The theme for the forthcoming annual meet (26-28 January 2017) is Chronic Diseases in relation to Poverty and requires shifting focus from women and child health issues and infections to chronic illnesses. This theme has had a somewhat long gestation period, with a preparatory discussion occurring during the mid Annual meet of 2015 with some significant papers being published in the MFC Bulletin (365-366) Mar-Oct 2015. The discussion at that time was to decide when it would be feasible to take up chronic diseases as a theme for the annual. I had been invited to be a commissioner for Lancet NCDI Poverty Commission. During the MFC mid annual meeting, it was felt that an annual just preceding the Lancet Commission’s meeting in India would serve as an ideal backdrop to raise issues from a perspective that usefully challenges mainstream perspectives of looking at NCDI and thus complement the efforts of the Lancet Commission to look anew at the situation. Thus, a decision was taken to address chronic diseases among the poor in the Annual theme for January 2017. The Lancet meeting will be held as planned at Ganiyari on 13 and 14 March 2017.

The papers that follow are a result of a yearlong preparation for this theme.

A few papers will describe NCD burden among poor people and show that the patterns of diabetes or spectrum of heart diseases as well as types of cancers are vastly different than those seen among the affluent.

Most NCDs are traditionally considered to be due to a lifestyle of high consumption and less physical activity. Are these chronic illnesses determined primarily by factors that operate at an individual/lifestyle/behavioral level? Or like most infectious illnesses, do socio-economic, nutritional or environmental factors play the most important role in causing these chronic illnesses too? Two background papers explore the relative importance of these individual vs. social factors in causation of these illnesses. This alone will allow choosing the right strategy to address these groups of illnesses at a preventive level.

As it stands, the health systems are completely ill prepared to handle these chronic illnesses. Screening programmes are needed to diagnose these illnesses early. Once diagnosed, they require regular care over several years, if not lifelong. We need to explore potential resources beyond our hospitals and village health workers to address these needs. Three papers in this bulletin explore some care pathways through some early work done in different areas of India.

It is imperative that we explore the gender dimensions of these chronic illnesses well. Is there a differential burden of chronic illnesses among men and women? Taking the example of the commonest cancer in women, cancer of the cervix, we will like to explore how the issue of vaccine choice, screening programmes and care plans are made.

Since care of these chronic illnesses requires expenses to be made over years, it requires a welfare state to fund the care plans, best through universal health coverage. How do the public health systems allocate finances for these? And in the absence of such support, how do people cope up with these expenses? These will be explored through two short papers.

Also, we would like to see how does the pharmaceutical industry respond to the possibilities of multifaceted organizations such as WHO and that of the PHM to non-communicable diseases.

As a physician working in the community, I realise that we can’t ignore the chronic illnesses any longer and it is important that we understand them better, and find correct ways of handling them together. I welcome you to read these diverse set of articles in this pre-annual meet Bulletin.
Background Note (MFC Annual 2017)
Addressing non-communicable diseases (NCDs)
among the poorest in the current health care scenario

1. Confusing, inadequate definitions

The phrase non communicable diseases (NCDs) is a negative term for a heterogenous group of illnesses that are not transmitted from one individual to the other through infectious organisms, even though they some of them may be caused by infectious agents. Most of these illnesses develop over a long period - months if not years. However, symptoms often are not observable in affected people, who may be diagnosed late and may require treatment for several years, if not life-long. Thus, most of the NCDs are chronic illnesses. If we add the management of tuberculosis, HIV and leprosy among the infectious illnesses to these NCDs, most chronic illnesses would be covered.

However, as Dr Anurag Bhargava, a public health expert had so eloquently elaborated in an earlier communication in the Medico Friend Circle (MFC), and in his essay in this bulletin, these binaries of acute vs. chronic or communicable vs. non-communicable are neither perfect nor always valid. Thus, we should accept the conventional division of human ailments into broad categories such as maternal and child health problems, infectious illnesses, NCDs and injuries only as loose groups with some overlap.

The term NCDs is only 30 odd years old. When it was coined, a great deal of emphasis was placed on individual risk factors like tobacco use or sedentary lifestyle, often at the expense of determinants at the community level (like dearth of supply of safe drinking water or failure of mosquito-control). Second, perhaps because the first four risk factors postulated for these NCDs were excess of bodyweight, blood glucose, body lipids or blood pressure, it was assumed that NCDs did or could not arise from deprivation of resources. NCDs appeared to be associated with risk factors seemingly opposed to conventional risk factors such as undernourishment, insanitation, crowding leading to infections such as diarrhoea, pneumonia and tuberculosis. All of these were conventionally seen more among the poor, as well as the maternal and child health problems, which too were more common in the poor or those who had poor health systems to support them.

How these associations of NCD with excess and affluence evolved over last 30 years is an interesting revealing story. It is well established that 'illnesses are biological embodiments of deprivation'. However, during the last 50 years or so, likely deeper socio-economic causation is at work because of which there is an epidemic of 'modern diseases' among both the poor and the non-poor. On one hand there is deprivation, under-consumption among unorganised workers, while on the other, overconsumption and a disease-prone life-style of the middle-class and the rich is now spreading to the working class to a certain extent.

This new epidemic arises out of a model of socio-economic development which is based on production that has little other purpose than to cater to the profit motive of corporations. This leads to a glut of consumer goods while giving rise to a population which, as a response to the alienation and stress of competition at work and home, finds solace in excess consumption. Such a populace is easy prey to the advertising and other gimmicks of these same corporations. For the unorganised and the poor, the same profit-driven and senseless productive system results in deprivation from healthy food and a structural push towards cheap unhealthy food, harsh work for long hours, and lack of good living conditions as well as addictive substances that offer temporary solace from alienation and boredom at the workplace.

As a result, in India, unorganised workers and the poor suffer from a double burden: traditional diseases of infections and undernourishment born out of development, deprivation as well new epidemics of cardiovascular disease, mental distress and illness and others, borne out of a broken model of development.

How and when did the poor experience the epidemiological transition to double burden of diseases - the continued suffering from the communicable diseases and additional burden of NCDs? Is this transition a product of the increased socio-economic disparities brought about by the post-1991 neoliberalism or does it pre-date these developments? It may be interesting to look at historical data, if available, to understand the inter-relationship of NCDs and poverty.

It also brings to the fore an issue for the MFC members involved in the community health projects for last few/several decades to ponder over. At the core of the MFC’s or primary health care project work and its design is the understanding of the local health care needs, or undertaking community diagnosis. For long, the discourse in the MFC has revolved around the communicable diseases and/or the resurgence of communicable diseases post-1991, with not so significant mention of the rise of the NCDs till recently, giving an “impression” that the NCDs among the poor are being captured only recently in the community diagnosis. This “impression” needs to be verified and validated. We need to understand whether we had in the past missed the importance of the NCDs among the poor because of our bias in assuming that NCDs are the diseases of rich or urban people.

2. Burden and pattern of NCDs: whither the poor?

The confusion about this relative distribution may have appeared because of this clubbing of disparate illnesses. We need to unpack these illnesses to see their individual association with deprivation or otherwise. The four conditions that account for 80% of the NCD burden globally - diabetes, cardiovascular diseases,
chronic lung diseases and cancers - are themselves large groups. Diabetes for instance is a heterogeneous illness umbrella; it includes type 1 diabetes which has a low and almost constant rate across populations, as well as type 2 diabetes, which is associated with obesity and insulin resistance in over 80% of those with the condition in the Western Hemisphere, in addition to a large and not-easily-classifiable group of highly undernourished and very poor people in Asia and Africa. In this last group, there is a glaring lack of information about burden.

Similarly, heart diseases are a rather heterogeneous group of illnesses. Some researchers based in the west, and in urban and peri-urban areas of poor countries such as India have mistakenly drawn generalisations from their small studies that over 75% of the heart diseases are coronary artery and atherosclerosis related. Since data from poor areas are patchy and often not of very good quality, contrary observations on cardiovascular disease profile don't seem to affect sweeping generalization such as that most cardiac disease burden all over the world is of ischemic origin.

There are some data sets that show that only as few as 20% of heart diseases in, say central Indian and sub Saharan African villages are of coronary artery disease origin and rheumatic diseases still account for over 40% of all heart diseases. Third, cancers could be infection related such as those of uterine cervix in women and many lymphomas and others may be related to use of tobacco or other toxins, exposure to dust exposure. All these are likely to be more common in the poorer income quintiles.

We need to question whether in developing countries these four NCDs really do account for the majority of all NCDs over 80%). We see a large spectrum of problems such as mental health problems, chronic arthritis, blood disorders especially hemoglobinopathies, chronic skin disorders, epilepsy (two thirds of these presently go untreated), strokes, as well as illnesses that require surgery for treatment. This points to a heady mix of illnesses that affect the poor substantially, so much so that it becomes almost immoral to make the statement that NCDs afflict the affluent alone, or even primarily.

In a small study of looking at the diagnosis of all new patients who presented to the outpatients at Jan Swasthya Sahyog (JSS) hospital in Central India, it was found that NCDs constituted 57% of all diagnosis, and a very wide spectrum of illnesses within the NCD basket (see figure 1).

We need to document the pattern of these NCDs among the poor. Our attempt to get state level data in Chhattisgarh has met with disappointment as the data is so incomplete as to make no sense. This is same problem exists at the national level too. And we know that since many of these illnesses have a significant proportion of asymptomatic people, a true estimate of the burden depends heavily on good screening methods as well as on well-functioning and citizen-responsive health systems which can enthuse people to access them for care.

In some African countries, where such burden of disease documentation is being attempted, they call it the long tail of NCDs, implying that some 30% of NCDs are distinct from the big 4. These diseases include rheumatic heart disease and cardiomyopathies, Burkitt's lymphoma and cervical cancer, asthma and bronchiectasis, type 1 and malnutrition-associated diabetes, appendicitis and peptic ulcer disease, hemoglobinopathies, post-infectious glomerulonephritis, epilepsy and suicide, burns and drowning. This data seems incomplete, and we have to wait and watch whether the tail will wag the dog or the other way around.

3. What we need to better understand moving beyond individualized risk factors to contextualized, gendered analyses

This reality points to a host of research areas to better enlighten the burden of chronic diseases among the poor communities. Our attempt to get state level data in Chhattisgarh has met with disappointment as the data is so incomplete as to make no sense. This is same problem exists at the national level too. And we know that since many of these illnesses have a significant proportion of asymptomatic people, a true estimate of the burden depends heavily on good screening methods as well as on well-functioning and citizen-responsive health systems which can enthuse people to access them for care.

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factors accounted for ~90% of MI risk. A closer look suggests that psychosocial factors accounted for an Odds Ratio of 2.67 and a Population Attributable Risk of 32.5%, almost the same as that of smoking.

The need to move “beyond individual risk factors” and for gendered analyses of the risk factors of NCDs and access to care is critical. Findings from a recently published study point to women, particularly from socio-economically disadvantaged backgrounds in India being disproportionately affected by NCDs. The study analysed data from the NSSO (71st Round, 2014) survey and concludes that the prevalence is higher among women (63) as compared to men (47), in a context where the overall prevalence is (55) per thousand persons. In a departure from prevalent understanding about NCDs, the study also indicates that rural women had a higher risk of NCDs (86) as compared with rural men (64) and in comparison, with women in urban areas (53).

Public health discourse on health globally has mostly perceived women’s health within the limited contours of their reproductive capacities. This overwhelmingly focuses on “maternal health” while extremely critical, reflects a bias that obscures women’s varied social identities and wider health needs and vulnerabilities to other NCDs. As a result, current policy, program implementation, diagnosis and treatment for NCDs amongst women is negligible or may be affected as compared with men. For instance, programs or services may not ask women relevant questions, fewer tests may be conducted for NCDs that may result in delayed treatment resulting in disability and other poor health outcomes. Women are also likely to experience NCDs differently from men given that they form a large majority of those living in poverty, experience poor nutrition, due to their lack of control over or access to economic resources, information, decision making, control over mobility, experiences of stigma that may impact their access to quality diagnosis, treatment and care.

In the forest fringe and forest villages of central India, Jan Swasthya Sahyog (JSS), found that hypertension is seen two times more commonly among women than men. Similarly, because of cancer of cervix and breast being almost exclusively seen in women, over two thirds of cancers are in women in these marginalized areas. Third, rheumatic Heart diseases are seen two times more commonly among women than men, a fact not otherwise well established or documented.

Women have a two times a higher risk of Depression in all studies done globally. The differential burden of NCDs among women and men needs to be documented better. Further, caregiving is extremely gendered in most societies and invariably women assume the role of caregivers in families and communities for those with NCDs, often in the long term and in the absence of provision of such services / care by healthcare systems. This may add to their ‘informal’ work burden and may even restrict their participation in formal economic activities or even continuing education for younger women.

Further, NCDs continue to be discussed mostly in the context of the "big four"; this excludes addressing of health consequences of gender violence, mental ill-health, etc. for example, which are experienced disproportionately by women. Although gender-based violence is not a 'disease' and necessitates response that is beyond medical care, its prevalent character and long term physical and psychological implications for the health of girls and women are well established which would benefit from being integrated within the wide spectrum of NCDs.

Why do we limit potential risk factors such as those mentioned above as the only cardiovascular risk factors to be considered? How does one start increasing the pool of risk factors to include income poverty, lower birth weight, chronic undernutrition, or extreme sadness due to a tragedy or loss? not What does ‘chronic stress’ even mean for a poor person? It is well known that even the biochemistry of stress is very different in responses to diverse physically/ pathologically/s socially/ economically/ politically stressful situations. Hence, different NCDs may respond very differently to different kinds of stress.

We need to have careful studies that study association with less known or unproved risk factors of these NCDs.

For certain populations within the poor, additional vulnerabilities emerge. For example, even for a genetic illness like Sickle cell disease, the outcomes in the tribals is poorer than among those who come in the OBC (lower and middling classes in India) group. Like in other illness groups, it is not the biological agent causing the disease that is most important; the host characteristics are the ones that determine the severity and the outcomes most. In perhaps no other illness group do the quality of the public health systems affect the outcomes and course of illnesses as in NCDs.

To understand and address this better, we need to go beyond individual risk factors and explore the social-cultural structures which have arisen which have led to the high prevalence of these risk-factors. Atomization, dearth of community life, paucity of...
social mechanisms for sharing of stress arising out of economic and social insecurity etc need to be explored.

4. The role of the pharmaceutical industry

Sales estimates in ‘growing markets’ (such as Brazil, Russia, India and China) indicate huge growths of up to US$300 billion annually by 2020. Further, the pharmaceutical industry contributes to the medicalised approach by creating increasing illness categories and conditions, such as “pre-diabetes” “pre-hypertension”, and broadening these boundaries so that more patients are diagnosed and prescribed drugs for NCDs. Clinical trials by Indian pharmaceutical companies in the period 2005-2015 were also found to focus on NCD related drugs. Interestingly, the Global Health Watch (GHW) report explains the role of big pharma in the context of NCDs. The major pharmaceutical companies such as Bristol-Myers Squibb, Eli Lilly & Company, Merck, Novo Nordisk and Sanofi support the NCD Alliance, which claims to “combat the NCD epidemic by putting health at the centre of all policies.

Sama’s study found that 657 phase III clinical trials were conducted for 307 drugs during 2005-2010. Of the 130 sponsors of the trials, 58 per cent were multinational pharmaceutical companies such as Sanofi Aventis,Boehringer Ingelheim,Novartis, Bristol-Myers Squibb, Glaxo Smith Kline, Pfizer and Astrazeneca that conducted 73 per cent of the trials.

The disease focus of the trials pointed to a maximum number of phase III trials conducted for diabetes followed by neurological disorders, cardiovascular, cancer and others. A stark observation from the entire list of 657 trials, only four phase III trials were conducted for HIV (1), Tuberculosis TB (1) and Malaria (2).

The number of clinical trials of drugs for cardiovascular diseases, cancer and diabetes increased progressively from 2005, with diabetes accounting for 20% of the clinical trials, cardiovascular diseases 12%, and cancer 11% of the clinical trials conducted in India. Similarly, the study also analysed that the sales revenue for a company is not only dependent upon the number of products in the market but also on the disease category that they target. For example, it was seen that diabetes medications contributed the most to the sales figures of companies like Sanofi and Merck.

Globally, R&D investments of pharmaceutical companies are influenced by various factors including prevalence of the disease condition, market share, profitability associated with a drug etc. The focus of R&D is for drugs for conditions like cancer, diabetes, cardiovascular conditions etc., among the non-communicable diseases (NCD) whereas HIV/AIDS is a principal area of focus among communicable diseases (CD). A WHO expert working group report exploring the R&D investment in the pharmaceutical sector showed that irrespective of whether in the private, public or not for profit sector, investments for NCD and CD were in the range of 68% and 32% respectively. The following figure indicates the investment in health R&D in different sectors in different disease categories.

Overall, it also needs to be noted that the global system for pharmaceutical research focuses on areas which affect patients in the High Income Countries and thus where profits can be maximised given the much higher purchasing capacity of patients (or insurance coverage) in High Income Countries. In contrast there is very little investment on diseases which affect the poor in Low and Middle Income Countries as neither public nor private (individual out of pocket funds) are available to service the high profit margins demanded by innovator pharmaceutical countries. Thus diseases such as TB, malaria, kala azar receive scant attention and neither does the entire array of new antibiotic development as these target infectious diseases that are largely prevalent in Low and Middle Income Countries. Creation of demarcated hierarchies between NCDs and other diseases are deleterious for any public health system and people's access to healthcare.India accounts for 21 per cent of the global burden of disease. The burden...
of communicable diseases—e.g., TB, malaria, HIV, and, waterborne and vector-borne diseases—in the country is very high, especially among children and mothers, which poses serious health problems. The burden of communicable diseases such as TB and vector-borne diseases is also very high. Out of 1,00,000 people, 176 people in India are suffering from TB. Despite this, very few clinical trials have been conducted for them on their benefit.

It is by now well established that any approach to address NCDs cannot be “individualistic” given that root causes contributing to NCDs include structural factors including poverty, exclusion, gender, food insecurity, trade, global political economy amongst other. When, for instance, obesity is medicalized, the general approach of its diagnosis and treatment tend to see the condition as an individual problem rather than locating the larger social, political and economic determinants of health.17

While development of drugs to treat non-communicable disease is of relevance to the population, there is also an urgent need for R&D for communicable diseases. Another extremely relevant concern emerges from the conflict of interests of the powerful pharma conglomerate; many of them are known to have worked towards contributing to the current discourse and are likely to use it towards expansion of their markets and profits.

While clinical trials / R&D for NCDs are important and all efforts initiated to ensure affordability of drugs for NCDs, this overwhelming focus must not obliterate local health concerns and priorities.

5. What ought to be done: the disconnected UHC agenda

We need nothing short of a range of approaches to tackle NCDs among the poor. When there is adequate evidence based preventive measures and strategies to minimise morbidity as well as cause management technologies, non-implementation of those steps must be highlighted and force the policy planners and implementers to take remedial measures. For example, in silicosis, known strategies such as stopping dry pulverization of rocks and mined pellets, installing motors and dripping sets for wet processes, setting up of dust enclosures, exhaust ventilation for closed buildings and yards, ensuring free distribution and wearing of personal protection masks and respirators, compulsory periodical check-ups for workers and medical treatment of affected workers, etc. have to be enforced strictly by the owners of mining sites and factories, with government oversight. Similarly, in fluorosis, the responsibility of department of rural water supply and drinking water mission in mitigating the chronic suffering of poor must be reinforced and sustained.

While there is government sponsored behaviour change campaign for reduction of stress, promotion of physical exercise, avoidance of tobacco, alcohol etc., there exists hypocritical government involvement of generating revenue through licensing of production and sale of alcohol. These contradictions must be highlighted and removed wherever possible, particularly inasmuch as the campaigns for wellness often skip the poor, while the campaigns of illness seem to target them. Historically in the context of communicable diseases and their prevention the role of the state was considered critical and hence interventions related to them came to be regarded as “public health” and were granted public goods status by economists. As healthcare development took place this dimension faded away and health and healthcare increasingly was being regarded an individual’s responsibility and this got consolidated with the emergence of private health insurance in the USA.

Now in an era of NCD domination this perspective of health being an individual problem and being characterised as a life-style issue is gaining momentum. Countries which have achieved universal access to healthcare, including developed capitalist countries have evolved healthcare systems in which health and healthcare in its entirety are regarded as public goods and hence public resources to the maximum are committed in the budgets of these countries, even though often service delivery may be under a regulated contract with private providers. USA is the only exception amongst developed capitalist countries and a few developing countries like India and Philippines seem to be unfortunately following that track.

Since universal healthcare coverage is on the agenda of the government we need to emphasize the public good dimension of all health and healthcare and advocate for its status as a public good and get the state to commit at least 2.5% of GDP for healthcare through which we can take the first steps in universal access to healthcare for all with equity. With this approach all healthcare whether preventive, promotive or curative and whether targeting communicable or non-communicable diseases will get come within a comprehensive approach (See Figure 5, below).

Figure 5. Continuum depicting the degree to which we treat health as a public good

The quality of service delivery in public health systems
is tested more in the secondary and tertiary management of complications of NCDs. Management of congestive and ischaemic failure in congenital or rheumatic heart disease, stroke complications, repeated dialysis for chronic renal failure, haemolytic crisis in those with Sickle cells, complications of haemophilia etc needs best use of technologies for repeated episodes and long periods. Quality drugs and diagnostics and strict adherence to evidence based management protocols are a must in public health institutions.

6. Addressing NCDs: A major challenge

Drugs and hospitals are important components of management at an individual level, particularly if someone presents with an acute complication. We are aware that for acute and for severe presentations of any illnesses, communicable or non-communicable, a hospital is justifiably important, and if the management strategy could be communitized, it could also go to a health worker 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, among others.

But for chronic/continuous illnesses, there are only some models available on a large scale, like delivery of blister packs for leprosy and tuberculosis drugs or DOTS. Similar strategies for bipolar diseases, epilepsy and other mental illnesses could be explored. Hospitals are inadequate for optimal care, while most NCD clinics in cities and in rural public health facilities dispensing of medicines is done over few days. It is a challenge to keep people motivated to continuing their medications for years and public health strategies need to be devised to address this.

What can work for NCDs? Frankly we need good answers. There must be a focus on identifying the right delivery platforms to address NCDs. Well-functioning health systems for the care of NCDs is as much a need if not more, in comparison to MCH and infectious disease care. These health systems have to provide comprehensive, affordable and appropriate care. Good data recording systems and surveillance systems must be put in place along with a focus on sufficiently communitizing them for expanding their reach. Supportive supervision for all community functionaries has to be built in upfront.

Further, we need new ways too. We have to learn from the models of disease based patient groups, like People Living with HIV or Alcoholics Anonymous. At Jan Swasthya Sahyog, there was an attempt to address this issue over the last two years, and their early results are promising. Similarly, in rural Rwanda and Mozambique, some strategies have focused on formation of disease patient groups and use of trained mid-level health workers have shown some promise.9 The Community based Palliative Care model for Cancer, Stroke and severely disabled persons in Kerala is worth expanding in other states. Many gram panchayats and local self-governments in Kerala are bringing in community-led resources for their palliative care programme and require only minimal technical back up from specialists. But a lot more needs to be done. The point is - we desperately need effective models for managing chronic diseases, not just preventive strategies.

This is not to say that there is no need for preventive strategies to address risk factors. Controlling intake of salt and sugar is important. There is a need to see the impact of our public distribution systems on causing imbalance of food constituents, such as making our diets even more predominant on cereals and their carbohydrates with very little pulses, oilseeds and animal foods, and institute remedial measures. In terms of diet, controlling intake of salt and sugar is an important public health message to disseminate. If birth weights determine occurrence of adult illnesses decades later, there is merit in instituting and strengthening preventive nutritional measures during pregnancy and pre-pregnancy periods. Once we know the contribution of chronic stress in causation of NCDs, how to handle chronic stress is another major challenge that we will have to confront.

In a context where public spending on health is dismal and health care priorities compete for finances, it is indeed necessary to reinvigorate campaigns for universal health coverage. It can only be a stop-gap arrangement that in the absence of universal health care, prioritisation of illnesses to address must be based on robust and reliable data.

In late 2015, the Lancet set up a commission to address the problems of NCDs in the poorest billion in the world, the largest proportion of them are in India and selected sub-Saharan African countries. Essentially as an academic coalition, the concerns they plan to address include settling the burden and pattern of NCDs among the poor as opposed to the non-poor, and then to suggest best delivery platforms, and to make a case for correct financing of NCDs focusing on the concerns of the poorest. They would like to learn majorly and specifically from the Indian context. We have a responsibility to rise to this occasion and contribute.

Yogesh Jain

(With inputs from Ravi Duggal, N.Sarojini, Anant Phadke, Antony Kollannur, Amar Jesani and R.Srivatsan)

References

There is a rich man’s tuberculosis and a poor man’s tuberculosis. The rich man survives, the poor man dies. - Edward Trudeau.

It has been said that if you stay in a place for a week, you can write an article on it and if for a year, perhaps a novel. However if you have witnessed something for years, then describing or even analysing it becomes very difficult. Three things come to my mind, when it comes to writing about 'non-communicable diseases' (or whatever this non-descriptor means). The first are enduring images (often very moving ones) of patients - their bodies and lives scarred and destroyed by diseases which unlike cancer, have names which do not communicate the horrors that may be in store for the many who suffer from them: essential hypertension, diabetes, stroke. Secondly, with regard to many of the encounters with patients and their diseases on a daily basis, I feel like a Rip Van Winkle, who wakes up in a landscape and climate which looks familiar, but isn't. Why does this patient with an acute febrile illness of even 3 days, look so unfamiliar and ominous? Were we simply not aware about scrub typhus or leptospirosis earlier, or have these re-emerged and why? In these patients with urinary tract infections, how have things come to such a pass that making a therapeutic decision without a culture is risky or where oral therapy is most often no longer effective because of drug resistance to both quinolones and cephalosporins? Were we missing diabetes in the poor earlier, or has it exploded in our face because of a combination of undernutrition and low lean body mass, a high carbohydrate diet and relatively high proportion of body fat, and change in levels of activity? The WHO in 1985 had proposed a classification of malnutrition related diabetes in 1985, but was its acceptance and then its removal premature? Would that category have promoted an understanding of the relationship between undernutrition and chronic diseases like diabetes? Is undernutrition the reason why we see patients develop alcoholic cirrhosis in India at levels of consumption and durations of intake that do not appear sufficient to cause cirrhosis? On the other hand did we really see the form of cirrhosis related to obesity earlier, that we now term as non-alcoholic fatty liver disease? When and how did hepatitis B or C emerge as major problems in India, and how much of it is related to unsterile injections, body-piercing, haircuts and the like? Are these really much more prevalent in the tribal populations - with the Jarawas of the Andamans registering the highest known prevalence of hepatitis B? What proportion of these are vertical transmission and what proportion due to an environment of poor access to healthcare (unsterile injections, etc.)?

(continued from previous page)

8. Unpublished observational study. JSS October to December 2015 study of All diagnosis in the Ganiyari OPD.
The experience of bewilderment inside a clinic is mirrored by a sense of bewilderment outside - at the malignant growth of the city (also of its glitter and squalor in equal measure) at the expense of the village, at the disappearance of trees and public spaces, at the sight of young and poor children buying 2 rupees worth of biscuits at a Kirana shop in the morning in lieu of a breakfast, and their parents who are daily wage labourers, buying a worthless soft drink at the same shop on their way back in the evening.

Finally, for most of these diseases, we could discuss them in the Indian context and come to an overarching generic conclusion - that the epidemiology is uncertain with a paucity of reliable estimates from the community level, that level of awareness is low, that the clinical presentation in an Indian context is possibly different from that reported in the west, that there is a huge unmet need for screening, diagnostic, therapeutic, counselling and rehabilitative services, that the outcomes are worse in the poor, the rural and the marginalised. For each of these diseases we would realise that the term non-communicable is an inadequate descriptor.

As an illustration of the predicament of patients and to lay out the issues which confront us in dealing with them, let me share experiences of patients that are currently admitted or have been seen very recently. These are not outliers in my experience as a physician working in a medical college in Mangalore. Most of the patients are from rural areas, belong to the poorer sections and from Northern Karnataka. The names have been changed to protect their privacy.

1. Hamid (name changed) is a patient with tubercular meningitis who came to us in a state of coma as well as paralysis, and severe undernutrition. He was successfully diagnosed as having TB meningitis but the family decided to consult a faith healer. Hamid's course has been stormy. TB meningitis has caused multiple vascular occlusions and resulted in complete paralysis on one side, and multiple palsies of his cranial nerves. He had severe hydrocephalus (accumulation of fluid in the brain) requiring a surgery to shunt his cerebrospinal fluid to the abdominal cavity. He promptly developed anti-TB treatment related hepatitis a few days after starting anti-TB treatment, given his severe undernutrition. He started responding minimally after 1 month of admission, but has a long, long road ahead. He was admitted for a month in our ICU which is more affordable than any private medical college ICU I have seen. TB meningitis was supposed to be a disease of children, but in my previous stint in Uttarakhand, according to the medical records, there were at least 3 times as many adults with TB meningitis as children. I was witness there to its crippling effects as well as its fatal outcome. Communicable diseases like tuberculosis or leprosy often result in serious and long term disability which have the same need for assessment and rehabilitation as a patient with a stroke.

Are we in any position to cater to these patients?

2. Lakshmi, a 55-year-old was never diagnosed as having diabetes. She came to us following a fever and unresponsiveness. She was detected to have diabetes with a blood sugar of more than 400 mg/dl and a glycosylated hemoglobin of 13 percent (which would mean that her estimated average glucose over the past 3 months would have been around 326 mg/dl). She was found to have pyogenic meningitis due to staphylococcus aureus, a nasty organism which would usually be a cause of meningitis in a post-operative neurosurgical patient. She is on insulin and will have to be in the hospital for 3 weeks. Her examination reveals that she has peripheral neuropathy and diabetic retinopathy, obvious indications that she had diabetes since many years.

We just discharged recently a 65-year-old underweight patient with no history of diabetes who came with a blood sugar of 600, a glycosylated hemoglobin value of 17 (her estimated average glucose over the past 3 months would have been around 441 mg/dl), already established kidney failure and a bad urinary tract infection with highly drug resistant organisms. Diabetes often announces its presence through acute and serious infections like these one or even as tuberculosis, as we now repeatedly see. One can only speculate on the duration of diabetes in these patients, but a screening test may have revealed their diagnosis. In my own experience with diabetes patients, sustained control of diabetes in poor patients is an uncommon event and the disease progresses rapidly, and often inexorably.

3. Shivanna is a 60-year-old lorry driver who has had diabetes for a number of years, uncontrolled, but insists that he was never detected to have hypertension, right up to his last check up 2 months ago. He came to us with severe hypertension and a brain hemorrhage, which was fortunately not massive enough to produce unconsciousness, but unfortunately caused paralysis of his left upper and lower limb. Shivanna is very well built for his age with an imposing appearance and whiskers, but cried uncontrollably at his own situation. The son makes a very modest living as a teacher and there are 2 daughters yet to be married. He asks me repeatedly when he will be well enough to work, and I have no answer. Was he really normotensive and the BP spiked suddenly to dangerous levels? Why?

4. Ramanna hardly looks the kind to have suffered a major heart attack 4 days ago. He has a diminutive appearance with a height of 5 feet 2 inches, a weight of around 50 kg, and has been a smoker for many years. He has no diabetes, hypertension, raised lipids or a positive family history of heart disease. His father died of an unknown disease when he was in his 20s. Ramanna worked at odd jobs in Goa and then worked in the Gulf for a few years but couldn’t sustain the long and killing working hours. He now works as a
cook, mainly for marriage functions. Over the past month, he had a slump in earnings owing to demonetisation and he was worried over payment of his son's and daughter's fees college fees. He suffered a heart attack and was given streptokinase therapy, but has still been left behind with poor cardiac function.

Apart from his stunting which indicates chronic undernutrition in early life and childhood, and features of accelerated cardiovascular disease at a young age which might be ascribed to smoking, he has other features of accelerated aging. He had his first cataract surgery 3 years ago, and now has a dense cataract in the other eye. He also turned out to have hepatitis B antigen in his serum on investigating the cause of his deranged liver function test. We are wondering how we will manage his cardiac condition with his chronic hepatitis B infection, which will require expensive tests and medications costing about 70 rupees per day for about a year.

5. Rahim has congestive heart failure with very poor cardiac function, as well as liver cirrhosis and his hepatitis B antigen is positive. The workup for hepatitis B would cost Rs. 6000. Recently a patient presented with Hepatitis C related cirrhosis. Both the workup and the treatment are out of reach of the patient. However patients from all over the world are now sourcing drugs for hepatitis C like Sofosbuvir from India. If we assume that the National Centre for Disease Control estimates of 40 million carriers of Hepatitis B (3% of the population) and 10 million people with Hepatitis C virus (around 1% of the population), are correct (NCDC Newsletter Jan-Mar 2014), these figures are higher than the prevalence of tuberculosis in India.

6. Mahadev has alcohol related cirrhosis, a disease which I see in admitted patients, even more frequently than I saw smokers with pulmonary disease in the tobacco growing belt in rural Gujarat. The profile of all these patients is disturbingly similar, men in their 30s and 40s, drinking for a number of years and then suddenly developing the features of cirrhosis, with potbellies due to litres of accumulated fluid. Most of them would qualify as candidates for liver transplantation, and in its absence their 5-year survival rates are as bad as for patients with cancer. The women, their wives have an air of resignation writ on their faces, and they are always still there by their side. One of them asks me, suppressing her tears, whether they could have the liver transplantation if she donated her eyes, and kidney, and part of her liver...

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To put the meeting theme into a larger perspective, while we talk of addressing chronic diseases of the poor, we are far from understanding our own patterns of acute diseases of the poor. Suresh a young farmer came to us with 3 days of fever in this season when there have been no rains. He was breathless and jaundiced. Soon both his lungs became white on X-rays, and he started coughing up blood. He was intubated and even the routine mechanical ventilation was to no avail. Leptospirosis was suspected and later confirmed. He was then ventilated in a prone position, administered antibiotics and high dose steroids. He thankfully survived to the relief of his wife who was bearing their first child. While we were treating this patient, we heard of a professor in another medical college with a fever of 1 day duration who landed with the same problems, and had to be dialysed for the renal failure.

In Uttarakhand over a period of 3 years we documented hundreds of patients with scrub typhus (Bhargava A et.al., forthcoming in the Indian Journal of Medical Research) a cause of acute febrile illness, spread by the bite of infected larvae of a mite, which has been reported from all over India of late, but which is still not widely recognised as a cause of a potentially lethal acute febrile illness. In fact out of 8 patients who had an undiagnosed fever I saw on the request of the district CMO of Tehri Garhwal, 7 had scrub typhus. The disease has a seasonal predilection, presents most often as a severe community-acquired pneumonia often progressing to a stage requiring mechanical ventilation. Scrub typhus also presents with brain involvement and has now been proven to account for a significant proportion of children originally diagnosed with Japanese encephalitis in Gorakhpur. In the face of such illnesses our old practice or suggestion of waiting out for a few days before getting investigations for causes of acute non-malarial illnesses is potentially dangerous.

I am flagging some points for reflection and discussion in the meet:

1. The invisible, silent and interlinked nature of many NCDs. The distinctions between host and environment, between acute and chronic, CDs and NCDs, are artificial and detrimental to public health. There are synergies between CDs and NCDs that can be very profitably exploited.

Can diabetes which may result in an asymptomatic elevation of glucose or hypertension which is mostly an asymptomatic elevation of blood pressure even be called diseases? These conditions form clusters and cascades with a particular condition being a risk factor for others, and the resultant conditions being risk factors for many other problems. E.g. obesity is a risk factor for both hypertension and diabetes, which in turn are risk factors for cardiac disease, strokes, renal failure.

Can an individual be viewed separately from his physical or social environment, in our attempt to place risk factors into the domain of individual lifestyle? As I explained earlier in a note, NCDs are seen as chronic diseases though they can cause potentially fatal
acute complications e.g. heart attack, strokes, respiratory failure, gastrointestinal bleeding (in liver diseases), while many infections run a chronic course.

There are synergies between CDs and NCDs. Control of tobacco, alcohol and diabetes would also have an impact on the problem of TB, while having a significant impact on cardiovascular, respiratory and liver diseases? The infrastructure that had been developed to address the problem of leprosy neuropathy could be used to provide foot care and footwear to India's diabetics too.

2. Undernutrition is in the no-man's land between the CDs and NCDs and affects the burden of both. The neat classification of CDs and NCDs does not consider undernutrition in either category. Undernutrition is the main cause of immunodeficiency in the world and increases the frequency, severity and fatality of acute infections. Maternal undernutrition and low birth weight leading to increased cardiovascular risk and risk of diabetes in adulthood is now an accepted example of fetal origins of adult disease, and a significant body of evidence in this regard has emerged from the work of Dr. CS Yajnik and team at Pune.

During a 3 year period we studied the profile of patients with a recent diagnosis of diabetes, at JSS. 90% of these patients had type 2 diabetes and almost half were under the age of 40 years. Only 15% could be classified as overweight or obese on the basis of their BMI. The mean heights of both men and women showed evidence of chronic undernutrition. Complications like neuropathy were the most prominent, and 1 in 6 patients had suffered from TB.

3. Some facts should be accepted as truisms, should be considered unacceptable, and be addressed urgently. Low birthweight is not healthy, nor is stunting, nor is the PDS diet of only rice or wheat, and nor is abdominal adiposity which is driving the problem of metabolic syndrome and diabetes in a large section of the population.

We should no longer debate the detrimental effects of the above phenomena, but work toward eliminating these anomalies. Short stature increases diabetes risk, while tall stature is protective.

4. The Indian city and its environs are hostile to health in all its dimensions, and we need cities which are More Equitable, Healthier, rather than merely Smarter.

We need to reclaim the open spaces in our cities. The smart cities project has a component on affordable housing for the poor which should be pushed aggressively.

5. The answer to the prevention of both CDs and NCDs is creating Health- ONE HEALTH, addressing risk factors, conditions and structural factors which impact on both CDs and NCDs, across the continuum of the life-cycle. This will require a healthier diet, water and sanitation, healthier home and workplaces, healthier leisure and culture, healthier relationships, safer doctors, and policies which address both health-specific issues in particular and are health-sensitive in general.

As research has shown there are critical periods in the life-cycle which impact on risk of cardiovascular diseases. Also the risk factors accumulate through the life course of a person and interact to produce the disease.

In terms of a policy that needs to be revised, we could start with the National Nutrition Policy 1993.

6. The education system as well as medical education system need radical restructuring to deal with the prevention and management of these conditions. I find that medical students fumble when they are asked to work up a patient with diabetes, advise patients about diet or insulin.

7. Public health is not rocket science, and medical care of these diseases need not cost the moon. Apart from efforts at prevention, we shall have to evolve the concept of health promotion at every encounter with the healthcare system and a rational evidence based routine screening examination conducted at appropriate intervals.

We should be asking and advising about tobacco and alcohol use and advising on diet and exercise on every available opportunity, while also offering women simple tests for cancer screening. BP should also be recorded during healthcare related visits and appropriate advice given. We need screening for diabetes even below 40 years of age, including in patients who are not obese. Rescreening every 3 years would be appropriate.

In the guideline for management of hypertension in India that I helped develop, the cost of 2 or even 3 antihypertensives plus aspirin and statin could be less than a rupee a day if procured through a public procurement system.

8. An approach focused on primary care with active referral linkages, is feasible and cost-effective, and the burden of morbidity and mortality and the costs of addressing them is largely due to the neglect of these diseases at the primary care level.

A standard treatment guideline for screening, diagnosis, evaluation, management and follow up of patients with essential hypertension has been developed for the National Health Mission.

9. The care models for these diseases need to have strong components of health education and counselling, self-care and community based care. We need not look at the West for training and inspiration, and interactions with countries like Sri Lanka and Cuba, or even China are likely to be more productive and relevant.
Moving beyond the risk factor model for coronary artery disease to community led prevention

Anand Zachariah

This article focuses on examining the framework of causation of coronary artery disease from the perspective of successful models of primary prevention and see what we can learn about possible approaches for our communities. It is a review of experiences of primary cardiovascular prevention in the North Karelia project in Finland and other similar projects that were initiated primarily in the Western world (Reference 1 and 2).

There are two approaches to prevent coronary artery disease: (1) Primary prevention in the community (that focuses efforts on the behaviour and environment of the entire community) and (2) High risk preventive program: prevention that focuses on screening, behaviour modification and treatment of high risk individuals. The evidence so far suggests that effective population interventions require the first approach. This is because only a small number of people have significant elevation of a single parameter, whereas a large number of people have small elevation of multiple risk factors. Therefore programmes which lead to mild reduction of risk factors across the population are likely to have a more substantial reduction in coronary event and deaths. This article examines successful models of primary prevention, to see what we can learn from them about cardiovascular disease causation and prevention.

North Karelia project

North Karelia was the site of one of the first projects started in 1974 to attempt primary prevention of coronary artery disease.

Context

North Karelia is a province in the Eastern part of Finland bordering on Russia and is populated by an agricultural community. It was relatively well off than other parts of Finland. In the first half of the last century there was a shift of occupation from timber logging to dairy farming. Therefore the local diet had adapted to dairy products with high fat content from butter, milk and pork and it was low in vegetables that had to be imported from southern Europe.


Prevalent studies

In the first half of the 20th century clinicians had noted that North Karelia had a high rate of heart attacks and deaths in young active lumberjacks. Interaction with Ancel Keys in Minnesota in 1954 (who proposed the link between fat intake, hypercholesterolemia and heart attacks) led to further collaborative work on the role of dietary fat in heart attacks in North Karelia. These studies showed that dietary fat intake and hypercholesterolemia were higher in North Karelia than comparable areas in Western Finland. A 10 year East West longitudinal study showed very high rates of heart attacks in North Karelia. Here, chief risk factors were hypertension, smoking and high dietary fat intake. Meanwhile, studies were performed on how to modify Finn diet to reduce fat intake by replacing milk fat by vegetable oil and increasing unsaturated to saturated fat ratio.

Political initiative of the local community

The local community showed serious concern over the report of the 10 year longitudinal study; this was particularly true of women who had lost a family bread winner. The political representatives of North Karelia discussed the report of the 10 year follow-up study and prepared a petition to start a preventive project. The governor of North Karelia and other representatives went to Helsinki to petition the parliament. This led to the government providing funds for starting the North Karelia project.

Notes

1. This quote was written circa 1900. We may dispute whether the poor have a higher or lower burden of all NCDs, but the outcomes are indisputably worse, and the social consequences are clearly catastrophic.
3. Over 60% rates of positivity in this tribe have been recorded. Alarming prevalence of hepatitis-B infection among the Jarawas—a primitive Negrito tribe of Andaman and Nicobar Islands, India.Murhekar MV, Murhekar KM, Sehgal SCJ Viral Hepat. 2003 May;10(3):232-3.
4. This is a form of hemoglobin that is measured primarily to identify the three-month average plasma glucose concentration to assess the long term control of diabetes.
5. This is an acute febrile illness caused by contact with soil or water contaminated by bacteria which are present in urine of infected animals especially rodents. People involved in agriculture and related activities or living in unsanitary conditions in urban slums are at particular risk. It is a potentially fatal illness which is grossly underreported.
For this project they identified a young public health specialist (not a cardiologist) who had previous training in political science, Pekka Pushka. He was politically active and acquainted with the President of Finland, Urho Kekkonen.

Description of project
At one level, the North Karelia project could be described as a conventional health programme. It was as a 5 year programme to reduce mortality related to heart attacks, reduce risk factors that were leading to heart attacks and improve the health of the local community. The intervention was conducted in North Karelia province (Population 1,66,500) with a control reference province of Kuopio (Population 250,000).

The project focused on risk factors that had been identified in the local community (hypertension, smoking and hypercholesterolemia) by behavioural modification of diet to reduce fat, smoking cessation and screening and treatment of hypertension. Towards these goals, the project included activities such as: (i) Media (TV programme); (ii) Health service reorganisation; (iii) Community organisation; (iv) Environmental change and (v) Policy changes

However, there were several aspects that made it an unconventional public health programme:

1. It was a political initiative of the local community which emerged as a local health movement.

2. Conceptual framework: The epidemiological framework helped to identify risk factors for the intervention and in development of the objectives and targets. However the design of the intervention was based on a social and behavioural model. It was based on three theoretical frameworks: (1) Behaviour Change Communication: (2) Innovation-Diffusion and (3) Community Organisation. These different approaches were combined in a unified model of behavioural and social model of community intervention. This model emphasised methods of changing behaviour through providing information, motivating, training the community, changing the physical environment, and community building towards better health.

3. External inputs: WHO was actively involved in North Karelia project from the beginning, helping to collaborate with other similar projects across the world and disseminating the findings. Geoffrey Rose, public health expert from UK who emphasised population level preventive interventions for chronic disease was consulted. Everett Rogers, a sociologist who developed the innovation-diffusion theory and was involved in developing the behavioural interventions of the programme.

4. Community consultation, diagnosis and participation: The project actively and continuously involved many different community participants: Women's groups, employers, schools, informal leaders, farmers, industry, media etc. The process involved community diagnosis, to consider the different ways in which the risk factors were operating in the community and opportunities and feasibility for intervention.

5. Integrated programme that worked on a range of activities that addressed the pathway of the risk factors with active community involvement (see Figure 2 and Table 4).

Behaviour change involved working with women's groups to change cooking habits away from butter to margarine produced from rape seed, lower fat content and more vegetables in diet, planned media activities (Quit Win smoking campaign, cholesterol lower competition between villages), education programmes in schools, work places and in health centres and use of lay leaders to initiate behaviour change by talking to people.

6. Health system reorganisation with a nurse run hypertension programme encouraging people to come for hypertension screening at health centres and special hypertension clinics.

7. Changing the environment

More healthy food: Working with farmers to shift dairy land to berry cultivation, sausage industry to reduce salt and fat content, supermarkets to promote more health foods and bakeries to shift from butter to margarine. Legislation for healthy foods and requirement for nutritional information on food packets.

Smoke Free Karelia: Banning of cigarette advertisement, sales to teenagers (<18), smoker free public environment by legislation

8. Community organisation and social support: Women's groups, work place, schools, lay leaders and public representatives to promote active involvement of community in the program. They worked with industries, farmers and supermarkets overcoming resistance.

9. Determination, commitment and leadership of team: Pushka and his small team were determined and convinced that they could change unhealthy behaviours with active involvement of the community. They worked with limited resources but used the strengths of the community. They used unconventional strategies to create a local health movement.

10. Model project upscaled nationally and internationally: The government and WHO were involved through the early phases. When the initial project outcomes were beneficial, it served as the model for Finland and was quickly disseminated by WHO as a model for cardiovascular prevention in other countries.

North Karelia project outcomes

The risk factors were documented by mailed cross sectional risk factor surveys every 5 years between 1972-2007 in North Karelia (intervention area), Kuopio (reference area) and a third area in south western Finland that was included from 1982. The mortality data was obtained from the central statistical office of Finland for North Karelia and rest of Finland and cause of death ascertained from the death certificates.

Risk factors

In the first years of the project there was a decline in mean blood pressure and cholesterol and rates of smoking in North Karelia project compared to reference area. The difference in the rates of smoking...
persisted for 10 years. Thereafter the decline in rates of risk factors became similar in both areas. Over 35 years (1972-2007) there has been fall in blood pressure and cholesterol in men and women and rates of smoking among men in North Karelia. However smoking rates went up in women although from a lower level than men (see table 1).

During the 35 years of the project there has been an improvement in the quality of diet: decline of use of butter on bread, whole fat milk, increased use of low fat margarine, vegetable oil for cooking, skinned milk and daily vegetable intake in North Karelia.

**Mortality**

In the period between 1969-71 and 2007 there has been a decline of all cause mortality in the group 35-64 of 63% with fall in cardiovascular mortality of 80% (IHD 85% and CVA 69%) and cancer mortality of 67% (See Table 2). The mortality reduction was rapid during 1970-1990 and then slowed down (See Figure 1). North Karelia which had a higher cardiovascular mortality than the rest of Finland has approached the national average. The benefits of the project were not just for preventing deaths due to heart attacks but also for cancer related deaths and overall longevity.

This model project was up scaled to the rest of Finland. This led to similar and parallel decline in cardiovascular death rates, cancer deaths and overall death rates across Finland from mid 1980’s, although at slightly slower rates than in North Karelia (See Figure 1). Between 1969-71 and 2007 there was an all-cause mortality decline in men between age 35-64 of 56% cardiovascular disease mortality of 75% (IHD 79% CVA 73%) and cancer mortality of 53%. A similar decline occurred in women except for a lower rate of decline of cancer mortality (29%) (See Table 2).

Analysis of the decline of cardiovascular mortality between 1982-97 suggests that about 53% of the total decline occurred due to fall in cholesterol, smoking and blood pressure and only 23% due to medical interventions (procedures, surgery and secondary prevention) emphasising the importance of behavioural interventions. It was estimated that the majority of decline occurred due to fall in cholesterol (37%), followed by smoking (9%) and blood pressure (7%) [REFERENCE 3].

**International experiences of Primary prevention of coronary artery disease**

There are more than 100 projects have been published on primary prevention of cardiovascular disease. They vary in their methodology some with more community involvement than others. Most projects show mild to moderate reduction in risk factors (See Table 5: summary of 13 selected primary prevention programmes). The magnitude of effects of the projects is thought to be related to the dose of intervention and none have shown adverse outcomes. However the dramatic decline in mortality that was seen in North Karelia in Finland was not replicated by any other project. The reasons for this lack of mortality decline are suggested to be the lack of sufficient sample size (150-200,000 population size is required), secular decline of coronary artery disease related to national level prevention efforts and diffusion of effects of intervention to control population. It is suggested that the levels of risk factor decline that were documented may have been associated with a small but significant population mortality

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<td>5.7</td>
<td>137</td>
<td>83</td>
<td>550</td>
<td>22</td>
<td>5.5</td>
<td>132</td>
<td>78</td>
</tr>
<tr>
<td>2007</td>
<td>357</td>
<td>31</td>
<td>5.5</td>
<td>139</td>
<td>83</td>
<td>395</td>
<td>18</td>
<td>5.2</td>
<td>134</td>
<td>78</td>
</tr>
</tbody>
</table>

Table 1 Risk factor changes over time in North Karelia in adults age 30-59

<table>
<thead>
<tr>
<th>Year</th>
<th>Number Subjects</th>
<th>Smoked %</th>
<th>Mean HDL cholesterol</th>
<th>Syst BP</th>
<th>Diastolic BP</th>
<th>Number of Subjects</th>
<th>Smoked %</th>
<th>Mean HDL cholesterol</th>
<th>Syst BP</th>
<th>Diastolic BP</th>
</tr>
</thead>
<tbody>
<tr>
<td>1972</td>
<td>172</td>
<td>52</td>
<td>6.9</td>
<td>119</td>
<td>92</td>
<td>1886</td>
<td>10</td>
<td>6.8</td>
<td>153</td>
<td>92</td>
</tr>
<tr>
<td>1977</td>
<td>176</td>
<td>44</td>
<td>6.5</td>
<td>143</td>
<td>89</td>
<td>1834</td>
<td>10</td>
<td>6.4</td>
<td>141</td>
<td>86</td>
</tr>
<tr>
<td>1982</td>
<td>1229</td>
<td>46</td>
<td>6.1</td>
<td>144</td>
<td>87</td>
<td>1267</td>
<td>15</td>
<td>6.1</td>
<td>141</td>
<td>85</td>
</tr>
<tr>
<td>1987</td>
<td>1138</td>
<td>46</td>
<td>6.1</td>
<td>144</td>
<td>88</td>
<td>1249</td>
<td>15</td>
<td>6.1</td>
<td>139</td>
<td>83</td>
</tr>
<tr>
<td>1992</td>
<td>519</td>
<td>32</td>
<td>5.9</td>
<td>122</td>
<td>85</td>
<td>610</td>
<td>17</td>
<td>5.6</td>
<td>135</td>
<td>80</td>
</tr>
<tr>
<td>1997</td>
<td>537</td>
<td>31</td>
<td>5.7</td>
<td>140</td>
<td>88</td>
<td>576</td>
<td>16</td>
<td>5.6</td>
<td>131</td>
<td>78</td>
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<tr>
<td>2002</td>
<td>402</td>
<td>33</td>
<td>5.7</td>
<td>137</td>
<td>83</td>
<td>550</td>
<td>22</td>
<td>5.5</td>
<td>132</td>
<td>78</td>
</tr>
<tr>
<td>2007</td>
<td>357</td>
<td>31</td>
<td>5.5</td>
<td>139</td>
<td>83</td>
<td>395</td>
<td>18</td>
<td>5.2</td>
<td>134</td>
<td>78</td>
</tr>
</tbody>
</table>

Table 2 Proportional change in annual age adjusted mortality rate (per 100,000 population) between 1969-71 and 2006 in All of Finland and North Karelia among 35-64 age in men and women.

<table>
<thead>
<tr>
<th>Year</th>
<th>Percentage in mortality decline</th>
<th>All Finland</th>
<th>North Karelia</th>
<th>All Finland</th>
<th>North Karelia</th>
</tr>
</thead>
<tbody>
<tr>
<td>1972</td>
<td>All cause</td>
<td>-56</td>
<td>-63</td>
<td>-40</td>
<td>-51</td>
</tr>
<tr>
<td>1977</td>
<td>Cardiovascular</td>
<td>-72</td>
<td>-80</td>
<td>-79</td>
<td>-82</td>
</tr>
<tr>
<td>1982</td>
<td>IHD</td>
<td>-79</td>
<td>-65</td>
<td>-83</td>
<td>-90</td>
</tr>
<tr>
<td>1987</td>
<td>CVA</td>
<td>-73</td>
<td>-68</td>
<td>-78</td>
<td>-82</td>
</tr>
</tbody>
</table>

Figure 1. Age-adjusted mortality rates of coronary heart disease in North Karelia
benefit which may have been difficult to measure.

It is clear that designing primary prevention projects to demonstrate fall in heart attacks and deaths is not easy. A concerted and unusual effort as in North Karelia project is required to show a mortality benefit.

Why was North Karelia project successful in a manner that other projects were not?

The North Karelia project was an unusual model which went far beyond standard biomedical model of experimentation (for example a controlled clinical trial) to create a community based movement (“A community which went on diet” was a term used in a magazine article). It had committed, persistent and unconventionally innovative leadership which believed that they could succeed in changing the behaviour of the community. The project was premised on the epidemiological model, but it was designed on a social and behavioural principles. It was an integrated intervention that used all feasible opportunities and changed dynamically. It worked towards building community and changing environment toward better health. All this was done with a rigorous documentation which was able to demonstrate the beneficial outcomes and helped in its dissemination.

Framework of cardiovascular causation: moving beyond the risk factor model

The epidemiological model that emerged with the Framingham study has emphasised the importance of risk factors, their screening and treatment as strategies for preventing cardiovascular disease. The case study of the North Karelia project provides scope for alternative way of thinking about cardiovascular causation that moves beyond the Framingham model. My reading of the use of the term, risk factors in the North Karelia project refers to risk factor not as absolute determinants of development of disease but as markers of a risk profile associated with increased risk of development of disease. A number of

![Figure 2: NORTH KARELIA PROJECT INTERVENTION: PATHWAYS FOR PREVENTION](image)

Reflections for prevention in communities in India

development pathways in the community through individual and community behaviour related to diet, cooking, habits, activity, industry, agriculture, governmental policy may lead to heart attacks and coronary artery disease. These may be mediated through these risk factors (for example smoking, hypercholesterolemia, hypertension) or the risk factors may be markers of these development factors (for example risk factor profiles of overweight, hypertension, impaired fasting glucose, hypercholesterolemia, physical inactivity). The way development affects different communities may be different (for example North Karelia and Gudalur) although the risk factors and the cardiac events may be same (see references 4 and 5 for more discussion). The reason why North Karelia project succeeded was that they could analyse different pathways whereby development affected coronary artery disease and implement a set of community led strategies to address these (See Figure 2). Therein lies the success and message of the North Karelia project.

The situation in Finland and communities in urban India and villages which are rapidly urbanizing is very different. Communities in India are structurally adjusting to social and economic changes which are affecting diet, activity and stress (see Table 3). The slum communities in urban areas and tribal communities in rural areas are economically vulnerable and have limited access to good quality food, opportunities for leisure physical activity and ways of dealing with developmental stress. The epidemic of diabetes and vascular disease (heart attacks and strokes) in India are increasing and not in a declining phase.
While the contexts are different, the message of North Karelia project is that community based and community led prevention is possible. As Puska wrote, “There is firm knowledge on what should be done for prevention of these diseases, the key question is: How should it be done?”

For a community based prevention programme it is necessary to have:

1. Local epidemiological information based on risk factor studies
2. Community discussion on the epidemiological data. Community analysis of how development is leading to these risk factors and disease in the local community.
3. Active discussion with different community stakeholders regarding feasible preventive interventions that can be taken forward in the community through education, nutritional interventions, working with health system for screening (hypertension, diabetes and dyslipidemia), towards healthier environment (shop keepers, farmers, housewives, ration shop owners) and strengthening community (See Table 3 for potential interventions).
4. Monitoring systems that can evaluate the effect of the interventions.

Table 3: RISK FACTORS FOR ISCHAEMIC HEART DISEASE AND POTENTIAL INTERVENTIONS IN INDIA

<table>
<thead>
<tr>
<th>Risk factor</th>
<th>Potential interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Rapidly urbanizing communities</td>
<td>1. Nutritional interventions: course cereals, reduced fat and salt</td>
</tr>
<tr>
<td>2. Poor diet: shift from traditional foods to refined cereal diet, increased fat, low in vegetables, fruits and proteins (pulses, milk and animal products)</td>
<td>2. Agriculture: kitchen gardens, organic agriculture initiatives (see referenced)</td>
</tr>
<tr>
<td>3. Moderate rates of hypertension</td>
<td>3. Hypertension screening and treatment; diabetes screening for people &gt;40 and overweight people</td>
</tr>
<tr>
<td>5. SEDENTARIA: increasing weight, impaired fasting glucose and diabetes</td>
<td>5. Alcohol initiatives</td>
</tr>
<tr>
<td>7. Stress related to education, employment, money, loans, housing, health care and changes in family structure and supports</td>
<td>7. Education programmes: women’s groups, youth, schools, workplace, shop keepers</td>
</tr>
<tr>
<td>8. Different measures to address stress at the community level</td>
<td></td>
</tr>
</tbody>
</table>

Concluding remarks

Vertical structures of traditional public health systems may be structurally unfit to handle such preventive initiatives. On the one hand we need systems for medical management of coronary heart disease, heart attacks and secondary prevention. Similarly, we need social and behavioural interventions that address the development pathways that are causing disease. Both local community initiatives (such as the North Karelia project) and governmental interventions for health system strengthening and policy interventions are necessary for an NCD programme and need to be advocated both by WHO and the Government of India.2

While these efforts may not cause a sharp decline in the evolving cardiovascular epidemic in India, they may ameliorate the effects of ‘development’ on the cardiovascular system in communities by fostering more healthy behaviours, changing the environment favourably and working towards building more healthy communities.

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Email: zachariah@cmcvellore.ac.in

Notes

1. The term development pathway refers to a pathway of factors of a particular development vector’s influence on the disease outcome. For example in the case of the North Karelia project, government subsidy for high fat milk and meat, food manufacturing processes, dietary habits and culinary styles, food marketing processes could be a development pathway which leads to a high fat diet that contributes to hypercholesterolemia and heart attacks. A pathway of prevention refers to potential and feasible preventive measures that could address the pathway at different levels.

2. The HIV prevention and care programme is an example of involving communities in local initiatives such as high risk interventions and government policy interventions for prevention and strengthening care delivery through the ART programme.

References:

### TABLE 4: NORTH KARELIA CARDIOVASCULAR PREVENTION PROGRAMME

<table>
<thead>
<tr>
<th>Type of Intervention</th>
<th>Description of Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>TV programme</td>
<td>A survey of six villages was conducted; the smoking rate decreased by 40% among males and 20% among females.</td>
</tr>
<tr>
<td>Hypertension programme</td>
<td>Strengthening and reorganizing the health system through education and public awareness campaigns.</td>
</tr>
<tr>
<td>Working with community organization</td>
<td>Collaboration with the North Karelia Heart Association to promote healthy lifestyle changes.</td>
</tr>
<tr>
<td>School programme</td>
<td>Peer education programme for smoking and alcohol prevention, school health programmes, and promotion of healthy lifestyle.</td>
</tr>
<tr>
<td>Lay leaders programme</td>
<td>Training of lay leaders to promote healthy lifestyle changes in their communities.</td>
</tr>
<tr>
<td>Working with industry</td>
<td>Encouraging industries to offer healthier workplace options.</td>
</tr>
<tr>
<td>Working with farmers</td>
<td>Encouraging farmers to grow and promote healthier food options.</td>
</tr>
<tr>
<td>Campaigns and competitions</td>
<td>A series of competitions were held to promote healthy lifestyle changes.</td>
</tr>
<tr>
<td>Legislative and policy changes</td>
<td>Implementation of policies to support healthy lifestyle changes.</td>
</tr>
</tbody>
</table>

[REFERENCE 3 CHAPTER 3, 15 AND 16]

### TABLE 5: INTERNATIONAL EXPERIENCES WITH COMMUNITY BASED CVVD PREVENTION PROGRAMMES AND THEIR EVALUATION

<table>
<thead>
<tr>
<th>Name of project</th>
<th>Number of participants</th>
<th>Intervention</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Three community study (1977)</td>
<td>Three communities</td>
<td>Media campaigns</td>
<td>Reduction in CVVD risk factors.</td>
</tr>
<tr>
<td>Child programme</td>
<td>Housing project</td>
<td>Interventions</td>
<td>Reduction in CVVD risk factors.</td>
</tr>
</tbody>
</table>

Karelia to National Action (Reference 3)
Community based responses to non-communicable diseases in North India - four case studies

Kaaren Mathias

Non-communicable diseases and injuries (NCDi) account for 52% of deaths in India [1]. Community-based screening, re-oriented health services and health promotion in communities are key responses to the growing NCDi burden in India and other low-middle income countries (LMIC) [1-3]. This paper profiles four diverse community-based responses to NCDi in North India focusing on relatively neglected aspects of community based NCDi programmes: screening for oral cancer; community-based palliative care services; social organisation of communities to respond to domestic violence and suicide risk; and strengthening community awareness in mental health. These projects are implemented by the Emmanuel Hospital Association (www.eha-health.org), a non-governmental organisation with a network of 20 hospitals and 40 community health development programmes working across North and North-east India. The overall vision of the organization is to support the holistic transformation of communities through affordable healthcare and empowered communities. The four case studies are profiled below and followed with a short discussion and conclusions section.

Community based screening for oral cancer in Fatehpur district, Uttar Pradesh

Contributed by Dr Sunitha Varghese, Project Director, Broadwell Christian Hospital, Fatehpur;

The problem - In India one third of deaths due to cancer are because of Oral cancer[4]. The North Indian population is at risk due to cultural practices of tobacco chewing which are widespread[5].

A way forward - Visual screening of the oral cavity is a low cost effective tool that can identify precancerous lesions to refer for early diagnosis and management [6]. Visual screening has a high discriminatory ability as a screening test with a sensitivity of from between 0.60 to 0.95 and specificity of 0.94 to 0.99 [7].

The setting - Broadwell Christian Hospital's community health programme has been working in 19 slums on the outskirts of Fatehpur, Uttar Pradesh since 2011.

The actions taken - Community health department conducted community based oral cancer visual screening clinics over a period of three months in mid-2016 in 17 target villages with a target population of 10392 people. Screening was conducted by a dentist at every clinic using both daylight and torch lighting.

The outcome - A total of 930 persons were screened of whom 283 were identified with possible precancerous lesions requiring follow-up and biopsy. Of those identified 38 people presented for follow up at the dentist's clinic held at Broadwell Christian hospital.

Reflection - Screening is recommended for high risk populations [6] but identifying high risk people was problematic in this context. Failure to follow-up with those who screened positively was very high, raising concerns around the ethics of screening in a setting where further intervention requires high out-of-pocket expenses for those identified in the screening process. Key deterrents identified by the Broadwell team include perceived costs of any health services, traditional beliefs (for example that any wound/ ulcer touched by loha (steel) e.g. a biopsy needle is exacerbated, a powerful community mistrust of angrezidawai” (English medicine) which is considered too powerful for slum dwellers health and the prevalent service provision of unregulated and influential local medical practitioners.

Responding to domestic violence and attempted suicide in rural communities in East Champaran district, Bihar

Contributed by Dr Vandana Kanth, Project Director, Duncan Hospital, Raxaul

The problem - People living with poverty, unemployment and in households with violence and conflict are more likely to attempt suicide and participate in domestic violence[8]. Suicide is the cause of about twice as many deaths as is HIV/AIDS, and the same number as maternal causes of death[9].

A way forward - Framing violence (towards self and interpersonal) in an ecological model assumes violence is influenced by social contexts[10]. In a low resource setting a promising way forward to reduce domestic violence and suicidality is to seek primary prevention of violence by strengthening community relationships, and by creating opportunities for dialogue and social engagement in high risk households[11].

The setting - East Champaran district is one of the most economically disadvantaged in North India. The ROSHNI program, as part of the Community Health and development project in Duncan Hospital, Raxaul, East Champaran District, Bihar consists of about 6 staff and 10 community mobilizers and from 2014 has been working in a target population of 93,000 people in rural and semi-urban communities to reduce domestic violence, suicide and to strengthen mental health.

The actions taken - The ROSHNI team has facilitated formation of 65 community task force groups made up of five women and five men who were nominated by the community and agreed to volunteer their time in this role. Task forces have been given training in domestic violence, suicide and mental illness and its varied determinants. Task forces are first called to support in incidents of domestic violence, familial conflicts and suicidal attempts for community members at individual and family level. They also engage in their communities to increase community knowledge,
identify and families at high risk of violence or suicide (job loss, relationship difficulties, active domestic violence) and to support them with facilitated motivational problem solving discussions, home visits and referrals, crisis management and support in accessing government entitlements.

The outcome - Taskforce groups have engaged with referred 45 cases of domestic violence, have identified and supported 42 people with mental distress, and have taken up a further 26 'social issues'. One task force group raised Rs10,000 from the community to contribute to the health care costs for a community member hospitalized for a suicide attempt.

Reflection - Some key challenges have been supporting community members to move beyond stigma and discrimination attached to the disease, cultural practices and lack of adequate health services in the district. Building skills for taskforces to engage sensitively and constructively with families has been another important strategy to deal with mental health determinants at community level.

Providing palliative care services in rural Lalitpur, Uttar Pradesh

Contributed by Dr Ann Thyle, Senior consultant, Palliative care, EHA

The problem - An estimated 6 million people with chronic terminal illnesses such as cancer, HIV/AIDS require end of life care in India each year[12], but fewer than1% of these has access to palliative care[13]. In rural north India cure for terminal illnesses such as cancer is often impossible because of late presentation, limited treatment options, and extreme poverty.

A way forward - Palliative care can reduce catastrophic health expenditure by bringing affordable care, hope and confidence by supporting those with life-limiting diseases (cancer, HIV, organ failures, neurological deficits and special needs of children), to improve the quality of life through medical, psychological, social, and spiritual support in the final weeks and months of life.

The setting - While palliative care is a part of the cancer component of the national NCD programme [14], palliative care funds are channelled primarily to Regional Cancer Centres. Additionally, few institutions have the requisite narcotics license to allow dispensing of morphine, a critical adjunct therapy in palliative care. EHA first established a palliative care service in 2010 at Harriet Benson Memorial Hospital, Lalitpur, Uttar Pradesh with funding from individuals and funding agencies.

The actions taken - A trained team provides home-based care with supporting out-patient and in-patient care at the hospital. During home visits the team provides subsidised/free medicines, emotional and social support to patient and family. This model has since been replicated at nine further rural EHA hospitals and in one Delhi healthcare facility, allowing the rural poor the dignity of a 'good death' with symptom management and the companionship of family members.

The outcome - Up to 31 March 2016, 14,066 patients had been supported through palliative care services in Lalitpur and other EHA units. Of these 94% had a cancer diagnoses and 6% had a diagnosis of HIV or incurable organ failure. Palliative care team informs patients/families of government benefits, helping with requisite forms/documents. One team educated 171 village heads with a 5% increase in palliative patients receiving benefits. We are also collaborating and advocating for increased Government engagement - recently Lalitpur district was selected for palliative care funding and the Lalitpur District Hospital now had 10 cancer beds, and with our support is developing home-based care.

Reflection - Obtaining a narcotics license is essential for effective palliative care and can be a lengthy process. Training has been a critical component and we recommend all team members undergo a national training programme, such as the basic course offered by the Indian Association of Palliative Care (IAPC). Lalitpur is a recognized centre and Dr Ann Thyle is a member of the IAPC national faculty. All team members must have this basic training. We advocate that a minimum team size is a doctor, two nurses, one multipurpose worker, one documentation officer and one driver.

Strengthening knowledge and awareness in mental health in communities in Uttarakhand

Contributed by Dr Kaaren Mathias, Project director, Burans community mental health project

The problem - Strengthening community knowledge and skills in mental health is an important strategy to increase awareness and reduce stigma and discrimination. Typically strengthening knowledge occurs using a format that is uni-directional (expert to community) with a didactic teaching method which risks framing community members as passive recipients who have no prior knowledge, limiting dialogue and partnership and ignoring the ways that poor communities can advance their own interests [15-17].

A way forward - Strengthening knowledge by communicating in informal formats that allow conversation and two-way learning could make knowledge more accessible and owned by a community, and allow integration with alternative explanatory frameworks used to understand mental distress.

The setting - Burans, a community mental health partnership project, started working in Dehradun district in June 2014. There are a total of 25 full-time team members, mostly community based, who work with a target population of around 100,000 people. In June 2016, 537 people with psycho-social disabilities were registered with the project.

The actions taken - A key strategy for building knowledge was to use informal and opportunistic community 'corner' meetings to share information about
mental health. A pictorial flipchart and use of storytelling was also used to stimulate dialogue, discussion and co-learning.

**The outcome** - Assessment with 11 focus group discussions with team and community members described this format as an effective, engaging and acceptable. Outcome indicators measuring community members understanding of common and severe mental disorders, actions to increase inclusion of people with psycho-social disability and numbers of people accessing care at both bio-medical and traditional healers all increased markedly in the first 20 months of project implementation.

**Reflection** - Informal, opportunistic and conversational strategies to increase mental health awareness in communities were effective and well-accepted. Introducing this approach requires some level of organizational culture change and paradigm shift away from formal didactic teaching. Young team members with less formal education were quicker to learn to operate in this way than older or more educated team members.

**Discussion and conclusions**

Typically, community based programmes addressing the non-communicable disease burden have focused on modifiable risk factors for cardio-vascular disease[1-3], yet these are not a focus in any of the community-based responses to NCD is profiled here. Two of these cases studies are focused on issues around mental health, which often co-occurs with NCD and is increasingly integrated within the NCD agenda[18]. Two further case-studies focus on cancer, one of the long-standing 'pillars' of NCD[2]. Oral cancer however is a particularly South Asian diagnosis linked to pan eating [7], and community-based palliative care until recently has received relatively little attention in the Indian setting [13]. Key components of effective community based NCD programmes in LMIC include: community organisation and empowerment, advocacy and coalition development, individual empowerment, reorienting health services and sustainability measures such as ongoing funding, community ownership and links to the programmes and policy of government[1, 2].

Considering these in turn, each of these programmes were supported by a current or historical community health and development programme. This ensured that processes for community organisation and empowerment could support and strengthen the more specific actions related to NCDs and also ensured an approach to address the neediest or 'unreached' groups. Three programmes (oral cancer screening excluded) also worked on strengthening community collective action and voice. Individual empowerment was addressed through the development of IEC materials, knowledge and skill building with all community members, to create community-based knowledge resources, one key aspects of sustainability. The processes used for knowledge development required a strong understanding of the community context and

culture-specific adaptations for delivery of teaching and information as well as ongoing critical reflection about the processes used[19].

Each of the programmes profiled acted in an area where the duty-bearer (public health services) provided essentially no service at all related to the programme. Since 2010 in place in India has been the National Programme for prevention and control of cancer, diabetes, cardiovascular diseases and stroke (NPCDCS) which has a policy framework, operational guidelines, and associated funding [14], however implementation at district level is patchy and often absent[1]. All the programmes profiled here have link to current national policy or legislation (for example, the National Mental Health programme, NPCDCS, Protection of Women from Domestic Violence Act, 2005 etc.) [14, 20, 21] but only the palliative care project had achieved some formal district level service provision and partnership in Lalitpur district, Uttar Pradesh. While one critique of these programmes could query the ethics of screening/strengthening community knowledge on NCDs in a context where there are essentially no publicly funded services to address these issues, on the other hand, these approaches of empowerment and building community skills to 'give voice', open opportunities for communities to advocate for access to care, and to increase demand for Government to provide these services.

These four programmes showed some key characteristics of sustainability such as capacity building at the community level, building and supporting community resources (e.g. formation of voluntary task force groups, and reflexive learning in mental health) and adaptation to the local community context, a critical feature for long-term effectiveness and sustainability[19]. They each also built on a strong knowledge and relationships with the target communities to increase the programme 'reach' to those in greatest need. Each however was limited in long term sustainability by the fact that they were operating with time-bound donor funding.

To take the models of community-based NCD care profiled here to be developed at scale at a block, district or state level would require a number of further steps: these include robust description of the models and implementation (process evaluation), measurement of outcomes and effectiveness and then a step-wise process to assess if or how they can be implemented at scale at district or state level using existing structures in the public health system. Any such initiative would need to be supported by a community that is skilled, knowledgeable and participating in mechanisms of social accountability. Documentation and critical review of the diverse community-based innovations which seek to address the burden of non-communicable diseases in India, is an important first step in this journey.

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Comprehensive health care demands that all common and important health concerns - be they infectious illnesses, or the needs of women and children, injuries, or conditions that need surgery, or those that fall under the rubric of non-communicable diseases (NCDs) - be managed by health systems. Early on, health care services were developed to cater to the most prominent illnesses in the communities - infections and injuries - for which the primacy of doctors as the most visible provider of health care, and that of a hospital as the health facility that provides care, was rather obvious. The development of health services, following this expressed need, led to creation of hospitals and medical schools where doctors and nurses were trained, which was followed by development of public health divisions that focussed on prevention of these illnesses and early diagnosis.

The recognition of chronic illnesses and disabilities, those that last many years if not a lifetime, came later, but were not quickly followed by development of appropriate changes such as allocating sufficient resources and staffing to manage these problems. On the basis of the realization that management of chronic illnesses requires shifting away from a provider dominant focus to a community based model wherein the community works to handle its own problems, we looked towards developing and facilitating models for optimising care through peer support groups. Nothing about us without us - was the message about planning care that we first heard from people with disabilities, and then realised that this philosophical standpoint is equally valid for people with diverse chronic illnesses, most of which are NCDs. This is a paradigmatic change where people suffering from illnesses or helpees become helpers and thus providers of health care. That is, those who are considered to be suffering a problem (a person with an illness) becomes a resource or asset in being able to look after one's peers and also become a spokesperson for the illness. Equally important in this paradigm is the emphasis on the origin of internal resources - self-determination, self-reliance, self-production and self-empowerment for help.

Underlying reasons beneath this idea of Peer Support Groups

Our health care systems were organized historically to respond rapidly and efficiently to any acute illness or injury that came through the door. The focus was on rapidly recognising and diagnosing an immediate

References (continued from previous page)

problem, excluding more serious alternative diagnoses, and initiating professional treatment. The patient's role was largely passive. In most infectious, traumatic and maternal and childhood illnesses, the full clinical course often played out over days or weeks, and there was little urgency to develop patient self-management skills, tracking programs or any form of patient centred programmes.

Many non-communicable diseases (NCDs) are diagnosed in outpatient clinics and hospitals when patients present with acute manifestations. After receiving a diagnosis during the healthcare visit, the chronic management of most NCDs needs compliance with treatment and monitoring of disease process. People living with chronic conditions need more than medical treatment from their health care providers; they need support in mastering and sustaining the complex self-care behaviours that are necessary to enable them to live as healthily as possible. Ideally, the health care provider and patient and family work together to fine tune medication, enact lifestyle changes, and mobilize social support. In the absence of good community health programs, the outcomes of most NCD control programmes are very poor. It is our thesis that communitization of care of NCDs is the only way forward, since health institution-based models can't achieve the desired follow-up rates for care.

A central question in this is: can the physician-only model of health care deliver care for NCDs? Or do we need to look for patient-centred health care models?

Let us take the example of epilepsy. India has 12 to 15 million people with epilepsy. Fewer than 3000 neurologists, most located in a few big cities take care of all neurological illnesses including epilepsy. Even if non-neurologists pitch in, the number of doctors falls far short of the number of epilepsy patients requiring care. Neither doctors nor nurses and other paramedics have the time or inclination to spend the required time with each patient. Nor does the system in most hospitals have the structure to ensure follow up care for patients.

In the face of this shortage, the only way the epilepsy treatment gap - like that of many other conditions - can be narrowed within the foreseeable future is by enlisting alternative care providers. This could include paramedics, health care workers and nurses. For doctors and other health care providers to provide this support on a one-on-one basis is often too costly in time and money, and is not feasible.

To add to this, we could empower and support patients with long term conditions to manage their illness as has been done in several urban chronic illness care models in the West. A platform was needed where patients with the same illness and their families could get together and discuss the disease and its treatment. This form of communitization of health care through peer support groups was taken on in order to answer the specific needs for people with chronic illnesses, the bulk of which are NCDs.

This is as viewed from a 'systems' point of view. If viewed from an individual patient's viewpoint, the basis of developing such groups is to pull together the individual strengths of the members to provide support and strength to everyone instead of each individual struggling to cope on their own with their problems.

Hoping patients and their families learn about their illness is perhaps too much to expect from most hospitals. Hospitals' focus on disease cannot take into account the patient's complete life picture and economic and social needs in the face of a new diagnosis of an NCD.

In addition, peer support among patients with the same chronic health problem allows patients to both give and receive social support. Lack of effective social support is a risk factor for poor self-care behaviours and increased morbidity and mortality. Our model provides patients and their families with an additional opportunity to get and build social support. For example, one of our patients has left her marital home due to marital friction. She now lives primarily with her mother. The two are able to seek regular care for her epilepsy at one of our monthly support meetings.

The process we followed at Jan Swasthya Sahyog (JSS), Bilaspur

A community approach to the treatment of any NCD is done by facilitating the formation of patient groups for people with that illness. One to one discussions were started with patients when they came for their follow up or for refilling of medicines. The idea of a group was explained. A day and venue was fixed for the meeting after a critical number of 6 interested members was achieved for each group.

This provides a platform where patients with the same illness and their families could get together and discuss the disease and its treatment. A health worker-facilitator would discuss the disease and its treatment and encourage members to ask questions and clarify doubts, that they would otherwise not feel confident to ask the hospital doctors and other health professionals. This group now seemed to ensure that the health worker had all the time to understand the patients' problems, to explain the disease and the importance of complete treatment, side effects of medicines etc. Individual members could now share their experiences not only with the health workers but also with each other and learn from one another. And for most patients, the health worker could issue the refill of medicines without consulting the doctor, say in controlled epilepsy or in sickle cell disease, being supported by written standing orders from the physician.
These facilitators could variably be professionals—physicians or counsellors who lead the group or parents (in case of child patients), peers or peer coaches (i.e. those people who suffer the same illness or those who suffer the same illnesses and have come out of it with great success) and community health workers. Group meetings would be steered by community health workers trained in disease management as well as a range of group facilitation skills, including active listening, group management, knowledge of group processes, role modeling, awareness, willingness, agreeableness, and openness.

In fact, at our hospital we have people from all these roles working with our community health group: patients in a young adult type 1 diabetes group enjoy getting to see a different side of their doctor at these lively monthly meetings. Different types of facilitators have their advantages, and a few limitations. We could also have more than one type of facilitator for a single group. The most important quality for success is persistence and a genuine commitment to patient well-being and growth. International evidence has shown that professionally led support was associated with improvement in HbA1c and decreased self-reported diabetes type 1 burden, along with a trend for an increase in diabetes-related self-care behaviours among 18 to 30 year olds.

When these groups meet, information on the disease and its treatment is shared with participants by the facilitators. The facilitators encourage discussion of challenges and concerns and identify topics of common interest. Among people with epilepsy, topics like structure and function of the brain, the mechanism of seizures, and the issue of pregnancy and antiepileptic drugs, and risk of epilepsy in their children are on the agenda. In type 1 diabetes mellitus (DM) group, discussion topics identified by participants included managing diabetes in day-to-day life, experiences and interactions with others who do not have diabetes and emotions related to diabetes.

Most group members felt that not enough time can be spent with each patient in the hospitals and health centres and therefore these patient groups fulfilled their information needs. Many groups started as health professional facilitated groups but the aim was to empower people to take on these roles of informing and sharing information in the long term and become true peer support groups as well as be advocacy groups. Health workers encourage discussion of challenges and concerns and together, the group identifies topics of common interest. Topics like drawing a family tree to understand the inheritance pattern of sickle cell disease, and managing pain are discussed in the sickle cell disease groups. Among people with epilepsy, topics like structure and function of the brain, mechanism of seizures, and handling pregnancy while being on anti-epileptic drugs are on the agenda. Family members are encouraged to participate and are trained to provide care. Parents reported gaining new knowledge and became more active and future-oriented in their planning. Further, studies have found in similar cases that patients value the facilitator role and benefits from the social support provided by the group.

The meetings are usually divided into four sections. They start with an introduction, leading to a game where in the members were asked to sit in a circle and talk in turns. Then the whole group about one happy and one sad moment which took place in the past two months. After that is an open sharing session. Not everyone responds well to group activity early even after introducing themselves. So methods of getting shy or reserved people to speak have to be used often. Further, meetings that feature informal socialization time and food add to the sense of community.

At JSS, patient groups have been formed for type 1 diabetes, sickle cell disease, epilepsy, major psychiatric illnesses, alcohol dependence, airborne contact dermatitis, type 2 diabetes, hypertension, chronic arthritis, as well as asthma and chronic lung diseases. The groups meet regularly, with the venue rotating between villages so members have to travel equal distances.

Reflections on the JSS process

We noted that both in the happy moments section and the open sharing section, we have found that members acknowledge the positive impact having these sessions has on them. Notwithstanding this, unpredictable attendance was among the biggest complaints in the process. It is important to address barriers to attendance (e.g., location, meeting dates) and to have robust advertising and recruitment efforts. Ideally, village health workers encourage and remind the patients in their rosters to come to our meetings.

That said, for those who attended, we observed that patients started discussing their problems related to treatments, dosages, side effects, social and economic causes etc. Second, mutual motivation was seen clearly among this group, particularly in relation to therapeutic compliance, or staying the course with medical regimens.

For example, in our community programme in rural Bilaspur, our compliance rates for taking antiepileptic drugs used to be dismal—at about 40%—even though the drugs were provided free of charge. Mutual motivation has resulted in greater adherence to recommended treatments and the compliance rate is now over 90%. In fact, the repeat prescriptions for those doing well are done by the health workers and doctors are consulted only every three to six months. People can see the effect of compliance with treatment in terms of freedom from seizures and being able to return to school. Family members are encouraged to participate and are trained to provide care such as managing an epileptic seizure. Myths about the disease and its treatment prevented many more from seeking care.
Deaths or major injuries from drowning or falling into fire due to untreated epilepsy were a common occurrence until recently. We have now four such treatment groups in epilepsy.

Even in type 1 diabetes, 29 of our 35 young patients were fully compliant over the last year. In alcohol dependence, the abstinence rates are over 70% in our patients who attend the groups.

The success of this idea became more obvious when patient members started coming to these group meetings bringing with them new people with symptoms suggestive of epilepsy who were seeking treatment.

Some groups have initiated monthly savings by members to help out with small and urgent needs that most poor people frequently have. It is worth mentioning here that our groups provide a convenient method for patients to purchase low-cost drugs that our hospital sources. This way they can ensure they are taking the cheapest generic drugs and, in an area where transportation is very challenging, they can get a regular and convenient supply.

Global Evidence on disease-related patient groups

There is a wide range of convincing evidence that peer support is a very valuable coping tool for patients and caregivers for a wide variety of chronic problems such as burns survivors, spinal cord trauma, breast and other cancer survivors, dementias and HIV.

In a study of caregivers of psychotic patients, participation in support groups and sharing of emotional expression, thoughts and ideas helped the caregivers deal with their physical and psychological demands related to the caregiver load. Intervention strategies offered to caregivers in the support groups appear to positively contribute to the family with a psychotic patient and improve the quality of life of both patients and their main caregivers. Similarly, in a Chinese study on people with schizophrenia, those who participated in the mutual support group had significantly greater improvement in family and patient functioning and social support for families and in reducing patients’ symptom severity and length of re-hospitalisations at 12 and 24 month follow-ups compared with psycho-education and standard care.

In a small study of people with rheumatoid arthritis, a crippling chronic joint disease, participating in peer support groups indicated an improvement in the quality of life of the participants through improved social support and empowerment of the participants with increased knowledge and self-efficacy. In a group of hepatitis C patients due to intravenous substance abuse, the formation of strong group cohesion was shown to facilitate participants’ behavioural change, regardless of their level of substance use. The structure of the group provided stability and was characterized by consistent weekly meetings, knowledge exchange and the provision of multiple services in one location. The support from peers and staff allowed participants to develop personal goals. Participants began to see themselves in a new and changed way; expressing this change in a variety of positive behaviours. Burns survivors, who were members of a peer support group, reported that the group aided the process of adjustment through the encouragement of adaptive coping strategies and the facilitation of community and relationships. Support group intervention programs are an effective nursing strategy that can be employed for improving the overall well-being of the caregivers of stroke patients. A study of younger patients with strokes demonstrated improved socialization, healthy coping, and role attainment in them. Similarly, parent support group showed to be a promising supportive, therapeutic and psycho-educative space where parents could strengthen their role in the upbringing of their child with type 1 diabetes. Finally, peer support groups have been shown to promote adjustment among many different patient populations, such as breast cancer survivors, men with the human immunodeficiency virus and individuals with spinal cord injuries.

In terms of building these groups, Approaches may be drawn from the sisterhood technique, used to find out about maternal mortality, since people with an illness often know a few others with the same illness in their neighbourhood. We have found this fraternity technique working very well in our programme. Alternative methods of communication between members of peer support groups such as video-conferenced support group for rural spouses of individuals with atypical and early-onset dementias have shown promise, both as use of this technology as well as a way for a relatively uncommon disorder such as this atypical form of dementia.

A 2000 survey of 252 self-help groups found that 27 percent of them were led by peers with no professional involvement; 34 percent of them were led by peers but with some professional involvement; 28 percent were led by professionals; and 11 percent had shared leadership between peers and professionals. Although support group members should be in charge, health system professionals can provide important support: for example, providing meeting locations, helping to facilitate meetings, providing information about meeting times and places, and referring people to groups. In these groups, by discussing personal challenges and successes with others, the global evidence is conclusive that members are able to develop many adaptive coping strategies.

Are there any concerns regarding forming same disease patient groups?

Some patients with stigmatized conditions may fear participating in disease-specific groups. This may be a concern in HIV positive people, or in epilepsy. We
don't know but it may operate in tuberculosis, leprosy, or alcohol-abuse related support groups. Certain genetic illnesses such as sickle cell disease may also invite casteist associations that prevent new members from joining in, fearing being labeled. These concerns need not be brushed under the carpet, but we have not seen any stigmatization in the last 3 years of our work. Planning to ensure that this concern be sorted out is important for ensuring success and sustenance of the groups.

Sustaining interest and participation in the groups is another concern. As part of any group work, it is always a challenge to maintain the continued interest of members in being part of the group. We suggest introducing some element of novelty in each group meeting with a focus on activities that build emotional bonds and trust among members.

Since self-help ideology avoids a systematic doctrine, meetings have a risk of becoming unfocussed and chaotic with intuition, feelings and gut responses exceeding their limits. The democratic spirit that characterises self-help formations also poses a challenge to its effectiveness. In contrast, the strengths of the professional model such as expert knowledge and skills, leadership abilities and a broad intellectual perspective are something which self-help formations should learn from and not belittle them.

There are always comparisons of effectiveness of self-help models with professional delivered care. Professionals feel that not only is their control over the knowledge and quality of service delivery becomes insecure. They may be dismissive about the abilities of peer educators and supporters. Many professionals don't also like empowered patients asking them many questions. However, more and more professionals now realise the specific advantages of self-help groups as being complementary to their roles, and in many instances, actively encourage and direct their patients to attend the groups.

The potential (especially but not only for advocacy)

Peer support is so effective in part because of the non-hierarchical, reciprocal relationship created through the sharing of experiences and knowledge with others who have faced or are facing similar challenges. This exchange promotes mastery of self-care behaviours and improves disease outcomes.

People often learn better when they are taught by peers with whom they identify and share common experiences. The more homogeneous the peers are (for example, sharing similar life experiences and age), the more likely it is that the support will lead to understanding, empathy, and mutual help. These findings are consistent with the long-standing tradition of group therapy and mutual support groups as a means of improving psychosocial outcomes for patients with chronic conditions. Thus, both the intensity and mechanisms linking peer support to health outcomes are different from and probably complementary to those provided by clinical care services from professional health care providers.

Another undeniable outcome of having groups in health is an all-important intangible of a sense of belonging, of making a difference and of self-esteem. Overall, social connectedness and relationships as well as growth after adversity were key themes in the meaning made in peer support groups. For some, the support group provided space for the translation of their growth into advocacy for others and supporting similar processes in their recovery journeys. In these instances, the support group provided a medium to transition the focus from their own recovery to a guiding, supportive role in the recovery of others.

Federations of groups could be formed of groups from different villages and clusters of villages. These could form pressure group for appropriate disease care in specific areas of interest. Our hope is that patients will build agendas for advocacy (even if very local) based on their own identification of their needs. Concerns might range from local water provision or educational accommodation in village schools to lobbying for increased research funding at the national and international level. Groups would be best placed to demand for free drugs, diagnostics, free rations, housing, transport and other support that optimal care of their ailments deserve. One inspiring example is the way in which HIV-infected people around the world have used their “people power” to demand better treatments and social supports.

A concern raised by some about disease based groups is that they tend to take the attention away from social determinants of health and from health promotion and that they end up emphasizing treatment adherence and access and confining the discourse or campaign or focus of an initiative. On the contrary, we feel these people who suffer from specific illnesses could also advocate for preventive strategies that require state intervention. Who else will pressure the state to curtail sale and consumption of junk food or salty sugary food, if not the people with hypertension or type 2 diabetes? Similarly, cervical cancer survivors would be the best advocates for a community based screening programme. People with breast cancer would become champions of self-breast examination by women. Peer groups of people with sickle cell anaemia would be great champions to ensure that they get hydroxyurea at free or reasonable rates, besides ensuring that the disease does not derail boys or girls’ studies. Who else but those who face debilitating and cruel pain crises will lobby for permission for local health centres to dispense oral opiates if needed?

As we see now, there is no alternative to the communitization and primacy of patient centred care for NCDs. And peer support groups are one of the major component of care provision for them.
Introduction

A vast majority of the workforce in India is engaged in informal employment, which comprises of workers in the unorganised sector and informal workers in the organised sector (ILO 2016). The beedi industry, with an estimated 48.12 lakh workers across the country, rests on both these forms of informal employment (GoI 2015). The beedi industry is a labour-intensive cottage industry. The poor and landless make up a sizeable proportion of the beedi workforce (ILO cited in Nandi et. al. 2013, ILO 2003). 65 percent of beedi workers are women while 11 percent are children (NSSO cited in ILO 2003). A large percentage of beedi workers either belong to the Other Backward Classes (OBCs) or are Muslims (S K Das cited in Best Practices Foundation 2001).

The beedi manufacturing process commences with the procurement of tobacco and tendu leaves by beedi manufacturers or their representatives. Tendu leaves and tobacco are stored in godowns and then handed over to contractors or directly to beedi rollers who are either home-based or work out of the manufacturers’ factories. Beedi rollers follow several steps in the preparation of beedis viz. soaking, drying and cutting of tendu leaves before filling the leaf with tobacco, rolling the leaf, tying the beedi with a thread (John 2008: 3) and then plucking the end.

Health conditions of beedi workers

Long-term exposure to tobacco and poor working conditions wreak havoc on the health of beedi workers. Numerous studies have identified the adverse health conditions commonly seen among beedi workers. Boils in the mouth, severe burning in the throat and discomfort in the stomach was reported among beedi workers in Tirunelveli in Tamil Nadu (Gopal 2000). A study conducted in 2014 in Uttar Pradesh among 214 beedi workers in the age group of 20-75 showed that 33.8 percent suffered from eye problems, 22.68 percent had respiratory problems, 48.05 percent experienced bone problems, 29.68 percent had skin

References (continued from previous page)


Perils of beedi rolling: health of workers in the beedi industry

Priya John
problems and 14.81 percent of workers suffered from headaches (Singh et al. 2014). In the same year, a research in Tamil Nadu reported reduction in lung functions among beedi workers (Kouser et al. cited in Singh and Singh 2015). Cancer was seen in more than half the respondents in a study carried out in the year 2013 with 100 beedi workers in age group of 18 to 50 years in Andhra Pradesh (Nagalakshmi, T. and Sudhakar, A. 2013).

Women workers identified their symptoms or ailments stemming from beedi work as aches and pains, coughs, giddiness, stomach pains, burning of the eyes, leg pain, numbness in fingers, breathlessness, gas, spasmodic pains, piles, urinary burning, white discharge, palpitation, wheezing, fever, worry, joint pains and swelling (Gopal 2000, Pande 2001). The main disease groups based on symptoms of beedi workers are shown in Table 1.

In the case of home-based beedi workers, the presence of large quantities of tobacco in the house invariably puts all the members of the family at risk (Dharmalingam 1993, Gopal 2000). For instance, in the course of an interview with a beedi worker, a researcher reported that the respondent found two small pieces of tobacco in her baby's mouth (Dharmalingam 1993). Women were seen to be breastfeeding their babies while rolling beedis and also, without washing their hands (Gopal 2000, Pande 2001). Additionally, the pressure to meet beedi targets or report to the units on time led to undue stress among girls and women (Gopal 2000, Pande 2001). It was common for women to skip or delay their meals, work for long hours in the seated position and not take adequate rest (ibid.). Most women were burdened with household chores and caring for children apart from working as beedi rollers (ibid). Older children supported the women workers by helping out in the chores and the beedi work.

Local studies have found that beedi workers described their work as tiring and painful (Buvaneswari and Srivedi 2008). More than 88 percent of beedi workers in a study conducted in Mumbai suffered from fatigue and weakness (Sabale et. al. 2012).

### Working conditions

As per the Labour Bureau’s 1995 survey, there were considerable lapses in the provision of basic facilities for workers in manufacturing units (ILO 2003). 11 percent of units did not provide drinking water to their workers (Table 2). Urinals and latrines were not available in 24 percent and 29 percent units, respectively. An alarming 40 percent of units had no washing facilities for workers within the premises. Separate facilities for women were even harder to come by. Only 56 percent of the units had separate toilets for women while a mere 21 percent of units provided gender-segregated washing facilities.

<table>
<thead>
<tr>
<th>Type of Facility</th>
<th>Percentage of Units Providing Facility</th>
<th>Percentage of Units Making Separate Arrangements for Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drinking water</td>
<td>89</td>
<td>56</td>
</tr>
<tr>
<td>Urinal</td>
<td>76</td>
<td>54</td>
</tr>
<tr>
<td>Latrines</td>
<td>21</td>
<td>40</td>
</tr>
<tr>
<td>Washing</td>
<td>64</td>
<td>22</td>
</tr>
</tbody>
</table>

(Source: GOI cited in ILO 2003)

Nearly 40 percent of units reported less than an hour’s rest in a working day while among home-based workers regulating the number of working hours without rest was not possible (GoI cited in ILO 2003). Inadequate ventilation, poor lighting, overcrowding and dust were reported in 35 percent of the units (ibid.). Loss of sleep, irregular working hours, back breaking monotonous work, poor nutrition, high stress levels and unhygienic working conditions leave the beedi workers susceptible to all kinds of diseases (Gopal 2000, Pande 2001).

### Lack of awareness regarding health hazards

Studies also revealed that 97 percent of beedi workers were unaware of the health hazards of tobacco and 81...
percent were unaware that regular exposure to tobacco could lead to tuberculosis and cancer (Joshi et. al. 2013). In a study conducted in Mumbai, workers did not consider their work as a factor for the low birth weight of their babies (Sabale 2013). There was also no awareness regarding safety measures to be followed while rolling beedis (ibid.). In Andhra Pradesh, none of the workers wore any protective clothing such as gloves, masks and socks (Joshi et. al. 2013). Only 12.76 percent claimed to wear full shirts and pants or sheets to cover themselves while rolling beedis (ibid.).

Legislations and welfare schemes

The legislations passed specifically for beedi workers do not adequately address these health concerns. Health is largely addressed in the Beedi Workers Welfare Fund Act of 1976. The health schemes under the Act include the setting up of allopathic and ayurvedic dispensaries, reservation of beds in TB hospitals, domiciliary treatment of beedi workers suffering from TB, cancer, mental diseases, leprosy etc. (ILO 2003: 124).

As per the latest annual report of the Ministry of Labour, the expenditure on health was higher as compared to housing, education and recreation in 2013-14 and 2014-15 (Table 3). Yet, the expenditure on health was a mere Rs. 7.98 lakhs in 2013-14 and Rs. 5.21 lakhs in 2014-15 (up to October) for a population of 48 lakh beedi workers.2

Table 3: Collection and expenditure under BWWF 2013-15

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Utilisation of Welfare funds</td>
<td>17,34,395</td>
<td>8,45,554</td>
</tr>
<tr>
<td>Expenditure on health</td>
<td>7,98,719</td>
<td>5,21,939</td>
</tr>
<tr>
<td>Expenditure on education</td>
<td>2,17,658</td>
<td>1,07,715</td>
</tr>
<tr>
<td>Expenditure on housing</td>
<td>1,25,566</td>
<td>74,183</td>
</tr>
<tr>
<td>Expenditure on recreation</td>
<td>1,521</td>
<td>972</td>
</tr>
</tbody>
</table>

There are 7 beedi hospitals and 204 dispensaries in the country. The beedi dispensaries are located in Ajmer, Allahabad, Bengaluru, Bhubaneswar, Hyderabad, Jabalpur, Karma, Kolkata and Nagpur (PIB 2010). It is yet to be seen whether the beedi hospitals and dispensaries reach out to workers in remote rural areas. About the maternity benefit schemes, a study in Tamil Nadu revealed that beedi companies and contractors avoid this payment by adding the names of the women’s partners in the passbooks and official records (Gopal 1999).

Conclusion

The beedi industry receives incentives in the form of tax exemptions and minimal regulation on account of the poor that it employs. The industry is misusing this to exploit labour, under-report production and make unfair profit. The welfare benefits received by workers are marginal, especially in the case of those working in unregistered manufacturing units and in the contractual system without ID cards. At present, serious gaps exist in the available information regarding the industry, the number of workers employed, forms of operational units, production and consumption levels, etc. These gaps need to be addressed at the earliest in order to fully understand the scale of the beedi industry in the country. The strict implementation of all industry related legislations is important to improve working conditions, provide welfare benefits, regulate production systems etc. Also, health conditions commonly seen among beedi workers should be treated without any charge in government and private health facilities. The treatment for these conditions need not be subject to any insurance cover. Implementation of the health schemes under the BWWF should be ensured and tracked. Most importantly, alternative livelihoods should be identified for beedi workers based on their local contexts. Beedi making is hazardous and housed within an oppressive and exploitative system. Beedi workers should be provided livelihoods that pose no health risks and allow them to lead a life of dignity.

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Notes:

1. This paper is extracted from a policy and literature review of the beedi industry conducted for the Centre for Health and Social Justice, Delhi

2. This figure of total beedi workers was provided in response to unstarred question no. 979 in the Rajya Sabha on 1 March 2006. The estimate has not been revised since the year 2006. The official estimate of 48 lakh beedi workers was later cited in the Parliament in response to a question regarding the population of beedi workers in December 2015

Bibliography


In this article I will try to present a picture of stroke in rural central India using data from epidemiological studies conducted by us in rural Gadchiroli as well as my personal observations while providing clinical care in this area.

Let me start out by describing the public health context which is the key determinant of health. Gadchiroli is a district on the eastern border of Maharashtra bordering Chattisgarh on the east and Telangana on south. It has a population of about 10 lakh and close to 40% of the population is tribal. It is one of the most underdeveloped districts of India. There are very few physicians in this district with a physician to population ratio of about 1:5000 as against a ratio of 1:15000 for India. I was perplexed when our community-based study in rural Gadchiroli showed stroke as the leading cause of death(1). This was a study conducted over two years from 2011 to 2013 in a population of about 100,000. Causes of death were studied using verbal autopsies. Stroke accounted for one in seven (14%) deaths in this district, one of the most underdeveloped in India. The question that troubled me was -why is a non-communicable disease, a disease that is supposed to affect predominantly urban and rich population, affecting poor rural populations of central India? A subsequent community-based study conducted by us in year 2014 further confirmed the emergence of stroke as a public health problem in rural India. The study showed that the crude prevalence of stroke was 388/1000,000 population(2). In other words, on an average, there were four patients surviving with stroke per 1000 population, the typical village population size in the area where this study was conducted. A relook at the data on stroke prevalence in rural areas of India over time showed linearly increasing trend in the prevalence of stroke after 1980s (2).

Who are the people affected by stroke in rural Gadchiroli?

In our community-based study, the average age of stroke survivors was 60 (60.9) years(2). The age of the people affected by stroke is younger than that seen in developed countries by about 10 years. The average age of those who died due to stroke was 67 (67.47) years(1). In the age group of 41-50 years stroke contributed to 11.5% of all deaths while in those more than 50 years of age, stroke contributed to about 20% of all deaths. Stroke prevalence was double among males as compared to females (520 vs 255 per 100,000 population). Among stroke survivors, 83% were farmers and labourers and 55% were illiterate (2). Collectively, these data show that in rural Gadchiroli stroke is a disease of the poor and illiterate and is affecting relatively younger people.

Challenges to management of stroke in rural Gadchiroli

(continued from previous page)


Pande, Rukka (2001) “Health issues of women and children: A case study of the beedi industry”. Women’s Link Vol. 7 No. 5 9 October 2016 from https://www.academia.edu/3716738/Health_issues_of_Women_and_Children_a_study_of_the_Beedi_industry-


*Note a gap of 20 years in these two studies

<table>
<thead>
<tr>
<th>State</th>
<th>Study year</th>
<th>Crude stroke prevalence/100,000 rural population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Karnataka</td>
<td>1982-83</td>
<td>52</td>
</tr>
<tr>
<td>Haryana</td>
<td>1986</td>
<td>88</td>
</tr>
<tr>
<td>Kashmir</td>
<td>1986</td>
<td>145</td>
</tr>
<tr>
<td>West Bengal</td>
<td>1989</td>
<td>126</td>
</tr>
<tr>
<td>Karnataka</td>
<td>1994-95*</td>
<td>165</td>
</tr>
<tr>
<td>Maharashtra (Gadchiroli)</td>
<td>2014</td>
<td>388</td>
</tr>
</tbody>
</table>


Yogesh Kalkonde
While stroke has emerged as a public health challenge in rural Gadchiroli, the healthcare resources needed to address this challenge have not developed. This creates many challenges to management of stroke. We found high early mortality due to stroke. Close to 50% (46.3%) of those who died due to stroke died within first 30 days after the onset of symptoms while almost one third (31.4%) of the patients who died due to stroke died within the first week after the onset of symptoms(1). The high early mortality is likely to be due to higher number of haemorrhagic strokes from uncontrolled hypertension which are associated with higher early case fatality. In rural Gadchiroli, among patients who died due to stroke only 10% (10.5%) died in hospitals - 15.4% men and 9.1% women(1). Thus, there was a clear sex difference in healthcare seeking with lower number of women dying at hospitals. Most patients (87.3%) who died due to stroke died at home(1). Until very recently there was only one brain imaging facility in the district (now there are two) which has a total population of about 11 lakh. The stroke subtype and its aetiology remain largely undiagnosed due to the lack of imaging facilities. In the stroke prevalence study conducted by us, only 12% of patients with stroke had some form of brain imaging (2).

We found that healthcare seeking from formal sector was low and stroke patients commonly sought care first from herbal providers. As many patients seek informal care after stroke, few patients receive secondary prophylaxis or have their blood pressures adequately controlled. Use of physiotherapy for rehabilitation after stroke is rare. Collectively, lack of awareness about stroke and its risk factors, healthcare seeking mainly from informal healthcare sector, poverty and lack of facilities for healthcare are the likely contributors for the high disease burden of stroke in rural Gadchiroli.

**Observations on post-stroke morbidity**

Physical and occupational rehabilitation after stroke remains almost non-existent in rural Gadchiroli. Some motivated stroke patients try out simple exercises but most of the patients do not receive physical therapy. Many develop spasticity which significantly limits their functionality. This reduces their ability to work in the fields and men become jobless in absence of alternative jobs in this region. Other than physical disability, stroke patients are also at risk of post-stroke depression and dementia. I remember evaluating a stroke survivor who was able to ambulate but has lost interest in living and had not stepped out of his hut for more than three months after suffering a stroke. His wife could not leave him alone and work to earn living. The finances of the family were severely strained. The patient clearly had post-stroke depression which was untreated. Unless the treating physician actively evaluates for this condition, patients often remain untreated for depression. I also remember meeting a couple in their sixties, both of whom had a stroke. On evaluation, both of them had dementia and they were living by themselves as their sons were working at other places. Thus, other than physical disability stroke patients also suffer from a significant burden of cognitive and psychiatric disabilities.

**Why are people in rural Gadchiroli developing strokes?**

One potential reason why stroke has emerged as a public health problem in rural Gadchiroli could be epidemiological transition. Abdel Omran proposed a theory of epidemiological transition where with change in ecobiological (related to infectious agents and hosts), socioeconomic, political and cultural determinants of health and improvement in preventive and curative measures, non-communicable diseases replace communicable diseases as a leading cause of death(3). In the early phase of this transition which Omran called Age of Receding Pandemics, deaths due to infections start to decline and those due to non-communicable diseases such as hypertension-driven diseases start to increase(3,4). Rural Gadchiroli could be in this phase of transition. As facilities for diagnosis and treatment of hypertension are often lacking in underdeveloped areas, risk of death due to stroke, hypertensive heart disease and renal failure increases.

Other well known risk factors for stroke such as tobacco and alcohol use, lack of healthy diet, increased stress, exposure to indoor air pollution are likely to be at play as well for increasing the risk of stroke in rural regions(5,6).

An additional factor which might explain higher number of strokes in an underdeveloped region such as Gadchiroli would be the foetal origins of chronic diseases. David Barker posited that (Barker hypothesis) chronic diseases such as stroke, coronary artery disease and diabetes are caused by nutritional and environmental factors in infancy and early childhood(7). Several studies have supported this hypothesis. He is quoted as saying "If you want to know how much heart disease or stroke there is in any city, any town, any rural village, do not count the hamburger outlets, the tobacconists, the playground. Ask instead how many mothers died in childbirth seventy years ago? How many babies died soon after birth? Without any exception, across the land that is the best predictor of cardiovascular diseases"(8). In underdeveloped regions of India, as the risk of undernutrition during foetal life and infancy is more, this could lead to increased risk of chronic diseases later in life. Such individuals are thought to be genetically programmed to sustain in a thrifty environment and an improvement in socioeconomic status later in their life might put them at a higher risk of chronic diseases such as stroke.

Our finding of emergence of stroke as the leading cause of death could have implications for the rest
of rural India. If such an epidemiological transition has occurred in an underdeveloped rural region of India, then it is likely that a similar change would have occurred in other rural and underdeveloped regions of India.

Can the risk of stroke be reduced?

While stroke is a disease with high mortality and disability, it is also a preventable disease. Among all the risk factors for stroke, hypertension has emerged as the most important risk factor. The population attributable risk of stroke due to hypertension is 47.9% according to INTERSTROKE, the multinational epidemiological study on stroke (5). Put simply, this means that the number of stroke cases can be reduced by 47.9% if hypertension is fully controlled. This is great as low cost generic medicines are available to treat hypertension. While one may think that hypertension may not be a big problem in rural areas, a recent nationally representative study shows evidence to the contrary. The prevalence of hypertension among adults was 21.2% in rural men, 27.9% in urban men and 25% in rural women and 27.2% in urban women(9). Thus, more than one in five adults in rural India will have high blood pressure. In tribal regions the prevalence of hypertension was 27.1% and 26.4% among men and women, respectively(10). The high prevalence of hypertension could put a large number of people in rural and tribal areas at risk for stroke. Also, this is a large burden on healthcare systems, both public as well as private, as currently there are not enough healthcare providers who could provide appropriate treatment of hypertension in rural India.

Challenges to the diagnosis and treatment of hypertension in rural India

Hypertension is often asymptomatic. This poses a significant challenge to its diagnosis and treatment as people in rural areas seek medical care only when they have some bodily symptoms. Facilities for diagnosing and treating hypertension are often not available in rural areas. In a study by Moser and colleagues hypertension remained undetected and therefore untreated in close to 70% men and 50% women in rural areas(9). Among those with detected hypertension, only about 50% had their blood pressure adequately controlled(9). Together, these data indicate poor detection and treatment of hypertension in rural areas. In rural Gadchiroli, patients are currently dependent on diagnosis and treatment of hypertension by providers who practice at block or district level. Informal providers who practice at village level do not provide treatment for hypertension. A need for travel to seek care creates a barrier to the diagnosis and treatment of hypertension in rural areas and adds to the expenditure on care in addition to doctor’s fees, laboratory investigations and cost of medications. There is a concern that increasing burden of non-communicable diseases might bring a new wave of poverty to rural and underdeveloped regions of India. Poverty is also a common reason for treatment interruptions in rural Gadchiroli as patients only buy medicines for controlling hypertension and other chronic disease when they have money. The government of India has launched an ambitious National Programme For Prevention and Control of Cancer, Diabetes, Cardiovascular Disease and Stroke (NPCDCS) in 2010(11). Some primary health centres have started dispensing free medicines for hypertension in rural Gadchiroli under this programme which is a welcome step. However, this programme faces many challenges to its effective implementation. Management options are also available for hypertension in the private set up but these incur costs. Close to 50% of out of pocket expenditure on chronic diseases is on medications(12). Although low cost generic medicines are available for the treatment of hypertension, these are not yet widely available in rural areas. Often patients end up paying four to five times higher for a branded version of an antihypertensive medication compared to a generic one. Healthcare financing and providing safety net to citizens in rural India against economic shocks due to healthcare expenditures on chronic diseases is an urgent need.

Can we reduce risk of stroke in rural India?

The risk of stroke can be reduced by controlling hypertension, a key risk factor for stroke. Community-based control of hypertension has reduced the risk of stroke in Japan and Taiwan where stroke was a major killer(13,14). In rural India, an early emphasis on primary prevention by controlling hypertension can potentially reduce the risk of stroke significantly. In addition, hypertension control will also reduce the risk of coronary artery disease, hypertensive heart disease, renal failure and dementia. Primary prevention of stroke is thus likely to pay larger dividends than acute care or secondary prophylaxis for stroke. However, currently there are no rigorously tested interventions to assess the effect of hypertension control in rural communities on stroke deaths. We are testing such an intervention in a cluster randomised controlled trial in rural Gadchiroli.

Healthcare set up for caring for acute stroke patients (e.g. imaging facilities, stroke units) also needs to be developed vis-a-vis primary prevention. The emergence of chronic diseases as a health priority in rural and underdeveloped regions of India also calls for realignment of healthcare systems to cater for chronic non-communicable diseases as well. In fact, in such regions, healthcare systems have a difficult task of dealing with a double burden of communicable and non-communicable diseases.

Efforts also need to be taken to modify lifestyle in rural area to reduce the risk of stroke such as reducing tobacco and alcohol use, improving diet and exposure to indoor pollution. However, lifestyle modifications are relatively harder to achieve and usually occur over
Coping with chronic illness among the poor in the old city area of Hyderabad

Mithun Som

Any illness results in a significant dent in the finances of the poor and affects the whole family. Unlike a bout of acute illness, chronic illness keeps the family in distress for a longer duration. This paper is based on a study of two slums in the old city area of Hyderabad. It focuses on the kind of illness one finds in the old city, their access to health services, the financial implications and the overall effect on the family.

The two slums, like other areas in the old city of Hyderabad, have numerous small industries and workshops. Majority the population is Muslim. Most of the Hindus in the area belong to the Valmiki caste.

The slums are densely populated with narrow roads and the workshops and factories are located alongside the old and new houses. High density of population leads to shortage of houses and consequently higher house rents. More than one family sharing a big house called bada is quite common. Girls are married early. Education levels are low, with boys often dropping out of school to take up a vocation to supplement the income of the parent. Girls drop out to assist in household work or generate income through home based industry. As most families are large, women spend a substantial amount of time and energy for household chores. Most women who were interviewed are part of some income generating activity, mostly home based, like gota work (fixing stones in bangles), making safety pins etc. or in small scale industry like incense stick manufacturing unit. For home based work, the materials are generally supplied by the contractors, all men, and are collected by them once the work is done. Men do outdoor work and half of them are self-employed. They work in small factories or shops as fruit sellers and tea shop vendors. Some do embroidery work, while others drive autos. This area is also communally sensitive. The study was done from September to December 2014 and due to the sensitive nature of the area, data was collected from women coming to the training centers of ‘Shaheen’. 24 women were interviewed in total. Among these, 13 women reported that they have one or more members in their family with some chronic illness. The diseases ranged from kidney problems, diabetes, blood pressure, heart problems, chronic headache, and

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a longer term. Increasing awareness about the ill effects of tobacco and alcohol, increasing tax on these products and controlling their supplies, increasing community participation in action against alcohol and tobacco can potentially help reduce their use. While lack of food and hunger does persist in some underdeveloped regions of India, diet poor in essential nutrients and fruits and high in salt is very common in rural India. Interventions need to be developed and tested so see if dietary modifications can reduce the risk of stroke.

At a more primordial level, prevention of stroke as well as other chronic diseases, as suggested by David Barker, could lay in the care and nutrition of young women in rural India.

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chronic pain in knee, neck or eyes. Women reporting high BP in their family have all pointed to the stress existing in their families due to financial constraints like loans or other problems in family like domestic violence. Women attribute the chronic pain in eyes, knees etc. to their occupation and strenuous work that they do without having taking a day off. For example, many women who complained of continuous headaches or pain in eyes for months make bangles at home.

Accessing health services:

People generally go to the local ‘doctors’ who do not have an MBBS degree but have picked up some skills while working with a qualified doctor earlier. These local ‘doctors’ have set up their clinics in almost every locality in the area. These ‘doctors’ apart from being accessible at odd timings are also affordable. For simple cold, the entire treatment including cost of medicines could be as low as Rs. 20-30 whereas consultation fee for an MBBS doctor or specialist is Rs. 100 to 200. Some women in one of the slums also used government health centre as it was accessible by walk. Men preferred to visit a private clinic as their work was considered more important and they could not afford to lose a working day.

However, for major ailments and chronic diseases, everyone had visited more than one healthcare provider. People try different clinics or hospitals till they get a definitive or satisfactory diagnosis. Sometimes, they are not even diagnosed. For example, Muneera’s father was taken to different hospitals for two years when he had loss of appetite and vomiting. It was only after his death that the hospital confirmed that he had a problem in his kidney. Often when none of the clinics or hospitals could cure their ailment, they rely on ‘dua’.

Once they are diagnosed with an illness, mostly in a tertiary hospital, they come back to their local ‘doctor’ for repeat visits or the regular medicines. This helps reduce the commute and related cost, besides cost of treatment by a huge margin. Like Sadika’s mother had cold intolerance and would catch cold while washing utensils or clothes. She went to a big hospital and was told that she has thyroid, after which she started going to a local ‘doctor’ for medicines. Similarly, when Afrah’s nephew got fits for the first time, they took him immediately to a children’s hospital where he was admitted and it cost them Rs. 4000. When he had seizures for the second time, they took him to a ‘doctor’ in their locality and were charged Rs.500 and they continue to go to him. Sadia’s mother goes to the pharmacy to get her BP medicines regularly and goes to the local ‘doctor’ in case of any problems. At times, the local ‘doctor’ is known to the family as they have been going to him for treatment for a long time and he often gives them a discount too. In one case, they could negotiate with the hospital as well. Once, Afrah’s mother had high BP and was not taking regular medicines. She was also undergoing heavy bleeding due to menopause when she felt dizzy and fell. Later she was not able to recognize anyone. She was taken to a private hospital which kept her in ICU and charged Rs. 24,000. However, after negotiations by one of their relatives who was in the police, they could bring it down to Rs. 18,000.

The urban health posts function only for a few hours in the morning. The long queue and inconvenient timing deters people and they prefer private practitioners. The distance, travel costs and long queues in secondary and tertiary government hospitals discourage people from using them. Government health facilities are utilized only if alternative options are exhausted. ESI is unheard of even though there are numerous small industries in the locality.

Financial and familial implications

Chronic illness affects the whole family. Savings are wiped out and the family gets into debt. Muneera’s family had to sell off the pan shop and her mother’s jewelry for her father’s treatment in the two years preceding his death. When any family member is seriously ill and cannot contribute to income or household work, the burden falls on others. Very often in such cases, mostly the son has to drop out of school and join some work. Aneera’s father has taken huge loans and sold off the house without consulting or giving the reason and this led to discord between Aneera’s parents. Aneera’s mother developed BP, sugar and joint pain after this. In these circumstances, her brother dropped out after 10th and started working in a shop and now works as an auto driver. Aneera says their family could stand up only because of her brother. Her mother needs regular insulin shots and they have to spend about Rs. 1000-2500 per month for her mother’s medicines. She said they have tried the government medicines but that does not work. Afrah’s father, a fruit seller has had two heart attacks and he has stopped working for the last two years. As a consequence, they had to sell off the cart. Later, Afrah’s mother with some help from her father managed everything including going to mandi, buying fruits and keeping accounts. Her two brothers who had earlier dropped out of school to join work got all her four sisters married. Women have also dropped out to join some income generating work like Muneera and her sister joined the gota work. In some cases, they drop out of school to do the household chores and take care of the family. However, if the married daughter falls ill, she comes back to her parent’s house to recuperate. So Afrah was worried about her married sisters who come home as it is an additional burden for them.

The family also has to adjust in other ways, for instance, Muneera is delaying her marriage because she knows that she is an important earning member of the family. She is waiting for her family to get settled and her sibling to finish her education. Sadika’s family
Hospital based universal newborn hearing screening
A SERVICE WE CANNOT AFFORD TO MISS
Amit Kumar Tyagi, Anjali Lepcha, Ann Mary Augustine, Achamma Balraj

Brief description
Childhood hearing loss is the most prevalent sensory disorder often referred to as the silent epidemic with more than 90% of these babies residing in the developing world.(1) Over 100,000 babies are born with hearing deficiency every year in India.(2) Universal newborn hearing screening (UNHS) in India has not yet been properly implemented and hearing loss is often detected as a consequence of parental concerns regarding delays in speech and language development. Most parents and paediatricians suspect hearing loss only after the child shows a delay in language development. By then 2 to 3 years are lost and this is the critical period for speech and language development. Lack of awareness about relation of deafness with poor speech and language development and lack of infrastructure (especially in rural area) with poverty push these children into chronic disability of hearing loss with delayed or no speech and language development. This permanent disability of hearing loss seemingly behaves on the pattern of chronic disease and leads to vicious cycle of delayed language development, academic underachievement, social isolation, high risk of injuries and increased poverty. Neonatal hearing loss has a prevalence that is more than twice that of other new born disorders which can be screened such as congenital hypothyroidism and, phenylketonuria.(3) Studies done in India using different screening protocols have estimated the prevalence of neonatal hearing loss to varies between 1 and 8 per 1000 babies screened.(4)(5) Congenital, bilateral hearing impairment occurs in approximately 1.2 to 5.7 per 1000 live births.(6) Two to five percent of neonates with one or more risk factors (for hearing loss) exhibit a moderate to profound hearing loss while 50% of all children with moderate to profound congenital hearing loss exhibit no risk factors for hearing loss.(7) Because of the latter, screening all neonates for hearing loss is the only effective measure for detection of congenital deafness. Early identification and intervention for hearing loss provides better prognosis in language development, academic success, social integration and successful participation in the society. This underscores the

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break from work every half or one hour. She asks, how can she not do the work?
To sum up, all the respondent's families are part of the informal workforce and get low and irregular wages. In this hand to mouth existence, any illness episode pulls the family down financially and disrupts their lives. It is for this reason that both men and women go to the local 'doctor' on the same day they fall sick, for small ailments also as they cannot afford to be sick. A chronic illness totally disrupts the situation as other members in the family have to take on the workload both financially and the share of household chores. It greatly affects the children who often have to drop out of schools and join the unskilled informal labour force and the cycle continues.

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Notes
1. This study was funded by 'Shaheen Women's Resource and Welfare Association'.
2. Shaheen provides free vocational training like mehendi design, tailoring and basic computers to the women in twenty slums. A training center is established in every slum where women come and learn.
urgency in diagnosing children with congenital hearing loss and initiating rehabilitation by age six months. According to American Academy of Paediatrics, screening should be done by age one month, diagnostic hearing test by age 3 months, and appropriate early intervention should be started by age six months. Universal neonatal hearing screening program in Christian Medical College, Vellore was started in January 2010. The program tries to screen all babies born in CMC Hospital within 24 to 48 hours of birth and the coverage of the service was 97% for the last 2 years. Those requiring re-test are followed up at ENT department for diagnostic tests and if hearing loss was confirmed, early intervention by either hearing aid fitting or cochlear implantation was done.

Challenges faced

Hearing screening programs using different screening protocols have been set up in many centres across the country. However, in 2010, systematic identification and rehabilitation on a large scale was yet to be tested and implemented in an Indian setting.

Many babies (about 50 a day) had to be screened each day at CMC and the service had to be seamless, for which it had to be integrated into the normal operation of the ward. Background ward noise was so high that the software algorithm had to be reworked. Short and long term follow up of babies required persistent requests to parents to bring the child back since many parents had other priorities and this required counselling of parents and care givers. The seed money from ICMR was useful but there was an additional financial burden on the institution and on the parents.

Objectives of program

This project was undertaken with the primary objective of exploring feasibility and then implementing a universal neonatal hearing screening program in a tertiary care hospital (handling an average of 15000 deliveries/year), using the BERA (Brainstem evoked response audiometry) phone and intervening early by either hearing aid fitting or cochlear implantation followed by auditory rehabilitation. The secondary objectives included estimating the prevalence of neonatal hearing loss in a tertiary care setting.

Follow up

Follow up (after the child failed the test the first time) in practice was found to be poor. So, repeated phone calls and letters were used to contact the parents and follow-up has improved since.

The main reasons for poor follow up (based on interactions with parents):

1. Financial issues and time consuming follow-up visits: Most of the parents are from rural and semi-urban areas and they belong to low socio-economic status. It takes at least 6-8 hours for parents to travel and undergo the screening or diagnostic tests. Their priority is to earn daily wages and this postpones their follow up visits repeatedly.

2. Awareness: There is lack of awareness about relation of deafness with poor speech and language development.

3. Familial constraints: The difficult relation between child’s mother and her parents-in-law, her conditioned dependency on men in family, and her busy household activities all constrain follow up visit.

Results

Coverage of the hearing screening was 97% for the last 2 years, ninety (90) children were rehabilitated out of 183 children with confirmed hearing loss. The cost of screening test is two hundred (200) rupees presently. A cost of approximately 13,000 rupees per child with confirmed hearing loss is identified (considering potential costs involved in universal screening program, including instruments cost, recurring cost and costs related to involved doctors, audiologists & technicians).

In comparison to the profound challenges faced by a child, attaining three or four years of age with undiagnosed hearing loss, this seemed a reasonable investment.

Future road map of the program

1. The service would be extended to secondary and primary care areas by finding innovative ideas

2. Emphasis should be concentrated not only on identifying infants with hearing loss early but also on early-intervention programs collaborating families.

3. Research should be focused to develop low cost, more effective screening tools and algorithms for the Indian situation

4. The need of national program for UNHS would be advocated.
Challenges in rheumatic care for the aam-admi in India

Tarun K George, Ashish J Mathew, Debashish Danda

Rheumatology is a relatively new subspecialty that was established in the mid 20th Century and has made great strides over the past five decades(1). Most patients are unaware of what this field deals with, and many a times physicians are unsure of how to diagnose and manage these diseases.

One would describe a rheumatologist as a trained physician who diagnoses and treats musculoskeletal diseases and systemic autoimmune conditions. An autoimmune process is one where a possible environmental trigger in a genetically predisposed person incites a white blood cell mediated response against the self. If an organ is involved in isolation, this is usually managed by the corresponding specialist - Eg: type I diabetes mellitus by an endocrinologist, inflammatory bowel disease by gastroenterologist, multiple sclerosis by neurologists and so on. But the diseases in rheumatology, classically present with multiple organs involved - like skin, kidney and blood in systemic lupus erythematosisis (SLE); kidney and respiratory system in forms of vasculitis; joints, skin and lung in rheumatoid arthritis etc. It is a non-communicable disease (NCD), in the sense that it is non-infective and cannot be transferred from one affected person to another. It is also a chronic disease requiring months and years of treatment, with challenges to get an early diagnosis and good quality care, about which details are provided later.

If one could broadly categorize the manifestations of rheumatic diseases that present to a physician, they would be overlapping islands of - joint complaints, muscle aches and constitutional symptoms (fever and weight loss) on a sea of skin manifestations that may range from subtle and minimal to overt and devastating. Since these symptoms and signs are so diverse the clinician requires having a good understanding of the common illnesses that are commoner and also a high index of suspicion for the not so common rheumatic problem.

Not just another NCD

Although one notices that the contributions of rheumatic problems may not be as significant as the big four, one should note that many a times these too are initially passed off as lifestyle or work related

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Conclusion

When favourable outcomes could be achieved with early identification and rehabilitation through universal neonatal screening program, it requires serious consideration among public health programs in India.

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The duration from the onset of symptoms to diagnosis in AS is around 8.6 years and in SLE from 6 months to over 8 years (13,14). These delays can become further prolonged for the poor as they arrive later at health centres, and are unable to follow up at referral hospitals.

**Inadequate Lab facility**

Many a times for the diagnosis and follow up of these diseases specific serological tests are required which mandate a well-established and reliable lab. Such availability is limited and diseases result in remaining undiagnosed and sub-optimally treated often resulting in recurrent worsening or flares.

**Lack of trained personnel**

In a country with over 1.2 billion populations, we currently have a formal training program for around 26 rheumatologists every year (15). Also the training to identify and appropriately manage these diseases is significantly lacking during undergraduate and postgraduate training in India. The training curriculum concentrates only on certain and often even the common rheumatic problems are not dealt with. Such shortage of personnel adds to the challenges that the poor face as these specialists are mostly located in larger cities.

**Limited political will**

Despite the wide prevalence of this problem, the government has no policy or program to deal with musculoskeletal disorders. The limited awareness and restrained advocacy to implement changes is glaringly absent.

**Chronic and overbearing treatment**

Almost all these diseases require a chronic treatment and in many cases it has to be lifelong. Patients find it difficult to reconcile with such a situation and when managed inappropriately, after losing faith in the western modes of treatment most patients resort to native practitioners. These practices are heterogeneous and outcomes are varied.
Outcomes in rheumatology have significantly improved over the past decades. With the advent of newer drugs, Disease Modifying Anti Rheumatic Drugs (DMARDs) and biological therapy (Engineered antibody mediated therapy) treatment has become more effective with less side effects. The multitude of clinical trials has optimized protocols to improve outcomes and reduce side effects.

Drugs in rheumatology are notorious for their side effects. If one reviews their incorporation into practice, they have historically stemmed from anti-cancer treatment and are used in the transplant setting. As a doctor if one were to explain the side effects of the most common drugs used in rheumatology, i.e. - Steroids, Methotrexate, Sulphasalazine, Azathioprine and Cyclophosphomide; the list would terrify any person. Can you imagine convincing a patient to take any of these drugs? And sometimes it's a cocktail or in sequence. This is where the treating doctor plays a very important role in communicating the risk and benefit ratio, being prudent about choosing the right drug and ensuring cautious follow up and monitoring. The cost of care also continues to remain high. With newer drug discovery, outcomes have improved but most of this is out of reach of the average Indian.

The estimated median annual income of an Indian in 2013 was $616 which is around Rs 3200 per month(16). And the approximate monthly expenses, on optimal maintenance treatment, for RA Rs.1200; AS Rs. 800 and SLE ranges from Rs.900 to 5000. The costs for biologicals range from Rs 60,000 to over 2.5 lakh for a 6-month course depending on the disease and the drug required. This leaves the majority of our population finding it not feasible to continue treatment for these problems.

Hence here is a problem where many times both doctors and patients don’t know what they have. If the doctor knows, often the patient does not understand. If the doctor and patient understand, often treatment is too expensive and chronic. However if both understanding and treatment is achieved outcome is excellent.

Possible Solutions ahead

So in this scenario the following are potential solutions that one considers:

- Improving awareness - Being relatively uncommon diseases to diagnose and treat, this should be the first step. This should be approached as a two-pronged strategy at the community level and at the level of health personnel. At the population level, we should increase the dissemination of relevant information through regional periodicals, newspapers, radio interviews and relevant events. We should capitalize on world arthritis day (12th October) and World Lupus Day (10th May) to educate the public on the possible rheumatic disorders and conduct screening camps in various districts.

- Semantics - Many a times the name for most of our diseases is not known. They are often just referred to as a type of arthritis. We should spearhead an effort to decipher or confer names for these diseases in the common regional languages so that further communication becomes more meaningful.

- Educating the Health System in Rheumatology - The personnel at the point of contact should have an improved understanding of the possibility of a rheumatological problem. We should create training modules that cater to healthcare personnel - from doctors to the peripheral community health worker. If these modules address certain alarm signs and screen for the major diseases, the delay of diagnosis may be reduced. These will need to be regularly administered with refresher classes and clarification sessions. We can utilize the growth of digitalization to provide this information through telecommunication or you-tube videos.

- Strengthening Community level centres at the district levels - Specialized focus should be at district level hospitals with training in diagnosis and follow up guidelines. Initially regions with a rheumatologist can be identified as a District / Regional Centre. This can be done through a collaborated Public-Private partnership where private institutes can take the onus of training. Orthopedicians, internists, general physicians and even physiotherapists of the region can be trained along the same lines. These centres will also need to be equipped with reliable laboratories or courier services for special samples to be followed up.

- Education at UG and PG level - A review of training at the under and postgraduate level reveals that most of our doctors are not confident of identifying or managing rheumatic diseases. We need to incorporate modules that deal with the most common diseases and enable a better pick up rate. We should also focus on the training students in communication, explanation of disease, information providing and follow up. These diseases require a sensitive, attentive and instructive doctor.

- Negotiating treatment strategies- The cost of drugs is prohibitively high for most of our patients. We can recommend to governments that they create funds/ schemes where young and deserving patients can enroll to avail supervised monthly stipends, ensure regularity of follow up and adherence to medications. Like the schemes that permit treatment for chronic kidney disease, PPP (Public Private Partnership) schemes for certain rheumatic conditions can be structured that provide transient support to tide over critical periods of diagnosis, control of disease and
flares. Private companies can be persuaded to contribute their Corporate Social responsibility (CSR) to strengthen such ventures. PPP can set up innovative insurance schemes that serve needy patients. Authorities can venture to negotiate the cost of some of our drugs to being more affordable. We can encourage newer pharmaceutical companies to manufacture some of these drugs at a lower cost. Institutions can aid in setting up helplines and support groups. These can serve as information dissemination and provide clarification for patients providing links to others who have the same problems.

Concerted effort converging different systems - There is still much in our field that is uncertain and growing. From the basic science understanding to management guidelines, there are vast areas that need to be discovered and fine-tuned. We need to pay due heed to the ancient and alternate forms of medicine that have also faced these diseases over the past centuries. A scientific, safe and consorted effort to integrate these disciplines is important to improve and provide holistic care to our patients.

In conclusion

The field of rheumatology is a relatively new, heterogeneous and rapidly growing discipline. The challenges in rheumatology in India are numerous, which stems from the lack of awareness and extends to improper treatment provided. National Authorities and specialist institutions need to spearhead the task of overcoming these challenges and improve the quality of care for the aam-admi.

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Glossary:


DMARDs - Disease modifying anti rheumatic drugs.

Prevalence = the percentage of a population that is affected with a particular disease at a given time.

DALY = One DALY can be thought of as one lost year of "healthy" life. DALY's for a disease or health condition are calculated as the sum of the Years of Life Lost (YLL) due to premature mortality in the population and the Years Lost due to Disability (YLD) for people living with the health condition or its consequences:

References:

A commentary on medical education and cardiovascular medicine

Anand Zachariah

The greater challenge is for us to examine the objects that constitute the field of medicine.

In medical education we are so increasingly focussed on curricula, teaching methods and assessment, that we are forgetting the field of knowledge itself, and being able to think about that knowledge. Rather than comment on priorities in teaching hours and skills that a practitioner should have, I would like to focus on the challenges in thinking about frameworks of medicine and NCDs at this particular moment. Towards finding a theoretical way to approach the impasse that faces cardiovascular disease and its prevention in India.

My own clinical experience at CMC and working on cardiovascular risk factors in Gudalur, has drawn me closer to believing that development is closely linked to the cardiovascular disease and that the modes of development and its nodes differ from place to place and community to community. If we examine closely the development of the knowledge of medicine, the cardiovascular risk factors are being hardened to becoming disease entities with downward trends in their definition, and increasingly we are being demanded to start more and more people on drug treatments to modify risk factors to prevent heart attacks and strokes. This is the stranglehold that the epidemiological frame and evidence based medicine has on us as members of the medical establishment. Anything that cannot be measurably described cannot exist.

It is in this search for a developmental frame to think about chronic disease that I was enthralled by the experience of North Karelia. We are all familiar with the Framingham study. On the other hand, as I have described elsewhere (see "Moving beyond the risk factor model for coronary artery disease to community led prevention in the current issue of MFC bulletin"), the North Karelia project followed an entirely different trajectory of health care to deal with cardiovascular disease. Despite the fact that the lead researcher Pesha Puska became the head of the NCD division of WHO and North Karelia project has influenced NCD prevention across the world, I (as a teacher of medicine) had not come across this work till now. The weight of a large number of studies across the world tells us that primary cardiovascular prevention is not possible and that North Karelia was the exception. To understand the exceptionalism of North Karelia one has look beyond the objectives, design and outcomes which science encourages us to do, to examine the context, the people behind it, their frameworks of thinking and the actual things that they did. Clearly the circumstances in North Karelia occurred in a certain way together (the longitudinal studies, the political concerns, the force of PeskaPuska’s leadership) that led to the fostering of a health movement. Can a health movement be studied through a randomised controlled trial or quasi experimental study? No, yet what the North Karelia project showed was that a persistent and sustained health movement could do what a controlled trial could not. The question is, can it be replicated and if not why not? This is what leads me to the developmental framework of thinking of NCD, which helps me to think about the exceptionalism of North Karelia.

North Karelia project started before the publication of the Framingham study. Would another North Karelia project be possible, in the post Framingham period that we are living in? Stated in another way, despite the origins of the Framingham study in an initiative to start a local health movement to address NCDs, the Framingham study and the subsequent cardiovascular cohorts of that community did not lead to a primary prevention intervention for the community in Framingham. On the other hand the Framingham study led to an epidemiological model of disease that has emphasised individualised preventive treatment in a market mode. The Framingham risk factor calculators, the guidelines for preventive treatment and the large proportion of Western populations on cholesterol lowering drugs are evidence of this. This model of thinking of high risk screening and treatment as the only evidence based approach to preventing cardiovascular disease is being applied across the world. What does this tell us about the current model of epidemiological research in cardiovascular medicine?

We are moving into the post-risk factor world where our thinking is so governed by pharmacological risk factor prevention, that we see unable to perceive the developmental frame of cardiovascular disease. And we are viewing development as an inexorable reality that is natural to our world that we cannot confront and definitely outside the frame of medicine. What space is there for communities to start thinking about the control that can exert and choices they can make on the processes of development that are causing ill-health in our lives (reference 4)?

As a teacher of medicine, these questions lead me to ask what constitutes the objects of field of cardiovascular medicine and is there another way of thinking about it?

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The diabetes we see: description of a retrospective cohort of diabetes mellitus in a referral center in impoverished rural central India

Sushil Patil, Bassem Ghali, Yogesh Jain

Abstract

India is struck by high levels of poverty and associated malnutrition and has a rising diabetes epidemic. This retrospective cohort study of diabetic patients seen at Jan Swasthya Sahyog aimed to determine the proportion of lean diabetes in a secondary center in rural India, to describe the phenotype of patients and compared to obese peers. We found 38% of our diabetes patients to have low BMI. They were on average, 4.8 years younger and often required insulin. More of the younger diabetics were lean. More than half of tribal diabetics were lean diabetics.

Background

Malnutrition related diabetes as an entity has had a controversial history; it was recognized by the WHO in their 1985 document [1] but was subsequently removed from the classification. At the time it encompassed two entities: one being fibrocalcific pancreatic diabetes with clinical and radiologic evidence of pancreatic damage and the other being a heterogeneous protein deficient pancreatic diabetes[1] for which different investigators have applied various terms. Others from Ethiopia and from within India [2-4] have published about diabetes in lean patients but there continues to be no clear consensus on the classification, the terminology, the pathophysiology and the best treatment. The most recent iteration by George et.al., is ketosis resistant diabetes of the young (KRDY), which is characterized by onset younger than 30 years of age, high glucoses, body mass index (BMI) less than 18, absence of ketosis on withdrawal of insulin, childhood malnutrition or poor socioeconomic status and high insulin requirements (more than 60 units per day or 1.5 units/kg) [5].

Jan Swasthya Sahyog (JSS) runs a community health program and as part of that secondary care hospital at Ganiyari in rural central India that serves the poorest of the poor since last 17 years. The hospital registers about 18,000 new patients every year and provides more than 50,000 consultations. During the years 2010-2013, 92.5% (54,651/59,039) of the registered patients belonged to backward social groups. In the same period 41.01% patients were undernourished (BMI<18.5). JSS diagnoses over 450 new cases of diabetes every year.1 41% of our patients from 2010 to 2013 had BMIs less than 18.5 kg/m2[6]. Over the years, we have seen a variety of phenotypes, including well described ones like Type 1 diabetes mellitus presenting in ketoacidosis or overweight adults with insulin resistance and Type 2 diabetes. However, we observed other phenotypes that defy this classic categorization but share the common trait of profound malnutrition. This retrospective study describes the characteristics of diabetic patients we see here in Ganiyari, with particular focus on the subset of patients who are lean. We aim to calculate the prevalence of lean diabetes in our center, to compare clinical characteristics of lean diabetics to their obese peers, to investigate if disenfranchised or young subpopulations have higher rates of lean diabetes.

Methods:

This is report describes a retrospective cohort of patients seen at Jan Swasthya Sahyog (JSS), a secondary care hospital in rural central India that serves a particularly vulnerable population. Since June 2013, JSS has been using an electronic medical record (EMR, Bahmni, ThoughtWorks, Inc., Bangalore India) for clinical care. The EMR allows us to track patients affected by various chronic diseases including diabetes. The inclusion criterion was every patient diagnosed with diabetes (using standard criteria) in either outpatient or inpatient care who was referred to the hospital or the facility.

Note:

1. The Framingham study in the town of Framingham, Boston in USA was the first cohort study of cardiovascular risk factors that studied the relationship between risk factors and cardiovascular outcomes (heart attacks). The results showed that hypertension, hypercholesterolemia, smoking and obesity are associated with the development of coronary outcomes (reference 1). The terms ‘risk factor’ and the ‘risk factor model’ were first articulated in the early publications of Framingham study (reference 3). The Framingham study led to shift to an epidemiological way of thinking about cardiovascular disease (reference 2). The randomised controlled trials that followed showed that treatment of hypertension and dyslipidemia lead to positive outcomes in terms of prevention of heart attacks and deaths. The combination of the cohort studies of risk factors and successful preventive treatment studies of risk factors have cemented our conceptual thinking of risk factors as etiological agents. They have emphasised the importance of health system screening for risk factors and preventive treatment which are important elements of an NCD programme.

References:


a diabetes counselor for education and subsequently enrolled in the diabetes program in the EMR. Patients diagnosed prior June 2016 were retroactively enrolled. In December 2016, we used the EMR reporting feature to obtain a report of all patients enrolled in the diabetes program from Jan 1, 2014 through Nov 30, 2016 in a Microsoft Excel spreadsheet. This spreadsheet was sorted by visit. Only initial visits were analyzed; all follow up visits were excluded from analyses. Exclusion criteria were patients with age <18 years to minimize patients with Type 1 Diabetes. Records without BMI or with BMI <10 kg/m² and >40 kg/m² were excluded as they appeared to represent clerical error.

We used the conditional formatting function to search the medication list string for "Insulin", "Metformin", "Glipizide", "Glimepiride", "Pioglitazone", and made a new column for each with binary result. We defined "lean", or low body mass index (low BMI) as less than or equal to 18.5 kg/m², normal as greater than 18.5 kg/m² but less than or equal to 23 kg/m², and high BMI as greater than 23 kg/m². We defined young patients as those older than 18 and less than or equal to 30 years old. Elevated waist-to-hip ratio, a surrogate for abdominal obesity, was defined at greater than 0.9. To investigate degrees in levels of hyperglycemia we compared one of either fasting, or post-prandial, or random glucose (whichever was available during the first patient visit).

Data was imported into RStudio software (Version 1.0.44, RStudio, Inc, Boston, MA) for statistical analysis. Means of continuous variables including age and BMI were compared using the t-test while proportions of binary or categorical variables - young patients, sex, BMI category, caste - were compared using the Chi squared test.

The study proposal was presented and reviewed by our institutional research committee.

Results:

The EMR reported 1154 unique patient visit records in this period for patients enrolled as having diabetes. Of the 1154 patients, 269 (23.3%) patients were from scheduled tribes (tribals, ST), 375 (32.5%) patients were from scheduled castes (Dalits, SC), 392 (33.97%) patients were from other backward castes (OBC) and the remaining 118 (10.23%) patients were from the general category.

For the purpose of present paper, we excluded 23 patients younger than 18 years at initial visit. We excluded 70 patients who did not have a BMI recorded at the initial visit. We also excluded 38 patients with physiologically impossible BMIs likely representing physiologically impossible BMIs likely representing...
clerical errors. These exclusions represented 11.4% of our data (131/1154).

Of the 1023 patients where age and BMI records were available (Table 1) the mean age was 51.1 years (±12.5) and BMI 20.6 kg/m2 (±4.5) with a slight male predominance 55.6% (569/1023). Overall, 22% of patients were on insulin and 81% on metformin. Only 131 patients had anthropometric data recorded: of these the mean waist to hip ratio was 0.94 (±0.06) and 79.4% had a ratio > 0.9 a surrogate for abdominal obesity.

Table 1: Descriptive Data of diabetic population

<table>
<thead>
<tr>
<th>Variable</th>
<th>N (proportion)</th>
<th>Mean (standard deviation)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body Mass index, BMI (Kg/m²)</td>
<td>1023 (100%)</td>
<td>20.56 (4.52)</td>
</tr>
<tr>
<td>Age (yrs)</td>
<td>1023 (100%)</td>
<td>51.07 (12.52)</td>
</tr>
<tr>
<td>Gender, Male</td>
<td>569 (55.62%)</td>
<td></td>
</tr>
<tr>
<td>Gender, Female</td>
<td>454 (44.38%)</td>
<td></td>
</tr>
<tr>
<td>Drugs, on insulin</td>
<td>210 (21%)</td>
<td></td>
</tr>
<tr>
<td>- on Metformin</td>
<td>812 (81%)</td>
<td></td>
</tr>
<tr>
<td>- on Glipride</td>
<td>513 (51%)</td>
<td></td>
</tr>
<tr>
<td>- on Glimpiride</td>
<td>117 (11%)</td>
<td></td>
</tr>
<tr>
<td>- on Pioglitazone</td>
<td>48 (4%)</td>
<td></td>
</tr>
<tr>
<td>Waist (cm)</td>
<td>111</td>
<td>93.93 (11.98)</td>
</tr>
<tr>
<td>Hip (cm)</td>
<td>111</td>
<td>98.87 (9.87)</td>
</tr>
<tr>
<td>W/H Ratio (nd)</td>
<td>111</td>
<td>0.93 (0.06)</td>
</tr>
<tr>
<td>- Ratio &gt;0.9</td>
<td>104 (79.4% of 131)</td>
<td></td>
</tr>
<tr>
<td>Serum glucose levels (mg/dl)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- 141-200</td>
<td>110 (11.75%)</td>
<td></td>
</tr>
<tr>
<td>- 201-300</td>
<td>130 (35.26%)</td>
<td></td>
</tr>
<tr>
<td>- 301-400</td>
<td>185 (51.53%)</td>
<td></td>
</tr>
<tr>
<td>- More than 400</td>
<td>103 (21.69%)</td>
<td></td>
</tr>
</tbody>
</table>

Analysis by BMI subgroup

37% of our patients (375/1023 patients over the period of the study) were lean (BMI < 18.5 kg/m2) while 27% had a BMI greater than 23 (276/1023, Table 2). Patients with a low BMI were on average 4.7 years younger than those with high BMI (p<0.001); in fact 12% of patients in the low BMI group were younger than 30, compared to 2% in the high BMI group. The low BMI group were more often male than the high BMI group (63% versus 40%), and more often on insulin (43% vs 5%). As expected, fewer patients had waist to hip ratio (W:H) greater than 0.9 in the low BMI group compared to the high BMI group (36.5% versus 100%); although, this was limited by missing data.

Analysis by Age group

Only 61 (6%) patients were younger than 30; however, this group was distinct from the older diabetics - they were more often male (72% versus 55%, p 0.008) and had a significantly lower BMI (2.9 kg/m², p <0.001). In fact 75% of younger patients were in the low BMI group and only 9.8% was in the high BMI group, as compared to older diabetics where the 34% were in the low BMI group, and 28% were in the high BMI group which a more uniform distribution. 75% of younger patients needed insulin compared to 19% of older diabetics, fewer were on metformin (43% versus 84%) and sulfonylureas (11% versus 63%). Anthropometric differences were not found but were limited by missing data.

Analysis by Social group

A cross tabulation of social groups and nutritional status (BMI) showed that progressively more deprived social groups more frequently had lower BMI groups; tribals (ST) accounted for 23% of the sample, and 57.6% of their patients having BMI less 18.5 kg / m2. This proportion was 30% in SCs, 36% in OBCs both also considered to be deprived social groups, and 21% in the general population.

The serum glucose of 936 patients were studied. 21.7% of patients presented with glucoses more than 400 mg/dl blood sugar and of these...
Discussion:

The official poverty line in India, which some have called the starvation line [7], is below half a US dollar per person per day [8]. 270 million people in India live below this line; in Chhattisgarh, a state in rural central India, 10 million people live below the poverty line, or 39% of the population [9]. Despite this utter destitution, or perhaps related to this poverty, cases of diabetes mellitus in India are increasing at an alarming rate. The INDIAB study estimates 62.4 million diabetes and 77.2 million pre-diabetic patients [10].

We serve a population rich in disenfranchised groups (Table 4) - a mix of scheduled tribes, scheduled castes and other backward castes. These groups are familiar with high levels of deprivation and destitution. Our study shows a substantial number of patients with low BMI and diabetes in our health programme. Only 25% of our patients had BMI greater than 23. In contrast, data from the US shows that 85% of diabetics were obese or overweight and 55% were obese [11].

The lean subgroup of diabetics seen at Ganiyari is characterized by poor nutrition (low BMI), younger age, male sex, social deprivation, and higher rates of insulin use. They defy the binary classification of type 1 and 2 diabetes. These individuals often have high blood sugar levels at presentation and thus are similar to the KRDY population described by George et al [5]. Three Ethiopian studies report similar type of diabetes characterized by low BMI [2,4,12]. In these studies, median BMIs for adults were 20.6 kg/m2 with associated impoverishment, early onset and severe hyperglycemia needing insulin [2,4,12]. Although we did not record the amount of insulin they required, these patients often present with high glucoses and initially need high levels of insulin to correct the glucotoxicity; moreover, more lean patients fail oral agents and need insulin for sugar control.

The etiology behind the early age of onset of diabetes and poor nutrition in these diabetics remains unclear; we suspect that deprivation is a driving factor through an unclear mechanism of this lean diabetes phenomenon. Other groups have suggested that KRDY is a manifestation of autoimmune diabetes but individuals lack the protein stores to develop ketosis [13]. Various assumptions which need to be studied include undernutrition (in utero, in childhood and in adulthood) leading to impaired insulin secretion and action and excess hepatic glucose production which manifest in the syndrome of diabetes at an early age.

Because this so different than the mainstream diabetes illnesses mentioned in the medical literature, the management protocols have also not clearly evolved nor have protocols clearly addressed how to nutritionally rehabilitate these patients while maintaining euglycemia to prevent diabetic complications. Optimal treatment remains challenging as they present at young age and many require insulin with its known complexities in resource limited settings, and although this was not specifically addressed here, other studies have shown a high proportion of lean diabetics develop complications [3,5,14]. Other challenges to improving care are improving nutritional advice (to people who already starving), improving foot care (to people who largely walk barefoot), ophthalmologic care, access to medications and proper use of insulin and blood sugar monitoring.

Based on our data, a substantial portion of these patients will be both poor and diabetic, thus, further study is necessary to best classify these patients using some pathophysiological basis, which will help us treat these patients optimally and perhaps understand and prevent the disease in the first place. Further, more studies are also required for evolving better management protocols.

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Figure 4: boxplot of age for each of the BMI categories

Figure 5: boxplot by gender comparing a) age for each of the BMI categories and b) BMI for each of age categories.
Table 2: Analysis BMI subgroup * p<0.001 (low versus High), **p <0.001 (low vs. normal)

<table>
<thead>
<tr>
<th></th>
<th>Low BMI (&lt; 18.5)</th>
<th>Normal BMI (BMI between 18.5 and 23)</th>
<th>High BMI (≥ 23)</th>
</tr>
</thead>
<tbody>
<tr>
<td>N (%) of total</td>
<td>275 (27%)</td>
<td>372 (36% of total sample)</td>
<td>276 (27%)</td>
</tr>
<tr>
<td>Mean [SD]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BMI (Kg/m²)</td>
<td>16.22 (1.39)</td>
<td>20.63 (1.28)</td>
<td>26.45 (3.05)</td>
</tr>
<tr>
<td>Age, <strong>”</strong></td>
<td>57.3 (10.9)</td>
<td>52.8 (11.9) <strong>”</strong></td>
<td>52.77 (10.8) <strong>”</strong></td>
</tr>
<tr>
<td>Age &lt;50</td>
<td>46 (15%)</td>
<td>5 (2%)</td>
<td>52 (%)</td>
</tr>
<tr>
<td>Age &gt;50</td>
<td>129 (84%)</td>
<td>302 (96%)</td>
<td>270 (80%)</td>
</tr>
<tr>
<td>Gender, Male</td>
<td>23 (63%)</td>
<td>222 (65%)</td>
<td>111 (24%)</td>
</tr>
<tr>
<td>Gender, Female</td>
<td>12 (27%)</td>
<td>100 (40%)</td>
<td>165 (60%)</td>
</tr>
<tr>
<td>Insulin</td>
<td>143 (43%)</td>
<td>54 (15%)</td>
<td>13 (3%)</td>
</tr>
<tr>
<td>Metformin</td>
<td>581 (70%)</td>
<td>215 (54%)</td>
<td>250 (33%)</td>
</tr>
<tr>
<td>Sulfonylurea</td>
<td>204 (64%)</td>
<td>233 (65%)</td>
<td>174 (63%)</td>
</tr>
<tr>
<td>Dipeptidase</td>
<td>11 (3%)</td>
<td>20 (6%)</td>
<td>14 (2%)</td>
</tr>
<tr>
<td>Waist</td>
<td>82.34 (6.8)</td>
<td>94.33 (6.8)</td>
<td>106.51 (9.8)</td>
</tr>
<tr>
<td>Hip</td>
<td>91.05 (4.36)</td>
<td>98.50 (6.1)</td>
<td>107.34 (7.35)</td>
</tr>
<tr>
<td>Weight Ratio</td>
<td>0.90 (0.08)</td>
<td>0.99 (0.08)</td>
<td>0.99 (0.08)</td>
</tr>
<tr>
<td>WtRRatio&lt;0.5</td>
<td>20 (46.3%)</td>
<td>45 (52%)</td>
<td>59 (100%)</td>
</tr>
</tbody>
</table>

Figure 1. a. Histogram of BMI and b. Age in our diabetic population
### Table 3: Analysis Age subgroup * p<0.001 (young versus old)

<table>
<thead>
<tr>
<th></th>
<th>Young Patients (Age &lt;=30)</th>
<th></th>
<th>Older Patients (Age &gt;30)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>N</strong></td>
<td><strong>Mean</strong></td>
<td><strong>N</strong></td>
<td><strong>Mean</strong></td>
</tr>
<tr>
<td>N (% of total sample)</td>
<td>61 (6%)</td>
<td></td>
<td>962 (94%)</td>
<td></td>
</tr>
<tr>
<td>Age (Years)</td>
<td>61</td>
<td>24.69 (3.54)</td>
<td>962</td>
<td>52.75 (10.9)</td>
</tr>
<tr>
<td>BMI (Kg/m^2) *</td>
<td>61</td>
<td>17.79 (4.72)</td>
<td>962</td>
<td>20.76 (4.45)</td>
</tr>
<tr>
<td>L BMI</td>
<td>46 (75.4%)</td>
<td></td>
<td>329 (34%)</td>
<td></td>
</tr>
<tr>
<td>NBMI</td>
<td>9</td>
<td></td>
<td>363</td>
<td></td>
</tr>
<tr>
<td>HBMI</td>
<td>6 (9.8%)</td>
<td></td>
<td>270 (28%)</td>
<td></td>
</tr>
<tr>
<td>Gender, Male</td>
<td>44 (72%)</td>
<td></td>
<td>525 (55%)</td>
<td></td>
</tr>
<tr>
<td>Gender, Female</td>
<td>17 (28%)</td>
<td></td>
<td>437 (45%)</td>
<td></td>
</tr>
<tr>
<td>Insulin</td>
<td>46 (75.4%)</td>
<td></td>
<td>184 (19%)</td>
<td></td>
</tr>
<tr>
<td>Metformin</td>
<td>26 (42.6%)</td>
<td></td>
<td>806 (84%)</td>
<td></td>
</tr>
<tr>
<td>Sulfonylurea</td>
<td>7 (11.5%)</td>
<td></td>
<td>606 (63%)</td>
<td></td>
</tr>
<tr>
<td>Pioglitazone</td>
<td>0 (0%)</td>
<td></td>
<td>46 (4.7%)</td>
<td></td>
</tr>
<tr>
<td>Waist</td>
<td>11</td>
<td>87.27 (17.52)</td>
<td>120</td>
<td>94.54 (11.24)</td>
</tr>
<tr>
<td>Hip</td>
<td>11</td>
<td>92.27 (11.7)</td>
<td>120</td>
<td>99.48 (8.37)</td>
</tr>
<tr>
<td>W:H Ratio</td>
<td>11</td>
<td>0.94 (0.09)</td>
<td>120</td>
<td>0.945 (0.06)</td>
</tr>
<tr>
<td>W:H Ratio &gt;0.9</td>
<td>7 (63.6%)</td>
<td></td>
<td>97 (81%)</td>
<td></td>
</tr>
</tbody>
</table>

*Table 3: Analysis Age subgroup * p<0.001 (young versus old).*

<table>
<thead>
<tr>
<th>Social Groups</th>
<th>BMI Less than 18.5</th>
<th>BMI 18.5 to 23</th>
<th>BMI Over 23</th>
<th>Total Patients</th>
<th>Proportion social groups</th>
<th>Proportion less than 18.5 BMI</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>22</td>
<td>26</td>
<td>56</td>
<td>104</td>
<td>9.97</td>
<td>21.15</td>
</tr>
<tr>
<td>OBC</td>
<td>150</td>
<td>126</td>
<td>100</td>
<td>356</td>
<td>34.15</td>
<td>56.52</td>
</tr>
<tr>
<td>SC</td>
<td>102</td>
<td>141</td>
<td>97</td>
<td>340</td>
<td>32.60</td>
<td>30.00</td>
</tr>
<tr>
<td>ST</td>
<td>140</td>
<td>80</td>
<td>23</td>
<td>243</td>
<td>23.30</td>
<td>57.61</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>394</strong></td>
<td><strong>373</strong></td>
<td><strong>276</strong></td>
<td><strong>1043</strong></td>
<td><strong>100.00</strong></td>
<td><strong>37.78</strong></td>
</tr>
</tbody>
</table>

*Table 4: Social groups and BMI classification.*
Table 5: social groups and glucose levels

<table>
<thead>
<tr>
<th>Case</th>
<th>Number of patients with glucose (mg/dl)</th>
<th>Proportion of group with glucose (mg/dl)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>141-200</td>
<td>201-300</td>
</tr>
<tr>
<td>General</td>
<td>11</td>
<td>81</td>
</tr>
<tr>
<td>ODC</td>
<td>35</td>
<td>127</td>
</tr>
<tr>
<td>SC</td>
<td>34</td>
<td>105</td>
</tr>
<tr>
<td>ST</td>
<td>30</td>
<td>96</td>
</tr>
<tr>
<td>Total</td>
<td>110</td>
<td>330</td>
</tr>
</tbody>
</table>

Notes

1. Unpublished data.

2. Criteria for diagnosis were usually fasting blood sugar (FBS) and / and two hour post-prandial blood sugar (PP2BS) >= 200 mg/dL.

References


Chronic stress and disease

**What is stress?**

- Claude Bernard postulated in 1865 that for life to exist, the body had to maintain a stable internal equilibrium of constant factors (temperature, blood pressure, etc.) in the face of a changing environment.
- This was later called homeostasis.
- Hans Selye in 1950 used the term ‘stress’ to describe anything that disturbed homeostasis.
- Selye argued that the body went through what he called a General Adaptation Syndrome (GAS) to counter external stress. The derailment of this syndrome through prolonged maladaptation would result in what he called tissue damage and diseases of adaptation.
- Later, the biochemical responses to stressors that resulted in a long-term shift of the homeostatic set points were described as "allostatic load".

The central nervous system attempts to cope with threats through an appropriate response. When fight or flight is possible, the body’s hormonal and autonomic activities increase allowing muscular exertion. Where active coping strategies are not available, the body’s sympathetic nervous system (SNS) activates a vigilance response and a general inhibition of movement. The diverse situations that activate these two different biological responses are called **situational stereotypy**.

On the other hand, different individuals also respond differently to the same situation (depending on personality, opportunity, state of mind, etc.) and this range of responses to the same situation is called **response stereotypy**. It has been shown in animals that response stereotypy varies not only due to genetic differences, but also due to neonatal environmental conditions.

It is thought that acute or short phase stress is healthy and does not damage the body. However, chronic stress, especially among the old and the immunocompromised, may result in disease. It has been argued that the capacity for symbolic thought (human character) may result in chronic stresses due to the interpretation of diverse situations in very similar terms with no possibility of fight or flight, hence resulting in a prolonged state of vigilance.

In general, this backgrounder discusses the somatic effects of psychological stress of this kind which has been theorized to arise when the environmental demand on the person exceeds the adaptive capacity. There are other kinds of stress, i.e., a) psychological stress that results in mental breakdown (e.g., PTSD), and b) physiological stress that results in pathological morbidity and mortality (e.g., physiological stress induced ischemia), both of which are not covered in this brief note.

**Stress and its relation to illness in biomedical research**

Lay and clinical opinion (see box below for an example) is fairly explicit about the relation between stress and illness, and stress has been established in epidemiological studies as a (statistically significant) risk factor in type II diabetes and stroke. However, biomedical proof of causation has been difficult to obtain. Until 2007, there were only plausible hypothetical causal links established between stress on the one hand, and depression, cardiovascular disease, cancers or HIV-AIDS on the other.

Anand Zachariah adds: In relation to the stress and the heart, there is a clinically observed entity called stress cardiomyopathy or broken heart syndrome. Also called Takotsubo cardiomyopathy (the name refers to Octopus pot in Japanese - the ECHO findings look like an Octopus pot). It is a temporary weakening of the heart related to severe emotional stress such the loss of loved one. About 85% of patients have a severe stress preceding the illness. It is diagnosed by typical Lechocardiography findings of ballooning of the apex of heart. Generally the condition improves on its own.

**Neurohumoral Features of Myocardial Stunning Due to Sudden Emotional Stress**

Ilan S. Wittstein, David R. Thiemann, Joao A.C. Lima, Kenneth L. Baughman, Steven P. Schulman, Gary Gerstenblith, Katherine C. Wu, Jeffrey J. Rade, Trinity J. Bivalacqua, and Hunter C. Champion


February 10, 2005

Generally speaking, the causal hypotheses/theories are:

First, stress induces significant behavioral changes that impact body coping mechanisms, e.g., smoking, decreased sleep, poor adherence to medical regimen, increased sedentary behavior.

Second, stressors induce endocrine responses through the hypothalamus-pituitary-adrenocortical (HPA) and
the sympathetic-adrenal-medullary (SAM) axes. Cortisol on the HPA axis regulates metabolism of carbohydrates, fats and proteins, and the process of gluconeogenesis; SAM activation releases catecholamines which work with the autonomic nervous system and affect regulation of cardiovascular, pulmonary, hepatic, skeletal muscle and immune systems. The effects of these processes going awry due to stress have so far found partial confirmation through different types of medical research (clinical, animal, laboratory, controlled experimental) and epidemiological (cross-sectional, prospective cohort) studies.

There have long been hypotheses linking stress to the imbalances in the immune system. More recent breakthrough research reported by Sheldon Cohen et. al., in 2012 based on the controlled exposure of subjects to the common cold virus has confirmed that stress affects the immune system resulting in a stress induced vulnerability to infection. It has also becoming evident that the path through which stress affects the immune system is through the response of the target tissue to cortisol (independent of cortisol levels in the blood). These experiments show that stress working through a complex biochemical pathway reduces glucocorticoid receptor response (GCR), thus increasing the time and intensity of inflammatory reaction. This reduction of GCR and persistent inflammation has the potential to affect both acute conditions like asthma and autoimmune disorders, and also the progression of chronic inflammatory diseases such as CVD and type II diabetes. All these potential implications need to be proven through further painstaking research.

**Measurement of stress**

One of the widely used measures of stress is the Cohen Perceived Stress Scale, which asks questions about psychological responses to stressful events in a given span of time, e.g.

1. In the last month, how often have you been upset because of something that happened unexpectedly?
2. In the last month, how often have you felt that you were unable to control the important things in your life?

This scale attempts to elicit responses regarding what may be termed universal responses to varied particular stressors without focusing on the particular character of the stressor event.

Another well known measure of stress as a predictor of illness is the Holmes and Rahe Stress Scale, which grades specific stressful events through “life change units” on a scale of 100. Life change units are a proxy for effects on health. E.g., Death of a spouse is graded 100, while breaking up with a boyfriend or girlfriend is graded at 53. This scale elicits information about particular stressors and the total number of ‘life change units’ scored are predictors of stress related disease.

As Cohen et. al., observe, measuring stress has to be strategized according to the purpose of the research, the biomedical conditions, variables or factors that are to be measured, the characteristics of the community or sample that is to be studied and the environmental conditions like access, language, etc.

In addition, there are various ways of characterizing stress according to intensity, duration and quality. One such classification for example is as follows:

a) Acute time limited stressors: e.g., solving arithmetic problems, public speaking;
b) Brief naturalistic stressors: e.g., appearing for an examination (where the end of the stress period is known).
c) Stressful event sequences: e.g., loss of a spouse (where the individual cannot see when or how the stressed period will end).
d) Chronic stressors: e.g., traumatic injury leading to physical disability (where the person may well know that the stress will never end).
e) Distant stressors: e.g., sexual abuse as a child, having been a prisoner of war (where the effect continues long after the stressful event).

Each research method will have to find a classification of stress that suits its objectives.

**Difficulties and possibilities in the field**

During 2015, Anand Zachariah and I worked with many collaborators in Gudalur on a community based study of chronic diseases. As part of this study, we attempted to approach the problem of stress in a preliminary mode of interviewee experience, and this was included as part of the sociological questionnaire. In our search for a well-established and standardized questionnaire, we first found the Cohen Perceived Stress Scale. As we tried it out, we found that the scale was too abstract and difficult to relate to even for urban based test interviewees. The difficulty was that the Cohen scale was more suited to screen and select experimental subjects, than to establish whether and what percentage of morbid or normal individuals experienced stress (in the selection of experimental subjects, people who didn’t respond well to the stress questionnaire would be simply found unsuitable as experimental subjects, whereas with our research objective, a failure to respond would mean we don’t have adequate stress information about a respondent who is part of an interview sample). We abandoned the Cohen scale in search for a more appropriate
instrument, and then located the Holmes and Rahe scale. While this scale was easier to administer, the concrete stressor descriptions were culture specific and didn't contain the necessary detail of stressful events in the Adivasi life and culture.

In an attempt to find a more culturally specific list of concrete stressors, Anand Zachariah, Stan Thaekaer and I had a meeting with some of the elders and leaders of the Mullakurumba, Bettiakurumba, Kattunayakan and Pania community, during which we tried to brainstorm and list possible stressors. This resulted in several new items including elopement of daughter with a person who didn't belong to the community, and the presence of elephants in the vicinity. We made a short list of such stressors. We then faced two problems. One, it was impossible to establish without several trials of standardization (which we hadn't the resources for), what the hierarchy of intensity or persistence of stress was (e.g., were elephants more of a problem than elopement?). Thus, it was very difficult to arrive at 'life change units' of the particular stressors among the people we interviewed. The answers we received from the 35+ people interviewed were indicative of some kind of stress in many cases, but the somewhat vague quality of the answers and the lack of the ability to establish intensity and duration with precision left this arm of the study in limbo.

And yet, the stress aspect of the questionnaire, though weak in an epidemiological and statistical register, had a major strength in its qualitative description of the range of stressors that people underwent, i.e., the change in life from the forest to more urban living, problems of education, house, employment, health care, loan etc. Clearly the effect of development in the community caused stress (developmental stress). Among these, there were stresses that were not comparable. For instance, not being able to do the rituals for ancestors at the burial grounds is quite different from the other stressors. Some people felt that modern stress was more intense than in the past. Others felt that stress in their childhood was not less but it was different (lack of food and periods of hunger).

Clearly psychological stress was a facet of everyday life. This was fairly evident to clinical commonsense from medical consequences such as the significant rates of suicides. Since stress could not be quantified, it was not possible to draw an epidemiological conclusion of stress as a risk factor, its prevalence or its contribution to cardiovascular events. On the other hand, developmental stress is the milieu within which there is undernutrition, moderate rates of hypertension and deaths due to heart attacks the strokes (stress may be more in the way Selye was arguing, the milieu within which disease in general occurs).

**Reflections**

Psychosomatic stress is a clear link between the social environment, individual response and pathology. While on the one hand, there is slow and steady biomedical research progress in finding the stress induced disease mechanisms, there are also field research instruments that measure socially induced stress as described above on the other (presuming in some ways the link that is being tackled by biomedical research).

The difficulty is that while there are limited forms of situational and response stereotypy (see first section), their combination, and the diverse cultural conditions that are symbolically reduced to these limited forms are potentially infinite. In the environment of the current mainstream bias towards biomedical solutions, we would expect a tendency to look towards biomedical solutions. However, this does not seem to be the case with the research on stress (at least in the five or six papers reviewed for this note). Perhaps it is too early and the scientific community knows how little it understands stress to suggest biomedical measures (but also see following section in Selye).

Most of the reflections in the scientific papers are about the problems of identifying stress pathways and sources, focusing on mechanisms of causation rather than on solutions.

**A brief note on Hans Selye**

A recent dissertation in the history of medicine sees Hans Selye's work as an ambiguous contribution to medical science. On the one hand, his conceptualization of stress ran against the mid-20th century doctrine of specific etiology, where one illness was attributed to one specific pathogen. "By proposing a universal etiological power to the adrenocorticotoid and pituitary hormones, Selye offered a means of understanding all disease as a product of cumulative exposures to a myriad of extremes-extreme exposure to chemicals and toxins, extreme temperatures, extremes of physical activity or immobility…" [p 15].

On the other hand, the dissertation also argues that Selye was a proponent of anxiolytic drugs thus blurring the distinction between biological stress (which he essentially investigated) and psychological stress which presumably results in anxiety. What is unclear in all this is how exactly psychological anxiety and psychosomatic stress are related and whether treating for anxiety will inhibit the pathophysiology of stress. Selye was also a proponent of the theory that psychosomatic stress was an inalienable concomitant of modern life.

**Stress and the Indian condition**

Whatever the ambiguity of the term stress may turn out to be, it is easy to imagine in India:
a) the insecurity of poverty, unemployment and migration in the regime of neoliberal capitalism
b) the consequent lack of certainty of a livelihood and a daily wage for the majority of the people
c) the shortage of foods, hunger and related morbidity
d) the extreme challenge of living with family and relatives in poverty and scarcity
e) the demands of modernity
f) the cultural difficulties of schooling and education for the children
g) changing social mores, the pressures of tradition and economic burdens that arise with respect to love, marriage, caste purity, childbirth and death
h) the absence of any safety net when catastrophic illness strikes

All the above will be factors in the development of epidemic levels of stress among the population.

It seems unlikely that governments will pay attention to stress, since they are reluctant to look at any indices that don't have the blessings and surveillance of international health and funding organizations.

From a different perspective, it is certain that we know next to nothing about how stress actually plays out (whether it makes things worse, becomes a habituated feature to be ignored by the body, causes complications in unexpected directions, etc.). The added difficulty is that stress is an experience since it is a psychosomatic response to a stressful situation.17

Unlike blood pressure, cholesterol and blood sugar which are quantitative physiological/biochemical indices of risk, stress is a complex concept not amenable to a simple quantification. Perhaps stress requires a qualitative "thick description" of a milieu or ground for the progress of various causative mechanisms of chronic disease. This would entail at least a partial reversal from the current mainstream trend towards dependence on quantitative laboratory indices and statistically valid evidence based epidemiology.

Thus, while biomedical research may point more and more clearly towards stress as an important (but not the only) factor in the development of chronic diseases, using this knowledge to the advantage of treatment is likely to remain a challenge for innovative methods of community health care at least in the near future.

Finally, it is left to the vigilance of medical activism to keep an eye on how much the pharmaceutical and medico-industrial complex will try to find drugs that like a 'golden bullet' will profitably 'solve' the problem of psychosomatic stress and its pathophysiology.

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Notes

6. For type II diabetes, see Andrew Steptoe, Ruth A. Hackett, Antonio I. Lazzarino, Sophie Bostock, Roberto La Marca, Livia A. Carvalho, and Mark Hamer, "Disruption of multisystem responses to stress in type 2 diabetes: Investigating the dynamics of allostatic load", PNAS November 4, 2014 vol. 111, no. 44, 15693-15698;
8. See reference in note 5.
13. I would like to make special mention of Durga Manoharan and Jiji Elamanu who were my mediators and co-interviewers in the sociological interviews.
15. I would like to express deep gratitude to Anand Zachariah here for these two paragraphs that reminded me of the positive value of the study we conducted.
17. This further point is again in response to Anand Zachariah's reflections on an earlier draft of the paper.
Pharma, clinical trials and non communicable diseases

Sarojini N & Adsa Fatima

The global health discourse focuses on cardiovascular diseases, chronic respiratory diseases, diabetes and cancer as major NCDs. While this provides significant global momentum to NCD, it sidelines other risk factors for NCDs from public health perspectives (Schuftan, 2015).

Risk factors based on individual behaviour alone with complete sidelining of social determinants of health can be extremely misleading. For instance, poverty, gender, etc. exposes people to increased risk factors for NCDs while healthcare for the latter may fuel high expenditures resulting in a vicious cycle of poverty. Thus, the disproportionate vulnerability to and impact of NCDs fall increasingly on low and middle-income countries, and on poor and marginalized groups of people within them.

The global focus on these NCDs serves as an opportunity for the pharmaceutical sector to bring out drugs for treatment of NCDs. In India, according to estimates, cardiovascular disease (24%), chronic respiratory disease (11%), cancer (6%) and diabetes (2%) are a leading cause of mortality (Sharma, 2013).

Sama’s study found that 657 phase III clinical trials were conducted for 307 drugs during 2005-2010. Of the 130 sponsors of the trials, 58 percent were multinational pharmaceutical companies who conducted 73 percent of the trials (Sama, 2016). The disease focus of the trials pointed to a maximum number of phase III trials conducted for diabetes, followed by neurological disorders, cardiovascular and others. Refer Figures 1 and 2 (Sama 2016).

Clinical trials by Indian pharmaceutical companies in the period 2005-2015 were also found to focus on NCD related drugs (Mandal and Abrol, 2015).

The number of clinical trials of drugs for cardiovascular disease, cancer, diabetes increased progressively from 2005. Clinical trials for diabetes account for 20%, cardiovascular diseases 12%, and cancer 11% of the trials conducted in India. The approval status of drugs in India, as per the study showed that 32 % were for diabetes, cancer, and cardiovascular diseases. Only 1 trial each was conducted for conditions of HIV and TB, and 2 trials for malaria, although their disease burden remains substantial in the country (Sama 2016).

The global discourse on NCDs points to the increase in NCD incidence and prevalence. The need, however, for robust analysis and scrutiny of the existing data and factors contributing to NCDs is critical. Any action on NCDs cannot exclude underlying ‘risk’ factors such as poverty, hunger, gender, etc., and the critical gaps in public health systems.

Simultaneously, it becomes absolutely essential to ensure that this global prioritization does not neglect other ‘communicable’ diseases of huge concerns for low and middle income countries, including India. Demarcated hierarchies between NCDs and other diseases are deleterious for any public health system and people’s access to healthcare.

While development of drugs to treat non communicable disease is relevant to the population, there is an urgent need for R&D for communicable diseases. Another relevant concern emerges from the conflict of interests of the pharma conglomerate; many of them are known to have worked towards contributing to the current discourse and are likely to use it towards expansion of their markets and profits.
Mapping NCD budgets and expenditures

Ravi Duggal

Context

India's health is in a transition phase. While we face increasing burden of non-communicable Diseases (NCDs) and injuries which account for 62% (including ill defined) of deaths we still have a huge burden of communicable diseases at 38% (including maternal and nutritional). Further NCDs account for 53% of the disease burden, 40% of hospitalizations and 35% of outpatient care (WHO 2014).\(^1\) This scenario should imply that greater resources are being allocated in the public health budget to NCDs. The 12th Plan working group on NCDs recommended that for the Plan period to address the growing burden of NCDs Rs. 58072 crores were needed additionally for prevention and control of these diseases with the largest share for Cancers, CVD, Diabetes, Stroke and Trauma/Burns. (see Table 1 and Graph 1). But such a volume of resources did not find its way into the actual Plan allocations. The Union government in 2016-17, the last year of the Plan allocated only Rs 555 crores for NCDs.

While overall budget transparency is reasonably good at both the national and subnational levels, getting disaggregated budget data is a struggle. Until 2013-14 fiscal year we had access to much more disaggregated data, but since then a) changes in the fiscal architecture brought about by the 14th Finance Commission provisions, b) the scrapping of the Planning Commission and c) return to the treasury route for flow of funds of flagship Central schemes have together created various asymmetries in documentation of budget information. Thus prior to 2014 we were able to access data in the main budgets for each major disease program but after that it all became part of the National Health Mission flexipool as transfers to states. Not that this data has disappeared but it has become more inaccessible and one has to access it from the NHM Program Implementation Plans (PIPs)/Record of Proceedings (ROPs). Getting access to the state PIPs/ROPs and then navigating through them is not an easy task.

NCD Budgets and Expenditures

The public health sector is grossly underfinanced and underinvested and a mere 1.2% of GDP or about Rs.1300 per capita (2016-17) ends up providing services to less than one-fourth of outpatient care and 38% of hospitalizations (NSSO 71st Round - 2014).\(^2\) Across states there is a clear divide - states that spend more than Rs. 1500 per capita have significantly higher levels of public facility utilization and low out of pocket expenditures and those spending less than the national average have much lower levels of public facility utilization and much higher out of pocket expenditures. The estimated out of pocket (OOP) expenditure today is about Rs.3000 per capita or 2.5 times that of public health expenditure. NSSO 71st Round conducted in 2014 indicates that OOPs for OPD averages about Rs.509 per ailment in rural areas and Rs 639 in urban areas with medicines accounting for 70% of this. For hospitalizations, the OOPs is Rs 18268 per case. Of all this about 50% is spent on NCDs. The 60th NSS Round - 2004 had estimated


that OOPs for NCDs was Rs 52606 crores (22% on public facilities) and this was 46% of total OOPs. Using the same proportion for 71st Round the NCD OOPs would be about Rs. 113160 crores or a little over Rs 900 per capita. So, that’s what we know about OOPs spending for NCDs.

**Table 1:** 12th Five Year Plan Working Group Recommendations for 2012-17

Source: Report of Working Group on NCDs WG3 (2) for 12th Plan, DGHS, MoHFW

<table>
<thead>
<tr>
<th>Component</th>
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<th>%</th>
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<td>19005</td>
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<tr>
<td>Medical Colleges &amp; Tertiary Care Institutes</td>
<td>20987</td>
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<td>Training</td>
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<td>2449</td>
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</tr>
<tr>
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<tr>
<td>M&amp;E</td>
<td>1190</td>
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</tr>
<tr>
<td>Others</td>
<td>801</td>
<td>1.4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>58072</strong></td>
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**Graph 1:** 12th Plan Working Group Recommendations for NCD allocations 2012-17 Rs. crores

Source: Report of Working Group on NCDs WG3 (2) for 12th Plan, DGHS, MoHFW

Public Health Expenditure as reflected in the Budget 2016-17 is estimated at Rs. 164000 crores (Central contribution about 25%). With regards to NCDs what we know is that the Union government has allocated Rs. 555 crores, 80% of which is as grants to states and UTs, for all the NCD programs as listed in Graph 1. What we also know is that the allocation is in the ratio of 60:40 for Union: States, so for the Rs 444 crores from the Union Govt. transferred to the states and UTs the state contribution should be around Rs.296 crores giving us a total allocation of Rs.740 crores for NCDs. While we have not been able to compile this information from all states Table 2 lists NCD allocations across three years for 7 states and the union government. It must be noted that these allocations are for prevention and control activities for NCDs. Treatment costs for NCDs are additional and come from the normal budgets of Public Hospitals and Primary Health Centres.

**Table 2:** Total NCD and NPCDCS Budget Allocations for Selected states 2014-15 to 2016-17 Rs crores

Note: NPCDCS is National Program for Cancer, Diabetes, CVD and Stroke; About 80% of the Union Govt allocation for NCDs goes to states and is reflected in state budgets so the entire Union Govt allocation cannot be added up with the states. The Union Govt data is from Budget Document (Expenditure Vol 2) and the state data is from PIP/ROP of respective states. This table was compiled by Richa Chintan from CBGA.

If we have to map the clinical budgets of NCDs then we would have to take each PHC, dispensary and hospital and work out the service load of NCDs and then calculate the expenditure incurred on them. What we know is that of the entire public health budget about 70% is spent on service delivery institutions like PHCs, Hospitals and Teaching Hospitals. We also know from NSSO data that NCDs account for about 53% of the load of these institutions ranging from 35% at primary healthcare level to 65% in tertiary care institutions. So, a back of the envelope estimate for clinical expenditure related to NCDs could be calculated as follows:

70% of Total Public Health Budget = Rs 114800 crores

53% of above = Rs 60844 crores or Rs 475 per capita on NCDs in public health institutions as the lowest possible estimate of expenditure (the unit cost of treating NCDs is generally higher than communicable diseases but lower than injuries)

In addition to the above from NSSO 71st Round we know that OOPs on NCDs is about Rs. 900 per capita. So, the total expenditure in the country on NCDs may be estimated at Rs 1375 per capita or Rs 176000 crores.

**Conclusion**

To conclude this brief mapping of budgets and expenditures what we can say is that within the public health system and within the existing resource envelope made available NCDs do get a fair share. The problem is that adequate resources as per unit cost
are not available and this leads to distortions in spending which results in poor quality of delivery of care on one hand and a large OOP burden on users even when most services may be free. What we also know is that 70% of OPD and 45% of inpatient OOPs is on medicines and if this single provision can be made available free of cost as per the draft new health policy and the 12th Five Year Plan suggestions then a large part of the burden on households for seeking care can be reduced significantly as also improve the quality and credibility of public health facilities. And of course, what we also need is greater transparency of budget information, including appropriate disag aggregations which can help facilitate better planning and decision making. This is important because NCDs are going to become an even larger share of the healthcare burden in the coming years.

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Notes
2. NSSO 2016: Health in India - NSSO 71st Round, Report no. 574
I grew up with a paranoid fear of impending cancer as there was a high incidence of cancer deaths in my maternal family. Grandfather died of pancreatic and grandmother of uterine cancer. One aunt of breast cancer and four uncles of stomach, lungs, colon and liver secondary to hepatitis-B All of them had pain and indescribable suffering, were in and out of hospitals with helplessness and despair writ on the faces of family members. Nobody knew about palliative care in the 1960s.

Forty years after my clinical exposure to cancer patients as a medical student, one afternoon last year next to my village church at Kottekkad in Thrissur district, I saw a Maruti-Omni van parked with a signage on the side “Kolazhy Gram Panchayat Palliative Care Programme” in memory of the late father of the panchayat vice president. There was a driver and a staff nurse on their mission of visiting patients in their homes with a clearly chalked out itinerary for the day and a route chart. Usual medical equipment like, stethoscope, B.P.apparatus, thermometer, gloves, enema can, medicines, syringes, needles etc. are there. The vehicle is donated by the vice president, fuel and salary cost met out of the allocated budget from the panchayat. The families welcome them with a smile; receive instructions and advices regarding back care and bladder care, breathing exercises, active and passive physiotherapy, timely medications, appropriate feeding, management of visitors etc. Above all they learn the right attitude to patients and their peculiar behaviours, complaint and demands. This adds quality of life to the months and years of life of patients at the “setting sun” phase. It is really extending hospital care to their own homes, bringing down out of pocket expenses of repeated hospitalisation to the lower and middle class families drastically. There is a monthly planning and review meeting by the Medical Officer of the PHC. Once in three months the project monitoring committee assesses the progress of activities. There are 450 registered beneficiaries and 150 of them are provided regular domiciliary care. They have an annual convention of beneficiaries also. Kolazhy Gram Panchayat under Puzhakkal block allotted Rs.5 Lakhs for running of the programme. It is the first such to undertake palliative care in Thrissur district.

Similar community based and community owned palliative care programmes are running in many gram panchayats and municipalities in Kerala. What was started as an extension of hospital based care by anaesthetist and medico social workers of medical colleges of Kerala in Kozhikode, Trivandrum and Thrissur has extended beyond the hospitals to communities.

A novelist, writer and Gandhian philosopher Dr. K. Aravindakshan along with many retired bank employees and teachers of town are now devoting their full time for palliative care. The anaesthetists and pioneer doctors in Thrissur Municipal Corporation had registered a Pain and Palliative Care Society way back in 1997. Apart from running both out-patient clinic and inpatient ward they also run a physiotherapy unit and conduct home care visits. Their rehabilitation programme initiated creative steps to rehabilitate 15 families in screen printing and in making of soaps, garments, carry bags, fancy ornaments etc. They are aiming for a home for the orphaned cancer patients.

What is palliative care?

It is any care that alleviates symptoms of the primary disease or side effects of its treatment, whether or not there is hope of a cure by other means. This area of healthcare focuses on relieving and preventing the suffering of patients. Quite a noble task! Now a day, it is being used in relation to chronic and progressive pulmonary disorders, neurological disorders, stroke, renal failures, chronic heart diseases, HIV/AIDS, not necessarily and beyond cancer. WHO defines it as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems-physical, psycho-social and spiritual.”

Palliative medicine utilizes a multidisciplinary approach to patient care, relying on input from physicians, nurses, pharmacists, chaplains, social workers, psychologists and other allied health professionals in formulating a plan of care to relieve suffering in all areas of a patient's life. This approach allows the team to address physical, emotional, spiritual and social concerns that arise with advanced illness. Patient's quality of life has increased during the last two decades by this concerted effort in palliative care. It is appropriate at any age and at any stage in a serious illness and can be provided along
with curative therapies, such as chemotherapy or radiation therapy. Palliative care in its philosophy regards death as a normal end process in life, never hasten nor postpone death but enhances quality of whatever life span that is left. It uses a team approach to address the needs of patients and their families, helping the patient to be active and families to cope.

Any medication or treatment that can relieve symptoms, not necessarily cure the disease or underlying cause is a palliative medication e.g.: medicines for control nausea and vomiting during chemotherapy or morphine for pain due to crushing of nerve roots due to secondary growth of cancer.

**Implementation of a policy for pain and palliative care in Kerala**

Government of Kerala declared a policy for Pain and Palliative Care in 2008 and brought out a circular regarding guidelines to implement the policy (66373/DA1 dated 02/11/2009) with detailed explanations (71179/DA1 dated 22/02/2010). Based on the experience of implementation of the activities for two years, it had come out with a revised order 228/2012/Local Self Government, dated 23/08/2012 under 12th Five-year Plan. This administrative direction with technical leadership and funding support, palliative care has become a social revolution in Kerala, very much community based and a family centered care and support for terminally ill and bed ridden from a hospital or old age home care. Every municipal corporation, town municipality and gram panchayat take pride in their palliative care projects.

Under the policy, primary palliative care system is a mandatory project for all local self government bodies. As a preliminary step, they must convene a meeting of motivated volunteers and grass root level government functionaries and from among them form a team for home care. The team members then will undergo training on the aims and objectives of the project and its daily operational tasks and co-ordination. The team members will undertake a survey to identify deserving beneficiaries for the primary list. Then a situation analysis of the consolidated primary list of eligible beneficiaries and their needs vis a vis scope of services that can be provided will be undertaken with the guidance of technical and managerial experts. A 15-member Palliative Care Management Committee will be formed and they will review the recommendations arising out of the Situation analysis. The PCMC meet every three months. How many home care days are required per month is based on the number of eligible beneficiaries and the type of needs they have as per the assessment made by the Community Nurse. Approximately one hundred thousand populations require one home care team.

Ernakulum District hospital under the Kochi Corporation area has a palliative care unit which started 8 years ago now coordinates 100 primary care Units in gram panchayats and urban wards, secondary care units in block and taluka level and tertiary care unit at the district hospital. National Health Mission allocated Rs.46 lakhs and state government Rs.7.5 Lakhs. The municipal corporation provides material supply like water bed, air beds and cushions, commode, walker, walking sticks, wheelchair, spectacles, pampers, under-pads etc. But the sign of public involvement is the generous contribution of about Rs.10 Lakhs and the remarkable volunteer team motivated to identify, regularly visit the deserving beneficiaries and support by all means, emotionally and even financially.

Neighbourhood volunteers are the back bone of the programme. They are of all types, housewives, teachers, retired persons from banks, factories, government service, Kudumbashree members, self Help groups, college students especially of MSW, MA-sociology, pharmacy, etc. anganwadi workers, ASHA and ward members also join the team. They are given a three-day’s orientation before accompanying the home visit team from the hospital. Every second Saturday there is a centre level review and sharing of experiences. There is provision for periodical refresher trainings also. The State Resource Centre in palliative care attached to Institute of Palliative Medicine, Kozhikode recognizes training centres at various locations in the state which provides three basic certificate courses in palliative care Nursing.

**What do they do?**

The main activity is home visits for which a route chart is made for each day in advance. The visiting team consist of a nurse, assistant and a driver along with trained local volunteers. Occasionally a doctor from the PHC or CHC accompanies. Practically it is possible only to visit around 8 houses per day without compromising quality in care.

Apart from advices and training of family members in giving back care, physiotherapy, massage, toilet care, bath, sponging and slow feeding with patience they provide supply items like condoms, pampers, pads etc. Medicines based on prescriptions are provided to each beneficiary on weekly basis every Thursday. Now the staff nurses are confident of giving
domiciliary care for colostomy, gastro-jejunostomy and tracheostomy patients. Each visit is looked forward to by paralysed patients as an occasion "just to chat" especially when the family members are less interested in engaging them in family discussion. There is so much uninhibited "openness in sharing" and this mutual trust they both enjoy. Some volunteers interact even beyond the routine scope of work and schedule. They mobilise dry ration for poor families, search for livelihood and daily wages, rehabilitation and occupational engagements, find sponsors for their children's education, distributing food kits especially during festivals, facilitate pension withdrawal, availing benefits of other schemes like Annapoorna, Antyodaya, Ashraya etc. They even convince some auto rickshaw drivers' union to provide free transport to hospitals.

Joyce a volunteer women activist and Kudumbashree member was informed of a lady locked up in room uncared for by son and daughter-in-law with minimal support feeding. She overcame the resistance of the family and forced herself to open the doors and see this lady with matted hair stinking of purulent discharge from bed sores and soiled with excreta. Changing her saree to a night gown, Joyce gave the old lady an oil bath, dressed her up with fresh clothes, combed her hair and changed her mattress and bed linen to the amazement of neighbours and embarrassment of family members. Joyce's husband and two school going sons are supportive of her leadership and involvement in caring for the neglected in her ward.

Sheeba, a staff nurse in Ernakulum district team is deeply involved in her mission as she feels it as an extension of same service which she offered to her loving husband who died of cancer a few years ago. She feels her professional empathy often slips to an emotional attachment to some of the neglected and suffering patients. This is a human weakness she admits. Like many volunteers, the contractual staff members of the team, also derive a lot of personal satisfaction from their work. That makes them continue in their mission, in spite non-payment of salaries for the past eight months due to bureaucratic delay. At times some of the over demanding local leaders try to dominate and interfere in their smooth work schedule. They take it as challenge, but never give up. The only type of families who do not like a mobile team coming to their house and it is an intrusion to their privacy are those who still keep diagnosis of a cancer a secret from neighbours because of its stigma. Same goes with HIV positive patients.

Conclusion

Caring for a dying relative is quite demanding. There is a need for interventions designed to improve support for caregivers at home. Family caregivers have acknowledged some unmet needs associated with their caregiver role.

Home-based palliative care giving has resulted in life-enriching experiences for many caregivers. Shifts toward providing care closer to home not only changed caregivers, but also changed the home setting where palliative care was provided. This community based model can be replicated in many other states with some funding from National Health Mission and technical guidance.

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Chronicles from Central India is not an easy book to introduce in a couple of pages. This is because it reflects the huge, rich experience and in-depth study of rural health and health care as seen in parts of Central India by Jan Swasthya Sahyog (JSS). JSS is well known in the MFC circle. This group with headquarters in Bilaspur district has been providing for the last 15 years, quality health care almost, if not fully, free to thousands of people every year. JSS gets patients from almost 2500 villages in north western Chhattisgarh and south eastern Madhya Pradesh. The organization is also involved in various levels of health training, observational research on important health problems of the rural poor, and in public advocacy to improve the health status of the marginalized rural communities. The book is packed with interesting information, observations, and insights. Secondly, it has different, discrete sections. It is therefore difficult to give in brief a gist of what it contains, without losing its flavour.

This book tries to prepare a very innovative health-map of India which brings forth in an effective and graphic way, the spectrum of diseases which afflict the rural poor. It is not a comprehensive volume nor does it aim to be. Out of a large spectrum of ailments seen in the largely tribal population in rural areas in central India, JSS has selected some 50 common illnesses which the JSS team encounters commonly in its hospital and health centres. Out of these, this volume, probably a first of a series, describes 27 odd illnesses. JSS considers this book to be an Atlas because as explained in the introduction to the book, “it tells us about the journey of illnesses through time and includes graphics preferentially to make a point about the causes. This tries to capture the ills in rural health in its right coordinates. For example, tuberculosis in Delhi is not the same in rural Bilaspur or many other rural areas. It is thus important to reposition the understanding of illnesses.”

The book has five parts. The first part consists of narratives of 27 common ailments - narratives of a certain kind. Each narrative starts with a real-life story which describes briefly, the living conditions of a patient, the progress of the symptoms and the disease s/he suffers from, the family's response to it, including attempts to seek help from some bhat or traditional healer and the family's encounter with the public health system which sometimes leads to an "encounter death". These "encounter deaths" are due to inaccessibility of the public health system, and its gross negligence, callousness as well as incompetence. The primary health centres and even the CHCs are by and large hardly of any use in serious ailments and situations. These features of the Public Health System seem to be widespread in rural central India where even private health care, or anything beyond quackery, is hardly available. The book describes how a poor villager who manages, if at all, to reach a high quality centre like the All India Institute of Medical Sciences in Delhi, is likely to be choked by the faceless, bureaucratic system there and is likely to succumb to death before being taken up for treatment by an appropriate expert.

Each of these tragic stories is heart-breaking indeed. In case after case we read how a people ground to dust by poverty, deprivation, and accompanying superstitions/misconceptions, and compounded by almost non-existent or inappropriate health care, face immense hardships - a situation that many a time results in deaths, all of which can be avoided. Even simple malaria many times presents here in its pernicious form and despite the National Malaria Control Programme, the rural poor in this part of India do not get appropriate care in the public health system, causing unnecessary morbidity and even deaths. But the public health system feigns ignorance of these tragic deaths! Thus, this book tells us: “In the year 2010 Chhattisgarh and some other central Indian states witnessed a major epidemic of malaria with arguably over a few thousand deaths, of which at least 200 were reported by us from a single development block in the Bilaspur district. However, the official state-wide count of deaths due to malaria stood at 42!”

These numbers are eye openers but equally disturbing are the graphic narratives, The heart-breaking stories, coming one after another, leaves one dumbfounded and benumbed. For example, take the case of Dhansaye who lived with his wife and 3 children in the city of Bilaspur and earned a livelihood by driving a cycle-rickshaw. He brought home up to Rs. 75 a day. The family paid a monthly rent of Rs.400 and an electricity bill of Rs.100 and lived mainly on 35 kg of grain (15 kg wheat + 20 kg rice) bought at a BPL price of Rs 2 per kg from the ration shop. He was just 43 kg in May 2010 when he was caring for his sister who was admitted with TB in JSS. In the next ten months he himself lost another 8 kg. Despite such clear signs, a major medical institution in Bilaspur had failed to diagnose his tuberculosis. "I asked the doctor to take a better look since my sister had already fought with TB a few months ago. But the doctor shooed me away," Dhansaye said with resignation. Dhansaye spent Rs.550 buying medicines which were completely useless for his condition.
Each of these stories is accompanied by very apt, revealing, coloured photographs of the patient's living and health condition. Each narrative also contains a couple of paragraphs about the clinical picture and appropriate treatment. These lines would be quite useful to a basic doctor or trained health worker to diagnose, treat and advise about each of these ailments. In addition, there are a few paragraphs on the social epidemiology and social aetiology of each of these ailments. This is because JSS does not limit itself to clinical medicine alone. It delves into socio-economic conditions which explain the social causes and social distribution of diseases. Thus, about malaria, the book draws attention to the poignant fact that when we map the worst-affected states we also map the poorest states. Ironically, these states are rich in natural resources even as the people are desperately poor.

Hjarkhand, Chhattisgarh, Madhya Pradesh, Orissa and Assam are high-burden states for falciparum malaria. Further, the government's own data suggests that of all the falciparum malaria episodes that happen, 50% of them happen among the tribals, who happen to be only 8% of the country's population and they account for over 90% of those who die due to malaria. These narratives also draw connections between socio-economic factors and the government policies with the social epidemiology of India. After going through this first part one cannot agree more with the book's contention that "illnesses are the biological embodiments of deprivation."

The second part of the book consists of one page "picture stories", 46 of them, which mostly depict the important ailments seen in JSS clinics and hospital. About half the page is occupied by one or two photographs, in most cases of patient's affected part(s). The rest of the page containsa short description in three-four paragraphs about the disease and its clinical presentation. Unlike in the first part, there is no other information. But yet these one page stories are quite revealing, they reveal what kinds of clinical presentations are seen in the deprived rural population because of the peculiar social conditions of the rural poor.

The third part, "The Blogs", stretching up to about 60 pages, consists of blogs and articles. The blogs are reflections of some of the doctors who worked in JSS. In these blogs they creatively reflect on and share their dilemmas, frustrations, experiences. Then there are analytical articles reflections, by Yogesh Jain and colleagues about the nature, extent and distribution of diseases they saw in rural Chhattisgarh. Among other things, these articles reflect on the stark difference between the presentations of diseases in urban middle class Indians with the presentations in poor, tribal population. For example, in urban Mumbai among newly diagnosed TB patients the proportion of multi-drug resistant (MDR) TB was found to be as high as 30% and it is far higher, 67%, among those who have been treated before. Compared to this, the JSS team found that in Chhattisgarh 3% of the newly diagnosed patients and 16.1% patients treated before showed MDR TB. In rural Chhattisgarh the central problem about TB is different - very high levels of undernourishment among TB patients. JSS found that among TB patients,80% of women and 67% of men had moderate-to-severe undernutrition (BMI<17 kg/m2). Similarly diabetes, among the rural, tribal population, presents quite differently than among the people in Western countries and in middle class urban Indians. In Chhattisgarh JSS found that firstly diabetes is not uncommon among the rural poor. Secondly, though diabetes is supposed to be the disease of the overweight, sedentary population, the proportion of "thin diabetics" was very high among the rural poor. The median BMI of tribals with diabetes was 16.3 and 16.4 kg/m2, respectively for men and women. Over 70% of the diabetics had BMI less than 18.5. This is in contrast with the usual association between obesity and diabetes as seen in the West and among the Indian urban middle class. These articles point out that these and other such findings have important implications for the diagnosis, treatment and prevention of these conditions.

The fourth part of the book - "Maps of Inequity" - is as interesting and novel as the first three parts. It consists of a series of "illness-maps" of India in which each map depicts the geographical distribution of a disease in a peculiar, visually effective way. In this map, the area occupied by each state is proportional to the prevalence of the disease in question in that state. For example, in the map which depicts prevalence of malaria in India, the area occupied by Tripura, Orissa, Chhattisgarh and West Bengal, the four high prevalence states, occupy much more space compared to the area occupied by states with lower prevalence. Therefore, even a glance at this map tells us graphically the geographical distribution of malaria in India.

Use of more area or less area to depict geographical distribution in a country's map, of social conditions (like extent of poverty for example) is not new. In anatomy books this technique of mapping has been used to show for example, how extremely sensitive parts like the thumb have proportionately very high presence in the sensorium of the brain compared to other organs. However, I have not seen any Indian book on health using this technique to depict comparative prevalence of diseases in different states. My compliments to JSS for using this method in this book. Though these maps in this book are multi-coloured, this method of mapping has a particular advantage when multicolour printing is done, whereas in mono-colour printing, there is limited scope to graphically depict in a country's map, high or low prevalence of a disease. I hope, other health books in India which include depiction of geographical distribution of diseases in India will increasingly use this technique.

The above is only a brief introduction meant to arouse interest in this very important book among mfc bulletin readers with the hope that one of the readers will be prompted to write a detailed, critical review of this book to give justice to its rich contents!

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Let me begin this review of the book Dissenting Diagnosis by declaring up front my conflict of interest. Both the authors of the book are good friends whom I have known for many years; and I am one of the 78 doctors on whose interviews the book is based.

This book has two parts. Part One, "Diagnosing the Malady", is constructed on a series of interviews with a group of "practising" doctors. These were conducted as part of a study done by the authors. Summary of the responses was first published in Marathi and then as a smaller booklet in English. This book is an enlarged version with part two added which are the views of the authors on the subject.

Part Two, "Initiating the Cure", is in some ways easy to review and therefore I shall deal with it first. In this section, the authors have highlighted and summarised many of the fault lines of Indian health care especially the private sector. They also offer solutions including moving towards universal health care and establishing citizen doctor forums. Most of the material here is what we already know. For the readers of mfc bulletin it is certainly familiar territory. In fact, they may find it a tad simplistic. If on the other hand, it is read by an average citizen reader they may find it too analytical. I shudder at the thought of ever being asked to give a prescription for the wrongs of Indian health care in 70 to 80 pages. In that sense I sympathise with the authors who attempt to do so.

One interesting chapter in Part Two is called "How Can I Recognise a Rational, Ethical doctor?" The authors propose a few criteria. For example, they say that "A rational, ethical doctor does not pretend to know everything," and a "rational, ethical doctor does not advise additional investigations and procedures, due to demands from the patient" and "a rational, ethical doctor does not mind being asked questions by the patient." I found this chapter particularly disturbing partly because it is accurate but also because one would have thought that the criteria described by the authors are germane to the practice of medicine. That they have to be specially stated in this manner is a grim reminder of where we are. In the same chapter, they also give us an interesting classification of four types of doctor-patient relationships. They recommend that we should move from the "paternalistic"", "informative" types to the "interpretive", "deliberative" types. Alas they do not tell us who will do this and whether it will happen ever, independent of larger societal relations and hierarchies. To be fair, these are complex questions and deserve deeper discussion which is difficult in a book of this size. However one cannot help feeling that the authors while touching upon some interesting ideas have lost the opportunity to expand on them.

Now I shift to Part One, which really is the book's core and makes it rather unique. This part is a summary of transcripts of personal interviews with 78 doctors, a large majority from the private sector, and specialists at that. They were asked nine questions largely relating to the current practice of medicine in India. Some of them were leading questions. For example, sample this: "Can you give example of inflated rates being charged for medical services?" Of course, there are problems with such questions. What is inflated? What is the standard?

But this part of the book will naturally interest the lay reader and the media, which it already has. After all, these are practising doctors being candid about their secrets in print. Again though, to the readers of MFC there may not be many new revelations: hospitals fixing targets, cuts and commissions to doctors, unnecessary operations, etc., are now well known. But I guess the value of this part lies in the fact that these
are doctors on record corroborating in the public domain many areas that citizens suspected and experienced. Unnecessary hysterectomies, saline drips, inducement from pharma companies, false advertisements - it is all there from the horses' mouth. Even so the gory details can be revealing and shocking if true. For example, in the first chapter of the book is an interview with Dr Aig aoakar, a well-respected, senior physician from Mumbai, who talks about how an MD in pathology gives a fake report of high blood sugar to oblige a general practitioner so that the patient becomes a lifelong customer with a diagnosis of diabetes. Or even worse, on page 55, a surgeon relates how the removal of pus from the abdomen is purposely delayed in a hospital as it had a policy of charging double rates in the second week of admission. I find this difficult to believe and I hope it is not true.

From a purist research perspective, is this an accurate method of knowing what the medical profession in India currently thinks? The answer is obviously no because this bunch of doctors was selected from "contacts" in the ethics and people's health movement, and hence very likely to be a part of the miniscule minority who is critical and reflective. To be fair, the authors acknowledge this flaw. I also have a problem with the refusal of a majority of those interviewed to be named. While acknowledging the fear and isolation that they feel, this does take away a little from the value of these interviews. Also, the authors do not tell us the age profile of those interviewed but I suspect they are not young doctors. It would be important to know what those in their early years feel. Maybe someone else can do that research but this time with a less self-selected/biased sample and with less leading questions.

More significant for me though is the fact that these 78 doctors do not really accurately represent the average doctor's thought process and views. If one reads the book with a certain naiveté it may raise false hopes that there are many doctors critical of the current system and desperately want change. That is wishful thinking.

I think there is a significant number who have a lot of stake, and support the way the system currently works. Though it may not be a conscious, deliberate act, they certainly do not see anything fundamentally wrong in the direction in which market based medicine is going. In moments of professional crisis, they may be critical but as a collective there is very little critique of the dangers of unregulated practice of medicine in the private sector. On the contrary, the massive expansion of private specialty medicine is seen by many as an exciting entrepreneurial opportunity!

Historically, there has been a robust and long tradition of whistle blowing by medical professionals across the world. This has usually been in the form of interesting first person accounts by doctors who have been disgusted with the neglect, by their colleagues, of professional ethics and values, and spilled the beans. One example was Arun Limaye's autobiographical work in Marathi, Chloroform, which was published in 1978. An mfc bulletin issue circa 1978 has a one paragraph review of the book! It chides Limaye for not doing enough "ideological" analysis. Bernard Lown's reflective book The Lost Art of Healing is partly in this genre but more analytical. A recent book by a cardiologist, Sandeep Jauhar, Doctored, is a searing first person account of big medicine in the USA. I wonder whether part one of the book under review partly qualifies as whistle blowing.

So while the book has been welcomed by the media and middle class citizen groups, for those who are interested in something more than what has been known for the last few decades there are not many fresh insights on offer here. I suspect this has something to do with the fact that the book was an afterthought, and piggybacks on what started as a rather simple, if not simplistic, research exercise.

In 1997, a book called Market Medicine and Malpractice was edited by three authors, Amar Jesani, P.C.Singhi and Padma Prakash, the first and last hard core MFCites. It was perhaps one of the first books from India, which made the critical connection between "malpractice" and the "market". This book was partly based on the experience of the mfc Bombay group, which engaged with cases of medical malpractice. Fifteen years later, Arun Gadre and Abhay Shukla, though in a different form and style, essentially say the same thing. The difference is that they now have a big publisher, bigger media coverage and the power of social media to help spread the word. This book therefore has reached a larger audience. That is a good thing.

Gadre and Shukla are primarily community health specialists who through this book have chosen to enter an arena, which some of us at the Indian Journal of Medical Ethics, have tried to engage and grapple with for almost 25 years. If the authors have indeed caught the book writing bug and would like to write more I would rather read their dissenting diagnosis, if it were to come in print, on primary health care, health rights, equity and health policy. I feel they may offer more solid and original insights there. In the meanwhile, market based medicine in India though critically ill is unlikely to easily accept the dissenting diagnosis that this book offers. The patient is currently under the thrill of the dominant diagnosis.

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Reflections and learnings from a journey in community health

John Oommen (On behalf of the Mitra Community Health Team)

It is now 23 years since I joined the Mitra program of the Christian Hospital, Bissamcuttack (CHB) in a small area outside Bissamcuttack, Odisha. It’s been a good ride: ups and downs, unpredictable and shattering at times, but worthwhile all the way.

CHB is now a 62-year-old, 200-bedded mission hospital situated in one of the most beautiful and vulnerable parts of the country. The Adivasi and Dalit communities form 62% and 17% of the Block’s 90,000 population, though it is fair to say that the tail wags the dog: the power lies with the remaining 21%.

Mitra is the name given to the ongoing, evolving interaction of the hospital with 12,700 people of 53 predominantly-tribal villages between 7 and 30 km from CHB. The work that began mostly as mother & child Care has evolved through the interaction to include:

1. Community based responses to malaria, TB, sickle Cell anemia, hypothyroidism, health care financing, elderly needs, hypertension, chronic renal failure etc.
2. Interventions in education, initially through adult literacy and non-formal education, that has paved the way to the present portfolio, including, MRSK (an adivasi primary school), AQTE (volunteers in dysfunctional government schools), MKB (care for pre-school children), youth fellowships, scholarships etc.
3. The Kuvi Sanskriti Kendra - initiatives to promote and celebrate the Kuvi language and culture
4. A training & resource unit that shares the lessons learnt through training, consultancy and publications

It’s a small population we work with. This is not a project or part-time engagement; it’s an ongoing life-journey together, where the lines between the agency and the community are blurred; and about half the Mitra team members are also members of the Adivasi community.

When we first put together our rudimentary health management information system (HMIS) in 38 villages in 1994-96, the IMR was 201 - 203; the Under 5 mortality rate was 295 - 356 per thousand live-births. One third of our deaths were due to fever. Malaria was rampant and babies were named only if they survived two years.

Much has happened; some through us; much more in spite of us. And today the IMR is around 65 and U5MR around 93. Malaria is now 10 % of deaths. Much distance have we travelled, but we have a long way yet to go for the dream of Health for All.

Over the years, we have learnt many things; unlearnt many too. We will just share here some of wisdom carefully crystallised into seemingly off-the-cuff lines:

The Dream is Health For All; Alma Ata downscaled to the panchayat and village level. People’s Health in People’s Hands. The dream has not changed.

Development is unconsciously defined as making others become like us. That would be a major tragedy. Help the community dream of what they can be. And then help that happen or get out of the way, as needed for the dream to come true.

What you see depends on where you are looking from. Choose to let go and cross over. Develop an "Insider Perspective". Your definition of the zoo depends on which side of the bars you are on.

Use numbers and indicators like milestones, to know if you are going forwards or backwards; not as project targets that you force the community to dance to.

The difference between patient care in a hospital setting and out in the community is like the difference between seeing a tiger in the zoo, and tiger in the forest. You are on his turf. Be respectful, Say Namaskar, Climb a tree.

Three stages in the evolution of our thinking about the community:
We initially think community work is like riding a goat. Get it to go where you want by inducement or shoving; or just pick it up and take it there -- then call it community participation.

After A fails, we look down and realise the community was actually a horse you were riding. There is now a 50-50 chance that you and the horse will go in the same direction.

After one's hair starts greying, one looks down and realises one was actually riding an elephant all this time. We can claim we drove it. But it is actually humouring us. The view is good; just enjoy the ride.

After years of struggle, you realise you cannot really change the world. You can at best allow yourself to be changed. We now realise our role. Our calling is to share the pain of people; to get alongside, merge, share... And in the process, we change, they change and the situation changes. So stop splashing and be still. Just be the change you want to see.

Disclaimer: I am on holiday as I write this, Hence the philosophical, Himalaya-perched tone and viewpoint. To see it like this in the field, in the middle of the busy confusion - ah! that's the challenge.

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