

“A journey of discovery: V”

The discussion on demographics and genetics emphasized the shift in medical thinking from curative to preventive

Arnavaz S. Mama

The first part of the report on the two-day Parzor seminar held in Bombay last December focused on Dr Shalini Bharat's study on family and marital issues. The second part dealt with Dr Lata Narain's report on a quantitative study of the Parsi youth. The third instalment covered Dr Siva Raju's research on the elderly, both home based and institutionalized. The fourth reported on Dr Katy Gandevia's identification of the community's health problems.

Demography and genetics

A pilot study of the blood samples from 50 families — husband, wife and two children per family — was conducted by Prof P. K. Gadhia of the department of biosciences at the South Gujarat University. He said he set out to see if there was any genetic factor contributing to the demographic decline. The hematological, biochemical and cytogenetic analy-

ses failed to reveal any major disturbance. Gadhia reported mild anemic conditions. His report notes, “Since the majority of the parameters have given normal or near normal results, no concluding assertion could be made regarding a genetic contribution for the Parsi population decline.” His recommendations therefore echoed the normal advice to marry early and have more children, financial incentives, lifestyle change et al.

Renowned gynecologist and obstetrician Dr Rustom Soonavala who chaired the session, felt the study sample was too small. Jamsheed Kanga, a member of the B. D. Petit Parsee General Hospital executive committee, was worried that by isolating particular diseases in the community its insurance and employment potential could be affected. Samy Gazdar of Avesthagen sought to ease anxiety: “What we aim to find is

new bio markers to help identify future health problems... Breast cancer is only one case. This is a frontier science so we don't have all the answers. We are not only into diagnosis but also prevention.”

Referring to the several dimensions the quest could take, Dr Shalini Bharat, professor in the School of Health Systems Studies at the Tata Institute of Social Sciences (TISS), urged caution that the results should not lead to stigmatization. “These are huge ethical issues and there is the political economy behind it...Any research has to be done with proper information extended to everybody. The ICMR (Indian Council of Medical Research) has clear guidelines.” According to insurance expert Fali Pocha, only three percent of the community is medically insured today.

Dr Narendra Joshi of the Tata Cancer Research Institute explained that there are “very few genes that cause diseases



Top: Parzor president Trilochan Singh, National Minorities Commission chairman Mohamed Shafi Qureshi and BPP chairman Dinshaw Mehta
Above (from left): Khojeste Mistree, Rustom Tirandaz and Keki Gandhi. Alongside (from left): Dr Hoshang Vakil, Fali Pocha and Samy Guzder

Top row: Drs Armaity Desai and Shernaz Cama, Minoo Shroff, Dr Keki Grant. 2nd row: Drs Rustom Soonavala and V. Saroja Vorouganti, Prof P. K. Gadhia and Dr Shalini Bharat

singly. Disease is the result of a combination of genes.” Dr Hoshang Vakil of Merck Sharp and Dhome added, “There are so many variables. Can we be selective about what markers are required?”

Dr V. Saroja Vorouganti of the US supported Joshi and explained that genes take millions of years to change. They are responsive to the environment and express themselves differently in changing circumstances. “Just because you are (genetically) susceptible to a particular disease does not mean you will get it... You can make lifestyle changes.”

“A scientific paper is important if everyone participates in the discussion. Five hundred years ago human life expectancy was only 20 years. There has been a shift in the medical profession from the curative to the preventive; future medicine will be genetic and immunization based. Immunization for cervical cancer is already in the market in India,” opined Soonavala, adding, “We can’t play God but the end of a human being should be comfortable.”

Noting that “gene hunting and hypothesis testing” were the main aims of genome research today, Joshi said that more than 3,000 individuals would be required to search for the breast cancer gene. It entailed a lot of technology, team effort, time, money and manpower. Reiterating that most disorders were multigenetic, he added that ethnic variations can neutralize or attenuate genetic influence. Lifestyle and diet are modifying factors in a limited way.

Dr Keki Grant of Poona commended Joshi’s study with one reservation. He suggested that the immunologist compare the Parsi community with the European community rather than with the rest of India. “You will find that the differences are not so great.” Adding a dollop of old-fashioned optimism to the discourse, the nonagenarian Grant challenged, “There are so many diseases, but Bombay was built by Parsis. How do you account for so many famous Parsi doctors despite Parsi defects? Don’t get depressed. There is still a lot of fire in the community... Parsis have been heads of all defence services, at the top of all institutions there are still Parsis. Do research on why they are coming up — research by keen observation. Penicillin was not found in an elaborate laboratory but a room one-tenth this size. It was found by keen observation... Parsis live long. So what? Japanese live long despite smoking... Remember to take good

people from other communities into your fold. Does anybody have a problem? Khojeste (Mistree, trustee of the Bombay Parsi Punchayet — BPP)?” bantered the doughty doctor and continued: “Remove the depressing thought that we are de-

“No concluding assertion could be made regarding a genetic contribution for the Parsi population decline”

clining. We are not declining. Have the courage to work hard. Every one of you has the fire in your belly... Zarathushtra said the way to be happy is to make others happy. So Parsis contributed to all institutions — schools, colleges, hospitals! So keep your head up and contribute.”

The genetics of complex diseases

The Avestagenome Project — a population genetics and multidisciplinary study on the Parsis of India — aims to understand the molecular basis of longevity seen in the Parsi-Zoroastrian population. It also aims to create a medical database of the community in order to study the increased incidence of age-related diseases like cancer, cardiovascular disease and neurological disorders, osteoarthritis, schizophrenia, diabetes, etc as compared to the rest of the Indian population. Being a small, localized population that has married within itself showing both high positive traits and achievements at various levels and in a variety of fields, the community makes a good target for study. Avestagenome’s aim is to collect blood samples, isolate and archive stem cells to serve as a repository for use in potential future therapy as well as collect complementary family histories for genealogical study.

The Avestagenome Project was explained by Guzder who noted that the company was devoted to increasing wellness rather than treating illness. Their aim is to collect 20,000 samples by 2010 in the age distribution of 40 to 65. “Each specimen will be assigned a bar code to ensure privacy... What we find will need to be validated with cross information

from Indian samples,” he noted. A detailed questionnaire of 45 pages will also be bar coded to make it easy to go back into the database without revealing identities.

Certain families seem more prone to particular ailments than others. Hence the need to take a multi-gene approach to differentiate between the genes and the impact of the environment which includes lifestyle and diet among other things, explained Vorouganti, a postdoctoral scientist from the Southwest Foundation for Biomedical Research (SFBR) in the US. Their aim is to identify and recruit families with two to three generations, including siblings and cousins, collecting blood samples to isolate the DNA on the one hand and collect the socio demographic history on the other. SFBR has been working with the Inuit and Mexican American communities and proposes to take on a similar study on Parsis in the US.

Action plan?

Content to have broad suggestions in place of a detailed action plan, Parzor research coordinator Dr Armaity Desai noted that the studies have thrown up gaps. A new pilot study is being planned at TISS under the National Commission for Minorities on employment. “We also need your support to establish a data bank, save the material generated by these studies.” Parzor is also in a dilemma regarding who they should partner with. Another source of study is a comparison of the community in India with its counterpart diasporas around the world. “Do the attitudinal aspects, family size, differ? Is there continuation or do they get dispersed in two or three generations?” she wondered, wanting to know what the anjumans and punchayets were planning.

“Up to now we did things on the basis of what we thought the community needed,” Kanga was the first to respond. “Now for the first time there is a systematic assessment of what the community needs. It would be appropriate for the anjumans and the Federation to decide what to implement and how.”

Joint honorary secretary of the Federation of Parsi Zoroastrian Anjumans of India Keki Gandhi informed Desai that the Federation president and BPP chairman Dinshaw Mehta has agreed that at the next meet of the Federation one afternoon would be devoted to discussion of the Parzor research.

According to then BPP trustee Rustom Tirandaz the BPP had decided that whenever they have more than 250 flats they would incorporate a home for senior citizens. His fellow trustees Mistree and Jimmy Mistry had also undertaken to start a system of mentoring the youth. Tirandaz also spoke of having a chair in Avesta studies in Bombay University. Mehta endorsed Tirandaz's statements.

Bharat urged the anjuman leaders to ensure that the research reaches the community. "We have identified the challenges. It's up to you how you deal with them," she noted, putting conflict resolution as one of the priorities.

Erstwhile BPP chairman Minoo Shroff directed the anjumans to read the reports, address the attitudinal issues. "Diet, nutrition of minority communities impact their longevity." Calcutta has an excellent system but it works because the population is small, he noted. "What are the broad issues to be taken up by organizations, issues that individuals cannot do? First do what is doable. Then get to controversial issues," he advised.

Data Bank and Research Centre

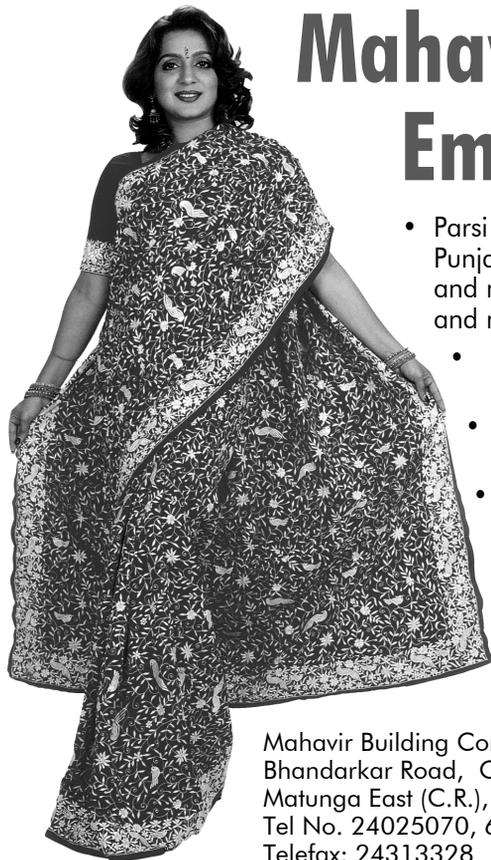
Acknowledging that "we have a long

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way to go, both in India and in studying the diaspora of the Zoroastrians, with comparative studies between India and those settled abroad," Desai urged the gathered anjumans to support the Parzor project of setting up a Data Bank and Research Centre. "It would give us a more holistic understanding of where the community is today," she noted, adding, "Some studies were undertaken earlier also pertaining to demography and other social as well as health aspects, but these are so scattered that researchers have problems to identify them, and also to access their data. Simi-

larly, Census data are not easily available to researchers. The result is that we may constantly reinvent the wheel, treading the same territory, instead of moving our insights forward... Our researchers also have difficulties in the scientific area searching for samples when they are studying specific diseases such as cancer."

The envisaged Centre would house all the data and studies, as well as samples of medical data, such as blood and skin samples and electronic information, derived through the various hospitals and clinics with the approval of the doctor and the patient, Desai noted. "We are looking for a place to house the Centre and funds to maintain it. Your generosity, as trusts and philanthropic individuals... will take us a long way in achieving our goal to help the community in its very different hour of need than when charities were initially established several centuries ago... (At) the Data Bank and Research Centre we have envisaged, a host of interested researchers in India and from elsewhere (would) have access to data with which they can undertake studies," Desai appealed to the "informed heart of the community." ❁



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Hello! I am a slim, tall, 30 year old Parsi woman who is ready to start looking for a life partner. I have a wonderful college education in design and currently work in Bangalore on applying design thinking to the needs of urban waste. I find myself moving towards work that is meaningful to myself and others, as well as being holistic in how I want to live. I love living with animals, growing plants, obscure street-interaction type of travel, and hiking. I am looking for a man who is deeply connected with his work, has a strong sense of common human decency, and sees himself as a very involved father. A gentle and emotionally mature man, who seeks joy and balance in everyday living. I am attracted to tenacious people, people who like working with their hands, quite often well educated people, and people with a developed personal world view. I come from a happy, well educated, well travelled family of professionals. I believe that all communities and religions are equally precious, and that a person's sense of compassion and humility is a keen value.

If you feel that you are in a similar space, please write to me at dd9878@yahoo.in