

Diabetes Experience – a Pilot Study

-R Srivatsan and Veena Shatrugna¹

Rationale

A major concern in India is the rampant prevalence of metabolic syndrome, which has its origins in the intrauterine period. A large number of pregnant women subsist primarily on a cereal diet which is bereft of good

quality proteins,

vitamins and minerals.

As a result the foetus

grows in an

environment of scarcity

with most of its organs,

functions and

metabolism

shrunk/compromised.

Metabolic syndrome is the name of a condition marked by a series of high risk factors for diabetes (Type 2) and stroke. These are:

- A large waistline (abdominal obesity)
- High triglyceride level
- Low HDL cholesterol level
- High blood pressure
- High fasting blood sugar

It is now almost certain that vitamin B12, and amino acids like methionine, and other nutrients like folic acid largely derived from animal foods and milk are necessary for maintaining methyl transfers and preventing the metabolic syndrome described by Barker.*

* EC Rush, P Katre and CS Yajnik. Vitamin B₁₂: One Carbon Metabolism, Fetal Growth and Programming for Chronic Disease. *European Journal of Clinical Nutrition* (2014) 68, 2–7.

The newborn thus emerges with a low birth weight. Such babies do not thrive as they progress through infancy because of the continued context of poverty and a near absence of good food like milk, eggs, nuts, etc. Thus they remain underweight with a poor muscle mass and a high body fat percentage. When these children grow up to be adults, their bodies and metabolism are ill-equipped to deal with any excess nutrition in their adult life. These so called stunted populations are of course from the poorest strata of society (Dalits, other castes who do heavy

¹ <r.srivats@gmail.com> and <veenashatrugna@yahoo.com>

work as carpenters, agricultural labourers, cobblers, stone breakers, toddy tappers, metal workers, iron smiths, and many more!). When they give up their usually heavy work, and migrate to the cities, but continue with a cereal pulse diet devoid of all vitamins and minerals, you find that they suffer the consequences of metabolic syndrome.

This study is necessary to understand the ramifications of the epidemic of diabetes (Type 2) which is most likely to ravage the ST/ST and other marginalized groups because they are populations a) with the largest proportion of stunting and low birth weight; and b) they are making a transition to living patterns which are more sedentary than those they followed during decades of early deprivation.

We had many rounds of discussions with several friends who were interested in the problem and then had in-depth interviews with five Dalits who had diabetes in a pilot study to understand the scope of the problem in terms of everyday life. Given that they come from middle-class backgrounds, their responses may be seen as ones that focus more around the problem of caste culture rather than class.

Findings

The following description of findings are intended to open the problem area to research, and point to some specific hazards and difficulties we think these efforts are likely to confront. They also focus on how the patients and care givers deal with the disease in their daily lives, their experience, perspective and knowledge.

Anxiety and Fear

Responses from our interviewees suggest that there is anxiety and panic about diabetes in the rural areas. There is a great deal of anecdotal knowledge about relatives, friends and

acquaintances losing eyesight, limbs, and organs, and of dying due to the uncontrolled progress of the disease. This anxiety and the stigma associated with diabetes (which we will describe in the following section) tend to prevent people from admitting to having the disease. Therefore mindless government programmes (encouraged by Corporate Social Responsibility) screening for diabetes are likely to raise panic among populations in relation to both having diabetes and the stigma associated with it.

From interviews it is apparent that when one is clinically diagnosed with the disease, this anxiety becomes palpable fear – it is somewhat like being told how you are going to die. The expected progress of “the game” of one’s life is revealed. It is almost as if the person has been handed a living death sentence. This results in the patient going into depression for as long as a year, unable to come to terms with the disease. The effects of this depression and fear reflect in the conduct of the patient and are often the emotional burden to be carried by the care givers.

Stigma

There is again a widespread knowledge that diabetes Type 2 runs in families. This is understood as a hereditary transmission of diabetes, leading to a social stigma, with the result that people do not want to be known as having the disease. In one of our interviews we were told that the father, being a diabetic, did not want to let his friends, acquaintances and colleagues know that he had the disease. The reason for this seems to be that there is a fear that the children in a diabetic’s family will not be able to find a marriage match. This unwillingness to let others know the secret of the disease would be an obstacle to following diet and medication programmes that are prescribed to the patient. One of the interviewees also spoke of the irritation she felt over the excessive “concern” expressed by friends on a daily basis, asking about general health, sugar levels, etc., which she felt were none of their concern. Fear and

anxiety coupled with this stigma which a majority of our interviewees spoke about are major obstacles to public health screening for this emerging chronic disease in India.

Stress

...[S]tress has long been shown to have major effects on metabolic activity. Energy mobilization is a primary result of the fight or flight response. Stress stimulates the release of various hormones, which can result in elevated blood glucose levels. Although this is of adaptive importance in a healthy organism, in diabetes, as a result of the relative or absolute lack of insulin, stress-induced increases in glucose cannot be metabolized properly. Furthermore, regulation of these stress hormones may be abnormal in diabetes.²

Stress seems to stalk diabetes in the everyday life of the interviewees. In one case, unending stress in the project of setting up a political network against caste discrimination precipitated diabetes (no doubt the content of the activity had nothing to do with the disease). This person said that given his family history, while the disease was perhaps inevitable, it was most probably hastened by the kind of work he did. In another case, the need to take care of a diabetic father who refused to eat adequately on a daily basis resulted in extreme stress among different members of the family – wife, daughters and nephew. It is easy to imagine that this stress was also reflected back on the patient in a perpetual feedback. In a third case, the physical stress of attending a funeral of a Dalit intellectual on a severely hot summer afternoon precipitated a diabetic coma, leading to hospitalization and an ICU stay lasting over 20 days.

² Surwit RS, Schneider MS, Feinglos MN. 1992. Stress and diabetes mellitus. *Diabetes Care*. Oct;15(10):1413-22.

In general, this kind of stress seems to have common features with other diseases, as well as with other castes, communities and populations. However, our many fact finding interviews with Dalit students in university campuses in relation to the problem of suicides makes it clear that Dalit individuals face stress at an extremely high everyday level due to the sheer pressure of living in a hostile and humiliating environment. While there is no such direct evidence in the case of the few patients we have investigated, it is easy to see the possibility of such stress from a cross-comparison. The problem would be to design probes to examine how this stress plays out in relation to the lives of diabetics.

Doctor's Advice

Typical bullet points in doctors' advice are:

- **Do not** eat rice
- **Do** eat chapatti
- **Do not** eat meat
- **Do** eat vegetables
- **Do not** eat fruit
- **Do not** use oil for cooking
- **Do** walk for exercise

We asked the interviewees what the doctors advised them with respect to medication and diet.

The general practitioner seems to provide advice to cut down ones food. "Instead of rice, eat chapatis, eat two not four chapattis or idlis." This first bit of advice throws the patient into a confusion, and particularly in the geographical region of our study because the term for a meal,

and the term for rice are the same (*annam*). Eating well translates into eating more rice. To change the cereal from rice to chapattis is a huge change in terms of habit and culture. The patient is simply thrown in the deep end and left to sink or swim. Next, “Eat as much vegetable as you can, but not potatoes or other starchy foods.” And “Do not eat too much fruit, but you can eat less sweet fruit.” There is some advice to spread out the eating in several small installments. Each of these lines of advice runs against the culture of patients and families. They come as a shock to the habit and sense of well being of someone living in a food culture that has so far not thought seriously about what constitutes a healthy diet. The diabetologist in contrast to the GP seems to work through charts that propose Indian diet plans and measured quantities of what must be eaten in each small meal. The chart typically shows how many measures (cupfuls, gm or ml) of each type of food may be consumed. Specialists also give readymade sheets with glycemic indices. Charts are extremely difficult to follow and the technical jargon that these charts use is incomprehensible to patients who are struggling to come to terms with the diagnosis.

Most doctors said stop eating meat. Nowadays doctors seem to advise eating some fish. One of our interviewees said that red meat eating was not endorsed. That is, the doctors he met advised a restriction of non-vegetarian intake to chicken or fish once a week.

There seem to be many misconceptions in the doctors’ advice. For example, the patient is told to avoid red meat because it contributes to saturated fats and cholesterol— which is valid in the American and European context where grain and stall fed cattle (and poultry) pumped up with different hormones and steroids yield fatty and cholesterol rich red meats. In India, free range cattle and sheep grazing on grass and leaves provide meat that is not dangerously fatty. In fact, Indian beef is preferred in many countries abroad because of its healthy, low fat composition.

Initial investigations (which need to be verified) seem to suggest that Indian doctors and diabetologists simply adapt Western research results to Indian vegetarian diets according to the dominant cultural pattern. There is apparently not much thought given to developing serious dietary advice to Indian populations, given the epidemic that confronts us today.

On the other hand, doctors have no clue about the life patterns of the rural and urban poor who are now increasingly being afflicted by the disease. Simple questions have no answer: Cost of a diet, frequency of eating, and feasibility in the social, cultural and economic circumstances. There is also no research regarding dietary diversity and food choices, the availability of which would lead to strategies to make it possible for a diabetes patient have a fighting chance to have a normal life.

We do not have solutions to these criticisms but we are at this stage simply pointing to the many problems that arise in the context of the doctors' advice.

Guilt

There seems to be an experience of guilt in patients, as if diabetes were punishment for the sin of a lifestyle. This is doubled by the doctors' non-endorsement of their food cultures. The lack of endorsement is liable to be seen by Dalit patients as scientific evidence that the dietary pattern of the Dalit is being proven to be unhealthy by science. This is seen in another context when students from a university came to one of the authors (VS) for a certificate that beef is healthy food, which they wanted to submit to the university authorities in order to cook beef at a festival. This kind of (not so) subtle non-endorsement could lead the patient to the ambivalent status of being untouchable twice over – once through culture, and again because science confirms the error of “indulgence” of the non Brahmin diet. All this feeds into the guilt. In the context of the

cultural hegemony of vegetarianism in India, this results in a pell-mell adoption of a diet that is a denial of all aspects of a food culture that may in fact alleviate the problem. Such flawed diet strategies include starving oneself, restricting oneself to low carbohydrate foods and some vegetables, and elimination of many key elements in diets (like animal protein to provide energy) that may help control blood sugar and tackle long term obesity. The tragedy is evident in one of our interviewees understanding about the truth of diabetes: “as a result of the disease we simply have to lose all interest in food for the rest of our lives!”

Dietary Chaos

The general description of food consumption in terms of content and schedule among all the interviewees is best described as absolute dietary chaos: a) hunting futilely for foods that would be healthy without a clue about what constitutes healthy food for diabetics; b) struggling to make proper food choices work in familial constraints; c) having spouses who do not understand the disease and either strive to express love by encouraging the patient to eat more food (rice, sweets) or simply do not try to make changes to help the patient cope with the disease; d) totally denying oneself any and every enjoyment of foods that are to be eaten, indeed actually starving oneself. In addition one interviewee recalled a strong memory of the bewilderment regarding social constraints about when it is proper to eat food and what the etiquette of sharing food was in their culture, and the dilemma of circumventing these constraints to take care of the diabetic's need for frequent and small meals. For example, a Dalit teacher had to play around with the medication because a long teaching period made it impossible for him to eat a small meal at the appropriate time. Anxiety about food and places to eat on long trips makes travel a nightmare. Interviewees described a completely disoriented, sometimes unhelpful, always unassisted and

nearly pathetic search for a diet and schedule that would help them cope with the complex and (for them) unpredictable turns the disease would take in the context of culture, family and social life.

It is hard for a normal person to understand this complete chaos that results from a diagnosis of diabetes. Different patients find their own strategies to cope with the disease according to their own understanding, with very little positive help from the doctors about how to do so. The seriousness of the problem arises from the fact that food culture is tied into the body's need of energy and the patient simply goes into either a perpetual state of hunger or resigns to a loss of blood glucose control. It is our speculation (which needs to be verified by some innovative research) that the extreme weight loss seen in many diabetics in India is not only due to the disease pathology, but also due to the dietary chaos caused by misunderstanding and mismanaging this disease.

Destabilization

Another insight from one of the interviews we had was that it is likely that diabetes will overturn the lifestyles of the family around the person who has it. Finding proper food, making each meal palatable, useful and healthy, making a sometimes reluctant and depressed patient eat adequately was a daily battle waged by one family. The interviewee cared for a diabetic father suffering from a low appetite and a self-imposed practice of vegetarianism (his family ate meat). This man punished himself for his disease, and as collateral damage made the family's daily schedule center on the need to take care of him: the mother had to bear the burden of his illness, the cooking, and the constant battle to get him to eat; the daughter suffered educational setbacks to help her mother take care of him; and a brother had to come and give him his insulin injections (which the patient could not take himself) whenever the man was left alone by the family.

While this is common to other diseases like cancer, the duration of destabilization is very much longer and therefore has more cumulative effects with a chronic disease like diabetes.

Recurrent Health Expenditure

An important implication we found from one of our interviews was that diabetes reverses the economic growth process of a not too wealthy family -- the slow and constant increase in medical and dietary expenditure sucks out family reserves at a steady pace. Spending a spot average of Rs 3,000 a month on medication from a salary of Rs 15,000 would strain the budget of most middle class families in India, not to mention the guilt the individual feels in straining familial resources to such a level. An expenditure of Rs 3000 per month over 20 years is a total expenditure of Rs 7.2 lakhs, without counting in any catastrophic expenditure that may arise due to episodes of hyper and hypoglycemia. This sort of expenditure erases the possibility long-term investments in the well being of the family members. In this sense its effect is slower than, yet as sure as, catastrophic expenditure due to acute illnesses. This could be termed "recurrent health expenditure" to differentiate it from "catastrophic health expenditure". Thus insurance systems like Aarogyasri meant to handle health care expenditure as a public agenda or market driven process are theoretically suited to minimizing out of pocket "catastrophic expenditure", are not suited to recurrent health expenditure. No programme exists for "recurrent health expenditure" related to diabetes, which if it becomes the epidemic it threatens to be will be an immense drain on personal resources of the lower middle class patient.

There is no doubt that a crying policy need in this context is the availability of free medicines for diabetes, without which there is bound to be prolonged misery and economic chaos among the poor who suffer the disease.

Discriminatory Effects

For first generation literate families that are marginal or are just beginning to achieve economic stability, a person being diagnosed with diabetes in the family may mean that a child has to drop either temporarily or permanently out of school or college. A temporary, yet crucially long, drop out period was reported in one of our interviews. Coupled with expenses, the demand on care giver time upsets family stability which is the basis for growth of well being through generations. It is impossible to provide a routine for children to study, even if it were hypothetically possible to sustain her education, when the familial routine is turned upside down by this disease. This, in one of our interviewees' account, lasted nearly two decades. This is especially critical with families who are on the threshold of moving from non-formal, insecure forms of subsistence to more stable organized forms of work. It is not so critical with families that come from better off backgrounds. Given the epidemiological pattern we have sketched in the first part of this paper, it is likely that diabetes will hit precisely these populations making a transition. It is overwhelmingly true that populations making the transition from the informal to the formal sector, and thus from the impoverished to the lower middle classes, come from the "lower" castes. Thus there is a discriminatory effect exerted by the presence of a seemingly "secular" disease like diabetes. This is because the poorer a family is, the more vulnerable to unrelenting recurrent economic expenditure it would be, descending steadily to economic and social insecurity. This means that the developmental promise held out by the long processes of disciplinary education and the acquisition of somewhat predictable formal employment are negated by the ravages of the disease on the family as a whole.

We thank our friends and interviewees for their patient and generous sharing of time, insight and experience in this small project.