

Chronic diseases: Some reflections

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Thought provoking sensitively written papers by Anand Zachariah, Yogesh Jain and the long mail from Anurag.

Some random thoughts of mine:

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” profile provided by physicians may not have much resemblance to the chronic “illness” profile 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 dripfor. In Tamil Nadu, there is the concept of “neer” (water; yes, sanskritisation of language even at the village level Tamil) which is the “cause” of many ailments (the reported symptom is ‘accumulation of neer’, but there is no oedema) which I have not had the time to apply my mind to. Similarly the ubiquitous *jhunjhunahat* which many will recognize.

In the preface to the ‘*The order of things: An Archeology of the Human Sciences*’, Foucault (1970) writes:

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)

What of the classification in the other systems of medicine? How do they fit in with the modern system of medicine? Do we want to fit it 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?

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.

2. chronic illnesses = non communicable diseases and NCDs = CHD, and Diabetes?

How is disease to be defined? Dis-ease, illness or 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?

In a study carried out in 2005 in UP and TN (Ritu Priya and Sathyamala)¹ 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 Sathymala 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 (TN, MH, HP, MP, UP and OR) (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).²

¹ This excerpt is from the unpublished monograph. Citation for this: Ritu Priya 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](https://doi.org/10.1080/09540120601114519)

² This table is excerpted from an unpublished monograph. Citation for this: C. sathyamala, N.J. Kurian, Anuradha De, K.B. Saxena, Ritu Priya, Rama Baru, Ravi Srivastava, Onkar Mittal, Jacob Puliye, Claire Noronha, and M. Samson (2011). *Public Report on Health*. Council for Social Development, New Delhi.

Table 1: Self-perception of health status across gender (%) – 6-village study

| Study village | Gender | Self-perception of health status | | | | NR%* (n) |
|---------------|----------|----------------------------------|--------------|-------------|-----------|------------|
| | | good | satisfactory | Not-so-good | worrisome | |
| TN | Male | 73.2 | 5 | 21.6 | 0.2 | 1.1 (7) |
| | Female | 60.8 | 9 | 30.2 | 0 | 3.2 (41) |
| | Combined | 67.0 | 7 | 25.9 | 0.1 | 5.2 (34) |
| MH | Male | 60.0 | 26 | 10.7 | 3.2 | 12.7 (15) |
| | Female | 57.0 | 30.7 | 8.2 | 4 | 16.2 (87) |
| | Combined | 58.7 | 28.2 | 9.6 | 3.6 | 9.4 (102) |
| HP | Male | 13.5 | 76.9 | 8.1 | 1.6 | 3.6 (16) |
| | Female | 11.8 | 74.5 | 12.3 | 1.4 | 2.6 (11) |
| | Combined | 12.7 | 75.7 | 10.1 | 1.5 | 3.0 (27) |
| MP | Male | 19.6 | 55.8 | 24.1 | 0.4 | 16.4 (91) |
| | Female | 18.9 | 51.5 | 28.7 | 0.9 | 16.7 (94) |
| | Combined | 19.3 | 53.6 | 26.4 | 0.6 | 16.5 (185) |
| UP | Male | 14.9 | 46.4 | 34.1 | 4.4 | 4.4 (28) |
| | Female | 12.9 | 37.1 | 46.3 | 3.6 | 4.4 (28) |
| | Combined | 13.9 | 41.9 | 40.1 | 4.5 | 4.3 (56) |
| OR | Male | 57.4 | 27.1 | 13.6 | 2 | 1.4 (7) |
| | Female | 52 | 36.4 | 10.2 | 1.4 | 1.9 (11) |
| | Combined | 54.5 | 32 | 11.9 | 1.7 | 1.7 (18) |

Percent calculated per 100 population after subtracting NR from denominator; * NR= non-response

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).³

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

³ Sathyamala et al. (2012) ‘Public report on health:some key findings and policy recommendation’ EPWXLVII (21):43-54.

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.⁴ 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?⁵

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?⁶

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?⁷

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’ (and pray how did the heavy metals get there in the first place?) and ‘use of pesticides’ (again at the level of victim blaming). **Please read their recommendations!**

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).⁸ If not what else could it be?

⁴ Pranavam, D. et al (2011) ‘Groundwater Pollution in the Palar Riverbed near Vellore, Tamil Nadu, India. Indian Journal of Science and Technology, [S.l.], p. 19-21, jan. 2011. ISSN 0974 -5645. Available at: <<http://www.indjst.org/index.php/indjst/article/view/29925>>. Date accessed: 07 Aug. 2015. doi:10.17485/ijst/2011/v4i1/29925.

⁵ u-tube documentary entitled ‘en payar pallaru’ (my name is Palar)
<https://www.youtube.com/watch?v=K0k2jhQ4VJQ> (accessed 7.8.15).

⁶ Manoranjitham et al. (2009) ‘Risk factors for suicide in rural south India’, The British journal of Psychiatry 196(1):26-30.

⁷ Thakur et al (2008) ‘Epidemiological study of high cancer among rural agricultural community in Punjab in northern India Int. J. Environ.Res. Public Health 5(5): 399-407.

⁸ Kaushik et al (2008) ‘Plasmodium falciparum malaria presenting with vertebrobasilar stroke’ International Journal of Infectious Diseases (2009) 13, e292—e294

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? 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 Vasant and Semanthini Niranjana could be read as excellent background papers.⁹

Let us not forget that (historically) public health agenda are subject to many interests and most often than not, the “patient’s” or “people’s” do not form the central concern.

4. Is there an increase /“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?¹⁰ 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 that the “epidemiological” data generated is now considered adequate for the purposes of pathogen mapping and 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. 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

– Peptic ulcer, Helicobacter pylori and stress (Stress and peptic ulcer: life beyond helicobacter Levenstein 1998 BMJ).¹¹

⁹ Zachariah et al (2010) *Towards Critical Medical Practice*. New Delhi: Orient Black swan.

¹⁰ Incidentally, one of the unqualified non-formal local private practitioner in the village where I did my study in 2011-12 started “diagnosing” and treating “diabetic” patients as an one-upmanship on the other two practising in the village and because it was becoming a “major” problem in the village)

¹¹ 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

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"? That this is so is so clear 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 trauma of finding my best friend in coma). How is this to be explained? (I was a smoker then but was still normotensive). One of the revered members of MFC 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!

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