

UPSIDE DOWN MEDICAL RESEARCH

The Case of Anaemia

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What conditions and influences the development of medical research? What motivates a researcher to choose a particular problem area? Under colonial rule research was a monopoly of a small group of scientists, mostly British some Indian. Curiosity and the need for experimentation and perhaps some concern for the suffering generated a number of interesting and relevant studies. After the '50s the orientation and the ethos of medical research have changed — the problem areas are not those which benefit the majority but those which are most likely to bring recognition to the researcher. Even when occasionally, an area of relevance such as anaemia is chosen, it is looked upon as a purely medical problem, deemphasising the social and epidemiological aspects. This results in a medical/technological solution which can at best, provide temporary relief. The author critically reviews the studies on anaemia over the years to illustrate her contention that the choice and treatment of problems in medical research is rarely governed by factors such as people's needs

Doctors and scientists from the very early part of this century belonged to a privileged class trained and employed by the British and lacking in involvement with the needs of the native population. We find however that there is a certain amount of eagerness to learn, experiment, and change things in spite of the primitive technology and little basic knowledge in the field of physiology. Although the knowledge of science was incidental and the doctors were guided by the prevailing assumptions and biases of their class, the mood of liberalism sweeping the country encouraged them to be open in their pursuits.

The science of medicine was still young and technology not so well developed. The lack of sophisticated laboratories and equipment was compensated, it appears, by more sincere attempts to learn about the lives of the poor and to look at the wretchedness of their condition that resulted in killer diseases. Curiosity and the need to experiment were also important considerations of that time. Scientists were new to the discipline and had not yet mastered it, to start the manipulations so obvious in the seventies, and eighties. This could have been the result of moral concern or a more humanistic approach.

The independence movement, world war and the general political atmosphere could have diverted the efforts of the scientists to what were seen as the needs of the country, but there was a persistence and determination to eradicate anaemia. The callousness of the later research is absent, though anaemia must have been uninteresting and unexciting to the whites (as a condition rarely encountered in the West) and the Indians bred in their tradition. In contrast

after independence when anaemia still tops the list of killers during childbirth, scientists are bored with the problem unless it lends itself to molecular manipulation and sophisticated technology use. There is no patience or concern with the lives of the poor, or with the neglect of women, and the environment of infection and infestation. The age of cold hard objective reasoning demanded ruthlessness with the poor. The human angle was sidetracked and with that out went methodical epidemiological research. If anaemia has not disappeared with the iron pills — the country cannot stop its march to the 21st century with the electron microscope, ELISA, molecular biology, monoclonal antibodies and so on. "Socio-economic problems are not the concern of the scientists", as one award winning consultant scientist to international agencies remarked. Even technology has not been used for the poor. We have sensitive tests developed to detect diabetes (less than 5 percent have it) inborn errors of metabolism (prevalent in 1 in ten thousand or 1 lakh population), but the method of anaemia detection is the same as that we had in the thirties!

Research today has stepped out of the homes of the poor, by passing the dirty lanes, open drains, concrete monstrosities and smoke emitting factories, straight into the air-conditioned labs and test tubes. Problems that are rooted in an exploitative socio-economic system are sought to be solved from the rarefied atmosphere of the laboratories. Solutions to hunger and anaemia are sought through statistical manipulations of mean and standard deviation. It seems as if scientists are now fighting by proxy the battles of the ruling classes regarding food needs, minimum wages and hunger; their scientific vision can accept strips of data fed into the com-

paper, but not the living, half dead tired women who flock to the hospitals everyday. This myopia seems characteristic of our research today. This mechanical transfer of data reflecting the lives of the poor had occurred in the west almost 25 years ago. India seems to be one of the few developing countries trying to catch up in this field. The price we pay for the use of these advanced techniques is that we lose sight of the human being at the other end. Increasingly we isolate ourselves and our research from the human reality out there. The study of the historical research on anaemia serves as a paradigm.

Anaemia : A Case in Point

In 1915 Dr. A.L. Mudaliar in the Annual Clinical Report of the Raja Sir Ramaswamy Iyengar Lying-in Hospital vividly described the clinical picture which cannot be improved any further. "The anaemia of pregnancy is a malignant type of anaemia that seems to be much more frequent than is supposed — it is not only a fairly common complication during pregnancy but is one of the most fatal complications. In 1914 the disease was responsible for 35 percent of the mortality — more frequent in multipara than in primipara, and has a very insidious onset; patients hardly realised the gravity of this condition till the whole body is swollen up and they get an attack of dyspnoea when they seek admission. Breathlessness on slight exertion and extreme weakness are prominent symptoms. An analysis of the blood shows reduction in the RBC ----" (Mudaliar, 1915). In 1927 Margaret Balfour from the Haffkine Institute, Bombay published her findings on Anaemia (Balfour, 1927). This is an important study by a white woman. Her meticulous observations betray her colonial background, but her concern for the enormity of the problem is real. As a woman she is also concerned about the maternal mortality due to anaemia much more than the other researchers of that time. The study is well documented with her starting observations, "In view of the frequency with which the disease occurs in India, it is surprising how little attention it has attracted", a fact which is true to this day. She adds, "This is no doubt partly owing to the fact that little obstetric practice is in the hands of medical practitioners". (Balfour, 1927). It was a period when the medical profession seriously believed that only they could understand problems and change the whole face of society. They feel that the key to the health of the community lay in their hands. Even Balfour identifies her hurdles typically "It is notoriously difficult to get a correct history from hospital patients

in India" is her starting shot. The formal training of the doctor was obviously not different then. The framework in which they functioned had nothing to do with the real lives of the people. Any patient who deviated from the textbook pattern of disease was non-compliant or difficult. The woman's real experience of pain and illhealth did not fit into the classical patterns of disease. Doctors expected direct, well-defined, specific answers to their curt questions whereas the woman's understanding of pain was different. This socio-cultural void has only increased with time because today doctors do not even demand answers to questions any longer. They already know it all and have no time to ask the questions.

Nevertheless Balfour's research is exhaustive because she finds that anaemia is not just anaemia but is associated with a host of other problems such as fever 83.3 percent, diarrhoea 38 percent, Albuminuria 30 percent, liver enlargement 8 percent, spleen enlargement 18 percent, oedema 100 percent, vomiting 40 percent, sore tongue 31 percent, Epistaxis 7 cases and weakness — always (It is heartening to note that an important symptom now dismissed as "subjective" and "imaginary", was actually elicited and documented). Her startling findings of 42 percent maternal mortality and 53 percent stillbirths led to the recognition of the fact that Anaemia had to be tackled somehow.

Her treatment consisted of rest, diet, iron, blood injections (i.m.). She also visited the homes of the poor anaemics and attempted to link up the problem with the lives of the women (a rare quality compared with the clinical detachment of the present day doctors). Since the incidence of anaemia was higher among the Muslims in her study she states "— The main cause of this is probably the purdah condition under which Mohammedian women live. The poorer classes are confined in a single room where they lead a very inactive life. Hindu women, though under the same general conditions as regards poverty, overcrowding and epidemics, do not observe purdah in Bombay and so have a freer life". She continues, "contradicting herself" — "The Hindu woman does not go out much because customs and habits did not encourage it. — The work of the home does not require a great deal of activity, especially if it is shared by several women. Modern conveniences also tend to reduce domestic duties (sounds familiar) while modern principles regarding physical exercises and games for women have not yet taken root in India except in a few cases. A generation ago the women of the family ground

the corn daily and fetched water from the well. Now in Bombay atleast they buy the corn ready ground in the bazar and the pipes bring the water to the poor".

These observations betray the prevailing assumptions about women. Instead of recognising that these were much needed conveniences and looking for causes elsewhere she feels that the women had no right to look sick, flabby and unhealthy with anaemia and confuses inactiveness which is a symptom of severe anaemia with the cause.

The major flaw in the study was, however, the fact that only women with haemoglobin (Hb) levels less than 50 percent were considered anaemic. Now the normal Hb level in the West was 14 gms. whereas the normal detected in the Indian poor was between 9.5 to 10 gms. Hence 50 percent (4.5 – 5gms.) of the normal in India was obviously a very precariously low cut-off point. (The cut-off point for anaemia in pregnancy today is Hb less than 11 gms). Obviously the actual incidence of anaemia in Balfour's study was much higher. She had no problems accepting lower standards for Indians. This is true of the other researchers too. They may not have had the expertise then, but they did have the information of higher standards being applied in Britain. They did not find it necessary to question the norms, nor did this upset them. *It is not surprising that science rejected and gave credence to the Britisher's view of the quality of the Natives life. In fact scientists strengthened these myths. To this day Science has fought shy on the challenges of racism, facism, sexism, or social inequalities. It has conveniently toed the line of the dominant ideology and under the garb of scientific truth has disallowed debates and questions.* In fact scientists employed by the government are true, lawful servants! In spite of Balfour's incidence of 10 to 20 percent (the prevailing figures are 60-70 percent) the high maternal mortality rate led her to postulate a toxic condition associated with pregnancy. She could not demonstrate cure with medicinal iron etc., because we know that treatment for anaemia is very long drawn out.

In the same year McSwiney recorded 43 cases of anaemia (McSwiney, 1927). Unfortunately the hospital stay of the women and treatment was for a few days only, because women came only when they were critical and did not stay long enough to get treated after delivery. She was convinced that follow-up of the patients was not possible as "They were all poor and ignorant folk who became

restless after some weeks of improvement and bitterly resented the innumerable injections and demanded their discharge at the earliest moment". McSwiney like today's doctors was unaware that women's labour was needed to run the home and care for the children and that she could not allow herself the luxury of treatment in the hospital! McSwiney however talks of preventive treatment early in pregnancy to be followed up to term to see whether anaemia could be prevented.

The search for a "cause" of anaemia continued and in the meanwhile experiments on animals were carried out with two diets "a Hindu Diet" and a "Muslim Diet" (Wills and Mehta 1930). But it was too early to 'detect' iron deficiency anaemia by manipulating diets because contributing factors were many including Malaria, Kalazar, Syphilis, and host of other infections

In 1932 A.L. Mudaliar and K. Narsimha Rao from the Government Hospital for women and Children, Madras reported their detailed study of anaemia (Mudaliar and Rao, 1932). Their criteria for Anaemia continued to be (4.5-5.0 gms). But they had made attempts to focus on the multiple factors such as gastric acidity diet infections and others, and postulated the following theories to explain the cause of this killer disease: 1) Infective theory 2) Vitamin deficiency 3) Toxemia 4) Deficiency of Anti-anaemia factor.

A Landmark in Anaemia Studies : 1940s

Upto this point the studies were not organised, but by 1942 L.E. Napier and Neal Edwards published their report financed by the Indian Research Fund Association (IRFA) which was a major document - and has, I think, come nearest to defining the problem (Napier and Edwards 1942). It dealt with most of the questions including Haematological techniques and included a guide for research and extension work. It is a landmark in the field of anaemia.

Part I deals with a short history of anaemia research in India and it was documented that Dr. V.R. Khanolkar was investigating into the Hb standards in health and disease. The findings of the earlier Anaemia Sub-Committee appointed by the Scientific Advisory Board of IRFA, in 1939 by MI Neal Edwards, V R. Khanolkar and S S. Sokhey was also reviewed, where the major conclusions were that the cause of anaemia is 'common to a large percentage of the population though the dominant cause will be different' and recommended a study of "normal Hb"

and incidence of Anaemia including the effect of treatment. They had also recommended the study of clinical data and diet intakes in pregnant and non-pregnant women during and after pregnancy (Napier and Edwards 1942).

The report also accepted that "In the past anaemia has attracted less attention than it deserved, partly on account of the general attitude of complacency that is adopted towards a disease state not commonly associated with a high mortality and partly on account of a physiological misconception, namely that the normal Hb in the blood of persons living in tropical countries is lower than that of the residents of the temperate climate. The misconception regarding the Hb level in the tropics has now been fully exposed — Anaemia is a very important factor in causing death in infections and other diseases in which, had the patient started with full complements of blood — they would have recovered ..." (Napier and Edwards 1942). At last there was some light at the end of the tunnel.

The report also reviews the work done on pregnancy anaemia. Significant reviews are those of Margaret Balfour where she reported that anaemia was responsible for 61.9 percent of all maternal deaths in Bombay and 35.6 percent in India (Balfour, 1927). Neal Edwards, with data from the Women Hospital gave an incidence of anaemia 49.5 per thousand pregnant women in 1936 (taking Hb less than 50 percent) and Napier and Dasgupta's figures of 158/1000 pregnant coolie women in Assam (Napier and Dasgupta, 1937).

The earlier studies had found that the causes of maternal mortality was in the following order: (1) Sepsis, (2) Anaemia and (3) Eclampsia, and report that among the cases of sepsis which heads the list, there are many cases in which if the patients had not been severely anaemic as well, they would have recovered. (It was also known that in Britain and Wales, anaemia was the cause of only 0.05 percent maternal deaths).

The review of the epidemiological data shows that the associated problems such as fevers, syphilis and other infections were very important and reported that "the discrepancies in the findings of the different observers may well be explained on the grounds that there are multiple causes and that these are not equally represented in the various series of different observers".

Reviewing the haemoglobin level from various parts of India they seem to miss the important

finding related to the socio-economic gradient reflected in the following figures.

	Indian	West
Men	14.5 — 16.0	14.5 — 16.0
Men (Coolies)	12.63	
Women (Students)	13.73	
Women (Middle Class)	12.63	
Women (Coolies)	10.5	
Women (Coolies) (Pregnant)	9.22	

Hb levels in gms/100 ml.

According to the table the poor and specially women were at a disadvantage at the start of pregnancy. This "normal" low Hb levels resulted in anaemia at the onset of pregnancy when the needs are more, and by the end of pregnancy, the condition was so critical (Hb less than 5 gms) that their symptoms were of heart failure.

They were also surprised that the coolie population of both Assam and Shivrajpur in Maharashtra had the same Hb. levels, but less than the Western levels. They at last postulated economic and dietary factors, because in 1936 Napier and Dasgupta had given iron to coolies and raised their Hb to 12 gms and had suggested that there was another limiting factor too (obviously food) (Napier and Dasgupta, 1936). In another experiment by the same authors they found that coolies who were well fed for four weeks before iron therapy showed better responses than those who were not given food (Napier and Dasgupta, 1937.b). The haemoglobin of the well fed group had come up to the levels of healthy men.

Another finding by Napier and Dasgupta was that when the obviously anaemic women had been excluded, the mean Hb was much the same as amongst non-pregnant normal women (Napier and Dasgupta, 1937 a).

Given the limitations of 1942 the scientists were very close to the truth by virtue of their keenness and determination to get to the truth. They were not looking for easy solutions yet. The major findings can be summed up:

(1) that the food intake was low in anaemics; (2) there was a massive hookworm infection; (3) there was inadequate iron intake; (4) Associated infections and other infestations. (Mitra, 1939). They had no knowledge of the following yet because science had yet to unveil some of the mysteries of the cell.

(1) The mechanics of the cell cycle, and haemoglobin synthesis; (2) Need for folic acid and other nutrients; (3) Results of experiments with radioactive substances. In spite of the limitations of that time they humbly accepted the fact that "the essential difference between the study and the treatment of a case in a sanitary advanced country on the one hand and a sanitary backward country such as India on the other is that in the latter one has always to make one's study against a background of widespread infections such as malaria and hookworms, and of malnutrition both general and special. Each infection and each food deficiency must be considered as possible contributory factors ...".

Part III of the report is optimistic because the authors are convinced that anaemia can be prevented and perhaps special anaemia clinics would help understand the "social, environmental and dietary factors ...". It would also help treatment and research. They felt that the "hit and miss procedures" were wasteful and expensive, and the severe cases were being admitted to purdah hospitals where the facilities were absent and the pathologist who saw the slide never saw the patient. Hence "the background, environmental and personal diet and family customs must be given the same consideration as is applied to the blood slide and clinical findings".

There is a chapter on the details for conducting an anaemia enquiry and research. It is very well thought out with the women as the centre, and not the scientists ego, pet hypothesis or personal ambitions. They suggest that "questions should be intelligently considered and not mechanically noted. For example in a meat eating family the mother who may be the subject of investigations may herself take practically no meat if she eats what remains after the other members of the family have eaten. Similarly lack of sunlight entering a particular room where the woman spends 24 hours a day may be in fact of more importance than the degree of ventilation of the room".

The approach is sympathetic and explores qualitative details beyond the narrow confines of

"science" as will be obvious in the more recent work on anaemia. There is another interesting human observation differentiating the moderate anaemia from severe. The authors are surprised and find it worthwhile to document that in "Moderate anaemia" the patient usually makes no complaints and is found on routine enquiry. On enquiry she may admit to feeling tired, but many women expect this in pregnancy and think nothing of it. (Today we have lost even this sensitivity that the medical profession had in 1942! It is seen as a subjective symptom and therefore not to be relied on). In severe anaemia there may or may not be presenting symptoms. The degree of anaemia which may develop without symptoms is a testimony to the low standard of well-being with which many women seem satisfied. Questioning will reveal increasing lassitude, shortness of breath, palpitation and swelling of the feet and face ...".

The recommendations and the propaganda leaflets are again documents with well thought out solutions to tackle the teaching of anaemia and even "A method of haemoglobin estimation should be taught to every midwife ... " has been suggested. They cry out for early detection, and regular examination of the pregnant women.

The propaganda leaflets could be used even today because they deal with the questions of a good diet, special foods, medicinal iron, care and so on and also notes the responsibility of men " ... It is in the hands of the fathers and husbands to take steps to prevent the mother's suffering and ensure their health and safety during pregnancy and childbirth".

This optimism was understandable, because science had opened up new frontiers and the combination of scientific knowledge with the resolve to apply it for the good of womankind made everything seem possible. *The whole attempt appears like a dream today and anaemia still tops the list of killers during child birth followed by sepsis and eclampsia.*

Abortive Search for Quick Cures

Independence saw the report of Dr. S. Pandit published in 1948 entitled *Causes of maternal mortality* (Pandit 1948) — positive report still in the same optimistic mood. But major research bodies like ICMR were not touched by the strong winds of change sweeping the country. There was no sense of urgency, only clinical detachment for the next 10-15 years. Normal levels of Hb were worked out and the role of folic acid and iron confirmed. Instead of getting on with eradication, scientists

betrayed their contempt for the poor people with studies like *Role of rice diet contributing to increased fertility* (Annual Report NRL, 1956). They had jumped on to the band wagon of population control even before they were invited. From this time onwards one finds them bending over backwards to please the powers that be and "science was placed at the service of the ruling classes" even when the rest of the country and the bourgeoisie was talking of plans, people, democracy rights etc. The scientists were not impressed. They had internalised the ruling class contempt for people's lives and food needs and a lot of time was spent looking into Ducks egg protein and its virtues and the role of mothers milk in causing malnutrition. The studies on anaemia were secondary. An important finding in 1956-57 was allowed to pass by because it was not exciting or sophisticated enough (Annual Report, NRL, 1957). It was down to earth and pedestrian. The study showed that iron cooking vessels helped in increasing the iron content of foods cooked in them. Such a study obviously would not lead to international and national recognition and awards, and one could not "claim" anything for this - hence the disinterest. By now research had turned into an industry which could churn out huge spin offs for scientists in terms of patients, trips abroad, publications and awards! The new breed of scientists were not going to settle for simple iron cooking vessels.

A search for a miracle and a quick cure was launched to put an end to the nagging problem and to claim credit for having wiped out anaemia. The environment, foods, infections, poverty had to be bypassed, "All that takes time" as one of them exclaims. In the sixties sketchy details of iron needs were worked out by simple additions of the need during pregnancy, lactation, menstruation and by 1969 Dr. C. Gopalan announced the findings that iron and folic acid would be distributed all over the country as a National programme (Gopalan, 1969).

He said "Till such time as we are able to bring about a significant improvement and diversifications in the dietaries of the poor sections of our population, the *practical* (emphasis mine) answer to this problem must lie in the systematic distribution of iron to our poor pregnant women through MCH centres and PHCs". (Note the significant patronising tone!) Even this is recommended in the latter half of pregnancy because "A significant proportion of the poor pregnant women can be reached only in the latter half of pregnancy". The researcher's pragmatism must be appreciated along

with his candid confession! This reflects how the researcher has stopped identifying with the subjects of research and has instead objectified them. By 1970 Dr. Gopalan even announced the well worked out doses of iron to wish away the problem of anaemia from all segments of the population (Gopalan 1970). Dr. Gopalan was of course oblivious of the problems of long distance storage, distribution, lack of commitment of the staff, the felt need of the women, the massive problem due to inadequate food, overwork, infection and anaemia was reduced to a farce, by the pill. It was not the fault of the women that it did not work. Any wonder it has not even been evaluated!

In the meantime the WHO in 1968 had recommended fortification of food with iron, one of the exciting new suggestions that would increase iron in food, and do away with pills (WHO, 1968). Hence work was started at the National Institute of Nutrition to identify the chemical composition of an iron compound that would mix well with common salt (which is consumed by all). The research was time consuming because the hurdles are numerous. The drug (tonic) industry watched this progress with apprehension but they need not have feared because since iodine fortification of salt in the goitre area had been a failure - it was a foregone conclusion that this research would remain a curiosity until such time as the system became really concerned with the poor.

Upside Down Research: 1970s

In the seventies it was forgotten that anaemia was still a killer, it again became an "exciting problem" and gained fresh recognition. Anaemia means less blood, less oxygen and (?) alteration in utilisation of food for energy for work, with many other associated changes. Hence while the researchers now marked time waiting for anaemia to disappear, their curiosity was raised with questions of anaemia and immune response, anaemia and work output (we had studies on the same plantation coolies in the Nilgiris by Dr. Rahamatullah, who made anaemic women (Mean Hb. 6.2 gms.) work and calculated the increase in work after they were given iron (Rahamatullah, 1983). There were also studies of alteration in the immune response in anaemics, and other molecular level changes such as changes in enzymes functions.

In the meantime by the late seventies, when anaemia could not be wished away nor used for "exciting" research we have a breed of scientists

who were willing to flog a deadhorse—the pay offs would be recognition, awards etc. It was obvious that anaemia had to be presented differently. Hence statistical jugglery was resorted to in thousands of anaemics showing that anaemia had a role in prematurity, stillbirths, abortion, IUCD, Pill use, maternal and child morbidity, toxæmia, body weights, arms circumference, skinfold thickness, sore tongue etc. Research had now been turned upside down. (Ann. Repts. NIN 1979-83) *The causes of anaemia were no longer important — the correlations with absurd parameters started, and by a process of elimination the researchers arrived at the "Risk Care Approach" a bastard of the eighties* — an attempt at planning for the 21st century by efficient and smooth salesmanship based on statistical manipulations (ICMR, 1985). It states that indices of MCH care like low birth weight and prematurity rates — have not shown the decrease commensurate with expansion of health services — an attempt to cover the entire vulnerable population (pregnant and lactating women, infants and children) with the available limited health man power — might have prevented effective functioning and resulted in lack of perceptible impact... and "Dealing with problems of large magnitude with available limited resources, adapting a risk care approach might pay higher dividends —"

The health care system was now using the language of the stock exchange. The philosophy being that since only a small section of women are really in the "risk group" — contributing to mortality, the others may be in the border line — and never mind about them — they should be identified and treated. There is no concern for the quality of life, the nagging tiredness and the inability to work. Further it is felt that in the rural communities it is not possible for the doctor to visit far flung areas and hence one must find out the minimum number of antenatal visits needed. (Ann Rep NIN, 1982).

By process of statistical elimination the following women are placed in the "Risk Group". Hb - less than 8 gms Wt - less than 40 kg; Ht - less than 140 cm. Any other problems during the earlier pregnancies.

Other scientists impatient with the slow progress of the tablets devised ingenious methods of injecting the whole dose of iron into women (who had Hb less than 8 gm.). Exploiting the popularity of injections in our country, scientists recommend large scale injections of iron to overcome the non-compliance of the patients and

cover up thus our lack of will and perseverance in tackling the problem of anaemia. (Note the similarity to the use of Net-en in F.P. Programmes).

Considering the huge government funding that goes into research today, the question that faces us is one of ethics. What is the researchers' responsibility to society? What are the attitudes and assumptions that should inform his/her research? Is s/he justified in sacrificing even scientific rigour to expediency. Should not a sense of humility underline every piece of research undertaken and attempts be made to make it relevant to the needs of the people? Today the role of science in solving the problems of the people is being increasingly questioned. If the scientists do not recognise how enormously privileged they are at the cost of the country and attempt to fulfil even the limited tasks before them they are in danger of rapidly becoming redundant.

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