The biopolitics of the diabetes epidemic in India:  A search for perspectives

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# Statement of Problem and Objectives

This proposal is for a project to explore the biopolitical dimensions of diabetes.

**Objectives**

I would like to probe the following questions:

What are the implicit and explicit assumptions made in scientific, public health and clinical discourse on diabetes about individuals and populations who are seen as either at risk or as actual bearers of the disease?

What is the mismatch between these assumptions and actuality of the disease, the life circumstances, limitations and capabilities in the context of clinical care and public health programmes?

What can we understand about the politics and economics of medical care in India from an examination of the mismatch between the assumptions and the reality of the lives of individuals either at risk or afflicted by the disease?

**Conceptual Framework**

In a talk in Brazil, Michel Foucault (1978) had asked a critical question: why was it that people in Europe, after the long medical revolution in antibiotics, anesthesia and surgical procedures, didn’t seem to get any healthier, yet medical expenditures of nations were crossing 10% of the national budget? In his own response, Foucault harked to the pride and humility of the (Latin American) economists who had dared to critically examine mainstream economic theory’s proposals for a classical take off of new economies, and instead propose alternatives that were more suitable to the Third World. He argued that in a similar manner, a critical understanding of medicine must effectively grasp the history of its ‘take off’ in the west with spectacular advances in science and technology, and in institutional practices, but which were coupled to stagnation in well being. The issue was whether in developing countries, the same trajectory should be followed, or some attempt must be made to find new pathways and strategies. This did not mean going back to a concept of ‘health’ that pre-existed modern medicine, rather, finding better and more appropriate ways of taking care of ourselves.

Essaying the directions traced by Foucault’s work Zachariah, Srivatsan and Tharu eds. (2010) proposed in the introduction to their volume *Towards a Critical Medical Practice* that it is necessary to critically conceptualize how the politics and economics of medical care functions in twenty first century India. In this context, it was argued that there was a mismatch between the patient’s need and the solutions proposed both at the clinical and public health level.

What then is the structure of this mismatch?

Biomedical science finds explanations for illnesses (disease categories), and methods of diagnosing and treating them. It claims to be the scientific norm of medical diagnosis and treatment worldwide. However, medical research, diagnoses and treatments are typically a) commissioned by nation-states’ health budgets with their economic constraints that are neither applicable nor sensible at the individual level; and b) assume conditions of living, education and follow up health care that avail in wealthier cultures and more technically developed economies. Cures are inappropriate, due to culturally biased research that is employed to solve the problem. Treatment is also expensive due to recovery of huge profits in the name of research expenditure. These forms of medicine become unaffordable except to governmental or philanthropically funded health care programmes. Such medical treatments are then forced in Third World conditions as the most scientific and effective ones by protocols, evidence based medicine and business interests. At the same time, there is a historical shift from governmental welfare to neoliberal minimalism, which forces the patient and family to confront gargantuan costs. Thus many dimensions of inappropriateness interfere with the cure or management of the diseases under conditions that differ extensively from those under which the treatments were developed. In many situations doctors have strategies to circumvent the mismatch between the treatment protocols, ideal conditions and practice. However the paradigm of modern medicine and its support by the medical industry are so strong that these critical practices, and the flaws, failures and wastages of inappropriate, erroneously universalized medical care are ignored.

Public health with this kind of a biomedical perspective spends much money on programmes that are designed as one-way processes of providing preventive and curative medical care for large populations. Such programmes are handicapped by limited perspectives, minimalist population models and poor feedback mechanisms to study ongoing effectiveness. They are often driven by pharmaceutical interest lobbies who want a large volume single point sale of medicines.

What drives biomedical science and the medical institution, not in cases where something is done in bad faith (unnecessary immunization, catastrophic expenditure by patients in corporate hospitals), or governmental negligence (absent primary health care), but with the best intentions? Diabetes provides a complex case for such a study where the public health intention and clinical or research effort are driven ostensibly by a genuine effort to cure disease and ensure the health of populations.

# Problem description: emergent diabetes epidemic

Public health literature (e.g., Ramachandran et.al. 2010) records a rising epidemic of diabetes in India (prevalence of known diabetes is 5.6% among urban populations—ibid: 7; also see Madaan et. al. 2014 for a local study of Sonepat, Haryana). This is part of a rise in chronic, degenerative diseases[[1]](#footnote-2), seen as an index of what is called an epidemiological transition (Omran 1971) from an underdeveloped economy to a developing one. It was originally argued by Omran that this transition is marked by an increased life expectancy accompanied by a rise in degenerative diseases and a fall of infectious diseases[[2]](#footnote-3) due to better living conditions. The pathological condition that is mapped on to this transition is abdominal obesity and increased insulin resistance that characterizes type 2 diabetes (see appendix for an elementary description of types of diabetes). However, in India (and other third world countries) the emergence of chronic disease epidemics like heart disease and diabetes is not paralleled by any drastic fall in prevalence of infectious diseases (See e.g., Global Burden of Disease Report 2010). The emerging epidemiological profile of diabetes in India indicates that the disease affects the poor to a significant extent (Bhojani et. al. 2013). Also the age profile of diabetes in India is different: unlike in the west where diabetics come from aging populations, in India they come from the young and middle aged populations (Ramachandran et. al. 2010: 7). A recent study (Das 2012: 381-90) has also suggested that a significant percentage of adult diabetics in India are lean unlike the majority of obese diabetics in developed countries. Indian diabetics may thus have social, anthropometric and clinical profiles that differ from those found among similar patients in the West. On the other hand it has been discovered in the 1990s, type 1 diabetes which emerges at infancy due to autoimmune disorders also manifests itself as latent autoimmune diabetes in adults [LADA], (Tripathy & Groop 2012: 141). Thus the clean categorization of diabetes into type 1 and type 2 (leaving gestational diabetes out of the picture) is complicated in the current literature. Overall there is an indication that diabetes is not an affliction restricted to the wealthy in the emerging crisis of the disease.

The WHO status report on non-communicable diseases (2010) lists diabetes alongside cancer and heart disease as one of the major emerging killers in the developing world. The risk factors for NCDs as a whole are smoking, a sedentary life style, drinking, poor quality diet and obesity. The report points to the need for control of blood glucose as a specific problem to be addressed in the battle against diabetes.

The Global Burden of Disease, Risk Factors and Injuries Study has published a paper on the global trends in diabetes (Danaei et.al 2010) which maps the rising epidemiological profile of diabetes (and impaired fasting glucose tolerance – a measure of diabetes risk) across the world. This report too stresses the need for strategies to ensure control of blood glucose among populations. However, the paper argues that since drug therapy for glycemic (blood glucose) control as a preventive measure is still at the investigative stage, most developing countries will have to improve strategies to detect diabetes early and manage it effectively.

And yet a recent study (Yudkin & Montori 2014) indicates that the concept of pre-diabetes (marked by a fasting blood sugar of 100-125 mg/dl and post lunch blood sugar of 140-199 mg/dl) which was used to determine the heightened risk of diabetes is probably not helpful in handling the public health and clinical aspects of the problem. This was because of the lifelong marking of the patient, and the fact that a significant percentage of pre-diabetics revert to normal sugar levels. It is also because the treatment for pre-diabetes is the same as that for diabetes, and the new norm simply increases the populations under medication, with no effect on the number who ultimately acquire the full blown disease. This is of fundamental importance in India because it will affect both public health programmes and thousands of clinical diagnoses across the country. It is also likely to have a deterrent effect on the development of large volume, money spinning pharmaceutical products designed to address pre-diabetes.

 These reports barely touch on the multidimensional structure of the public health, sociological problem of the disease and the transformation of public health effort required to ensure that a patient’s life is more productive and of a higher quality.

I am currently thinking about the possibility of studying this problem from different but related perspectives:

# Diabetes as a public health issue

The emergence of chronic diseases like diabetes as a public health problem marks a new era in the policy and administration of public health in India.

Diabetes as a public health problem needs prolonged engagement with the patient in medication, diet and lived culture of the patient. Given the variety of life patterns and cultural differences due to caste and community, the treatment of diabetes as a public health problem requires a much more sophisticated, diversified and sustained health engagement process than any disease hitherto. I argue in the following paragraphs that such a programme would demand a paradigm for public health that differs from the one based on biomedical models of the disease and the patient.

In the first three decades after independence, public health policy was largely focused on the control or elimination of infectious diseases (malaria, cholera, whooping cough, etc.). Such programmes largely consisted of sporadic, event based interventions to control disease (e.g., outbreaks of cholera) on the one hand, and strategic warlike initiatives (e.g., immunization against polio) to prevent disease on the other. Thus you had teams of public health workers fanning out into the countryside to provide vaccinations, polio immunization etc. Some of these classical programmes addressed causative external factors like mosquito control in the malaria programme, which had to undertake fumigation and disinfect stagnant water in habitations. Others were forced to contend with questions of infected water supply as in the case of cholera. However diet and exercise were rarely a major consideration in these programmes.

Tuberculosis and leprosy control were two early public health initiatives of a different kind that have needed special programmes of extended engagement with patients in the public health system. This was because in both these diseases, prevention of spread was predicated on the control of prevalence, i.e., the only way to ensure that the infectious spread of the disease was limited was to treat it in sick populations. Both these diseases needed long term chemotherapeutic interventions, typically over a year. The moment extended intervention was required, the structure of public health changed from an acute (short term) engagement to a prolonged one. The additional challenge was with TB eradication. Before the 1950s the TB programme made serious attempts to engage with the problem of emaciation and thence with the diet of the patients. However, with the advent of antibiotics for TB, public health priority was given to antibiotic treatment rather than to nutrition (Bhargava 2012:53). The adoption of the WHO DOTS programme, which follows a strategy of ensuring short course treatment observed directly by a peer, is a prime example of this withdrawal of interest from nutrition (Bhargava et.al. 2013: 8). It also marks the beginning of a new kind of public health strategy that makes allies of community members in treatment of the disease. The limited success of the DOTS chemotherapy programme has resulted in a resurgence of interest in the problem of nutrition.

Another important segment of public health geared to bringing down infant mortality and raising childhood survival rates has been the ICDS, which includes a major component to address malnutrition. The ICDS programme and its nutritional component have been criticized for the ineffectiveness of what could have been an exemplary model of public health (Sundararaman, 2006). Sundararaman has argued that the ICDS as a public health programme has failed in the development of community ownership of the programme with respect to child nutrition, the poor development of community institutions to run the programme or guide it with adequate feedback from the field.

Thus, tuberculosis and maternal and child mortality programmes have had varying needs to engage with food culture and community, and yet the emerging record of these public health programmes in this cultural domain is not encouraging.

What are the underlying changes required in the public health system to deal with a problem of diabetes? It would seem as if the concept and design of public health thought would have to undertake an overhaul of its notion of its ‘target population’ and reconfigure it in terms of some sort of community. However, given the complexity of real world communities in India (think of caste proscriptions, community discrimination, social apathy), this reconfiguration is likely to pose a major challenge.

# Speculations regarding the epidemiology of diabetes in India

Orthodox theory had it that type 2 diabetes is caused by a combination of genetic and environmental factors (NDIC 2011). Among different genetic hypotheses, the earliest was the ‘thrifty gene hypothesis’ (Neel 1962) which influentially proposed that there was a primitive survival advantage in a genotype that was able to extract energy from food efficiently and store excesses as fat reserves for use in times of hunger. With the epidemiological transition and increasing well being, changes in the environment convert this genetic advantage of thrift into a liability. Thrift and storage of residual energy sources as fat lead to abdominal obesity, which is theoretically a biochemical factor in the development of insulin resistance and type 2 diabetes. Thus, before the 1990s the thrifty gene coupled with the epidemiological transition was a strong explanatory candidate for the increase in prevalence of diabetes in modern India.

In 1991 DJP Barker (Hale et. al. 1991) offered a different hypothesis for diabetes based on extensive empirical studies of the correlation between poor nourishment during fetal and infant stages, and adult onset diabetes measured at age 64. A nutritional crisis during the critical stages of organ development in the fetal and infant stages could lead to programmed, permanent weaknesses in the functioning of the pancreas in the production of insulin (in addition to many other conditions), leading to diabetes at a later stage. Barker’s Hypothesis has implications for public health. Since type 2 diabetes is a result of fetal programming, it would be necessary to strengthen the mother and child health care programmes to ensure that nutritional insult during these formative stages is eliminated. In this epidemiological model of the disease, it is not only insulin resistance, but also the relative deficiency of the pancreas in insulin production that is seen as the pathological correlate. This broad hypothesis drives much current research, e.g., Ruchat et.al. (2013), CS Yajnik (2010), Heijmann et.al. (2008), Ferrannini (1998).

In parallel, S Das (2012) has argued that there is a specific type of lean diabetes in India, a sub-category of type 2 diabetes with distinct features. His argument has been that the anthropometric profile of a majority of diabetics in India is lean, rather than obese. Further he has argued that the clinical complications profile differs from that presented by the patients who align with the canonical western model. How does this theory of prevalence of lean diabetics link up with the earlier hypotheses of epidemiology and population level causation mentioned in the previous paragraphs? It also remains to be seen through scaling up investigations whether this hypothesis corresponds better to conditions of the patients in India.

As mentioned earlier, recent investigations suggest that type 1 diabetes which is an autoimmune problem doesn’t occur always during infancy. There are several cases of autoimmune diabetes that show up during adolescence and early adult life, and progress slowly. This kind of diabetes has been named Latent Autoimmune Diabetes in Adults [LADA] (Yudkin & Montori 2014).

Each of these hypotheses of diabetes prevalence uses an implicit biomedical concept of the patient as an individualized risk bearing organism in a population, and this concept has specific interactions with how the disease is handled by clinical settings and public health systems.

# ****Diabetes as a sociological problem****

Veena Shatrugna[[3]](#footnote-4) and I have coauthored a small preliminary study (Srivatsan and Shatrugna 2014) of the sociological and cultural problems of diabetes, which is in some sense a precursor to this current project. We found that there were several aspects of diabetes that were barely understood by the biomedical paradigm. What follows is based on these initial observations.

### Food and culture

Diabetes is understood as a physiological failure in the transportation of glucose into cells leading to high blood glucose levels (see appendix). In lived terms, managing this problem (diabetes is incurable) involves a) spreading out and control of food quantity across several meals to ensure normal levels of blood glucose; b) a change in the quality and variety of food eaten to ensure lessened load on insulin production; often medication to augment insulin availability in the blood stream; c) exercise to burn off the glucose and keep blood levels under control. All these mean that the physiological failure translates into a lived problem of food and exercise. The problem is exacerbated by the consumption of large quantities of cereals in three concentrated meals that characterizes vegetarian diets either due to choice or circumstance, and a sedentary lifestyle. Such consumption, for either reason, becomes part of habit, culture or affordability. When a diabetic condition calls for a shift in a diet pattern away from refined carbohydrates (e.g., polished rice, fine wheat, sugar) the battle against the disease is complicated by a battle against food habit and culture. Our preliminary study has seen tentative evidence that the problem of dietary control is worsened by the tendency of doctors who treat diabetics to give advice that is sometimes conflicting, sometimes wrong, and sometimes simply leaving the patients to cope by themselves. In addition, we saw that such advice was rarely attentive to the food cultures of the patients and resources they brought to the table. These problems we saw had led to dietary chaos and a frantic scramble to cope with the daily effects of the disease and its control.

### Family difficulties and social stigma

Our preliminary study indicates that there is a dislocation of family stability, disruption of life schedules and a severe constraint of economic capability that occur when patients have diabetes. These have profound effects especially among families that are just making a transition from extreme poverty to slightly better and economically sounder living. Our study found that it is likely that the expenditure and stress caused by the treatment of diabetes could make the family slide back into a condition of poverty. The loss of productive lives due to diabetes could well be exacerbated by the difficulties families of patients confront on a daily basis throughout the life of the patient. All these issues have been confirmed by the International Diabetes Foundation Factsheet (2010) on what diabetes does to neutralize Millennium Development Goals for Global Health.

The second indication we found in our study was that a social stigma attaches to this disease due to its reputation for genetic transmission. The most serious aspect of this stigma is that people do not want marriages into families with diabetics. There was more than one respondent in the preliminary study who either directly or implicitly pointed to the stigma that diabetes represents. Our tentative finding was confirmed by the literature on diabetes and stigma (Parshley 2013), and by the existence of a diabetic matrimony website to help patients find partners ([www.diabeticmatrimony.com](http://www.diabeticmatrimony.com)). However this seems to be a characteristic of type 1 diabetes rather than of type 2, with the various complicating factors already noticed. Some critical comments on our study also seemed to suggest that type 2 diabetes is sometimes flaunted as a status symbol, and therefore stigmatization may be a regional phenomenon. This needs to be investigated.

One example case in our preliminary study will highlight the scope of all these problems:

Sujatha M is currently pursuing her PhD in Linguistics. She is unmarried and is 35 years old. She comes from a small town in Andhra Pradesh, a dalit background. Her father was educated, and she is the first doctoral student in her family. As she grew up, her father was diagnosed with diabetes at the age of 38. The diagnosis led to extended depression for a period of over a year. Apparently he was lean, refused to eat regularly or well, and chose to be a vegetarian. Each meal was an ordeal of coaxing and cajoling that led to immense chronic tension in the family. He needed tending hand and foot on a regular basis and this led to the complete engagement of his wife’s and Sujatha’s time. The family’s savings dwindled. Sujatha’s elder sister developed gestational diabetes when she was pregnant. After the child was born, her husband abandoned her. Her diabetes continues. As the father’s condition worsened, Sujatha had to take a break from her education to take care of him. Eventually her father died, leaving the family poorer, and Sujatha coping with her educational collapse. She is having a difficulty finding a marriage match.

# Strategy

The proposed project is based on an analysis of conceptual frameworks in medical discourse (research, clinical reports and public health) on the one hand, and on a field study of the mismatch between these conceptual frameworks and lives of patients.

The outlining of frameworks draws on a discursive analysis of medical logic using sociological and historical tools.

The field study involves informal qualitative in depth interviews with 5 doctors and 15 patients probing questions of opinion, conviction, experience and practice in relation to managing diabetes.

# Method

There is no existing methodology for the kind of work I propose to do. One contribution of the project will be the development of a method appropriate to the objective.

The method involves finding contradictions between the expectations about the patient implicitly assumed in the medical discourse and what actual patients are able to do with respect to controlling the disease. This method of comparing the discursive description with empirical reality is an extension of what I have developed in my PhD research on *seva* welfare and development (Srivatsan 2014). Exploring this mismatch between the implicit assumptions about the patients in clinical and health care discourse and what happens on the ground is an essential aspect of unraveling the politics of health care. Two examples in the register of nutrition and diabetes, which presented itself in the preliminary study (I would have to find different ways to examine the public health and epidemiological perspectives):

One, diabetologists routinely hand out diet sheets listing specific foods and measures to be used by the patient to plan meals. Take for example breakfast could be 3 idlis, I cup upma or 1 egg. The assumptions behind this recommendation are:

1. The patient’s food culture is urban where breakfast is typically idli, dosa, or eggs and not a full meal at 10:00 am like a working farmer would typically have. The diet assumes a certain patient profile.
2. The patient has access to the kinds of items specified in the diet sheet – this implies that the patient is imagined to be of a specific socioeconomic class.
3. Following Western literature, the diet sheets typically ‘permit’ eating fish or chicken twice a week. It is not clearly established what the ideal diabetic diet is in carbohydrate rich, protein deficient Indian food cultures; it is simply assumed that Indian diets are compatible (often vegetarian) subsets of Western diets, with implications for the patient model.

Two, health care policy studies (e.g. Siegel et. al. 2008: 1080) typically argue that Indian diets have shifted from complex carbohydrate low, fat composition to refined carbohydrates, high fat, and sugar. While the statistic may be true of a national average, it does not reflect changes within specific socioeconomic groups accurately. The assumption that average change can drive policy proposals implicitly assumes that one recommendation suits all patients – i.e., there is a standard diabetes patient regardless of class and caste.

Against such assumptions uncovered through reading of the discourses of medical care at levels of policy, research and clinical practice, I will design sensitive interview questionnaires to elicit information about the difficulties faced by patients in relation to these assumptions. For this, I will draw on the insights derived from our preliminary study (Srivatsan and Shatrugna 2014) and by studying the details of other socioeconomic studies of diabetes like Bhojani et. al. (2013).

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#### Appendix I : Types of diabetes

Carbohydrates in the food we eat are broken down into glucose that is transported by the bloodstream to the cells in our body. Glucose that enters the cells is converted to energy that forms the basis of life processes. Glucose enters the cells through the biochemical action of insulin, which is produced by the pancreas. The failure of insulin production, and/or the body’s resistance to insulin as a key to facilitate entry of glucose into the cells, results in the disease called *diabetes mellitus*, characterized by reduced energy to maintain the body’s life processes and high levels of glucose in the bloodstream. Persistent high levels of blood glucose result in failure of the body’s organs and tissues, including heart disease, kidney disease, blindness and peripheral nerve damage (often leading to amputations typically of the foot). Uncontrolled diabetes ends in death.

The problem of managing diabetes is one of providing adequate energy to the body while simultaneously preventing toxic levels of glucose in the bloodstream. Excessively low blood glucose levels (hypoglycemia) lead to immediate damage to organs (most importantly the brain). Blood glucose levels that are too high (hyperglycemia) lead to long term damage to organs and obesity, which latter in turn (in many cases) makes the diabetes progressively worse. Long term diabetes management has to be achieved through a combination of medicine, exercise and diet.

There are three types of diabetes (see main text for a complication of this picture):

1. Gestational diabetes occurs in women during pregnancy with a global frequency of 1 in 25. There are some studies suggesting that the frequency is rising in India (Yajnik 2010).
2. Type 1 or juvenile onset diabetes, is an autoimmune disorder that attacks the pancreas.
3. Type 2 or adult onset diabetes occurs due to insulin resistance and/or relative insulin deficiency. It appears at any age and is sometimes accompanied by obesity. Type 2 Diabetes accounts for over 90% of all kinds of diabetes.

When the term ‘diabetes’ is used without qualification in this proposal, it refers to type 2 diabetes.

This proposal is for a project to study the sociological and political dimensions of type 2 diabetes as a clinical and public health problem. But do see the main paper for a complication of this preliminary characterization.

1. Chronic or degenerative diseases are long term afflictions that cause degenerative changes in the body. [↑](#footnote-ref-2)
2. Infectious diseases are usually short term, communicable and cause reversible damage. Exceptions are TB, leprosy and AIDS which are all communicable but chronic. [↑](#footnote-ref-3)
3. Formerly Deputy Director National Institute of Nutrition. [↑](#footnote-ref-4)