chronicity to be defined? In terms of the “length” (duration) or intractability of finding a “cure” or suffering and pain it entails. And whose point of view — the patient’s or physician’s? The list of chronic “disease” profiles provided by physicians may not have much resemblance to the chronic “illness” profiles at the “ground” level. For instance, I have often been intrigued by the concept of “low blood pressure” among lay people (that is also diagnosed by some physicians of modern medicine) but have found no reference to it in text books as a specific “disease” entity; this is one “condition” that people go and get an IV drip or. In Tamil Nadu, there is the concept of “neer” (water) which is the “cause” of many ailments (the reported symptom is ‘collection of neer in a part of the body; but this is not oedema) which I have not had the time to apply my mind to. Similarly the ubiquitous jhunjhunahat which many will recognize and there are many more such “local” symptoms which does not fit into modern medicine’s typology.

When I saw the figure in Yogesh’s paper (Fig.1: Illness profile for new patients over one calendar month at JSS clinics- November 2010), I thought what a wonderful way of classifying the illness profile – cancer standing cheek by jowl to disease of poor access, nutrition, illness requiring surgery. It would be important to know the process by which this classification was arrived at.

In the preface to The Order of Things: An Archaeology of the Human Sciences, Foucault (1970) writes on categorisation:

This book first arose out of a passage in Borges, out of the laughter that shattered, as I read the passage, all the familiar landmarks of my thought — our thought, the thought that bears the stamp of our age and our geography — breaking up all the ordered surfaces and all the planes with which we are accustomed to tame the wild profusion of existing things, and continuing long afterwards to disturb and threaten with collapse our age-old distinction between the Same and the Other. This passage quotes a ‘certain Chinese encyclopaedia in which it is written that ‘animals are divided into : (a) belonging to the Emperor, (b) embalmed, (c) tame, (d) sucking pigs, (e) sirens, (f) fabulous, (j) innumerable, (k) drawn with a very fine camelhair brush (l) et cetera (m) having just broken that water pitcher, (n) that from a long way off look like flies’. In the wonderment of this taxonomy, the thing we apprehend in one great leap, the thing that, by means of the fable, is demonstrated as the exotic charm of another system of thought, is the limitation of our own, the stark impossibility of thinking that. (Foucault 1970:xv) (italics as in original)

The question is what of the classification in the other systems of medicine? How do they fit in with the modern system of medicine? Do we want them to fit in? Can it be fitted in? What is “our” and what is the “other”? Can we work out a new classification? Do we need to work out another?

2. On Disease Definition

How is disease to be defined? Dis-ease, illness: on the basis of identification of a “causative” organism, or patho-physiological changes, or the “experience” of being “ill”? How is illness to be defined? And how is long-term illness or chronic illness to be defined?

In a study carried out in 2005 in Uttar Pradesh and Tamil Nadu (Ritu Priya and Sathyamala) on “long-term” illnesses we arrived at a working definition for long-term illness

The working definition of Chronic Disease supplied by the WHO is “Diseases which have one or more of the following characteristics: they are permanent, leave residual disability, are caused by non-reversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation or care”. The Census 2001, UK used a specific question for assessing health status: “Over the last twelve months would you say that your health has on the whole been: Good? / Fairly good?/ Not good?” Limiting long-term illness or disability which restricts daily activities was calculated from a ‘yes’ response to another question in the 2001 census “Do you have any long-term illness, health problem or disability which limits your activities or the work you can do?” For the purpose of our study the UK 2001 census definition of ‘limiting long-term illness’ was used as it elicits layperson perceptions directly.

The WHO definition of chronic diseases, on the other hand is based on a technical assessment of a person’s health condition. Responses to the UK census definition was supplemented, wherever possible, with available medical documentation. In the analysis, both the perceived and the technically assessed health condition were used. With this definition the illnesses likely to get reported range from weakness, aches and pains (as in cases of anemia/ lack of calories/ osteoporosis); pelvic inflammatory disease, epilepsy,
mental illness, injuries; to tuberculosis, leprosy, AIDS and cancer. (Priya and Sathyamala 2005)

I find that the response elicited by the question ‘over the last twelve months would you say that your health has on the whole been: Good?/ Fairly good?/ Not good?’, is reflective of the quantum of pain and suffering in a population and gives a good idea of the chronic illnesses as defined by “them”, only some of which may be “diagnosed” to fit into “our” classification of “disease”. This question was used later in a national level study, the Public Report on Health (PRoH) covering six states (Tamil Nadu, Maharashtra, Himachal Pradesh, Madhya Pradesh, Uttar Pradesh and Orissa) (see table 1; I am not presenting other interesting findings from this study related to chronic illness here as it would be a full length paper).

A surprising finding was that UP and TN had high prevalence of “chronic” illness, which was mostly “aches and pains”. I am quoting from the published report in EPW:

While it may not be surprising that UP and MP report high levels of illness rates, the high rate in TN needs some explanation. During Morbidity Round I, approximately 53% reported aches and pains. If seeking treatment is taken to indicate the seriousness of illnesses, then 85% had taken some form of treatment and one-third had taken treatment from the modern private provider, at a cost. Instead of dismissing this category of illnesses as minor, the reason for such high prevalence was investigated. The fact that water in this village was brackish provided a clue as did the fact that this village is situated in an area which has matchmaking and fireworks industry. Therefore water from all the sources in the village was sent to a laboratory in Delhi to estimate its fluoride content. While all the sources had fluoride that of two of the sources was found to be above the acceptable limit. Skeletal fluorosis was a likely explanation for the high prevalence of aches and pains in this village. The high fluoride content of the groundwater could also explain, partly, the high rate of spontaneous abortions and stillbirths in the TN village. (Sathyamala et al. 2012:50).

As the above quote shows, 85% sought treatment and one third from a practitioner of modern medicine, yet their aches and pain had not been linked to chronic exposure (from utero) to fluoride. An epidemiological mapping of this part of Tamil Nadu contaminated by the match and fireworks making industry would surely reveal a high prevalence of “chronic” illnesses which would be reported as “aches and pains”. And how should treatment be proposed for this “endemic”? And how about mapping all polluting industries in India epidemiologically speaking? The Palar river bed near Vellore, for instance, is highly contaminated by the leather tanning and dyeing industry and Pranavam et al (2011) found that ground water contamination to be higher than the BIS and ICMR recommendations. I am not sure if CMC Vellore, which has a wonderful Community health department examined the public health consequences of this and made any recommendations. How is this to be seen in the context of patients landing up with serious “disease” and “illness” in the tertiary teaching hospital; are they linked in any way?

Excellent studies on the high rates of suicide in Kaniyambadi block near Vellore have been published since the mid-2000. Manoranjitham et al (2010) conclude that ‘psychosocial stress and social isolation, rather than psychiatric morbidity, are risk factors for suicide’. What of interventions as part of community health programme? Have the rates come down? The completed suicides are the tip of the high prevalence of mental distress and morbidities; they could perhaps be classified as “long-term” illnesses or diseases. But they may not figure in the discourse on long-term illnesses.

After much “advocacy” and media attention on the increasing cancer rates in the green revolution belt of Punjab which was associated with the poisoning of soil and water due to excessive pesticide use, PGI, Chandigarh carried out a study on causal factors in one of the high prevalent districts (Thakur et al 2008) and how do they conclude?

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Table 1: Self-Perception of Health Status Across Gender (%) – 6-Village Study

<table>
<thead>
<tr>
<th>Study village</th>
<th>Gender</th>
<th>Self-perception of health status</th>
<th>NR%* (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Good</td>
<td>Satisfactory</td>
</tr>
<tr>
<td>TN</td>
<td>Male</td>
<td>73.2</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>60.8</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Combined</td>
<td>67.0</td>
<td>7</td>
</tr>
<tr>
<td>MH</td>
<td>Male</td>
<td>60.0</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>57.0</td>
<td>30.7</td>
</tr>
<tr>
<td></td>
<td>Combined</td>
<td>58.7</td>
<td>28.2</td>
</tr>
<tr>
<td>HP</td>
<td>Male</td>
<td>13.5</td>
<td>76.9</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>11.8</td>
<td>74.5</td>
</tr>
<tr>
<td></td>
<td>Combined</td>
<td>12.7</td>
<td>75.7</td>
</tr>
<tr>
<td>MP</td>
<td>Male</td>
<td>19.6</td>
<td>55.8</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>18.9</td>
<td>51.5</td>
</tr>
<tr>
<td></td>
<td>Combined</td>
<td>19.3</td>
<td>53.6</td>
</tr>
<tr>
<td>UP</td>
<td>Male</td>
<td>14.9</td>
<td>46.4</td>
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<td></td>
<td>Female</td>
<td>12.9</td>
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<td>41.9</td>
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<td></td>
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<tr>
<td></td>
<td>Combined</td>
<td>54.5</td>
<td>32</td>
</tr>
</tbody>
</table>

Percent calculated per 100 population after subtracting NR from denominator; * NR= non-response
In conclusion, the cancer cases and deaths are higher in Talwandi Sabo block probably due to a cocktail of risk factors which were [surprise, surprise] more common use of tobacco and alcohol, consumption of non-vegetarian and spicy food, high levels of heavy metals in water, and excessive pesticides use’ (Thakur et al 2008: 406) (italics mine)

Apart from the intriguing question why multiple regression was not carried out (remember this study is from PGI), the ordering of “risk factors” first blames the victims, and ends up on a neutral note of ‘heavy metals in water’ without any attempt to identify the reasons for the high presence of heavy metals and the ‘use of pesticides’ (again at the level of victim blaming).

Yogesh refers in his paper to the large number of stroke patients, which he refers to as ‘felt’ problem. Was it only a felt problem, was it not real, if indeed the numbers were large and why were there such a large number in a tribal village ; was it linked to falciparum malaria, not far removed from what the reason for their presence in the village (Kaushik et al 2009). If not what else could it be?

3. Question of Perceptions
Yet another question is what if a “disease” is not being perceived as “illness”’? This is a question that has plagued the practitioners of modern medicine and is linked to the risk factor epidemiology and public health. What if people do not know they are “diseased”? Does the notion of prevention mean that we go “hunting” for “diseased” individuals by performing screening surveys and diagnose them as “hypertensives”, “diabetics” and tell them that they are now hypertensives and diabetics and “condemn” them to the rest of their lives with this sentence, particularly when they do not have the possibility of financing their life-long treatment? How is one to view screening as “prevention”? What are the ethics of screening populations when treatment cannot be ensured for these lifelong conditions? Is medicalization and universalization of medical care the only response we have?

I think before one rushes with missionary zeal for mapping NCDs (in their narrow definition), it is important to understand how people deal with their illnesses. Two chapters from Zachariah et al. (2010) i.e., ‘The Intractable patient’ by Lakshmi Kutty and ‘Patient questions’ by Duggirala Vasanta and Seemanthini Niranjana could be read as excellent background papers.10 Let us not forget that (historically) public health agenda are subject to many interests and most often than not, those of the “patient’s” or “people’s” do not form the central concern.

4. Is there an Increase or “Epidemic” of Chronic Illnesses?
Is there a real “epidemic”? How do we know? Is it linked to changes in diagnostic possibility and increased access to them?11 Is it linked to increased life expectancies or is it the consequence of the social-ecological environment.

Was it just a decade (or two) ago, when suddenly there was an “epidemic” of “white discharge” in women in rural areas, particularly from the labouring classes. Women were told that their discharge was full of all sorts of pathogens and not only were they “diseased” but they were “disease producing” and sources of contamination. Now we no longer seem to hear the word. Have we been able to “eliminate/eradicate” the “disease”? Or is the “epidemiological” data generated now considered adequate for the purposes of pathogen mapping? Who knows there may be series of vaccines in the pipeline waiting to be marketed to prevent white discharge among women in the Third World!

5. Chronic Illnesses = Non Communicable Diseases (NCDs) and NCDs = CVD, and Diabetes?
The discourse on chronic illnesses has been reduced to discussion on non-communicable diseases which the WHO defines as:

Non communicable diseases (NCDs), also known as chronic diseases, are not passed from person to person. They are of long duration and generally slow progression. The 4 main types of non communicable diseases are cardiovascular diseases (like heart attacks and stroke), cancers, chronic respiratory diseases (such as chronic obstructed pulmonary disease and asthma) and diabetes. (WHO. Accessed 30 September 2015 at http://www.who.int/mediacentre/factsheets/fs355/en/)

Under the heading of ‘Chronic diseases and health promotion’, the WHO mentions heart disease, stroke, cancer, chronic respiratory diseases and diabetes (Accessed 30 September 2015 http://www.who.int/chp/en/). Patel et al. (2011) mention cardiovascular, mental disorders (perhaps because the lead author), diabetes and cancers as chronic diseases.12 They identify high blood pressure, suboptimum blood glucose, low fruit and vegetable intake, tobacco use, high cholesterol, indoor smoke from solid fuels, physical activity (lack of), overweight and obesity and alcohol use as the nine major risk factors (in the order presented) for the chronic disease mortality. This “classification” once again raises the question of classification discussed in point 1 of this paper.

6. On the Question of Causality
Yet another dimension to the fuzziness of borders of communicable and non-communicable: The question
of disease/“causality”, clinically, epidemiologically and epistemologically speaking; e.g., Peptic Ulcer, Helicobacter pylori and Stress (Levenstein, 1998, BMJ).\(^1\)

TB’s “causal” link to nutrition: yes, but what about its “causal” link to stress (in terms of manifestation of disease, its severity, duration and cure) and how is stress to be defined? Diabetes in the obese versus diabetes in the undernourished: pathways different, but should treatment be the same or will the treatment pathways also take different “routes”? It is clear that this is so in tuberculosis.

**Ending on a Personal Note**

I was normotensive one day and literally the next day became hypertensive (an almost deadly combination of dengue haemorrhagic fever and the shock of finding my best friend in coma). How is this to be explained? (I was a smoker then but was still normotensive). In the past, one MFC member would often remark that the immediate cause of illness/disease was peptic ulcer but the “distant” cause was capitalism!

I think it will be quite interesting if we can look at the prevalence of chronic disease and illnesses (pattern and prevalence) in our MFC “population” and how we (as “informed” individuals) make sense of our state of health/illness/disease. Why not subject ourselves to what we subject others to and recognise our narratives in the silences of our non-response!

**Postscript**

Following the mid-annual meeting there has been some discussion in the MFC e-group on the prevalence of CVD within the MFC “population” and how we (as “informed” individuals) make sense of our state of health/illness/disease. Why not subject ourselves to what we subject others to and recognise our narratives in the silences of our non-response!

**Endnotes**

\(^1\)This paper is a slightly edited version of the paper circulated for the MFC mid annual meet of 8-9 August 2015.

\(^2\)This excerpt is from the unpublished monograph. Citation for this: RituPriya and C. Sathyamala (2005) Community Responses to Long-term Illness and Death among Adults: Women’s Experiences and Perceptions in two Low Caste Groups in India. Monograph, unpublished. Study supported by UNRISD. For the published report (which does not contain these definitions) see: Priya and Sathyamala. ‘Contextualising AIDS and Human Development: Long-term Illness and Death among Adults in Laboring Low-Caste Groups in India.’ AIDS Care: Psychological and Socio-medical aspects of AIDS/HIV. 19:S1: 35-43, doi: 10.1080/09540120601114519


\(^6\)you-tube documentary entitled ‘En payar pallaru’ (my name is Palar) at https://www.youtube.com/watch?v=K0k2jhQ4VJQ (accessed 07.8.15).


\(^11\)Incidentally, one of the unqualified non-formal local private practitioners in the village where I did my study in 2011-12 started “diagnosing” and treating “diabetic” patients as one-upmanship on the other two practising in the village and because it was becoming a “major” problem in the village.


\(^13\)Levenstein, S. (1998) ‘Stress and peptic ulcer: life beyond helicobacter.’ BMJ. Summary points: Psychosomatic factors in the aetiology of peptic ulcer have become unfashionable since the discovery of Helicobacter pylori. Most people harbour H pylori so the organism cannot serve as the sole explanation for ulcer disease. Psychological stress has an impact on the onset and course of ulcer disease. Psychological stress probably interacts with H pylori and other risk factors in causing ulcer disease. Peptic ulcer is an important example of the biopsychosocial model of disease.
New Vaccines for All: Why, Which, When?

This concept note was presented to start the discussion session on immunization at the Mid Annual held in August 2015. It was a preliminary to a wider discussion on the politics, economics, logic and ethics of immunization in India to be conducted by a joint group of health activists and experts over the following year.

-Yogesh Jain

Over the last few years, the Hepatitis B Vaccine has been added to the initial group of six vaccines against tuberculosis, diphtheria, whooping cough, tetanus, poliomyelitis and measles in the Universal Immunization Programme. Secondly a combination vaccine against diphtheria, whooping cough, tetanus, poliomyelitis and hepatitis B, the pentavalent vaccine, is on its way to be included in the UIP, but not without attendant doubts and questions. Thirdly a slew of new vaccines are competing to get into the national schedule. These include the vaccines against rotavirus, rubella and Human Papilloma Virus, and injectable inactivated polio vaccine. These developments have led to the following question - Which vaccines should be added to the national immunization schedule, so that they are offered to all children in the country? The answer to this question should be based on evidence that a particular vaccine is, compared with other interventions, not only more effective against an infectious disease of public health relevance but is also safe and cost effective on the ground and is affordable for the country. Further, the delivery systems should have the organizational capacity to provide this additional vaccine at appropriate time to all the needy, without a negative impact on the coverage of the previously used vaccines, or on other services offered by the Public Health System. It should also be able to monitor its effectiveness and safety. Accordingly, the National Vaccine Policy recommends a detailed evaluation of these factors before a decision to include a new vaccine is taken.

How do new vaccines find their way into the national schedule? Once a vaccine has gone through the mandatory stages of testing, professionals, public health experts and possibly vaccine manufacturers lobby and submit proposals for inclusion of a candidate vaccine into the national schedule for approval by a National Technical Advisory Group on Immunization (NTAGI), a body that includes technical experts chosen by the Ministry of Health. This is a closed group which deliberates and finally comes out with a recommendation based on majority voting that is then put up to the Ministry of Health for a final administrative decision and budgetary allocation.

Vaccines are special and a sensitive tool. This is the only medicine given on a mass scale to healthy people. Hence not only are they expected to prevent adequately the illnesses they are meant to guard against, but they cannot be accepted by the community if there is risk of any major adverse events such as hospitalization, death or disability. That the majority of vaccines are given to children in the first months of life, which is a vulnerable period as it is, makes safety concerns doubly important. Further, there is a greater need to have well-functioning health systems in order to run universal and effective vaccine delivery and monitoring mechanisms for a preventive programme than is needed for, say, a malaria treatment programme.

The situation is further complicated by another set of processes that operates for some vaccines. There are a few vaccines that have variable levels of effectiveness in preventing potentially life threatening infections such as pneumococcal infections, typhoid. There are also those vaccines which protect against those illnesses that may result generally in milder and sometimes troublesome illness such as chickenpox, hepatitis A and mumps. Then there are vaccines like those against Human papilloma virus (HPV) which variably protect against cancer of cervix and some other cancers. All these vaccines are presently far too expensive for being considered for universal use. They are being recommended by several medical professional bodies to the ‘affording population’. Some people would ask the question: in case of some of these new vaccines the people who can afford them are least likely to acquire the infections against which they provide protection. - So why go for it? Others would argue that since vaccines are biological drugs, and are no different from any other technology, that the people who can afford it should go for it, and that physicians should prescribe it! The fact that such vaccines are a special class of technologically advanced drugs prescribed by doctors, and are not consumer products open to lay knowledge, personal choice and affordability only makes matters more complicated.

We cannot deny that vaccines also mean big business even if their unit cost is low if they are used in large populations (as would happen for a universally used vaccine). Pharmaceutical companies claim that they invest huge amount of money in producing a new vaccine and, therefore, it is legitimate to accrue huge profit from their sale. It is another matter that they spend more on marketing than on research.

Further, it would be naïve to deny that many physicians are tempted to prescribe more and more vaccines because pharma companies offer huge ‘discounts’ to private practising physicians. The interaction of vaccine manufacturers and of many health administrators (sometimes unhealthy) with the Global Alliance for Vaccine Initiative (GAVI) only increases the level of suspicion about motives and even recommendations
made by such regulatory bodies. It would suffice to say that if checks and balances are not in place, professional bodies like NTAGI will have major challenges to remain objective and take decisions based only on scientific evidence.

Given this background as it stands today, there is confusion and paucity of correct information, lack of trust and breakdown of dialogue among all stakeholders on the question: does a particular vaccine deserve to be included in the national immunization schedule? The stakeholders include medical scientists and vaccine experts, health administrators, doctors, parents and the lay public. Even now, NTAGI or for that matter any other technical body, has not been able to convince the people about the safety of some of the new vaccines such as pentavalent, and both safety and effectiveness of the rotavirus vaccine, by coming out with well researched and referenced guidelines. Recent changes in the methodology of investigating adverse events following immunization (AEFI) recently, and cases of AEFI investigated inadequately and without transparency, have furthered the sense of distrust between vaccine enthusiasts and those who question such events (branded as ‘anti vaccine lobbyists’). NTAGI should place all evidences regarding safety and efficacy of a new vaccine in the public domain so that it could be scrutinised by independent experts. In the case of many of these infections that these vaccines prevent, there are other preventive measures such as improving water quality and sanitation practices or improving health care services or food availability, where data show that it is more cost effective to do the latter.

The Centre has drastically slashed the health budget while it has decided to spend a large amount of money on inclusion of some of the new vaccines in the National Immunization Schedule. Even if we say that we should go for both vaccines and improving social determinants of these illnesses, arguing for vaccine first and these measures later tends to unburden the state of its responsibility to provide the latter.

The need of the hour is to have a dialogue on ‘New vaccines’ in the true spirit of public health and should be of high scientific quality that moves towards building a consensus as well as a perspective on this issue. The dialogue will have to be divided into two parts:

**The first part of the discussion** will be on generic principles of use of vaccines such as efficacy, cost effectiveness as compared to other public health measures, safety profile, investigations into adverse effects following investigations, and about how to strengthen the health system to effectively deliver and monitor vaccines.

This would include such questions: At what level of cost effectiveness should one advise a vaccine as a public health tool for the governments to take cognisance of? What incidence of side effects is too much for a vaccine to be advised as a preventive health technology? What is an acceptable death rate in a vaccination programme? Would this ‘acceptable level’ be the same for all vaccines or would it depend upon the incidence and consequence of the infectious disease on the one hand and the incidence and severity of side-effects of the vaccine on the other? How is an investigation into an AEFI done and then documented and publicised? And then compensated for? When there is more than one tool besides a vaccine to prevent a disease, how do you weigh which one is more important? Is it really important to measure it?

The most transparent way to handle a new vaccine introduction should be a technical report accompanying the launch, which lays out the pros and cons and takes a clear stand on the reasons why the vote went in favour of a new vaccine. Is this something that NTAGI should do?

The second part of the discussion will be about the following five new vaccines, as regards their inclusion in the National Immunization Schedule, with a dedicated session for each of the following:

a. Pentavalent vaccine,

b. Rotavirus vaccine
c. Human Papilloma Virus vaccine
d. Routine UIP vaccines, especially DPT and OPV/IPV
e. Measles-rubella vaccine.

In this section, we can look at each vaccine through the lens of the five generic principles enlisted above, one by one.

The Seminar could have two presentations by chosen invited experts for each of these five vaccines. During the discussions people would put up points and counter points in the spirit of a dialogue, tempered by principles of science and keeping in view equity and justice concerns. There could be a free session at the end of each vaccine discussion. The answer we are looking for is: Which new vaccines do we think should be included in the National Immunization Programme of India?

*Some people would argue that this relative cost argument is not very real, because there is greater possibility of a child receiving a vaccine than a sanitary latrine, given the implementation challenges for the latter.*
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