MEDICAL RESEARCH ISSUES IN DECENTRALISED HEALTH CARE

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Prepared for the workshop “Towards a Decentralised Health Care: A Fresh Look at the National Health Policy” organised by National Institute of Advanced Studies, Bangalore

September 20 to 23, 1990.
Bangalore
CONTENTS

1. Introduction
2. Need for a situation analysis
3. Identifying areas for study
4. General issues concerning medical research
5. Need for clarifying goals
6. Epidemiology and health planning
7. Developing indicators
8. Understanding health culture of the people and the role of Idnaian and other systems of medicine.
9. People’s perceptions – participatory research.
10. Need to study micro level projects and areas where decentralisation has been attempted
11. References
12. Appendix
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1. INTRODUCTION

The role of research in any plan for the decentralisation of Health Care in India could be likened to that of a beacon light to a ship sailing uncharted seas. Intuitively, for various reasons, and also at a heart level for those concerned about the health of the poor, we may feel that decentralisation is the need of the hour. Yet, if we put ourselves in the shoes of those actually responsible for executing such an exercise, starting with the existing structure of health services that have been built up and come into existence over the years, it seems sensible to take sufficient time off to reflect objectively on certain questions, viz.,

- Why are we seeking such an alternative?
- What are we aiming to achieve?
- Where are we trying to go?
- How do we propose to get there?
- Where do we focus our efforts?
- Who are we trying to reach the most?
- Who will participate in this endeavour?
- When do we reasonably expect to be there?
- When would be a long enough time to check and make midcourse corrections?

There could be several more such questions which would be vital when undertaking an exercise of such dimensions. It is this spirit of enquiry of trying to think through the process that we are embarking on, of trying to identify issues that need to be studied, that reflect the scientific approach of research into the areas of decentralisation of health care in contemporary India. Different disciplines have developed systematic approaches of enquiry from their own perspectives. By its very complex nature this area would require inputs from the social sciences, epidemiology and health services research, clinical sciences representing all the different systems of medicine prevalent in India, management, communication and economics among others. I will try and contribute some thoughts from the epidemiological community health points of view and dwell only on some of the questions mentioned above.

2. Need for a situation analysis:

As a starting point it would probably be useful to have a critical analysis of the functioning of the present health care system.

Perhaps for many, even today, the age-old, totally decentralised, individualised, healer-sick person relationship still prevails. Here, access to care depends on one’s situation in life in terms of class, caste, gender, geographic location, age, etc. The Sokhey and Bhore
Commitees have suggested that in Independent India the State should take the responsibility for the provision of comprehensive health care for all. Whether this step towards centralised planning was taken to fruition i.e, whether the goals envisaged are being realised has been a matter of study and discussion. Several subsequent Committees (the ICSSR-ICMR study group of Health for All – an alternative strategy, being the latest in 1981) seems to concur that inspite of some remarkable achievements like eradication of small pox, control of plague and malarial, increase in life expectancy at birth etc., we have not progressed far along the road of making available comprehensive health care for all and much less in improving the health status of the masses of our people, particularly the underprivileged.

However it is necessary to analyse in greater details (than that given in the National Health Policy document) the reasons why the proposed system of health care which had been meticulously spelt out by the Bhore Committee has not achieved its 20 years long term goals even more than 40 years later. In our anxiety to remedy the situation and try an alternative we must not lose the lessons this experience has to offer or else we may find ourselves in a similar situation several years hence, as the same factors continue to play their role. Important reasons probably lie in the influence that broader socio-economic political factors have on the development of the health system. Their impact needs to be determined.

At the same time, in spite of limitations of coverage, quality, acceptability and maybe efficacy of the Governmental health care delivery system has over the years built up a massive infrastructure and an army of health personnel. Considerable experience has been gained in the areas of training various types of health personnel, in the provision of the health services under different conditions, in controlling various infectious diseases, in coping with epidemics, natural and man made disasters, and also in the area of research, be it basic, clinical, operations research, evaluation of programmes etc., Learning about the strengths and weaknesses from all these areas would greatly help us in the planning of decentralised health services. This research exercise could be part of a preparatory phase of planning for decentralisation.

3. IDENTIFYING AREAS FOR STUDY

Decentralisation of health care, as part of a general philosophy of decentralisation power has several aspects which together would form an integrated, functioning whole. As an issue to be researched, planned and implemented we need to look at each of these aspects seperately in detail and then, one would also have to study feasibility, efficacy and efficiency of the functioning of the system as a whole.

This would be similar to taking a motor car apart looking at its various components, and then at the most crucial aspect of its functioning as a whole. However, aside from the mechanical aspects, we are also interested in the more difficult to determine and measure factors such as the direction the driver wants to take it, who the passengers will be, are they sufficiently equipped for maybe a long and arduous journey, who all will be able to make it to the end, etc.,

Aspects of decentralised health care requiring separate study that come to mind are:
a) its medical or technical aspects of training, service, research and communication
b) financial control,
c) administrative aspects and issues concerning management of health services.

These are the more traditional areas where we have already grown in experience. However, equally important and as mentioned earlier more difficult to determine and measure are

d) socio-cultural aspects, and
e) political awareness of people which vary from region to region.

4. GENERAL ISSUES CONCERNING MEDICAL RESEARCH

Medical research in the context of decentralised health care could contribute to providing a scientific basis to health care planning and policy, by studying the health status of populations understanding some of the major causative factors of disease, evolving and evaluating intervention strategies. It would need to draw upon basic, clinical, epidemiological and sociological research and as an applied aspect attempt to translate them into meaningful and effective health programmes and services. It would also play a role in the monitoring and evaluation of health services.

None of this is really new. It has been used in several countries for a long time. It has also been used in India for developing some of our national health programmes. Based on several years of Indian experience, some factors concerning medical research in general merit consideration.

a) There is a need for a shift in conceptual emphasis from a biological model of understanding disease to a more composite model where the important role of sociological factors including cultural, economic, political and environmental factors in the causation of disease are also recognised.

The biological model results in a disease or discipline oriented, vertical approach to health problems. Planning for and providing health care services which are responsive and more caring to people’s illnesses and suffering would need a more holistic to health services and to research design study approach.

b) This would necessitate a change in research methodology in terms of definitions, classifications, mathematical approaches to analysis of data. Sociological indicators would have to be evolved and integrated.

c) The Westernized bias which is evident by the emphasis on the Allopathic system and by the influence that international funding agencies and public health groups and experts have on our research priorities, methodologies and acceptance of findings needs to be questioned. There is need for building greater self-reliance and greater openness and dialogue with our own traditional health practices and systems of medicine.

d) Medical research has been moving along certain well-beaten tracks for several years, eg., in TB, malaria and other infectious diseases. Though it is refreshing to hear about new approaches like integrated vector control that has been researched by the
National Institute of Communicable Diseases and the Vector Control Research Centre, we need to have more fresh approaches and a more dynamic body of researchers. Though research into emerging health problems has been mentioned in our national health policy, there is very little research in areas like health effects of chemicalisation of agriculture, of industrialisation or into the health problems of urban slum dwellers.

e) Researchers have traditionally an sure of being objective, neutral, unaffected by emotion etc., However in the process they may be used by other very real forces at work, eg., international pressures, industrial lobbies, political lobbies. Medical Research after the Bhopal Disaster is an example of various wider forces at play, similarly the research into the efficacy of vitamin A concentrate on morbidity and mortality. Research controversies have occurred in the determination of the role of saturated fats in the causation of cardiovascular disease with the butter lobby producing its own data sets. These are just a few examples of broader issues that influence all types of research.

5. NEED FOR CLARIFYING GOALS

When considering the medical or technical aspects of decentralised health care as a National Policy it would be necessary to work out in adequate detail what is to be decentralized.

It is most easy to conceive of decentralisation of curative services and well established preventive services like immunization of children, providing safe water and sanitation etc., However there are some health programmes against various diseases and problems which are not considered or known to be important by health practitioners and administrators – what about these?

What would be the position of the present National Health Programmes? Has a procedure of transition been thought of? Would decentralisation allow total autonomy in the drawing up of health plans at the State or District level or would certain areas like Family Welfare still be planned and monitored centrally. Who could be the decision makers in the decentralised planning process?

Many aspects of the present National Health Programmes are funded by the Centre. It has been observed that if those funds are not available, States often do not consider certain public health aspects of a programme important enough to generate local funds. In this context would there be a need for certain basic health programmes that would be mandatory. How would these be decided?

What would be the role of National Institute of Training and Research and their linkages with the decentralised system?

We already have a lot of expertise in the decentralization of medical knowledge and skills though the training of community health workers mainly in the NGO sector. However
when innovative ideas such as this or other innovative ideas in delivery of health services or in disease control programmes are moved from their “project” or “pilot” phase to the general health system they have been found to flounder. The ‘other’ aspects of the projects in terms of motivation, personnel, money etc., are just as crucial as the technical aspects.

In the area of research from the first bacteriological lab set up for research in Agra in 1982 a large pool of expertise especially in basic and clinical research has been developed in the country. Today, under the ICMR itself there are 40 permanent research institutes, 6 regional medical research centres including centres for tribal health, desert medicine, high altitude medicine and 17 centres of advanced research covering various fields from Community Mental Health, Virology, Reproductive Biology, MCH care, Child Health, research on selected traditional remedies, biomedicine etc.,

These centres of research would need to continue functioning at a national level. The Mudaliar Committee way back in 1961 had suggested a reconstitutinal of research activity and suggested that the States should take a greater interest in this vital field of medical acticity and set up state level centres.

Besides ICMA, there are four separate Central Research Councils for Ayurveda and Siddha, Homeopathy, Yoga and Naturopathy and Unani Medicine.

The research expertise available in medical colleges, universities, departments in the sciences and Humanities, research centres run by private and Voluntry Organisations could be utlized to study local health problems.

Would decentralization mean a change in philosophy, structure, content and method or would we be left with smaller state level versions of the existing system.

There is thus a need to develop a certain degree of clarity about what we are planning to do, by laying down time-bound goals and specific objectives.

6. **EPIDEMIOLOGY AND HEALTH PLANNING**

If health services have to be responsive to changing health needs, epidemiology could play an important role with its technique of being able to identify and quantify disease loads in a population. With a relatively clear picture of the distribution of disease and the populations at risk, more rational health care programmes can be planned. However, epidemiological studies have to be decentralised, in the sense that it would be erroneous to generalize from one or a few particular studies done in a particular place, at some point of time, to the rest of a very large and diverse population as in India. To utilize and quote the same numbers and rates for 2 to 3 decades also seem rather strange. Disease patterns and the health status of people are very dynamic conditions which respond to several factors, known or unknown. Hence smaller epidemiological studies, done in each State and at most frequent intervals would give us a much better picture of the health status of the people. This information could be used effectively for health planning. Unfortunately,
reasons such as feasibility and cost etc., are raised when it comes to issues as this which are important to public health, however the same reasons are not even considered when it comes to setting up some high tech facility which however useful would serve the needs of only a few.

As an illustrative example, I must mention the experience of a health project in Kerala, where simple epidemiological methods were taught to health workers, who then planned out a cross sectional study of general morbidity, evolved a questionnaire, conducted interviews and analysed the findings, with only consultative support from their doctor. Findings, revealed that certain diseases eg., filariasis, malaria, leprosy were not a problem in that particular area and it would make much sense having provisions of a National Health Programme for them. On the other hand there were other major problems in the area of mental health, alcoholism and disability for which the existing health service was unprepared and ill-equipped. The experience demonstrates how simple community based research was demystified and used as an educative experience for health workers, as a basic for health education of the people and also for planning their health programme.

In several countries data from the general health services is sometimes used to study disease problems in the region. In India, however, several systems of medicine are practised, each with their own philosophies and approaches to diagnosis and treatment. The utilization of Government Health Services (where records are supposed to be maintained) vary and are generally low. The quality of the data recorded is also highly questionable. Due to all these factors utilizing routine records for research purposes serves no useful purpose. In fact it could be positively misleading. Hence there is no other option than to conduct special surveys on representative samples of populations. Having said this I must mention that several microlevel health projects have standardised record keeping and make use of this data to work out various indicators of health on a yearly basis, eg., Infant Mortality Rate, Maternal Mortality Rate, Under Five Mortality Rate and Immunization coverages. I must emphasize though that even well kept data derived from persons reporting to hospitals or health centres as patients does not give an indication of the disease pattern in the community. For this purpose data collection has to be population or community based.

Various Government Committees over the years have recognized the need for “health information systems”, “sanitary cum epidemiological units”, ‘epidemiological intelligence’ and ‘epidemiological trouble shooting’ (whatever that may mean!). However the reality is that this is one area that has not been able to get off the ground sufficiently. Besides the traditional stigma attached to community medicine and the lack of glamour; exactness, documentation and quantification in the sphere of health are not exactly our strong points.

One of the latest reports of the working group on Medical Education, Training and Manpower Planning chaired by P.N. Tandon (June 1989) has this to say, “There is a dearth of genuine epidemiological data in the country. It is now universally recognised that neither proper manpower planning nor an appropriate health care delivery system is possible without such data.” This would hold true at a National or Decentralised level.
7. **DEVELOPING INDICATORS**

A key component of any research exercise into decentralisation health care would be the identification of suitable indicators. Only a few indicators concerning the health status of the population and the impact of health programmes will be considered.

We already have well established indicators like the infant and maternal mortality rates and life expectancy at birth. Besides providing information on the physical status of health these also reflect general socio-economic, conditions in the community, status of women over time, and would indirectly reflect the impact of the health programme. Besides official sources of such information collected through the Sample Registration System, a few Voluntary Health Projects provide such data. We must plan for the collection of such data at least at the District if not Taluk level. We also need to get break ups according to different subgroups of the population viz., social class, occupational groups, tribal populations, urban slums, IMR and MMR’s are relatively simple to determine and provide much useful information.

Morbidity and mortality rates for specific disease conditions are much more difficult to come by, except under conditions of specific studies being conducted. More training is needed for valid data collection.

When one moves from physical health to indicators of mental and social health one is in much deeper trouble. Mental health is not an area I am conversant with hence I would only venture to say that defining different states of mental illhealth, identifying situations of social stress, studying their effects and evolving appropriate interventions, training of skilled interviewers, understanding different cultural backgrounds would be some of the important factors.

Indicators of social health and of social change processes however are crucial in the context of the change over to decentralised health care, which is essentially a part of the wider process of social change. I will outline some tentative ideas in this respect. Some of these are areas that appear to be important based on collective field experience. They have not been tried out in the field.

a) A breakup of some of the earlier indicators (IMR, MMR, under 5 mortality, morbidity rates) atleast by social class and sex from a few centres would be informative. Monitoring this over time would give some idea of changes that are taking place in the health status of the underprevilieged groups. Our present, often quoted, health indicators at a national level probably hide more than they reveal.

b) Utilization of health services by social class and sex and their changing pattern over time is also important and would reflect changes in the quality of services and their social sensitivity.

c) Functional efficacy of the health system would be covered by the management section eg., availability of essential drugs, etc.,

d) Active participation in decision making processes at the Mandal and Gram Sabha levels especially by the marginalised. It has been observed that representatives from
the SC’s and ST’s and the women representatives are only nominal. Their silent presence serves the political needs of certain groups and does not represent participation in any way. On the other hand the experience with these some marginalised groups by Voluntary Health Projects/Health Activists is quite different – they are capable, with a tremendous capacity to learn, work and take leadership to improve the lives of their children and fellow beings. It is obvious that social environmental factors are at work producing different results.

e) The role of women in health care, their perception of the health care services, their levels of knowledge regarding health, their status in the local community are crucial factors as they are the first primary health care providers.

f) Organizational capacity of people Viz., their ability to work together towards solving some of their common problems.

g) Ability to question and even resist unethical medical practices starting from simple issues like regular attendance of health staff, misuse of drugs and funds, taking payment for free services, to more technical issues like negligence, improper conduct of procedures like tubectomies resulting in bodily harm.

h) Self image and confidence of the people especially the marginalised.

i) Growing self reliance in managing their affairs, a feeling not of being controlled by, but controlling the health care services.

j) Awareness of the functioning of health services and their rights as consumers and citizens, besides other health knowledge, would indicate if an enabling method of health education is being used.

k) Awareness levels of people of political events and personalities at a National, State and local level has been used as an indicator of political awareness.

l) Literacy rates especially of women, income levels of the family and income of women, family size or control of fertility have been established and continue to be important social indicators.

m) A study of the knowledge, skill and attitudes of health personnel working in peripheral institutions would indicate the efficacy of the services, provided the “health service culture is also an important component to be understood.” Accountability of health service staff and health committee members would determine quality of service.

8. UNDERSTANDING HEALTH CULTURE OF THE PEOPLE AND THE ROLE OF INDIAN AND OTHER SYSTEMS OF MEDICINE

A major lacunae of some of the earlier national reports and health programmes was the insensitivity to people beliefs regarding illness and inadequate importance given to local health practices and to the systems of medicine widely practised in different regions of the country.

In the proposed change of system it would be important to study and be sensitive to local health beliefs and practices, to study the availability of health practitioners be they folk healers or practitioners of different systems of medicine, to initiate a process of dialogue and involvement in the planned decentralization of health services.
9. PEOPLE’S PERCEPTIONS – PARTICIPATORY RESEARCH

There are groups in the country for eg., PRIA, ANITRA Trust, ACHAN etc., who have been developing expertise in the area of participatory research during recent years. This would be a very crucial area to explore if people, especially the marginalised are to participate more effectively in their own health care. It implies a radical shift in “us” studying “them” to “we” looking at our health problems together. Though it could be challenging and even threatening to “us” the results seem impressive, with much shared learning and with the possibility of more practical solutions to basic problems.

10. NEED TO STUDY MICROLEVEL PROJECTS WHERE DECENTRALISATION HAS BEEN ATTEMPTED

Several Health Projects across the country have experimented with decentralising various aspects of health care and with various components of Primary Health Care. A study of these components would provide valuable insights into the potentials, strengths and weaknesses, besides knowledge of the actual process involved in implementing them. Though mentioned last it should be one of the initial steps to be undertaken.

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12. APPENDIX

THE NATIONAL HEALTH POLICY STATEMENT (1981) ON MEDICAL RESEARCH STATES THAT: (A SUMMARY)

- the overall effort should aim at the balanced development of basic, clinical and problem oriented operational research.
- besides building up fundamental and basic research priority attention should be given to existing, widely prevalent diseases and to deal with emerging health problems.
- they state that the basic objective of medical research and the ultimate test of its utility would involve the translation of available know-how, into simple, low cost easily applicable appropriate technological, devices and interventions suiting local conditions.
- hence a high priority is accorded to applied, operational research, including action research.
- priorities would need to be identified in collaboration with social scientists, planners, decision makers and the public.
- priority areas mentioned are:
  - communicable and tropical diseases
  - contraception research.
  - nutrition research.

CONCLUSION

With a large and diverse population of about 850 million it seems sensible it decentralize health care in India. Because of the sheer magnitude of the proposed shift it would be equally sensible to base the changes on solid foundations of research.

This paper explores some issues and questions that would need to be considered in this context.